

HEALTH

Epilepsy and the small risk of death from seizures

A mother thought her son had a 'safe' type of epilepsy, but it wasn't

By **Bella English** | GLOBE STAFF FEBRUARY 10, 2014

On Valentine's Day 2013, Lise Stern got a call from the University of Miami, where her son Eitan was a freshman. She thought for a moment it might be someone soliciting donations for the school. But then a dean's voice said: "There is no easy way to say this. Your son has passed away."

Eitan Stern-Robbins was 18 when he died in bed in his dorm room, from something neither he nor his parents had ever heard of: Sudden Unexpected Death in Epilepsy (SUDEP). Eitan had suffered from epileptic seizures since age 11, but with medication had been able to limit them to every year or even two.

Stern worried about her son, but Eitan led a full life and didn't like to talk much about his condition. And his doctor at Boston Children's Hospital never explicitly mentioned the possibility of death to him or his parents.

"Since the majority of people don't die from epilepsy, doctors feel why needlessly worry the patient?" says Stern, a writer who lives in Cambridge. "My feeling is that awareness can bring prevention."

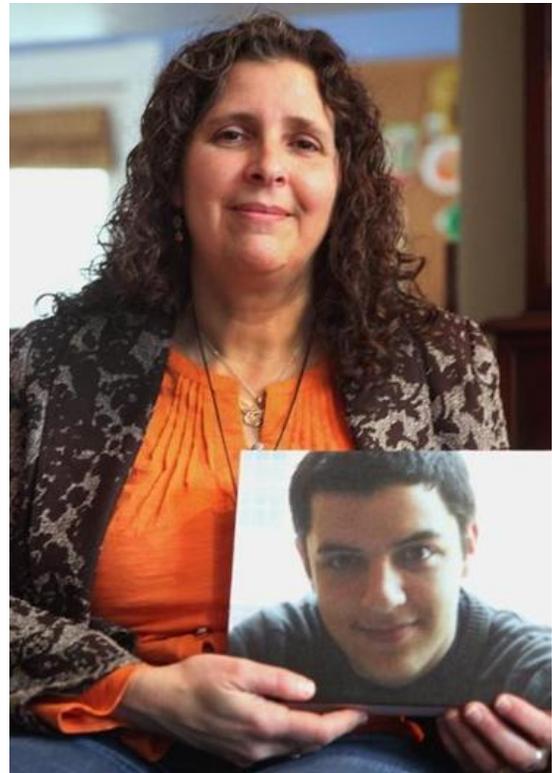
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It is both difficult and comforting to speak about Eitan, the middle of her three children, who was close to his brother, Gabriel, 23, and his sister, Shoshana, 16. He was on the wrestling team at Cambridge Rindge and Latin School, he loved video games, had lots of friends, and was artistic. Stern's home is full of ceramic pieces he made in high school.

For college, he wanted a warm climate and applied early to Miami, where he was pledging a fraternity. "He lived his life to the fullest," says his mother.

Stern believed her son had a "safe" epilepsy, since he always had his seizures while lying down, as he was awakening in the morning. She would later learn that Eitan's type actually has the highest rate of SUDEP, though even in this group it's uncommon.

Eitan's parents are divorced, and his father, Jeffrey Robbins, says that though he hadn't heard of SUDEP, he knew "in a vague sense" that seizures could be fatal. "It was a very high worry for me," says Robbins, who owns a software



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Cambridge resident Lise Stern holding a photo of her son Eitan Stern-Robbins, who died Unexpected Death in Epilepsy (SUDEP) on Valentine's Day 2013.

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When he was 15, Eitan himself wrote of his seizures: "They are also not life threatening, so even if I do have one, I can't die."

His father says he is grateful that Eitan didn't live in fear. And he doesn't blame his doctor for not spelling out his risk of death. "I don't think doctors find it easy to talk to their patients about death," Robbins says. "I get back to the pragmatics of it. Nothing would change the results [death], and Eitan was able to lead his life relatively unscathed by fear."

According to The Epilepsy Foundation, a nonprofit dedicated to helping those with the condition, SUDEP is a non-accidental death of a person with epilepsy — that is, no car crash or other trauma — "who was otherwise in a normal state of health" and an autopsy can find no other cause of death.

Epilepsy is a neurological condition, often of unknown origin, that causes seizures from electrical disturbances in the brain. The Epilepsy Foundation estimates that about 3 million Americans, or about 1 in 100, suffer such seizures. Eitan experienced grand mal, or full-body, seizures in which he would shake uncontrollably, become disoriented, and sometimes briefly stop breathing.

His neurologist at Children's, Dr. Mark Libenson, was not available for comment, according to a hospital spokesman. Dr. Phillip L. Pearl, director of the Department of Epilepsy and Neurophysiology at the hospital, says that statistics on SUDEP are hard to come by. "The figures are all over the place," he says. "But in general terms, the risk of SUDEP among those who have epilepsy is 7 percent over 40 years of the disease."

He stresses that most of epilepsy's fatalities are not SUDEP but are related to the underlying cause of the seizures, such as stroke or brain tumors, or accidents during a seizure, such as drownings, chokings, or car crashes.

"The notion of SUDEP has really gotten a lot more attention in the last 10 years," says Pearl. "More conferences are held, more studies have been done. There was a concern that this issue was in the closet, a little bit swept under the rug."

Seizure control is the major way of reducing SUDEP, Pearl says. "For me, if seizures are accelerating and getting more severe, then I think it's time to bring SUDEP up with the patient. It's important for people to be aware of this risk and be careful about taking their medication."

But Pearl emphasized that most people with epilepsy live full lives. "I know many physicians with epilepsy, including some neurologists. John Roberts, the chief justice of the Supreme Court, has epilepsy."

In the summer of 2012, after Eitan graduated from Cambridge Rindge and Latin, he had a seizure, his first in more than a year. His parents no longer called 911 each time, but this time, Stern did. "I didn't want to take chances," she says.



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Dr. Phillip L. Pearl is director of the Department of Epilepsy and Neurophysiology at Boston Children's Hospital.

But Stern wasn't about to simply stand by. "I forced his jaw open to get him to breathe again," she says. He was still convulsing, but began breathing. Doctors increased the drug he was on — Trileptal — which helped control his seizures but came with side effects that included fatigue and headaches.

On the morning of Feb. 14, Eitan's college roommate discovered him unresponsive in bed in their dorm room. His mother believes he suffocated as a result of a seizure. In a phone conversation a week before, he told her he'd had a few seizures at college but was handling things himself.

In June, The Epilepsy Foundation held a SUDEP workshop in New York for medical examiners, coroners, neurologists, and parents, aiming to increase awareness of the phenomenon so that it's accurately recorded on death certificates. "The need for a unified approach to SUDEP reporting is a pressing matter," the Foundation reported.

On Jan. 1, 2014, laws went into effect in New Jersey and Illinois that require education on SUDEP for and reporting by medical examiners. The Illinois law was named for Danny Stanton, a 4-year-old Chicago boy who died from SUDEP.

After Eitan's death, Lise Stern contacted his friends on Facebook to ask them to share stories about him, and to let them know about SUDEP. She says she doesn't blame the doctors who treated her son. But she does wish she'd known — and now wants others to know — about SUDEP.

"I say knowledge is safety," she says.

Dr. Ronald Thibert is a pediatric epilepsy specialist at Massachusetts General Hospital. Sometimes he tells parents about SUDEP, sometimes he doesn't. "It's a tough call," he says. "For the patients at high risk, we typically have that conversation. But it's a tricky question for low risk. Do we bring it up and bring undue worry if there's not a higher risk than getting in a car accident on the way home?"

An even trickier question is figuring out who exactly is at high risk of SUDEP. What is known is that the incidence rate is lower for patients who have responded to drugs and have infrequent seizures.

"The risk is not zero, but it is very low," says Thibert, who did not treat Eitan. "The fact is, we don't even know why it happens. Since we don't know what causes it, it is really hard to prevent it."

The SUDEP rate is known to be higher among those who have a genetic form of epilepsy, and those whose cases are so severe that they have surgery.

"It's one of the things that scares everyone the most," Thibert says. "We see lots of kids who have struggled, struggled, struggled and then they had a bit of a better time, and still had SUDEP."

Jeffrey Robbins believes that parents of children with epilepsy should ask doctors to better explain the risks. "Seek an open dialogue with your doctor," he says, "but be aware that this is an area of many unknowns."

A small Cambridge park that Eitan loved has been named for him, and at the dedication, his friends read some of his own words aloud, including his remarks about reaching out to others, especially someone sitting alone. "You never know, that person could be your new best friend or even your soul mate. Life's too short to be shy."

His mother would also like his legacy to include letting others know more about the condition that made Eitan's life too short indeed.

Bella English can be reached at english@globe.com.

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