

Dealing with Diabetes in Times of Crisis

Hurricane Katrina and its aftermath have deeply affected hundreds of thousands of people, including many families with type 1 diabetes, who are now forced to deal with the daily challenges of the disease in the most difficult of circumstances.

JDRF—in a coordinated effort involving staff, volunteers, donors, and corporate partners throughout the U.S.—has been working with national and local support and medical organizations to help people in the Gulf Coast region and where significant numbers of people have found refuge.

To support families in the wake of the hurricane or any event involving emergency conditions, this special issue of Life with Diabetes provides critical information on such topics as caring for your child with diabetes in times of crisis, an emergency “survival guide,” and tips for dealing with new schools. The JDRF Web site at www.jdrf.org provides additional information and materials. All of this information is available through JDRF’s 100 chapters, which as always, offer you extensive local information about diabetes care and support services and activities within the chapter and in the community.

TOPICS IN LIVING WITH TYPE 1 DIABETES

Caring for Children in Troubled Times

By Barbara J. Anderson, Ph.D.

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In my 25-year practice as a pediatric psychologist, I learned a lot about traumatic stress in children from an 8-year-old patient with type 1 diabetes named Silas. Silas was attending a summer day camp near his home in Boston, when one day he saw lightning strike a tent at the camp, which caused minor injuries to the children and adult counselor inside. Silas was very verbal and vividly expressed his feelings of fear. In our sessions, he spoke of worrying every time the sky turns dark before a rain storm. His anxiety spread to his diabetes. To an extreme degree, he insisted on carrying all his supplies in a fanny pack with him at all times because he feared sudden swings in his blood sugar levels. He was even afraid to ride the bus because he worried that the bus driver would not know what to do in case he had a diabetes-related emergency.

I thought Silas could, in time, overcome his fears if he could articulate them. Children can be remarkably resilient when we listen to them. We spent our sessions writing a story about a child who had seen lightning strike. Silas also drew pictures of lightning and chose the art medium to depict some of his difficult experiences with diabetes. After three months of expressing his fears through storytelling and art, Silas was ready to move on and flourish.

The hidden toll of disasters like Katrina may lie in the minds and hearts of children. When a disaster strikes, children typically exhibit loss of trust and fear that what happened once may happen again. Even secondhand exposure to disaster on TV can be traumatic

for them. And if trauma is left untreated, it could lead to serious behavioral problems in the future.

We can help our children cope by reassuring them that they are safe. We can also encourage them to express their feelings and assure them that it is normal to feel upset. We must listen to them and watch for signs of distress in order to respond effectively.

In the case of a child with diabetes, the situation is aggravated, because besides emotional stress, there is an accompanying physical reaction to stress—swings in blood sugar levels. Here is some guidance for guiding children with diabetes in times of stress.

Reassure your child that she is safe: Assure your child that you are doing everything you can to keep her safe and get your lives back on track.

Look at your child’s reactions: Expect immediate regression or lapses in your child’s level of functioning and behavior, including self-care. Expect some decrease in your own level of functioning—you and/or your child may be less attentive, more forgetful, distractible, impulsive, depressed, or angry. Other signs of stress include excessive crying, fearfulness, separation anxiety, school avoidance, insomnia, or lack of appetite. This is all normal emotional fallout after surviving a disaster.

Encourage your child to express his feelings: Ask age-appropriate questions about how your child is feeling. “You look sad. Are you missing our old neighborhood? What are you worried about?” Some children cope with trauma by asking lots of questions; others by asking the same question over and over again.

Empathize with your child: Share your own feelings with your child in age-appropriate ways. Expressing feelings is an important part in the healing process.

Re-establish daily routines: Structure helps to re-ground your family and child, especially at a time when there are many distractions from your child's diabetes care. Try to return to stable going-to-bed and wake-up times for all family members. Making concrete plans with your child—what she will do next or whom she can write to about her experience—will help your child develop the emotional muscles to regain a sense of normality.

Focus on your child's self-care: Focus on the behavior that produced high numbers on your child's blood glucose meter, rather than on the numbers alone.

Empathize with your child: Share your own feelings with your child in age-appropriate ways. Expressing feelings is an important part in the healing process.

Organize a family-team effort: Once you have secured the adequate diabetes supplies and identified where the supplies are kept, decide who will be responsible for each of the many tasks in your child's diabetes care routine. If your child is in a new school, secure school educational materials from your diabetes team or an organization like JDRF to give to school staff. An organized approach to your child's diabetes care can help your child regain some sense of control. **Stay involved:** Be involved with what your child watches on TV and limit the family's overall exposure to media coverage of the disaster. If signs and behavioral symptoms of stress in your child (or yourself) continue beyond a two- to three-week period, seek professional mental health counseling for your child and/or family.

ASK A MEDICAL PROFESSIONAL

Preparing for an Emergency

By Kathy Spain, R.N., C.D.E.

Mother of Will, age 10, diagnosed age 2

The disaster in the Gulf Coast region has deprived many people with diabetes of necessary medical supplies and life-sustaining insulin. Fortunately, there is help for these vulnerable people. The American Red Cross and other relief agencies have been working to help those with medical problems. Pharmacies, such as Rite Aid, have offered to provide insulin and other supplies desperately needed by storm victims with diabetes, and major pharmaceutical companies and medical device companies have

Guidelines for Carrying Insulin

Insulin may be left un-refrigerated (between 59-86 degrees F) for up to 28 days and still maintain potency. As a general rule, insulin loses its potency according to the temperature it is exposed to and the length of the exposure. Under emergency conditions, when the storage temperature exceeds 86 F, insulin may still need to be used, but it may have lost some of its potency, which over time could result in less effective blood glucose control.

Patients should try to keep their insulin as cool as possible, avoiding direct heat and sunlight. Do not allow insulin to freeze if it is placed on ice.

Evacuation Checklist

- Keep your devices out of direct sunlight.
- Use a dry cloth to regularly wipe off devices.
- Do not use disposable devices that are wet (e.g., wound dressings, disposable thermometers, tubing).
- Do not use ice if there is danger of water contamination; use dry ice or instant cold packs instead.
- Wear medical ID bracelets or necklaces at all times.
- Do not use contaminated water to wash hands. Use a waterless hand sanitizer or bottled water.

Source: U.S. Food and Drug Administration

donated medicine and diabetes supplies.

No one with diabetes ever expects to be in a situation where they are unable to get to their supplies, but Katrina has dramatically illustrated that we must always be prepared in case of an emergency.

Here are some simple guidelines to follow when we do not have ready access to medical care or supplies.

To ensure you're never caught without insulin diabetes-care supplies:

- Keep (and always have with you when you leave home) a small backpack filled with snacks, insulin, insulin administration devices, a waterless hand sanitizer, and blood glucose testing supplies. Include plenty of testing strips, and supplies for the treatment of hypoglycemia: Glucotabs, juice boxes, glucagon, phenergan suppositories (in case of vomiting), and medical identification.
- Place medical products in plastic containers to keep them dry (e.g., wound care supplies).
- Heat and humidity can alter the function of your blood glucose test kit and your glucose meter. Keep a copy of the relevant portions of your owner's manuals in your backpack to help ensure the devices continue working properly.
- Always have extra insulin available in your refrigerator that

you can grab in an emergency.

If you wear an insulin pump, include these items in your backpack:

- Pump supplies, such as batteries, insertion sets, tape, and cartridges
- Written guidelines regarding switching back to shots
- Bottled water to clean your insertion site.

If you find yourself in a situation where you are without diabetes supplies, first of all, remain calm, since stress is known to cause swings in blood sugar levels. Seek out emergency personnel to assist you in obtaining insulin; and, unless you are feeling hypoglycemic, avoid eating or drinking carbohydrates until you are able to obtain insulin. Keep yourself well hydrated, taking care that you drink only from clean water sources. Upon arrival at a shelter or other temporary location, identify yourself to a health provider or relief organization member to make sure you are evaluated properly.

ASK A PARENT

Help from JDRF's Online Diabetes Support Team

Q: We had to evacuate our home in New Orleans and move to a new community in Dallas, and I'm worried about enrolling my child in a new school that doesn't know about his diabetes or his care plan.

A: *from Lisa Shenson, member of JDRF's Online Diabetes Support Team, mother of a daughter with type 1 diabetes, and an advocate for the rights of children with diabetes:*

If you are enrolling your child in a new public school, either on a temporary basis or for a longer period, it is important that you take the following steps to ensure appropriate diabetes care for your child. (This information also applies to private schools that receive federal funding.)

Inform the school that your child has type 1 diabetes. If they do not already have students with type 1 diabetes, you may need to explain that this diagnosis requires constant medical attention and the entire staff needs to be trained in how to care for your child. Explain that each child has his or her own unique approach to managing diabetes.

Send a letter to the school formally requesting a 504 plan. Federal law mandates that the school provide *reasonable accommodations* related to your child's diabetes before, during and after school. The 504 plan is a legally binding, written agreement that spells out these accommodations. The school is obligated to provide a 504 plan to all children who have a "medical disability," a category that encompasses diabetes. The school should respond to your request promptly, typically within

a few days. At that time, they will schedule you to meet with all teachers directly responsible for supervising your child, the school nurse, and the school's on-site 504 coordinator.

Develop a 504 proposal. Once you've been given a date for your meeting, you should develop a proposal for a 504 plan based on your child's needs. Make sure to consider factors based on your child's age, ability to self-manage his or her diabetes, the length of time he/she has been living with diabetes, the type of insulin therapy (pump vs. injections), and his/her emotional state given the events of recent weeks.

Create an Individualized Healthcare Plan. Attached to the 504 plan is a separate document that you should create called an Individualized Healthcare Plan (IHP). The IHP spells out all information specific to your child's medical care such as: dosing instructions, symptoms and treatment of hypoglycemia and hyperglycemia, administration of emergency glucagon, and phone numbers to reach you and your child's physician. A healthcare plan is not a substitute for a 504 plan; If the school says you only need a healthcare plan, insist on a 504 plan as well.

Take charge of the meeting. You know more than anyone else about your child's diabetes care, so it makes sense that you should steer the meeting. Begin by thanking everyone for their support. It is a good idea to give a brief description of type 1 diabetes, the issues that it can create on a daily basis for both students and teachers, and how it differs from type 2. Then, go through the 504 plan and IHP, taking questions as you go. If there are any disagreements or concerns regarding the 504 plan or the IHP, get those in disagreement to state their reasons. Schools may well have experience in helping manage the care of a child with diabetes; they might also, however, not fully understand the demands of the disease, and underestimate the importance of some of your concerns. At the end of the meeting, you may request that all items which are agreed upon be followed, stating that you will consider any points of disagreement and respond to them in a short period. Do not sign the 504 plan unless you and the school are both satisfied with the plan as written.

Follow up. For those items still under discussion, you can e-mail your inquiry to JDRF's Online Diabetes Support Team (go to jdrf.org) for advice on how you might resolve these items with the rest of the 504 team. Then follow up with a letter to the school. If everything has been agreed to in the 504 meeting, send a letter thanking the school personnel for their support in implementing the 504 plan and IHP.

Keep in regular contact with the school and your child's instructors. In addition to helping you and your child manage

their diabetes, communication will usually prevent minor problems in the day-to-day care of your child from escalating into larger issues.

Keep written records. Any time the school fails to implement the 504 plan or IHP, send a letter to the 504 coordinator explaining the circumstances, including the date, details of what happened, and the persons involved. Inform them of your concern about the incident and that you expect corrective action to be taken.

While all of these steps may seem a bit overwhelming, but the effort is well worth it in terms of your child's well-being and your peace of mind. I wish you all the best, and remember, you are your child's best advocate.

[Click here for emergency checklists for new schools.](#)

[Click here for sample 504-related forms for schools.](#)

WHAT'S NEW ON THE JDRF WEB SITE?

For hurricane victims and those assisting them, there is emergency preparedness information with at www.jdrf.org. It offers a comprehensive overview of what diabetes is, the special needs of people with diabetes, what to do in an emergency situation such as an evacuation, and checklists to provide to schools and other caretakers. These resources are will be useful in informing individuals who are not familiar with the clinical aspects of diabetes what to do in case they are faced with a diabetes emergency.

WHAT A JDRF CHAPTER CAN DO FOR YOU

JDRF chapters in every part of the country have played an integral role in supporting families affected by hurricane Katrina by offering volunteer support and providing critical information and resources. Here are excerpts from an e-mail sent from volunteer Judy Haley from JDRF's Houston Gulf Coast Chapter within days after the disaster.

"In so many ways, the Juvenile Diabetes Research Foundation is an organization of hope for the future of our loved ones and all families who live with diabetes. The challenges presented by Hurricane Katrina to so many people—with extra challenges for those with diabetes—have provided our chapter in the last few days with the opportunity to share our hope and our passion with many new families.

Cities receiving evacuees, like Houston and Atlanta, quickly

began hearing of the need for diabetes supplies, which were left behind in the haste to escape flood waters. While our chapter members began donating insulin, meters, syringes, and other necessities, to these families, medical professionals like Morey Haymond, M.D., head of diabetes care at Texas Children's Hospital and a member of our Chapter Board, treated the traumatized children, and his staff helped to place some of them in homes. We provided every family with the Bag of Hope, our 'care package' of support materials, as the first step in restoring a sense of hope to their lives. Meanwhile, our volunteers and staff worked with psychologist Barbara Anderson to provide information on how to minimize the trauma for these children (see 'Topics of Living with Diabetes,' p.1). As always, our goal is to reach out with a hand of friendship to help restore these precious children's confidence in the future, to re-establish their diabetes care as quickly and completely as possible, and to always remain available as a source of help and hope."

In Case of Emergency: Important phone numbers

Insulin Manufacturers:

Aventis	1-800-633-1610
Lilly	1-800-545-5979
Novo Nordisk	1-800-727-6500

Glucose Meters:

Abbott	1-888-522-5226
Bayer	1-800-348-8100
BD	1-888-232-2737
Lifescan	1-800-227-8862
Relion	1-800-992-3612
Roche	1-800-858-8072

Insulin Pumps:

Accu-Chek (Disetronic)	1-800-280-7801
Animas	1-877-767-7373
Dana Diabecare	1-866-342-2322
Medtronic MiniMed	1-800-646-4633
Nipro	1-888-651-7867
Smiths Medical	1-800-826-9703