

## Chapter 1

# Membership in a Club You Didn't Ask to Join

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### *In This Chapter*

- ▶ Understanding what diabetes is
  - ▶ Knowing you're not alone
  - ▶ Dealing with the news that you have diabetes
  - ▶ Looking at the impact of diabetes on your relationships
  - ▶ Fitting diabetes management into your busy life
  - ▶ Coping with diabetes
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**A**s a person with diabetes, you already know that diabetes isn't "just a sugar problem." In fact, the moment you were told you had diabetes, many different thoughts may have run through your mind. You have feelings, and you have your own personal story. You're not the same person as your next-door neighbour or your sister or your friend, and your diabetes and the way you respond to its challenges are unique to you.

And unless you live alone on a desert island, your diabetes doesn't affect just you. Your family, friends, and co-workers are influenced by your diabetes and by their desire to help you.

In this chapter we consider how you might feel after you first find out you have diabetes, and we also look at some coping strategies to help you deal with this unwelcome news.

## *Figuring Out What Diabetes Is*

Because we spend so much time discussing diabetes in this book, we want to start by defining the condition. *Diabetes* is a *metabolic disorder* (a problem with the body's internal chemistry) characterized by the presence of high

blood glucose because the pancreas is unable to make enough insulin hormone or because the insulin the pancreas makes is not working properly, or both. (We take a closer look at glucose in Chapter 2.)

That may be the technically correct definition of diabetes, but to leave it at that would be akin to defining Paris as “a city with a metal tower located in France.” France does indeed have a metal tower — and diabetes does indeed have high blood glucose — but to limit your perspective to such simple definitions would be to miss out on so, so much. Diabetes isn’t just a sugar problem; it’s a whole body problem. But fortunately this is a problem with many available ways to tackle it head on.



*Diabetes* is actually the short form for diabetes *mellitus*. The Romans noticed that the urine of certain people was *mellitus*, the Latin word for “sweet.” The Greeks noticed that when people with sweet urine drank, fluids came out in the urine almost as fast as they went in the mouth, like a siphon. They called this by the Greek word for “siphon” — *diabetes*. Hence “diabetes mellitus.” Nonetheless, we think the essence of diabetes is much better captured by the 17th-century definition of diabetes: “the pissing evil.” Talk about calling it the way you see it!

You may have done some searching in books or on the Internet and come across another form of diabetes called *diabetes insipidus*. This term refers to an entirely different condition than diabetes mellitus. The only thing they have in common is a tendency to pass lots of urine. And now that we’ve clarified that, you won’t see diabetes insipidus mentioned again in this book.

## You’re Not Alone

It seems unimaginable, but the number of people worldwide living with diabetes has risen from an estimated 30 million in 1985 to a mind boggling 366 million in 2011 and, by 2030, it is predicted 552 million people will be living with diabetes. In Canada, currently over 2.5 million people are living with diabetes. Clearly, as the title of this section says, you are most definitely not alone.

Hardly a day goes by when a person with diabetes isn’t in the news. Even better, so far as we’re concerned, is that their diabetes is not part of the news. Clearly the media and society in general have come to recognize that living with diabetes is, in and of itself, not the newsworthy part of most stories. We couldn’t have found a better example of this than the 2009 appointment of Sonia Sotomayor to the US Supreme Court. Nearly all the news stories spoke of her intelligence and education and hard work and abilities. Her having diabetes was hardly mentioned. And those stories that did mention it did so in passing. Diabetes didn’t — and doesn’t — define her life.

It is not hard to find other examples of people living with diabetes who have achieved the loftiest of goals. Sebastien Sasseville ([www.sebinspires.com](http://www.sebinspires.com)) did so quite literally when he successfully climbed Mount Everest. And Gary Hall Junior is one of the most successful athletes in Olympic history with a bucketful of medals to his credit. Ian remembers meeting John Chick when John was playing with the CFL's Saskatchewan Roughriders (he now plays in the NFL). (Ian never felt so small in his life than he did that day, standing beside the towering athlete!) John is a past winner of the CFL Most Outstanding Defensive Player award. All these amazing individuals have diabetes.

Away from the sports arena, Ernest Hemingway, Thomas Edison, Jack Benny, Elizabeth Taylor, Drew Carey, and — Ian's all-time favourite piece of diabetes lore — Elvis Presley have all lived with diabetes.

You may not have spoken to Stephen Steele, but he has quite possibly spoken to you. Stephen is a commercial pilot with a major Canadian airline. And if you've ever had the bad luck to be on some sinking vessel off the Atlantic coast, the hero who plucked you from the ocean may have been none other than Major Chuck Grenkow, a Medal of Bravery-winning former Canadian Forces pilot and aircraft commander, who performed search and rescue operations with the Canadian military. Oh, by the way, they both have diabetes.

Diabetes is a common disease, so it's bound to occur in some very uncommon people. But you don't have to be famous to be considered exceptional. Indeed, every day of the week in our practices we see special people, people who have diabetes yet look after families, work in automotive plants or office buildings, write exams, go to movies, and do their best to live life to the fullest — people, perhaps, just like you.

The point is, diabetes shouldn't define your life. You're the same person the day after you found out you had diabetes as you were the day before. But you've been given an additional challenge to contend with. Diabetes shouldn't stop you from doing what you want to do with your life. Certainly, it does complicate things in some ways. But if you follow the principles of good diabetes care that we discuss in this book, you may actually be healthier than people without diabetes who smoke, overeat, under-exercise, or engage in other unhealthy activities.

## *Handling the News*

If you are like most people, you were likely quite shocked when you were first told you had diabetes. Nobody wants to have diabetes and your first thought may well have been, "How can this be?" But, alas, it did come to be and you

have had to deal with it ever since. You may have had your share of emotional ups and downs in coming to terms with your diabetes. For each person with this condition the journey toward acceptance is unique.

Hopefully, you not only came to accept your diabetes diagnosis, but also shared the news with your family and other people close to you. Having diabetes isn't something to be ashamed of, and it isn't something that you should have to hide from anyone. Your diabetes isn't your fault. You didn't want to have diabetes. You didn't try to get diabetes. And no one can catch it from you.

## *The Impact of Your Diabetes on Your Relationships*

Everyone is involved in relationships with others. These might be family relationships, relationships with friends or workmates or, with some other people. And although living with diabetes needn't be front and centre in your interactions with people, it needn't be a secret either. In this section we look at how having diabetes may affect your relationships.

### *Looking at the impact of your diabetes on your relationships with your family*

If one person in a family has diabetes, then, in a sense, everyone in the family has diabetes. Or at least has to live with it and deal with it.

If you've recently been diagnosed with diabetes, your family likely has had as many questions as you. What is diabetes? How can it affect you? How is it treated? Will you be okay? Some of the answers are simple. Some are complicated. (To help answer their questions we'd suggest you let your family members borrow this book from you and read it, too.) The fact your family is asking these questions isn't, of course, to play J. Edgar Hoover on you. Rather, it is simply a reflection of their concern and caring.

Ultimately, your diabetes is, well, *your* diabetes, and you need to take ownership of it. It is — and always will be — your decision about how you eat, if and how you exercise, if you test your blood glucose levels, attend doctors' appointments, and so forth. But all of this will be easier if you see your family as partners in your journey with diabetes. This may not, however, always be easy or straightforward.

Here are some ways you can help maintain positive, mentoring family relationships:

- ✔ **Don't keep your feelings about your diabetes to yourself.** Let your family members know if your diabetes is getting you down. Let them know if you are feeling positive about how things are going.
- ✔ **Feel free to test your blood glucose and, if you're giving insulin, inject this in front of family members.** You're the one *doing it*; it's a far lesser deal for someone else to *watch* when you're doing it. (And even at that, it will soon become routine enough to your family that they won't even notice.)
- ✔ **Remember that your blood glucose results are yours.** You only need to share the numbers if you want to. (We discuss this further later in this chapter.)
- ✔ **Make grocery shopping a collective experience and share your knowledge about healthy food with your family members.** Indeed, you can help ensure the whole family is eating healthfully because, as we discover in Chapter 10, a "diabetic diet" is, basically, a healthy eating diet.
- ✔ **Make exercising a family experience.** As we look at in Chapter 11, diabetes loves exercise and should be a regular part of your existence. But it should also be a part of *everyone's* existence, whether or not they have diabetes.
- ✔ **If you feel you'd like a supportive "extra set of ears" when you see a member of your health care team, bring a sufficiently mature family member with you to your appointment.** This is especially helpful for appointments with your diabetes educator or dietitian. (We discuss the members and roles of the diabetes health care team in Chapter 8.)
- ✔ **Remember that your family cares about you and wants to help you.** This is especially important when helping you in an emergency situation. Teach your family members what to do if ever you should need their help to treat a bad episode of low blood glucose. We discuss this in detail in Chapter 5.

## *Looking at the impact of your diabetes on your relationships with your friends*

Your friends are your friends for a reason. Maybe you share the same interests in music or sports or hobbies, or perhaps you share opposite sides of the same picket fence. Whatever the case, your diabetes needn't interfere with your relationships with your friends. If anything, it can strengthen

friendships and even foster developing new relationships. Indeed, we know many people living with diabetes who developed friendships *because of* their diabetes. For example, they met new friends at meetings of the CDA (Canadian Diabetes Association) or JDRF (Juvenile Diabetes Research Foundation) or at local diabetes support groups.

Here are a couple of ways that diabetes may affect your friendships:

- ✔ **As with family (see the preceding section), your friends care about you.** Therefore, if you want to share your thoughts or feelings about your diabetes with your friends, do so. And if you need to test your blood glucose or you need to give yourself an injection of insulin, don't feel obliged to do this in private. (You're welcome to, of course, but we hope you won't feel you *have* to.)
- ✔ **Keep right on doing the same activities with your friends that you've always done.** You may have to modify to some degree the way in which you do the activities, but your friends won't mind. For example, if you like to bike, because of your diabetes you may need to sometimes stop to check your blood glucose or to take some extra fluid to keep hydrated. Your friends will likely enjoy the excuse to rest; Ian sure does when he bikes with his friends who have diabetes!



We never recommend drinking alcohol to excess. But it is a fact of life — especially among teenagers and young adults — that overindulging with friends may happen. If you and your friends like to drink together and you've had more than your share, make sure your friends know the difference between being drunk and having low blood glucose. If ever your friends are unsure if you're drunk or having low blood glucose — especially if you are getting sleepy or confused and are unable to check your blood glucose — then your friends should call 9-1-1. We discuss the treatment of low blood glucose in Chapter 5.

## ***Looking at the impact of your diabetes on your relationships with your workmates***

Although we encourage you to share the fact of your diabetes (and its impact on you) with your family and friends, it's not quite as straightforward with your workmates.

Of course, some of your workmates may also be your friends; people you play hockey with, have over for a barbeque, and so forth. For these particular workplace relationships our advice is the same as in the preceding section about friends. Most of your workmates, however, are probably not

your friends. They're more likely to be people that you work with, but do not socialize with much, if at all. Regarding these relationships and your diabetes, we suggest the following:

- ✔ **Be as open or as closed about your diabetes as you wish.** If you want to share the fact of your diabetes, feel free to do so. If you want to keep it private, do that. It is no one else's business unless you want it to be. (Exceptions do apply, however. For example, if you have a job in which you can be endangered or can endanger others if you have a diabetes emergency, you may be obliged to let your workplace know you have diabetes.)
- ✔ **If you are on medication — particularly insulin — that can cause your blood glucose level to go low, and especially if you have previously experienced bad episodes of hypoglycemia that required someone to assist you, try to find at least one workmate you can confide in and who can help you out if you run into a bad low.** Show this person where you keep your diabetes emergency supplies (such as dextrose tablets or juice). Also keep a glucagon kit at work (we discuss glucagon kits in Chapter 5) and teach your trusted workmate when and how to use it.

## *Juggling Your Diabetes and Your "Real Life"*

Most people these days feel like they are constantly run off their feet. They juggle work (in or out of the home) and family life. They run here, run there, and try to squeeze in time for friends, sports, hobbies, volunteering, and so on. This never-ending rush of activity, often accompanied by stress, leaves very little time or energy for anything else. Oh, but wait, you have diabetes. How in the world are you going to fit managing your diabetes into your life? We look at that in this section.

### *Juggling your diabetes and your family life*

Many of Ian's patients — especially the mothers of young children — tell us that they are so busy looking after their family that they have no time or energy to look after themselves. Time and again we see young women who manage their diabetes beautifully leading up to and during pregnancy, only to see it go off the rails when the realities of having a newborn (then infant then toddler. . .) are added to the mix. Whether you are the mother of a youngster

or the father of a teenager or live in some other sort of family relationship, you likely find that sometimes family commitments get in the way of paying close attention to your diabetes. That makes perfect sense. However, your diabetes isn't going away and you have to deal with it. Here are some tips you may find helpful for juggling your diabetes and your family life:



- ✓ **Involve your family in your diabetes.** Take your kids grocery shopping (okay, sure, it will double the time it takes . . . maybe don't do this every time), have your child help you write down your blood glucose readings, and so on.
- ✓ **Exercise with your family.** Make it a collective experience. Or go out for a walk after you've dropped your kids off at hockey or soccer practice.
- ✓ **Make time for yourself.** Looking after your own health isn't selfish. Quite the opposite: Keeping yourself healthy is one of the *very best* things you can do for your whole family.

## *Juggling your diabetes and your work life*

Depending on your occupation and where you work, time constraints or other challenges can make looking after your diabetes difficult while on the job. Table 1-1 illustrates some examples of these challenges and possible options available to help. (In Chapter 16 we look in detail at diabetes, employment issues, and your rights.)

**Table 1-1 Dealing with Challenges at Work**

<i>If Your Work . . .</i>	<i>We Recommend You . . .</i>
Provides no or insufficient breaks for eating, blood glucose testing, or injecting insulin	Speak to your employer. It is your legal right to be given sufficient time to perform these health-related tasks.
Makes it impossible to do fingerstick blood glucose tests because your hands are always dirty or greasy	Talk to your pharmacist about alternative-site blood glucose meters that allow you to test your blood glucose from, for example, your forearm. (We discuss this topic in more detail in Chapter 9.)
Does not have a discrete place for you to give your insulin and you're not comfortable injecting yourself in front of others	Speak to your diabetes specialist or diabetes educator about discrete ways to give your insulin.
Is in a hot environment and you do not have access to a fridge to store your insulin	Bring an insulated container to work in which to keep your insulin. (We discuss insulin storage in Chapter 13.)

## *Putting Your Energies into Your Diabetes*

Living with diabetes is a time-consuming, energy-demanding, unceasing commitment. Diabetes doesn't take holidays, breaks, or any time off. Indeed, living with diabetes can sometimes feel like a full-time job. So if ever anyone has the audacity to tell you that your diabetes is no big deal, ask them if they want to try having diabetes for a while! Anyhow, the fact remains that you do have diabetes, it's not going away, and you have to invest time and energy to keep yourself healthy. This isn't easy, but it is essential.

How much energy goes into managing your diabetes? Well, you need to invest energy into choosing the right foods and preparing them in the right way. You need to check your blood glucose and take your medicines. You need to attend appointments with doctors and nurses and dietitians and other health care professionals. You need to visit the pharmacy regularly and you need to do lab tests and go for eye exams and check your feet. And you need to put physical energy into expending energy; that is, exercising. And you need to do all this in addition to doing everything else that goes on in your life. To effectively juggle and manage all these many things is, for most people, simply going to be impossible at times and something will, for a time, slip through the cracks. This is perfectly understandable, but for many people leads to feelings of guilt. We discuss this next.

### *Feeling guilty with your diabetes*

Given what we say in the preceding sections, sometimes you'll find that you simply can't muster all the energy you need, and something has to give. If you've been living with diabetes for a while, you probably can recall different times when you let your diabetes slide. Perhaps you didn't eat as healthfully as you knew you should, or you tested your blood less often, or you stopped exercising. If so, we hope you didn't feel guilty about it. Or at least kept your guilt to a minimum. It is perfectly normal to have stages where your energy feels sapped and looking after your diabetes seems like more effort than you can muster. The key is to recognize that although this is both understandable and normal, you need to get back on track — preferably sooner than later. Your diabetes demands it and you deserve it. And as for feelings of guilt, don't beat yourself up over what you think you should've done better in the past; instead think about how you're going to better manage your diabetes in the future. Just like driving a car, you should be spending a lot more time looking forward than in your rear-view mirror.

We provide coping tips later in this chapter.

## *Feeling frustrated with your diabetes*

The fact that you have diabetes doesn't change day-to-day, but lots of other things do. We're talking changes in the workplace, stresses at home, short-term illnesses, travel, and so forth. And that, in turn, will impact on your diabetes and in particular on your blood glucose control. It can be frustrating, indeed, when factors often beyond your control adversely impact your diabetes. Longer-term changes can also impact on your diabetes and lead to feelings of frustration. For example, perhaps you have developed arthritis and cannot exercise as much. Or, as typically happens if you have type 2 diabetes, the medications that were working just fine at first start to work less well.

Faced with all these changes that affect your glucose control, you may feel like you're trying to hit a moving target. Actually, it's not *like* trying to hit a moving target. It *is* trying to hit a moving target! Everything can seem to be going well, your blood glucose levels in check, your diet on track, your daily walks a well-honed ritual, then, *Wham!* A few holiday dinners or a sprained ankle or a bout of bronchitis or trouble at the office, and all of a sudden your blood glucose levels are up. Or pills that were working well start to be ineffective, and your blood glucose levels are on the rise. Or the insulin dose you give seems to work beautifully one day, and poorly the next. Feeling frustrated? Who wouldn't! Although your diabetes isn't going away, coping strategies can help you deal with the frustrations that diabetes presents. We look at this topic in the very next section. (As for bringing your glucose levels back in check, we discuss this in Chapters 10 to 13.)

## *Coping with diabetes*

Whether you've had diabetes for ten days or ten years (or much longer), sometimes you will feel frustrated, discouraged, or simply fed up with dealing with it. This is perfectly understandable. Diabetes is a full-time job that you didn't apply for and would rather not have been hired for, thank you very much.

If your diabetes is getting you down, you can do a whole host of things to help lift yourself out of the doldrums. Here are some options:

- ✓ **Don't deny your feelings.** They are not unjustified and in any event, your feelings are your feelings.
- ✓ **Don't bottle up your emotions.** Share your feelings with those that are close to you, especially your family.
- ✓ **Seek support.** Participate in a support group (whether virtual or in-the-flesh).

- ✔ **Don't be too hard on yourself if your blood glucose levels are not as good or as consistent as they should be.** Perfect blood glucose control is not possible given that we have *imperfect* therapy. (Speaking of which, one of Ian's dictums is that the word "perfect" and the word "diabetes" should never be used in the same sentence.)
- ✔ **Think positively.** Focus on your successes (be they eating a healthy meal, going out for a walk, and so on) and pat yourself on the back more often.
- ✔ **Exercise regularly.** If you're feeling stressed and tired and burnt out with your diabetes, the idea of exercising may be the furthest thing from your mind. But exercise can hugely improve one's energy level and well-being.
- ✔ **Speak to your doctor about how you're feeling.** Discuss temporarily lightening some of your diabetes workload. For example, ask if for a period of time you can safely test your blood glucose less often. Or, if you're on four times daily insulin, ask if you can safely, temporarily, switch to a different insulin that is given twice per day.
- ✔ **Know that help is available.** Your doctor, depending on your specific situation, may recommend antidepressant medication or other forms of psychological support.

Feeling at wits' end with diabetes is common enough that an entire book is devoted to the subject. *Diabetes Burnout* by Dr. William Polonsky is an excellent resource to help you cope.

## Diabetes etiquette

If you have diabetes, you've probably run into situations where people have offered you well-intentioned, but unsolicited and unhelpful advice. (We love the term for these people — especially those who question your food choices when you're in the cafeteria lineup or at a restaurant: the diabetes police!) The Behavioral Diabetes Institute (BDI; [www.behavioraldiabetesinstitute.org](http://www.behavioraldiabetesinstitute.org)) has developed etiquette cards for people with diabetes to give out to others (who don't have diabetes). With the BDI's kind permission, here's what the card says:

**1. DON'T offer unsolicited advice about my eating or other aspects of diabetes.** You may mean well, but giving advice about someone's personal habits, especially when it is not requested, isn't very nice. Besides, many of the popularly held beliefs about diabetes ("you should just stop eating sugar") are out of date or just plain wrong.

**2. DO realize and appreciate that diabetes is hard work.** Diabetes management is a full-time job that I didn't apply for, didn't want and can't quit. It involves thinking about what, when, and

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how much I eat, while also factoring in exercise, medication, stress, blood sugar monitoring, and so much more — each and every day.

**3. DON'T tell me horror stories about your grandmother or other people with diabetes you have heard about.** Diabetes is scary enough, and stories like these are not reassuring! Besides, we now know that with good management, odds are good you can live a long, healthy and happy life with diabetes.

**4. DO offer to join me in making healthy lifestyle changes.** Not having to be alone with efforts to change, like starting an exercise program, is one of the most powerful ways that you can be helpful. After all, healthy lifestyle changes can benefit everyone!

**5. DON'T look so horrified when I check my blood sugars or give myself an injection.** It is not a lot of fun for me either. Checking blood sugars and taking medications are things I must do to manage diabetes well. If I have to hide while I do so, it makes it much harder for me.

**6. DO ask how you might be helpful.** If you want to be supportive, there may be lots of little things I would probably appreciate your help with. However, what I really need may be very different than what you think I need, so please ask first.

**7. DON'T offer thoughtless reassurances.** When you first learn about my diabetes, you may want to reassure me by saying things like, “Hey, it could be worse; you could have cancer!” This won't make me feel better. And the implicit message seems to be that diabetes is no big deal. However, diabetes (like cancer) IS a big deal.

**8. DO be supportive of my efforts for self-care.** Help me set up an environment for success by supporting healthy food choices. Please honor my decision to decline a particular food, even when you really want me to try it. You are most helpful when you are not being a source of unnecessary temptation.

**9. DON'T peek at or comment on my blood glucose numbers without asking me first.** These numbers are private unless I choose to share them. It is normal to have numbers that are sometimes too low or too high. Your unsolicited comments about these numbers can add to the disappointment, frustration and anger I already feel.

**10. DO offer your love and encouragement.** As I work hard to manage diabetes successfully, sometimes just knowing that you care can be very helpful and motivating.