EPILEPSY ACTION

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# Paediatric Epilepsy

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## Seizures, epilepsy and driving

A tragic story in July 2023 would almost certainly have caught many people's attention and particularly those with epilepsy and those caring for and treating them. It involved a 48-year-old woman who stated that she had no recollection of what took place when her SUV went through the fence of a school and killed two eight-year-old girls. The initial police investigation concluded that she had experienced an epileptic seizure at the wheel of her car and lost control. She had not previously experienced any type of seizure-like episode. The initial police conclusion was challenged by the headteacher and the girls' parents, and following a repeat investigation in November 2024, she was re-arrested for dangerous driving and then bailed. The case remains under investigation. This case came to mind when reading a commentary on a paper in 'Epilepsy Currents' published by the American Epilepsy Society [Milligan, 2024].

Regulations about seizures, epilepsy and driving have remained largely unchanged for some years. In the UK, a person may not drive a car or motorbike and will have to give up driving (and surrender their licence) for periods that depend on the type of seizure and when it (they) occurred. These are summarised below. If someone has had:

### Epileptic seizures while awake and lost consciousness

The licence must be surrendered. It can be re-applied for if there hasn't been another seizure for at least a year.

### A seizure because a doctor changed or reduced anti-seizure medication. A licence can be re-applied for when:

- the seizure was more than six months ago
- the person has been back on their previous medication for six months
- the person hasn't had another seizure in that time

### A first-ever seizure while awake and lost consciousness

The licence is taken away and can be re-applied for when both the following are true:

- the person hasn't had a seizure for six months
- the DVLA's medical advisers decide there is a low risk of another seizure

### Seizures while asleep

The person may still qualify for a licence if the only seizures that have occurred during the past three years have been while asleep. The DVLA will let the person know whether or not they qualify after the form (FEP1) has been completed. The person must not drive until they have heard from the DVLA.



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### Seizures only while asleep

The person may still qualify for a licence if it has been 12 months or more since the first seizure. The DVLA will let the person know whether or not they qualify after the form (FEP1) has been completed. The person must not drive until they have heard from the DVLA.

### Seizures that do not affect consciousness

The person may still qualify for a licence if the only type of seizure they have had has been where:

- they were fully conscious and aware of what was happening around them
- they were able to move and did not lose control of their movements

The first seizure must have been 12 months ago or more.

The DVLA will let the person know whether or not they qualify after the form (FEP1) has been completed. The person must not drive until they have heard from the DVLA gov.uk/epilepsy-and-driving (accessed 24th February 2025)

It is important to understand that it is the DVLA, and not the patient's medical advisors (GP or hospital consultant), that make any decision to either allow or bar licensing. The patient has a clear and legal obligation to inform the DVLA of their epilepsy and this is regardless of any clinical or domestic circumstances or extenuating factors. The obligation on the doctor is to inform the patient about the regulations and their requirement to inform the DVLA. This instruction should be recorded in the medical notes, to avoid claims of negligence.

These regulations have been established to prevent or reduce road traffic accidents (RTA) in people with epilepsy and which may cause serious injury to themselves or to others. Such accidents also have implications for the cost of car insurance, not only for people with epilepsy but, potentially, all drivers in the UK. Clearly, most of the above regulations apply if someone is known to have epilepsy and is already driving or if they are about to apply for a driving licence. The situation is different if someone is already driving but has not been diagnosed as having epilepsy when they have one or more seizures. This includes people who may have experienced one or more episodes and who didn't seek medical advice or where medical advice was sought but the doctor (initially their GP) considered that the episodes were not epileptic seizures or anoxic seizures caused by a cardiac arrhythmia. An additional factor is where a health professional has failed to correctly identify epileptic seizures and particularly where the seizures have been subtle, brief and non-motor seizures.

A recent study from the US found that 5% of individuals with focal epilepsy experienced seizures while driving (SzWD) prior to a diagnosis of epilepsy [Bases et al, 2023]. In this study, the authors identified 23 people of 447 participants (5%) who had experienced one or more SzWD before they were diagnosed with epilepsy; the 23 people had experienced a total of 32 seizures. For six of the 23 people, the seizure while driving was reported to be their first-ever seizure, 14 (61%) had experienced seizures before their first SzWD and the remaining three (13%) did not report or could not remember whether the SzWD was their first life-time seizure. Twenty seven of the 32 seizures (84%) were focal seizures with impaired awareness. Fourteen of the 23 participants (60.9%) had experienced one and four had experienced at least two motor vehicle accidents (MVAs) with a SzWD prior to their diagnosis of epilepsy (RTA and MVA: 'The un-intended collision of one motor vehicle with another, a stationary object or person that results in injuries, death and/or loss of property': medical-dictionary.thefreedictionary.com/MVA%2FRTA (accessed 30 March 2025).

Of the 19 SzWD-related MVAs, 11 (57.9%) resulted in hospitalisations. The injuries were: one bitten tongue, one dislocated thumb, one fractured sternum, one cerebral haemorrhage and one near-drowning with an anoxic injury which did not result in a fatal outcome. Six participants (26.1%) were unable to recall whether they had sustained any injury as a result of their SzWD MVA.

After adjusting for sex, family history, seizure semiology, seizure awareness, onset age, and time to diagnosis, two factors were found to be significant predictors of experiencing a pre-diagnostic SzWD. The first was employment with an almost four-fold increased risk in those who were employed (95% CI 1.2–13.2, $p = 0.03$); the second was seizure semiology with focal non-motor seizures being associated with an almost 5-fold increased risk (95% CI 1.3–17.6, $p = 0.02$). There may be a number of reasons why employment was a risk factor; a likely one may have been not wishing to disclose a seizure and particularly if the employment was dependent on having a driving licence. Disclosure might result in having to give up their licence. In the 24 years that we ran a transition epilepsy clinic for young people with epilepsy (aged 17-22 years), I can recall two young people with epilepsy that had been poorly-compliant with anti-seizure medication and were involved in a minor RTA. They did not disclose their epilepsy for fear of losing their licence and their subsequent independence. The obvious reason for the other factor (non-motor focal seizures) identified in the US study [Bases et al, 2023] is that this seizure type, particularly if brief, might be dismissed by the person because they did not feel they were anything significant for which to seek advice. It is also possible that, when medical advice was sought, the doctor did not consider that they were epileptic seizures.

The authors then extrapolated their findings to the whole country. Based on a US population of just over 200 million aged 16-64 years, and the annual incidence of epilepsy [Fiest et al, 2017], there are roughly 126,180 people of

driving-age diagnosed with epilepsy each year. This indicates that if the authors' data are generalisable, approximately 6,500 people per year experience pre-diagnosis SzWD which would result in almost 4,000 MVAs and over 2,200 hospitalisations. Much of this may be preventable with earlier diagnosis.

Finally, in the USA approximately 0.1-1% of MVAs per year are estimated to be the result of SzWD. Most of these data reflect accidents that had occurred in people with an established diagnosis of epilepsy; the contribution from people with as yet undiagnosed epilepsy is unclear [Kang and Mintzer, 2016]. To put this into perspective, this 1% incidence of MVAs is considerably lower than accidents caused by substance abuse, speeding or distraction (e.g. because of using a mobile phone) but is still significant. This situation is likely to be similar to that in the UK, although there are no directly comparable and contemporary data.

A similar, but not identical study was undertaken in Great Britain over 30 years ago [Taylor et al, 1995]. Collaborating neurologists provided a central office with clinical information, driving experience and accident rates in all drivers they counselled after diagnosing seizures or other unexplained episodes of loss of consciousness. Each patient received and was asked to return a notification slip to the DVLA. Of 638 patients counselled, 70 (11%) had been involved as a driver in an RTA in the previous year; in six of the 70 patients, the accident had caused serious injury. These estimates do not differ from those expected in a population of drivers who did not have epilepsy with the same age and sex distribution. Of patients counselled, 27.1% returned a reply slip to the DVLA. Notification was more likely if the patient was aged 50 or over at the time of counselling, if the counselling was undertaken by a consultant, if an accident had occurred in the previous year and if the subject had also been advised to start or was already taking anti-seizure medication. Patients counselled after a single seizure were more likely to notify than those with a diagnosis of epilepsy.

A number of questions arise out of many similar studies, the primary one being; are drivers with epilepsy more likely to experience an accident than people without epilepsy? A large study undertaken in the UK and published in 1996 [Taylor et al, 1996] found that, after adjustment for differences in age, sex, driving experience, and mileage between the two populations, there was no evidence of any overall increase in risk of accidents in the population of drivers with a history of epilepsy. However, there was an increased risk of more severe accidents in those with epilepsy; severe was crudely defined as requiring hospitalisation. This was increased by about 40% for serious injuries (defined as requiring hospitalisation) and there was evidence of a twofold risk of increase in non-driver fatalities. Clearly, these data are again almost 30 years old and it is unclear, but probably unlikely, that this pattern persists today.

A much more recent and large systematic review [Naik et al, 2015] concluded: "The evidence for the difference in MVA rates in drivers with epilepsy compared to the general population is inconsistent and therefore no conclusion can be made. Important methodological differences across the studies contribute to the imprecision. Future research should be performed using objective measures rather than self-reporting of MVAs by drivers with epilepsy and 'miles driven' as the denominator to more appropriately calculate the rate of MVA."

## Conclusions

- It is crucial that the correct diagnosis of epilepsy and its type has been established before a young person (or adult) applies for a driving licence.
- It is important that the young person's (or adult's) doctors (GP and/or hospital specialist) provide the young person with the correct information about epilepsy, compliance with their anti-seizure medication and latest driving regulations and direct them to the DVLA website. This information must include what to do if they experience a seizure or any other type of episode after they have started to drive, which includes contacting their GP or hospital specialist as soon as possible.
- It is important for a GP to review any young person (or adult) who is already driving and who then has any unexplained episodes of impaired consciousness (awareness) and/or abnormal movements as soon as possible.

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# Forthcoming courses and conferences

The following are details of forthcoming conferences and courses in epilepsy and general paediatric neurology.

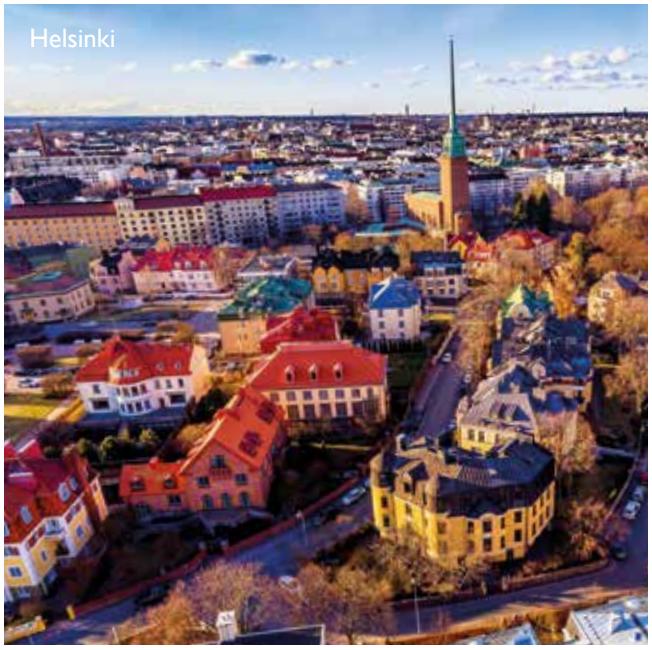
**2025**

**June**
20
The Comorbidities of Epilepsy Course
London, UK and online
*bit.ly/45cDkVk*

21-24
11th Congress of the European Academy of Neurology
Helsinki, Finland
*ean.org/congress2025*

**August-September**
30-3
36th International Epilepsy Congress
Lisbon, Portugal
*ilae.org/congresses/36th-international-epilepsy-congress*

**September**
4-6
5th International Congress on Mobile Health and Digital Technology in Epilepsy


Helsinki


Bournemouth

Copenhagen, Denmark
*na.eventscloud.com/website/74027/*

14
ILAE British Young Epilepsy Section (YES) Early Career Building Day
Bournemouth, UK
*bit.ly/43cogo6*

15-17
ILAE British Branch 2025 Annual Scientific Conference
Bournemouth, UK
*ilaebritishconference.org.uk*

17-19
9th Global Symposium on Ketogenic Therapies
Paris, France
*keto-paris-2025.com*

**2026**

**May**
3-6
18th Eilat Conference on New Antiepileptic Drugs and Devices
Madrid, Spain
*bit.ly/3Wq6dcc*

EPILEPSY ACTION

# We need more experts to join our forces!

Our health information needs professional feedback to continue to be PIF tick accredited.

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This is a great opportunity for your CPD portfolio as well as making a huge difference to people affected by epilepsy.

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*Patient Information Forum*

# The epilepsy surgery pathway: experiences of children and their families and key outcomes

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**Overview**

The aim of this article is to provide an overview of the experience of children and their families under the care of the epilepsy surgery team to evaluate whether a surgical procedure, and specifically resection of a lesion, would be a suitable treatment option for their seizures. It will briefly outline the surgery pathway and summarise key points from the literature on the patient and family experience, the impact on the child's emotional wellbeing, and surgery outcomes and adjustment to life after surgery. It aims to highlight the multifaceted needs of children with epilepsy and their families whilst they are on the pathway and beyond.

**Overview of the pathway**

The aim of epilepsy surgery is to remove the underlying cause of the seizures which ideally will lead to seizure freedom or, in many cases, a reduction in the frequency or severity of seizures. To reach a decision on whether surgery is a suitable treatment for a child, a range of outpatient and inpatient investigations are routinely undertaken, including a review of the child by a paediatric neurologist within the epilepsy surgery team, a hospital admission of a number of days for video-EEG, an MRI brain scan, neuropsychological assessment of the child and an assessment of the child and their family factors by neuropsychiatry. In around a third of cases, additional neuroimaging is undertaken, such as functional MRI, PET and SPECT scans. A small number of children may also require a neurosurgical procedure to allow invasive monitoring using stereo-EEG before a decision by the Multi-Disciplinary Team (MDT) can be made as to whether the child is suitable for a surgical resection. Once the child has been discussed by the MDT, families are seen in an Epilepsy Surgery Clinic to discuss any treatment options, as well as the risks and benefits if surgery is likely. Families are encouraged to take time to think about the decision and ask questions. If the family decide to proceed, a date for surgery will be scheduled along with any necessary pre-operative preparation. For resections, children are usually admitted for around five days. They will have access to any required rehabilitation whilst they are an inpatient. Following surgery, most children will require a few weeks off school to recover. They will be reviewed in the neurosurgical clinic within the first few weeks after surgery and subsequently, will be reviewed at regular intervals with their local paediatrician or paediatric neurologist, or both. Anti-seizure medications (ASMs) are not reduced until at least six to 12 months following surgery, although this may vary. Children are typically seen for neuropsychological evaluation at 12-18 months post-surgery.

Most of the neuropsychological evaluation pathway for epilepsy surgery has been facilitated by the Children's Epilepsy Surgery Service (CESS) established in England and Wales by the NHS Commissioners in 2013. This provided new or additional funds to either set up de novo or expand pre-existing neuropsychology services in the designated CESS centres. These services have also been invaluable in the neuropsychological assessment and support of many children and young people with epilepsy for whom surgery was never an option.

**Child and family experience**

The journey through the epilepsy surgery pathway can be complex and emotional for children and their families. However, for many families, the potential for improved seizure control and certainly seizure freedom and improved quality of life can make the process worthwhile. The experience is unique for every child and family and depends on many factors: the severity of the child's epilepsy, their emotional and developmental needs, and the perceived success of the surgery. Support from a dedicated medical team is key to helping children and their families navigate and journey on this pathway. There is limited research on the emotional experience of the journey through and beyond surgery for children and their parents, but a few key articles have provided useful insight into a pathway that may be accompanied by fear and uncertainty, as well as hope. O'Brien et al. (2020) suggest a conceptual model consisting of themes which can be characterised by three distinct categories or phases to help understand the lived experience of families. These phases are 'the experiences of epilepsy before surgery', 'the journey to surgery', and 'adjusting to life after surgery'.

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*Experiences of epilepsy pre-surgery*

Living with epilepsy can be a challenging experience for the child and their family. Approximately 37% of children with epilepsy have a co-existing mental health disorder. This is a higher prevalence than is found in other long-term childhood conditions and two to three times higher than that reported in the general child population [Davies et al, 2003; NHS Digital, 2022]. Individuals with epilepsy are also reported to have a lower health-related quality of life (QoL) than healthy individuals and individuals with other chronic illnesses [Wang et al, 2012]. Another major contributor to the burden of epilepsy is the impact of cognitive dysfunction on everyday life [Lodhi & Agrawal, 2018] and the higher incidence of neurodiversity [Strasser et al, 2018]. Rodenburg et al. [2005] highlighted that family functioning, including communication, social support, adaptation, mastery and conflict, is often adversely impacted by epilepsy. All these factors, together with the severity of their epilepsy, the use of ASMs and other treatment options (eg the ketogenic diet), support systems around them and their coping mechanisms contribute to the experience of living with epilepsy for the young person and their family. Children with drug-resistant epilepsy are at increased risk of experiencing a range of emotional and psychological challenges [Phillips et al, 2021].

O'Brien et al [2020] provide a sense of the lived experience for families in the pre-surgical phase, highlighting some of the personal experiences and making statistics real. Children and families speak of feeling tired, worrying about the condition and their future, feeling scared or nervous, and being unable to join in activities with peers. The authors highlight 'normalisation of experience' in the pre-surgical phase with families reporting that 'when you have always had epilepsy in your life it is all you have ever known'. When the option of surgery is introduced to children and families, many parents report initial feelings of shock. The prospect of surgery may feel overwhelming, as it introduces uncertainty and concerns about their child's future. The thought of surgery can be daunting, particularly because it can be seen as a 'last resort' when other treatments have failed. However, it can also introduce a sense of hope for a different or improved future or for a 'normal' childhood.

*Journey to surgery*

On the journey to surgery families talk about feeling that this might be the 'final hope' [O'Brien et al, 2020]. Naturally, there is worry that surgery might not be successful but also hope of an improved quality of life for the young person and their family. Families also talk about fears of the young person that relate to the surgery itself. Nelson et al [2021] provides further insight into the journey to surgery for families and identified a number of key themes that were consistent with O'Brien's work, including initial discussions about surgery shocking parents, families viewing surgery as their only and last hope, and concerns about the process itself or their understanding of the various investigations. Families also spoke about the burden of waiting for investigations, feeling the need to progress through the pathway as soon as possible, as well as managing the impact of distress within the family unit during this phase. Families reported a change in pace once surgery was confirmed and also spoke about the importance of access to professional emotional support throughout the process and the importance of gaining information and a sense of control through shared experiences of others.

*Adjusting to life post-surgery*

Epilepsy surgery can have a positive impact on children's psychological, social, and behavioural functioning. However, O'Brien et al [2020] reported both children and parents experienced unanticipated difficulties in making sense of changes following epilepsy surgery and described a period of adjustment in becoming accustomed to changes in behaviour, family roles and self-identity. Families described surgical outcomes as 'life changing', in terms of seizure reduction or freedom and a positive impact on psychological wellbeing, although some reported more emotional lability initially, with improvement over time. Parents reported a positive impact of improvement at school and the ability of the young person to participate in new activities. Families report an adjustment to a 'new normal' and although feeling positive about outcomes, they needed to adjust to difference or changes in the young person or family life, including letting go of the caring role and worries about seizure recurrence. Research and clinical experience suggest that it is not just the surgical outcome itself that ultimately affects adjustment but also how the child and family perceived the post-surgical change or lack of change and how that aligned with their expectations.

**Surgery outcomes**

The primary outcome measure following epilepsy surgery is seizure control which uses the Engel Classification. The percentage of children achieving seizure freedom varies by resection type and time since surgery (see Widjaja et al, 2020 for a meta-analysis of seizure outcome). Important secondary outcomes of surgery are to improve neurodevelopmental outcomes and psychosocial outcomes.

**Psychosocial outcomes**

*Anxiety*

Anxiety can persist post-surgery but the focus shifts from the impact of seizures on life and coping with treatment to one of managing social and identity-related concerns [O'Brien et al, 2020]. Ljunggren et al [2021] highlight that the child's anxiety can also be driven by

uncertainty about recovery, the possibility of seizure recurrence, and potential cognitive changes. Consequently, even when achieving the optimal outcome of seizure freedom, a fear of the future can remain a significant emotional burden for children, at least in the initial pre-operative phase.

*Mood*

Reilly et al [2019] conducted a systematic review examining the relationship between seizure control post epilepsy surgery in children and the impact on behavioural and emotional outcomes. Some of the studies suggest that a post-operative reduction in seizure frequency is associated with fewer depressive symptoms and improvements in long-term health-related quality of life. However, significant improvements in emotional functioning may take longer to emerge, even in children who are not completely seizure-free. Reilly et al [2019] highlight that much of the existing literature relies heavily on parent-reported measures, underscoring the need for future studies to adopt a prospective design that incorporates both qualitative and quantitative data collection. A more comprehensive approach considering a wider range of influencing factors is crucial. Longitudinal research is particularly important to better understand why some children show improvement while others do not, as even those who remain seizure-active may experience reductions in depressive symptoms over longer periods of time given a period of adjustment and acceptance [Phillips et al, 2021].

*Quality of Life (QoL)*

Achieving seizure freedom is not only generally associated with lower levels of depression but also relates to improvements in QoL. For instance, Widjaja et al [2023] observed an increase in health-related quality of life within the first year following surgery that remained stable over subsequent years. However, surgery does not always guarantee an improved quality of life [Reilly et al, 2019]. Some children experience worsening depressive symptoms, potentially due to difficulties adjusting to life without seizures [McLellan et al, 2005] and the challenges of adapting to a 'new normal'" [Vakharia et al, 2018]. It is important to understand that surgery does not always result in seizure freedom and this is likely to have an emotional impact because children expect that there will be a good surgical outcome [Englot et al 2014]. Children who experience ongoing seizures after surgery tend to show no change in QoL than before surgery [Sabaz et al, 2006].

*Social functioning and self-esteem*

Living with epilepsy can have adversely affect self-esteem. Scatolini et al [2017] found that children with epilepsy were at risk of low self-esteem. This was due to a number of factors including: duration of treatment, the use of ASMs and their associated side effects. Children often worry about having seizures in front of their friends and peers at school. The unpredictability of the condition can also contribute to struggles with self-identity and a decline in physical functioning [Murugupillai et al, 2016]. This reduced ability to participate in typical childhood activities can lead to social withdrawal with increased parental dependence and poor coping mechanisms [Dunn & Walsh, 2018; LaGrant et al, 2020]. Successful surgery has been shown to lead to marked improvements in several aspects of social functioning [Shih et al, 2020], with the potential to improve QoL and self-esteem.

*Post-traumatic stress disorder (PTSD)*

Current literature offers limited insight into the specific impact of surgery itself and the PTSD symptoms that may arise from both hospitalisation and major surgical procedures. Research consistently shows that childhood surgery can result in traumatic stress [Turgoose et al, 2021], with studies indicating that approximately 16-18% of children will develop traumatic stress related symptoms following all types of surgery [Stanzel & Sierau, 2022]. Most research on epilepsy surgery and associated experiences of hospitalisation has focused on adults, suggesting that procedures involving the temporal lobe may increase PTSD risk due to the removal of brain structures essential for emotional processing [Yrondi et al, 2020]. It is important that children on the pathway who are treated surgically are monitored post-surgery to identify and support psychological distress.

**Neurodevelopmental outcomes**

Neurodevelopment is broadly defined to encompass cognitive and behavioural function which then impact on long-term educational outcomes. Children with epilepsy are at a higher risk of academic underachievement and perform below that expected for their intellectual potential [Reilly & Neville, 2011]. Ultimately, educational outcomes affect access to higher education and career choices available in early adulthood. Our clinical experience suggests that older children want to know about the likely impact of surgery on their educational outcome and they use this information in their decision about surgery.

*Intellectual functioning*

Most studies that have reported on the impact of surgery on cognitive outcome have taken a rather limited approach that is basically a snapshot of changes in intellectual function, or in children younger than three years, developmental quotient, at or within 12 months following surgery. Approximately 70% of children show no change in function. A roughly equal proportion of the remaining 30% of children show improved function or a deterioration at this time point for testing [Flint et al, 2017; Moosa & Wyllie, 2017; Skirrow et al, 2019]. It is clear that a high proportion of children on the pathway have intellectual function that falls below the average range prior to surgery and that those who have the

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lowest scores on intelligence tests are more likely to show an increase following surgery. Improved intellectual function is also associated with discontinuation of ASMs [Boshuisen et al, 2015]. Some researchers suggest that the beneficial effects of seizure freedom on neuroplasticity are important factors in improvements in function. However, the neuropsychological gains associated with neuroplasticity are not fully apparent until several years post-surgery [Skirrow et al, 2019].

*Long-term outcomes*

A dearth of studies on long-term outcomes makes it difficult to help children and their families think through the likely long-term impact of surgical treatment on cognitive development and the potential effect on their academic attainments many years following surgery. A recent well-powered study by Eriksson et al [2024], reported on the long-term outcomes of children old enough to have undertaken intelligence testing as part of their surgical evaluation. Of the 500 children included with a full data set, approximately 30% scored within the average range or above (Full Scale Intelligence Quotient [FSIQ]>85) prior to surgery, with another 30% falling in the intellectual disability range (FSIQ <70) and the remaining 40% falling between 1-2 standard deviations below the mean (FSIQ 84-70). Most children showed a stable performance between the last pre-operative assessment and the 12-month post-surgical assessment. Children who were seizure free and off all ASMs had higher scores in: working memory, processing speed and numeracy scores than those who were still taking medication. Long-term neuropsychological assessments of children undertaken five or more years following surgery showed ongoing improvements if they were seizure free and taking no ASMs. Scores on verbal IQ, working memory and academic attainments related to reading and spelling were reported as higher than those children still taking ASMs. Predictably, children do not describe the post-surgical changes they notice in intellectual function using the same constructs than those used in neuropsychology tests. Children and families often describe their subjective experiences more simply and in terms of feeling brighter and more able to concentrate.

*Memory*

Memory disorders are commonly experienced in people with various types of epilepsy, with between 20 and 50% having difficulties [Aldenkamp, 2006]. Memory is important for the acquisition of the skills and knowledge required in academic and work settings. However, memory deficits can have broader impact on a child's socialisation and their personal identity/sense of self. Memory function is an area of particular concern in children treated by a temporal lobe resection because of the important role of temporal lobe structures in memory. A systematic review highlighted that the majority of children have stable memory function from before to following surgery [Flint et al, 2017], at least in the short-term. Children with left temporal lobe dysfunction have poorer language and verbal memory skills before and after surgery but a decline in word-finding and object-naming was associated with left temporal lobe surgery. Children with an average memory performance prior to surgery were at greater risk of developing a decline in verbal memory following surgery. Long-term studies undertaken five years or more since surgery showed that visual memory improved in children who had left temporal surgery and verbal memory improved in those who had right temporal surgery. Clinically, difficulties with word-finding are of real concern to children and their families. Even quite subtle changes after surgery can be a cause for concern and frustration for children. Although these difficulties may lessen within months of surgery, they may persist for years and potentially indefinitely. This mandates early support to minimise any functional impact.

*Neurodiversity*

Epilepsy often co-occurs with heritable neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). These are often associated with a range of cognitive, behavioural, and mental health difficulties in their own right. It can be difficult for children to understand that surgery will not 'fix' these difficulties. The epilepsy surgery MDT make this clear to families when they are making decisions about surgery and children, in particular, find this a complex issue to understand. Children at post-surgical follow-up share a sense of disappointment that they are still struggling with their attention, mood or friendships, despite no longer having seizures.

**Helping families through the journey**

O'Brien et al [2020]recognise the importance of healthcare professionals working together with families to discuss and consider the impact of epilepsy and surgery issues, at all stages of the surgery pathway. The authors suggest that there is also a need for increased support for families, particularly in relation to sharing their experiences with others to help facilitate adjustment and help children to consolidate altered aspects of their self-identity in life after surgery. Nelson et al [2021] highlights a need to remain mindful of the emotional needs of families throughout the process of consideration for surgery, increase psychosocial support to families by facilitating the sharing of their experiences with others and provide direct contact with clinical psychology services when required.

## Conclusion

In conclusion, the journey through the epilepsy surgery pathway can be complex and challenging for children and their families. Although surgery can have a very positive effect on seizure reduction or freedom, recognising the difficulties that families face with managing the various investigations required to establish if surgery is an option and the difficulties faced with decision-making around whether to proceed with surgery is important. There is a need for psychological support on the surgery pathway that does not end when surgery is performed. Following surgery, children and their families can struggle to adjust to change whether the change is cognitive, emotional, physical or simply a change in seizures. The high expectations that some children and their families hold about what surgery can 'fix' means that adjustment issues can arise even when there has been little change in their cognitive, behavioural, emotional or social function months following surgery. It is important that epilepsy surgery pathways and access to the professional MDT extends beyond the surgery itself to ensure we achieve optimal long-term outcomes for children and their families in terms of psychological adjustment and capture longer-term changes in neuropsychological functioning.

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# Recently published papers

This section highlights recently published papers. There are many (often more than 300) epilepsy papers published every three months, so what follows has been edited. All animal papers have been excluded.

We hope you find the papers of interest in your pursuit to keep abreast of the very latest knowledge.

CORNWALL CD, Kristensen SB, Ulvin LB, Heuser K, Taubøll E, Strzelczyk A, Knake S, Rosenow F and Beier CP.
**Trajectories of long-term survival after status epilepticus**
*Epilepsia.* 2025 May 8.
doi: 10.1111/epi.18428

DLUGOS D, Lozano M, DiVentura B, Farfel G, Shellhaas RA, Sullivan JE, Thio LL, Kessler SK, Sadleir LG and French J.
**Appropriate selection of participants in pediatric developmental and epileptic encephalopathy trials: Lessons learned and future opportunities**
*Epilepsia.* 2025 May 2.
doi: 10.1111/epi.18440.

MEISE E, Bertsche T, Jeschke S, Bertsche A and Neininger MP.
**Treatment modifications of antiseizure medications in children due to adverse drug reactions: The parents' perspective**
*Epilepsy Res*. 2025 Jul:213:107548.
doi: 10.1016/j.eplepsyres.2025.107548.

ARIPIRALA P and Jagtap SA.
**Approach to Progressive Myoclonic Epilepsies: Clinical Clues for Genetic Testing**
*J Child Neurol*. 2025 May 8:88307382513379 72.
doi: 10.1177/08830738251337972.

TOMLINSON SB, Galligan K, Kessler SK and Kennedy BC.
Two-year outcomes following modified transsylvian peri-insular hemispherotomy
*Childs Nerv Syst.* 2025 Apr 25;41(**1**):168.
doi: 10.1007/s00381-025-06825-1.

TAN Q, Cheng M, Yang Y, Wang T, Ouyang S, Liu C, Yang X, Liu W, Wu Y and Zhang Y.
**The phenotypic spectrum of YWHAG-related epilepsy: From mild febrile seizures to severe developmental delay and epileptic encephalopathy**
*Dev Med Child Neurol*. 2025 Jun;67(**6**):e116.
doi: 10.1111/dmcn.16333.

OLIVEIRA AVD, Machado HR, Thomé Ú, Santos MV, de Angelis G, Leite JP, Dos Santos AC, Wichert-Ana L, Hamad AP, Sakamoto AC and Velasco TR.
**Impact of epilepsy surgery on the adaptive behavior of children with drug-resistant epilepsy**
*Epilepsia*. 2025 Apr 29.
doi: 10.1111/epi.18437.

FERRER M, Jandhyala N, Pellinen J, Greenwood H, Thio LL, Dlugos D, Park KL, Kanner AM, French J and Human Epilepsy Project Investigators.
**Delayed diagnosis in adolescent onset focal epilepsy: Impact on morbidity and mental health**
*Epilepsia*. 2025 Apr 28.
doi: 10.1111/epi.18434.

PATRICK KE, Shields AN, Dustin HA, Patel AD and McNally K.
**Cognitive screening informs referrals for neuropsychological evaluation in children with epilepsy**
*Epilepsia*. 2025 Apr 26.
doi: 10.1111/epi.18421.

LIU Q, Zhu R, Wang Y, Yu H, Liu C, Sun Y, Wang Y, Liu X, Wang S, Ji T and Cai L.
**Surgical outcomes and motor function in pediatric peri-Rolandic epilepsy: A single center's experience with 152 cases**
*Epilepsia*. 2025 Apr 16.
doi: 10.1111/epi.18368.

FEDELE T, Burman RJ, Steinberg A, Selmin G, Ramantani G and Rosch RE.
**Synaptic inhibitory dynamics drive benzodiazepine response in pediatric status epilepticus**
*Epilepsia*. 2025 Apr 15.
doi: 10.1111/epi.18398.

FLAMINI R, Fogarasi A, Omatsu H, Milh M, Phillips S, Patten A, Takase T and Ngo LY.
**Long-term safety and efficacy of adjunctive perampanel in pediatric patients (ages 4 to <12 years) with inadequately controlled focal-onset seizures or generalized tonic-clonic seizures**
*Epilepsia*. 2025 Apr;66(**4**):1097-1109.
doi: 10.1111/epi.18242.

HALAWANI LM and Myers KA.
**Comparative analysis of new-onset refractory status epilepticus in adult and pediatric patients: immunotherapy timing and functional outcomes**
*J Neurol*. 2025 Apr 18;272(**5**):348.
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**Characterization of immune cell profiles in the blood of children and adults with tuberous sclerosis complex disease**
*J Neurol Sci*. 2025 May 15:472:123465.
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*Seizure*. 2025 Apr 12:129:59-69.
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*Brain Dev*. 2025 Apr 3;47(**3**):104357.
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**Resective epilepsy surgery in pediatric patients with normal MRI: outcomes, challenges, and cost-effectiveness in low-resource settings**
*Childs Nerv Syst*. 2025 Apr 5;41(**1**):152.
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**Circumstances surrounding sudden unexpected death in epilepsy in children: A national case series**
*Epilepsia*. 2025 Apr 5.
doi: 10.1111/epi.18339.

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**The relationship between ghrelin, epilepsy-related inflammatory biomarkers (IL-1β, IL-1R1, HMGB1), and drug-resistant epilepsy in children**
*Epilepsy Res*. 2025 Jul:213:107553.
doi: 10.1016/j.eplepsyres.2025.107553.

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**Combined Ketamine and Midazolam Versus Midazolam Alone for Initial Treatment of Pediatric Generalized Convulsive Status Epilepticus (Ket-Mid Study): A Randomized Controlled Trial**
*Pediatr Neurol*. 2025 Jun:167:24-32.
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**What extent of adverse drug reactions seems acceptable for what degree of seizure reduction in paediatric patients with epilepsy?-An exploratory study on the parents' perspective**
*Seizure*. 2025 Apr 2:129:29-32.
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*Seizure*. 2025 Mar 24:129:25-28.
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*Epilepsia*. 2025 Apr 4.
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*Epilepsia*. 2025 Apr 1.
doi: 10.1111/epi.18393.

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**Clinical Features and Predictors of Unfavorable Outcomes in Infantile Epileptic Spasms Syndrome: Results from a Multiancestry Cohort**
*J Child Neurol.* 2025 Mar 29:8830738251326631.
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**Addressing the long-term growth impact of the modified Atkins diet in pediatric epilepsy: A call for further research**
*Epileptic Disord*. 2025 Apr 4.
doi: 10.1002/epd2.70022.

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*Ann Neurol*. 2025 Apr;97(**4**):688-693.
doi: 10.1002/ana.27192.

NAGARAJAN L.
**Risk of epilepsy in neonates with seizures**
*Dev Med Child Neurol*. 2025 Mar 14.
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