

Diagnosis: Diabetes The Adjustment Process

Common Feelings

Your child has just been diagnosed with diabetes. Many parents of newly diagnosed children say that one of the first things they want to hear is “**It will be okay,**” “**Your life will return to a new normal.**” And it will, but before life reaches the “new normal,” most families experience a period of time during which you may feel **shock, disbelief, anger, sadness, fear, guilt, confused, and overwhelmed.** Experiencing some or all of these feelings is very common. Whether your child was diagnosed after feeling sick for some time or had relatively few symptoms, you are likely to experience a sense of loss and grief. It is common to experience multiple feelings (shock, denial, anger, etc.) at the same time, and to go back and forth between these emotions.

Here are some tips to help you reach your “new normal”:

- Allow yourself to have, or experience, whatever emotions are present in you. Even though this may be uncomfortable, you will be able to move forward more easily if you have allowed yourself to work through difficult emotions now.
- Fears that have no reason will go away.
- Sadness and anger may still come and go periodically, but they will decrease in intensity and duration over time.
- Anxiety and feeling overwhelmed will diminish as you practice the skills you have learned and they become part of your daily routine.
- As you live with diabetes, you will gain confidence each day that will lead to your “new normal.”
- Our diabetes team is always available for you.

Coping with Stress

The experience of having your child diagnosed with diabetes and working toward your “new normal” is stressful for most people. Stress is felt when:

- An event occurs that puts a strain on a person
- When a person thinks of a situation as challenging or threatening

Stress can affect us in the following ways:

- Physically – the body sends out “stress hormones” that can:
 - increase your heart rate and blood pressure
 - make your breathing rapid and shallow
 - raise or lower your blood sugar
 - make you feel tense and tired
 - cause headaches
- Emotionally – stress can:
 - make it difficult to concentrate or stay focused
 - cause you to feel anxious, harried, overwhelmed, angry, afraid or hopeless.

It is helpful to identify coping strategies that work for you. Everyone copes with challenging situations in their own way. Do what works for you. Some people cry, talk, exercise, etc. Some people need quiet time alone to process what is occurring. Some people get involved with others facing similar circumstances through ADA or JDRF. Be honest about your feelings with other adults and with your

child(ren) making sure you don't give them more information than they can process at their age(s). Give your child permission to express their feelings. Reassure your child that you will get through this adjustment and will always do whatever needs to be done to take care of them. Remember to look at your "Living with Diabetes" worksheet from time to time and practice your own coping strategies to prevent your "burnout."

Age Appropriate Expectations:

See chapter 18 in the Pink Panther book. Children understand what is happening to them according to their current developmental level.

- Under Age 3: Parent does all care. Child does not understand what diabetes is, why you need to poke fingers, give shots, and place restrictions on when and what is eaten. They will come to accept diabetes care as part of normal life fairly quickly if you are consistent and loving. Don't apologize for shots and pokes. Don't allow stalling tactics, manipulation or tantrums to put off getting the task done. May give shots after seeing how much is eaten.
- Ages 3-7: Parent does all care. Some kids in this age group can do their own finger poke, and some may even assist with an injection, but parents continue to have full responsibility to supervise and be fully aware of every blood test and injection. The child accepts that this must be done, but doesn't really understand what diabetes is (may think they are going to die-of-betes). Child gradually learns to cooperate. May still need to give shot after meal if inconsistent intake. Parents may notice "delayed reaction" to diagnosis (the child may adapt very quickly to regime at first, but become sad or resistant weeks or months later when they realize the regime is permanent).
- Ages 7-12: Child is able to perform finger stick blood checks by themselves. By age 10 or 11, the child can draw up and give an injection, or a pump bolus, but continues to need adult supervision. Can do basic carb counting. Child does not have an understanding of the concept that doing something now, helps prevent problems later. Parental involvement and supervision must continue. "Delayed reaction" to diagnosis may also occur at this age. Encourage expression of feelings in appropriate ways. Reassure them "getting diabetes is no one's fault." It's not a punishment.
- Ages 13-18: Child possesses the intellectual and physical capabilities to do the majority of tasks (blood sugar checks, injections, pushing pump buttons), but lacks the maturity or responsibility of an adult to make sure every task gets done on time, every day. The purpose of the adolescent stage of development is to "separate" from their family and become their own person. Adolescents do this by being highly focused on peers, social activities, school activities, sports, etc. (anything else but diabetes management). For this reason, continued parental involvement is essential throughout adolescence. Transitioning responsibility for diabetes management is a process, not an event. Child is capable of carb counting well. Gradually begins to understand the concept that doing something now, will prevent problems later.

Sibling Issues

Diabetes is a condition that affects all members of your family, not just the person who does blood tests and takes shots. When a child first develops diabetes, it is a crisis for the whole family. Often brothers and sisters feel left out. This is because so much attention is given to the child with diabetes. Some common concerns may be:

- trouble understanding what diabetes is
- fearing that their brother or sister will die ("die-of-betes")
- thinking they caused the diabetes by having an angry thought against the child with diabetes
- fearing that they will be the next one to be diagnosed

Ways to help siblings:

- Allow them to be a part of the process and educate them in ways that are appropriate for their own developmental level.
- Encourage contact with the child who is in the hospital, or bring them with you to clinic so they can see where you (and their brother or sister) goes when you leave them. Bring along another caretaker or use Children’s “Kids Camp” for the siblings, so you can concentrate on the reason for your visit.
- Ask them what they think and understand, even if you think you know (you might be surprised).
- Reassure them that chances are very, very small they will develop diabetes, but if they do, you will take care of them just like you are taking care of their sibling.
- Discipline should not be different for their brother or sister with diabetes than it is for them.
- Plan individual time with each child in the family.

Extended Family Issues:

Because “diabetes” (all types) is prevalent in our society, many people know someone who presently has diabetes or knew someone who had diabetes. Knowing someone, even casually, who has or had diabetes often leads a person to believe that they know how to treat diabetes, but because 90% of all people with diabetes have type 2 diabetes and only 10% have type 1 diabetes, whatever knowledge someone does have about diabetes most likely pertains to someone with type 2, not a child with type 1 diabetes. So remember, these well intended folks think they know, but “they don’t know what they don’t know.” When your child is in the care of an extended family member, remember to:

- discuss the ways you take care of your child (how to give the injection, how you do the blood tests, how you treat a low blood sugar, etc.)
- write down your child’s current doses and meal instructions
- remind them not to “feel sorry” for your child or treat them differently than how they did before the diabetes.

Besides siblings and extended family members, the rest of your diabetes team consists of our staff here at the hospital. Many of our staff are certified diabetes educators. Here is a general description of how each of our staff members can help you.

Doctor/Physician’s Assistant/Nurse Practitioner	Makes recommendations for treatment of your child’s blood sugars and oversees all teaching.
Nurse Educator	Teaches you and your child about diabetes and how to take care of it.
Dietitian Educator	Teach you and your child how to use a meal planning system and will help you develop a personalized meal plan for your child.
Social Worker	Offers guidance, and support to you as you make your way through this adjustment, and help with any areas of concern you have (i.e. school and/or day care issues). The Social Worker is also here to provide you with information about community resources and financial assistance programs.
Child Life	Here to help your child understand diabetes at their own developmental level, and to inform you about our school re-entry program.
Psychologist	The Psychologists at the Behavioral Health clinic have experience working with children who live with chronic diseases. Appointments are available on an as needed basis.

Remember, we are all just a phone call away, and want to help in whatever way we can. In Omaha call 402-955-3871. If you are outside the Omaha area and in Nebraska, call 1-800-642-8822, extension 3871. If you are outside Nebraska, call 1-800-228-9513 extension 3871. Our fax number is 1-402-955-8738 and our e-mail address is diabetes@childrensomaha.org.