

A deadly form of diabetes that doctors sometimes miss

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Amanda Di Lella

Common signs of type 1 diabetes often resemble symptoms of other illnesses.

(HealthDay)—Addie Parker was a happy 4-year-old who appeared to have the flu. But within hours she was in a coma.

Tragically, her parents weren't familiar with the signs of type 1 diabetes—[extreme fatigue](#), thirst and sweet-smelling breath, among others—in time to save their little girl. Soon after she was diagnosed, Addie's brain hemorrhaged. She died six days later, about a month shy of her fifth birthday.

Experts say a lack of awareness of the signs of type 1 diabetes is all too common. Just this month, a Wisconsin toddler died apparently because of undiagnosed type 1 diabetes.

"Addie had [flu symptoms](#)," recalled her mother, Micki Parker, who works in the operating room at a nearby hospital but was unfamiliar with type 1 diabetes.

"By the next morning, she was throwing up every hour," Parker said. Addie didn't have a fever, but later that day, she couldn't get up from the bathroom floor because she was so dizzy.

Eventually, the Parkers learned that Addie's [blood sugar](#) level was 543 milligrams per deciliter (mg/dL)—more than four times higher than normal, according to the [American Diabetes Association](#).

Most people have heard of [type 2 diabetes](#), but type 1 diabetes is far less common. It can strike at any age—even though it used to be known as juvenile diabetes—and it always requires treatment with injected insulin or insulin delivered through a pump. People with type 1 diabetes don't produce insulin, a hormone needed to convert the food you eat into fuel for the body. Without insulin, glucose (blood sugar) rises to unhealthy levels.

Untreated, type 1 diabetes causes serious complications and even death. But it's often mistaken for other illnesses—even by doctors.

"There's an underawareness of type 1 diabetes in the public, and in the healthcare system," said Dr. Richard Insel, chief scientific officer for JDRF (formerly the Juvenile Diabetes Research Foundation). "Missed diagnoses even occur in emergency rooms; people don't always think of it."

Every day, about 80 Americans are diagnosed with type 1 diabetes, and the total number rose 23 percent between 2000 and 2009 in children under 20. Currently, about 3 million Americans—most of them adults—are living with type 1 diabetes, according to the JDRF.

One of them is 20-year-old Amanda Di Lella, who was 13 when she knew something was seriously wrong.

"I was losing weight, but I was always hungry. I was always tired. My symptoms weren't extreme at first, but they quickly got worse," she said. "I went from being tired to not being able to get out of bed, from being thirsty to drinking 10 bottles of water in the middle of the night. I had lost 15 pounds, and only weighed 75 pounds when I begged my mother to take me to the doctor."

Her pediatrician told her mother that Di Lella probably had an eating disorder and he prescribed protein shakes.

Within a few days Di Lella wasn't waking up. Her mother took her to the hospital, at about the same time the doctor got blood work back showing that she had type 1 diabetes.

Her [blood sugar level](#) was over 400, and she was in diabetic ketoacidosis, or DKA. When your body doesn't get the glucose it needs for fuel (and when there's no insulin, glucose doesn't get into the body's cells), it burns fats for energy. This produces an acidic substance called ketones, which can build up in the blood, causing DKA.

"Once you're in DKA, you're set up for some major complications, and approximately 30 percent of people diagnosed with type 1 diabetes still present with DKA," Insel said.

After a week in the intensive care unit, Di Lella recovered. Her doctor apologized for the error and said he had never had a case of type 1 diabetes, so it wasn't something he normally looked for.

Insel said it's important to compare a child's changes in behavior to the other children in the family. Is the child drinking excessively compared

to a sibling? Is a child who has mastered nighttime bladder control suddenly wetting the bed again?

The good news is that it's easy to test for type 1 diabetes. A urine test can detect whether there's sugar in the blood. If that test is positive, then a simple test drawing a drop of blood from the fingertip can confirm whether you have diabetes.

Di Lella, now a student at the University of Florida, said she would advise others to "not ignore symptoms that seem so basic. Even small symptoms can be a sign of something much bigger."

Parker said she wants other parents to know that a child with type 1 [diabetes](#) "doesn't necessarily look sick. Trust your gut instinct, and push to have your child tested."

The signs and symptoms of [type 1 diabetes](#) that everyone should know include:

- Increased thirst
- Frequent urination
- Wetting the bed in a child who has previously had good nighttime bladder control
- Unintended weight loss

- Extreme fatigue
- Sudden changes in vision
- Unusual irritability
- Increased appetite
- A fruity odor on the breath
- Heavy or labored breathing

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

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