

Childhood epilepsy and mental health

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Overview

This fact sheet provides basic information about the links between epilepsy and mental health difficulties in children. It can be used as an accompaniment to the [Understanding child mental health and chronic physical conditions](#) e-learning course, which highlights the links between chronic illnesses/conditions in childhood and associated mental health difficulties.

This fact sheet covers general information about epilepsy, as well as details such as prevalence in Australia and the implications of the condition for children, including mental health impacts. Some content also pertains to adults.

Key points include:

- Epilepsy is an umbrella term for a family of disorders that comprise various types of seizures.
- An estimated one in 200 Australian children aged 0–12 years has epilepsy.
- While some children grow out of epilepsy, or their seizures can be managed, epilepsy may have significant impacts on quality of life and physical and mental health and wellbeing, and may reduce life expectancy.
- Support from family and health professionals can help children manage their epilepsy, enhance their quality of life, and improve their mental health and wellbeing.



What is epilepsy?

Epilepsy is an umbrella term for a diverse family of disorders that comprise many seizure types and frequencies. Seizures are changes in motor function, sensation and/or consciousness that are the consequences of abnormal synchronised electrical messages in the brain (Martini, 2010). Seizures can be focal and arise in one part of the brain, or they can be generalised and arise on either side of the brain (Royal Children's Hospital, n.d.).

Onset of epilepsy more often occurs during childhood or in later adulthood, however it can be diagnosed at any age (Epilepsy Foundation, 2019). Globally, most incidence studies show that epilepsy is more commonly found in males than females (Neligan & Sander, 2013), with an association between lower socioeconomic status and higher prevalence (GBD Epilepsy Collaborators, 2016).

What is the prevalence of epilepsy in Australia?

Estimating the prevalence of epilepsy can be complex, with stigma and lack of awareness of the condition affecting disclosure and survey data, suggesting that the prevalence could be higher than estimated (Epilepsy Australia & Deloitte Access Economics, 2020). In Australia, estimates suggest that one in 20 children aged 0–12 (5%) will have a seizure during childhood, and one in 200 children have

epilepsy (Royal Children Hospital, n.d.). About 1% of the whole population is estimated to have epilepsy (Epilepsy Foundation, 2019). There is a peak in prevalence of epilepsy in the 5–9-year age range, and then again in people over 80 years (GBD Epilepsy Collaborators, 2016).

Epilepsy across the globe

Worldwide, epilepsy is one of the most prevalent neurological diseases: an estimated 50 million people have the condition (World Health Organization, 2019).

What are the implications of epilepsy for the child?

Use of antiepileptic medication is common in treatment of children with epilepsy. Some children and adults with epilepsy may also have surgery if medication is not effective (Epilepsy Australia, n.d.). A commonly asked question among parents of newly diagnosed children is, 'Will my child outgrow their epilepsy?'. Many children do outgrow epilepsy, depending on the cause and type of epilepsy and response to treatment. In 70% of children, medication can be withdrawn without later relapse (Epilepsy Action Australia 2019; Royal Children's Hospital, n.d.).

Children who experience paediatric illness and chronic disease, such as epilepsy, are at greater risk of failing to achieve the developmental milestones of young adulthood (Maslow, Haydon, McRee, Ford, & Halpern, 2011; Pinquart, 2014). Children with epilepsy are more likely to experience difficulties with school and lower academic achievement (Bujoreanu, Ibeziako, & Demaso, 2011), leading to poorer educational and vocational outcomes in young adulthood (Maslow et al., 2011).

A systematic review investigated the experience for epilepsy for children and young people under 21 years (Chong et al., 2016). Children reported feeling emotionally vulnerable, and experiencing challenges managing medication. Key impacts of epilepsy for children and young people were found to include:

- loss of privacy (e.g. needing to declare the illness; sense of humiliation and embarrassment)
- bodily powerlessness (e.g. susceptibility to injury, such as hitting one's head in a fall; memory loss; fatigue; loss of control; awareness of own mortality); and
- inferiority and discrimination (e.g. being vulnerable to prejudice; feeling a sense of abnormality and limited social freedom; challenges with academic achievement; parental shame) (Chong et al., 2016).

The risk of premature death in people with epilepsy is three times greater than the rest of the population (WHO, 2019). Premature death may occur for reasons such as head injury, but it may also be of unknown cause. One in 4,500 children are at risk of Sudden Unexpected Death in Epilepsy (SUDEP), where a child dies prematurely, suddenly, and where no reasons for their death can be identified (Epilepsy Action Australia, n.d.). Risk of SUDEP increases depending on type and frequency of seizures.

Receiving healthcare that is responsive and empathic may help children through challenges they encounter with epilepsy, and help them to better manage their illness. Some children have reported feeling empowered as they gain a sense of control over their epilepsy (Chong et al., 2016).

What are the mental health impacts of epilepsy?

Epilepsy is a chronic physical illness that can be challenging for both the child and their family. A child with epilepsy may present with emotional and behavioural difficulties, and is more likely to experience adverse mental health impacts and a lower quality of life (Puka & Smith, 2015). A review of literature found that children with epilepsy experience a range of physical, emotional and social challenges (MacKinnon, Roberts, & Wylie, 2016). Children with epilepsy may experience excessive fatigue, heightened levels of stress in coping with the unpredictability of the condition, and feelings of social isolation linked to experiences of bullying and social exclusion. They may feel different to their peers and lack self-confidence. Over time, experiences of bullying can reinforce negative self-perceptions. Children may be fearful of participating socially, or parents may impose restrictions and high levels of monitoring, which can reduce a child's sense of autonomy (MacKinnon et al., 2016).

Children with epilepsy are 1.5 times more likely to develop a range of psychiatric disorders in adolescence or later in life – such as schizophrenia, mood disorders, anxiety, and stress-related disorders – and are at greater risk of alcohol abuse later in life (Dreier, Pedersen, Cotsapas, & Christensen, 2019). A meta-analysis estimated the prevalence of anxiety in young people aged 0–18 with epilepsy to be 18.9%, while depression prevalence in young people with epilepsy was estimated at 13.5% (Scott, Sharpe, Loomes, & Gandy, 2020). People with epilepsy are also at increased risk of suicide, compared to the general population (Abraham et al., 2019).

Paediatric epilepsy is associated with lower cognitive functioning (Bujoreanu et al., 2011) and a high prevalence of neurobehavioral comorbidities, with several population-based studies finding 23–40% of children with epilepsy were also diagnosed with

attention deficit hyperactivity disorder (Williams, Giust, Kronenberger, & Dunn, 2016).

A useful metric in assessing psychosocial wellbeing is the Health-Related Quality of Life (HRQoL) which encompasses physical, mental, emotional and social wellbeing domains, and offers an understanding of the child's and parents' self-perceptions of enjoyment and satisfaction with life (Sabaz et al., 2000). After being diagnosed with epilepsy, many children experience initial reductions in HRQoL. For most children HRQoL improves over roughly two years, though for others HRQoL can decline. Factors that predict an improved HRQoL include an absence of cognition problems, fewer antiepileptic drugs, and better family environment (Speechley et al., 2012). Parental anxiety and seizure frequency are strongly associated with reduced HRQoL, both of which are amenable to intervention (Ferro, 2014).

Both epilepsy and mental illness are highly stigmatised conditions. The negative impacts of stigma on quality of life and treatment adherence are well known, with stigma also acting as a barrier to help seeking behaviour (Mula & Kaufman, 2020). The frequency of co-occurring epilepsy and mental health conditions can lead to a phenomenon known as double stigma, whereby perceived stigma (stigma experienced by an individual) is a risk factor for anxiety and mood disorders, and in turn, these disorders are a risk factor for perceived stigma (Mula & Kaufman, 2020). While limited research exists on this phenomenon, especially with children, the potential for double stigma is worth considering in terms of its impact on wellbeing.



What impact does epilepsy have on families?

Parents of children with epilepsy are reported to have lower HRQoL (Jones & Reilly, 2016) and higher levels of anxiety compared to parents of healthy children (Jones & Reilly, 2016; Thompson & Upton, 1992). They may also experience depression (Thompson & Upton, 1992), as well as stress and other psychological concerns (Ellis, Upton, & Thom, 2000). Family functioning can be impacted when there is a child with epilepsy in the family (Ellis et al., 2000), and families report concerns with restricted social lives (Ellis et al., 2000; Puka, Ferro, Anderson, & Speechley, 2018; Thompson & Upton, 1992). Families may also experience marital problems, stigma and reduced self-esteem (Ellis et al., 2000).

Conclusion

Epilepsy can have significant implications for children's overall development and wellbeing, including ongoing mental health concerns. Early identification of these concerns and access to professional services, including allied health practitioners and social workers, offers the potential to alleviate the challenges for children and their families. Further information about the impact of chronic conditions on mental health can be found within the [Understanding child mental health and chronic physical conditions](#) e-learning course.

Where can I go for further information on epilepsy?

[Epilepsy Action Australia](#)

A source of epilepsy information and support, as well as provider of education and a research organisation. Epilepsy nurses are available on 1300 374 537 (1300 EPILEPSY) from 9 am to 5 pm, seven days a week.

[Epilepsy Australia](#)

A coalition of Australian epilepsy organisations, Epilepsy Australia provides information and resources for the public, and lists sources of research, policy and training. Epilepsy support workers can be contacted on the Epilepsy Australia National Helpline 1300 852 853.

[Epilepsy Foundation](#)

Foundation with information, support, education and training. The 1800 761 487 information line is available 9 am to 5 pm Monday to Friday.

What are some other supports for children and families?

[Beyond Blue](#)

Beyond Blue provides information and support to help everyone in Australia to achieve their best possible mental health. The service supports those experiencing depression, anxiety or going through a difficult time. The phone service 1300 224 636 operates 24/7, while the website offers online chats, email support and online forums.

[GP and psychologist](#)

Families can consult with their local health professional to get access to specialised support.

[Healthdirect Australia](#)

Healthdirect is a national, government-owned, not-for-profit organisation supporting Australians in managing their own health and wellbeing through a range of virtual health services. Health advice is available on 1800 022 222.

[Kids Helpline](#)

Kids Helpline is a free, private and confidential 24/7 phone and online counselling service for children aged 5–12 years and young adults aged 18–25. Qualified counsellors are available via phone on 1800 551 800 or via WebChat or email.

[Lifeline](#)

Lifeline is a national charity providing all Australians experiencing emotional distress with access to 24-hour crisis support and suicide prevention services. Available via phone on 13 11 14.

[Parentline](#)

Parentline is a confidential telephone service providing professional counselling and support in Queensland and the Northern Territory. Available via phone on 1300 301 300.

[Raising Children Network](#)

Raising Children Network is a comprehensive and trusted online resource for parenting information. A website includes information on children's health and wellbeing across the ages. It includes videos, fact sheets and downloadable toolkits on child development, behavioural problems and health issues.

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