

#### Tallaght University Hospital

Ospidéal Ollscoile Thamhlachta

An Academic Partner of Trinity College Dublin



# Foreword



A friend told me about his 18 year old daughter's Type 1 Diabetes diagnosis, how she spent a mere 36 hours in hospital and was good to go with Pens and Sensors. He contrasted it with his own diagnosis 40 years before. He spent one month in hospital, going home with phials of insulin and long injection needles.

While he was struck by the advances in medical and technical care procedures, I was struck by what wisdom he could impart to his daughter after all those years living with diabetes.

I also recognised, that this young lady would have her own unique relationship with diabetes, yet to unfold.

Diabetes is another relationship in a person's life, one that needs a type of care and inclusion in Daily living. It involves interfacing with health systems and revealing so much of their personal world. I wondered if all this wealth of experience could be brought to the surface so that the person, and the reader, might be able to truly see, value and digest the lived experience of having Diabetes.

These letters, kindly submitted by Patients at the Diabetes Department at TUH, are that lived experience. They show wisdom, balance and commitment that may indeed hold cornerstone's for treatment intervention, through the patient's own voice.

We hope you find some useful insights that will be of benefit to you and your relationship with diabetes.

Noelle O' Keeffe Senior Counselling Psychologist Tallaght University Hospital

This is what I know to be true, for me, after nine years of having Diabetes.

Everything looks scary and complicated at the start. You feel like this thing will ruin your life and will limit your everyday life. I can tell you, that it doesn't. You can find a way to work it into your schedule. It only takes about two minutes.

I hated that my life was all about my illness. It is important to take care of yourself, however when you stop putting pressure on yourself you will become more accepting of this new identity. As long as you check your sugars and take the appropriate amount of insulin you are good to go. It's this little thing that needs attention from time to time and will not bother you when you provide it. Think of a little baby: once it's fed and changed it falls asleep and you can relax. Diabetes is like that and will not grow into a grumpy teen that makes your life hell, as long as you keep it 'happy'.

Every time you go to the hospital you will be looking at your results and trying to figure out why you were low on a morning and high two days later before dinner. There isn't always an answer. Sometimes your sugars change and you don't know why. The blood sugar levels from the past help you to establish certain patterns, but it's important to know that they are in the past.

Don't think about it too much and move on with your day. There are plenty of other things that require your attention like your family, friends, even school or your job. Just because your diabetes decided to be cheeky today doesn't mean you get a pass to ignore those other things.

Listen to your medical carers they are trying to help you, not be your enemy. It's all about trial and error and they aren't always sure, but they are trying their best and it only works if you cooperate.

Don't stress, enjoy your life, it will all be okay!

Female Aged 20



This is what I know to be true, for me, after 25 years of having Diabetes:

A quarter of a century on and things haven't necessarily gone as expected. Marriage and two daughters have been a blessing and they focus and refocus me on what matters. But I matter too and these days my goals are to be there for them in the long-term.

I was not immune to complications as my younger self once thought. My eyes are letting me know that overall control needs to improve. My feet walk with me but they inform me when I've had enough, for now. My hands and fingers now tingle with pains instead of anticipation or excitement of events to come.

Self-care and care of the diabetes body can be overwhelming, but small, calculated and long-term changes make a difference. Patience and consistency show in the medium and long-term. Remember this.

Sleep and much tighter control over the 8pm-8am blood sugar is where I would have focused most of my energy. This is no new revelation, yet it's where I could have saved myself the anguish of what has developed. It is where I now target my improvements.

The future still looks bright. Day-to-day living and management has improved. As I enter my 5th decade in the coming months, I aim to have this 10 year span as my best controlled yet. For my girls, my wife and for me, I know I will succeed.

Male - Aged 39



This is what I know to me true, for me, after eight years and seven months of having diabetes.

After diagnosis the frightened, fearful girl you are will dig deep and find an inner strength you didn't know you possessed.

This inner strength will help you overcome all obstacles in your life. After seven years you'll be lucky enough to get an insulin pump, which will give you a much better quality of life. It will be an end to your sleepless nights and you'll start to gain a healthy control over your illness.

It won't always be easy but you've got this!!!

Female - Mid 30's



This is what I know to be true after six years of having Type 1 Diabetes.

**Listen to your body -** I first fell ill in 2011. I had no energy which was odd as I always had bundles of it despite my "maturing age". Friends and family dismissed these symptoms and reassured me that it was only natural to tire more as you age. While their intentions came from a loving place, I'm so sorry that I didn't listen to my body and go to see my doctor sooner. You know your body better than anyone. Listen to it and trust your gut feeling.

Attitude & Outlook - When I was diagnosed in 2012, I went into shock. I was upset, angry, fed up but relieved in a way that I had been right along. It felt like my body had betrayed me. I cried a lot at first and felt very sorry for myself but I soon realised that it wasn't the worse disease to get. I still get good and bad days. I can't stress enough the importance of following the recommended diet. If you do, you will feel so much better and at times you're able to forget that you're a diabetic.

**Accept Help -** My daughter was very supportive. When I would get a low, sometimes in the middle of the night, it was incredibly frightening for me. Just like the umbilical cord was still attached, she always woke up and found me in the kitchen stuffing grapes down my mouth and drinking orange juice. My body had instinctively known I needed sugar. I would ask where I was until my sugars came up. I would get this awful feeling that I just had to eat loads of chocolate and was in full panic mode. Now I know that it only takes one small bottle of orange juice to get my blood sugar level within the normal range and I'm fine. There is a great support system in Tallaght, but it took me a long time to reach out to the Diabetic clinic, I wanted to do everything myself. Had I asked for advice sooner, it would have made life easier.

**Knowledge is Power -** It's so important to read up and educate yourself on what to do when you go very high or low. Learn how your body reacts to different solutions. There is no one size fits all solution to living with Type 1 diabetes. But the more you learn about other people's experiences and your own, you adapt and learn to live the best life you can.



**Regular Mental & Physical Check Ups -** Test yourself regularly, I do it five or six times a day. Attend the Diabetic clinic when you receive appointments, do not cancel them. Stick to your diet but don't beat yourself if you fall by the wayside and have that cake. Go for a walk every day as it helps your physical and mental fitness and releases much needed endorphins on your diabetes journey. But it's worth it.

Dear Jem,

I am you, 40 years in the future and what a marvellous one it is. Your Diabetes is permanent, at this moment in time, but, there are all sorts of treatments in the pipeline. I know I was terrified of injections. While you will start off in the 1980s with injections with needles like six inch nails, within a very short time the needles will be so fine as to be almost invisible and painless.

If you progress to injections the hardest part is injecting yourself for the first time but, after that it will become routine. Rotate your injection sites.

So what are the benefits of being under a doctor's care? Well, you will be completely monitored. Everything you do over a six month period can and will be monitored with a test called **HBa1c**.

Watch your weight, cholesterol and diet, you are a complex organism and neglect yourself in one area and you may end up paying for it in another. Thankfully with the grace of God and by keeping the rules (mostly) I have managed to avoid any complications.

But, here is a song from the future, by a group called Sister Sledge *"We are family"* So, think of every part of your body as a family, with some distant relations, such as your heart, lungs, but all united in one unit.

I hope this helps you, you should have a great life ,enjoy it .

Jem (Male, aged 74)



## Notes to remember: