epilepsy action

ISSN 2631-7400

Paediatric Epilepsy

Volume Seventeen | Number Two | June 2023

CURRENT AWARENESS SERVICE

Fabricated or induced illness and epilepsy

It is well recognised that there is wide differential diagnosis of epileptic seizures in children and particularly in young children under five years of age. Most of these differential diagnoses will have an organic or physiological basis, such as benign neonatal sleep myoclonus, reflex anoxic seizures, shuddering spells, hypoglycaemia and a cardiac arrhythmia. Non-organic or psychological causes are less common, particularly in young children. In older children (10 years of age and above), psychogenic non-epileptic seizures (PNES) are the most common type of non-organic causes. In younger children (typically under five years of age), fabricated and induced illness (FII) is the most common cause although it is probably rare. However, it is also probably the most difficult to recognise and diagnose. It is obviously an example of child abuse and if the seizures are induced, this can lead to physical injury and, potentially, even death.

Fabricated and induced illness in children presents in a limited number of ways. One of the most common is probably with non-epileptic paroxysmal events that mimic epileptic seizures. Consequently, seizures or epilepsy is one of the more common types of FII.

Munchausen syndrome by proxy

Fabricated illness (of epilepsy) was previously called Munchausen syndrome by proxy. It is where the parent or carer (most often the mother) fabricates or makes up a story of events or episodes ('seizures') that the child is experiencing. Induced illness (of epilepsy) is where the parent or carer actually does something to the child that causes them to have an event or 'seizure'.

In many cases it is likely that the child is subject to both fabricated and induced illness. The diagnosis of FII is more difficult if the child also has a definite diagnosis of epilepsy or if there is a positive family history of epilepsy, particularly if it is the mother who has epilepsy. However, most children who are subject to FII do not have epilepsy.

The two most common active ways of inducing a non-epileptic seizure are suffocation and poisoning.

Suffocation

This is almost certainly the most common behaviour used to actively cause (induce) a seizure. The parent will partially suffocate the infant or child by holding or cuddling the infant's face or body, or both, very tightly to them or by using their hands, a pillow, a towel, a piece of clothing or a nappy over their mouth and nose so that

→

CONTENTS

they are unable to breathe. The infant may initially struggle with vigorous movements but then will become hypoxic or even anoxic and then cyanosed.

If the period of suffocation and consequent hypoxia are long enough and the infant is unable to breathe, they may then become stiff and have a few irregular jerks, or myoclonic and even clonic movements. This may look almost identical to a reflex anoxic seizure for obvious reasons. The myoclonic or clonic movements usually last a number of seconds and rarely more than one or two minutes. The more prolonged episodes can resemble an epileptic tonic-clonic seizure.

If the suffocating 'material' is then removed, the child will start to breathe, initially with some irregular and gasping breaths. They will be floppy and pale and may appear sleepy. Recovery is then typically relatively rapid over the course of the next five to 10 minutes. Infants will rarely sleep after these events.

Clearly, and in contrast, an epileptic tonic-clonic seizure occurs spontaneously and without an obvious trigger. It starts with stiffening of the body and limbs and is then followed by cyanosis and rhythmic jerking movements, usually of all four limbs. These initially increase in frequency, peak and then decrease in frequency before slowly stopping. There is often excessive salivation ('frothing at the mouth') and urinary or faecal incontinence. The tongue may also be bitten. The entire epileptic tonic-clonic seizure usually lasts three to four minutes. After the seizure stops, the infant or young child will be pale and then will usually sleep, which may last from 20 or 30 minutes to over many hours. Recovery after an epileptic tonic-clonic seizure is much slower than after an induced (hypoxic) seizure.

Poisoning

This is probably the second most common behaviour used to actively cause a seizure. A number of substances may be used to do this. Salt is a common 'poison', in part because it may be difficult to detect. Giving salt can cause a hypernatraemic seizure, which can look like an epileptic tonic-clonic seizure. Giving insulin may cause severe hypoglycaemia, which may then cause a tonic or tonic-clonic seizure and, if the hypoglycaemia is profound, even death.

When to suspect FII

As already mentioned, FII is probably quite rare and the diagnosis may not be considered for some time. Fabricated or induced illness should be suspected in the following situations:

- Where the history of the child's events is vague and remains repeatedly vague even if the events are repeated, frequent and continue to occur over days or weeks.
- When the reported events are frequent but have only ever been witnessed by one person. This is typically, but not exclusively, the child's mother.
- Where it may be difficult to identify the type of epilepsy or epilepsy syndrome from the (repeated) history of the events.
- Where an epilepsy type or epilepsy syndrome seems to have been identified, and the child's seizures should be easy to control but are not. This is even with increasing doses of anti-seizure medications (ASMs) or with the use of two or more ASMs simultaneously and where concordance (compliance) with the medication is felt to be good. Childhood-onset absence epilepsy is a good example of this scenario.
- Where the parent or carer is reluctant to, or refuses to video their child's events or repeatedly say that it was not possible for a number of reasons including: 'There was no 'phone signal'; 'The battery was dead'; 'It was dark'; 'I accidentally deleted what was recorded'; 'I was so scared that I dropped the 'phone'; 'I didn't want to embarrass them'.
- Where the child's parent seems relatively unconcerned by the frequency of events in which their child appears to have stopped breathing and become cyanosed – and particularly if they attend the Accident and Emergency Department (AED) very frequently. This is particularly relevant if attendances are at different AEDs.
- Where the child's seizures have been reported to have continued after an appropriate dose of emergency (rescue) anticonvulsant (such as rectal diazepam or buccal midazolam) has been given. In approximately 60-70% of cases, a tonic-clonic seizure will stop after a single dose of this emergency anticonvulsant.
- The events or seizures cease when the child is separated from the person reporting or causing them, or both.
- When repeat prescriptions for anti-seizure medications, including rescue medications, are not picked up or are requested before they are due to be reissued.
- Where an interictal EEG remains normal despite a prolonged history of frequent and poorly controlled seizures.
- Where an ictal EEG (i.e. an EEG recorded during the child's reported typical events) is normal.
- Where the child's episodes suddenly cease if there is a suggestion or direct confrontation with the family (or parent) that the episodes might be fabricated.

• A combination of a number of the above scenarios.

For obvious reasons, the greater the number of the above scenarios, the greater the chance is of the diagnosis being FII. Finally, FII is more likely to occur if the parent (and nearly always the mother), has had or continues to have underlying social or mental health problems or both.

One of the main difficulties in making an early diagnosis of FII is that epilepsy remains very much a diagnosis based on history and a detailed account of a child's episodes given by an eyewitness. When the perpetrator of the FII has a nursing, medical or healthcare-related background or knowledge, the history may, at least initially, seem to be clear and convincing.

There is no doubt that the use of video or camcorders (pre-2005) and then smartphones has significantly improved the diagnosis of all paroxysmal events, both epileptic and non-epileptic. However, the real value of a recording of a child's events or seizures is when the entire event has been recorded, from its beginning to its end. If only the middle of an event is recorded, it is possible to reach a wrong diagnosis. Specifically, if the recording shows only stiffness or jerking and/or cyanosis and then stops, the differential diagnosis is wide. It can include: reflex anoxic seizures, cardiac syncope, hypoglycaemia and a hypoxic seizure due to an induced illness. In these conditions, a provoking factor or trigger will have caused the stiffness or jerking and cyanosis. However, in the absence of a complete and reliable history or video footage that did not include the situation (circumstances) or trigger at the beginning of the event, the conclusion might be that the event was an unprovoked epileptic seizure.

There are two further areas of caution in the interpretation of events that have been filmed by families. The first is that they may video a large number of events that are not fabricated or induced but simply represent changes in their child's behaviour. This may simply be because they are confused about what might or might not be an epileptic seizure or, and in FII, to set up a 'smoke-screen' to try to deflect any suspicion from medical and nursing staff. The second is that if the video shows a floppy and sleepy child (following a reported 'seizure'), this might not be a post-ictal phase but the result of the child having being given rescue medication.

Fabricated or induced illness carries a risk of significant harm to the child and siblings, with long-term physical and emotional consequences. This is particularly the case if the diagnosis has been unrecognised. In some cases, it has been considered that previous sibling deaths may have been due to abuse, including FII [Davis et al, 1998].

Managing FII

The management of FII is difficult, as might be predicted. As with PNES in older children, the management of FII tends to be somewhat easier, and the outcome more favourable, the more quickly it is considered and diagnosed. One of the key difficulties in FII is thinking about the diagnosis in the first place. Intuitively, healthcare professionals are 'programmed' to believe the parent or carer and also that someone in this role would not deliberately harm their child. While this is entirely appropriate, it must not cloud their objectivity and result in failure to acknowledge all the potential warning signs described in this article.

Decades of experience, including at the current time, have shown that early suspicions of child abuse may be minimised or ignored. As healthcare professionals working with children, we must never forget that their safety is our priority. Fabricated and induced illness often requires overt or covert CCTV undertaken in hospital. This must be to record the onset of at least two of the child's reported episodes to confirm the diagnosis of fabricated and certainly induced seizures.

As most children subject to FII that present with seizures are under five years of age, it will be important to liaise with other healthcare professionals, specifically the child's GP and health visitor, and also nursery schools. Clearly, social services must be involved as soon as it is felt appropriate, because FII is a form of child abuse. The approach to management must be holistic and with the prime objective being the safety and wellbeing of the child. The specific management process is identical to that of any child with suspected or proven child abuse [Barber and Davis, 2002].

Richard Appleton
Co-Editor

References

Davis PM, McClure RJ, Rolfe K, et al. Procedures, placement, and risks of further abuse after Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation. *Archives of Disease in Childhood* 1998, 78:217-221

Barber MA, Davis PM. Fits, faints or fatal fantasy? Fabricated seizures and child abuse. *Archives of Disease in Childhood* 2002, 86:230-233

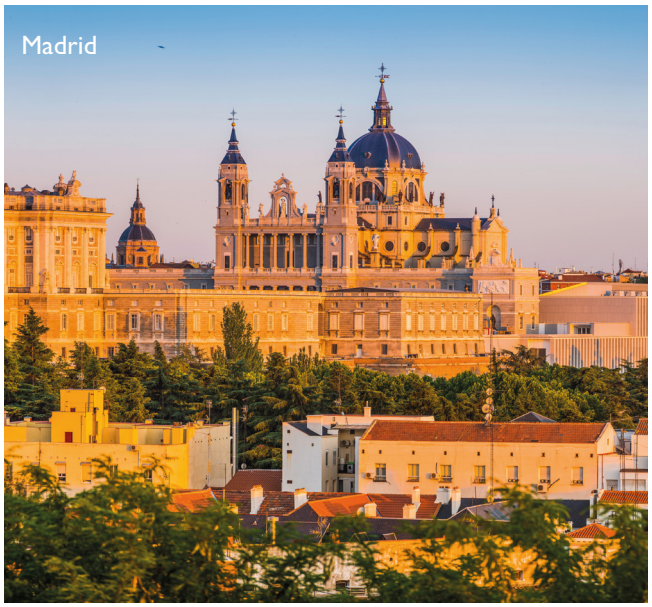
Forthcoming courses and conferences

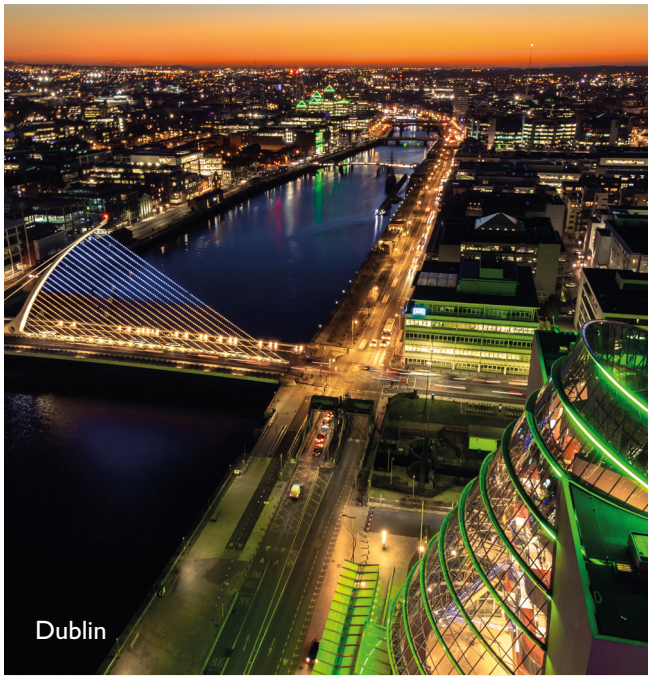
The following are details of forthcoming conferences and courses in epilepsy and general paediatric neurology.

September 2023
2-6
35th International Epilepsy Congress
Dublin, Ireland
bit.ly/3S5ANDj

October 2023
2-4
ILAE British Branch Annual Scientific Meeting
Gateshead, UK
ilaebritishconference.org.uk

November 2023
11
ILAE British Branch Clinical Epilepsy Course for Doctors in Training
Birmingham, UK
bit.ly/45kfy7E


Madrid


Dublin

March 2024
3-8
4th International Training Course on Neuropsychology in Epilepsy
Lyon, France
bit.ly/3VvHu2Z

May 2024
5-8
Seventeenth Eilat Conference on New Antiepileptic Drugs and Devices (EILAT XVII)
Madrid, Spain
bit.ly/3fdKAbT

September 2024
7-11
15th European Epilepsy Congress
Rome, Italy
ilae.org/congresses/15th-european-epilepsy-congress

epilepsy action

epilepsy.org.uk/yourchild

Your child and epilepsy

Grow your confidence managing epilepsy in your family

Your child and epilepsy is a new online course for parents and carers of children with epilepsy. It's been developed with parents, epilepsy nurses and psychologists.

This course is a helping hand to support families on their epilepsy journey. It's full of advice and stories from parents. It aims to give parents and carers the confidence, skills and knowledge to support their child to manage their epilepsy.

There are eight parts that cover:

- Understanding epilepsy
- Supporting your child with their epilepsy
- Keeping your child safe
- The impact of epilepsy on family life
- Your child's wellbeing
- Learning and behaviour
- Growing up and independence
- Sources of help and support

Free course

The course is free and flexible. It can be accessed at any time on a computer, tablet or smartphone with internet access.

Leaflets about the course to give to families can be requested by emailing **nurseorders@epilepsy.org.uk**

To view the course go to: **epilepsy.org.uk/yourchild**
Get in touch **learning@epilepsy.org.uk**

Registered charity in England and Wales (No. 234343)

The psychological and cognitive wellbeing of children and young people with epilepsy

Dr Victoria Gray, Consultant Clinical Psychologist and Dr Cathy Grant, Consultant Clinical Neuropsychologist, Clinical Health Psychology, Alder Hey Children's NHS Foundation Trust, Liverpool

Overview

The aim of this brief article is to provide an overview of the current literature regarding the psychological and cognitive wellbeing of children and young people (YP) with epilepsy. It will summarise key points from the literature on mental health, quality of life (QoL) and cognitive difficulties for YP with epilepsy. It will explore the terminology used around mental health and psychological wellbeing and key guidelines that support the provision of integrated psychological services within physical health settings. It will also consider the move towards proactive screening and identification of mental health needs and the provision of targeted interventions in this population and in so doing will highlight the multifaceted needs of YP with epilepsy and their families. Finally, the paper aims to encourage services, policy makers and commissioning bodies to continue to move towards an end goal of preventative and systemic services that meet the needs of this group of YP and their families and, ultimately, improve holistic outcomes.

Mental health

Children and YP with epilepsy are at a significantly increased risk of experiencing mental health problems. About 37% of children with epilepsy have a co-existing mental health disorder, 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]. The relationship between seizures and mental health is complex and multifactorial. The development of anxiety, for instance, may relate to dysregulated neurobiological mechanisms, fear of seizures themselves, stress directly related to the consequences of seizures, such as injury or exclusion from activities or peer relationships, feelings of being different or cognitive difficulties making school life more stressful.

Comorbid mental health problems have a number of serious implications for people with long-term conditions. These include poorer clinical outcomes (mediated by a number of mechanisms, such as reduced ability and motivation to manage health conditions, medication side-effects and poorer health behaviours) and lower QoL. Overall, comorbid mental health problems are reported to have a greater effect on QoL than physical comorbidities [Naylor et al, 2016].

Quality of life

Individuals with epilepsy have a lower health-related QoL than healthy individuals and individuals with other chronic illnesses [Wang et al, 2012]. Health-related QoL trajectories for newly diagnosed children followed over a two-year period suggested that better outcomes were related to less severe seizures, no cognitive and behavioural problems, lower parental depression scores, adaptive family functioning and fewer family demands [Sajobi et al, 2017]. Sillanpaa and Cross [2009] report that in addition to the medical impact of epilepsy with respect to loss of control, medication side-effects and comorbidity, epilepsy has a marked impact on a child's life. They highlight that population-based studies indicate that 70-76% of children with epilepsy have some type of disability that affects their daily life and choices for the future. They propose that supporting the development of acceptance, self-reliance, self-respect and self-empowerment of children with epilepsy is crucial to them achieving a place in the community that is equal to their abilities.

Cognitive dysfunction

Another major contributor to the burden of epilepsy is cognitive dysfunction [Lodhi and Agrawal, 2018]. Epilepsy affects cognition through a number of mechanisms in a complex interrelationship. There is considerable overlap in the cognitive difficulties seen across the epilepsy syndromes, with executive function, working memory and attention difficulties being particularly common [Hermann et al, 2021]. Aldenkamp [2006] stated that the prevalence of memory disorders in people with epilepsy is between 20% and 50%; more than half of these individuals have memory difficulties in daily life. It goes without saying that memory is crucially important for the acquisition of skills and knowledge, but it also plays an important role in personal identity and sense of self. Understandably, individuals with epilepsy frequently find these cognitive consequences more debilitating than the actual seizures themselves. It is no surprise that people with epilepsy often report a poor QoL resulting from the complex interactions between the physical and psychosocial factors related to their condition.

Children with epilepsy are at a higher risk of academic underachievement, performing below what would be expected for intellectual function [Reilly & Neville, 2011]. This has implications for access to higher education, future career and income potential, placing people with epilepsy at a major disadvantage in terms of life outcomes.

Effect on family

Epilepsy does not just affect the individual, but also their family. The witnessing of seizures is experienced as

Dr Victoria Gray, Consultant Clinical Psychologist and
Dr Cathy Grant, Consultant Clinical Neuropsychologist,
Clinical Health Psychology, Alder Hey Children's
NHS Foundation Trust, Liverpool

traumatic, especially when they are seen for the first time. Family members can be fearful of seizures and may inadvertently model fear to the child having seizures. Reilly [2018] reports that mothers of young children with epilepsy are at a high risk of mental health difficulties, and that all should be screened for such difficulties. They suggest there is a need to explore what parent- and child-focused interventions might be useful to reduce the mental health difficulties reported by mothers of young children with epilepsy.

Ellis et al [2009] reported that children and adolescents with epilepsy were at a greater than average risk of having increased dependence on parents. Rodenburg et al [2005] highlighted that family functioning, including communication, social support, adaptation, mastery and conflict, is often impacted by epilepsy. As epilepsy often co-occurs with heritable neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD), families may already have an increased burden of care through other family members having a neurodevelopmental condition that requires a high level of support.

Neurodevelopmental comorbidities

In children with ADHD, approximately 14% have or will develop seizures. In addition, ADHD occurs more frequently in children with epilepsy than in the general population, with 30-40% of children with epilepsy having comorbid ADHD or attention deficit disorder (ADD). Inattention is more common than hyperactive and impulsive symptoms [Dunn and Kronenberger, 2005]. ADHD is associated with a range of cognitive, behavioural and mental health difficulties and is independently associated with poorer long-term outcomes. In children diagnosed with ASD, estimates of the prevalence of developing epilepsy in a lifetime range from 2.7% to 44.4%.

A recent US population sample reported a sevenfold increase in the risk of epilepsy in individuals with ASD relative to the general population [Thomas et al, 2017]. The presence of intellectual disability was a clear risk factor that increased the risk of epilepsy developing in children with ASD by three to five times. ASD also occurs more frequently in children with epilepsy than in the general population, with a prevalence of 6.3% compared to 1% in the general population [Strasser et al, 2017]. ASD is a complex condition that presents with social communication difficulties that often require intervention and additional support in their own right.

Intellectual disabilities

Around a third of people with an intellectual disability have epilepsy. The risk of epilepsy increases in those with severe to profound intellectual disability to approximately 50% [Robertson, 2015]. Intellectual disability occurs more frequently in epilepsy than in the general population, with about 20% of children with epilepsy having an intellectual disability [Camfield and Camfield, 2013]. Children with epilepsy and intellectual disability have a high level of care needs due to the likely increased presence of additional medical conditions (e.g. congenital heart conditions, cerebral palsy, constipation and reflux), disordered sleep and limitations in communication, and increased family stressors (e.g. need for adapted equipment and housing, poorer access to community resources).

Given the comorbid intellectual disabilities and neurodevelopmental conditions common in children with epilepsy, it is important for teams that treat children with epilepsy (and their families) to be able to discuss and support potential difficulties beyond epilepsy. Service organisation often means that the child is seeing multiple specialists separately for different aspects of their condition. This adds further to the burden of care and consequently stress.

NICE guidelines

The complex challenges for YP who live with epilepsy is now clearly recognised in national guidelines. In 2022, the National Institute for Health and Care Excellence (NICE) published guidance for "Epilepsies in children, young people and adults". A section highlights the higher prevalence of psychological, neurobehavioural, cognitive and developmental comorbidities in epilepsy and recommends coordinated care for people with epilepsy who have a mental health condition or intellectual disability and are using a multidisciplinary team approach.

The guidelines recognise that a diagnosis of epilepsy can have a significant adverse impact on a person's mental health and that people with epilepsy may feel socially excluded and stigmatised. They recommend that epilepsy services should review neurodevelopment, cognitive function, mental health, social and emotional wellbeing, and intellectual disability as part of the routine management for people with epilepsy.

Epilepsy12 was established in 2009 with the aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and YP with seizures and epilepsies. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

The most recent results published in 2021 report that only 15% (18/119) of health boards and trusts facilitate mental health provision within epilepsy clinics and 17% (20/119) of health boards and trusts have formal screening for mental health disorders. It is recommended that health board and trust managers should ensure that all children and young people with epilepsy are provided with psychosocial support and signposting to help them manage their condition and their related worries or anxieties.

It is also recommended that all YP with epilepsy have ongoing screening for mental health problems using a validated tool as part of their routine epilepsy care. It is advised that where there are concerns about mental health, children and YP are referred to an appropriate mental health service via an agreed pathway and there should be timely access to diagnosis and treatment. The report concludes that hospital and community commissioners should commission increased integrated psychosocial and mental health support for children and YP receiving care for long-term conditions and that this should be co-located within the epilepsy clinic and inclusive of comorbidities.

Integrating services

The PAVES project (Psychology Adding Value – Epilepsy Screening) is an example of a pilot project integrating psychological services into a paediatric epilepsy clinic. The PAVES team recognised that children and YP with epilepsy are particularly vulnerable to developing social, emotional, behavioural and learning difficulties. If not identified or addressed at an early stage, these can impact adversely on QoL and long-term psychosocial outcomes.

The group developed a screening protocol and a pathway of early, 'stepped' intervention, with the aim to address this issue. The Strengths and Difficulties Questionnaire (SDQ) was completed by YP and their parents prior to routine epilepsy clinic appointments. A traffic light system was devised to indicate the reported level of concern and a potential route through an early intervention pathway. Self-help materials were offered to all families scoring within the amber or red range, as were parent workshops. Those scoring in the red range were also offered the opportunity to attend a psychosocial intervention group for children with epilepsy, which was aimed at improving epilepsy knowledge, self-management skills and QoL. Of all those YP screened, 53% were found to be experiencing elevated levels of mental health difficulties, which had not previously been identified. Initial feedback on the PAVES pathway is reported to have been positive, with high levels of feasibility and acceptability indicated by YP, parents and clinicians [George et al, 2021].

Screening

The recommendation of screening for mental health disorders encourages healthcare providers to move towards a proactive model of care, ensuring mental health needs are identified in a timely manner. Epilepsy12 recommends screening for mental health disorders using a 'validated tool'. The approach to 'screening' and the choice of tool will vary across different healthcare providers and settings, as will the personnel available to complete screens, score them, complete appropriate onward referrals or provide the required follow-up. Some services may consider a questionnaire that measures anxiety or depression an appropriate way to identify mental health needs, as mental health difficulties have been identified as the most prevalent in the epilepsy population.

The anxiety and depression scales from the Beck Youth Inventory (BYI) are well-validated measures that are commonly used within mental health. Another alternative is the Paediatric Index of Emotional Distress (PI-ED), which aims to screen for emotional distress in YP, modelled on the Hospital Anxiety and Depression Scale (HADS). BYI and PI-ED questionnaires focus on a specific aspect of mental health and provide a clinical cut-off. They are targeted and specific but will not capture all aspects of difficulties for YP with epilepsy, such as impact on QoL, behavioural dysregulation or impact on the family. Other services may opt for more generic measures of wellbeing such as the SDQ (as used by the PAVES pilot) or a QoL measure. These will provide broader information on several aspects of the YP's life but do not specifically measure mental health difficulties per se.

Alternatives to standardised measures include using simple Likert scales, asking about key areas of holistic care including emotional wellbeing, family wellbeing, behaviour, school performance and impact of seizures. Such scales aim to act as an aid to guide discussion in medical clinics so that holistic aspects of need are reviewed and considered. Whichever way services approach screening, it is important to remember that it is not a 'catch all' for identifying difficulties or accessing intervention.

Mental health services

Once mental health difficulties in YP with epilepsy have been identified through screening, it is important to consider what services are, or are not, currently available to accept referrals and provide psychological intervention.

YP with very severe presentations of depression, anxiety or trauma will meet the threshold for Child and Adolescent Mental Health Services (CAMHS). During the PAVES pilot, some YP screened were identified to have significant mental health difficulties and referred to local CAMHS services, supported with the early intervention resources until they were seen. However, some generic mental health teams can be reluctant to accept a referral for children with epilepsy presenting with mood problems as they may attribute the presentation to being related to uncontrolled seizures. It is often more challenging for generic mental health teams to link directly with the medical MDT to offer holistic care, as recommended by NICE.

In developing pathways of care for children with epilepsy, referral routes to community services must be based on the mental health needs rather than the severity of presentation. If the mental health presentation is related to the physical health condition, the YP is likely to benefit from integrated paediatric psychology. Joint working would be appropriate in some cases to ensure the YP is accessing appropriate care to meet their needs. YP receiving mental health care in co-located or integrated physical health services are provided with more focused and targeted provision. The epilepsy team has a clear line

Dr Victoria Gray, Consultant Clinical Psychologist and
Dr Cathy Grant, Consultant Clinical Neuropsychologist,
Clinical Health Psychology, Alder Hey Children's
NHS Foundation Trust, Liverpool

of communication, which allows the YP seamless care.

Epilepsy12 refers to screening for mental health disorders. Many YP with epilepsy who have mental health issues have a mild or moderate presentation with lower clinical risk, and are unlikely to meet the threshold for a mental health disorder. However, these YP have mental health difficulties that are severe enough to cause a significant level of disruption to their day-to-day function. This is of concern for their families and epilepsy teams, but they are unlikely to meet the threshold for CAMHS, often representing an unmet need.

Naylor et al [2018], in the document Bringing Together Physical and Mental Health: A New Frontier for Integrated Care, commissioned by the Kings Fund, recognised that the need to integrate support for mental and physical health is not limited to those people meeting formal diagnostic criteria. They report that all physical health problems have a psychological dimension, particularly when they involve learning to live with a long-term condition, which may require a profound process of internal adaptation and can be accompanied by significant functional impairment, economic disenfranchisement and social isolation. It is argued that failure to provide integrated psychological support to help people adapt and manage their health effectively can be associated with poor outcomes and faster disease progression [De Ridder et al, 2008].

There are also additional benefits of co-located psychology services to the physical health team in terms of skill sharing, teaching, consultation and liaison. Christie and Khatun [2012] reported that psychologists working in paediatric and adolescent medicine services have the specialist skills to understand the complex relationship between physical and emotional wellbeing. However, all healthcare professionals can help families identify strengths, abilities and resources to contribute to positive adjustment and healthy outcomes. They highlight that healthcare professionals can also make a significant contribution to positive adjustment by ensuring they offer timely, thoughtful, effective and accurate information, communicated at the time of diagnosis but also reviewed and repeated at different developmental stages. They propose that successful adjustment is the responsibility of everyone in the YP's support network.

Support networks

Often the most important people in a YP's support system are parents, siblings and peers. NICE guidelines recommend increased psychological provision for YP with epilepsy, but this should also extend to the YP's family, taking a systemic perspective. There is a recognised impact on parents, and indeed siblings, of YP with chronic conditions and, as such, services should consider provision of resource that includes parents and siblings, as well as screening that encompasses the family system. The PAVES pilot recognised the needs of parents, utilising the SDQ impact supplement to identify impact of problems in the systems around the child.

Workshops were provided for parents and had a psychoeducation and behaviour management focus. It is likely that parents would also benefit from workshops or groups focusing on supporting their own psychological needs in relation to caring for a YP with epilepsy, incorporating parents of pre-school children and those with special educational needs (who were unable to participate in the PAVES pilot).

Moving towards proactive identification and referral for mental health difficulties, or the psychological aspects of physical health for YP with epilepsy and their families, requires considerable work. However, there is also an opportunity to start to move towards a preventative model and improved QoL at the point of diagnosis for YP with epilepsy and their families. In the PAVES pilot, those YP or families identified to be in the amber or red ranges were offered self-help material or parent workshops. To further build on this pilot project, it is worth considering what could be offered to all groups, including those screened to fall in the green range. These YP and families may have had no additional needs and may not go on to develop any. However, some may not show any increased need at the time of screening but may develop difficulties further along their chronic health journey. The needs of some YP and families may also be missed due to the screening tool used. Workshops targeting this 'no current concerns' group could help prevent the development of psychological difficulties related to physical health.

Christe and Kahtun [2012] highlight a risk-resistance-adaptation model proposed by Wallander that determines a child's physical, neurocognitive and psychosocial adaptation [Wallander et al, 1989]. When risk factors (disease/disability, functional independence, psychosocial stressors) are excessive, and resistance factors (intrapersonal, socio-ecological, stress processing/coping strategies) are low, there are difficulties in emotional, physical and psychosocial function and adaptation [Brown et al, 1993]. The impact of a diagnosis of a chronic illness on families, children and young people, and the adjustments that they make to overcome future challenges, are dependent on many interrelated factors. These factors are both internally and externally determined, and the role each factor plays in enabling positive adjustment is complex. Many young people draw on a range of strengths and abilities, and parents and families can act as significant resources [Christie and Kahtun, 2012]. Resources or workshops aimed at building strengths and resilience in relation to chronic illness will support improved outcomes for YP and their families.

Cognitive screening

It is also important to remember that cognitive difficulties are inextricably linked to mental health, behaviour, social development, educational difficulties and QoL. Cognitive difficulties in epilepsy are likely to be caused by multiple factors, including underlying brain pathology, seizures, interictal activity, sleep disturbance and the medications

used to treat seizures. Although the drive within Epilepsy12 to screen for mental health in children with epilepsy is an important step forward, there is an equal need to screen for cognitive difficulties. Good control of seizures is associated with a positive effect on cognition. However, anti-seizure medications can negatively impact on attention, working memory, processing speed, verbal fluency and language, and exacerbate pre-existing neuropsychological difficulties [Operto et al, 2020; Reuner et al, 2016].

In newly diagnosed epilepsy, cognitive screening pre-medication and post-medication is warranted to inform medical management [Witt and Helmstaedter, 2012]. As neuropsychological functions continue to develop throughout childhood, regular screening is necessary to ensure that any cognitive difficulties are identified and well understood by both the family and educational establishments. Attention and executive function are strong predictors of educational achievement. The importance of maximising function and supporting difficulties should not be underestimated. Epilepsy-specific screening tools have been developed for this purpose and are freely available (e.g., Epitrack Junior, eisai-epitrack.com). However, the practicalities around the added time required to screen within clinics means that screening is not standard practice within the UK. Moreover, clinical psychology time is not routinely part of epilepsy clinics to advise on how best to support identified difficulties.

Conclusion

In conclusion, a move towards recognising the need for integrated and co-located physical and mental health services for YP with epilepsy is welcomed. However, practitioners, services and commissioning groups need to continue to develop and explore models of care that will improve lifelong outcomes for YP with epilepsy and their families. Bringing Together Physical and Mental Health [Kings Fund, 2018], states that efforts to develop integrated care should focus more on the integration of physical and mental health to address high rates of mental health conditions among people with long-term physical health problems. The document highlights that failure to address these issues affects outcomes for patients, but also increases the cost of providing services. They recommend that NHS England support and encourage vanguard sites and other areas to develop integrated approaches towards physical and mental health as part of efforts to build new models of care.

What this looks like will vary across healthcare providers and settings. Medical teams based in hospitals that have not previously employed mental health practitioners for physical health-related care will need support to establish appropriate governance around the role, access specialist supervision and provide a peer network to support safe and effective practice. Establishment of such posts does not need to be condition-specific and a clinical psychologist could work across a number of different conditions or across some lifespan services.

With appropriate funding, regions could look at ways to provide some cross-regional access to workshops and groups, as well as targeted integrated support in each epilepsy MDT. As the number of new psychological professions continues to evolve, it will be appropriate to look towards a skill mix to ensure a cost-effective but robust care team. Paediatric psychology needs to be integrated into regional networks to support the development of new posts. Services may be commissioned and implemented in different ways across regions, but all services will have the shared aim of improving holistic outcomes for YP with epilepsy and their families.

Take home points

- National guidelines support the need for timely assessment and intervention of mental health needs in YP with epilepsy.
- Services should provide intervention for mental health disorders as well as psychological aspects of physical health conditions.
- Services should move towards preventative as well as proactive models of care.
- YP with epilepsy would benefit from cognitive screening.
- Models of care should be systemic and include parents.
- 'PAVES' provides a model for identification of psychological needs and providing targeted intervention. Future projects can be creative if offering an increased range of interventions.

References

Aldenkamp AP. (2006). Cognitive Impairment in Epilepsy: State of affairs and clinical relevance. *Seizure*, 15, 219-220.

Brown RT, Doepke KJ and Kaslow N. (1993). Risk resistance model for paediatric chronic illness: Sickle cell syndrome as an example. *Clinical Psychology Review*, 13, 119-132.

Camfield PR, Camfield CS. (2014). What happens to children with epilepsy when they become adults? Some facts and opinions. *Pediatric Neurology*, 51, 17-23.

Christie D and Khatun H. (2012). Adjusting life to chronic illness. *The British Psychological Society,* March, 2012.

Davies S, Heyman I, Goodman R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine and Child Neurology*, 49, 292-295.

de Riddler D, Geenen R, Kuijer R, van Middendorp H. (2008). Psychological adjustment to chronic disease. *Lancet*, 19, 372(9634):246-55.

Dunn DW, Kronenberger WG. (2005). Childhood epilepsy, attention problems, and ADHD: review and practical considerations. *Seminars in Pediatric Neurology*, 12, 222-228.

Ellis N, Upton D, Thompson P. (2009). Epilepsy and the family: a review of current literature. *Seizure*, 9, 22–30.

George C, Felix SA, McLellan A, Shetty J, Middleton J, Chin RF, Poveda B, Brand C, Small M, Verity K. (2021). Pilot project of psychological services integrated into a pediatric epilepsy clinic: Psychology Adding Value – Epilepsy Screening (PAVES). *Epilepsy & Behavior*, 120, 107968.

Hermann BP, Stuck AF, Busch RM, Reyes A, Kaestner E, McDonald CR. (2021). Neurobehavioural comorbidities of epilepsy: towards a network-based precision taxonomy. *Nature Reviews Neurology*, 17, 731-746.

Lodhi S, Agrawal N. (2018). *Neurocognitive Problems in Epilepsy*. Cambridge University Press: UK.

Naylor C, Das P, Ross S, Honeyman M, Thompson J, Gilburt H. Bringing Together Physical and Mental Health: A New Frontier for Integrated Care. London: The King's Fund, *www.kingsfund.org.uk/ publications/ physical-and-mental-health*.

NHS Digital (2022). Mental Health of Children and Young People in England 2022 – wave 3 follow up to the 2017 survey – NDRS (*digital.nhs.uk*) (Last Accessed May 2023).

Operto FF, Pastorino GMG, Mazza R, Carotenuto M, Roccella M, Marotta R, di Bonaventura C and Verrotti A. (2020). Effects on executive functions of antiepileptic monotherapy in pediatric age, *Epilepsy & Behavior,* 102, 1525-5050.

Reilly C and Neville BGR. (2011). Academic achievement in children with epilepsy: A review. *Epilepsy Research*, 97, 112–123.

Reilly C, Atkinson P Memon A, Jones C, Dabydeen L, Das KB, Gillberg C, Neville BGR, Scott RC. (2018). Symptoms of depression, anxiety, and stress in parents of young children with epilepsy: A case controlled population-based study. *Epilepsy & Behavior*, 80, 177-183.

Reuner G, Kadish NE, Doering JH, Balke D, Schubert-Bast S. (2016). Attention and executive functions in the early course of pediatric epilepsy. *Epilepsy & Behavior*, 60, 42–49.

Robertson J, Hatton C, Emerson E, Baines S. (2015). Prevalence of epilepsy among people with intellectual disabilities: a systematic review. *Seizure,* 29; 46–62.

Rodenburg R, Meijer AM, Dekovic M and Aldenkamp AP. (2005). Family factors and psychopathology in children with epilepsy: a literature review. *Epilepsy & Behavior*, 6, 488-503.

Rosa M, Tang V, Goldstein LH, Reuber M, LaFrance WC, Lundgren T, Modi A, Wagner JL. (2018). Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International Leave Against Epilepsy Psychology Task Force. *Epilepsia*, 59, 1282-1302.

Sajobi TT, Wnag M, Ferro MA, Brobbey A, Goodwin S, Speechley K, Wiebe S, *et al.* (2017). Multivariate trajectories across multiple domains of health-related quality of life in children with new-onset epilepsy. *Epilepsy & Behavior*, 75, 72–78

Sillanpaa M, Cross JH. (2009). The psychosocial impact of epilepsy in childhood. *Epilepsy & Behavior*, 15, 5-10.

Strasser L, Downes M, Kung J, Cross JH, De Haan M. (2018). Prevalence and risk factors for autism spectrum disorder in epilepsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 60, 19-29.

The National Institute for Healthcare Excellence (NICE). Epilepsies in children, young people and adults. NICE guideline, April 2022.

Thomas S, Hovinga ME, Rai D, Lee BK. (2017). Brief report: prevalence of co-occurring epilepsy and autism: the U.S. national survey of children's health 2011-2012. *Journal of Autism and Developmental Disorders*, 47, 224-229.

Wallander JL, Varni JW, Babani L, Banis HT and Wilcox KT. (1989). *Journal of Pediatric Psychology*, 14 (2), 157-173.

Wang J, Wang Y, Wang LB, Xu H, Zhang X. (2012). A comparison of quality of life in adolescents with epilepsy or asthma using the Short-Form Health Survey (SF-36). *Epilepsy Research*, 101, 157–65.

Witt JA, Helmstaedter C. (2012). Should cognition be screened in new-onset epilepsies? A study in 247 untreated patients. *Journal of Neurology*, 259, 1727-1731.

epilepsy action

epilepsyspace.org.uk

The Epilepsy Space

The mobile friendly website is a helping hand for 16-25 year olds to live their best life with epilepsy

The Epilepsy Space will help young people to:

- Manage their epilepsy
- Feel less alone
- Increase their confidence
- Get the support they need

There's lots of epilepsy facts, tips and stories from young people sharing their experience.

The content is short and interactive. It's not all reading, there's video and young people can share their own quotes, stories and videos too.

It's been created with young people and reviewed by epilepsy nurses.

Take a look at:
epilepsyspace.org.uk

Leaflets about The Epilepsy Space to give to young people can be requested by emailing:
nurseorders@epilepsy.org.uk

Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust

Recently published papers

This section highlights recently published papers. Hopefully this will be very useful to all, helping to keep everyone up to date with the latest developments. It will certainly save you research and reading time, not having to search so many journals.

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 and as many review papers as possible have been included. We hope you find the papers of interest in your pursuit to keep abreast of the very latest knowledge.

Armeno ML, Kossoff EH.
Let food be thy medicine. The interaction between ketogenic diet therapy and anti-seizure medications: A systematic review
Epileptic Disord. 2023 Feb. doi: 10.1002/epd2.20055

Aum DJ, Reynolds RA, McEvoy S, Tomko S, Zempel J, Roland JL and Smyth MD.
Surgical Outcomes of Open and Laser interstitial thermal therapy (LITT) approaches for Corpus Callosotomy in Pediatric Epilepsy
Epilepsia. 2023 Jun 11. doi: 10.1111/epi.17679.

Bamgbose O, Boyle F, Kean AC, Stefanescu BM and Wing S.
Tolerability and Safety of Lacosamide in Neonatal Population
J Child Neurol. 2023 Mar. doi: 10.1177/08830738231164835.

Buraniqi E, Guerin JB, Miller KJ, Van Gompel JJ, Krecke K, Wirrell EC, Nickels KC, Payne ET and Wong-Kisiel L.
Temporal Encephalocele: A Treatable Etiology of Drug-Resistant Pediatric Temporal Lobe Epilepsy
Pediatr Neurol. 2023 May. doi: 10.1016/j.pediatrneurol.2022.12.015.

Chen KR, Yu T, Lien YJ, Chou YY and Kuo PL.
Childhood neurodevelopmental disorders and maternal diabetes: A population-based cohort study
Dev Med Child Neurol. 2023 Jul. doi: 10.1111/dmcn.15488.

Chiron C, Chemaly N, Chancharme L, Nabbout R.
Initiating stiripentol before 2 years of age in patients with Dravet syndrome is safe and beneficial against status epilepticus
Dev Med Child Neurol. 2023 May 17. doi: 10.1111/dmcn.15638.

Choudhari PR, Lowden A and Dolce A.
Exploring the Age-Old Question: What Is the Predictive Value of EEG for Future Epilepsy in Children With Complex Febrile Seizures?
J Child Neurol. 2023. doi: 10.1177/08830738231171799.

Cooper MS, Fahey MC, Dagia C, Reddihough D, Reid SM and Mackay MT.
Paroxysmal Nonepileptic Events in Children With Epilepsy and Cerebral Palsy
J Child Neurol. 2023 May. doi: 10.1177/08830738231176055.

Dal-Pai J, Dos Santos MP, Donida NDS, Cesarino MR, de Oliveira VHMS and Nunes ML.
Health consequences and daily life modifications in children and adolescents with epilepsy during the COVID-19 pandemic – a systematic review
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.04.017.

Delle Baite L, Harvey EE, Fong MWK, McGonigal A and Wilson SJ.
Life following epilepsy surgery: Building a holistic framework for enhancing postsurgical recovery and rehabilitation
Epilepsia. 2023 May 13. doi: 10.1111/epi.17646.

Eriksson MH, Ripart M, Piper RJ, Moeller F, Das KB, Eltze C, Cooray G, Booth J, Whitaker KJ, Chari A, Martin Sanfilippo P, Perez Caballero A, Menzies L, McTague A, Tisdall MM, Cross JH, Baldeweg T, Adler S, Wagstyl K.
Predicting seizure outcome after epilepsy surgery: Do we need more complex models, larger samples, or better data?
Epilepsia. 2023 May 2. doi: 10.1111/epi.17637.

Eriksson MH, Whitaker KJ, Booth J, Piper RJ, Chari A, Sanfilippo PM, Caballero AP, Menzies L, McTague A, Adler S, Wagstyl K, Tisdall MM, Cross JH and Baldeweg T.
Pediatric epilepsy surgery from 2000 to 2018: Changes in referral and surgical volumes, patient characteristics, genetic testing, and post-surgical outcomes
Epilepsia. 2023 Jun 2. doi: 10.1111/epi.17670.

Esmaeili B, Hakimian S, Ko AL, Hauptman JS, Ojemann JG, Miller JW and Tobochnik S.
Epilepsy-Related Mortality After Laser Interstitial Thermal Therapy in Patients With Drug-Resistant Epilepsy
Neurology. 2023 May. doi: 10.1212/WNL.0000000000207405.

Francey G, Currie N, Lew A, De Goede C, Basu H and Cain K.
Text integration processes in children with Childhood Epilepsy with Centro-Temporal Spikes
Epilepsy Res. 2023 May. doi: 10.1016/j.eplepsyres.2023.107136

Gabrielsson A, Tromans S, Watkins L, Burrows L, Laugharne R, Shankar R.
Poo Matters! A scoping review of the impact of constipation on epilepsy.
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.03.023.

Güzin Y, Yılmaz Ü, Devrim F, Dinçel N, Ünalp A.
Kidney Stones in Epileptic Children Receiving Ketogenic Diet: Frequency and Risk Factors
Neuropediatrics. 2023 May 31. doi: 10.1055/s-0043-1768987.

Jing J, Ge W, Hong S, Fernandes MB, Lin Z, Yang C, An S, Struck AF, Herlopian A, Karakis I, Halford JJ, Ng MC, Johnson EL, Appavu BL, Sarkis RA, Osman G, Kaplan PW, Dhakar MB, Arcot Jayagopal L, Sheikh Z, Taraschenko O, Schmitt S, Haider HA, Kim JA, Swisher CB, Gaspard N, Cervenka MC, Rodriguez Ruiz AA, Lee JW, Tabaeizadeh M, Gilmore EJ, Nordstrom K, Yoo JY, Holmes MG, Herman ST, Williams JA, Pathmanathan J, Nascimento

FA, Fan Z, Nasiri S, Shafi MM, Cash SS, Hoch DB, Cole AJ, Rosenthal ES, Zafar SF, Sun J and Westover MB.
Development of Expert-Level Classification of Seizures and Rhythmic and Periodic Patterns During EEG Interpretation.
Neurology. 2023 Apr 25. doi: 10.1212/WNL.0000000000207127

Kapoor D, Garg D, Beriwal N, Sidharth, Kumar A, Mukherjee SB, Kumar Pemde H and Sharma S.
Clinico-Etiologic Profile of Children and Adolescents with Drug-Resistant Epilepsy in a low-Resource Setting: 10 Years' Experience.
J Child Neurol. 2023 May 18. doi: 10.1177/08830738231174493

Kapoor D, Garg D, Beriwal N, Sidharth, Kumar A, Mukherjee SB, Pemde HK and Sharma S. Karakas C, Houck K, Handoko M, Trandafir C, Coorg R, Haneef Z, Riviello JJ, Weiner HL, Curry D, Ali I.
Responsive Neurostimulation for the Treatment of Children With Drug-Resistant Epilepsy in Tuberous Sclerosis Complex
Pediatr Neurol. 2023 May. doi: 10.1016/j.pediatrneurol.2023.05.008.

Kregel M, Coulson S, Nabavi Nouri M, Sorzano R and Andrade A.
Families' Knowledge Change in Paediatric Drug Resistant Epilepsy: A Novel Clinic Model
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.04.019.

Legouhy A, Allen LA, Vos SB, Oliveira JFA, Kassinopoulos M, Winston GP, Duncan JS, Ogren JA, Scott C, Kumar R, Lhatoo SD, Thom M, Lemieux L, Harper RM, Zhang H and Diehl B. Levine A, Davis P, Zhang B, Peters J, Filip-Dhima R, Warfield SK, Prohl A, Capal J, Krueger D, Bebin EM, Northrup H, Wu JY, Sahin M and TACERN Study Group.
Epilepsy Severity Is Associated With Head Circumference and Growth Rate in Infants With Tuberous Sclerosis Complex
Pediatr Neurol. 2023 Jul. doi: 10.1016/j.pediatrneurol.2023.03.015.

Lo Barco T, Corona L, Solazzi R, Fiorini E, Galati G, Cossu A, Proietti J, Francione S, Dalla Bernardina B, Darra F and Cantalupo G.
Gelastic seizures and "smiling spasms": A peculiar ictal pattern
Epileptic Disord. 2023 Apr. doi: 10.1002/epd2.20012.

Lo Barco T, Offredi F, Castino E, Proietti J, Cossu A, Fiorini E, Fontana E, Cantalupo G, Dalla Bernardina B, Darra F.
Adaptive behaviour in adolescents and adults with Dravet syndrome
Dev Med Child Neurol. 2023 Jun. doi: 10.1111/dmcn.15448.

Lopes-Santos LE, de Angelis G, Nakano FN, Thome U, Velasco TR, Santos MV, Machado HR, Hamad APA, Sakamoto AC and Wichert-Ana L.
Executive functioning in children with posterior cortex epilepsy compared to temporal and frontal lobe epilepsies
Epilepsy Res. 2023 May;192:107141. doi: 10.1016/j.eplepsyres.2023.107141.

LoPresti MA, Katlowitz KA, Sharma H, McGinnis JP and Weiner HL.
Pediatric Vagus Nerve Stimulation: Case Series Outcomes and Future Directions
Neurosurgery. 2023 May 1;92(5):1043-1051. doi: 10.1227/neu.0000000000002326

Makridis KL, Hoyer S, Elger CE and Kaindl AM.
Is There a Cognitive Decline in Pediatric Patients Following Epilepsy Surgery?
Pediatr Neurol. 2023 Jul. doi: 10.1016/j.pediatrneurol.2023.03.020

Marques VD, Hackbart BA, Guilhoto LM, Duarte JTC, Peixoto-Santos JE, Yacubian EMT and Bittar Guaranha MS.
Minimum effective sodium valproate dose in genetic generalized epilepsies
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.04.009.

Matsuura R, Hamano SI, Hirata Y, Takeda R, Takeuchi H, Koichihara R, Kikuchi K and Oka A.
Long-term analysis of adrenocorticotropic hormone monotherapy for infantile epileptic spasms syndrome with periventricular leukomalacia.
Seizure. 2023 Jul. doi: 10.1016/j.seizure.2023.05.012.

Meng Y, Geng G, Ren Y, Zhang H, Gao Z, Liu Y and Shi J.
Long-Term Outcome of Adrenocorticotropic Hormone Therapy in Children With New-Onset Infantile Spasms
Pediatr Neurol. 2023 Jun. doi: 10.1016/j.pediatrneurol.2023.02.009.

Milne-Ives M, Duun-Henriksen J, Blaabjerg L, Mclean B, Shankar R and Meinert E.
At home EEG monitoring technologies for people with epilepsy and intellectual disabilities: A scoping review
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.05.007

Pang EW, Lawn ND, Lee J and Dunne JW.
Mortality after a first-ever unprovoked seizure
Epilepsia. 2023 May. doi: 10.1111/epi.17567.

Peariso K, Arya R, Glauser T, Abend NS, Aguilar CB, Amengual-Gual M, Anderson A, Appavu BL, Brenton JN, Carpenter J, Chapman KE, Clark J, Gaillard WD, Gaínza-Lein M, Goldstein J, Goodkin H, Grinspan Z, Guerriero RM, Horn PS, Huh L, Kahoud R, Kelley SA, Kossoff EH, Kapur K, Lai YC, Marquis BO, McDonough T, Mikati MA, Morgan L, Novotny E, Ostendorf AP, Payne ET, Piantino J, Riviello J, Sands T, Stafstrom CE, Tasker RC, Tchapyjnikov D, Vasquez-Avila A, Wainwright MS, Wilfong A, Williams K and Loddenkemper T; for Pediatric Status Epilepticus Research Group (pSERG).
Early Clinical Variables Associated With Refractory Convulsive Status Epilepticus in Children
Neurology. 2023 June. doi: 10.1212/WNL.0000000000207472.

Pekeles H, Al Amrani F, Perez-Morgui M, Wintermark P, Shevell M.
Characteristics of Children With Cerebral Palsy in the Post-Therapeutic Hypothermia Era
J Child Neurol. 2023 Mar. doi: 10.1177/08830738231159162.

Reilly C, Bjurulf B and Hallböök T.
Intellectual functioning and adaptive behaviour in children with Dravet syndrome: A population-based study.
Dev Med Child Neurol. 2023 Jun. doi: 10.1111/dmcn.15495.

Schnier C, Chin RF.
Mortality in children with epilepsy: Cohort study using the clinical practice research datalink
Seizure. 2023 Jul. doi: 10.1016/j.seizure.2023.05.020.

Sherlock C, Linehan C, Madigan C and Downes M.
'A rollercoaster of emotions': Reflections on growing up with epilepsy in Ireland.
Seizure. 2023 May. doi: 10.1016/j.seizure.2023.04.007.

Singh RK, Eschbach K, Samanta D, Perry MS, Liu G, Alexander AL, Wong-Kisiel L, Ostendorf A, Tatachar P, Reddy SB, McCormack MJ, Manuel CM, Gonzalez-Giraldo E, Numis AL, Wolf S, Karia S, Karakas C, Olaya J, Shrey D, Auguste KI, Depositario-Cabacar D and PERC Surgery Registry Workgroup.
Responsive Neurostimulation in Drug-Resistant Pediatric Epilepsy: Findings From the Epilepsy Surgery Subgroup of the Pediatric Epilepsy Research Consortium
Pediatr Neurol. 2023 Jun. doi: 10.1016/j.pediatrneurol.2023.03.001.

Smith ML, Puka K, Speechley KN, Ferro MA, Connolly MB, Major P, Gallagher A, Almubarak S, Hasal S, Ramachandrannair R, Andrade A, Xu Q, Leung E, Snead OC 3rd, Widjaja E.
A longitudinal cohort study of mediators of health-related quality of life after pediatric epilepsy surgery or medical treatment
Epilepsia. 2023 May 22. doi: 10.1111/epi.17660.

St-Denis A, Hooker M, L'Abbée Lacas K, Corriveau I, Pirmoradi M, Simard-Tremblay E, Atkinson J and Myers KA.
Awake Craniotomy Language Mapping in Children With Drug-Resistant Epilepsy due to Focal Cortical Dysplasia.
Pediatr Neurol. 2023 Jul. doi: 10.1016/j.pediatrneurol.2023.04.003.

Stefanos-Yakoub I, Wingeier K, Cserpan D, Gennari AG, Latal B, Reuner G and Ramantani G.
Lesion Extent Negatively Impacts Intellectual Skills in Pediatric Focal Epilepsy.
Pediatr Neurol. 2023 May. doi: 10.1016/j.pediatrneurol.2023.05.005.

Tartibzadeh G, Feizollahzadeh H, Shabanloei R and Mwamba B.
Epilepsy risk awareness and background factors in patients with epilepsy and family caregivers
Epilepsy Res. 2023 Jul. doi: 10.1016/j.eplepsyres.2023.107146.

Türay S, Cangür Ş, Kahraman G, Kayabaşı E, Çetiner ÖF, Aydın B, Öztürk CE.
Can the Gut Microbiota Serve as a Guide to the Diagnosis and Treatment of Childhood Epilepsy?
Pediatr Neurol. 2023 Apr. doi: 10.1016/j.pediatrneurol.2023.04.006.

Wang S, Yao B, Zhang H, Xia L, Yu S, Peng X, Xiang D and Liu Z.
Comorbidity of epilepsy and attention-deficit/hyperactivity disorder: a systematic review and meta-analysis
J Neurol. 2023 Jun 16. doi: 10.1007/s00415-023-11794-z.

Yozawitz E.
Neonatal Seizures.
N Engl J Med. 2023 May 4. doi: 10.1056/NEJMra2300188.PMID: 37133587.

Yozawitz EG, Cilio MR, Mizrahi EM, Moon JY, Moshé SL, Nunes ML, Plouin P, Vanhatalo S, Zuberi S and Pressler RM.
Application of the International League Against Epilepsy Neonatal Seizure Framework to an international panel of medical personnel
Epileptic Disord. 2023 Apr. doi: 10.1002/epd2.20005.

Paediatric Epilepsy Current Awareness Service is published by: Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK
Date of preparation: June 2023

 ISSN 2631-7400
New Anstey House, Gate Way Drive, Yeadon,
Leeds LS19 7XY, UK
tel: 0113 210 8800 | fax: 0113 391 0300 | Epilepsy Action Helpline freephone: 0808 800 5050
email: editor@epilepsy.org.uk epilepsy.org.uk
To subscribe, email: editor@epilepsy.org.uk