

## TOPICS IN LIVING WITH TYPE 1 DIABETES

### Managing Emotions after Diagnosis

Coming to grips with the emotional challenges of a new diabetes diagnosis can be an overwhelming experience for families. At a time when patients and parents are at their most vulnerable, they must quickly overcome the initial shock of the diagnosis, learn complex information, make considerable lifestyle changes, and develop new attitudes and behaviors. Diabetes experts Katie Marschilok, R.N., Joseph Solowiejczyk, R.N., M.S.W., C.D.E., and Barbara Anderson, Ph.D., help you navigate the emotional shoals families face with a new diagnosis and talk about how to get past a diagnosis and to the “coping stage.”

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## ASK A MEDICAL PROFESSIONAL

### Insurance Matters

If you or a family member has recently been diagnosed with diabetes, chances are that meeting the cost of diabetes medications and supplies and finding good health coverage are significant concerns for you. You may wonder about a range of health care coverage concerns. Are large-ticket items such as pumps covered? What are the rights of a person with diabetes when it comes to medical insurance? A registered nurse and certified diabetes educator, Kathy Spain provides resources that can help you answer your questions.

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## ASK A PARENT

### Help from JDRF's Online Diabetes Support Team

**Q:** My son was diagnosed three months ago. I feel alone, scared, exhausted. My worst fear is that I may mess up, and something will go wrong.

**A:** *from a parent of a child with diabetes:* I am the mother of a 14-year-old girl who hits the start of her ninth year of living with diabetes this month. It seems like only yesterday (and yet so long ago) that I was in exactly the same position, situation, and emotional state you are in. When my daughter was diagnosed, I swear I could barely breathe. Everything seemed new and upsetting—I even cried while food shopping! I remember thinking, “I will never have a

normal life again,” and “How will my child ever grow up happy and normal with all this on her plate?” I felt alone, isolated, and scared. I think the first time for everything is rough. First birthday party (figuring out the cake thing). First play date (trust of other parents!) First holiday. First family trip (oh, the packing of medical supplies!), first school field trip (chaperone for life!) But after you’ve done things once, the second time comes a little easier.

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## WHAT'S NEW ON THE JDRF WEB SITE?

### Cooking to Fight Diabetes

World-renowned chef Michel Nischan says his two sons’ type 1 diabetes diagnoses strengthened his commitment to cooking for well-being. His philosophy of preparing foods for kids with diabetes is to work favorites into a meal plan so they become a regular, but not constant, part of the weekly diet. This allows kids to encounter their favorites regularly and to feel less deprived. Chef Nischan shares his family’s personal story as well as a sample meal plan, ideas for tasty snacks, and tips on how to make holiday meals and celebrations diabetes-friendly. Go to <http://www.jdrf.org/ChefQandA>.

## WHAT A JDRF CHAPTER CAN DO FOR YOU

### A Grandparents Club

“I have two grandchildren with type 1 diabetes. When the first was diagnosed, I wanted to learn the daily routine so that I could do my part. I got involved with the local JDRF chapter and learned a great deal by participating in a parent support group. Later, after my second grandchild was diagnosed, another grandparent and I conceived the idea of starting a grandparents club. With the chapter’s help, we organized the club and invited guest speakers to our monthly meetings. One was an expert on insulin pumps. A grandchild who already used a pump was there to show how it worked. At another meeting, we invited a scientist to talk about new developments in diabetes research. We’ve learned an incredible amount, and we’re looking forward to bringing in other interesting and educational speakers. Best of all, I now feel as though I’m a part of my grandchildren’s diabetes team.” (from a JDRF volunteer in California)

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## TOPICS IN LIVING WITH TYPE 1 DIABETES

### Managing Emotions after Diagnosis

Coming to grips with the emotional challenges of a new diabetes diagnosis can be an overwhelming experience. At a time when you are at your most vulnerable, you must learn complex information about glucose levels, blood testing meters, and insulin—and make considerable changes in your lifestyle. If it's your son or daughter who receives the diagnosis, you must help your child develop new attitudes and behaviors toward a chronic illness at the same time you're coping with the news. In fact, how you deal with the diagnosis—and the emotional support you receive during this stressful period of adaptation—can have a profound impact on your child's adjustment to the disease.

Katie Marschilok was no stranger to diabetes. A registered nurse, who worked at St. Mary's Hospital in Troy, New York, she was experienced in caring for people with diabetes. But when her child, David, was diagnosed at age 8, Ms. Marschilok was overpowered by intense emotions: shock followed by tremendous sadness. "My child's perfect health was gone forever," she says. People told her she was lucky to be working in the diabetes field, but she didn't feel lucky at the time. Such reassurances seemed lacking in empathy. She needed someone to acknowledge that the diagnosis was very difficult. Fortunately, Ms. Marschilok found support from Eileen, a diabetes educator, that enabled her family to rebuild their lives. In time, Ms. Marschilok earned a certificate as a diabetes educator. When her 21-year-old daughter Amy developed diabetes eight years after David's diagnosis, more acquaintances labeled Amy lucky to have a diabetes expert in the family, yet the sadness was the same.

Unlike Ms. Marschilok, who experienced and dealt with the gamut of emotions after a diagnosis, patients and parents who don't confront their feelings tend to feel overwhelmed without knowing why. "Some people get into denial that the disease won't change their lives," she says. Ms. Marschilok wants parents to know these feelings are normal. "People need to go through stages from shock to acceptance in order to get to the coping stage," she says. "Diabetes is a terrific challenge in life, but you can make a remarkable difference by becoming a student of your own emotional progress. That will help you work with this new reality and make it your own."

In doing so, parents should try not to display their fears and anxieties to their children, as adults' reactions will influence how their children perceive diabetes and themselves. "Parents really need to get over the hard part on their own, either with friends or a support group," she says. "It takes coaching to get parents to respond in a way

that is not judgmental and does not come out of hurt."

### Finding a Sensitive Health Care Team

In the days following a diagnosis, parents may have great difficulty in telling their child what is happening to them or what the new diagnosis means for their future and that of the entire family. "We used to lie to families at diagnosis and tell them that nothing in their lives has changed and that they can live life as they used to," says Barbara Anderson, Ph.D., Professor of Pediatrics at Baylor College of Medicine, in Houston, Texas. "That's not true." A key to successfully navigating the transition is a sensitive health care team that is interested in your child as a developing person, not a blood sugar number, and that acknowledges how you feel about the diagnosis and can help you stay on course. "So much of you learn about diabetes is from a health care team," she says. "If you have a health care team that doesn't like to see mothers crying, you try to stifle your emotions. If you have a nurse who doesn't understand that children are frightened, your child has a more stressful time in medical visits."

The first year after diagnosis is a series of firsts: the first time you forget insulin or the first time your child has a hypoglycemic reaction in school. Parents eventually learn to navigate the emotional hazards of these new experiences (for an illustration, see "Ask a Parent," below). But without a guide through this leg of the journey, you risk doing additional emotional damage to yourself and your children later, says Dr. Anderson. She remembers a young mother who believed she was responsible for causing her son's diabetes because she had given him milk when he was three months old. Without a chance to air her concerns, the young woman was so riddled with guilt that she could not set limits and had forfeited her authority as a parent. She was raising a "brat with diabetes," says Dr. Anderson.

### More support to help you cope

In addition to learning technical know-how, families need help managing their emotions associated with diabetes. "So many patients and parents come in and say, 'I'm the worst diabetic' or 'I am the worst parent.' That is a function of not knowing where to look for support," says Dr. Anderson. "I reply, 'What do you do well?' Then I help them find their little successes to build on." Sometimes, though, health care professionals avoid dealing with emotional issues because they are afraid of opening something they can't deal with, according to Joseph Solowiejczyk, R.N., M.S.W., C.D.E., Clinical Manager of Counseling & Presentations with the Animas Corporation. If you find yourself in this situation, there

are many other avenues of support. JDRF can play a crucial role in helping. “Getting people to the support they need and drawing them into a network of other families with the same struggles are some of the most important things that JDRF does,” says Dr. Anderson.

Your role as a parent is to make your children feel safe and secure as their lives unfold, says Mr. Solowiejczyk. The degree to which you succeed will have a tremendous effect on your child’s emotional adjustment to living with diabetes. Mr. Solowiejczyk emphasizes this point with a study by the Children’s Hospital in Philadelphia. The study showed that the most important factor in a child’s metabolic control in the first year after diagnosis was the family’s ability to communicate and set ground rules for the child about diabetes management. In two-parent families, a powerful predictor of the child’s blood sugar control was how respected and supported the mother felt by other family members. Similarly, in single parent families the support network that the parent had developed was the determining factor.

It is true that your regular health care provider, friends, and family can help you with emotional issues, but if you’re finding it harder to cope, it’s best to seek help from specialists, says Mr. Solowiejczyk. A mental health professional can help your family adjust to the diagnosis and reorganize itself as close as possible to the way life was like prior to the diagnosis. “Most people think you just have to pull yourself up by the bootstraps and move on. I think it actually takes more courage to cry and breakdown than not to fall apart,” he says. “The health care professional can make it feel safe for you to collapse and be reborn again.”

## ASK A MEDICAL PROFESSIONAL

### Insurance Answers & Questions

By Kathy Spain, R.N., C.D.E.,  
Mother of Will, age 10, diagnosed age 2

If you or a family member has recently been diagnosed with diabetes, chances are that meeting the cost of diabetes medications and supplies such as insulin, meters, and test strips, and finding good health coverage are significant concerns for you. You may wonder how your family can afford health coverage or how you would go about finding health insurance for your child with diabetes. Are large-ticket items such as pumps covered? What are the rights of a person with diabetes when it comes to medical insurance? There are many resources to help you answer your questions and to assist you in finding satisfactory coverage. If you have trouble obtaining or keeping your insurance, there are

resources to help you explore options.

### Covering the Cost of Your Coverage

If you are concerned that you cannot cover the costs of diabetes care, a publication titled “Financial Help for Diabetes Care” can help you learn about your options. Published by the NIH’s National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), this easy-to-read guide offers an overview, with contact information, about resources such as Medicare, Medicaid, and health insurance programs that cover diabetes-related medical expenses or low or no-cost health care for people with diabetes. You can view this publication on the NIDDK website at <http://diabetes.niddk.nih.gov/dm/pubs/financialhelp> or order copies from the National Diabetes Information Clearinghouse at 1-800-860-8747.

### Laws to Protect You

An important insurance issue a person with diabetes may face is when a new insurer defines diabetes as a ‘pre-existing condition’ and excludes or limits diabetes-related care coverage. There are laws that protect people with diabetes who encounter pre-existing condition exclusions. For people with individual (as opposed to employer-sponsored or group) health insurance coverage, 46 states now have laws requiring health insurance coverage to include treatment for diabetes. (The exceptions are Alabama, Idaho, North Dakota and Ohio.) Laws governing health coverage vary from state to state, and you will want to start with the health-care regulations and laws for your state. “A Consumer Guide for Getting and Keeping Health Insurance,” a resource published by the Institute for Health Care Research & Policy at Georgetown University is available for each of the 50 states. It can be accessed online at [www.healthinsuranceinfo.net](http://www.healthinsuranceinfo.net).

For those insured through an employer-sponsored group health plan, protection from coverage being denied to a person with diabetes is offered by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The Act also helps workers who change or lose jobs to maintain their health insurance. (The HIPAA provision, however, only refers to group plans, such as employee health plans, and not individual health plans.) You can read detailed information about HIPAA on the US Department of Health and Human Services website at [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa).

### Insurance Programs for Children

For children of families with limited financial resources, there are multiple programs available at the state level. Medicaid is a state-administered program and each state sets its own guidelines

regarding eligibility and services. You can find information for your state at the Medicaid site for consumer information at <http://www.cms.hhs.gov/medicaid/consumer.asp>. For families who earn too much to qualify for Medicaid yet still find their resources too modest to cover their children's diabetes care, the states operate a low-cost private insurance program called the State Children's Health Insurance Program, or SCHIP. To find out more about this program covering eligible children until the age of 19, go to the Insure Kids Now! Web site offered by the US Health & Human Services Department: [www.insurekidsnow.gov](http://www.insurekidsnow.gov), or call 877-KIDS-NOW.

## Help with Supplies and Prescriptions

Many drug companies offer pharmaceutical assistance programs to help offset the cost of supplies or prescription medications for people with diabetes who have little or no insurance. Enrollment in the programs requires a letter or application from your doctor. Listed below are some of the companies offering patient assistance:

Aventis	800-221-4025
Bayer Corporation	800-998-9180
Bristol-Myers Squibb	800-437-0994
Eli Lilly & Company	800-545-6962
Novo Nordisk	800-727-6500

In addition, the Partnership for Prescription Assistance offers a point of access to 275 assistance programs, including 150 programs through pharmaceutical companies that have joined together to provide savings to the uninsured. To see if you qualify for any of these programs, visit [www.pparx.org](http://www.pparx.org) or call 1-888-477-2669. The Children with Diabetes Foundation also offers diabetes supplies on a short-term basis for children with diabetes who are in emergency situations in which their families are unable to obtain basic supplies for diabetes care. You can find information on this program at: [www.cwdfoundation.org/supplies.htm](http://www.cwdfoundation.org/supplies.htm).

## Are Pumps and Pump Supplies Covered?

Last, but certainly not least, pumps can present a financial burden for families, with the devices themselves costing on average \$5,000 and basic supplies more than \$100 a month. Insurance companies vary in their coverage of pumps, but most insurance plans cover costs associated with pump use. Pumps and supplies are usually included in the Durable Medical Equipment (DME) component of major medical plans. Some plans have a deductible or co-pay, so ask your health insurance carrier or check your benefits summary to find your level of coverage. The major pump manufacturing companies have insurance experts who can verify your benefits and out-of-pocket expenses when you consider the purchase of a pump.

These manufacturers are aware that their products are costly, and they often are able to work with potential customers and/or their insurance companies to make them more affordable. Here is contact information for several leading pump manufacturers:

Accu-Chek (Disetronic)	<a href="http://www.disetronic-usa.com">www.disetronic-usa.com</a>	800-280-7801
Animas	<a href="http://www.animas.com">www.animas.com</a>	877-767-7373
CozMore (Deltec Cozmo)	<a href="http://www.cozmore.com">www.cozmore.com</a>	800-826-9703
Medtronic MiniMed	<a href="http://www.minimed.com">www.minimed.com</a>	800-646-4633

As one further option, the Diabetes Trust Foundation (in partnership with Animas) provides financial assistance through its Insulin Pump Program for Children, as well as assistance for medications and testing supplies for individuals who qualify. For more information, visit their web site at [www.diabetestrustfoundation.org](http://www.diabetestrustfoundation.org).

## ASK A PARENT

### Help from JDRF's Online Diabetes Support Team,

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And let me reassure you: The fear of messing up is quite normal. With diagnosis, we all go from regular 'ole mom to medical expert and administrator in the blink of an eye. People go to school for years to learn what we have to learn in an instant: how to keep a child alive and happy through medical intervention. It can be overwhelming, and coupled with the lack of sleep, emotionally draining. Take a deep breath and give yourself a giant pat on the back. Now look around for support: do you have a relative who would learn all about type 1 and help you out? Have you looked for other parents in your situation? It took me a full year to figure it out, but a key is finding the help and support of others who walk the walk and talk the talk.

Next, don't worry about making mistakes—just take it one day at a time. And let me share a secret: we all make mistakes, and our kids are fine for it. I remember the first time I forgot to give my daughter her morning shot before school (back in the days before she was on a pump). The shot had become like giving out lunch money, it was such a part of the routine. So I drew it up and in the flurry of the morning, never gave it to her. Three hours later when I realized it, I called the school nurse to have her check on my daughter and called the doctor with my confession. He said, "I'm so happy this happened." "What?" I responded, shocked. "It means you are relaxing and living your life. Now, don't make it a habit, but it's fine." He was right. My daughter was high, but we gave her a shot and she came down. The day went on. And I learned: we survive it all.

*Have a question? Go to the JDRF Online Diabetes Support Team at <http://www.jdrf.org>.*