

Life



with diabetes

Juvenile Diabetes Research Foundation International

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Topics in Living with Type 1 Diabetes

It Takes a Team...and a Family

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Certified Diabetes Educator Catherine Marschilok reflects back on the 20th anniversary of her son's diagnosis and talks about the medical professionals, friends, and countless others who provide guidance, advice, and a helping hand.

The anniversary of the day the uninvited guest—type 1 diabetes—came into my life to stay is one I would rather not have to acknowledge. It was exactly 20 years ago that our oldest son, David, was diagnosed with type 1 diabetes at age eight. Nine years later came the news of our daughter Amy's type 1 diagnosis at age 21. Like many parents learning to deal with a child's chronic condition, I had to struggle at first to let positive thoughts and actions overcome the emotions I felt: sadness, frustration, powerlessness, fear, and anger. I realized I had no power to prevent diabetes, but I did have the power to make decisions about how to deal with it, and the ability to cultivate what I needed to help our whole family.

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Ask a Peer

Pregnancy and Type 1 Diabetes

Q: I was diagnosed with type 1 diabetes at 11 and am now in my 20s and looking to have a baby. I was just wondering how safe it is and what my blood sugar range should be?

A: I am not a medical professional and cannot give you medical or legal advice, but I have lived with diabetes for 27 years. I hope that through my years of learning about diabetes I can be helpful with the situation you are facing.

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Juvenation Updates

This month [Juvenation](#) added another new feature to its [Educating Others About Type 1](#) resource center. You can now post a widget to your Facebook, MySpace, and blog pages and use it to tell people about your diabetes in a fun and friendly way. The widget allows you to upload a photo and directs people to the resource center on Juvenation.

If you haven't yet joined the largest social network for people with type 1 diabetes and their families, go to www.juvenation.org and sign up today! You can also follow Juvenation on Twitter: <http://twitter.com/juvenation>.

Ask a Parent

Traveling with a Child with Type 1

Q: We will be traveling to Algeria and to France with our 8-year-old daughter this summer. She was diagnosed with type 1 diabetes a few years ago, but I am so worried about keeping her diabetes in control on this trip. I could use all the tips and advice I can get.

A: My daughter Allie was diagnosed with type 1 more than two years ago at age 12. We travel from our home in Arizona to Virginia every summer, so we are well acquainted with traveling with type 1 diabetes. The first thing I would suggest is taking extras of everything, from vials of insulin to test strips, and even a back-up glucose meter. I'm not sure how easy it would be to obtain insulin overseas, but just in case, you may want to ask your daughter's doctor to write a prescription that you can take with you.

[Read more...](#)

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Underlying our every action was the knowledge that we were in charge of our children's diabetes care. However, as both a parent and a medical professional, I quickly came to see that it takes much more than caring parents to raise a child with diabetes. Rather, it takes a larger "family"—a team with key medical professionals with whom you become acquainted, and then recruit.

Who are the members of this team, and what should you look for them to provide?

Physician: Depending on the age of the person with diabetes and the availability of specialty care, your physician may be a pediatrician, primary care doctor, pediatric endocrinologist, or adult endocrinologist. He or she is responsible for the management of your/your child's diabetes, prescribing necessary tests, medications, supplies, equipment, and referrals.

A **diabetes educator** is the medical professional with special, advanced training in caring for and teaching people with diabetes. When certified in the field of diabetes, he or she is known as a certified diabetes educator (CDE). CDEs are most often registered nurses (RNs). The diabetes educator will be able to guide you and your child through the issues of living day-to-day with diabetes, and teach you about home testing and record keeping.

A **registered dietician** (RD), who often is also a CDE, will work with you to develop a meal plan, increase your knowledge about eating well and counting carbs, and guide you on sports nutrition, weight control, and special occasion dining.

A **mental health professional** (psychologist, psychiatrist, social worker) can help you/your child and/or the family with stress, depression, anxiety, and other emotional challenges often associated with diabetes.

The **school nurse or other school or day care personnel** provide essential help in dealing with blood sugar testing, insulin therapy, and symptoms of blood sugar highs and lows.

As you assemble your team, keep in mind that your health care providers must be compassionate people who can communicate well with you/your child, and each other. Remember, it is your right—and responsibility—to receive clear answers to your questions and even to switch doctors if you are not satisfied with the care and service you are receiving.

Once you have a team, I encourage you to reach out to them as often as needed, even if you have to talk to them daily, to answer your questions. I promise you, things will get easier as you gain experience and confidence.

The Rest of the "Family"

Looking beyond your health care team, I cannot stress enough the importance of the invaluable emotional support and practical advice you can receive from other people.

Look for an adult relative, friend or neighbor who is willing to listen, learn, and understand what it means to have diabetes in your lives. Any friend who learns enough to care for a child with diabetes is a friend to keep.

The same goes for your child's friends. Once they learn that your child is the same person they knew who needs to be a kid and have fun, they can make such a difference. Sometimes children can be quicker than adults to learn the signs of low blood sugar and help a friend through it.

Teachers and day care providers are also part of the wider diabetes "family," and they should be involved in your child's management plan.

Find different people with diabetes whom you can admire. When my child was young, every time I met a new teen or young adult with diabetes, I felt a bit better about my child having it. Meeting happy, healthy people who have lived well with diabetes for a long time can be a great experience. There are many such examples in the public arena: professional entertainers, athletes, businessmen, and politicians.

Finally, and perhaps most critically, you will learn that parents or family members of people with diabetes have walked in your shoes, have most likely felt what you are feeling, and can become a tremendous source of information and inspiration. If the opportunity to meet other families is not available locally (have you tried your local JDRF chapter?), the [JDRF Online Diabetes Support Team \(ODST\)](#) volunteers can fill that gap.

In closing, let me say that I have great hope that researchers will cure diabetes during my child's lifetime. They're part of the family as well. Research progress is advancing at a much more rapid pace than when I started following it 20 years ago. Recent improvements resulting from scientific progress—types of insulin, delivery systems, pumps, meters, food labeling, and

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much more—make better management of diabetes more possible than ever before.

Putting these thoughts on paper has helped me get through this anniversary and acknowledge that there are reasons to “celebrate” it. I wish you all the best.

To locate a CDE in your area, talk to your doctor or contact the American Association of Diabetes Educators (www.aadenet.org).

Ask a Peer

Pregnancy and Type 1 Diabetes

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I was also diagnosed when I was 11, and I now have two healthy children. It is not easy to be pregnant with type 1 diabetes, but it is possible to have a healthy baby and to keep yourself healthy, too. It will take work on your part to first make sure your blood sugars are under control. Pre-pregnancy care is essential! You want to make sure that you are very healthy before you even start to try to get pregnant. I got my blood sugars under tight control and made sure I was exercising four to five times per week and was eating a balanced diet. You want the baby to come into an environment (your body) that is at its healthiest.

I would definitely recommend that you see your endocrinologist and diabetes educator and tell each of them what you have planned. I am sure they will give you tips on what you should be doing to prepare your body. They will not discourage you—nor will I—I just want to make sure you know what you need to do to get your body ready for a healthy pregnancy.

When you are pregnant with type 1 diabetes, you are immediately considered a high risk pregnancy. That is because you are a good candidate for many complications. I am not trying to scare you, that is just the reality of the situation. Diabetics are susceptible to high blood pressure and pre-eclampsia. If you are not under tight control, your baby could also be at risk for being a very large baby. JDRF has a great article on diabetes and pregnancy, here: http://www.jdrf.org/index.cfm?page_id=103524

When I was pregnant, I had to see my ob-gyn twice as often as most non-diabetics would. I had pre-eclampsia and had to have a blood pressure machine in my house, which we checked three

times per day. I delivered at 38 weeks—in the normal range—but ended up having a C-section.

I tell you all of this not because I want to deter you, but just to make you aware of the potential mental and physical challenges that face expectant mothers with type 1. With the proper preparation and care it is certainly possible to have a healthy, happy baby, and I wish you all the best.

Pregnancy is one of the areas where research has resulted in significant progress over the past few decades. As recent as the 1970s, women with type 1 diabetes were advised to not become pregnant, because of the risks to them and their babies. But as research has shown the benefits of tight control, and as methods to achieve control have grown by leaps and bounds, women with type 1 can now expect much the same outcome from pregnancy as anyone else—albeit with the proper care and monitoring outlined above.

Ask a Parent

Traveling with a Child with Type 1

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There are many convenient travel containers that may give you ideas on how to carry items with you. There are even “micro-coolers” that will keep insulin cool for extended periods of time. Here is a page with lots of great items: http://www.medicool.com/diabetes/diabetes_travel.php?gclid=CKSG8vvEwpkCFRjdxw0dm0_iuA

We have never had any issues taking Allie’s diabetes supplies through security, and have never been asked to put her items in a special bag. I’m not sure how that would be handled outside of the U.S., but perhaps if you check the website of the airline on which you will be flying; they may have pertinent information. Often, they’ll tell you to have a prescription handy.

Sometimes travel can cause blood sugar levels to behave strangely, either unusually high or low. You may want to have your daughter check her sugars a little more frequently during the trip. Also, be sure to have glucose tabs easily accessible, such as in your pocket. Also, let a flight attendant know that your daughter has type 1 diabetes and that she may require an extra snack or drink during the flight. They are usually very helpful with food items once they know there is a medical condition.

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Some people recommend that you use a long-acting insulin such as Lantus. I would also carry along one watch that you should not change as you cross time zones, and follow that watch (rather than the local time at your destination) for insulin that needs to be taken at a certain time of day.

If you have a carb-count book, that may be a good item to take along, too, especially if you will be eating new and different foods, or if carb counts aren't available. Even if the precise food item isn't in the book, it may help you get a close estimate.

I hope that helps! If you have any further questions, please feel free to contact me again. Have a wonderful trip!

If you have a question for JDRF's Online Diabetes Support Team, go to www.jdrf.org/diabetessupport.