

epilepsy review checklist

epilepsy
society

factsheet

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It is recommended that everyone with epilepsy has a review of their epilepsy, at least once a year. This might be with a GP or neurologist for adults, or with a paediatrician for children. This factsheet includes some suggested topics that you may want to cover in your review.

why should I have a review?

NICE (the National Institute for Health and Care Excellence) say in their guideline on the treatment and management of epilepsy, that everyone with epilepsy “should have a regular structured review. For adults this should be at least yearly and with their GP or a specialist. For children this should also be at least yearly, and be with a specialist.”

A review is an opportunity to discuss your epilepsy and seizures, how they affect your life, any treatment you are taking, and any questions or concerns you have.

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Seizures – the frequency and nature of your seizures may have changed in the last year and this is something you should discuss with your healthcare professional.

Medication – your seizures may be well controlled but you may be having side effects such as dizziness, tiredness, weight change, memory loss or cognitive impairment.

Your prescription – you may be worried that you have been given a different version of your usual medication and may be concerned about how this will affect you.

Remembering to take your medication – if this is an issue you might like to discuss using a reminder service such as alarms or timed text messages.

Stopping your medication – if you are seizure-free you may wish to discuss stopping your medication although this should only ever be considered in consultation with an epilepsy specialist.

Other tablets – if you are taking the oral contraceptive Pill you should let your GP or nurse know. The Pill can be less reliable when taken with some epilepsy medicines. You should also mention any other medication you take.

Women and epilepsy – some women feel that their seizures are worse around the time of their periods and this is something you could discuss.

If you are pregnant or are thinking of starting a family, it is important that you receive expert advice. Your GP may refer you to an epilepsy specialist.

Menopause and hormone replacement therapy – these can affect epilepsy and this is a chance to review any necessary adjustments to your medication.

Feeling anxious or depressed – this affects many people at some point in their lives and you may like to talk about ways of coping with these feelings.

Lifestyle issues – you may like to discuss safety advice about cooking and bathing or sport and leisure activities.

Current driving regulations – if you have uncontrolled seizures, you can check the regulations for your situation.

Employment issues – this could include whether or not you disclose your epilepsy at work and how to cope with seizures in the workplace.

Stress, lack of sleep, alcohol and recreational drugs – these can all trigger seizures and may be something you would wish to talk about.

Sudden Unexpected Death in Epilepsy (SUDEP) – SUDEP only happens to a very small number of people with epilepsy (about 1 in 1,000). The better your epilepsy is controlled, the less likely it is that this could happen to you. A review is a good place to talk about how you can reduce your risk.

Taken from an article by Jenny Nightingale, Epilepsy specialist nurse, in ‘Epilepsy Review’, January 2013.

 See more about the NICE guideline at [nice.org.uk/guidance/cg137](https://www.nice.org.uk/guidance/cg137)

 Your GP or specialist can download a copy of our yearly review template from our website epilepsysociety.org.uk/yearly-review

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