

Epilepsy is a common neurological condition there are over 450,000 sufferers in the UK alone; every day approx 75 new cases are diagnosed. Epilepsy is a tendency to have recurrent seizures that originate in the brain.

Gathering information about epilepsy can seem difficult whether you are a long term sufferer or have recently been diagnosed, however with the right questions you can find ways of accessing both the information and the support you need to enable you to live with the condition.

Below are a number of questions; by answering these as accurately as you can, you may find concerns which you can raise with your Dr on your next visit. Having as much information at hand as possible will not only aid in a correct diagnosis but should also guide you towards the information you require.

Working towards Diagnosis

Who diagnosed your epilepsy?

- The doctor in the Accident & Emergency Dept.
- Your own doctor
- A Neurologist
- A Specialist Epilepsy Consultant

What tests have you had towards a diagnosis?

- CT* scan
- MRI*
- EEG*

Not all of these are always necessary for an accurate diagnosis. *Please see end of document for full medical term.

Was a full medical carried out?

- Physical exam
- Blood tests
- Blood pressure
- ECG*
- A full medical history
- Allergies

Is there anything in your history that could be relevant?

- Has anyone in your family been diagnosed with epilepsy
- Have you received a head injury
- Have you been ill with a temperature or infection
- Have you a history of substance or alcohol misuse.

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Do you keep a record of your seizures?

- Do you keep an epilepsy diary
- Does someone help you to fill in the missing details
- Do you keep details of injuries you sustain during seizure activity
- Are you aware of the onset of a seizure and what occurs during it
- How long did your seizure last
- How long does it take you to recover from a seizure
- Is your seizure activity increasing/decreasing unvarying

Are there any triggers to your seizures?

- Worry or stress
- Allergies
- Foods
- Missed Meals
- Flashing lights
- Menstruation
- Constipation
- Temperature
- Tiredness/lack of sleep
- Alcohol
- Smells
- Any other common factors

Do you know about the drugs you are taking?

- What is the name of your AED* and how does it work
- What is the recommended dose and when do you need to take them
- Do you know why it is important to take your AED`s at regular times
- It is important that these drugs are increased/decreased slowly do you know why
- Are there side effects and do you know what these may be
- Regular blood tests may be necessary do you know why
- Sometimes more than 1 AED may be necessary
- What do you do in the event of missing a dose
- Do you know it is dangerous to suddenly stop taking this medication without supervision from your Dr.
- Your local pharmacist can help advise you about the drugs you are taking and discuss with you possible side effects.

Are you aware that some medications maybe affected by AED`s please discuss all your meds with your Dr.

Did you know you are eligible for free prescriptions and that you may also qualify for certain welfare benefits?

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Have any other treatments been mentioned?

- The Ketogenic diet-usually used in the treatment of children
- Vegus nerve stimulation
- Surgery
- Specific medications for prolonged seizures.

Do you need more information about the possible effects of AED's on:

- Pregnancy
- Fertility
- Breastfeeding
- Young children
- The elderly
- Sexual function
- Someone with a learning disability
- The menopause

Have you been offered the opportunity to speak with the epilepsy specialists in your area? Do you know who the epilepsy nurses or the epilepsy specialists are?

Have you or those closest to you been advised on what to do in the event of a seizure? Has basic first aid been offered i.e. the recovery position?

Has anyone offered you advice on the following and the impact this can have on epilepsy?

- Drugs and alcohol
- Stress
- Lack of sleep
- A poor diet
- Lack of exercise



Do you know about epilepsy and driving regulations?

Do you know how to go about putting safety precautions in place whilst at your place of work/school/college etc. What about staying safe whilst travelling or participating in your leisure pursuits?

Have you been advised about what safety aids are available for people with epilepsy? e.g.




- Identity jewellery detailing your condition

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-  Certain alarms
-  Identity cards

Have you been given information about the local support services?

Would you like to talk to some one about:

-  Further education, a change of career, job prospects etc
-  How epilepsy has impacted on your life and those around you
-  How epilepsy and it's treatments affect sexual relationships, fertility, pregnancy and contraception?

- * CT Computerised tomography scan
- * MRI Magnetic resonance scan
- * EEG Electroencephalograph
- * ECG Electrocardiogram
- * AED Anti-Epileptic Drug