

When Your Child Is Diagnosed with Diabetes: Parents' Questions for the Healthcare Team

By Janet Silverstein, MD, Eric A. Storch, PhD, and Laura Williams, MS

Learning that their child has diabetes can be a very stressful experience for parents, other family members, and of course for the child. In the days and weeks following diagnosis, children and parents typically have numerous questions for their health-care team concerning how diabetes may affect their family. School nurses play an important role in helping the child and family adjust to living with diabetes. Although medical appointments are the best time to have questions answered, many families find appointments to be rushed and overwhelming, particularly given the complexities of managing a new condition such as diabetes. As a result, families often leave their medical appointments with unanswered questions.

While healthcare professionals almost always solicit questions from families, open-ended prompts such as "Do you have any questions?" may not effectively elicit all of a family's concerns. Furthermore, even if parents do ask questions, they may not fully understand or remember the responses, particularly given the large amount of information that may be presented during medical appointments.

Given the challenges of addressing the questions of families with newly diagnosed children, we can use several techniques to provide important information. Open-ended questions are a good starting point. It is also helpful to follow up with more specific ones (e.g., "Do you

have any questions about the emotional impact of diabetes? Are you concerned about managing your child's diabetes at school?") The school nurse could suggest that parents write down questions before their medical appointments to help organize and remember pertinent issues. Perhaps the most effective means for addressing the concerns of newly diagnosed children and their families is to provide written lists of resources. Written materials are advantageous because families can digest the information at their own pace. The materials can reference web sites or other information of interest, where parents may learn more on a subject. The school nurse could be an important source of such family support materials.

The National Diabetes Education Program's Work Group on Diabetes in Children and Adolescents has developed a list of some of the most common parental questions that can be effectively used to stimulate further questions during medical appointments – when a child is newly diagnosed and later on as well. The list addresses basic topics such as the different types of diabetes and the recommended frequency of medical appointments, to more complex concerns, such as when children should begin taking responsibility for their own diabetes care.

This resource also provides web sites for parents and children to gather additional information. By ensuring that families of children with diabetes have

the opportunity to ask questions, the health-care team can provide effective support and information during a difficult time. A copy of the questions is provided here as a ready resource for the school nurse to provide to families. Contact the NDEP to find this set of questions and other resources for youth with diabetes: <http://ndep.nih.gov/diabetes/youth/youth.htm> or 1-800-438-5383.

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Parents of children with diabetes often have concerns about the disease, its impact on their family, and how to keep their children safe and healthy. Use these questions to talk with your child's health-care team to learn about your child's diabetes care needs at diagnosis, and later on as well. To find out more about possible answers, link to http://ndep.nih.gov/diabetes/parents/parents_questions.htm

QUESTIONS

What are the different types of diabetes?

- Which type of diabetes does our child have?
- Will it ever go away?

What does this mean for other members of our family?

- Does it mean our other children will get diabetes too?
- What about other family members?

What are my child's treatment goals?

- How can we help our child meet these goals?
- How often will our child need to visit you each year?

What other healthcare team members can help care for our child's diabetes?

- How do we contact them?

How can we work together as a family to help our child?

- How can we help our child check blood glucose, take insulin, eat healthful foods, and learn about diabetes?
- Who can help us work together as a family?

What emotional issues might our child and family face?

- Will diabetes affect the way our child behaves?
- When do we start letting our child manage his own diabetes care?
- Who can help us cope with these issues?
- Should we tell friends and family about our child's diabetes?
- Who can help us if we don't have medical insurance?

- What resources are there to help our child in school?

What research is going on?

Three large nationwide studies are under way.

- The TODAY study wants to find the best ways to care for type 2 diabetes in children and teens and is taking place in 13 medical centers throughout the country. To find out if you can join go to www.TODAYstudy.org.
- Type 1 Diabetes TrialNet is a group of studies looking at ways to prevent or treat type 1 diabetes early and help preserve insulin production. To find out if you can join go to www.diabetestrialnet.org/public.html or call 1-800-HALT-DM1 (1-800-425-8361).
- The SEARCH for Diabetes in Youth study will help us learn about how type 1 and type 2 diabetes differ, what medical problems arise, the health care children receive, and how diabetes shapes their daily lives. www.searchfordiabetes.org

A lot of other research is going on. To find studies in your area, talk to your health-care team and visit the JDRF and ADA web sites (links below). 🐼

ADDITIONAL RESOURCES FOR PARENTS AND CHILDREN

American Diabetes Association (ADA)
www.diabetes.org or call 1-800-DIABETES (1-800-342-2383)

Children with Diabetes
www.childrenwithdiabetes.com

Juvenile Diabetes Research Foundation
www.jdrf.org or call 1-800-223-1138

National Diabetes Education Program
www.ndep.nih.gov or call 1-800-438-5383



The U.S. Department of Health and Human Services' National Diabetes Education Program is jointly sponsored by the National Institutes of Health and the Centers for Disease Control and Prevention with the support of more than 200 partner organizations.

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