

Submission to the Senate Inquiry into Epilepsy in Australia

Submitted to: Committee Secretary

Senate Standing Committees on Community Affairs

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Submitted by: Parent and Primary Carer (Anonymous)

Location: Victoria, Australia

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Dear Committee Members,

I am writing this submission as the parent and primary carer of a child living with severe epilepsy and multiple disabilities. My child has epilepsy, Autism Spectrum Disorder – Level 3, intellectual disability, and a rare genetic condition. They also have very limited ability to communicate and cannot reliably tell us when they feel unwell or if something is wrong.

For our family, epilepsy is not simply a medical diagnosis that appears occasionally in our lives. It is something that shapes every day and every night. My child experiences frequent seizures, including during sleep, while falling asleep, and particularly upon waking. These seizures significantly affect their ability to learn, develop, attend school consistently, and participate safely in everyday activities.

The seizures also create significant safety risks. My child has experienced several falls related to seizures and has sustained injuries including hitting their head and fracturing their knee. Because seizures can happen suddenly and without warning, constant supervision is necessary to reduce the risk of injury. Even with close supervision, accidents still occur.

Epilepsy has a profound impact on participation in daily life. Some days my child is able to attend school and engage in learning, but on other days seizures make this extremely difficult. Even when they are present at school, seizures and the fatigue that follows can interrupt their ability to participate or concentrate. Children with severe epilepsy are often trying to learn and develop while their brain is constantly being disrupted by seizures.

One of the most challenging aspects of managing epilepsy is the gap between the health system and disability support systems. Epilepsy is typically considered a medical condition and therefore sits within the health system. However, the safety and supervision needs created by seizures are clearly part of daily functioning and disability support.

Our child does receive some supports through the NDIS for their other disabilities, but epilepsy-related needs are often excluded because seizures are considered a medical issue. At the same time, the public health system does not provide in-home supervision or carers to help manage epilepsy-related safety risks. Families can therefore find themselves in a position where neither system fully recognises or supports the reality of living with severe epilepsy.

Another major challenge is access to safety and monitoring equipment. Because my child cannot communicate symptoms and experiences seizures during sleep, monitoring technology could play an important role in safety and peace of mind for families. However, this equipment is extremely difficult to access. It is generally not funded through the public health system and is often not recognised by the NDIS as necessary disability support.

Equipment that may be needed for safety can include seizure monitoring devices, seizure detection mats, oxygen saturation monitors, wearable seizure alerts, night-time monitoring systems, and other assistive technologies designed to detect seizures or alert carers. These devices are often very expensive and can cost thousands of dollars, placing them out of reach for many families.

There are also other practical supports that could significantly improve safety and participation. Because seizures frequently cause falls, protective equipment such as helmets and knee pads may be necessary to reduce the risk of injury. Clothing designed to support participation can also be important. For example, waterproof outerwear or overalls can allow children who are prone to falling during seizures to safely spend time outdoors without becoming wet and cold.

For children who fall frequently, particularly in winter, the risk of falling onto wet ground can limit time outside and restrict opportunities for play and participation. With appropriate protective equipment and clothing, many of these limitations could be reduced.

The emotional impact of caring for a child with severe epilepsy should also be acknowledged. As a parent, it can feel like living in a constant state of alertness. Seizures can happen at any time, and night-time can be particularly difficult because seizures occur during sleep and upon waking. It is hard to sleep deeply when you are always listening and watching for signs that something might be wrong.

Living with this level of vigilance over long periods can take a significant toll. The lack of sleep, constant stress, and responsibility for monitoring seizures can contribute to ongoing anxiety and exhaustion. For many parents, this ongoing pressure can also lead to periods of depression.

Families caring for children with severe epilepsy are not expecting systems to remove every challenge. However, we do hope for recognition and practical support that reflects the real impact epilepsy has on daily life.

Epilepsy can be a very life-limiting condition. Not necessarily because it shortens life, but because it can significantly limit safety, independence, learning opportunities, and participation in everyday experiences that other children take for granted.

Greater recognition of epilepsy within disability support systems, particularly when seizures create substantial supervision and safety needs, would make a meaningful difference for families like ours. Clearer pathways for funding seizure monitoring equipment and safety supports would also improve safety and reduce some of the burden currently carried by families.

Better coordination between healthcare services and disability supports would help ensure families are not left navigating gaps between systems when trying to access essential supports.

Children living with severe epilepsy and complex disabilities are among the most vulnerable members of our community. Behind every seizure disorder is a family working constantly to keep their child safe while also trying to support their development, education, and quality of life.

I appreciate the opportunity to contribute to this inquiry and hope that it leads to greater recognition of the real-world impact of epilepsy for children and families across Australia.

Yours sincerely,
Parent and Primary Carer (Anonymous)