TOPIC:
Psychosocial Adjustment

TEACHING OBJECTIVES:

1. Describe extra stresses which a person/family may experience as a result of diabetes.
2. Provide healthy coping strategies for individual/family stress.

LEARNING OBJECTIVES:

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

1. Identify the stresses experienced by the person/family with diabetes.
2. Describe a healthy coping strategy for an identified stress.

Chapter 17
Family Concerns

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WORKING AS A FAMILY

The challenges a person or a family may have following the initial diagnosis of diabetes include more demands on their time, money and energy. This is due to the daily routine of the diabetes management and the regular clinic visits. Parents and families must decide how to fairly share these new responsibilities. We encourage **both** the mother and father to share the responsibility for the diabetes care of their child. This should include giving the insulin injections. It is important for the parents to support one another. Both parents should also try to attend all clinic visits.

Diabetes affects the entire family. The family must work together to solve problems and manage the diabetes. Research has shown that children and individuals do best with strong family support and involvement.

SINGLE-PARENT/ BLENDED FAMILIES

Approximately one-fourth of children in the U.S. now live in single-parent families. For children who live in two households, it is important to share vital diabetes information between the households.

This information includes:

- ✔ blood sugar levels
- ✔ recent low blood sugars

- ✔ insulin dosages and recent changes
- ✔ food intake
- ✔ exercise
- ✔ illnesses
- ✔ other items/events which may effect diabetes management

GOOD COMMUNICATION AND COOPERATION ARE ESSENTIAL

Some suggestions for two households are:

- ✔ diabetes supplies can be neatly packed in a carrying case to go with the child between households
- ✔ keep a vial of glucagon and some foil-wrapped urine ketone strips permanently in each household
- ✔ keep a **current** log book with insulin doses and blood sugars to ensure consistency from household to household
- ✔ remember that the care of the child is the most important thing. Try to put individual differences and conflicts aside and focus on helping the child make a healthy adjustment to their diabetes.

LEADING A NORMAL LIFE

Diabetes care has changed tremendously over the past 20 years. New insulins, blood glucose meters and added flexibility with meal planning and insulin dosing make it easier for children or adults to live normal, healthy lives. It is important for children or adults with diabetes to lead normal active lives. Though there may be many new worries, it is possible to normalize one's life with diabetes.

For children, leading a normal life means participating in age appropriate activities with their family and peers. There is no question; diabetes can make fun things like sleepovers and birthday parties a little more stressful. But with a little flexibility and creativity, children with diabetes are able to participate in these activities just like their siblings or friends. When in doubt about allowing your child to take part in an activity, ask yourself, "Would I let my child participate if he/she did not have diabetes?" If the answer is "yes," it should not change because of the diabetes. If you are uncertain, contact your care provider so they can help you create a plan for the activity.

The issue of discipline and diabetes is also an important aspect of leading a normal life. Whether your child has diabetes or not, there will be times when he/she will test limits and act up. Children with diabetes need limits set like any other child. Sometimes it is hard to tell if your child is being difficult because he/she is "acting like a teenager" (or "a toddler") or because their blood sugar is low. When in doubt, check the blood sugar and then deal appropriately with the behavior.

Care providers, parents and children need to strike a balance between good diabetes control and an emotionally healthy lifestyle. It is important for all of us to work as a team so that kids with diabetes can grow and develop physically and emotionally.

CONCERNS OF BROTHERS AND SISTERS

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
- ✔ thinking they caused the diabetes by having an angry thought against the child with diabetes
- ✔ fearing that they will be the next to be diagnosed

Important things for the brothers and/or sisters:

- ✔ to be a part of the beginning education
- ✔ young children will feel less frightened if they can visit the hospital or clinic

- ✔ asking the children what they think and understand, even if you think everything has been thoroughly explained. *One child used the word "diabetes" very literally. When asked why he was so very sad, he said he thought diabetes meant "die of betes."*
- ✔ discipline should not be different for their brother or sister with diabetes than it is for them
- ✔ all children in a family should be treated in a similar way. *One sister said she eats a candy bar in front of her brother with diabetes when he gets away with something. She said, "That's how I get even with him."*
- ✔ it is important to plan individual time and special activities with all children in a family

Some children with diabetes have the opportunity for group activities such as diabetes camp and ski trips. Many brothers and sisters say, "I wish I had diabetes so I could do special things, too." A family can prevent future stress if siblings understand that these activities need special medical care. Make sure the sibling without diabetes gets their special time too.

FAMILY STRESS

The diagnosis of any serious condition, especially in children and teens, is stressful for the whole family (including the extended family). Getting through the initial shock and grief that comes with the diagnosis is difficult. This can be especially hard if families have had medical or other serious problems to manage. Parents usually have different coping styles around grief. It is normal that some family members find they are less patient or even irritable with one another for a period after the diagnosis. These feelings usually resolve as everyone adjusts and begins to feel more comfortable managing the diabetes.

When grief or conflict does not get better, this can obviously be stressful for parents and for the whole family.

The crisis of diagnosis can bring up many fears and feelings, and:

- ✔ an individual can become quite anxious or depressed
- ✔ parents or significant others may feel the strain on the relationship with one another. It is particularly important to seek help to try to be understanding and to get the support that is needed.
- ✔ children and teens can sense tension between parents and may feel responsible for something they can't help

Talking with the psychosocial member of your diabetes team can be helpful in sorting out these problems.

PROMOTING A HEALTHY DIET

When a child is diagnosed with diabetes, one of the first things that parents often wonder about is how their diet will change. Many people still believe sugar is what causes diabetes and think they will need to have a sugar restricted diet for their child with diabetes. These days, we understand that eating a healthy diet is more important than ever for everyone. Americans already eat more added sugar than is recommended and this contributes to too much weight gain. Diabetes education teaches families about carbohydrates (sugars and starches) and how they affect blood sugars. It is important that everyone in the family try to support one another by selecting healthy foods and snacks.

If possible, foods in the home should not be restricted from the child with diabetes. If too many high carbohydrate, sweet foods and drinks are available in the home, they are hard for anyone to resist, let alone the child with diabetes. Too much of this "junk food" is a growing health problem in our country. When parents can, it is important to look at the importance of how everyone eats in the family and how they can make healthy changes and limit the amount of "junk food" available.

A healthy diet includes foods from all food groups in appropriate amounts. It is permissible to include some sweets as a part of a healthy diet.

Fresh fruit and frozen yogurt are good examples of treats that can provide both nutrition and great taste! With or without diabetes, one should not consume sweets and special treats in excess! When diabetes is part of the picture, the appropriate insulin dose must be given/taken for carbohydrates (including sweets) that are consumed. Trying to avoid all sweet foods may create undue focus on food restriction. Healthy sweet treats may be allowed as a part of a healthy family diet. When in doubt, please consult with the diabetes dietitian.

DEALING WITH STRESS AND EXCITEMENT

Emotions and stress may have a big effect on diabetes control. *Many different life events can cause stress such as:*

- ✔ family problems
- ✔ arguments with parents or between parents
- ✔ parent separation or divorce
- ✔ death of a relative, friend or pet
- ✔ a move to a new home or school

Other kinds of stressful situations include special events such as:

- ✔ athletic competitions
- ✔ school exams
- ✔ holidays like birthdays, Christmas or Hanukkah

Most people will have high sugars following stress, though some children can have low sugars because of extra activity. It is important to think ahead and reduce the insulin dose or give extra food. Monitor blood sugars at least four times during the day to prevent low blood sugars on days of excitement.

The diagram in Chapter 14 on Diabetes and Blood Sugar Control shows how the insulin dose, oral medicine dose, diet, exercise and stress must be in balance for the best sugar control. Sometimes, despite our best efforts, blood sugars just don't behave the way we expect! But it helps to keep working at it.

NEEDLE ANXIETY (FEAR OF SHOTS)

It is now known that needle anxiety of some degree occurs in almost everyone. Children and adults have worries about shots. In a person with diabetes, we used to assume that this anxiety would just go away because they had to have shots every day. We now know that needle anxiety, if strong, doesn't "just go away." There are some things that can be learned to reduce this anxiety if we identify it is a problem.

First of all, anxiety about shots is normal. When we fear something, we get tense and tend to hold our breath. Our head is filled with thoughts about pain. Parents who have to give these shots can be just as needle anxious as their child. Remember, the syringes that are now used for insulin are much smaller and have shorter needles so that shots are much more comfortable these days. With a few easy techniques, shots can be less stressful. The diabetes educators in our clinic always have parents or significant others practice injections on each other using saline solution. The practice nearly always reassures them that giving insulin injections to their child is not the trauma they imagine.

Tensing can make shots hurt. So take a couple of deep relaxing breaths ("breathe in through the nose and breathe slowly out the mouth") and try to imagine yourself made of Jell-O. By relaxing the tension, shots can be done more comfortably. Sometimes a little distraction can help refocus the mind from fear to something else. Watching cartoons or listening to some favorite music with headphones can help the mind from thinking too much about the shots and aids relaxation.

Sometimes a person with diabetes doesn't get over their stress about shots. *A few symptoms that might indicate this is going on are:*

- ✔ persistently high HbA_{1c}
- ✔ a child wanting to do <u>all</u> their own shots – particularly when they want to do the shot

in a room by themselves (some shots will probably be missed)

- ✔ lack of site rotation (hypertrophy or swelling of the injection site)
- ✔ missed insulin shots
- ✔ excuses for wanting to "put off" the shot (stalling)
- ✔ parental fear or worry about injections or blood draws

The psychosocial member of the team can be very helpful to children or parents with sorting out this problem. Treatment can include behavioral techniques and purposeful distraction. The latter includes TV, music, toys, blowing bubbles and books. Sometimes injection devices help the problem (Inject-Ease, Chapter 9) though they do not "cure" it. Behavioral techniques include learning to relax, reward programs, systematic desensitization and biofeedback. As fear of shots, blood or injury decreases, the HbA_{1c} usually improves.

PSYCHOLOGICAL DISORDERS

Families need to be aware of two types of psychological disorders that have been described in people with diabetes. The first is **depression** and the second is **eating disorders**.

Depression: Depression (defined in Definitions at the back of this chapter), is one mood disorder that may be more common in older teens and adults with diabetes than in the general population.

Symptoms include:

- ✔ change in sleep habits
- ✔ change in appetite
- ✔ decline in school or work performance
- ✔ irritability or sadness
- ✔ isolation
- ✔ lack of pleasure in things and decreased energy

If you see such changes, it is wise to seek professional help from your diabetes team or a mental health provider. *Be aware that depression can affect diabetes care in the following ways:*

- ✔ poor blood sugar control (high HbA_{1c}) due to not following treatment plans
- ✔ irritability about testing blood sugars or getting shots
- ✔ decreased energy with higher blood sugars
- ✔ not caring about daily diabetes tasks

If left untreated, depression can lead to long term poor control and complications. Treatment of depression and other mood disorders can be very effective these days with a combination of counseling and medications (usually antidepressants). Please ask your primary care physician or diabetes team for recommendations and referrals.

Eating disorders: *The most common types of eating disorders are explained below:*

- ✔ ***Anorexia*** usually involves limiting food intake and often engaging in excessive exercise. The goal of these is to lose weight and maintain unrealistic and unhealthy weight loss. This can become life threatening.
- ✔ ***Bulimia*** is defined by excessive intake of food and self-induced vomiting, use of laxatives and/or excessive exercise. This is a very risky form of weight loss or weight maintenance.

Both of these conditions can result in low blood sugars. Many people are not aware of an additional form of eating disorder specific to people who have diabetes.

- ✔ ***Insulin omission***. Some people *miss shots* or *underdose their insulin* to achieve weight control. This is a particularly dangerous form of eating disorder because it leads to chronic poor control and can result in DKA (diabetes ketoacidosis). *The effects of missing insulin doses include the following:*

- The calories consumed go out in the urine rather than into the body. Blood sugars are very high.
- If left untreated, chronic complications (Chapter 22) are more likely.
- Blood sugars sometimes become very erratic. This may mean the person is alternating between restricting food (with low sugars) or binging (with high sugars).

✔ ***Binge eating*** is the fourth type of eating disorder. People who binge eat often skip meals during the day and eat excessively at night. It is most frequently associated with type 2 diabetes.

Any of these disorders can be very dangerous for a person with diabetes. They require immediate psychological care from a professional with expertise in this area and who understands diabetes. A healthy body image is important and a healthy body is essential.

CHANGING BEHAVIOR

Sometimes children with diabetes have difficulty with their insulin injections, blood sugar tests at home, the suggested diet, the recommended exercise or other parts of diabetes management. These "problems" can be opportunities to assess what is bothering a child or teenager. At these times it may be very helpful to meet with the clinical social worker or psychologist who specializes in working with families. They can help evaluate problems and suggest ways to effect change. Behavioral change takes time, patience and usually requires help from the whole family. A few visits can often be very helpful to the patient and the family.

SCHOOL/WORK ATTENDANCE

People with diabetes generally shouldn't have more school/work absences for illness. They may have to miss school/work occasionally for routine clinic visits. If a lot of school/work is being missed for diabetes related reasons, it is very important to review this with your medical team. Working together, the underlying cause can be found. With good blood sugar control, there is no reason why people should not participate fully in activities of their choice. However, they may have other concerns that contribute to missing school/work. These concerns should be examined and addressed as soon as possible.

If school/work is missed for a period of time due to illness or hospitalization, the person may be very worried about returning. It is not uncommon for the diabetes to remain in poor control when a person is worried about unfinished work, exams, fellow students, teachers, co-workers or other problems.

If a significant amount of school/work has been missed the following can be helpful:

✔ Encouraging the person to return to school/work as soon as possible.

✔ The family may wish to ask members of the diabetes team to help coordinate matters with the school/work. Sometimes a person may fear how peers or co-workers will treat him/her.

✔ Talking with the school counselor or teacher can help people of school age. They can assist in arranging a schedule and homework after a long absence.

✔ Arranging for a nurse educator or parent to talk to the class about diabetes can be very helpful for a student. It allows for the development of good peer support and understanding.

DEFINITIONS

Clinical Social Worker: A person with a Master's degree in social work trained to help individuals or families with stress, emotional or behavioral problems, as well as problems with resources.

Psychologist: A person with a doctorate degree (PhD or PsyD) trained in helping people with behavior, stress or feelings that are causing problems or discomfort.

Psychiatrist: A physician who specializes in psychiatric medicine and may be helpful in diagnosing and prescribing medications for moods disorders and attentional problems.

Stress: Problems or events that make people feel worried, afraid, excited, upset or scared.

Depression: A mood state in which one may show sadness, a lack of energy, inability to do one's normal work or activity or self-depreciation. They may show a lack of interest in enjoyable activities, irritability or withdrawal from friends and family.

Eating disorder: *The most common types of eating disorders are:*

1. Anorexia: People with a distorted body image who limit their food intake and often exercise in excess to remain very thin.

2. Bulimia: People who eat excessively at times and then vomit (or take medicines such as laxatives) in order to not gain weight.

3. Binge-eating: People who intermittently eat excessively but do not vomit. They may gain excessive weight and develop type 2 diabetes.

4. Insulin omission: In a person with diabetes, skipping insulin shots or lowering doses to maintain or avoid weight gain. This is an extremely dangerous form of weight loss because of the risk of ketoacidosis.

QUESTIONS AND ANSWERS FROM NEWSNOTES

What are the occupational restrictions for a person with diabetes?

Restrictions are based on the idea that all people with diabetes are at a greater risk for hypoglycemia. There are studies which show hypoglycemia does result in an increased risk for accidents. In one study, approximately 10 percent of the accident reports, in which the accident was due to a medical condition other than alcoholism, were due to an insulin reaction.

My own opinion is that restrictions should not be generic and should be individualized. Some people test their blood sugars frequently and are careful to eat or make sure they are not low before driving a car. Others are less careful. Everyone pays the price from the latter group.

Currently, legal restrictions include working in the military, commercial truck driving and flying a passenger plane. Some state and local governments may also deny employment in the police or fire fighting forces, but this is changing. Most physicians also recommend that people who have frequent low blood sugars do not work at heights, operate heavy equipment or handle toxic substances. Working rotating shifts can also result in more difficulty with blood sugar control. Generally, if the rotations are on a monthly or greater basis, it is possible to alter the insulin dosage to cope. The use of the insulin pump or Lantus and short-acting insulin can be very effective in providing shift workers the ability to maintain good blood sugar control.

Q **Are psychological problems more or less common in children and adolescents with diabetes compared with people without diabetes?**

A It is a common belief that the presence of any chronic illness increases the likelihood of psychological problems. The presence of pimples or blemishes that make the adolescent feel different from peers can be devastating. We ask youths with diabetes to eat differently than their peers (and not to eat foods generally considered the most tempting), to give two or more insulin shots and do four or more finger pokes for blood sugar every day of their lives. With this, one might expect some psychological problems!

Surprisingly, this is not the case. In the years the Barbara Davis Center has been open, we have had far fewer serious psychological problems (including drug addiction and suicide) than in the general population. Why is this? It is likely related to several factors. One is "preventive counseling" has been available from the day the Center opened. The psychosocial member of the team (usually the clinical social worker) can help to identify problems early and offer intervention or referral for treatment. When families come for their three-month clinic visits, the staff is alert for people who might need some extra help. I often ask teenagers to grade their current stress level from one to 10. An answer of five (or above) usually means the person is asking for help and a visit to the psychologist or clinical social worker might be helpful. I strongly believe the regular clinic visits and the "preventive counseling" have been major reasons for the low incidence of major psychological problems.

Diabetes often results in the entire family focusing on the holistic health of the individual and family, often in ways that might not otherwise have occurred. These often include eating better, getting more exercise and not using tobacco. Factors such as these may also relate to the good mental health of the people seen at our Center.

An added factor in the low incidence of serious problems may be the schedule and seriousness of diabetes care. A number of youths have written in their college applications that having diabetes required them to "grow up" sooner – to learn at an earlier age when they could have fun or when they had to be serious. Good diabetes control and the use of illegal drugs and alcohol do not mix. With the monitoring of diabetes control every three months, any change from good control is quickly detected. Preventive counseling can then be done before the problem becomes too serious.

One parent saw some wonderful, older kids who were in the clinic when her child was diagnosed. Many were in getting check-ups during their winter break from college. She asked how it could be that these kids seemed to be so much more successful than average. She was told, "It's the extra hugs!" All in all, kids with diabetes are special. I have felt very privileged to work with each of them and their families throughout the years.