Chapter 1 Dealing with Diabetes

In This Chapter

- Meeting others with diabetes
- Coping with the initial diagnosis
- ▶ Upholding your quality of life
- Finding help

As a person with diabetes, you are more than the sum of your blood glucose levels. You have feelings, and you have a history. The way that you respond to the challenges of diabetes determines whether the disease will be a moderate annoyance or the source of major sickness.

One of my patients told me about working at her first job out of college, where each employee birthday was celebrated with cake. She came to the first celebration and was urged to eat a slice. She refused and refused, until finally she had to say, "I can't eat the cake because I am diabetic." The woman urging her said, "Thank God. I thought you just had incredible willpower." Twenty years later, my patient clearly remembers being told that having diabetes is better than having willpower.

Another patient told me this: "The hardest thing about having diabetes is having to deal with doctors who do not respect me." Several times over the years, she had followed her doctor's recommendations exactly, but her glucose control had not been satisfactory. The doctor blamed her for this "failure."

And unless you live alone on a desert island (in which case I'm impressed that you got your hands on this book), your diabetes doesn't affect just you. Your family, friends, and coworkers are affected by how you deal with your diabetes and by their desire to help you. This chapter shows you some coping skills to help you deal with diabetes and its impact on your important relationships.

You Are Not Alone

Are you as pretty as Nicole Johnson, the 1999 Miss America? Are you as funny as Jackie Gleason or Jack Benny? Are you an actor with the talent of James Cagney, Spencer Tracy, or Elizabeth Taylor? Can you hit a tennis ball like Arthur Ashe? Can you paint like Paul Cézanne? Do you have the charisma of Gamel Abdel-Nasser? Can you write like Ernest Hemingway or H. G. Wells? Can you sing like Ella Fitzgerald or Elvis Presley? Do you have the inventive powers of Thomas Alva Edison? You have at least one thing in common with all of these famous people. That's right — diabetes.

Keeping good company

Diabetes is a common disease, so it's bound to occur in some very uncommon people. The list of people with diabetes is long, and you may be amazed at the caliber of the company you keep. The point is that every one of these people lives or lived with this chronic illness, and every one of them was able to do something special with his or her life.

Many politicians have diabetes — perhaps the result of eating too many fundraising dinners full of alcohol, starchy foods, and calorie-rich desserts. (See Chapter 4 for the role diet plays in the onset of diabetes.) Among the Russian premiers who have had diabetes are Yuri Andropov, Nikita Krushchev, and Mikhail Gorbechev. Israeli Prime Minister Menachem Begin had diabetes. Balancing him on the Arab side is King Fahd of Saudi Arabia. Winnie Mandela of South Africa has it. President Clinton's mother, Virginia Kelley, a politician by association, had diabetes. Rounding out the list are Clinton Anderson, a U.S. Senator from New Mexico, Fiorello LaGuardia, a New York mayor, and Josip Tito, former ruler of Yugoslavia.

Among actors and comedians with diabetes, Jackie Gleason is memorable for his motto, "How sweet it is!" (Could he have been referring to his diabetes or his blood glucose?) Among the other great talents with diabetes are Halle Berry; Mary Tyler Moore; Kate Smith, who sang "God Bless America"; and Mae West, who told men to "Come up and see me sometime."

Walt Kelly, who drew the *Pogo* comic strip, joins Paul Cézanne in the category of artists with diabetes. Mario Puzo, author of *The Godfather*, joins Ernest Hemingway and H. G. Wells among the great writers. In the business world, Ray Kroc founded the McDonald's chain while dealing with diabetes.

The list of singers and musicians with diabetes contains some of the greatest voices you will ever hear. Besides Ella and Elvis, the list includes Jerry Garcia of the Grateful Dead, Johnny Cash, Carol Channing of *Hello, Dolly!* fame, jazz

musician Dizzy Gillespie, and gospel singer Mahalia Jackson. The great composer of operas, Giacomo Puccini, also had diabetes.

Diabetes doesn't prevent the achievement of great records in sports. It didn't stop Arthur Ashe from winning the U.S. Open Tennis Tournament more than once. Jackie Robinson lived with type 1 diabetes all of his life — and, unfortunately, at a time when doctors didn't possess the tools that we have today to control diabetes. Catfish Hunter could strike out many a batter, even when his glucose was a little off. The great Ty Cobb got plenty of hits despite his diabetic condition. Billie Jean King put women's tennis on the map when she beat Bobby Riggs; diabetes certainly didn't slow her serve. (To read about the role of sports and exercise in your life, see Chapter 9.)

Realizing your potential



The names in the preceding paragraphs are just a few examples of people with diabetes who have achieved greatness. My point is this: *Diabetes shouldn't stop you from doing what you want to do with your life.* You must follow the rules of good diabetic care, as I describe in Chapters 7 through 12. But if you follow these rules, you will actually be healthier than people without diabetes who smoke, overeat, and/or don't exercise enough. If you follow the rules of good diabetes care, you will be just as healthy as the person without diabetes.

Perhaps the many people with diabetes who have achieved greatness used the same personal strengths to overcome the difficulties associated with diabetes and to excel at their particular callings. Or maybe their diabetes forced them to be stronger and to persevere more, which contributed to their success. Chapter 15 shows you a few areas (such as piloting a commercial flight) in which certain people with diabetes can't participate — due to the ignorance of some legislators. These last few blocks to complete freedom of choice for those with diabetes will come down as you show that you can safely and competently do anything that a person without diabetes can do.

Reacting to Your Diagnosis

Do you remember what you were doing when you found out that you had diabetes? Unless you were too young to understand, the news was quite a shock. Suddenly you had a condition from which people die. Many of the feelings that you went through were exactly those of a person learning that he or she is dying. The following sections describe the normal stages of reacting to a diagnosis of a major medical condition such as diabetes.

Experiencing denial

Your first response was probably to deny that you had diabetes, despite all the evidence. Your doctor may have helped you to deny by saying that you had just "a touch of diabetes," which is an impossibility equivalent to "a touch of pregnancy." You probably looked for any evidence that the whole thing was a mistake.

Ultimately, you had to accept the diagnosis and begin to gather the information you needed to help yourself. But perhaps you neglected to take your medication, follow your diet, or perform the exercise that is so important to maintaining your body.



When you accepted the diabetes diagnosis, I hope you also shared the news with your family, friends, and people close to you. Having diabetes isn't something to be ashamed of, and you shouldn't hide it from anyone. You need the help of everyone in your environment, from your coworkers who need to know not to tempt you with treats that you can't eat, to your friends who need to know how to give you *glucagon*, a treatment for low blood glucose, if you become unconscious from a severe insulin reaction (see Chapter 4).

Your diabetes isn't your fault — nor is it a form of leprosy or some other disease that carries a social stigma. Diabetes also isn't contagious; no one can catch it from you.



When you're accepting and open about having diabetes, you'll find that you're far from alone in your situation. (If you don't believe me, read the section "You Are Not Alone," earlier in this chapter.) One of my patients told me about experiences she had that helped her feel part of a community. She arrived at work one morning and was very worried when she realized that she had forgotten her insulin. But she quickly found a source of comfort when she remembered that she could go to a diabetic coworker and ask to borrow some insulin. Another time, she was at a party and stepped into a friend's bedroom to take a shot of insulin, and she found a man there doing the same thing.

Feeling anger

When you've passed the stage of denying that you have diabetes, you may become angry that you're saddled with this "terrible" diagnosis. But you'll quickly find that diabetes isn't so terrible and that you can't do anything to rid yourself of the disease. Anger only worsens your situation, and it's detrimental in the following ways:

- \checkmark If your anger becomes targeted at a person, he or she is hurt.
- \checkmark You may feel guilty that your anger is harming you and those close to you.
- Anger can prevent you from successfully managing your diabetes.



As long as you're angry, you are not in a problem-solving mode. Diabetes requires your focus and attention. Use your energy positively — to find creative ways to manage your diabetes. (For ways to manage your diabetes, see Part III.)

Bargaining for more time

The stage of anger often transitions into a stage when you become increasingly aware of the loss of immortality and bargain for more time. Even though you probably realize that you have plenty of life ahead of you, you may feel overwhelmed by the talk of complications, blood tests, and pills or insulin. You may experience depression, which makes good diabetic care all the more difficult.

Studies have shown that people with diabetes suffer from depression at a rate that is two to four times higher than the rate for the general population. Those with diabetes also experience anxiety at a rate three to five times higher than people without diabetes.

If you suffer from depression, you may feel that your diabetic situation creates problems for you that justify being depressed. You may rationalize your depression in the following ways:

- ✓ Diabetes hinders you as you try to make friends.
- ✓ As a person with diabetes, you don't have the freedom to choose your leisure activities.
- ✓ You may feel that you're too tired to overcome difficulties.
- ✓ You may dread the future and possible diabetic complications.
- ✓ You don't have the freedom to eat what you want.
- ✓ All the minor inconveniences of dealing with diabetes may produce a constant level of annoyance.



All of the preceding concerns are legitimate, but they also are all surmountable. How do you handle your many concerns and fend off depression? The following are a few important methods:

- ✓ Try to achieve excellent blood glucose control.
- ✓ Begin a regular exercise program.
- ✓ Tell a friend or relative how you are feeling; get it off your chest.
- Recognize that every abnormal blip in your blood glucose is not your fault.

Moving on

If you can't overcome the depression brought on by your diabetic concerns, you may need to consider therapy or antidepressant drugs. But you probably won't reach that point. You may experience the various stages of reacting to your diabetes in a different order than I describe in the previous sections. Some stages may be more prominent, and others may be hardly noticeable.



Don't feel that any anger, denial, or depression is wrong. These are natural coping mechanisms that serve a psychological purpose for a brief time. Allow yourself to have these feelings — and then drop them. Move on and learn to live normally with your diabetes.

Maintaining a High Quality of Life

You may assume that a chronic disease like diabetes leads to a diminished quality of life. But must this be the case? Several studies have been done to evaluate this question.

The importance of taking control

One study, which lasted only 12 weeks, was described in the *Journal of the American Medical Association* in November 1998; it looked at the difference in the perceived quality of life between a group that had good diabetic control and a group that had poor diabetic control. The well-controlled group had lower distress from symptoms, a perception that they were in better health, and a feeling that they could think and learn more easily. This translated into greater productivity, less absenteeism, and fewer days of restricted activity.

Most of the other studies of quality of life for people with diabetes have been long-term studies. In one study of more than 2,000 people with diabetes who were receiving many different levels of intensity of treatment, the overall response was that quality of life was lower for the person with diabetes than for the general population. But several factors separated those with the lower quality of life from those who expressed more contentment with life.



One factor that contributed to a lower quality of life rating was a lack of physical activity. This is one negative factor that you can alter immediately. Physical activity is a habit that you must maintain on a lifelong basis. (See Chapter 9 for advice on exercise.) The problem is that making a long-term change to a more physically active lifestyle is difficult; most people become more active for a while but eventually fall back into inactive routines. Another study demonstrated the tendency for people with diabetes (and for people in general) to abandon exercise programs after a certain length of time. This was reported in the *New England Journal of Medicine* in July 1991. In this study, a group of people with diabetes received professional support for two years to encourage them to increase physical activity. For the first six months, the study participants responded well and exercised regularly, with the result that their blood glucose, their weight, and their overall health improved. After that, participants began to drop out and not come to training sessions. At the end of the two-year study, most participants had regained their weight and slipped back into poor glucose control. It is noteworthy that the few who didn't stop their exercise maintained the benefits and continued to report an improved quality of life.



When you're having trouble coping

You wouldn't hesitate to seek help for your physical ailments associated with diabetes, but you may be reluctant to seek help when you can't adjust psychologically to diabetes. The problem is that sooner or later, your psychological maladjustment will ruin any control that you have over your diabetes. And, of course, you won't lead a very pleasant life if you're in a depressed or anxious state all the time. The following symptoms are indicators that you're past the point of handling your diabetes on your own and may be suffering from depression:

- ✓ You can't sleep.
- You have no energy when you are awake.
- ✓ You can't think clearly.
- You can't find activities that interest or amuse you.
- ✓ You feel worthless.
- You have frequent thoughts of suicide.
- ✓ You have no appetite.
- You find no humor in anything.

If you recognize several of these symptoms as features of your daily life, you need to get some

help. Your sense of hopelessness may include the feeling that no one else can help you — and that simply isn't true. Your primary physician or endocrinologist is the first place to go for advice. He or she may help you to see the need for some short-term or long-term therapy. Well-trained therapists — especially therapists who are trained to take care of people with diabetes can see solutions that you can't see in your current state. You need to find a therapist whom you can trust, so that when you're feeling low you can talk to this person and feel assured that he or she is very interested in your welfare.

Your therapist may decide that you would benefit from medication to treat the anxiety or depression. Currently, many drugs are available that are proven safe and free of side effects. Sometimes a brief period of medication is enough to help you adjust to your diabetes.

You can also find help in a support group. The huge and continually growing number of support groups shows that positive things are happening in these groups. In most support groups, participants share their stories and problems, which helps everyone involved cope with their own feelings of isolation, futility, or depression.

The (minimal) impact of insulin treatments

Perhaps you're afraid that intensified insulin treatment, which involves three or four daily shots of insulin and frequent testing of blood glucose, will keep you from doing the things that you want to do and will diminish your daily quality of life. (See Chapter 10 for more information about intensified insulin treatment.)

A study discussed in *Diabetes Care* in November 1998 explored whether the extra effort and time consumed by such diabetes treatments had an adverse effect on people's quality of life. The study compared people with diabetes to people with other chronic diseases, such as gastrointestinal disease and hepatitis (liver infection), and then compared all of those groups to a group of people who had no disease. The diabetic group reported a higher quality of life than the other chronic illness groups. The people in the diabetic group were not so much concerned with the physical problems of diabetes, such as intense and time-consuming tests and treatments, as they were concerned with the social and psychological difficulties.

Other key quality of life factors

Many other studies have examined the different aspects of diabetes that affect quality of life. The following studies had some useful findings:

- ✓ Family support: People with diabetes greatly benefit from their family's help in dealing with their disease. But do people with diabetes in a close family have better diabetic control? One study in *Diabetes Care* in February 1998 attempted to answer this question and found some unexpected results. Having a supportive family didn't necessarily mean that the person with diabetes would maintain better glucose control. But a supportive family did make the person with diabetes feel more physically capable in general and much more comfortable with his or her place in society.
- ✓ Insulin injections for adults: Do adults with diabetes who require insulin shots experience a diminished quality of life? A report in *Diabetes Care* in June 1998 found that insulin injections don't reduce the quality of life; the person's sense of physical and emotional well-being remains the same after beginning insulin injections as it was before injections were necessary.

✓ Insulin injections for teenagers: Teenagers who require insulin injections don't always accept the treatment as well as adults do, so teenagers more often experience a diminished quality of life. However, a study of more than 2,000 such teenagers in *Diabetes Care* in November 2001 showed that as their diabetic control improved, they experienced greater satisfaction with their lives and felt in better health, while they believed themselves to be less of a burden to their families.



- Stress management: A study described in *Diabetes Care* in January 2002 showed that lowering stress lowers blood glucose. Patients were divided into two groups, one of which received diabetes education alone and the other diabetes education plus five sessions of stress management. The latter group showed significant improvement in diabetic control compared to those who received only diabetes education.
- ✓ Quality of life over the long term: How does a person's perception of quality of life change over time? As they age, do most people with diabetes feel that their quality of life increases, decreases, or persists at a steady level? The consensus of studies is that most people with diabetes experience an increasing quality of life as they get older. People feel better about themselves and their diabetes after dealing with the disease for a decade or more. This is the healing property of time.

The bottom line

Putting all the information in the previous sections together, what can you do to maintain a high quality of life with diabetes? Here are the steps that accomplish the most for you:



- ✓ Keep your blood glucose as normal as possible (see Part III).
- Make exercise a regular part of your lifestyle.
- ✓ Get plenty of support from family, friends, and medical resources.
- ✓ Stay aware of the latest developments in diabetes care.
- Maintain a healthy attitude. Remember that someday you will laugh about things that bug you now, so why wait?

8 Part I: Dealing with the Onset of Diabetes _____