NICE National Institute for Health and Care Excellence

NICE Pathways

Special considerations for women and girls with epilepsy

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/epilepsy
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This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.

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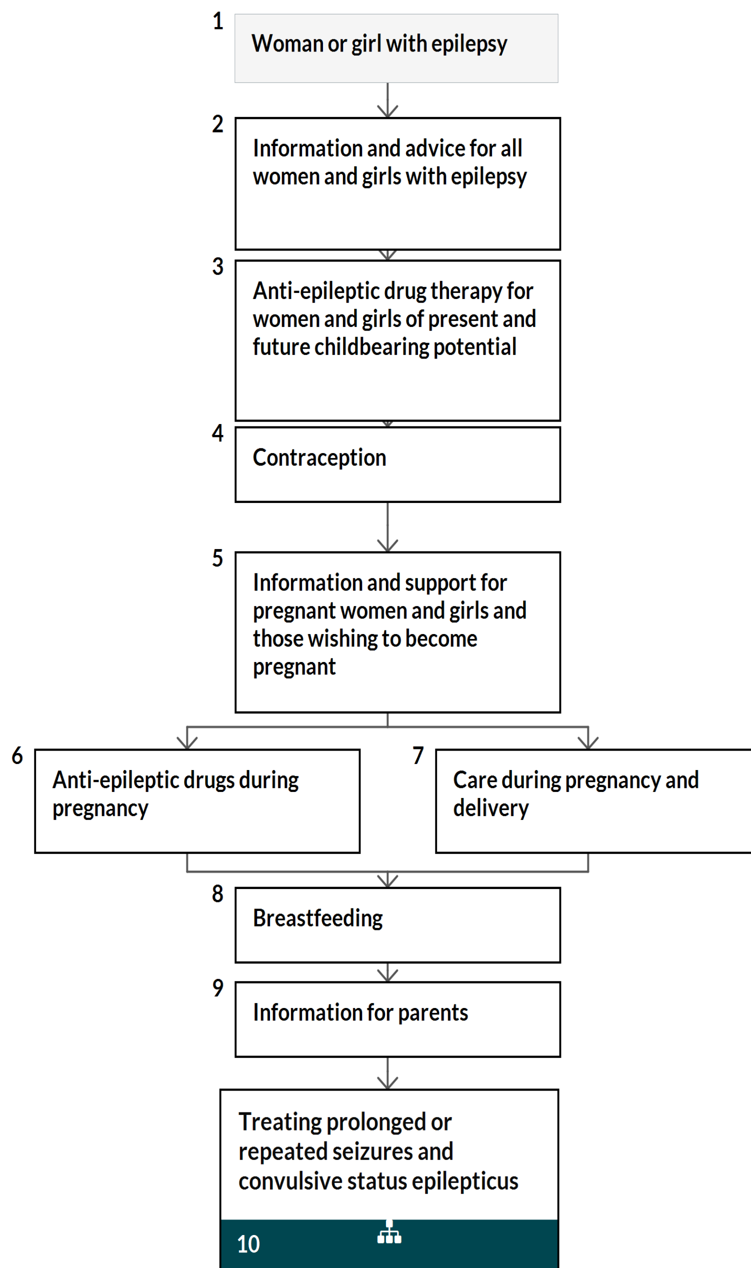

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1 Woman or girl with epilepsy

No additional information

2 Information and advice for all women and girls with epilepsy

In order to enable informed decisions and choice, and to reduce misunderstandings, women and girls with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children and breastfeeding, and menopause.

Information about contraception, conception, pregnancy, or menopause should be given to women and girls in advance of sexual activity, pregnancy or menopause, and the information should be tailored to their individual needs. This information should also be given, as needed, to people who are closely involved with women and girls with epilepsy. These may include her family and/or carers.

All healthcare professionals who treat, care for, or support women and girls with epilepsy should be familiar with relevant information and the availability of counselling.

Discuss with women and girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), and their parents and/or carers if appropriate, the risk of AEDs causing malformations and possible neurodevelopmental impairments in an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Specifically discuss the risk of continued use of sodium valproate to the unborn child, being aware that higher doses of sodium valproate (more than 800 mg/day) and polytherapy, particularly with sodium valproate, are associated with greater risk. Follow the MHRA safety advice on valproate use by women and girls.

See also information and support.

NICE has written information for the public on epilepsy.

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3 Anti-epileptic drug therapy for women and girls of present and future childbearing potential

Be aware of the latest data on the risks to the unborn child associated with AED therapy when prescribing for women and girls of present and future childbearing potential.

All women and girls on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy.

Refer to the summary of product characteristics and BNF for individual drug advice on the interactions between AEDs and hormonal replacement and contraception.

Aim for seizure freedom before conception and during pregnancy (particularly for women and girls with GTC seizures) but consider the risk of adverse effects of AEDs and use the lowest effective dose of each AED, avoiding polytherapy if possible.

Do not offer sodium valproate to women or girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), unless other options are ineffective or not tolerated and the pregnancy prevention programme is in place. Discuss the risk of malformation and neurodevelopmental impairments in an unborn child. Be clear that the risk is particularly increased with high doses of this AED or when using as part of polytherapy. Follow the MHRA safety advice on valproate use by women and girls.

For more information see pharmacological treatment of epilepsy.

4 Contraception

In women of childbearing potential, the possibility of interaction with oral contraceptives should be discussed and an assessment made as to the risks and benefits of treatment with individual drugs.

In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the possibility of interaction with oral contraceptives should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs.

In women and girls of childbearing potential, the risks and benefits of different contraceptive methods, including hormone-releasing IUDs, should be discussed.

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If a woman or girl taking enzyme-inducing AEDs chooses to take the combined oral contraceptive pill, guidance about dosage should be sought from the summary of product characteristics and current edition of the BNF.

Specific advice for women and girls taking lamotrigine

Discuss with women and girls who are taking lamotrigine that the simultaneous use of any oestrogen-based contraceptive can result in a significant reduction of lamotrigine levels and lead to loss of seizure control. When a woman or girl starts or stops taking these contraceptives, the dose of lamotrigine may need to be adjusted.

Contraception in women and girls taking enzyme-inducing anti-epileptic drugs

The progestogen-only pill is not recommended as reliable contraception in women and girls taking enzyme-inducing AEDs.

The progestogen implant is not recommended in women and girls taking enzyme-inducing AEDs.

The use of additional barrier methods should be discussed with women and girls taking enzyme-inducing AEDs and oral contraception or having depot injections of progestogen.

If emergency contraception is required for women and girls taking enzyme-inducing AEDs, the type and dose of emergency contraception should be in line with the summary of product characteristics and current edition of the BNF.

For more information see pharmacological treatment of epilepsy.

5 Information and support for pregnant women and girls and those wishing to become pregnant

Women and girls with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women and girls who plan to stop AED therapy (for more information, see information on sudden unexpected death in epilepsy).

All pregnant women and girls with epilepsy should be encouraged to notify their pregnancy, or allow their clinician to notify the pregnancy, to the UK Epilepsy and Pregnancy Register.

The clinician should discuss with the woman and girl the relative benefits and risks of adjusting

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medication to enable her to make an informed decision. Where appropriate, the woman or girl's specialist should be consulted.

Women and girls with GTC seizures should be informed that the fetus may be at relatively higher risk of harm during a seizure, although the absolute risk remains very low, and the level of risk may depend on seizure frequency.

Women and girls should be reassured that there is no evidence that focal seizures, absence seizures and myoclonic seizures affect the pregnancy or developing fetus adversely unless they fall and sustain an injury.

Women and girls should be reassured that an increase in seizure frequency is generally unlikely in pregnancy or in the first few months after birth.

Generally, women and girls may be reassured that the risk of a tonic–clonic seizure during the labour and the 24 hours after birth is low (1–4%).

Women and girls with epilepsy should be informed that although they are likely to have healthy pregnancies, their risk of complications during pregnancy and labour is higher than for women and girls without epilepsy.

Genetic counselling should be considered if one partner has epilepsy, particularly if the partner has idiopathic epilepsy and a positive family history of epilepsy.

Although there is an increased risk of seizures in children of parents with epilepsy, children, young people and adults with epilepsy should be given information that the probability that a child will be affected is generally low. However, this will depend on the family history.

6 Anti-epileptic drugs during pregnancy

Aim for seizure freedom before conception and during pregnancy (particularly for women and girls with GTC seizures) but consider the risk of adverse effects of AEDs and use the lowest effective dose of each AED, avoiding polytherapy if possible.

Do not routinely monitor AED levels during pregnancy. If seizures increase or are likely to increase, monitoring AED levels (particularly levels of lamotrigine and phenytoin, which may be particularly affected in pregnancy) may be useful when making dose adjustments.

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7 Care during pregnancy and delivery

Care of pregnant women and girls should be shared between the obstetrician and the specialist.

Pregnant women and girls who are taking AEDs should be offered a high-resolution ultrasound scan to screen for structural anomalies. This scan should be performed at 18–20 weeks' gestation by an appropriately trained ultrasonographer, but earlier scanning may allow major malformations to be detected sooner.

The risk of seizures during labour is low, but it is sufficient to warrant the recommendation that delivery should take place in an obstetric unit with facilities for maternal and neonatal resuscitation and treating maternal seizures.

All children born to mothers taking enzyme-inducing AEDs should be given 1 mg of vitamin K parenterally at delivery.

Advanced planning, including the development of local protocols for care, should be implemented in obstetric units that deliver babies of women and girls with epilepsy.

Joint epilepsy and obstetric clinics may be convenient for mothers and healthcare professionals but there is insufficient evidence to recommend their routine use.

It is, however, important that there should be regular follow-up, planning of delivery, and liaison between the specialist or epilepsy team and the obstetrician or midwife.

8 Breastfeeding

All women and girls with epilepsy should be encouraged to breastfeed, except in very rare circumstances. Breastfeeding for most women and girls taking AEDs is generally safe and should be encouraged. However, each mother needs to be supported in the choice of feeding method that best suits her and her family.

Prescribers should consult individual drug advice in the summary of product characteristics and the BNF when prescribing AEDs for women and girls who are breastfeeding. The decision regarding AED therapy and breastfeeding should be made between the woman or girl and the prescriber, and be based on the risks and benefits of breastfeeding against the potential risks of the drug affecting the child.

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9 Information for parents

Parents of new babies or young children should be informed that introducing a few simple safety precautions may significantly reduce the risk of accidents and minimise anxiety. An approaching birth can be an ideal opportunity to review and consider the best and most helpful measures to start to ensure maximum safety for both mother and baby.

Information should be given to all parents about safety precautions to be taken when caring for the baby (see appendix D of the full guideline which provides a checklist for the information needs of women and girls with epilepsy, and practical information for mothers with epilepsy).

Parents should be reassured that the risk of injury to the infant caused by maternal seizure is low.

10 Treating prolonged or repeated seizures and convulsive status epilepticus

See Epilepsy / Treating prolonged or repeated seizures and status epilepticus

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Glossary

Absence seizures

(seizures characterised by behavioural arrest associated with generalised spike wave activity on EEG)

AED

(anti-epileptic drug: medication taken daily to prevent the recurrence of epileptic seizures)

AEDs

(anti-epileptic drugs: medication taken daily to prevent the recurrence of epileptic seizures)

Focal seizures

(seizures that originate within networks limited to one hemisphere, discretely localised or more widely distributed)

GTC seizures

(a seizure of sudden onset involving generalised stiffening and subsequent rhythmic jerking of the limbs, the result of rapid widespread engagement of bilateral cortical and subcortical networks in the brain)

Idiopathic

(a syndrome that is only epilepsy, with no underlying structural brain lesion or other neurological signs or symptoms; presumed to be genetic in aetiology and usually age dependent)

IUDs

intrauterine devices

Myoclonic seizures

(sudden brief (<100 ms) and almost shock-like involuntary single or multiple jerks due to abnormal excessive or synchronous neuronal activity and associated with polyspikes on EEG)

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Polytherapy

(2 or more medications used in combination therapy)

Specialist

(for children and young people: a paediatrician with training and expertise in epilepsy; for adults: a medical practitioner with training and expertise in epilepsy)

SUDEP

(sudden unexpected death in epilepsy: sudden, unexplained, witnessed or unwitnessed, non-traumatic and non-drowning death in people with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death)

Tonic–clonic

(an epileptic seizure characterised by initial generalised muscle stiffening, followed by rhythmical jerking of the limbs, usually lasting a few minutes; the person may bite their tongue, be incontinent, feel confused or sleepy afterwards, and take a while to recover fully)

Sources

Epilepsies: diagnosis and management (2012 updated 2021) NICE guideline CG137

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them

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and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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