Chapter 1

Dealing with Type 1 Diabetes

In This Chapter

- Discovering what type 1 diabetes is
- Dealing with physical and emotional effects
- Treating type 1 diabetes
- Living life to the fullest with type 1 diabetes

In 2005, the most recent year for which there are statistics, there were 340,000 people in the United States with type 1 diabetes (T1DM) according to the Centers for Disease Control. About half were children up to age 20. There are 30,000 new cases every year, almost all in children.

Whether you're an older child or young adult able to take care of your own diabetes, or a parent or other caregiver for a young child with this disease, you should be aware that there's a great deal that you can do to minimize both the short- and long-term complications that may develop and live a long and healthy life with T1DM.

What! You don't believe me! Consider the story of two brothers, Robert and Gerald. Robert is 85 years old and developed T1DM at age 5. Gerald is 90 and developed T1DM at age 16. The physician who follows them, Dr. George L. King, research director of the Joslin Diabetes Center in Boston, studies patients with T1DM who have lived more than 50 years with the disease. He has more than 400 such patients.

Dr. King says that these patients have a lot in common. They

- Keep extensive records of their blood sugars, their diet, their exercise, their insulin dosage, and their daily food consumption
- Do a lot of exercise
- Eat very carefully
- Have a very positive outlook

These actions form the basis of effective T1DM treatment, which I introduce in this chapter. I also give you an overview of the potential consequences of T1DM and tips for living well with it.

At the present time, there's no way to prevent T1DM, but I believe a change isn't far off and T1DM may be preventable in perhaps in the next five years. The breakthrough will come with the use of stem cells, transplantation, or the elimination of the cause of T1DM. You can read much more about this subject in Chapters 13 and 21.

Understanding What Type 1 Diabetes Is (and Isn't)

T1DM, simply stated, is an autoimmune disease. Immunity is what protects you from foreign invaders like bacteria and viruses. In autoimmunity, your body mistakenly acts against your own tissues. In T1DM, the immune cells and proteins react against the cells that make insulin, destroying them. (Insulin is the chemical or hormone that controls the blood glucose; glucose is sugar that provides instant energy.)

Although it often begins dramatically, T1DM doesn't occur overnight. Many patients give a history of several months of increasing thirst and urination, among other symptoms. Also, T1DM usually begins in childhood, but some folks don't develop it until they're adults. In either case, to verify a diagnosis of T1DM, a sample of blood is taken and its glucose level is measured. If the patient is fasting, the level should be no more than 125 mg/dl; if there's no fast, the level should be no more than 199 mg/dl. For further confirmation, tests should be done at two different times to check for inconsistencies. However, a person with a blood glucose of 300 to 500 mg/dl who has an acetone smell on his breath clearly has T1DM until proven otherwise.

So how is type 1 diabetes different from type 2 diabetes (T2DM)? The central problem in T2DM isn't a lack of insulin but insulin resistance; in other words, the body resists the normal, healthy functioning of insulin. Before the development of T2DM, when a person's blood glucose is still normal, the level of insulin is abnormally high because the person is resistant to the insulin and therefore more is needed to keep the glucose normal.

To complicate matters, a type of diabetes called *Latent Autoimmune Diabetes in Adults* (LADA) is a cross between T1DM and T2DM; a person with LADA exhibits traits of both diseases.

Chapter 2 details the basics of T1DM, including how insulin works, what goes wrong when blood glucose levels are too high, the specific symptoms to watch for, and gathering a team of doctors and other specialists after a diagnosis. Chapter 3 fully explains how T2DM and LADA are different from T1DM.

Handling the Physical and Emotional Consequences of Type 1 Diabetes

What makes diabetes a difficult disease are the physical complications associated with poor control of the blood glucose. These complications are generally divided into short-term complications and long-term complications.

- **Short-term complications,** which I cover in Chapter 4, are the result of a blood glucose that's either very low or very high. Low blood glucose (called *hypoglycemia*) can occur in minutes as a result of too much insulin, too much exercise, or too little food, but high blood glucose often takes several hours to develop. Whereas low blood glucose often can be managed at home, severe high blood glucose (called *diabetic ketoacidosis*) is an emergency that's managed by a doctor in the hospital. Nevertheless, it's important that you understand how it develops in order to prevent it. Chapter 4 describes the signs and symptoms associated with both of these complications and the best ways of handling them.
- **Long-term complications,** which I cover in Chapter 5, can be devastating. It's much better to prevent them with very careful diabetes management than to try to treat them after they develop. Fortunately, they take 15 or more years to fully develop, and there's time to slow them down if not reverse them if you're aware of them. All long-term complications can be detected in the very earliest stages.

  The long-term complications consist of eye disease known as *retinopathy,* kidney disease known as *nephropathy,* and nerve disease known as *neuropathy.* Diabetes is the leading cause of new cases of blindness; new cases of kidney failure requiring dialysis, which cleanses the blood of toxins when the kidneys can no longer do their job; and loss of sensation in the feet as well as other consequences of nerve damage.

Not only does T1DM have short- and long-term physical consequences, but as an autoimmune disease, T1DM also is associated with other autoimmune diseases such as *celiac disease,* an inflammation of the gastrointestinal tract; thyroid disease; and skin diseases. Chapter 5 explains the importance of checking for those diseases and correcting them, if present.

As you may expect, people with T1DM also have significant psychological and emotional needs. It's important, first of all, to realize that T1DM has been present in some very high achievers. (I name names in Chapter 6.) In addition, T1DM is not only a disease of the particular patient but also a disease of the entire family. All family members are affected in one way or another. In Chapter 6, you find out ways that family members can help themselves and help the patient to maintain his self-esteem and a high quality of life.

If you're the patient with T1DM, the people around you need to know that you have diabetes and how to help you when you can't help yourself. Often people with T1DM try to keep their disease secret, as though it's a blot on their character. T1DM isn't your fault. There will be times when you may need the help of others, and it will be a whole lot easier for them to help you if they know about your condition and what to do in different circumstances. (All this is also true for your child with T1DM.)

Treating Type 1 Diabetes Effectively

Part III may be the most important part of this book. Your willingness to do all the things I recommend in that part (which I preview in the following sections) means the difference between living a long and healthy life or dying at a much younger age (whether for your child or yourself if you're the patient).

Undergoing regular testing

There are a number of tests that your child's doctor should be doing on a regular basis. Chapter 7 outlines all these tests, explains what they mean, and discusses how often they should be done. These tests include the following:

- Blood pressure check
- Height and weight check
- Foot exam
- Hemoglobin A1c
- Microalbuminuria
- Eye exam
- Lipid panel
- Thyroid function check
- Ankle-brachial index study

Don't leave it up to your child's doctor to order these tests. On the Cheat Sheet at the front of this book, I provide a chart that lists the tests that need to be done and the frequency for each test; it also has spaces for you to enter the test results. Make copies of the blank chart, fill out a copy, and take it to your child's doctor at every visit to remind him or her to do these tests.

Regular testing outside the doctor's office is crucial, too. Daily self-monitoring of blood glucose may be the most important thing that you and your child can do to control his blood glucose. The available meters are simple to use, highly accurate, and require tiny amounts of blood. The more you know about your child's blood glucose under all circumstances, the easier it is to keep it in the normal range — not too low and not too high. Flip to Chapter 7 for full details on monitoring blood glucose.

Eating wisely

If you're a parent of a child with T1DM, you need to make sure that your child gets the right nutrients for proper growth and that he balances the food intake with insulin at all times. If you're meticulous about the food your child eats, you'll find that controlling his blood glucose is much easier. I have numerous patients whose blood glucose levels improved dramatically after I sent them to a dietitian.

Chapter 8 discusses how to count carbohydrates so that your child takes the right amount of insulin for the food that he eats. I explain how to include the right mix of protein, fat, vitamins, minerals, and water along with carbohydrates; the diet challenges you face when you feed a child of any age; and how to take other food factors into account, such as sugar substitutes and fast food. I also offer advice on coping with eating disorders.

Exercising for more control

Exercise helps to reduce the amount of insulin that your child requires and makes it easier to control his blood glucose. Any exercise is better than no exercise, but 30 minutes a day should be your minimum goal for your child. In Chapter 9, I explain how to take care before your child starts an exercise plan by talking to the doctor and adjusting insulin intake, among other tasks. I show you how to encourage your child to exercise at any age and help him pick an activity (even a competitive sport!). I also give you my picks for the best exercises around: walking and training with weights.

Taking insulin

Chapters 10 and 11 tell you all you need to know about insulin (including types and dosages), and all the old and new ways to administer it.

- The types of insulin are long-acting, rapid-acting, and some in-between insulins. The insulins that most closely mimic the action of human insulin in the body are clearly the best. Insulin can be taken by shots, using jet injections, and by inhaling it into your lungs. I give you the pros and cons of each method in Chapter 10 and let you choose for yourself.
- Delivering insulin with a pump deserves to have Chapter 11 all to itself because it's quite different from the methods in Chapter 10. Many patients use pumps to administer their insulin. The clever manufacturers have tried to arrange the pump so that it delivers insulin just like your own pancreas. Unfortunately, the pump currently can't detect the level of glucose in your blood and provide insulin accordingly just like your own pancreas, but modern insulin pumps aren't far from that ideal.

Using other medications and treatments

At one time, insulin was the only drug given to the patient with T1DM. Today, there are some new drugs that can assist insulin in controlling the blood glucose. Chapter 12 looks into these drugs and some promising treatments for people with T1DM, such as acupuncture and biofeedback.

At the other end of the spectrum are drugs that make it even more difficult to control your blood glucose (or your child's). Alcohol and nicotine in cigarettes top the list, but there are a number of illegal drugs that also complicate diabetes management. Avoid these drugs at all costs. In Chapter 12, I explain how they make glucose control so difficult.

Deciding to transplant

Chapter 13 could be called "the chapter of hope." It discusses potential cures for T1DM. I tell you about transplanting a kidney, the entire pancreas, or both at the same time (now that's a neat trick!). I also discuss transplanting only the beta cells that make insulin. I describe the preparation and process for each type of surgery and explain the continuing issues that you have to deal with afterward.

Living Well with Type 1 Diabetes

Unfortunately, type 1 diabetes is a lifelong chronic disease. As you find out in the following sections, it requires your child to make adjustments in his life that many people who don't have diabetes take for granted. But making these adjustments is a small price to pay for being able to live life to the fullest!

Handling school, work, and other daily activities

A number of laws mandate the accommodations that schools must provide for your child with diabetes. Chapter 14 tells you how to get the school authorities on your side with the use of Section 504 Plans and individualized education programs. I also discuss how to handle T1DM in college.

Done with college? If you have T1DM, there are certain jobs that aren't open to you. For example, you can't serve in the military, and you can't fly commercial airliners. There was a time when you couldn't fly a private plane either, but fortunately that time is past. Chapter 14 discusses the jobs you can't have when you have T1DM, what to do if you suspect discrimination at work because of your T1DM, and the ways that employers can integrate their employees with T1DM into the workplace. I also talk about some other issues for adults, including driving with diabetes and obtaining insurance.

Adjusting to sick days and travel

If your child has another illness in addition to T1DM, there are special adjustments that you have to make. He may not feel like eating, and you may think that he needs less insulin as a result. The truth is usually the opposite. Your child's body responds to an acute illness by pouring out hormones that promote the production of more glucose, so his blood glucose rises. He may actually need more insulin during an illness when he can't eat than he'd need when he's healthy. Chapter 15 provides the information you need to manage your child's illness when he also has T1DM.

Another special circumstance that affects diabetes care is travel. When traveling, you and your child may go through different time zones. This complicates taking insulin because each type of insulin has a certain duration of action, and you may lose or gain hours as you travel. In Chapter 15, I share suggestions for handling your child's insulin smoothly and traveling with his supplies safely.

Getting through pregnancy and menopause

Women with T1DM have special needs. Starting with oral contraceptives, Chapter 16 takes you through preparing for pregnancy, getting through the pregnancy, and considering hormone replacement therapy during menopause. The surge of estrogens and progesterones that occurs every month in a menstruating female makes it even harder to control the blood glucose, so you find out the best ways to handle this tricky situation.

As a woman with T1DM, you shouldn't even consider pregnancy without reading Chapter 16. The likelihood that you'll produce a baby with malformations will be much lower if you understand the information that I present here and take care of yourself accordingly. Keeping your diabetes under excellent control throughout the pregnancy ensures a much easier delivery and a healthy child. I can't overstate the importance of diet and exercise throughout the pregnancy. Every mother-to-be wants an easy delivery and a healthy baby; if you keep your blood glucose under control throughout the pregnancy, the healthy baby is guaranteed.

Aging with type 1 diabetes

The elderly person with T1DM deserves special consideration. He may not exhibit the same signs and symptoms as younger people. He usually has other illnesses and afflictions that complicate his diabetes care, including loss of hearing, diminished vision, and maybe even loss of mental function. All these circumstances may make insulin administration very difficult. The dosage of drugs given to the elderly is usually significantly lower than the dosage for the non-elderly. What's a caretaker to do? Chapter 17 has the information that can make caring for the elderly person a lot easier.