FACT SHEET

Down Syndrome
Western Australia

Down Syndrome and Diabetes

What is diabetes?

When someone has diabetes their body cannot maintain healthy levels of glucose (a form of sugar) in their blood. The pancreas, an organ near the stomach, produces a hormone called insulin which converts glucose from food into energy.

When someone has diabetes their body either does not produce enough insulin or cannot use the insulin as well as it should. This results in glucose staying in the blood and the person having high blood glucose levels which if not managed well, can lead to health complications in a variety of organs including the heart, eyes and kidney.

Types of diabetes

- There are three main types of diabetes: **Type 1**, **Type 2** and **Gestational diabetes**.
- Anyone can develop diabetes and all types require daily care and management. Diabetes is a serious medical condition and needs to be managed as such.

> "There should not be any difference in the care given to people with or without Down syndrome, except that those with Down syndrome are likely to require a greater degree of supervision and monitoring by health professionals and carers."

(Down's Syndrome Association, Health Series: Diabetes, 2020, www.downs-syndrome.org.uk)

Read about Lily's journey and more diabetes facts on the following pages.

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Lily's Story...

Being diagnosed with Type 1 Diabetes at the age of 10.

Lily was a healthy 10-year-old with Down Syndrome. She was recovering from what I thought was a bad cold that winter. The flu-like symptoms were subsiding but Lily was not getting better.

I took her to the local Urgent Care and was told she was just recovering from a cold and to bring her back if she developed a temperature. The next day she could hardly move. She slept most of the day and I noticed how much weight she appeared to have lost. She looked skinny and weak., and Lily was generally very athletic and strong. She was dehydrated and her lips were cracked and she did not have the energy to do anything. There was still no temperature but I knew something was not right. I was lying next to her in her bed watching her sleep and I had my arm over her, and I could feel her heart racing. I put my Fitbit watch on her so I could see what her heart rate was. I realised her heart rate was alarmingly high so I called Health Direct and told them what was going on. They suggested calling an ambulance and the next thing I knew we were being told she had diabetes and was in Diabetic Ketoacidosis (DKA).

I remember the guilt I felt when the doctor said she had diabetes. I initially thought I had caused this for Lily. I remember saying, 'but she isn't even a sweet tooth, she doesn't eat a lot of sugar'. The doctors were quick to reassure me that Type 1 Diabetes had nothing to do with what Lily had eaten or how healthy Lily was, this was an autoimmune disorder. They also mentioned that she had been fighting Influenza Strain B and they believe that triggered the diabetes. They said it was likely she was predisposed to diabetes and would have developed it eventually.

We spent a week at Perth Children's Hospital (PCH) following diagnosis. Lucas (Lily's dad) and I had to attend education sessions at the hospital every day for a whole week. I remember feeling very overwhelmed and quickly realised the seriousness of this and the affect it was going to have on us every day going forward. But at the same time, I felt grateful for the hospital system and the staff at PCH. Lily had a phobia of needles before diagnosis so the idea of many needles a day was initially traumatising! However, we were supported by PCH and the staff tried many ways to keep Lily calm and happy during treatment.

I remember noticing that the doctors and nurses who talked to Lily and explained to her what they were doing, got a better response from Lily. Even though she was only 10 years old, asking Lily for her consent before touching her made a huge difference.

We were lucky that before we left the hospital, Lily was fitted with a Continuous Glucose Monitor (CGM) so we were better able to monitor her sugar levels right from the start. I think this made a big difference for us, understanding Lily's diabetes, how her eating habits affected her blood sugar levels and how her levels affected how she felt overall.

Now 2 years post-diagnosis, living with diabetes is our 'new normal'. Lily has around 4 to 5 needles a day and two finger pricks to calibrate her CGM. She is now at the stage where she gets everything ready for the injections and finger pricks though is not yet able to self-administer the injections. Lily understands the need for the injections and does not fuss anymore.

I remember thinking I didn't know how I would cope giving her needles every day but Lily adapted quickly to everything, so I just followed her lead. Lily is resilient and I think kids in general are quick to adapt to changes like this. Lily just does what she must do and lives her life to the fullest, without letting the diabetes worry her. As her mum, it is still a worry. Since diagnosis, we have not yet had a full night's sleep each night.

Diabetes does require constant care and it is a relentless disease, but it is manageable.

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Type 1 Diabetes

- It is said that children with Down syndrome are **four times more likely** to develop type 1 diabetes.
- Type 1 diabetes is an autoimmune condition where the immune system destroys the insulin producing cells in the pancreas.
- We do not know what causes this, it is not linked to lifestyle factors and cannot be prevented. There is no cure for Type 1 diabetes, it is managed with insulin injections or the use of an insulin pump.

"In many cases diabetes occurs alongside problems with thyroid function. This may be hypothyroidism (underactivity) or less commonly hyperthyroidism (over activity) of the thyroid gland. This is because both problems are caused by the body producing antibodies which destroy vital tissues… This autoimmune process seems more likely to develop in people with Down syndrome, although the reasons for this are not yet clear.

Other autoimmune problems such as alopecia and vitiligo may also co-exist. Markers in the blood called antibodies are a sign that a person is at increased risk of autoimmune disorders. It is not until about 80% of insulin producing cells have been destroyed that the clinical symptoms of diabetes appear. There is also an association between Type 1 diabetes and an increased risk of coeliac disease (gluten intolerance), in children with and without Down syndrome."

(Down's Syndrome Association, Health Series: Diabetes, 2020, www.downs-syndrome.org.uk)

Type 2 Diabetes

- Type 2 diabetes is the most common type of diabetes in the general population. It occurs when the pancreas does not produce enough insulin, or the insulin is not used effectively by the body's cells.
- Type 2 diabetes is commonly associated with lifestyle factors and is often connected to being overweight. Some people with Down syndrome will have type 2 diabetes, generally as adults.

Gestational Diabetes

- Gestational diabetes is a form of diabetes that occurs during pregnancy and most women will no longer have diabetes once the baby is born.
- For further information on gestational diabetes go to www.diabetesaustralia.com.au

Learn how to recognise symptoms of diabetes on the next page…

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Recognising symptoms and diagnosing diabetes

If someone has undiagnosed type 1 diabetes they may display some or all of the following symptoms and this will generally come on suddenly, so diagnosis generally happens quite quickly whereas in type 2 diabetes many people will have few or none of the following symptoms so it may be overlooked.

- Being more thirsty than usual
- Passing more urine
- Feeling tired and lethargic
- Always feeling hungry
- Having cuts that heal slowly
- Itching, skin infections
- Blurred vision
- Unexplained weight loss (type 1)
- Gradual weight gain (type 2)
- Mood swings
- Headaches
- Dizziness
- Leg cramps

If you need more information
the following references may be of help.

www.diabetesaustralia.com
www.downs-syndrome.org.uk

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Disclaimer

The information in this resource is general in nature and does not constitute advice. Down Syndrome Western Australia will not be held responsible for any decisions made as a result of using this information. The contents of the resource do not constitute medical and legal advice and should not be relied on as such.

☎ (08) 6253 4752
office@downsyndromewa.org.au
www.downsyndromewa.org.au
32 Burton St Cannington WA 6107
PO Box 833 South Perth WA 6151

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Western Australia