

# This Is What It's Like To Live With Type 1 Diabetes

By [Judy Koutsky](#) May 9, 2016



IMAGE POINT/SHUTTERSTOCK



You probably know someone with type 1 diabetes (there are 1.25 million American children and adults living with the autoimmune disease), but do you really know what they're going through each day? Here's a brief glimpse: They're constantly checking their glucose numbers, watching what they eat, and worrying about how stress and other factors will influence their blood sugar. To learn more about what it's like to manage the condition day in and day out, read on. (Take back control of your eating—and lose weight in the process—with our 21-Day Challenge!)

**You worry about every little thing you eat.**



CHRIS RYAN/GETTY IMAGES

Always. "You cannot be a diabetic without thinking about food and how it will affect you," says Taylor, 25, from Salem, OR. "Each item of food that I put into my mouth has so much more to it than the taste. When you eat, you have questions running through your mind such as, 'How many carbs does this have?', 'Did I take enough insulin for this?', 'What if I am full but took too much insulin, do I still have to finish it?' Those are just some of the questions, and that is for every single item I eat."

It used to be that people with type 1 diabetes had to check their blood glucose values at least three or four times a day. However, according to Gregory Dodell, MD, a board-certified endocrinologist at Central Park Endocrinology New York, keeping up can be lower maintenance, thanks to new technology called a continuous glucose monitor (CGM)—which is a sensor that checks glucose values consistently throughout the day and is viewed via a separate device, including an iPhone app.

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**You constantly have to explain to people the difference between type 1 and type 2 diabetes.**

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"It is hard having a disease you feel you have to defend. Many people think I brought this on myself with a poor diet and lack of exercise—and that simply isn't true," says Allison Caggia, 39, from New York City. If you didn't know, a little background: According to the [National Institute of Diabetes and Digestive and Kidney Diseases](#), in type 1 diabetes, which usually is diagnosed in children and young adults, your body no longer makes insulin or enough insulin because the body's immune system has attacked and destroyed the cells that make it. However, with type 2 diabetes, which can be diagnosed at any age, your body doesn't properly use the insulin you do make. It's linked to being overweight and inactive, which means that, unlike type 1 diabetes, it can be prevented.

### **You're always aware that you need meds to stay alive.**

Dodell likens managing diabetes to having a part-time job. "And that's difficult, because we all tend to work hard at our full-time jobs," he says. Karen Bryant, 44, from Henderson, NV, agrees. "The hardest part, for me, is having to rely on medication to keep living. I remember standing at the pharmacy counter one day as I waited for my prescriptions and thinking that my very life depends on that pharmacist being able to give me the medications that I need. That was a very sobering thought." And as Caggia puts it, "The [hardest part about diabetes](#) is having to think about it *all* the time. It's mentally and emotionally draining. It is always there and never goes away."

### **So many things—besides food—can affect your blood sugar levels.**

Stress, [lack of sleep](#), illness, and lack of physical activity all raise glucose values, explains Dodell. And "each diabetic is different, so what affects one of us might not affect another," says Taylor. "Nondiabetics can see an increase in their blood sugar due to some of these same things, so it's only normal that it would happen to diabetics as well, but we are in charge of managing the high levels without the immediate help of our [nonfunctioning] insulin hormones." Also of note: If someone is put on steroids for any reason (back pain, sinus infection), this can increase glucose values. The CGM can help monitor those levels, explains Dodell.

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### **Everyone with diabetes feels low blood sugar in a different way.**

"Some people, like me, have to deal with what's called hypoglycemia unawareness, which means we don't always feel it when our blood sugar is low," says Rachel Kerstetter, 27, from Cleveland. "Others get the textbook symptoms—shaking, sweating, confusion, irritability—but not me. I won't feel symptoms of a low and won't even know I'm low if I didn't check my numbers. Often when I'm low, I know in my head what I need to do, but sometimes I have trouble making myself do it." (Here are [7 diabetes myths people still believe](#).)

### **The disease is unpredictable.**

It's not as simple as the idea that eating a [salad for lunch](#) will mean stable blood sugar for the rest of the day. Sometimes, it can feel like there's no rhyme or reason to your blood sugar readings. "I don't really mind having high or low blood sugars if I have overindulged or clearly miscalculated, but oftentimes there is no accounting for these levels," says Gail Isenberg, 61, from Chicago.

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### **You have to cart around loads of supplies.**

Which means that being far from home can be stressful. "I have a handy lunch bag that I carry my supplies in. I also have a small insulin cooler to protect my insulin from heat. I keep these in the car when I run my errands, but I always carry my meter and an emergency sugar source in my purse. I also always try to keep my supply bag stocked and ready for any incidentals. It can be very

stressful to be away from home and realize you are short on supplies," says Bryant.

**There's an upside.**

All that monitoring does have its perks. "I have often told people that I am healthier with type 1 diabetes than I was before," says Kerstetter. "That's because I have to be mindful of everything I put into my body and be aware of how exercise and general activity affects my blood sugar. Diabetes also motivates me to be aware of any illness, injury, or ailment and get them checked out. I stay on top of all parts of my health, even those that don't seem related to diabetes."

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