WHEN A CHILD HAS DIABETES

5th Edition

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The Hospital for Sick Children

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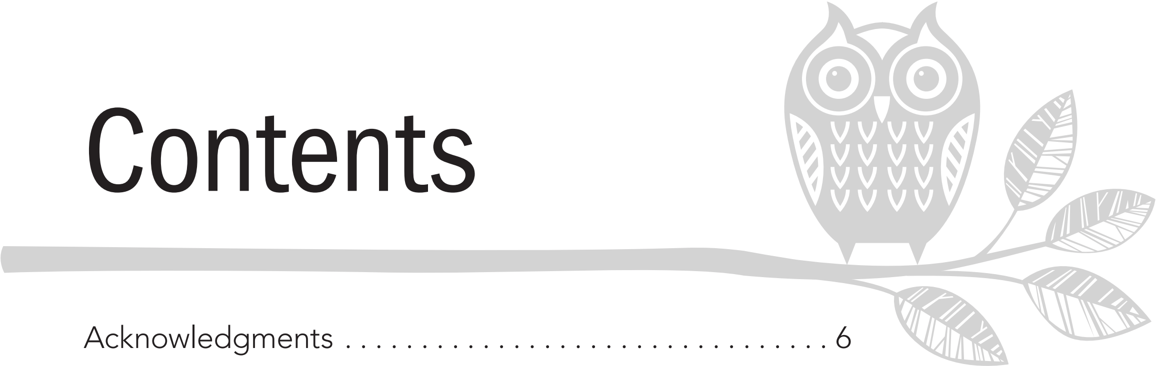


Introduction

Terminology

When referring to someone who has developed diabetes, health care professionals most frequently use phrases like “children and teens living with diabetes” or “children and teens with diabetes.” We prefer not to use the term *diabetic*, which is somewhat stigmatizing and fails to recognize aspects of the individual other than the diabetes.

Diabetes at any age can be a real challenge. However, learning about this condition, and how to manage or control it, is essential so that children and teens can get on with their lives with as little risk and as much vigor as possible.

This book is a practical guide for families of young people with diabetes and everyone who cares about them: friends and relatives, health care professionals, teachers, coaches, school bus drivers and camp counselors. In the majority of this book, the focus is on the child or teen with type 1 diabetes. Type 2 diabetes is the focus of chapter 6. Throughout, we will address these and many other questions:

- What is diabetes?
- What is the cause of diabetes?
- What is involved in “managing” or “controlling” diabetes?
- How do growth and development affect diabetes and, conversely, how does diabetes impact growth and development?

The information and insights presented here will interest both those who are new to diabetes in young people and those who are experienced with it. Each phase of adapting to the condition and each stage of child and family development brings new questions, concerns and expectations related to diabetes management. Families and care providers will find this book an excellent resource, but it has its limitations. It cannot and should not replace the comprehensive education program and support provided to the child or teen and family, at the time of diagnosis and beyond, by a team of experienced health care professionals, known as the diabetes team (see pages 22–23).

There are a few important principles to remember as you read this book. First, different diabetes health care teams have different approaches to some or all of the aspects of diabetes care we deal with here. If you are confused by something we have written, or it conflicts with the approach of your health care providers, discuss it with them. Most often you will find that what we have provided is a variation, rather than a radically different approach.

Second, this book was written in 1998, revised in 2002 and again in 2009, and rewritten now in 2018 — things change! We expect that biomedical research will continue to advance our understanding of many aspects of diabetes care in the foreseeable future. So expect an evolution in our thinking in years to come. Perhaps the biggest change since the last edition is in the book’s format. In order to make the information more easily accessible to the reader, we have created various boxes that provide, in each chapter, key messages, “recipes” for performing routines or approaching different situations, and examples of our experiences, which we believe will support the day-to-day management of children with diabetes.

Third, not everything works for everybody. If something doesn’t seem applicable to you or your child, discuss it with your team. Once you have a good understanding of the condition, work with your team to do some further experimentation. Try things out and see how successful they are. If they work well, tell us about them — we’re always ready to learn.

Finally, at times having a child or teen living with diabetes seems overwhelming. The message we wish to send is far more optimistic and hopeful than that. Present-day therapy has gone a long way to improving outcomes for these individuals and their families. Furthermore, advances in research are being rapidly applied to further improve the quality of life of those with diabetes. We look forward to the day when a book like this may be unnecessary.

Did You Know?

Repetition for Reinforcement

You will notice a fair amount of repetition in this book. There are two main reasons for this: first, the key concepts warrant reinforcement, and, second, the basics of diabetes care (monitoring, preparedness, observation) are needed in all situations.

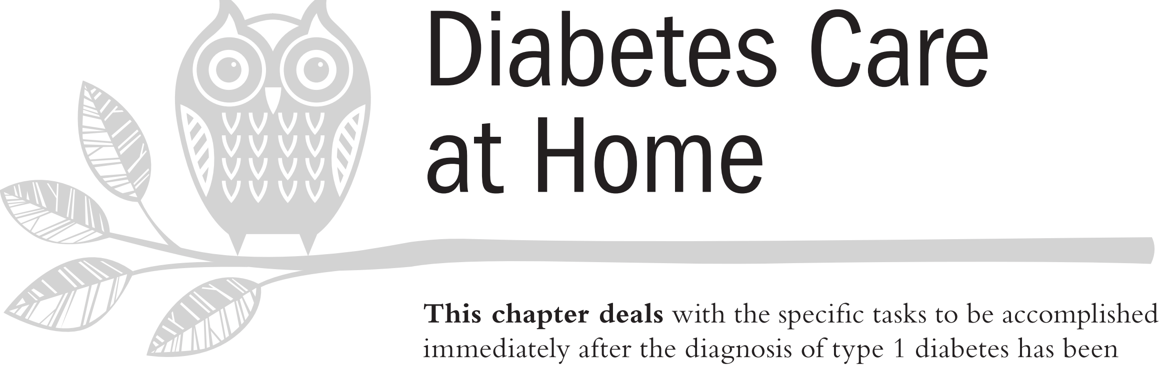
Diabetes Self-Management Education

Both the American Diabetes Association and Diabetes Canada recommend that children and teens with type 1 diabetes and their parents/caregivers (for those below 18 years of age) receive *culturally sensitive* and *developmentally appropriate* individualized diabetes self-management education and support according to national standards at diagnosis and routinely thereafter.

- **Cultural sensitivity** is being aware that cultural differences and similarities between people exist without assigning them a value — positive or negative, better or worse, right or wrong.
- **Developmentally appropriate** means you use knowledge about child development to create a program that is suitable for the age and stage of development of your group of children. At the same time, your program considers the needs of the individual child.

Chapter 2

Supporting Diabetes Care at Home



This chapter deals with the specific tasks to be accomplished immediately after the diagnosis of type 1 diabetes has been made. Independent of whether your child or teen is admitted to the hospital at the time of diagnosis, your family will need to know how to give insulin injections and monitor blood glucose and urine/blood ketones. These are the first steps in learning about and directly managing diabetes. The details of recognizing and responding to patterns of blood glucose will be dealt with in chapter 3.

Key Messages

To ensure that your child or teen with new-onset type 1 diabetes is safe at home, your family will need to immediately acquire what are called survival skills, specifically the ability to:

- Monitor blood glucose
- Administer insulin injections
- Check urine or blood ketones
- Recognize and treat low blood glucose reactions (hypoglycemia)

> Parents quickly learn what they need to do to keep their child healthy and are able to follow through in performing blood glucose checks and administering insulin.

Needing to learn and then follow through with these diabetes management skills at home can at first be very difficult and upsetting for parents, especially those of younger children, who often do not understand why these tasks are being done. However, in our experience, parents quickly learn what they need to do to keep their child healthy and are able to follow through in performing blood glucose checks and administering insulin. As well, children themselves are quite resilient and trust that their parents are not doing harm to them. Often just being in the home environment itself and carrying out these skills helps children be more cooperative, likely because they are in a familiar setting and have other normal routines occupying a larger part of their day.

In the early days following diagnosis, you will set up a structured schedule with your nurse and dietitian around the timing of meals and snacks throughout the day. Since food impacts the blood glucose levels, eating at consistent times is important to achieve accurate results and overall blood glucose balance. If your child already has a consistent routine, which is often the case with those in school, then hopefully there will be minimal changes to when meal and snack times are, and the diabetes care routines can fit into an existing schedule. (See chapters 7 and 10 for more information about the dietary management of type 1 diabetes.)

Did You Know?

Getting Support

All families will need the support and assistance of members of their diabetes team to help in early insulin dose adjustments, interpret blood glucose results and deal with any questions or problems that might arise. This means having the contact information for their key diabetes health care professional, as well as a hotline number to call in case of an emergency.

Blood Glucose Monitoring

Blood glucose monitoring is of critical importance in guiding treatment and in assessing the effectiveness of the treatment plan (regimen). Starting at diagnosis, blood glucose results provide the crucial information to guide insulin dose adjustments promptly and safely. Beyond the initial stabilization phase, blood glucose monitoring is essential to targeting and maintaining good glucose control and responding to unusual situations, including changing exercise patterns, food intake or an intercurrent illness.

When to Monitor

Blood glucose levels should be checked *at least* four times a day:

1. Before breakfast
2. Before lunch
3. Before dinner
4. Before bedtime

Blood glucose checks 90 to 120 minutes after a meal may be recommended to provide information about how well the insulin is matching the mealtime carbohydrate content and whether the pre-meal dose of fast-acting insulin is working well enough.

Pro Tip

There is good evidence that the more tests that are performed, the better the blood glucose achieved.

Your family will need to work out, with the help of your diabetes team, how best to do blood glucose checks (and possibly insulin injections) at lunchtime during school. The involvement of school personnel in this, most especially in supporting younger children, will vary from family to family and may also involve visiting nursing services.

How to Monitor

Regardless of what monitor your child has, the best one is one that is used often, with results frequently looked at to make treatment decisions.

Since about 1980 it has been possible for people with diabetes to check their blood glucose levels themselves with a blood glucose meter. These meters require that a drop of blood from a finger prick be applied to a strip in a glucose meter. The accuracy of these meters/strips has dramatically improved over time.

There are many good monitors available, and over time you may switch to a different meter that has features that suit your child or teen best. Regardless of what monitor your child has, the best one is one that is used often, with results frequently looked at to make treatment decisions. (See chapter 3 for more information about blood glucose measurement devices, including continuous blood glucose sensors, and tracking blood glucose to make dose changes.)

HOW TO: Do a Blood Glucose Check

To test the blood glucose level, you will need a blood glucose meter and a testing kit that includes a lancing device (also called a finger poker), lancets and test strips.

1. Wash and dry your hands.
2. Insert a test strip into the blood glucose meter.
3. Prepare the lancing device by removing the cap and inserting a lancet. Twist off and remove the lancet cover, then replace the cap of the lancing device.
4. Pick a finger and push the button on the lancing device to give the finger a poke.
5. Gently squeeze the finger to get a drop of blood and apply blood to the test strip.
6. Record the blood glucose level reported by the meter in a logbook.
7. Change the lancet once a day, disposing of the lancet in a sharps container.

Checking for Ketones

When our body cannot use glucose for energy because of a lack of insulin, it turns to our fat and protein stores. As our bodies break down fats, they produce a toxic by-product called ketones, which can make children and teens with diabetes very unwell. Ketones are a type of acetone that can be checked for in urine or blood.

Pro Tip

At the time of diagnosis, or when your child is unwell with an intercurrent illness, urine or blood ketones should be checked until they are negative. This provides a measure of safety.

Testing for Ketones in the Urine

1. Take one test strip out of the Ketostix container and recap the container carefully.
2. Briefly dip the test strip in the urine, or wet the test strip in the urine stream.
3. After 15 seconds, compare the color on the test strip to those on the container label. Do not read beyond the 15 seconds.
4. Record the result of ketones and the time of testing.

Checking Blood Ketones

Blood ketone checks may be particularly useful for young children who are unable to provide a urine specimen on demand. A special meter capable of measuring blood ketones is required for this purpose. As well, different strips for testing ketones will be necessary, and often a larger sample of blood will be needed than is the case with blood glucose checks. Steps to check blood ketones are exactly the same as those used for a blood glucose check.

Pro Tip

Ketone test strips expire six months after the container is opened.

Understanding What Blood Ketone Results Mean

Ketone	Blood Ketone Result
Negative	<0.6 mmol/L
Small	0.6–1.5 mmol/L
Moderate	1.5–3.0 mmol/L
Large–Very Large	>3.0 mmol/L

Preparing and Administering Insulin Injections

Often, for parents of children who have been newly diagnosed, injecting their child with insulin is the biggest hurdle to overcome. Many are squeamish about needles, never mind giving one to their own child. Teenagers, and indeed some younger children, quickly become quite skilled at administering their own insulin. Initially, however, all caregivers need to become good at this too. Other people closely involved in your child's life, such as grandparents, family friends and babysitters, should also be able to give an injection in case of illness or emergency.

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Children who are preparing and injecting their own insulin must be supervised very closely at first to ensure:

- The *right type and amount* of insulin is being given *at the right time*.
- The full dosage of insulin is being properly administered.
- All appropriate injection sites are being used.

Using Insulin Pen Devices

Although syringes are still used by some people with diabetes to administer insulin, the majority are using insulin pen devices, which are a much more convenient and easier way to learn how to give insulin. Rather than withdrawing insulin from a bottle, you use a cartridge of insulin that fits into a pen-like device that has a special needle tip that screws onto the end of the pen. By turning the dial on the side of the pen, you can set the dose. When you push down on the end of the pen (like a plunger), the insulin is delivered. Each 3-mL cartridge holds 300 units of insulin. Some insulin pens are able to measure doses in half-unit increments, a feature that is important for young children requiring smaller doses. Needles of a shorter length can also be used with insulin pen devices, which often makes them less intimidating to children and teens.

For instructions on preparing the pen device to administer an insulin dose and on giving an insulin injection using a pen device, see Further Resources, "Using an Insulin Pen." But remember, these are skills that you should first perform with a member of your child's diabetes team.

Pro Tip

Many insulin pen devices are reusable, but there are also disposable pens available that come with the insulin cartridge already loaded in the pen device.

Diabetes Identification

All children and teens with diabetes should have readily accessible identification at all times in case of an urgent need for assistance from someone unaware of their medical history. The most frequently used identification is a medical-alert bracelet or necklace that states the presence of type 1 diabetes and includes the name and number of someone to contact for further medical or personal information.

The U.S. MedicAlert Foundation can be accessed at www.medicalert.org; the Canadian MedicAlert Foundation can be accessed at www.medicalert.ca.

Both foundations offer programs to support the costs of these products, which include enrollment and monthly fee, plus the initial costs of the products.

Rotating Injection Sites

There are four main places (sites) where insulin can be given: the arms, the buttocks, the abdomen or the thighs. In the beginning, you should try using a different injection area each time. This will help your child become comfortable with different sites. Ensure that each injection is about 1 inch (2.5 cm) or two finger widths from the previous one.

In the beginning, try using a different injection area each time.

Many people with diabetes — and especially children — develop "favorite" injection sites, where the pain seems to be less and injections seem easier. If the same small area is used repeatedly, the fat tissue below the skin swells (**lipohypertrophy**). This creates large bumps that may lead to poor insulin absorption, which can lead to poor diabetes control. They may go away in time when the injection site is left alone. Until the bumps have disappeared, inject into another area to promote better insulin absorption.

At each clinic visit, a member of the diabetes team will examine the injection sites to help with site selection and the prevention of lumps and bumps.

Did You Know?

Acting on Hypoglycemia

Hypoglycemia is rare in the immediate period after diagnosis, but action should be taken if signs of low blood glucose are present: check the glucose level and eat or drink about half an ounce (15 grams) of carbohydrate (for example, half a cup of fruit juice or two to three glucose tablets) and recheck the glucose in 15 minutes to be sure it is no longer low.

Recognizing and Treating Hypoglycemia

For someone with type 1 diabetes, once the dose of insulin has been given into the fat tissue, the body cannot "turn off" how the insulin works, unlike individuals who don't have diabetes and are able to switch on and switch off insulin production as needed. As a result, if there isn't enough food intake to balance the insulin dose, or if there is an added demand for glucose during, say, intense exercise, the blood glucose may decrease below 72 mg/dL (4 mmol/L), causing low blood glucose symptoms, called hypoglycemia.

Updated edition from the highly respected Diabetes Team at the world-renowned Hospital for Sick Children

- Offers the latest medical expertise on juvenile diabetes and information on underlying causes, clinical features and effective treatments.
- Previous editions are among the most highly respected resources on the subject, making this new edition a must-have for anyone caring for a child diagnosed with diabetes.
- Includes new content based on cutting-edge research and current standards for diagnosis and treatment.
- This comprehensive and supportive guide will help parents, caregivers and children understand diabetes and live happy, healthy lives.
- The approach of the book is friendly and accessible, with sections that include relatable case studies, easy-to-understand charts and answers to frequently asked questions.

An essential guide for the parents and caregivers of the over 15,000 children diagnosed with diabetes every year.

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