

Type 1 diabetes: an unrelenting disease

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How the blood sugar condition constantly affects daily living.

(HealthDay)— Although more than one million Americans have type 1 diabetes, most people don't understand the toll it can take on daily living.

"It would be easier to tell you how [diabetes](#) *doesn't* affect my life," said Meri Schuhmacher-Jackson, a mother of four sons—three with type 1 diabetes.

"Type 1 diabetes affects every aspect of our lives. It looks invisible from the outside. But, it's anything but invisible for us. There's a hamster running on a wheel in your brain all the time," she explained.

November 14 is World Diabetes Day, an international campaign designed to raise awareness about diabetes.

Type 1 diabetes is an autoimmune disease that occurs when the body's immune system mistakenly attacks and destroys the body's insulin-

producing cells. Insulin is a hormone that helps the body use the sugar in foods as fuel for the body and brain.

Because the body can no longer make enough insulin, people with type 1 diabetes have to replace that lost insulin. This can be accomplished with insulin injections—about four to six shots a day—or from a tiny tube inserted under the skin that's attached to an insulin pump. The tubing has to be changed and reinserted in a new place under the skin approximately every three days.

People with type 1 diabetes have to make a number of potentially life-challenging decisions about their care throughout the day. They need to check their [blood sugar](#) levels by lancing their fingers to draw a small drop of blood at least four times a day, and often more, according to the American Diabetes Association (ADA). And, unfortunately, insulin dosing is not a precise science.

"Eating, exercising, stress, illness and more can all impact [blood sugar levels](#)," said Mark Heyman, director of the Center for Diabetes and Mental Health in Solana Beach, Calif. Heyman has type 1 diabetes.

All of those factors make getting the right amount of insulin a difficult balancing act. Too much insulin can cause blood sugar levels to dip dangerously low, leading to confusion and mood changes, or even seizures and death, according to JDRF (formerly called the Juvenile Diabetes Research Foundation). Too little insulin leaves blood sugar levels too high.

Over time—in addition to making someone feel tired and thirsty —high blood sugar levels can eventually lead to a higher risk of long-term complications, such as heart disease, vision problems and kidney disease, the ADA says.

People with type 1 diabetes have to become nutrition experts and learn how to count the carbohydrates in their food. It's the carbohydrates in foods that get processed into blood sugar in the body. Then they need to learn a mathematical formula to figure out how much insulin they'll need.

Insulin pumps may help with the math, but they don't do all the work—not yet, anyway.

"Contrary to what many people believe, an [insulin pump](#) is not an intelligent device," said Derek Rapp, chief executive officer of JDRF and the father of a 21-year-old son with type 1 diabetes. "People with type 1 diabetes still have to make decisions for the pump about insulin dosing."

Complicating matters, everyone responds to insulin a bit differently. And, from day-to-day, insulin needs may change for the same person, Rapp noted.

"In high school athletics, my son's blood sugar would go down during a practice. But, if it were a game or a race, his blood sugar would go up. He was doing the exact same activity, but his blood sugar would go in opposite directions," Rapp said.

And Heyman added that's one of the most frustrating parts of living with type 1 diabetes. "It's unpredictable. You can do everything you're supposed to be doing, and still have an outcome that wasn't supposed to happen."

Another frustrating aspect is dealing with the many misconceptions surrounding the disease. When Schuhmacher-Jackson's third son was diagnosed with type 1 diabetes, one of her sons' teachers said, "Meri, what have you done?" implying that it was somehow her fault. But there

are currently no known ways to prevent type 1 diabetes, according to JDRF.

"It was a terrible feeling knowing we were being judged. There's such a stigma attached to the word diabetes," Schuhmacher-Jackson said.

Another difficult part of living with type 1 diabetes is the personal cost.

A study from *Diabetes Care* found that diabetes costs about \$7,900 a year per person. That works out to about \$660 a month on doctor visits, insulin, syringes, [insulin](#) pump supplies, test strips, blood glucose meters and continuous glucose monitors, along with supplies for treating low blood sugars.

But, despite the many challenges, most people with type 1 diabetes learn to live—and to live well—with the condition. For example, Rapp's son has run in three marathons and is a senior in college.

Heyman agreed there are definitely positive things that can come from living with type 1 diabetes.

While I would love to get rid of it, diabetes has given me a career I love, and I'm more in tune with my body. Diabetes has also taught me some really good communication skills and how to have difficult conversations with people," he said.

Still, it's hard when people don't understand "how demanding and unrelenting this disease is," said Rapp. "They see our son running marathons and doing well in school, and assume he's just like everyone else. But, he has to be vigilant while he's living his life."

And, Rapp added, people don't understand that while someone with type 1 diabetes may look perfectly healthy, something as simple as a stomach

flu can make them very sick, very fast.

"Type 1 is a serious condition, but it can be managed. Having type 1 diabetes doesn't mean that we can't do anything that other people can. It just takes a lot of extra planning," Heyman said.

More information: Learn more about type 1 diabetes from [JDRE](#).

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