

PART 2:

SOCIAL CONSEQUENCES OF EPILEPSY



An agency of the Government of Ontario
Un organisme du gouvernement de l'Ontario

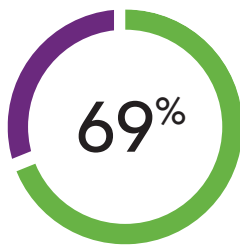


Introduction

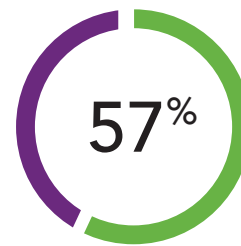
Students living with epilepsy can display: poor social processing (e.g., reading facial cues, understanding language nuances, taking perspective), lower level of functional independence, and lower educational status which can make it difficult for them in the social realm.

They may also remove themselves from social situations to avoid having an unpredictable or embarrassing seizure in front of their peers. This worry can be significantly reduced through teacher and classroom preparedness. If everyone knows what to expect prior to a student having a seizure and how to help when a student has a seizure the collective response can be reassuring and calming. It can reduce the worry of the student with epilepsy, their parent(s), teacher(s) and classmates.

Social stigma is common in epilepsy and can lead to a child having low self-esteem and a reduction in motivation to engage with school learning and activities (Elliott et al., 2005).



In an Ontario survey, 69% of parents (99/144) felt that their child with epilepsy was not doing well socially (ESWO, 2018).



In the same survey 57% of parents (82/144) were worried that their child with epilepsy would be teased or bullied at school (ESWO, 2018).

Children who do not socialize or interact with their peers are at risk for poor outcomes as adults (Camfield et al., 2014). Often the effects of seizure activity, medication and close adult supervision will have delayed the development of independence and emotional self-control in a child with epilepsy. To meet the social-emotional competence of their peer group, children with epilepsy may need more support.

Childhood-onset seizures can impact the development of basic and complex cognitive skills that form the core foundation for long term educational, vocational and interpersonal adaptation (Smith et al., 2013).

- In some students with epilepsy, typical developmental milestones may have been missed and may need to be re-taught.
- Throughout development, children are learning to share and to socially interact with others. Due to their epilepsy, some children may not have acquired these important skills and may have difficulty with social interaction. They may appear self-focused and not play well with others.
- They may experience emotional or behavioural outbursts after relatively small issues because they do not have the social skills or emotional control to deal with their peers.
- They may experience severe separation anxiety when they are away from their parents and/or withdraw socially and isolate themselves from their peers.

Adult Overprotection and Restrictions at School

Students may experience reduced autonomy due to ongoing seizures and the need for greater adult supervision.

A parent or teacher may overprotect the student with epilepsy as a way to cope with the unpredictable nature of seizures. Conversely, children and youth living with epilepsy may become over-reliant on parents or teachers.

Fearing that the student is not safe or will be injured, a parent or teacher may restrict the student's activities and remove them from social encounters, recreation and school programming (Elliott et al., 2005).

Adult monitoring and placing restrictions on age/appropriate activities suggest to the students that they are not "like other children", that the world is a dangerous place, and that they are not capable of doing things on their own. The restrictions can cause the student with epilepsy to experience discontinuous and fragmented learning, to feel helpless or to withdraw from social groups.

Asking parents whether their child's health care provider has placed restrictions on activities, and if so for what, can help to ensure students engage in the activities they are capable of doing.

Strategies to Support the Development of Autonomy and Prosocial Skills

Checklist:

- Provide opportunities that will help the student develop a sense of mastery.
- Support the development of decision-making skills and resiliency.
- Model and explicitly teach appropriate social behaviour.
- Teach alternative behaviours to achieve the student's social goal (e.g. other ways to gain attention, other ways to create fun).
- Model ways of showing interest and respecting personal space.
- Incorporate "Social Mapping" to support the student's understanding of what is acceptable and how to meet the expectations.
- Encourage involvement in extracurricular activities of interest.

References:

- Camfield, P. R., & Camfield, C. S. (2014). What happens to children with epilepsy when they become adults? Some facts and opinions. *Pediatric neurology*, 51(1), 17-23.
- Elliott, I. M., Lach, L., & Smith, M. L. (2005). I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & behavior*, 7(4), 664-678.
- ESWO (2018). Living with Epilepsy: Voices from the Community, www.clinictocommunity.ca
- Smith ML, Gallagher A, Lassonde, M. Cognitive Deficits in Children with Epilepsy. In Duchowny M, Cross H, Arzimanoglou A (Eds.). *Pediatric Epilepsy*, New York: McGraw-Hill, 2013, pp. 309-322.