EPILEPSY NEW ZEALAND
Kia titiro ki te tangata | See the person

Ava's Story



EPILEPSY SMART SCHOOL HAD A POSITIVE IMPACT ON LEARNING

As any parent knows, coping with school can be tough enough on kids on a day-to-day basis without the added complication of a chronic illness and its effects. For thirteen-year-old Ava Beck, who struggled with learning in primary school due to epilepsy, her experience at school was made much easier after her school, Berwick Primary, became an *Epilepsy Smart School*.

Ava has had epilepsy since she was nine years old, although it was some time after her first seizure that she was diagnosed with the condition. "She had a seizure one night after basketball training," says Ava's mum, Lisa, "although we didn't know it was a seizure at the time and she was conscious through it. She just said she felt sick, which we now know was an aura, or feeling, that always precludes one of her seizures. She then went on to have several more seizures over the next week and, one night, we had to take her to the emergency department at the hospital."

"Ava saw her GP, and then was referred to a pediatrician who ordered an EEG and prescribed medication, but that didn't work. She was then referred to a neurologist who specialises in epilepsy, who ordered extensive testing, including a PET scan, an MRI and a video EEG at the Royal Children's Hospital. Ava was finally diagnosed with focal epilepsy, but it took several months to get the diagnosis."

Lisa says, in addition to managing Ava's epilepsy and its effects on her health and lifestyle during this difficult time, she also became aware of the way in which the epilepsy was affecting her daughter's schooling. "Ava missed a lot of Year 4. She was tired for much of the time due to the number of seizures she was having as well as from the different medication she was taking. Her schooling really suffered."

"In that first year, Ava was having multiple seizures, which required many trips to hospital and absences from school, and the medication just wasn't working. It took over a year of tests and trialing different medication to find the right medication that was able to stop the prolonged seizures with as few side-effects as possible, so that she could get back to a more 'normal' life."

"During that year, the school was really helpful," Lisa says, referring to Berwick Primary School. "They used to send work home for her and they were very understanding about it. Then when Ava was in Year 5, the school became an *Epilepsy Smart School*, which was an incredible commitment to understanding and meeting Ava's needs at school and boosted their level of support for her to a whole new level."

According to Michele Barry, project manager for Epilepsy Foundation Australia's *Epilepsy Smart Schools* program, Berwick Primary School was one of the first Australian schools to become *Epilepsy Smart*.

"Unfortunately, not all schools are as proactive as Berwick Primary, with less than 5 percent of the 9,500 schools across the nation properly trained in coping with and understanding the needs of students with epilepsy.

"Research shows 1 in 200 students has epilepsy, meaning it is likely that every teacher in Victoria will teach a student who has epilepsy at some stage," Michele says. "Many teachers would be surprised by how epilepsy can affect a child's learning – it's not just missing school due to days absent with illness, or knowing seizure first aid. Epilepsy is so much more than just seizures," she says.

Michele says some of the effects of epilepsy on students can include cognitive overload (e.g., finding it hard to keep up at school), which can cause seizures, difficulty concentrating and remembering new information, side-effects from medication and tiredness. Some children with epilepsy also have a co-existing developmental condition (e.g., Autism).

Children can also face obstacles at school such as not being able to participate in activities, such as sports and camps, missing classes, embarrassment due to seizures, seizure behaviours or accidents and anxiety, depression and moodiness, including anger and frustration from seizures or medication.

"First aid training is not enough – beyond seizures and daily medication, teachers need to understand the psychological, social and cognitive impact epilepsy can have and adapt their teaching methods accordingly."

Once Berwick Primary School Principal, Kaye Seton, identified she had a student living with epilepsy enrolled at her school, Ava, she knew she had a duty of care to support her. Importantly Kaye knew that she needed to ensure her teaching staff understood the learning needs of Ava and any other current or future students with epilepsy.

"Our school decided to become an *Epilepsy Smart School* to learn more about the impact of epilepsy and ensure we were managing our duty of care," Kaye says.

"When we became an *Epilepsy Smart School* it gave me a lot more confidence to be able to support a child with epilepsy," says Michael, a teacher at Berwick Primary School.

There are three steps to becoming a recognised *Epilepsy Smart School*: schools need to hold specific epilepsy management plans for each known student with epilepsy. Teachers then need to participate in epilepsy-specific training to understand epilepsy and manage a child's epilepsy, especially if the child needs emergency medication. They then undertake either an event, such as a Purple Day activity, or a curriculum-based learning project, designed to raise awareness of epilepsy in the school community and reduce stigma.

Lisa Beck says when Berwick Primary School became an *Epilepsy Smart School*, they were even better at supporting Ava. "Having the school trained in Ava's specific needs, especially around her Epilepsy Management Plan and her Emergency Medication Management Plan, meant they knew how to administer Midazolam if she needed it. It gave me peace of mind."

"They also learned about how Ava's seizures made her tired and affected her learning. They learned what her triggers were such as over-heating and stress. They also learned that when she has an absence seizure, the teachers needed to make sure they repeated information for her, but to do it in a way that did not obviously single her out from other students."

"They use iPads at her school, so the teachers made sure any new work was on her iPad so she could look at it at home and refer back to it. They gave her time to complete what she was working on, which, in turn, gave her more confidence. It helped me to know that they were more aware of what to look for."

Berwick Primary School also organised a Purple Day event for the school community to create more awareness of epilepsy and help to create a more inclusive and accepting environment for Ava.

Michele says, "There is a real need for schools to exercise their duty of care under the Australian Government's Disability Standards for Education 2005 framework, to create safe and supportive educational environments for the thousands of students with epilepsy. Berwick Primary is a great example of how the *Epilepsy Smart Schools* program can help students like Ava."

Lisa says, "Ava definitely had a much better time at school in Year 6. She was attending more, her seizures were better controlled, she was on the right medication and was just a lot healthier. She was also feeling more secure and comfortable at school with the teachers, knowing they were trained in the management of her seizures. Ava has now started high school and is doing well."

© 2026 Epilepsy NZ