



**BEHAVIORAL  
DIABETES  
INSTITUTE**

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## Top 10 Patient Gripes

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By Amy Tenderich

Most people with diabetes will tell you this: Everything about having it is a hassle, an annoyance and sometimes utterly overwhelming. Endless worrying over meal plans, carbohydrate counting, finger-stick checks, pills, injections, lab tests, prescriptions, supplies and doctors' appointments are nobody's idea of fun.

But of course, we must soldier on. And we can take some comfort in knowing that if we do all these things, we can avoid the devastating effects of this particular disease.

So we're lucky, right?

Considering that we don't usually feel very lucky to have diabetes, it seems high time that someone documents some of the universal complaints of patients with diabetes and offers a little advice on what you can do to alleviate them, too.

We queried a number of experts on the psychological side of diabetes to learn what patients across the country grumble about most.

### **GRIPE #1: People Giving You Unsolicited or Wrong Advice**

"In our experience, the number 1 complaint among people with diabetes is the exasperating stuff other people say," says William Polonsky, MD, author of "Diabetes Burnout" and a clinical professor of psychiatry who runs dozens of sessions with frustrated patients at his San Diego-based Behavioral Diabetes Institute ([www.behavioraldiabetes.org](http://www.behavioraldiabetes.org)). "People say things like, 'Your blood sugar is low—you need some insulin,' or 'My grandmother lost both legs and went blind—she had diabetes too!' That's just not helpful. You don't need to hear that," Polonsky says. "What we really need is wallet-sized diabetes etiquette cards to hand out to people," he adds with a chuckle.

### **What You Can Do**

Polonsky notes that simply asking people to stop making comments doesn't help. What does work is to find a relaxed moment and say, "I know you're trying to be helpful, but you're not. Here are some things you can do to help me: Don't ask if I can eat that piece of candy or drink that glass of Coke. But do make sure there's always some diet soda in the fridge. Don't tell the waiter not to bring me some food or other. But do help me by doing X,Y or Z—and let them know exactly what they can do to be of help." Make sure that whatever you're asking for is reasonable. On the one hand, you may want people to treat you as if you're "normal," as if you didn't have diabetes. On the other hand, you need them to recognize all the work and difficulties involved with

managing this disease. So what should friends and family say and do to be supportive? Think about the things people have done that were actually helpful, and keep those in mind to suggest at an appropriate moment.

### **GRIPE #2: Feeling Lost and Alone**

Isolation is a major grievance of people with diabetes. Most lack a confidante who really understands what it means to live with this disease. And many even have trouble finding a medical professional who can help them. “Our medical system seems to abandon many people with diabetes,” Polonsky says. “Most people complain about struggling with it alone—feeling completely on their own. In America, we’ve always had an ‘every man for himself’ mentality, so that seems normal to us.”

There’s no underestimating the value of community support for everyone from the newly diagnosed to the long-term patient who might be feeling burned out by diabetes.

#### ***What You Can Do***

First, it’s worth taking the time to find the right doctor and other medical providers, says Matthew Riddle, MD, a specialist in endocrinology, diabetes and clinical nutrition at Oregon Health and Science University in Portland, Oregon. “Ask your friends. Ask the local ADA chapter. Each community has people who know more about diabetes and want to help. Find them. When you go to see them, tell them that you appreciate their efforts. Stick with them. Keep your appointments.”

Finding local support groups, classes and seminars is usually as simple as doing a quick online search or calling your local hospital. Most of these programs are free or low cost, and they offer a great way to meet and mingle with other people with diabetes and learn some ways to improve your diabetes care at the same time. Many clinics and medical groups across the country now offer top-notch personalized programs as well, which allow you to talk over your biggest challenges with an educator or nutritionist.

Finally, online message boards, forums and Web logs allow you to connect with other people who are in the same boat without leaving the comfort of your own home. You might be surprised to find someone on the other side of the country or even overseas who is struggling with the same diabetes-related frustrations. Being able to toss out questions, share ideas and gain support and empathy is key. You don’t have to be a Web expert; you can easily find these resources with any Internet search engine by typing in the term “diabetes support” or something related.

### **GRIPE #3: Feeling Frustrated With Your Doctors**

Many people with diabetes feel shunned by their own doctors. “The biggest gripes new patients seem to have when they come to me are things like, ‘I couldn’t reach the doctor when I needed him,’ ‘He or she never called me back with my test results’ or even ‘The doctor didn’t remember who I was,’” says Anne Peters, MD, director of clinical diabetes programs at the University of Southern California (USC) and author of the new book “Conquering Diabetes.”

When these patients visit the doctor, they will leave feeling deflated. “Doctors’ recommendations sound fine in the office, but when you walk out of the clinic and back into your real life, they may seem impossibly difficult,” Peters says. “The doctor needs to understand the person’s own unique learning style in order to help them succeed.”

#### ***What You Can Do***

See the hints above about finding the right doctor. All the experts agree that it’s worth shopping around until you find a provider you’re comfortable with.

And remember that simply believing “it’s all the doctor’s fault” is unproductive. This distracts you from what you need to do yourself. Quite a lot depends on how you approach your appointments. Keep in mind that you

are the leader of your diabetes care team. Everyone else is there to support you. You'll get more out of your visits if you go prepared with specific questions and action items.

“Passive dependency is bad news. When things don't go well, patients get really upset, and they don't know what to do. It's never a good choice to think, 'I'll just have to wait three weeks to see my doctor,' ” says Larry Fisher, MD, a clinical psychologist at UCSF who treats numerous patients with diabetes.

It's important to be sure that you leave the doctor's office with goals that are behavioral, Fisher advises. “Not a number, but something you can do physically. For example, to lose 10 lbs in the next three months is not an attainable goal, because you cannot control your weight. But you can control your eating. You can say, 'I'll stick to a 1,500-calorie diet,' for example. Have your doctor help you pick one action-oriented goal at each appointment.”

“Folks who are proactive and take an active role in their management are going to do better than those who are passive and follow the party line. You're making many more decisions on a daily basis than your doctor,” Fisher concludes.

#### **GRIPE #4: Hassling With Diabetes Supplies and Devices**

This is a two-part gripe: first, the hassle of filling and refilling numerous prescriptions, and the never-ending hassle of carrying and using them.

“A lot of people are frustrated about getting their meds and dealing with the insurance, and they wonder, why does my pharmacy make me tell them that I have diabetes every month?” Polonsky says.

And as if blood glucose checks four or more times a day weren't inconvenient enough, your routine may be bothersome to others. “I have a patient who works at a loading dock, and his boss told him, 'You can't test your blood here, right out in front of everyone.' But the bathroom is far away and totally inconvenient. That's just not right,” Polonsky says.

#### ***What You Can Do***

When it comes to prescriptions, it helps to get organized. If you're picking up your supplies at a local pharmacy, ask your doctor to help you synchronize the prescriptions so you have to do only one pickup per month. Also, review your supplies carefully each month so you don't run out too early, or, you may need to ask your doctor to increase the quantities.

Find out if your health plan covers a mail-order service for prescriptions. These generally offer three months' worth of supplies delivered to your doorstep, usually with a cheaper co-pay. And the convenience of phone or online ordering is life-altering for anyone dependent on multiple prescriptions.

When it comes to other peoples' reactions to your self-care, you might want to brief people in advance. Explain to your boss or coworkers what it is that you'll be doing with your meter, pump or injection pen. Assure them that while this is essential to your health, it's no big deal for them. It's just a tiny drop of blood you're drawing, and there's nothing remotely dangerous or contagious about it.

#### **GRIPE #5: Diabetes Burnout— Never Getting a Break**

Pending a cure, diabetes is forever, and it requires constant attention. The 24/7 demands can really grate on you. Wouldn't it be sweet just once to be able to go for a long bike ride without worrying about carbohydrate calculations and glucose monitoring, or to eat an ice cream cone on a hot summer day?

“If you ask people nationally, in a large-scale survey, about their everyday frustrations with diabetes, they tend to say it's the enormity of the thing: How do I stay on this blasted diet? How do I keep physical activity up? Do I really have to do all this sticking and testing? Don't I ever get a break?” Fisher says.

## ***What You Can Do***

There are a couple of ways to ease up the pressure and give yourself a little “diabetes vacation” now and then. “The dirty little secret is that everybody takes vacations; no one can do it perfectly all the time,” Polonsky says. “You’ve just got to individually find a way to take a safe vacation from your diabetes.”

“Unsafe” means ignoring your diabetes for months or years. “Safe” means planning ahead. It’s OK to take a day off, to eat a few “taboo” foods or check your glucose less often one day—as long as you’re prepared for the consequences. You will need to recover from that day. And this needs to be a one-time, conscious break; you don’t want to create an “on” or “off diet” mentality.

It helps to stay focused on your specific goals for the week or month. Are you trying to maintain an A1C level of 7, or reduce from 10 to a 7? Are you trying to decrease your food intake, or start an exercise program? If you can break down your diabetes care into smaller, do-able increments, you won’t feel so overwhelmed by trying to be the “perfect diabetic” on every front at all times.

It all boils down to rejecting discouragement and embracing hope, Polonsky says. “To keep yourself going, you have to have hope that it’s possible to live a long and healthy life with diabetes. With all the research, we know it’s true, but you have to believe that.”

## **AND ANOTHER THING . . . (Gripes #6-#10)**

Many people who take insulin throughout the day, and others who are intensely tuned in to their own daily diabetes care, have an additional set of frustrations. These include:

### **I have too much stuff I have to carry around with me.**

New “combo devices” on the horizon will integrate the glucose monitor with an insulin pump, for example, and a variety of improved bags and carrying cases are available now to consolidate your supplies.

### **I have to check my BGs over and over again.**

Continuous glucose monitoring (CGM) is on the way. This next generation of glucose sensors will provide “real time” readings and warning alarms for dangerously high or low blood glucose levels. Medtronic’s Guardian RT is the first CGM approved by the U.S. Food and Drug Administration.

### **I hate logging my diabetes numbers.**

Ask your meter manufacturer about software downloads and the newest tracking programs. Ask your CDE for suggestions on what and when data logging is most important—it may be necessary for only a few days before your appointment.

### **New diabetes technologies take too long to get to us.**

The FDA is currently evaluating dozens of new diabetes care products. There’s never been a time when so many new treatments were so close to approval. See [www.fda.gov/diabetes/](http://www.fda.gov/diabetes/) for details.

### **I wish my doctor knew as much about diabetes as I do!**

Try contacting a university-based diabetes center in your area, where you’ll find cutting-edge care and research.

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