

## Service, Support and Success

**The Direct Support Workers Newsletter****Already Sweet Enough:**

Understanding and Supporting Individuals with Intellectual Disabilities who have Diabetes



By: Céline Parent

Have you ever tried to stand on a teeter-totter? Right in the middle? And tried to keep it from teetering and tottering?

Even if you haven't, you can probably imagine how difficult it might be to keep it balanced. It tips one way, you try to compensate; it tips the other way, you compensate more. Nothing you do seems to be able to keep it in the ideal spot for very long.

Having diabetes is a lot like balancing on a teeter-totter.

As a direct support worker, chances are that you support someone who has diabetes. If you don't, odds are good that you will in the future.

With diabetes, knowledge is key so let's start off with a bit of a lesson.

### "Do you have the bad kind of diabetes?"

There are several types of diabetes. All are different but similar in that they have to do with insulin and blood glucose (or blood sugar). The two most common, and the ones we will be focusing on in this article, are Type 1 and Type 2.

#### ***Type 1 Diabetes***

Type 1 diabetes used to be called juvenile diabetes. The term 'juvenile' turned out to be very misleading because Type 1 diabetes can strike at any age.

Type 1 diabetes is an **autoimmune disease**. It occurs when the body's immune system attacks the cells of the pancreas. It destroys the beta cells that produce insulin. It is not known why this happens but it is most likely caused by a combination of genetic and environmental factors.

Some facts about Type 1 diabetes:

- it is not caused by lifestyle or diet
- there is nothing that can prevent it
- once it starts it cannot be stopped
- there is no cure
- the only treatment is insulin and, without insulin, the person will die
- 10% of people with diabetes have Type 1 diabetes
- in Canada, more than 300,000 people have Type 1 diabetes

## ***Type 2 Diabetes***

Type 2 diabetes is a **metabolic disease**. In Type 2 diabetes, the pancreas still produces insulin, but one of two things typically happen:

1. the pancreas no longer produces enough insulin to meet the body's requirements,
2. the body is no longer able to use the insulin effectively.

Type 2 diabetes is usually diagnosed in adulthood although it is becoming more common in children due to an increase in childhood obesity.

Depending on the situation, Type 2 diabetes can be treated with diet, lifestyle changes, oral medication or insulin.

Some facts about Type 2 diabetes:

- it is sometimes, but not always, caused by a lack of physical activity and excess body weight
- there is a strong genetic component meaning that, in many cases, it cannot be prevented
- certain ethnic groups have a much higher chance of developing it
- most overweight people never develop Type 2 diabetes and many people with Type 2 diabetes are not overweight
- more than 9 million Canadians live with Type 2 diabetes

Did you know that people with certain types of disabilities are at higher risk of developing Type 2 diabetes? In particular, people with spinal cord injuries, learning disabilities, developmental disabilities and those with mental health difficulties are at highest risk. That is because they face specific challenges that can increase their chances of developing diabetes. The biggest challenges they face are social and physical barriers to supports and services.

## Team Insulin and Team Glucose

When you eat, your body breaks down carbohydrates into glucose. All carbohydrates, whether they come in the form of chocolate ice cream, a bowl of pasta or an apple, are transformed into glucose.

Glucose is the main form of energy for your cells.

Insulin is a hormone that is produced by the pancreas. Insulin transports the glucose from your blood into your cells.

Without insulin, the glucose stays in your blood, starving your cells of energy.

Over time, high blood glucose can lead to a variety of complications.

## The Dreaded Diabetes 'Complications'

A diagnosis of diabetes comes with a long and scary list of possible complications. Typically, people with diabetes are at greater risk of problems that involve damage to small vessels and nerves because of the high level of glucose in the blood.

Damage to the eyes, kidneys and nerves are possible. Heart disease and stroke are also risks.

In an ideal world, the best way to manage diabetes is to keep blood glucose in a range that is as close to ideal as possible. With Type 1 diabetes, the only way to do that is by checking blood glucose frequently and (simply put) treating high numbers with insulin and low numbers with food. With Type 2 diabetes, a combination of healthy diet, exercise and oral medication can help keep blood glucose in range.

## Are You Allowed to Eat That?

Now that we know that all carbohydrates are transformed into glucose, and insulin is needed to transport glucose from the blood to our cells, let's talk about what people with diabetes are, and are not, allowed to eat.

All carbohydrates affect blood glucose. Carbs in foods like cake, cookies and donuts affect blood glucose more dramatically because they cause it to rise faster and higher. Carbs in food like pasta, fruit or yogurt also cause blood glucose to rise, just not as high or as fast.

So yes, people with diabetes can have cake. And cookies. And donuts. In moderation, of course. Just like the Food Guide suggests. They are probably not a good idea when blood glucose is already high but they can be part of an otherwise healthy diet.

No food should be off limits and telling people over and over that they can't eat something only makes it more appealing. When and how much is up for negotiation perhaps, but whether or not it's 'allowed' shouldn't be.

## Are You High? Are You Low?

For people without diabetes, their body is able to regulate their blood glucose levels, keeping them between 4.0-6.0 mmol/L (72-108 mg/dl) at all times.

For people with diabetes, the recommended ideal range is 5.0-7.0 mmol/L (90-126 mg/dl).

In reality, people with diabetes can see numbers as low as 2.0 mmol/L (36 mg/dl), as high as 30.0 mmol/L (540 mg/dl) and anywhere in between.

## Is Your Diabetes Under Control?

On paper, diabetes is a numbers game. It is straightforward to understand and easy to manage. All you have to do is get blood glucose numbers to a good range and keep them there.

In reality, things are rarely that easy. A shocking number of things can affect blood sugar, causing it to go up or down, depending on the situation. Here is just a short list of examples that can wreak havoc on blood glucose numbers:

- illness
- exercise

- lack of exercise
- sex
- the amount of fiber in the last meal eaten
- the weather
- stress
- fatigue
- hydration
- menstruation
- roller coaster rides
- sad movies
- change of routine
- birthday parties
- time change
- air travel

To make it even more confusing, different people are affected differently. What causes one person's blood glucose to go up can cause another's to go down.

There are so many factors that affect blood glucose levels that it's a never-ending battle to try to manage everything.

Like trying to balance on a teeter-totter.

### My Grandmother had diabetes. She had both of her feet amputated. She's dead now

As direct support workers, we are often responsible for making sure that the people we support are educated about their health and we end up feeling a burden of responsibility to make sure they make healthy choices and 'good decisions.' We feel pressure to keep their diabetes in check.

It's hard to watch people make diet or lifestyle choices that go against what the doctor ordered. It's frustrating to feel that diabetes education and information is being ignored.

And it's all too easy to resort to using fear in the hopes of motivating change.

Telling someone that they will go blind, have their feet amputated or have a heart attack may seem like a good way to scare them into better diabetes management. In reality, it often does the opposite. Being told by doctors, diabetes educators, family, friends and well-meaning support workers all the horrible things that can happen often leads to people feeling overwhelmed and helpless in the face of such awful predictions. They often just stop trying.

### Knowledge is Power.

Many illnesses are treated with medication. One small pill can be all it takes to keep someone's seizures under control or help reduce someone's anxiety level.

Diabetes is not that easy. There are simply too many variables that affect blood glucose and, what worked today may not work tomorrow. The more information and knowledge we have about diabetes, the easier it is to understand and the more we can help someone who has it.

The challenge is that too much information can be overwhelming. Not everyone is able to read nutrition labels, understand how different foods and activities can affect blood glucose and figure out how to interpret and properly respond to a high or low blood glucose reading.

How can you help?

Go to the Diabetes Centre. Ask questions about how to deal with high and low blood glucose readings. Learn how to interpret blood glucose numbers. Learn what foods and situations lead to high numbers. Learn what activities lead to low numbers.

Help the person you support understand what affects them. Help them experiment with it. If their blood glucose is high after lunch, encourage them to drink water or go for a 20-minute walk and then test their blood sugar again. Chances are it went down which means they probably feel better...and they just learned a really valuable lesson about how they can have a positive impact on their numbers and on how they feel.

Keep a blood glucose log for a few weeks. Help the person write down their blood glucose results along with other things like the food that they ate and any physical activity that they did. Look for trends.

And don't tell people all of the awful things that will happen to them if they don't take better care of themselves.

They've heard it already.

They know.

## Educate, Educate, Educate

Once you have a bit more knowledge about the ins and outs of diabetes, help the person you support educate others about it. Work with them to create a one-page profile about diabetes to teach other direct support staff how to support and how not to support them. Help organize a diabetes information session for friends, family members and support staff. Create a vision board or other graphic representation of where they are now in their diabetes management and where they would like to be in the future.

## The Buddy System

Diabetes is an invisible disease. Unless we spot someone testing their blood glucose in public, we have no way of knowing who has diabetes and who doesn't. It can feel pretty lonely if you're the only person who can't eat something at dinner because your blood sugar is too high. It can feel even worse if you don't really understand why your blood sugar is so high to begin with.

Diabetes is one of those diseases where we often learn more from other people who have it than from medical professionals. The medical profession can be a valuable source of information, but they often rely on scare tactics, warning people of the bad things that can happen to them if their blood glucose levels are too high.

Help people you support find others who really get it. If you know someone who was recently diagnosed, help connect them to others who have had it for a while and can understand the fear and confusion they are probably feeling. Look for diabetes support groups. Check out the local Diabetes Centre for upcoming speakers and information sessions.

There is a vibrant diabetes online community (DOC) that can be a wonderful source of support, encouragement, information and stories. There are countless blogs written by people who have Type

## Control is an Illusion

No matter how much effort is put into it, diabetes management will always be teeter-totter management. The perfect nutrition label reading, the perfect insulin dose, the perfect exercise routine won't prevent highs and lows.

It's okay to get frustrated.

It's more important to understand that highs and lows are often not someone's fault.

So take a deep breath, try to learn from each blood glucose reading, and don't blame.

And learn how to live with teeter-totter balancing.

## More Information

If you are looking on-line for more information on diabetes, a good place to start is:

<http://www.jdrf.ca/>

<http://www.health.gov.on.ca/en/public/programs/diabetes/>

<http://www.diabetes.ca/>

## About the Author

Céline Parent has been living well with Type 1 diabetes for eleven years. She proudly wears Lucky, her Irish green insulin pump, on her belt and he helps keep her safe as she competes in triathlons and half marathons. Céline shares her diabetes and athletic adventures on her blog: Running on Carbs ([www.celineparent.blogspot.com](http://www.celineparent.blogspot.com)) and has mentored new adults recently diagnosed with Type 1 diabetes. Céline has worked at Mainstream for the past 16 years. She worked as a direct support worker for most of that time and is currently the Quality Improvement Coordinator, focusing her efforts on helping Mainstream prepare for their second accreditation.

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