



life with Diabetes

JUVENILE DIABETES RESEARCH FOUNDATION INTERNATIONAL

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TOPICS IN TYPE 1 DIABETES

Grandparents: No Greater Reward

“When people ask me to go back to those first days and recall what would have made them easier and more bearable, my answer would be simple: a loved one, preferably a mother, who cared about me and my child,” says JDRF volunteer, Moira McCarthy Stanford, whose daughter was diagnosed with type 1 diabetes at the age of 6. “My husband and I basically had to do it on our own. I cannot tell you the power of having someone who really cares.”

It’s often been said that it’s not just a child who gets diabetes. Diabetes is a “whole family” diagnosis, and grandparents can be an extremely important part of the mix. Whether they live nearby or some distance away, grandparents must deal with the same emotions and adjustments as the rest of the family, and then determine how they can best support their loved ones. That support can take many directions, from stepping in to giving their children some well deserved “time off;” to offering emotional support and understanding, to volunteering their time and energy to the fight for a cure. JDRF’s Online Diabetes Support Team, made up of volunteers from around the country, includes several grandparents of children with diabetes, and they all speak passionately about both the challenges and rewards of becoming integral members of the family team.

Sharon Koets, whose first granddaughter, Mazzy, was diagnosed at 20 months, remembers being shocked and overwhelmed in the beginning. But she and her husband felt they had no choice but to become experts in diabetes care. “We so wanted to do all the things we had always dreamed of doing with our grandchildren, yet we were fearful of taking on the responsibilities, and even wondered whether ‘quality grandparent time’ was possible at all,” she says. “We decided right at the beginning that we had to learn as much about diabetes as we could. We had no choice if we wanted be part of Mazzy’s life.” The couple also wanted to give Mazzy’s parents as much relief as possible. “They’re the primary caregivers, but a well deserved ‘time off’ is invaluable, because we all know that diabetes doesn’t take a day off,” she says.

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ASK A MEDICAL PROFESSIONAL

Diabetes Myths and Misconceptions

A constant source of frustration for parents of children with diabetes are questions or comments from well-meaning but ill-informed

people that reflect common misconceptions about type 1 diabetes. Catherine Marschlok, a registered nurse and diabetes educator, provides a sampling of some of the most frequently encountered diabetes “myths,” along with the facts.

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ASK A TEEN

Help from JDRF's Online Diabetes Support Team

Summer vacation is upon us, and traveling is an exciting opportunity to explore new places, meet new people, and experience new cultures. But it can also be a stressful experience for the unprepared. Allison Blass, a member of JDRF’s Online Diabetes Support Team and manager of the Internet site, [Diabetes Teen Talk](#), has been a traveler for all of her 20 years, 12 of them since she was diagnosed with type 1 diabetes. Over that time, she has garnered a few tips that have served her well through a variety of great adventures – with family and on her own – and that will help kids and teens have a safe, fun and relaxing vacation.

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WHAT’S NEW ON THE JDRF WEBSITE?

JDRF was founded in 1970 by some parents of kids with diabetes. Since it began, JDRF has been about only one thing: finding a cure for diabetes. In a special section prepared especially for kids, you and your children can learn a lot about the search for a cure: what research has already accomplished, the latest breakthroughs, and new and coming products designed to make life better and easier. Go to kids.jdrf.org and click on [The Search for a Cure](#).

WHAT A JDRF CHAPTER CAN DO FOR YOU

Guidance and Support

JDRF chapters offer a wide range of support services for families dealing with a new diagnosis. For example, the Greater Iowa Chapter has formed the Juvenile Diabetes Family Network to introduce newcomers to other families going through similar experiences. The Chapter’s *Time to Talk* program is for parents who want to talk to one another in an informal setting and hear presentations on everything from insulin pump therapy to self-esteem. Go to the JDRF website at www.jdrf.org and click on [Locations](#) to find events at a chapter near you.

You can let us know what you think of *Life with Diabetes* or subscribe today by sending an e-mail to info@jdrf.org. In subscription request, Please include **SUBSCRIBE LIFE WITH DIABETES** in the subject line.

TOPICS IN TYPE 1 DIABETES Grandparents: No Greater Reward

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Similarly, Phyllis Steingard recalls that when she learned 15 years ago that her 6-year-old granddaughter, Britni, had type 1 diabetes, she plunged into depression. “My days were filled with worry,” she recalls. Searching for a diabetes support group, she placed an ad in her local paper: “Anyone interested in fighting diabetes, come to our house for a meeting.” Fifty people showed up, and before long she was able to offer support herself—both in giving her children a break from their daily routine and lending them a compassionate, knowledgeable ear.

Barbara Altman was already all-too-experienced in dealing with type 1 diabetes: her father, her husband, and one of her three sons all have the disease. But when each of her other two sons fathered children with diabetes (a granddaughter, Amy, diagnosed at age 6 and a grandson, Andy, at age 13), she jumped back into the arena. She began by reading “everything around” and sitting through educational sessions along with her children and grandchildren. “There were so many changes since I was a diabetes caregiver, that I was eager and anxious to have an update,” she says. Nevertheless, when she saw that her children had quickly developed into management experts, Mrs. Altman decided to learn their techniques rather than draw on her own experience. “They became the current experts, so it was important that I learn their routines,” she says. Soon, the Altmans were babysitting regularly, seamlessly assuming the daily routine. Doing things her children’s way was the best strategy, she says, but she admits to regularly bombarding them with e-mails containing any new information she picks up. “I’m sure they groan every time they receive one, but they’re good natured about it,” she laughs.

Mrs. Koets agrees that respecting the parents’ routines is important, but feels that education is the key. Because she doesn’t live with her granddaughter, it took her a while to get up to speed on Mazzy’s care. “After all,” she says, “this is my precious granddaughter, and nothing was going to go wrong on my watch!” She asked her daughter to ‘think out loud’ and explain everything she was doing with diabetes care. She learned carb counting, testing, giving shots, and, later on, everything about pumping. “I even practiced giving myself shots in my stomach, and I tested my own blood sugar,” she says. The first time she gave Mazzy an injection was difficult, “but I could hear my daughter’s words, ‘You are saving her life.’” She says that cell phones have been essential to call Mazzy’s mom and dad just to make sure she’s doing things right. Putting things in writing also helps.

Likewise, Mrs. Steingard stresses her supportive role. “I’m there not to second guess my children’s decisions, but to listen to them, be supportive, and give them confidence

and strength,” she says. She admits it can be hard for a grandparent not to be the one in control, but “we have to trust the judgment of our children and support their decisions.”

Mrs. Altman says her efforts have paid off to the fullest and that she has developed a special bond with her daughters-in-law. “It was worth the effort to get everyone comfortable with the fact that I’m on their team and supportive of them, and not an interfering mother-in-law,” she says. Like all the other grandparents interviewed for this article, Mrs. Altman has become an activist for the cure. When she moved to San Diego, she helped start a grandparent’s club through her local JDRF chapter, and she has long been involved in promoting research that is leading to a cure.

Mrs. Steingard expresses optimism for the future. “I had many tearful nights at the outset, but I’ve also had many wonderful days and nights watching my granddaughter develop into a mature, accomplished, capable young woman,” she says. Mrs. Steingard says that becoming a JDRF volunteer “makes me feel I am helping her to achieve a better future.” Mrs. Koets agrees. “Most of us would do anything for our children and grandchildren,” she says, “and there’s no better reward than the smile on my granddaughter’s face.”

Coming in the next issue: How brothers and sisters cope with diabetes in the family.

ASK A MEDICAL PROFESSIONAL Diabetes Myths and Misconceptions

By Catherine Marschilok, M.S.N., C.D.E.,
Board Certified in Advanced Diabetes Management

We all know a diagnosis of type 1 diabetes is hard on families as they learn to cope with a number of changes in their daily life. While people care, it is all too common for them to ask questions that reflect a lack of knowledge about type 1, such as, “When will she outgrow it?” It can be frustrating to explain the battle that all families face every hour of every day, and that can be compounded by having to deal with people’s common misunderstandings and misperceptions, including the widely-held belief that type 1 diabetes is not a serious disease. Here are some of those myths:

Myth: Taking insulin cures diabetes.

Fact: Taking insulin keeps people with type 1 diabetes alive, but does not cure the disease. While progress toward finding a cure has been substantial, there is still no cure for diabetes.

Myth: Diabetes is caused by obesity, or eating too much sugar.

Fact: While obesity has been identified as one of the “triggers” for type 2 diabetes, it has no relation to the cause of type 1 diabetes. Scientists do not yet know exactly what causes type 1 diabetes, but they believe that both genetic and environmental factors are involved. Eating too much sugar is not a factor.

Myth: With strict adherence to a specific diet and exercise plan, and multiple insulin injections each day based on careful monitoring of blood sugar levels, a person with type 1 diabetes can easily gain tight control over his or her blood sugar levels.

Fact: While the above strategy is the most effective way to achieve and maintain tight control of blood sugar levels, optimal blood sugar control can be very difficult for some patients. Many factors, including stress, hormone changes, periods of growth, and illness can easily cause blood sugars to swing out of control. Teenagers, in particular, may be susceptible to this problem, as their bodies go through many changes during adolescence. Also, some people with type 1 find that even though they strive for tight control and follow their meal plan and insulin schedule, they still experience rapid fluctuations in their blood glucose. Those fluctuations do not mean the person with diabetes has done anything wrong.

Myth: People with diabetes should never eat sweets.

Fact: Limiting sweets will help people with type 1 diabetes keep their blood sugar under control, but, with advice from their doctor or nutritionist, sweets can fit into their meal plan, just as they would for people without diabetes. And there are times when sweets are a must: if the blood sugar level drops too low, sweets (or juice, or soda) can be the surest to raise it, and prevent the onset of hypoglycemia.

Myth: People with diabetes can't engage in athletics.

Fact: Physical exercise is important for everyone's health, and is especially important for people with diabetes. Regular exercise helps lower blood sugar levels and keep them in the target range. There are countless examples of athletes who have had great success, from Olympic Gold Medalist swimmer Gary Hall to baseball great Ron Santo to hockey great Bobby Clarke.

Myth: Only kids get type 1 diabetes.

Fact: Type 1 diabetes, also known as "juvenile" or "juvenile onset" diabetes, is usually first diagnosed in children, teenagers, or young adults. However, people may develop type 1 diabetes at any age.

Myth: Kids don't get type 2 diabetes.

Fact: Though type 2 diabetes is usually diagnosed in adulthood, increased obesity and other factors have led to a recent "epidemic" of this form of diabetes in young adults and children under 10. Still, most children diagnosed with diabetes get type 1.

Myth: Women with diabetes shouldn't get pregnant.

Fact: Thanks to advances in diabetes research, the outlook for pregnant women with diabetes is significantly better today than it was a generation ago. However, diabetic pregnancy requires extra effort and commitment, excellent blood sugar control, and education in all areas of diabetes management.

Myth: No matter what you do, a person with diabetes for years will eventually get complications.

Fact: Complications are not inevitable. The mechanisms that cause complications are not yet fully understood, and the extent to which they develop varies from person to person. Tight blood sugar control is the only method demonstrated to reduce the risk of developing complications, but their occurrence remains unpredictable in any individual. Some individuals with type 1 diabetes may be genetically predisposed to develop complications (one of the critical issues being addressed by JDRF's research).

ASK A TEEN

Allison's Top 10 Travel Tips,

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1. The More, the Merrier

When I travel, if you take a look at my suitcase, you might think I'm moving. I usually bring enough diabetes supplies to last me twice as long as I'm going to be gone (just in case!) My father says my supply bag is the equivalent of an infant's diaper bag with everything in it. Back-up supplies are probably the most crucial items. Go through your checklist really carefully and don't forget extra batteries and an extra glucose meter. In France, my meter broke and my mother and I spent half a day scoping out pharmacies for batteries or an American-brand meter, but they were all European. (P.S. We found them at a British pharmacy on the Champs d'Elysee.)

2. A Note from the Doctor

Getting a medical exam before departure is a good idea to make sure your child's diabetes is in good control. At the same time, get a letter from the doctor explaining what she does to treat her diabetes and what supplies she needs (useful if there is any confusion at airport security). And save time and avoid unnecessary inconvenience by bringing copies of prescriptions for insulin and syringes or other needed medications. It's also a good idea if your child is on an insulin pump to either bring Lantus or have a prescription for it. A pump malfunction once forced me to switch to Lantus for two days while on vacation. I bought a bottle and extra syringes at a local pharmacy after my doctor faxed a prescription.

3. Temp Basals Are Your Friends

For pumpers, a temporary basal rate is ideal for traveling. Whether on a 12-hour flight to Europe or a 10-hour car ride through California, as your travel time increases so will your blood sugars. Adjusting the basal rates you take to match the amount of activity (or lack thereof) will help fight high blood sugars during travel. Those travelers on a pump, Lantus, or multiple daily injections should talk to the doctor about how to make changes in insulin dosing or other medication to accommodate time changes and

other travel factors. And don't be reluctant to call the doctor from your destination if you still have concerns.

4. "How do you say 'carbohydrate' in Italian?"

Those little travel dictionaries probably don't have the direct translation of "How many carbohydrates are in this croissant?" But it is important to know how to say a few basic phrases when traveling to another country, such as "I have diabetes," or "Please help me find some juice." Dictionary.com is a great online translator, and ChildrenWithDiabetes.com has a page on how to say, "I have diabetes," "pharmacy," and "hospital" in nearly 40 different languages. Larger foreign language dictionaries also have the translation for certain words like diabetes and carbohydrate.

5. Location, Location, Location

Before leaving, find out what supply and medical services are provided by the place your traveler is visiting. If you're like me, you're prone to taking side trips away from your main destination. It's important to know all the places where your young traveler is staying and the accommodations they provide. For example, will there be a refrigerator? A restaurant or grocery store close by? A pharmacy or a hospital nearby? And who can they count on in an emergency (either you or other family and friends?) Examine the itinerary and figure out possible snags and trouble-shoot them before they happen.

6. Wear It Loud, Wear It Proud

Lots of teens don't like to tell people they have diabetes. They don't talk about it, they don't test in public, and they don't like to wear a medical ID bracelet. When traveling, however, it is critical that all teens (and younger kids) wear some kind of medical alert bracelet or necklace. The medical ID is universally recognized by all medical personnel. Your teen may not always be around you or other traveling companions, and should they find themselves in a situation where it is difficult to explain to a medic what is going on, having an ID is an important safeguard. In fact, bring an extra one in case of loss.

7. Testing, 1, 2, Testing, Testing

Traveling to new and exciting locations (or even grandma's house) can bring unexpected activity (or lack of activity if you're spending the day in a lounge chair), and changes in sleeping schedules and

meal plans. That means blood sugars can be tough to get a hold of. The best way to figure out how to adjust for a Danish pastry or the roller coaster ride at Disneyland is to test, test, and test again throughout the course of the day.

8. Speed Dial.

When they're traveling without you, your kids should have a cell phone at all times, in case of emergencies. Keep important phone numbers, like the doctor's direct line, your cell phone number, and the pharmacy in the address book or speed dial. Since cell phones don't work everywhere, those numbers should also be written down and kept in the traveler's wallet.

9. Be Your Own Convenience Store

Glucose tabs, granola bars, cereal bars, and juice boxes. These are great items that pack well and stay fresh for several days. When traveling, there is no telling when, where or what the next meal will be and it's always a good idea to travel with several snacks.

Growing up, my family would often travel to a hotel in Central Oregon, which required a three-hour drive in the middle of nowhere. And we've had the experience of being in an airport at night when the food vendors are closed. Also keep in mind that some airlines now charge for meals, and that when you're on the road, it could be several hundred miles between restaurants.

10. Keep an Eye on Your Stuff

The voice at the airport saying "watch your luggage" is right – you don't want to lose it. Although you or your young traveler have already brought back-up supplies and prescriptions, you'll want to avoid the hassle and cost of replacing them or not having them when you need them. Always keep the supplies and medications in carry-on luggage and where you can see them (especially at the hotel or grandma's house, when insulin can vanish or be forgotten.) That way, they'll be with you at all times.

Officially no longer a teenager, Allison Blass is a 20-year-old journalism student at the University of Oregon. Her favorite travel destinations are New York City, San Francisco, and Paris.

Have a question? Go to the [JDRF Online Diabetes Support Team](http://jdrf.org) at jdrf.org.