

THE ORANGE COUNTY REGISTER

48-year diabetes journey finds missteps, joy

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2013-10-31 16:26:21



Joanne Laufer Milo pings and beeps as she sits in the living room of her Newport Beach home.

The sounds come from devices that monitor her disease, commonly known as juvenile diabetes.

Every three minutes, a kiwi-sized device attached to her stomach pumps insulin, the hormone that regulates blood sugar, into her bloodstream. It makes up for the insulin her pancreas fails to produce, so she naturally calls it her pancreas.

Every five minutes, a sensor taped to her leg measures blood sugar. It produces a readout – a graph of blood sugar highs and lows – on a credit card-sized computer she keeps in her pocket.

“It’s impossible to forget I have this,” says Milo, 59. “I beep constantly.”

The disease means her body can’t make insulin. People with the more widespread form, Type 2, generally produce at least some.

About 3 million Americans have Milo’s form, Type 1, and their numbers are rising.

Diagnosed at age 11, Milo has tallied the number of insulin shots and blood tests since then. She thinks the numbers reach into the hundreds of thousands.

The unending vigilance exacts a toll. On her. On others.

A friend, who’d had juvenile diabetes for years, asked how she hung on. He broke down and told her, “This is too hard.”

“He killed himself,” she said.

The disease doesn’t forgive imprecision. Milo said another friend died at 33 because her blood sugar was too high. In time, the excess can shut down the kidneys.

“Back then, keeping levels high was the thinking,” Milo explained about treatment growing up on New York’s Long Island. Today, doctors view high sugar levels as dangerous.

‘Good girl’ fights disease’s restrictions

Milo was diagnosed in the 1960s, a different era of medicine.

“It was like ‘Steel Magnolias,’” she said, referring to the movie in which a diabetic played by Julia Roberts dies of kidney failure after a pregnancy.

“You weren’t expected to live past 40. You weren’t expected to have children.”

Back then, home blood tests were unheard of. Instead, Milo used urine strips to test her blood sugar. Twice daily, her parents injected her with insulin, and later, she learned to do it herself.

Aware that the disease made her different, she pretended her blood sugar was OK when it wasn't. She ignored the possible consequences: kidney failure, blindness, heart attack or stroke.

"I wanted praise. I wanted to be a good girl," she said.

She said the disease, in which genes play some role, sparked a blame game between her parents. But it also inspired them to start a local chapter of the Juvenile Diabetes Research Foundation in Long Island, only the second one there.

As she grew up, her mother counseled her to hide the disease from boyfriends, worried they'd reject her.

"I never did," Milo said.

With regular treatment, Milo went off to college, grad school and got married. She worked in corporate marketing and taught yoga. She never had children.

The first marriage didn't work out, but her ex helped her find husband No. 2 through an ad in the Register.

Happy, her disease under control, Milo's idyll was jolted five years ago by an emergency appendectomy nearly 3,000 miles from home.

Hospital reveals value of control

Sitting in a hospital room in Long Island, Milo thought, "I've been in charge of this disease nearly 50 years."

But now, doctors – strangers – were suddenly controlling the insulin keeping her alive.

"It was frightening," she said. "I lost control."

Control is a touchstone for Milo. It's the way she feels on top of her disease, her life. In the hospital room, she was surrounded by the pings and beeps of lifesaving devices – none under her control.

She wanted the reins back.

Along the way, she thought she might help others.

Having support team key to proper care

Milo started writing a book about living with diabetes two years ago.

Dr. Mark Daniels, a pediatric endocrinologist at Children's Hospital of Orange County, likened the experience to a marathon.

"Blood tests are simple," he said. "It's doing it every single day that's hard."

Published this summer, "The Savvy Diabetic: A Survival Guide" goes into detail about how to deal with hospitals, because soon after Milo started the book, she wound up in the hospital – again.

Since then, she's had a handful of surgeries. The experiences highlight the peril diabetics like Milo face.

"Four months ago she had surgery," Richard Milo, her husband, recalled. "Pre-surgery, they started mixing her antibiotics in glucose."

Glucose is sugar, a no-no for someone like her.

Richard Milo, an engineer, is exactly who you'd want bedside. Sitting at home, he reels off facts about the disease. He wears a green T-shirt from a walk for juvenile diabetes research that his wife started 18 years ago, which has raised more than \$200,000. They held the most recent walk on Sunday.

He said he made the nurse swap out the glucose. Then it happened again.

"First thing out of surgery, they put antibiotics in dextrose," he said.

Dextrose is also sugar.

It didn't stop there.

“There have been many, many instances in hospitals where they wanted to administer a large dose of insulin, more than was necessary,” he said. “They would've put her in a coma.”

Both ascribe the errors to the fact that hospitals largely treat patients with the more widespread Type 2 diabetes – not her kind.

Still, the errors drove home her reliance on her husband as her eyes, ears and voice.

In the book, she includes a chapter on finding an advocate and building a support team. Chapters also deal with traveling internationally, choosing doctors and coping day-to-day – information that applies to nearly anyone with a lifelong disease.

The book also offers words of silly inspiration from the likes of Dr. Seuss and comedian George Carlin. It ends with a remembrance of the friend who died at 33.

“This isn't diagnosis and treatment. There are books on that,” she said. “This is: ‘How do you live?’”

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