



life with Diabetes

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ASK A MEDICAL PROFESSIONAL

Kids Find Power in Helping and Advocacy

By Catherine Marschilok, M.S.N., C.D.E.

Nobody can explain what it's like to live with type 1 diabetes the way kids can. Children gain an invaluable sense of empowerment and strength in learning how to talk about their life with the disease, in meeting others who share the same daily challenges, in helping those new to the disease to learn the ropes, and in speaking out to advocate for their own cure. Thousands of young people and their families have joined a grassroots movement to change their future by telling their personal stories to our nation's leaders and the world at large. The impact — on legislators, the public, and on themselves — is tremendous.

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ASK A PARENT

Help from JDRF's Online Diabetes Support Team

Q: My daughter was diagnosed just last week. My husband and I are devastated. We are going through a range of emotions in the midst of learning how we are going to deal with this disease. Where do we start?

A: You are not alone. It is very common for parents to have difficulty in adjusting emotionally upon diagnosis of a child.

I can remember feeling overwhelmed and sad back in those early days and weeks after my daughter's diagnosis. Frankly, I can't imagine any parent feeling much else. But we quickly realized that our daughter was looking to us to lead the way down this new path, and we had to overcome our intense anxiety about making sound decisions about her daily care. Here are some of the things that helped us cope in our early weeks and months of living with diabetes. [CLICK HERE TO READ MORE.](#)

TOPICS IN TYPE 1 DIABETES

Diabetes Burnout: The "I Can't Take It Anymore" Syndrome

By Allison Blass

Anyone who has had diabetes for, oh, a day, knows how challenging it can be. Whether you are a parent, friend, or someone with diabetes like me, the disease is a never-ending source of demands, confusion, and frustration. Most people eventually feel a sense of "diabetes burnout" (a term coined by diabetes psychologist Dr.

William Polonsky) from having dealt with the literal and figurative ups and downs of the disease. "The thing that contributes to being burned out the most is when people feel alone with diabetes," says Dr. Polonsky. "Obviously they have family and friends and a doctor, but if they feel like no one gets it, then they don't feel like anyone understands or is rooting for them." Another burden is caused by the "expectations" and high standards of self-care that family, medical professionals or even you put on yourself. But the fact is, no one is perfect. "Sometimes people burn out because their expectations are unreasonable, and that they just feel like failures," says Dr. Polonsky. "Perfectionism traps patients, family members and health care providers in a vicious cycle of unrealistic expectations, which blames the person." He recommends that patients work to achieve open communications and explain their feelings to the person imposing such expectations. "They need guidance from you about how to help," he explains. "They'll respond when you say, 'I know you mean well, but what you do isn't helping.'"

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WHAT'S NEW ON THE JDRF WEB SITE?

Whether they are there to offer support when you are feeling down or to give you a juice when you are low, friends can make life a whole lot easier—and more fun. In "Ya Gotta Have Friends," JDRF's Kids Online explores the rewards of friendship and offers tips from kids and teenagers on building meaningful new friendships. Go to KIDS.JDRF.ORG

WHAT A JDRF CHAPTER CAN DO FOR YOU

Guidance and Support

Finding out your child has type 1 diabetes can be overwhelming. Once the initial shock passes, you must deal with everything from learning management basics to setting up a network of healthcare practitioners to educating school officials about your child's needs. But you are not alone. JDRF can help. For example, the St. Louis/Greater Missouri Chapter has formed "JDRF St. Louis Family Connections" to help families living with type 1 diabetes. The network offers various support groups, a resource list of baby sitters familiar with type 1 care, and mentoring programs for parents. Go to the JDRF website at WWW.JDRF.ORG to find support activities 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.

ASK A MEDICAL PROFESSIONAL

Kids Find Power in Helping and Advocacy

by Catherine Marschilok, M.S.N., C.D.E.

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Nobody can explain what it's like to live with type 1 diabetes the way our kids can. What's more, countless children with type 1 diabetes have found a tremendous sense of empowerment and satisfaction in learning how to talk about their life with the disease, helping others, and advocating for their own cure. They often begin by telling their friends about their diabetes, finding that the more open and comfortable they are, the more likely their friends will respond in kind and be there when they are needed, such as during a high or low blood sugar emergency. They also gain from connecting with other children with diabetes, for example through a support group, diabetes camp, or online blog. Such activities help to raise children's self-esteem, reassure them they are not the only one with the disease and help them to gain mastery to better manage their diabetes.

From that point, many children learn that they have the power

to make life easier for other people with diabetes. They may talk to newly diagnosed children in their local community, or volunteer at their local clinic or diabetes camp. By reaching out to help someone else, their own problems seem to become more manageable.

The next level of action is to become an advocate for diabetes awareness and the cure for the disease. I think sometimes that families are reluctant to venture out into that arena, but speaking as a parent of two (now adult) children with diabetes, and as a veteran of many years of advocacy efforts by the whole family, I can tell you that the rewards are significant.

How do you get started as an advocate? Many children begin by talking about diabetes at school or a local event, or they help to raise money for scientific research by participating in their local Walk to Cure Diabetes. JDRF's Family Walk teams raised over \$35 million last year! Over the last several years, many thousands of children — along with their families — have moved to the wider public arena. They have achieved extraordinary success by helping to raise awareness, secure critical funding for research, and advancing legislation on vital issues that will advance cures and treatments for type 1 diabetes.

Every two years, JDRF's Children's Congress gives kids with diabetes — from ages 2 to 17 — the opportunity to go Washington, DC to explain how they deal with their diabetes every single day of their lives, and tell our leaders that they need a cure. To date, some 700 children have had the unique and empowering opportunity to help Members of Congress understand what life with type 1 diabetes is like and why research is so critical. (Incidentally, the idea for Children's Congress came eight years ago from a child with diabetes, when 8-year-old Tommy Solo said to his mother, "Why should you go to Congress? Kids should go and tell them what it's like, because we're the ones with diabetes.")

Similarly, through JDRF's "Promise to Remember Me" campaign, children and their families in every state have met with their U.S. Senators and Representatives to tell their personal stories about life with diabetes, reflect on their fears, and share their hopes and dreams. Through the "Promise" campaign, Children's Congress, and other grassroots advocacy programs, our representatives in Washington have come to see children instead of statistics and have begun to care about diabetes in the way that we families do. As a result, they have passed critical legislation like "The Special Funding Program for Type 1 Diabetes Research and the Pancreatic Islet Cell Transplantation Act." For the children, a meeting with their legislator is a living social studies lesson — you actually can meet with your Senators and Representatives and have an impact! — and one they will never forget. As Carolyn (Children's Congress 1999 delegate, now age 16) puts it, "I think I helped put a face on diabetes,

GREAT CONNECTIONS: JDRF YOUNGSTERS REFLECT ON THE REWARDS OF HELPING AND ADVOCACY:

Marlee, 17 (Children's Congress delegate): "A cure is not a dream. A cure is an aspiration that we can achieve through hard work."

Megan, 17 (hospital teen advisory board): "I feel great when I reach out to kids who are having trouble with their diabetes, because when I was their age, I didn't have anyone to talk to, and I bottled up a lot of my emotions."

Allison, 21 (advocate/*Life with Diabetes E-Newsletter* contributor): "Children's Congress changed my life. After returning home, I continued as a diabetes advocate, and I haven't stopped since."

Emily, 12 (Walk, local speeches and interviews) "I used to be shy, but now I like people to talk about my diabetes, because I know it will help find the cure for me and all the other kids who have it."

Keith, 20 (mentor, JDRF Youth Ambassador): "What keeps me going most is helping younger kids, like showing them how to give injections or change a pump site. I help them learn to cope so that they control diabetes and it doesn't control their life."

Samantha, 16 (advocate since age 5): "With the help of JDRF, I found what I like to say was my 'calling' — public speaking. Diabetes has not only allowed me to meet many interesting and amazing people, but it has helped me be independent and responsible. Although one day diabetes will be cured, I know that the people who I have fought with against this disease will always be in my life."

and being involved in finding a cure has helped me in dealing with diabetes. I'm doing something about it rather than just sitting back."

We learned very quickly that education is empowering and helped put us in the driver's seat.

TIPS ON BECOMING A VOLUNTEER OR ADVOCATE

To get started, check with your school guidance counselor, your healthcare team, or your local JDRF chapter. To learn how you can participate in a meeting with your lawmakers or join other grassroots initiatives, go to JDRF's advocacy Web site at JDRF.ORG/ADVOCACY. To learn more about JDRF's Walk to Cure Diabetes, go to WALK.JDRF.ORG or call (888) 533-WALK.

For those that go on to participate in a meeting with their legislators, here are a few suggestions:

- Bring along your written personal story, with your photo attached.
- Convey your passion, but also maintain a respectful tone.
- Be concise, honest, clear, polite and specific when delivering your message and asking something of your Member of Congress.
- Give personal insight into your experiences with Type 1 diabetes.
- Be patient when interacting with your legislators or their staff.
- Thank them for any attention given to you and for past support.
- Work at being articulate about diabetes and the issues you are advocating for.
- Pick a group spokesperson who can open the meeting and briefly express the case.
- Have one person act as timekeeper and step in at the right moment to summarize and wrap things up.

ASK A PARENT

Help from JDRF's Online Diabetes Support Team

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1. Join a local support group, meet other families, connect with your local JDRF chapter. I cannot overemphasize the importance of reaching out to other families. In addition to the reassurance you will receive that you are not alone, this is a vital way to learn other styles of diabetes management, helpful tips, and coping skills that you can use to create a successful, winning style that works for *your* child and family.

2. Continually educate yourself about diabetes and stay up on current developments in research, products, advocacy, and daily care.

3. Make time for you. As one parent once told me, "It's so exhausting to be a pancreas!" Parents deserve and need breaks from their child's diabetes, and your child needs to build the confidence to spend some time away from you.

4. Call upon friends and family for help when you need it. Whether it's help with an errand to be run, a sibling to be transported, or a nap, you simply must have some time to recharge your battery. We found that friends and family are eager to help out during the beginning weeks and months. Acknowledging your needs and simplifying your life will allow you to integrate diabetes into your household so it will quickly become a "natural" course of things.

5. Create an emotionally supportive family environment. Because diabetes affects many aspects of daily life, everyone in the family should be involved in supporting your daughter in her goal to maintain her good health. Encourage emotional expression so that meltdowns do not become the norm.

6. View diabetes control in a much broader sense than good blood glucose management. There's an oft-quoted saying, "Be a kid first, and a kid with diabetes second." Don't feel pressured to make each and every day "perfect" in terms of diabetes management. Some days go well and others don't. Be able to accept this and keep your eye on the big picture: Is my child adjusting to this new life? Is she beginning to accept some of her daily care needs? Is she comfortable sharing her diagnosis with her "inner circle?" Is she resuming her regular activities?

7. Acknowledge the challenges of living with diabetes. Many children and their families go through a grieving process upon diagnosis. Dismissing or minimizing these feelings isn't recognizing this fact. So, to be most helpful to your daughter, simply listen, sympathize, and let her know that her feelings are natural and understandable. These compassionate and empathetic responses will help to open doors of healthy communication, whether it is about diabetes or other life issues.

Your daughter is really lucky to have you at her side during this important transition. While words don't always come readily to your tongue, hugs and smiles are sometimes all we parents can muster, and fortunately, that is frequently plenty for a young child. I have no doubt that you and your family will look back on this time and marvel over how far you have come.

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With all the factors to coordinate and priorities to meet, it helps to develop a reasonable diabetes management “workload.” This includes identifying specific obstacles or struggles, then sitting down with family and healthcare team to develop a realistic action plan for achieving your goals.

Although the child suffers the greatest burden of diabetes, parents can also feel burned out. They are the decision-makers for many years, and when their child gains independence, they still feel a sense of responsibility. Both children and parents also can suffer from the awkwardness of social situations — I have seen and experienced this often over the years. Teens end up feeling frustrated and tired because “no one understands.” Diabetes goes against everything a teen wants to be. Being a teen is about conforming with peers, looking like them, hanging around with them, and doing the same things they do. When you have to count carbohydrates, check blood sugar and take injections, it can be humiliating if you’re the only one.

Support is a great way to overcome diabetes burnout, and support groups can be found through your local clinic or JDRF chapter. If there is no support group near you, start one! Choose a central location, perhaps your JDRF chapter office or a room at the clinic. Hang fliers and ask the clinic or chapter staff to invite people.

At the meeting, you can talk about the issues that are important to you, whether it’s diabetes technology, research, or emotional issues. Make it a regular event at the same location and you will soon see your group grow as more people hear about it.

A great thing about support is that you can share information and troubleshoot with others. Asking questions is the best way to learn about diabetes. It is encouraging during challenging times to have someone who can smile, nod and say, “I know exactly what you mean.” It can give you strength when you are faced with pressure and uncertainty to know that you are not the only one.

Dr. Polonsky’s book, *Diabetes Burnout: What To Do When You Can’t Take it Anymore*, explains in detail how you can work to overcome burnout. Living with diabetes is challenging, but it also gives you the opportunity to find your inner strength. That strength comes from having the right resources and the right people beside you.

You are not alone.

To find support online: Go to jdrf.org, Children with Diabetes, or The Diabetes OC, a new website that lists blogs by parents and adults with diabetes. My Web site, Diabetes Teen Talk, offers support and educational interviews to teens with diabetes.

Twenty-one-year-old Allison Blass has volunteered for JDRF and a support group in the Portland, Oregon, area since she was 15.