



PRACTICE

CLINICAL UPDATES

Practical aspects of childhood epilepsy

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What you need to know

- Official guidance advises consistency in brand prescribing of anti-epileptic drugs
- Sleep disorders are very common, can trigger seizures, affect the whole family, and can often be managed in primary care
- Most children need a timely educational or neuropsychological assessment to inform an education and health care plan, and these can be initiated by parents or a special educational needs coordinator
- Buccal midazolam is the preferred rescue drug in young people at risk of prolonged seizures
- Routine blood tests, including monitoring of serum drug concentrations, are unnecessary

Children and adolescents with epilepsy are medically managed by paediatricians with expertise in the condition, but non-specialist doctors can also help these young people live a fuller life. In this update we focus on important issues that are sometimes misunderstood, particularly those with little published guidance or where new evidence or guidance has emerged. The advice applies mainly to children with common epilepsies attending mainstream schools. Children with complex epilepsy require specialist guidance.

Is it safe to switch between drug formulations?

Official guidance and discussions on social media are conservative on the question of switching¹ between different products, while prescribers are encouraged to use cheaper generic drug treatments. On balance, we advise consistency in prescribing (in the UK it not uncommon for the pharmacy to have different formulations every time the patient goes to renew the prescription) because comparative bioavailability data are incomplete for every anti-epileptic drug.² Only the 2016 EQUIGEN study³ showed that switching between branded and generic lamotrigine was safe. Furthermore, the different names,

packaging, and appearance of alternative products may cause confusion, anxiety, or occasionally non-adherence when prescriptions are refilled.

Table 1 lists anti-epileptic drugs stratified by risk of switching, according to their therapeutic index and release characteristics.⁴

Missing a single dose

Management of a missed dose depends on the length of the delay, drug half life, and bioavailability. As a general rule, a missed dose should be taken within four hours of the prescribed dose (drugs with long half lives or sustained release preparations should be taken within 12 hours), after which patients should take the next dose at the usual time. Further advice is available from the Royal College of Paediatrics and Child Health (see box 'Information resources for patients').

What's the recommended rescue treatment for prolonged seizures in the community?

Some children need a supply of emergency or rescue medication to treat prolonged seizures and help prevent unnecessary attendance at emergency departments.^{5,6} Benzodiazepines are still the first line treatment but rectal diazepam has mostly been replaced in the UK by buccal midazolam liquid. This formulation is packaged in prefilled syringes conveniently dose stratified by age group (eg, Buccolam), and applied between the cheek and gums. Advise children and/or their carers to store these prefilled syringes securely and at room temperature, both at home and in school. When prescribing, offer training to patients and carers in administration and basic life support (box 'Information resources for patients'), plus a written care plan typically provided by community nurses, school nurses, or

epilepsy specialist nurses. Patients require a doctor's letter for airport security when taking benzodiazepines abroad.

Are routine blood tests necessary?

No. Children with epilepsy do not need routine monitoring with blood tests, and the National Institute for Health and Care Excellence (NICE) specifically advises against them.¹ Routine monitoring of liver function or full blood count does not prevent adverse drug effects or save money, and blood testing distresses some children. Full blood counts and liver function tests (including pancreatic amylase and ammonia for children taking valproate) are necessary only when clinically indicated—for example, if a child develops bruising, frequent infections, abdominal pain, or tiredness. Anti-epileptic drugs increase the risk for vitamin D deficiency and children should take supplements of 400 IU/day (10 µg) throughout the year, without serum monitoring.⁷ Blood testing for therapeutic levels of anti-epileptic drugs should be done only if recommended by a specialist and indicated by non-adherence, suspected toxicity, or for pharmacokinetics monitoring (metabolism of the drug in the blood and metabolic interactions with other drugs).

How should families approach sports and exercise?

Historically, sport and physical activity have been restricted for children with epilepsy because of mistaken ideas about triggering seizures or excessive risk of injury.⁸ However, lack of participation in sports is socially isolating, results in poorer physical fitness, and negatively affects self esteem.⁹ Evidence shows that physical exercise does not trigger seizures and has beneficial effects,^{10,11} ranging from better mental and physical health to improved social integration, reductions in stress, and even in seizures and abnormalities on electroencephalogram (EEG).

Social support can provide encouragement and may help overcome perceived barriers to exercise.¹² Young people should be encouraged to take regular physical exercise, including contact sports if they wish, and be supervised for water sports, harnessed climbing, and horse riding.¹³ Restrictions are recommended for scuba diving, skydiving, and other sports at heights.¹³ Risk of accidental drowning in young people with active epilepsy (where the person has had a seizure in the past year or is taking anti-epileptic drugs) is five times higher than in the general population, therefore close supervision is necessary in or around all bodies of water, from bath to ocean.¹⁴ Individual risk assessments in people with poorly controlled epilepsy (where seizures continue, despite the person taking anti-epileptic medication) should take into account seizure types, triggers, and responsible adult supervision.¹⁵

What can parents and carers do to minimise sleep disturbance?

Poor sleep quality impairs daytime alertness, behaviour, learning, cognitive functioning, and quality of life.^{13,16,17} Many common epilepsies of youth are exquisitely sensitive to sleep fragmentation resulting from tiredness, travel, late nights, and sleepovers. Sleep fragmentation can even be caused by seizures, abnormal EEG discharges, certain anti-epileptic drugs, and behavioural or obstructive sleep disorders.

Sleep disorders are 12 times more common in children with epilepsy, even without nocturnal seizures^{13,18} and can adversely affect parents' marital satisfaction and maternal health.^{19,21}

Children can be helped to fall asleep by excluding light (using thick curtains or blackout blinds); switching off all screens before 8 pm (the blue light spectrum inhibits endogenous melatonin release); establishing a relaxing pre-bedtime routine, such as a bath, reading a book, listening to music; and maintaining a comfortable temperature in a well ventilated room. Children who display persistent sleep behavioural issues (eg, refusing to go to bed, not staying in their own bed) may benefit from interventions guided by a clinical psychologist.

Sleep is inevitably disturbed by travel. Advise families to plan ahead for long trips, especially if leaving the country. Build in rest days, and if there is a change in time zone such that the normal dose of medication would be in the middle of the night, then gradually change the times that the child takes medicines in the weeks before travel.

Should parents and carers use seizure alarms?

Seizure detection and alarm devices are widely used but are far from perfect. They must be matched to predominant seizure type: bed alarms (convulsive), out of bed/door alarms (non-convulsive focal onset), video monitors, anti-suffocation pillows, and mobile seizure detectors (nocturnal seizures). Carers often believe alarms can act as a proxy, or substantially reduce the risk of sudden death in epilepsy, although there is no evidence for such a preventive effect.²² Users frequently report high cost, the impracticality of wearing a device, and the disruption caused by overly sensitive alarms going off in the night. Current systems offer sensitivity ranging between 2% and 100% with an unsatisfactory 0-4 false positive alerts per hour.^{23,24} They perform best for children with generalised tonic-clonic seizures when integrated with additional parameters such as accelerometry, heart rate, respiration, or electrodermal changes (changes in skin electrical conductance).

What educational support is available?

Academic underachievement (attainment below that predicted by IQ) affects 42% of children with epilepsy²⁵ because of reduced school attendance, the effects of anti-epileptic drugs on cognition, neurodevelopmental comorbidities, and specific cognitive difficulties with attention, working memory, language, or literacy. These children require specialist assessment by an educational psychologist or neuropsychologist who may recommend modifications to the curriculum or classroom. Extra time may be allowed in school examinations, and the epilepsy specialist nurse should contact the examinations officer several months before the examinations are scheduled to take place. The International League Against Epilepsy recommends regular screening of cognition, behaviour, and mood in children with epilepsy.²⁶ In the UK, assessment is undertaken through Individual Education Plans. If the child is not making sufficient progress on their targets under this plan then parents can apply for an Education and Health Care Plan²⁷ to obtain extra resources from the local education authority. The Education and Health Care Plan, which superseded the Statement of Special Educational Needs in April 2018, integrates educational, health, and social care needs, and comes with a personal budget.

Special considerations during adolescence

Epilepsy during adolescence can affect the development of independence, social functioning, peer relationships, income,

risk of unplanned pregnancy, mental health, and self esteem.^{28 29} Young adults are often concerned about obtaining a driving licence, going out late at night, or drinking alcohol with friends because of fears that they might experience a seizure in front of others; or because they are being bullied or excluded (and perceive this to be because of the epilepsy).²⁸ They may also have concerns about marriage, children, and the heritability of their condition.²⁸

Transition

General practitioners can help plan the transition of paediatric patients to adult services³⁰ in a way that encourages a healthy self image, supports independence and self management skills, and encourages sharing of key information.³¹ In the UK, GPs can help maintain continuity and coordinate referrals and social services. NICE recommends starting transition planning when children are in their pre-teens, and that this should be coordinated by a named key worker, for example, an epilepsy specialist nurse, GP, allied health professional, or youth worker.³⁰ Ask the young person how they want to be involved in their transition planning; offer support and ask about their parents' involvement. The Royal College of Paediatrics and Child Health has developed the Epilepsy Passport,³² a paper record with a personalised emergency care plan, medication history, and key professional contacts, to aid independence.

Physical and mental health

Counselling about the risks associated with alcohol (such as interactions with sedating medicines) and recreational drugs is important. An informed conversation about safe limits, ensuring rest and good adherence to medication, may be better received than advice for complete abstinence.

Young women with epilepsy have an increased risk of accidental pregnancy.³³ The American Academy of Neurology recommends folic acid supplementation for women and girls over the age of 12 (0.4 mg pre-conceptually and 5 mg while on anti-epileptic drugs); discussion of contraception methods and their interactions with anti-epileptic drugs; and the teratogenicity of anti-epileptic medication,³⁴ which includes dose-dependent learning disability in offspring.³⁵ Guidance from the Medicines and Healthcare Products Regulatory Agency states that valproate must no longer be prescribed for women or girls of child bearing age unless a pregnancy prevention programme is in place, with some exceptions.³⁶ This issue was covered in *The BMJ* but policy may change over the coming months.³⁷

Transition is also a suitable time to review bone health³⁸—osteopenia and falls from seizures increase the risk of fractures. Unfortunately, there are no guidelines, good quality evidence, or calculators for risk of fracture that are specific to epilepsy, but it is common practice in some countries to screen patients for 25(OH)D deficiency. Dual energy x ray absorption studies can be considered for patients with additional risk factors for low bone mineral density.³⁹

One third of children with epilepsy have an anxiety disorder and just under one quarter have depression. While the Ontario Task Force on Epilepsy Transition recommends periodic screening around adolescence,²⁹ no such guidelines exist in the UK. We recommend the Revised Child Anxiety and Depression Scale (parent and child versions) as an easy, free, and validated screening tool.⁴⁰ Children with mental health concerns can be referred for psychological support to child and adolescent mental health services; young people can also use self help materials (box 'Information resources for patients') or be supported by family or counsellors at school.

Diagnostic reappraisal

The Ontario Taskforce highlights the need for reappraisal of genetic diagnosis where appropriate.²⁹ Many adolescents were investigated when modern gene sequencing panels were unavailable. Reinvestigation is important if there is drug resistance, neurodevelopmental comorbidity (such as autism spectrum disorder or intellectual disability), or a family history of epilepsy. Genetic diagnosis can be a huge relief to patients and their families; inform risk of recurrence in future pregnancies, offspring, and relatives; and in some cases can lead to treatment modifications.⁴¹

Education into practice

- How do you question patients about their sleep habits?
- Consider an audit to quantify the proportion of patients who had an educational psychology or neuropsychological assessment before entering secondary school?
- Think about the last time you talked to a patient about their anti-epileptic medication. To what extent do you think the patient would have felt able to discuss poor adherence? How might you alter your discussion next time?

How patients were involved in the creation of this article

- Coauthor JC has epilepsy and is the parent of a young person with epilepsy
- The manuscript was reviewed before submission by the CASTLE NIHR Programme Parent Advisory Panel, and after submission by two *BMJ* patient reviewers. In response to the panel's review, we revised the language of the article to be more patient friendly.

How this article was created

This update was prepared from a PubMed search using keywords "(childhood OR pediatric) AND epilepsy" combined with "sleep," "sports," "bioequivalence," "transition," "adolescence"; as well as statutory guidance and consultation with expert colleagues. Articles were selected on relevance and quality of evidence.

Questions for future research

- Should there be specific screening and monitoring of bone health in young people with epilepsy taking anti-epileptic drugs?
- Develop an evidence base evaluating routine mental health screening in adolescents and young adults with epilepsy

Additional educational resources

- A free training tool for teachers to assist them in supporting students with epilepsy in the classroom: <https://epilepsyontario.org/at-work-school/epilepsy-and-education/for-educators/>
- Reviews by Epilepsy Research UK and Young Epilepsy on seizure alarms: https://www.epilepsyresearch.org.uk/wp-content/uploads/2015/10/Epilepsy-Research-UK-tonic-clonic-seizure-alarm-report_October-2015.pdf. <https://www.youngepilepsy.org.uk/for-parents-and-carers/epilepsy-and-your-child/night-time-safety-equipment.html>.
- Free RCADS forms and scoring: <https://www.corc.uk.net/outcome-experience-measures/revise-childrens-anxiety-and-depression-scale-and-subcales/>

Information resources for patients

- Free short videos from St John Ambulance on how to put a person in the recovery position and administer basic CPR: <https://www.youtube.com/watch?v=GmqXqSV3bo> (recovery position) <https://www.youtube.com/watch?v=avYRvVAVfM> (babies CPR) <https://www.youtube.com/watch?v=0aV9NS0ogIM> (children CPR)
- Video from ViroPharm, the manufacturers of Buccolam, on how to administer rescue medication: <https://www.youtube.com/watch?v=B08WEXzXVo4> (how to give buccolam)
- Royal College of Paediatrics and Child Health Medicines for Children leaflets (carbamazepine example) <https://www.medicinesforchildren.org.uk/carbamazepine-oral-preventing-seizures-0>
- NHS site for self-help of anxiety in children: <https://www.nhs.uk/conditions/anxiety-disorders-in-children/>
- Free and comprehensive advice and factsheets from Epilepsy Action along with training courses <https://www.epilepsy.org.uk/training>

Contributorship statement and guarantor DKP is professor of paediatric epilepsy at King's College London and honorary consultant paediatric neurologist at Evelina London Children's Hospital and King's College Hospital, London. He conceived the idea for the article and jointly planned the article with the coauthors and is guarantor. The guarantor accepts full responsibility for the work, had access to the data, and controlled the decision to publish. KB was a specialist paediatric epilepsy nurse in Lambeth and Southwark communities, now community paediatric matron at St George's Hospital and coauthored the article. JC is a parent of a young person with epilepsy and coauthor. M-CP is a general paediatrician at University College London Hospital with expertise in epilepsy and coauthor. All authors revised the text in successive drafts.

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Table

Table 1 | Risk categories for switching between generic and branded formulations of anti-epileptic drugs⁴

Category	Advice	Drug
1	Ensure that the patient is maintained on a specific manufacturer's product	Phenytoin, carbamazepine, phenobarbital, primidone
2	The need for continued supply of a particular manufacturer's product should be based on clinical judgment and consultation with patient and/or carer taking into account factors such as seizure frequency and treatment history	Valproate, lamotrigine, perampanel, retigabine, rufinamide, clobazam, clonazepam, oxcarbazepine, eslicarbazepine, zonisamide, topiramate
3	Usually unnecessary to ensure that patients are maintained on a specific manufacturer's product unless there are specific concerns such as patient anxiety and risk of confusion or dosing errors.	Levetiracetam, lacosamide, tiagabine, gabapentin, pregabalin, ethosuximide, vigabatrin