



Sláinte Leanaí Éireann



Children's Health Ireland

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SUPPORTING CHILDREN'S HEALTH IRELAND

Introduction:

“Letter to My Younger Self” is a psychosocial support booklet co-written by adolescent patients with Type 1 Diabetes and their parents at CHI Crumlin. This resource emerged from a four-week peer support programme facilitated by the diabetes psychology service, where young people shared their lived experience of receiving a life-changing diagnosis.

Each participant wrote a personal letter addressed to his or her “younger self” — capturing the emotions, challenges, and coping strategies that shaped their journey from diagnosis to resilience. These letters explore common emotional responses such as shock, sadness, fear, frustration, and adjustment, and outline how the young people learned to manage their condition and build support systems.

These letters are verbatim their words..... there may be some unusual spelling at times, however these stories are authentic.



Rationale for the Booklet

A diagnosis of Type 1 Diabetes is a life-altering moment for any family. At CHI, newly diagnosed patients receive excellent medical education through our clinical nurse specialists, advanced nurse practitioners, and dietitians. However, the emotional impact of diagnosis is often overwhelming, and families can struggle to process their feelings in parallel with absorbing clinical information. While psychological support is available, many families are not ready to engage in one-to-one sessions during the early stages. Adolescents in particular may find it difficult to connect with adult clinicians or articulate their emotions. As a result, key opportunities for early emotional validation and support can be missed.

“A Letter to My Younger Self” is designed to bridge this gap. By hearing directly from peers who have “been there,” newly diagnosed patients and their families can gain emotional anchoring, normalisation, and hope. The content tackles universal struggles such as diagnosis shock, diabetes burnout, fear of injections, loss of control, and the search for identity.





Stories from Patients

My Diabetes Journey from diagnosis to today:

Name: Anon

Current Age: Teenager

Age at Diagnosis: 10

When I was diagnosed with a DKA I was told I had diabetes and I was really sick. I have had struggles when using the insulin pen, because when I use it at times it gives me bruises. Blood sugar levels were annoying for me before I received my sensor. Before my sensor, I had to finger prick all the time and it sometimes bruised the areas I had pricked.

Sometimes my friends joke about my diabetes as they use stereotypical terms like are you allowed to have sugar. It was annoying at first but now I just ignore them.

My parents would constantly ask me about my blood sugar levels, I found it annoying. I wanted them to stop asking me and I wanted to show them I could do the blood sugar on my own.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Whenever I feel stressed or feel overwhelmed, I would do things that keep me calm such as drawing, talking with friends or spending time with my parents.



My Diabetes Journey from diagnosis to today:

Name: Alana

Current Age: 14 years old

Age at Diagnosis: 2.5 years old.

I was very young when I was diagnosed, so I don't really remember life without diabetes. I were moved to an insulin pump when I was three and still use it. When it comes to friends, I have always told them early on so all of them know that I am a diabetic.

So far, I do not have many mean comments, there has been the occasional you cannot eat sugar, as a joke, but that is about it. One of the most annoying things about diabetes has to keep your blood sugar in range. It can be very annoying if you are high and very thirsty but you have drank so much water that you physically cannot drink anymore.

Another annoying thing about diabetes is when you wake up at 3am because you are low and while half asleep you have to check your bloods. One plus with Diabetes is that you get a fast pass for theme parks.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

When I am fed up with diabetes or just annoyed in general, I often turn to my Mum or Dad. If I have been high and feel awful, my dad actually knows how I feel, as he has type 1 diabetes too.

I have also been to quite a few camps for diabetics. It is really nice there because there are other people who are going through the exact same thing as you.



My Diabetes Journey from diagnosis to today:

Name: Ross

Current Age: 12

Age at Diagnosis: 11

When I was first diagnosed, I was worried what my family and friends would think about me. I first thought it would be hard at first, but in reality, it is not too hard. The only thing that is annoying is my parents asking me how are my blood sugars every five minutes. However, diabetes does not really stop me from doing the things I like. I can still go out with my friends and play rugby and football.

The injections do not hurt they just leave a small mark on your leg. When I was diagnosed, it was the day before Halloween, so I was annoyed and I just wanted to go home and trick or treat. Although, I knew I had to stay in to feel better.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Playing sport helped me forget about diabetes. My teachers help me and check up on me every day to see if I am managing okay. My parents help me and the team at Crumlin helped me at clinics.



My Diabetes Journey from diagnosis to today:

Name: Isabelle

Current Age: 16

Age at Diagnosis: 23 months old

Before I turned two I was diagnosed with T1DM, I did not really understand it until I got to school. I had an SNA and all of the management was done for me. However, when I got to secondary school, I did not really have any support in school, and things went downhill. In third year, my HbA1c went up quite high and I was told there was a chance of being admitted to hospital to stabilise my diabetes.

I got lots of help from the psychology team in Crumlin, but I ended up being admitted to hospital at the start of transition year. When I left hospital my bloods started to get better, and my management is easier now.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

I was really burnt-out and did not care about my diabetes, so the doctors decided to make an appointment with the psychologist, on the team. It really helped to talk to someone who was not a parent and who did not judge. She supported me and helped me process my life with diabetes.



My Diabetes Journey from diagnosis to today:

Name: Chloe

Current Age: 13

Age at Diagnosis: 3

I honestly do not know what it is like not having diabetes, as I was three when diagnosed. However, having diabetes can be tricky; sometimes I get annoyed easily with my parents when I feel they are constantly asking about my diabetes. Even though I get annoyed easily with my parents, I like it when my friends are genuinely concerned about my lows, as it shows that they really do care about me. I am still learning about managing my diabetes and how to carb count accurately. I have no problem asking my parents for help around my management, and they are always willing to give me help.

When I meet new people, I do not tell them about my diabetes, not because I am ashamed of having diabetes- it is just I do not know what to say.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Drawing or art talking with my friends, or even watching something entertaining, it can help me cope or calm me down. Sometimes sport can help me too.



My Diabetes Journey from diagnosis to today:

Name: Tom

Current Age: 12

Age at Diagnosis: 6

I was diagnosed when I was six years old. At the start, I felt very confused. I missed a week in school, my family and friends were so kind when I was diagnosed. It took a while for me to adapt to diabetes, the injections were annoying and painful. However, once I got the pump it has really helped. My Mum diabetes is a struggle but things could be lot worse. She reminds me to remember that I am well and that diabetes is a small adaption.

Today, I am 12 and diabetes has become a part of my everyday life. All of my friends are kind and understand my needs. They are all willing to help me when I am feeling low.

**Supports/Hobbies
or other things that
have helped you cope,
manage and deal with
living with Diabetes.**

The group has really helped me with coping skills around Diabetes. It was great to meet and share out journey and life with diabetes. When I first was diagnosed my Dad showed me a rugby player Henry Slade, who is a diabetic and he inspired me to continue with my sports.



My Diabetes Journey from diagnosis to today:

Name: James

Current Age: 12

Age at Diagnosis: 10

When I first was diagnosed, it was hard. I was sick and was in hospital for a few days. The most difficult thing was that everything was new, confusing and scary. At first, I was not sure what was happening and I did not fully know what diabetes was.

I felt weird and confused, and I had many feelings all at the one time, biggest feeling was sadness.

However, over a short amount of time, I became used to it, I told all my friends and I do not really sweat it anymore.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Talking and getting support from my parents, I found that helpful. The nurses in Crumlin are really nice and helpful. The education session was great; they went through everything with my parents and me. Really enjoyed taking part in the group and meeting other boys and girls like me.



My Diabetes Journey from diagnosis to today:

Name: Leo

Current Age: 15

Age at Diagnosis: 13

For a while, before I was diagnosed I was unwell. I arrived to hospital by ambulance and was in ICU because I had a DKA. After a few days, I recovered and my education began. I was very overwhelmed with all the information at first. It felt like nothing would ever be the same again. As I was unwell for a while, it did not have a honeymoon period; I had to deal with full diabetes, from the start. After a little while, I became really well at handling my insulin and blood sugars.

When I got my Dexcom sensor, it really helped my management. Soon I will be getting an insulin pump, which will be a game changer for me.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

I enjoy going on walks especially when diabetes is stressing me out. In addition walking lowers my blood sugar, which is useful when I have hyperglycaemia. Attending psychology was useful, and the peer support group helped me talk and meet other young people with T1 Diabetes.



My Diabetes Journey from diagnosis to today:

Name: Anon

Current Age: 16

Age at Diagnosis: 14

When I started with Diabetes, I was honestly overwhelmed with all the changes. I knew that diabetes is something about food. All the nurses really helped my worry. What made it easier is that I know I can eat anything once I have taken enough insulin I check my bloods before meals with a finger prick or with my Dexcom G7, I portion off my food and then I know how much insulin to take. I trust the readings from the G7 it helps with my worries.

At times having to step out of activities to manage a low can be annoying. It does not happen that often, as I trust the G7 alarm to let me know if I need to make an adjustment.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

I feel that I just need to keep doing what I am doing. If I manage as well as I have been I will not miss anything my friends are doing. Some days it gets hard and I talk with my parents or teachers. Psychology and the nurses really helped me when I required special support.



My Diabetes Journey from diagnosis to today:

Name: Katie

Current Age: 12

Age at Diagnosis: 10

When I first found out, I had diabetes it was hard but as time went by it got easiest. At first I didn't want any of my friends to know, and when I told them they were fine about it. At first my blood sugars were difficult to manage, they were all over the place. Once I learned how to calculate the carbohydrates in the food and measured portion size, I can eat anything I like.

Now it is easier to manage and to calculate carbs and insulin doses using my sensor. I find the sensor easy to put on and take off. Life with diabetes at first can be hard, but if I can manage it, anyone can do it.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

I have many hobbies like gymnastics, swimming, football tennis and running. Sport and exercise can be helpful as it can bring your bloods down if they are high. My Mum was really supportive and my friends really helped me through hard times.

The nurses are nice and they explained all of the diabetes stuff well. The psychologist is nice and I saw her a few times.



My Diabetes Journey from diagnosis to today:

Name: Jack

Current Age: 14

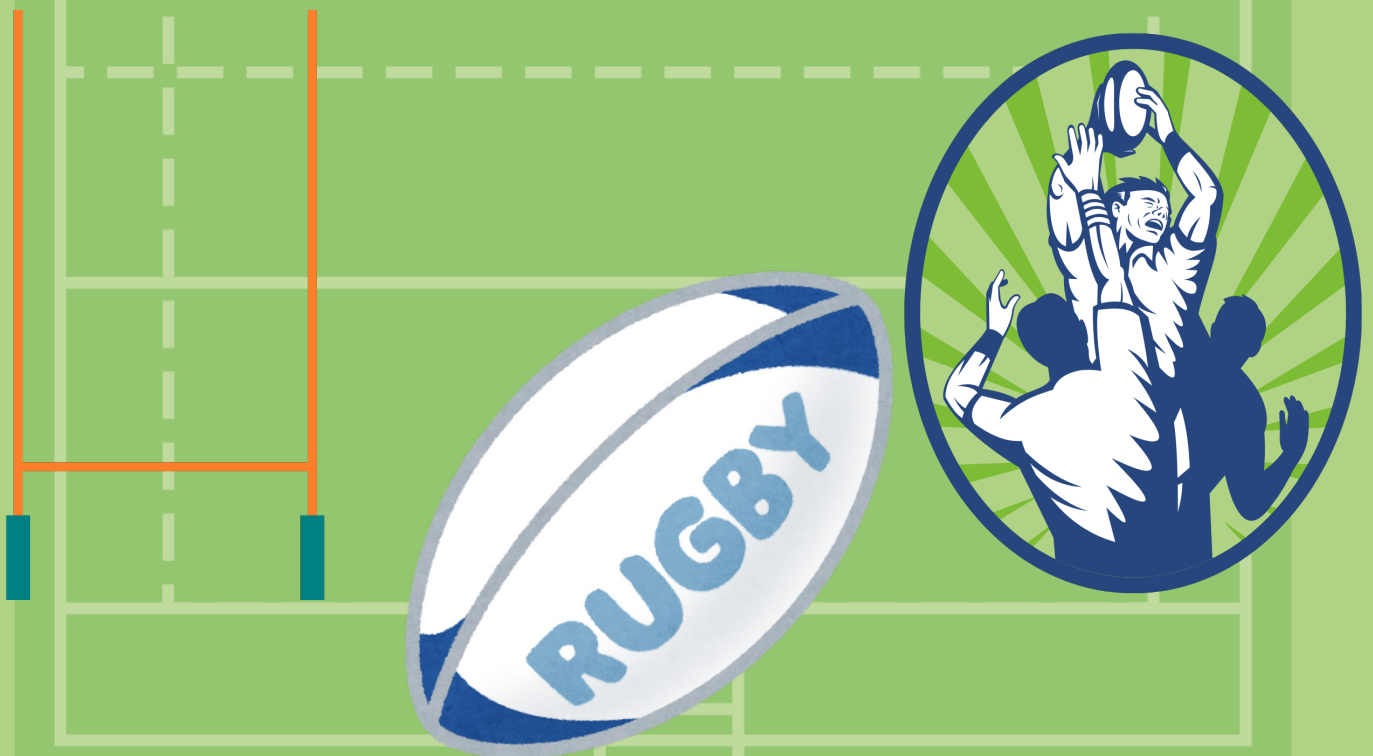
Age at Diagnosis: 3

I was three when I was diagnosed, so I do not remember life without diabetes. As I grew older, I started getting more independent and I was doing my own set changes, and injecting myself with insulin.

It gets easier as you grow older and it starts to become an everyday thing. There are some bad things, parent nagging you all the time and you start to get annoyed. I think the nagging is a way to show that they care. I think you just have to keep going and eventually it gets easier.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Playing rugby is one of my favourite ways that help me cope with the stress. When I play rugby, I forget about everything and just have fun.

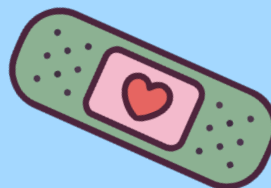


My Diabetes Journey from diagnosis to today:

Name: Emma

Current Age: 11

Age at Diagnosis: 10



Before I was diagnosed, I was always thirsty; I lost a lot of weight and was always going to the bathroom. My GP said I did not have diabetes and I was fine. I ended up in Crumlin A&E because my blood sugar was at 17. I felt fine and didn't know what was happening. I was in the hospital for five days. I was not sick so I was having a grand time. When I got out all my friends and family were supportive to me. Now I am eleven and diabetes does not stop me from being me.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

I have an SNA who helps me with my blood sugar in school. When you explain it to people, it is easier, although it is sometimes embarrassing. Diabetes for me is not hard, once I got used to it. The team in Crumlin have been supportive too.



My Diabetes Journey from diagnosis to today:

Name: Eoghan

Current Age: 11

Age at Diagnosis: 10

My name is Eoghan and I am eleven years old. I was diagnosed on 17th December 2024. When I was in hospital I was scared and nervous. I thought that I would never be able to eat sweets again, but I was too scared to ask the nurses. Later, I found out I could eat sweets stuff in moderation and once I gave myself insulin.

At first I was scared of the needle and injections, however I got used to it after a week or two. I always focus on what I am eating and have learned to carb count. I am really focused on my time in range, I always like to have a high percentage of TIR when at clinic. Clinic happens every three months, nurses and doctors check on your diabetes, and answer questions if you any.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

Football has been very helpful because if I was high I could play and have fun, this would help to stabilise my sugars. The dexcom has really helped because I do not have to scan all the time with Libre 2.



My Diabetes Journey from diagnosis to today:

Name: John

Current Age: 14

Age at Diagnosis: 12

My diabetes journey began on 17th December 2022. I came in with suspected tonsillitis, however when I was triaged they noticed it was type 1 diabetes. I was in the burns unit first as they did not have a bed for me in St. Michael's Ward.



I remember the nurses showed me how to do the injections; my Mum did one or two. Before I left the hospital, I was doing all of my own injections, and I have continued this way.

I was worried about going back to school after my diagnosis, telling my friends and my teacher was a bit scary they all understood. At first, it is strange, after a while, it becomes normal.

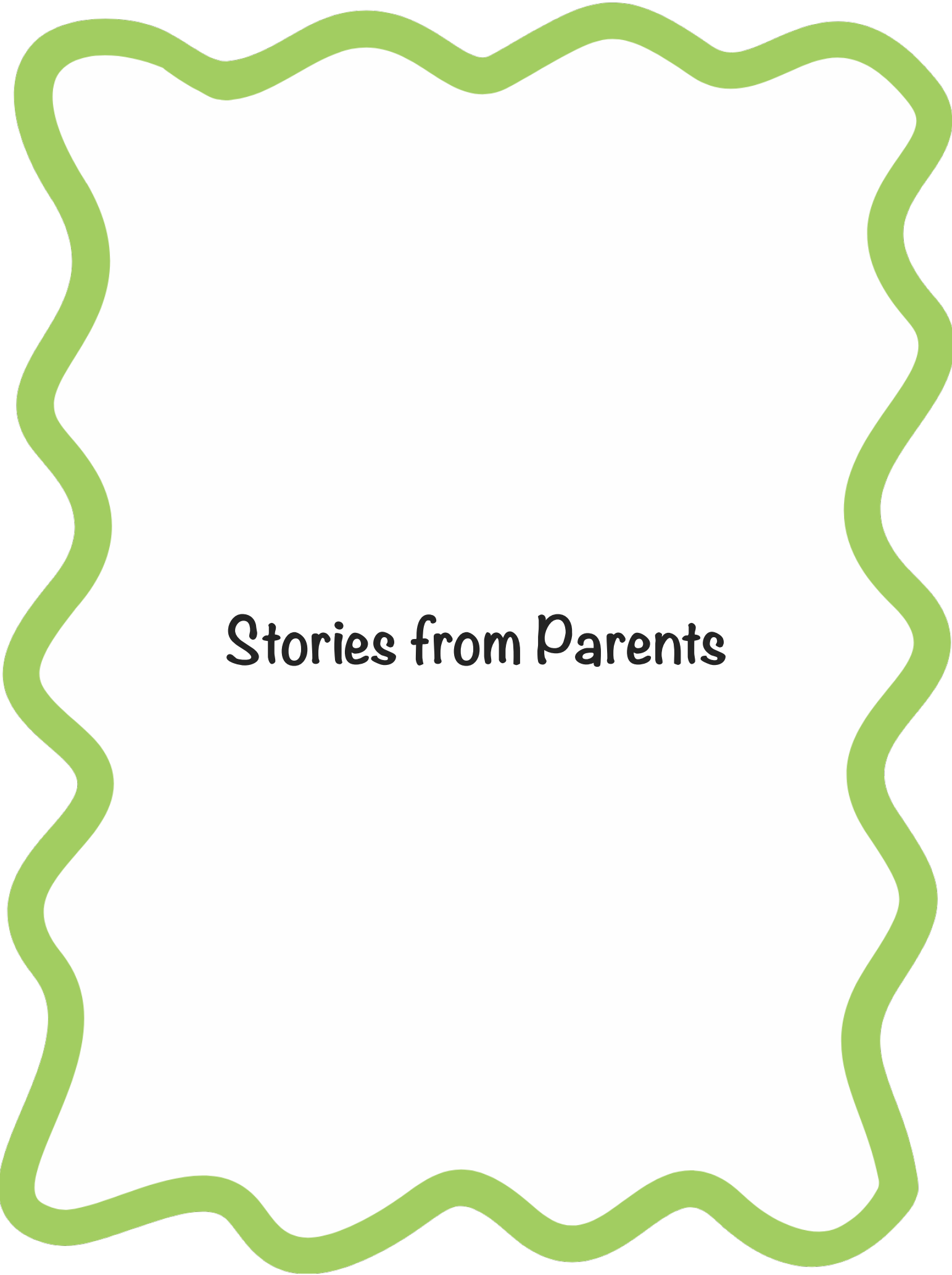
I moved to a pump, which was strange at first, now I feel comfortable with it. I like that I do not have to carry around all my injections with me anymore.

Supports/Hobbies or other things that have helped you cope, manage and deal with living with Diabetes.

My Mum has been a great support to me.

Diabetes has never stopped me from doing what I want to do. I continue to do all the things I used to do before my diagnosis. I will never allow diabetes to get in my way.





Stories from Parents

Mary's Story:

Dear newly diagnosed parent of T1D,

When my son was diagnosed with type 1 diabetes, I felt like my whole world had come asunder. I could not get my head around it, and could not believe I had missed so many clues. We are 18 months in to our journey now, and managing well.

Firstly, you have this. You might think right now that you do not, but you absolutely do.

This may all be very new and overwhelming, that is ok, there is a lot of information we need to learn.

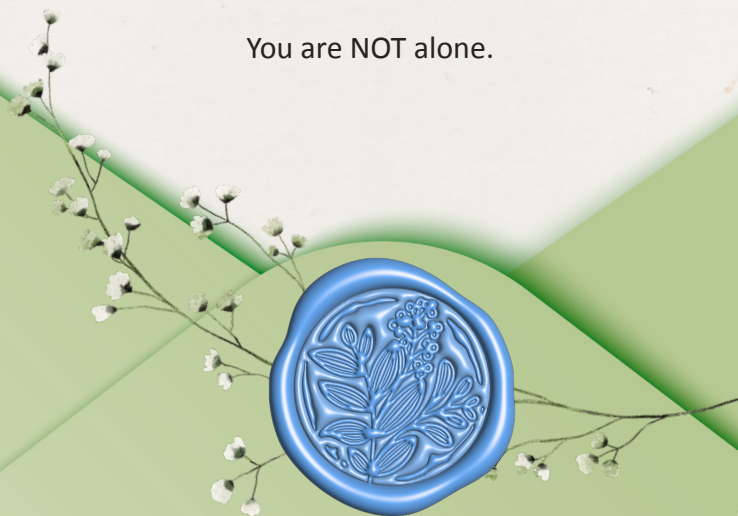
Your hospital team is amazing, trust them, they know exactly what they are doing, they will guide us all the way. They are my rock.

Talk to someone, have as much support as you can. Maybe you need to speak to a professional, maybe you are lucky enough to have good friends, and family who support you, and your family now. Talk to them. You need to mind yourself. As they say before take-off on a plane, you need to attend to your own oxygen mask before you help others. Otherwise, you cannot help anyone.

Be kind to yourself. There will be ups & downs on this journey. As much as we do not want to need or know, we live in a wonderful age of medicine and technology.

Very best wishes to you on this journey.

You are NOT alone.



Jenni's Story:

We just do not know what curve balls life will throw at us. It all seemed to happen quite quickly over the period of about a week during the summer of 2013. My daughter had been particularly grumpy and tired, which I put down to the "terrible twos" and the fact that I had just started a new job. As the week went on, she started asking for more and more water and was going to the toilet more and more often. I will never forget THE DAY. We noticed that she went to the toilet three times within half an hour, so we used my husband's glucometer to do a blood glucose test on her (he is also Type 1). The result just read "HIGH". Our fears were confirmed and we rushed straight to A&E!

As a mother I was HEARTBROKEN and AFRAID - how were we going to manage a 2 year old with this condition? How would we constantly prick her little fingers to do blood tests and give her daily insulin injections? What damage had already been done to her little body? Would we ever sleep again for fear she would slip into a diabetic coma overnight? We also felt quite LONELY - we realised quite quickly who our real friends were and that some people would just never understand the impact (and potential danger) of this disease no matter how much we tried to educate or explain. We received a lot of "At least she doesn't have cancer", or "Sure that's fine, isn't your husband a Type 1 so it'll be no bother", or "Sure she's so young she'll know no different" and the classic "Did you give her too many sweets?"

Then there was the GUILT - had we done something to cause this? Nevertheless, the cause of Type 1 diabetes remains unknown. A person does need to be predisposed to the condition but for many families it seems to strike from nowhere. Something needs to trigger the autoimmune response that causes the beta cells in the pancreas to be attacked. With my daughter, it is presumed to have been triggered by a virus. Nothing we did caused this monster to take over our child's body.

The first few weeks after the diagnosis were a complete blur of recording blood sugar readings and food quantities, learning how to give injections, count carbs, do blood sugar readings, watch for hypos or hypers, hospital calls and visits and sleepless nights whilst also dealing with the emotional roller-coaster of our daughter having to live with this condition for life. When I picked up my daughter's first prescription from our local pharmacist, they took my number and passed it onto another mum in the area whose son is also a Type 1 diabetic. It was so wonderful to talk to another mum in the same situation as me and to hear that everything would be ok. I will be forever grateful to that mum who is still a close friend. As time went on things did indeed become easier and easier. My daughter got an insulin pump quite soon after diagnosis because she was so young and this helped immensely. Then a few years ago she started using a CGM sensor with her pump and again management became easier as she no longer needed to do as many finger pricks and we know that the sensor and pump are working together continuously to ensure her blood sugar levels remain as in range as possible.

There are a couple of private Facebook support groups for parents where you can ask advice, share tips or just rant to people that understand. There is a wealth of information online as well as kids clubs, outings and opportunities for Type 1 children, teens and parents to get together. There are also family weekends and camps where your child (and the rest of the family) can really get a break and just be silly in a fun and

very inclusive environment.

The staff in Crumlin Hospital have been wonderfully supportive to us on our journey. My daughter is now a teenager, and there have been the usual teenage bumps along the way as well as further autoimmune disease diagnosis', which they have helped us, manage. Dealing with her diabetes is just part of her daily routine – it does not get in the way of any of her interests or hobbies at all. I wish it was not there but at least it is manageable and it is just part of the inspiring and beautiful young person that she is.

If your child is newly diagnosed and you are reading this book, as hard as it may seem at first, this will get better – you really do need to just take it day by day. A nurse told us that we would go through a grieving process similar to if we had actually lost our child. Knowing that those feelings and emotions were a normal reaction to the diagnosis really helped me get through that period. As soon as you can, reach out for support, whether that be from a professional or from other parents of children with Type 1 diabetes. Take any offers of help from friends and family and cherish the people that are willing to learn more about Type 1 diabetes and how to manage it in order to help you and your child on this journey.

Naomi's Story:

The weeks before my son was diagnosed as T1D were a little strange, it had been a difficult Christmas as a family and it was now January so always the worst time of year for illnesses and bugs.

My son had been up most nights for the toilet but a lot of this was puberty, or so I thought.

During the first week back at school after the Christmas break he complained of craps in his legs, I had put this down to an intense PE session and as he was not, sporty this made sense and when they lasted a few days, I put it down to growing pains.

He had no temperature, which was always something that was a check if he was unwell. Therefore, I was not concerned.

The next few days he was not himself but he was up and down and was not complaining of being unwell so we carried on as normal.

Then he was not feeling the best he was sleepy during the day very unusual for him and then it got scary his lips went very blue and he started slurring his words and rolling his eyes.

It was the weekend so the doctors were not open so we went straight to A&E at Crumlin.

It was such a strange experience I knew nothing about T1D and somehow I thought about was it a possibility so when we went to the triage nurse I mentioned it to her and the reasons why and she checked his bloods. I ever knew this time that your blood range should be! He was 29 and in DKA.

The team on the rota that day just calmly and speedily got my son set up in the emergency department and did what they needed to do (save his life).

I knew he was going to be admitted so my husband went home and got all the necessary supplies. While my son lay there exhausted and getting the necessary attention I just sat there and read the HSE Type One Diabetes information booklet online. Now at this stage nothing by had been confirmed to us as priority was my sons health.

However, I read that booklet and just could not comprehend what life was going to be like.

The next few days I think I was just numb and I felt so guilty thinking did he have too many sweets at Christmas. Can this be cured? So many questions?

All the new words and new life dependent rituals entered our lives; ketones; insulin carb ratios; carb



counting; blood check; insulin pens; glucose drinks; high bloods; low bloods; bolus....it was overwhelming. I just couldn't comprehend that this was my sons and our life for ever more and I was really struggling and was sad as every piece of new information received (while so important) just made me feel so useless and terrible as a parent.

The team in the hospital were amazing their objective was to teach and educate us as quickly as possible of the necessary tasks of this life changing diagnosis. While it was so much information and it came at such speed, (I never thought I would remember it all) it was all as important as it was necessary for living.

From the diabetic nurses teaching how to check bloods and do insulin injections; to the dietitians who made me realise that carbs is not just bread, pasta and potatoes! While it was all an overload of education they made sure we understood what we had to do, we had questions after questions, and they answered them all.

I was still in a state of shock before we left the hospital for home and one very kind member of staff gave me the glimmer of hope I needed (because at this stage my lack of understanding of T1D I thought my son's life was over), she told me that she had T1D and that my son will be fine. We had a good chat and honestly, it gave me the hope & reassurance I needed.



Once we got home that was another big change without the nurses on standby. But each day we spoke to the nurses by phone and as each week went by living with new life of T1D we did get to grips with Carb counting and correction factors and insulin pens. We also did not need to ring the diabetes team as often as we had realised we had now learnt what they had taught us.

I found I became obsessed with finding everything out I could about T1D and then finding out that so many people have it, even a Strictly Come Dancing dancer and this all gave me the hope that yes my son can have a good life.

I also found out about the downsides of T1D and long term side effects if it's not looked after which was again another big worry as a parent.

Nevertheless, within a few weeks, we were approved for the Continuous Glucose Monitor (CGM) and that was just amazing at helping to manage the blood range. It did not stop highs or lows but it did help with the management of it and helped at night, as the alarm would go off for lows.

Each time we meet with the diabetes team for the reviews we would eagerly await the HbA1c numbers to see if things were going right. In addition, thankfully, with all the education, we received and being disciplined in writing down every meal for carb counting correctly, they came down to a healthy range.

We are now 2 years on and my son recently went onto an insulin pump. Moreover, I can honestly say that

life is now so much better with T1D. I know I'm not wearing the pump and it's attached to my son 24/7, he has gone from approximately 150 injections a month to 10 set changes which is just life changing. As a parent, the worry is lessened as the pump really does help keep time in range so well. In addition, yes, there are still highs and there are still lows.

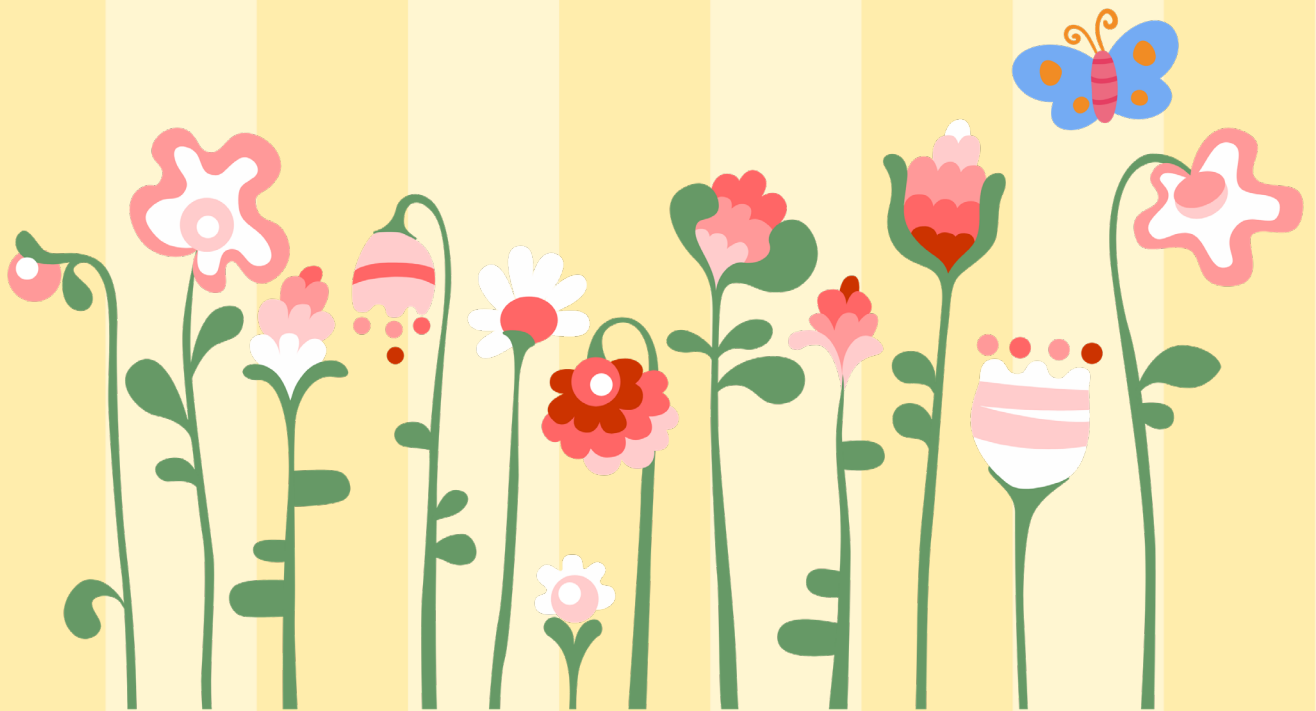
T1D is forever but I am so grateful to the diabetes team in the hospital who educated us and helped whenever we had questions.

I am also grateful to live in a country where we have access to insulin and all the necessary medical supplies to keep my son alive.

I am grateful to the science and technology that have enabled for CGM and insulin pumps to exist and to have access to these.

My dream would be for a cure, but for now, I just learn from other diabetics on tips and how they live life to the fullest.

And finally I found talking so important, none of this hiding T1D, it is too important to hide and so many people have it or know someone that has T1D so sharing really is caring as it's so helpful to know you are not alone and all the information you receive can help live life to the fullest.



Michelle's Story:



On the 17th December 2023 is a night I will never forget. My son aged 12 at the time came to me complaining of tonsillitis. It was a recurring complaint he suffered with and I was waiting many years to have them removed.

Decided to head to A&E in Crumlin, we checked in as normal and waited to be seen by a nurse we were called in and the nurse said she could not get a reading- I did not know what she meant within two minutes we were in resus.

My son was given two injections in his stomach I asked the nurse why she was injecting him if he has tonsillitis. The doctor explained to me it is life or death, and I will never forget those words.

They told me if I had sent my son to bed that night he would have been in ICU or worse. His bloods came back 52.2 and doctor told me my son was seriously unwell. We stayed in hospital for a week-received education on type 1 diabetes.

With the help of the diabetic team, consultants and dietitians who were absolutely amazing they saved my sons life and I will be forever grateful. It was scary to think I had to take my son home with no support, but I was wrong I was given phone numbers and reassurance from the staff before going home. I did ring many times but they were always reassuring at the end of the phone.

Now 2 years on they all were right Type 1 diabetes is manageable. Yes, our lives have changed and I still worry and text him many times a day. And it does get easier in the way of sleepless nights are not so frequent. My son now goes out by himself and I don't panic as much, we keep in touch by phone.

At the start, you are in shock and panic sets in. However, it is comforting to know you can call the diabetes team for support.

Now, my son goes out for the day with his friends for food or the cinema, and I do not have to worry. For anyone still thinking how are you going to get through this?

You will and your child will live there best life and diabetes will not hold them back.



Marta's Story:

My son was 3 years old when he was diagnosed with Diabetes Type 1 and he is 14 years old now. It was very difficult time for me on the beginning, shock, disbelief, tears and questions: Why me? Why my little boy? Especially since us already struggling with effects of congenital cytomegalovirus infection, changes in his brain and developmental delay from his birth, hyperactivity, sensory processing disorder, autism and we did not need another new disease, but no one asked us for permission.

Therefore, I had to learn in few days how to do injections with insulin, count carbs, check blood sugar and many more. With the help of amazing team from the Crumlin Hospital now everyday life with diabetes is easier. During this difficult time, my faith in God get stronger and I repeat to myself: "Do your best and God will do the rest". I belief in better eternal life where will be no tears, no diseases, no pain, no death. That gives me hope, courage and strength for every day.

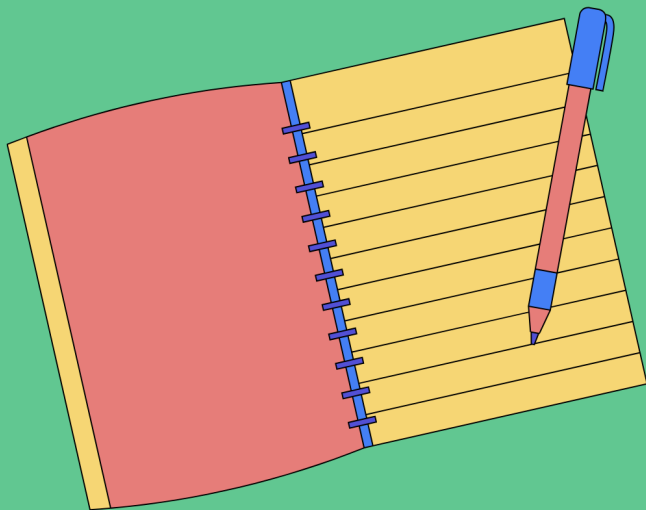
Stephanie's Story:

My son was diagnosed December 2024. For 2 years, I felt he was always tired, was not growing and was not gaining weight no matter what he ate. He was more tired after food. I brought him to the doctor, referred to consultants and nobody could tell me what was wrong. Nothing showed up on his bloods. I asked for fasting blood tests and that is when he was diagnosed with Type 1 Diabetes. I was so angry that nobody listened to me; we were all completely overwhelmed and exhausted.

The first few months are hard, I will not lie to you, there is a lot to learn but there is fantastic support with the Diabetes team in Crumlin. I did not hesitate to call them even if that was a daily call at times and they were more than helpful.

It is a stressful time, there will be sleepless nights and bad days, I found linking in with other parents of Type 1s helpful, and they just got it.

I joined Fb groups, Whatsapp groups and I found listening to podcasts, especially Juicebox very helpful.



The best piece of advice I got from another parent was to get myself a notebook for recording my son's meals and snacks. I split it into sections Breakfast, Lunch, and Dinner, Fruit, snacks and Take Away. I wrote down every day that my son ate; I worked out what it was per 100g so I would not have to keep working things out. I recorded how his sugars reacted to each food type. I still use it for reference almost every day. It is all a learned experience and how your child's sugars react will be different to other children.

The nutritionist in the hospital will give you sheets 'The diabetes management diary' this is good for establishing a routine. We photocopied this and made a book. It was great to reference back to previous days to save time recalculating. We kept this going for 6 months until we had a good routine and me and my husband understood everything.

I gave one press/ drawer in my kitchen to diabetes. After I calculated and had given insulin then I put everything away before we ate. Diabetes is constantly there but you just do not need it in your face all the time.

Remember there are 42 factors effecting blood's sugars, things out of your control such as hormones, excitement, temperature, sickness etc. You will learn these with time and you will get better with managing

Diabetes.

Every day is learning and progress, even if it is a bad day.

We are still learning every day; Diabetes is just part of our lives now. Do we want it, no, not but we just have to live with it. My son is healthy now, he looks good and strong. He is happy and loves playing football.

After the first few days of taking insulin, he said he felt he had energy again. He just needed insulin.

It takes a long time to accept this diagnosis so go easy on yourself. So cry and talk to heal. Take one hour at a time.



Julie's Story:

On the 25th October 2024, our family were on a bank holiday car journey, little did we know what was around the corner! The long car trip to Baltimore was a redeeming feature, it highlighted that our 11 year old had two of the TEST symptoms-thirst and toilet trips.

Over the weekend, we could see Ross was lethargic (Energy) and was not thriving (Sudden weight loss). We were worried; we had not noticed the signs. A GP appointment was quickly arranged and after a urine test, we were instructed to go straight to hospital.

On admission to Crumlin Hospital, more tests followed and a Type 1 Diabetes diagnosis was confirmed. We had so many questions, how did this happen? what caused it?, what did this diagnosis mean?

The Doctors and Nurses in Crumlin were excellent and very professional but our heads were melted with worry and medical jargon. The unexpected responsibility of caring for a child with a long-term illness was like having a newborn all over again! Except this time, he had adolescent attitude and self-awareness.

We were all learning on the spot about blood glucose, hypos, hyperglycaemic, ketones, needles, Dexcoms, Fiasp and Lantus. What were we going to feed him going forward? The very sight of the orange Glucagen hypokit sent tremors of panic through us. Over a weekend, we became "medical Doctors" and our first patient would be our child!

Change management is hard and I will not lie, we were all exhausted -remembering to bring the injections, to change the sensor, counting calories, calculating insulin injections, and nightly Lantus. Our mobiles were hopping with Dexcom alarms sounding night and day. Treating lows, checking highs and nagging our 11 year old to remember to take his injection and move injection sites along his thigh.

As parents, we felt very vulnerable. As the saying goes, "What doesn't kill you makes you stronger!" A year and half post diagnosis, Ross felt comfortable to move to the Medtronic pump. Its early days, but we are hopeful Medtronic Smartguard will maintain consistent in range blood glucose levels and it has eliminated the need for multiple injections. It is discreet and gives Ross ownership to confidently treat his condition.

Type 1 Diabetes is a long-term illness and guardians can apply for Domicillary Care Allowance. We are fortunate to-days technology has made huge advancements. Along our journey, we have adapted to change and met the pleasant professional family that is the Diabetes Nurse Specialists, Doctors, Dietitians and Psychologists in Crumlin. We have also benefited from meeting other children and families with Type 1 diabetes.

As time goes by, the Type 1 diabetes journey becomes familiar and enjoyment returns.

Acknowledgements:

I would like to thank all of the young people who took part in the Adolescent Peer Support Group, you took a chance and agreed to take part in each session fully. I understand many of you did not know any other teenagers with diabetes, you enabled and supported each other and validated each other's experience.

All of you agreed that you wanted to create something meaningful for newly diagnosed patients and their families, and you shared your stories as a way of helping others.

This booklet belongs to you and it is important to understand the impact your story could have on a newly diagnosed young person and family.

Lastly, a big thank you to all of the parents who dropped and collected their young person to the group each week. A special thank you to all of the parents who added their own personal stories, it was not an easy task and I am appreciative that at times it was and is emotional. I am grateful that I was able to coordinate and facilitate the group, I was able to interact with wonderful young people, and you showed us that T1DM does not define you.

Thanks to Emma, Aisling, Vincent and Eric who all contributed their time and expertise.

Forever grateful,

Jules Thompson

Senior Psychologist, Diabetes Department, CHI Crumlin

Letter to My Younger Self is a collection of personal stories written by young people living with Type 1 Diabetes and their parents at CHI Crumlin. Created through a four-week peer support programme led by the diabetes psychology service, the booklet gives an honest insight into what it is really like to be diagnosed with diabetes and learn to live with it.

Through letters written to their younger selves, the young people share their feelings, challenges, and the things that helped them cope along the way. Written in their own words, these authentic stories offer comfort, understanding, and hope to newly diagnosed children, teenagers, and their families.

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