Epilepsy care – your rights

3

Referral to tertiary care

Our ‘Epilepsy care – your rights’ factsheets explain your rights and choices with regard to your epilepsy care and treatment. ‘Rights’ are in the NHS Constitution and the Handbook to the NHS Constitution, and you are entitled to them by law. Where we say ‘you should’, you may not have a legal right, but these are recommendations made in the NICE (National Institute for Health and Care Excellence) guideline on epilepsy.

If your epilepsy is difficult to diagnose or manage, you should be referred to a tertiary service for specialist care and treatment.

> *Children, young people and adults may need access to tertiary services at certain times during their care and these services should be available to everyone who needs them. NICE clinical guideline*

Tertiary care is provided by specialist hospitals or units that focus on specific care for different conditions. You will need a referral from either your GP (primary care) or your local hospital or clinic (secondary care). Anyone referred to tertiary services should be seen within four weeks. You should be referred to tertiary services or ‘tertiary care’ if:

- the diagnosis or cause of your epilepsy is unclear, or if there is uncertainty about your seizure type or epilepsy syndrome;
- your seizures are not controlled with medication or if you are having problems with side effects, or if you or a child has a syndrome that is unlikely to be controlled with medication;
- you need further assessment, tests, or specialist treatments (such as the ketogenic diet or epilepsy surgery); or
- you are eligible to participate in a clinical trial or research study and wish to do so.

Particular groups of children should be prioritised for more urgent referral within 2 weeks.

In tertiary care, you should be seen by someone with expertise in epilepsy and have access to investigations to help you. This might include reviewing your diagnosis to see what kind of epilepsy and seizures you have, looking at what treatment you have already tried and how it worked for you, and to plan your treatment and management for the future. The aim of managing epilepsy is to fully control your seizures (so that you don’t have any), with the best treatment option for you and the least impact on your life.

If you have a learning disability, physical disability, or mental health problem you should be offered additional support to access a tertiary epilepsy service if needed. This may include having a family member or carer accompany you.

For more information visit:
nhs.uk/NHSConstitution
gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england
nice.org.uk/guidance/ng217

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For a printed copy of this information, call our helpline.

Helpline
0300 102 0024
Information and emotional support.
Confidential.
Visit epilepsysociety.org.uk/helpline for opening hours.