Health Implementation Research Hub

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University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

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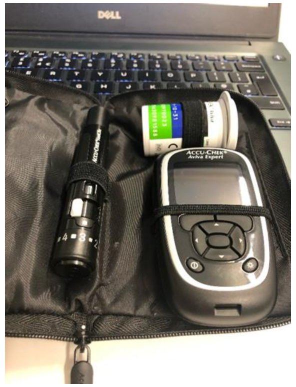
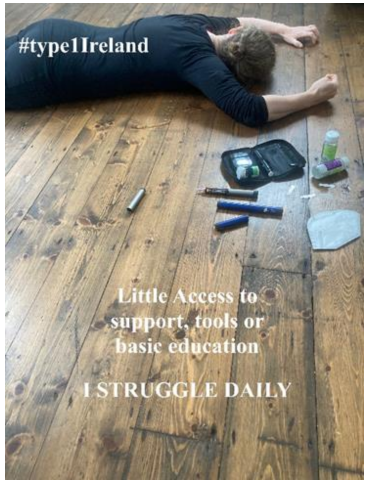
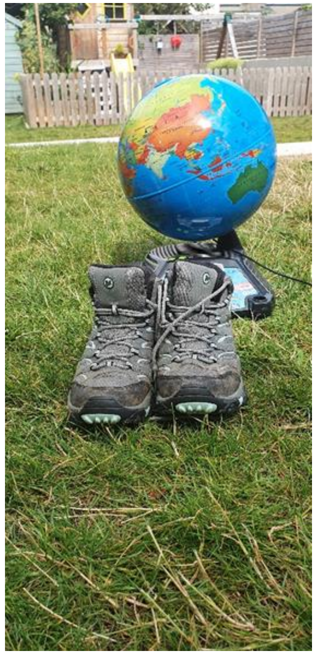
Experiences of the DAFNE structured education programme, and managing type 1 diabetes during Covid-19: A photovoice project







Experiences during Covid-19

Covid-19 disrupting self-management routines

There was that sense of isolation and lack of human interaction. I would go for walks in the garden for 15 minutes trekking around, you know? **It was a bit like a prison yard. That sort of thing really impacted on my daily routine** in terms in of self-managing my diabetes. But I mean with modern technology I was still able to contact people

Administrative burden of supplies during the pandemic

It's a full-length wardrobe of supplies and essentially you have to be ready for everything, especially when COVID first hit. You're hearing about supply chains and your insulin not being available, your needles not being available, and you know they're real realities. I don’t want to say I overstocked, but I was certainly being very cautious and maybe ordering unusual amounts and trying to use less at the start...I know there's a kind of journalistic hysteria, but it does sit with you and go, I'm going to die if I don't have this stuff. **It's just there's just such an administrative burden around diabetes**

Vulnerability and lack of support at a national level

At a certain point, **the narrative changed around Covid and it's kind of like everything has gone back to normal** and you don't need to wear a mask or socially distance anymore but the medically vulnerable still need to protect themselves because no-one else is going to. Society at large has stopped protecting more vulnerable people so now it's up to us to keep getting vaccinated, keep wearing masks, stay isolated and everybody else can go off and live normally

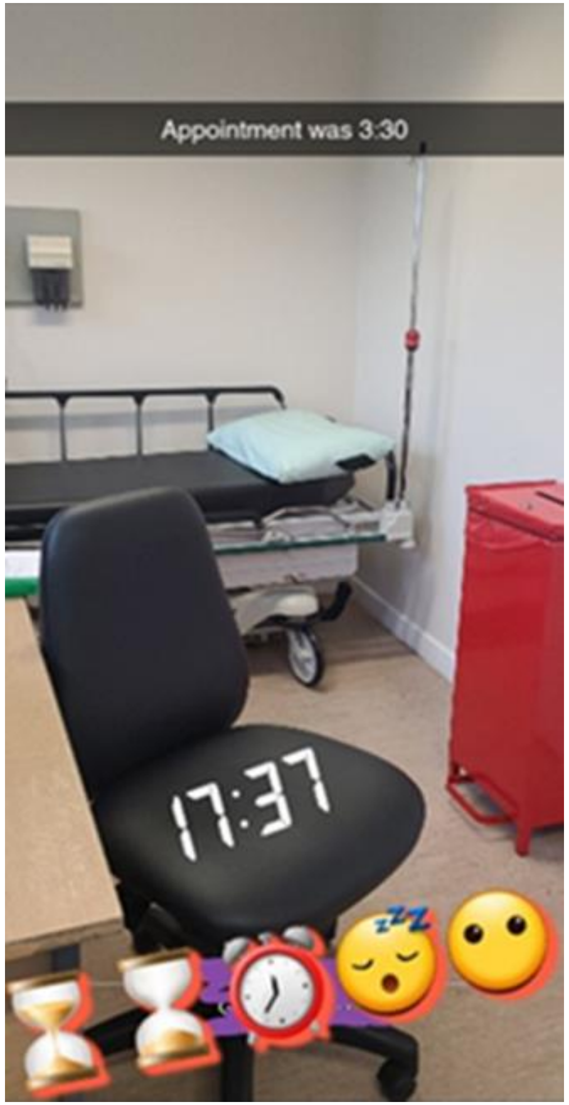
Vulnerability, stress and the impact of lockdown

My mum was in a nursing home, so **stress definitely affected my diabetes.** That was taken in July 2020 after the nursing home had been in lockdown for nearly 6 months. My mother's dementia progressed so rapidly because there was no human interaction. , Unfortunately, there's still people this week in isolation in the nursing home, so it's a continuum of openings, closings and window visits. It might not be hitting the headlines, but it's still ongoing

Limited disruption during the pandemic

I didn’t experience major changes during the pandemic because I continued to work but **it got moved online so it was more convenient.** During the pandemic we had a lot of free time, and this is one of the benches that we built during this time

Embracing the potential of online health services and appointments

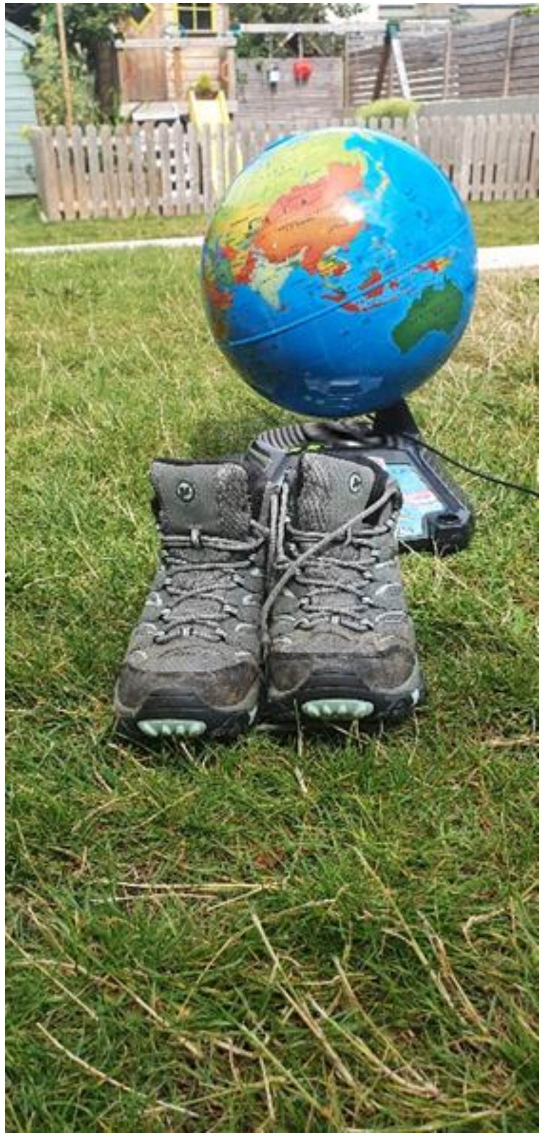


I’m coming from a very privileged position being able to get access to diabetes, endocrinologists so I don't want to be giving out about stuff but it's hard when you take time off work and rush to appointments but have a fair idea you will be sitting there for probably at least 2 hours before you are seen. **Sometimes we're waiting so long for what could be a 15-minute consultation.** During COVID, some of these would have reverted back to telehealth but I wasn't given the option of video calls, it was all telephone calls and you do lose a certain amount of connection there too and **you just wonder if enough services embrace video calls**.

Experiences of the DAFNE programme

Flexibility and freedom to engage in exercise and make dietary choices

Flexibility and freedom to make dietary choices



Just to be able to have the freedom to take that [6 month] trip the following year after my diabetes diagnosis, I felt very free that I could do that.

I felt very lucky, and I really feel that if I hadn't done DAFNE at that stage, I definitely wouldn't have had the knowledge to allow me to just take off and know how to manage things.

DAFNE isn't restrictive on what food you have to eat, and **it helped me venture out there and, you know and give things a try as well**

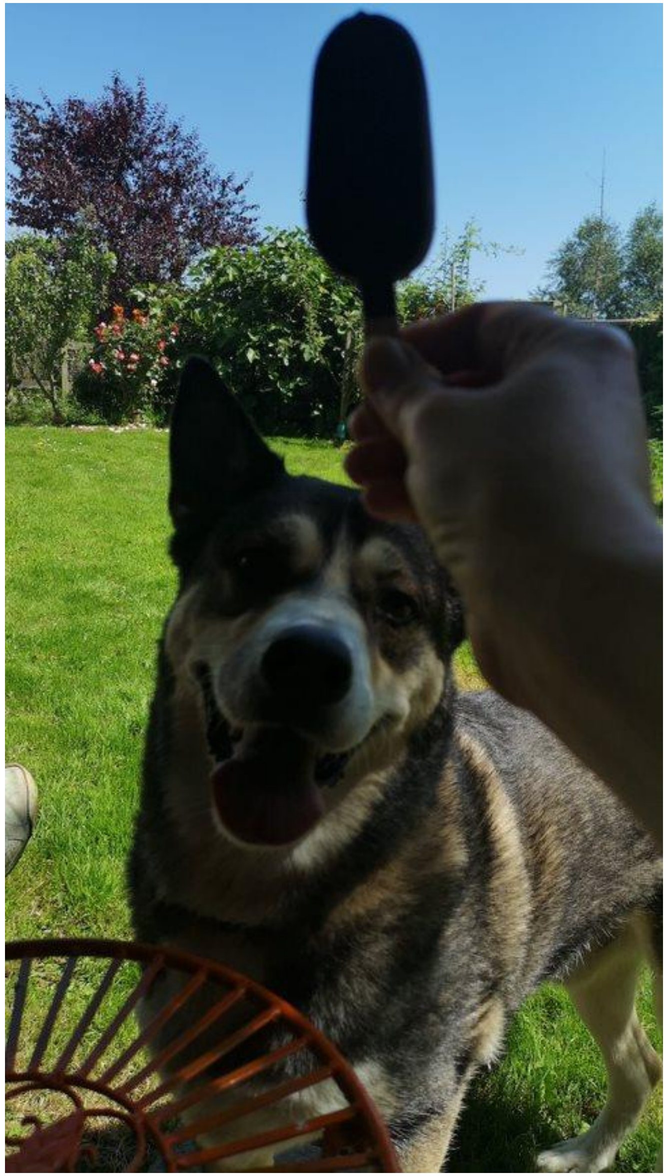
Flexibility and freedom to engage in hobbies

With the DAFNE programme, **I was able to manage hiking and was able to regulate coming up and down**. This is something that I wouldn’t have been able to do as much when I became a diabetic. It would have had a massive impact. I wouldn’t have been able to do it as easily…I can now do a solid hour’s walk or two hours and I’m not going to fall down and go into a coma or something like that

Flexibility and freedom to make dietary choices

This was a summer holiday picture with my family. It was just a great day and we hope to repeat it this year, possibly even going abroad and not having the same restrictions as before DAFNE. You know when you go abroad and the food is a little bit different and everything is a bit different but **it's about being able to work with what you have**

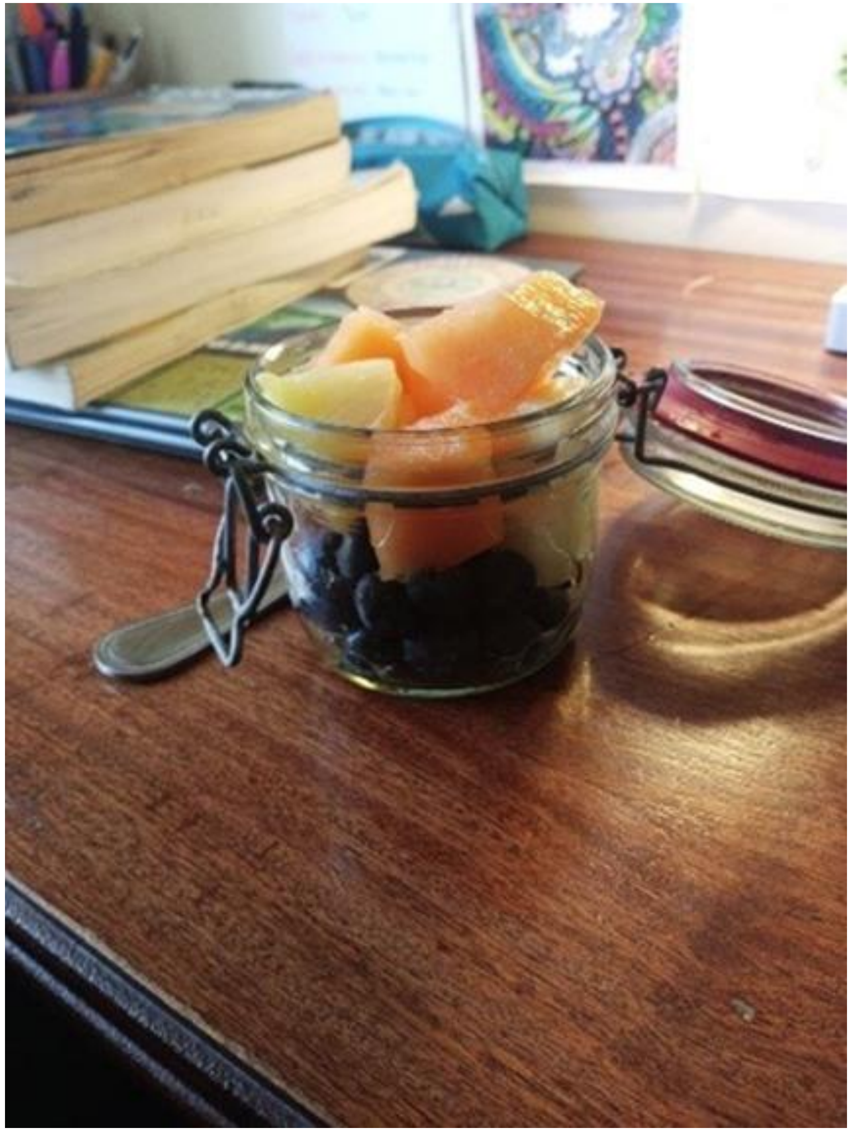
Flexibility and freedom to make dietary choices



That was us chilling, hanging out with the dogs in the back garden with ice creams. It’s simple but important to me. After DAFNE I could eat ice-cream again and not keel over with the sugars. I haven’t eaten ice-cream in years.

It does mean an awful lot to me that I can now eat more foods

Flexibility and freedom to make dietary choices



I think when I became a diabetic, everybody said “Oh you don’t eat chocolate, you don’t eat sugar,” you know, whereas DAFNE gave me structure. It explained foods that I could eat and the result of what happens when I eat them. You can eat chocolate, it’s just three hours later you’re going to have the effect. It explains how different foods work. It gives a structure in your life that you can follow.

I was never restricted with DAFNE. It gave me more options and helped explain it and how to manage it. So, it gives you freedom again

Flexibility and freedom to make dietary choices

One of the things I think they covered well was alcohol and junk food. I think they covered how various drinks would affect your blood sugar. **I think the approach of including it and not shaming people for eating like a take-away after going to the pub is excellent**.

Applying and adapting the DAFNE programme principles

Applying the DAFNE principles: Exercise

I play a lot of golf and I always have a banana on the 8th hole because I find that it's the right time. If you’re doing exercise, it’s very important to plan for it by reducing your insulin. I also have glucose shots or a glucose drink that. I’d always take with me.

I found the DAFNE program covered exercise well, but **every individual is physiologically different, so it does come down to trial and error.**

Applying the DAFNE principles: Exercise

With the DAFNE course the goal is to always keep your blood around 6:00 to 8:00 but my blood sugars are heavily affected by exercise so if I kept them at that level throughout the day, I would constantly be going low regardless of how little insulin I took

Applying the DAFNE principles: Exercise

They [DAFNE] also recommended to only to eat something if you need to, but I had to explain a couple of times If I don’t drink a couple of glucose syrups or a can of coke before I go swimming, I will get 15 minutes and then I will spend an hour recovering in some significant discomfort. I feel like they never take that into account. It’s horrific and I lose an hour of my life just sat there and not able to do anything. **I’d much rather go slightly high than be low and not be able to do anything with my life.**

Applying the DAFNE principles: Exercise

I think **the DAFNE course's advice on exercise is not very cohesive** and a major shortfall of the course. If you were doing regular active work throughout the day such as heavy labour or for example construction work, its not covered. They focus more on concentrated periods of pre-planned exercise which isn't realistic for some people. It's the background exercise that you are doing during the day that going to get you.

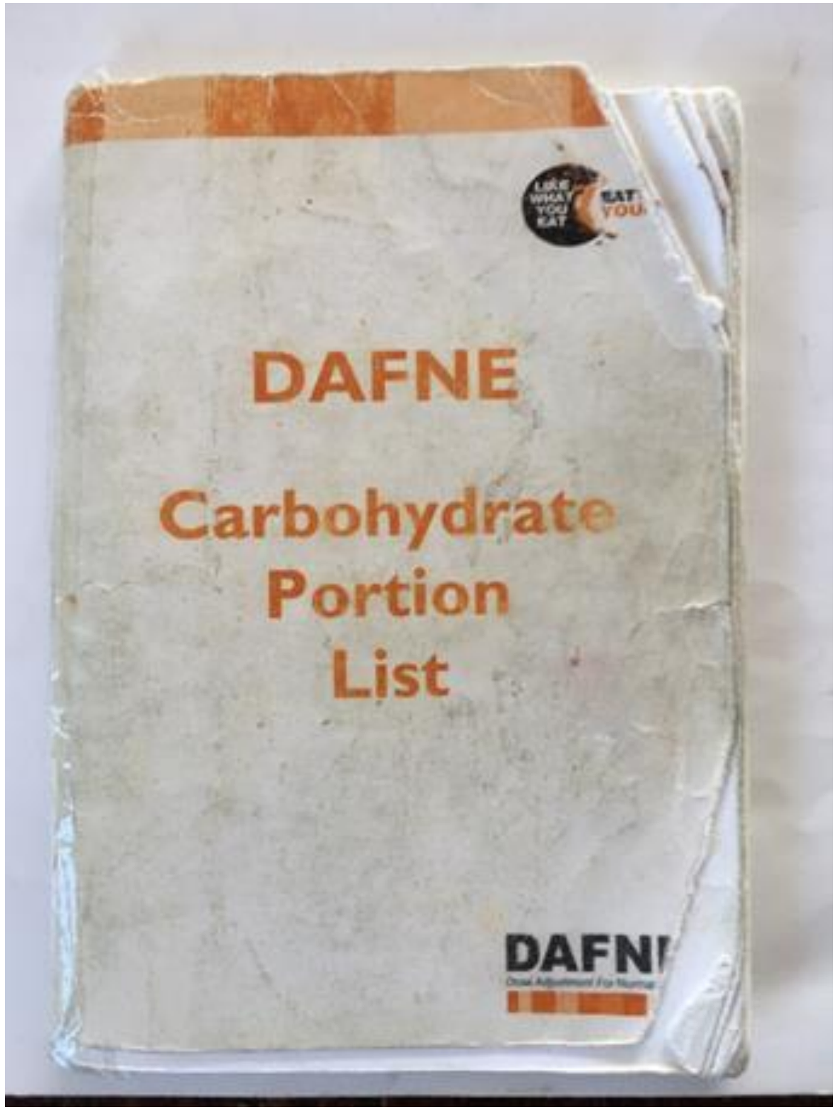
Applying the DAFNE principles: Exercise

Weaving is a nightmare for my blood sugars. I told my dietician, and she said that look as long as I’m not in danger when I’m going low, she was sorry but didn’t know how to handle it. I don't think that the information is there for them to give the after support. Even if they had **just a couple of pages where they gave a loose outline of how various exercises would affect your blood sugar would be helpful but that wasn’t there**.

Applying the DAFNE principles: Diet

I have a real problem there [with calculations]. Most of the items that I buy in the shop like boxes of cereals and things like that would have it written at the side of them, how much carbohydrates they have per 100 grams, for instance. So, as long as I know whatever I’m taking, I can calculate the carbohydrate and from that and then the insulin. Then I have to add any other foods that I have for example a glass of orange juice or a slice of toast. **It’s a bit of a chore and if I were to apply it diligently, I don’t think I’d have a minute to spare in the day to be honest. So, I take a guess here**.

Applying the DAFNE principles: Diet



The DAFNE book. You can see how used that is. I would certainly say I use it weekly if not every few days to just double check on carbohydrate portion values and all sorts of advice about sick days and alcohol and what have you. **I found it very valuable, and it goes everywhere with me.** I also have it on my phone as an app.

Applying the DAFNE principles: Diet

The carbs and cals app is brilliant, but **you're still doing essentially a bit of guesswork.** I was out for an Indian and I went very low afterwards. I've had diabetes since I met my husband and I consider him to be very educated, but I remember him saying "You've had a big meal, how were you so low" People often don't understand that if you're taking, between 12 to 14 units for example for a meal, one unit is the difference between coasting along at a very nice 5.5 or being a 2.5. Sometimes it's not worth eating out in restaurants because you have a lot less control.

Applying the DAFNE principles: Diet

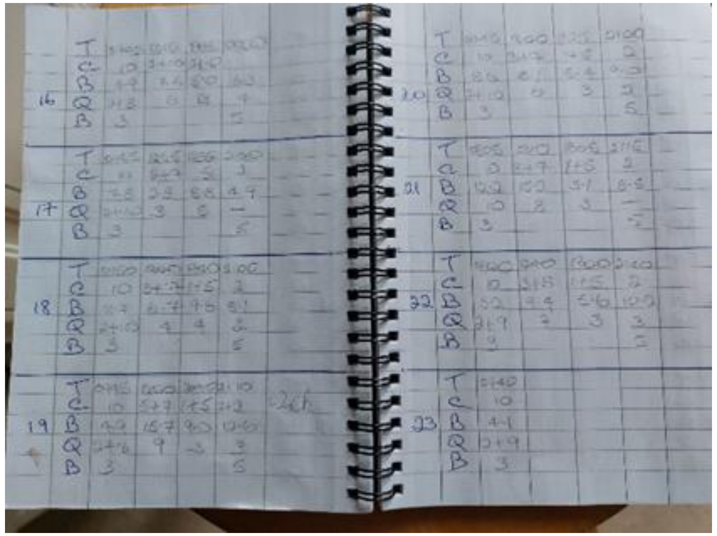
I did the carb count for it [a homemade dessert] with the carbs and Cals app, but since it was pre-programmed for a premade store-bought mousse, which was the only one that I could find, it gave me a lot more sugar than what was actually there. When you try to say here's all the answers, **you are invariably going to come across things that don't fit into a strict binary of food**. I'm personally very good at estimating how many carbs are in something. So, I was technically doing the carb counting, but I didn't use the resources they gave us because I found that trying to make them work was just more of a hazard than anything else.

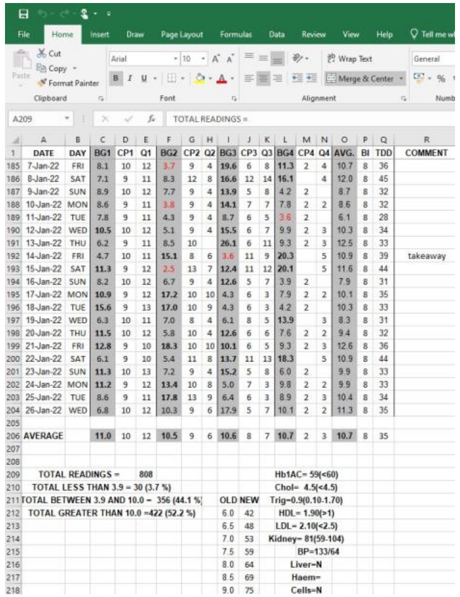
Applying the DAFNE principles: Diet

Every now and then team in the hospital ask me to take a food diary which is a very detailed account of everything that I’ve been eating with measurements. I don’t do that everyday because I wouldn’t have time for anything else, but **it sets me up to see if I should change course in any respect.**

Applying the DAFNE principles: Diet

I designed this book myself with the dates down the left-hand side and the times that I take the readings going along the top. The stands for time of BG reading, the C stands for carbohydrate, the B stands for blood glucose, the Q is for quick-acting insulin and the B is for background insulin. I transcribe the notebook data onto an Excel spreadsheet, a portion of which I print out and discuss with the diabetes team at clinic. **The activity I undertake between BG readings has a significant bearing on how I manage my diabetes** and making allowance for this is particularly challenging.





TOTAL READINGS =

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
1	DATE	DAY	BG1	CP1	Q1	BG2	CP2	Q2	BG3	CP3	Q3	BG4	CP4	Q4	AVG.	BI	TDD	COMMENT
185	7-Jan-22	FRI	8.1	10	12	3.7	9	4	19.6	6	8	11.3	2	4	10.7	8	36	
186	8-Jan-22	SAT	7.1	9	11	8.3	12	8	16.6	12	14	16.1		4	12.0	8	45	
187	9-Jan-22	SUN	8.9	10	12	7.7	9	4	13.9	5	8	4.2	2		8.7	8	32	
188	10-Jan-22	MON	8.6	9	11	3.8	9	4	14.1	7	7	7.8	2	2	8.6	8	32	
189	11-Jan-22	TUE	7.8	9	11	4.3	9	4	8.7	6	5	3.6	2		6.1	8	28	
190	12-Jan-22	WED	10.5	10	12	5.1	9	4	15.5	6	7	9.9	2	3	10.3	8	34	
191	13-Jan-22	THU	6.2	9	11	8.5	10		26.1	6	11	9.3	2	3	12.5	8	33	
192	14-Jan-22	FRI	4.7	10	11	15.1	8	6	3.6	11	9	20.3		5	10.9	8	39	takeaway
193	15-Jan-22	SAT	11.3	9	12	2.5	13	7	12.4	11	12	20.1		5	11.6	8	44	
194	16-Jan-22	SUN	8.2	10	12	6.7	9	4	12.6	5	7	3.9	2		7.9	8	31	
195	17-Jan-22	MON	10.9	9	12	17.2	10	10	4.3	6	3	7.9	2	2	10.1	8	35	
196	18-Jan-22	TUE	15.6	9	13	17.0	10	9	4.3	6	3	4.2	2		10.3	8	33	
197	19-Jan-22	WED	6.3	10	11	7.0	8	4	6.1	8	5	13.9		3	8.3	8	31	
198	20-Jan-22	THU	11.5	10	12	5.8	10	4	12.6	6	6	7.6	2	2	9.4	8	32	
199	21-Jan-22	FRI	12.8	9	10	18.3	10	10	10.1	6	5	9.3	2	3	12.6	8	36	
200	22-Jan-22	SAT	6.1	9	10	5.4	11	8	13.7	11	13	18.3		5	10.9	8	44	
201	23-Jan-22	SUN	11.3	10	13	7.2	9	4	15.2	5	8	6.0	2		9.9	8	33	
202	24-Jan-22	MON	11.2	9	12	13.4	10	8	5.0	7	3	9.8	2	2	9.9	8	33	
203	25-Jan-22	TUE	8.6	9	11	17.8	13	9	6.4	6	3	8.9	2	3	10.4	8	34	
204	26-Jan-22	WED	6.8	10	12	10.3	9	6	17.9	5	7	10.1	2	2	11.3	8	35	
205																		
206	AVERAGE		11.0	10	12	10.5	9	6	10.6	8	7	10.7	2	3	10.7	8	35	
207																		
208																		

		OLD	NEW	
209	TOTAL READINGS = 808			Hb1AC= 59(<60)
210	TOTAL LESS THAN 3.9 = 30 (3.7 %)			Chol= 4.5(<4.5)
211	TOTAL BETWEEN 3.9 AND 10.0 = 356 (44.1 %)	OLD	NEW	Trig=0.9(0.10-1.70)
212	TOTAL GREATER THAN 10.0 =422 (52.2 %)	6.0	42	HDL= 1.90(>1)
213		6.5	48	LDL= 2.10(<2.5)
214		7.0	53	Kidney= 81(59-104)
215		7.5	59	BP=133/64
216		8.0	64	Liver=N
217		8.5	69	Haem=
218		9.0	75	Cells=N

Applying the DAFNE principles: Guessimation

For a diabetic, like everyone else you have to eat, but we have to measure everything. If I’m at home, I use a weighing scales. I would use that weighing scales every day for the past 17 years. **It's guesswork really, but you do learn over time**. Your blood sugar levels will tell you if you underestimated or overestimated.

Applying the DAFNE principles: Guessimation

It's a lot better now than it used to be in, you know, and people are much more aware about it now and I think one thing about people who don't have diabetes, they're really scared that you're going to have a high glycemic reaction and you know, faint or go weird on them or whatever. I do my best to explain to people about what I'm doing when I'm injecting. It's very important for people who have diabetes to tell people that they have it and explain to them the different things and also what to do if something happens.

Applying the DAFNE principles: Guesstimation

3 average size chips relate to one carbohydrate portion. You can count them as you eat them, or you can estimate. You learn to be quite efficient at doing it. Part of the DAFNE programme was showing us food and letting us guess the carbohydrate portion. A big part of the Daphne program was to help you and when you were say out visiting somebody or out having a meal outside and you can't really take a weighing scales out of out of a bag? **I still use the rule of thumb 17 years later.**

Applying the DAFNE principles: Guesstimation

This [photo] is about guesstimation and the way I wouldn't accurately carb count, but I would take guesses. That's one of the advantages of DIY looping…I don't enter any carbs or any insulin. I let the pump and algorithm do it all for me. You do need to have some DAFNE education to be able to do that and access to technology, but I think a common feature of people living with Type 1 diabetes is guesstimation. Maybe I'm different, I know a few people who weigh out and calculate everything but that is not my experience at all.

Applying the DAFNE principles: Understanding irregularities

That’s the life blips and you can plan for everything but maybe a bus breaks down or maybe you get Covid, or the temperature is hotter than you prepared for or something, you know, and it just knocks the hope of getting a balanced day ahead. This picture represents **the impossibility of balance**. The DAFNE programme helped me to understand irregularities and how you can only swing in a general direction and hope you get there. If I eat breakfast cereal and fruit and just sit tight all day, I can get the balance right, but if I move it all, forget it, you know.

Applying the DAFNE principles: Understanding irregularities

I like that DAFNE looks at variables. **It gives us excellent training in looking at consequences**. My meals became more precise after DAFNE. For that two first two or three years, I weighed everything. I don't do it now. I have an idea and I take a third of the insulin I ever would have taken because of experimenting through DAFNE.

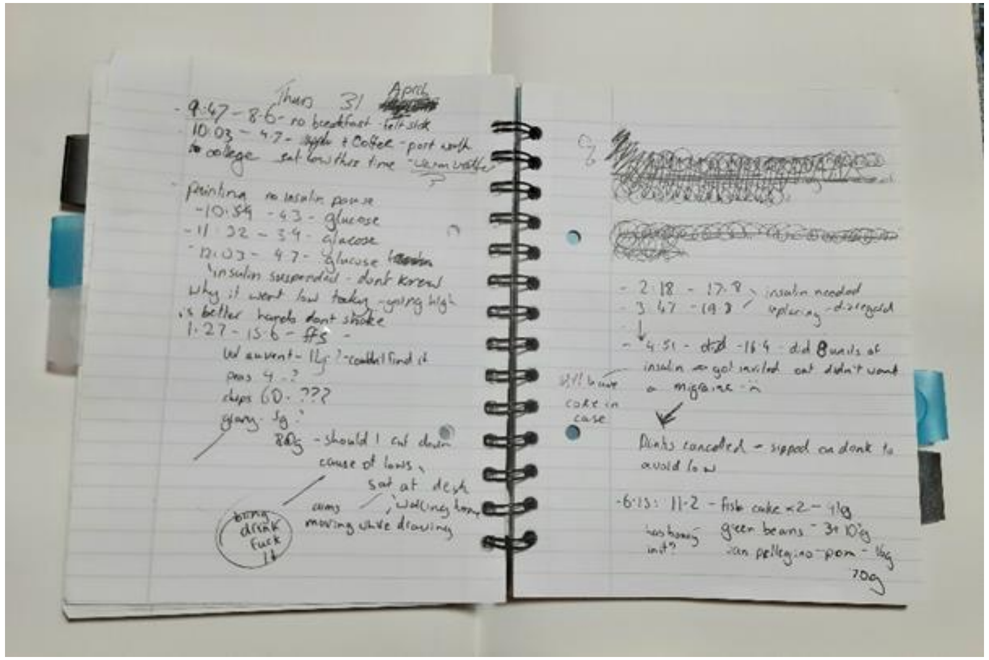
Applying the DAFNE principles: Understanding irregularities

So, it [DAFNE] has been majorly beneficial. It’s not always giving me the results I want but giving me very definite results that I can trace back what happened, for example is my insulin in date, is the temperature different to the way it was a week ago when I had the same meal, did I do extra exercise the night before? I know hundreds of questions to ask. It's a retraining in looking at the tiny things that will work for other people too. Diabetes is restrictive. I found **DAFNE just gives me the magnifying glass to look for the restrictions**, or I can focus the restrictions.

Applying the DAFNE principles: Challenges with carb-counting

Essentially if you want to lose weight you count calories, but everything also has to be carb counted. You do it for two months and you get some results, and the results drop slower than whoever you're working with. **It’s exhausting. I find that I work really hard to limit my calories and then you could have a hypo in the evening, and you could end up with 300-400 calories just sorting out that hypo**.

Carb-counting: Stressful and time-consuming



Thurs 31 April [redacted]
- 9.47 – 8.6 – no breakfast – felt sick
- 10.03 – 4.7 – [illegible] + Coffee – part walk to college – sat low this time "[illegible]"
- painting – no insulin pause
- 10.54 – 4.3 – glucose
- 11.32 – 3.4 – glucose
- 12.03 – 4.7 – glucose [illegible]
insulin suspended – dont know why it went low today – going high is better hands dont shake
1.27 – 15.6 – ffs –
W [illegible] – 11g ? – couldn't find it
peas 4 – ?
chips 60 – ???
gravy 5g ?
80g – should I cut down cause of lows,
sat at desk, walking home
arms moving while drawing
bring drink fuck it

[redacted]
- 2.18 – 17.8 – insulin needed
- 3.47 – 19.3 – exploring – disregard
- 4.51 – did – 16.4 – did 8 units of insulin – got invited out didn't want a migraine – n
still have cake in case
Drinks cancelled – sipped on drink to avoid low
- 6.13: 11.2 – fish cake x2 – 11g
green beans – 3+10g
san pellegrino pom – 16g
70g
was having int?

This is one day out of this kind of diary that I kept for the first few weeks out the DAFNE course. **It would just make my day really stressful.** They said; "Oh this should take the stress out of your life", but I still have to walk but now I have to spend half an hour writing it down and figure out how it's going to affect me rather than just tossing a glucose syrup forever and saying it will be fine.

Access to the DAFNE progamme; frustration and empowerment

Access to the DAFNE programme

After returning home from being abroad, I told them [healthcare provider] I had done DAFNE, and they said that **they didn’t offer DAFNE, so I was going to have to switch to** [an alternative structured education course]. That was very frustrating because bearing in mind, day in, day out, this is how I lived my life and I had been well trained on it. You know carb counting is interchangeable between the two programmes, but for me, I couldn’t reframe how I learned but I was probably biased by now because I enjoyed DAFNE so much.

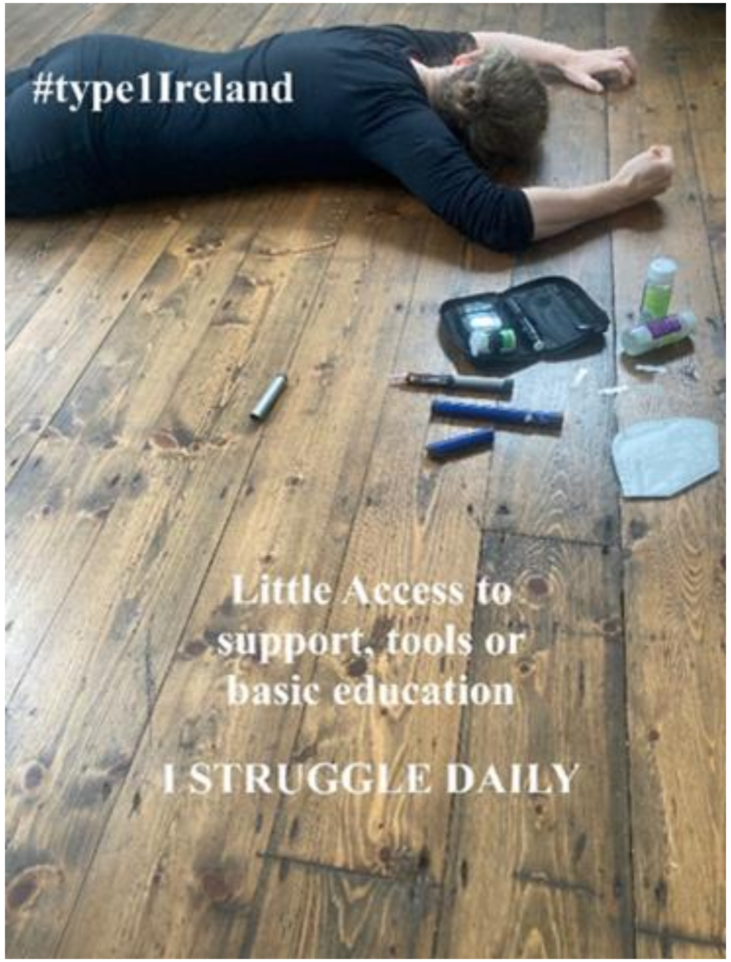
Access to the DAFNE programme

DAFNE made so much more sense to me, it was so much more simplistic, I kept coming back to that. Not having the option of continuing DAFNE was very restrictive I thought. Maybe someone who'd done BERGER would like to stick to BERGER but there should be a way of allowing them to continue it. Even if it was remote support.

Frustration with access to the DAFNE programme

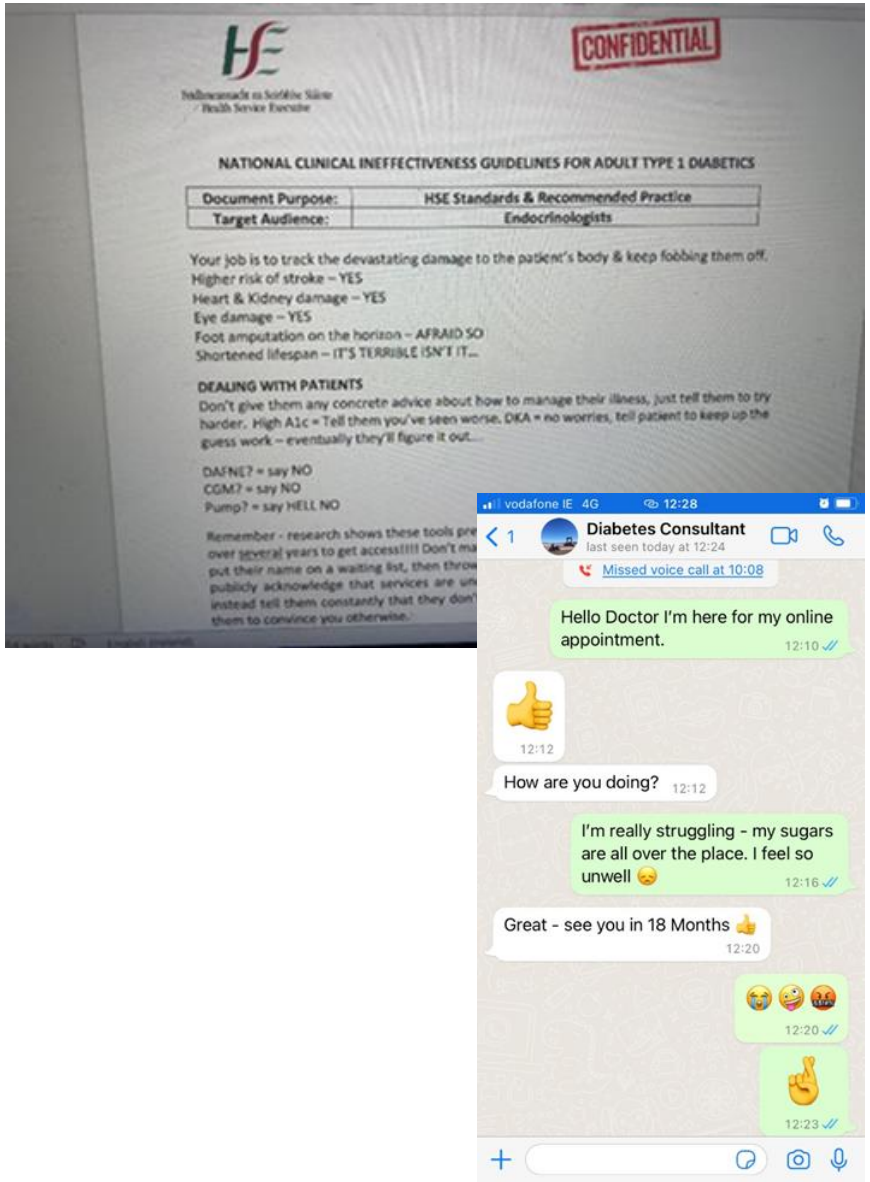
This photo describes how absurd it is that I had to wait 12 years to do a basic education course on diabetes. I just cannot understand how this makes sense not to give people basic information about managing their disease when they are first diagnosed and it’s not information that you can just find online. It’s like its kept hidden in secret. It’s almost like they think this information is dangerous for us to have because it relates to insulin, a powerful drug, but then you’re just left with no information or guidance at all, and you still must inject yourself daily and get on with your life. **I just feel like the information should be available from day 1 and it should be accessible to everyone**.

Frustration with access to diabetes services



It feels like so much energy has to go into the convincing medical professionals that you support and tools like basic diabetes education, CGMs, a pump. There’s this sense that you should be happy that you’re on the waiting list but being on a list for years doesn’t improve my HbA1c in any way. **The narrative needs to change**. It shouldn’t be the patients trying to convince the consultant that these things are necessary when everyone knows that they improve quality of life and prevent complications. For me living with Type 1 diabetes, it’s a daily struggle - there’s no break from it. It's not like you can say, okay, well, I’m going to take today off, I'm just not going to worry about it, I'm not going to test, inject, monitor myself. You can't do that.

Frustration with access to diabetes services



Feidhmeannacht na Seirbhíse Sláinte / Health Service Executive

CONFIDENTIAL

NATIONAL CLINICAL INEFFECTIVENESS GUIDELINES FOR ADULT TYPE 1 DIABETICS

Document Purpose:	HSE Standards & Recommended Practice
Target Audience:	Endocrinologists

Your job is to track the devastating damage to the patient's body & keep fobbing them off.
Higher risk of stroke – YES
Heart & Kidney damage – YES
Eye damage – YES
Foot amputation on the horizon – AFRAID SO
Shortened lifespan – IT'S TERRIBLE ISN'T IT…

DEALING WITH PATIENTS
Don't give them any concrete advice about how to manage their illness, just tell them to try harder. High A1c = Tell them you've seen worse. DKA = no worries, tell patient to keep up the guess work – eventually they'll figure it out…

DAFNE? = say NO
CGM? = say NO
Pump? = say HELL NO

Remember - research shows these tools pre
over several years to get access!!!!! Don't ma
put their name on a waiting list, then throw
publicly acknowledge that services are un
instead tell them constantly that they don'
them to convince you otherwise.

vodafone IE 4G 12:28

Diabetes Consultant
last seen today at 12:24

Missed voice call at 10:08

Hello Doctor I'm here for my online appointment. 12:10

👍 12:12

How are you doing? 12:12

I'm really struggling - my sugars are all over the place. I feel so unwell 😞 12:16

Great - see you in 18 Months 👍 12:20

😭🤪🤬 12:20

🤞 12:23

It feels to me that clinical appointments are always just 'box-ticking'. There's no real or concrete support with blood sugar management. It's like okay you feel terrible, fine, see you at your next appointment.. One of my last appointments I couldn't attend because someone close to me had symptoms of Covid and my appointment got scheduled for the same date 12 months later. I wasn't offered an online appointment or a closer one.

Frustration with access to diabetes services

The reason I'm really trying to get a pump, trying to get a CGM, trying to get basic education about my illness is because it's shortening my life. Research from University of Manchester shows that every year my A1c is above 7 I’m losing 100 days off my life expectancy. **There's also an ageism component to access to services and it’s totally normalised**. You can get a flash CGM if you're under 21 but not if you're over 21. If you’re diagnosed as a child you’ll get a pump but if you’re an adult you won’t. Why this difference? Doesn’t my health and life count too?

Frustration with access to diabetes services

There has to be a better model for diabetes care, and it has to move away from the medical expert model who is a gatekeeper to the tools that will help you manage your illness. There has to be a better way people with Type 1 are empowered to be in the driver’s seat. **What I would like to see is diabetes education that is peer-led by people who actually have Type 1** and offers ongoing support in a large group format. This is this is what I love about this project. It’s the first time I've been asked my opinion. It’s the first time someone has asked me what it’s like to have type 1 diabetes and how it affects me

Access to diabetes care: workarounds

There's more than one way to open/get over a gate. I got trained on my first pump during Covid over Zoom. I had the support of my [clinical] team during this period, but it was patient led – my team perhaps weren't happy with how quickly I went live with insulin on the pump but that was my choice. **There were a few of us, mostly from up north, that were progressing through DIY looping at this stage all over a WhatsApp group and this peer led support was fantastic**.

Access to diabetes care: workarounds

So that is in the context of the gate and that there are possible ways to maneuver around a closed gate – unfortunately **in Ireland you have to push (perhaps even shove) that gate to open it and it needs a person with a certain tenacity and doggedness to actually open it and not all people have that ability.** Now with back in-person DAFNE programmes, there's a long waiting list, 5 days in person – if they offered it remotely, they could get through a lot more people however I appreciate that remote education may not be the best approach for all, but educators need to take the view of people with diabetes into consideration.

Access to diabetes care: workarounds

The kits are generally sent into the clinics and the clinics withhold them until you have the training. **I was lucky all that they were sent out to me by post during the pandemic.** Covid worked out for me from that point of view.

Other forms of support for Type 1 diabetes

The role of technology

Positives of using technology

I’m definitely a technology person so when they gave me the option of switching to a pump, I was all for it and wanted to learn about it. What I liked is that when I first got that glucometer, it was connected to everything. So, my blood sugars were connected to my Apple Watch and all the technology was all looped together. I could look at it straight on my phone. It made all kind of easy. I find that really compact to carry as well. That was probably one of the things **when I first became diabetic, the thought of having to carry all this equipment with me, but I just find that stuff is so neat and small now, it can be just invisible**.

Positives of using technology

The Dexcom has been a major life changer for me. I put a transmitter on my arm every 10 days, and it’s connected to a server, so my clinic is able to review my blood sugar levels. It is connected to my phone so it’s able to tell me on a real-time basis 24/7 what my blood sugar level is and how it’s behaving within the parameters that I’ve set for it…That’s the transmitter on my arm. **It’s very discreet, nobody sees it, although I see people walking around all the time with them stuck in their arms**. It’s a fantastic device.

Negatives of using technology

The pump that I use, There’s a 12-hour gap between calibrations on the insulin pump that I use. **They often come at awkward times and this day I was in work and had to stop to do the calibration.** We could be in the middle of a meeting and you're not necessarily telling everybody you're diabetic, but this thing is beeping and everybody's like, what's that noise? And I’m not necessarily trying to hide it, but you wouldn’t know by looking at me otherwise.

Negatives of using technology

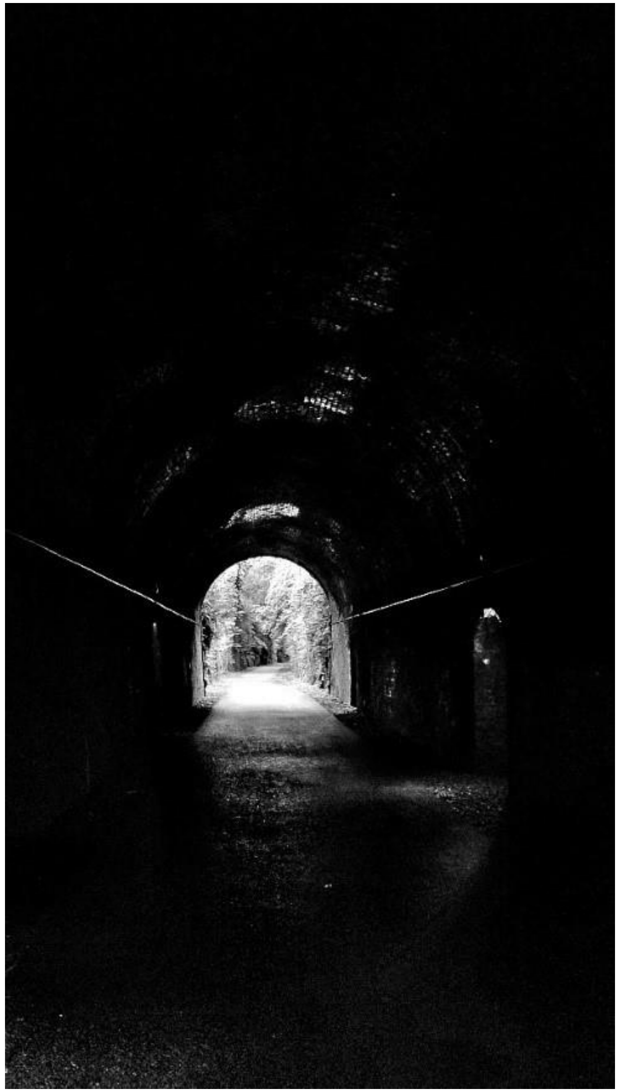
I used a Dexcom sensor for a while which meant that I didn't have to prick my finger to check my blood glucose and could get a constant flow of readings directly on my phone, but **my skin rejected the sensor and was left with a rash so had to give it up and go back to manually checking blood glucose**. It was a major departure and potentially a very useful one, but it didn't work for me.

Accessing technology

I use a Dexcom and that's been lifechanging. I got that pre-Covid, and, in terms of my mental health, it's been amazing. I was looking at starting a family pre-Covid and that's the only reason I got Dexcom. Later I was told, "now that you're not trying to get pregnant anymore you don't need Dexcom". I had to stand up for myself, but I do wonder what would happen to people who don't...I've been unwell for months after Covid and to do that without Dexcom, I wonder how other people would have done this and DAFNE as well to be able to see what's actually happening with your blood sugar. **Without it it's stabbing in the dark essentially**.

Support or lack of support from others

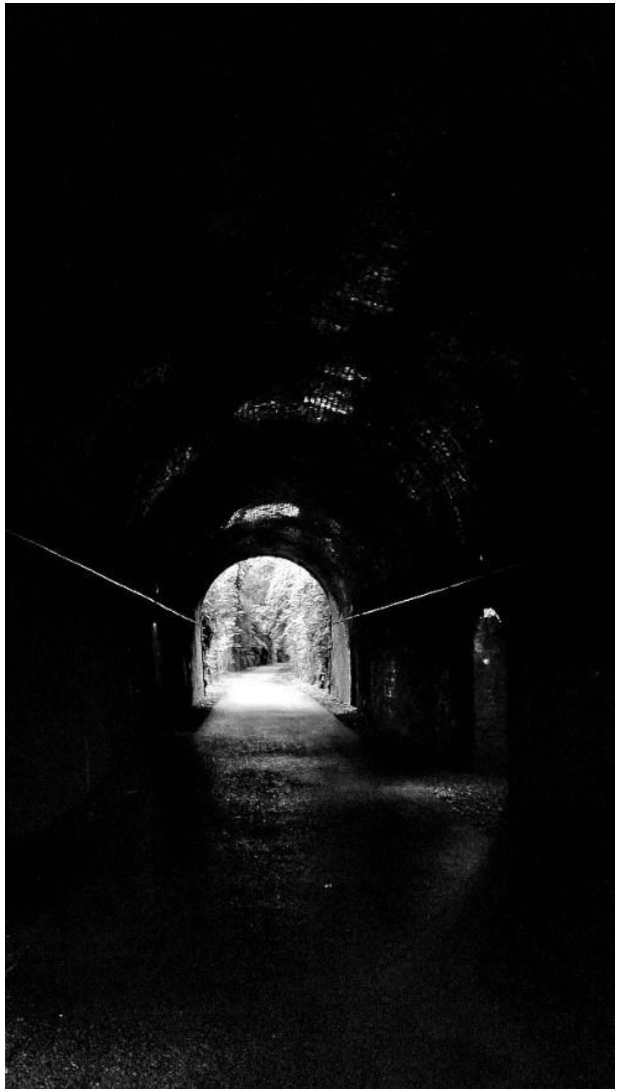
Hiding diabetes in the workplace



The tunnel is about hiding hypos in work. The DAFNE crew kept telling me to insist on having a planned workday, but my boss kept insisting that it wasn’t possible to give me a planned workday. I needed this so that I could estimate my insulin doses for the day.

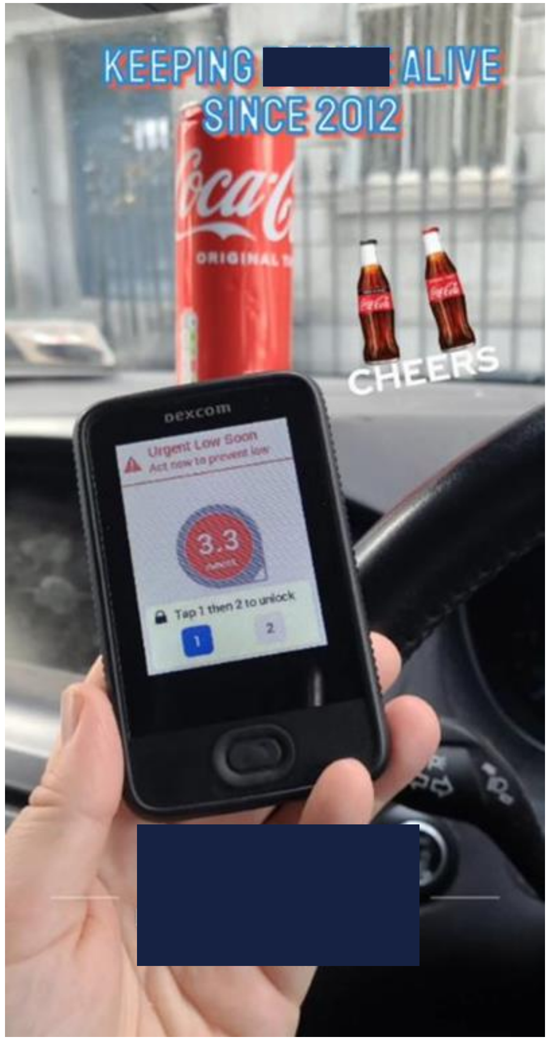
I used to have to hide my hypos. Not all employers are supportive of diabetics, and it is harder for diabetics to get jobs as well. These are things I want people to know...

Hiding diabetes in the workplace



…Low blood sugars can be deeply scary: I've had a few in my last job where **it felt like my body was going through a heavy tunnel**, I'm barely able to be anything in this tunnel's weight, I'm bones made from air, I'm nothing more than this. I didn’t want anyone to notice my 'not working' and I didn't want to give them a chance to throw a song and dance about me having low blood sugar. To them low blood sugar is so simple to solve, a bar and a coca cola and it's cured. They never tried to understand why I wanted to avoid the lows.

Support from family and friends



My family and friends are great and supportive with a lot of things, but no one wants to hear you complain all the time. **People get burnt out very quickly so I’m conscious not to say too much about my diabetes**. I send these kinds of messages to my family and friends from time to time to remind them that I’ve a lot going on, but they’re not digs. I use humour to minimise it because you don’t want to be that complainer (P8).

Support from other sources

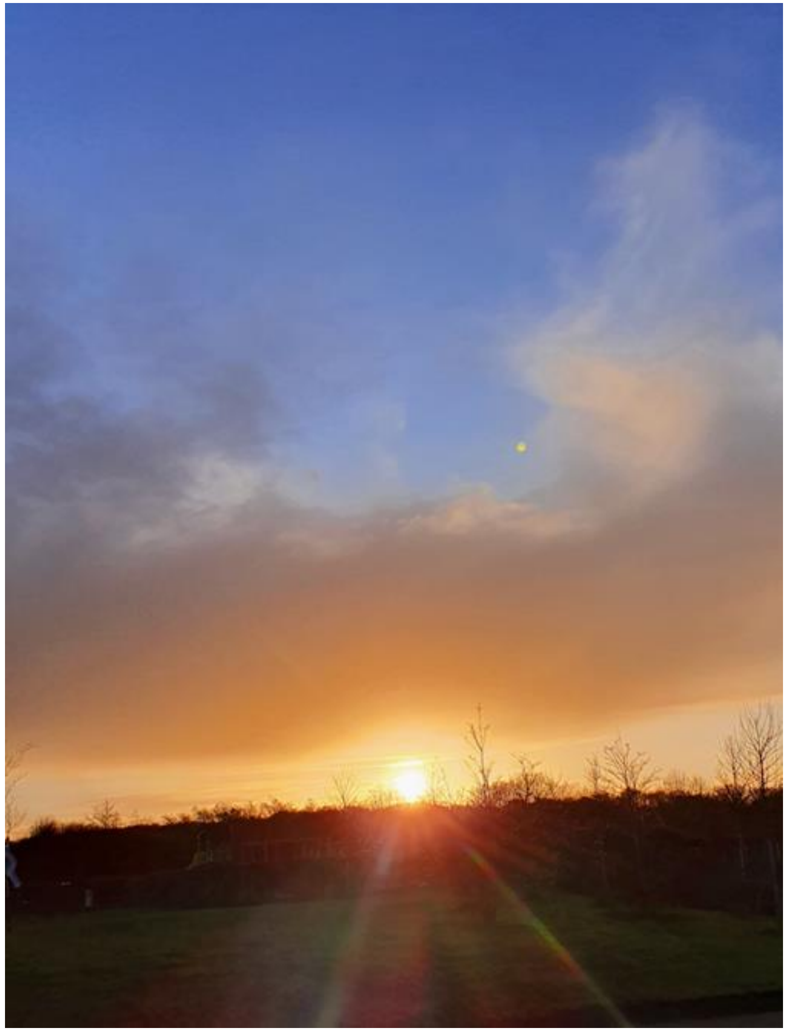
This is trigger, He’s 17. He's been amazing. **He has been my lifesaver**. I got him around the time I did DAFNE. I started walking a half a mile every few days. He used to notify me of my hypos by touching my knee. This was before Dexcom. He used to tip my knee with his nose to let me know my blood sugars were going low. He's been a great little guy. He's untrained, just protective.

“You don’t get a holiday from it”

The need for escapism

I was down by the sea and decided to take a picture because I use it as a switch-off from diabetes and I forget about everything. I have suffered from burnout where I don’t want to be diabetic anymore and I don’t want to do this which comes in cycles. The beach is at my doorstep and it’s where I can switch off and I don’t think about how many carbs I have to count and stuff because **for me diabetes can be all-consuming**.

Fighting for what works for you

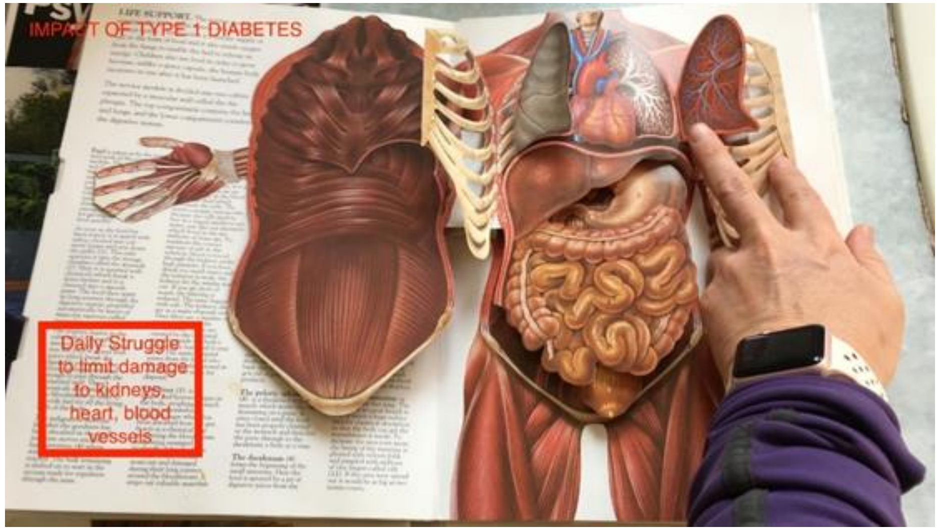


This symbolises that there will be storms above and you'll have dark days with diabetes, but there is always something radiating, and you have to kind of look for that yourself. Pertaining to the health system, **you have to find what works for you and what can make your life easier, but you do have to fight for it**.

The need for escapism

That's where I was discovered as a diabetic. I visited regularly during COVID. I don't know if it was a psychological thing, but I felt a closeness to it.

Physical and mental impact of T1DM



When I see that my sugars are out of range despite my best efforts, **it weighs heavily on me knowing that I'm damaging my body**, that I'm damaging my kidneys, my heart, and I'm at a higher risk of stroke and this is going to continue to get worse as I get older and my body's more and more damaged. Type 1 is having a progressively negative impact on my health over time. It also really affects my mental health because it’s this sense of helplessness and not being able to do things to prevent this from happening. It just feels like there’s not enough support.

Physical and mental impact of T1DM

When I was diagnosed, I was healthy. I was into triathlons and doing lots of different things. Being diabetic has so negatively impacted my health and my life and that that's not fully acknowledged. **I wish someone had said that to me in the beginning that this disease will have a serious impact on your health, and you have to take it really seriously.** This image is also powerful to me because almost two thirds of my hair has fallen out, the texture of my hair has changed, and I don’t have the same energy I used to have.

Physical and mental impact of T1DM

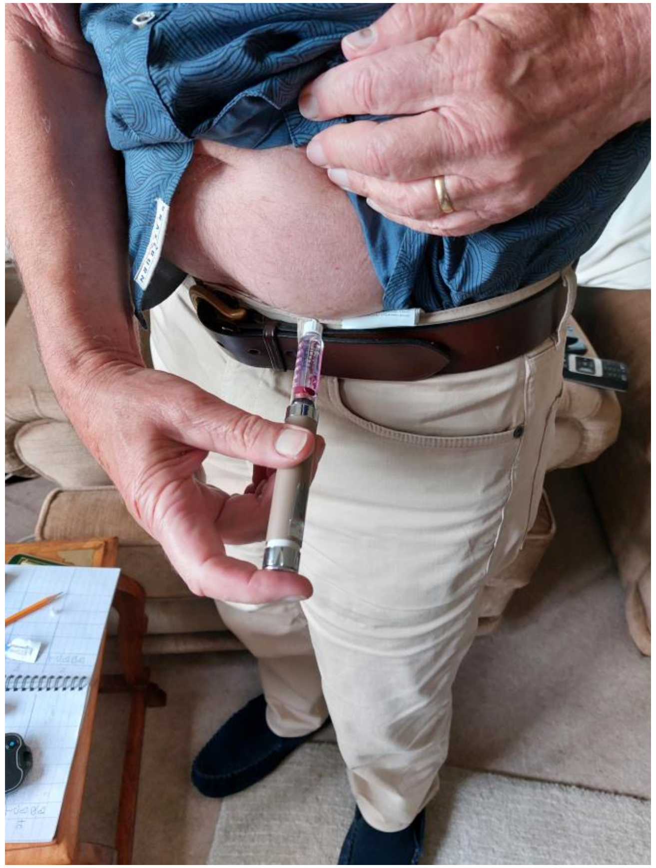
I feel unwell a lot of the time. You share this at medical appointments, and it feels like it's just not taken seriously even though it's directly related to Type 1 diabetes.

Tools for self-management

Tools for self-management of T1DM

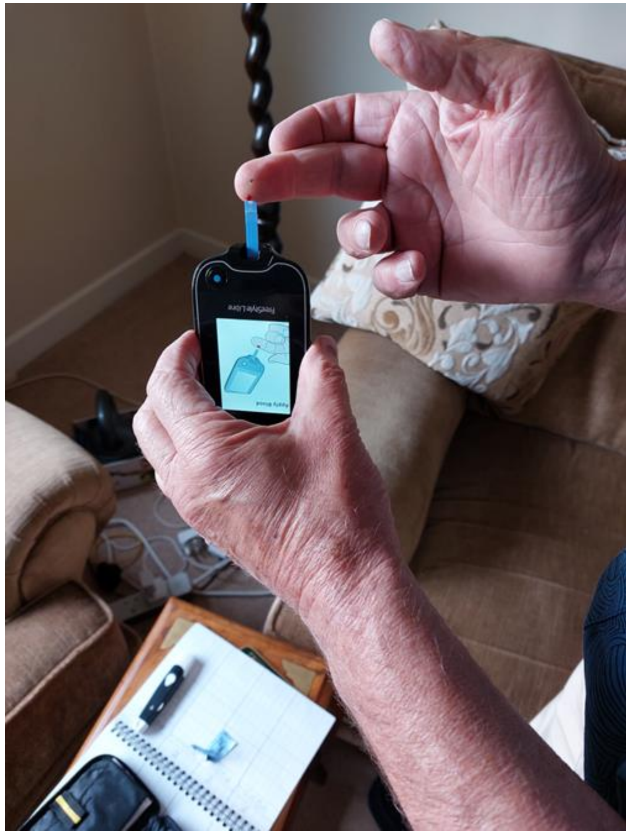
Without the bits and pieces that I have here, I wouldn’t be going anywhere. All of my equipment is manual because I don’t have an insulin pump. I have to make sure that I have all these available. I'd be at a serious loss if I forgot it or lost it.

Tools for self-management of T1DM



That’s me injecting quick-acting insulin. The dosage is based on what I learned at the DAFNE course. I do that about six or seven times a day. **There’s two types of insulin.** The quick-acting insulin which I take with a meal and long-acting or background insulin which keeps things steady between meals and throughout the night. People with an insulin pump don’t need to do that.

Tools for self-management of T1DM

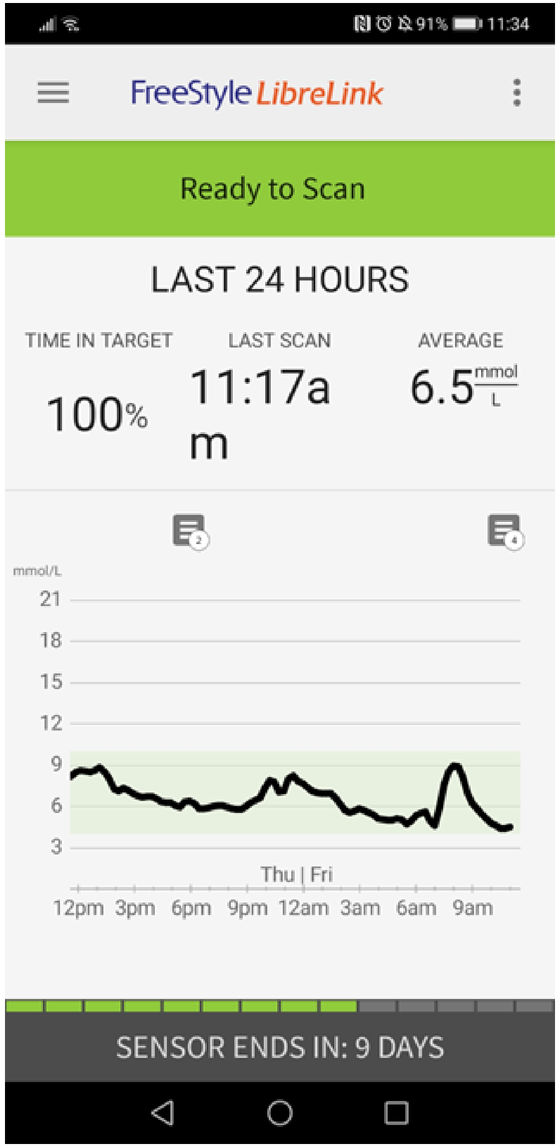


I check my blood glucose four or five times a day by taking a drop of blood from the from the tip of my finger and putting it on a test strip to get a reading as I don’t have a Dexcom sensor. That's something that I've been doing for a long while now, so the tips of my fingers get a little bit ragged.

Tools for self-management of T1DM

A glucose shot is such an efficient tool for dealing with hypoglycemia, particularly in the middle of the night. You can just keep it on the bedside table or if you're out doing exercise or playing sport, I keep one of those in my pocket all the time. Prior to that I used to use glucose tablets but if you are hypoglycaemic it gets a bit messy trying to open them and then chew and swallow them. I read about it in the Diabetes Ireland magazine and then contacted the hospital and they put it on my prescription.

Tools for self-management of T1DM



TIME IN TARGET 100%

LAST SCAN 11:17am

AVERAGE 6.5 mmol/L

This was the first time that I had hit 100%. And that was just huge to me because it's very hard to get to 100.

Slide show prepared by Aoibheann Kavanagh and Dr Fiona Riordan.

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