

YOUR CHILD HAS TYPE 1 DIABETES



THE DIAGNOSIS

Your child has Type 1 diabetes.

After the initial shock of the diagnosis, you may be anxious about two questions, among many:

Will I be able to do what is needed to protect my child's life and health?

Will my child be able to live a full and normal life?

As parents and as members of the Juvenile Diabetes Research Foundation, we too have faced these concerns. We want to assure you that the answer to both questions is a resounding 'Yes!' What may now seem an overwhelming jumble of confusing instructions and difficult techniques will soon become second nature to you. And before too long, your child – depending on age – will learn to take over much of his or her own care.

To help, we've compiled some information and advice. There's much to be learned about diabetes and you will certainly want to educate yourself. After all, the more you understand about diabetes, the better you, your child, and your family will live with it. This brochure is meant to serve as a quick introduction and handy reference source. For now, there are three important things to bear in mind:

- *Diabetes will not prevent your child from living a full and active life.*
- *You are not alone.* JDRF can help you. Whether it's practical information, information about research or – often most important of all – someone to talk with who has been where you are now, JDRF wants to help. Information about the resources offered by JDRF such as how to find your local chapter, volunteer opportunities, and the latest news on research for a cure can be found on the web at www.jdrf.ca.
- *There is hope for the future.* JDRF's mission is to find a cure for diabetes and its complications through the support of research, and we are closer than ever to achieving our goal.

THE BASICS

What is Type 1 diabetes?

Type 1 diabetes is a chronic autoimmune disease that strikes without warning. In Type 1 (insulin-dependent or juvenile) diabetes the body's T-cells attack and destroy the insulin-producing beta cells in the pancreas, stopping the body from producing the insulin needed by body cells to properly use glucose for energy and fuel. Normally, glucose – a form of sugar produced when food is digested – is used to supply the body with energy. Without insulin, glucose builds up in the bloodstream and overflows into the urine. High glucose levels in blood and urine are hallmarks of diabetes.

Until a cure is found, a person with Type 1 diabetes must take insulin injections. The injections are taken four to six times a day. In recent years, many children have begun receiving insulin through insulin pumps, which provide them with greater flexibility in their diet and sleep schedule, and a greater degree of freedom to pursue activities. You, your child, and your diabetes care team will decide if and when 'the pump' is right for helping to manage your child's diabetes.

What is diabetes control?

Diabetes control means keeping the level of blood glucose as close to the normal range (between 4 - 7 mmol/L before eating) as possible. But the target range for your child – determined by your doctor or diabetes educator – may be different for a number of reasons. It will be based on several factors, including the age of your child. The target range is a goal, one that may not always be reached. The goals of control are:

- To achieve the right balance between insulin levels, food intake, and physical activity.
- To avoid blood glucose levels that are too low (hypoglycemia) or too high (hyperglycemia).
- To help your child achieve normal growth and development.

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Diabetes control is a matter of balancing three variables: food intake, physical activity, and insulin. The quick rule is: food makes glucose levels rise; exercise and insulin make glucose levels fall. Self-monitoring of blood glucose is the tool for maintaining the balance.

What happens when the balance is upset?

When glucose levels swing too far in either direction, two emergency situations can develop: hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar).

Hypoglycemia (low blood sugar)

Hypoglycemia (an insulin reaction or insulin shock) can come on rapidly. Low blood sugar may be caused by eating too little food or not eating soon enough after a previous meal, by too much physical activity, or by taking too much insulin. This condition must be treated quickly because hypoglycemia can lead to loss of consciousness.

- Symptoms include headache; sweating; pale, moist skin; cold and clammy; extreme/sudden hunger; weakness/dizziness; shakiness; fatigue/drowsiness; rapid pulse rate; blurred/double vision; shallow breathing; confusion/inattention; loss of coordination. Rapid response to these symptoms can prevent a medical emergency.
- Treatment for low blood sugar involves eating a fast-acting form of sugar such as glucose tablets, non-diet soda, juice, or sugar water. A person taking a diabetes medication that can result in low blood sugar should always carry a source of fast-acting sugar. If necessary, glucose gel, cake icing from a tube, jam, or syrup can be rubbed on the inside of the cheek or on the gums with a finger. To prevent an immediate recurrence, once the reaction subsides, the person should eat some type of complex carbohydrate such as milk, or half of a meat, cheese, or peanut butter sandwich. Keep glucagon – a prescription drug for emergency use to raise the level of sugar in the blood – on hand in case of an emergency. If the person is unconscious or having a seizure, you should inject glucagon and call their doctor. Do not give anything by mouth. If you do not know how to administer glucagon, do not have it available, or there is no response to glucagon, call 911 and get the person to the hospital immediately.

Hyperglycemia (high blood sugar)

Hyperglycemia usually develops gradually, although it can occur more quickly if the child is ill. The symptoms of high blood sugar are similar to those your child had before diabetes was diagnosed: excessive thirst, frequent urination, drowsiness, lethargy, labored breathing. If not recognized and corrected, hyperglycemia can lead to ketoacidosis, a serious emergency.

Ketoacidosis develops when the body, starved for glucose, breaks down stored fats for energy. The products of this process, ketones, are excreted in the urine. You should check urine ketone levels when your child is ill or any time symptoms are present. Home kits are available for testing. A high level of ketones in the urine is a signal to call your doctor.

Can these emergencies be prevented?

You and your child will not be able to prevent all episodes of low or high blood sugar. Many factors, some out of anyone's control, can affect blood sugar levels. However, these emergencies can be minimized through self-monitoring of blood glucose. You and your child, depending on age, will learn how to use a self-monitoring meter to check blood sugar, which will enable you both to track falling or rising blood sugar levels and take corrective action. Self-monitoring meters available today are fast and easy to use.

WHAT KIND OF PROFESSIONAL HELP DO I NEED?

A Team Approach to Care

A team approach to diabetes care is the best plan. The team should include a physician (preferably a pediatric endocrinologist or diabetologist) who has experience in treating children with diabetes, a nurse-educator, a dietitian, and perhaps a social worker.

Diabetes Education

You, your child, other family members, and, if applicable, the child's caregiver should receive education in self-care. Taking daily care of diabetes requires knowledge that many people have learned – from how to draw up and give an insulin injection to self-monitoring of blood glucose to how to handle sick days and emergencies. Diabetes education classes are often taught by a Certified Diabetes Educator (CDE), who may be a nurse, dietitian, physician, pharmacist, or other qualified health professional.

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Because much of Type 1 diabetes is out of a patient's control, the disease creates stress. Some families find support groups useful, still others appreciate just talking one-on-one with other people or parents who are further along in the process of learning to live with the disease. Your local JDRF chapter can provide a list of specialists and diabetes treatment and education programs in your area.

CARING FOR A BABY WITH DIABETES

Babies have special needs, especially babies with diabetes. Your health care team will show you how to take care of your baby's diabetes – when and how to administer insulin, blood and urine tests, feeding your baby, and managing low or high blood sugar emergencies.

Here are some general tips that may be useful:

- Crying may mean nothing important – or it may mean that your baby's blood sugar is falling. Test the baby's blood sugar, and if it's low, give the baby some juice or a sugared snack. If you can't test or the crying continues for no apparent reason, again give the baby some juice or a sugared snack. As a general rule, it's better to err in the direction of too much sugar (hyperglycemia) rather than too little sugar (hypoglycemia).
- Keep the baby's insulin at room temperature to make injections more comfortable; rotate injection sites to avoid lumps or depressions under the skin.
- Be calm, direct, and firm when giving injections. Remember, they are necessary for your baby's life. If you are fearful or shaky, your baby will sense your anxiety and may be upset by it.
- Teach other caregivers how to give an injection. Your baby should not depend on one person exclusively.
- Avoid the risk of an insulin reaction during sleep by giving your baby a snack before a nap and at bedtime.
- Teach the baby-sitter how to recognize and treat an insulin reaction. Provide snacks for the baby-sitter to give the baby and leave detailed instructions, including how to reach the baby's doctor.
- When going out with your baby, be sure to pack diabetes supplies, including extra insulin and snacks to treat insulin reactions.

CARING FOR A CHILD WITH DIABETES

Young children may have difficulty understanding the sudden changes that Type 1 diabetes brings to their lives. Some common reactions among children are:

- A feeling they are being punished for disobedience.
- Feelings of shame or guilt.
- Fear of death because diabetes starts with the sound 'die'.

These reactions may prompt your child to act with hostility toward you, feeling that somehow you have failed him or her. Because children think their parents are all-powerful, your child may believe you can make the diabetes go away. It is important to talk about diabetes with your child and to assure them that it is not something to feel guilty or ashamed about.

Children with diabetes have extra needs, but they need not feel different. The goal is for you to help your child accept the diabetes routine with a minimum of fuss and without being overprotective. Self-care creates self-confidence. You must learn to provide supervision while giving your child the opportunity and responsibility for learning self-care.

- Don't make mealtimes a battleground. Children's appetites vary. Your job is to provide a choice of nutritious, well-balanced foods to promote normal growth and development.
- Make sure your child has an extra snack before engaging in strenuous activity. Exercise burns glucose, lowering blood sugar levels.
- Straying from one's meal plan once in a while is not life threatening. One candy bar occasionally will not harm your child.
- Don't expect perfect control or automatically blame the child for exceptional swings in blood sugar levels. A child can be very responsible about diet and insulin and still experience blood sugar levels outside the usual range.

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- JDRF's Position Statement Regarding Diabetes Management in Schools states it is essential that children with Type 1 diabetes be able to monitor their blood glucose levels, eat food, and administer insulin when necessary, in order to manage their diabetes to the maximum extent possible. Failure to do so could lead to life-threatening insulin shock and coma and long-term complications such as kidney failure, blindness, amputation, heart disease, and stroke exacerbated by high blood glucose levels.

In the fall before the school year starts or if your child is newly diagnosed, you should schedule a meeting with school officials to develop an accommodation plan to address your child's special needs.

DIABETES AND ADOLESCENTS

Adolescence can be a difficult period of life, even without the added stress of diabetes. Teenagers may have mood swings, become grumpy or distant, or suddenly become casual about following self-care routines. Also, poor control may not always be their fault: hormonal changes during adolescence can affect blood sugar levels. So remember, poor control is not just in your teenager's head – it's in the body, too.

For a more detailed discussion, see JDRF's "Diabetes and Teens" brochure.

DIABETES AND THE FAMILY

Diabetes isn't solely the child's problem. It affects the whole family, and it is important that all family members be educated about the disease. The way the family accepts and responds to the situation will affect your child's acceptance or denial of diabetes and how he or she copes with its management. Evidence suggests that:

- A child with diabetes will do well physically and emotionally and at an appropriate age, take responsibility for self-care in a relaxed, knowledgeable, and supportive environment.
- An overly strict and punishing attitude will often result in an angry and rebellious child who deliberately neglects self-care.
- An overly protective attitude may produce a fearful, overly dependent child.

Please contact your local JDRF chapter if you want to talk to others who are dealing with the same problems you and your family are facing.

The information in this brochure is not intended to take the place of medical advice. For guidance on topics discussed, consult your health care professional.

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Visit us on the Web at www.jdrf.ca.