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DIABETES HEALTH COACH

Your Child Has DIABETES

> **My child, the love of my life, the one who I would do anything for, has diabetes. I wish I could take it away ... If I only could... and I don't even know how to take care of them.**

Sound familiar?

Virtually all parents feel this way when their child gets diabetes. Its natural. Just like in any circumstance where our children are hurt. It hurts us. We get scared and angry.

It's all right.

But, how to get past this? How do you go from feeling overwhelmed to feeling empowered and confident that you can take care of your child and more importantly, empower them to take care of themselves?

They say, 'knowledge is power' so let's start there.

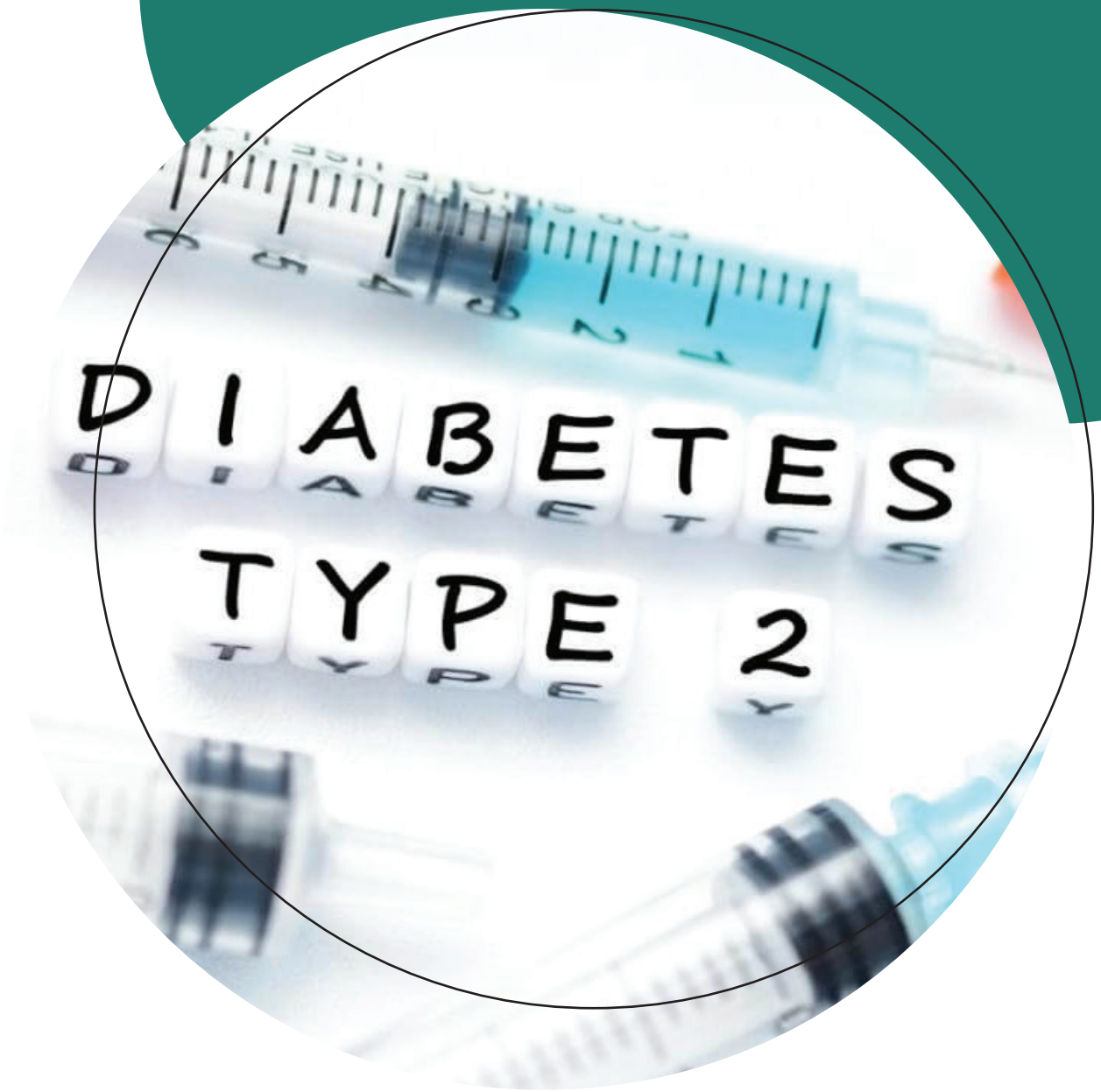
What is Diabetes?

There are two types of diabetes –

Type I and Type II (not very original names but it is what it is).

Type 1 - diabetes (T1D) is an autoimmune disease in which insulin-producing cells in the pancreas (called beta cells) are mistakenly destroyed by the body's immune system. T1D seems to have a genetic component and can be diagnosed early in life but also in adulthood. Its causes are not fully known, and there is currently no cure – however the search for the cure is aggressive and we are close.

Because of the destruction of the beta cells, the body does not produce sufficient insulin. Think of insulin as a latch key. This key unlocks cell walls enabling glucose (sugar) to move across the cell wall and into the cell where it is used as fuel.



Type II diabetes (T2D) on the other hand is often diagnosed later in life and can be due to genetic predisposition or behavior. T2D is a metabolic disorder in which a person's body still produces insulin but is unable to use it effectively. Many times, obesity, poor diet choices and life habits contribute to the severity of T2D. For some, it can be managed with diet and exercise and in some cases go into remission with aggressive self-care. Medication may also be required. More serious cases may require insulin therapy.

Though they share the name diabetes, the two diseases are quite different.

Diabetes has a bit of a unique history

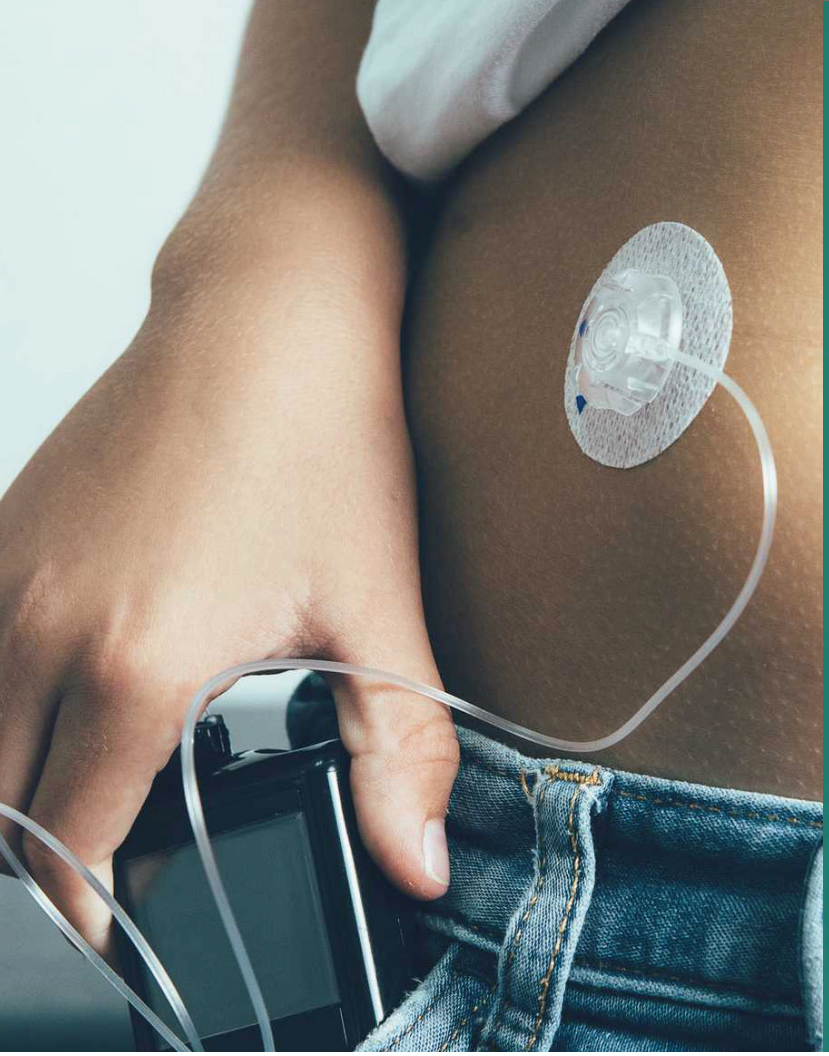
Type 1 diabetes was first documented more than 3,500 years ago. The first known mention of diabetes symptoms was in 1552 B.C., when an Egyptian physician, Hesy-Ra, documented frequent urination as a symptom of a mysterious disease that also caused patients to waste away. In 150 C.E., the Greek physician Arateus described the disorder as “the melting down of flesh and limbs into urine.”

Now how the condition got its name is interesting. The term diabetes is the shortened version of the full name diabetes mellitus. Diabetes mellitus is derived from the Greek word *diabetes,* meaning siphon -to pass through and the Latin word mellitus meaning honeyed or sweet – because of the excess sugar found in the urine and blood of “ancient” diabetics. This sweet taste had been noticed in urine by the ancient Greeks, Chinese, Egyptians, Indians, and Persians as is evident from their literature.

My question?

“Why are people tasting urine and what type of person would want to?

Early treatments for diabetes included exercise and a highly restricted diet. Early 19th-century diabetic diets included the “oat cure,” “potato therapy” and the hugely popular “starvation diet.”



Signs and symptoms

T1D is identified in children and adults as they show signs of the following symptoms:

- Frequent urination
- Increased thirst
- Dry mouth
- Bedwetting in children who were consistently dry
- Itchy or dry skin
- Increased appetite
- Unexplained weight loss
- Yeast infections

What's supposed to happen?

As we eat, food moves into the gastrointestinal tract to begin the digestive process. This process breaks down the foods we ingest into the nutrients we need to survive and thrive. Among these nutrients are glucose (sugar). Glucose is absorbed into the blood stream from the gastrointestinal tract and insulin is waiting to help that fuel get into the cells so it can be utilized by the body. As blood sugar levels rise in the body, the pancreas will make even more insulin (more latch keys) for our cells to utilize that glucose as fuel.

This doesn't happen in a Type I Diabetic

Well, the eating and digesting part happens but the body doesn't make any insulin so the body can't utilize the glucose that had been absorbed into the bloodstream. As a result, not nice things happen.

It's pretty straightforward

No Insulin Latch Key = No Open Cell Door = No Cellular Fuel and High Blood Sugar = Cells Running on Empty = Not Nice Things

OK, so what are the "not nice things?" Let's focus on one, Diabetic Ketoacidosis (DKA), because its directly related to a lack of insulin and glucose for fuel.

The cells in your body MUST have energy, must have fuel in the same way that gas guzzlers won't run without gas or your Tesla won't run without electricity.

So, what's a cell to do?

The body looks for an alternative fuel source. In this case, fat. Seems reasonable, after all, we store fat for energy and other purposes. But, and this is a big but. The liver breaks down this fat which produces ketones for energy. The problem is ketones are acids (fatty acids to be precise) and in large enough quantities are poisonous to the body. When they get too high, a diabetic will usually go into DKA.

DKA typically occurs in individuals with uncontrolled diabetes. So, take a breath, calm your heart and say your mantra.

As I said, knowledge is power, right? So, let's be powerful.

Warning signs of DKA can include

Initial symptoms

- Thirst or a very dry mouth
- Frequent urination
- Weight loss
- High blood glucose (blood sugar) levels
- High levels of ketones in the urine

Later stage symptoms

- Fatigue
- Dry or flushed skin
- Nausea, vomiting, or abdominal pain
- Fruity odor on breath
- A hard time paying attention, or confusion

PSA: DKA is serious. If you see any of the above symptoms in your child, contact your health care provider IMMEDIATELY, or go to the nearest emergency room of your local hospital.

Some of the good stuff Treating Type I Diabetes

Diabetes is a lifestyle.

There. I said it. Well, it is. Unfortunately, one that you don't choose. It's foisted upon us and you need to embrace it. Which can be hard – giving up a sense of normalcy for a "new normal" is daunting. Not to mention the fact that there is a cycle of grief associated with having to adopt this "new normal" including denial, anger, negotiation, depression and acceptance (sometimes acceptance doesn't happen).

But think of it this way. Much of what you will do to support your child you would do anyway.

1. **You want them to eat a healthy and balanced diet. But now you're going to add carbohydrate counting**
2. **Exercise – were you going to let your kid become a couch potato? Of course not. But now you'll be on the lookout for low blood sugars.**
3. **Get a good night's sleep**
4. **Make friends**
5. **Explore the world**
6. **Take on challenges**

And of course, take insulin and live this *chosen for you* lifestyle.

It's also a learn by doing disease. The more you work on blood sugar control, the better it becomes. And yes, there's a learning curve but isn't life-long learning an integral part of being human?

Here are the basics. It's all about daily monitoring and smart choices.

Insulin

Insulin is a pillar for control. As you've learned by now, without insulin, there is no control. There are multiple types: short acting, intermediate acting and long acting. There are also multiple ways to deliver insulin. Among these are, daily injections, insulin pumps and emerging therapies such as Inhaled Insulin. You and your endocrinologist will discuss and select the treatment approach which best fits your child's particular needs.

Blood Sugar (BG) monitoring

Knowing your child's blood sugar levels and acting accordingly is super important. Monitoring lets you know when insulin may be needed to correct high blood sugar, how much insulin to take for meal or when carbohydrates may be needed to correct low blood sugar. There are two ways to monitor BGs - finger stick blood sugar meters or continuous glucose monitors (CGMs) which provide a 24/7 view of BGs.

Carbohydrate counting

Why do you have to count carbs? Well, since a diabetic isn't making insulin but eating nonetheless, you will need to figure out how much insulin your child will need should to cover that meal – so the child can utilize that food and keep blood sugars in a normal range.

How much insulin is needed is determined by how many carbs are being consumed. With practice, it will be easy for you to figure out the correct ratio to get this done. Having an accurate ratio of insulin to carbs is one of those factors which will help maintain stable BGs.

Diet

Like **ANYONE ELSE,** a balanced diet is important for good health. You may choose a low carb diet, vegan, vegetarian, whole food etc. This is a lifestyle choice. Find the one that works best for you **AND** your family. Don't forget about the other members of your family because, in a sense, they have to live with diabetes too.

Exercise

Again, part of anyone's healthy lifestyle but in this case, exercise not only keeps your child fit but also helps avoid long-term complications. It's also a great tool to manage blood sugars. Guess what? An exercising muscle doesn't need insulin to access glucose fuel. It does it all by itself. Isn't that wonderful?

So, don't say to your kid, "go play in traffic" rather tell them to "go race the cars down the road."

Becoming one with your healthcare team

People with T1D regularly meet with a team of medical professionals (endocrinologist, ophthalmologist, therapists etc.) to help manage diabetes and to avoid the effects it has on the body. It's a multi-dimensional condition, needing a multi-dimensional team.

Parents of children with diabetes are not bystanders in their care who only listen to the guidance of an expert. You are the leader of that healthcare team until your child can do it themselves. Sometimes experts are wrong. It happens. The best healthcare team leaders weigh expert guidance with their real-life experiences managing their child's diabetes. Expert input should be considered. You'll combine their expertise with your knowledge, gleaned from daily experience with your child. In this way, you will make the best decisions possible for your child.

At the end of the day, a diabetic is their own doctor, coach, cheerleader and CEO.

But what about long-term complications?

Yes, there can be problems.

Diabetes, as any chronic condition CAN cause long-term complications. These range from heart disease, stroke, vision impairment, kidney damage as well as negative effects to blood vessels, nerves, and gums.

While these problems don't usually show up in kids or teens who have had T1D for only a few years, if the diabetes is poorly controlled, they can experience them in young adulthood and beyond.

These complications are not "just there" with no way to address them. There are many treatments to mitigate or reverse some complications. But the best way to treat them is to not have them in the first place.

As Yoda said; "You must learn control!"

Emotions and Relationships

The inevitable, "why him, why her, why us," has rattled around your brain. And you can pick any reason you want, god, fate, karma, statistical anomaly, or dumb luck. And you could perseverate over the reason. But when it comes to the health and welfare of your family, it doesn't matter. It's happened and the question is, how are you going to respond to it.

Diabetes is a whole family condition.

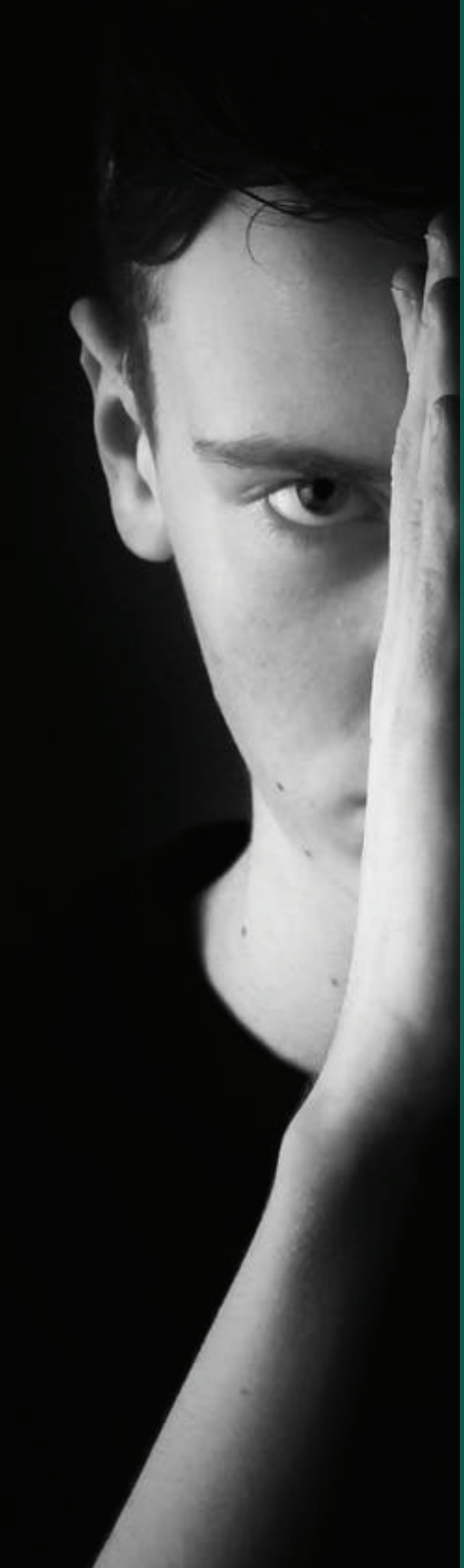
It affects the child with diabetes, siblings and parents. Both parents need to step up to the role of caretaker. This is important because the child can perceive a parent's lack of engagement as a lack of caring even though that is not the case. And what's fascinating is that when the child with diabetes senses their parent's engagement, it improves the child's adjustment to diabetes.

Guilty feelings are pervasive.

Everyone feels like it's their fault – parents feel that it was their genetics or lifestyle choices that caused the diabetes. That child with diabetes feels they are not being a "good" child. They can think, "look at the pain, I've caused my family." Or the sibling that feels guilty for being healthy or somehow caused the diabetes by wishing their sibling ill will.

In many instances the child with diabetes will withdraw and will need familial and/or therapeutic support. The notion of "why me" is an unfortunate and powerful demotivator for self-care and is wrapped up in the depression associated with the condition. Getting past "why me" is a critical step for acceptance.

Siblings may also withdraw or play a placater role. They may try to minimize disruption in the family, either out of guilt or a realization that further disruption will cause even more heartache and pain above and beyond what has already taken place.



Anger and Depression

There is a tremendous amount of anger in adolescent children with diabetes. There can be a resounding "why me" that's internalized or yelled aloud. Withdrawal, depression, stress and health-related anxiety are all common in children with diabetes. The depression can be insidious. All aspects of the child's life can be impacted – relationships, activity, self-esteem and self-care. It's imperative that you as a parent keep a watchful eye and intervene quickly.

And what about you?

Parents of children with diabetes must deal with many pressures. Among these are:

- Overwhelming guilt
- Fear that your child will experience severe low or high blood sugar
- Concerns over physical development as a result of diabetes
- Stress on your relationship with spouse or partner - one parent may blame the other not only in regard to genetics, but also in regard to division of diabetes management
- Parents can also be in conflict about being too over protective or not responsible enough in the care of their child

Sound daunting?

Fortunately, there is a lot you can do to gain mastery over the familial impacts of diabetes. Just remember that everyone needs to go thru the stages of grief: denial, anger, bargaining, depression and acceptance.

Here are some concrete steps you can take:

1. Family meetings. Get ahead of potential conflicts and encourage healthy siblings to become part of the team.
2. Create space for your self-care. Whatever it is, make sure to carve out space for yourself to do the things that give you joy.
3. Carve out space for you and your partner. Incredibly important to continue to nurture your relationship given the stressors that are placed on them by chronic illness in the family.
4. Online and offline community support. There are amazing resources out there for families, individuals and parents. There are numerous groups on Facebook and individual communities such as tuDiabetes and diatribe which are dedicated to those with diabetes. Non-profits, such as JDRF or ADA, have both online communities and resources to support parents, families and the individual.
5. Diabetic camps. there are amazing camps typically staffed by people with diabetes. At camp, your child will realize they are not alone. They will build lifelong friendships while learning self-management skills in a group setting. Many of these camps also provide therapeutic support. There are direct evidence-based studies demonstrating that peer support not only aids a child in adjusting to diabetes but also in improving his/her diabetes control.
6. Training. The good thing about adolescents and young adults is that they are striving for independence. Ride that wave. Use that desire to train and encourage self-management. They will be eager to take responsibility of their own care.
7. Therapy. Group, individual, family and partner to air issues in a non-confrontational and solution oriented environment.

What are your obligations to the outside world?

Your child has the same rights as any other child. They can't be sidelined in a sport or activity they love. Schools and other social organizations need to be educated not to treat your child any differently.

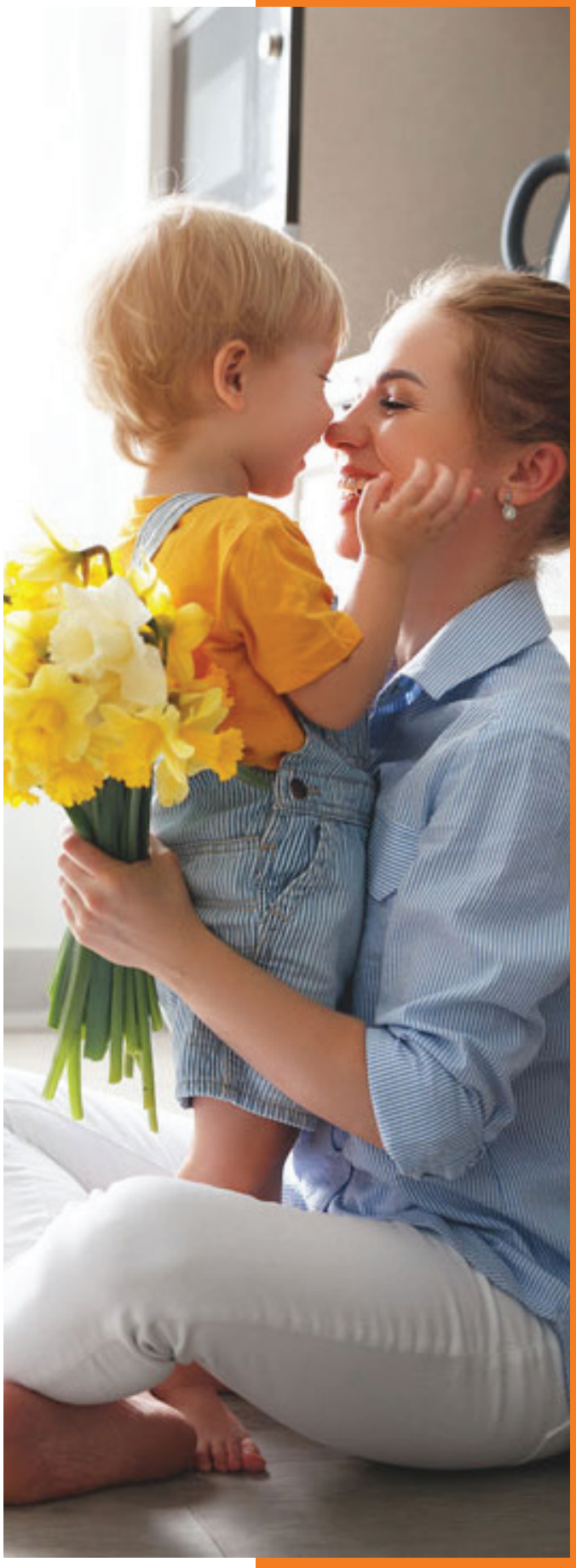
You will need to ensure your child's educators understand the specific needs of a child with diabetes. Schools need to have the appropriate medical and treatment supplies on hand. Teachers should be trained on your child's unique low blood sugar indicators or how to treat a low BG.

And super important? That your child know that NOTHING can be taken away from them. Every dream they had prior to diabetes is still attainable. Maybe even more so as the resilience and discipline they will develop will serve as the foundation for achieving those dreams.

So where does that leave us?

In a pretty good place actually. You're in a place right now that allows you to not beat yourself up. You understand a bit of what to expect and that you have lots of resources at your disposal. There is a huge community that has lived what you're living right now and can help you through it. And most of all you have each other.

Live T1D Strong.



Selected Resources

1. Facebook: Moms of Type 1 Diabetics: https://www.facebook.com/groups/59548417413
2. Facebook: Parents of Children With Type 1 Diabetes https://www.facebook.com/groups/104811746342626
3. Facebook: Type 1 Diabetes Support Group: https://www.facebook.com/groups/210509455804121
4. American Diabetes Foundation www.diabetes.org
5. JDRF www.jdrf.org
6. tuDiabetes.org
7. Diatribe.org

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9. Juvenile Diabetes Research Foundation (https://www.jdrf.org/t1d-resources/about/)
10. Emotional & Mental Wellbeing In Children With Diabetes (www.kidshealth.org.nz)
11. Psychosocial Issues for Children and Adolescents With Diabetes: Overview and Recommendations (https://spectrum.diabetesjournals.org/content/16/1/7)
12. Families With Children With Diabetes: Implications of Parent Stress for Parent and Child Healthhttps://www.ncbi.nlm.nih.gov/pmc/articles/PMC3334535/#:~:text=Parents'%20stress%20related%20to%20caring,health%20is%20not%20uniformly%20negative
13. What is Insulin? Hormone Health Network (www.hormone.org)
14. Type 1 Diabetes in Children (www.mayoclinic.org)