‘Doctor’s Orders’

Type 1 Diabetes and the Consultative Relationship, 1948-2002

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Signed: Stuart Bradwel

Date: 14/06/2020

Abstract

Since 1922, insulin has saved the lives of countless individuals diagnosed with what we now know as Type 1 Diabetes. It is, however, not a cure. Insulin therapy is a lifelong commitment that involves regular self-medication. This treatment can be complex, as dose titration and timing must be balanced with carbohydrate intake to prevent dangerous long- and short-term complications. In Britain, for much of the twentieth century, the medical profession sought to achieve this via the imposition of carefully prescribed, and usually highly restrictive, treatment regimens that precisely outlined a timetable of diet and insulin, deviation from which was strongly discouraged. By the mid-2000s, however, orthodox management tended to eschew such an approach, encouraging a more autonomous framework in which the individual was taught to determine personal therapeutic requirements according to their own diet and lifestyle, while healthcare professionals were reconceptualised as remote sources of support should advice or assistance be required. This thesis analyses the process by which this transition occurred, arguing that from the late 1970s a confluence of factors both within and without diabetology provided the practical, scientific, and political rationale for the cautious enlistment of the patient as a medical auxiliary, and that, moreover, due to the material conditions of insulin therapy, this development inadvertently rendered laypeople a distinct political and moral force in their own right, able not only to exert influence over the framework of care but also over the construction of value within it, and in doing so often directly challenged the fundamental assumptions of professional practice. Twenty-first century ‘patient-led’ approaches to care, it concludes, reflect an imperfect compromise that attempts, but often fails, to reconcile orthodox medical power structures to an increasingly alienated patient-body with which it often has profound ideological differences, and upon which it struggles to impose its traditional authority.

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Acknowledgements

Writing this thesis has without a doubt been one of the most exhausting yet fulfilling experiences of my life to date. However, I cannot claim full credit for any of what follows. Without the generosity of those who I interviewed as part of my research, it could never have existed. Perhaps more than anyone else, they deserve my utmost thanks for their time, patience, and enthusiasm. To every single one of them, I express my utmost gratitude and hope that, somehow, I have done their testimonies justice.

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Many others are also owed a debt. Thanks are due to Martin Moore for some excellent early pointers as I was just getting started, to Angus Ferguson for giving me the sorely needed encouragement to pursue a PhD after my MLitt, and to Peter Sciacaluga, without whom I would never have begun to study history in the first place. My co-supervisees Rachel Meach, Iain Ferguson, and Erin Lux have each provided invaluable friendly advice for which I am very grateful. Thanks also to, in no particular order, Aly and Marcel Haas, Aileen Lichtenstein, Nicola Cacciatore, Yun Huang, Diana-Andreea Novăceanu, Emma Newlands, Roisin Convery, Maaike de Vries, Alistair Tough, to everyone at Diabetes UK, and to the many others I have almost certainly forgotten to include who have, in some way great or small, knowingly or unknowingly, helped me turn a muddled ball of half-formed thoughts into a (mostly) coherent piece of work.

Thanks to my parents, Stephen and Barbara, who have never stopped believing in me. Their unconditional love and support has been invaluable. I am fairly sure that both would have preferred I get a secure job rather than embarking headlong into the uncertain world of academia, but after thirty years on this planet I'm hardly about to start making sensible decisions now. I can't express my gratitude enough for all that they have done, both over the last few years and before.

And finally, to Alyssa McGrow, one of the best people I have ever known: I owe more to you than I can begin to describe. You have helped shape more of the ideas presented here than you could possibly know, and this thesis would have been ten-thousand times harder to finish in your absence. Never stop being you.

Abbreviations

BDA - British Diabetic Association

BERTIE - Beta Cell Education Resources for Training in Insulin and Eating

BMA - British Medical Association

BMI - Body Mass Index

BMJ - British Medical Journal

CFS - Chronic Fatigue Syndrome

CGM - Continuous Glucose Monitoring

DAFNE - Dose Adjustment for Normal Eating

DCCT - Diabetes Control and Complications Trial

DKA - Diabetic Ketoacidosis

DSN - Diabetes Specialist Nurse

EPP - Expert Patients Programme

FDA - Food and Drug Administration

GP - General Practitioner

HbA1c - Glycated haemoglobin

HCP - Healthcare Professional

IDDM - Insulin Dependent Diabetes Mellitus

JDRF - Juvenile Diabetes Research Foundation

MDI - Multiple Daily Injections

NDDG - National Diabetes Data Group

NHS - National Health Service

NIDDM - Non-Insulin Dependent Diabetes Melltus

NPH - Neutral Protamine Hagedorn [Insulin]

PZI - Protamine Zinc Insulin

PWD - Person/People with Diabetes

SBGM - Self Blood Glucose Monitoring

T1D - Type 1 Diabetes Mellitus

T2D - Type 2 Diabetes Mellitus

WHO - World Health Organisation

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Preface

“This will work”, the nurse practitioner at my local General Practitioner (GP)’s office told me as she pushed an Eli-Lilly insulin pen into my hands. “It won’t”, I responded. “I’ve been prescribed Lantus, so I need something manufactured by the same company otherwise the cartridges won’t fit.” “No, it will. They all work together. Trust me.” It didn’t.

It was mid-2009 and I had not long before been diagnosed with Type 1 Diabetes Mellitus (T1D). The immediate shock of this event had given way to something approaching acceptance, or in all likelihood exhausted resignation. The hospital staff had explained the basic principles of basal/bolus therapy to me (in short, taking one or two daily shots of long- or intermediate-acting insulin alongside a variable dose of a more rapidly processed variety with meals), and a very helpful diabetes specialist nurse (DSN) had even attended my home to discuss my individual needs. Despite my grief, I was remarkably impressed and felt ready to begin independently managing my new lifelong condition, safe in the knowledge that a competent group of experts were ready to provide support if necessary.

Insulins are not, however, created equal. Levemir – the Novo Nordisk-made long-acting variety I had been initially prescribed – was in my experience unpredictable. Rather than maintaining a consistent level of background blood sugar, it would cause unexpected hypoglycaemic crashes followed by equally frustrating spikes. At a prior clinic appointment, I had discovered that the DSN I had previously spoken to had left the job but was assured by her replacement that moving onto Lantus (another major long-acting formulation made by Sanofi, designed to be taken once daily) would be no problem should I run into any difficulties.

After around two months of calling into the hospital, leaving voicemails, and doing everything in my power to contact this DSN, I had *still* been unable to speak to her directly.

Throughout this period, my blood sugar levels had been – to put it mildly – chaotic, and my mental health was suffering as a result. Pharmacists told me there was nothing they could do without a prescription, my GP suggested I contact a specialist at the diabetes clinic, the hospital-based care team were not returning my calls, and permeating almost every discussion I had with each was the palpable subtext: 'Stop bothering me, you have insulin, use it like you've been told and you'll be fine.'

Some time later, an envelope arrived in the post containing a prescription for Lantus, though without any form of accompanying note or explanation for the delay. Only after having it filled did I realise the obvious omission – I had the insulin I had asked for, but had no way of getting the stuff into my body! Surely, though, the local GP surgery could arrange for that? Not so. In the end I was able to acquire the insulin pen I required and the new insulin proved – after I (against professional advice) started splitting my dosage between morning and night – considerably more stable than what I had originally been prescribed. The whole experience had, however, left me shaken, alienated, and angry. I felt that I had spent months bashing my head against a Kafkaesque bureaucracy that stood arrogant and apathetic as my health had deteriorated.

This is not a work of autoethnography, and apart from this brief preface I have consciously avoided alluding to my own life with T1D. However, in addition to providing some explanation for my own interest in the subject, I found the extent to which this small personal anecdote mirrors the experience of those I have interviewed for this thesis striking. I am not unique, and it is vitally important to recognise the implications of that: almost every single person living with T1D that I spoke to had numerous examples of similar frustrations, and many of them relatively recent. Many may, I think, be surprised at the lack of archival sources to be found in my bibliography. The experience of T1D is – with some notable exceptions – rarely committed to paper by those who experience it day-to-day, while as a scholar concentrating primarily on the late twentieth century those clinical records produced by physicians are often presently inaccessible due to the personal data they contain. I have, therefore, chosen to lean heavily on an oral history methodology. Such an approach, I believe, has allowed me to access the deep and richly textured stories of those living with this condition that published material and other traditional forms of documentary evidence often ignore, and that my analysis has greatly benefited for this.

This preface should also serve – appropriately – as a confession of sorts: this is an area of great personal relevance to me and this work will, as a result, reflect that. I am hopeful that by analysing the history of twentieth century insulin therapy and discussing some of the shortcomings of care during this period, it will provide some food for thought for healthcare professionals (HCPs) as they seek to improve and refine standards of care.

Chapter 1 – Introduction and Literature

‘[T]he diabetic life demands self-control from all its subjects, but it gives in return a full and active existence, with no real privations… But [they] must accept the diabetic creed and follow it faithfully.’

Robert Daniel Lawrence, *The Diabetic Life*, 1st ed (London: J. & A. Churchill, 1925), p. iv.

Part 1: Jack Eastwood

In 1925, thirteen year old Jack Eastwood (1912-1987) was diagnosed with 'severe' diabetes mellitus, the disease that had been responsible for his elder brother's death six years previously.[1] Derived from the ancient Greek for 'siphon/pass through' and later appended with the Latin for 'sweet like honey', the term refers to the excessive passage of sugar laden urine so characteristic of those with the misfortune to develop the condition. By the twentieth century it had long been apparent that diabetes was particularly dangerous in children and adolescents. While older people with diabetes (PWD) often lived for many years with the condition in what was considered its 'mild' form, it had a grim prognosis when diagnosed in the young. After initial symptoms of thirst, polyuria, and exhaustion, rapid deterioration and death were inevitable – the only moderately effective treatment was a starvation diet that could prolong life for a few months or years at the cost of great suffering.[2] Writing in 1962, G.A. Wrenshall of the University of Toronto's Banting and Best Institute did not exaggerate when he described pre-insulin treatment as little more than a 'counsel of desperation'.[3] Having witnessed one son's traumatic end, Jack's parents must once again have prepared for the worst.

Fortunately, Eastwood was spared the fate of his brother. His diagnosis came just as a viable pharmaceutical treatment was becoming widely available throughout medical practice in Britain. One of the great successes of early twentieth century biomedicine, the isolation of insulin in 1921 and its first clinical use in 1922 won a Nobel Prize and made an instant – though controversial – celebrity of Frederick Banting (1891-1941), the Canadian

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[1] Jack D. Eastwood, 'Insulin and Independence', *BMJ (Clinical Research Edition)* 293 [6562] (1986), p. 1659.

[2] Elizabeth Lane Furdell, *Fatal Thirst: Diabetes in Britain until Insulin* (Leiden: Brill, 2009), pp. 148-149.

[3] G.A. Wrenshall, G. Hetenyi, and W.R. Feasby, *The Story of Insulin: Forty Years of Success Against Diabetes* (London: Bodley Head, 1962), p. 87.

researcher given the lion's share of the credit.[4] Spoken of triumphantly as a near-religious miracle, the hormone did undoubtedly produce impressive results – particularly in the young.[5] Photographs documenting the progress of children treated with it are certainly very impressive: their initially emaciated subjects are shown quickly restored to a healthy weight and regaining strength (See Figure 1.1).[6] Jack was one of thousands to benefit from this new drug, and after only three weeks as an inpatient was told that he was fit to return home.

From the outset, it was clear that insulin's success was a qualified one. Those taking it were reliant on daily injections to avoid the immediate return of symptoms. Dosages required precise calibration: large enough to prevent relapse but not so great as to produce hypoglycaemia.[7] While the long-term effects of elevated but asymptomatic blood sugar would continue to be disputed for much of the twentieth century, most – though not all – physicians advocated strict control as the key to successful treatment.[8] This undoubtedly took on a moral dimension for some, such as Boston's Elliott Joslin (1869-1962), whose approach to management was deeply influenced by his frugal, Protestant asceticism.[9] Regardless, the importance of strict control could also be argued in biomedical terms.

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[4] The successes of the Toronto research group were marred by interpersonal conflict, while Bucharest's Nicolae Paulescu (1869-1931) insisted in vain that he had isolated insulin first; Michael Bliss, *The Discovery of Insulin [1982]* (Basingstoke: Macmillan, 1987), pp. 229-233; Francisc Ion Dworschak and Constantin Ionescu-Tîrgoviste, *Paulescu and Collip: Insulin's Unsung Heroes* (Bucharest: Editura ILEX, 2008).

[5] Robert Tattersall, 'A Force of Magical Activity: The Introduction of Insulin Treatment in Britain, 1922-1926', *Diabetic Medicine* 12 (1995), p. 744.

[6] H. Rawle Geyelin, George Harrop, Majorie F. Murray, and Eugenia Corwin, 'The Use of Insulin in Juvenile Diabetes', *Journal of Metabolic Research* 2 (1922), pp. 767-791.

[7] Tattersall, 'A Force of Magical Activity', pp. 743-744.

[8] For example, Tattersall describes a 1953 survey of eighty-one English physicians with responsibility for treating those with diabetes. Of these, thirty fully believed that hyperglycaemia was responsible for the development of long-term complications, while six were sure that it was not. The majority – forty-five – were simply not sure enough to give an answer; Robert Tattersall, *Diabetes: The Biography* (Oxford: Oxford University Press, 2009), p. 89.

[9] Chris Feudtner, *Bittersweet: Diabetes, Insulin, and the Transformation of Illness* (Chapel Hill, NC: University of North Carolina Press, 2003), pp. 34-36.

Contemporary thinking held that hyperglycaemia was a *cause* – rather than a *symptom* – of diabetes, intimating that damage to the pancreas could be halted, and potentially even reversed, by 'resting' it through the maintenance of near-normal blood glucose levels.[10]

In practice, the goal of treatment involved keeping the urine clear of sugar as effectively as possible. While urinary measurement is relatively imprecise, acquiring direct blood readings in this period was a complex undertaking that required laboratory analysis and could not feasibly be performed with regularity. Consequently, those diagnosed were usually expected to abide by a disciplined lifestyle within boundaries prescribed by their physician. A fixed amount of insulin was to be taken at specified times once or twice daily, while mealtimes were determined in advance. The nutritional content of food to be consumed was also fixed (see Figure 1.2). Control was to be assessed regularly using Benedict's solution, generally in the morning and before bed. An unenviable process, this involved boiling urine with the reagent for several minutes before approximating sugar content based on the resulting colour. Brick red, brown, or yellow indicated a considerable amount of glucose, green a trace, and blue none – there was little in the way of precision.[11] Any deviation from this routine was to be made only with the approval of a physician. Despite almost permanent engagement in the business of diabetes management, PWD and their families were consciously divorced from any real decision-making responsibility – that was considered the sole preserve of the professional. Obedience, above all, was considered an absolute necessity for successful therapy: a principle alluded to poetically by the London

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[10] Robert Daniel Lawrence, *The Diabetic Life*, 1st ed (London: J. & A. Churchill, 1925), pp. 59-60; Elliott Joslin, 'The Changing Diabetic Clientele', *Transactions of the Association of American Physicians* 39 (1924), p. 307.

[11] Stanley R. Benedict, 'The Detection and Estimation of Glucose in Urine', *Journal of the American Medical Association* 57 (1911), pp. 1193-1194.

specialist Robert Daniel Lawrence (1892-1968), who in 1925 wrote that 'the faithful diabetic is sure of his reward in health.'[12]

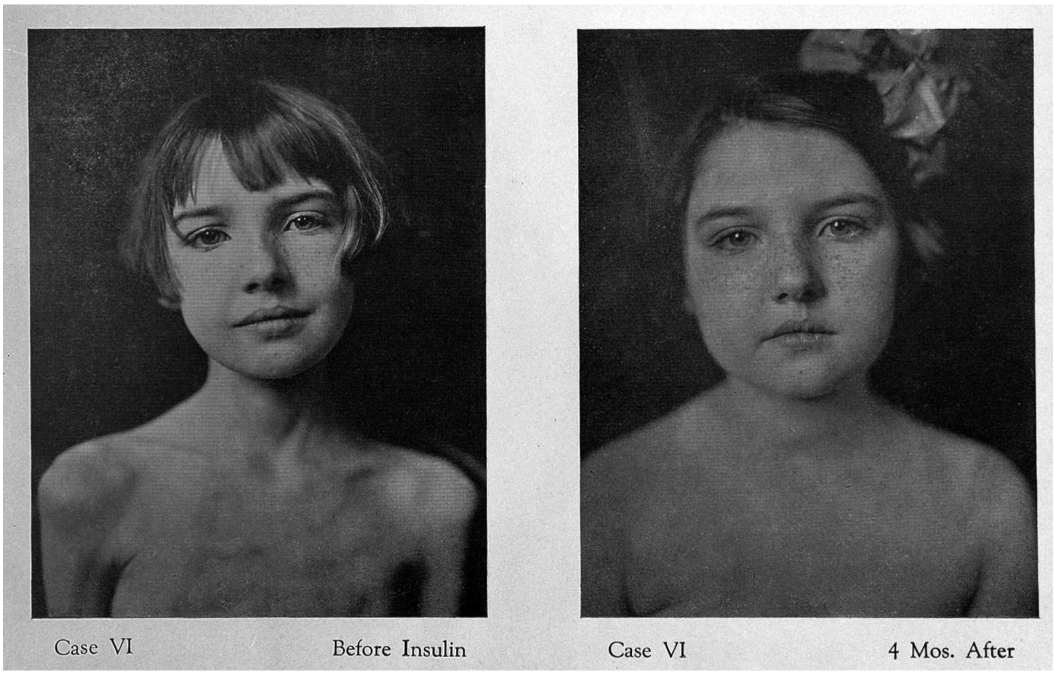

Figure 1.1: ***Young Girl Before and After Insulin Treatment*****, 1922, L0031615, Wellcome Images**

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[12] Unsurprisingly, this line was removed in later editions as the prevalence of long-term complications became clear; Lawrence, *The Diabetic Life*, 1st ed, p. 68; Lawrence was a fascinating character in his own right. Before becoming one of the foremost British diabetologists of the early twentieth century, he had narrowly avoided dying of the very same condition in dramatic fashion. Terminally ill and having moved – implicitly to die – to Italy, the semi-delirious Lawrence had, upon learning of insulin's availability in Britain in 1923, embarked on a ten day trans-European drive from Florence to London; Jane Lawrence and Robert Tattersall (ed.), *Diabetes, Insulin and the Life of RD Lawrence* (London: Royal Society of Medicine Press, 2012), pp. 10-17.

Eastwood's early treatment appears to have been typical of the late 1920s. Writing about his life in an article for the *British Medical Journal* (*BMJ*) in 1986, he recalled the detailed guidelines provided to his parents: '[A]ll of my food was weighed, and no excesses were allowed at all... [while] subcutaneous injections of soluble insulin were given before breakfast and supper each day… about 20 U[nits] with the carbohydrate content of my food amounting to about 25g.'[13] He also made reference to the limitations of the education he and his parents were provided: 'At this stage my knowledge was confined to a clear understanding of how important it was to keep to the rules, and to early recognition of the symptoms of an overdose of insulin [hypoglycaemia].'[14]

As he entered adolescence and won a scholarship to St Paul's public school in London, Eastwood began to be troubled by the claustrophobia of living within such an inflexible and restrictive routine. He was particularly frustrated with the idea that it might hinder his pursuit of an active social life or indeed his ability to do anything with spontaneity – a feeling that only intensified when he moved to Oxford to attend university. Determined to master his condition, he assiduously compiled notes detailing his consumption of food and insulin, alongside the results of urinary tests and any other miscellaneous observations he felt were relevant.[15] The relative ease of life at Oxford (he found the time to play golf 'most days'!) gave Jack the opportunity to analyse his records and develop, with some trial and error, a bespoke approach to treatment based on constant adaptation, adjustment, and self-assessment:

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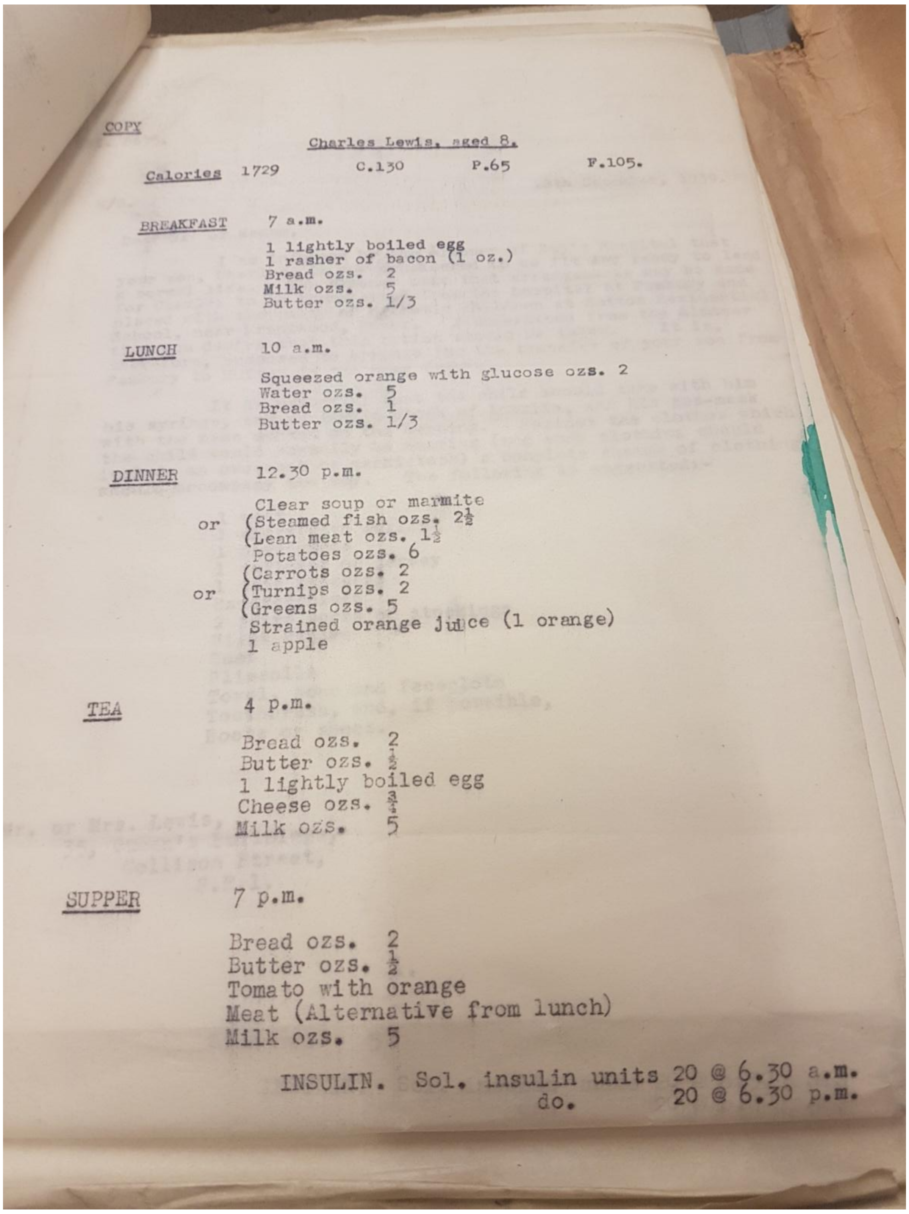
[13] Eastwood, 'Insulin and Independence', p. 1659.

[14] *Ibid*, p. 1659.

[15] *Ibid*, p. 1659.



COPY

Charles Lewis, aged 8.

Calories 1729 C.130 P.65 F.105.

BREAKFAST 7 a.m.

1 lightly boiled egg
1 rasher of bacon (1 oz.)
Bread ozs. 2
Milk ozs. 5
Butter ozs. 1/3

LUNCH 10 a.m.

Squeezed orange with glucose ozs. 2
Water ozs. 5
Bread ozs. 1
Butter ozs. 1/3

DINNER 12.30 p.m.

Clear soup or marmite
or (Steamed fish ozs. 2½
(Lean meat ozs. 1½
Potatoes ozs. 6
(Carrots ozs. 2
or (Turnips ozs. 2
(Greens ozs. 5
Strained orange juice (1 orange)
1 apple

TEA 4 p.m.

Bread ozs. 2
Butter ozs. ½
1 lightly boiled egg
Cheese ozs. ¾
Milk ozs. 5

SUPPER 7 p.m.

Bread ozs. 2
Butter ozs. ½
Tomato with orange
Meat (Alternative from lunch)
Milk ozs. 5

INSULIN. Sol. insulin units 20 @ 6.30 a.m.
do. 20 @ 6.30 p.m.

Figure 1.2: ***Charles Lewis: Diet Sheet*, December 1939, EO/WAR/2/32, London Metropolitan Archives**

> In brief summary, its distinctive feature is that I inject insulin at every mealtime and vary the dose according to the food eaten, instead of basing the treatment on a fixed dose of insulin each morning and then trying to adjust my diet, exercise, etc, to this throughout the next 12 or 24 hours… eating almost anything I wanted… due allowance being made for what I expected to be doing during the next few hours.[16]

By adopting this highly unorthodox style of treatment, Eastwood was able to adapt to the changing demands of his lifestyle and, as a result, was able to escape the ritualised monotony experienced by many of his contemporaries. He went on numerous holidays (at the time generally discouraged for those with 'severe' diabetes) and had a successful career as a schoolteacher.[17] Despite all of this, he reported consistently satisfactory urine tests and was happy to have developed no diabetic complications at the time of writing.[18]

Advocating the more widespread adoption of his method, Eastwood was nevertheless aware of its potentially controversial nature, directly acknowledging that some might feel that this 'attitude entailed an unwarrantable risk… that [he] was lucky not to suffer in consequence of.'[19] Perhaps it is with this in mind that he often appealed to the authority of physicians in a manner that sat somewhat awkwardly with his lifelong commitment to independence from their control. Recounting that 'many doctors have described this to me as the nearest approach they have ever met to nature's method of treating diabetes [i.e. metabolising carbohydrate]', he also referenced contemporary research that he believed supported his contention that 'the success that I have had in controlling my diabetes by frequent injections may well be partly responsible also for the freedom from complications

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[16] *Ibid*, p. 1659-1660.

[17] Those with 'severe' diabetes were generally encouraged to stay at home and avoid any potentially unpredictable or stressful activity; Lawrence, *The Diabetic Life*, 1st ed, pp. 114-115.

[18] Eastwood, 'Insulin and Independence', p. 1660.

[19] *Ibid*, p. 1660.

that I have now enjoyed for 60 years.'[20] Recounting his last regular meeting with a specialist in 1935, he claimed that 'at the end of the visit he said that he thought there was no need for me to go and see him again, because by then I knew more about controlling my own diabetes than he did, and I remember hearing this verdict with a strange mixture of pride, humility, and gratitude.'[21] While Jack was far from the only PWD to consciously 'tinker' with treatment, he was unusual in that he developed, and documented, a fully realised alternative (and importantly, semi-scientific) framework of management that foreshadowed later 'intensive' approaches even while it contradicted contemporary orthodoxy.

Eastwood died in 1987 at the age of seventy-five (See Figure 1.3).[22] While this lends his optimistic 1986 *BMJ* paper an undeniably melancholic air, he was nevertheless extraordinarily long-lived for someone diagnosed as a 'severe' diabetic in the early insulin period. I have chosen to begin with a brief narrative of Jack's experiences because in many ways they encapsulate the recurrent themes of this thesis. By abandoning the contemporaneously orthodox method of diabetes management for a novel approach that would later be thoroughly vindicated, his example raises questions that resonate well beyond the scope of simple therapeutic efficacy, asking us to consider the relative strengths and weaknesses of professional knowledge and lay expertise, the proper roles and obligations of physicians and those they treat, and even the very meanings we attribute to superficially simple terms like 'health' and 'sickness'.

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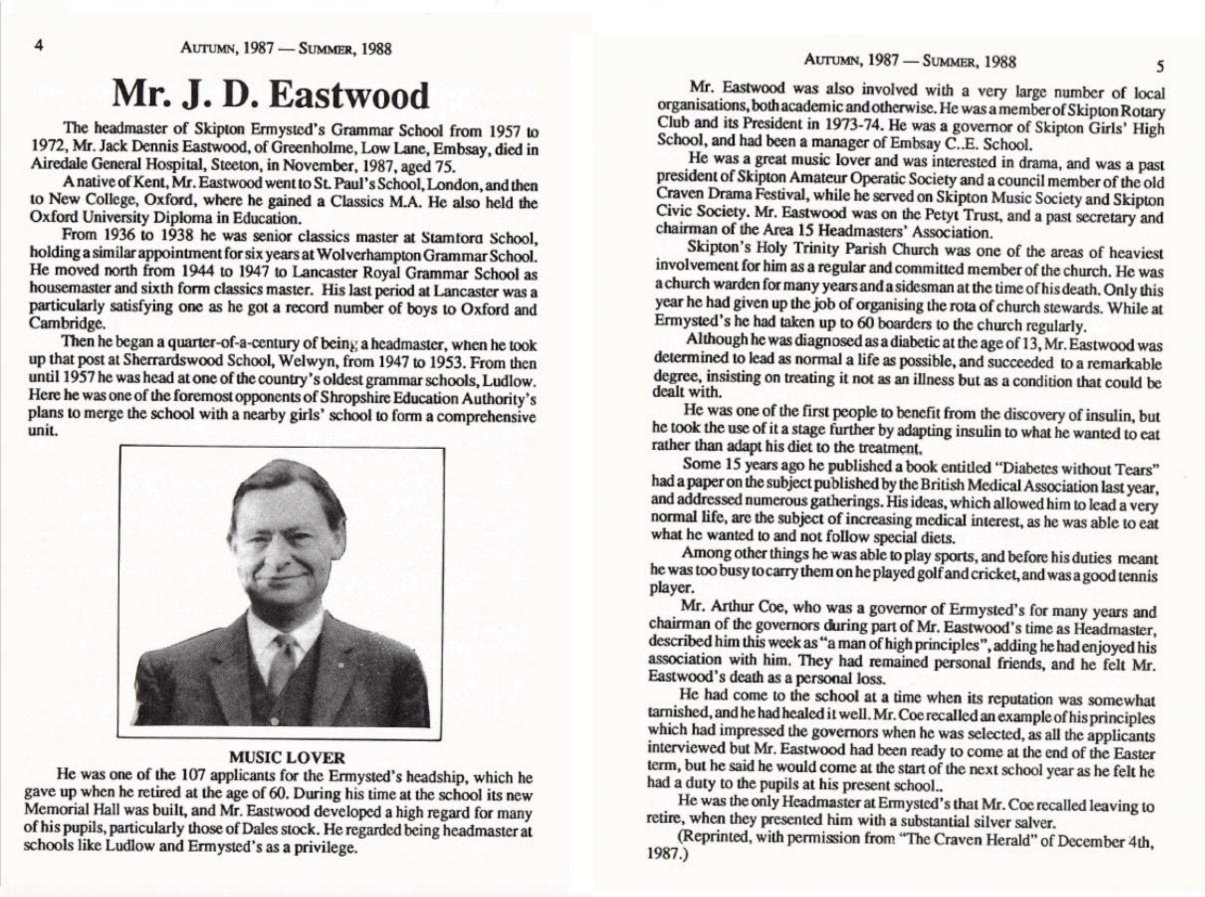
[20] *Ibid*, p. 1660.

[21] Eastwood, 'Insulin and Independence', p. 1660.

[22] Anonymous, 'Obituary: Mr. J.D. Eastwood', *The Craven Herald*, 4 December 1987, reproduced in *Ermysted's Grammar School Chronicles*, Autumn 1987-Summer 1988, pp. 4-5. Courtesy of Ermysted's Grammar School Old Boy's Network.



4 AUTUMN, 1987 — SUMMER, 1988

Mr. J. D. Eastwood

The headmaster of Skipton Ermysted's Grammar School from 1957 to 1972, Mr. Jack Dennis Eastwood, of Greenholme, Low Lane, Embsay, died in Airedale General Hospital, Steeton, in November, 1987, aged 75.

A native of Kent, Mr. Eastwood went to St. Paul's School, London, and then to New College, Oxford, where he gained a Classics M.A. He also held the Oxford University Diploma in Education.

From 1936 to 1938 he was senior classics master at Stamford School, holding a similar appointment for six years at Wolverhampton Grammar School. He moved north from 1944 to 1947 to Lancaster Royal Grammar School as housemaster and sixth form classics master. His last period at Lancaster was a particularly satisfying one as he got a record number of boys to Oxford and Cambridge.

Then he began a quarter-of-a-century of being a headmaster, when he took up that post at Sherrardswood School, Welwyn, from 1947 to 1953. From then until 1957 he was head at one of the country's oldest grammar schools, Ludlow. Here he was one of the foremost opponents of Shropshire Education Authority's plans to merge the school with a nearby girls' school to form a comprehensive unit.

MUSIC LOVER

He was one of the 107 applicants for the Ermysted's headship, which he gave up when he retired at the age of 60. During his time at the school its new Memorial Hall was built, and Mr. Eastwood developed a high regard for many of his pupils, particularly those of Dales stock. He regarded being headmaster at schools like Ludlow and Ermysted's as a privilege.

AUTUMN, 1987 — SUMMER, 1988 5

Mr. Eastwood was also involved with a very large number of local organisations, both academic and otherwise. He was a member of Skipton Rotary Club and its President in 1973-74. He was a governor of Skipton Girls' High School, and had been a manager of Embsay C..E. School.

He was a great music lover and was interested in drama, and was a past president of Skipton Amateur Operatic Society and a council member of the old Craven Drama Festival, while he served on Skipton Music Society and Skipton Civic Society. Mr. Eastwood was on the Petyt Trust, and a past secretary and chairman of the Area 15 Headmasters' Association.

Skipton's Holy Trinity Parish Church was one of the areas of heaviest involvement for him as a regular and committed member of the church. He was a church warden for many years and a sidesman at the time of his death. Only this year he had given up the job of organising the rota of church stewards. While at Ermysted's he had taken up to 60 boarders to the church regularly.

Although he was diagnosed as a diabetic at the age of 13, Mr. Eastwood was determined to lead as normal a life as possible, and succeeded to a remarkable degree, insisting on treating it not as an illness but as a condition that could be dealt with.

He was one of the first people to benefit from the discovery of insulin, but he took the use of it a stage further by adapting insulin to what he wanted to eat rather than adapt his diet to the treatment.

Some 15 years ago he published a book entitled "Diabetes without Tears" had a paper on the subject published by the British Medical Association last year, and addressed numerous gatherings. His ideas, which allowed him to lead a very normal life, are the subject of increasing medical interest, as he was able to eat what he wanted to and not follow special diets.

Among other things he was able to play sports, and before his duties meant he was too busy to carry them on he played golf and cricket, and was a good tennis player.

Mr. Arthur Coe, who was a governor of Ermysted's for many years and chairman of the governors during part of Mr. Eastwood's time as Headmaster, described him this week as "a man of high principles", adding he had enjoyed his association with him. They had remained personal friends, and he felt Mr. Eastwood's death as a personal loss.

He had come to the school at a time when its reputation was somewhat tarnished, and he had healed it well. Mr. Coe recalled an example of his principles which had impressed the governors when he was selected, as all the applicants interviewed but Mr. Eastwood had been ready to come at the end of the Easter term, but he said he would come at the start of the next school year as he felt he had a duty to the pupils at his present school..

He was the only Headmaster at Ermysted's that Mr. Coe recalled leaving to retire, when they presented him with a substantial silver salver.

(Reprinted, with permission from "The Craven Herald" of December 4th, 1987.)

Figure 1.3: Anonymous, 'Obituary: Mr. J.D. Eastwood', *The Craven Herald*, 4 December 1987, reproduced in *Ermysted's Grammar School Chronicles*, Autumn 1987-Summer 1988, pp. 4-5. Courtesy of Ermysted's Grammar School Old Boy's Network.

Part 2: Defining Diabetes

By the early insulin era, it was clear that the symptomatic intensity and overall prognosis of diabetes could vary considerably between cases, with age and weight appearing to be particularly significant in predicting the likely progression of the condition. Most individual diagnoses in this period were therefore classified as either 'mild' or 'severe', with larger and older people who could get by via dietary adjustment and exercise primarily falling into the former group, while the young and thin, who almost without exception required insulin, were allocated to the latter.[23] The boundaries between these groups remained remarkably consistent across the twentieth century even while the terminology used to describe them changed to reflect the evolution of medical knowledge and a shifting socio-cultural environment.[24] It is unlikely that many were overly surprised when a series of studies conducted throughout the 1970s conclusively demonstrated an autoimmune process at work only in insulin-dependent 'severe' cases, leading the USA's National Diabetes Data Group (NDDG) to recommend diabetes be understood as a 'genetically and clinically heterogeneous group of disorders that share glucose intolerance in common', and outline two major forms – T1D and Type 2 Diabetes Mellitus (T2D) – as biologically distinct pathological phenomena.[25] This classificatory system has been adopted by the World Health Organisation (WHO) and most national healthcare providers, and continues to act as the conceptual framework for our understanding of diabetes today.[26] For the avoidance of

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[23] Lawrence, *The Diabetic Life,* 1st ed, pp. 42-47.

[24] Alongside 'mild/severe', 'juvenile/adult-onset' was used to reflect the characteristic youth of those requiring insulin. Once it became apparent that older PWD could in rare cases also develop the rapidly fatal form, 'Insulin Dependent Diabetes Mellitus/Non-Insulin Dependent Diabetes Mellitus (IDDM/NIDDM)' became common. The use of these terms overlapped a great deal, and even today many laypeople understand diabetes according to the framework of 'mild' and 'severe'.

[25] In addition, several less common (and usually more transient) conditions presenting with glucose intolerance were identified – gestational diabetes for example; National Diabetes Data Group, 'Classification and Diagnosis of Diabetes Mellitus and Other Categories of Glucose Intolerance', *Diabetes* 28 (1979), pp. 1041-1042.

[26] WHO, *Diabetes*, <http://www.who.int/topics/diabetes_mellitus/en/> [accessed 4 February 2016].

unnecessary confusion, this work uses ‘T1D’ even where contemporaries might have used alternative terminology such as ‘severe’, ‘juvenile’, or ‘IDDM’.

T2D is by far the more common of these two major forms, accounting for approximately 90% of cases in the UK at present and roughly corresponding to historically ‘mild’ diagnoses.[27] T2D is primarily the product of insulin *resistance*, characterised by reduced cellular sensitivity to the hormone and the pancreas’ resultant inability to produce sufficient quantities to compensate. This results in inefficient but functional carbohydrate metabolism.[28] As a result, affected individuals develop raised levels of blood glucose and the resultant symptoms of thirst, polyuria, and exhaustion. While they are prone to infections, suffer from reduced wound healing, and are statistically vulnerable to a variety of complications arising from organ damage (in particular to the eyes, nerves, kidneys, and cardiovascular system) those with T2D develop acutely threatening diabetic ketoacidosis (DKA) very rarely.[29] Physicians quickly realised that administering insulin in these cases, where no ketone bodies could be detected in the blood, was necessary only if lifestyle changes failed to adequately control glucose levels.[30] As a result, treatment today makes use of it sparingly, opting instead to focus where possible on dietary regulation, exercise, and the use of pharmaceutical products such as Metformin to restore sensitivity to that produced endogenously.[31]

By contrast, ‘severe’ cases like Eastwood would now be understood to have the much rarer T1D. This is the product of an autoimmune response that results in damage to, and the

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[27] Diabetes UK, *Facts and Stats* (2016), <https://www.diabetes.org.uk/Documents/Position%20statements/DiabetesUK_Facts_Stats_Oct16.pdf> [accessed 2 February 2016].

[28] Peter J. Watkins, Stephanie A. Amiel, Simon L. Howell, and Eileen Turner, *Diabetes and its Management*, 6th ed (Oxford: Blackwell, 2003), p. 7.

[29] *Ibid*, pp. 125-131.

[30] Robert Daniel Lawrence, *The Diabetic Life,* 15th ed (London: J. & A. Churchill, 1955), pp. 40-41.

[31] Watkins, Amiel, Howell, and Turner, *Diabetes and its Management*, 6th ed, pp. 55-65.

eventual destruction of, the β-cells found on the islets of Langerhans: tiny structures within the pancreas responsible for the manufacture of insulin.[32] While sensitivity is not affected in those with T1D, declining quantities of it are secreted before production eventually ceases entirely. This *deficiency* results in raised blood glucose levels as breaking down carbohydrate becomes increasingly difficult and eventually impossible, creating comparable (though often substantially more intense) symptoms to T2D. In T1D, however, the inability to utilise *any* sugar results in the use of fat and protein tissues as an alternative, causing the individual to waste away and leading to the development of potentially fatal DKA.[33] As T1D involves no resistance to insulin, those affected usually recover quickly when it is administered but must continue to receive injections for the duration of their lives, and like those with T2D are susceptible to the various long-term complications associated with hyperglycaemia.

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[32] *Ibid*, p. 7.

[33] *Ibid*, pp. 89-91.

Part 3: Insulin therapy today

Today, the day-to-day work of insulin therapy for T1D is often considerably different to that experienced by those diagnosed in the early twentieth century. While much-hyped non-invasive methods of delivery never achieved meaningful success, innovations like pen injectors and continuous infusion pumps (bulky and unreliable when first used in the late 1970s, but discreet and efficient by 2008) have both dramatically minimised the inconvenience of administration.[34] Only one type of insulin – soluble (referred to as 'regular' in the North American parlance) – existed in the 1920s, but was joined by the longer-acting protamine 'insulinate' in 1936.[35] At the time of writing a multitude of different preparations exist; many of them genetically engineered analogues with a wide variety of different properties that allow treatment to be fine-tuned.[36] Personal blood glucose monitors have released those with T1D from a reliance on tiresome and imprecise urinary testing, allowing them to acquire accurate and direct feedback at any time.[37]

Perhaps most dramatically, the specific *role* of the person with T1D today would be inconceivable by the standards of the 1920s. While in the early twentieth century the

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[34] Tattersall, *Diabetes*, pp. 146-152; Exubera, a form of Inhaled insulin, was released in 2006. However, the cost, relatively inflexible dosage calibration, and many potential respiratory side-effects prevented its wide adoption. Similarly, jet injectors (which use immense pressure to force insulin through the pores) are available, but are expensive, painful, complicated to use, and offer little advantage over standard subcutaneous injection. Consequently, non-invasive administration remains rare and is utilised mainly by those with insurmountable needle phobias; Jacob Oleck, Shahista Kassam, and Jennifer D. Goldman, 'Commentary: Why Was Inhaled Insulin a Failure in the Market', *Diabetes Spectrum* 29 (2016), pp. 180-184; William T. Cefalu, 'Concept, Strategies, and Feasibility of Noninvasive Insulin Delivery', *Diabetes Care* 27 (2004), pp. 239-246.

[35] Tattersall, *Diabetes*, pp. 80-82.

[36] These can have a wide variety of different action profiles – some are taken up slowly over the course of up to twenty-four hours, while others are metabolised rapidly and produce a marked reduction in blood glucose over the course of only a few hours (see Chapter 5); B. Sheldon, D. Russell-Jones, and J. Wright, 'Insulin analogues: an example of applied medical science', *Diabetes, Obesity, and Metabolism* 11 (2009), pp. 5-19.

[37] While initially large, unwieldy, and requiring mains power, meters operated by battery and small enough to be discreetly carried had become ubiquitous by the mid-1990s; S.F. Clarke and J.R. Foster, 'A history of blood glucose meters and their role in self-monitoring of diabetes mellitus', *British Journal of Biomedical Science* 69 (2012), pp. 88-93.

consultative relationship was fundamentally one-sided and paternalistic, PWD have been widely encouraged to play an increasingly active role in care since the mid-1980s. Pre-empted in many respects by individuals like Eastwood, this increasing (official) lay-involvement culminated in the development, in late 1970s West Germany, of what have come to be known as 'intensified' regimens. Despite this, however, and despite some attempts to utilise 'basal-bolus' regimens integral to 'intensive' care, such patient-led approaches were not adopted on a large scale in Britain until the Dose Adjustment for Normal Eating (DAFNE) programme in 2002.[38]

'Intensive' regimens are generally characterised by a reversal of the 'conventional' approach to management. Instead of being prescribed a fixed amount of insulin to be taken at a particular time with set meals to be eaten around it, PWD can eat without so much restriction (refined sugars such as non-diet cola are the only items heavily discouraged). To allow this, insulin dosages and the timing of injections (or rate of infusion, if using a pump) are continuously evaluated and adapted accordingly. DAFNE-style 'intensive' therapy attempts to avoid unhelpful rigidity unsuited to the management of a condition as unpredictable as T1D. As factors like insulin, diet, exercise, illness, stress, and so on are intimately interconnected, one small and often unavoidable variation can threaten glycaemic equilibrium and cause hypo or hyperglycaemia. By allowing for rapid, ad hoc adaptation to such developments, disruption can be minimised.[39] As a welcome side-effect

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[38] 'Basal-bolus' systems attempt to match as closely as possible to statistically 'typical' patterns of endogenous insulin production. Those using injections (now usually via insulin pen) make use of two formulations of the hormone – one rapid-acting variety and one slow. The latter is taken once or twice daily to stabilise fasting glucose levels (the 'basal' element), while the former is taken every time food is eaten to deal with consumed carbohydrate (the 'bolus'). Those with pumps achieve the same via the constant infusion of small amounts of fast-acting insulin, increased to compensate for meals as necessary; Tattersall, *Diabetes*, p. 147-199. For one early description of the principle see R. R. Holman and R. C. Turner, 'A Practical Guide to Basal and Prandial Insulin Therapy', *Diabetic Medicine* 2 (1985), pp. 45-53.

[39] Peter Mansell, 'The Dose Adjustment for Normal Eating (DAFNE) Education Programme', *Journal of Diabetes Nursing* 16 (2012), pp. 364-369.

(and certainly, for some, a primary motivating factor), ‘intensive’ approaches often permit much greater freedom in lifestyle: so long as changing insulin requirements are compensated for there is no reason to prohibit any particular food or activity, or to abide by any rigid structure of mealtimes.

In order to be successful, ‘intensified’ insulin therapy in practice relies upon the active participation of the person with T1D, who must become proficient at judging the nutritional values of foodstuffs and determining their insulin requirements, while factoring in the impact of various secondary factors that can interact with blood glucose such as exercise, illness, and alcohol consumption. Much of the work once done by the physician is now performed by PWD themselves.[40] To a large extent, the medical professional now becomes directly involved only at the clinics most PWD attend intermittently, where complications can be screened for via glycated haemoglobin (HbA1c) testing.[41] While they quickly accepted the need for it, many early twentieth century doctors were initially uncomfortable with even the idea that laypeople might always draw up their own insulin and perform their own injections, this previously having been done only by morphine addicts (most of them members of the well-heeled classes). By contrast, many most diabetes specialists today openly advocate for patient self-reliance.

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[40] Though, as we shall see, ‘intensified’ therapy does not necessarily *require* this at the theoretical level (See Chapter 3).
[41] Feudtner, *Bittersweet*, p. 210.

Part 4: Literature

4a: T1D and Chronic Illness

Neither T1D nor diabetes more broadly received a significant amount of historical attention during the twentieth century. Notwithstanding several Whiggish accounts concerned with preserving accurate – but essentially descriptive – records of specific innovations and achievements, only the circumstances surrounding the isolation and initial clinical use of insulin were examined in any detail.[42] While this was heralded as one of the great successes of scientific biomedicine and acquired a firm place in the global – and particularly the Canadian – cultural consciousness, scholarship investigating the events in Toronto is characterised by a focus on the scientific innovations involved and the interpersonal politicking surrounding the 'discovery'.[43] As such, they do not address diabetes as a subjectively meaningful lived experience in its own right: it could easily be replaced by any other pathological bogeyman with little need for substantial editing.

As early twenty-first century scholarship has come to appreciate the conceptual value of medicine and health as vehicles for the analysis of socio-cultural structures, case studies have emerged on a wide variety of specific disease categories. Robert Tattersall (1943-), a retired diabetologist turned historian, produced *Diabetes: The Biography* as part of William and Helen Bynum's Biographies of Disease series and later followed it up with *The Pissing Evil: A Comprehensive History of Diabetes Mellitus*.[44] Tattersall's works tend to eschew deep

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[42] For examples of this kind of older teleological work, see N.S. Papaspyros, *The History of Diabetes Mellitus* (Stuttgart: Georg Thieme, 1964); Jacob E. Poulsen, *Features of the History of Diabetology* (Copenhagen: Munksgaard, 1982).

[43] For example Bliss, *The Discovery of Insulin*. The Nobel Prize received by Banting for insulin's 'discovery' was the first awarded to a Canadian citizen, and regular commemoration of the achievement, such as on postage stamps, gives an indication of the esteem in which he was (and is) held.

[44] These two works cover much of the same ground. Tattersall, *Diabetes*; Robert Tattersall, *The Pissing Evil: A Comprehensive History of Diabetes Mellitus* (Fife: Swan & Horn, 2017).

thematic analysis to focus on the general outlines of theoretical and practical development. Tattersall freely admits this, writing in the postscript to *The Biography* that 'there is a tendency to think of progress in diabetes in terms of new drugs, new insulins, and other technological developments on which I have concentrated, perhaps excessively.'[45] While he does not consciously marginalise the experience of the patient – and does indeed refer to several autobiographical accounts of T1D – the disproportionate weight of material produced by doctors and scientists in his bibliography necessarily dictates a professional orientation. Tattersall only superficially engages with T1D's socio-cultural context and the meanings bound to it by those undergoing insulin therapy and their contemporaries.

Nevertheless, Tattersall appreciates his own blind spots. Among the first to meaningfully address T1D from a historical perspective, his 1995 article 'A Force of Magical Activity' examines the initial response to insulin therapy in Britain while expressing disappointment that (with some exceptions like Eastwood, who he references) the lived experiences and social lives of those with the condition are 'difficult to discover because the scientific literature concentrate[s] on the practical aspects of therapy and the few accounts by patients stressed their miraculous resurrection and their gratitude to the discoverers of insulin'.[46] The same article introduces some of the major themes that have gone on to influence subsequent work: identifying the potentially controversial nature of self-injection, the shortcomings of early glucose monitoring technologies, and the inconsistent quality and content of patient education efforts.[47]

The Biography was narrowly preceded by the publication of Chris Feudtner's *Bittersweet: Diabetes, Insulin, and the Transformation of Illness*, a thematically focused study addressing

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[45] Tattersall, *Diabetes*, p. 197.
[46] Tattersall, 'A Force of Magical Activity', p. 754.
[47] *Ibid*, pp. 748-752.

the development of management strategies in the USA during the pre- and early insulin period. In this, Feudtner draws together and expands upon threads introduced in a string of earlier work.[48] His central thesis is that the characteristics of chronic illness are produced dynamically via what he terms a ‘cyclical process of transmutation’.[49] By this, he means that successful attempts to control the course of a condition – for example via the use of insulin in diabetes – avert certain problems inherently associated with it in its present form, but in doing so allow for the emergence of sequelae that present new difficulties. As further efforts are made to control these novel outcomes the process begins anew, creating an endless, cruel paradox in which ‘we have a hand in making the disease with which we struggle, thereby shaping the way we live and die.’[50] Apparently static disease categories are therefore limitlessly malleable on the individual level, experience taking on a unique character for each affected person as material reality is shaped by, and in turn shapes, attempted interventions.

To Feudtner, T1D provides the perfect case study for this process. Just as the characteristics of life with the condition differ markedly between an individual living today with access to the latest technology and medical care and one of the first to be treated with insulin in 1922, the experience of both differs from that of the resident of the global south who possesses only sporadic access to medical supplies. Even within similar cultural contexts, experiential divergence is commonplace. The style of insulin regimen, the use of pen-injectors over a pump, the need for dialysis or an organ transplant: all dramatically influence the way the individual lives around – or over – their diagnosis. There is a

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[48] Feudtner, *Bittersweet*; Chris Feudtner, ‘A Disease in Motion: Diabetes History and the New Paradigm of Transmuted Disease’, *Perspectives in Biology and Medicine* 39 (1996), pp. 158-170; Chris Feudtner, ‘The Want of Control: Ideas, Innovations, and Ideals in the Modern Management of Diabetes Mellitus’, *Bulletin of the History of Medicine* 69 (1995), pp. 66-90.

[49] Feudtner, ‘A Disease in Motion’, p. 167.

[50] Feudtner, *Bittersweet*, p. 43.

commonality amongst all this lived diversity in T1D, of course – the need to self-administer insulin in isolation from medical authority to stay alive, and as a result to be invested by necessity with considerable control over therapy.

While Feudtner clearly appreciates the diversity potentially contained within the label of T1D, this, perhaps understandably given his medical background, is contrasted by a slightly awkward terminological essentialism in which the autoimmune destruction of the pancreas itself is invested with vital significance in categorising an individual. However, it is uncertain how useful such an approach can be for historical analysis. At which point does a condition become transmuted to such an extent that it can no longer be understood as the same thing that it once was? Did those who experienced acute insulin deficiency prior to 1922 live with the same condition as those taking regular injections today? The natural conclusion of Feudtner's thesis would suggest that the answer is a qualified 'no'. The introduction of insulin as a viable therapeutic agent transmuted the course of the earlier condition – acute and deadly – to an almost unrecognisable form: chronic and liveable, though permanently threatening.

While the pathological origin of T1D has remained consistent since its characteristic symptoms were first described almost four millennia ago, the distinct condition with which most of those diagnosed in today's developed world live was effectively born wholesale when Leonard Thompson (1908-1935) became the first individual injected with a crude prototype insulin resembling 'thick brown muck' in January 1922.[51] Following Feudtner, this event represented the birth of what he called a 'terrible beauty': an entirely new iatrogenic condition around which new expectations, obligations, and dangers were to crystallise. The oft-repeated refrain that 'insulin is not a cure' is somewhat misleading: in banishing

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[51] Tattersall, *Diabetes*, p. 57

immediate peril it does banish, through a Faustian pact, T1D as it *was*. The material reality of managed T1D is not characterised by hormonal deficiency, but rather by the challenges inherent to insulin's exogenous administration – the substance paradoxically both cure and cause: 'a Greek myth of rebirth turned ironic and macabre'.[52] Indeed, common symptoms such as occasional hypoglycaemia invite the onlooker to suggest that, perversely, the abrupt withdrawal of insulin and resultant deficiency may constitute some form of remission, albeit almost certainly an unwelcome one.

Significantly, Feudtner makes a concerted effort to analyse the implications of T1D's transmutation from acute to chronic for the people actually affected by it. Alongside professionally produced sources, he benefits from the Boston diabetes pioneer Joslin's puritan fastidiousness, gaining access to the remarkably complete collection of papers left after his death in 1962 – patient records, correspondence, and other personal notes. Through a close examination of correspondence between the doctor and his patients, he is able to build several case studies that illuminate the challenges and expectations faced by those with T1D as it was transmued ever further from its natural course. Feudtner identifies three terms as the loci of debates concerning the way those with T1D should live: 'management', 'control', and 'responsibility'.[53] The first two are unproblematic. Different styles of 'management' involved different 'rules' and aim to achieve a particular level of glycaemic 'control'. Physicians regularly argued about the merits of different management styles, and in Joslin's early twentieth century USA context independent practitioners could freely prescribe according to their own instinct and experience with little legislative oversight. More important, however, is the concept of 'responsibility': the idea that, as an active participant, obedience to medical instruction carries a moral weight and should be

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[52] Feudtner, *Bittersweet*, p. 36.

[53] *Ibid*, p. 65.

rewarded – literally in the case of Joslin.[54] However, Feudtner notes the dark implication of this logic: 'tight control would prevent complications; patients could control their disease if they followed the rules set down by doctors; completing the syllogism, patients were responsible for their health, good or bad.'[55] A responsible patient, ostensibly, was a healthy patient, so it stood to reason that complications were a sure sign of personal irresponsibility and moral failing.

Feudtner's uncompromisingly bottom-up approach was refreshingly original at the time of publication, and admirably self-reflective given his status as a practicing paediatrician. As one of the earliest scholars rigorously examining T1D in its socio-cultural context, his deliberate aversion to overtly 'professional' sources and commitment to reconstructing the values, priorities, and meanings that emerged from its experience is undoubtedly a great strength. However, his reliance on letters sent by and to Joslin creates several limitations. His analysis of events beyond early twentieth century North America cannot become anything more than superficial. While he does address more recent developments, he does so only briefly. Additionally, lending such significant weight to correspondence between doctor and patient potentially obscures the influence of the power dynamic between the two upon what is written and how. While Feudtner is undoubtedly aware of this factor, his methodology does little to compensate for it. In a sense he is trapped by the same difficulty that plagues all efforts at bottom-up history: the voices of the marginalised are almost always distorted by proximity to the powerful, which are rarely absent from surviving sources in one form or another. Elizabeth Lane Furdell's exploration of diabetes prior to the introduction of insulin suffers from the same limitation. Extending her scope of inquiry as

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[54] Joslin's clinic awarded (and continues to award) 'victory medals' to those who reached certain milestones of longevity while exhibiting no signs of complications. It is perhaps ironic that Jack Eastwood, after half a century of disobedience – albeit principled and careful disobedience – was eligible, *Ibid*, pp. 175-176.

[55] *Ibid*, p. 175.

far back as the classical period and including substantial sections on management during the early modern period, her attempts to engage with the lived experience of PWD struggle with a simple lack of wholly 'lay' accounts.[56]

Christiane Sinding has suggested that while the publication of the results of the Diabetes Control and Complications Trial (DCCT) in 1993 (see Chapter 3) effectively demonstrated the better prognosis of PWD utilising 'intensive' approaches, the moralistic foundation of management for both T1D and T2D persisted in adapted form through monitoring technologies like the HbA1c test: 'the moral dimension of diabetology became embodied in a technical molecular device rather than being espoused in a 'catechism' as in the early 1920s.'[57] Despite this, she argues that the recent history of T1D has been characterised by 'a historical 'shift' in the doctor-patient relationship – from the constitution of the patient as an object of science to the return of the 'experiencing person', and a gradual shift towards more 'flexible norms in medicine.''[58] As one of the only scholars considering the post-DCCT history of T1D, her position has gone little challenged. It may however be fair to suggest that she optimistically overstates the issue. While some physicians – including Feudtner – have emphasised the need to take into account the priorities of PWD and base therapeutic decision-making upon them, such a project must necessarily exist within strictly delineated boundaries determined by the medical establishment. An individual living with T1D who forgoes medical advice entirely can still be widely considered 'irresponsible', even if they have fully accepted the potential implications of their lifestyle. Their capacity to

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[56] Furdell, *Fatal Thirst*.

[57] The HbA1c test measures average blood glucose values over the preceding few months; Christiane Sinding, 'Flexible Norms? From Patients' Values to Physicians' Standards' in Ernst Waltraud (ed.), *Histories of the Normal and the Abnormal: Social and Cultural Histories of Norms and Normativity* (Abingdon: Routledge, 2006), p. 237-239.

[58] *Ibid*, pp. 239-231.

determine treatment according to their own subjective needs and priorities enjoys little respect where they stray too far from the mainstream.

Martin Moore uses diabetes – primarily T2D – in a broader work concerning the emergence of highly disciplined medical labour. While his focus is significantly different from that of this work, his observation that the moralistic language of physicians in diabetic history – particularly in cases of perceived ‘irresponsibility’ – might mark a general effort to reassert control by ‘enrol[ling] patients into medicalised behaviour patterns through the moral force embedded in frameworks of metabolic ‘control’ and treatment ‘compliance’’ is highly relevant.[59] Moore’s argument implicitly accepts one of the central themes of this thesis: that physicians were acutely aware of the emancipatory potential of insulin therapy, and that ideological concerns as much as any genuine concern for the welfare of those with T1D shaped their responses to this.

The current body of work dealing specifically with T1D’s history is fairly sparse, and all extant work in this category exhibits two distinct limitations. First, a thematic link is persistently drawn between T1D and T2D. Many pieces of scholarship that address diabetes do not establish a firm initial conceptual distinction between these two conditions, and as a result implicitly accept a similarity between the two that inevitably leads to messy analytic conflation. The historical association here is inescapable, and though some scholars like Aaron Mauck have used this to their advantage to investigate the implications of ‘diagnostic ambiguity’ this approach complicates work that intends to analyse the lived experience of people with one form or another.[60] Second, they have generally relied upon printed source material that to some extent always hinders the construction of genuine bottom-up

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[59] Martin D. Moore, ‘A Question of Control? Managing Diabetes and it Professionals in Britain, 1910-1994’ (unpublished PhD thesis, University of Warwick, 2014), p. 27.

[60] Aaron Pascal Mauck, ‘Managing Care: The History of Diabetes Management in Twentieth Century America’ (unpublished PhD thesis, Harvard University, 2010), p. 21.

narratives: something that must be achieved if we are to understand the condition in its rich social reality.

A comparatively substantial body of literature exists on the topic of chronic disease more generally, some of which uses T1D as a significant case study. Interestingly, these pieces of work – in which it is only one element and not the overall focus – tend to easily avoid the implicit association between T1D and T2D so common elsewhere. Writing more broadly and thematically, they are able to shrug off the historical weight felt so keenly by those seeking to address 'diabetes' more specifically.

A general theme that runs through almost all work on life with long-term illness is that such a diagnosis does not simply constitute an additional burden thrust upon an otherwise unchanged individual but invokes a dialectical process that synthesises their perceived 'original self' with the challenges and expectations, both biological and otherwise, implied by the condition. People need not *become* their diagnosis – as some worry they might – but inevitably they must reconstitute themselves in light of it and become something wholly new. This process – the reformulation of the 'self' amidst the destabilisation wrought by chronic disease – has been described by Juliet Corbin and Anselm L. Strauss as 'biographical work'.[61]

Warwick Anderson and Ian R. Mackay's *Intolerant Bodies: A Short History of Autoimmunity* makes use of T1D as one case study in a broader analysis of autoimmune conditions – a category to which they suggest the concept of 'biographical work' is particularly relevant. Like fever in the nineteenth century, they suggest that where autoimmune dysfunction is concerned the emphasis on 'systemic derangement... prompt[s] thoughts of significant

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[61] Juliet Corbin and Anselm L. Strauss, 'Accompaniments of Chronic Illness: Change in Body, Self, Biography, and Biographical Time' in Julius A. Roth and Peter Conrad (eds.), *The Experience and Management of Chronic Illness* (Greenwich: JAI, 1987).

alteration in identity, even of the reconstitution and reformation of the individual.'[62] The perception of a body at war with itself takes on what Anna Katharina Schaffner has described as a 'reality-generating' quality, directly influencing the experience of the condition.[63] Biological disarray has a psychological corollary: it precipitates – demands – a fundamental re-ordering of the sense of self and a full re-examination of individual identity.

Anderson and Mackay give one telling example of an individual with T1D engaging in 'biographical work' following diagnosis. Peter Corris, an Australian author, was diagnosed with the condition as a teenager. Imagining those with T1D as weak and impotent, he rejected the label and, perhaps to affirm this, ate poorly, drank copiously, and smoked often. Later in life, he resolved to live more 'responsibly' after being angrily chastised by his physician for 'wasting' the expensive resources he had been given by living in a way that would see him 'blind in five years and dead in ten.'[64] Corris' experience demonstrates the challenges that emerge as an individual reconstitutes their sense of self. The diagnosis is not only medical, but is also socio-cultural. In addition to being diagnosed with T1D Corris became 'a diabetic', and in doing so became subject to a novel set of responsibilities and expectations that exerted their influence as he sought to find 'himself'. Concepts of 'responsibility' – to the self, the physician, society at large – came to the fore.

While he does not use the term 'biographical work', Arthur Kleinman has also addressed the role of chronic disease in shaping the self-perception of those who live with it. Making use of case studies gathered from his own experience as a psychiatrist, his intimate knowledge of the context of his sources gives him an advantage over scholars working

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[62] Warwick Anderson and Ian R. Mackay, *Intolerant Bodies: A Short History of Autoimmunity* (Baltimore, MD: Johns Hopkins University Press, 2014), p. 9.
[63] Anna Katarina Schaffner, *Exhaustion: A History* (New York, NY: Columbia University Press, 2016), p. 234.
[64] Anderson and Mackay, *Intolerant Bodies*, pp. 111-112.

entirely with printed and archival material. One of these short case studies concerns Alice Alcott, a forty-six year old woman who had been diagnosed with T1D as a child.[65] Raised in a Calvinist environment typical of her New England hometown, she was taught to value self-reliance, perseverance, and moral fortitude. These cultural values formed the foundation of her approach to her condition, prompting her to cultivate a tenacious attitude and live as 'normally' as possible despite it. While she was, as a result, able to enjoy an active social life, marry, and have children, such an emphasis on individual independence created its own set of problems. After having a badly infected foot amputated and developing cardiovascular issues and retinopathy, she became unable to maintain the confident and independent lifestyle she had previously valued as an integral part of her sense of 'self'. Her subsequent experience – characterised by intermittent bouts of rage and depression – can therefore be seen as a direct result of T1D's interaction with her broader life context – or, as Kleinman put it, 'Her problem was not a mental disease but a reaction, in large part (it seemed to me) justified by her suffering and disablement.'[66] Psychological and socio-cultural factors are as much a part of illness as its physical reality and can dramatically influence the experience of the individual, introducing a further layer of potential differentials to Feudtner's transmutative thesis.

Kleinman also makes another valuable observation. When he first attended to Alcott, having been summoned for his psychiatric expertise to assist with her frequent depressive episodes, he found her initially unwilling to speak to him. The doctors more familiar with her considered her irritable and unpleasant to be around, as did many members of her family.[67] After encouraging her to open up, however, he became aware that her

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[65] Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York, NY: Basic Books, 1988), pp. 32-39.
[66] *Ibid*, p. 38.
[67] *Ibid*, p. 34.

brusqueness was an expression of grief for her lost freedom and a direct consequence of her condition. The implicit message is that her regular doctors and even her family saw simply the disease that appeared on paper. By failing to understand the more nuanced interaction between disease and patient as illness is produced, they allowed a wall of misunderstanding and frustration to isolate her, further compounding her troubles and standing directly in the way of successful treatment.

4b: The Consultative Relationship

The case-studies Kleinman presents – Alcott only one amongst them – together demonstrate a fundamental anxiety at the heart of the medical project. The *expectations* with which each individual approaches treatment can vary considerably according to their own life-context, and may in turn diverge significantly from the *purpose* attached to intervention by physicians and other professionals.

Take, for example, the case of Iphigenia (not, of course, her real name) discussed by Jay Katz in his book *The Silent World of Doctor and Patient*. A newly engaged twenty-one year old, she was diagnosed with breast cancer and informed that a full mastectomy was the recommended treatment. Hesitantly agreeing to the procedure, she was approached by her physician the night before the operation. Full of misgivings about the prospect of someone so young being irreversibly mutilated, he outlined several potential alternative therapies that she had been unaware of. After some consideration, Iphigenia decided to cancel the surgery and instead opted for the much less invasive procedure of a lumpectomy alongside radiation therapy – she would remain outwardly unscarred but might perhaps have a greater chance of the cancer returning. Later addressing a panel of doctors and associated professionals, she re-affirmed her decision and expressed joy at being able to begin married life without disfigurement. Despite this, her account was met with hostility by those present, many of whom were incredulous that she had been allowed, with no medical training, to decide upon a therapy perceived as inferior – a full mastectomy being then considered the 'correct' treatment.[68] Katz does not record Iphigenia's eventual fate, but in truth it does not matter. His point is that she was, in a sense, lucky. A temporary

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[68] Jay Katz, *The Silent World of Doctor and Patient* (Baltimore, MD: Johns Hopkins University Press, 1984), pp. 90-91.

breakdown of the medical power structure had allowed her to initiate a therapeutic programme centred on her own individual needs.

As Iphigenia's example demonstrates, the asymmetric nature of the consultative relationship can be the source of great potential anxiety between its participants. Expected to take on the passivity of the Parsonian 'sick-role', the patient's individual needs are subordinated to those of the profession while their ability – and, implicitly, right – to meaningfully inform treatment is severely curtailed.[69] While this is perhaps less controversial in cases of temporary illness or injury, it is particularly problematic where long-term health conditions are concerned. Where an individual lives with chronic disease, the concept of 'successful' treatment becomes far more ambiguous. Unable to be 'cured', meaning is instead invested in more abstract, distant outcomes, and in the potential trade-offs between factors such as potential longevity, quality of life, and flexibility of lifestyle. In short, the environment of chronic disease distils the *philosophical* content of medicine, drawing into sharp focus the beliefs and values of the decision-maker – whether that be doctor, bureaucrat, or perhaps even patient – on issues of wellness and sickness, life and death, success and failure.[70]

Scholars have addressed this potentially difficult facet of medical treatment. While few doubt the commitment of medical practitioners to the welfare of their patients, authors like Katz and Kleinman have emphasised the tendency of the profession to marginalise the individual needs of those it treats in favour of a broadly reductionist focus on normalising biological function and promoting longevity. From the 1980s such overtly critical work has,

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[69] Talcott Parsons, *The Social System* (New York, NY: Free Press of Glencoe, 1951), pp. 439-447.

[70] Apart from physical disorders, this theme holds a significant amount of relevance for learning difficulties and mental health conditions, the precise boundaries of which are the subject of ongoing (and likely impossible to resolve) debate; for example see Mitzi Waltz, *Autism: A Social and Medical History* (Basingstoke: Palgrave Macmillan, 2013).

however, become less common. This may reflect a perceived shift within medical orthodoxy to accommodate the individual needs of patients – as Alex Mold has identified, reforms to the British National Health Service (NHS) under the Thatcher and Major governments tended to reframe users as citizen-consumers invested with the power to choose personally preferable treatment options.[71]

While the political language used to justify such reforms played on contemporary discourse in bioethics to lend itself a degree of legitimacy, Moore's work shows any sighting of Nicholas Jewson's 'sick-man' in these developments to be essentially illusory.[72] A central element of his thesis is that the neoliberal reformers of the NHS were committed to ensuring a highly disciplined body of medical labour. Where physicians previously had a significant amount of freedom to disagree with one another and to debate the 'grey-areas' of medical practice – the importance of strict blood glucose control in T1D, for example – these structural changes to the management of the health service came to emphasise the importance of consistency: all doctors were expected to follow 'best-practice' guidelines and to respond to any event according to agreed protocol. This, of course, is perfectly consistent with the privatising zeal of the period: if NHS users were to become consumers and the service was to compete with private options, a consistency of 'product' was paramount. Through the imposition of managerialist principles, medical practice came to be rigidly controlled: a widely unpopular development amongst practitioners.[73] 'Medical

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[71] Alex Mold, 'Making the Patient-Consumer in Margaret Thatcher's Britain', *The Historical Journal* 54 (2011), pp. 509-528.

[72] Despite the similarity of terminology, Jewson's 'sick-man' bears no resemblance to the Parsonian 'sick-role' previously mentioned. In fact, it is quite the opposite: according to Jewson the 'sick-man' characterised pre-nineteenth century medical practice in which the subjectivised perception of sickness by the individual was the focus of attention, as opposed to any objectively discernible disease entity or pathological malfunction; Nicholas Jewson, 'Medical Knowledge and the Patronage System in 18th Century England', *Sociology* 8 (1974), pp. 369-385; Nicholas Jewson, 'The Disappearance of the Sick-Man from Medical Cosmology, 1770-1870', *Sociology* 10 (1976), pp. 225-244.

[73] Moore, 'A Question of Control?', pp. 305-313.

power', Moore wryly observes, 'turned on those traditionally seen as wielding it.'[74] But while control over Foucault's 'medical gaze' may no longer be fully held by practitioners, the individual patient remains little more than an object – or rather, a collection of statistical data points to by analysed.[75] In ostensibly attempting to distil 'quality' care, nothing was done to add nuance to the term. The patient remains subject to medical authority, albeit originating from an alternative source. Their needs remain subordinate: assisted suicide is, for example, still prohibited regardless of the individual's desire to die.

Similarly, Jeremy Greene and Charles Rosenberg have shown that medical diagnosis and treatment has become increasingly standardised across the developed world since the middle of the twentieth century even while 'patient choice' has surfaced as an important rhetorical feature of healthcare discourse.[76] Running parallel to the establishment of significant public health infrastructures, this suggests that the neoliberal impulse described by Moore is only one catalyst of standardisation and bureaucratisation. Echoing Ackerknecht and Foucault's assessment of medical culture in the Parisian hospitals of the late eighteenth and early nineteenth centuries, the implicit message is that as physicians have been incorporated into the apparatus of state, their priorities have come to include concepts of public health and have become increasingly divorced from the individual needs of specific patients.[77] Whereas a sole private practitioner can prioritise the exact needs of those who engage them – and are encouraged to by the need to claim fees and maintain a good reputation – a salaried NHS professional can be seen as a single cog within a far

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[74] *Ibid*, p. 346.

[75] Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception [1963]* trans. A.M. Sheridan (London: Tavistock, 1989).

[76] Jeremy Greene, *Prescribing by Numbers: Drugs and the Definition of Disease* (Baltimore, MD: Johns Hopkins University Press, 2007); Charles E. Rosenberg, 'The Tyranny of Diagnosis: Specific Entities and Individual Experience', *The Milbank Quarterly* 80 (2002), pp. 237-260.

[77] Erwin Heinz Ackerknecht, *Medicine at the Paris Hospital: 1794-1848* (Baltimore, MD: Johns Hopkins University Press, 1967).

greater machine over which they have little control, and whose demands they must acquiesce to in order to retain their position.

Whether controlled by medical professionals or wider bureaucratic structures, modern biomedicine is characterised by a reductionist commitment to scientific principles. In its gaze disease becomes synonymous with statistically abnormal biological function, while treatment is determined according to the results of standardised clinical trials. While the practical benefit of such an approach to the development of new and innovative technologies and techniques should not be understated, Harry Collins and Trevor Pinch have explored the potential dangers of reliance on a self-consciously ‘objective’ science. Developing their ideas over three books, they describe the scientific profession as a ‘golem’ (after the powerful but difficult to control magical being from Jewish mythology), emphasising its potential flaws, its intimate connection with its social context, and the problems of its persistent image (and self-perception) as value-neutral and concerned only with ‘truth’.[78]

Collins and Pinch address the interactions between lay experience and professional expertise, discussing situations where anxiety might emerge between them and the implications of this. For example, as radioactive fallout from the 1986 Chernobyl disaster fell over rural Cumbria, scientists arrived to assess the situation, take samples, and set up monitoring stations. Local sheep-farmers – whose livelihoods had already been seriously damaged, and to whose land government representatives demanded unfettered, and often disruptive, access – were repeatedly ignored as they suggested methodological problems

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[78] Harry Collins and Trevor Pinch, *The Golem: What You Should Know about Science,* 2nd ed (Cambridge: Cambridge University Press, 1998); Harry Collins and Trevor Pinch, *The Golem at Large: What You Should Know about Technology* (Cambridge: Cambridge University Press, 1998); Harry Collins and Trevor Pinch, *Dr. Golem: How to Think about Medicine* (Chicago, IL: University of Chicago Press, 2005).

with the studies being conducted on their doorstep. In one experiment, for example, sheep were placed into fenced-in plots where bentonite – a mineral that it was hoped would absorb radioactive caesium – had been spread across the ground, before being compared with a control group that had been allowed to freely graze on the fells. When the farmers pointed out that the sheep would become ill if confined to a small area for an extended period of time their advice was neglected, and yet soon after the study had to be abandoned for exactly those reasons.[79] While far from the only source of frustration in this scenario, this demonstrates the crucial point: as self-anointed 'objective' professionals – and often implicitly social superiors – the scientists were utterly disinterested in the farmers and did not even consider that they might possess relevant insight. Simultaneously, the advice they provided to the same group compounded their arrogant, out of touch image: suggesting, for example, that sheep be given straw in place of the contaminated grass – a ridiculous proposition to anyone with experience of livestock.[80] In short, science fell victim to its own sense of 'objectivity', its failure to respect the value of lay experience an act of clear self-sabotage.

The interaction between lay and professional expertise where a clear power differential exists is plainly relevant to healthcare. Collins and Pinch investigate this in the context of medical practice by drawing attention to activism surrounding HIV/AIDS during the 1980s. Frustrated by the slow and cautious licensing process of the USA's Food and Drug Administration (FDA), grassroots organisations emerged quickly. These groups rapidly became powerful, and began to set themselves up in opposition to the medical establishment by smuggling medication and running their own community-based research programmes and trials. Most importantly, they taught those with HIV/AIDS to speak in the

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[79] Collins and Pinch, *The Golem at Large*, p. 156.
[80] *Ibid*, pp. 158-159.

accepted language of the scientific discipline and, essentially, to take on the traditional authorities at their own game by attending conferences and publishing critical articles.[81] While they took issue with elements of accepted scientific procedure in a way not dissimilar to the Cumbrian sheep farmers – randomised clinical trials, in this case – they were much more successful at being heard. Despite initial hostility, scientists and activists worked together well by the 1990s, and in many cases the learned specialist knowledge of the latter meant the two groups could appear indistinguishable.[82]

As Collins and Pinch make clear, the success of the HIV/AIDS activists was based in large part on their willingness to subsume themselves into the medical collective. They essentially *became* scientists, and used the language of professional discourse to argue for a new methodology that addressed their broader social concerns but nevertheless could stand up on purely 'objective' grounds. For example, they suggested that those undergoing clinical trials for diseases so perilous as HIV/AIDS would likely corrupt any potential results by turning to external, supplementary sources of medication like buyer's clubs. As a result, studies would consequently achieve more meaningful results if all participants were given the actual drug under investigation – while the need for a 'sacrificial' control group was also averted.[83] The case of the HIV/AIDS activists is however simplified by the broad agreement between all parties about the goal of treatment. Despite initial hostility on professional grounds, almost everyone agreed that the priority should be curing, or halting the progression of, the virus. While it is certainly a long-term condition, the microbial basis of HIV/AIDS precludes any significant disagreement at the fundamental therapeutic level. The activists' issue was with the speed and efficiency of research, and with the ethical

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[81] Collins and Pinch, *Dr. Golem*, pp. 177-178.

[82] With the interesting consequence of divisions emerging within the activist community between the scientifically literate and others; *Ibid*, p. 178.

[83] *Ibid*, p. 171.

implications of precluding those in control groups from potentially life-saving medication, not the general principle, or priorities, of treatment.

The experience of HIV/AIDS activists demonstrates the reductionist attitude of orthodox biomedical science – their success came as the result of their willingness to accept this orientation and work within its framework. One of Collins and Pinch's recurrent themes – medicine as succour vs medicine as science – illustrates the ongoing problems with this approach. Medicine, they hold, is at once a science and a source of relief: a collective enterprise devoted to explaining and perhaps circumventing particular biological events and an individual attempt to reduce suffering regardless of bodily factors at work.[84] The demands of these two faces often contradict one another – as in the case of HIV/AIDS, where the careful introduction of demonstrably safe therapies had to be balanced with the needs of those already suffering and dying. Since the nineteenth century, medicine has increasingly adopted this primarily scientific form while its other face has taken a back-seat: expressed, for example, in the importance of 'evidence-based medicine' to state organisations like the NHS.[85]

When medicine is approached not as an objective 'science' but as a source of succour its meaning is far less clear. Outside of the realm of national bureaucracies and scientific departments, this is the face most relevant to the individual experience of illness. It is also one that lacks reductionism and counts its successes based on the personal satisfaction of those it treats. Collins and Pinch conclude their book on medicine, *Dr. Golem*, by warning that their critique should not be read as an endorsement of 'a facile populism under the banner of consumer choice.'[86] While this is undoubtedly a fair point to make, and the fact

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[84] *Ibid*, pp. 2-3.
[85] *Ibid*, p. 31.
[86] *Ibid*, p. 223.

that medical science has great value is indisputable, this tells us nothing of the profession's other face – of how to define succour. Take, for example, their example of Martin Delaney, a San Francisco HIV/AIDS activist. When previously undergoing a clinical trial for hepatitis, he had been administered with a subsequently withdrawn drug that had freed him of this condition but had led to nerve damage. Despite this, he considered the treatment a success and pushed for those with HIV/AIDS to be allowed to undergo potentially damaging therapies if they wished to.[87] In short, Delaney did not dismiss medical science, in fact he directly endorsed it. What he challenged was the right of the profession to determine 'acceptable risk' – a wholly individualised concept. He took issue with the unquestioned authority of the values of orthodox medical science over more abstract personal notions considerations.[88] While medical science has achieved many great things, we should not allow it alone to colour our assessment of health in the broad sense: biology is only one part of a much greater whole.

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[87] *Ibid*, p. 160.

[88] He is far from the only relevant example used in Collins and Pinch's work. For example, they draw attention to a certain subculture within the bodybuilding community which actively encourages its members to become scientifically literate in order to effectively make use of illegally obtained steroids; *Ibid*, p. 125-127.

4c: Conceptualising Health

In the context of T1D it is particularly important to discuss the meanings we attach to health. This is because, while the scientific medicine surrounding it is largely uncontroversial, its chronic status and the therapeutic control of PWD within its management makes it a battleground upon which the purpose of medicine as succour can be hashed out. While the interests of medical science usually dominate proceedings, the material conditions of insulin therapy strip away much of its traditional power to determine the character of treatment and allows those undergoing it to ask (and answer) questions about their health without any *physical* impediment. In order to make sense of T1D and its implications for medical practice, it is important to spend some time examining the variety of definitions and meanings that can be attached to health-related issues. Fortunately, this is a growing field of scholarly interest.

During the 1980s it became common for those in the humanities and social sciences to distinguish between disease as an imposed classificatory construct and illness as experienced by the individual sick-person, often as part of polemic literature heavily critical of a perceived trend to biological reductionism in medical orthodoxy. The aforementioned work by Katz and Kleinman contains an implicit normative message – illness and disease must be conceptually separated both analytically and practically. They felt that medical practice required the integration of a fundamental awareness of, and respect for, the meanings the sick attributed to their own suffering in order to make it fit for purpose.[89] In short, they wanted to separate the concept of 'illness' as experienced from that of 'disease' as diagnosed. Rosenberg acknowledged the analytical value of this distinction but suggested that, like Foucault before them, such authors unhelpfully envisioned a static

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[89] Katz, *The Silent World of Doctor and Patient*; Kleinman, *The Illness Narratives*.

arrangement in which diagnosis fulfilled a solely objectifying and alienating function. Instead, he felt it important to emphasise the reflexivity of such concepts, suggesting that in addition to their capacity to marginalise, 'disease categories provide both meaning and a tool for managing the elusive relationships that link the individual and the collective, for assimilating the incoherence and arbitrariness of human experience to the larger system of institutions, relationships, and meanings in which we all exist as social beings.'[90] In essence, the concept of disease, while categorising us, also allows us to contextualise our suffering, make sense of it, and begin to reconceptualise our 'self' in light of it.

In a sense, Rosenberg sees the reductionism inherent to the diagnosis of a particular condition as a vital prerequisite to successful 'biographical work' – without the perception of understanding, however grounded in truth, he believes it impossible to make sense of, and eventually overcome, suffering. This can be witnessed clearly in the case of Chronic Fatigue Syndrome (CFS). With ambiguous and largely subjective symptoms centred on long-term exhaustion and a highly elusive aetiological source, CFS has been the source of significant controversy as many physicians – and other commentators – have simply refused to consider it a 'real' illness.[91] In her recent monograph on chronic exhaustion, Schaffner identifies the scepticism with which many approach those with CFS – sometimes described in value-laden terms as 'yuppie flu' or 'lazy cow syndrome' – and the militancy with which those living with it respond, denouncing anyone who suggests that it lacks a pathological basis.[92] Ironically, Schaffner herself has come under fire from this quarter

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[90] Rosenberg, 'The Tyranny of Diagnosis', p. 257.

[91] Edward Shorter is one such example amongst historians; Edward Shorter, *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era* (New York, NY: Free Press, 1992).

[92] Schaffner, *Exhaustion,* p. 184 -189.

despite her conscious effort to avoid value-judgements.[93] Even the presentation of alternative aetiological theories – or rather a failure to condemn them – is read as an unacceptable implicit endorsement of their potential viability.

As Rosenberg has pointed out, the CFS patient lobby has not sought to emphasise their need to be understood holistically according to a patient-oriented model incompatible with contemporary medical cosmology.[94] Instead, they have adopted the same reductionist values of object-oriented epistemology, insisting aggressively and at every turn that there *is* a biological basis for their illness waiting to be uncovered.[95] While the CFS lobby clearly hopes to encourage further research by legitimising the objective 'reality' of their condition, their need to be recognised as *sick* demonstrates Rosenberg's earlier point: without a named 'disease' to blame, their suffering is meaningless and they are unable to engage in effective 'biographical work'. CFS is far from a unique case – 'contested diseases' crop up across the spectrum of heath, from chronic pain to allergy to sick building syndrome.[96]

Contested conditions can be directly contrasted with what might be termed 'diseases of probability' – diagnosable pathologies that lack symptoms and cause no immediate

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[93] For example, see the Amazon reviews of her work, *Amazon.co.uk* <https://www.amazon.co.uk/Exhaustion-History-Anna-K-Schaffner/dp/0231172303/> [accessed 08/12/16].

[94] Charles E. Rosenberg, 'What is Disease? In Memory of Owsei Temkin', *Bulletin of the History of Medicine* 77 (2003), pp. 498-499.

[95] Perhaps this is why CFS now enjoys greater attention and legitimacy than other contested conditions. Echoing the HIV/AIDS activists of the 1980s USA, CFS patient groups have consciously allied themselves with, and sought to participate in, modern biomedical orthodoxy rather than setting themselves up in opposition. By emphasising the biological 'reality' of CFS as the product of some hypothesised internal process, acquiescence to the demands of the patient lobby on the part of physicians becomes possible.

[96] In addition to Schaffner's work on exhaustion, there are numerous other studies dealing with potentially contested diseases. For example, Matthew Smith, *Another Person's Poison: A History of Food Allergy* (New York, NY: Columbia University Press, 2015) and Michelle Murphy, *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Durham, NC: Duke University Press, 2006). Many of the cases in Kleinman's work fall also into this category, especially those concerning patients in chronic pain centres; Kleinman, *The Illness Narratives*, pp. 172-186.

suffering. Greene has investigated the emergence of such conditions within medical discourse.[97] Generally unthreatening in themselves, issues like hypertension and high cholesterol suggest the possibility of future deterioration if left unmanaged. Such conditions have significant and often troubling implications for the person concerned. Frequently puzzled by their categorisation as somehow not healthy despite feeling well, the individual struggles to reconcile their own perception of health with the diagnosis of disease. One recent study illustrates this, quoting one hypertensive person interviewed as having insisted that 'I have to feel sick, or have a sore neck, and then I'll have my blood pressure taken', while another suggested that 'the doctor told me [my blood pressure was high]… but I didn't think that was important.'[98]

In some cases, this draws attention to the reflexive nature of 'disease' and 'illness' that Rosenberg highlights – by diagnosing a pathological abnormality in the absence of perceived sickness it is possible to iatrogenically create suffering. Kleinman describes one middle-aged man who, despite recovering well from a heart attack he had suffered some years previously, took on the medicalised language of his physicians to describe his condition as 'terminal'. The anxiety and stress resulting from his diagnosis and the subsequent sustained attention of medical professionals overwhelmed and disheartened him, permeating his everyday life and leaving him unable to constitute a meaningful sense of self.[99] Despite the presence of what had become a relatively unthreatening pathological abnormality, his own perception of illness was constructed in his social milieu.

It is therefore possible to delineate three interconnected but separate features of health. 'Illness' is the *individual* experience of feeling unwell. This is ultimately a wholly subjective

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[97] Greene, *Prescribing by Numbers*, pp. 2-3.
[98] Juan J Gascón, Montserrat Sánchez-Ortuño, Bartolomé Llor, David Skidmore, and Pedro J Saturno, 'Why hypertensive patients do not comply with the treatment', *Family Practice* 21 (2004), p. 127.
[99] Kleinman, *The Illness Narratives*, p. 151.

category that remains unknowable to all but the person living through it. A headache, cramp, or waves of nausea are perceived internally and in isolation from wider experience. ‘Disease’, on the other hand, is a *social* category conferred upon the individual by a community via the process of diagnosis. In being characterised as ‘diseased’, they are cast in a special role that invests them with – or condemns them to – a distinct set of immunities, obligations, and expectations separate from those of the general population.[100] To these, it is necessary to add a third category: the reality of harmful internal biological processes that develop as the body contends with age, systemic malfunction, or interaction with external agents – ‘pathology’, for lack of a better term. Together these concepts map the terrain of health, influencing one another in a reflexive constellation but nonetheless constituting distinct entities in their own right. In most simple cases they complement and inform one another while raising few difficult questions, but on occasion anxieties between them can arise – such as in the case of CFS or hypertension. Where there is discord between these conceptual categories, the self-consciously ‘objective’ edifice of medical orthodoxy begins to crumble. By observing the cracks that appear as a result, it is possible to examine the reality of concepts of health and sickness as they shape, and are shaped by, the individuals and communities with which they interact.

So what of T1D? Pathologically, a form of biological malfunction is clearly involved in producing the deficiency of insulin that characterises the condition. This, consequently, makes it a relevant disease category according to the principles of scientific biomedicine –

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[100] It is important to point out that the medical profession is only one such group – though a privileged one. Homosexuality, for example, used to – and, unfortunately, sometimes still does – represent a lay-constructed disease category amongst certain communities: Jennifer Terry, ‘The Seductive Power of Science in the Making of Deviant Subjectivity’ in Vernon A. Rosario (ed.), *Science and Homosexualities* (New York, NY: Routledge, 1997).

the management and control of which therefore falls under its remit.[101] However, it is deeply ambiguous as an illness. Those living with managed T1D do not feel unwell for the great majority of the time, and only experience related personal illness in the context of potential complications like hypoglycaemia and long-term sequelae. As suggested by Feudtner's thesis, illness in insulin-treated T1D is a fundamentally separate entity to the pathology that informs its diagnosis. The transmuted disease observed by medical science can be likened to a 'disease of probability' from which – dependent on therapeutic approach, lifestyle, and blind luck – further pathologies may or may not emerge. Any illnesses that result should therefore be understood as consequences of these potential sequelae: *secondary* diseases prompted by, but not the same as, T1D. In itself, T1D can be understood as a pathologically grounded disease but not as an illness per se, though certainly a condition which portends potential future difficulties. It is this particular character that makes it so analytically valuable: a 'disease of probability' in which the affected have no choice but to attempt to balance their own personal needs with the knowledge of barely concealed and ever threatening danger, often in isolation from professional instruction.

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[101] Interestingly, like other 'unseen' conditions some communities may be reluctant to acknowledge T1D as a legitimate 'disease' due to its lack of obvious symptoms. For example Alcott noticed that her peers regularly wrote off the severity of her condition and the reality of her struggles with it: Kleinman, *The Illness Narratives*, p. 39.

Part 5: 'Existential Eudaimonia' and the Emancipatory Paradox of T1D

The idea of eudaimonia features heavily in many works of classical philosophy. While quite difficult to translate directly, it denotes a hypothetical state of well-being in which the individual leads a 'good life'. One of the key attributes of eudaimonia, and one that distinguishes it from simpler concepts such as happiness, is its multi-faceted nature: personal health, familial contentedness, job satisfaction, and so on might all feature. It is not necessary – and would in fact be counterproductive – to attempt to present categories for eudaimonia here, only to emphasise its fundamental premise: a 'good life' is attained via the confluence of several elements and cannot be reduced to any single one of those without demeaning the whole exercise.[102]

Classical scholars – and many subsequent ones – approached the idea of 'eudaimonia' as what might be described as a deontological challenge. Much of their work is concerned with determining rules to live by and attributes to cultivate in the pursuit of the 'good life', but such accounts naturally emphasise priorities contingent on the cultural context of the author: to Aristotle philosophical contemplation and participation in the political life of the city-state were significant components, but these likely would have significantly less relevance to, for example, a medieval peasant.[103] The inherent tension created by this changeability can be somewhat resolved by adopting an existentialist perspective towards eudaimonia as a concept. By abandoning the idea that the term has – or can have – an essential meaning contained within it, and rather seeing it as an empty vessel to be filled with the uniquely subjectivised values that arise from individual experience, the nebulosity that at first appears a weakness becomes its greatest strength. To attain this 'existential eudaimonia' one must follow no rule but their own: it becomes simply an indicator that the

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[102] Darrin M. McMahon, *Happiness: A History* (New York, NY: Atlantic Monthly Press, 2006), pp. 3-4.
[103] *Ibid*, pp. 45-47.

individual's material conditions of existence are sufficient to enable them to live in accordance with their own self-determined value system and as a result to achieve self-actualisation.

According to this principle, the attributes of a 'good life' must be subjectively formulated by each individual according to their own values, priorities, and desires – its precise definition shifting from person to person and from moment to moment as visions of 'fulfilment' diverge, continually reshaping themselves in light of new experience and insight. Some may invest great meaning into professional success, others to ensuring the security of their families, and yet others to personal health and vitality, or to something else entirely. These individualised eudaimonic ideals come to shape the lives of each person as they act to fulfil them and to achieve self-actualisation.[104] Material reality, however, presents kinks in the road: some minor (e.g. a demotion at work), some near-insurmountable (e.g. living amidst war and absolute poverty).

Our approach to our biological existence is an integral element of any eudaimonic ideal. Do we prioritise longevity at all cost? Should we throw caution to the wind and live hedonistically despite the potential consequences? Or would we be best treading a line somewhere between these two extremes, and if so where should that line be? These are all questions that can be answered only by the individual concerned as they seek to live in accordance with their own conception of the 'good life' – as they construct what Georges Canguilhem might have termed 'normative theories of health'.[105]

But biology is also material; our bodies may *be* us, but they also *limit* us. As we are threatened by age, sickness, and injury, new barriers are thrown up that may challenge our

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[104] Where the term is used, 'eudaimonic ideal' should be understood as shorthand for 'individually subjectivised value-system, life-priorities, and attribution of meaning'.

[105] Georges Canguilhem, *The Normal and the Pathological* [1978] trans. Carolyn B. Fawcett (New York, NY: Zone Books, 1991).

capacity to achieve our goals. In addition to the physical constraints of weakness and infirmity, we are also thrown into the midst of power structures over which we have little control. We enlist the aid of physicians and other HCPs, whose authority over us ensures that it is *their*, not *our*, needs that are prioritised. While we (usually) have the power to accept or reject treatment, we must accept the therapy offered by medicine, or accept none at all.[106] It is after all (usually) the doctor who must provide final approval for any decision: for example by writing a prescription. As Collins and Pinch have made clear, the approach of medical science may be fundamentally divergent from an approach based on succour – or, in other words, one that takes into account our eudaimonic ideal.

The great majority of those subject to medical authority are not as fortunate as Katz's Iphigenia. They must acquiesce to the demands of this power structure, whether it is in accord with their own needs or not. Control over potential treatment – and therefore over a significant portion of the very biological fabric of humanity – remains outside of the control of the individuals to whom it means the most. By contrast, T1D is unusual in that its treatment is, by necessity, *fully under the control of those receiving it*. While it is often listed as one of the prototypical 'chronic' diseases, this is in reality a superficial and perhaps over-simplified reading of its nature. T1D is undoubtedly a long-term condition, but it is fundamentally distinct from the majority of others in that class. It is important to take some time to ask what we truly mean by chronicity here. Most definitions generally emphasise 'invisibility' (except to proper medical screening procedures) and the potential to cause disability or impact longevity, citing such examples as atherosclerosis and hypertension. In contrast, T1D is immediately threatening and relies upon the constant administration of precisely measured insulin to prevent catastrophe. Unlike T2D, it cannot be unknowingly

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[106] Many alternative practitioners do of course offer a wide array of therapies from acupuncture to homeopathy and everything in between. However, for the purposes of this work the term 'therapy' will be limited to those based on orthodox biomedical science.

lived with for years, and those who develop it suffer acute illness without treatment. In practice, it is perhaps better to understand T1D not as a chronic disease per se, but as a *chronically treated acute condition*.[107] Understood in this way, it becomes rather a different beast: one of the only imminently life-threatening medical conditions that must in all but the rarest circumstances be treated by the person experiencing it. The practical realities of daily (at least) insulin injections necessitate that PWD must become proficient at self-injection, dose calibration, and self-monitoring – only the very wealthiest can afford to have an attendant HCP permanently on hand to assist.

All individuals are provided with a common set of tools: insulin and the means to administer it. There are no viable ‘alternative’ therapies and there is little scope for disagreement on the basics – all parties agree that T1D results from a lack of insulin and therefore no one disputes that its replacement is the ‘proper’ treatment.[108] However, this is only half of the story. Within the context of insulin therapy, long- and short-term outcomes can vary considerably based upon the way in which it is used. Consequently, PWD are able to alter their approach even where this conflicts with the ‘optimal’ regimen as determined by medical orthodoxy – whether this is based upon a genuine distrust of professional opinion or simply an alternative priority in treatment.

While in the majority of medical conditions the doctor possesses a final veto, able to block a proposed treatment by simply refusing to prescribe or endorse the drug or procedure they consider unwise, this privilege is at the basic level rescinded in cases of T1D. Physicians and

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[107] A vanishingly small category that may potentially include cases of dialysis-treated End Stage Renal Disease; Steven J. Peitzman, *Dropsy, Dialysis, Transplant: A Short History of Failing Kidneys* (Baltimore, MD: Johns Hopkins University Press, 2007).

[108] Excepting a tiny number of fringe cases, such as the small minority of religious fundamentalists who reject insulin (and biomedicine generally) in favour of prayer – often with predictably tragic consequences; Associated Press, ‘Christian Scientists Found Liable in Death’, *New York Times* (1993), 19 August, <http://www.nytimes.com/1993/08/19/us/christian-scientists-found-liable-in-death.html> [accessed 10 February 2017].

other professionals might express consternation where they feel that their instructions are going unheeded, but they have no real power to influence treatment. Those with T1D are in effect freed from the structures of medical hierarchy and control that so colour the experience of so many other conditions.[109] They are free to experiment with and vary their approach at will, and do not rely upon the approval of any medical professional in order to do so.[110]

The material conditions of insulin therapy therefore result in it taking on a paradoxically emancipatory character. PWD can undoubtedly feel trapped and worn-down, but within its structure there is also the opportunity to achieve genuine bodily sovereignty by adapting treatment to fit subjective requirements. This is not to downplay the importance of other external pressures such as employment, but to suggest that within the context of T1D *medical* influence can often be bypassed. What precisely is done with this may vary considerably according to the other forces at play – Eastwood was unique in that his privileged background minimised such factors. Simultaneously, his commitment to the therapeutic goals of his physicians (despite his alternative method of achieving them) may have insulated him from significant criticism. Nevertheless, there is significant potential for anxiety between PWD and medical professionals where treatment objectives differ – priorities that become ever more complex as individuals are exposed to greater internal and external pressures.[111] As a result, insulin therapy forces us to engage deeply and

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[109] This applies to basic treatment and excludes certain very specific cases, such as when individuals have had requests for NHS provision of expensive equipment like insulin pumps rejected.

[110] Though, while this power to inject more or less insulin, or to alter dietary or lifestyle factors, has remained consistent throughout the history of T1D, its implications for management have, as we shall see, not. The prescription of a shorter-acting insulin like that developed in 1921, for example, allows for a high degree of flexibility in approach – as in the case of Eastwood – that longer-acting varieties produced later in the century do not (see Chapter 4).

[111] The case of Arnold Burns discussed by Feudtner, for example, demonstrates this process starkly; Feudner, *Bittersweet*, pp. 132-143.

critically with the conceptual boundaries of wellness, and to consider abstract questions about what medicine is ‘for’, and how we should determine its ‘success’ or ‘failure’.

Part 6: Arguments

This thesis is a work of social history, and one that concentrates on the lay experience of health – of T1D in the latter half of the twentieth century – while taking a particular interest in the interplay between the lived reality of insulin therapy and the ideological processes that shaped it. As a result, it is necessary to make the admission that it is, consequently, relatively light on discussion related to the scientific and technical history, and similarly does not engage at any significant length with more formal institutional and policy-related factors. These are worthy subjects for focused analysis in their own right, but to incorporate them to an extent sufficient to do them justice here would, I think, be overly ambitious in a work of this length, though I acknowledge that this treatment does lead to the omission of some notable discussion points surrounding, for example, public health policy. There is, of course, considerably more to unpack in the history of T1D than I could possibly have achieved in a single thesis, and I hope that future work continues make use of what is a fascinating condition with much to say about health, medicine, and society.

With that said, the central thrust of this work is derived from a series of interrelated observations. While there have always been isolated cases of individuals who *had* used the emancipatory potential of T1D to engage – like Eastwood – with entrenched attitudes towards health and medicine, for much of the post-insulin period they remained very much in the minority, particularly by the latter half of the twentieth century. As we shall see, many appear to have not only accepted their passive role, but also the idea that it was vital to the continued success of their treatment. During the late 1980s, however, we begin to see evidence of the beginnings of a significant anxiety in T1D management. Letters to *Balance*, the organ of the BDA (British Diabetic Association) from this period begin to occasionally describe a perception of dismissiveness and arrogance on the part of medical staff and allied professionals.[112] This is in sharp contrast to earlier correspondence that was characteristically humble and uncritical, representing an emergent challenge to the right of the medical establishment to determine and police definitions of wellness. After a period of tension, however, 2002's DAFNE programme appears to have consciously attempted to reconcile, superficially at least, lay-assertiveness with professional authority.

This thesis presents three central arguments. First: efforts by British HCPs to, from the 1980s, ensure stricter control of blood glucose amongst their patients was initially driven largely by increasing consensus that hyperglycaemia was implicated in the development of long-term diabetes-related sequelae. Originally taking the form of a cautious move towards the incorporation of very limited self-adjustment of dosages by laypeople within 'conventional' therapy, the formal publication of the results of the DCCT – which had been running throughout the 1980s – made this untenable. While the full adoption of the DCCT's recommendations was not considered feasible – the impressive biomedical outcomes achieved in this clinical trial, it was widely felt, would be difficult to replicate amongst the general public given the labour and resource costs deemed necessary to provide adequate support to each individual – towards the end of the study and particularly following its publication HCPs began to encourage their patients to adopt 'semi-intensified' approaches that incorporated 'basal-bolus' strategies into essentially prescriptive frameworks, preserving the traditional power relations of twentieth century medical practice. Such approaches nevertheless demanded the provision of increasingly sophisticated self-diagnostic technologies such as self-blood glucose monitoring (SBGM) equipment, alongside shorter-acting – and therefore more flexible – types of insulin. Simultaneously, innovation in insulin delivery methods facilitated the discreet, simple, and quick correction of sub-optimal results. This energised an emancipatory potential within T1D that had been

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[112] The BDA continues to operate under its rebranded name Diabetes UK.

suppressed by the kind of longer-acting or mixed formulations (that required fewer daily injections, but which relied upon considerable dietary and lifestyle rigidity) that had become ubiquitous by the late twentieth century. 'Semi-intensified' therapy therefore allowed for individual refinement and experimentation at a level that had not previously been possible for those now utilising it, assisting in the development of tacit knowledge.[113] Initially intended as a way to preserve professional authority, by allowing for de facto individual experimentation this development in fact contributed to an increasingly assertive patient-body that provoked significant anxiety amongst professionals as they worried about the implications of further lay-autonomy for the health and longevity of both their patients and their careers.

Second: the official adoption of lay-led 'intensified' management in the form of DAFNE must therefore be seen as not merely a biomedical development but as the product of a confluence of political, technological, and pragmatic factors. The tools necessary for 'semi-intensification' were identical to those required for full 'intensification', and after their widespread provision physicians had quickly become aware that, despite regular warnings of the dangers of 'non-compliance', they were increasingly unable to prevent a significant number of those with T1D from unilaterally taking charge of therapy to an extent most had not previously seen.[114] DAFNE, alongside similar programmes that followed in its wake, can therefore be read in a distinctly *ideological* context.[115] Gaining considerable purchase in the

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[113] To borrow Harry Collin's terminology, PWD were able to develop relational tacit knowledge – that is, knowledge that could be described, but in this case may well contradict its professional corollary; Harry Collins, *Tacit and Explicit Knowledge* (Chicago, IL: University of Chicago Press, 2010), pp. 85-98.

[114] It is perhaps unsurprising that Greene dates the emergence of the word 'non-compliance' in medical discourse to the 1960s and 1970s, as chronic diseases and the role of the state in population health were becoming major subjects of debate; Jeremy Greene, 'Therapeutic Infidelities: Noncompliance Enters the Medical Literature', *Social History of Medicine* 17 (2004), pp. 327-343.

[115] Several other lay-education training programmes quickly followed DAFNE. The most significant of these was BERTIE (Beta Cell Education Resources for Training in Insulin and Eating), which it narrowly preceded and with which it has a long-running rivalry; Malik Asif Humayun et al, 'Intensive structured education for type 1 diabetes management using BERTIE: Long-term follow-up to assess

neoliberal climate of the New Labour era by appearing to demonstrate the potential value of the NHS' Expert Patient's Programme (EPP) (an initiative that attempted to – ostensibly at least – promote the idea of the patient as rational consumer, invested with the freedom to make choices about their own body), DAFNE turned 'conventional' therapy on its head by radically reconceptualising the HCP as a vital, though passive, source of advice, while transferring all overall control and responsibility to the layperson, to whom much of the necessary additional labour of 'intensification' was now outsourced. In doing so, it effectively killed two birds with one stone: by ensuring lay-autonomy was *embraced*, fully 'intensified' therapy could be effectively implemented in a way that nevertheless preserved professional interests.

Third: despite the widespread adoption of 'intensified', lay-led therapy in T1D management, many unresolved anxieties remain. As suggested by the neoliberal origin of DAFNE-style approaches, PWD are not merely accepted as the primary moral actor within their own treatment, but are often *expected* to participate regardless of their own willingness to take on the extra work and pressure that this implies. Additionally, as physicians have taken a more passive role, the moral dimension of insulin therapy so epitomised by Joslin's philosophy has become crystallised. As the primary decision-maker within therapy, accountability for clinical outcomes has shifted ever further away from the practitioner and toward the PWD, posing awkward questions about the boundaries of responsibility and duty within the consultative relationship. Compounding this, medical science has effectively retained control over the arbitration of *meaning* in health within the broader discourse around T1D. Through the use of assessment procedures like the HbA1c test, practitioners are able to identify and, occasionally, discipline those who fail to meet

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impact on glycaemic control and quality of life indices', *Diabetes Research and Clinical Practice* 143 (2018), pp. 275-281.

collectively determined expectations of control. While those on insulin therapy are more able than most to work towards their eudaimonic ideal, and, particularly with the development of physical and internet-based support networks, to provide mutual assistance and advice, their right to do so freely is by no means universally accepted, exposing an ongoing unease about the purpose attributed to medicine by individuals, professionals, and state actors.

Part 7: Methodology and Sources

In 1985, Roy Porter called for a new way of studying the history of medicine that emphasised the role of the patient. Concerned that preceding scholarship had been characterised by a teleological focus on scientific advancement, he suggested that more attention should be given to 'bottom-up' analyses that fleshed out and interpreted the experiences of the hitherto invisible recipients of medical attention. As a social interaction between physician and patient, he felt that the consultative relationship could never be properly understood while one half of it was ignored.[116]

This thesis follows Porter in his commitment to understanding the lived experience of those contending with disease and illness. However, it also acknowledges and works with Flurin Condrau's later observation that his stated objective is self-limiting and impossible to achieve satisfactorily while old categories like 'patient' and 'disease' remain static.[117] The choice of T1D as a case study is directly inspired by this point: its complex conceptual layers make it a perfect lens through which to isolate and challenge such traditionally held definitions. Using an approach that Condrau may find surprising, this work will attempt to resolve the dichotomy he appears to perceive between 'empirically driven accounts of the history of patients and... a more Foucaultian perspective which emphasises the patient as a construct of the medical sciences.'[118] Examining a condition that is considered a disease by medical science but is not characterised by meaningful personal illness, it will utilise sources produced by individuals whose status as 'patients' is decidedly uncertain to investigate and engage with concepts of definition and categorisation in heath.

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[116] Roy Porter, 'The Patient's View: Doing Medical History from Below', *Theory and Society* 14 (1985), pp. 175-198.

[117] Flurin Condrau, 'The Patient's View Meets the Clinical Gaze', *Social History of Medicine* 20 (2007), pp. 525-540.

[118] *Ibid*, pp. 535-536.

This thesis will focus on the UK, primarily subsequent to the foundation of the NHS in 1948. The context of this universalised healthcare system, alongside domestic political developments during the period in question, are central to understanding the themes discussed. While occasional references and comparisons to other nations are made, this work makes no effort to elucidate the history of T1D in any other country.

In terms of sources, this work will take an ethnographic approach, making significant use of oral testimony from those living with, and those involved in the treatment of, T1D to build a meaningful body of upward facing empirical source material fleshing out the subjective experience of both parties. Despite some initial hostility, oral history has emerged as a widely accepted methodological approach for scholars across the humanities and social sciences. As Lynn Abrams has noted, one of its greatest strengths lies in its ability to 'uncover the experiences of a number of groups who had traditionally been disregarded by conventional histories: women, gays and lesbians, minority ethnic groups and the physically and learning disabled to name the most prominent.'[119]

Oral history's potentially emancipatory character makes it a natural boon to the production of studies 'from below'. This has been particularly valuable to scholars working on human conflict, where the historical context has often led to the loss – and sometimes deliberate destruction – of physical records.[120] By directly engaging with the individual, this methodology can also overcome many of the limitations inherent in sources to which the

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[119] Perhaps for this reason, it has also been used extensively for political purposes – for example in South Africa's Truth and Reconciliation Commission; Lynn Abrams, *Oral History Theory,* 2nd ed (London: Routledge, 2016), p. 4.

[120] For example, Graham Dawson, *Making Peace with the Past: Memory, Trauma and the Irish Troubles* (Manchester: Manchester University Press, 2007); Susana Kaiser, *Postmemories of Terror: A New Generation Copes with the Legacy of the 'Dirty War'* (New York, NY: Palgrave Macmillan, 2005); Erin Jessee, *Negotiating Genocide in Rwanda: The Politics of History* (Basingstoke: Palgrave Macmillan, 2017).

historian is a third party, allowing for the collection of focused data and the elucidation of genuinely subjective values.[121]

Oral history is therefore at once an exploration of the past and a dynamic and creative effort to shape our interpretation of it. As Abrams has argued, it is both a methodological approach *and* the end result of that approach – both the object and productive process that creates it.[122] Cast as an active participant in the production of source material, the scholar is afforded a rare opportunity to tailor its character according to the demands of their own research focus – but also places upon them a responsibility to ask the 'right' questions and to do justice to the experience of the narrator.[123]

It is important to recognise the potential challenges brought up by the peculiarities of oral history as a source of historical data. The dialogue between researcher and speaker is not merely a statement of experience but also a narrative performance shaped by those involved in its production – by the choice of questions put forward by the scholar and the individual priorities and concerns of the respondent. Contributing to the complexity is the intersubjective relationship between parties: the way in which an interviewee's perception of the researcher – based on race, gender, nationality, even something as simple as how they are dressed – can directly inform the narrative they deliver. Together these factors interact to determine what is said and, just as important, what is not.

These issues are starkly visible in a recent piece of work by Erin Jessee on the 1994 Rwandan genocide. Reflecting on her interviews with the perpetrators of often shocking

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[121] Written material is always subject to an editorial process whether self-imposed or otherwise. The letters used by Feudtner, for example, tend to be pieces of correspondence between Elliott Joslin and his patients, in which the latter are unlikely to have mentioned things he would have found disagreeable.

[122] Abrams, *Oral History Theory*, p. 2.

[123] Anna Sheftel and Stacey Zembrzycki, 'Who's Afraid of Oral History? Fifty Years of Debates and Anxiety about Ethics', *Oral History Review* 43 (2016), pp.338-366.

crimes, she is struck by the effort with which they attempt to legitimise their actions. For example, her work opens with a discussion of Philippe, a convicted génocidaire who 'participated willingly in the massacre of Tutsi women, children, and elders who sought refuge in his local church, as well as in the hunting of Tutsi survivors in the fields, forests, and swamps, the raping of young Tutsi women, and the looting of Tutsi homes.'[124] Largely unapologetic about the atrocities he committed, Philippe uses the context of the interview to construct a narrative in which he is the victim – imprisoned by the Tutsi administration for his participation in a justified rebellion against an elite minority that had historically oppressed its Hutu neighbours. His account is plainly a political statement as much as overtly historical one.

Additionally, Jessee recognises the importance of acknowledging the impact of intersubjective factors on her work. As a Western academic, she is aware that those she engages with will sometimes attempt to engage in 'ethnographic seduction'.[125] That is, she understands that the narratives she is presented with – whether by perpetrator, survivor, or bystander – might be consciously constructed to encourage her to 'adopt their truths', and imbue them with legitimacy 'via [her] perceived status as an international expert'.[126] The knowledge that her cultural capital might grant her the influence to shape broader understanding of this period of Rwandan history directly informs the content of the accounts available to her.

The politically charged context of genocide draws these issues into sharp focus in Jessee's work, but they are inevitable features of any oral history project. Ronald Johnston and Arthur McIvor's investigation of asbestos-related disability and sickness amongst the

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[124] Jessee, *Negotiating Genocide*, pp. 1-2.

[125] The term is Antonius Robben's; Antonius Robben, 'Ethnographic Seduction: Transference and Resistance in Dialogues about Terror and Violence in Argentina', *Ethos* 24 (1996), pp. 71-106.

[126] Jessee, *Negotiating Genocide*, p. 15.

industrial workers of Clydeside includes an admission that some might criticise oral testimony as ‘unrepresentative and distorted’ – of relying on source material in which narrators have said what they felt was expected, or conversely attempted to embellish and/or omit evidence to fit polemic objectives.[127] Similarly, in her recent monograph on men working in reserved occupations during the Second World War, Alison Chand refers to Graham Dawson’s insight that the memories underpinning narrative accounts of reserved occupations are often ‘composed... according to social and cultural understandings of their reserved employment, both in wartime and the time period in which the interviews were undertaken, decades later.’[128] However, as Chand identifies, intersubjective factors do on occasion prove beneficial. While their perception of her as a young, educated, and relatively privileged woman meant the elderly, working-class, and largely male narrators she interviewed sometimes approached her with a degree of uncertainty, their frequent assumption that she was, as a result, entirely ignorant of industrial working practices allowed her to collect highly detailed testimony. Likewise, as a woman she found many of them significantly more willing to talk about things discouraged in traditionally ‘masculine’ discourse – particularly topics related to their emotional experience.[129]

Consequently, oral history as a source must not be understood as contemporaneous with physical documents produced during the period under investigation, but as an artefact created during the interview itself: its content informed by the subjective and intersubjective factors at work during that precise moment. An interview conducted today may well take a significantly different form to one conducted a year from now, even if the

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[127] Ronald Johnston and Arthur McIvor, *Lethal Work: A History of the Asbestos Tragedy in Scotland* (East Linton: Tuckwell, 2000), p. 222.

[128] Alison Chand, *Masculinities on Clydeside: Men in Reserved Occupations During the Second World War* (Edinburgh: Edinburgh University Press, 2016), p. 20; Graham Dawson, *Soldier Heroes: British Adventure, Empire, and the Imagining of Masculinities* (London: Routledge, 1994), p. 25.

[129] Chand, *Masculinities on Clydeside*, pp. 21-22.

topic and all other factors remain consistent: the present is as important as the past. Testimony is not so much a historical source – at least at the time it is spoken – as it is a source *about history*.

Abrams suggests that the scholar making use of this methodology sets out to determine four things – 'what happened, how they felt about it, how they recall it, and what wider public memory they draw upon.'[130] However it is tempting to suggest that her first point is slightly misleading. The challenges inherent to oral history ensure that it *cannot* be a true and accurate retelling of precise historical fact but can *only* constitute perception. Instead, as Alessandro Portelli – one of the pioneers of the discipline – has emphasised, interview testimony must never be considered *factual*, but rather valuable in its ability to elucidate the meanings attached to events as individuals incorporate experience into the broader material and ideological context of their lives. Introducing his seminal work on the death of the young Italian steelworker Luigi Trastulli in 1949, Portelli explains that he was first drawn to the stories surrounding this event 'because their imaginative errors expressed the shared subjective dreams, desires, and myths of the narrators.'[131] Oral testimony is limited as a means to access meaningfully accurate data on historical fact, but is invaluable to an understanding of the individual as a *historical actor*.

In many respects, the use of oral history directly enables us to take up Condrau's challenge – reconstituting the individual as a complex whole rather than struggling to observe them through the murky lens provided by assorted pieces of correspondence and other written material. This study will join the growing corpus of work consciously applying this methodology to the study of health history that was – perhaps unintentionally – initiated by

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[130] Abrams, *Oral History Theory*, p. 78.

[131] Alessandro Portelli, *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History* (New York, NY: State University of New York Press, 1991), p. ix.

Kleinman nearly three decades ago.[132] Interviews will be facilitated by the relatively recent focus of the work – dealing primarily with developments from the mid-twentieth century means that there is no shortage of living individuals who have dealt with T1D throughout the period in question.

This thesis uses oral history testimonies from both those living with T1D and HCPs responsible for providing care to those with the condition. These participants were recruited via a range of strategies. First, Diabetes UK was approached and agreed to include a brief advertisement for the study in both the print and online editions of *Balance*. Second, social media provided an excellent avenue for recruitment, particularly within Twitter's informal 'diabetes online community'. Third, in a small number of cases, high profile medical professionals were contacted directly with interview requests. Fourth, on several occasions a meeting with one participant allowed contact to be made with another. The recruitment approaches employed were very successful, and more potential interviewees were identified than could realistically be included. However, this meant that participants could be effectively selected to represent a diverse range of demographics. All interviews followed a semi-structured format, utilising a common basic framework while allowing for flexible discussion. While my own status with T1D potentially enabled me 'insider' status with some of those I interviewed, I consciously avoided mentioning this unless directly asked to minimise assumed knowledge and, in the case of certain HCPs, significantly

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[132] For example, Johnson and McIvor, *Lethal Work*; Arthur McIvor and Ronald Johnston, *Miner's Lung: A History of Dust Disease in British Coal Mining* (London: Routledge, 2007); Joanna Bornat, Robert Perks, Paul Thompson, and Jan Walmsley (eds.), *Oral History, Health, and Welfare* (London: Routledge, 2000); Nancy K. Bristow, *American Pandemic: The Lost Worlds of the 1918 Influenza Epidemic* (Oxford: Oxford University Press, 2012).

altering the nature of the interview by placing me into a Parsonian ‘sick-role’.[133] An appendix providing a full list of participants is provided following the main text of this work.

Oral history testimony is complemented by an analysis of the relevant archival and printed material, which is particularly useful for reconstructing the approaches of medical professionals. For example, back-issues of *Balance* effectively demonstrate the development of anxieties within the consultative relationship in the context of T1D (and T2D). As an official publication aimed at laypeople but with a significant professional presence on the editorial board, the content of (and response to) its letters pages, alongside the type of articles it chose to publish, can be very informative. Government produced policy documents, self-help guides written by physicians, and traditional journal material are also assessed. Finally, evidence from the social media platform Twitter is used to help elucidate ongoing issues in T1D management. As an almost unprecedentedly horizontal platform with no editorial policy, such sources present a (perhaps unlikely!) window into the interplay between lay and professional spheres. As this kind of evidence is non-physical, ephemeral, can be deleted at any time, and is reliant on the commercial and technological stability of the servers upon which it exists, screenshots of all cited material of this type is included in an appendix for posterity.

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[133] It was often fascinating that, on occasion, the nature of conversation with HCPs changed after revealing my status post-interview. A small though not insignificant number immediately adopted a professional tone and began to question me about the particulars of my own treatment. This is a major intersubjective issue that, had it occurred prior to recording, would have drastically altered the testimonies produced. For more on the concept of ‘insider’ and ’outsider’ status in oral history, see Rob Perks and Alistair Thomson, *The Oral History Reader*, 3rd ed (Abingdon: Routledge, 2016), p. 137.

Part 8: Chapter Outlines

This work will be split into four distinct sections. The first three will be overtly historical, and will examine the nature of insulin therapy alongside the way in which its character interacted reflexively with its social, technological, and political context, analysing the experience of the condition for both PWD and HCP from the creation of the NHS in 1948 until the DAFNE programme's official announcement in 2002. The fourth chapter will be more philosophical – and more political – in tone, assessing the characteristics of therapy today while highlighting the themes and problems that persist.

Chapter 2 will present an outline of the lay experience of 'conventionally' managed T1D. Focusing primarily on subjective evidence gathered from original oral history interviews, it will map the lived experience of the condition and the perceptions of those affected. Through an analysis of the variety of 'rituals' that characterised life on insulin therapy, it will highlight the often significant differences between orthodox management on paper and in practice, making particular reference to ways in which – and reasons why – individuals chose to defy defied medical authoritarianism, and the social and professional consequences of doing so. It will go on to explore the development of patient perceptions as they began to utilise 'semi-intensified' therapy, highlighting perceived shifts in experience both in their relations with doctors and society more broadly.

Chapter 3 will constitute an ideological analysis of traditional medical authority in T1D, paying particular attention to the response of HCPs to growing evidence in the late 1970s and 1980s that hyperglycaemia posed a statistically significant risk-factor in the development of sometimes serious long-term complications related to T1D, and arguing that efforts to 'intensify' therapy came as a direct consequence of the realisation that 'conventional' approaches led to sub-optimal outcomes by the standards of the medical model. It will go on to outline the way some very cautious moves towards the acceptance of laypeople making minor adjustments to their insulin dosages were made during this period, highlighting the palpable hesitance of HCPs as they discussed this possibility. Finally, it will engage with the publication of the results of the DCCT in 1993 and the widespread reaction to its conclusions in the UK, arguing that HCPs began to advocate unpopular 'semi-intensified' approaches as a result of the perceived economic infeasibility of adopting the DCCT's recommendations across the board.

Chapter 4 will discuss the origins of 2002's DAFNE programme. Situating its argument in the context of an emergent neoliberal political climate, it will argue that the novel material conditions of 'semi-intensified' insulin therapy allowed for greater de facto lay-autonomy than had previously been possible. In this context, DAFNE can be understood as an ideological adaptation that successfully harnessed the privatising zeal of New Labour to engage productively with an increasingly assertive patient-body while retaining a privileged position for HCPs by reconceptualising them as remote sources of support.

Chapter 5 will consider some of the ongoing challenges in T1D management in the wake of DAFNE, engaging with the themes raised throughout this thesis to critically appraise our contemporary approach to health, well-being, and medicine. It will unpick the precise meaning behind oft-repeated concepts such as 'patient-led care', before engaging with some of the remaining areas of contestation in T1D management as we move into the 2020s. Finally, it will outline a tentative programme of suggestions for improvement, arguing that the case of T1D contains lessons with broad relevance to the management of all chronic disease, and to some extent the entire way we conduct medical practice and think about health.

Chapter 2 – The Lived Experience of ‘Conventional’ Insulin Therapy

‘And I would often be, you know, sat up the night before diabetes clinic colouring in like that...

Making sure that there was a spattering of orange and green obviously!’

Gillian Clifton, Interview

Part 1: Lived Experience

After its transmutation to chronic form by the commencement of insulin therapy, T1D is no longer characterised primarily by the autoimmune process from which it originated. While DKA remains a risk, especially for pump users, few of those diagnosed in Britain now die as a consequence of insulin insufficiency.[134] No longer immediately terminal, T1D instead became a long-term condition linked to a variety of potential co-morbidities. The drive to *cure* has, accordingly, been overtaken by a focus on effective long-term *management*. The post-insulin history of T1D has been defined primarily by the development of a variety of strategies of control, while the search for a 'magic bullet' has been relegated to the background – always present but of little direct day-to-day relevance. The 'severe' diabetes that existed at the turn of the twentieth century ceased to exist for those who could access insulin, replaced by an iatrogenic experience shaped and textured through the cyclical interplay of deterioration and intervention.

Before it is anything else, T1D is a lived experience. Unlike many other long-term conditions, it is not defined primarily by meaningful physical or mental illness. It rarely produces pain, confines the individual to bed, or interferes significantly with the demands of daily life (though it may complicate them). Instead, it is characterised by the routine behaviours demanded of the individual by the adopted strategy of control. Insulin must be administered and dietary requirements considered; therapeutic efficacy must be assessed and the infrastructure of healthcare engaged with. The pathological root of T1D causes immediate sickness via DKA only in rare cases following the adoption of insulin therapy,

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[134] Even a small amount of slowly processed basal insulin in the bloodstream can avert DKA despite significant hyperglycaemia. Pumps, however, rely on the constant infusion of rapidly metabolised short-acting formulations. In the case of mechanical failure, deterioration can be startlingly swift.

assuming access to insulin is maintained and sufficient is used.[135] However, the often taxing demands of self-management may, in their interaction with an individual's life context, constitute in themselves a source of ill-health. T1D as we understand it is wholly iatrogenic: an entity born in early 1922 at the intersection of pathology and medical interventionism.

While the pathological root of T1D lies in the destruction of the insulin producing β-cells of the pancreas, most immediate illness experienced by those living with the condition is a consequence not of this but of the concerted effort to prevent hypoglycaemia or the development of potentially threatening long-term complications associated with hyperglycaemia. Associated ill-health in the case of T1D is therefore primarily a reflection of the interaction between the demands of management and the broader life context of those undergoing it. As a source of illness, therefore, it is infinitely malleable – its precise character contingent upon the individual living with it. The nature and magnitude of their health or sickness is determined not by the condition itself as a conceptual category, but by the strategy of control adopted and the person concerned. It is therefore vital that the importance of the subjective world of the PWD is appreciated fully as a meaningful construct that both shapes, and is shaped by, the experience of life with T1D.

Martyn Hammersley and Paul Atkinson have suggested that ethnography is but one thread of many that together characterise the 'dynamic tapestry' of social science and humanities research.[136] Oral history is certainly one strand with which this particular approach is deeply intertwined. Like the ethnographer, the oral historian is concerned with charting the contours of experience within particular settings, and contextualising that experience alongside broader social, political, and economic trends. This is not to say that either seeks

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[135] Severe hyperglycaemia and the onset of DKA, of course, represents the only *absolute failure* of insulin therapy.

[136] Martyn Hammersley and Paul Atkinson, *Ethnography: Principles in Practice,* 3rd ed (London: Routledge, 2007), p. 2.

to reconstruct a painstakingly accurate vision of what *is* or *was* – or, to put it another way, to reveal a hidden *truth*. Rather, the goal for both is to elucidate the *lived experience* of those individuals or communities studied, concentrating on the process by which such subjects assign value and interact with the wider world.

This thesis is not a work of ethnography, at least in the sense that Hammersley and Atkinson would understand it. As a historian, it is impossible to conduct the kind of fieldwork integral to such an approach.[137] Instead, the oral historian is able to work only through the retrospective accounts of those narrators who lived through a particular event or era. Nevertheless, a close analysis of the variety of ways in which T1D has been experienced and understood by those living with it is an essential foundation for the central arguments of this thesis. As this is a condition shaped in large part by socially contingent factors, an ethnography-influenced approach provides excellent access to the 'bottom-up' patient's perspective. T1D cannot be understood by recourse only to professional publications and official documentation. By taking the time to concentrate entirely on the narratives of laypeople while relegating grander medico-scientific discourse – for now – to the periphery, an otherwise inaccessible depth of meaning can be tapped. Accessing this invaluable resource will be the focus of this chapter.

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[137] *Ibid*, p. 3.

Part 2: Expectation, Routine, and Private Ritual in 'Conventional' Insulin Therapy

While Frank Kaye (1939-) describes the way he used to sterilise his injection equipment, his wife Sylvia interjects to claim that the process constituted 'a ritual'.[138] This is a succinct way of expressing the routine characteristics of T1D management, but how accurate is it? This is a difficult question, as the word itself continues to defy simple definition. 'Defining 'ritual'', Ronald L. Grimes suggests, 'is like defining 'jazz'' – there are as many answers as there are people asked, none of them fully satisfying.[139] As fascinating as the digression would be, however, ritual studies is well outside the scope of this work and a working definition is required. One passage Grimes cites from a (now dated) work by Pascal Boyer comes close:

> I posit that human rituals are generally recognized as such by virtue of features that apply to many types of animal displays as well. Stereotype, repetition, and the rigid sequencing of elementary actions are all aspects that make animal and human ritual structurally similar.[140]

While this is by no means an incontestable position – and indeed Boyer acknowledges this – it provides a useful heuristic approach to identifying ritualistic behaviour.[141] Does insulin therapy constitute a series of ritual behaviours by Boyer's criteria, as Kaye suggested? Certainly it seems so.[142] More importantly, if we can categorise the labour of T1D

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[138] Frank Kaye and Sylvia Kaye interviewed by Stuart Bradwel, 22nd June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[139] Ronald L. Grimes, *The Craft of Ritual Studies* (Oxford: Oxford University Press, 2014), p. 186.

[140] Pascal Boyer, *The Naturalness of Religious Ideas: A Cognitive Theory of Religion* (Berkeley, CA: University of California Press, 1994), p. 189.

[141] *Ibid*, p. 185.

[142] Boyer, like most scholars working on ritual, hails from the discipline of religious studies. Unsurprisingly, his primary (though not only) concern is therefore faith-based ceremony – generally speaking rather symbolic in nature. This should not, however, be taken as to mean that ritual must by definition lack a functional component. As Barry Stephenson has pointed out, growing awareness of ritualised behaviour in the animal world 'brought human rites and ceremonies, often associated with lofty concerns, back down to Earth, linking ritual to everyday run-of-the-mill social life, locating ritual in the body and group interactions rather than in the heavens'; Barry Stephenson, *Ritual: A Very Short Introduction* (Oxford: Oxford University Press, 2015), pp. 11-12.

management as such, what does this actually *mean*? All insulin therapy is not, of course, alike. As discussed in Chapter 1, approaches to management can, broadly speaking, be separated into two strategies of control: 'conventional' and 'intensive', the latter of which did not become prevalent until the latter end of the twentieth century. For most of its history, insulin therapy was characterised primarily – though not exclusively – by a reliance on what we now understand as 'conventional' treatment. The following discussion will, therefore, address this approach except where otherwise indicated.

'Conventional' approaches to insulin therapy involved the expectation that those with T1D would engage in a series of defined behaviours at predetermined points throughout the day. While the precise content of these actions could differ between cases, their basic shape remained the same. For example, one person may have been prescribed ten units of soluble insulin to be taken at eight o'clock in the morning, while another was instructed to take five units at nine o'clock. These behaviours are aligned *in principle* despite considerable variety in detail.[143] However, these broad routines are not rituals in themselves – they are public, external expectations shaped by the contemporary paradigm of medical orthodoxy. The ritual of diabetic care is almost entirely *private* – created by the interplay of expectation, life context, and subjective value. Nonetheless, delineation of the public expectations of routine that characterised 'conventional' therapy provides a useful structural framework for the analysis of such private ritual.

First, and highly symbolic of T1D as a whole, is the routine of administering insulin itself. Traditionally achieved via injection, this is a universal constant of life with the condition. It

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[143] There were of course exceptions to this existing on the fringes of medical orthodoxy. For example, 'free diets' were promoted by a minority of mid-twentieth century physicians who disputed the idea that glycaemic control and long-term complications were related. As a result, they tended to take a rather liberal attitude toward dietary restriction. These cases were not common, and as such they are not addressed in detail here, though they shall be returned to in Chapter 3; Tattersall, *The Pissing Evil,* pp. 158-159.

is a daily necessity that cannot be ignored without inviting rapid and catastrophic deterioration. The administration of insulin is, however, not as simple as occasionally piercing the skin with a needle. The expectations of ‘conventional’ therapy stipulated that medication must be taken at the correct time in pre-determined dosages, while administration equipment must be carefully prepared and maintained as necessary.[144]

Second, diet is a vital component of management. At first glance this may appear a strange observation, for the process of taking nourishment is a universal one around which many of everyone’s private rituals are centred.[145] However, for those with T1D – and particularly those on ‘conventional’ therapy – the dietary consideration is an all-encompassing and vitally important feature of life. The consumption of a suitable amount of carbohydrate at the correct time is vital should it be expected to interact properly with injected insulin and, so it is hoped, ensure normoglycaemia.[146] In the context of ‘conventional’ therapy, strict dietary guidelines were generally provided as part of the prescribed course of medication.

Third, the effectiveness of therapy must be assessed. Today, blood glucose concentrations can be measured quickly and easily via the use of a variety of handheld monitors. While such devices did begin to be introduced to clinical practice from the late 1970s, urinary testing was considerably more common in ‘conventional’ management for much of the twentieth-century. In the very early post-insulin years this was generally achieved by boiling urine with Benedict’s solution before assessing the colour of the remaining mixture. Clinitest tablets and reagent strips went some way towards making this process more

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[144] The latter, of course, remains vital regardless of approach.

[145] For example, anything from the preparation of a favourite meal to the complex etiquette of fine dining could be considered to possess ritualistic qualities.

[146] To complicate things further, non-carbohydrate foodstuffs can have unpredictable effects of blood glucose levels. Highly fatty foods, for example, can slow digestion and, as a result, cause a delay between consumption and the subsequent impact of glycaemic levels.

efficient and less offensive to the nose, but the principle remained the same.[147] Those with T1D were generally encouraged to test often and to record the results for consultation by staff during clinical visits.

Fourth, in order to access treatment at all the individual with T1D needed (and needs) to engage with the local healthcare infrastructure – for the great majority of those in the UK after 1948, that is, with the NHS. Pharmaceutical products and equipment vital to management must first be prescribed by a physician, and subsequently dispensed by a chemist. The expectation to attend regular clinical reviews has long been a feature of T1D for those on both 'conventional' and 'intensive' therapy. Such occasions afford the opportunity for medical staff to make an assessment as to the effectiveness of treatment and suggest amendments if not satisfied, while screening for potential complications.

These four broad expectations of routine form the loci of T1D's interaction with the broader life of the affected individual. Some, such as the administration of insulin, are vital to survival and cannot be ignored wholeheartedly, while others are less important to immediate health but nonetheless feature heavily as expectations in the accepted framework of care – regular attendance at clinical reviews, for example. All of those with T1D must engage with each of these demands to one extent or another, and in doing so establish a private ritual of self-management that reconciles in some fashion their own needs with that of the broader demands of treatment. To put it another way, there is a *routine expectation* of 'conventional' therapy common – in principle at least – to all those who are, officially, subject to that regimen. This is not, however, a *ritual*. There is no defined stereotypy: similarities exist only in the broad lines of abstraction. Ritual emerges

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[147] Clarke and Foster, 'A History of Blood Glucose Meters', p. 90.

when the abstract principles of expected routine and the subjective world of the individual collide to determine its precise form.

This is a vitally important distinction. There is a reason that Kaye alluded to the term in the way in which she did. Rituals are not merely heavily prescribed routines but rather conceptual and behavioural stores of meaning. They are more than their specific physical content suggests, and are capable of illustrating the values, priorities, and anxieties of those who create them. In the context of T1D, the analysis of private ritual reveals much about the way those with the condition understand themselves and their predicament. As Feudtner has suggested, T1D is a condition in a constant state of flux and transmutation – complications arise and are treated, giving rise to further complications. As a result, continuous adaptation is required. By observing the private rituals of those with T1D, we become privy to information that reveals in intimate detail the process by which, following Anderson and Mackay, the self, along with its private rituals, is continuously reconstituted.

What do these subjectivised private rituals of self-management mean for the experience and treatment of T1D in the context of ‘conventional’ therapy? How do they tie into the broader history of the condition and those living with it? The broad routines previously identified provide an excellent framework by which to begin answering these questions. By identifying and contextualising the private rituals that relate to each, it becomes possible to demonstrate the variety of meanings that those living with T1D have attached to the condition, its management, and their own health over the twentieth century.

Kaye is not alone in alluding to the frequent necessity of sterilising needles and syringes. Indeed, this was a common feature of life with T1D prior to the proliferation of disposable plastic variants and, later, insulin pens. Vic Marriott (1946-) remembers using 'glass syringes... with metal fittings... [that had] to be boiled or sterilized in surgical spirit' after his diagnosis in 1955, while Anne Cooper (1963-) was discharged from hospital almost fifteen years later 'with a glass syringe... [and a] really old fashioned metal needle' having been instructed 'to boil it fairly regularly to sterilise it, and... to change the needle fairly regularly.'[148] These narrators, however, tend to simply describe the ways in which hygiene was maintained without revealing much about its meaning in their lives. For most it appears to have been simply a monotonous aspect of everyday life, and not one that posed any real difficulty: no more personally important than taking out the bins or any other chore. It is after all no great hardship to spend a few moments boiling some water. For most, sterilisation became as routine as making a cup of tea – and about as outwardly meaningful too.

There are exceptions, however. Gillian Clifton (1961-) gives a fascinating glimpse into the potential depth of meaning hidden beneath the monotony of everyday life with T1D. Diagnosed in 1967 at only six years old, she describes the daily routine of a childhood with the condition:

> I have very clear images actually, in my mind, of those days, because my brothers had a boiled egg for breakfast and mum used to put my glass syringe and a steel needle in the pan with the boiled egg to boil it all up, and then – certainly to begin

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[148] Vic Marriott interviewed by Stuart Bradwel, 9th May 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections; Anne Cooper interviewed by Stuart Bradwel, 12th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> with and possibly for the first couple of years – my dad used to do my injections for me and so we used to... draw it all up then we went upstairs to the bedroom so he could do my jab for me.[149]

The nostalgic aura of this passage is palpable. It is replete with references to Clifton’s immediate family, while the private rituals of T1D appear intertwined with those unrelated to the condition. The ostensibly superficial detail of a stovetop pan is highly symbolic here. Clifton describes her mother boiling her needle and syringe alongside the eggs her brothers would eat for breakfast. The rituals of T1D and the rituals of daily life exist alongside one another – or rather they are one and the same. Diagnosed as a young child, diabetes for Clifton was an integral part of life itself rather than an unwelcome intruder. In short, the act of sterilisation had become wholly incorporated into the structure of her existence. Her memory of this occasion is as much a general recollection of childhood as it is one concerning a private ritual associated with T1D. The nature of the passage makes this clear – it *involves* T1D but it is not wholly *about* it. It is also about familiarity, safety, and home.

There is more overt symbolism in Clifton’s account of the preparation of equipment than in the testimony of other narrators. However, she supports the earlier suggestion that this ritual was defined in a sense by its *lack* of immediate meaning. As a fairly innocuous routine, it demanded little. This is instructive, but what, then, makes an act *meaningful* in this context? Anderson and MacKay’s work provides a clue – the reconstitution of the self in light of chronic illness arises from a realisation that the status quo *cannot* be maintained and that new approaches to health and life are necessary. The individual with cirrhosis of the liver may be forced to acknowledge that their continued life depends on, among other things, abstinence from alcohol. A cancer patient must come to terms with the reality of

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[149] Gillian Clifton interviewed by Stuart Bradwel, 8th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

chemotherapy-induced exhaustion and its impact on their day-to-day existence. These new approaches may constitute major, or only minor, disruptions to the status quo, and it is important to recognise that the severity – and consequently the intensity of meaning – of such events must occur on a spectrum. The meaningfulness of these life changes are directly proportional to the level of reconstitution demanded: by how much it threatens the *original sense of self* – what might be called the *ego cost* of adaptation. This is of course wholly individualised. What constitutes a sacrifice is directly relative to the values of the person making it. Loss of hearing, for example, might – though by no means must – demand a far more radical reconstitution of self for the musician than it would the writer. Sterilisation of equipment, then, is certainly a private ritual of diabetic management, but it is not one that is commonly invested with considerable meaning. Other demands, however, ask a greater toll.

The preparation of equipment is not performed for its own sake, but to enable the passage of insulin into the body. Throughout the twentieth century this has primarily been achieved via injection. Until, and in many cases for some time after, the introduction of disposable syringes in the late 1950s, relatively large metal needles were used almost ubiquitously. Given the crudity of this equipment, it is little wonder that the prospect of self-medicating was often met with a degree of anxiety – particularly in children.

Mary Moody (1949-) remembers distancing herself from taking injections after her childhood diagnosis in 1954:

> I didn't really start injecting 'till I was older, because I just refused to inject. I would only have injections in my arm, and as you can see my arms are... a bit of a mess. And my mother used to just walk past me and stick the needle in. And in these days

> they were like big, thick, glass syringes with the big thick needles and... I was into my teens before I actually started using these myself.[150]

Margaret Howie (1965-), diagnosed at the age of eight in 1974, was similarly averse:

> I didn't do my own injections ‘till I was about eleven or something. I didn't mind having injections, I just couldn't actually do it. I do remember my mum and dad getting me... a long sort of crossbow thing... metal thing that you put your syringe into and you had to fire it, which didn't help in the slightest really. And then I also remember one that you put... [a] cover... over the bottom of the syringe [so] that you couldn't see the needle. That was a bit better, and eventually, when I was maybe twelve, I sort of actually finally plucked up the courage and once I'd done one it was fine.[151]

Despite Howie’s contention that she ‘didn’t mind having injections’, it is clear that she approached the ritual of receiving them with no small amount of trepidation.[152] An aversion to injections is of course no strange thing. Few people enjoy having sharp implements pierce their skin. The physical – and perhaps psychological – pain associated with such an event is of course the major object of contention here. Pain is neither a common nor a welcome experience to most healthy people, particularly in the West and amongst children. But pain itself is superficial. More important is what the sensation represents.

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[150] Mary Moody interviewed by Stuart Bradwel, 18th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[151] Margaret Howie interviewed by Stuart Bradwel, 27th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[152] The ‘crossbow thing’ Howie refers to is almost certainly a Palmer Injector or similar. These devices were built to hold a prepared syringe that would automatically inject its contents in one movement at the click of a button. While they were designed to spare the subject the task of pushing down the plunger manually, the speed of the mechanism makes Howie’s allusion to medieval weaponry understandable. Similar paraphernalia was advertised regularly in *Balance* prior to widespread use of insulin pens. For example see Figure 2.1.

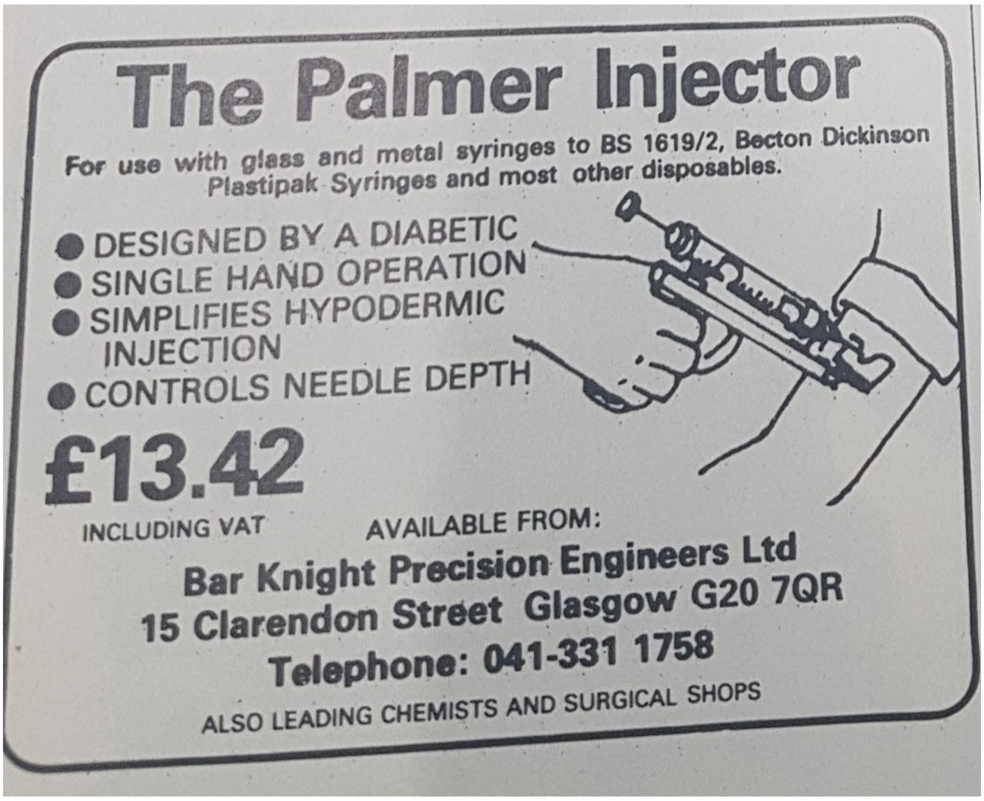

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Figure 2.1: Advertisement for 'Palmer Injector', *Balance*, Oct/Nov 1987, p. 12.

Like Howie, Clifton's parents performed injections for her as a young girl. Usually, this was her father's responsibility: 'My mum couldn't face doing the injections, and if she did have to do them, if Dad was away, then I had to kind of lay down. It really made her feel quite poorly.'[153] Clifton's mother can easily be compared to Howie, for the actions of both speak to the investment of similar meaning into the ritual of insulin administration. To inject insulin regularly is to acknowledge a change of circumstance in a direct and unavoidable way. It is to accept that 'normality', as it was understood, has been disrupted – and is in fact to *create* this change through the act of doing.

Actions like the boiling of needles and syringes can be abstracted but the visceral and invasive nature of piercing the skin – either of the self or of a loved one – confronts the

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[153] Clifton, Interview.

individual with the inescapable reality of the situation and at once confirms it. For better or for worse, things are different. By avoiding the duty of administering insulin, however, Clifton’s mother avoided acknowledging that her daughter had changed even where, in truth, she had. But unlike family members, the individual with T1D cannot avoid this responsibility forever. Howie was able to avoid performing her own injections while her parents would act out the ritual by proxy, but in doing so she only delayed the inevitable reconstitution of self demanded. It is telling that once she ‘plucked up the courage [to perform an injection]’, however, she ‘was fine.’[154] In doing so she acknowledged her new reality and recognised the need to change and adapt along with it.

After those with T1D begin injecting themselves, few appear to struggle with the act itself. Notwithstanding individuals with severe needle phobias, the pain of injections, after it has been acclimatised to, is not particularly significant. ‘Conventional’ insulin therapy asks little mental labour of its adherents compared to its ‘intensive’ relative. What work exists is so heavily pre-determined as to be simple, and is primarily conducted in the home. As Moody recalls, ‘There wasn’t really that much to do in these days. [The injection] was only once a day in the morning, and also it didn’t really matter. You didn’t have to do it when you were out or anything like that.’[155] Precision in timing is a key demand, but this is an issue of self-discipline. As a young man, Mike Turner (1944-) remembers having his injection ‘at 8am every morning. 8.30 wasn’t good enough. Everything was fixed. You had a fixed amount of carbohydrate and a fixed amount of insulin and you stayed with it.’[156] ‘Siobhan’ was diagnosed in 1971 at the age of seven, and elaborates on the consequences of this:

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[154] Howie, Interview.

[155] Moody, Interview.

[156] Mike Turner interviewed by Stuart Bradwel, 29th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> Whereas now... children will do blood glucose at school, and the school will react to whatever that result is, that didn't happen because you did that in the morning. You had an injection and your day just went on. Chances were you had a packed lunch because obviously your parents could control what you were eating. You had to have a Penguin or chocolate Club bar at 10.30am at break time because that's the amount of carbohydrate that you had in the morning at break time. But in those days, that was no different to any other child that had a chocolate biscuit at break time. You weren't singled out or any different. There was no knowledge of the fact that if you exercised it would do different things to your blood sugar so nobody panicked, but on the positive side you weren't really... any different to anyone else... [and] you were never stopped doing anything. So, I was never stopped going on a school trip. I never stopped taking part in anything. There was never an expectation that I wouldn't do something.[157]

'Conventional' therapy is meticulously pre-determined. Injections are taken at defined times, usually once or twice daily. Whereas today's 'intensive' therapy demands constant vigilance via regular blood tests, self-assessment, and corrective action, mid-twentieth century 'conventional' treatment required little thought outside of a few defined routines. As a result, and as 'Siobhan' highlights, T1D was less visible and in many respects less obstructive. As a child, she escaped being socially ascribed a 'sick role' because her condition was almost entirely invisible to those outside of her home, suggesting – in her words – that 'a little bit of ignorance actually helped.'[158] This is a deeply revealing statement. To 'Siobhan', the rigidity of 'conventional' therapy had an upside. Her *immediate* quality of life was better than it perhaps would have been had she been born

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[157] 'Siobhan' (pseudonym) interviewed by Stuart Bradwel, 15th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.
[158] *Ibid*.

several decades later. The ability to play with other children without being ‘othered’ was of great value, and perhaps carried more weight to her than strictly optimal glycaemic control would have.

Anxiety over being seen as ‘different’ is a common theme amongst those with T1D. Even as of 2017, ‘Siobhan’ makes a point of hiding her condition where possible: ‘I never inject in a public place. I always go and find a loo or quieter place or whatever to inject.’[159] This is not an uncommon response to the demands of therapy. Clifton admits that the condition did little for her self-confidence. ‘I did feel different. I did feel embarrassed by it, and certainly when I went away to college I didn't want anybody to know.’[160] Lisa Tozer (1972-), who was diagnosed at thirteen in 1985, remembers going to considerable lengths to hide her T1D. As a student, even those she lived with only discovered about it after she became seriously ill:

> I was living in halls of residence... [and] probably drinking way too much. Had gone to bed one night and had a hypo in the night and didn't wake up. And it must have been a university friend realised I wasn't at breakfast, you know, didn't see me during the day. And I don't know what they did. I don't know whether they got someone to unlock the door. I think they must have done. But an ambulance was called.[161]

To be seen to inject is, of course, a clear indicator of difference, at least compared to the statistically average individual. Few people must do so regularly. The potential for Othering is clear: injections are the stuff of illness or, even worse to many, drug abuse. It is not surprising that so many attempted to hide their condition, and worried that it might hinder their efforts to make friends or establish relationships. As a teenager, Clifton, for example,

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[159] *Ibid*.

[160] Clifton, Interview.

[161] Lisa Tozer interviewed by Stuart Bradwel, 14th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

worried that '[she] always felt a bit different, and [felt] that nobody would want to go out with [her] anyway.'[162] Howie, who also admits that she 'would tend not to tell people until [she] knew them reasonably well', remembers the beginning of her relationship with her husband:

> I kind of thought enough's enough, you know? I'll just tell him and if he goes, he goes, and if he doesn't, he doesn't. Well, it turned out he'd been out with a diabetic when he was at school anyway so he had half a notion of what was what... I think he took me for a picnic or something and... we were sitting on the beach. I just took my thing out and did my injection. He's like "Oh, right!"[163]

While the anxiety she felt that her condition might create a barrier between her and her partner is clear, Howie's decision to uncharacteristically perform her injection in front of him can be read as a genuinely intimate act. By allowing access to part of her life that she otherwise went to considerable lengths to hide, she risked being 'othered' and, potentially, rejected. However, she turned this principle on its head: it was he, not her, who became the subject of judgement. By gauging his reaction, she could determine their ultimate compatibility.

Sarah Gatward (1964-) takes this even further. Diagnosed in Macclesfield in 1972 at the age of seven, her father's work as an academic led to the family moving regularly. At the age of sixteen she found herself living in Connecticut. Here, she took part in a research project led by the Yale-based paediatric endocrinologist William Tamborlane (1946-), who was experimenting with the principle of continuous infusion – the beginnings of insulin pump technology. Gatward was, as a result, able to make use of a prototype device:

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[162] Clifton, Interview.
[163] Howie, Interview.

> It was probably, I don't know, maybe ten inches long by four or five inches wide... it was big and black there was a section on the top of it where you clipped a syringe and, whereas pumps these days just have little cartridges, this had the full sort of syringe with the plunger still attached and... whereas pumps these days can regulate how fast, obviously, the dose is going in... you couldn't do that with a pump like this. So I think the only way to try and get the dose to match the individual certainly from a background basal rate point of view was to dilute the insulin, so I had a mixture and saline, and I was given a sheet with sort of formulas for working out how. Every time I had to refill the cartridge I had to dilute the insulin to put into this syringe.[164]

The pump used by Gatward in the early 1980s demanded a considerably different approach to 'conventional' therapy. Making use of two insulin reservoirs (one to simulate a basal rate and another to provide mealtime boluses), 'there was a switch... to move between... basal and bolus, so if you were giving yourself a bolus dose before eating a meal you had to move the switch across, and then there was a button that you had to hold down, and you watched a digital counter sort of clock up the number of units, and then when the dose had been given you had to make sure you switched back so that it was in the background insulin setting.'[165] This early foray into 'intensified' therapy allowed Gatward to enjoy more freedom over mealtimes and nutrition than 'conventional' regimens generally allowed for. This came at a price, however. In sharp contrast to those who take only one or two injections daily, the pump user must carry their equipment wherever they go. More immediate labour is also required, as indicated by Gatward's need to use a formula sheet to effectively prepare her insulin. Compounding this, her early prototype was much larger

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[164] Sarah Gatward interviewed by Stuart Bradwel, 12th May 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.
[165] *Ibid*.

than those currently available and could not easily be hidden, and she had to carry it in a small bag at all times. In short, the pump constituted a visible marker of difference that was not lost on her:

> I played in... [an] orchestra and a band, and all the rest of it in high school in America, and I do remember... walking into an orchestra rehearsal, and I think it was the first time I had been to orchestra since getting the pump. And there was a boy I had a huge crush on and I just remember walking in and probably going scarlet just thinking "Oh god, they're looking at the pump!" And it really identified me as being different... I didn't ever really talk about it much, whereas this was a very physical sign that there was something different about me, and I do remember being sort of acutely embarrassed about it.[166]

Despite this early embarrassment, Gatward – like Howie – learned to invert her approach: 'I've almost partly looked at it and thought well, actually it's a good way of sussing out who's worth getting to know and who isn't, if people make snap decisions and snap judgements.'[167] By acknowledging and reconceptualising the meaning of her difference, she was able to neutralise, and even benefit from, its impact. Rather than experiencing shame on its account, she became able to essentially utilise it to exclude undesirable elements from her social circle. T1D ceased to be an entity that occurred to a passive figure, but an integral part of her 'self'. In this area, Gatward represents a clear example of successful reconstitution out of the flux of illness.

The expected routines of insulin administration led to the development of a variety of private rituals of self-management as the demands of treatment merged with the broader

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[166] Gatward, Interview.
[167] *Ibid*.

life-contexts and underlying eudaimonic ideals of those living with T1D. Taking insulin is, however, only one element of T1D management. In order to successfully maintain glycaemic control this hormone must be balanced properly with dietary intake.

Part 4: Diet

While the needle and syringe have together become an iconic symbol of insulin therapy, they are far from the only element of T1D management. The amount of insulin required by the body is, of course, determined by the amount of carbohydrate to be metabolised. Too much insulin and too little carbohydrate can lead to hypoglycaemia, while the reverse produces dangerously high concentrations of blood glucose which can in extreme cases lead to acute (and deadly) DKA, and, regardless, dramatically increases the likelihood of secondary co-morbidities in the long-term. Attention to diet – both to the timing of meals and to their nutritional content – is, as a result, an integral part of successful management. Without an effective balance between the amount of insulin administered and the amount of food consumed, the risk of unpleasant and/or dangerous complications is compounded.

The routine of preparing and consuming food might be considered ritualised behaviour amongst any population, but for those living with T1D this is particularly applicable. As such a central part of insulin therapy, nutritional expectations merge with broader attitudes to food and create a host of deeply meaningful private dietary rituals. For those utilising 'conventional' therapy, the simple act of eating often becomes bound up with a highly formalised routine in which every variable is meticulously pre-planned. With some exception, physicians expected strict adherence to rigorously controlled dietary regulation. After her diagnosis in 1953, Rose Douglas (1944-) 'had to keep weighing everything [she] ate. [She] had to have so many ounces for breakfast and then [a] mid-morning snack, so many ounces for lunch and an afternoon snack, and then a supper. So, [she was] having all these different amounts through the day and... had to have the insulin to cope with all that.'[168] John Meredith (1944-), whose younger sister was diagnosed as an infant only two years before Douglas, has similar recollections of strict dietary regulation, often with real consequences for the internal dynamic of his family: 'My mother still continued to bake but if I wanted a biscuit or something like that, I was sent out to the garden to eat it so I wouldn't eat it in front of my four year old sister.'[169] When he later developed T1D himself in 1959, things were no less regimented:

> I had to have my breakfast. Which I think was something like about forty grams of carbohydrate. I remember mid-morning I'd have thirty grams of carbohydrate. And lunch was about another forty... Mid-afternoon you had to have a snack. That was thirty. I can remember it was the same as the morning snack. And evening meal was something like fifty grams of carbohydrate. And then twenty grams of carbohydrate before you went to bed. So in terms of the number of carbs per day it was very high.[170]

This was typical of 'conventional' therapy throughout the twentieth century. 'Deborah' was diagnosed in 1980, twenty-one years after Meredith. Nevertheless, their experiences bore many similarities:

> We were given a diet sheet. I was given a fixed dose of insulin and had to follow a specific carbohydrate diet. It was twice daily insulin, so mixed insulin, and I still remember that I had to have forty grams of carbs for breakfast, ten for a mid-

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[168] Rose Douglas interviewed by Stuart Bradwel, 4th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[169] John Meredith interviewed by Stuart Bradwel, 7th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[170] *Ibid*.

> morning snack, fifteen for lunch, ten for a mid-afternoon snack, forty for dinner, and twenty for supper. That's still instilled in me.[171]

While specific dietary advice was, of course, not fixed and took on a variety of forms throughout, carbohydrate counting was, as a principle, characteristic of T1D management for most of the twentieth century before it was (temporarily) sidelined in the 1990s in favour of ambiguous 'healthy eating' (see Chapter 4).[172] The importance with which this routine was regarded by medical staff is alluded to by Meredith, who remembers the hospital dietician going so far as to provide him with weighing scales to take home: '[She] explained to me about diet and carbohydrates... and gave me some weighing scales and a list of foodstuffs... with the carbohydrate value per ounce or quarter ounce or half ounce.'[173] Turner had a very similar experience in 1954:

> You were given scales in those days. You don't get those any more. So, two ounces of carbohydrates and two ounces of mashed potato equalled one black line they used to call it. So black lines were carbohydrates, red lines were proteins and fats. I can still remember it actually. It's been drummed into me from the age of ten or eleven. I have never forgotten it.[174]

Howie remembers being given quite in-depth instructions much later, in 1974:

> A slice of bread was roughly counted as fifteen grams of carbohydrate and everything was either a slice of bread equivalent or half a slice of bread... You used to have to eat a snack in between breakfast and lunch and then another one

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[171] 'Deborah' (pseudonym) interviewed by Stuart Bradwel, 13th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[172] 'Free diets' were one significant exception to this, but were never particularly popular in the UK (see Chapter 3).

[173] Meredith, Interview.

[174] Turner, Interview.

> between lunch and dinner, and then your supper before you went to bed. And basically you pretty much had the same thing virtually every day.[175]

Turner and Howie are, in effect, describing a system of exchanges in which foods are categorised by carbohydrate content but can be freely substituted for others of equal value. A potato, for example, may be substituted for certain quantity of rice. This approach had been used since the very earliest days of insulin therapy, one of the first examples being Lawrence's 'line-ration' system.[176] The effectiveness with which this principle was explained was not always consistent, however. Kaye was disappointed by the education he was provided after his initial diagnosis in 1965: '[It was] so many grams of carbohydrate per meal, you know. Which was [the] equivalent of... cornflakes or- very limited... Cornflakes and tea or milk, and then your mid-morning was two tea biscuits... They never explained any flexibility.'[177] The inconsistency of face-to-face education across the UK was somewhat mitigated by an emergent literature concerned with explaining the principles of management in a manner accessible to laypeople. The BDA in particular produced a considerable number of information packs which could be highly useful to those who were chafing under the dietary restrictions they were expected to follow. Sylvia Kaye contacted them shortly after Frank's diagnosis: 'I phoned the British Diabetic Association and I said "How can you expect anybody to keep to this regime? Because it's so bland! It's so uninteresting!" "Right Mrs. Kaye, you're quite right." And they sent diet sheets.'[178] The BDA was not the only organisation producing information for those living with T1D. Guidebooks

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[175] Howie, Interview.

[176] The 'line-ration' system had been used by Lawrence since the 1920s. It divided 'approved' foods into 'black' and 'red' categories, with black portions representing carbohydrate, and red protein. Instead of prescribing exact meal composition, instructions were given in the form of corresponding black or red 'lines'. For example, both a measured piece of bread and an equivalent amount of pasta might represent a single 'black line'; Sue Durrant, 'The diet history – from lines to glycaemic index', *Practical Diabetes International* 17 (2000), pp. 231-234.

[177] Kaye and Kaye, Interview.

[178] *Ibid*.

written by physicians had been a feature since before the introduction of insulin, and often contained detailed instructions along with food tables. John Balfour (1948-), diagnosed in 1963, still possesses copies of Lawrence's *The Diabetic ABC* and Iris Holland Rogers' *The Complete Cookery Book for Diabetics*, texts that he credits with providing much of his initial education.[179]

The importance of diet in the context of T1D management is clear, but what private rituals emerged out of this expectation, and what did they mean to those living with the condition? Whereas insulin can be administered in private with little effort, meals often constitute an integral part of public life: they are regularly taken with friends, family, colleagues, and romantic partners. It was, after all, the social aspects of life at Oxford that prompted Eastwood's foray into experimental management. The demands of dietary regulation often collide with the broader context of life for those with T1D to a considerably greater extent than the act of taking insulin itself.

As 'Siobhan' previously suggested, 'conventional' therapy is, in many respects, simpler than the 'intensive' approaches that are more common today. With a clearly defined set of expectations based around faithful adherence to pharmaceutical and dietary instruction, the individual is left with little mental labour to perform for themselves. For children in particular this could be useful. In addition to performing (or closely monitoring) their insulin injections, parents could effectively tailor nutritional intake by determining the content of both home-cooked meals and packed lunches. Many took advantage of this. Balfour 'didn't

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[179] John Balfour interviewed by Stuart Bradwel, 6th July 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections; R.D. Lawrence, *The Diabetic ABC*, 12th ed (London: H.K. Lewis, 1960); Iris Holland Rogers, *The Complete Cookery Book for Diabetics* (London: H. K. Lewis, 1956).

stay [at school] for school lunches... [but] used to go home for lunch or take sandwiches.'[180] Howie addresses this in more detail:

> I think at that time it probably was less of a problem than it might be now, because in those days... you took whatever you were eating at the morning interval... to school. And everybody kind of did the same. So you didn't have the same choice that you do now. And certainly when I was at primary school I used to go home for lunch because we were quite handy for the school. So I mean that was never really an issue in that respect... and you tended to have much the same, you know. I mean you had like two tea biscuits in the morning and two in the afternoon for your sort of snack, and lunch was sort of two slices of bread and a packet of crisps kind of thing. So you kind of knew what you were doing.[181]

The dietary routines of 'conventional' therapy were simple and could generally be controlled by parents, but that is not to say that they were not taxing to those who had to abide by them. Not all children were given packed lunches. Lis Warren (1952-) remembers the difficulty of trying to 'guess what the carb portions were' when she ate school meals during the 1960s. Like Meredith, Warren remembers being expected to eat very large portions at regular intervals:

> You had to then eat to feed that [fixed] dose [of insulin]. So if you got up and you weren't hungry, you had to force-feed yourself, and that was a very prominent feature for me, and that affected me a lot, because, you know, a normal cereal bowl size might have been, I don't know, two or three portions of carbs. Ten gram portions. But I was on five portions for breakfast so I had to weigh my Rice Krispies

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[180] *Ibid*.

[181] Howie, Interview.

> and I used to serve it in the kind of serving bowl that you'd make a trifle in, or something for a family. A big bowl. Every day I used to sit down to a big bowl of cereal like that to get my fifty grams of carbs and I wasn't hungry! I didn't want it! So I got into the habit of overeating.[182]

The expectation to eat as instructed regardless of personal desire or preference could directly influence those with T1D's relationship with food. Clifton describes the way shame around eating came to colour her private dietary ritual:

> I got very plump again after being diagnosed. Well I wasn't plump, I was fat. And I couldn't fit into clothes that all my friends were wearing. I couldn't, you know. Mum had to have trousers made for me because I've got short legs and this big enormous bum and belly, you know. And I think food became – I wanted to eat but it felt like it was wrong to eat. It felt like it was wrong to eat because I had diabetes. It was wrong to eat because it would make me fat. Food became a bad thing... Certainly at the height of me having these issues with food I could think "Right, I'm not eating today" and I would monitor my blood sugar and everything. But if I'd just had an apple, that was it! I've blown it so now I might as well eat what I want. It was completely unreasonable and it was such a big block in my way. I just couldn't see past it. It felt like it was almost sinful and something I had to do secretly.[183]

The associations Clifton made between her body and the nutritional demands of insulin therapy appear to have quickly developed into a deeply disordered attitude to eating. This is not surprising. Within the routine of insulin therapy both 'conventional' and 'intensive', food is at once a source of vitality and the root of hyperglycaemia. It is simultaneously cure

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[182] Lis Warren interviewed by Stuart Bradwel, 5th May 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[183] Clifton, Interview.

and cause. The individual *must* eat to avoid acute hypoglycaemic symptoms, but is also perpetually aware that food might produce elevated blood glucose levels and ‘poor’ test results that imply failure.

Throughout her youth, Clifton’s dietary ritual maintained a clear division between two specific conceptual ideas of food – items ‘approved’ according to the rigid expectations of management and those which were ‘forbidden’. Even today, she struggles to enjoy many of the ‘approved’ meals of her youth:

> It was a Weetabix for breakfast and possibly a slice of toast. But Weetabix! To this day I can't look a Weetabix in the face! And then mid-morning I had two rich tea biscuits and lunchtime was a sandwich, either cheese or some sort of protein, and an apple... Mum and Dad had four children and money wasn't flowing a lot so we had cheese. It was pretty much cheese every day for lunch... Mum did roast dinners and, you know, making it last halfway through the week, but there wasn't really meat for sandwiches or stuff like that. The evening meals were probably more varied but the basic diet was the same. Again, I can't look a cheese sandwich in the face either! I love cheese but not in a sandwich![184]

Clifton is half-joking here, but nevertheless there is a lot to take from this passage. Despite enjoying a relatively wide variety of evening meals, her breakfasts and lunches were characterised by Weetabix and cheese sandwiches respectively, neither of which she can stomach today. This could be a simple case of eating a particular type of food to the point of boredom, but Clifton’s account suggests a level of *disgust*. Perhaps there is a deeper meaning to be taken from this. For Clifton, these foodstuffs symbolise the rigidity of ‘conventional’ management. As other meals changed they remained the same. As such,

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[184] *Ibid*.

they served as a constant reminder of the monotony and inflexibility demanded. This is, perhaps surprisingly, confirmed by her continued enjoyment of cheese – so long as it is not in a sandwich. It is not the specific tastes or textures that are important here but the abstracted meanings with which the object has been invested. Cheese sandwiches and Weetabix are not simply food here – they were ritual objects with profound significance. To Clifton, they were physical representations of the abstract cage within which she existed.

The routine of ‘conventional’ therapy involves more than eating the correct meals at the correct times. The individual is also expected to show discipline by avoiding ‘forbidden’ food and drink (usually those containing refined sugars or very high quantities of carbohydrate), and by eating only according to the provided timetable. ‘Forbidden’ foods, as a result, come to be invested with a distinct meaning of their own. Clifton recalls one occasion in which she defied the expectations of therapy:

> I can remember my dad giving me a Quality Street when we were on holiday, and it was a real guilty secret between the two of us, that I'd had [it]! So then, nice things did become really naughty, you know? As I grew up food became something that was bad. It was naughty.[185]

The influence of the expectation of ‘conventional’ management transformed what should have been a rather mundane event into an acute source of guilt. Cruelly, a simple piece of chocolate that to any other child might have represented an expression of parental affection was for Clifton also invested with a deeply negative meaning. The indulgent or ‘sinful’ pleasure of a particularly rich or sweet dessert is a common trope, but for those living according to the principles of ‘conventional’ insulin therapy this tongue-in-cheek cliché takes on a deadly serious tone. To consume ‘forbidden’ foods is to flaunt the basic

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[185] *Ibid*.

foundational principles of treatment. To indulge is to invite disaster, and to become deserving of it. The manner in which concepts of pleasure and guilt become intertwined in the context of insulin therapy is reminiscent of conservative religious dogma, with predictable effects. For Clifton the very enjoyment of food became sinful. Eating, and eating *correctly*, became a *duty*. Not even 'approved' foods were objects to be savoured, but purely functional means to achieve satisfactory glycaemic control. Food consumption became in a sense medicalised, and in becoming so also turned sterile, reductive, and severe. As a source of both denied pleasure and shame, it is no surprise that 'forbidden' food exerted a certain guilt-ridden attraction:

> It was such a strict diet and... I was probably getting fat because I was sneaking things I shouldn't have. God, this is awful but... Mum and Dad had a dinner party and there was a cheesecake left in the fridge, and I think I ate about half of it! I was- gosh was I ill!... But I was hungry and I felt like I wanted something nice.[186]

In this context, to enjoy 'forbidden' food is not merely to break temporarily from routine but to fundamentally reject its foundational principle: health and wellness can only be achieved via biological normalisation, and to achieve this obedience to instruction is vital. To incorporate 'cheating' – or the consumption of 'forbidden' foods – into the private dietary ritual of T1D is to demonstrate the subjectivity of successful treatment. It is to implicitly declare that the strict enforcement of paternalistic expectation may by actively harmful, and that longevity and stability are meaningless in the absence of quality of life.

Clifton's Quality Street example was not an isolated incident. Throughout her youth the expectations of management influenced her eating habits as they rendered off-limits and shameful not merely the items of food she desired, but also that very desire itself. Eating,

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[186] *Ibid*.

whether ‘approved’ or ‘forbidden’, became a source of considerable anxiety with serious implications for her life as a whole:

> I would not eat. I couldn't bear people to watch me eat. I think because I didn't want them to say “Should you be eating that?” But I did binge eat when I was on my own, particularly once I'd left home. So obviously my blood sugar would go from being quite low through the day to being very high after I'd eaten all this stuff, and you'd be amazed what I could put away! And for a long time – my first marriage broke down when my daughter was very young and I worked full time – I would be up at the crack of dawn to get her to nursery. Cycle to work, work all day, cycle home, pick her up, do all the stuff with my daughter then have stuff to do for work. I couldn't- I didn't have time to go hypo. I wasn't comfortable going hypo when I was on my own in the house with her... So my blood sugars were running higher than they should have been to avoid that happening... I was on my own for ten years and I think it was certainly when I met my second husband, who's a real foodie and taught me how wonderful food could be without, you know, having to eat it secretly, it sort of made a big difference.[187]

Clifton had internalised the association between food and shame to such an extent that, until she met her second husband, she was unable to eat in front of friends or colleagues while at home she would binge on ‘forbidden’ items that provided some comfort but reinforced the guilt she felt. There is more to this passage, however. Part of her reason for overeating was functional rather than symbolic. Those individuals who, like Eastwood, did engage with and significantly alter medication dosages had become exceptionally rare by the second half of the twentieth century, in no small part thanks to changes in prescribing

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[187] *Ibid*.

and the promotion of less flexible forms of insulin. Even bio-molecular scientist Joel Milner (1948-), a man possessed of advanced education in scientific methodology, found that under such conditions fine-tuned adjustment of medication was simply impractical, recalling that, in the late 1970s, ‘you weren't allowed to play with the insulin and it wasn't really very easy to do so because you're only taking one shot a day [of a long-acting and/or mixed preparation] anyway.’ However, to mitigate this somewhat, he, like many others with T1D, ‘played with the diet’.[188] Clifton is an excellent example of this. Alone with her daughter and aware that a severe episode of hypoglycaemia could threaten them both, she made a concerted effort to avoid this regardless of the consequences for her glycaemic control. Once again, this demonstrates the complexity – and subjectivity – of ‘wellness’ as a concept. To Clifton, her daughter’s health was as much a part of this as her own: a vital aspect of her eudaimonic ideal.

Issues surrounding quality of life are not always negotiated with such conceptually high stakes. The rigidity of ‘conventional’ insulin therapy meant that strict adherence to its demands could often stand in the way of unremarkable, though often personally meaningful, life experiences – particularly in adolescence. Carol Cowan (1951-) remembers one such example:

> Well, in sixth year at school my mother gave me dinner money. I’m not sure I should be telling you this! She gave me dinner money, which I did not [use to] pay for dinners. I used to pinch two digestive biscuits and an apple out of the house

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[188] For more on the trend towards ‘simplified’, and less flexible, ‘conventional’ regimens, see Chapter 4; Joel Milner interviewed by Stuart Bradwel, 26th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> every morning and that was my lunch, and I kept the dinner money for two Carlsberg Specials at the dancing on the Saturday![189]

Such an approach would never have been promoted by a physician, and would almost certainly have been considered dangerously ‘non-compliant’. However, the ability to socialise and go dancing with friends clearly meant a lot to Cowan. Her private ritual of care took into account not only the expectations of ‘conventional’ therapy but also her own personal concept of ‘wellness’. To Cowan, the quality of life she gained by going dancing outweighed what she lost by disobedience.

Clifton and Cowan were not alone in struggling to reconcile the demands of ‘conventional’ insulin therapy with their personal needs and preferences. As the son of a small business owner, Kaye worked in his father’s furniture company before taking over the running of it after his passing. His was a rather uncommon case, having being diagnosed in 1965 comparatively late in life, at the age of twenty-seven. Accordingly, he had already established himself at work and was married with several children. Perhaps as a result of this, he initially found the expectations of his newfound condition challenging. Rather than have lunch with co-workers, he began to go home to eat to ensure he was able to follow the guidelines he had been given, something that he admits came across as ‘very unusual’ to his colleagues at the time. His role as a senior member of the organisation also brought its own difficulties:

> You had to go entertain quite a bit. You know, with customers... In the early days going out to restaurants was quite a challenge... because you... had to fill your own carbohydrate out as you're doing it. But sometimes, on the menus... there wasn't

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[189] Carol Cowan interviewed by Stuart Bradwel, 20th June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> the right stuff to fill it out, you know? So you had to make sure you took plenty [of] bread... When we used to have what we called trade shows in the furniture trade, I used to say to the girls who were serving the drink "Every time I ask for two whiskies give me a ginger ale", you know?... Because I was socialising, you might say, with buyers... and they would often say "You can fairly hold your drink can't you!"... It was either say no, and when you said no it didn't look very nice, you know? So you were just saying it to sort of- kidology, you might say.[190]

Unlike those diagnosed in their childhood or teenage years, Kaye was unable to approach the challenges of adulthood with an existing awareness of, or experience with, T1D – he never enjoyed a 'training period' in which he could become accustomed to his new circumstances in the absence of other responsibilities before reconciling the demands of the condition with those of his broader life-context and proceeding accordingly. Instead, he was forced to work backwards and retroactively attempt to achieve this reconciliation while continuing to live up the social and professional expectations of a 1960s businessman. The decadent, hyper-masculine world in which he existed did not always make this easy. As Kaye was expected to live up to a cultural image defined by gregariousness – and often heavy drinking – he found the demands of his professional life began to conflict with the expectations of 'conventional' insulin therapy. It is amusing to imagine that one of his eventually successful strategies of reconciliation between the two – engaging in minor deception by passing off ginger ale as whisky – may actually have increased his standing amongst clients due to the subsequent perception that he was highly adept at holding his liquor.

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[190] Kaye and Kaye, Interview.

Kaye’s experience also highlights a marked class dynamic at work. As the boss’ son, a senior executive within the company, and later the owner, Kaye was able to approach the demands of T1D management at his own pace, somewhat mitigating the absence of a preparatory childhood. He was answerable only to his father and to himself, while the specific duties of his work do not appear to have been particularly physically demanding. It is doubtful that his continued livelihood was ever in any real jeopardy should his condition have caused any problems at work (by requiring, for example, a few extra breaks, or causing occasional tardiness). While pressure to reconstitute himself in light of his diagnosis did undoubtedly exist, he was able to engage with this process in a state of relative comfort and safety.

In stark contrast to this is Marriott, whose self-deprecating and often humorous reflections on his own background and health reveal much about the reality of living with T1D as a working-class man. Unlike Kaye, Marriott changed careers regularly throughout his life and worked variously as a shop assistant, bus conductor, coalman, demolition operative, coach driver, telephone engineer, taxi driver, and driving instructor. Reconciling the expectations of managing his condition with the demands of such work was not always easy:

> I did a couple of other things including working on demolition, because a mate of mine says “This is great, you do all sorts of things, get all sorts of perks!” So I went with him, climbed about a hundred and sixty foot up in the air, no problem whatsoever. I couldn't do it now, it was hard work. Made sure I didn't go hypo while I was up there. Very important. I was running a bit high. Yes, deliberately... Again with my brother I was a coalman. Didn't last very long ‘cause that's bloody

> knackering. And that is hard going, yeah. And again I had to watch the energy levels on that.[191]

The context of Marriott's working life meant that, unlike Kaye, he could not expect much flexibility on the part of his employment and did not have the professional power to demand any. Like Clifton with her daughter, any reconciliation had to be made via adjustments to his diabetic management. Up on scaffolding where an episode of hypoglycaemia could very well lead to a deadly fall, he was forced to weigh up his options and act accordingly – opting to eat a little more carbohydrate (or take a little less insulin) to ensure that he was always slightly hyperglycaemic and, as a result, unlikely to become unexpectedly incapacitated. The similarities to Clifton here are unmistakable – Marriott responded to the demands of a job he relied on in much the same way she responded to the demands of motherhood. The dietary routine of T1D does not exist outside of class or gender. Such conceptual structures are in fact fundamental to the construction of the private rituals that each individual develops in response.

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[191] Marriott, Interview.

Part 5: Monitoring

The administration of insulin and dietary regulation are the two main building blocks of insulin therapy – routines that are vital to the maintenance of life and its quality for those living with T1D. However, they are not the only routines of management around which ritual behaviour can form. In order to determine the effectiveness of treatment, glycaemic control must be measured regularly. This is now primarily achieved via blood glucose testing equipment, but in the mid-twentieth century urinary analysis was significantly more common. Even the most rudimentary pieces of blood glucose monitoring equipment are relatively recent innovations. Reagent strips able to measure blood glucose were not introduced until 1965, but these were difficult to use effectively and could not achieve particularly reliable readings.[192] The Ames Reflectance Meter, released in 1970, was the first accurate method of directly testing blood glucose outside of the laboratory, though this was a large, expensive machine that required mains power and was intended for – and initially only sold to – HCPs. As a result, only a small fraction of well-connected (and well-financed) individuals with T1D were able to acquire one.[193] Accurate self blood glucose monitoring devices did not become a widespread and integral part of management until the 1980s – prior to this urine tended to be the sole object of analysis outside of the clinic.[194]

From the earliest clinical use of insulin, boiling a few drops of urine with Benedict's solution was the only effective method of determining its sugar content. Benedict's solution could be bought, but was also relatively simple to make at home with a few specialist ingredients by following the detailed instructions given in patient guidebooks like Lawrence's *The*

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[192] Clarke and Foster, 'A History of Blood Glucose Meters', p. 85.
[193] Tattersall, *Diabetes*, p. 162.
[194] The process by which the self-measurement of blood glucose became incorporated into orthodox approaches to management will be revisited in Chapter 3.

Diabetic Life.[195] From 1945, Clinitest tablets became widely available, simplifying the process by automatically creating an exothermic reaction and changing the colour of the solution accordingly when added to dilute urine. Clifton describes the process of measuring urinary sugar as a child vividly:

> It was just this little box that had a test tube and a pipette, and this bottle of tablets called Clinitest tablets. So I had to pee in a bowl and, you know, it was ten drops of water and five drops of urine, and then you put in this tablet and I kid you not it was like Jekyll and Hyde cause it all frothed and fizzed and rose up the tube, and then as it settled down it settled on a colour and [if] it was a very beautiful midnight blue [it] meant that there was no glucose in your urine. And then it went from blue to green, two shades of brown, and then orange. And orange meant you were loaded. And that was it, so that didn't tell you what your blood sugar was. It maybe gave you a vague idea that two to four hours ago there was no excess glucose in your bloodstream because it hadn't then gone onto your urine sample. But it was very vague when I look back on it now... I did a urine sample in the morning, another one when I got in from school, another one in the evening before I went to bed, and then my parents would wake me up at about one o'clock in the morning to do it again, and if it was blue, yippee do da, I could have another Rich Tea biscuit to see me through the night.[196]

Urinary testing was not particularly difficult or taxing, particularly after the introduction of Clinitest. While this was not without its risks – Peter Davies (1954-) remembers burning his hand on the hot test tube – incorporating it into the private ritual of management as

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[195] Guidance on creating Benedict's solution continued to be provided in later editions of Lawrence's *The Diabetic Life*, suggesting that many continued to prefer making it themselves; Lawrence, *The Diabetic Life,* 15th ed, pp. 217-218.

[196] Clifton, Interview.

expected did not in practice ask a great deal.[197] It is therefore not surprising that, unlike dietary regulation, most of those with T1D did manage to perform it without much complaint. The frequency with which they did so, however, varied considerably. 'Deborah' remembers doing only one test per week in 1980, while Gatward could be performing three a day in 1972.[198] How can we account for these discrepancies?

Urinary measurement is of rather limited practical value, as sugar does not begin to spill through the kidneys and into the bladder until the glycaemic concentration in the blood reaches a level known as the renal threshold. This varies between individuals but tends to be approximately 10-11mmol/l, well over the 4-7mmol/l range considered 'normal'. The above quoted passage demonstrates that Clifton clearly recognised the weakness of this 'vague' system. An awareness of the limitations of urinary assessment is common amongst those who performed it. 'Deborah' suggested that 'obviously, being urine, it's kind of too late', while Marriott asks 'what are you measuring?.. Is the bit you're measuring... all mixed so it's all one homogenous mess, or is that half-past seven's bit? What were you then? There's no way of telling', and John Allison (1949-) reflected that 'the urine was what was stored in your bladder so... it was giving you an average over time rather than instantly what was there.'[199]

Given the wide acknowledgement amongst PWD that urinary testing was inaccurate and provided little practically useful information, it is not surprising that some simply went through the motions infrequently rather than measure as often as they were perhaps instructed to. But despite this, most *did* perform this self-analysis at least occasionally. As

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[197] Peter Davies interviewed by Stuart Bradwel, 10th May 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[198] 'Deborah', Interview; Gatward, Interview.

[199] John Allison interviewed by Stuart Bradwel, 21st June 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.; Marriott, Interview; 'Deborah', Interview.

he describes the various colours that could be produced by Clinitest tablets and what they represented, Meredith provides a subtle clue as to why this was the case:

> The colour for sugar went from blue, which was negative, no sugar, [to] dark green, light green, and then through to yellow. And orange was... you have committed the sin. Full of sugar. Two per cent sugar. I can't remember getting all that many orange tests. They were mainly... either the dark blue, the dark green, or the medium green. So they were fairly good in that sense.[200]

The use of terminology here is telling. Meredith frames an orange result (showing a considerable amount of sugar in the urine) not as a cause for specific concern or anxiety about potential health consequences but as *sin*. This is above all a *moral* reaction. 'Sin' is more than a personal reflection on 'right' or 'wrong' but a transgression of the principles of divine law as defined by appropriate religious authorities or holy texts. The concept of 'sin' cannot emerge from the ether to shape an individual's subjective consciousness, but instead must be *enforced* by extraneous socio-cultural factors. The implicit message is clear – urinary assessment was not *for* Meredith, but served a higher purpose.

This is confirmed by another aspect of the expected routine of urinary testing: the recording of results, not for personal use but for the benefit of the physician. Gatward remembers that 'you would go back for your appointment however often and the doctor would look through your tests.'[201] For most of those living with T1D, the responsibility for adjusting therapy based on assessment was, in principle at least, firmly held by medical staff. Gatward continues:

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[200] Meredith, Interview.

[201] Gatward, Interview.

> We wouldn’t change anything at home. I don’t know whether my mother would ever contact the hospital. I presume appointments were probably fairly regular... I think we wouldn’t adjust anything unless we consulted and I think it was always done at a hospital appointment. They didn’t ever say if you are high give yourself an additional dose of insulin or anything like that, it was literally always just the one a day and you would deal with lows based on how you behaved, so if I crashed out and I was obviously exhibiting signs of being hypo I would be fed chocolate, Lucozade, you know, something to push my blood sugar up.[202]

While the results of urinary tests had an ostensibly functional use for physicians, for those living with T1D the act of taking such measurements often took on a performative quality. The ritual of self-monitoring often became characterised by the desire to prove faithfulness to the outside expectations of self-management. This is confirmed by Clifton, who remembers being creative with the truth as she filled out her test record in one sitting the night before a clinic visit:

> To begin with Mum and Dad did the test, but as I grew up... fairly quickly I would do them myself, and I had been known to lie, it has to be said. That it would be orange but I would lie. And we also had a little book that we were meant to colour in these squares, a bit like the [blood glucose] diaries now, but you coloured them in. And I would often be, you know, sat up the night before diabetes clinic colouring in like that, you know? Making sure that there was a spattering of orange and green obviously![203]

Cowan also admits a habit of fabricating results in her youth:

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[202] *Ibid*.

[203] Clifton, Interview.

> At the beginning when I went to Stirling Royal... [the consultant] was horrible. He was a tall, very slim diabetic specialist who looked over his spectacles at the record book that I had completed the night before with six different coloured pens and pencils in my hand, and [would say] “Well, what made you high there?” And I thought ‘I don’t know, I invented it last night!’[204]

The results of urinary analysis were not *for* the individual with T1D, but a symbolic representation of obedience for the benefit of the clinician. A ‘poor’ red or orange result was not only a reflection of biological threat but a symptom of moral failure worthy of reprimand. In order to avoid punishment or admonishment, ‘acceptable’ readings could be invented. Nevertheless, it is interesting to note that both Clifton and Cowan clearly did include several ‘unsatisfactory’ entries when engaging in this attempted deception. Perfection, it seems, would have been suspicious. The relationship between clinician and patient was clearly not always one of mutual trust and respect, and indeed for many of those with T1D it appears to have been characterised by feelings of anxiety, frustration, and inadequacy.

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[204] Cowan, Interview.

Part 6: The Clinic

Life with T1D demands regular interactions with medical staff. After all, insulin and injection equipment must be acquired through the healthcare infrastructure. The expectations of diabetic management – in both ‘conventional’ and ‘intensive’ approaches – demand significantly more than the minimal contact strictly *required* for the maintenance of life, for example regular attendance at clinics where the quality of management can be assessed and potential complications screened for.

While some of those with T1D go to clinics more or less regularly than others, almost all have experience with them to one extent or another. The clinic is fascinating, as it constitutes the point at which individualised private rituals of management intersect most clearly with principles of orthodox expectation. As a physical embodiment of professional authority, the clinic represents the source of much expectation related to T1D. It is worth bearing in mind Barry Stephenson’s reflections on ritual behaviour here:

> [Ritual is] not a particular kind of discrete action, but rather a quality of action potentially available across a spectrum of behaviour... Ritual is first and foremost a doing. Like cooking or swimming or politics, we learn about ritual through the act of doing it. But alongside ritual enactment, people also step back to think, write and read about ritual... This is not to polarize action and thinking... Ritual is a way of thinking and knowing. The point is that our ideas about ritual are shaped not only within itself but also through other texts and other media.[205]

Religious ceremonies provide an apt metaphor for the role of the clinic and the professional in the management of T1D. In the Catholic Mass, the priest may demand of his parishioners a certain level of faithfulness to the strictures of religious law. He may seek to influence the

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[205] Stephenson, *Ritual*, p. 3.

private lives of the congregation by providing guidance and advice in order to ensure their godliness and, as a result, the safety of their immortal souls. The private rituals developed by each member of the flock may or may not, in their totality, meet the expectations he lays out but they must nevertheless be influenced by him. They are shaped in the doing – in the rosary or the recital of the Lord's Prayer – but also by external forces – the words of the priest. But the clergyman, of course, possesses only soft power. For all the threats of damnation and hellfire he, in practice, can appeal only to the moral sensibilities of those to whom he preaches and cannot *compel* obedience.[206]

Similarly the physician lacks the power to dictate the actions of patients outside the clinic. The private rituals developed by each individual are performed outside of the professional sphere in homes, in workplaces, and in public. The consultant here is much like a priest – responsible for encouraging the 'flock' to live according to the principles of a 'divine law' determined by medical orthodoxy, but nonetheless powerless to enforce compliance.

The fifteenth edition of Lawrence's *The Diabetic Life* was published in 1951. It contains a chapter titled 'The Choice and Management of Diet', which begins with a rather revealing passage:

> The Diabetic Diet is different from the normal both in quantity and quality. The diet of the normal man is controlled by his purse and his appetite alone, the diabetic's by his doctor's prescription weighed and measured. Not only must he take a definite amount of carbohydrate, but the total quantity of his diet is often restricted. Therefore he must display considerable skill in the choice of the articles of his diet, if he is to satisfy his appetite and his personal tastes, two essentials of

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[206] Since the Second Vatican Council in the early 1960s threats of fire and brimstone have become considerably less common within the Catholic Church, but nonetheless the point stands.

> successful treatment. Most diabetics become decided epicures and more particular about their food than the average individual. It is natural for them to become so, and if they do not, I take it as a sign of carelessness.[207]

Lawrence considers discipline and obedience to the ‘doctor’s prescription’ to be of vital importance. We shall return to the evolution of orthodox medical approaches to T1D in more detail in Chapters 3 and 4, but for now it is enough to acknowledge that this perspective – typical of ‘conventional’ management – had a marked influence on doctor/patient relations and directly shaped the way PWD experienced the condition. The medical profession, with the clinic as a powerfully symbolic conduit of power, was – and remains – the root source of orthodox expectation, and as such a major factor in the creation of private rituals of management.

The practitioner engages with the routine of T1D management only in the context of the medical establishment. For the majority of the time, therapy is the unsupervised responsibility of the patient and the patient alone. During the clinical encounter one of the primary concerns of the doctor is the enlistment of the patient into professional medical thought. In short, the doctor seeks to influence both the shape and content of their patient’s private rituals of management in order to ensure their adherence to orthodox expectation.

A concentration on enforcing compliance with the strictures of medical orthodoxy was impressed upon those diagnosed with T1D during this period from the earliest instance. Most of those diagnosed before the 1980s were hospitalised for several days or weeks while medical staff determined medication and dietary requirements, or, to use the

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[207] Lawrence, *The Diabetic Life*, 15th ed, p. 165.

language of the time, they were 'stabilised'.[208] Janette Tibbett (1942-) remembers a rather oppressive environment on the ward after her diagnosis in Ireland in 1948 as a young girl:

> I was left in this hospital, which was called the Bon Secours Hospital, in Cork for a period of six weeks. During this time, I wasn't allowed to see my mother. Mothers and parents weren't allowed to visit at the time in case they upset the children... I was told later that she used to watch me through a screen. Initially I spent most of my time in bed and everybody kept taking lots of blood tests and I found this rather terrifying. I was only five! And the nuns were wearing these black gowns and these white veils, and the nicest people there were the people that used to clean the floor! It was a highly polished floor and these young Irish girls – it's one of my abiding memories – these young Irish girls used to clean the floor with these cloth pads tied to their feet, and they used to skate across the floor. With regard to diabetes they were gradually trying different amounts of insulin in me to try and stabilise me, and they were taking blood out of me at least three times a day.[209]

From the outset, the importance of obedience and routine was emphasised heavily. 'Siobhan' remembers the rigidity of her instruction:

> In hospital it was quite rigid. So, it was very much... "This is how much you inject, this is how much you eat. You eat it all and then you don't eat anything else until

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[208] The abrupt change in policy here is fascinating – diagnoses in 1979 almost uniformly required hospitalisation while those from 1980 onwards rarely did. One exception to this rule is Kaye, who was never institutionalised after diagnosis in 1965. He was older than average, at twenty-seven, and there appears to have been some confusion as a result. For a long period he was treated as if he had T2D (or 'mild' diabetes), and in truth it is possible that this is the case. Certainly, he was taken off insulin for a long period and did not immediately develop DKA; Kaye and Kaye, Interview.

[209] Janette Tibbett interviewed by Stuart Bradwel, 28th August 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> the next time, and this is how much you eat, and this is what you eat". So, there was no element of choice of food or anything. It was rigidly set.[210]

Clifton had a similar experience:

> Not all of the nurses were very nice, you know... and certainly when you were in hospital in those days it was a very strict regime... In that, you know, you were in bed at a certain time, you were woken up very early. And I seemed to get in trouble an awful lot because I'd sat on the bed or I had... done something or other wrong... Some of them I remember being very strict and it was very schoolroom like.[211]

Much of this appears to have been a feature of hospitalisation in general during the mid-twentieth century, and most of those held for 'stabilisation' appear to have been sent to general wards rather than specialist units. It was common for those diagnosed to be in amongst patients with a variety of conditions. 'Siobhan' remembers 'the girl in the bed next to me had leukaemia, [there were] two boys with broken legs, [and] a young lad with tonsillitis'.[212] Moody recalls the children's ward she went to being 'one of the most terrifying places I had ever been in my life, because it was kids in oxygen tents, they had a kind of green stuff- plastic-y stuff, rubbery stuff, obviously to keep the oxygen in, and small wee kids in these things... And I was terrified I was going to end up in one of these oxygen tents!'[213]

Children with T1D from the outset often felt vulnerable, confused, and different – even to others on the ward. Clifton remembers:

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[210] 'Siobhan', Interview
[211] Clifton, Interview.
[212] 'Siobhan', Interview.
[213] Moody, Interview.

> I hated being in hospital, because I think I felt so different you know... In that time, you know, it was the old fashioned Victorian wards, just rows of beds and all the children in there had these sweet bowls that were brought out mid-morning and mid-afternoon where family and things would put sweets in. And I can remember looking at mine and it just had this real dodgy pear in it! And I think I just felt different from all of the others.[214]

Hospital staff sometimes did little to ameliorate this source of anxiety – Gatward remembers her mother being unable to gain any information from the staff after her hospitalisation:

> She got very nervous because she felt information wasn't being passed to her about what their concerns were... She said the parents were not allowed on the ward. The doctors came round and saw the patients, but parents were not allowed to be in there, so you were reliant on being able to then talk to the doctor afterwards and ask questions, and if they did not want to talk to you and did not want to answer the questions you were kept in the dark completely.[215]

Physicians are habitually referred to as unapproachable for those on the wards. Once again, Clifton has a clear memory:

> [The doctor] would trot round. He wouldn't talk to you as the patient, but he would murmur things to the sister. There was no nurse. It had to be the sister or the matron. And the younger doctors, everybody followed him around. It was like, you

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[214] Clifton, Interview.

[215] Gatward, Interview.

> know, these disciples. And if he talked to you it was terrifying. They were very much captain of that ship and you didn't argue. You didn't disagree.[216]

In the mid-1960s, doctors, as Cowan put it, were 'gods... you didn't challenge [them]. You didn't even speak to them.'[217] But this implies more than arrogance and the flaunting of power. By keeping patients in the dark, restricting the information they were given, and doing little to reassure them, their reliance on the professional was all but guaranteed. This is confirmed by the use of more aggressive strategies of compulsion by some physicians, who, if they were Gods, appeared to have taken considerably more inspiration from the Old Testament than the New. By actively seeking to frighten their patients with the potential consequences of 'non-compliance', they could encourage obedience. Little appears to have changed by the mid-1970s. Milner, for example, was subject to a particularly harrowing speech after his diagnosis in 1976:

> That was in the first week... "In twenty-five years time the likelihood is", you know, "you'll lose your eyesight, you'll lose your kidneys, you'll lose limbs etc etc." So that was absolutely laid on as a sort of super scary prospect. Not even so much a warning if you don't stick to it – that's likely to happen. And your only hope is sticking to this diet and regime strictly and controlling your blood sugar.[218]

This authoritarian and occasionally deliberately intimidating attitude defined the consultative relationship for some. It is not surprising that some fabricated their test results, and little wonder that even today Howie feels that the best way of approaching many of her clinics is to 'nod your head and say yes and then go home and kind of do what

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[216] Clifton, Interview.
[217] Cowan, Interview.
[218] Milner, Interview.

you want anyway.’[219] Her implicit belief is that medical orthodoxy approaches management from a reductive perspective that does not always appreciate the broader needs of the individual, and often fails to respect the lay expertise of the PWD. Cooper, too, is highly critical of the ‘education’ provided in hospitals during this period:

> It was very much then “This is what you have to do”... what I remember doesn’t in any sense resemble what I would consider to be education – diabetes education as you would see it today. It was completely different. It was more a prescription of things that you had to do rather than anything else.[220]

This ‘education’, or lack thereof, attempted to enforce a standardised approach to management that was unable to effectively take into account the individualised requirements of care. Even for those who attempted to abide by instruction faithfully, subtle factors such as exercise and stress meant that even those who strictly adhered to the expected framework often experienced unsatisfactory test results. Despite this, those on ‘conventional’ therapy were usually strongly discouraged from responding actively to such readings. Measurement was after all for the physician, not the patient. Marriott remembers that the expected response to an orange or red test result was simply to wait a few days and see if it corrected itself, before calling a doctor if the problem persisted:

> If it went – 2% was bright orange – and... if you had couple of days of 2%s you were in trouble and you'd be feeling pretty grotty anyway... I don't know what that was 2% of, I never found out! But I knew the 2% was bad and the varying colours down underneath that to get to bright blue, which is 0% of presumably sugar in your water. If you had 2% for a couple of days you’d phone up and ask for advice, and

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[219] Howie, Interview.

[220] Cooper, Interview.

> quite often it was "When can you get up here?"... And they'd say do this, do that, and try and balance you out again.[221]

Similarly, when Douglas recorded high test results, she would, 'if it was persistently high... show [it] to the senior member of staff who [would] then advise... what to do, what insulin to have, and what not to do.'[222] Clifton also remembers a similar expectation:

> I mean now if I did a blood sugar and it was high, I would do a correction dose. But back then there was no question of that. You went to diabetes clinic, and then a doctor might suggest that you put it up, you know, put your insulin doses up.[223]

'Conventional' insulin therapy values passivity, and the complete subordination of the individual living with T1D to the expectations of orthodoxy. To 'succeed' – i.e. to produce, in theory, consistently acceptable urinary (and later blood and HbA1c results) – was to obey medical instruction precisely. As Feudtner discusses at length, doctors often conflated this vision of 'success' with faithfulness to direction to such an extent that 'failure' – 'inadequate' test results – came in itself to represent *unfaithfulness*. The obedient patient must have satisfactory results and, by extension, the disobedient must not. 'Conventional' therapy cannot fail, it can only be failed.

This perception had a marked impact on the relationships those with T1D developed with physicians and other medical staff. 'Deborah' remembers the frustration she felt when her HbA1c tests were not considered 'satisfactory' as recently as the late 1980s:

> I remember getting them when I was about eighteen or nineteen. When that came out you would just get a retrospective bollocking! You'd get a letter from the

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[221] Marriott, Interview.
[222] Douglas, Interview.
[223] Clifton, Interview.

> doctor saying “Your HbA1c is, whatever, 14.5[%], you’re clearly not taking care of yourself.” I think the frustrating thing was that you didn’t know how to... [The doctor said] “If you’re taking the dose that I told you to take six years ago, it should still be working”... If you had been to the clinic and you had a high HbA1c – I didn’t even know what an HbA1c was – and you got the letter through the post saying your HbA1c is whatever, fourteen and a half, “You’re clearly not following our orders, take more care of yourself.”[224]

While the results of spot urinary (and even blood) measurements could, as we have seen, be fabricated, the HbA1c test prevented this revealing average glycaemic control over a period of approximately three months prior to the test. Suddenly, the priest could see into the bedrooms of his flock to determine for himself their piety, and adapt his sermons accordingly. It is little wonder that Clifton, with her tongue firmly in her cheek, referred to the ’horrible, horrible person who invented the HbA1c’:

> It changed the dynamic in that there was absolutely no point in me trying to make up stories of what my blood sugars had been doing... there was absolutely no point. My thought was still to get in and get out as quickly as I could and just hope that they would be all right and they'd be happy enough with things but it did change the dynamic.[225]

Clifton could no longer hide behind invented results to masquerade as a ‘faithful’ – and therefore ‘good’ – patient. The HbA1c demonstrated clearly that her average glycaemic control fell far short of that expected by her consultant. In essence, this meant that Clifton’s

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[224] ‘Deborah’, Interview.

[225] Clifton, Interview.

private understanding of health and wellness – her eudaimonic ideal – came into direct conflict with those of the medical profession with predictably stressful results.

In many respects, clinics became iatrogenic sources of unwellness in themselves. Clifton remembers the deeply unpleasant atmosphere she found after being transferred to adult care in mid-1970s York at the age of fourteen:

> You arrived, you were weighed in the waiting room in front of everybody, and there would be a nurse tut tutting or, you know. “You've lost too much”. And then “Have you got your sample Gillian?” Oh God! It was all so public, especially when you're fourteen, you know?... And then you would go in to be shouted at by Dr. Bingle, who everybody was terrified of, and all the women, they'd all go to the loo... [to] take off all their jewellery. One lady had taken off like all her underwear because he was so angry if you'd put on weight. He used to get so cross with you... and he sat there eating chocolate cake during my clinical appointment and I said “That's a really horrible thing to do” and – big slanging match. It was very strict. Everybody was worried sick about going because if you had put on weight he was cross, if you'd lost too much weight he was cross.[226]

Clifton is by no means the only narrator to have found their regular clinics unpleasant. In the 1980s, Balfour experienced a hostile environment in Margate Hospital:

> Well, there seemed to be thousands of people in the waiting area, probably for all the clinics that were going on. One vivid memory was one poor lady who was being weighed, and of course you were weighed in this room and the person that was doing the weighing was very subtle and she said to this woman who was obviously deaf, you know, “You’ve put on six pounds since last week!” This was bellowing

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[226] Clifton, Interview.

> around and all these people, head in hands, looking very embarrassed by the whole scene. Then the doctor we saw was not a man that we liked very much... In fact, he was extremely rude as far as we were concerned.[227]

Nevertheless, many narrators had positive experiences of clinics. Turner was very complimentary about his experience:

> You always spoke to a consultant in those days and usually, every single consultant, they always became a personal friend. Quite a lot of them said to me "If you have got problems at home", because you didn't have paramedics that you have now, "just ring me up at home"...They were, they became, after three or four years, they became very, very friendly. I always got on well with every one of them. Every single one. They were brilliant individuals.[228]

Clearly the provision and quality of care was not evenly distributed across the UK geographically or temporally. This was not the result of a teleological process of improvement – Balfour's comments demonstrate that even by the latter years of the 1980s there were examples of less than satisfactory clinics, and a common perception of unhelpful authoritarianism amongst HCPs. But how did the clinic shape the day to day private rituals of T1D? We have already considered the example of falsifying test results prior to appointments, but how did others react to the demands of medical authority? Balfour simply did not attend clinics until his daughter developed T1D:

> When we went down to London [in 1972]... I have no recollection of having seen a doctor about anything, and we were there for about eighteen months or something like that. Then we moved up north again [in 1974] to Eaglescliffe and we were

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[227] Balfour, Interview.
[228] Turner, Interview.

> there approximately eight years, and again I have no recollection of seeing a doctor or anybody else associated with diabetes at that time. We had a GP who you went to for general reasons... then down to Buckingham and there I think we registered with a GP and again, bear in mind we were only there for about two years. We went twice at least to Stoke Mandeville Hospital which is in Aylesbury, it's quite a distance but I was going there with my daughter who, at that stage had got Type 1 as well so, we went as a joint visit, if you like.[229]

Similarly, Karen Addington (1966-) was 'lost by the system' after moving away from home but made no significant effort to re-establish contact:

> [I] stopped when I went to university because the system lost me. And I can remember I was at Cambridge University and I can remember once taking myself to Addenbrooke's [Hospital], which is a long cycle. I was at New Hall, it's a long way, and saying, you know, "Hello, I have Type 1 Diabetes, should I be part of a clinic?" And I think I probably had one appointment during my undergraduate years... Then I went back to live in Spain for a couple of years so... I didn't access any.[230]

Simply not going to clinics or attending appointments related to T1D can be seen as a fundamental challenge to the dominance of the medical model. This is not to say that this constitutes a rejection of its basic principles, but that, by choosing not to attend, the implicit message that life factors beyond crude biology are occasionally privileged is clear. For example, while the demands of employment or geographical location may play a role in discouraging engagement, this in itself demonstrates that the individual has prioritised non-

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[229] Balfour, Interview.

[230] Karen Addington interviewed by Stuart Bradwel, 11th May 2017, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

medical considerations.[231] Like Clifton eating more to ensure the safety of her child or Marriott doing the same to avoid hypoglycaemia while working a difficult manual job, the rejection of professional guidance – for whatever reason – betrays an implicitly critical approach to the preoccupations of orthodox medical thought.

Addington cites her time in Spain during the mid-1980s, where she was outside the reach of clinical authority, as the point at which she realised she could begin to escape some of the more claustrophobic demands of 'conventional' therapy:

> I was [previously] horrendously strict with it. Always. So I never slept past seven o'clock even on holidays or weekends because I didn't think I could, you know... I did a modern and medieval languages degree and so when I was twenty-one I did a year abroad in Spain, and that was the first time I realised I could be a bit flexible... So because I was living quite a Bohemian, chaotic lifestyle there wasn't always food available at that time. I was doing casual teaching. I was travelling around quite a lot. I was living in shared accommodation with lots of different people at different times. [The] Spanish timetable of food is different anyway. And I felt... really uncomfortable one night coming back from somewhere and dinner time had gone and I hadn't eaten anything, and I kind of remember thinking 'But I'm OK!' And that was probably the first time I began to be a little bit more flexible around it... [I could] miss a meal and instead drink a Coke.[232]

Addington did not, however, feel comfortable adjusting her own insulin dosages as 'that was never something that was taught.' Flexibility was found in diet, not in medication. This was not uncommon – according to the ingrained expectations of 'conventional' therapy,

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[231] Outside of the context of free at the point of use NHS care this becomes more complex.

[232] Addington, Interview.

the idea that the individual might make ad hoc adaptations to their own insulin regimen according to varying requirements was anathema, even where this might have been feasible, by the mid-twentieth century it often was not thanks to the increasing use of less flexible long-acting and/or mixed formulations of insulin. This was the sole preserve of the physician, and nevertheless there were considerable implicit moral barriers to active engagement of this sort.[233] As Milner directly states, ‘only bad diabetics did that, and they ended up... being lugging around by a dog... and limping on one foot!’[234]

However, following the precedent of Eastwood, some individuals did successfully choose to bypass the expectations of orthodoxy and adapt insulin as well as diet according to their own personal needs. Marriott explains how he began slightly reducing his dosages occasionally:

> If I knew I was going to go all night fishing I made sure I wasn't going to go hypo. So I'd reduce insulin to make sure. I would rather be high than go hypo. On the end of Newhaven Pier I am in the middle of the bloody night, you know!... I don't think [the doctors] knew about it actually... and I seemed to get away with it pretty well.[235]

Similarly, Howie found herself beginning to adopt a more flexible attitude after moving to university:

> I have a feeling I probably started [adapting insulin dosages] before you were officially told to, because... [I] went to university... and you sort of end up- you leave home... and you've got a lot more freedom, and different food, really, because you can't afford the same stuff you had at home... I don't think [I

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[233] Milner, Interview.
[234] *Ibid*.
[235] Marriott, Interview.

> mentioned it at the clinic] because I think possibly if they had said something about your blood test results I might have said "Oh, that was the day I had such and such or whatever for dinner", but if they were reasonably happy then probably not, because I probably didn't want them to know what was up to if you see what I mean!... Sometimes you would have things that you kind of knew people thought you shouldn't have... We had a Chinese carry-out that night so you would maybe increase your insulin a bit and hope nobody noticed.[236]

Howie is describing adaptations she made in the mid-1980s after the widespread introduction of home blood testing equipment, while Marriott's fishing trips occurred long before this during the 1960s and 1970s. It is telling that, despite this, both take a very similar approach. Both too make a point of noting that their choice to adjust their insulin intake was not something that they mentioned to doctors, demonstrating a belief that had they done so they would have been met with sharp criticism. Nevertheless, neither was ever reprimanded on account of their actions because their physicians were simply not aware of them. As their control appeared acceptable when assessed at the clinic, they raised no suspicion.

This demonstrates the inescapable inversion of Feudtner's thesis that in the context of 'conventional' insulin therapy obedience equalled satisfactory control and, as a result, unsatisfactory control necessarily indicated 'non-compliance'. By the same logic, satisfactory control implied faithfulness regardless of reality. Physicians promoted passivity as a *route* to adequate glycaemic control, not an end in itself. 'Non-compliant' PWD who were nevertheless able to meet the demands of orthodoxy were not, and *could not be*, 'non-compliant'. Conflict between patient and practitioner could occur only where

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[236] Howie, Interview.

dissonance between personal and professional concepts of ‘wellness’ was implied (or inferred). Perhaps this goes some way towards explaining Eastwood’s rather positive reception in the 1930s – his unorthodox private ritual of management nevertheless shared a *purpose* with the concerns of HCPs even while it allowed him more freedom.

Part 7: 'Multiple Daily Injections' and the Influence of 'Semi-Intensification'

From the late 1980 and 1990s, and particularly after 1993, clinicians began to encourage the adoption of novel technological devices such as insulin pens and SBGM, and of the use of 'multiple daily injections' (MDI) in management. This differed from more traditional approaches in that it sought to more closely replicate the pattern of insulin production usually found in those without T1D via a 'basal-bolus' system – instead of one or two injections daily, MDI suggested that short acting insulin should be taken with meals, supplemented by a basal rate achieved via the use a of longer-acting formulation. This was not 'intensive' therapy per se, but rather reflected a highly moderated 'semi-intensified' alternative – an effort to introduce some elements of 'intensification' into essentially 'conventional', prescriptive approaches with a view towards achieving more effective glycaemic control. Meaningful lay-engagement with therapy was rarely encouraged, and often actively warned against. While providing some freedom with the timing of meals, precise dosages of insulin continued to be prescribed regularly, alongside strict dietary requirements. Mark Deakin (1973-), who has lived with T1D since early childhood and is now a consultant in diabetes and paediatrics at Alder Hey Children's Hospital in Liverpool, while greatly appreciating his newfound ability to eat at a time of his choosing, remembers the uncertainty and frustration he felt towards such prescriptive 'semi-intensified' regimens where he chose to make small adjustments:

> My regret at the time, and I didn't know it, but my regret was that there was no focus on dose adjustment. So that was a set dose of long-acting insulin, and I don't know how the mealtime insulins were arrived at. And I know for years I was two units at breakfast, four units with lunch, and six units with tea, but there was no room for if you have a big meal – how you increase it. And I know that if we went

> out for a family meal at the weekend, I would often double it to twelve units and think, “Oh my god, have I done too much?”[237]

Nevertheless, the material changes to insulin therapy necessitated by the adoption of such ‘semi-intensified’ approaches – that is, the provision of more flexible short-acting insulin, often delivered discreetly via insulin pen, and the SBGM equipment necessary to quickly assess the efficacy of therapeutic choices – had significant implications for the lay-experience of management, providing an opportunity for some to exert an increased degree of control over the shape of their own treatment. This potential was not lost on Addington, who took advantage soon after she was introduced to the concept of MDI:

> I was introduced to blood testing and multiple daily injections, and that suddenly gave me a freedom. I worked that out for myself. There was no education of it, but that gave me a freedom that I had never had before. Not to the extent that I have now because I have since done DAFNE and I use a pump. But compared to what it had been. Absolutely... I don't know [why]. I would love to know actually. It just felt as though there was a change within the advice you were given and the understanding... in the mid [to] late ‘80s.[238]

This account suggests that while she was not specifically *encouraged* to adjust her own insulin as part of MDI, the conditions of ‘semi-intensified’ management provided a context in which she was able to experiment productively with dosages just as she always had with diet. This was important: with these new tools, Addington found ‘a freedom’ that she had previously lacked, allowing her to engage with her own needs to informally adapt therapy based on an ever-evolving body of tacit knowledge.

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[237] Mark Deakin interviewed by Stuart Bradwel, 2nd August 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[238] Addington, Interview.

Similarly, Marriott adopted MDI during the early 1990s. Like Deakin and Addington, he was not shown how to adjust dosages to any meaningful extent, and continued to be expected to follow a fairly rigid programme of diet and lifestyle. Nevertheless, his new material circumstances allowed him to quickly adopt an approach that he uses to this day:

> Well, what I do now, I call it firefighting... Depending on what my blood sugar is and what I'm about to eat... You know, I don't rigidly have ten [units] then ten for that meal, then ten for that meal. I if know I'm going to be eating a trifle for example... Then I whack it up a bit... I consider it firefighting, but sensible firefighting... And so that is liable to adjustment depending on how I feel, what I test at... And what I'm likely to be about to undertake. Meal, long walk. Things like that. I mean for example I don't walk a great deal because my neuropathy makes me prone to trip a lot. So just occasionally I'll go out with Jackie and the dog. And where we walk is obviously not on pavements, all up and down hills and what have you.[239]

As of 2017, Marriott had never attended a DAFNE course, and has never been provided any specific education related to 'intensive' therapy – his approach is derived from a tacit knowledge originating in experience and self-assessment. Marriott's history shows that he has always been willing to experiment and adapt according to his immediate needs, but the tools afforded by MDI allowed him to radically alter therapy to an even greater extent.

Those with T1D were able to assert a previously elusive autonomy in light of 'semi-intensified' MDI largely because, in addition to SBGM, it involved the use of shorter-acting insulin similar to that developed in the 1920s, and therefore allowed for a considerably degree of flexibility by comparison to the longer-acting and pre-mixed varieties that had become ubiquitous in the 1960s and 1970s. While these innovations had been developed

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[239] Marriott, Interview.

with a view to ensuring glycaemic consistency and reducing the total number of injections required in management, they were unwieldy and allowed for precious little fine-tuning (see Chapter 4). ‘Semi-intensified’ MDI, in essence, appears to have allowed for the reactivation of a stifled liberatory potential held within insulin therapy: one that Eastwood had enjoyed decades previously.

This chapter has outlined the features of T1D as a lived experience following the creation of the NHS in 1948, arguing that managing the condition according to the demands of ‘conventional’ orthodoxy involved a number of interconnected expectations surrounding, primarily, the administration of insulin, dietary regulation, the monitoring of control, and interaction with the healthcare infrastructure. While most HCPs in this period appear to have believed that ‘satisfactory’ treatment as they understood it – that is, according to the medical model – could be achieved only by strict lay-adherence to instruction, and sometimes attempted to rather aggressively insist upon this, such deferential obedience amongst those with T1D was in fact relatively rare. Instead, official expectations intersected with the broader material needs and subjective values of those affected to produce highly individualised private rituals of management that occasionally diverged considerably from anything a professional would consider ‘appropriate’.

The adoption of individualised private rituals in the management of T1D, some of which directly contradicted professional advice, suggests two things. First, individuals with this condition, even those utilising the kind of inflexible formulations of insulin often prescribed as part of ‘conventional’ regimens, were never passive actors, and that some degree of lay-agency has been a consistent element of this condition for the duration of its post-1922 history. Diet and lifestyle could often be manipulated even where medication could not (easily) be, while the results of self-monitoring could be falsified and clinics avoided entirely, should this be considered necessary. Second, the experience of those living with T1D provides an effective critique of the medical model’s approach to healthcare. The adoption of such a disparate variety of private rituals suggests, instead, that the precise health values and priorities of individuals were both diverse and intimately connected to the ‘non-medical’ parts of their lives, and that some, for example, considered certain additional risk factors (raised blood glucose, for one) to be acceptable trade-offs in particular situations. ‘Good’ healthcare as understood by laypeople, therefore, often differed significantly from ‘good’ healthcare as understood by HCPs – a theme to which we shall return in the following chapters.

Finally, this concluding section has briefly described the experience of those with T1D as ‘semi-intensified’ therapy via MDI and SBGM was introduced to clinical orthodoxy during the late 1980s and 1990s. That individuals like Addington found ‘[their] own’ additional ‘freedom’ in MDI implicitly suggests that the introduction of short-acting insulin formulations and SBGM provided opportunities to adjust and refine therapy beyond what had been possible via diet and lifestyle alone. Given that official guidance continued to discourage significant self-experimentation without medical supervision until the 2000s supports the overall argument of this chapter – neither Addington nor those like her were passive, and they were willing to disregard orthodox advice where they felt it necessary.

How, then, should we understand the clinical trend towards providing laypeople with the equipment and medication necessary for MDI during this period, even while HCPs continued to adopt a prescriptivist attitude towards management as a whole? The reintroduction of soluble insulin, for example, appears to go against a trend towards more complex, longer-acting formulations consistent since the 1920s. In order to fully understand this process and its implications, it is necessary to more carefully consider the clinical, ideological, and political context within which it occurred.

Chapter 3 – Ideology and the Clinic

‘When medicine was ineffective, the only weapon doctors had was magic.’

Charles Fletcher, ‘Journal Interview 30: Conversation with Charles Fletcher’, *British Journal of Addiction* 87 (1992), p. 534.

Part 1: The Dark Ages?

One of the consistent themes of Tattersall's work is that between 1936 and 1952, the management of T1D (along with – to a lesser extent – T2D) can be characterised as a 'Dark Age' in the treatment of the condition.[240] The triumphant jubilation that had followed the isolation of insulin, he suggests, had by then been replaced by a pervasive sense of stagnation and pessimism as the limitations of therapy were reached and the scale and severity of long-term complications became clear.

In 1950, Joslin's colleague Ruth Reuting (1911-1964) published an article in the *Archives of Internal Medicine* that revealed the grim prognosis of a life with T1D. Of fifty young patients followed at Boston's New Deaconess Hospital since 1929, nineteen had died at an average age of just under thirty-five years with cardiovascular and/or renal failure the leading cause of mortality. Equally concerning was the fact that twenty-seven of the surviving number were presenting evidence of hypertension, atherosclerosis, and/or impaired kidney function.[241] Only four appeared to remain in good health. Reuting's contemporaries in Europe could report nothing more optimistic.[242] Henry Dolger (1912-1997) described the problem succinctly in 1947, writing that 'the optimism of that early period is now being dissipated by a number of anxious reports on the mounting incidence of seemingly inevitable degenerative sequelae.'[243] While Frederick Allen (1879-1964), once a pioneer of the pre-insulin 'starvation diet', had in 1930 declared that 'diabetes has been scientifically

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[240] Tattersall, *The Pissing Evil*, pp. 143-168; Tattersall, *Diabetes*, pp. 79-97.

[241] The participants in this study were selected randomly with only two conditions: that the individual was younger than forty and had lived with insulin-dependent diabetes for over five years; Ruth E. Reuting, 'Progress Notes on Fifty Diabetic Patients Followed Twenty-Five or More Years', *Archives of Internal Medicine* 86 (1950), pp. 891-897.

[242] For example; W. Korp and Ernst Zweymüller, '50 Years of Insulin Treatment at the Vienna Hospital for Children – the Fate of Diabetic Children from the First Insulin Era' in Dietrich von Engelhardt (ed.), *Diabetes: Its Medical and Cultural History* (Berlin: Springer-Verlag, 1989), pp. 437-450.

[243] Henry Dolger, 'Clinical Evaluation of Vascular Damage in Diabetes Mellitus', *Journal of the American Medical Association* 134 (1947), pp. 1289.

mastered... [and] every patient can be expected to live out his full natural lifetime', this seemed, by the middle of the twentieth century, hopelessly naïve.[244] During this 'Dark Age', New York physician Harold Rifkin (1916-1997) later confided, 'everybody was scared of complications – everybody.'[245]

While he never explicitly states it, Tattersall's work implicitly suggests that these 'Dark Ages' came to a close with the development of more sophisticated methods of screening for, preventing, and treating the potential long-term sequelae of diabetes during the 1950s and 1960s.[246] To Tattersall, the root of this era's sober tone lay firmly in an epidemic of complications that appeared, at the time, to be utterly insurmountable. While it is beyond question that innovations like dialysis, kidney transplantation, and retinal photocoagulation were welcome additions to the physician's arsenal that dramatically improved the prognosis of sequelae that could previously be managed only symptomatically, the reduction of contemporary inadequacies in management to the strictly biomedical is – while unsurprising – somewhat premature.

As Feudtner has consistently argued, novel interventions in T1D have been historically defined by a single crucial fact: they have only transmuted the course of the condition. The shape of experience has changed – and often in an apparently positive way – but nevertheless new problems and fears have emerged as old ones have receded. The individual undergoing haemodialysis, for example, must accept the necessity of long-term

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[244] Frederick M. Allen, 'Methods and Results of Diabetic Treatment', *New England Journal of Medicine* 203 (1930), pp. 1133-1139.

[245] E.A. Walker and J. Wylie-Rosett, 'Harold Rifkin MD: Selections from an Oral History', *Diabetes Spectrum* 8 (1995), pp. 256-263.

[246] This is visible in the structure of his work. The fourth chapter of *The Biography*, 'The Dark Ages', is, for example, immediately followed by one titled 'Treating Long-Term Complications', which covers developments in the ability of medicine to deal with common long-term sequelae – for example the first successful kidney transplant in 1954 and Gerd Meyer-Schwickerath's (1921-1992) experimentation with the use of light coagulation to treat proliferative retinopathy in 1955; Tattersall, *Diabetes*, pp. 98-114; Tattersall, *The Pissing Evil*, pp. 227-261.

invasive treatment that in many cases restores only partial health and comes with its own list of potential side-effects: side-effects occasionally so severe as to render them 'marginal men' in the unfortunate phrasing of one 1970s author.[247] Complications have become more manageable and less overtly disabling and deadly but nevertheless have continued to occur with grim frequency to the present day. A recent Scottish study suggests that, on average, those with T1D can expect to die twelve years earlier than the general population, with cardiovascular and renal impairment a leading cause of premature mortality.[248] Even for those diagnosed long after the period identified by Tattersall as the 'Dark Ages', the ever-present threat of complications constituted – and constitutes – a meaningful physical and psychological burden. The idea that science and technology ushered diabetic management out of the darkness and into the light is fundamentally an illusion – those living with T1D (and indeed T2D) continue to live under an ominous cloud of possibilities, shielded perhaps by the flimsy umbrella of clinical intervention but nonetheless bound sooner or later to be caught in the downpour.

It is untenable to suggest that Tattersall's 'Dark Ages' ended when he suggests – with the development of more sophisticated methods of managing complications from the 1950s – but nonetheless it is an apt concept with which to introduce this chapter. By clarifying and expanding the meaning of the term, it provides an excellent framework with which to assess the development of clinical approaches to the management of T1D and lay/professional relations in the latter half of the twentieth century. Beginning by

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[247] Peitzman, *Dropsy, Dialysis, Transplant*, pp. 130-134; Melanie K. Landsman, 'The Patient with Chronic Renal Failure: A Marginal Man', *Annals of Internal Medicine* 82 (1975), pp. 268-270.

[248] This is, however, affected by the same issues that emerge in any attempt to determine life expectancy. Much of the data used concerns older individuals who died after many years with T1D, a significant number of them on insulin since the mid-twentieth century. As such it is limited in its ability to assess the influence of more recent developments on longevity, for example in those who have utilised 'intensive' therapy throughout their lives with the condition; Shona J. Livingstone, Daniel Levin, and Helen C. Looker et al, 'Estimated Life Expectancy in a Scottish Cohort with Type 1 Diabetes, 2008-2010', *Journal of the American Medical Association* 313 (2015), pp. 37-44.

elucidating a more nuanced definition of the ‘Dark Ages’ that introduces an ideological component, this chapter will go on to assess late twentieth century developments in the context of this concept, arguing that in truth they never *really* ended: though perhaps by the time of the publication of the DCCT in 1993 several mitigating factors had emerged to fundamentally alter the condition and its historical course.

Part 2: A New Definition

Tattersall is correct to point out that the history of T1D management has often appeared statistically a hopeless, Canutian endeavour. The prevalence and severity of complications meant that, by the mid-twentieth century, there was a growing sense of resignation amongst professionals that those affected would almost certainly die unpleasantly at a relatively young age as the cumulative impact of various co-morbidities led to ever increasing damage and debility. While he is also right to suggest that such concerns were – to an extent – mitigated by improvements in medical technology over the following decades, this focus on the physical aspects of management does not fully cover the scope of clinical limitation suggested by the term 'Dark Ages'.

A passage in the postscript to Tattersall's *The Biography*, however, reveals another important characteristic that is not meaningfully addressed in the main body of his work – a pervasive sense of alienation between those living with diabetes and HCPs:

> Up until the 1970s, care in England was almost exclusively provided in hospital clinics staffed with doctors, with the token presence of a dietician and possibly a social worker. These clinics ran like production lines, where the doctor sat in judgement and dispensed advice about what, or more usually, what not to do. Patients' views were not solicited, and the idea that they might have any input in designing their regimen was unthinkable. The doctor in charge expected his instructions to be followed to the letter and blamed the patient when the desired level of glucose control was not obtained. This was unsurprising, because he (and it

> was usually he), had been trained to diagnose and treat acute illness such as pneumonia and heart attacks, where patient input was irrelevant.[249]

Given his professional background as a diabetologist and his own admission that in his writing he has 'concentrated, perhaps excessively' on 'new drugs, new insulins, and other technological developments', it is unsurprising that Tattersall's work implicitly links improvements in healthcare provision primarily to biomedical outcomes – to increased life expectancy and falling rates of disability.[250] This passage demonstrates that Tattersall clearly understands the importance of the less overtly physical aspects of T1D management, though he seems reluctant to invest them with adequate meaning.

The alienation of the mid-twentieth century medical profession from its patient body – like its commitment to a firmly biological understanding health and illness – did not happen by accident. Both must be understood as part of a pervasive ideological structure. James A. Trostle succinctly explained this concept in 1988: '[Ideology is] a system of shared beliefs that legitimize particular behavioural norms and values at the same time that they claim and appear to be based in empirical truths... transform[ing] power (potential influence) into authority (legitimate control).'[251] In short, the Foucaultian process by which the 'patient' was firmly decoupled conceptually from the 'pathology' within them (as in the biomedical model), while representatives of the orthodox medical profession were enshrined as experts solely qualified to pronounce on the boundaries of health and sickness and to determine treatment, must be considered an *ideological* development that converted

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[249] Tattersall, *Diabetes*, pp. 197-198.

[250] *Ibid*, p. 197.

[251] James A. Trostle, 'Medical Compliance as an Ideology', *Social Science and Medicine* 27 (1988), p. 1300.

individualised potential for *power* into collective *authority*.[252] While he does not discuss healthcare per se, this principle has been conceptually expanded by Slavoj Žižek, who emphasises that such an ideological construction's very influence rests on the ignorance of its constituent parts as to its reality: ''ideological' is a social reality whose very existence implies the non-knowledge of its participants as to its essence... not the 'false consciousness' of a (social) being but this being itself in so far as it is supported by 'false consciousness.''[253]

An integral element of any conceptually meaningful understanding of the 'Dark Ages' is therefore not to be found in the specific challenges of management, but in the hegemony of a particular ideological structure that, in this case, was defined by biomedical reductionism and a paternalistic outlook. In the context of T1D, this framework had, by the mid-twentieth century, become characterised by the 'sense of doom' described by Tattersall.[254] Tied to the medical model, despair over perceived clinical impotence and theoretical uncertainty were only a part of the shadow cast over the contemporary diabetic clinic that existed alongside a palpable alienation between patients and those tasked with caring for them. Appreciating the ideological context of the clinic is of vital importance to understanding the development of approaches to the management of T1D over the course of the twentieth century. Ideology is by definition not fixed, but shaped by the material structure with which it interacts. By bearing this in mind while assessing developments in the diabetic clinic as it responded to contextual developments, it is possible to explain in much finer detail the direction of its institutional growth.

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[252] Prior to the emergence of pathological anatomy in early nineteenth century Paris, physicians may of course have exercised *power* (or *potential influence*), but it was this ideological development that allowed them to claim *legitimate control*.

[253] Slavoj Žižek, *The Sublime Object of Ideology [1989]* (London: Verso Books, 2008), pp. 15-16.

[254] Tattersall, *The Pissing Evil*, p. 143.

Part 3: The Clinical Foundation

By the 1970s the ideological framework of the diabetic clinic was fairly typical of paternalistic mid-twentieth century medicine across the healthcare system. Despite some bureaucratic and structural innovations that improved the delivery of care – such as those devised by Joan Walker (1902-1995) and subsequently John Hearnshaw (1931-2008) at Leicester Royal Infirmary – the nature of care itself was largely unchanged when compared with that which had gone before. In 1974, Ronald Weir (1939-) became a consultant operating between the Gartnavel Royal Hospital and the Western Infirmary, both in Glasgow. Reflecting on the general clinical approach at this time, he describes the way those with T1D were managed within the setting of the hospital:

> [T]aking account... of the ability of the patients to understand their diabetes. Taking more time with some than others, and this was at the medical level- to explain the diabetes to them and hopefully their parents, and describing the condition, potential complications, and then the injections. And usually we would, from a practical point of view, pass the mechanics of the injections over to the nurses at the clinic, and they were general nurses, but at the diabetic clinic they were more geared to diabetes but hadn't had any specific training. And they would explain the mechanics of the injections and the procedures and so on, and the medics- we would make a decision about what insulin [to prescribe], and in these days it was basically soluble insulin- quick acting. Often three times a day, sometimes only twice. And then the longer acting ones... were becoming more used and we'd introduce them to the concepts of that. So, that was the mechanics of the insulin injections. Where to inject... when to inject, and also looking at their dietary things... Again, it would be advice, and in this instance it was advice from the

> dietician. We did have a dietician at the clinic whose particular interest was diabetes, but she was an overall dietician, and she would explain the diet... And the urine testing, they tested the urine in these early days. Dipsticks. And when to do that, how often to do it, and what to do if there was any abnormality.[255]

Weir provides a fascinating example of day-to-day clinical management in a relatively typical setting. Neither Gartnavel nor the Western Infirmary were – or became – major centres for cutting edge work in diabetes. Instead, they were very much ordinary clinics staffed by ordinary practitioners doing the best that they could with the available resources. An internal 1979 report into the provision of diabetic services in Glasgow's Western District (of which both formed part) makes this very clear:

> 1. Clinical facilities – satisfactory.
> 2. Biochemical and other back-up – satisfactory.
> 3. Records and secretarial services – satisfactory.
> 4. Dietetic – satisfactory.
> 5. Chiropody – not satisfactory – a part-time chiropodist is needed to attend the Diabetic Clinic one session per week, the wards one session per week and for home chiropody.
> 6. Education of patients in self-regulation – not satisfactory outwith the hospital – there is a need for a Health Visitor attached to the Diabetic Clinic who can maintain supervision and education in the community and follow up defaulters – especially in the adolescent and elderly groups. Liaison with District Nurses is also unsatisfactory.

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[255] Ronald Weir interviewed by Stuart Bradwel, 25th April 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

7. Ophthalmic and Obstetric Liaison – satisfactory.[256]

It is clear that Weir felt that his own job, as the consultant, was to determine treatment dosages, insulin formulations, and injection timing. He worried that, particularly with his younger patients, the demands of their broader lives might cause them to be 'erratic in the timings of the injections', or fail to attend the clinic at all.[257] The implication here is clear – a failure to attend the clinic, and a failure to abide by instruction, was a failure of treatment *in itself*. While there is no doubt that Weir's anxiety was genuine, it is telling that such issues feature so prominently amongst his memories. The values of the patient, implicitly, should always be subordinate to medical requirements – as he makes clear when describing one rather extreme case:

> A patient that comes to mind... [was] just not capable. Or partly not capable, but just choosing to be not capable of understanding and accepting the reasons why he needs good control, and binge drinking... and intermittent appearances at the A&E department. Out of control diabetes. I can think of one particular example who got very early complications, and even then he just felt he wanted to continue his lifestyle.[258]

While this is undoubtedly a rather ill-advised lifestyle, it is revealing that Weir describes the patient as '*choosing* to be not capable of understanding and *accepting* the reasons why he *needs* good control'.[259] *Value*, as it pertains to treatment, is for the professional to determine.

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[256] *Greater Glasgow Area Medical Committee, Sub-Committee in Medicine, Diabetic Services in Glasgow: A Report by J.T. Ireland and A.C. MacCuish*, 24th May 1979, HB55/912/DBO/O, NHS Greater Glasgow and Clyde Archives.

[257] Weir, Interview.

[258] *Ibid*.

[259] Emphasis mine.

It is also clear from Weir's testimony that many clinics during this period were marked by a fundamental lack of formal specialisation and specialist training. Indeed, he was never a diabetologist or even an endocrinologist, but was rather, officially, in 'general medicine with an interest in diabetes'.[260] The dietician and nurses he mentions were also not trained specifically to manage the condition, but were general staff whose knowledge came wholly from their experience in the clinic.

Weir's account is perhaps slightly sanitised, but throughout there is the implicit suggestion that hospitals during this period were often simply unsure how to deal with diabetic patients – and in particular those with T1D. At the beginning of his career, for example, Weir's patients were seen during general medical clinics rather than at dedicated diabetic ones. This sense of uncertainty was not unusual. Discussing his experiences at London's Guy's Hospital in 1970 – where defined diabetic clinics did take place and consultants were generally specialists – paediatrician Peter Swift (1943-) describes a rather disorganised environment:

> The outpatient clinic was held in a very antiquated part of Guy's. I guess the buildings would have been Victorian, and they were scruffy, they were small, they were crowded. There seemed to be a lack of organisation. In those days, of course, very often, a whole host of people would be given appointment times at exactly the same time. You know, come to the clinic at 4pm, and then there'd be a list of eighty patients all waiting there until they were seen. And then, of course, after an hour or two's wait, they would see me – a junior house officer, knowing very little about diabetes... I remember, after one or two of these clinics... just feeling that we were all, I suppose, trying to grapple with an extraordinarily

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[260] *Ibid*.

> difficult, lifelong disease, and not doing it very successfully, and not having the mechanisms to help patients to really get a grip on their diabetes... I think that the ancillary services, then, were either completely absent, or very, very minimalist. I suppose, you know, the only people who made contact with the patients, there in the clinic, were perhaps a nurse, who might have taken the blood pressure, or urine sample, of course... I'm not sure that they even took blood pressures, because I remember having to do that myself, and thinking 'You know, well, they're getting their blood pressure checked once a year, by me. That's pretty inadequate and rather a hopeless task.'[261]

Swift's admission that he knew 'very little about diabetes' is rather important here – as are his later statements about the general sense of bewilderment amongst professionals. Even those whose whole careers were dedicated to the management of this condition knew very little about it – and more to the point were unable to do a great deal to help their patients.

While Swift was one of those who did raise concerns, many of his contemporaries were easily able to continue investing their own instructions with both technical and moral value despite the palpable irony created by their own inability to agree on how best to approach T1D. Swift recounts that during this period 'the implication was, also, that people with diabetes didn't look after it, and therefore they got complications.'[262] Even more bluntly, John Saunders (1945-) attributes Arnold Bloom (1915-1992), of London's Whittington Hospital, with the phrase 'Diabetes is a just disease, as it crucifies the fools.'[263]

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[261] Peter Swift, Interview, *Diabetes Stories: An Oral History of Diabetes,* <http://www.diabetes-stories.com/transcript.asp?UID=61>, [accessed 30 July 2018].

[262] Swift, Interview, *Diabetes Stories.*

[263] John Saunders interviewed by Stuart Bradwel, 30th August 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

Certainly, the concept of professional authority and the irrelevance of the patient themselves remained deeply ingrained in the clinic of the late 1970s. Swift remembers raising the issue of the importance of psycho-social factors with a consultant while working in Bristol, only for his concerns to be roundly dismissed:

> I went to the consultant, and said, "Well, what about this diabetes? I think it's very, very interesting, and extremely difficult for the children and parents." And he said "Well, why do you say that?" And I said "Well, because diabetes is very difficult to control, and it has so many influences, particularly the influence of the family, of the psychological aspects, the emotional aspects, and the social influences on diabetes." And he said "Oh, no, no, no. Really, once you get the insulin dose right, everything else will fall into place." And I hesitated, and I said "I'm sure that's not true"... "You know, some of these parents are struggling hard with insulin injections and doses, but still the diabetes doesn't seem to be particularly well controlled." Of course, in those days, it was difficult to assess control, because we were basing this on urine testing. There were no blood tests in those days; this is 1976, '77. And so he said "No, it's very important to get on with getting the dose of insulin correct."[264]

The patient here is clearly a secondary concern; a battleground upon which the physician contends with a pathology but not, in themselves, a meaningful actor in the war – even where the general is as clueless as anyone else. The adoption of the traditionally passive Parsonian 'sick role' and obedience to instruction remains paramount. Despite an awareness that the profession was dealing with 'an extraordinarily difficult, lifelong disease,

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[264] Swift, Interview, *Diabetes Stories*.

and not doing it very successfully', there was no suggestion that this lent professional instruction any less authority.[265]

This is supported by the testimony of Anne Kilvert (1950-). In 1978, Kilvert accepted a position at a Birmingham diabetic clinic despite having never worked in the field previously. Like Swift, she remembers the presence of a number of consultants who were 'passionate about diabetes' – to the point that their 'enthusiasm just infected [her]' and led her to make her career in the speciality. Nevertheless, her description of clinics during this period is not complimentary:

> So, the clinic was- there was a room which... [was] maybe sixteen feet by twelve feet, something like that. And in it there were three desks each with a doctor sitting at the desk, and the patient would come in, and there were loads of patients. I mean it varied from week to week but there was no appointments system. If you said somebody had to come back in three months they'd just get their name added to the list, they wouldn't be given a time and they'd just turn up, and people could literally sit there three hours waiting to be seen. And we doctors could see anything between twenty and thirty patients in that time. So, literally you were talking about five minutes a patient. So there was... a waiting area outside in the sort of main reception... in order to speed things up, the sister in charge would have a seat in the room for the next patient, so that they could go to the first free desk. So that patient had a choice of three conversations to listen to!... There was no privacy, and as one of the consultants said on one occasion, there was also no impotence in Birmingham... because there were too many people listening to the conversation!... The patient would come in... they'd already had their blood sugar

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[265] *Ibid*.

> tested and you'd chart that on a graph. You'd find they'd have had their weight done as well. You'd find out what treatment they were on, and you checked their eyes and you'd ask if they had any foot problems. You wouldn't look at their feet unless they said they'd got a problem, which is an absolute no-no now... and then they'd be out in five minutes, so you didn't really get to know people at all.[266]

Kilvert's experience of multiple patients meeting multiple doctors in the same room in Birmingham may have been an extreme example, but as addressed in Chapter 2 a lack of privacy was a common frustration amongst those attending clinics during this period, though it was usually limited to the pre-consultation process of nursing staff taking blood and measuring weight in the waiting room. This conveyor-belt like approach to management appears to have been a common feature of many 1970s clinics no matter the good intentions of those running them.

Charles Fox (1942-) is equally scathing as he discusses his first experience of diabetic clinics at Leicester Royal Infirmary during the mid-1970s:

> We were in the Stone Age, we really were! We had no way of knowing how well people were doing, and obviously height, in the case of children, and weight was of great importance, and I suppose the miracle is that an awful lot of people didn't do badly on whatever it was... It was all based on urine, and people would come along, they would often have a blood sugar measurement which was done there and then and sent to the lab and they'd wait half an hour and get the result, and an awful lot was placed on that. One blood sugar measurement! I mean, it's embarrassing to even talk about it, but that is the fact of the matter! I mean, if you've only got one

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[266] Anne Kilvert interviewed by Stuart Bradwel, 29th August 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

> piece of evidence, you use it, you know? And of course, it depended on what time of day the clinic was taking place. And then there were the patient's urine tests which were taken quite seriously... and some people would go to great lengths to colour their books in. We would have books of results, which were actually produced by the BDA. And then lots of stories about how people would come with the same stuff each time, the same chart, with different dates or something.[267]

Fox clearly understood the limitations of contemporary diabetic care during this period. It is especially notable that he – and by implication many of his colleagues – well understood that their patients were not always entirely honest with their urinary glucose records. Like doctors, they realised that the tools available to them could simply not meet the requirements necessary to provide effective or meaningful feedback on glycaemic control. Fox goes on:

> Consultant diabetologists often got a reputation for being rather fierce and telling people off, because life is never quite as good as you'd expect and of course... everyone with diabetes was struggling with just information failure, you know? They didn't know themselves what was going on. How could they? You can test their urine but God, what a waste of time that is. So, I think a lot of people with Type 1 Diabetes felt guilty because they felt they were eating the wrong thing, or not doing enough urine tests – which were pointless anyway... it was a guilt inducing disease then. Of course, it still is.[268]

Fox attributes the perception felt by many of those with T1D that consultants were often ferociously authoritarian to a general environment of frustration and impotence that

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[267] Charles Fox interviewed by Stuart Bradwel, 24th May 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[268] *Ibid*.

surrounded the clinic itself – the very same cultural inertia Tattersall identifies as characteristic of the 'Dark Ages'. He goes on to use a rather telling metaphor that once again evokes the ritualised aspects of life with T1D (see Chapter 2) in the mid-twentieth century:

> There was a diabetologist in Kettering who was just a little bit younger than me... and he had this idea that going to the diabetic clinic was like a Catholic going to confession. You sort of turned up, you know? You told the doctor the things you had done wrong, and you were given a sort of blessing, and sent on your way for another six months... and you'd come back six months later. I mean, the clinics were pretty appalling really.[269]

This is an important statement that illustrates the ideological functioning of the clinic during this period and resolves the apparent contradiction of an institution in which professional authority remained intact despite undeniably poor outcomes as judged by the terms of that very professional authority. Fox's statement suggests that the clinic, paradoxically, had very little in the way of *medical* relevance. Instead, practitioners and their patients engaged in a sort of ritualised, quasi-Debordian theatre in which the *appearance* of proficiency, rather than proficiency itself, was the vital element.[270] This goes a long way towards explaining the frustration expressed by consultants where their patients refused to fulfil their ascribed Parsonian role. In failing to do so, they shattered the illusion that maintained the professional relevance of the physician and, at the same time, exerted a degree of psychological protection to PWD. By undermining the subconscious ideological structure, both parties were forced to confront the existentially terrifying reality that nothing in the clinic could reliably prevent deterioration.

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[269] *Ibid*.

[270] Guy Debord, *Society of the Spectacle [1967]* trans. Ken Knabb (London: Rebel Press, 1994).

To appreciate more fully this ideological process it is worth considering the diabetic clinic of the 1970s and prior in the context of the neo-Stalinist bureaucracy described by the late Mark Fisher in his 2009 work *Capitalist Realism*. Stalinism, he argues, was characterised by the 'valuing of symbols of achievement over actual achievement'[271] To Fisher, such an attitude was not, however restricted to the Soviet Union, but was enthusiastically embraced by neoliberal governments in the capitalist world.[272] Of the British education sector under New Labour, he writes:

> The drive to assess the performance of workers and to measure forms of labour which, by their nature, are resistant to quantification, has inevitably required additional layers of management and bureaucracy. What we have is not a direct comparison of workers' performance or output, but a comparison between the audited representation of that performance and output. Inevitably, a short-circuiting occurs, and work becomes geared towards the generation and massaging of representations rather than to the official goals of work itself.[273]

The patients of the 1970s diabetic clinic occupy the same conceptual position as the workers described in this passage. How else is the demand for comprehensive urinary test records – that all parties recognised were often faked, and nonetheless usually worthless – to be understood but as a layer of bureaucracy intended to shape an 'audited representation' of control with little or no relation to reality? The ritualised theatre of confession described by Fox's colleague served an important function here. Faced with the reality that contemporary medical orthodoxy was unable to meaningfully or consistently influence clinical outcomes with the tools and theoretical frameworks available, this

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[271] Mark Fisher, *Capitalist Realism* (Winchester: Zero Books, 2009), pp. 42-43.
[272] The influence of such political developments upon the management of T1D will be returned to in Chapter4.
[273] *Ibid*, p. 42.

process served as an ideological adaptation that simultaneously reinforced the professional power structure of the clinic and shielded patients from the truth of their own vulnerability.

The Žižekian principle of fetishistic disavowal is a vital part of this ideological operation. Žižek summarises the structure of the concept via the example of an incompetent and corrupt court official widely known to fall far short of the required standard in the exercise of their duties:

> This functioning involves the structure of fetishistic disavowal: "I know very well that things are the way I see them (that this person is a corrupt weakling), but none the less I treat him with respect, since he wears the insignia of a judge, so that when he speaks, it is the Law itself which speaks through him." So, in a way, I actually believe his words, not my eyes – that is to say, I believe in Another Space (the domain of pure symbolic authority) which matters more than the reality of its spokesmen.[274]

It is easy to see how this principle relates to the experience of HCPs as they interacted with those living with T1D during this period.[275] The ideological being of the clinic – or in other words the *symbolic authority* invested into it – is disconnected from its immediate physical representatives and even the efficacy of any given therapeutic decision. Even while it may be obvious to all concerned that in a particular clinical encounter nothing much is being achieved, the physician continues not only to speak for themselves, but also for what Žižek refers to as 'Another Space' – that is, for the *Institution of Medicine* itself. In this way, the actions or non-actions of the practitioner are entirely separated from the ideological structure. Perceived failings are individual failings not relevant to the profession as a whole

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[274] Slavoj Žižek, *The Ticklish Subject: The Absent Centre of Political Ontology [1999]* (London: Verso Books, 2009), pp. 389-340.

[275] This is not, of course, to accuse any medical professional practicing during this era of cynicism – only to emphasise the functioning of the ideological structure within which they operated.

– and yet as a member of that profession the individual is still accorded the respect and status considered proper to it.[276] How else should we understand the continued attendance at clinic of individuals who, at heart, knew their own treatment amounted to little more than a ritualised purification? The alternative was far more horrifying.[277]

There is more to this, however. Fetishistic disavowal does not occur on a conscious level. Even while the limitations of the clinic may be acknowledged, the ideological structure remains untouched – or perhaps even strengthened. It becomes possible to believe absolutely in the value of this *symbolic authority* even where doing so appears to contradict personal experience. This is the root of the confessional ritual: go through the motions, arrive at the clinic, provide or receive the necessary documentation, give or receive some superficial advice, hope that the blood and urinary tests display no deterioration in organ function – do all of this and it becomes possible to believe absolutely in its value and in its ability to maintain health. Meaning becomes invested not in pathology *itself*, but in *representations* of it. In the context of a condition that in reality was often unfair and arbitrary, this ideological adaptation constituted a valuable psycho-emotional buffer for both parties.

By adapting in this way, however, the ideology surrounding the management of T1D necessitated a degree of alienation between doctor and patient. By abstracting the quality of management into a representation of quality created through reductionist, standardised, and ultimately meaningless quantification like urinary analysis, any assessment was

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[276] Recalling Trostle, it is also important to recognise that the *symbolic authority* of the medical profession and the biomedical model emerged from simple *power* because it *did* have many major successes. Ironically, the isolation of insulin was one of these.

[277] This applied to the physician as much as it did their patient. It is telling that when Tattersall mentions a general reluctance to discuss complications with patients during his 'Dark Ages', he suggests that this was done not only for their benefit but also to protect the professional: 'It was the doctors who were afraid to tell their patients; the language in which case histories, however harrowing, are written almost seems to sanitise them, so as to protect the doctor from bursting into tears'; Tattersall, *The Pissing Evil*, p. 151.

fundamentally removed from both the lived experience of T1D as a condition and the reality of genuine efforts to manage it more effectively. This aspect is described in Chapter 2 as a major source of frustration amongst PWD – so long as the *representation* is satisfactory, nothing else matters. Even while the process of fetishistic disavowal solidified the symbolic authority of contemporary medical ideology, it hollowed out by abstraction the consultative encounter itself.

This principle was not limited to diabetic management but appears to have been endemic to mid-twentieth century medicine more generally – particularly as it was confronted with long-term conditions and sought to engage in preventative education. This is summarised (rather self-indulgently) in one passage of a letter sent to the *BMJ* by G.L. Davies of Brighton in 1958:

> To the many people who attend hospital all the voices they hear are *voces deorum*, even that of the newly qualified housemen, and they would only express an opinion which they thought would be in keeping with that of their mentors. Many years ago when I first qualified I used to try to teach young mothers who could not feed their babies themselves the method of modified cow's milk as taught by the distinguished paediatrician of my teaching hospital. Only very few of the more intelligent carried out my instructions, the rest merely going away and buying a tin of condensed milk. There must be many doctors like myself who, as a sort of corollary to any advice they may give their patients as to their existing illness, often try to explain to them the nature of it, as well as how to prevent it if possible in the future. To the more intelligent this is obviously welcome, but in the case of others

> like the foolish young mothers referred to above one felt that they were saying to themselves, “Oh! Cut the cackle and get on with the cure.”[278]

Davies is observing the ideological process of disavowal here, though of course does not appreciate it as such. Consider this passage alongside the testimony of many of those with T1D quoted in Chapter 2, who described the way they superficially agreed with whatever instruction was provided by the doctor before entirely disregarding it once home. The ‘foolish young mothers’ to whom Davies refers are engaging in precisely this same behaviour. The medical profession’s *symbolic authority* – the quality he refers to as ‘*voces deorum*’ – is entrenched and vital to both parties. Where disagreement with orthodox treatment is encountered, it is in the interests of the patient to simply produce the requisite *representation* no matter their intended course of action.[279]

Within the context of T1D this was only amplified by the underlying, unspoken acknowledgement that medical professionals were, ultimately, unable to offer any material guarantees or even any real hope in the long-term. The process of mass-disavowal required to maintain the ideological superstructure of the diabetic clinic relied at its very core on a generalised frustration with the character of that apparatus. In this context, internal contradictions within the framework are clearly pronounced. It is via these that it is possible to understand the significant changes within orthodox management that became unmistakable from the early-1980s.

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[278] G.L. Davies, ‘Disease Education by the B.B.C.’, *BMJ* 1 (1958), pp. 769-770.

[279] Infant feeding was, of course, a disputed topic during this period; Emily E. Stevens, Thelma E. Patrick, and Rita Pickler, ‘A History of Infant Feeding’, *The Journal of Perinatal Education* 18 (2009), pp. 32-39.

Part 4: Charles Fletcher

The experience of Charles Fletcher (1911-1995) demonstrates plainly the entrenchment of orthodox clinical ideology as the 1970s drew to a close, and provides clues as to its subsequent development. Fletcher – a physician – diagnosed himself with T1D as a young man. His memory of this event is rather telling in its own right:

> It all began one Monday afternoon in 1941 when, as a house physician at the Radcliffe Infirmary, Oxford, I suddenly became thirsty. This went on for two days and I began to feel I was getting neurotic, so I went to the Outpatients' Department to test my urine. In those days one had to mix urine with Fehling's solution and boil it. As the liquid boiled and the blue colour changed to orange I dropped the tube. Patients got diabetes not doctors, I thought.[280]

The final sentence in this extract is a clearly ideological statement. The distinction of 'patient' appears to exist even before the diagnosis of any medical condition! Doctors, implicitly, occupied such an inherently *different* position to those that they cared for that the very idea of these categorisations overlapping seemed to Fletcher initially unbelievable on an instinctual level.

Fletcher was never a specialist diabetologist – though in a sense he would become one informally. A chest physician by training, he made his name by performing the world's first penicillin injection in 1940 before going on to gain some household recognition as the presenter of the popular 1958-1964 television programme *Your Life in Their Hands*. This was one of the first public broadcasts in Britain to openly discuss medical and surgical

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[280] Fehling's solution can be, for the purposes of this thesis, considered chemically interchangeable with Benedict's; This extract is taken from the December 1980 edition of *Balance*, though an almost word for word passage appears in an near-identical article by Fletcher in the *BMJ* earlier that year; Charles Fletcher, 'An Active Diabetic Life', *Balance*, December 1980, p. 1; Charles Fletcher, 'One way of coping with diabetes', *BMJ* 280 (1980), p. 1115.

issues in a manner accessible to the general public.[281] Long before this, however, his formative professional years took place as a house physician at London's St. Bartholomew's Hospital, where he joined the Socialist Medical Association and found himself politically at odds with many of his colleagues in an often revealing way:

> I did want to be a clinician. But I had a sort of vain hope that I might be a professor of medicine. I wanted to be an academic physician. Because I strongly disliked the idea of private practice. I didn't only want to treat patients who could afford it. I wanted to do medicine unfettered, so I joined the Socialist Medical Association and vigorously supported the NHS... [which made me] a minority at Barts. On one day I was called a Communist by a medical student and a bloody Conservative by a member of the Communist Party. I was extremely keen on the Health Service and delighted when it came about. Medical students in those days were a tremendously conservative lot. They were mostly sons or daughters of doctors who were mostly Conservatives. Whilst at Barts some of us thought that it would be nice if we had some say in the way that we were educated. So we held a meeting and agreed that we ought to approach the staff to ask for some influence on the way they taught us. At the meeting one of the students got up and said that when he was at school he didn't criticise his masters and so why should he start now?[282]

The hierarchical ideological framework of 1940s medicine is very clearly on display in this passage. 'Junior' doctors were almost completely subordinate to their more experienced counterparts in a relationship that – likely not coincidentally – resembled the master/student dynamic prevalent in the Public Schools from which no small percentage of

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[281] Michael Essex-Lopresti, 'Your Life in Their Hands', *Lancet* 368 (2006), pp. S24-S25.

[282] Charles Fletcher, 'Journal Interview 30: Conversation with Charles Fletcher', *British Journal of Addiction* 87 (1992), p. 529.

them had come. They were not considered peers. The implicit message of this arrangement with regards the patient's role is obvious: in this highly entrenched hierarchy the layperson sat squarely at the base.

When Fletcher and other sympathetic colleagues approached their superiors to demand more of a say in the teaching conducted at St. Bartholomew's, they directly rejected this paradigm and criticised the accepted culture of professional orthodoxy. In doing so, they represented a contemporary ideological battle occurring during the 1940s. Though they were clearly primarily concerned with the unrestrained authority of the senior 'masters', their attack on institutionalised, dogmatic authority, and entrenched hierarchical thinking, set a much greater precedent that would form the bedrock of Fletcher's approach to the profession throughout his life.

When Fletcher started presenting *Your Life in Their Hands* in 1958, the response of his colleagues was as fascinating as it was critical. In 1992, he recalled their reasoning:

> Many of them were bitterly opposed... I think it was a feeling, dating from Victorian days, in [the] middle classes that the inside of the body should be treated with disgust. My mother told me that in the early part of the century, a guest at her home mentioned the word appendicitis at lunch. There was a ghastly hush and the subject was quickly changed by my grandmother.[283]

This general appeal to decorum and an implicit belief that the general public simply lacked the constitution to witness the gruesome reality of surgery was not uncommon. Graham Black of Newcastle upon Tyne wrote to the *BMJ* with an account of one individual who had found the spectacle altogether overwhelming:

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[283] *Ibid*, pp. 533-534.

> I have to report a television emergency to-night. I was called upon to diagnose (as an emergency call) a fainting attack in a male patient who revolted at the sight of skull bone, flap, and brain in the medical department of TV's Your Life in Their Hands (neurosurgery) production. The general public are not in my opinion as yet educated or perceptive enough to take these programmes in. Those who are can find other means if they are interested. This programme was pointless, and I would suggest that the medical advisors, if they can find nothing better, would be well advised to let Champion the Wonder Horse have a further run at this time.[284]

George Davidson of Cramlington reacted to the transmission with a level of venom only marginally surpassed by his pretension:

> Man has aye been entertained by the sufferings of his fellow men. For the Romans it was the agony of the dying gladiator that gladdened the heart: we content ourselves with the drenching of the clown, or savour suffering in imagination only as in the novel. But it grieves me that a leader of our profession should, in his public demonstration of his patient suffering from heart failure, lend himself to this beguilement. For let those sincere men, striving to help suffering humanity by a process of education, know that this was the end of their toils – a common spectacle, a vulgar entertainment. Let them know also that they are rendering harder the task of those of us who, in this age of scientific materialism, are striving by precept and example to imbue our students with the humanity of our profession.[285]

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[284] Graham Black, 'Disease Education by the B.B.C', *BMJ* 1 (1958), p. 708

[285] George Davidson, 'Disease Education by the B.B.C', *BMJ* 1 [5071] (1958), p. 641.

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Not all physicians were quite so opposed to the visceral nature of the programme. Arnold B. Cowan of Glasgow wrote concerning the furore:

> So another patient has fainted whilst watching the programme Your Life in Their Hands, and the B.B.C. are accused of playing up to and pandering to the public. What was to prevent the patient from turning her head away before fainting, or, better still, switching off the television set or not even looking at the programme at all? As for accusing the B.B.C. of sensationalism, why should not they televise what they see fit? After all, they have their business to run and have their own censors and advisers, who are no doubt experts in their jobs, just as we have specialists in our profession. How would the medical profession like to be told by outsiders how to treat their patients? It is one of the many duties and responsibilities of the B.B.C. to enlighten the masses in everything concerning them, and that surely includes matters relating to their health, especially when this is done with the closest co-operation of medical experts.[286]

There was clearly a considerable amount of disagreement on the merits of *Your Life in Their Hands* amongst practitioners. That the *BMJ* – a publication owned by the then famously conservative British Medical Association (BMA) – adopted a rather dim editorial view towards Fletcher is unsurprising: however, it would be a mistake to assume that criticism stemmed entirely from concern for 'civility'. Kelly Loughlin has suggested that this hostility must be understood in its full political context. As a 'hymn to the equitable provision of facilities throughout the NHS hospital system' and, in effect, a celebration of the kind of socialised medicine it represented, *Your Life in Their Hands* inspired little enthusiasm amongst a professional body that had long attacked the principle of state intervention in

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[286] Arnold B. Cowan, 'Television Casualties', *BMJ* 1 [5073] (1958), p. 770.

healthcare.[287] Moreover, by rendering diagnostic and therapeutic procedures public, it threatened to undermine the consultative relationship by impinging on the authority of individual practitioners. In one case, for example, an incensed GP complained that a patient had, using knowledge gained from the programme, correctly determined that he had developed cancer – while the doctor had already known this, they had chosen not to inform the patient, feeling that it would be against their best interests.[288] While Loughlin quickly (and understandably, given her media-oriented analysis) moves on, this highlights an additional ideological dimension to the controversy that quite clearly demonstrates not only the paternalism of contemporary medical practice but the manner in which it was sustained. When pressed on the reasons for the negative reception to *Your Life in Their Hands* in his 1992 interview, Fletcher alludes to the same process more directly:

> Another [reason] was that when medicine was ineffective the only weapon doctors had was magic. Here was somebody breaching the secret code which doctors thought was their own. The BMJ published five leading articles in successive weeks called 'Disease education by the BBC', or something like that, attacking the television series. There was even a debate in the House of Commons on the impropriety of talking about this sort of thing in public.[289]

This is an important and highly revealing reflection that cuts to the heart of the ideological framework of contemporary medical practice. Fletcher's statement that 'when medicine was ineffective the only weapon doctors had was magic' implicitly acknowledges not just the limitations of mid-twentieth century biomedicine but also directly references the process of fetishistic disavowal that allowed it to sustain its symbolic authority as it reached

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[287] Kelly Loughlin, ''Your Life in Their Hands': The Context of a Medical-Media Controversy', *Media History* 6 (2000), p. 186.
[288] *Ibid*, p. 178.
[289] Charles Fletcher, 'Conversation with Charles Fletcher', p. 534.

those limits – in the absence of an empirically measurable ‘positive’ clinical outcome, the value of the medical professional can be sustained only by recourse to abstraction and faith. *Your Life in Their Hands* was, in this context, *threatening*.

Fletcher’s participation in *Your Life in Their Hands* caused such consternation amongst some of his contemporaries that his then-boss worried that he was sabotaging his own career:

> My chief, John McMichael, asked me to see him after the second programme which showed a heart operation. He told me I must withdraw from the series and assured me that if I did not I would not be promoted in the distinction awards system, and that I would lose the confidence of my colleagues. That was fairly tough. But I felt I couldn't leave it in mid-stream. I thought its benefits were going to be greater than any harm it might do... that year I was elected to the Council of the Royal College of Physicians and I was promoted from a C to a B merit award. So the warnings he gave me were disproved within a year... [but] in a friendly way he was saying “Look I don't think it is in your interests to do this.”[290]

While Fletcher considered McMichael’s words a friendly warning rather than a threat, it is clear that what he was doing was deeply threatening to the established ideological orthodoxy of contemporary professional practice. The commitment to, in a sense, democratise medicine and open it up to public debate that had characterised his entire career made him something of a rebellious character within the community: his approach constituted a major contradiction within the ideological framework. By revealing this underlying structure, he threatened to collapse it – and with it the status of those who profited by it.

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[290] *Ibid*.

While this side of Fletcher's life is not concerned with T1D in particular, it provides a fascinating though perhaps all too superficial glimpse into the operation of clinical ideology and how it developed across the twentieth century. It does, however, raise a question. How, precisely, was he able to perceive the presence of something that – by definition – should be imperceptible to those beholden to it? The answer can be found in his own history with T1D. At once a doctor and a 'patient', the ritualised theatre of confession that underpinned the contemporary clinic broke down. Existing at once on both sides of the divide, Fletcher could not fail to acknowledge the superficiality of the confession and the flimsiness of the ideological shield it provided. In response, he abandoned any pretence whatsoever – after five years of fairly strict adherence to prescription in terms of both diet and insulin following his diagnosis in 1941, Fletcher decided to adapt his treatment significantly, well beyond the traditional boundaries of orthodoxy:

> At my wife's suggestion I tried doing what the normal pancreas does and went over to three injections of soluble insulin daily before my mean meals... I also supplement the evening dose with a little isophane (NPH) [Neutral Protamine Hagedorn] insulin to cover the next early morning. I have always tested my urine three or four times daily and adjusted my insulin day by day... When I had as many as two consecutive urine tests full of sugar on any day I would take small insulin supplements (5 or 10 units) until the tests became blue again, and if I had been hypo on one day I would reduce the relevant dose the next day. It isn't necessary to be a doctor to do this sort of day by day adjustment.[291]

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[291] Fletcher, 'An Active Diabetic Life', p. 15.

After his account of this unorthodox approach to management appeared in *Balance*, Fletcher was received with considerable hostility by laypeople. One correspondent to the publication*,* *'*Mrs AT' of Northumberland, wrote in the following issue:

> I refer to the article by Professor Charles Fletcher in which he recounts some of his experiences and the general management of his diabetic life... Whilst finding his views interesting, I was surprised by some of the attitudes he revealed. For instance, it would appear that Professor Fletcher does not regard it necessary to stick closely to a prescribed diet, preferring instead to adjust his insulin dosage according to the food eaten. As a result, it seems that he has suffered a number of serious hypos which could have been avoided. Of course, he was privileged by being surrounded by knowledgeable people who knew precisely what to do to bring him round. To the average diabetic such facilities are not usually available. I feel the position of diabetics generally would be jeopardised in the eyes of the general public if they did the same because they could be regarded as unreliable citizens, dangerous drivers and a heavy liability on the already over-taxed National Health Service. While being glad for Professor Fletcher's sake that he suffers no diabetic complications, it is a pity that some diabetics might infer that such management is an insurance against the development of any complications since they do not appear to have developed in Professor Fletcher's case. Such an assumption could be entirely wrong and the lack of complications entirely fortuitous.[292]

On the same page, 'JPB' of Yorkshire was even more succinct:

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[292] 'Mrs AT', 'Surprised', *Balance*, February 1981, p. 2.

> Thank you for Professor Fletcher’s article. It seemed that the attitude of the article was one that would be viewed with horror by most of those looking after diabetics. Whilst it may be all right for a doctor to take liberties and call on the services of his colleagues to remedy his mistakes, I don’t think it is the sort of thing that should be put into Balance.[293]

The following edition contained yet more criticism, with ‘Mrs E J’ of Bristol also questioning whether the inclusion of Fletcher’s account was a responsible editorial decision on the part of *Balance*:

> I am concerned that you gave such a privileged spot to Professor Fletcher’s diabetic experiences... It is a fascinating account but I would query whether he has shown us a good example of diabetic control. Not many of us have friendly young doctors, or other helpers nearby to cope when we go hypo.[294]

The volume of negative feedback received after the publication of his article led Fletcher to write a follow-up letter to *Balance* in which he (in characteristically unapologetic fashion) clarified, or rather restated, his position:

> I am so sorry to have shocked some of your readers with my account of my active diabetic life... of course, CHO [carbohydrate] intake should be reasonably constant. But there are times when one is away from home when it’s impossible or inconvenient to avoid high carbohydrate. This only causes a temporary rise of blood sugar which only occasionally needs correction by a few extra units of insulin. My hypos were as frequent during my first five years of diabetes when I kept to a strict diet. Help from medical colleagues has been useful but not essential. It was

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[293] ‘JBP’, ‘Horror’, *Balance*, February 1981, p. 2.
[294] ‘Mrs E J’, ‘Concern’, *Balance*, April 1981, p. 2.

> convenient when I was at work to have a hypo corrected immediately by intravenous glucose instead of waiting 20 minutes of so for swallowed sugar to act. I have managed without this help in the five years since I retired. My method of doing two or three urine or blood sugar tests every day and adjusting my insulin dose according to the results has enabled me to avoid high and low blood sugars as much as possible in spite of a total insulin dose varying, usually for no obvious reason, between 50 and 80 units a day. One does not have to be a doctor to use this method which involves being careful, not casual, and has the merit of having not restricted my activities in any way, while keeping me remarkably free of complications.[295]

On the surface, Fletcher's lay detractors are primarily concerned with his 'taking liberties' by tolerating increased instances of hypoglycaemia. This, they suggest, is only possible for him because, as a HCP, he is habitually surrounded by knowledgeable people who know exactly how to react should he require assistance. Despite Fletcher's assurance that his 'hypos were as frequent... [as when he] kept to a strict diet', and that the assistance of colleagues has been convenient but never absolutely necessary, his account does suggest that after adopting his new method he did become somewhat more susceptible to low blood glucose levels:

> Since I have aimed at such full control I have had a considerable risk of hypoglycaemia (hypo attacks) and this has been one of my main problems. First I was nearly always aware of them by day, and I always woke at night, but as time went on it gradually became more difficult. I now feel quite normal and do even delicate manipulations quite easily with a blood sugar as low as 2.5mmol/l (45

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[295] Charles Fletcher, 'Prof Fletcher replies...', *Balance*, June 1981, p. 2.

> mg/100ml). Sometimes double vision, difficulty in formulating words, weariness, or inability to think may lead me to measure my blood sugar to check whether I am hypo or not: I nearly always am on these occasions. But I often become too muddled to know what is wrong when I am hypo, and I have to thank my wife, my children, my secretaries and many young doctors who worked with me for spotting when my blood sugar was getting low.[296]

It does certainly seem like Fletcher was experiencing fairly classic signs of hypoglycaemic unawareness and relatively frequent severe episodes (i.e. those requiring the assistance of a third party). Nevertheless, he continued to adopt a fairly liberal attitude towards lifestyle, noting that, until a few years previous, he had 'worked, played, travelled, dined, and wined without serious limitation.'[297] Even had recurrent hypoglycaemia not been an issue, many of his contemporaries with T1D would not have dreamed of being able to live such an unencumbered lifestyle in the mid-twentieth century – travelling to Moscow, for example:

> Another tiresome occasion was in 1961 when, having queued for an hour and a half in late morning, I had eaten all of my sugar and nearly collapsed in Lenin's tomb and had to be helped to a taxi to get more sugar in my hotel. An eminent US doctor who was there said I ought not to travel abroad again. If I had taken any notice of that I would have missed many interesting trips.[298]

It is clear that Fletcher's approach did occasionally lead to more hypoglycaemia than other regimens perhaps would have. It is also true that, on several occasions, he was reliant upon others to pull himself out of severe episodes – most often his wife but regularly his colleagues. There is much to be said about the relevance of class and gender here: Fletcher,

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[296] Fletcher, 'An Active Diabetic Life', p. 15.
[297] Fletcher, 'One way of coping with diabetes', p. 1115.
[298] Fletcher, 'An Active Diabetic Life', p. 15.

as a relatively privileged professional man, was able to accept the risk of hypoglycaemia where many others could not (for example some of those described in Chapter 2).

These criticisms are not unfounded, and it is doubtless that Fletcher's particular position *did* facilitate his successful adoption of this more flexible approach. His authority as a doctor allowed him privileges that were simply not available to the general population. For example, most of those with T1D in 1980 were simply prescribed a particular kind of insulin. Often, a moderate to long-acting variety that was usually rather inflexible and necessitated precise mealtimes was considered preferable because such formulations required fewer injections. Trostle's observation of the relationship between technology and ideology is highly relevant here:

> Recently we can see medical technology used to reduce the need for patient initiative. For example, long-acting medications are recommended over short, injections recommended over pills, and office-centered interventions valued over those in the home. These interventions may be effective, but they risk turning patients from responsible subjects into responsive objects.[299]

That Fletcher was able to decide to simply to abandon isophane and begin to use much faster acting soluble insulin is a clear demonstration of his privileged position. A layperson would have almost certainly struggled to convince their physician to allow them to do the same.

Nevertheless, there is something else happening here – another reason why Fletcher was received with such hostility by the readership of *Balance*. The dialogue between him and his correspondents draws into stark focus the manifestation of the ideology surrounding medical practice and its power amongst laypeople. Fletcher's comments threaten the very

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[299] Trostle, 'Medical Compliance as an Ideology', p. 1306.

basis of the subjective authority of the clinic. If he, at the age of sixty-nine, could not only remain complication-free despite an approach 'that would be viewed with horror by most of those looking after diabetics', but also endorse it and suggest others emulate his strategy *as a professional*, the ideological framework and all its contradictions are laid bare for all to see – and in becoming so exposed the whole structure threatens to evaporate into nothing.

As a representative of the profession, Fletcher speaks not only for himself but as a living conduit of Žižek's 'Another Space' – invested with the ideological authority of the medical profession as whole. Non-professionals can easily be marginalised where they criticise the central assumptions of medical practice, but Fletcher cannot be so easily dismissed because he speaks *for* the profession – indeed his television work casts him as the definition of a trustworthy representative in the public eye. In this context, he *is* the profession at the ideological level. The operation at work here is almost the precise opposite of that in the case of the corrupt judge: Fletcher is not an incompetent doctor given legitimacy via ideology but rather an ideological representative nevertheless utilising the very authority that lends him to (perhaps unknowingly) challenge its very foundation. This ideology is as vital to the patient-body as it is to the professional interest – a shield against a deeply threatening reality. Fletcher, however, implicitly tears away that shield *with the very symbolic authority that he as a result undermines*.

As Fletcher's experience and approach directly contradicted the paternalistic ideological framework that characterised contemporary medical practice more broadly despite his being a part of that framework, the only way to successfully preserve the structure was to undermine the universal applicability of his argument *without* criticising its basic premise (attacking such a revered physician directly on this level would, of course, implicitly accept his point and as a result be entirely self-defeating). For example, the critics found within

Balance do not suggest that Fletcher's approach is *wrong* per se, though one does (correctly) point out that his successful avoidance of complications cannot necessarily be attributed to his management style and instead may be 'entirely fortuitous'. Instead, most concentrate on attempting to demonstrate that the cost of adopting such a method (primarily hypoglycaemia and a consequent reliance on others) would make it impractical for many. In this way, the ideological structure is maintained: Fletcher's individual symbolic authority as a physician is temporarily suspended – in a sense he is the subject of a reversed process of disavowal.

Nevertheless, despite the hostile reception to Fletcher's *Balance* article, both it and its sister work in the *BMJ* were important in the way that they implicitly critiqued the very basis of prescriptive paternalism. In a later 1983 paper based on a talk given to the 1981 Conference on Assessment and Management of Complex Disability at London's Royal College of Physicians, he took aim much more directly and explicitly at the orthodox framework of T1D management:

> Freedom from... complications is usually attributed by endocrinologists to the 'strict control' of the diabetes which they seek to impose upon their diabetic patients. The diet is limited by precise amounts of carbohydrate (CHO) to be taken at the same time every day. Injections of insulin are ordered at similarly strict times, often with a preference for long-acting insulins in order to maintain constant action that matches the rigorous diet; the dosage is usually adjusted at fairly infrequent clinic attendances. In between these, daily urine testing is

> recommended, with a cautious increase of insulin under medical advice if the tests are particularly sugary.[300]

This is a very succinct description of orthodox diabetic management for much of twentieth century, and certainly an approach adopted by a considerable number of contemporary doctors. An awareness of the ideological consequences of technological innovation outlined by Trostle is clearly not far from Fletcher's mind in this passage. Passivity and obedience, maintained indefinitely, are in themselves sources of anxiety and frustration – active barriers to the enjoyment of life and therefore, in a sense, to well-being:

> My next rebellion was against strict control of CHO in my diet... I never ask hostesses to prepare anything special when I dine out and at formal dinners I eat what comes. Any consequent hyperglycaemia is short-lived and often avoided by a little extra insulin. I believe it is the strict imposition of dietary monotony that so many diabetics resent. This was shown in one recent Swiss study in which diabetics reported their attitude to their illness. They felt isolated by never being able to eat out with friends or in restaurants, and resented it greatly.[301]

Most cutting, he then went on to give several examples of situations in which he felt that the general approach of paternalistic medicine had failed patients and left them isolated and anxious. For example:

> A friend of my daughter's, a very intelligent girl, recently developed diabetes after her first pregnancy. She was very fond of meringues. When she asked the dietician if she could have them the answer was "Of course not", and the poor girl burst into

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[300] C.M. Fletcher, 'Avoiding Diabetic Disabilities without Loss of Freedom', *Journal of the Royal College of Physicians of London* 16 (1982), p. 78.
[301] *Ibid*, p. 78.

> tears... When she had asked the doctor at the clinic a number a questions, he had said: “Why are you asking all these questions? Don’t you believe what I tell you?”[302]

Fletcher concludes with an impassioned defence of self-management and an uncompromising rebuttal of paternalistic approaches to the treatment of long-term conditions:

> We doctors who have to manage chronic disabling conditions should pay far more attention to the importance to patients of their being independent of as many restrictions as possible, and we should encourage them to be original in their self-management. We should more often ask the question: “How do you feel about your illness?” or “What bothers you most about your treatment?”[303]

Fletcher’s critique of paternalism within medical orthodoxy at the beginning of the 1980s was a rather radical position for a respected senior doctor and well-known TV personality, though perhaps not surprising to many of his contemporaries given his political leanings. His rebelliousness can in many respects be seen as direct challenge to the ideological basis of the ‘Dark Ages’ – if we are to take one thing from Fletcher’s attitude towards medicine throughout his life it is that it should be open, democratic, and most of all should value its patients as distinct moral actors in their own right rather than as tapestries upon which disease unfolds.

Fletcher’s position certainly gave him considerable privilege, a large platform, and a ready-made audience. However, he was not the only ‘rebel’. In 1977, *Balance* received a letter from Eastwood (see Chapter 1) that pre-empts Fletcher’s approach to management:

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[302] *Ibid*, pp. 97-98.
[303] *Ibid*, p. 98.

> I found your medical expert's reasons for the wisdom of giving two rather than one injection a day particularly interesting. I myself have now done three, or more often four a day for more than forty years and in 1975 completed fifty years as a diabetic. I adopted this policy of injecting little and often at an early stage in my diabetic life and only after several years of detailed and carefully documented study both of diabetes in general and my own case in particular. I was therefore very glad to find that my reasons for adopting such a policy were almost identical with those given today for preferring a twice-daily to a once-daily regime, namely the closer resemblance to the healthy body's mechanism for providing insulin at the right times and in the right quantities. This leads to easier and more effective control of blood sugar levels, which is surely the main object of all diabetic treatment. Since this control is achieved by maintaining a strict balance between the food eaten and insulin provided, it must be easier to achieve good control by injecting insulin each time food is taken than by injecting it once or twice a day and then trying to eat exactly the right food at the three or four mealtimes which follow. I realise that many people do not like doing injections but I have used this little-and-often method for many years and with excellent results – including having avoided at the age of sixty-five any complications. I wonder how many other diabetics have treated themselves in the same way as I have and whether the results in their cases have been as successful as mine?[304]

This letter, along with *Diabetes Without Tears*, a self-published book Eastwood had produced in 1976, represents the first time something resembling 'intensified' therapy was

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[304] 'J.D.E'., 'Many a time and oft', *Balance*, October 1977, p. 2.

seriously discussed in Britain in print: and by a layperson no less.[305] The expert advice to which Eastwood referred is however worth reproducing:

> Natural insulin is released into the blood stream automatically in response to any rise in blood sugar – i.e. after feeding. Hence, in a non-diabetic person a squirt of insulin is released from the pancreas several times a day, depending on the number of feedings. This frequent release of an amount of insulin tailored automatically to meet varying carbohydrate intakes, and released promptly as the blood sugar rises, is what maintains the blood sugar within a fairly narrow range of limits. When we use insulin by injections we are attempting to mimic as closely as possible the control of blood sugar obtained automatically in the non-diabetic by pancreatic insulin. In the diabetic who has virtually no natural insulin – which applies to most diabetics who develop the disease under the age of about forty – we could most nearly achieve the normal physiological control of the blood sugar by giving injections of short acting soluble insulin before each meal. However, fortunately this is not required, because with the mixtures of short and longer acting insulins which are now available, we can usually achieve a satisfactory balance between the carbohydrate intake and the insulin injected by giving two injections daily.[306]

Clearly the author here recognises that an approach like the one Eastwood (and Fletcher) used would likely achieve tighter control of blood glucose than either once or twice-daily injections of insulin. That this is not 'required' is however, raised as a positive! Even while the author acknowledges that 'there does seem to be a relation between the control of the blood sugar and the development of some of the later complications of diabetes', the

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[305] Jack D. Eastwood, *Diabetes Without Tears: A Layman's Account of his Fifty Years on Insulin* (Skipton: Self-Published, 1976).

[306] Anonymous, 'One or two', *Balance*, August 1977, p. 4.

implication is that ‘satisfactory’ control is sufficient – there is no need to pursue absolute normoglycaemia. It appears to have been taken without question by many that it was injections, rather than – as Fletcher later addressed – the deprivation of freedom that most concerned those with T1D. That a system involving more injections might enable the relaxation of certain lifestyle restrictions does not appear to have featured in this particular author’s thinking as particularly relevant.

Despite Eastwood’s basic agreement with the publication’s medical expert, his letter is accompanied by a polite editorial warning: ‘Congratulations, J.D.E.! It would not be wise, however, for any other diabetic to consider adopting this method of treatment without close consultation with their doctor.’ In 1980, however, Fletcher was given a front page article in *Balance* to describe an approach for which Eastwood had been relatively unenthusiastically received only three years previous. Earlier in the same year the *BMJ* – with which he of course had some history – had also published his account. What had changed here? Certainly, Fletcher received a relatively hostile lay-response to his *Balance* article, but its publication suggested his approach seemed now to be more or less acceptable amongst professionals themselves. His position as a doctor certainly gave him considerable power, but is this all there is to it? His colleagues had certainly had not failed to make their displeasure known when he appeared on *Your Life in Their Hands*. To explain this it is necessary to consider these editorial decisions in light of contemporary developments in clinical research.

Part 5: The Value of Control

For much of the twentieth century, the link between blood glucose control and the development of long-term complications was not particularly clear. While figures like Joslin had always emphasised the importance of strict adherence to treatment and the avoidance of glycosuria, this generally stemmed from an instinctive belief that keeping biological markers as close to statistically 'normal' was self-evidently desirable – and in Joslin's case it became a moral duty inspired by his Puritan values of moderation and self-discipline. Nevertheless, there was little solid evidence that control had any relationship to the myriad co-morbidities so common amongst those who had lived with T1D for a significant period of time. To many physicians, such deterioration seemed the inevitable fate of those diagnosed – sooner or later all would succumb, no matter how diligent their management.

Determining the influence of persistent hyperglycaemia was not easy because by all accounts it was impossible to accurately measure long-term control of blood glucose levels in those with T1D until the introduction of the HbA1c test in the mid-1970s.[307] Before this, assessment was limited to single blood tests and largely unreliable urinary test records. As Derrick Dunlop (1902-1980) wrote in 1954:

> The diabetic condition of no patient requiring a significant amount of insulin is perfectly controlled over 15 to 31 years' time in the sense that the urine is always sugar free and the blood always normoglycaemic. One deals perforce with individuals whose diabetes has been under varying degrees of inadequate control and one speaks of the best of them as having good control.[308]

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[307] Tattersall, *The Pissing Evil*, pp. 271-272.

[308] D.M. Dunlop, 'Are Diabetic Degenerative Complications Preventable?', *BMJ* 2 (1954), p. 384.

Nevertheless, experimentation by figures such as New York's Edward Tolstoi (1897-1983) with so called 'free diets' in the USA and continental Europe during the 1930s had, by the 1950s, demonstrated quite clearly that unrestricted dietary intake (and implicitly prevalent long-term hyperglycaemia) could produce – or at least accelerate – complications. Free diets were conceived as a direct acknowledgement of the limitations of orthodox T1D management, with Tolstoi noting in 1952 that 'a system of deception developed with the patient and the doctor, but as long as the patient got along everyone was happy.'[309] In principle, free diets rejected the notion that blood glucose levels made much of a difference at all to the long-term prognosis of those with T1D. Tolstoi wrote in 1943:

> Since excreting large quantities of sugar exerted no deleterious effects on the patient, why calculate diets? The next step was to let patients eat what they liked and see what would happen... good health... a state of social and economic usefulness, and infections among them are no more frequent than in the average individual. All these patients enjoy their freedom as there appeared no necessity for careful dietary management, and it is not necessary for them to carry their insulin and syringe with them. They administer the insulin to themselves in the morning and then put the equipment away until the following morning... the view that retinal changes were due to the hyperglycaemia is not too strongly championed today. Most ophthalmologists are of the opinion that the retinitis found in diabetes is the retinitis of arterio-sclerosis.[310]

Tolstoi comes across as something of a rebellious character, and it is certain that he saw himself as such. The same article goes on to say:

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[309] This certainly echoes the confessional metaphor alluded to by Fox; Anonymous, 'Diabetes Mellitus: Practitioner's Conference', *New York Medical Journal* 8 (1952), pp. 16-33.

[310] Edward Tolstoi, 'Newer Concepts in the Treatment of Diabetes Mellitus with Protamine Insulin', *American Journal of Digestive Diseases* 10 (1943), pp. 247-253.

> The patients were not too happy about the glycosuria, and reasonably so, as we ourselves had always pointed out to them that continuous excretion of sugar would lead to numerous dangerous complications. Such was the accepted hypothesis, it was postulated by men of reputation and authority, and we, as others, perpetuated these dicta as we neither had the experience, facts, nor the courage to challenge them.[311]

Free diets were, in a sense, a direct critique of the dominant ideological structure of contemporary management in T1D and the obsession with control that often characterised it.[312] Fletcher and Tolstoi would likely have found much to admire in one another: both were concerned with the consequences of unrestrained professional authority and domination, and appear to have sought to free – via radically different means – those with T1D from the unnecessary stress of adherence to a strict diet that they felt often served primarily the self-interest of the physician, even where such professionals did genuinely mean well. Unlike Fletcher, for Tolstoi this backfired when it became increasingly clear that the kind of unrestricted free diets (without the alteration of insulin dosages) that he promoted could, in fact, be rather dangerous indeed.

While their proponents continued to downplay the risks, by the 1950s it was becoming clear that free diets often produced less than satisfactory results. They had never been particularly prevalent in the UK, though one formal trial of the principle involving Dunlop was conducted in Edinburgh in 1951 – an experiment that the researchers later described as ‘disastrous’ for those who had taken part.[313] Only nine of fifty original participants

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[311] *Ibid*.

[312] Free diets were, of course, not comparable to those described by Fletcher or Eastwood . The major distinction is that free diets – for all their lack of ‘rules’ – retained an essentially passive role for the patient.

[313] C.C. Forsyth, T.W.G. Kinnear, and D.M. Dunlop, ‘Diet in Diabetes’, *BMJ* 1 [4715] (1951), pp. 1095-1101.

remained in good health after nine years on a free diet, corroborating the results of several studies from the USA.[314] The exact aetiology was unknown, but it did appear that there was a very clear correlation between hyperglycaemia and the deterioration of long-term health.

In many respects, the discrediting of free diets strengthened the paternalistic ideology of the clinic. Having demonstrated clearly that they might be seriously injurious to health, it seemed only natural to return to a system in which patients were given strict instruction and were closely monitored. As Dunlop concluded in his 1954 article:

> As the result of this and my experience of 'free diets' I have returned to my original simple diabetic faith. I believe that whatever specific aetiological factors may be causing diabetic degenerative lesions – endocrine, infective, or metabolic – the careful control and aggressive treatment of the disorder over the years is a most important factor in their prevention or postponement. I believe that to obtain good control diabetic diets should not usually contain much more than 200g of carbohydrate; that patients should be initially trained in the hard school of food-weighing, for it is only in that way that they learn to appreciate quantities; and that they should report regularly to a diabetic clinic to be assessed as regards symptoms, weight, glycosuria, and occasionally blood-sugar concentration, and, depending on the findings, to have their insulin dosage and diet suitably altered, for it is most exceptional to encounter a well-controlled diabetic who has been made entirely responsible for his own treatment.[315]

Dunlop is not only acknowledging the potentially catastrophic consequences of persistent hyperglycaemia here, but is also making an ideological point – patients *cannot* be trusted to

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[314] For example; R.L. Jackson et al, 'Degenerative changes in young diabetic patients in relationship to level of control', *Journal of Pediatrics* 5 (1950), pp. 959-971.

[315] Dunlop, 'Are Diabetic Degenerative Complications Preventable?', p. 385.

responsibly determine their own treatment, and will inevitably deteriorate if left to do so. The only way to ensure successful management is to provide clear instruction and strictly monitor progress at all times. While making an essentially biomedical argument, Dunlop is also implicitly reasserting the paternalistic authority that he feels should characterise the clinical setting, and which figures like Tolstoi directly threatened.

By the mid-1970s, the principle that strict control of blood glucose could mitigate the risks of long-term complications was made considerably more persuasive by several studies which demonstrated the systemic damage that could occur as a result of hyperglycaemia. In 1977, Fox – along with long-term collaborator Peter Sønksen (1936-) and others – published the results of a series of studies using rodents.[316] These demonstrated clearly the hyperglycaemic origins of several microvascular and nervous lesions. Fox's work corroborated the conclusions of several studies conducted across the UK, USA, and mainland Europe. None of these were in themselves absolutely conclusive, but collectively they suggested convincingly that glycaemic control was important in preventing complications.

By 1978, there was broad consensus amongst most professionals that a link existed between control and long-term clinical outcomes.[317] Clinical attention, as a result, began to shift. Rather than focusing simply on the avoidance of disabling hypoglycaemia or ketoacidosis, the importance of strictly maintaining blood glucose at as close to normal levels as possible was acknowledged as the ideal objective of management.

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[316] CJ Fox, SC Darby, JT Ireland, and PH Sønksen, 'Blood glucose control and glomerular capillary basement membrane thickening in experimental diabetes', *BMJ* 2 [6087] (1977), pp. 605-607; CJ Fox et al, 'Long-term study on nerve conduction in diabetic rats', *Clinical Science* 52 (1977), 24P; L Horton, CJ Fox, B Corrin, and PH Sønksen, 'Streptozotocin-induced tumours in rats', *British Journal of Cancer* 36 (1977), pp. 692-699.

[317] G. Tchobroutsky, 'Relation of Diabetic Control to Development of Microvascular Complications', *Diabetologia* 15 (1978), pp. 143-152.

Part 6: Self-adjustment

As the importance of maintaining tight control of blood glucose to prevent or delay the development of long-term complications was gradually accepted by most of the medical profession in the late 1970s, the overall objective of treatment shifted to achieving this. To this end, the self-recording of accurate blood glucose values performed regularly in the home provided an opportunity for considerably more nuanced analysis of therapeutic efficacy. As such those living with diabetes were soon encouraged, albeit hesitantly, to move away from urinary testing and instead use blood analysis.

By 1979, *Balance* was advertising blood glucose monitors suitable for domestic use, though an article titled ‘Which blood glucose monitor?’ makes it clear that professionals approached this new innovation with considerable caution:

> It is vital that those who do use this technique should receive instructions not only on the method of performing the test but also on the interpretation of the results. Blood sugar levels vary considerably and isolated readings are often unhelpful. Very careful instruction, therefore, is essential before embarking on this.[318]

However, as the DCCT Research Group would later observe (see Part 7), the constant supervision of patients was impractical. Simultaneously, recording data and then waiting until a clinic appointment in order for the doctor to make necessary alterations was not sufficient to produce satisfactory glycaemic control. One solution to this apparent paradox could be found in the principle of educating patients to self-adjust their insulin dosages. This was unheard of in the mid-1970s, as demonstrated by the second edition of the textbook *Diabetes and Its Management* – designed, as stated in the preface, as ‘a practical

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[318] Peter Watkins, ‘Which blood glucose monitor?’, *Balance*, October 1979, p. 9.

guide to the management of diabetes for the benefit, we hope, of clinicians.'[319] In one telling passage concerning potential variations in insulin requirements based on circumstance, it remains clearly the responsibility of the doctor to properly advise suitable adjustments to the regimen. Directly addressing the professional, it states:

> Insulin requirement is also reduced by exercise and therefore tends to fall when diabetics leave hospital and return to a normal and more active life. The combined effect of remission and exercise may greatly reduce insulin requirement, and it is important to lower the insulin by about 20 per cent, or increase the carbohydrate content of the diet, when a diabetic leaves hospital after initial stabilisation; the necessary reduction is usually less in diabetics previously treated with insulin – about 10 to 15 per cent.[320]

The notion that those with T1D might alter their own insulin is not discussed once throughout this work. By contrast, the same publication's fourth edition, published in 1990, was far more amenable to the idea, giving advice on self-adjustment: albeit in an extremely cautious manner. Displaying an anxiety that – as we shall see – characterised much medical advice on this topic during the late twentieth century, the authors worried that:

> A few patients become obsessed by blood glucose monitoring which comes to dominate their lives. This arises particularly in those who fail to understand the blood glucose profile and the need to detect peaks and troughs before changing their treatment. These patients undertake an increasing number of blood glucose

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[319] W.G. Oakley, D.A. Pyke, and K.W. Taylor, *Diabetes and Its Management*, 2nd ed (Oxford: Blackwell Scientific Publications, 1975), p. vi.
[320] *Ibid*, p. 86.

> estimations, change their insulin too often, and suffer multiple hypoglycaemic episodes.[321]

The importance of patient education in the management of T1D has been empathised by diabetologists since (and even before) the first clinical use of insulin. For much of the twentieth century, this was understood in the spirit of Joslin: the individual should be taught the nature of their condition and its treatment at length in order that they would be able to properly implement the instructions provided to them by medical professionals. Rather than *education*, it is perhaps more helpful to understand this as *training*. For example, in 1978 one author concluded his paper on the importance of strict glycaemic control by emphasising the need to ensure patient compliance:

> Of course if one strives to achieve the best control possible day after day, there may be immense difficulties. For such goals we must use improved techniques for teaching and education; we must persuade the patient to follow his diet strictly, to divide his daily insulin administration into two or three doses (at least for the majority of patients), to be as close to ideal body weight as possible and to include physical exercise as an important aid to his treatment.[322]

This was no different in the context of self-adjustment. In 1981, Anthony Knight, then consultant physician at Stoke Mandeville Hospital, wrote in *Balance* that the growing availability of blood glucose measuring equipment designed for home use made possible a framework of management within which the individual was, ostensibly, a much more active participant. He outlined an approach in which regular self-monitoring was vital, the

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[321] Peter J. Watkins, Paul L. Drury, and Keith W. Taylor, *Diabetes and Its Management*, 4th ed (Oxford: Blackwell Scientific Publications, 1990), pp. 83-84.

[322] Tchobroutsky, 'Relation of Diabetic Control to Development of Microvascular Complications', p. 149.

information gleaned from which could then be used to refine therapy and, as a result, improve glycaemic control:

> It is a system in which a diabetic regularly measures his own blood glucose level and uses the information to control his diabetes by making appropriate adjustments to diet or insulin... [the objective being] for the diabetic to become his own laboratory technician, dietitian and doctor in the day to day management of diabetes.[323]

The great majority of those on insulin therapy in 1981 remained on 'conventional' regimens consisting of fixed daily injections, most commonly twice per day – one before breakfast and a second prior to an evening meal. Regimens of this kind generally involve a combination of short- and longer-acting insulins which produce several daily 'peaks' in carbohydrate metabolism, with the primary objective being to ensure that these high-points align correctly with prescribed mealtimes, and that the dosage given is sufficient to process the nutritional content of the food eaten. By their very structure, such twice daily regimens precluded the possibility of any real flexibility of lifestyle. Alterations to the dosage of fixed injections could change the daily pattern of insulin action, but could not be adapted reactively according to unpredictable requirements. To put this another way, no amount of tweaking could remove the need for a largely uniform daily lifestyle and diet.

To Knight, then, the principle of self-adjustment existed as a tool by which *recurrent* episodes of hypo and hyperglycaemia could be analysed and addressed *within the framework of 'conventional' care*. This did not imply any significant change to the basic premise of treatment, which remained essentially inflexible, or, moreover, any reworking of the precise roles and responsibilities of HCPs and their patients. This vision of self-

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[323] Anthony Knight, 'Blood glucose self-monitoring', *Balance*, October 1981, p. 5.

adjustment occurred within the context of the paternalistic tradition – dosages, mealtimes, and nutritional intake continued to be prescribed. Changes to treatment were to be made *extremely* cautiously, and *never* without the approval of a responsible professional:

> If such an abnormal pattern can be identified, then an appropriate change of dietary carbohydrate distribution or insulin dosage or timing may be made to correct the abnormal pattern. Treatment changes are made in small steps such as shifting 10 grams of carbohydrate or changing an insulin dose by two or four units... A knowledge of the expected effect of the type of insulins being used is required to make such changes intelligently. Medical guidance is essential for this stage... Changes in treatment should be small, should only be made every two to three days and should be made to correct an identified pattern of abnormality.[324]

By the standards of 1981, asking those with T1D to take an active role in the management of their own therapy – even in such a limited way – was nevertheless an unusual and perhaps even controversial step that directly contradicted the Parsonian foundation of contemporary medical practice. This remained the case over half a decade later. Judith M. Steel, a diabetes specialist at the Royal Infirmary of Edinburgh, and Margaret Dunn, a patient of hers, reported in their 1986 guidebook *Coping with Life on Insulin* that many individuals remained deeply reluctant to make even minor self-adjustments to dosage, arguing that '[They were] told never to mess about with the insulin [themselves]' and/or '[They] should be far too scared to alter [their] insulin.'[325]

It is perhaps Knight himself who most succinctly captures the ideological anxiety here, while answering the simple question of *why* some patients should self-monitor their blood

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[324] *Ibid*, p. 11.

[325] Judith M. Steel and Margaret Dunn, *Coping with Life on Insulin* (Edinburgh: W&R Chambers, 1987), p. 60.

glucose. Alluding to the previously referenced studies by Fox and others from the late 1970s, he suggests that 'the long-term complications of diabetes... may be due at least in part to excessive levels of glucose in the body over a long time', while explaining the advantages of blood glucose testing over considerably less accurate urinary analysis.[326] Importantly, however, he makes a point of asserting that '[Self-monitoring] is not a ploy to get diabetics to look after themselves to make the busy diabetic clinics more manageable. When self-monitoring is actively encouraged the clinic staff find they are even busier than before.'[327]

This rather defensive statement is telling. Knight is concerned that those with T1D might become frustrated at the additional labour of performing regular blood glucose tests and making – with advice – small alterations to treatment in order to mitigate clearly problematic patterns. This, he suggests, could be read as a 'ploy' designed to shift traditionally 'professional' responsibilities onto the patient-body, and in doing so reduce the considerable workload of clinical staff. While Knight makes clear that this is not the motive behind his enthusiastic advocacy of self-monitoring, it is true that the adoption of such a method does require more of the layperson than had previously been expected. The very fact that he is concerned about this reveals a palpable anxiety about the implications of such a development – an as yet unresolved contradiction within the ideological framework of care. Moreover, in recognising this contradiction, Knight is implicitly acknowledging that what the lay-patient is being asked to do is essentially *medical labour.* In doing so, he demonstrates that the overall goal of his programme is not to meaningfully involve the patient in determining the shape of therapy but rather to enlist them as low-

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[326] Knight, 'Blood glucose self-monitoring', p. 5.

[327] *Ibid*, p. 5.

level auxiliaries within the framework of ideological orthodoxy – patient involvement in this context can be understood as form of form of what might be termed *active unfreedom*.

By *active unfreedom*, I refer to a particular conception of the layperson's role in therapy in which their 'active participation' is enthusiastically encouraged. To this end, the individual may, for example, in the context of T1D, be expected to perform and record urinary or blood test results, learn to understand the relationship between nutritional intake, stress, exercise, and illness on the one hand, and glycaemic levels on the other, and to competently titrate insulin dosages in isolation from traditional authorities. However, within this framework *activity* should not be conflated with *autonomy* – despite the frequent use of the language of empowerment those professionals who historically promoted this kind of approach expected, in most cases, to retain full control over the moral and intellectual foundation of therapy. Implicitly, the values of the recipient of care remain, in effect, an irrelevance – their engagement extends only so far as they are able to follow instruction.

This is perhaps best – though almost certainly unconsciously – encapsulated by South African diabetologist Larry A. Distiller, the cover of whose (perhaps insensitively titled) 1980 guidebook *So you have Diabetes!* is replete with quotations and extracts promising life-changing advice to those diagnosed with the condition: 'a diabetic can lead a perfectly normal life with only minimal important alterations in lifestyle... the single most important factor is a complete understanding of diabetes... This book will help diabetics to proceed in good health and a happy state of mind.'[328] Despite this, Distiller's book does not diverge meaningfully from those of his contemporaries. While he does take the time to include chapters on the emotional and social aspects of diagnosis and treatment, his approach to

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[328] Larry A. Distiller, *So you have Diabetes!* (Lancaster: MTP Press, 1980).

management remains distinctly uncontroversial, and focuses on the importance of a consistent regimen of diet and medication. Key to successful treatment, he believes, is the development of a 'close rapport' with a 'doctor who is frank with you.'[329] Distiller does not appear particularly comfortable with self-adjustment of insulin, for example believing that when exercising dietary adaptation is preferable: 'Many diabetics tend to reduce their dose of insulin on the day that they are planning to exercise. This is not good practice at all as it will interfere with diabetic control over the entire day for the sake of a few hours exercise. Rather, the insulin dose should be kept constant and the exercise compensated for by eating more, preferably before the exercise.'[330]

Three things are worth noting here. First, Distiller's understanding of the 'insulin dose' is as 'conventional' twice-daily formulation with a long and complex action profile, which should be altered cautiously and ideally not without supervision, as opposed to the kind used by Eastwood or Fletcher (this will become important in Chapter 4). Second, he understands that many of those with T1D *do unilaterally alter their dosages*, though he disapproves. Third, he believes that a central role of the doctor is to 'be frank' – that is, to enact *de facto ideological discipline*.

Acknowledging that 'Diabetes is a unique disorder because... no matter how frequent the medical check-ups... [or] how excellent one's physician, diabetes will never be controlled and good health cannot be maintained without self care by the patient... [who must] make daily decisions about his diet, exercise and insulin dosage', he goes on to insist that the PWD 'must therefore understand the nature of disease completely and learn what he can and cannot do without upsetting the control of his condition.'[331]

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[329] *Ibid*, p. 73.
[330] *Ibid*, p. 44.
[331] *Ibid*, pp. 85-86.

For all of his talk of ‘a normal life’, Distiller takes a deeply authoritarian view that entirely marginalises the values of his readership and does not appreciate any of the potential deeper explanations for an individual’s failure to adhere to the strict rules of orthodox management (see Chapter 2), instead preferring to fall back on dismissively moralistic – and altogether weak – arguments characterised by ad hominem attacks:

> It is not unusual for a patient to ignore all instructions from one visit to the next and not bother to test his urine or keep to any sort of diet, only to discipline himself strictly for 2 or 3 days before the next visit to the doctor, so that his blood sugar levels, when checked, appear well controlled. This sort of patient will also prefabricate urine tests in order to mislead his doctor. This is obviously a stupid, immature type of approach that courts disaster. Without mutual understanding and trust it becomes that much more difficult to a diabetic to keep himself healthy and well.[332]

The last sentence of this passage is particularly revealing in its broader context, because by all accounts Distiller’s understanding of ‘mutual understanding’ is considerably different to a perhaps less ideologically loaded version of the concept. To him, it is the responsibility of the patient to come around to understanding ‘correct’ value. This is not an isolated example. Distiller also describes one young woman as possessing a ‘ridiculous attitude’ on account of her ‘[steadfast refusal] to increase her daily insulin dose above 25 units, and... [satisfaction] if she can reduce it by 1 or 2 units for a few days.’ ‘Once you are injecting yourself’, he suggests, ‘you might as well use enough insulin to bring the blood sugar down.’[333]

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[332] *Ibid*, p. 73.

[333] *Ibid*, p. 32.

While he is certainly correct at the biomedical level here, Distiller makes no effort to understand the reasons behind his young patients' aversion to increasing insulin dosages – indeed the notion that insulin is a medicine (as opposed to a hormonal replacement) and that increasing requirements represent some form of 'failure' has been a common one throughout its history. It is not so much the point that Distiller is technically correct to point out an irrational fear in therapy, but rather that in doing so he fails to look beyond his ideological horizon, using language that threatens to alienate those he purports to care for.

At the beginning of his book, Distiller makes the revealing statement that:

> Many books written for the diabetic start with a statement such as "a diabetic can lead a perfectly normal life", and then go on to give a long list of do's and do not's, must's and must not's, can's and cannot's, so that at the end of it the diabetic is left with the conclusion that a perfectly normal life, for a diabetic, consists of a regimented, jailed and restricted lifestyle with all the fun, enjoyment and spontaneity removed. In fact a diabetic *can* lead a perfectly normal life with only minimal important alterations in lifestyle. In order to do this, the single most important factor is a complete understanding of diabetes... This has prompted me to write this short book, attempting to explain the necessary principles and guidelines in a language that can be understood by any intelligent adult without scientific or medical training.[334]

Nevertheless, despite his ostensible commitment to enabling those with diabetes to 'live a normal life' while avoiding long lists of commands and prohibitions, his text ends up *doing exactly that*. While Distiller does provide relatively more supplementary discussion of more abstract secondary factors related to the lived experience of T1D than some of his

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[334] *Ibid*, p. vii.

contemporaries – the management of stress, alcohol, sex, etc – and is clearly deeply invested in 'education', he exudes an undeniable paternalism. Those who worried that 'a perfectly normal life, for a diabetic, consists of a regimented, jailed and restricted lifestyle with all the fun, enjoyment and spontaneity removed' are in a sense absolutely correct to be anxious. The normality offered by Distiller is an *active unfreedom* that demands ideological subordination to a medical profession that remains entirely apathetic to the personal values of individual patients.

While it comes from an North American perspective, Charles Kilo and Joseph R. Williamson's *Diabetes: The Facts That Let You Regain Control of Your Life* – as the title suggests, a piece of work directed squarely at patients – demonstrates this impulse within the context of 'education' in the mid-1980s particularly well. Education, to Kilo and Williamson, is a 'vital ingredient' in the management of T1D (and T2D).[335] To facilitate this, they suggest that:

> The arms-length distance between patient and physician must be overcome. There are more education materials and classes than ever before to help you, the patient, acquire the information you need to understand what is going on. Without a real understanding of why strict control of diet, exercise, and medication must be maintained, it is easy for you to stray from the path that you must now walk for the rest of your life.[336]

It is tempting to read the first sentence of this passage – 'the arms length distance between patient and physician must be overcome' – charitably: as a call for doctors to respect the personal expertise of their patients while offering advice based on their deeper specialist

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[335] Charles Kilo and Joseph R. Williamson, *Diabetes: The Facts That Let You Regain Control of Your Life* (New York, NY: John Wiley & Sons, 1987), p. 119.

[336] *Ibid*, p. 121.

biomedical knowledge. However, as the remainder of the extract makes clear, this is not Kilo and Williamson's intention. It is the layperson who is expected to bridge that gap alone via the consumption of media and training programmes designed by professionals to enlist them into the value-system of orthodox medicine and, consequently, protect them from 'straying from the path'. In this context, educational materials such as guidebooks are invested with the symbolic authority of the medical profession and invested with its authority by proxy. Indeed, the remainder of Kilo and Williamson's book is concerned with the establishment of strict dietary plans, routines of medication, and exchange lists typical of the time. While, like most contemporaries, they do accept that minor changes can (in rare cases) be made to treatment by the individual to account for changing circumstances, they are at pains to ensure that this is only performed once that individual is ready – physically, intellectually, and, implicitly, ideologically:

> The importance of adhering to a routine schedule for meals, exercise, and medication has been stressed, but perhaps not strongly enough. Once a diabetic establishes regular schedules, he is less likely to have an insulin reaction or to get out of control.
>
> But even the most conscientious person can be faced with an unexpected break in routine. For instance, it is sometimes necessary for a person to leave home for a week or two, during which time it may very well, by unavoidable circumstances, be impossible to maintain the regular eating and exercise schedule followed at home.
>
> Still, the individual can adjust for that kind of break in normal activity. This is one of the advantages of taking two or more insulin shots a day, rather than just one, and of using self monitoring of blood sugar. A person can always change the times and adjust the dosage of the second shot to compensate for unanticipated changes in

> the time of the evening meal or in physical activity, IF he knows what his blood sugar is and ONLY AFTER he has been educated in how to make these adjustments.[337]

Enlistment into the ideological apparatus of the clinic is therefore seen by Kilo and Williamson as an absolutely vital prerequisite to any form of autonomy. As if to reiterate this even more unmistakeably, the newly diagnosed should – they believe – never be introduced to such concepts and should instead be cared for according to the Parsonian tradition, suggesting that 'Because this is such a difficult time, diabetics should be taught only the essentials at first. All they really want to know at this early stage is what they need to do in order to survive – what they should eat today and tomorrow and how to take their medication.'[338]

A similar attitude is discernible in the tone of a 1990 *Balance* article entitled 'Adjusting Your Own Insulin', in which Geoff Gill and Suzanne Redmond discuss the principle of dosage self-adjustment. In characteristically cautious style, it suggests that:

> Good control of blood glucose levels greatly reduces the risk of diabetic complications. For someone on insulin, achieving good control means a sensible diet, reasonable exercise, and appropriate insulin doses. Traditionally, dosage adjustments are made by the clinic doctor or the specialist nurse. But what about you? What about self-adjustment of insulin? In this article we will look at how people with diabetes may safely and effectively alter insulin doses and also who, in practice, should or should not be self-adjusting... Though control of your own blood glucose levels is the ultimate aim of diabetic education, not everyone is suitable for

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[337] Emphasis in original; *Ibid*, p. 147.
[338] *Ibid*, p. 124.

> self-adjustment. If doses are changed wrongly or in a haphazard fashion, then disastrous results will follow... Thus good basic diabetes education is essential, as well as experience in diabetic skills. Self-adjustment is not therefore usually advised straight after diagnosis, as confidence in successfully living with diabetes is vital. People who do not feel experienced, knowledgeable or confident enough are best leaving dose changes to their clinic staff.[339]

This approach is typical of the majority of efforts to promote the self-adjustment of dosage and diet by patients throughout the 1980s and early 1990s. *Coping with Life on Insulin* reflects the peculiarly contradictory nature of this particularly well. Steel and Dunn are extremely enthusiastic about the adoption of self-adjustment by patients, writing that such modifications allow for a certain degree of flexibility where variations in insulin requirements can be predicted in advance – for example for special occasions such as Christmas lunch – and lament those individuals who live unnecessarily restricted lives, too scared to take a more pro-active approach. They also afford a little more independence and responsibility to the layperson than Knight, writing that 'You cannot have a doctor with you at all times and, with a bit of experience, you will become rather better than most doctors at making the necessary adjustments.'[340] Nonetheless, for all of their rhetoric of liberation, their position is not so radical as it might superficially appear. Like Knight, Steel and Dunn advocate small and cautious adjustments within the boundaries of prescribed treatment, maintaining the professional privilege of the physician in determining the overall character

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[339] Geoff Gill and Suzanne Redmond, 'Adjusting Your Own Insulin', *Balance*, December/January 1989/1990, p. 31.

[340] Steel and Dunn, *Coping with Life on Insulin*, p. 60.

of treatment: ‘There are many different insulin regimens. Your doctor will decide which is best for you.’[341]

When discussing self-adjustment, *Coping with Life on Insulin* cites an information leaflet provided to Steel’s patients. This outlines the basic principles of dose alteration in a succinct manner that demonstrates clearly the *active unfreedom* inherent to early attempts to formally encourage lay-participation:

> There are many different types of insulin and you are using two of them... Your *short-acting* insulin... acts for 4-6 hours after injection. It is a clear liquid. Your *medium-acting* insulin... acts for 5-12 hours after injection. It is a cloudy liquid. Both can be mixed together. You will take some of each insulin *before breakfast* and *before your evening meal*... Carry out blood tests four times a day to find out how efficiently each insulin is acting. Record the results of *all* your blood tests in your record book and *always* bring the book to the clinic. Your doctor will advise you how often each week to do the tests... If you have a blood glucose of more than 9 at the same time of day 3 days running, increase the appropriate insulin by 2 units (some may need to alter by more or less). If you are unwell, you may need to increase your insulin more rapidly. If you are unsure how to make this alteration, especially if you are being sick, telephone you doctor or clinic for advice... If you have a reaction (hypo) your blood sugar is *too low*. You must ask yourself why this happened... If you have not eaten enough then you must avoid that mistake in future. If you took extra exercise you must take *less insulin* next time you plan to do

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[341] *Ibid*, p. 61.

> this or *eat more* if the exercise is unexpected. If you have a reaction/hypo that you cannot explain, reduce the insulin which acts at that time by 2 units the next day.[342]

The timings of insulin injections and mealtimes remain, to Steel and Dunn, entirely fixed. The small amount of flexibility afforded to patients is comprised of small scale tinkering within the established framework of care, performed according to extremely strict guidelines drawn up by professionals. Despite encouraging a more *active* role for those with T1D, this does not meaningfully *empower* them. In fact, it is deeply conventional in character. Steel and Dunn's chapter on the adjustment of insulin ends with a call for those on insulin therapy to 'Learn to be... [their] own doctor.'[343] This short statement is more meaningful than it first appears. Those with T1D, implicitly, should become their own doctor practically in the context of day-to-day management, but should also *become* their own doctor at the ideological level – they should adopt the philosophical outlook of the profession and internalise the values implied by that.

This is further reinforced by the language used in *Diabetes: a Guide to Patient Management for Practice Nurses*, a 1993 handbook by Jennifer Farr and Maggie Watkinson concerning, as its title suggests, the management of diabetes by nursing staff.

> The aim of educating the diabetic patient is to effect a change in their behaviour. It therefore makes sense to devise an individualized learning plan for each patient which is expressed in term of behavioural objectives. These should be clear and precise and stated in such a way that the eventual desired outcome is measureable or observable... If objectives are written in this way there is no ambiguity, and they are explicit for both the educator and the learner. It is also easier to ensure that the

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[342] Emphasis in original; *Ibid*, pp. 66-68.
[343] *Ibid*, p. 68.

> objectives are realistic, achievable, desirable, measureable and above all agreed with the patient.[344]

The book's subtitle sets the tone from the very beginning: patients as a group require 'management' by nursing staff. Unsurprisingly, therefore, there is a very clear distinction made here between the 'educator' and the 'learner'. While some lip service is paid to the importance of treatment being 'agreed with the patient' it is clear that the authors of this work view the process of education as a one-way street: professionals possess special knowledge which they deign to impart upon the layperson, whose duty it is to listen carefully and alter their behaviour in line with recommendation – to *become* their own doctor, perhaps. 'Partnership', for all its connotations, has often been – and is often – code for a particular form of subtle ideological coercion.

This is reflected in the attitude of HCPs towards those on insulin treatment who, for whatever reason, approached management in a manner considered 'inappropriate': that is, a manner that contradicted the value-system of medical orthodoxy, usually indicated by a level of control considered 'unsatisfactory'. As late as 1996, the fifth edition of *Diabetes and its Management* betrayed a deep anxiety about patient 'manipulation':

> Considerable ingenuity can be employed in manipulating diabetes. Some patients give additional insulin, hidden in transistors, taped behind doors or windows or in the bottom of a jewel case. One patient was eventually found to drive the insulin needle into the skin and out again before depressing the plunger... Falsified blood glucose and urine testing results are not rare and must be suspected if the readings are quite incompatible with the clinical problem.

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[344] Jennifer Farr and Maggie Watkinson, *Diabetes: a guide to patient management for practice nurses* (Oxford: Radcliffe Medical Press, 1993), p.27.

> Deep-seated emotional, social or psychiatric problems underlie manipulation of diabetes. Discovering the exact cause is never easy. The problem can sometimes be alleviated by patient support of the family, but on other occasions more formal family counselling is required. The advice of a psychiatrist should only be sought if there is real evidence of a psychiatric disorder. Very occasionally, patients are incapable of an independent life and may need institutional supervision.[345]

While it is certain that there are circumstances in which 'deep-seated emotional, social or psychiatric problems' lead individuals to manage T1D in neglectful or sometimes even self-destructive ways, it is worth reflecting on the manner in which someone like Eastwood might have been viewed by the authors of this passage, had he drawn their ire. By the standards of the 1930s profession, his 'many a time and oft' approach represented a major departure that could, superficially, be read as 'manipulation' – as a deliberate unwillingness to follow treatment instruction. While *Diabetes and its Management* does generally suggest that a pattern of 'disruptive diabetes' without clear cause should be identified before 'manipulation' may be considered an issue, it remains very telling in its conceptualisation of the relationship between professionals and their patients – the latter are sometimes not reliable and must be *made so*, while medical staff should remain constantly vigilant for examples of 'non-compliance'.

Concerns about the unreliable nature of the patient-body were very common throughout the late 1980s and early 1990s. Steel and Dunn include a section in *Coping with Life on Insulin* titled 'Honesty with results', which is extremely telling:

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[345] Peter J. Watkins, Paul L. Drury, and Simon L. Howell, *Diabetes and its Management*, 5th ed (Oxford: Blackwell Science, 1996), pp. 103-104.

> While most people are honest about the recording of results, some find that there is a natural tendency to underestimate them and to keep to diet rules more strictly on the day of doing the test. It also seems a fairly common human failing to falsify even more than that.
>
> On a clinic morning, it is amazing the number of record books which are ‘left on the bus’, ‘torn up by the children’, ‘burned away when the chip pan went up’, even ‘eaten by the dog’!...
>
> Many children go to great lengths to manufacture fictitious results. Children soon learn that a book in which all the tests are recorded as being negative tends to be disbelieved, so they insert a few episodes of glycosuria (sugar in the urine)... a few pluses of sugar written down... stand a better chance of being believed...
>
> Then there are the results written throughout with the same pen, and the more devious efforts produced by writing results for alternate days with different pens. Some, in a fit of absentmindedness, will produce a week of results – for the following week!...
>
> The problem of falsifying is not restricted to children. Rather than from mischievousness, or wickedness, it seems to stem from an inborn desire in some diabetics, possibly as a result of anxiety, to please the doctor, the relatives or themselves...
>
> It is difficult to see why they should feel a need to do this. In the end, it is only themselves that they cheat.[346]

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[346] Steel and Dunn, *Coping with Life on Insulin*, pp. 42-43.

As shown in Chapter 2, such professional concerns about ‘dishonesty’ were not unfounded. Nevertheless, the important thing to take from this is that it reflects just how concerned professionals were with ensuring that patients were enlisted into the ideological apparatus of contemporary medical care.

The promotion of strictly regulated *active unfreedom* reflects a relatively awkward effort to resolve the contradiction highlighted by Knight in 1981 – by recasting the ‘active’ patient (that by now, most professionals understood was necessary to the effective management of T1D) as an *auxiliary clinician*, the fragile coherence of the Parsonian tradition was tenuously maintained. In addition to their ‘sick-role’, patients now also possessed a ‘physician-role’ as ‘their own doctor’ – an abstracted reflection of the professional ‘educator’ entirely divorced from the individual themselves. In becoming so fractured, the ‘active’ patient reinforced the values and priorities of orthodox medicine: in a sense, they became architects of their own ‘unfreedom’.

Part 7: The DCCT and ‘Intensification’

By the late 1970s and early 1980s, HCPs generally understood that the most promising method of successfully normalising blood glucose levels and consequently improving long-term clinical prospects was to adopt a new approach that more closely imitated the natural functioning of the pancreas. It was in this context that the BDA, in 1977, purchased a prototype ‘artificial pancreas’ which was loaned to George Alberti (1937-) in Southampton. This machine – it was hoped – would automatically release insulin as required by combining an infusion pump with a blood glucose monitor and would, eventually, not only free those with T1D from the necessity of injections (in the hospital) but also dramatically improve control by mimicking natural endogenous insulin production. When the acquisition was announced on the front page of *Balance*, the accompanying article explained the reasoning behind this research direction while emphasising the distance yet to go:

> The BDA is to spend £22,000 on buying Britain’s first artificial pancreas. The pancreas will be on loan to Professor George Alberti of Southampton University... After the meeting Professor Alberti predicted that in the long-term the pancreas will drop from its present filing-cabinet dimensions to the size of a pocket calculator. Many man-hours of work remain, however, before the machine can be made 100% safe to be implanted in the human body... An implanted artificial pancreas would act like the real organ and long-term problems would be avoided. So would the inconvenient daily injections.[347]

Here we can see a potential clue as to why Fletcher was able to have his novel approach published in both the *BMJ* and on the front page of *Balance* – recall the passage in which he describes his adoption of unorthodox methods: ‘At my wife’s suggestion I tried doing what

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[347] ‘BDA is to buy Artificial Pancreas’, *Balance*, August 1977, p. 1.

the normal pancreas does and went over to three injections of soluble insulin daily before my mean meals, which was much better.'[348] By 1980, the cutting-edge of medical research – that is, the part of the profession that makes up journal committees and editorial boards – had largely adopted *in principle* the idea of replicating normal pancreatic function as a desirable objective to ensure stricter control of blood glucose and, implicitly, better long-term clinical prospects. Fletcher was not challenging this with his method – what was he doing if not attempting to do exactly what the 'artificial pancreas' intended, albeit via careful use of injections? The medical expert Eastwood had responded to in *Balance* some three years previously had themselves admitted that such a method was feasible (even while they had, at the time, been unconvinced of its desirability). The strategy of orthodox ideology had, effectively, begun to align with that of Fletcher – though not for the same reasons.

This is not to say that medical practice had jettisoned the more rigid approach of traditional therapy wholesale, or even that a majority of doctors had done so. Ideology does not move so rapidly, but instead responds dynamically to the material conditions upon which it is structured (and upon which it reflexively exerts influence). Discussions around the 'artificial pancreas' and novel methods of achieving glycaemic control were very much 'elite' considerations debated by researchers and senior practitioners. To an individual hospital doctor like Weir, getting by day-to-day and dealing with patients who had utilized 'traditional' approaches to therapy for decades, the discussions over the possible implications of such developments were of little immediate relevance.

The 'artificial pancreas' purchased by the BDA in 1977 represented a novel approach to the management of T1D – though one that was initially considered feasible only in hospital.

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[348] Fletcher, 'An Active Diabetic Life', p. 15.

Aware of the limitations of 'traditional' regimens and increasingly convinced of the importance of maintaining as close to normal levels of blood glucose as possible in order to mitigate the threat of complications, the idea of creating a machine that could essentially normalise glycaemic values in the same way as a biological organ inspired a great deal of enthusiasm. While the truly autonomous device imagined in *Balance* did not come to pass due to technological limitations, the idea of continuous infusion prompted a great deal of interest and influenced later developments in 'intensive' pump approaches aimed at emulating the natural pattern of insulin secretion.[349]

In September 1993, the *New England Journal of Medicine* published the results of the DCCT, a large-scale study that had recruited 1441 participants from twenty-nine separate centres in the USA between 1983 and 1989.[350] This cohort was divided into two groups. The first was treated according to the principles of 'conventional' therapy, involving 'one or two daily injections of insulin, including mixed intermediate and rapid-acting insulins, daily self-monitoring of urine or blood glucose, and education about diet and exercise.'[351] Conversely, the second adopted 'intensive' treatment, entailing '[the] administration of insulin three or more times daily by injection or an external pump... [with] dosage adjusted according to

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[349] Clinical trials attempting to create a wearable version are ongoing. The University of Cambridge, for example, has an active research centre on the subject. See R. Hovorka J. M. Allen, D. Elleri et al, 'Manual closed-loop insulin delivery in children and adolescents with type 1 diabetes: a phase 2 randomised crossover trial', *Lancet* 375 (2010), pp. 743-751; D. Elleri, J. M. Allen, M. Biagioni et al, 'Evaluation of a portable ambulatory prototype for automated overnight closed-loop insulin delivery in young people with type 1 diabetes', *Pediatric Diabetes* 13 (2012), pp. 449-453; More recently, lay patient-innovators have produced usable de facto 'artificial pancreas' technology with mixed responses from the medical profession (see Chapter 5).

[350] DCCT Research Group, 'The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus', *New England Journal of Medicine* 329 (1993), p. 978.

[351] *Ibid*, p. 978.

the results of self-monitoring of blood glucose performed at least four times per day, dietary intake, and anticipated exercise.'[352]

By June 1993, the divergent clinical outcomes between participants in each of the two groups were so stark that the study's independent data monitoring committee advised its early conclusion on ethical grounds.[353] Patients utilising 'intensive' insulin therapy had, on average, HbA1c levels of around 7%, while those who remained on 'conventional' treatment trended at approximately 9%. Quarterly assessments of participants found that, when given spot blood glucose tests, the mean value for the 'conventional' group was 12.8mmol/l, considerably higher than the 8.6mmol/l of their 'intensively' treated equivalents.[354] Furthermore, the generally lower average blood glucose values experienced by the latter corresponded with a marked reduction in long-term sequelae. By comparison to those undergoing 'conventional' therapy, participants in the 'intensive' category demonstrated a 63% reduction in sustained retinopathy, a 54% reduction in advanced nephropathy (defined by urinary albumin excretion in excess of 300mg/24hrs), and a 60% reduction in neuropathy.[355] The only observed shortcoming of 'intensive' therapy appeared to be an approximately tripled risk of severe hypoglycaemia.[356]

The DCCT made it clear that 'intensified' therapy – that is, the close emulation of natural fluctuations in insulin production according to tailored individual requirements, utilising a basal/bolus framework via pump or MDI – resulted in decreased instances of hyperglycaemia. Moreover, this reduction dramatically improved long-term clinical outcomes when compared to 'conventional' treatment. Nevertheless, like the principle of

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[352] *Ibid*, p. 978.

[353] *Ibid*, p. 978; Carolyn Siebert and Charles M. Clark, 'Operational and Policy Considerations of Data Monitoring in Clinical Trials: The Diabetes Control and Complications Trial Experience', *Controlled Clinical Trials* 14 (1993), pp. 30-44.

[354] DCCT Research Group, 'The Effect of Intensive Treatment of Diabetes', p. 979.

[355] *Ibid*, p. 981.

[356] *Ibid*, p. 982.

self-adjustment itself, this implied no meaningful critique of paternalism. In fact, the DCCT was marked by a significant level of professional control, *particularly* over the 'intensified' group. The timings and dosages of insulin (or rates of infusion in the case of pump-users) were – officially at least – strictly controlled by medical staff. 'Intensive' group members were 'contacted... frequently by telephone to review and adjust their regimens.'[357]

Stephanie Amiel (1954-), a diabetologist at King's College London and one of those directly responsible for creating the DAFNE programme in 2002, for example, highlights that those running the DCCT were in fact *so* paternalistic in outlook, and insisted on micromanaging every aspect of treatment to such an extent, that once the trial had ended their patients were, for the most part, unable to sustain the level of control achieved during the study:

> [In the] DCCT, they had 2.8 patients per researcher... And I was there when they did it. The patients on the 'intensive' arm were contacted weekly by the diabetes nurse... They reported their blood glucose results and she told them what to do for the next week. So, it was all run by [the clinicians]... and what proves it is at the end of nine years of intensive therapy, when they stopped DCCT prematurely, the patients in it could not sustain the HbA1c... Because they'd learned nothing in nine years of being told what to do... It didn't empower the patients... I mean, they were seen monthly and they were contacted weekly for nine years![358]

In their concluding discussion the DCCT Research Group endorsed the widespread adoption of 'intensive' therapy amongst all but the most incapable (or unwilling) patients, but stopped well short of suggesting that responsibility for those aspects of treatment traditionally considered the prerogative of the 'professional' – that is, the modification of

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[357] *Ibid*, p. 978.

[358] Stephanie Amiel interviewed by Stuart Bradwel, 27th February 2019, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

insulin dosage and diet – should be transferred to lay control in part or in whole. Indeed, the report contains no reflections on any potential social implications of ‘intensified’ therapy:

> On the basis of these results, we recommend that most patients with IDDM be treated with closely monitored intensive regimens, with the goal of maintaining their glycaemic status as close to the normal range as possible. Because of the risk of hypoglycaemia, intensive therapy should be implemented with caution, especially in patients with repeated severe hypoglycaemia or unawareness of hypoglycaemia.[359]

To the DCCT Research Group, ‘intensive’ therapy was ‘intensified’ in that its basal/bolus framework involved more daily interventions than ‘conventional’ approaches, but also in that the timing and dosages of these interventions were continuously refined to ensure the minimisation of hyperglycaemia. Unlike later developments such as DAFNE, which encouraged patient self-assessment and problem solving away from professional supervision in the first instance, overall control of therapeutic modification was retained by professional staff throughout the DCCT. The results of blood glucose measurement were reported and assessed alongside dietary and lifestyle factors to identify the potential causes of any glycaemic fluctuations before suitable alterations were provided to compensate. This process was repeated frequently, with monthly attendance at clinic expected of those in the ‘intensive’ group, alongside regular telephone consultations. By comparison, those in the ‘conventional’ group were contacted only once every three months.

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[359] DCCT Research Group, ‘The Effect of Intensive Treatment of Diabetes’, p. 983.

‘Intensive’ therapy did not – to those participating in the DCCT – contain the implicit promise of a liberalised approach to diet or lifestyle. There was negligible difference reported in quality of life between those in the ‘intensive’ and ‘conventional’ groups, suggesting that the day-to-day experience of T1D was broadly comparable in both.[360] This can be explained with reference to the DCCT’s overall design: ‘Long-term microvascular and neurologic complications cause major morbidity and mortality in patients with insulin-dependent diabetes mellitus (IDDM). We examined whether intensive treatment with the goal of maintaining blood glucose concentrations close to the normal range could decrease the frequency and severity of these complications.’[361] While ‘conventional’ management in the study concentrated on ‘the absence of symptoms attributable to glycosuria or hyperglycaemia; the absence of ketonuria; the maintenance of normal growth, development, and ideal bodyweight; and freedom from severe or frequent hypoglycaemia’, the ‘intensive’ approach was concerned with:

> [Achieving] preprandial blood glucose concentrations between 70 and 120 mg per deciliter (3.9 and 6.7 mmol per liter), postprandial concentrations of less than 180 mg per deciliter (10 mmol per liter), a weekly 3-a.m measurement greater than 65mg per deciliter (3.6 mmol per liter), and haemoglobin A_{1c} (glycosylated haemoglobin) [HbA1C], measured monthly, within the normal range (less than 6.05 percent).[362]

Clinical outcomes – measured primarily by HbA1c and spot-glucose tests – were from the outset the priority: ‘intensive’ therapy was simply a tool that was shown to effectively reduce average blood sugar levels and, subsequently, the risk of long-term complications.

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[360] *Ibid*, pp. 982-983.

[361] *Ibid*, p. 977.

[362] *Ibid*, p. 978.

What any of this meant for the participants at the *personal* level was completely irrelevant to the investigators. In neither the 'intensive' nor 'conventional' groups was the patient invested with any meaningful role in adjusting treatment according to their subjective needs, or even in assisting in the analysis of results.

The DCCT proved the importance of minimising hyperglycaemia in reducing the incidence of long-term sequelae of T1D, and clearly demonstrated that 'intensive' treatment was effective at achieving this, but it did so while adhering to a fundamentally paternalistic framework. In fact, within this ideological context the principle of 'intensified' therapy can be seen as *necessarily* paternalistic. If the persistent refinement of treatment based on monitoring is necessary to ensure more effective control of blood glucose levels and the competent analysis of results to this end relies on direct professional assessment (the layperson lacking this necessary competence), then a comprehensive system of surveillance and precise instruction inevitably becomes necessary. Tattersall, along with the Czech diabetologist Michal Andel (1946-), tacitly addressed – and criticised – this implicit resurgence of paternalism in 'intensified' models of treatment in a short 1989 editorial for *Diabetic Medicine*:

> People are objects to be moved around like pawns on a chessboard in accordance with a grand scheme which will lead to a victory which will give the pawns no pleasure and which most will not live to see... In accordance with the grand scheme, most diabetologists believe that normoglycaemia will delay or prevent the serious complications with which we are unhappily all too familiar. In theory, we have the tools with which to reach this goal; blood sugar can be measured directly with strips or a meter, and indirect surveillance is possible by measuring haemoglobin A_1 [HbA1C]. In the unreal situation of a clinical trial, intensified insulin

> therapy with multiple injections or a pump can achieve near-normoglycaemia... [unfortunately] the benefits of good blood glucose control may be counterbalanced by increased hypoglycaemia, neuroticism, anxiety and what the patient sees as an intolerable interference with social, sexual or professional life. To rebel against the grand scheme requires considerable courage and usually results in the rebel being stigmatized as a dissident or non-complier.[363]

This editorial is quite unusual for 1989, recognising the importance of patient's values in good care and imploring its professional readers to '[Defend] against the totalitarian Hyde in diabetology'. Indeed, that the authors felt the need to so boldly state their position suggests that it was not one that was particularly widely held in this period. Andel and Tattersall implicitly make the point that the approach to therapy advocated by their contemporaries – whichever form it took – continued to be conducted, ideologically speaking, for the benefit of the professional. Limited patient self-adjustment in the absence of direct consultation is possible, to an extent, under 'conventional' approaches, via the prescription of guideline rather than diktat – that is, via the enlistment of the patient into an *active unfreedom*. However, to *ensure* accurate adjustment on a day-to-day basis – the foundation of 'intensified' therapy – this is simply not sufficient, because at a fundamental level the patient cannot be trusted. The only solution is therefore to micromanage every last element of treatment. To 'intensify' therapy is therefore to *reassert professional control*.

As such, early moves towards 'intensified' insulin therapy appeared to involve *reduced* patient involvement in therapeutic decision-making when compared to self-adjustable – though nonetheless *unfree* – 'conventional' approaches utilising one, or more usually two,

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[363] Michal Andel and Robert Tattersall, 'Authoritarianism in Diabetology', *Diabetic Medicine* 6 (1989), p. 471.

daily injections alongside a rigid dietary pattern. These new regimens attempted to more strictly regulate glycaemic control, but this was seen as incompatible with direct lay-involvement, and indeed a potential source of additional psychological harm. In 1994, the diabetologist Harry Keen (1925-2013) makes his reservations about 'intensified' approaches clear in a feature for *Balance*:

> It [the DCCT] was a marvellous study but I have mixed feelings about it. I start from the assumption that the one thing people with diabetes want is to not be diabetic; anything which brings the condition more firmly to their attention or involves them in more activity is something which they may greet with less than wild enthusiasm. The appeal of extra self-care has to be at the level of it being worthwhile for people to do. The notion that people naturally fall into compliant behaviour and do things which are rational and sensible and reasonable is not entirely right. We know that people don't do that.[364]

To Keen, 'intensified' therapy was entirely unrelated to patient values but represented an additional layer of responsibility in the pursuit of improved clinical outcomes dictated according to the biomedical model. Patients themselves, he worried, might balk at the imposition of such approaches *because* their subjective values were entirely irrelevant to the process. 'Intensification', therefore, required a greater sacrifice than 'conventional' management with little obvious reward beyond the *possibility* of avoiding complications that in any case might never occur.

The greater potential burden required of PWD by early concepts of 'intensification' was tacitly acknowledged by the DCCT Research Group in the conclusion to their 1993 paper, and was likely widely discussed well before this – the study had been running since 1983

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[364] Harry Keen, 'DCCT', *Balance*, August/September 1994, p. 25.

and had not occurred in a vacuum, after all. The group stated that the labour and resources required to so closely monitor, evaluate, and advise such a large volume of individuals over such a long period of time would pose significant difficulties should the principle of 'intensified' therapy – as they understood it – be adopted more broadly:

> Intensive therapy was successfully carried out in the present trial by an expert team of diabetologists, nurses, dieticians, and behavioural specialists, and the time, effort, and cost required were considerable. Because the resources needed are not widely available, new strategies are needed to adapt methods of intensive treatment for use in the general community at less cost and effort.[365]

The publication of the DCCT crystallised a certain anxiety that had been coalescing throughout the late 1980s and early 1990s – for 'intensified' therapy to be successful, it seemed, close control of those utilising it was required, but this was simply infeasible to implement on the requisite scale. One somewhat awkward resolution to this problem was to encourage PWD to adopt what I have called 'semi-intensified' approaches to management: that is, non-'conventional' regimens that utilised the 'intensive' basal/bolus principle but replaced the strict supervision of the DCCT with the continued application of *active unfreedom* to care via strict, cautious instruction that continued to cast anything beyond very minor self-adjustment as undesirable and potentially dangerous. In doing so, management continued to utilise patients as medical auxiliaries in much the same way that earlier explorations of self-adjustment had done, bypassing the need for direct control by HCPs. Like the DCCT, 'semi-intensification' promised no great liberalisation of lifestyle and, if anything, suggested in some cases the opposite.

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[365] *Ibid*, pp. 983-984.

In their 1990 *Balance* piece, Gill and Redmond make only a brief reference to basal/bolus regimens, which were at the time still a fairly unusual form of treatment, and which they are clearly not yet altogether comfortable discussing:

> 'Novopens' [insulin pens] are becoming increasingly popular as they allow more flexible timing of mealtimes. The pen contains short acting insulin (Actrapid) and is given 3 times daily before meals. In addition an intermediate or long-lasting insulin (usually Ultratard) is given at night to give background or overnight control... When adjusting doses, particular care must be taken with Ultratard. This is a *very* long acting insulin, and dosage changes take at least 3 days to have an effect of pre-breakfast tests.[366]

Apart from the ability to slightly vary mealtimes, this regimen suggests little autonomy and yet does not resemble the DCCT to any meaningful extent. While they adopt the same basal/bolus approach, 'semi-intensified' regimens involve none of the constant refinement and adjustment of their more fully 'intensified' counterparts. Indeed, while Gill and Redmond's article contains some superficial allusions to cautious dose-adjustment, it remains very much in the vein of previous advice provided to those on 'conventional' therapy, and their article – predictably – ends with a stark warning to avoid what they understand as risky behaviour: 'Remember the basic rules mentioned above; and in particular *don't* make too frequent dose alterations, and only treat consistent abnormalities.'[367] Unlike 'intensified' therapies, 'semi-intensified' approaches rejected the continuous ad hoc adjustment of treatment according to lifestyle and diet, while attempting to mitigate the glycaemic consequences of this via the continued imposition of a culture of *active unfreedom*.

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[366] Emphasis in original; Gill and Redmond, 'Adjusting Your Own Insulin', p. 32.
[367] *Ibid*, p. 32.

In the second edition of *Diabetes: A Beyond Basics Guide,* Rowan Hillson (1951-) takes the time to outline a variety of potential regimens both 'conventional' – 'Fixed proportion mixtures', 'Fast and medium separately twice a day', 'Once daily' – and 'semi-intensified' – 'Fast before meals and medium or long before bed'. However, she nevertheless remains deeply cautious in her advice, suggesting regardless of approach 'anyone who needs to alter the insulin dose starts by adjusting it by one unit at the appropriate time and watches what happens over the next two or three days, making further one unit changes as needed after this.'[368] Furthermore, she instructs those intending to engage in such self-adjustment to 'Discuss how you should set about adjusting your insulin dose with your doctor or diabetes adviser', emphasising the importance of professional instruction and approval.[369]

It is perhaps unsurprising, then, that 'semi-intensified' therapy did not fully satisfy anybody. As late as 2000, a national report into diabetes services in England and Wales found major shortcomings in provision, alienation between HCPs and their patients, and far fewer individuals being given adequate education than was considered acceptable.[370]

This chapter has outlined the process by which clinical orthodoxy came to embrace the principle of 'intensification', introducing an ideological analysis of the British medical system that suggests the presence of a persistent – and biomedically reductive – authoritarian paternalism throughout the foundation of much twentieth century practice. Discussing the ways in which the expectations imposed upon laypeople by 'conventional' approaches to T1D functioned to serve primarily to maintain the ideological framework upon which the legitimacy of the profession relied, it goes on to argue that, from the 1970s,

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[368] Rowan Hillson, *Diabetes: A Beyond Basics Guide*, 2nd ed (London: Optima, 1992), pp. 30-32.
[369] *Ibid*, p. 32.
[370] Audit Commission for Local Authorities and the National Health Service in England and Wales, *Testing Times: A Review of Diabetes Services in England and Wales* (London: Audit Commission, 2000).

increasingly persuasive studies demonstrating the relationship between hyperglycaemia and the development of long-term sequelae led HCPs to begin to consider potential strategies to lower average blood glucose levels amongst their patients. While this resulted, during the 1980s, in some hesitant moves towards encouraging the incorporation of very limited self-adjustment of dosages by *some* laypeople where clear glycaemic fluctuations could be observed, the palpable caution with which such ‘innovations’ were introduced rendered them barely distinguishable from their ‘conventional’ precursors.

This final section has argued that the publication of the DCCT in 1993 demonstrated with some finality that ‘intensification’ could dramatically improve biomedical outcomes in T1D far beyond what was possible via ‘conventional’ strategies, but required a level of dosage adjustment frequent and substantial enough to account for ever-changing secondary factors. As the DCCT envisaged it, however, necessary adjustments remained prescriptive – determined by a dedicated team of HCPs responsible for analysing the individual’s day-to-day activities and refining treatment accordingly: if anything a *reduction* in lay-autonomy, and in any case something that was economically unviable to implement on any significant scale.

However, in 2002 the DAFNE programme demonstrated that ‘intensified’ approaches could be successfully integrated into T1D management without creating any significant excess resource requirements by encouraging lay-engagement with therapy to an extent unprecedented in Britain.[371] Consequently, it is difficult to read the commitment of British HCPs throughout the 1990s to confusing ‘semi-intensified’ strategies as anything but the expression of an ideological anxiety within the profession: mass ‘intensification’ was possible, but the only way to successfully implement it implicitly threatened the

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[371] Though, as discussed in Chapter 4, such patient-led ‘intensified’ therapy had been successfully trialled in mainland Europe as early as the late 1970s.

professional status of the clinician. Given this impasse, how can we understand the eventual success of DAFNE in the opening years of the new millennium? In order to explain this, it is necessary to more closely examine the ideological and material developments in T1D management throughout the 1990s while contextualising both in terms of the neoliberal political environment characteristic of the period.

Chapter 4 – DCCT to DAFNE: The Neoliberal Paradox

‘Long live expert patients — but, in the interests of doctor-patient relations, let us find something else to call them’

Joanne Shaw and Mary Baker ‘‘Expert patient’ – dream or nightmare?’, *BMJ* 328 [7442] (2004), p. 724.

Part 1: DAFNE

If professional forays into the encouragement of ‘semi-intensive’ approaches to T1D management in the early 1990s could be characterised by the reification of a reductionist biomedical approach via the continued imposition of a form of *active unfreedom*, it should perhaps come as some surprise that only a decade later, in 2002, the DAFNE programme was formally announced. Based on an approach to management developed in Düsseldorf some twenty years previous, DAFNE – or rather, the principle by which it operated – was in Britain a revolutionary development that for the first time invested in those with T1D a genuinely meaningful role not only in therapy, but in the determination of *value* within it. By contrast to Knight and those like him, who clearly felt that patient involvement in decision-making was an unfortunate necessity for achieving better clinical outcomes, DAFNE was marketed from the outset as having the potential to allow for a dramatically liberalised lifestyle. This is made very clear in an article in *Diabetes Today* – a publication aimed at HCPs – as it announced the impending development:

> People with Type 1 diabetes could soon be offered greater freedom from the constraints of diabetes. A trial of a new education programme was published in the *BMJ* in early October. The programme has the theme: ‘Eat what you like, like what you eat’ and could offer many people with Type 1 diabetes the holy grail – flexible lifestyle with more dietary freedom and improved diabetes control.
>
> The DAFNE programme (Dose Adjustment for Normal Eating) funded by Diabetes UK, is a five-day course teaching people with Type 1 diabetes how to adjust their insulin to fit their lives, freeing them from a strict diet and injection regimen. Results of the trial show significant improvements in blood glucose control and in

> the participants' quality of life in general. There was no increase in severe hypoglycaemia.
>
> Suzanne Lucas, Diabetes UK Director of Care, said "DAFNE has been a liberating experience for people on the trial. Many found their whole lifestyle and outlook on life has improved following the course and with better diabetes control their worries about complications have reduced. Participants also found they were able to travel abroad without worrying about missing a meal or eating on time. This is a fantastic breakthrough and offers people with diabetes the chance of a more spontaneous, normal life."[372]

That improvements to blood glucose control are mentioned only briefly while improvements to quality of life are highlighted in a publication *aimed at professionals* is important. By 2002, the ideological foundation of care had clearly changed – there is little Parsonian anxiety here. Instead, patient self-adjustment is enthusiastically embraced not only in the sense of small, cautious modifications to an essentially fixed and inflexible regimen of diet and injection, but in a much more all-encompassing sense. The theme 'eat what you like, like what you eat' suggests that prescribed diet was jettisoned entirely, with those with T1D now encouraged to dynamically – and radically – alter dosages on a daily basis to account for constantly fluctuating requirements. It appeared that DAFNE represented true patient-led 'intensified' therapy – a clean break from both its 'conventional' and 'semi-intensified' forebears.

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[372] 'Breakthrough offers freedom for people with diabetes', *Diabetes Today* 5 (2002), p. 119.

This was a major change of management strategy from the British perspective.[373] Recognising that earlier attempts to 'intensify' therapy had been characterised by 'frequent outpatient visits with close supervision of insulin dose adjustment' and that 'three patients to each healthcare professional is beyond the scope of most healthcare systems', this initiative turned the traditional British approach to management on its head.[374] Working on the basic premise that 'type 1 diabetes is an insulin deficiency disorder, best managed by insulin replacement as needed and not by dietary manipulation to match prescribed insulin', DAFNE aimed to 'build confidence and appropriate independence, with patient autonomy as a goal... [teaching] the skills and confidence to adjust insulin to suit... lifestyle rather than being told to adapt the timing and content of meals to more fixed doses of insulin.'[375] Perhaps most importantly of all, the DAFNE Study Group argued both that in the management of T1D a bio-reductionist model was not necessarily sufficient, and that adopting the above described approach while consequently allowing a liberalisation of diet and lifestyle would in any case improve clinical outcomes:

> Other reasons why intensified treatment has not been widely adopted may exist. Clinicians usually propose treatment goals formulated from the medical perspective, focusing on biomedical outcomes, whereas patients are more concerned about the immediate demands of treatment and how to integrate these into daily life. Diabetes and its treatment have a negative impact on quality of life, particularly in terms of dietary restrictions imposed by traditional treatment regimens... an approach in which intensive insulin management is used to increase

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[373] Today, DAFNE-style approaches based on carbohydrate counting and regular self-adjustment are generally recommended for all individuals diagnosed with T1D, whether or not they actually attend one of the structured education courses.

[374] DAFNE Study Group, 'Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial', *BMJ* 325 [7367] (2002), p. 746.

[375] *Ibid*, p. 747.

> dietary freedom is likely to improve quality of life, as well as biomedical outcomes, and may result in its wider adoption.[376]

This chapter will explain how and why DAFNE-style treatment that rejected both the inflexible daily pattern and strict dietary regulation of earlier ‘conventional’ therapy evolved from the extremely cautious and limited early moves towards ‘semi-intensification’ in Britain. It will argue that, supported by a backdrop of individualist neoliberal politics, the 1990s witnessed a process of transmutation in the management of T1D driven, in part at least, by the patient-body itself. This process forced professionals to radically re-evaluate the relationship between themselves and their patients, providing a solution to the inertia that had set in following the DCCT’s suggestion that clinical goals could only be optimised by closely supervised ‘intensive’ therapy that was, in practice, impossible on any significant scale.

DAFNE, alongside its sister programmes created as part of the EPP, represented a tentatively stable solution that simultaneously improved clinical outcomes and, ostensibly, respected the importance of lay-value judgements, while reconceptualising professionals as a hands-off – yet vital – source of support. In resolving the paralysis that had characterised T1D management during the 1990s, however, it exposed a fundamental contradiction at the heart of the neoliberal approach to health.

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[376] *Ibid*, p. 746.

Part 2: Michael Berger

By the 1990s, the principle of emulating as best as possible patterns of endogenous insulin production in order to maintain strict glycaemic control and potentially mitigate the long-term complications of T1D was largely accepted amongst professionals However, as clinicians too contended with the realisation that 'intensified' treatment appeared impractical within the NHS as it existed, they attempted to compromise via the introduction of 'semi-intensified' approaches – that is, approaches that adopted the basal/bolus framework of 'intensive' management while utilising the soft authority of *active unfreedom* to maintain moral control over the structure and implementation of treatment while strongly discouraging any real lay-innovation.

In mainland Europe, however, an alternative approach had coalesced some years previous. In early 1982, Michael Berger (1944-2002), a senior figure in the European Association for the Study of Diabetes (EASD), reported on a pioneering research trial conducted in Düsseldorf and Vienna:

> Teaching was organised as an inpatient course... the therapeutic and educational goals, as well as strategies for insulin therapy, were identical in both hospitals. The patients were to attempt normoglycaemia and gain a certain 'liberalisation' of lifestyle with respect to exercise and eating schedules. All patients, irrespective of their educational status or intelligence, should be trained for self-management of their diabetes. Patients were instructed to monitor glucose three to four times per day, using either urine, blood, or both. The use of regular [soluble] insulin was encouraged and patients adjusted their insulin dosages by themselves.[377]

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[377] Michael Berger, 'Evaluation of a Teaching and Treatment Programme for Type 1 Diabetic Patients', *The Diabetes Educator* 10 (1984), p. 37.

This form of education had been in use at Düsseldorf since 1978, and its unusually patient-centric character was unheard of in Britain.[378] Berger effectively argued against 'semi-intensified' compromises, suggesting that those with T1D should learn to adapt their own treatment via similarly structured, hospital-based courses.[379] SBGM was, of course, vital to this:

> These [blood glucose] measurements are, however, hardly useful in improving metabolic control unless the patients have learned to translate the results of their metabolic self monitoring into appropriate insulin dose adjustments, adaptations of diet, and other elements of therapy.[380]

Berger's vision of 'intensified' therapy in non-pump users – which he described somewhat awkwardly as 'intensified conventional therapy' – worked according to the same 'basal-bolus' framework as British 'semi-intensified' approaches, though with a markedly more active role for the patient:

> Different concepts of intensified (conventional) insulin therapy have been proposed, all of which include the preferential use of short-acting (regular) insulin before the main meals in addition to a 'basal' component of insulin substitution, which is delivered by one or two daily injections of intermediate – or long-acting insulin preparations. In particular, the pre-meal bolus injections of regular insulin are variable, and are adjusted by the patient, on the basis of the actual results of self-monitoring of glycaemia or glucosuria and of the amount of carbohydrate to be

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[378] I. Mühlhauser, I. Bruckner, M. Berger, D. Cheța, V. Jörgens, C. Ionescu-Tîrgoviște, V. Scholz. and I. Mincu, 'Evaluation of an intensified insulin treatment and teaching programme as routine management of Type 1 (insulin-dependent) diabetes: The Bucharest-Düsseldorf Study', *Diabetologia* 30 (1987), p. 681.

[379] J. Mirouze, 'Insulin Treatment: A Non-Stop Revolution', *Diabetologia* 25 (1983), p. 212.

[380] J.P. Assal, I. Mühlhauser, A. Pernet, R. Gfeller, V. Jörgens, and M. Berger, 'Patient education as the basis for diabetes care in clinical practice and research', *Diabetologia* 28 (1985), p. 602.

> consumed. These new concepts of intensified conventional insulin therapy (ICT) require an increasing level of understanding, cooperation and compliance. They have gained in popularity with patients and physicians since they should eventually lead to better metabolic control and to more independence from the earlier rigid dietary regimens.[381]

Berger talks about 'compliance' here, and he was certainly concerned with maintaining absolute control over the process of education in order to instil patients not only with the technical ability to act independently but, where possible, with the values of the clinic itself. When adapting the programme for DAFNE, for example, one element that Amiel struggled with was the strict prohibition of between-meal snacks:

> There were some really difficult things. For example, you ate when you wanted, and you did not snack between meals. Now, to me, that was anathema. I cured a lot of people of hypoglycaemia by introducing a between-meal snack! Now, I think part of that was because we depended on the meal insulin to provide the background between meals. It was too much and so you did have to snack between… so that was the thing I had trouble with.[382]

Nevertheless, Berger acknowledged the value of patients having a formal role in their own treatment in a way his more paternalistic forebears (and colleagues) did not, while also acknowledging – in an admittedly rather secondary sense – that *value* in treatment could

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[381] Michael Berger, 'Insulin therapy: conventional' in K.G.M.M. Alberti and L.P. Krall, *The Diabetes Annual* 1 (Amsterdam: Elsevier, 1985), pp. 111-112.

[382] Amiel, Interview.

not always be reduced to the purely biomedical. In doing so, he pre-empted later discussions in this area by a considerable margin.[383]

This was extremely unusual for the time, and such attitudes were notably absent amongst contemporary British voices. Nevertheless, Berger's approach was an impressive ideological manoeuvre that contained the potential to resolve the paralysis so troubling his Anglo-Saxon counterparts. The most significant contribution of Berger – alongside his wife Ingrid Mühlhauser (1953-) and other colleagues – was to expand the scope of education to encourage genuine autonomy. The patient, they implicitly suggested, should not rely upon careful attention to professional instruction, but become competent enough to adapt their own treatment as necessary to become fully independent – the professional, for their part, should reconceptualise themselves as hands-off supervisors where possible. In this context, the need for active intervention by HCPs became in itself a sign of failure. That this threatened to disrupt the traditional power differential previously accepted as inherent to the consultative relationship did not go unnoticed:

> The ability and motivation of *patients* to learn about their disease and to assume an active role in its treatment is closely related to their particular health beliefs, their personality structure, their actual psychosocial situation, the presence of disease – and/or treatment-related symptoms, the prognosis of their disease(s), and their ability to cope with and actively accept their disease. *Physicians* may not be inclined or able to motivate their patients for self-care because their own medical school training was predominantly biomedical and their hospital training was largely restricted to crisis intervention; furthermore, many physicians (consciously or subconsciously) object to sharing knowledge with patients as this may result in

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[383] For example, Howard A Wolpert and Barbara J Anderson, 'Management of diabetes: are doctors framing the benefits from the wrong perspective?', *BMJ* 323 [7319] (2001), pp. 994-996.

> having to give up authority, power and financial benefits; others are not prepared to tolerate mistakes made by patients during the self management of their treatment, although similar mistakes committed by physicians are quite readily excused.[384]

Opposition to 'empowerment' of this sort was not always the product of cynicism or self-interest. Echoing Knight, as late as the mid-1990s, when 'semi-intensified' therapy was becoming more widely discussed and implemented in Britain, some physicians opposed the development on ethical grounds. Ceding any control to the individual with T1D, they argued, could potentially directly threaten their health:

> Some patients may be reluctant to accept responsibility for their own diabetes management, and need to be encouraged with the knowledge that they are best placed to make decisions which impact on the day to day running of their lives. They then need access to professional support, education in the knowledge of their condition, self-care skills, and choices available to them. Healthcare professionals may also misunderstand patient empowerment. They may see this as an unethical suggestion that they should abdicate responsibility for care and relinquish clinical control and decision making. At the other end of the spectrum, some may see patient empowerment as a license to divest themselves of the more intractable problems associated with diabetes care. In reality, however, patient empowerment involves the active participation of the health professional in the role of facilitator,

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[384] All emphasis in original; Assal, Mühlhauser, Pernet, Gfeller, Jörgens, and Berger, 'Patient education as the basis for diabetes care in clinical practice and research', p. 604.

> enabling patients to set individual goals for diabetes management and to achieve optimal outcomes in both medical and psychosocial health.[385]

By 1987, Berger's approach had been utilised effectively in Bucharest as part of a major study of its broader efficacy.[386] Despite this, his influence outside of the German-speaking world remained relatively insignificant. Simon Heller (1953-), another important figure in DAFNE and a colleague of Amiel, remembers his relative lack of recognition: 'I think he had influence in Germany for sure, 100%. And I know, again, a colleague and friend in Austria – they'd adopted [his program]. But they were German-speaking, and they were instantly inspired, but in many other European countries it wasn't really understood.'[387] Predictably, British diabetologists were even more dismissive of their counterparts in mainland Europe:

> It was either not known about in the UK or it was regarded suspiciously and not understood... people talked about Michael Berger in Britain for about ten years and I always used to say, "What is that?" And I remember somebody who was big in education, I won't say who it was, but he was dominant in the early '90s, he said, "Oh, they select their patients, I wouldn't take any notice of their data." This is… and it's still there today... [with] Brexit... this attitude towards Europe – Brits can't learn from anybody.[388]

Amiel and Heller, two of the UK-based physicians responsible for introducing DAFNE to Britain, both directly credit Berger for providing the inspiration.[389] In truth DAFNE was a

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[385] C. Bradley, M.B. Pierce, C. Hendrieckx, A. Riazi and S. Barendse, 'Diabetes Mellitus' in M. Johnston and D.W. Johnston (eds.), *Comprehensive Clinical Psychology Vol 8: Health Psychology*, Vol. 8 (Oxford: Elsevier Science, 1998), p. 277-304.

[386] Mühlhauser, Bruckner, Berger, Cheța, Jörgens, Ionescu-Tîrgoviște, Scholz. and Mincu, 'Evaluation of an intensified insulin treatment and teaching program', p. 681-690.

[387] Simon Heller interviewed by Stuart Bradwel, 3rd July 2019, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

[388] *Ibid*.

[389] Somewhat ironically, Berger died the same year DAFNE was formally adopted in the UK.

direct translation of the material used in Germany.[390] Amiel bluntly admits as much: ‘We started setting up the DAFNE program in about 1998. We published it in 2002... but basically we sent teams over there [and] we brought the curriculum back to the UK. We translated it into English word by word. We did not change anything.’[391]

Until Berger’s programme was brought to the UK in 2002 as DAFNE, no similar patient-led ‘intensified’ approach was taught in the British Isles. Management instead continued to rely upon either ‘conventional’ or ‘semi-intensified’ treatment. Heller suggests that the major shift in opinion that allowed DAFNE to emerge came as a simple result of British professionals accepting the advantages of Berger’s approach ‘once [they] saw it and... saw how ready they [the Germans] were to share it.’[392] While there is almost certainly an element of truth to this as it pertained to individual doctors, this does not adequately explain the necessary structural and ideological transition. Düsseldorf’s programme had been running for almost a quarter of a century prior to the adoption of its approach in the UK. How can we understand this?

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[390] DAFNE Study Group, ‘Training in flexible, intensive insulin management’, p. 747.
[391] Amiel, Interview.
[392] Heller, Interview..

Part 3: The Resurrection of the Patient as 'Responsible Subject'

Trostle's observation that medical technology has 'reduce[d] the need for patient initiative... [potentially turning them] from responsible subjects into responsive objects' (see Chapter 3) is an important reflection when it comes to understanding the broader history of T1D.[393] When insulin was first used in 1922, only one form existed: soluble. While those with T1D were provided with strict dietary instruction and generally advised to administer insulin once or twice daily before eating around this, this was not strictly necessary. Soluble insulin possesses a relatively short duration of action and is well suited to ad hoc tinkering. As Eastwood's example shows, a layperson – given the time, inclination, and intelligence – could successfully self-adjust their dosages unilaterally to meet the demands of variations in diet and lifestyle.

Longer-acting 'protamine' and 'protamine zinc insulin' (PZI), however, feature much slower absorption rates, and are therefore trickier to fine-tune – particularly where they are being used instead of, rather than in addition to, the soluble formulation. Such varieties were in use from 1936, and by 1952 the trend reached its predictable conclusion with Copenhagen's Novo laboratory releasing 'Lente' insulin, designed as a 'once-daily' preparation that also avoided the often severe side-effects of its PZI precursor. Appearing to many as what Tattersall has described as the 'holy grail' of management – an injection that could be taken once daily and then forgotten about – Lente was immediately popular with practitioners and indeed with many patients.[394] Similarly, by the 1980s pre-mixed insulins were becoming increasingly popular – formulations prepared in the factory to contain a precisely measured combination of soluble and longer-acting varieties (see Figure

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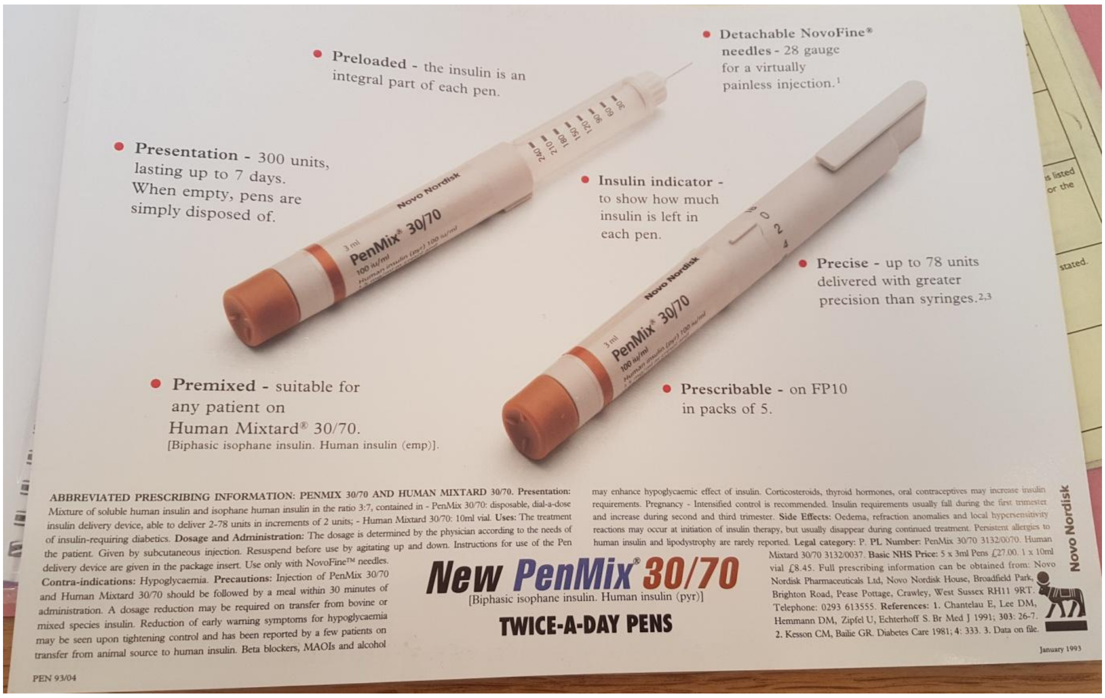
[393] Trostle, 'Medical Compliance as an Ideology', p. 1306.

[394] Tattersall, *The Pissing Evil*, pp. 147-149.

4.1).[395] These were marketed as more ‘modern’ and efficient than the alternative, but in practice imposed considerable rigidity upon those using them. Such formulations produced extremely inflexible action profiles throughout the day, making all but the most superficial modifications very difficult. As Gill and Redmond pointed out in their late 1980s *Balance* article on dose self-adjustment, ‘Fixed combinations... are simple and quick to use, but they do not allow such fine adjustments of doses as with separately mixed clear and cloudy combinations.’[396] A strict daily pattern of diet and exercise with minimal variations was, when using pre-mixed insulins, extremely important to avoid dangerous fluctuations in blood glucose. Minor alterations could potentially tweak the precise shape of that pattern, but it remained regardless.



- **Preloaded** - the insulin is an integral part of each pen.
- **Detachable NovoFine® needles** - 28 gauge for a virtually painless injection.[1]
- **Presentation** - 300 units, lasting up to 7 days. When empty, pens are simply disposed of.
- **Insulin indicator** - to show how much insulin is left in each pen.
- **Precise** - up to 78 units delivered with greater precision than syringes.[2,3]
- **Premixed** - suitable for any patient on Human Mixtard® 30/70. [Biphasic isophane insulin. Human insulin (emp)].
- **Prescribable** - on FP10 in packs of 5.

ABBREVIATED PRESCRIBING INFORMATION: PENMIX 30/70 AND HUMAN MIXTARD 30/70. Presentation: Mixture of soluble human insulin and isophane human insulin in the ratio 3:7, contained in - PenMix 30/70: disposable, dial-a-dose insulin delivery device, able to deliver 2-78 units in increments of 2 units; - Human Mixtard 30/70: 10ml vial. **Uses:** The treatment of insulin-requiring diabetics. **Dosage and Administration:** The dosage is determined by the physician according to the needs of the patient. Given by subcutaneous injection. Resuspend before use by agitating up and down. Instructions for use of the Pen delivery device are given in the package insert. Use only with NovoFine™ needles. **Contra-indications:** Hypoglycaemia. **Precautions:** Injection of PenMix 30/70 and Human Mixtard 30/70 should be followed by a meal within 30 minutes of administration. A dosage reduction may be required on transfer from bovine or mixed species insulin. Reduction of early warning symptoms for hypoglycaemia may be seen upon tightening control and has been reported by a few patients on transfer from animal source to human insulin. Beta blockers, MAOIs and alcohol may enhance hypoglycaemic effect of insulin. Corticosteroids, thyroid hormones, oral contraceptives may increase insulin requirements. Pregnancy - Intensified control is recommended. Insulin requirements usually fall during the first trimester and increase during second and third trimester. **Side Effects:** Oedema, refraction anomalies and local hypersensitivity reactions may occur at initiation of insulin therapy, but usually disappear during continued treatment. Persistent allergies to human insulin and lipodystrophy are rarely reported. **Legal category:** P. **PL Number:** PenMix 30/70 3132/0070. Human Mixtard 30/70 3132/0037. **Basic NHS Price:** 5 x 3ml Pens £27.00. 1 x 10ml vial £8.45. Full prescribing information can be obtained from: Novo Nordisk Pharmaceuticals Ltd, Novo Nordisk House, Broadfield Park, Brighton Road, Pease Pottage, Crawley, West Sussex RH11 9RT. Telephone: 0293 613555. **References:** 1. Chantelau E, Lee DM, Hemmann DM, Zipfel U, Echterhoff S. Br Med J 1991; **303**: 26-7. 2. Kesson CM, Bailie GR. Diabetes Care 1981; 4: 333. 3. Data on file.

New PenMix® 30/70
[Biphasic isophane insulin. Human insulin (pyr)]
TWICE-A-DAY PENS

Novo Nordisk

PEN 93/04

January 1993

Figure 4.1: ***Pre-mixed Insulin Marketing Leaflet*, January 1993, T/1993/1446-1454, Science Museum Technical Object Files**

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[395] Prior to this, those using both soluble insulin and longer-acting versions were usually instructed to take both twice daily in prescribed amounts. While they could be given in two separate injections, most were instructed to measure out the appropriate amounts of each before mixing together; *Ibid*, pp. 143-145.

[396] Gill and Redmond, ‘Adjusting Your Own Insulin’, p. 32.

Each of these developments was based on the principle that *fewer interventions* represented a refinement of therapy, especially in light of the common belief that the process of injecting insulin itself constituted a serious quality of life issue for those with T1D. This was, in reality, likely not the case – as Amiel points out: 'There's always been this feeling from the paternalistic medical profession that the fewer injections the better, [but] If you talk to patients then it wasn't the injections that they hated at all!'[397] Regardless, developments such as mixed formulations were very commonly prescribed, and did reduce the daily labour of T1D for the individual. In doing so, however, following Trostle's thesis, they made passive objects of patients – their ability to meaningfully innovate or engage with treatment was severely curtailed. The increasingly long-acting, pre-mixed nature of prescribed insulin in the UK by the 1980s made significant patient empowerment very difficult. Eastwood, had he been diagnosed fifty years later, may never have been given the opportunity to develop his unique system because, to put it simply, he may not even have been prescribed soluble insulin, but rather a pre-mixed and consequently entirely inflexible preparation, or some other difficult to adjust long-acting formulation.

The principle of 'intensification' – by the early 1990s widely acknowledged to be clinically preferable – therefore required those on insulin (and not using an infusion pump) to be prescribed separate short- and long-acting formulations to be administered individually in variable dosages as necessary. This development was significant. 'Intensified' – or, rather, at the time, 'semi-intensified' – therapy required *more* injections, *more* blood tests, and *simpler*, unmixed formulations of insulin. While clinicians were attempting to assert further control via a culture of *active unfreedom* in their effort to emulate the mass supervision of the DCCT, 'semi-intensification' required, ironically, the reversal of the trend towards patient passivity by its very nature: 'basal-bolus' approaches necessitate the separate

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[397] Amiel, Interview.

administration of short- and longer-acting insulins. Pre-mixed varieties are simply not practical. Recall that Berger’s education programme in Germany required the use of soluble insulin. This process produced a set of material conditions in which the patient as a *responsible subject*, and perhaps more meaningfully as a relevant *moral actor*, could return to centre stage.

To the medical profession – and, indeed, to many patients – this seemed something of a backwards step. The move away from pre-mixed insulins given once or twice daily alongside strict but simple dietary plans, and towards MDI with ever more regular blood glucose testing appeared – inevitably – to distance treatment even further from Tattersall’s ‘holy grail’. Most strikingly, the labour of carbohydrate counting – an integral element of ‘intensification’ – was reminiscent of the earliest, and therefore – implicitly – antiquated, forms of insulin therapy. After the introduction of DAFNE in 2002, Amiel noted that some were highly sceptical:

> Patient dose adjustment by carbohydrate counting – DAFNE. If you go right back, in the days when they first had just fast acting [soluble] insulin, it's exactly what they did, except that they prescribed the carbohydrates as well. So the man after whom my previous chair was named, R.D. Lawrence, he was famous for something called ‘Lawrence’s Lines’... which was considered to be flexibility. So, you know, you don't have to eat that slice of bread every day, you can replace it with half a potato... So they fitted the food around the insulin... So a lot of my older patients will say, “Well, why do I need DAFNE? I’ve been carbohydrate counting ever since I was fifteen!” But they were taught to carbohydrate count and then take that number of carbohydrates on that day, so it's a very different use of the system. But certainly...

> some of its enemies in the beginning said, “Why would we go back to carbohydrate counting?” You know? “That’s what we used to do in the old days.”[398]

Amiel is correct to point out that strict carbohydrate counting had, despite the failure of ‘free diets’ in the 1940s and 1950s, been largely phased out of professional advice by the 1990s in favour of a more general – and perhaps more nebulous – encouragement to eat ‘healthily’. Elaborating on this, she reflects:

> We had gone from teaching patients to carb count, not so they could judge their insulin requirements but so we could tell them how much to eat at each meal, and we'd gone from that to a much more laissez-faire attitude of “Let's just teach them healthy eating because they're a high cardiovascular risk”, and for… at least a decade, patients weren’t taught anything except the principles of healthy eating, which told them nothing about how to use the insulin with regard to the food. And the dietitians were very loath to give the patients any rights to choose their own diets, and I remember when we tried to sell DAFNE to the Department of Health somebody said to us, “But you can't tell people with diabetes to eat what they like! That's irresponsible!”[399]

The shift in dietary advice described by Amiel is borne out by patient guidebooks. While textbooks in the 1970s and 1980s were replete with in-depth guides to dietary ‘carbohydrate exchanges’, these simply do not feature to any meaningful extent in material published in the mid-1990s.[400] By contrast, the focus shifts away from carbohydrate and onto energy and fibre intake. For example, in Joan Gomez’ 1995 *Living with Diabetes* there

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[398] Amiel, Interview.

[399] *Ibid*.

[400] For examples of such ‘exchange lists’, see Anonymous, ‘DH123 - Carbohydrate Exchange List [1971]’ in BDA, *The Diabetic’s Handbook* (London: British Diabetic Association, 1973); Steel and Dunn, *Coping with Life on Insulin*, p.26; Watkins, Drury, and Taylor, *Diabetes and Its Management*, 4th ed, p. 70.

is no mention whatsoever of exchanges. Instead, readers are advised to eat limited salt, fat, and refined sugar, while incorporating plenty of fruit and vegetables into their diet alongside complex carbohydrates:

> About 15 years ago, it was thought that carbohydrates were harmful to diabetics and should be cut down as far as possible. All the diabetic associations in the world now agree that this is nonsense. Diabetics, like other people, need to step up their carbohydrate intake.
>
> The most beneficial kinds are bread, rice, pasta, potatoes and other vegetables and fruit. The ones to avoid are those that give you a sudden, large dose of sugar, such as jam, marmalade, honey, syrup, sugar, fizzy drinks, sweets, chocolate and cakes. Keep these as treats, not for every day.[401]

The apparent jettisoning of a strict focus on carbohydrate intake represented a stark change in clinical approach. Gomez goes on to outline her approach to nutrition in diabetes, characterised by the use of two diets: ‘maintenance’ and ‘reducing’. As their names suggest, these are centred on the careful planning of calorific intake in order to achieve a healthy body mass index (BMI) and make little reference to carbohydrate.[402] Hillson perhaps explains best the thinking behind the transition:

> Many of you will have been taught to weigh your food and to count exchanges of carbohydrate, and even of fat or protein. If you feel comfortable with this then continue, but nowadays dietitians are moving away from such rigid dietary control. I once met someone who dipped a urine testing strip into everything she drank to see if it was too sugary. She felt she needed an extremely strict diet to manage her

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[401] Joan Gomez, *Living with Diabetes* (London: Sheldon Press, 1995), p. 47.

[402] *Ibid*, pp. 117-119.

> diabetes and became very distressed when she was away from home and unable to calculate her exchanges exactly. She had become a prisoner of her diabetic diet.
>
> The problem is that our bodies are not machines. A car owner can calculate the number of miles his car goes per gallon and knows how much the fuel tank holds – so he knows how much fuel he needs and how often. But there are so many variables in the working of the human body that a simplistic view of food as a fuel may lead to a false sense of security.
>
> ...If there is such a variable glucose response to carbohydrate foods there seems little point in weighing out precise carbohydrate portions for every meal.[403]

Hillson is reflecting a growing understanding of the metabolic complexity of insulin therapy and the importance of factors beyond simply balancing medication with carbohydrate: fat, exercise, illness, and many other variables can also influence outcomes in diverse and often highly individualised ways. Additionally, her reference to a patient who ‘became a prisoner of her diabetic diet’ is telling: to Hillson, quality of life had clearly come to represent a meaningful consideration in its own right. The maintenance of strict control, while desirable, was no longer *necessarily* – for her – the primary goal of therapy should that interfere with the ability of the individual to maintain a balanced diet and overall well-being.

Hillson, for her part, was unusually thoughtful for a HCP for this period, and it would be significantly premature to consider her representative of any widespread cultural change when it came to respect for lay-value. Certainly, the move towards the encouragement of ‘healthy eating’ as opposed to an emphasis on strict control could also have less desirable consequences for the experience of T1D. Tozer, for example, remembers being offered very

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[403] Hillson, *Diabetes: A Beyond Basics Guide*, 2nd ed, p. 25.

little guidance or support when, attending a diabetic clinic in the mid-1990s, she was presented with an HbA1c result considered ‘unsatisfactory’:

> But this was either when I was at school age or, you know, sort of teens and early twenties. It was always a bloke and he would look at your HbA1c, or whatever results, and go “oh yeah, you're running high, you need to do something about that” and it was like “we'll see you in a year's time.” And that was it.[404]

As Tozer’s account suggests, while this shift in treatment parameters is important, it did not imply any fundamental alteration to the doctor-patient relationship. While Hillson was perhaps unusually comfortable with genuine initiative from those with T1D – and importantly, aimed *A Beyond Basics Guide* squarely at those with considerable experience – most authors maintained the traditional division of labour between PWD and HCP and emphasised the importance of traditional self-disciplinary principles in management.[405] There is the faint suggestion of moralism in Gomez’ book, for example:

> Now that you have the [dietary] groundwork, you need to make a meal plan with the help of a dietician. Considerations are:
>
> - your food preferences (check back over the last week to remind yourself what you enjoy)
> - your schedule, including times of meals and where you will be
> - timing of periods of physical exercise

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[404] Tozer, Interview.

[405] In a book aimed at those new to insulin therapy, Hillson remains rather cautious, advising those with T1D to ‘telephone [their] diabetes adviser to check that [they] have got it right’ before making any change to insulin dose; Rowan Hillson, *Diabetes: A New Guide* (London: Optima, 1992), p. 97.

> For the best results in terms of glucose control, try to be consistent in your eating. Multiple injections or an insulin pump give you a little more leeway, but your body thrives on a regular rhythm in food intake as in everything.[406]

The enforcement of strictly regulated – and minimised – carbohydrate portions had by the 1990s been largely abandoned. However, day-to-day consistency in terms of nutritional intake (and insulin dosages) continued to be strongly encouraged, while patients were still expected to follow dietary plans determined – ostensibly with their collaborative input – by a professional, in order to minimise variation. While they were to be administered more regularly, 'semi-intensified' approaches continued to operate according to the principle that essentially fixed daily insulin dosages were desirable, or at least pragmatically necessary.

If the carbohydrate counting aspects of DAFNE appeared rather 'old fashioned' to Amiel's more elderly patients, it is worth asking why her younger patients did not exhibit the same anxiety. The simple answer here would be that they could not have any appreciable position towards an approach they had never used. However, there is more to this. Her older patients had grown up in the ideological context of strict paternalism – carbohydrate counting was to them simply another laborious ritual that did not promise any meaningful improvement in lifestyle.

Adaptations in dietary advice, while important to the long history of T1D, are, however, somewhat besides the point here. The adoption of 'semi-intensified' therapy as best practice demanded patients be able to access both short-acting insulin and blood glucose monitoring equipment. In doing so, they gained the *potential* to determine the character of therapy according to their own value judgements in a meaningful and comprehensive way,

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[406] Gomez, *Living with Diabetes*, p. 48.

and most importantly in a way that HCPs were simply *unable* to effectively prevent. The patient-body, consequently, became a decisive political force in the evolution of care.

Part 4: Socio-cultural Transmutation

As discussed in Chapter 1, Feudtner's work is concerned with the 'transmutation' of T1D – that is, the process by which the precise character of the condition shifted as novel treatments were developed and utilised. A true *cure*, of course, continues to be a pipe dream, but the experience of each affected individual is shaped by the unique constellation of interventions that have led them to arrive at the present. The recipient of a donor kidney, for example, might be released from the necessity of frequent dialysis but must now suffer the side-effects of anti-rejection medication. Similarly, dialysis itself may avert otherwise sure death via organ failure, but necessitates a regular and invasive procedure. At its most basic, insulin itself is the original, and perhaps the most dramatic, transmutative intervention, changing the shape of the condition – at no small cost – from acute and fatal to manageable though life-changing. The experience of T1D is therefore not fixed, but is created at the precise intersection of a variety of divergent factors.

Since the creation of the NHS in 1948, most of those requiring insulin in Britain have been provided it at zero personal cost, this is not the case globally. In addition to severely deprived states in the global south where economic factors preclude the effective provision of universalised healthcare, this is also a fundamentally political issue. In the USA, T1D has once again become an effectively acute and fatal condition for many due to the cynical logic of predatory capitalism: those who need insulin to survive will pay whatever is asked of them, and in recent years its cost has increased exponentially. Feudtner understands the process of transmutation to be a primarily biomedical one: new drugs, procedures, and technologies shape the experience of illness. However, the experience of those in the USA demonstrates that the concept can be expanded well beyond this. In the USA, no small number of impoverished PWD are suffering and dying because of a *socio-economic choice* on the part of the pharmaceutical-industrial complex. Analogue insulin of the kind commonly prescribed in the UK is accessible but it is extremely expensive: sometimes costing in excess of $1000 for a monthly supply. Consequently, those with no health insurance (and even sometimes those with!) are forced to ration their stocks and/or rely on less effective, pre-analogue formulations available at more affordable prices, in some cases to the point of dangerous hyperglycaemia and even DKA.[407] This, however, represents no less a transmutation in the character of T1D than any novel product or technology – the nature of the condition ensures that it is not only the *what* that exerts transmutative potential, but also the *how*.

The present trials of those with T1D in the United States make for depressing reading, but they also show that Feudtner's thesis can be expanded beyond its original scope. As a paediatrician and member of the medical profession he – like Tattersall and many other authors on the subject of diabetes – possesses a particular cultural bias. This is illustrated by the following passage in *Bittersweet*: 'Depending on the therapeutic choices that a patient and physician made – and on what options were available at the time – each patient pursued an individually transmuted disease course.'[408] Here, Feudtner is arguing that the process of transmutation is a closed biomedical system with little to no relation to its broader social context. However, the evidence makes clear that agents of transmutation can be found in places far removed from the clinic.

As the medical profession in the UK began to utilise 'semi-intensified' approaches to T1D management from the mid-1980s, and, consequently, was forced to prescribe both shorter-

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[407] For one example amongst many, see Antonio Olivo, *Diabetic, 27, dies after taking cheaper insulin as he lost private health insurance*, 5 August 2019 <https://www.independent.co.uk/news/world/americas/diabetes-josh-wilkerson-death-age-counter-insulin-cost-lost-private-health-insurance-american-doctor-a9039656.html> [accessed 18th January 2020].

[408] Feudtner, *Bittersweet*, p. xiii-xiv.

acting insulin and blood glucose monitoring equipment, they in effect relinquished de facto control over therapy. While physicians could attempt to exert soft power to impose a form of *active unfreedom* much as they previously had done as patient self-adjustment of insulin dosages became a central part of 'conventional' management approaches, the power differential between practitioner and patient had shifted dramatically.

In order to understand this process and its implications, it is worth examining an article by the sociologist David Kelleher that appeared in the August/September 1987 issue of *Balance*. In this, Kelleher – who had received a grant from the BDA to investigate 'why people with diabetes don't always follow their doctor's instructions' – attempted to explain the prevalence of discrepancies between prescribed treatment and day-to-day reality in the contemporary management of T1D. Its opening paragraph clearly indicates the author's ideological framework:

> Being compliant, or doing what the doctor or dietician tells you to do, means more than taking insulin or tablets at the prescribed times. It also requires diabetic people to monitor their blood sugar levels and pay close attention to what they eat. In some ways it is the attempt to control eating that causes most difficulties and a great deal of non-compliance.[409]

Kelleher's article prompted Alexandra Weston of Oxfordshire to respond in the following issue of *Balance* with barely disguised contempt:

> I hope that all my BDA subscription does not go on projects such as that of David Kelleher! To begin with, he has started on completely the wrong track by researching into why people with diabetes do not 'obey' their doctors'

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[409] David Kelleher, 'Non-compliance and the toleration of symptoms', *Balance*, August/September 1987, p. 27.

> ‘instructions’. Though doctors may know more about the medical side of diabetes, it is the diabetes [sic] themselves who know the trials and tribulations of living with it, and as a result of this, in my experience, visits to the diabetic clinic consist of *Discussions* [sic] between doctor and diabetic., ending in mutual agreement to which the diabetic believes he or she will be able to stick. And anyway, does David Kelleher honestly think that any diabetic will deliberately ignore anything their doctor says? Of course we would all like to have perfect control and never have a hypo, but that is impossible as diabetes has to be adapted to changes in lifestyle. Mr Kelleher seems to think that diabetics should be thinking all the time about their diabetes and arranging their lives around it, whereas personally I do very much the opposite, and I very much doubt if I am the only one! I always value greatly my doctor’s help and advice, but like to have the freedom to adjust my levels as I see fit, after eight years’ experience. Diabetics should be able to deal with the disease as they find preferable, of course in conjunction with the much needed *help* and *advice* of their doctor.[410]

Weston is perhaps reacting a little defensively to this article. Kelleher certainly did acknowledge the limitations of bio-reductionism, though – like Berger – he was deeply concerned with the preservation of the professional as, in a sense, a ‘beneficent teacher’ tasked not only with technical education but responsible also for instilling the *values* of professional practice into each patient and encouraging ‘compliance’:

> Non-compliance is a serious problem which frustrates the careful treatment of even the most well-intentioned doctors. There is unlikely to be any simple way of reducing it dramatically because, as I have argued, it often stems from people

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[410] Emphasis in original; Alexandra Weston, ‘Non-compliance’, *Balance*, October/November 1987, p. 7.

> making rational decisions which relate to the complexities of their lives. When not complying is understood as more often being the result of people making rational decisions to ignore part of their diabetic treatment, rather than as wilfulness or laziness, then doctors and dieticians are able to discuss the social costs involved in complying as well as the medical costs of not complying.[411]

It is worth pointing out that Kelleher's research was conducted during the mid 1980s, at which time the concept of 'non-compliance' in healthcare literature – which had only entered the medical lexicon to a significant extent a decade prior – had reached something of an apogee of saturation.[412] It is no surprise that, writing in this context, he felt the need to engage with the concept at length. As Greene has pointed out, one way in which the discourse around 'non-compliance' can be understood is as one element of an 'ideology of control'.[413] Responding to the growth of the patient autonomy movement, which had emerged throughout the 1960s and 1970s and was often extremely hostile to traditional paternalistic medical authority, this constituted a strategy of containment: by pathologising dissent itself, challenges to professional legitimacy could be weaponised to instead bolster it.[414] While it is therefore unsurprising that the clearly pro-autonomy Weston approached him with some hostility, as both an individual not living with the condition upon which he wrote, and, perhaps, as a researcher perceived implicitly to hail from the same scholarly classes as physicians and other HCPs, Kelleher did make a reasonable effort to problematise the notion of 'non-compliance' given the time of writing. While the extent to which it can be attributed to such lay-criticism is uncertain, his completed research, published in 1988, was certainly more nuanced:

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[411] Kelleher, 'Non-compliance and the toleration of symptoms', p.8.
[412] Greene, 'Therapeutic Infidelities', p. 328.
[413] *Ibid*, p. 336-338.
[414] *Ibid*, p. 337.

> The treatment of diabetes is not concerned only with measuring blood sugar levels. An attempt must be made to consider what effects diabetes and the treatment regimen are having on an individual's life. Good care has to be directed towards restoring a diabetic person to an active and satisfying life as well as achieving a better metabolic balance. The personal concerns of the diabetic patient and of the family increasingly need to be brought to the fore in the provision of health care.[415]

There is a subtle but extremely important evolution in Kelleher's position between these two passages. While in the initial extract he acknowledges that 'non-compliance' might result from 'rational decisions' rather than 'wilfulness or laziness', and that 'compliance' itself can in some cases carry its own 'social costs', he still considers such behaviour 'a serious problem': an inherent failure, implicitly, of treatment rather than successful treatment as defined by the value judgement of those undergoing it. Only one year later, however, he appears to take the more thoughtful line that 'good care' must be as concerned with restoring 'an active and satisfying life' as it is 'achieving metabolic balance', prioritising 'the personal concerns of the diabetic patient and of the family'. In short, it appears that Kelleher had refined his argument, his language, or both to emphasise that *value* should be determined by the person undergoing therapy as opposed to the HCP. While occasionally the product of a lack of education or motivation, he now understood that 'some non-compliance is intentional and the result of patients giving their own meaning to diabetes'.[416]

By contrast to Weston's forthright message to Kelleher, another piece of correspondence to *Balance* printed a decade earlier clearly shows that the subordinate role of the patient was accepted as an integral part of contemporary care. 'N.D.', writing in 1977 at the age of

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[415] David Kelleher, *Diabetes* (London: Routledge, 1988), p.86.
[416] *Ibid*, p. 54.

71, states that ‘no-one knows as much about my diabetes as I do’ and that they had as a result ‘let custom and habit take over from weighing and rigidity of diet.’ They go on to describe how they test their urine only infrequently, and regularly adjust insulin and diet as necessary based on the results. By following this method, ‘N.D.’ claims to have achieved ‘reasonable control’. What is most interesting here, however, is the subsequent admission that they feel ‘momentary qualms’ about their behaviour, asking the editor of *Balance* – with palpable anxiety – for reassurance that this is acceptable.[417] According to the ideological framework within which they write, the rejection of paternalistic instruction at the abstract level is clearly deeply discouraged, and ‘N.D.’s concern echoes the instinctive hostility expressed by many laypeople towards Fletcher three years later. By 1987, however, Weston was confidently stating that, in essence, the *value* of the physician was irrelevant, their role reconceptualised as a source of advice and support rather than ultimate authority.

From the 1980s, the increasing prevalence of technological developments such as insulin pens facilitated significantly faster, more discreet, more accurate, and less painful treatment, while portable blood glucose monitoring equipment made appropriate analysis and self-adjustment considerably easier. Nevertheless, such developments were – contrary to the belief of many HCPs – not *absolutely necessary* for patient-led (and value oriented) therapy, though they certainly helped. Ironically, it was the return to widespread prescription of shorter acting insulins that in practice allowed for this development and created the conditions for its broad acceptance amongst medical professionals. By handing *de facto* control of all aspects of therapy to the individual with T1D as a precondition for ‘semi-intensified’ therapy, laypeople were able to adapt treatment according to their own health beliefs and values in a way that had always *existed* within insulin therapy – as

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[417] ‘N.D.’, ‘Bending the Rules’, *Balance*, August 1977, p. 2.

demonstrated by Eastwood, Fletcher, and others – but which had been largely stifled by the passivity instilled by the trend towards 'simplification' described by Trostle: towards longer-acting insulins, pre-mixed varieties, and other well-intentioned 'innovations'. More to the point, by doing so they opened the way to a further transmutative development: that is, the *absolute* privileging of lay values over professional ones.

Like the rationing of insulin by those unfortunate enough to live with diabetes while also having the temerity to be poor in the United States (and in other states lacking sophisticated socialised healthcare), this development can be understood as the product of a transmutation – though one characterised not by purely biomedical interventions, but rather occurring at the *socio-cultural* level. A liberated patient body able to satisfy their own value-requirements in security from medical authority was able to mount an assertive resistance to the authoritarianism of professional care. This is the root of Weston's increasingly confident rhetoric. PWD were able to directly influence the ideological framework of care via *becoming in themselves* transmutative agents over which the profession was unable to exert meaningful control. Unlike 'N.D.'s late-1970s pessimism, by the mid-1980s those with T1D were able to boldly state: 'It is most important that each diabetic realises that he or she is in control of their own diabetes, and that infrequent visits to a clinic or doctor are only a help to that control, and that much advice given by doctors, dieticians etc can be improved by the diabetic himself.'[418] Ultimately, the professional, in this context, is *powerless*. However, this alone was not enough to create the conditions for DAFNE. The final piece of the puzzle can be found in the political context of the 1990s and early 2000s.

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[418] 'P.G.' 'Failure', *Balance*, August 1984, p. 2.

Part 5: New Labour and the 'Expert Patients Programme'

Those with T1D were, as we have seen, by the 1990s and particularly from 1993, increasingly restored as 'responsible subjects' thanks to the expansion of 'semi-intensified' approaches to care. Consequently, able to exert *de facto* control over therapy. This is not sufficient, however, to explain the medical profession's acquiescence in permitting the *de jure* right to determine the legitimacy of therapeutic value-judgements to pass to the patient-body. In order to satisfactorily explain this development, it is necessary to look beyond the narrow frame of T1D and consider the broader political context within which DAFNE emerged in the UK.

The 1979 election of the Conservative Party under Margaret Thatcher (1925-2013) signalled the beginning of a sea-change in British politics. Tearing up the fundamentals of the post-war consensus, Thatcher became the consummate neoliberal head of government. Neoliberalism, as David Harvey has defined it, being:

> A theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade... entailing [also] much 'creative destruction'... not only of prior institutional frameworks and powers... but also of divisions of labour, social relations, welfare provisions, technological mixes, ways of life and thought, reproductive activities, attachments to the land and habits of the heart... hold[ing] that the social good will be maximized by maximizing the reach and frequency of

> market transactions, and... [seeking] to bring all human action into the domain of the marketplace.[419]

Thatcher advocated for exactly that – strongly arguing in favour of individualist values and the curtailment of state spending while placing a strong emphasis on the importance of the globalised free-market as both an economic and moral necessity for national growth. A staunch capitalist and vociferous critic of even moderate democratic socialism, she undermined – and almost irreparably damaged – trade unions, while promoting a philosophy of consumerism and personal choice at the individual level – so long, of course, as that choice did not involve mutual co-operation. During Thatcher's time in office the economics and morality of neoliberalism came to permeate Britain's public institutions of state, with the NHS no exception.

As Mold has described, the idea of the 'patient-consumer' did not by any means originate during the Thatcher era. During her tenure, however, the concept of consumerism took on a vital importance within medicine as it did elsewhere. Driven by patient activism during the 1980s, Mold identifies the publication of the *Patient's Charter* – a consultative paper produced by the early John Major (1943-) ministry – as one example of the culmination of Thatcher's efforts to curtail the role of the state in healthcare by replacing 'technocratic approach[es] to health service delivery' with 'business methods and market mechanisms', while recasting the patient's role as a decidedly consumerist one.[420] This document firmly laid out the 'rights' of patients within the healthcare system, attempting to enforce a top-

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[419] David Harvey, *A Brief History of Neoliberalism* (Oxford: Oxford University Press, 2005), pp. 2-3.
[420] Mold, 'Making the Patient-Consumer', p. 506; Department of Health, *Patient's Charter* (London: HMSO, 1991).

down restructuring of NHS that would replace its traditionally paternalistic culture with a new model based – ostensibly at least – on ideas of individual agency and choice.[421]

In 1989, the Berlin Wall was torn down. Signalling the beginning of the end of the Cold War, this event allowed for the reunification of multitudes of German families and preceded the gradual fading of contemporary fears of nuclear annihilation. The collapse of the Warsaw Pact and the Soviet Union itself over the following years, however, appeared to theorists like Francis Fukuyama to represent the ultimate, final triumph of liberal democracy – that is, of capitalism. Following the effective fall of communism as a global force, Fukuyama argued that the great majority of human civilisation had entered 'the end of history, [where] there are no serious ideological competitors left to liberal democracy.'[422] While he never said as much, this argument can easily – and was – read as an effective manifesto for the ascendancy of aggressively individualist *laissez-faire* free-market capitalism. Neoliberalism, as such a political orientation came to be known, no longer had any mainstream opposition amongst the political classes nor significant international barriers to limit its influence. The victory of Labour under Tony Blair (1953-) in the 1997 British General Election seemed to confirm Fukuyama's thesis. The once radical party founded by Keir Hardie (1856-1915) had, rebranded as New Labour, remodelled itself as a 'third way' organisation, abandoning its Clause IV commitment to nationalisation and embracing a policy of social democracy that posed no meaningful challenge to – and in practice reinforced – the market-oriented consensus. Blair's government remained enthusiastic

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[421] *Ibid*, p. 510.

[422] The Islamic world, he argued, was the only exception to this trend; Francis Fukuyama, *The End of History and the Last Man* (London: Penguin, 1992), p. 211.

about privatisation and while the NHS remained publicly owned, health policy during this period continued to reflect the political values of individualist consumerism.[423]

One example of the enduring 'neoliberalisation' of British health policy was the EPP, which was also instructive in demonstrating the hollowness of the project's rhetoric. This programme evolved out of the recognition that the growing incidence of chronic non-communicable disease required new health strategies, and the government's creation of a task force to investigate potential new policy directions to this end in 1999. When this group published its conclusions in 2001, one of its central proposals was the enlistment of patients themselves into the maintenance of their own conditions:

> [Those] with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.[424]

From 2002, the government began to implement the recommendations of the task force, gradually evaluating programmes and systematising the concept throughout the NHS with a goal of providing 100,000 places on EPP courses by 2012.[425] While ostensibly promising to

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[423] New Labour's health policy has – unsurprisingly – been the subject of much literature in and of itself. For one excellent history see Rudolf Klein, *The New Politics of the NHS: from Creation to Reinvention*, 6th ed (Oxford: Radcliffe, 2010). Unsurprisingly, the subject has also produced considerable amounts of more pointedly polemical – though no less necessary – work, such as John Lister, *The NHS after 60: For Patients or Profits?* (London: Middlesex University Press, 2008).

[424] Department of Health, *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century* (London: HMSO, 2001), p.5.

[425] Sara M. Glasgow, 'The Politics of Self-Craft: Expert Patients and the Public Health Management of Chronic Disease', *SAGE Open* 2 (2012), p. 5.

restore a degree of dignity to the patient by investing them with the skill and confidence to manage their own health effectively – captured succinctly by the tagline ‘Moving from patient to person’ – the initiative was not only a technocratic development, but at its heart the product of a pervasively neoliberal ideological orthodoxy. Patricia Wilson argued that the EPP represented ‘a move away from the objectifying of patients, to the subjectification of patients where they are looked at holistically by practitioners’, and there is certainly evidence that the programme did empower individuals to speak to medical practitioners on more equal terms.[426] One GP remarked, for example, that instead of asking ‘What should I do?’, his patients had instead started to ask ‘Do you think this will work?’[427] Nevertheless, as Sara Glasgow has argued, the neoliberal ethos central to the EPP implied an element of contractualism:

> Participants in this regard are brought to view and manage their lifestyle in such a way as to mimic the relations between agents in a market environment—the fulfillment of obligation for the generative end; in this case, not of wealth but rather of health and well-being.[428]

The message here is that, by implicitly ‘signing a contract’, the patient enters into an agreement in which acquiescence to the ideological foundation of the medical profession is integral. The patient may have been ‘subjectivised’ but this was *entirely conditional*. *Value*, in the context of the EPP, remained health *in the biomedical sense of the term*. Those who acted against this end could continue to be dismissed as ‘non-compliant’. In fact, it seems likely that this implicit message has, on occasion, become distinctly *explicit*. While far from a definitive piece of evidence in itself, one recent informal poll on social media ended with

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[426] Patricia M. Wilson, ‘A policy analysis of the Expert Patient in the United Kingdom: Self-care as an expression of pastoral power?’, *Health and Social Care in the Community* 9 (2001), pp. 138-139.
[427] Nicola Jones, ‘How are expert patients different?’, *EPP Update* 8 (2003), p. 3.
[428] Glasgow, ‘The Politics of Self-Craft’, p. 6.

39.8% of its 88 respondents declaring that they had been required to sign a 'patient contract' in order to access an NHS-provided insulin infusion pump.[429]

The EPP, understood in this sense, was an attempt to enforce an *active unfreedom* dressed up – in typical neoliberal fashion – in the language of liberty, individualism, and autonomy. This can be seen clearly in the response of some HCPs to the new programme. In one *BMJ* editorial tellingly named ''Expert Patient' – dream or nightmare?', Joanne Shaw and Mary Baker make explicit the scale of opposition to the term within the profession:

> We know from reading the press and listening to the debate that when doctors come across the term 'expert patient' they hear different things. For the chief medical officer, expert patients are 'people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases.' The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed.
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> A survey by the pharmaceutical industry body reported that only 21% of doctors were in favour of the government's proposals on the expert patient; 58% predicted an increase in the workload of general practitioners; 42% believed it would increase NHS costs; and only 12% thought it would improve relationships between doctors and patients. A more recent MORI survey of health professionals found that 3% of doctors think that in the long run better informed patients will require more of

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[429] @Dr_DianeJohnson, ('Diane Johnson, PhD'), 'If you are a UK pump user, were you told that you had to sign a patient contract before it could be issued to you?', *Twitter*, 3 January 2020, https://twitter.com/Dr_DianeJohnson/status/1212908001809571840.

> their time – a rather higher proportion than nurses (48%) but less than pharmacists (76%). For these anxious and overworked medics, the expert patient is the demanding patient, the unreasonable patient, the time consuming patient, or the patient who knows it all. And who in their right minds would want one of those in the consulting room on a Monday morning, with 10 other, more deserving people waiting patiently to be seen?[430]

To many HCPs, the EPP not only had the potential to increase their – admittedly already heavy – workload, but also represented an *ideological threat* to their status as arbiters of value in medicine, hence this article's references to 'deserving' patients 'waiting patiently to be seen' and the implied horror of a layperson suggesting a treatment 'the doctor has never heard of'. Shaw and Baker, for their part, are at pains to resolve this anxiety in a way that both preserves the relevance (and pride) of the professional while acknowledging the importance of lay expertise, but their conclusion only emphasises the apparent jealousy with which many HCPs appeared to guard their positions: 'Long live expert patients – but, in the interests of doctor-patient relations, let us find something else to call them.'[431] Even the notion that patients could be 'experts' was, to some, intolerable.

Shaw and Baker do, however, make an important point that touches on the ideological difficulties inherent to British healthcare:

> As highly educated professionals in well paid employment, doctors are not necessarily best placed to understand the realities of life for many of their patients, particularly those living with debilitating medical conditions, who are disproportionately non-working, old, and poor. In the surgery the expertise of

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[430] Joanne Shaw and Mary Baker, ''Expert patient' – dream or nightmare?', *BMJ* 328 [7442] (2004), p. 723.
[431] *Ibid*, p. 724.

> disadvantaged people who do not share the doctor's implicit model of the disease is therefore at the highest premium, rather than that of the so called expert patient.
>
> Doctors need to act on what they already know – that all patients are experts, however uninformed or misinformed they may be about health issues. Patients' expertise is valuable because by understanding the patient's views and situation, the doctor is better equipped to identify a solution that will lead to a successful outcome, however defined.[432]

Here, they clearly acknowledge the fact that doctors and their patients may have divergent 'models' of disease – that is, that their values related to health and the definition of 'success' in therapy may not necessarily align. In this sense, they critiqued not only the traditional paternalism of the profession but also the *active unfreedom* of many pro-EPP authors. The EPP aimed to apply to all individuals living with chronic medical conditions – asthma, arthritis, multiple sclerosis, and even mental health issues like depression. Concepts of value in healthcare may of course influence day-to-day management in all of these, but in the case of T1D this is particularly visible.

Those on insulin therapy do not make a simple, isolated decision to take medication or not, knowing that their choice will have particular consequences, but must instead engage in a *constant process of value judgement*. Catastrophically dangerous acute complications such as DKA and life-threatening hypoglycaemia are relatively rare, and so each individual in practice, even beyond genuine disagreements with HCPs on 'what works', must balance – or choose not to balance – the demands of the biomedical model (strict control of blood glucose to, perhaps, avert the threat of potential though uncertain long-term

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[432] *Ibid*, p. 724.

complications) with life considerations that could threaten control and make those complications statistically more likely: smoking tobacco, drinking alcohol, eating carbohydrate-laden junk food, forgoing exercise in favour of watching television. While these decisions are made by every living individual, in the context of T1D they are invested with an exaggerated *moral content* that amplifies their significance – life itself is medicalised and, in becoming so, is subject to the claims to authority of the medical profession.

Part 6: The Perfect Neoliberal Condition and the Paradox of 'Intensification'

DAFNE emerged as part of a milieu of EPP initiatives – the 2001 Department of Health report directly references it as 'a patient education model which involves a structured training programme in intensive insulin therapy and self-management... with minimal support from health care professionals.'[433] However, like the EPP more broadly, the neoliberal language of freedom and choice obfuscated a contractual, and therefore implicitly moralistic, logic. Those who benefited from DAFNE – which was, unusually for EPP courses, run by professionals – were provided with the information and tools to radically alter their diet and lifestyles in an unprecedented manner, but were still subject to a subtle form of the *active unfreedom* that characterised earlier 'semi-intensified' and self-adjusted 'conventional' therapies. Utilising the provided education to maximise their health *according to the medical model* continued to be invested with moral value. While the language was different, DAFNE was translated unchanged from a decades-old German teaching programme and so, consequently, reflected the culture of its origin in *ethos* if not in *rhetoric*.

By 1987, the Düsseldorf team had acknowledged that the utilisation of their programme could lead to the liberalisation of lifestyle by patients properly educated in carbohydrate metabolism, the pharmacological behaviour of insulin, and the potentially complicating factors of exercise, fat, stress, etc:

> Under the condition that insulin treatment is intensified, patients may liberalise their diet. This includes variation of amount and timing of carbohydrate intake, skipping of meals altogether and a prudent consumption of sucrose and sucrose containing nutrients... The more liberalised the diet becomes, the more frequent

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[433] Department of Health, *The Expert Patient*, p. 28.

> measurements of blood glucose and the more frequent injections of regular insulin and immediate adaptations of insulin dosage will be necessary to keep glycaemia in optimal control.[434]

Despite this, it must be emphasised that the liberalisation of lifestyle *was not* – as suggested by Berger's continued use of words like 'compliance' – the original goal. The objectives of the Düsseldorf model were as rooted in biomedical ideology as any other approach, with a focus on – in order of importance: '1) optimal metabolic control 2) prevention of both acute and chronic complications 3) a high quality of life, at 4) an acceptable cost'.[435] De facto patient autonomy was an unintended – and perhaps initially unwelcome – side effect in an otherwise still relatively paternalistic environment. While DAFNE in the UK was cleverly marketed in the neoliberal language of New Labour, those responsible for setting it up continued to view its value through the lens of orthodox medical ideology. Amiel, for her part, believes that the literature surrounding it overplayed the 'freedom' angle:

> If you overemphasise the freedom aspect, you don't get the good results... I think the flexibility is key, provided it can be done in the context of good diabetes control... I personally believe that it is my job as a health care professional to help my patients get the best diabetes outcomes they can get. And I'm afraid that means good glycaemic control. I would never define good glycaemic control in terms of HbA1c without talking about minimal hypoglycaemia, or indeed minimal weight gain, because those are important health goals. I also would add to it good quality of life, but I still think it is the aim of a diabetes service to get the medicine right

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[434] Mühlhauser, Bruckner, Berger, Cheța, Jörgens, Ionescu-Tîrgoviște, Scholz, and Mincu, 'Evaluation of an intensified insulin treatment and teaching programme as routine management of Type 1 (insulin-dependent) diabetes', p. 682.

[435] Berger, 'Evaluation of a Teaching and Treatment Programme for Type 1 Diabetic Patients', p. 36.

> because we are doctors... I would not wish to divorce the flexibility from part of the package, but I would not put it above getting a good medical outcome because I'm a medical service.[436]

While Amiel is clearly – like Berger before her – glad that those with T1D were able, when employing the principles taught by DAFNE, to live a more flexible lifestyle than their predecessors had (officially) enjoyed, she – again like Berger – remains fundamentally committed to the biomedical project and does not expand the concept of health to allow for individual interpretation at the level of patient *value*. Nevertheless, she understood that DAFNE represented a major shift in strategy. As we have seen, the importance of those with T1D becoming 'educated' about their condition had been emphasised by HCPs from before the discovery of insulin, and later they had been enlisted as active participants encouraged to make (extremely careful and minor) adjustments to dosages where clear patterns of high or low blood glucose could be identified. DAFNE, however, was the first time in Britain that significant patient engagement had been combined with the often complex, day-by-day alterations vital to truly 'intensified' – as opposed to 'semi-intensified' – therapy. Unlike previous attempts at 'intensification' such as that utilised by the DCCT, DAFNE effectively solved the major barrier to mass 'intensification'. In a manner doubtless met with enthusiastic approval by the architects of neoliberalism, the dramatically increased resource cost involved in closely managing such complex calculations for each individual patient could essentially be *outsourced to the patient themselves*.

Amiel's language when describing this process is instructive here:

> I mean, I think now because of the way society has changed, we've moved a long way from the paternalistic attitudes of yesteryear. And I think the diabetologists

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[436] Amiel, Interview.

> got there way before anyone else because of things like DAFNE, because we made a decision that we weren't the people taking the insulin and therefore we weren't the people who needed to know about it, so we made the decision to give our knowledge- to share our knowledge with our patients and put ourselves into what I would consider a support role.[437]

DAFNE, to Amiel, represented a move away from paternalism, achieved via the reconceptualisation of the professional into a more hands-off role as a remote source of occasional support and advice rather than a figure to be consulted on every decision. However, she also talks of 'giving' – which she quickly corrects to 'sharing' – the knowledge of the profession. This is important, because it demonstrates an implicit rejection of patient-created knowledge and therefore suggests an aspect of DAFNE that was as ideological as its predecessors – expressed in the imposition of a 'correct' framework of care aimed at the normalisation of blood glucose over secondary factors. Despite the rhetoric, the *value* of the profession remained paramount, and those who rejected that could still be marginalised.

The statement that '[diabetologists] moved a long way from the paternalistic attitudes of yesteryear... way before anyone else [in the medical profession] because of things like DAFNE' seems quite surprising. Made in the context of an interview conducted in 2019, this appears to invoke a strange form of frustrated presentism, suggesting that – for reasons grounded, ironically, in the medical model – DAFNE adopted a patient-centric approach that would come to be considered 'progressive' *according to the neoliberal context*, and would do so ahead of colleagues in other fields. However, notwithstanding the historically problematic implications of such a determinist position, this reading sits uncomfortably

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[437] *Ibid*.

with Amiel’s largely traditionalist approach to the role of the medical profession in society. The sense of tension here is understandable: to her, the theory behind DAFNE acknowledged that control must pass to the layperson, but considered this appropriate because it allowed for more effective treatment *according to the medical model*. While she certainly never considered improvements to quality of life to be irrelevant, that the system became known *primarily* for such lifestyle implications as opposed to for its strictly medical benefits appears, in Amiel’s reading, to have undermined, or at least diluted, the original point in order to serve the ideological ends of an ascendant neoliberal orthodoxy with which she was not entirely comfortable.

It is true that the rhetoric of DAFNE emphasised the development of adequate education to allow for the consistent performance of the kind of complex, day-to-day calculations required by ‘intensified’ therapy, and to therefore ensure self-sufficiency. In doing so, it – consciously or unconsciously – invoked the neoliberal symbol of the ‘rational consumer’ in the context of health, implicitly suggesting that with the correct (explicitly intellectual and implicitly ideological) training those with T1D would naturally engage in therapeutic decision-making beneficial to their long-term biological health. Of course, as we have seen, almost all diabetologists understood that their patients had complex lives and priorities, and regularly acted – for a multitude of reasons – in ways that did not do this. How then can we understand the sudden willingness to step back from direct care and take on a support role, trusting that PWD would make the ‘correct’ decisions in the absence of direct paternalistic coercion? DAFNE could attempt to instil the ideological values of the clinic into the patient-body, but developments in management strategies had severely limited the ability of professionals to *enforce* their demands.

This can be understood as a bold, but ultimately misfired, ideological manoeuvre. Physicians well understood that their patients would not always act according to the demands of the medical model, and would regularly engage in what some might have called ‘non-compliance’. After 1993 it was conclusively proven that ‘conventional’ approaches to care were not clinically acceptable, while truly ‘intensified’ therapy was impractical on any large scale – hence the tentative move towards ‘semi-intensification’ and a consequent socio-cultural transmutation within insulin therapy following the necessary prescription of shorter-acting formulations of insulin along with blood glucose monitoring equipment. The resurrection of the patient as Trostle’s ‘responsible subject’ – perfectly encapsulated by Weston – made it clear that the paternalistic, Parsonian tradition was insufficient to engage with an increasingly assertive patient-body that simply did not require professional approval before deciding upon the ‘correct’ approach to management, and could unilaterally determine strategy based on personal value.

DAFNE provided a solution to this by lending official legitimacy to radical self-adjustment (of the kind many of those with T1D had been doing anyway). By utilising the contemporary language of neoliberalism in concert with Berger’s education programme, DAFNE solved the cost and labour issues associated with ‘intensified’ therapy and allowed its mass adoption, resolving the contradictory practice of a profession continuing to prescribe sub-optimal ‘conventional’ or ‘semi-intensified’ regimens while claiming to be objective arbiters of proper treatment. In doing so, however, it directly *privatised* health in the abstract sense. Responsibility for treatment – and implicitly its results – was now squarely on the shoulders of the individual: now tasked with performing almost all of the labour associated with management. By reconceptualising themselves as remote sources of support divorced from the responsibility of making day-to-day decisions, diabetologists deftly preserved their relevance in a transformed, though no less important, technocratic role that shielded them from culpability should an individual patient’s value judgements – which they were of course still encouraged to make according the medical model – lead them to develop complications.

The potential shortcomings of DAFNE – and more generally the EPP – were not lost on contemporaries. Tattersall himself approached the development with a healthy scepticism, suggesting that ‘Some people... want to take control of their lives, while others find it more comfortable to be ‘mothered’ by HCPs.’[438] While he uses characteristically irreverent language, Tattersall’s concerns here are understandable. For those unable or unwilling to accept their new ‘empowered’ role, ‘intensive’ therapy offered little and risked much.

This also demonstrates the hollow cynicism at the heart of the neoliberal project as it relates to health: the language of freedom and autonomy is habitually utilised to obfuscate, and occasionally propagate, the very opposite. Neoliberal economics, for example, do not reflect freedom for people, but rather freedom for capital. Similarly, within the boundaries of T1D management the language of freedom does not, as we have seen, suggest genuine *freedom of value*, but supposes a contractual understanding of the consultative relationship that de facto invokes traditional paternalistic concepts to morally coerce acquiescence to the dominant ideology while officially declaring that paternalism a thing of the past. For example, one guidebook from 2002, John Day’s *Living with Diabetes*, succinctly encapsulates this new framework. Providing extremely in-depth instructions on how to adjust dosage while advocating the adoption of the DAFNE principle, it makes clear that self-reliance has now become an *expected* part of management:

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[438] Robert Tattersall, ‘The expert patient: a new approach to chronic disease management for the twenty-first century’, *Clinical Medicine* 2 (2002), p. 229.

> Many people are concerned about making changes in their treatment on their own. You may feel that it is up to your doctor or nurse specialist to tell you when to make changes. This is especially likely in the early stages of your treatment.
>
> However, your lifestyle will never be quite the same as anybody else's. Although the professionals can and will give you general advice, you will need to learn to make adjustments yourself.[439]

The language used by Day is nonetheless in many cases little changed from earlier publications in terms of his commitment to the medical model. A chapter titled 'What Can Go Wrong?' looks at various long- and short-term complications, explaining the proper responses to such events with regular uses of capitalisation and red text to highlight particularly important passages.[440] While many of these pieces of advice are very valid – such as to stop driving or operating heavy machinery on the onset of hypoglycaemia – they often also involve a value judgement. Most tellingly, he ends the chapter with a stark paragraph in red text titled 'A word of warning':

> Although the aim is to prevent hypoglycaemia, you must not achieve this by running a constantly high blood glucose. A high blood glucose may ensure against hypoglycaemia reactions, but over a prolonged period it will cause serious and permanent damage.[441]

The use of the word 'must' here is important, as is its prominent place on the page and the very deliberate use of the word 'will' in relation to statistically *possible* (or even *probable*) long-term complications. There is a certain anxiety here – a sense that Day knows that he

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[439] John L. Day, *Living with Diabetes: The Diabetes UK Guide for those Treated with Insulin*, 2nd ed (Chichester: Wiley, 2002), p. 81.

[440] *Ibid*, pp. 109-124.

[441] *Ibid*, p. 124.

must accept lay-control of therapy but is doing so with great reluctance. To mitigate this, he seeks to exert strict control over the *framework* of management – something that is effectively relayed by his use of an illustration in which a winding path snakes around various hazard signs towards an implicitly bright future (see Figure 4.2). Tattersall's, perhaps unintentionally, highlights the problem here:

> A much bigger stumbling block is that many doctors and other healthcare professionals feel uncomfortable with the idea of empowering their patients... many diabetologists pay lip service to the concepts of self management and patient autonomy, and behave like tinpot Caesars in their clinics.[442]

Figure 4.2: Illustration from John L. Day, *Living with Diabetes: The Diabetes UK Guide for those Treated with Insulin*, 2nd ed (Chichester: Wiley, 2002), p. 123.

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[442] Tattersall, 'The expert patient', p. 229.

It would be wrong to suggest that this reflects the attitudes of all professionals, but that some physicians were uncomfortable with developments while others spoke the language of autonomy while in practice maintaining – perhaps more subtly – their traditional authoritarianism is telling.[443] It is worth reiterating here that at the ideological level very few professionals were actively aware of their own role in this process – neoliberalisation was as painful for many professionals as it was for anyone. The subconsciously reproductive aspects of medical ideology had, however, formed a tenuous alliance with the state actors of post-Thatcherite Britain.

The EPP, and DAFNE, represent the culmination of what Gilles Deleuze understood as the transition from Foucaultian 'societies of discipline' to more insidious 'societies of control' – that is, the process we now understand as the ideological triumph of neoliberalism at 'the end of history'. In the context of medicine, 'in the crisis of the hospital as environment of enclosure [in the Foucaultian tradition], neighbourhood clinics, hospices, and day care could at first express new freedom, but they could participate as well in mechanisms of control that are equal to the harshest of confinements.'[444] Deleuze goes on to directly reference EPP-style reforms underway within global healthcare policy: 'For the *hospital system*: the new medicine 'without doctor or patient' that singles out potential sick people and subjects at risk, which in no way attests to individuation – as they say – but substitutes for the individual or numerical body the code of a 'dividual' material to be controlled.'[445] In short, the EPP did not – despite its rhetoric – privilege the individual, but rather atomised it within a culture of contractualism based on marketplace logic – or, as Deleuze himself puts

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[443] Shaw and Baker made a point of acknowledging that some physicians might feel that the EPP represented a growing belief that they were professionally 'redundant or replaceable' via the transition to a support role – or what Klein described the move from 'church' to 'garage' model, Shaw and Baker, ''Expert patient' – dream or nightmare?', p. 724.

[444] Emphasis in original; Gilles Deleuze, 'Postscript on the Societies of Control', *October* 59 (1992), p. 4.

[445] *Ibid*, p. 7.

it: 'Man is no longer man enclosed, but man in debt.'[446] That was the fundamental premise, too, of DAFNE – those who adopted the new principle would be trained to 'properly' manage their health, but in doing so they would cease to exist – ideologically speaking – as individuals, and instead become a series of representative obligations: DAFNE, in this sense, did not challenge *active unfreedom* but rather *reified it*. As the late Rosamund Snow commented in 2016:

> [R]eal patients are supposed to be a bit gormless. I've sat on a lot of PPI [Patient and Public Involvement] groups where healthy researchers provide the structure of the meeting and offer round the biscuits, and the patients provide the naivety. These are the groups where we end up 'commenting on lay summaries' rather than having any useful input on research questions and outcomes. We're allowed to remind the researchers why they went into the job in the first place, but we're not supposed to be able to comment on methodology, even if the methodology is flawed because the researchers aren't aware of their own biases.[447]

DAFNE, the 'expert patient', and the language of autonomy resonated with the neoliberal political context of the early twenty-first century, but they also served a pragmatic ideological purpose for clinicians in the management of T1D. However, this adaptation resolved one contradiction only to open another rather unexpected one. While the widespread resurrection of the patient as *responsible subject* in the late 1980s and early 1990s drew it into sharp focus, T1D has always contained the latent potential for direct individual value-based decision-making in isolation from and in spite of the medical

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[446] *Ibid*, p. 6.

[447] Rosamund Snow, *What makes a real patient?*, 19th July 2016 <https://blogs.bmj.com/bmj/2016/07/19/rosamund-snow-what-makes-a-real-patient/> [accessed 30 October 2019].

profession’s claims to authority, as demonstrated by the numerous figures discussed throughout this work.

In the USA (among other countries), the insurance-based private health system reveals the true meaning of politically neoliberal ‘freedom’. In Britain, however, the material context of universal provision at the point of use by the NHS ensures that, while it exists, healthcare *cannot be truly neoliberalised* at the cultural level no matter the creeping influence of its language, logic, and even the increasing involvement of outsourced private companies in its operation. Insulin therapy in the UK is characterised by the provision of the materials necessary for ‘intensified’ therapy to all and, as a result, the absolute power – notwithstanding some supplementary technologies such as CGM and insulin pumps – of the individual to determine the shape of their own management strategy. In this sense, it is in some respects philosophically *the perfect neoliberal condition* while also being *entirely too neoliberal for neoliberalism* – for which the language of liberation is but a strategic gambit with deregulation and the ensuing concentration of economic power as its goal. In the context of T1D, the imposition of a Deleuzeian ‘society of control’ was all but impossible to enforce in practice. Ironically, insulin therapy became one of the only areas of health management in which neoliberal rhetoric *could* be taken at face value, and in so being undid its entire philosophical foundation by demonstrating that equal access to the necessities of care is a necessary prerequisite for true freedom.[448] T1D, as a result, exposes the ideological contradiction at the heart of an essentially hollow politics.

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[448] In the United States at the time of writing, the ‘#insulin4all’ campaign (which, despite its Twitter-influenced name, is not confined to social media) has gained significant traction and is directly endorsed by numerous political figures, perhaps most notably the left-wing presidential candidate Bernie Sanders. While the overarching goal of this pressure group is to ensure the availability of affordable insulin, this regularly translates into a generalised call for universal healthcare. There is a certain poetic irony to the fact that the ‘perfect neoliberal condition’ has given rise to an essentially redistributive movement.

Beginning with a discussion of DAFNE as it was formally introduced to the landscape of UK T1D management in 2002, this chapter has argued that the initiative represented a genuinely novel innovation on an unprecedented scale. Derived almost entirely from an education programme that had been running in Germany from the late 1970s, it fundamentally turned the traditional approach to insulin therapy on its head. Laypeople, rather than clinicians, were now formally encouraged, using either an insulin pump or – more often in the UK – MDI, to alter their insulin dosages on an ad hoc basis to match fluctuations in requirements produced by variations in diet and lifestyle, allowing for the almost complete eradication of any requirement for fixed mealtimes or nutritional restriction. Where the DCCT had reified professional control over therapy, this alternative framework of ‘intensification’ instead *released* those utilising it from the rigidity that had become characteristic of ‘conventional’ and ‘semi-intensive’ approaches, largely by enlisting those with T1D as a form of auxiliary healthcare worker responsible for performing much of the labour traditionally left to the HCP.

DAFNE’s enthusiastic promotion of lay-autonomy in day-to-day therapeutic decision-making based on the personal analysis of SBGM results seems at first glance to have reflected a rather unusual about-face for the mainstream British medical profession – and indeed, as we have seen, neither it nor the EPP of which it was a part escaped considerable internal criticism. While the principle had, by the millennium, been successfully utilised in parts of continental Europe for over two decades, it appears to have had almost no influence on T1D management in the UK during this period – largely because it threatened the position of the professional, and, more importantly, the entire ideological framework upon which the profession stood.

The eventual adoption of DAFNE in 2002, this chapter has argued, must be understood as an ideological adaptation geared towards breaking the impasse described at the close of Chapter 3. Continuing to exhibit an implicit – and occasionally explicit – paternalism while advocating confused 'semi-intensified' insulin regimens that nevertheless empowered those with T1D to take further control over their own treatment regardless of medical instruction, HCPs found themselves in an effectively unsustainable position. Facing criticism from an increasingly assertive patient-body over which they struggled to impose their traditional authority while promoting an approach that had, in reality, always lacked credibility, it was clear that the profession needed to adapt to prevent its ideological contradictions exploding into crisis.

By reconceptualising the HCP as a less authoritarian figure responsible for providing general advice and screening for signs of long-term sequelae while rendering the individual layperson *officially* the final decision-making authority in management, DAFNE – and more broadly the EPP, of which it was a flagship part – provided a solution that neatly fell in with the individualist, privatising impulse of New Labour. Handing effective control over management to laypeople in this way provided an effective strategy by which 'intensive' therapy could be rolled out widely without significant additional investment, while simultaneously maintaining the position of the HCP and fulfilling lay-demands for autonomy. Despite some vocal critics from within the profession arguing that 'patient-led' care represented a dangerous experiment, DAFNE appears to have provided a successful resolution to the deadlock that had characterised British diabetology throughout the 1990s.

Like all historic interventions in T1D, DAFNE only transmuted the experience of T1D. Consequently, the post-2002 landscape of management has brought with it a host of new challenges (and opportunities) for both HCPs and laypeople, while revealing the persistence of some old ones. The neoliberal shift within healthcare that provided fertile ground for DAFNE has, in fact, had far broader – and often more insidious – cultural and ideological implications for healthcare well beyond the realm of diabetes.

Chapter 5 – Conclusions, Implications, and Avenues for Further Research

‘There is only one certainty: in the end, you die.’

Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice* (Abingdon: Routledge, 2008), p. 31.

Part 1: The New Millennium

Moves towards 'patient-centred' medicine were, as we have seen, often direct expressions of the neoliberal turn within British healthcare. Passing responsibility for care onto the individual while reconceptualising the professional as a remote source of technical support ostensibly represented a shift away from paternalism and towards the privileging of individual value, and as such the empowerment of laypeople. As discussed in Chapter 4, however, this was a largely illusory development that, if anything, succeeded only in transferring responsibility for health to the individual while failing in any meaningful way to redefine the concept.

It is certainly true that DAFNE-style 'intensified' approaches to insulin therapy *did* – via the necessary prescription of more flexible insulin preparations and blood monitoring equipment able to quickly provide accurate data on current glycaemic levels – allow those undergoing it to tailor treatment to their own practical and subjective requirements in a more nuanced manner than had been possible via the manipulation of diet and lifestyle alone, and, as a result, to engage with their condition according to their own values and health beliefs to an extent that is simply not possible in the context of many other chronic health conditions.[449] Nevertheless, neoliberalism in T1D has been anything but an uncontested success story. Indeed, the increased control held by patients over insulin therapy has often placed them at odds with HCPs while their experience has highlighted the inadequacy, hollowness, and often cynicism of neoliberal approaches to health more broadly. 'Intensively' managed T1D has, in many respects, become a battleground upon

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[449] The results of SBGM in the context of patient-led 'intensified' therapy has considerably more *utility* to the individual than in 'conventional' approaches, and often allows for significantly more effective day-to-day refinements to management than had possible under such earlier systems (see Chapter 2).

which philosophical questions about health, responsibility, and autonomy have played – and continue to play – out.

This concluding chapter will consider insulin therapy and medicine more broadly in post-DAFNE/EPP Britain. In order to do so, it will first engage with the ethnographer and philosopher Annemarie Mol’s powerful, diabetes-centric critique of neoliberal healthcare *The Logic of Care: Health and the Problem of Patient Choice*, before considering ongoing issues and debates surrounding T1D. Using evidence from social media to highlight the ongoing conflicts between PWD and HCPs, it will consider the continuing influence of ‘medical model’ ideology amongst professionals and the impact of this on care. Finally, it will synthesise the preceding discussion to sketch a hypothetical framework with the potential to resolve the palpable anxiety still present at the heart of medicine where it engages with concepts of chronic health.

Part 2: The Logic of Care

In 2008's *The Logic of Care*, Mol makes a strong case against the neoliberalisation of healthcare and the widespread reconceptualisation of the patient as a rational consumer according to market principles. This 'logic of choice', she argues, has, in attempting to 'foster 'patient choice' erode[d] existing practices that were established to ensure 'good care'.'[450] More desirable, Mol suggests, would be to approach health and medicine according to a 'logic of care' that 'starts out from the fleshiness and frailty of life.'[451] To highlight the difference, Mol provides a few personal anecdotes, of which the following is perhaps the most descriptive:

> It is still the early 1990s. I am pregnant and 36. A national committee of experts in the Netherlands where I live has looked at the statistics and suggested that pregnant women over 25 should have an amniocentesis and thus the option of abortion should their foetus have Down's Syndrome... I take a day off and go to the hospital where I also happen to be doing the field work for the book I am working on at the time. It is slightly strange to shift from the role of observer to that of patient. But I lie down on the examination table and feel the ultrasound probe moving over my belly. Still in my field-work habits, or just to break the silence, I say to the nurse who is preparing the long needle that will be inserted into my womb: "I hope it all goes okay." We both know that a small percentage of women have a spontaneous abortion as a result of the procedure. The nurse snaps back: "Well, it is your own choice."

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[450] Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice* (Abingdon: Routledge, 2008), p. 1.

[451] *Ibid*, p. 13.

> Back home I dutifully sit down on the couch, legs up, to reduce the chance of the threatened spontaneous abortion. But I also start to make notes for what turns out to be field work after all, albeit for some future book. I wonder what the nurse might have said that would have fitted a logic of care. “Let’s indeed hope it all goes well”, or “Most of the time there’s no problem”, or “Are you worried about it?” She might have touched me in a kind way. And she might even have used the moment to encourage me to behave and say: “You may want to have a quiet afternoon, then.” But instead she illustrates beautifully how mobilising the logic of choice can lead to poor care. It can shift the weight of everything that goes wrong onto the shoulders of the patient-chooser.[452]

Mol believes that by recasting the patient as a ‘customer’ or ‘consumer’, the relationship between them and the HCP dealing with them is undermined by – recalling Glasgow – its codification into an unfeeling contractual form bereft of any human compassion or kindness. In this context of individualisation, the professional – paradoxically – no longer *cares* about the individual, but performs the service requested, or, in the abstract sense, ‘purchased’. While nobody expects the artificial friendliness of, for example, the retail or hospitality employee to reflect genuine emotional investment, Mol suggests that within healthcare that investment is an *integral element* of treatment, without which the professional *cannot* be fully doing their job in its full scope. Using diabetes as a case study, she also makes the case that the ‘freedom to go where the birds go’ promised by the advertising for one blood glucose monitor – three young, healthy, and happy individuals hiking through remote, forested mountains feature prominently – demonstrates a cynical lie: that by obtaining the right equipment genuine freedom to forget the condition lies

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[452] *Ibid*, pp. xi-xii.

within reach.[453] To the contrary, Mol argues, diabetes *can never be forgotten* and real freedom is, consequently, *forever out of reach* – the additional burdens on life must be acknowledged and managed.[454]

Mol's criticisms of neoliberal healthcare are valid and convincingly argued, however her manifesto for a new framework has several problems. To Mol, this new way – healthcare according to a 'logic of care' – would, in contrast to the neoliberal approach, be characterised by sympathy, honesty, and – unsurprisingly – *care* for the individual, with the physician maintaining an actively *moral* role: there not only to facilitate the choices of the individual but also to encourage them to make the *correct choices*:

> Chronic disease makes life even more difficult than it already is. The logic of care is attuned to that difficulty and concludes from it that patients deserve support (advice, encouragement, consolation). However, offering support is not the same thing as doing what patients want. It does not mean going along with them. While the market fuels the desires that it mobilises (such as the desire for freedom), care seeks moderation. Balance is the magic word. "You don't really want an early death, do you? Or to go blind?" says a doctor severely to a woman who is taking good care of her children, her husband, her job, and her ideals, but not of her blood sugar levels. In this somewhat rough way he tries to make her realise how important it is for her to take better care of herself.[455]

This is a very important passage. Within Mol's 'logic of care' the idealised professional has an *obligation* to ensure as best as possible that the individual for whom they are responsible 'looks after themselves'. To her, there are a variety of reasons why a person

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[453] *Ibid*, p. 27.
[454] *Ibid*, p. 27.
[455] *Ibid*, p. 29.

may not be doing so – one of which is the simple fact that they *do not know what they really want*:

> [In] care practices our minds are called upon, not our desires. But this does not lead to rationalism. Our desires may not be rational, but, or so the logic of care has it, neither are our minds. Instead, they are full of gaps, contradictions and obsessions. Caring professionals therefore seek to cultivate our minds. They convey insights, ask probing questions, or try to reassure us. And in doing so, they try not just to reflect back what we thought already. In the hope of making us more balanced, they give counterbalance.[456]

Mol is here effectively describing one of the four models of the physician-patient relationship outlined by Ezekiel J. Emanuel and Linda L. Emanuel in 1992.[457] Pre-empting *The Logic of Care*, Emanuel and Emanuel's 'deliberative' model of the healthcare relationship was characterised by the casting of the professional as a 'teacher or friend, engaging the patient in dialogue on what course of action would be best. Not only does the physician indicate what the patient could do, but, knowing the patient and wishing what is best, the physician indicates what the patient should do, what decision regarding medical therapy would be admirable.'[458] Superficially, there appears to be little to criticise in this approach to healthcare. However, while the authors envisaged a model in which 'the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness, and their implications for treatment', this relies entirely on the good faith, genuine empathy,

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[456] *Ibid*, p. 29.

[457] Mol may not be familiar with the work, as it is not referenced in *The Logic of* Care.

[458] The 'deliberative' model was contrasted with the 'paternalistic' model (the traditional Parsonian arrangement), the 'informative' model (essentially characterised by the neoliberal framework – Mol's 'logic of choice'), and the 'interpretive model' (to which we shall return); Ezekiel J. Emanuel and Linda L. Emanuel, 'Four Models of the Physician-Patient Relationship', *Journal of the American Medical Association* 267 (1992), p. 2222.

and self-discipline of the professional, who must advise while avoiding unwarranted ideological coercion.[459]

Similarly, Mol also maintains a perhaps overly charitable view of the traditional Parsonian doctor, writing that:

> The logic of choice is drawn into health care with the promise that it will free patients from the patriarchal rule of professionals. But professionals are not quite feudal lords. Certainly, there are situations where professionals have a lot of power, but this tends to be due to the law. The law wants professionals to decide which people are too mad to function as citizens and thus should be locked up in a closed ward. The law states that people with a contagious disease may, under some conditions, be given medication against their will. In many countries, the law even asks doctors to sign papers that stipulate whether a person with diabetes is capable of driving a car or not. However, such combinations of state rule and medical control are relatively rare.[460]

While she is not strictly *wrong* here, this does appear to ignore the long history of often problematic paternalistic authoritarianism within medicine – the preceding chapters provide ample examples of occasions where such issues have arisen. In support of her belief in a generally benevolent medical profession, Mol later states that:

> [P]atients only rarely refuse all insulin or inject a lethal dose. This is not because they are being bossed around. Instead, most people do not want to die: they would rather live. This is why they visit health-care professionals. They are ill. And even if

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[459] *Ibid*, p. 2222.

[460] Mol, 'The Logic of Care', p. 46.

> doctors and nurses are not always as helpful as they might be, patients suffer first and foremost from their diabetes.[461]

Again, she is not *wrong* to say that (most) individuals would rather not die – the statement is so obvious as to be almost banal. However, this is entirely beside the point. Mol's assertion that those with diabetes – particularly T1D – go to the doctor because 'They are ill' is only half-right. They also go to the doctor because his or her approval is needed for an initial prescription of insulin and equipment, and potentially later to be screened for potential complications, all while perfectly 'well' despite their condition. Mol's argument that 'patients suffer first and foremost from their diabetes' skirts rather deftly around the iatrogenic nature of much diabetes-related suffering. While many PWD have plenty of overwhelmingly positive accounts of HCPs, there are countless others who do not, and – more to the point – plenty of examples of situations in which considerable harm occurred not because of therapeutic crudeness or techno-scientific limitation, but as the consequence of authoritarian ideological rigidity and an unshakeable paternalism that bordered on, and occasionally slipped into, arrogance.

This is not, of course, to suggest that the great majority of HCPs do not care deeply about the welfare of their patients, but rather to emphasise that they have historically been – and often still are – susceptible to the uncritical and unconscious propagation of ideology. While professionals do usually have the best interests of the individuals they treat at heart, what those best interests *are* is determined by, and fundamentally inseparable from, this. Given the divergent status between parties and the cultural acceptance of the physician as the 'expert', any supposedly equitable discussion between peers inevitably privileges one side. Take, for example, one of Mol's own observations:

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[461] *Ibid*, p. 46.

> [Mr Zomer has] learned to inject insulin and has adapted his eating habits. Now his physician explains to him that research has shown that tight regulation reduces his chances of developing complications. "This is something you might want to consider, Mr Zomer," she says. She adds that tight regulation would mean that he would need to measure his own blood sugar levels regularly. If he records the results and brings them along to the next consultation, then she – the physician – will prescribe a more accurate, slightly higher, dose of insulin...
>
> Alas, at the next visit, there are hardly any numbers in the notebook in which Mr Zomer was supposed to write down the results of his measurement. What is going on here? In the logic of choice, this situation suggests that maybe Mr Zomer does not really want to bother with tight regulation. Once he started to realise all the disadvantages of all the measuring required, he may have come to another conclusion. Or maybe he has changed his mind for some other reason. Either way, if he does not want to measure then so be it. It is his own choice. In the logic of care this makes little sense. A good health-care professional will not think that Mr Zomer changed his mind once he got home, but rather that measuring turned out to be too difficult to *do*.[462]

The physician here attempts – and expects – to control the provision of medication and the determination of dosage. Not only this, she unilaterally sets the *terms of 'proper' management*, determining that a failure on the part of 'Mr Zomer' to fulfil his agreed upon obligations *must* be a result of his struggling to adequately perform them. Of course, it is entirely possible that Mol's quoted professional is correct here, but the point is that she *may not be*. As Mol states explicitly, however, in her 'logic of care' this simply makes no

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[462] *Ibid*, p. 59.

sense. While working according to a superficially 'deliberative' framework, this demonstrates the way in which such an approach naturally favours the ideological lens of the professional – to the physician in question, Mr Zomer, despite being given a choice, *never really had one*. As a teacher, she knew the 'correct' answer from the beginning, and by definition any alternative *must be wrong*. The 'deliberative' model of care described by Emanuel and Emanuel and essentially restated by Mol as the 'logic of care' cannot help but collapse back into de facto paternalism because, while the final choice on how to proceed *does* – both agree – lie with the patient, this 'deliberation' does not occur between equals. The power disparity between parties ensures that the opinion of the professional carries considerably more *moral weight*, and therefore *coercive power*, than that of the layperson, while that professional maintains that their ideological position is the 'right' one, and that where it is rejected a 'wrong' choice has been made. There is only one valid value in care – that of the medical model. Mol encapsulates this succinctly:

> Things rarely go smoothly. There tend to be frictions. Doctors and patients sometimes laugh about the irreducibilities, the things that do not fit. So you had a third beer, did you? You never went to sleep that night of the party, and you lost count of how much insulin to inject and when. That is the way it goes. These things happen. But if you really no longer care, doctors will get serious again... health care meddles with every detail of our daily lives. And indeed, it tries to normalise our bodies. But it does not despise them. Care has little to do with repressing and all the more with cherishing our bodies.[463]

'Cherishing our bodies' is of course a value judgement in itself. To the individual concerned, the self-permission to have that 'third beer' – or fourth, or fifth, ad nauseum (literally) –

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[463] *Ibid*, p. 42.

before staying up all night at a party *in spite of its potential biological impact* could well represent a measured value judgement when weighed against a grimly austere reality of endless self-discipline. It is surprising that Mol does not entertain the idea that professional ideological authority over the construction of *value* in healthcare might be problematic, as she clearly does acknowledge the problems of bio-reductionism. The following passage seems somewhat at odds with the previously quoted extracts from *The Logic of Care*:

> Traditionally, health was the ultimate goal of health care. These days it rarely is. In chronic diseases health is beyond reach, and it has been replaced by the ideal of a 'good life'. But what counts as a 'good life' is neither clear nor fixed. Aiming for a long and happy life might sound nice, but it is often necessary to juggle between 'long' and 'happy'.[464]

Here Mol is (somewhat uneasily) articulating a similar principle to the concept of 'existential eudaimonia' sketched in Chapter 1. However, while she acknowledges that 'it is not always clear what to count as 'improvement'', she goes on to undermine this assertion by declaring that 'Despite these complexities, in one way or another, unstable blood sugar levels are bad. Thus, it is good care to try to figure out how to stabilise blood sugar levels.'[465] While it is likely that *many* – even *most* – individuals would agree with this analysis, it is by no means as self-evident as she claims. If unstable blood sugar levels are a likely consequence of a self-determined 'improvement' – say, to minimise diabetes-related labour while eating freely – can we really say that continued efforts at normalisation via more labour or stricter dietary control are 'good care'?

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[464] *Ibid*, p. 22.
[465] *Ibid*, p. 22.

Part 3: #WeAreNotWaiting

As previously discussed, in the context of post-DAFNE T1D, it did not particularly matter that the mainstream medical profession attempted to neoliberalise management via the imposition of a Deleuzian 'society of control', just as earlier variants of *active unfreedom* in the context of 'semi-intensified' therapies had not particularly mattered. With the resurrection of the patient as 'responsible subject' in the late 1980s and early 1990s, the latent potential for value-autonomy within the condition was realised. While it had always been *possible*, the widespread availability of SBGM technology and more refined insulins had, alongside ideological developments that reshaped the *role* of the patient into a more active participant, made such 'existential eudaimonia' an achievable prospect for those who wanted it at both the practical and psychological level. While HCPs might disagree on an approach or a therapeutic goal – and many certainly did – they had no power to actually enforce obedience despite their social weight. Mol's attempt to challenge the neoliberal consensus via a more 'deliberative' 'logic of care' sought to inject a little humanity back into the doctor-patient relationship but it – no matter its other flaws – faced the same reality: those with T1D simply did not have to listen to HCPs and could radically reshape the terms of their own management at will. This was not lost on Mol, who recognised that away from the clinic the physician was largely powerless:

> The physician who prescribes insulin... has no way of forcing [the patient] to inject this insulin once she returns home. While people can be punished for breaking the law, failing to observe medical advice only rarely leads to sanctions. It does,

> however, lead to other problems. If... [someone with T1D] does not inject the insulin prescribed... she will soon feel bad and before long she will die.[466]

What Mol misses here is that, as this thesis has shown, *medical advice is not always 'correct', even by biomedical standards* – lay-pioneers like Eastwood and Fletcher are clear evidence of that. While it is certain that failing entirely to inject prescribed insulin will lead to deterioration, the same cannot be said for its use in a fashion contrary to instruction. Perhaps such an approach will lead to more effective control of blood sugar; it absolutely has the potential to enable value-based improvements.

Thanks to social media platforms and the peer support networks that they facilitate, this process can now be seen clearly as it occurs, with individuals describing and discussing the daily value judgements made in the course of managing T1D. For example, one Twitter user posts a photograph of a very well stocked kitchen drawer full of various sweets, writing: 'I used to think this was 'low' blood sugar goals. BUT, food shouldn't be a reward, we shouldn't 'reward' our blood sugars. If we want Candy, just bolus and eat it. We have to really change the way we think about food.'[467]

Chris Aldred – better known by his online screen-name 'The Grumpy Pumper' – is a well known figure in the British diabetes online community who has consistently and forthrightly refused to give up many of the pleasures of life historically considered 'unsuitable' for those with T1D. He also regularly uses the hashtag #TalkAboutComplications to emphasise the importance of individuals acknowledging and understanding the potential impact of long-term sequelae regardless of their personal value-judgements. Having previously developed a serious and persistent foot infection,

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[466] *Ibid*, p. 46.

[467] Emphasis original in all quoted Tweets. Due to the format [sic] has been used sparingly; @T1dchick_ ('Jillian') 'I used to think this was 'low' blood sugar goals.', *Twitter*, 24 May 2019, https://twitter.com/T1dchick_/status/1131929008793411585.

Aldred found himself by September 2019 unable to continue maintaining his allotment: an activity of great importance to him. Posting a screenshot of his letter of tenancy resignation, he is clearly emotionally affected by the development: 'It's done. I'm absolutely gutted. I worked so hard to try to avoid this. #TalkAboutComplications'.[468] This demonstrates in stark terms the complexity of, and potential disappointments involved with, the constant value judgement that categorises T1D – even those who do exactly as they are advised at all times must sacrifice something. Aldred was able to live according to his own 'existential eudaimonia' for many years – and in many respects continues to do so. Indeed, choosing to give up his allotment was a great source of disappointment to him, but reflected a personal recognition that according to the ongoing, inescapable cost-benefit analysis inherent to life with T1D, maintaining it was no longer a viable option.[469]

HCPs often find it very difficult to comprehend the concept that good health (in the broad sense) might – in some cases – involve biomedical markers that appear substandard from their perspective. This is clearly on show in one Tweet, in which the user expresses frustration at the alienation of being ideologically at odds with her physicians: 'I've been underweight most of my life because I've been very sick. Looking back at old pics, I'm scrawny, but I'm yellow [jaundiced]. Now I'm at my healthiest ever, at 15lbs above the BMI 'healthy' weight window, and drs always bring the # up like it's a failure.'[470] Lay communication of this nature provides opportunities for those with T1D to provide and receive moral and emotional support as they engage with the multiple fluctuating – and

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[468] @grumpy_pumper ('The Grumpy Pumper') 'It's done.', *Twitter*, 30 September 2019, https://twitter.com/grumpy_pumper/status/1178571101435248641.

[469] This process is not always so dramatic but characterises life with the condition at every level – for example using an insulin pump might increase the risk of infection, as in this Tweet; @bad_diabetic ('Bad diabetic'), '#talkingaboutcomplications this is progression of cellulitis from a pump site despite iv antibiotics within 8 hours of it first appearing.', *Twitter*, 8 September 2019, https://twitter.com/bad_diabetic/status/1170651324284846080.

[470] @Emmerbetic ('Emmerbetic') 'So important.', *Twitter*, 28 September 2019, https://twitter.com/Emmerbetic/status/1177993929012252672.

sometimes mutually exclusive – definitions of ‘success’ in management, and the complex series of value judgements necessary to determine which to prioritise. It is very rare for any individual to achieve all of these goals.

Peer support networks – whether formal (such as those organised by Diabetes UK) or informal (such as loose Twitter-based groupings) – can also facilitate concrete material innovation, particularly in the area of insulin pumps. Milner describes how this cross-pollination in technique can work in practice, reflecting on a personal adaptation to treatment he made after discussing the technicalities with a colleague in iPAG, a pump-centric group awareness, education, and pressure group based in Scotland:

> Other people that are on pumps... [are] where the expertise is. That's where the expertise is. I mean, for instance, the reason why I am now so aggressive in chopping my basal [rate]... was because Mary Moody... who's on a 640G [pump]... it's got the low BG suspend on it, says she was surprised at how aggressive the pump was in suspending basal when she didn't think it was necessary, but in fact with a bit of tweaking it works very well and she hardly has any hypos. And I thought that that's obviously the key, is to be really, really aggressive. The difficulty is you have to keep watching it all the time because you can't set your alarms on a predictive basis.[471]

Perhaps the best example of this process of lay-value control can be found in the hashtag #WeAreNotWaiting. As the name suggests, this is utilised by individuals with T1D – often laypeople – who, dissatisfied with the management options available, attempt to alter the methodology of insulin therapy in sometimes radically experimental ways, developing not only new strategies but also engaging in a form of lay-led research and development to

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[471] Milner, Interview.

create new technologies while refining and repurposing old ones. The premise of his movement – and its ideological position – is communicated effectively in the following statement posted on Twitter: ‘Patients have – medical domain expertise, device security expertise, tech expertise. They are innovators, engineers, enablers, documentors, communicators, educators & there is an ever-growing group of grateful beneficiaries. #WeAreNotWaiting’.[472]

In a development that might provide some relief to those who, like Stanley Joel Reiser, saw medical technologies as filled with the potential to alienate and dehumanise, one of the most striking successes of #WeAreNotWaiting has been the open source development – via the unapproved exploitation of software vulnerabilities in Medtronic brand pumps – and distribution of code designed to force infusion equipment to respond reactively to the data provided by continuous glucose monitoring (CGM) technology: something that it had never previously been intended to do.[473] Essentially automating management, these algorithms drastically reduce the amount of necessary health-related labour expected of those with T1D in day-to-day life by functioning in the manner *Balance* envisioned ‘artificial pancreas’ technology eventually would in the late 1970s (see Chapter 3).[474] This often improves clinical outcomes, but more important for many is the impact it has on quality of life. One mother, for example, enthusiastically declares that ‘Today my 16-year-old daughter received her lowest A1C ever.....but so much more important than that is HOW SHE FEELS,

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[472] @T1Bionic (‘My Artificial Pancreas’), ‘Patients have – medical domain expertise, device security expertise, tech expertise.’, *Twitter*, 25 September 2019, https://twitter.com/T1Bionic/status/1176638568569044994.

[473] Stanley Joel Reiser, *Medicine and the Reign of Technology* (Cambridge: Cambridge University Press, 1978).

[474] In a development that Trostle would likely find amusing, the removal of this vulnerability in subsequent products has, as a result, prompted the emergence of a black market in supposedly obsolete models; Sarah Zhang, *People Are Clamouring to Buy Old Insulin Pumps*, 29 April 2019, <https://www.theatlantic.com/science/archive/2019/04/looping-created-insulin-pump-underground-market/588091/> [accessed 14 October 2019].

THE QUALITY OF HER LIFE AND HER LONGTERM HEALTH.'[475] Additionally, in bypassing professional control and the lengthy process of legislative approval, #WeAreNotWaiting is distinctly reminiscent of the lay-conducted research of HIV/AIDS activists during the 1980s (see Chapter 1), with involved organisations and individuals organising their own events and engaging with HCPs on their own terms.[476]

While there are numerous examples of those with T1D for whom 'looping' – as utilising hacked pumps in this way is known – has drastically improved both quality of life and glycaemic control, #WeAreNotWaiting also serves as clear evidence of the limitations of the 'expert patient' in its neoliberal interpretation. The anthropologist Samantha Gottlieb succinctly expresses the contradictions in this concept as it relates to lay-innovators in T1D management:

> Their 'super engagement', which in theory, the FDA might fantasize about in other patient populations, however, have [sic] not always been received enthusiastically by clinicians, regulatory, or commercial entities. The FDA's promises to include patients draw on existing clinical models of research and development, but they do not trouble the fundamental categories of what is possible. Perhaps it is unrealistic to expect the U.S. drug regulatory agency to restructure entirely, and, thus, the slow progress to include patients is still notable. But it is not just the anthropologist's fantasy that there are alternative worlds possible. The interventions the open source T1D communities have accomplished reveal concrete methods for patient expertise and knowledge to lead health technology.

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[475] @KateFarnsworth ('Kate Farnsworth'), 'Today my 16-year-old daughter received her lowest A1C ever.', *Twitter*, 8 October 2019, https://twitter.com/KateFarnsworth/status/1181614632940773376.

[476] Such events are often advertised via social media, for example this 'Build your own DIY artificial pancreas' workshop in London in early 2020; @Tims_Pants ('Tim S'), 'We're running a 'Build your own DIY Artificial pancreas' event in January at the #MicrosoftReactor site in London on 25th January, which makes it a no-cost event.', *Twitter*, 10 October 2019, https://twitter.com/Tims_Pants/status/1182204961087725568.

> Few disease conditions present as many decision-making moments for patients, and thus, T1D is unique; yet, this community also introduces a paradigm shift. Their enactment of 'engaged' patients illuminates how regulatory fantasies of empowered patients neglect patients' own versions of participation. The FDA imagined fantastical empowered patient is a compliant patient, rather than the patient-as-actor-creator and disrupter.[477]

As discussed previously, the neoliberal model of healthcare retains – despite its rhetoric – the traditional ideological outlook of its paternalistic forebears. Similarly, the 'deliberative' or 'care-based' model espoused by Mol and others does little to *seriously* engage with patients as – to use Gottlieb's term – 'actor-creator and disruptor' at either the practical or philosophical level. This is clear in many interactions between laypeople and professionals – many of which have been described throughout this work – where the overriding image seems to be one of people talking past one another rather than effectively communicating.

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[477] Samantha Gottlieb, *The FDA, Patient Empowerment, and the Type 1 Diabetes Communities in the Era of Digital Health*, 23 April 2019, <http://blog.castac.org/2019/04/the-fda-patient-empowerment-and-the-type-1-diabetes-communities-in-the-era-of-digital-health/> [accessed 14 October 2019]; While HCPs have begun to engage with such communities, they continue to do so in an uncertain and deeply cautious manner, for example Thomas S J Crabtree, Pratik Choudhary, Peter Hammond, Alistair Lumb, Alasdair McLay, and Emma G Wilmot, 'Health-care professional opinions of DIY artificial pancreas systems in the UK', *Lancet Diabetes and Endocrinology* 8 (2020), pp. 186-187; Emma G Wilmot and Thomas Danne, 'DIY artificial pancreas systems: the clinician perspective', *Lancet Diabetes and Endocrinology* 8 (2020), pp. 183-185.

Part 4: Insulin Analogues

The value of insulin analogues is one contested area in which this ongoing ideological misalignment can be observed clearly. This term refers to bio-engineered insulin formulations designed to act in highly specialised ways, for example by producing extremely rapid carbohydrate absorption over the course of a few hours, or conversely slow, long-term metabolism over a much longer period, to an extent that was simply not possible with traditional varieties. Now generally prescribed as default, their utilisation enables considerably finer control over 'basal-bolus' regimens. Analogues have been in use since insulin Eli Lilly's insulin lispro, or Humalog, entered the market in 1997, and subsequently a wide variety have become available.

Despite their technological innovativeness, however, analogues were not received as well as might be expected by HCPs. Decades after their introduction to management, articles continued to be published strongly questioning their value and cost-effectiveness. In 2007, F. Holleman and E. A. M. Gale's (aggressively titled) article 'Nice insulins, pity about the evidence' declared that:

> There is only one fully objective way of evaluating patient benefit and patient preference, and that is the double-blind clinical trial. It is with some despair that we observe that a few well-performed blinded comparisons would have clarified many of the issues discussed in this Editorial. In their absence, we can assume that such comparisons would, like open trials, show no evidence of improved glucose control, with perhaps some reduction in hypoglycaemia. As to whether patient-important

> outcomes would be affected, or whether patients could even tell the insulins apart, this we can only conjecture, for we have no objective means of deciding.[478]

Glycaemic control – as measured by HbA1c – is here the sole relevant category of assessment. Later in the article Holleman and Gale directly touch on the concept of subjectivised health values, but do not meaningfully engage with the concept at any length, returning quickly to a 'deliberative' position of the kind endorsed by Mol:

> Patient preference must be respected, but we should also allow for the power of suggestion. Some clinicians may consider it sufficient that their patients derive benefit, never mind why, but such benefits are impossible to evaluate in the absence of blinded comparisons. The only conclusion to be drawn at present is that prescribing behaviour has been driven by subjective preference rather than objective evidence, and that the studies needed to distinguish between the two have not been performed.[479]

This can be explained rather simply in the context of the ideological structure of contemporary medical practice, which as we have seen continues to adopt a fundamentally biomedical worldview even as it attempts to engage with concepts of subjectivity in health. As this extract makes clear, subjective preference and, implicitly, outcomes are irrelevant distractions that must be verified by supposedly objective analysis, with – predictably – an overall improvement in glycaemic control the major indicator of value.[480]

Similarly, one 2014 piece – published over half a decade later – concluded that, despite the latter being considerably more expensive, 'regular insulin is just as effective as the rapid-

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[478] F. Holleman and E. A. M. Gale, 'Nice insulins, pity about the evidence', *Diabetologia* 50 (2007), p. 1787.

[479] *Ibid*, p. 1788.

[480] To their credit, the authors, like Mol, do critically assess the neoliberal direction of contemporary healthcare; *Ibid*, pp. 1788-1989.

acting insulin analogs (lispro, aspart, glulisine). Similarly, NPH insulin is just as effective as the basal insulin analogs (glargine, detemir).'[481] However, this was based on an analysis that took into account only biomedical factors: HbA1c measurements and frequency of hypoglycaemia![482] This article discusses both T1D and T2D simultaneously, and does suggest that the former 'require basal analog insulin because they produce no endogenous insulin and need 24-h coverage.'[483] Nevertheless, this clearly shows the mainstream profession's commitment to the medical model in management at both the practical and *moral* levels. While the author is talking about T2D in this instance, the following passage is telling as to their general outlook:

> The most striking difference occurred in nocturnal hypoglycaemia; in the 43 comparisons in which it was evaluated, it was significantly decreased in 27. In the 45 comparisons in which severe hypoglycaemia was evaluated, it was significantly decreased by analog insulins in only 6. Thus, hypoglycaemia occurred less often in patients receiving analog insulins, especially overnight. However, in none of the 60 studies was a bedtime snack recommended. In our practice, we insist that patients taking insulin eat a small bedtime snack and very few experience nocturnal hypoglycaemia.[484]

By *insisting* that their patients take a bedtime snack to mitigate the risk of hypoglycaemia, the authors here implicitly assume control over their lives in a distinctly Parsonian sense. Despite the ability of analogues to allow for both decreased hypoglycaemia *and* satisfactory long-term control according to their assessment, the HCPs quoted here – in their attempt

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[481] Mayer B. Davidson, 'Insulin Analogs – Is There a Compelling Case to Use Them? No!', *Diabetes Care* 37 (2014), p. 1773.

[482] The author does make a brief reference to 'treatment satisfaction', but does not engage with the concept at any length, dismissing it on account of there being similar self-reported quality of life on an extremely limited 'eight-item questionnaire'; *Ibid*, p. 1772.

[483] *Ibid*, p. 1773.

[484] *Ibid*, p. 1772.

to ensure cost-effectiveness – see no issue with demanding lifestyle sacrifices. While insisting on a late snack seems at first glance a fairly minor issue, it actually represents a distinct, and persistent, ideological orientation.

Insulin analogues may not, to the strict adherent of the medical model, produce meaningful improvements in management according to the narrow parameters in which they are assessed. However, the experience of those *with T1D* demonstrates clearly that they are extremely valuable at the subjective level. To explain this, it is necessary to return to the rather bleak topic of T1D in the United States and the #insulin4all movement. One of the most common rebuttals to the demand that modern formulations – that is, analogues – should be made free (or at least drastically reduced in cost) is to point to the availability of what is commonly called 'Wal-Mart' insulin which can be purchased (relatively) cheaply without prescription in most states. While this seems at first glance a compelling argument, it is important to appreciate that these more accessible varieties *are not analogues*: Wal-Mart sells only 'regular' (soluble), marketed as Novolin R, alongside NPH, sold under the name Novolin N, both produced by Novo Nordisk.[485] While these more archaic formulations do *technically work*, their relative lack of refinement in action by comparisons to their analogue successors make it *much more difficult* (though not, as those like Eastwood demonstrate, impossible) to perform the kind of ad hoc adjustments central to 'intensified' approaches to management.

Even if we accept the premise that 'Wal-Mart' insulin is, 'objectively' speaking, no worse than analogue, reliance on earlier formulations has a considerable and no less meaningful subjective implication. Take, for example, Nathan Loewy, who uploaded a video to Twitter

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[485] Indiana is, at the time of writing, the one state in which these formulations are not available over the counter. While further comment here is beyond the scope of this thesis, it may be significant that this is also the home state of Eli Lilly, a direct market competitor of Novo Nordisk.

in which he describes his experience with early biosynthetic ‘human’ insulin prior to the introduction of analogues. Loewy describes having extremely unpredictable blood glucose levels to the point of developing a host of related sequelae. While it is possible that there were more factors than insulin formulation at play here – he was of course using ‘human’ insulin during a period in which ‘conventional’ or ‘semi-intensified’ management strategies predominated – this video contains an important insight. Towards the end of his statement, Loewy makes the following remark:

> If I were to switch back to the ‘human’ insulin, my quality of life would rapidly deteriorate and my chances of seeing my children graduate high school would be diminished exponentially. Stating that ‘human’ insulin is a viable option when compared to [now] traditional analogue insulin is irresponsible and just plain false. In closing I’d like to remind every politician, physician, and pharmaceutical executive that while every life matters, everyone’s quality of life matters too. We need affordable and accessible insulin of our and our doctor’s choosing for all and we cannot wait.[486]

Loewy clearly believes that ‘human’ insulin is an inferior formulation that leads to poorer clinical outcomes. Whether or not this is correct is besides the point here.[487] There is, however, a great deal of meaning invested in the phrase ‘while every life matters,

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[486] @NathanLoewy (‘Nathan Loewy - #Insulin4All’), ‘#MyInsulinStory #HumanInsulinTruths #Insulin4All’, *Twitter*, 14 October 2019, https://twitter.com/NathanLoewy/status/1183833265981005825.

[487] Holleman and Gale touch on the possibility of individuals misattributing the sources of their perceived improvement or deterioration in management: ‘The sceptics base their argument upon studies of less intensively treated patients who receive equal levels of support. Analogue enthusiasts, in contrast, tend to use more intensive regimens, and easily confound the medium with the message—the message being that well-motivated patients with good support do well, regardless of what is in the insulin syringe. Even the most enthusiastic advocate of the insulin analogues would probably agree that there is little or no benefit in switching poorly controlled patients from one insulin to another in the absence of any other intervention, and systematic reviews of the evidence point to the same conclusion.’; Holleman and Gale, ‘Nice insulins’, p. 1788.

everyone's quality of life matters too.' While Loewy may have been thinking primarily of the impact of health-related complications, this is a vitally important observation. 'Quality of life', of course, is by definition a subjective value, as has been shown by the numerous examples previously referenced. Insulin analogues, by virtue of their finely tuned action profiles – impossible to replicate using traditional formulations – would retain value to the individual with T1D even should they be proven to be *clinically* superfluous. While there are rare examples of individuals who – like Eastwood – developed personalised (and effectively proto-'intensified') management strategies according to their own needs using early formulations of insulin, analogues (along with SBGM technology) have made this much more easily attainable. It *may* be possible to attain effective *clinical* control utilising pre-analogue formulations, but it would be *very difficult* for many to fulfil their more subjective value-based requirements. Debates surrounding analogues therefore demonstrate the ongoing de facto biological reductionism inherent to 'deliberative' approaches to healthcare and in doing so expose an ongoing misalignment between doctor and patient. Holleman and Gale inadvertently summarise this effectively in their 2014 article when they write that 'When sensible people disagree, the usual reason is that they are not talking about the same thing.'[488]

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[488] *Ibid*, p. 1788.

Part 5: Ongoing issues

The ongoing ideological anxiety between some medical professionals and their patients has direct implications for the practical business of healthcare, and in many respects threatens to fundamentally alienate both parties. There is plenty of evidence of this – Shelly McNaughton remembers the frustration of taking her son to his endocrinologist for a routine appointment: 'So much shaming when we didn't hit the goal. Son now hates going to Endo and downloading his meter.'[489] Laura Marston, a figure in the #insulin4all movement, explicitly engages with the ideological chasm between her and her doctor: 'Went to my PCP [primary care physician] yesterday and had full bloodwork done. To the doctor who noted in my labs that my glucose tested at 106 [mg/dl – approximately 5.9mmol/l] was 'elevated,' go fuck yourself.'[490] A blood glucose value of this level is not, in fact, particularly high by any standard, particularly for someone with T1D, and Marston's incredulity is understandable. However, once again the important point here is more subtle. In dismissing the words of the offending doctor in such aggressive terms, Marston is directly challenging their right to determine value in treatment and, in doing so, casts herself as a distinct *moral actor* and, in many respects, an *expert in her own right*.

To give one example that perfectly distils this issue, Renza Scibilia, an Australia-based figure in the online diabetes advocacy community, uploaded to Twitter a photograph of a table – used in an Australian clinic – that lists a variety of HbA1c values and average glucose values alongside corresponding 'grades' descending from 'Outstanding A+' at the top, to 'Very Poor E' at the bottom (see figure 5.1).[491] This, she soon discovered, was not an isolated

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[489] @revshellymac ('Shelly McNaughton'), 'I remember the dreaded A1c reading at our son's Endo appt.', *Twitter*, 18 October 2019, https://twitter.com/revshellymac/status/1185235218980102144.
[490] @Kidfears99 ('Laura Marston'), 'Went to my PCP yesterday and had full bloodwork done.', *Twitter*, 18 October 2019, https://twitter.com/Kidfears99/status/1185188858822086657.
[491] @RenzaS ('Renza / Diabetogenic'), 'Okay diabetes healthcare professionals, listen up!', *Twitter*, 17 October 2019, https://twitter.com/RenzaS/status/1184677355442163714.

example. In addition to several accounts of similar experiences, one UK-based user uploaded a photograph of another almost identical document (albeit one from 2015).[492] Once again, this lists a variety of HbA1c readings alongside value-laden terminology such as 'good' and 'poor', and supplemented with pieces of advice encouraging the reader to 'improve food choices' and 'take much more care with tests'. A satisfactory result is annotated by hand with the phrase 'well done'. As Scibilia points out, 'it's like a fucking report card' (see figure 5.2).[493]

Perhaps most egregious is an appended note, stating that 'Please note if your HbA1c is >10% you will be seen in clinic in 6-8 weeks, if it is >14% you will be admitted for re-education of your diabetes management' – that is to say, 'you are expected to maintain a level of control that *we* consider adequate, if you do not, you are clearly in need of retraining.' How else can this be read than as a distillation of the whole concept of *active unfreedom*? Suffice to say, the response to this document was not kind, with various users criticising both the moralistic tone and the failure to incorporate any acknowledgement of contributing psychological, socio-economic, or cultural factors, while questioning what right HCPs had to make value-judgements about the lives of those under their care.

This ideological impasse can be seen just as easily from the other side of the proverbial fence. Cooper retweeted another lecture slide that described some of the (in her words 'appalling') reasons given by student nurses for being averse to specialising in diabetes care.[494] One declared that they 'have no patience for people who cause themselves to

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[492] @Colonelblighty ('Guardian of the Glucose'), 'Australia is not alone in this sort of thing.', *Twitter*, 17 October 2019, https://twitter.com/Colonelblighty/status/1184763278632898560; @Colonel Blighty ('Guardian of the Glucose'), 'In fairness it was from a few years ago.', *Twitter*, 18 October 2019, https://twitter.com/Colonelblighty/status/1185302753536593920.

[493] @RenzaS ('Renza / Diabetogenic'), 'It's like a fucking report card.', *Twitter*, 17 October 2019, https://twitter.com/RenzaS/status/1184763597638864897.

[494] @Anniecoops ('Anne Cooper RN FQNI'), 'This is appalling and shows the ignorance of HCPs re Diabetes', *Twitter*, 13 August 2019, https://twitter.com/Anniecoops/status/1161173396262195200.

become ill, lose limbs, and disregard their medication/diet regimen', and that they would 'become overwhelmingly frustrated working with this group of patients all day every day.' Similarly, another states that 'From what I've seen thus far, many of those who have diabetes are noncompliant and don't take care of themselves', which 'would be extremely frustrating for me.'[495] Once again, those with diabetes – and, again, there is seemingly no distinction made between T1D and T2D – are habitually 'non-compliant' with professional instruction: a fact that both students quoted agreed would be a great frustration.[496]

Similarly, one recent event organised in London by Urgo Medical – a private company specialising in wound care – was advertised with the tagline 'To scare or not to scare?' (See Figure 5.3).[497] This debate set out to determine the value of HCPs employing 'motivational interviewing' and 'scare tactics' in consultations with those living with diabetes-related foot ulcers. The response on social media from PWD – and even from some professionals – was predictably hostile, but as one commenter pointed out, that such an advertisement was published is 'absolute proof that massive ignorance in some of the medical profession is alive & kicking when it comes to treating PWD'.[498]

These examples emphasise a profession still beholden to a de facto paternalism, whether of the traditional Parsonian kind or its more subtle 'deliberative' cousin. HCPs know, supposedly, how best to maximise health according to the narrow view of the biomedical model, but also have the right to invest that model with *coercive moral value*. This is, of

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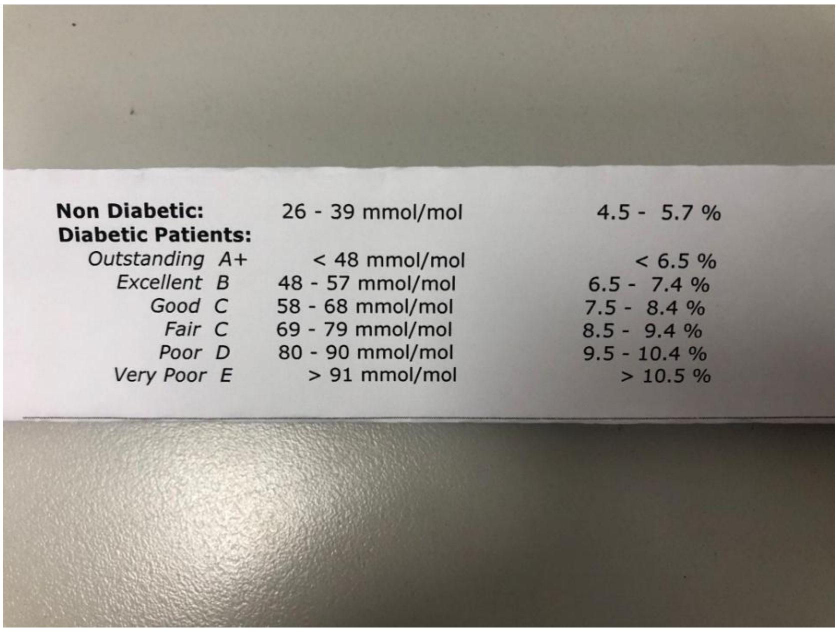
[495] The quotations are taken from Jane K. Dickinson, Ruth D. Lipman, and Catherine A. O'Brian, 'Diabetes Education as a Career Choice', *The Diabetes Educator* 41 (2015), p. 672.

[496] This is not to suggest a value judgement between those living with T1D and their equivalents with T2D, only to emphasise that a failure to distinguish between these two very different conditions amongst HCPs reflects a troubling superficiality that implies ignorance as to the unique challenges associated with each of them.

[497] @UrgoMedicalUK ('Urgo Medical UK'), 'The case for Motivational Interviewing', *Twitter*, 23 October 2019, https://twitter.com/UrgoMedicalUK/status/1187034276073824257.

[498] @Dr_DianeJohnson ('Diane Johnson, PhD'), 'This is absolute proof that massive ignorance in some of the medical profession is alive & kicking when it comes to treating PWD', *Twitter*, 24 October 2019, https://twitter.com/Dr_DianeJohnson/status/1187394784333316098.

course, disputed by many of those living with T1D. Miriam E. Tucker, for example, reflects that for all their rhetoric, ‘I would love for an endocrinologist to trail me for a day and tell me exactly how much insulin to take, just to see if their guesses were any better than mine.’[499] At the same time, T1D highlights the importance of personal value in medicine and the short-sightedness of reducing ‘health’ to the purely biological. Diane Johnson perhaps gets to the heart of the *ideological* root of this state of affairs, writing that ‘The ‘specialists’ can’t help it, they were taught badly – they don’t know any better (I try to feel sorry for them, but it’s often difficult), so I say focus on the real specialists opinion your own [sic].’[500]



Non Diabetic:	26 - 39 mmol/mol	4.5 - 5.7 %
Diabetic Patients:		
Outstanding A+	< 48 mmol/mol	< 6.5 %
Excellent B	48 - 57 mmol/mol	6.5 - 7.4 %
Good C	58 - 68 mmol/mol	7.5 - 8.4 %
Fair C	69 - 79 mmol/mol	8.5 - 9.4 %
Poor D	80 - 90 mmol/mol	9.5 - 10.4 %
Very Poor E	> 91 mmol/mol	> 10.5 %

Figure 5.1: Australian Hospital HbA1c guidelines (date unknown), @RenzaS (‘Renza / Diabetogenic’), ‘Okay diabetes healthcare professionals, listen up!’, Twitter, 17 October 2019, https://twitter.com/RenzaS/status/1184677355442163714.

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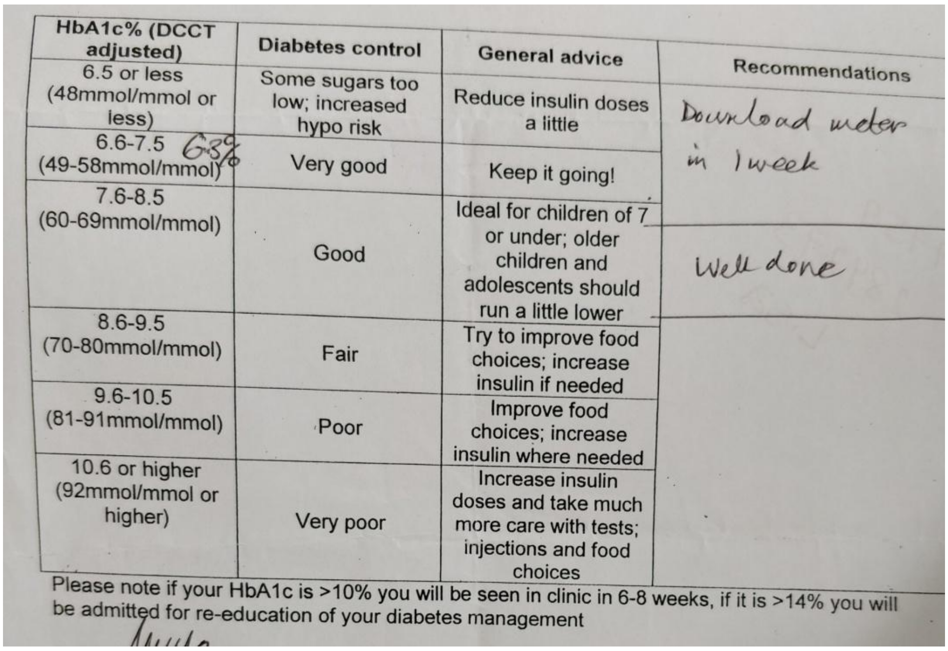
[499] @MiriamETucker (‘Miriam E. Tucker’), ‘I would love for an endocrinologist to trail me for a day and tell me exactly how much insulin to take, just to see if their guesses were better than mine.’, *Twitter*, 14 October 2019, https://twitter.com/MiriamETucker/status/1183563971468681217.

[500] @Dr_DianeJohnson (‘Diane Johnson, PhD’), ‘The ‘specialists’ can’t help it, they were taught badly’, *Twitter*, 18 October 2019, https://twitter.com/Dr_DianeJohnson/status/1185234589352108033.



HbA1c% (DCCT adjusted)	Diabetes control	General advice	Recommendations
6.5 or less (48mmol/mmol or less)	Some sugars too low; increased hypo risk	Reduce insulin doses a little	Download meter in 1week
6.6-7.5 (49-58mmol/mmol) 6.8%	Very good	Keep it going!	
7.6-8.5 (60-69mmol/mmol)	Good	Ideal for children of 7 or under; older children and adolescents should run a little lower	Well done
8.6-9.5 (70-80mmol/mmol)	Fair	Try to improve food choices; increase insulin if needed	
9.6-10.5 (81-91mmol/mmol)	Poor	Improve food choices; increase insulin where needed	
10.6 or higher (92mmol/mmol or higher)	Very poor	Increase insulin doses and take much more care with tests; injections and food choices	

Please note if your HbA1c is >10% you will be seen in clinic in 6-8 weeks, if it is >14% you will be admitted for re-education of your diabetes management

Figure 5.2: British Hospital Hba1C guidelines (early 2000s), @Colonelblighty ('Guardian of the Glucose'), 'Australia is not alone in this sort of thing.', *Twitter*, 17 October 2019, https://twitter.com/Colonelblighty/status/1184763278632898560.

To scare *or*
not to scare?

The question faced by HCPs when managing people with diabetes foot ulcers

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by television and
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- **Professor Paul Chadwick**
  Clinical Director, College of Podiatry
- **Donna Welch**
  Principal Podiatrist Diabetes
- **Sue Marshall**
  Editor of Desang magazine

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Figure 5.3: Image from Tweet advertising debate on 'To scare or not to scare?', @UrgoMedicalUK ('Urgo Medical UK'), 'The case for Motivational Interviewing', *Twitter*, 23 October 2019, https://twitter.com/UrgoMedicalUK/status/1187034276073824257.

Part 6: A Resolution?

Of course, this ideological impasse is unsustainable in the long-term – those living with T1D *want good healthcare*, while in almost all cases professionals want to *provide good healthcare*. However, the material fact that those with the condition need not listen to practitioners risks – and has already created – outright alienation. The issue, to put it simply, is that what *good healthcare* actually *means* is neither definite nor fixed. How, then, should we resolve this final contradiction? The answer may not, in fact, be so elusive as it first appears. While neither the neoliberal approach to care nor the de facto paternalism of more 'deliberative' approaches are sufficient, there is another option. In the early 1990s, Emanuel and Emanuel outlined *four* separate models of the physician-patient relationship. In addition to the 'paternalistic', 'informative (neoliberal)', and 'deliberative' forms, they also outlined an 'interpretive' alternative. Within this, 'The aim of the physician-patient interaction is to elucidate the patient's values and what he or she actually wants, and to help the patient select the available medical interventions that realize these values.'[501] Patient values are therefore at the heart of the 'interpretive' approach, and like the neoliberal model 'the interpretive physician provides the patient with information on the nature of the condition and the risks and benefits of possible interventions.'[502] However, it must then go further – the individual does not simply select an option from a dispassionately presented list, but engages in conversation with the physician, who 'assists the patient in elucidating and articulating his or her values and in determining what medical interventions best realize the specified values, thus helping to interpret the patient's values for the patient.'[503]

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[501] Emanuel and Emanuel, 'Four Models of the Physician-Patient Relationship', p. 2221.
[502] *Ibid*, p. 2221.
[503] *Ibid*, p. 2222.

According to this framework, the values of the professional are, as in the neoliberal approach, entirely irrelevant in the provision of advice. However, this is not to say that their role is limited to that of the technician. Instead, within the 'interpretive' model the doctor retains a vital role in translating the stated desires of the individual into coherent value-positions before subsequently evaluating which potential therapeutic option might best satisfy the needs so determined. Emanuel and Emanuel liken the 'interpretive' practitioner to a 'counselor, analogous to a cabinet minister's advisory role to a head of state'.[504]

More recently, Atul Gawande outlined an essentially 'interpretive' approach in his 2014 book *Being Mortal: Illness, Medicine, and What Matters in the End*. Acknowledging the weaknesses of both paternalistic medicine and its 'informative' neoliberal sibling, Gawande suggests that 'In truth, neither type is what people desire. We want information and control, but we also want guidance.'[505] The physician should not, therefore, attempt to exert influence – influence that given the previously described power differential can only ever take the form of de facto paternalistic coercion – but nevertheless should not *necessarily* accept apparent value-statements uncritically, instead acknowledging that 'the patient's values are not necessarily fixed and known to the patient... [but] often inchoate... partially under[stood]... and [potentially in] conflict when applied to specific situations.'[506] Or, as Gawande summarises: 'Doctors who listen to only the momentary, first-order desires may not be serving their patients' real wishes'.[507]

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[504] *Ibid*, p. 2222.

[505] Atul Gawande, *Being Mortal: Illness, Medicine, and What Matters in the End* (London: Profile, 2014), p. 201.

[506] Emanuel and Emanuel, 'Four Models of the Physician-Patient Relationship', p. 2222.

[507] Gawande, *Being Mortal*, p. 202.

The job of the professional, then, is to render these often chaotic value-laden impulses intelligible.[508] This is what Scibilia alludes to when she responds to Partha Kar – a Southampton-based diabetologist with something of a reputation for championing patient 'empowerment' – to criticise his statement that practitioners should endeavour to be 'nice to those whose lives... [they] dont live' while highlighting an NHS document titled *Language Matters: Language and Diabetes*.[509] 'Respectfully', she argues, '[it] is not about being (mostly, a little bit or completely) 'nice'... it is far, far more important than being about just 'good manners'.'[510] Instead, 'we should also try to ensure that diabetes is represented and presented in a way that does not harm those of us living with it' – *harm*, of course, is the key idea here.[511] Scibilia understands that medicine, because of its ideological orientation, can paradoxically become a source of iatrogenic *harm* even while it apparently promotes good health, and can as a result jeopardise *health* in its broad sense. Language, she observes, 'shape[s] attitudes & attitudes create reality.'[512] Consequently, careful consideration of that language can 'stop [those with T1D] being blamed, shamed, judged

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[508] For his part, Gawande appears to gently – though unhelpfully – conflate the 'interpretive' and 'deliberative' models, writing that 'At some point, therefore, it becomes not only right but also necessary for a doctor to deliberate with people on their larger goals, to even challenge them to rethink ill-considered priorities and beliefs'; *Ibid*, p. 202.

[509] @parthaskar ('Partha Kar'), 'Of note?', *Twitter*, 20 October 2019, https://twitter.com/parthaskar/status/1185866007014973440; NHS England, *Language Matters: Language and Diabetes*, 11 June 2018, <https://www.england.nhs.uk/publication/language-matters-language-and-diabetes/> [accessed 22 October 2019].

[510] @RenzaS ('Renza / Diabetogenic'), 'Respectfully, the #LanguageMatters movement is not about being (mostly, a little bit or completely) 'nice'.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126234754748416.

[511] @RenzaS ('Renza / Diabetogenic'), 'But we should also try to ensure that diabetes is represented and presented in a way that does not harm those of us living with it.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126252756750337.

[512] @RenzaS ('Renza / Diabetogenic'), 'Words & language shape attitudes & attitudes create reality.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126238055682049.

and stigmatised by HCPs, the media, researchers and the general public' and, implicitly, contribute to better holistic outcomes.[513]

While Mol openly acknowledges that according to the deliberative basis of her 'logic of care' it is sometimes necessary for professionals to avoid indulging 'misguided' individuals, this simply makes no sense in an 'interpretive' approach because, should it function as intended, there *can be no 'misguided' individuals*, only those who act according to their own best interests as personally defined. The professional may help them clarify that interest, but has no business *influencing* it. In the broad sense, this is healthcare in a much more meaningful and ultimately *truer* definition: 'health' as a socio-cultural concept as much as a biological one. The 'interpretive' model – by focusing entirely on patient value, and, importantly, on the *proper expression of that value* – cannot but incorporate this recognition into the consultation.

The 'interpretive' model has the potential to resolve the ideological contradiction still present at the heart of the management of T1D (and indeed within medicine more broadly), fulfilling Mol's vision of 'not frustrating emancipation but going beyond it... [by finding] ways of tackling abuses of power with suitable, but not necessarily neo-liberal, repertoires.'[514] Some HCPs have always understood this – for example one USA-based practitioner recalls a humorous and touching interaction with an elderly patient:

> 95 y/o patient with diabetes: I like to eat cake every day.
>
> Me: that's ok, a little sweetness at this point in your life is fine.

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[513] @RenzaS ('Renza / Diabetogenic'), 'Not because it is 'nice', but rather because it means that we – people living with diabetes – will stop being blamed, shamed, judged and stigmatised by HCPs, the media, researchers and the general public.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126254858047493.

[514] Mol, *The Logic of Care*, p. 123.

> Patient: You’re doing this wrong. You’re supposed to tell me to stop eating cake.
>
> Me: Stop eating cake
>
> Patient: Really?
>
> Me: No[515]

While still perhaps a minority, in the UK some medical staff are also beginning to adopt a similar approach. Having met a considerable number of alienated PWD who, like Howie in Chapter 2, patiently sit through instructions they have no respect for and no intention of following, Helen Partridge (1969-) has attempted to incorporate the patient as a meaningful actor during the consultation:

> The... second or third question you ask anyone is, you know, what's your relationship like with your diabetes? You know? Because if you don't work that out then forget it! It's academic what the numbers are doing and what the blood tests are... and so when you work in one of these great big centres where it's just about numbers... then the poor patients, you know, they just come away thinking “What a waste of time”, you know, “what was that, what did that achieve... whose boxes have I ticked there? It's not mine, it's the doctors”, and they carry that, you know? [516]

This ‘interpretive’ approach might certainly lead to worse outcomes according to the strict definitions of the medical model, but rather than seeing this as a weakness we should read this as an indication of the importance of critically re-evaluating and reconceptualising our

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[515] @ARCHDrNguyen (‘Tung Nguyen’), ’95 y/o patient with diabetes: I like to eat cake every day’, *Twitter*, 9 October 2019, https://twitter.com/ARCHDrNguyen/status/1181725462109646848.

[516] Helen Partridge interviewed by Stuart Bradwel, 7th March 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

definitions of health, sickness, and the purpose of medicine itself. By investing these concepts with socio-cultural and ideological, in addition to biological, content, we have the potential to create a healthcare that genuinely aims to make us *healthy* – something that can only truly be *truly* understood in light of our own eudaimonic ideal.

In the case of T1D, management – as we have seen – involves a constant value-judgement. But these value judgements deal only in statistical probabilities. ‘Good control’ as defined by the medical model *is not in itself health* even according to that model, but rather a state that perhaps might prevent health from failing over many years. Nevertheless, it has with some exception been advocated as the defining goal of insulin therapy for much of its history. But it is no guarantee. In the end, as Mol acknowledges in *The Logic of Care*, we all die. Twenty-three year old Glaswegian Anthony Clark, for example, was diagnosed with insulin-dependent diabetes in 1978.[517] Being found to be in good health despite this, he nevertheless frustrated his intensely paternalistic physicians by regularly failing to attend clinic appointments.[518] On the 23rd March 1985 he was pronounced dead at the age of only thirty – not of kidney disease or of any other diabetic sequelae but of bronchopneumonia.[519] With the power of hindsight, one wonders whether his absence from those clinics might have provided him a *healthier* life than his attendance would have.

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[517] *Clinic Report: Anthony Clark*, 16th November 1978, HB57, NHS Greater Glasgow and Clyde Archives.

[518] *Letter from Dr. R. J. Weir to Dr. Donald*, 14th June 1983, HB57, NHS Greater Glasgow and Clyde Archives.

[519] *Confirmation of Anthony Clark’s post-mortem*, 2nd April 1985, HB57, NHS Greater Glasgow and Clyde Archives.

Part 7: Concluding Remarks and Avenues for Future Research

The way in which those with T1D have been expected to manage their condition has changed immeasurably since the early days of the NHS in post-war Britain. From the late 1940s on, those diagnosed were treated – like most of those cast into the role of the ‘patient’ – as essentially passive objects upon which a carefully prescribed regimen of medication and diet should be imposed. In practice, this meant taking one or two fixed injections of long-acting or mixed insulin daily, while following strict rules on mealtimes and nutritional content provided by medical staff. Conversely, the experience of insulin therapy has, from the early twenty-first century, been marked by an overt reorganisation of the consultative relationship that has turned management, effectively, on its head. Those with T1D now control – and are encouraged to control – almost every aspect of treatment, determine for themselves what to eat, how much insulin to inject (or infuse), and when in the day to do both. HCPs are now cast as remote sources of support and advice specifically responsible for little else beyond occasional screening for potential signs of long-term complications. Recognising that this is an area that has been largely neglected by the extant historical literature, this thesis set out to elucidate the process by which the transition from physician- to lay-led care occurred, while taking time to consider the broader implications of this development for the management of T1D itself, and also for the practice of medicine more broadly.

While this superficially appears a relatively simple research problem, such an impression is, as has been demonstrated, somewhat illusory. As discussed in Chapter 1, figures like Eastwood provide a sobering tonic to the Whiggish assumption that the history of T1D management has been a gradual process of refinement running parallel to scientific and technological innovation to enable more ‘effective’ therapy. Unilaterally adopting an approach that in many respects constituted a proto-‘intensified’ strategy of care in the 1930s, and living a considerably more unrestrained life than contemporary HCPs might have considered appropriate, his survival to the age of seventy-five with minimal sequelae demonstrates quite plainly that the requisite equipment and medication to allow for *some level* of lay-engagement has been available from the earliest days of insulin therapy.

Similarly, as Chapter 2 discusses in some depth, those with T1D have never been *entirely* powerless or passive in the context of their condition. In fact, the characteristics of insulin therapy ensure that it is impossible that they might be. Almost every element of treatment is – and historically always has been – conducted within the home of the layperson, by that individual or members of their household. Performed far from the watchful eye of medical oversight, professional instruction could be disregarded where it contradicted either personal tacit knowledge or where obedience simply offered less subjective value to an individual than disobedience. A significant number of those living with T1D in the post-war period made, as a result, extensive use of officially unsanctioned dietary and lifestyle manipulation to exert a degree of autonomous control over their condition. While dosage, too, *could* always be adapted, the popular reaction to Fletcher’s account of self- adjustment discussed in Chapter 3 suggests that, by the early 1980s, few individuals felt comfortable doing so. How, then, can we explain the official adoption of lay-led therapy in the form of 2002’s DAFNE programme?

This thesis has presented three central arguments to explain the transition from (formally) physician-led to lay-led insulin therapy:

1) From the 1980s, it was increasingly clear to HCPs that hyperglycaemia was implicated in the development of the many of the long-term complications of T1D. After a period characterised by cautious attempts to promote lower overall blood

glucose levels in PWD by incorporating very limited lay-dosage adjustment within the boundaries of ‘conventional’ frameworks, the DCCT’s publication in 1993 made it clear that this was not sufficient while retaining a commitment to the medical model of health. Unable (or unwilling) to fully implement its recommendations due to a perceived economic infeasibility, British HCPs instead began to increasingly advocate ‘semi-intensified’ approaches: regimens occasionally prescribed from the 1980s that incorporated some ‘intensive’ principles – namely ‘basal-bolus’ strategies – into an essentially prescriptive framework that maintained traditional power relations within the consultative relationship. Nevertheless, this directly altered the material conditions of insulin therapy by encouraging the widespread (re-) introduction of short-acting soluble insulin alongside the increased provision of personal SBGM devices. Compounding this, novel delivery devices such as insulin pens allowed for the relatively fast, painless, and discreet administration of medication. Consequently, laypeople were empowered to make unilateral, ad-hoc refinements to therapy to a greater extent than had previously been possible. Preceding the emergence of an assertive patient-body often highly critical of medical authoritarianism, this came to provoke considerable discontent amongst HCPs concerned about both the long-term clinical and professional implications of this development.

2) Given that the tools necessary for ‘semi-intensified’ and fully ‘intensified’ therapy are identical, DAFNE cannot be understood as a wholly biomedical development. Based on a German programme some quarter-century old and occurring almost a decade following the DCCT’s recommendation that ‘intensive’ therapy be introduced to limit the incidence and severity of long-term sequelae, it must instead be understood as an ideological adaptation to the conditions of New

Labour-era Britain. Fully aware that PWD were increasingly asserting autonomy that they had little power to prevent, the neoliberal impulse of the early twenty-first century provided an opportunity for the medical profession to mitigate this via a realignment of the consultative relationship. By embracing, rather than resisting, lay-autonomy, assigning an unprecedented level of responsibility to PWD, and reconceptualising themselves as remote sources of support, DAFNE effectively allowed for the wider implementation of 'intensification' while satisfying, superficially at least, many of the criticisms – largely based on perceived authoritarianism – that had been made by more assertive individuals with T1D.

3) The implicit individualism on which DAFNE is founded has led to the emergence of new problems while allowing for the persistence of several older ones. Lay-led 'intensified' insulin therapy – which is now encouraged by default whether or not the individual attends a formal training course – has, even while it implicitly legitimised considerable practical autonomy, transferred much additional labour to PWD to an extent that some might find constitutes an additional source of stress and anxiety in itself. With HCPs now taking a back-seat in management even while the medical profession maintains the right to determine *value* in healthcare, culpability for therapeutic outcomes has also become largely the responsibility of the individual in a distinctly moralistic fashion. This situation demonstrates a continuing need to interrogate the individual and collective meanings we attribute to health, and the broader implications of strategies we use to pursue it.

The arguments made here suggest several conclusions. First, that a determinist reading of the history of T1D is unsustainable. The successful formal implementation of 'intensified' insulin therapy in the UK did not occur as a result of some abstract commitment to 'progress' following from an acceptance amongst HCPs that it was the 'correct' approach to ‘optimise’ biomedical outcomes. This approach to management had existed in Germany since the late 1970s. Even after 1993, when it was clear that ‘conventional’ approaches had become untenable according to the medical model, fully ‘intensified’ approaches did not arrive in the UK to any meaningful until almost a full decade later.

Second, and following from this, the medical profession, for all its rhetoric, does not always adopt policy based on a purely disinterested analysis of ‘health optimisation’, even where we understand that ‘optimisation’ in terms of the medical model that supposedly informs decision-making. The delay in adopting DAFNE makes clear that secondary factors both professional and ideological exert considerable influence, throwing considerable doubt onto the oft-repeated claim to ‘objectivity’ made by HCPs.

Third, that the claim to authority over matters of health made by professional interests often represents a statement of power rather than insight. In this context, criticism of ‘non-compliance’ takes a rather more troubling aspect. The consensus documents of a 1974 conference on ‘patient compliance’ held at Canada’s McMaster University, cited by Greene in ‘Therapeutic Infidelities’, declared that one of the criteria to be met before a patient might be described as ‘non-compliant’ was that ‘the proposed therapy had to be shown to do more good than harm.’[520] Even should we disregard notions of subjectivised health values and uncritically accept the medical model, this continues to rely upon the medical profession *knowing* what ‘works’. The history of T1D demonstrates clearly that this is simply not always the case. Indeed, figures like Eastwood in the 1930s and many of those who were later regarded as ‘non-compliant’ might well have adopted approaches that did considerably *less* harm – according to the medical model – than those promoted by contemporary clinicians! By claiming the sole right to legitimately arbitrate both value and

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[520] Greene, ‘Therapeutic Infidelities’, p. 336.

strategy in health, HCPs run the risk of becoming blind not only to the real needs of their individual patients but also to their own limitations. As we have seen, T1D provides one example of a condition in which clinicians have – usually with the best of intentions – manifestly adopted policy that has, by their own definition, done more harm than good; an issue only compounded in situations, as after 1993, in which they *know* as much but fail to change their practice due to essentially non-medical factors.

This thesis builds on a relatively limited historiography. While the value of much extant work, for example by Tattersall and Feudtner, is undoubted, this tends to concentrate primarily on the pre-'intensified' era of insulin therapy. However, as Feudtner would surely agree, the widespread adoption of such a novel framework of care has exacted a transmutative pressure that has transformed the experience of T1D to an extent likely surpassed only by insulin itself. It is therefore vitally important that scholars take the time to engage with the implications of this development: insulin therapy in 2020 is almost unrecognisable when compared to insulin therapy in 1948, and conclusions drawn from an analysis based on twentieth century evidence are by necessity going to be severely limited in their applicability to twenty-first century management.

With the notable exceptions of Sinding's thoughtful though brief 'Flexible Norms?' and, arguably, Mol's *The Logic of Care*, none of the existing literature on the history of T1D engages with the post-DCCT period beyond a few brief, superficial remarks. Providing a sustained analysis of the circumstances leading to the introduction of 'intensified' therapy has, therefore, been the primary contribution of this thesis. This is a vitally important chapter in the history of T1D and, I would argue, shows it to be an excellent case study through which to interrogate broader ideas about medicine and health both historical and current.

Additionally, there are two smaller but no less important points to make. First, by the standards of most writing concerned with the history of diabetes mellitus, this work may seem a little unusual in that it self-consciously speaks only of T1D while neglecting to discuss T2D at all beyond a few brief passages. This is not an oversight, but instead reflects a deliberate decision. Not only would an incorporation of analysis related to T2D be overly ambitious, it is – despite some shared history – a fundamentally different health experience to T1D. The tendency of some authors – across all disciplines – to speak of both as if conclusions drawn from one might be applicable to both is both analytically misleading and potentially harmful, and should be firmly discouraged.

Second, extant literature on the history of T1D focuses primarily on a relatively limited selection of published and archival sources. Without suggesting in the least that such formal material is without value, this work has explicitly made use of oral history and social media sources, demonstrating the potential of such non-traditional evidence. Direct accounts of lay-experience that often remain largely invisible throughout traditional historical sources have, along with the uncensored personal reflections of HCPs, been instrumental in elucidating the relationship between grander political and scientific developments and the human experience of T1D at the ground level. Without either of these elements this work would have, at the very least, been considerably more limited in scope.

This thesis has sketched the social history of T1D in post-war Britain, providing a bottom-up account of ‘conventional’ insulin therapy in the latter half of the twentieth century before describing the process by which ‘intensified’ approaches emerged from this context. It has emphasised the role of ideological factors in determining the evolution of approaches to management in lay and professional discourse throughout the late twentieth century, and has considered the implications of this for ongoing issues in healthcare related to diabetes in particular, and chronic medical conditions more generally. It has, however, limited itself to an analysis of the consultative relationship without delving too much into concrete policy or structural factors.[521] It has also consciously avoided any significant discussion of the scientific history out of a simple desire for clarity (and brevity).[522] There is much, however, left to say on the topic, and future research could build on the themes raised here in fascinating and practically valuable ways.

As this work has concentrated on T1D in the UK, there is much potential benefit in exploring some of its themes as they apply to other parts of the world. It is, for example, impossible to discuss DAFNE without addressing the fact that it constituted an effective facsimile of Berger's programme that had been running in Germany for over two decades before it was imported to the British Isles. Further analysis of this innovation would be valuable, particularly were it to unpack the contextual factors that allowed such an initiative to emerge in Düsseldorf so many years prior to the adoption of its principles in the Anglosphere.

The relationship between T1D management and neoliberal reforms to the NHS has been addressed here in terms of their influence on the accepted roles and responsibilities of practitioners and laypeople, but the broader political consequences of this – particularly in the USA – deserve considerably more attention. The #insulin4all campaign cuts to the heart of the issue here, and this is a topic with relevance well beyond the scope of T1D itself: the movement is in itself a damning indictment of the United States healthcare system.

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[521] This is the subject of much of Moore's work. His earlier quoted thesis is built upon in Martin D. Moore, *Managing diabetes, Managing Medicine: Chronic Disease and Clinical Bureaucracy in Post-war Britain* (Manchester: Manchester University Press, 2019).

[522] Tattersall's *The Pissing Evil* remains the definitive account of the scientific history, though it is light on post-DCCT developments.

Additional work on this – and on the socio-economic history of T1D (and T2D) – would be welcome, particularly should it engage with concepts of class, race, and gender.

Similarly, the lay self-experimentation seen in those associated with #WeAreNotWaiting echoes Eastwood's efforts almost a century prior, as well as those of more recent HIV/AIDS activists during the 1980s. Like these, it invites us to question the process by which legitimacy in innovation is constructed, while also challenging us to think critically about the implications of research and development processes controlled – in law – largely by traditional authorities. Many of the first children treated with insulin in 1922 would, for example, likely not have survived had the Toronto research team been subject to current regulations surrounding clinical trials.

Remaining in the sphere of technological innovation, when discussing 'intensified' management this thesis has concerned itself primarily with MDI regimens and has not made any significant attempt to highlight the differences between 'intensive' therapy as conducted via such pharmaceutical means and the alternative, mechanically-oriented pump-based approach. While the distinction here is not of great relevance to the argument presented in this thesis, there is much potential work to be done on the subject: particularly on the impact of wearing constantly attached and often highly visible technologies.[523] Rendering an invisible health condition visible is a deeply meaningful decision that shapes the social experience of the individual, and this is worth addressing in depth.

Throughout this thesis HCPs have been described – perhaps crudely – somewhat monolithically. While this was necessary in the context of my argument – which dealt with broad concepts of accepted orthodoxy in practice – figures like Tolstoi demonstrate that

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[523] This applies equally to CGM technology.

there is more nuance to be unpacked here, while geographic divisions were also often meaningful. DSNs, for example, were introduced to the landscape of the clinic in the mid-1970s, and according to many – though not all – of my interviewees quickly became quite notorious for taking on a much more practical attitude towards their patients, accepting that they would continue to indulge in vices and attempting to work around this while maintaining 'adequate' control of blood glucose.[524] While such professionals do not challenge the overall thrust of my argument, they reveal that clinical ideology is a subtly textured construct worthy of further attention to its finer workings.

By presenting a few potential areas in which this work could be expanded – and likely failing to present many more – this final section invites other scholars to consider the potential benefits offered by the further study of T1D and other long-term health conditions, and of incorporating the direct testimonies of those affected into such work. In this particular context, these benefits go beyond the theoretical and begin to raise meaningful policy questions as we attempt to build a healthcare service that works as effectively as possible in the interests of those it serves.

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[524] One exception was Rob Hirst (1979-), who felt that DSNs during the 1990s were 'very prescriptive, you know, sort of protocol driven', and felt that when asking for advice he would always 'get a very motherly response. A sort of patronising response.'; Rob Hirst interviewed by Stuart Bradwel, 2nd August 2018, GB 249 SOHC 64, University of Strathclyde Archives and Special Collections.

Appendix 1 – List of Oral History Participants

People with T1D

Karen Addington

- Born 1966 in Worcestershire.
- Diagnosed 1979.
- Lives in London.
- Currently CEO of Juvenile Diabetes Research Foundation (JDRF) UK.

John Allison

- Born 1949 in Kilmarnock.
- Diagnosed 1966.
- Lives in Ayrshire.
- Formerly worked as administrator for various local government and educational organisations.

John Balfour

- Born 1948 in Newcastle upon Tyne.
- Diagnosed 1962.
- Lives in Teeside.
- Formerly worked in scientific role in paint industry.

Gillian Clifton

- Born 1961 in Ipswich.
- Diagnosed 1967.
- Lives in Yorkshire.
- Former occupational therapist.

Anne Cooper

- Born 1963 in Middleborough.
- Diagnosed 1979.
- Lives in Yorkshire.
- Currently works as Registered Nurse. Active in diabetes advocacy.

Carol Cowan

- Born 1951 in Stirling.
- Diagnosed 1967.
- Lives in Stirlingshire.
- Former schoolteacher.

Peter Davies

- Born 1954 in Eldoret, Kenya.
- Diagnosed 1956.
- Lives in Surrey.
- Former schoolteacher. Active in diabetes advocacy.

Mark Deakin

- Born 1973 in Torquay.
- Diagnosed 1975
- Lives in Merseyside.
- Currently works as consultant in diabetes and general paediatrics.

‘Deborah’

- Anonymised at participant request.

Rose Douglas

- Born 1944 in Tyneside.
- Diagnosed 1953.
- Lives in Tyneside.
- Former civil servant.

Sarah Gatward

- Born 1964 in Amersham.
- Diagnosed 1972.
- Lives in Surrey.
- Works in finance. Active in diabetes advocacy.

Rob Hirst

- Born 1979 in Halifax.
- Diagnosed 1982.
- Lives in Merseyside.
- Works as GP.

Margaret Howie

- Born 1965 in Johnstone.
- Diagnosed 1974.
- Lives in Stirlingshire.
- Former schoolteacher.

Frank Kaye (interviewed with Sylvia Kaye)

- Born 1939 in Glasgow.
- Diagnosed 1966.
- Lives in Glasgow.
- Former businessman, owned furniture company.

Vic Marriott

- Born 1946 in Brighton.
- Diagnosed 1954/55.
- Lives in West Sussex.
- Formerly worked for BT, in addition to several other jobs in driving and manual labour.

John Meredith

- Born 1944 in Bangor.
- Diagnosed 1959.
- Lives in Teeside.
- Former civil servant.

Joel Milner

- Born 1948 in Birmingham.
- Diagnosed in late 1970s.
- Lives in Glasgow.
- Biomolecular scientist. Active in diabetes advocacy.

Mary Moody

- Born 1949 in Edinburgh.
- Diagnosed 1954.
- Lives in Renfrewshire.
- Businesswoman, owns auditing company. Active in diabetes advocacy.

‘Siobhan’

- Anonymised at participant request.

Janette Tibbett

- Born 1942 in Matlock.
- Diagnosed 1948.
- Lives in Gwynedd.
- Various admin and secretarial jobs throughout life.

Lisa Tozer

- Born 1972 in Toronto.
- Diagnosed 1985.
- Lives in Yorkshire.
- Works as project manager.

Mike Turner

- Born in 1944 in Nottinghamshire.
- Diagnosed 1954/1955.
- Lives in Yorkshire.
- Formerly worked as engineer.

Lis Warren

- Born in 1952 in Yorkshire.
- Diagnosed 1965.
- Lives in London.
- Former social worker. Active in diabetes advocacy.

Healthcare Professionals (not living with T1D)

Stephanie Amiel

- Born 1954 in Kent.
- Lives in London.
- Professor of Diabetes Research.

Charles Fox

- Born 1942 in Fordingbridge.
- Lives in Northamptonshire.
- Consultant diabetologist.

Simon Heller

- Born 1953 in London.
- Lives in Yorkshire.
- Professor of Clinical Diabetes.

Anne Kilvert

- Born 1950 in Manchester.
- Lives in Warwickshire.
- Consultant diabetologist.

Helen Partridge

- Born 1969 in Lincolnshire.
- Lives in Hampshire.
- Consultant diabetologist.

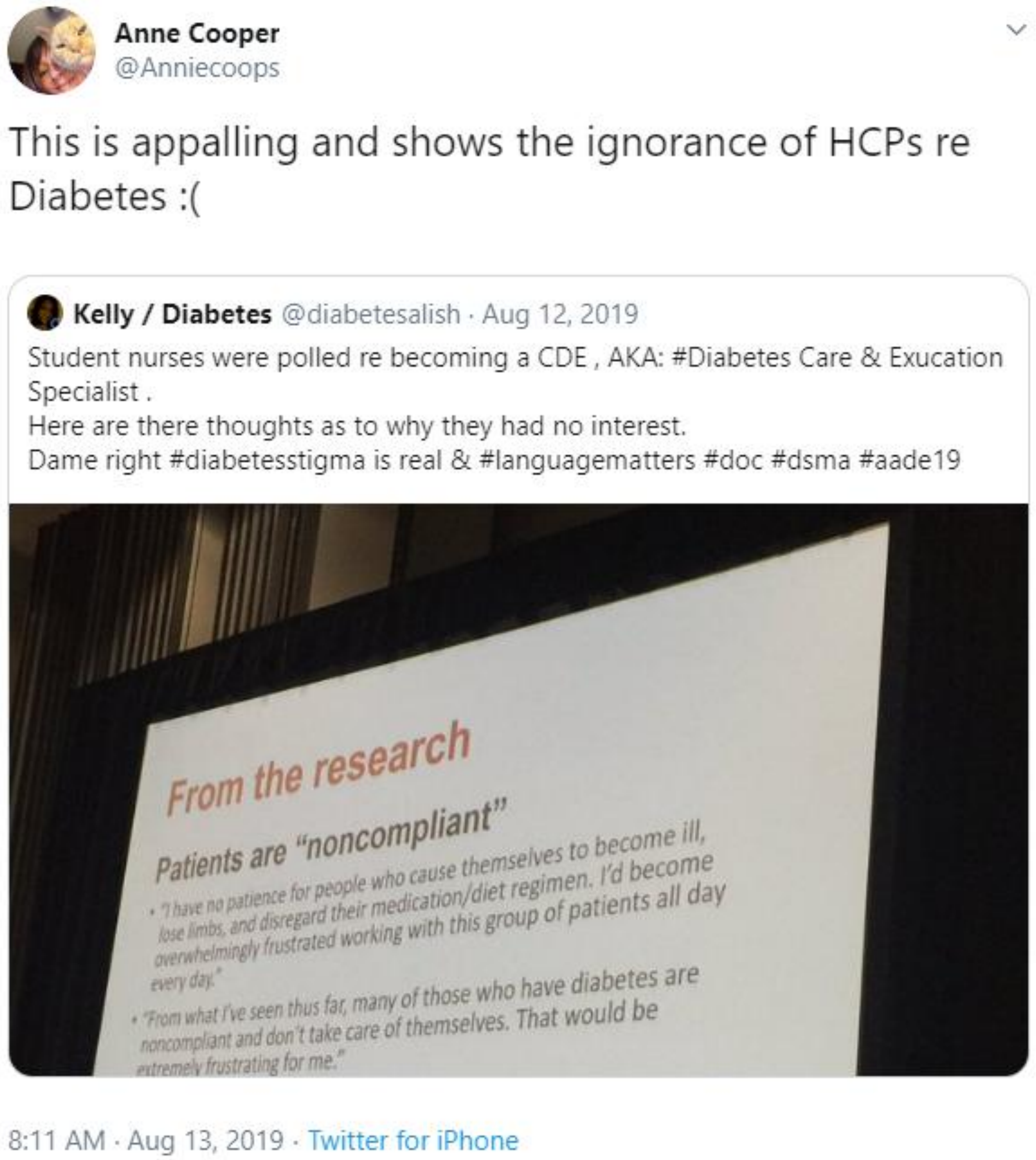
John Saunders

- Born 1945 in London.
- Lives in Glamorgan.
- Diabetologist, now working on a PhD in Philosophy of Healthcare.

Ronald Weir

- Born 1935 in Glasgow.
- Lives in Glasgow.
- Formerly worked as doctor ‘with an interest in diabetes’.

Appendix 2 – Social Media Sources



Anne Cooper
@Anniecoops

This is appalling and shows the ignorance of HCPs re Diabetes :(

Kelly / Diabetes @diabetesalish · Aug 12, 2019
Student nurses were polled re becoming a CDE , AKA: #Diabetes Care & Exucation Specialist .
Here are there thoughts as to why they had no interest.
Dame right #diabetesstigma is real & #languagematters #doc #dsma #aade19

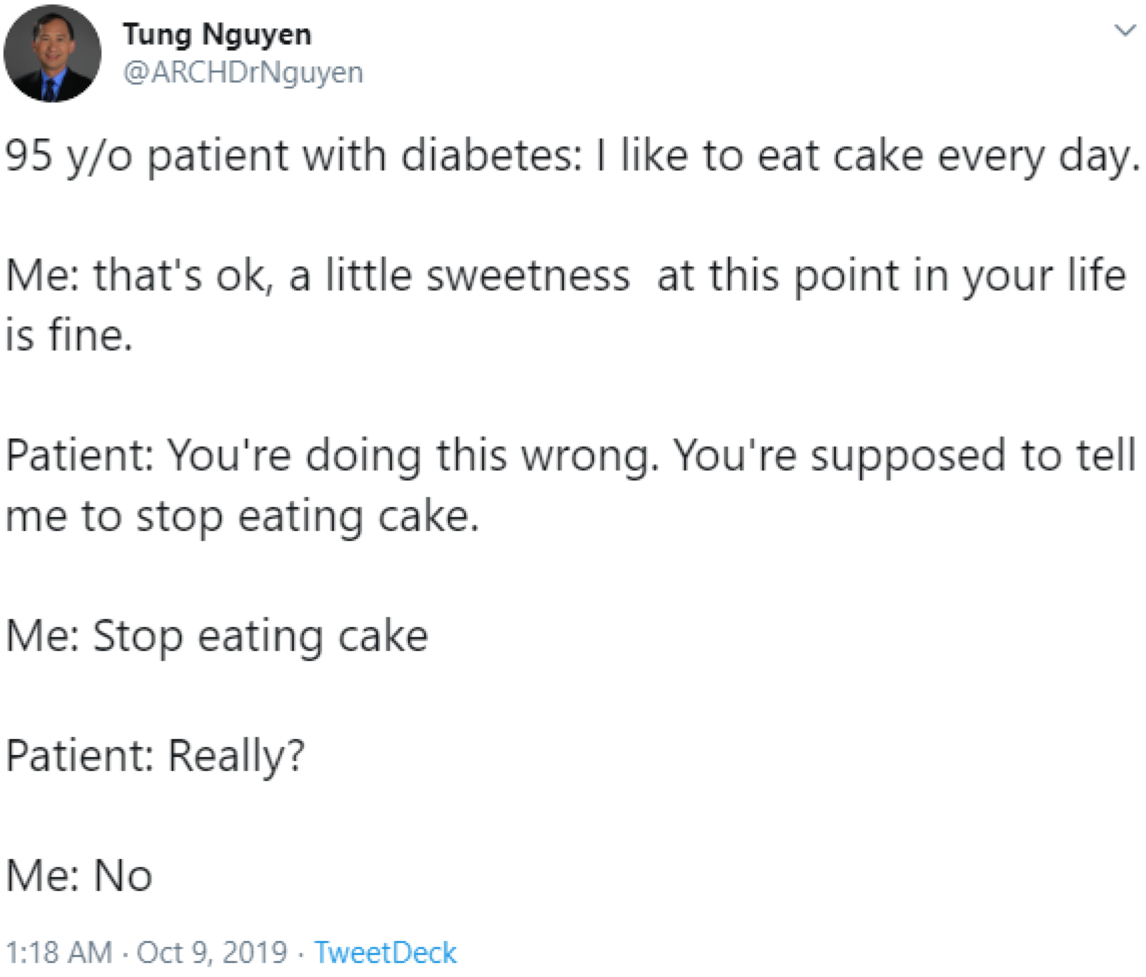
From the research

Patients are "noncompliant"

- "I have no patience for people who cause themselves to become ill, lose limbs, and disregard their medication/diet regimen. I'd become overwhelmingly frustrated working with this group of patients all day every day."
- "From what I've seen thus far, many of those who have diabetes are noncompliant and don't take care of themselves. That would be extremely frustrating for me."

8:11 AM · Aug 13, 2019 · Twitter for iPhone

@Anniecoops ('Anne Cooper RN FQNI'), 'This is appalling and shows the ignorance of HCPs re Diabetes', *Twitter*, 13 August 2019, https://twitter.com/Anniecoops/status/1161173396262195200.



Tung Nguyen
@ARCHDrNguyen

95 y/o patient with diabetes: I like to eat cake every day.

Me: that's ok, a little sweetness at this point in your life is fine.

Patient: You're doing this wrong. You're supposed to tell me to stop eating cake.

Me: Stop eating cake

Patient: Really?

Me: No

1:18 AM · Oct 9, 2019 · TweetDeck

@ARCHDrNguyen (‘Tung Nguyen’), ’95 y/o patient with diabetes: I like to eat cake every day’, *Twitter*, 9 October 2019, https://twitter.com/ARCHDrNguyen/status/1181725462109646848.

Bad diabetic
@bad_diabetic

#talkingaboutcomplications this is progression of cellulitis from a pump site despite iv antibiotics within 8 hours of it first appearing. i'm terrible at putting going to the drs off but so glad i listened to my gut and went to a&e because these infections can come on so fast

11:53 AM · Sep 8, 2019 · Twitter for iPhone

@bad_diabetic ('Bad diabetic'), '#talkingaboutcomplications this is progression of cellulitis from a pump site despite iv antibiotics within 8 hours of it first appearing.', *Twitter*, 8 September 2019, https://twitter.com/bad_diabetic/status/1170651324284846080.

Guardian of the Glucose
@Colonelblighty

Replying to @RenzaS

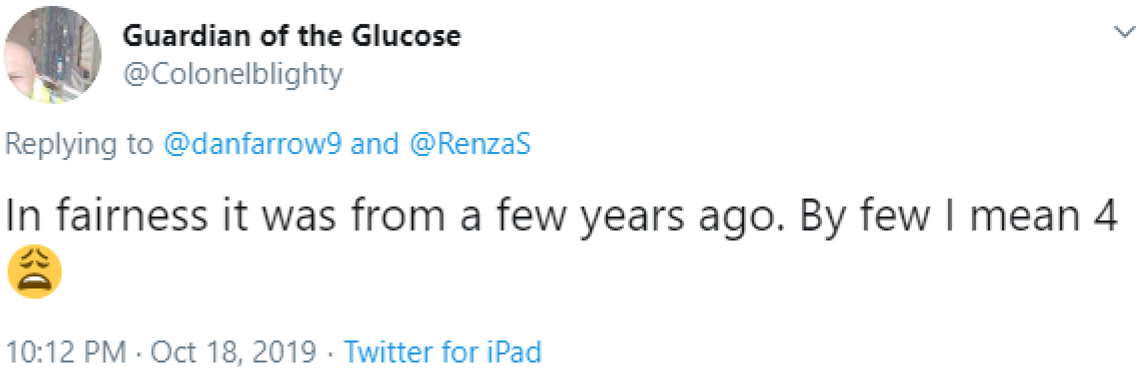
Australia is not alone in this sort of thing.#GBDoc

HbA1c% (DCCT adjusted)	Diabetes control	General advice	Recommendations
6.5 or less (48mmol/mmol or less)	Some sugars too low; increased hypo risk	Reduce insulin doses a little	Download meter in 1week
6.6-7.5 6.8% (49-58mmol/mmol)	Very good	Keep it going!	
7.6-8.5 (60-69mmol/mmol)	Good	Ideal for children of 7 or under; older children and adolescents should run a little lower	Well done
8.6-9.5 (70-80mmol/mmol)	Fair	Try to improve food choices; increase insulin if needed	
9.6-10.5 (81-91mmol/mmol)	Poor	Improve food choices; increase insulin where needed	
10.6 or higher (92mmol/mmol or higher)	Very poor	Increase insulin doses and take much more care with tests; injections and food choices	

Please note if your HbA1c is >10% you will be seen in clinic in 6-8 weeks, if it is >14% you will be admitted for re-education of your diabetes management

10:29 AM · Oct 17, 2019 · Twitter for Android

@Colonelblighty (‘Guardian of the Glucose’), ‘Australia is not alone in this sort of thing.’, *Twitter*, 17 October 2019, https://twitter.com/Colonelblighty/status/1184763278632898560.



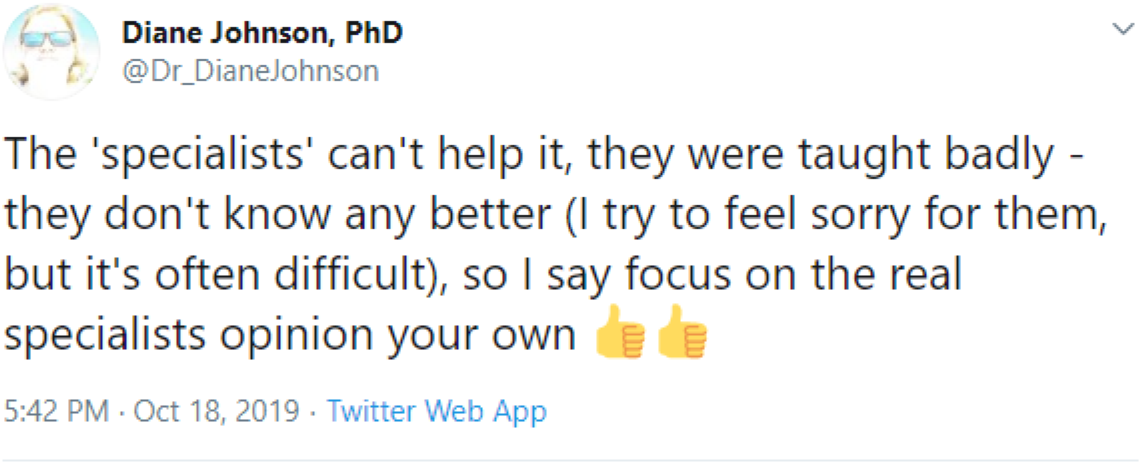
Guardian of the Glucose
@Colonelblighty

Replying to @danfarrow9 and @RenzaS

In fairness it was from a few years ago. By few I mean 4 😩

10:12 PM · Oct 18, 2019 · Twitter for iPad

@Colonel Blighty (‘Guardian of the Glucose’), ‘In fairness it was from a few years ago.’, *Twitter*, 18 October 2019, https://twitter.com/Colonelblighty/status/1185302753536593920.

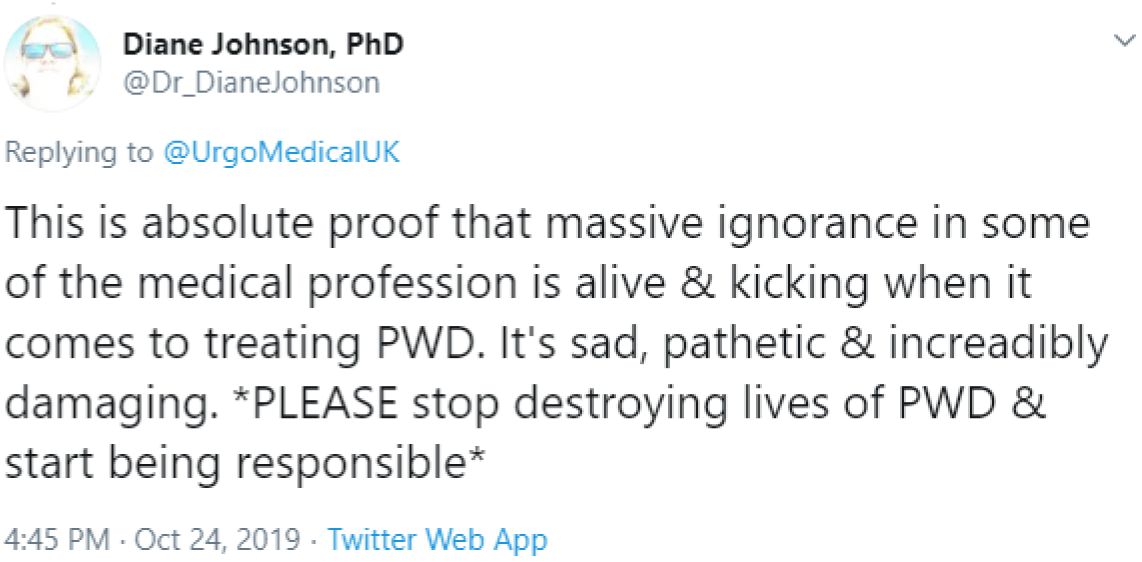


Diane Johnson, PhD
@Dr_DianeJohnson

The 'specialists' can't help it, they were taught badly - they don't know any better (I try to feel sorry for them, but it's often difficult), so I say focus on the real specialists opinion your own 👍👍

5:42 PM · Oct 18, 2019 · Twitter Web App

@Dr_DianeJohnson (‘Diane Johnson, PhD’), ‘The ‘specialists’ can’t help it, they were taught badly’, *Twitter*, 18 October 2019, https://twitter.com/Dr_DianeJohnson/status/1185234589352108033.



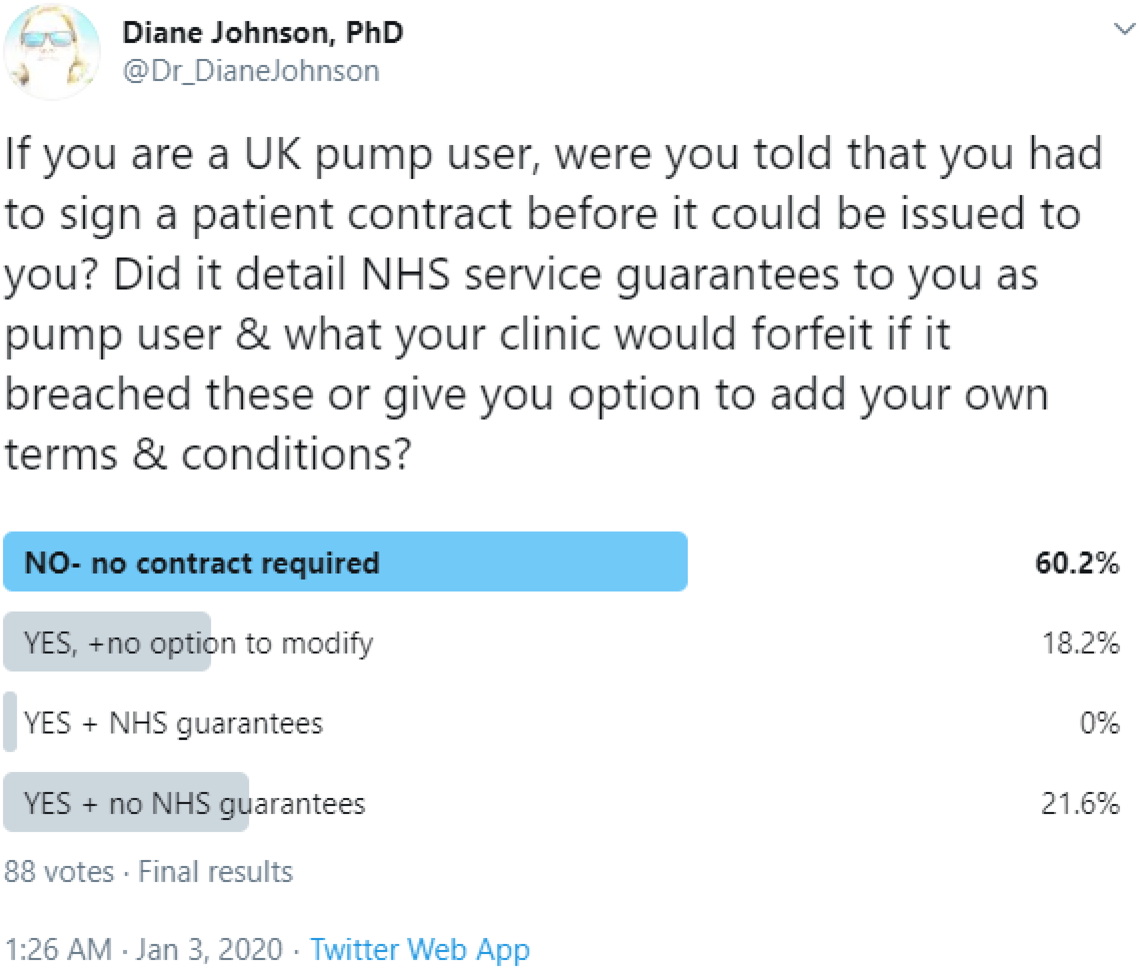
Diane Johnson, PhD
@Dr_DianeJohnson

Replying to @UrgoMedicalUK

This is absolute proof that massive ignorance in some of the medical profession is alive & kicking when it comes to treating PWD. It's sad, pathetic & increadibly damaging. *PLEASE stop destroying lives of PWD & start being responsible*

4:45 PM · Oct 24, 2019 · Twitter Web App

@Dr_DianeJohnson (‘Diane Johnson, PhD’), ‘This is absolute proof that massive ignorance in some of the medical profession is alive & kicking when it comes to treating PWD’, *Twitter*, 24 October 2019, https://twitter.com/Dr_DianeJohnson/status/1187394784333316098.



Diane Johnson, PhD
@Dr_DianeJohnson

If you are a UK pump user, were you told that you had to sign a patient contract before it could be issued to you? Did it detail NHS service guarantees to you as pump user & what your clinic would forfeit if it breached these or give you option to add your own terms & conditions?

NO- no contract required	**60.2%**
YES, +no option to modify	18.2%
YES + NHS guarantees	0%
YES + no NHS guarantees	21.6%

88 votes · Final results

1:26 AM · Jan 3, 2020 · Twitter Web App

@Dr_DianeJohnson, ('Diane Johnson, PhD'), 'If you are a UK pump user, were you told that you had to sign a patient contract before it could be issued to you?', *Twitter*, 3 January 2020, https://twitter.com/Dr_DianeJohnson/status/1212908001809571840.

Emmerbetic
@Emmerbetic

So important. I've been underweight most of my life because I've been very sick. Looking back at old pics, I'm scrawny, but I'm yellow. Now I'm at my healthiest ever, at 15lbs above the BMI "healthy" weight window, and drs always bring the # up like it's a failure.

YOU ARE FIGHTING A LEVEL 1 SNEAKY PIXEL GOOSE @Lu... · Sep 26, 2019
"physicians are required, in writing, to prove [to insurance/hospitals] that they have brought up their patient's weight & formulated a plan to bring it down" - I knew a lot of this stuff was happening but this article spells it out for the people in back. highline.huffingtonpost.com/articles/en/ev...
Show this thread

6:10 PM · Sep 28, 2019 · Twitter for Android

@Emmerbetic ('Emmerbetic') 'So important.', *Twitter*, 28 September 2019, https://twitter.com/Emmerbetic/status/1177993929012252672.

The Grumpy Pumper
@grumpy_pumper

It's done.
I'm absolutely gutted.
I worked so hard to try to avoid this
#TalkAboutComplications

Subject: Clay Road plot 14

Dear Sir,

It is with regret that due to continuing foot issues I am no longer able to cultivate my allotment plot to the standard required by the rental agreement.

I hereby resign my tendency and will not be renewing it for next year.

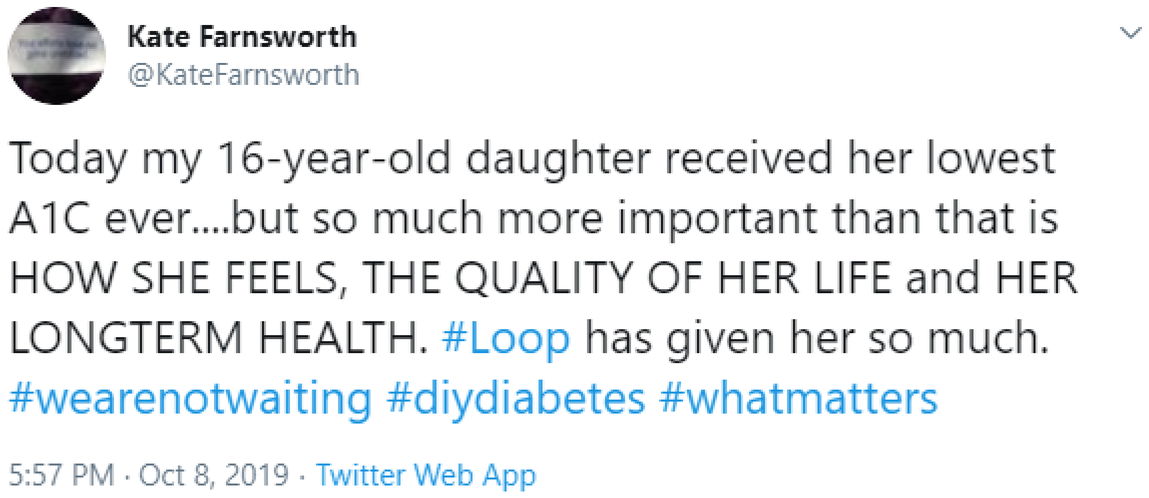
I will ensure the shed is cleared out by the end of October.

The shed and greenhouse can go free to the next tenant

Regards

8:23 AM · Sep 30, 2019 · Twitter for iPhone

@grumpy_pumper ('The Grumpy Pumper') 'It's done.', *Twitter*, 30 September 2019, https://twitter.com/grumpy_pumper/status/1178571101435248641.



Kate Farnsworth
@KateFarnsworth

Today my 16-year-old daughter received her lowest A1C ever....but so much more important than that is HOW SHE FEELS, THE QUALITY OF HER LIFE and HER LONGTERM HEALTH. #Loop has given her so much. #wearenotwaiting #diydiabetes #whatmatters

5:57 PM · Oct 8, 2019 · Twitter Web App

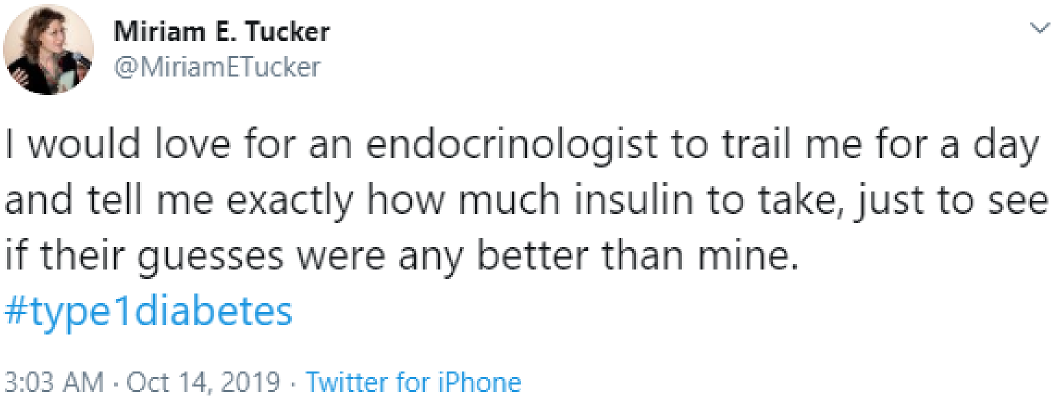
@KateFarnsworth ('Kate Farnsworth'), 'Today my 16-year-old daughter received her lowest A1C ever.', *Twitter*, 8 October 2019, https://twitter.com/KateFarnsworth/status/1181614632940773376.

Laura Marston
@Kidfears99

Went to my PCP yesterday and had full bloodwork done. To the doctor who noted in my labs that my glucose tested at 106 was "elevated," go fuck yourself.

2:40 PM · Oct 18, 2019 · Twitter for iPhone

@Kidfears99 ('Laura Marston'), 'Went to my PCP yesterday and had full bloodwork done.', *Twitter*, 18 October 2019, https://twitter.com/Kidfears99/status/1185188858822086657.

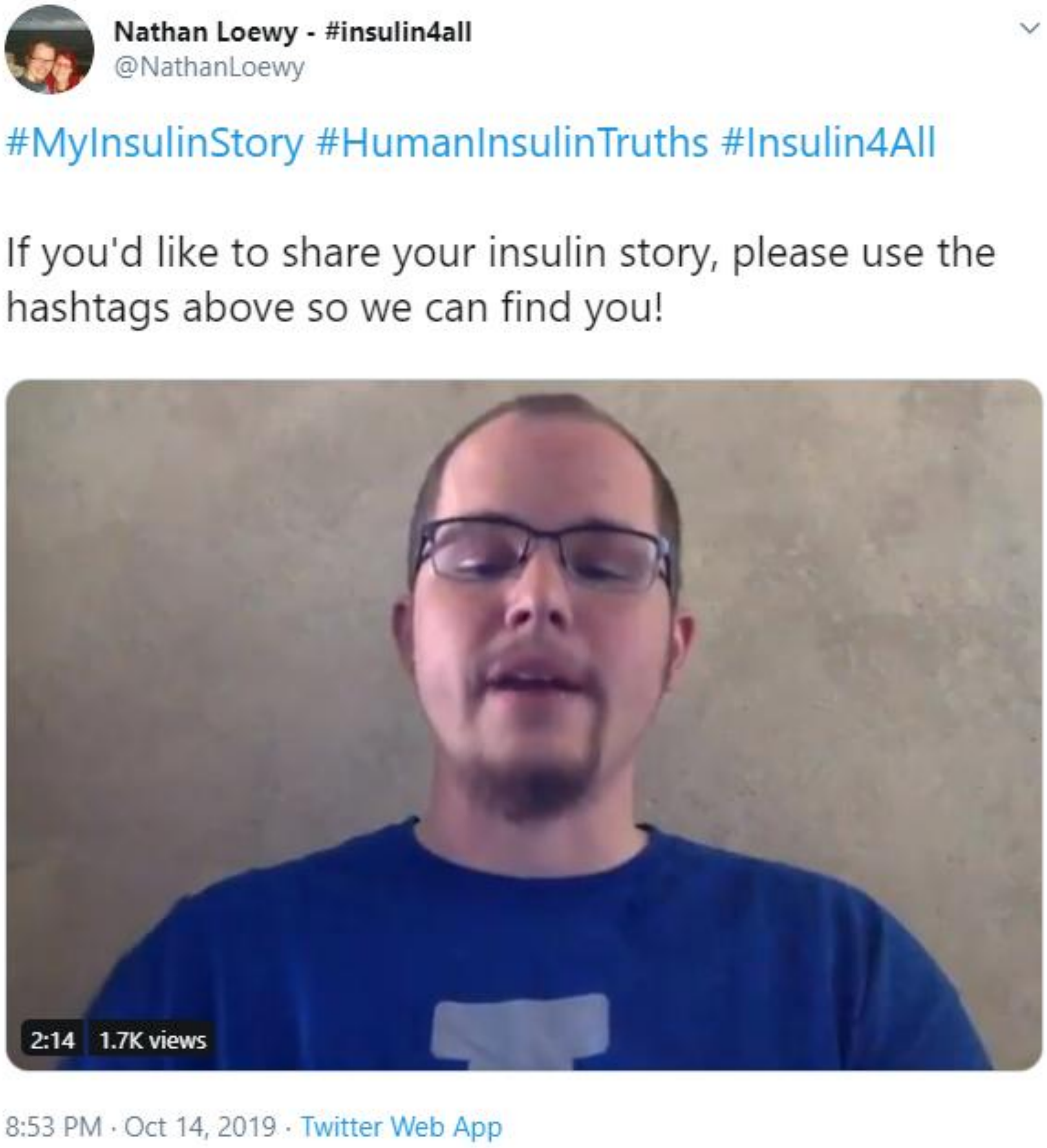


Miriam E. Tucker
@MiriamETucker

I would love for an endocrinologist to trail me for a day and tell me exactly how much insulin to take, just to see if their guesses were any better than mine. #type1diabetes

3:03 AM · Oct 14, 2019 · Twitter for iPhone

@MiriamETucker (‘Miriam E. Tucker’), ‘I would love for an endocrinologist to trail me for a day and tell me exactly how much insulin to take, just to see if their guesses were better than mine.’, *Twitter*, 14 October 2019, https://twitter.com/MiriamETucker/status/1183563971468681217.



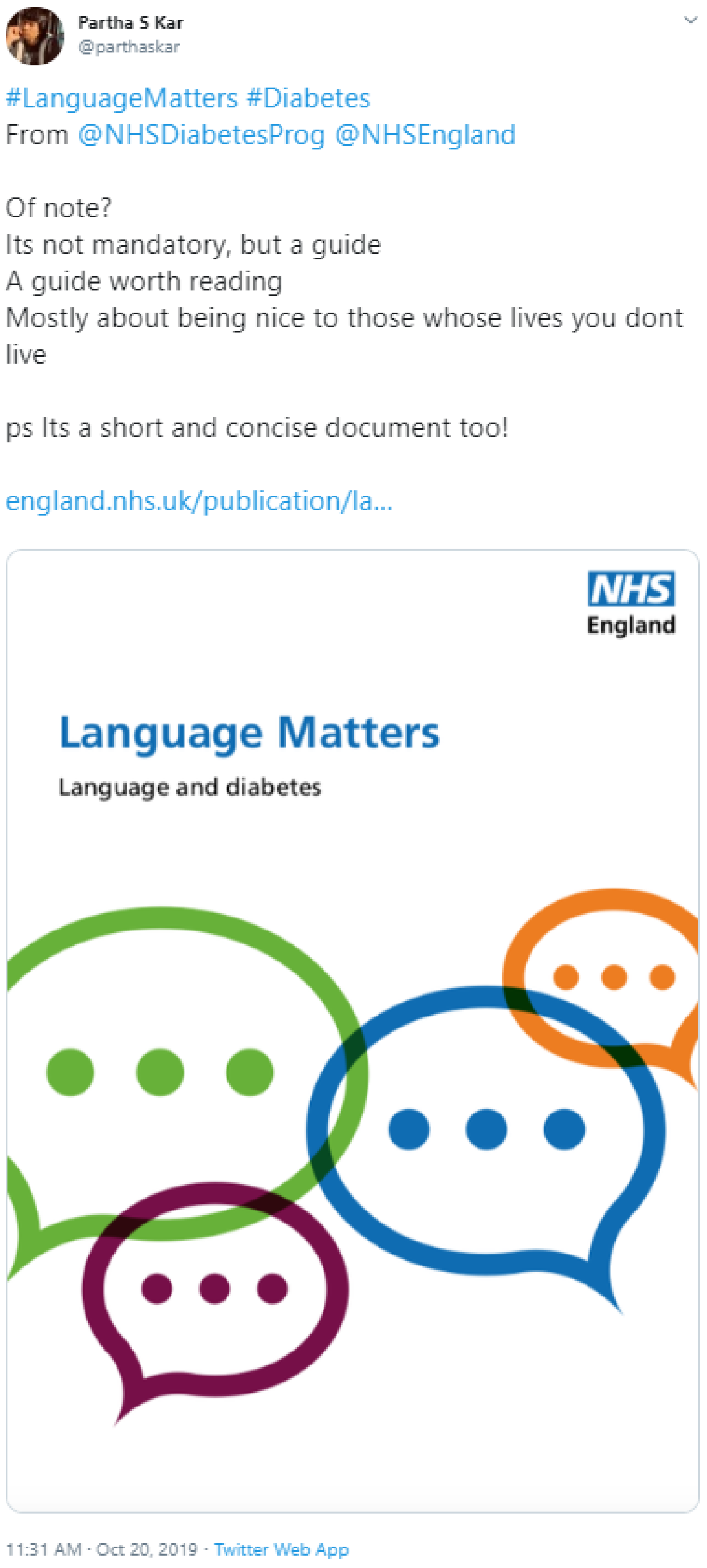
Nathan Loewy - #insulin4all
@NathanLoewy

#MyInsulinStory #HumanInsulinTruths #Insulin4All

If you'd like to share your insulin story, please use the hashtags above so we can find you!

8:53 PM · Oct 14, 2019 · Twitter Web App

@NathanLoewy (‘Nathan Loewy - #Insulin4All’), ‘#MyInsulinStory #HumanInsulinTruths #Insulin4All’, *Twitter*, 14 October 2019, https://twitter.com/NathanLoewy/status/1183833265981005825.



Partha S Kar
@parthaskar

#LanguageMatters #Diabetes
From @NHSDiabetesProg @NHSEngland

Of note?
Its not mandatory, but a guide
A guide worth reading
Mostly about being nice to those whose lives you dont live

ps Its a short and concise document too!

england.nhs.uk/publication/la...

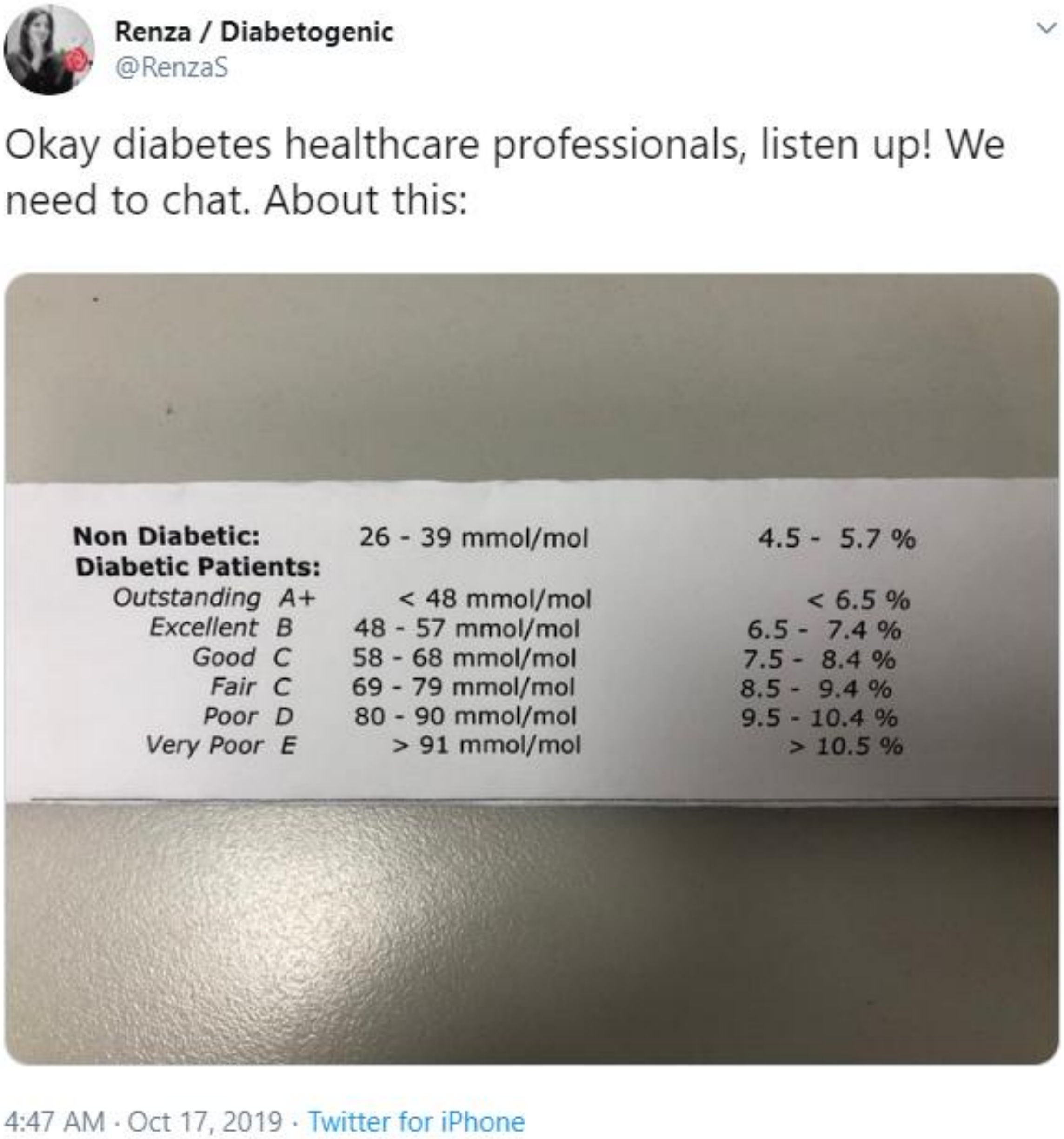
NHS
England

Language Matters

Language and diabetes

11:31 AM · Oct 20, 2019 · Twitter Web App

@parthaskar (‘Partha Kar’), ‘Of note?’, *Twitter*, 20 October 2019, https://twitter.com/parthaskar/status/1185866007014973440.



Renza / Diabetogenic
@RenzaS

Okay diabetes healthcare professionals, listen up! We need to chat. About this:

Non Diabetic:		26 - 39 mmol/mol	4.5 - 5.7 %
Diabetic Patients:			
Outstanding	*A+*	< 48 mmol/mol	< 6.5 %
Excellent	*B*	48 - 57 mmol/mol	6.5 - 7.4 %
Good	*C*	58 - 68 mmol/mol	7.5 - 8.4 %
Fair	*C*	69 - 79 mmol/mol	8.5 - 9.4 %
Poor	*D*	80 - 90 mmol/mol	9.5 - 10.4 %
Very Poor	*E*	> 91 mmol/mol	> 10.5 %

4:47 AM · Oct 17, 2019 · Twitter for iPhone

@RenzaS ('Renza / Diabetogenic'), 'Okay diabetes healthcare professionals, listen up!', *Twitter*, 17 October 2019, https://twitter.com/RenzaS/status/1184677355442163714.

Renza / Diabetogenic
@RenzaS

Replying to @Colonelblighty

It's like a fucking report card.

10:30 AM · Oct 17, 2019 · Twitter for iPhone

@RenzaS ('Renza / Diabetogenic'), 'It's like a fucking report card.', *Twitter*, 17 October 2019, https://twitter.com/RenzaS/status/1184763597638864897.


Renza / Diabetogenic
@RenzaS

Respectfully, the #LanguageMatters movement is not about being (mostly, a little bit or completely) 'nice'. As someone living with diabetes, I know it is far, far more important than being about just 'good manners'.

Partha S Kar @parthaskar · Oct 20, 2019
#LanguageMatters #Diabetes
From @NHSDiabetesProg @NHSEngland

Of note?
Its not mandatory, but a guide
A guide worth reading
Mostly about being nice to those whose lives you dont live

ps Its a short and concise document too!

england.nhs.uk/publication/la...

4:45 AM · Oct 21, 2019 · Twitter for iPhone

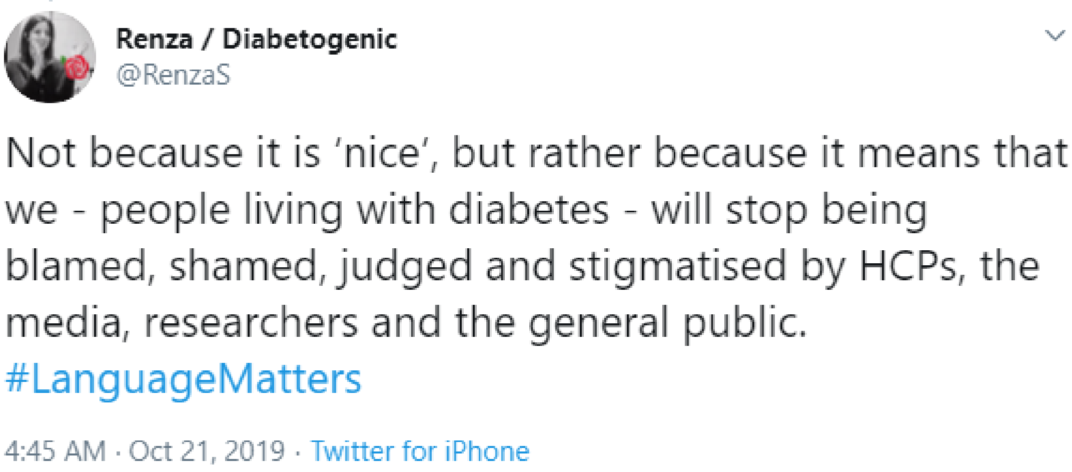
@RenzaS ('Renza / Diabetogenic'), 'Respectfully, the #LanguageMatters movement is not about being (mostly, a little bit or completely) 'nice'.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126234754748416.


Renza / Diabetogenic
@RenzaS

But we should also try to ensure that diabetes is represented and presented in a way that does not harm those of us living with it. #LanguageMatters provides ways to do that.

4:45 AM · Oct 21, 2019 · Twitter for iPhone

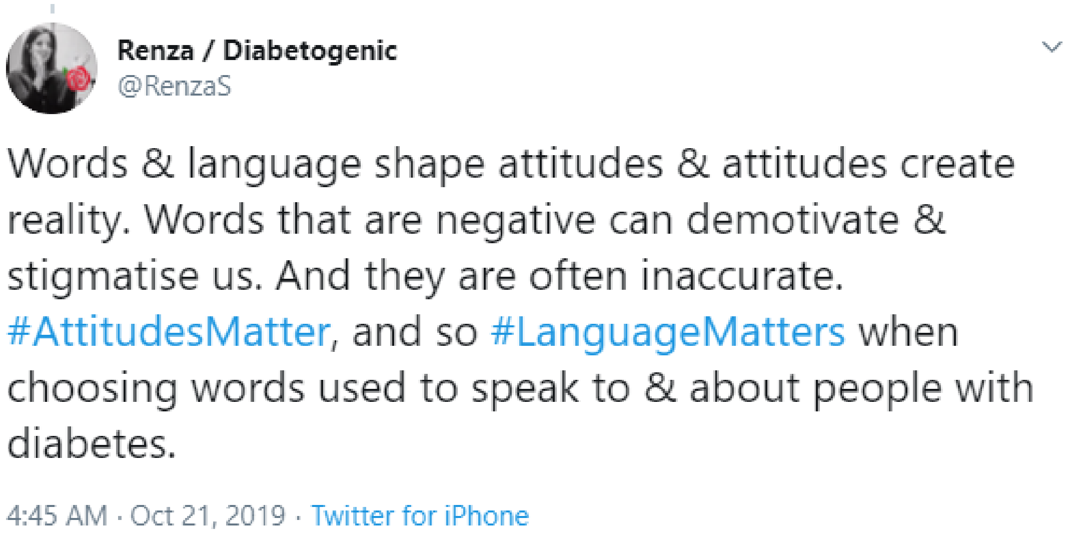
@RenzaS ('Renza / Diabetogenic'), 'But we should also try to ensure that diabetes is represented and presented in a way that does not harm those of us living with it.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126252756750337.


Renza / Diabetogenic
@RenzaS

Not because it is 'nice', but rather because it means that we - people living with diabetes - will stop being blamed, shamed, judged and stigmatised by HCPs, the media, researchers and the general public. #LanguageMatters

4:45 AM · Oct 21, 2019 · Twitter for iPhone

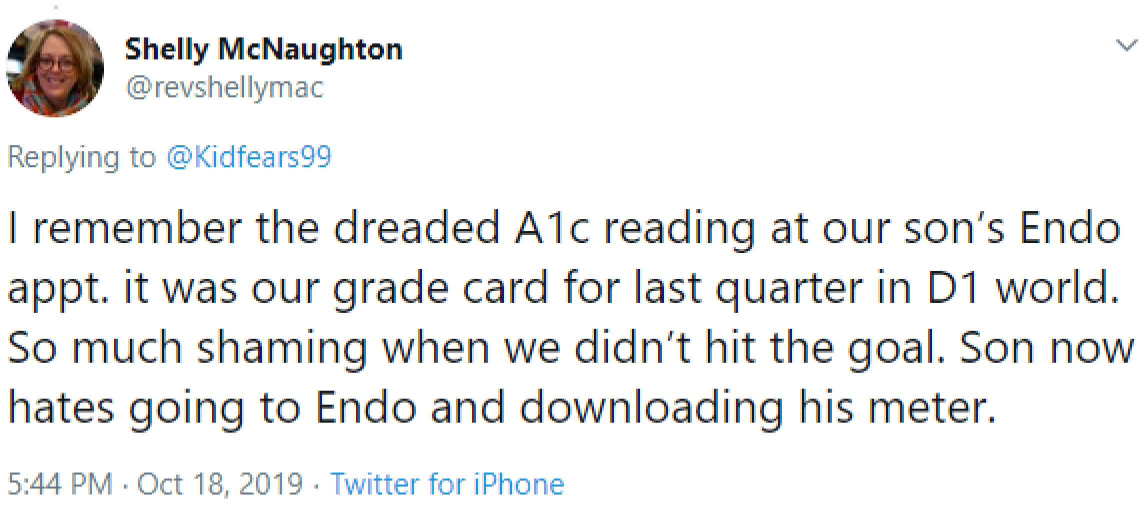
@RenzaS ('Renza / Diabetogenic'), 'Not because it is 'nice', but rather because it means that we – people living with diabetes – will stop being blamed, shamed, judged and stigmatised by HCPs, the media, researchers and the general public.', *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126254858047493.


Renza / Diabetogenic
@RenzaS

Words & language shape attitudes & attitudes create reality. Words that are negative can demotivate & stigmatise us. And they are often inaccurate. #AttitudesMatter, and so #LanguageMatters when choosing words used to speak to & about people with diabetes.

4:45 AM · Oct 21, 2019 · Twitter for iPhone

@RenzaS (‘Renza / Diabetogenic’), ‘Words & language shape attitudes & attitudes create reality.’, *Twitter*, 21 October 2019, https://twitter.com/RenzaS/status/1186126238055682049.


Shelly McNaughton
@revshellymac

Replying to @Kidfears99

I remember the dreaded A1c reading at our son’s Endo appt. it was our grade card for last quarter in D1 world. So much shaming when we didn’t hit the goal. Son now hates going to Endo and downloading his meter.

5:44 PM · Oct 18, 2019 · Twitter for iPhone

@revshellymac (‘Shelly McNaughton’), ‘I remember the dreaded A1c reading at our son’s Endo appt.’, *Twitter*, 18 October 2019, https://twitter.com/revshellymac/status/1185235218980102144.

My Artificial Pancreas
@T1Bionic

Patients have - medical domain expertise, device security expertise, tech expertise. They are innovators, engineers, enablers, documentors, communicators, educators & there is an ever-growing group of grateful beneficiaries. #WeAreNotWaiting

12:24 AM · Sep 25, 2019 · Twitter for iPhone

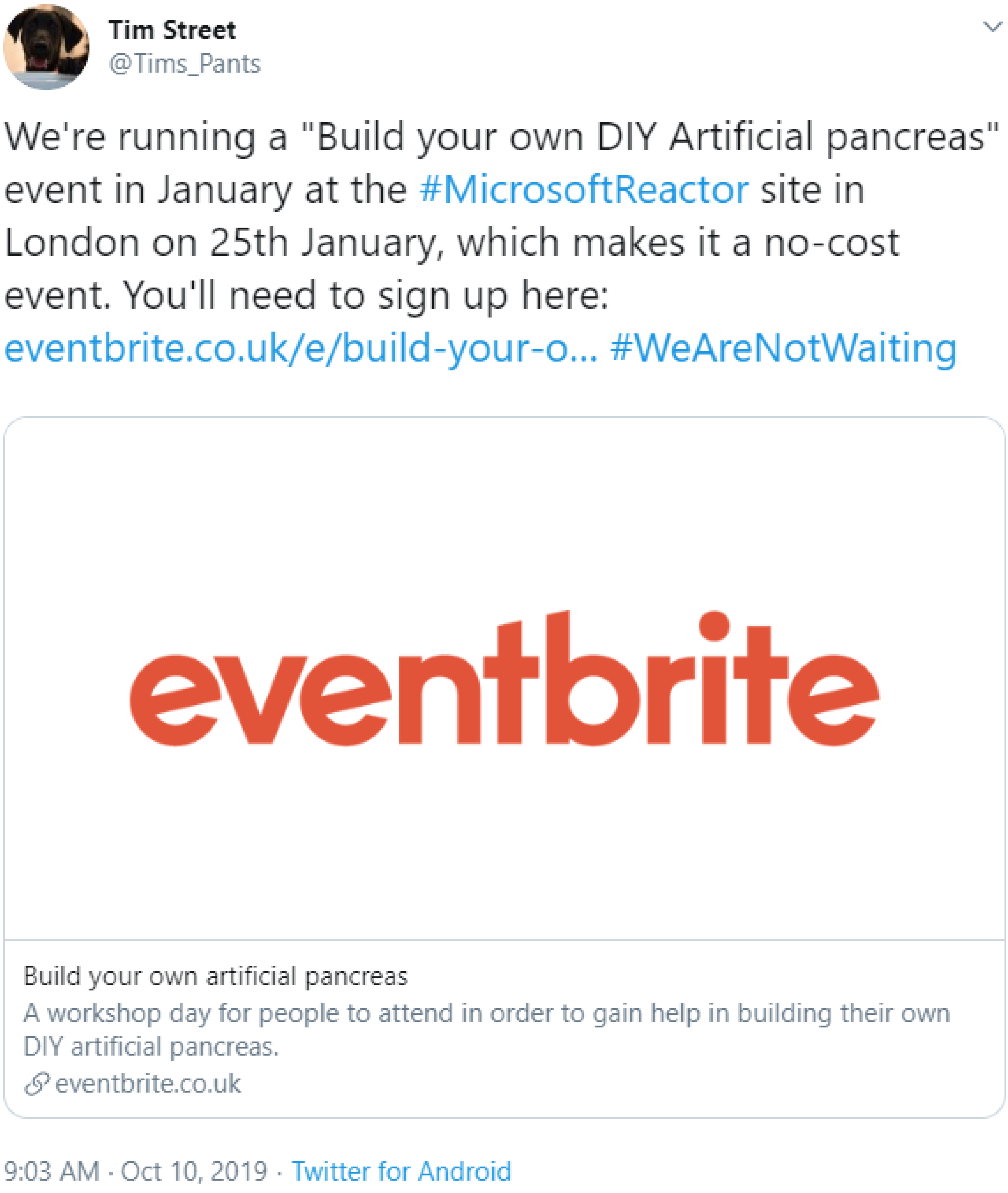
@T1Bionic (‘My Artificial Pancreas’), ‘Patients have – medical domain expertise, device security expertise, tech expertise.’, *Twitter*, 25 September 2019, https://twitter.com/T1Bionic/status/1176638568569044994.


Jillian
@T1dchick_

I used to think this was “low” blood sugar goals. BUT, food shouldn’t be a reward, we shouldn’t “reward” our blood sugars. If we want Candy, just bolus and eat it. We have to really change the way we think about food.

3:24 PM · May 24, 2019 · Twitter for iPhone

@T1dchick_ (‘Jillian’) ‘I used to think this was ‘low’ blood sugar goals.’, *Twitter*, 24 May 2019, https://twitter.com/T1dchick_/status/1131929008793411585.



Tim Street
@Tims_Pants

We're running a "Build your own DIY Artificial pancreas" event in January at the #MicrosoftReactor site in London on 25th January, which makes it a no-cost event. You'll need to sign up here: eventbrite.co.uk/e/build-your-o… #WeAreNotWaiting

Build your own artificial pancreas
A workshop day for people to attend in order to gain help in building their own DIY artificial pancreas.
eventbrite.co.uk

9:03 AM · Oct 10, 2019 · Twitter for Android

@Tims_Pants ('Tim S'), 'We're running a 'Build your own DIY Artificial pancreas' event in January at the #MicrosoftReactor site in London on 25th January, which makes it a no-cost event.', *Twitter*, 10 October 2019, https://twitter.com/Tims_Pants/status/1182204961087725568.

Urgo Medical UK
@UrgoMedicalUK

The case for Motivational Interviewing - Patients deserve better outcomes but motivational interviewing is not routinely used by HCPs in the management of DFU.
Debating current management via patient and clinician discussion improves learning #DPC2019 #diabetes

To scare *or* not to scare?

The question faced by HCPs when managing people with diabetes foot ulcers

URGO MEDICAL
invites you to a *'Judge Rinder-style' hearing* hosted by television and radio media medic
Dr Sarah Jarvis

Diabetes Professional Care Conference
- 14.00 to 14.45
  Tuesday 29th October
- Main Keynote Theatre
  Olympia

FOR & AGAINST
Expert witnesses to discuss:
"Motivational interviewing Vs scare tactics"
in the management of diabetes foot ulcers

WITNESS PANEL
- **Professor Karen Ousey**
  Professor of Skin Integrity
- **Professor Paul Chadwick**
  Clinical Director, College of Podiatry
- **Donna Welch**
  Principal Podiatrist Diabetes
- **Sue Marshall**
  Editor of Desang magazine

4:53 PM · Oct 23, 2019 · Twitter Web App

@UrgoMedicalUK ('Urgo Medical UK'), 'The case for Motivational Interviewing', *Twitter*, 23 October 2019, https://twitter.com/UrgoMedicalUK/status/1187034276073824257.

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Greater Glasgow Area Medical Committee, Sub-Committee in Medicine, Diabetic Services in Glasgow: A Report by J.T. Ireland and A.C. MacCuish, 24th May 1979, HB55/912/DBO/O, NHS Greater Glasgow and Clyde Archives.

Letter from Dr. R. J. Weir to Dr. Donald, 14th June 1983, HB57, NHS Greater Glasgow and Clyde Archives.

Pre-mixed Insulin Marketing Leaflet, January 1993, T/1993/1446-1454, Science Museum Technical Object Files.

Young Girl Before and After Insulin Treatment, 1922, L0031615, Wellcome Images.

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Fletcher, Charles, ‘Prof Fletcher replies...’, *Balance*, June 1981, p. 2.

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