

Living with Epilepsy

Lexi Crowe

Lexi Crowe, a grade 12 student at UCC, is a hockey superstar in the winter with the Kent County Fillies, and a baseball elite in the summer for Dover Centre. When she's not on the ice or field, she enjoys watching shows like Stranger Things, The Office, and Gossip Girl. On top of all that, Crowe lives with epilepsy.

"I was diagnosed with epilepsy when I was in the first grade. I had an absence seizure where I would just briefly stare several times in a day," explained Crowe. The older I got, the more frequent the seizures happened, I would still stare, but my head now turned to the right and I would usually fall forward as the seizure ended.

Crowe, being just a young girl when her seizures began, had trouble understanding her situation at first.

"I was too young to comprehend what was happening at the time. My mom had to explain to my friends later on what was happening to me." The ESWO educator came into my classroom and did a presentation on epilepsy awareness and first aid.

11 years later, the 18-year-old is still experiencing seizures, but of a different kind. Now they are focal dyscognitive and bilateral seizures and cause Crowe to lose consciousness and fall backwards with jerking movements of the arms and legs. They are triggered by heat and overexertion, which can, at times, limit the social, educational, and athletic activities Crowe can participate in.

The Crowe family has struggled with watching Lexi go through this difficult journey at such a crucial stage in her life. Her mother Becky explained how difficult it is to have her child miss out on things, like hockey games or parties, because if she has a seizure she has to come home to recover.

On January 14, 2019, Crowe had the Vegas Nerve Stimulator (VNS) surgery. The operation involves inserting a small battery under the chest wall, which produces mild pulses of electrical energy to the brain via the vagus nerve; "pacemaker for the brain." The decision to get the VNS done was because Lexi has been on almost every seizure medication with no long term control. At first, it was a scary decision for the family, but with the support they received from ESWO, they now they see it as "a possible life saver."

"When Lexi got the VNS, an ESWO Educator went into school to explain to the teachers the new technology. The school has always been very accommodating to any request we have for Lexi," said Becky.



ESWO continues to support the Crowe family in other ways, providing education to teachers, classmates and friends so that they know what to do in case of a seizure. Becky believes that teaching others about epilepsy is the best way to provide support and spread awareness about epilepsy.

“Education is key to saving lives,” she said. “There are so many questions that you have when your child has epilepsy, the ESWO has always been a great source of information and a wonderful connection to meet other families going through the same journey.”

It’s been a difficult journey for Crowe, but she is hopeful for the future of epilepsy. “It is hard accepting it at first, but later on you just have to live with it and live your life,” said the 18-year-old.

She feels that by increasing awareness about epilepsy, more people will begin to pay attention to it. “I want more people to acknowledge it and not be afraid of my seizures, that’s why I am doing this interview,” said Crowe. “I want people to understand what a seizure is and what to do about it.”