Chapter 10

Feelings and Diabetes

H. Peter Chase, MD
Rita Temple-Trujillo, LCSW, CDE

TOPICS:

Psychosocial Adjustment

TEACHING OBJECTIVES:

1. Reflect with the family typical adjustment feelings associated with diagnosis and encourage expression of feelings.
2. Provide information relating to additional support services.

LEARNING OBJECTIVES:

Learners (parents, child, relative or self) will be able to:

1. List two feelings of adjustment associated with diagnosis.
2. Describe how to access additional support services.

INTRODUCTION

This chapter is about the normal feelings you may experience after learning that you or your child has diabetes. The diagnosis of diabetes is a shock and can be overwhelming. Most people are unprepared for this diagnosis. They struggle with why it has happened to them or to their child. At diagnosis, families must drop everything to focus on their or their loved one's health. They must learn how to provide the necessary care. Learning is often difficult when you are in the middle of an emotional crisis.

We expect that people and families will go through many feelings after the diagnosis of diabetes. The emotions felt are common with the onset of <u>any</u> serious medical condition. People frequently wonder what they could have done to prevent this from happening. They think of all the "what ifs?" and try to imagine what they could have done differently. Young adults or parents sometimes blame themselves for eating (or letting their child eat) junk food or for not getting to the doctor right away. Bed wetting is a common problem in children prior to diagnosis and can cause sleep interruptions. Some parents feel guilty they didn't recognize the symptoms. It is very important to talk about these feelings in order to adjust and to help the medical team better understand how they can assist. Most parents feel grief and worry about how this will affect their family and their child's future. Adults worry about how diabetes will affect their lifestyle and future. In our clinic, EVERY newly diagnosed family meets with the clinical social worker, who can be helpful. Some of the feelings that may be experienced are described below.

GRIEF. Talking about the stages of grief can help people understand their own feelings as well as how to help their child through this important process. Adults and children react to the diagnosis and handle grief differently. Typically, adults are upset the most in the first few days after diagnosis. Children who have been feeling quite sick, may actually feel happier and have more energy when insulin is started. It is important to remember that they, too, will need to talk over how they feel about having diabetes and what it means to them. Even very young children get upset and will likely show some behavior changes.

CONFUSION AND SHOCK are common feelings for families. Many people describe feeling shocked, scared, upset or even angry that they or their child has been diagnosed with diabetes. They wonder why this has happened, and think: "this can't be real," or "this can't be happening." They worry whether they will be able to give shots without hurting and if they can remember everything that they were taught. Parents experience a stronger sense of anxiety about their child's well-being and worry more about ordinary separations, like going back to school. All of these feelings are very normal and are important to discuss in order to get information and needed reassurance.

Because of the shock, it is often hard for families to focus on what the medical team is saying about diabetes. Sometimes families will ask to have things repeated. The medical team understands and is happy to go over the information several times. Because of the initial shock and sometimes lack of sleep, many clinics teach only survival skills (the "basics") for the first day or two. They can generally go into more depth at future visits.

DENIAL is often expressed in comments such as: "there must be a mistake in the diagnosis." As a result, people may want to seek second opinions from other doctors. They hope to be told that they or their child doesn't have diabetes. Though initial doubt is a normal reaction, continued denial may make adjustment much harder. It can even interfere with medical treatment and education. If denial is very strong, it is important to understand the reason for this feeling. In some cases, there are complicated reasons and even cultural misunderstandings that can interfere with acceptance of the diagnosis.

For a child to accept his or her diabetes, parents need to accept the reality of diabetes and learn what they must to do to care for their child. A child takes important cues from their family and will need their involvement, love, support and care. Though an adult with recently diagnosed diabetes will provide their own care, they will also need love, support and involvement from people important in their lives in order to assist their acceptance of the diagnosis of diabetes. Siblings, grandparents, aunts, uncles and spouses (significant others) will all need to work through their feelings about the diagnosis. They can then discover how to be the most helpful. Support from all family members and friends is crucial when coping with diabetes.

SADNESS. It is common, initially, for parents or siblings to cry, be depressed and feel a loss. Some parents fear that their child's life will never be normal again. The child they previously thought of as healthy will now be "different." If their child has had previous medical experiences or has other medical conditions, people may feel it is terribly unfair that their child has yet another challenge. Adults with newly diagnosed diabetes can also have the very same feelings, fears and concerns listed above about themselves.

Sadness is part of grieving and may be experienced off and on during the adjustment process. Sometimes this sadness is affected by previous losses or other traumatic experiences and can be quite difficult for a parent or affected adult. If normal sadness begins to linger too long and is affecting the ability to function, it is a good idea to talk with the psychosocial member of the medical team and get some guidance about what might be helpful during this difficult time.

ANGER is an emotion that is often difficult or uncomfortable to express. Sometimes we feel anger over things we cannot control. No person wants to get diabetes, or to have his or her child get diabetes. This anger may be felt or expressed toward doctors, nurses, God, a spouse, and even friends whose children do not have diabetes. In a sense, anger can be a sign of a family's protection of a member and reflects the difficulty in accepting that a loved one must live with a chronic medical condition. Like sadness, anger can get "stuck" and not get better. When anger persists, it is very important to talk with someone who can help you.

Children can also feel anger about the many changes in their lives—-shots, pokes, diet changes, schedules, etc. They often direct it at the parent because they don't yet have the ability to express how they are feeling. Patience and talking will help children work out their feelings.

ANXIETY is a common feeling. Adults with diabetes may worry about how they will manage normal activities with this new diagnosis. Parents worry about their newly diagnosed child's safety and the extra responsibilities of caring for them. Brothers and sisters may worry about seeing shots and about whether they will get diabetes, too. The child with diabetes may worry about whether their friends will treat them differently. Young adults or parents may wonder how diabetes will affect their or their child's future. This anxiety will get better as the family gets practice and experience with care.

Normal everyday types of separations can take on a new meaning. A parent, who previously sent their child to day care or school without concern, may suddenly worry about whether their child with diabetes will be okay. Although some worry is normal and part of caring for a child, excessive worry can interfere with the child's need for growing independence. By educating others who care for the child with diabetes, a child will learn to trust that others can give assistance when it is needed.

> (A special note about shots: One of the biggest initial fears for both adults and children is having to give [or get] insulin shots. Nearly *everyone* has fears about shots. This is normal! Fortunately, newer smaller syringes and good technique can make shots almost painless. But fear often makes one shaky, nervous and tense. Giving or getting a shot when one is shaky, nervous or tense can be *painful*. Health care providers can help review the method used. They can also teach relaxation and breathing techniques to help shots be more comfortable [more about this in Chapter 17]. If pain persists, then further attention is needed.)

GUILT is something that adults and children often feel. When we don't understand why something has happened, it is easy to blame oneself. A parent with a family history of diabetes may blame him or herself. This idea occurs even when people have been told that autoimmunity (self-allergy), viral infections and other unknown factors are important in causing diabetes. We do not completely understand why someone develops diabetes. There is no proven way at this time to prevent it. Earlier diagnosis would <u>not</u> have prevented the diabetes from happening or change the way it is treated.

Children always seek a reason for why something has happened. When we can't provide clear answers, they sometimes develop their own "theories" about why they got diabetes. Children have told us they thought they got diabetes because they "were naughty," "ate candy" or "were not nice to their brother." It is important to reassure them they did nothing to cause their diabetes. These "theories" can sometimes pop up years later. Keeping an open dialogue with your child will help work through these times.

ADJUSTING TO DIABETES

The first few weeks after diagnosis may feel like an eternity. The emotional and physical energy needed to manage the many changes resulting from a diagnosis of diabetes can be exhausting. But the good news is that things do get better! As normal household chores, work and school routines are re-established, family members start to settle in with their new diabetes plan. Adults begin to feel more energetic and able to "meet the world" on their terms. Parents are often reassured to see their child feeling better and "back to their old self." Sometimes, a child may have great spurts in growth after just a few weeks of care. Everyone begins to feel more confident in new skills, but may still have many questions. These are very important to review with the health care team.

Adjustment over the long run takes time. Communication about feelings within the family is very important because everyone feels the effects of one member having diabetes. Brothers and sisters may feel jealous that much of a parent's attention is now focused on the child with diabetes. Parents need to be aware of this and avoid making this one child "special." Special treatment will only breed later resentment. Diabetes should not take the fun out of being a family. A child with diabetes is a capable child who wants to be treated like everyone else.

As with any chronic medical condition, there will be times when some of the feelings and frustrations will again feel overwhelming. This may signal that something is not going well and needs attention. Talking with a health care team member, particularly the clinical social worker or psychologist, can be extremely helpful. They can help identify a problem and assist in its resolution.

As individuals and families adjust, everyone usually feels more hopeful. People find strengths that they didn't know they had. Parents may seek out connections with other families who have children with diabetes. They may want to volunteer to raise money for research and care or participate in available clinical research studies. The world of the internet opens up new avenues for information and resources (see sites on inside cover). There is a strong worldwide community of families, medical providers and researchers who are very committed to advancing care for people with diabetes and, hopefully, eventually finding a cure. Having hope is a good thing.

DEFINITIONS

Adjustment (adaptation): Gradually learning to live with something (such as the diagnosis of diabetes).

Denial (deny): A refusal to believe something. A person may refuse to believe that he or she has diabetes.

Diagnosis: The process of finding that a person has a disease.

Guilt: A feeling that one caused something to happen.

QUESTIONS AND ANSWERS FROM NEWSNOTES

Q **Why is the Pink Panther character used in the educational manual, *"Understanding Diabetes"*?**

A Having a family member develop diabetes is often the most traumatic event that has happened to a family. If a child were pictured to demonstrate a side effect, such as hypoglycemia, it might be harder for a family member to accept than a picture of the Pink Panther having a reaction. Also, a bit of humor at this time of intense emotions can often be a big help.