Epilepsy checklist

In this leaflet Professor Helen Cross, a consultant paediatric neurologist in London, presents a checklist that will help you to access the information and support that you need.

Epilepsy is a common neurological disorder that affects approximately one person in every 103. It is a tendency to have recurrent seizures, which are caused by too much electrical activity in the brain.

For more information, see our leaflet entitled ‘What is epilepsy?’

If you have a diagnosis of epilepsy this checklist will help you to access information and support in managing your condition. It will help you ask the right questions about:

- diagnosis and investigations
- seizures
- treatment options
- medication
- lifestyle choices
- accessing information and support
- the information and support available

Investigations and diagnosis

Who investigated and diagnosed your epilepsy?

☐ Consultant specialising in epilepsy
☐ Neurologist
☐ GP
☐ Accident & Emergency doctor

Have you had a full medical examination? (Please tick all that apply)

☐ Medical history taken
☐ Physical examination
☐ Blood tests
☐ ECG (electrocardiogram)
☐ Blood pressure check

What tests and investigations have you had?

☐ EEG (electroencephalograph)
☐ MRI (magnetic resonance imaging)
☐ CT (computerised tomography) scan

N.B. Not all of these may be necessary
Do any of the following factors play a part in your epilepsy?

- Severe head injury
- Illness, infection or fever
- Family history of epilepsy
- Substance misuse

For more information, please see our leaflet entitled ‘Diagnosing epilepsy’.

Seizures

- Do you know how best to record seizures?
- Do you know what happens before, during and after your seizures?
- Have you kept a note of any injuries you have sustained during your seizures?
- Do you have a written eye-witness account of your seizures?

Does anything seem to trigger your seizures?

- Lack of sleep or disturbed sleep
- Missed meals
- Boredom/inactivity
- Anxiety/stress
- Menstruation
- Flashing lights
- Fever
- Alcohol
- Other recreational drugs
- Other: please state:

Do you, your family, your friends or your carers know the first aid procedure for your seizures type(s)?

Have you, your family, your friends or your carers had the opportunity to practise the first aid procedures for your seizure type(s)?

See also our leaflets entitled ‘What is epilepsy?’ and ‘Recording seizures’.

Treatment options

Do you know about the following treatment options?

- Anti-epileptic drugs (AEDs)
- Surgery
- Vagus nerve stimulation (VNS)
- Ketogenic diet (generally used for children)

What treatment has been recommended for you?

See also our leaflet entitled: ‘Treatment for epilepsy’.

Anti-epileptic drugs (AEDs)

Do you know:

- how your AEDs work?
- the name and dosage of your AEDs and when to take them?
- why it’s important to take your AEDs as prescribed?
- why AEDs are introduced and withdrawn gradually?
- what the possible side effects of your AEDs are, and what to do if you experience any?
- that in some circumstances a blood test may be required to check the level of AEDs in the blood?
Do you know what to do if you:
- miss a dose?
- take too much or too little medication?
- have vomiting or diarrhoea?
- suffer a fever or infection?
- are travelling across time zones?

Do you know that some drugs or preparations can reduce the effectiveness of AEDs and vice versa?

These include:
- some antibiotics
- some antidepressants and antipsychotics
- some oral and injectable contraceptives and hormone replacement therapy (HRT)
- some anti-allergy medications
- some anti-malarial medications
- some herbal medicines
- alcohol and other recreational drugs

For details, ask your doctor.

Do you need information about the possible effects of AEDs on:
- sexual function, fertility, preconception, pregnancy, or breastfeeding?
- infants and young children?
- older people?
- people with a learning disability?

Do you know:
- that there is emergency medication that families or carers can use if seizures are prolonged?
- when and how it should be used (only if you have been prescribed it)?
- that it is potentially dangerous to stop taking AEDs without medical supervision?
- that your local pharmacist can advise on any issues relating to AEDs and other medication?

For more information, please see our leaflet entitled ‘Anti-epileptic drug treatment’.

Lifestyle choices

Lifestyle choices can affect your epilepsy.

Do you know the benefits of:
- a healthy diet?
- good sleep patterns?
- taking a realistic approach to alcohol and other recreational drugs?
- regular, safe exercise?
- learning to relax?
- balancing risk and safety?
- learning to manage stress and anxiety?

Are you aware of methods of managing stress?
- complementary therapies
- self-management methods

Do you know:
- if anything triggers your seizures?
- what photosensitivity is, whether you are affected and how to manage it?

Do you know:
- about the driving regulations that apply to people with epilepsy, and how they affect you?
- what safety precautions to take at school, college and at work, when taking part in sports or leisure activities, and when travelling?
- about the range of safety aids available for people with epilepsy? These include:
  - alarms
  - epilepsy ID cards
  - bracelets and pendants
  - safety adaptations at home

Do you know:
- that you are eligible for free prescriptions?
- that you may be eligible for concessionary travel and some welfare benefits?
Have you had:

- advice on further education, choosing a career and finding a job?
- the chance to discuss the impact of epilepsy on relationships with family, friends and partners?
- the chance to discuss the impact of epilepsy and AEDs on sexual relationships, contraception, fertility, pregnancy, and menopause?

For more information, please read our leaflets entitled: 'Epilepsy: balancing risk and safety', 'Epilepsy: safety at home', 'Epilepsy: safety in sport', 'Epilepsy: safety at work', 'Epilepsy and leisure – safety issues', 'Epilepsy: safety in school, college and university' and 'Epilepsy and photosensitivity'.

Where to find more information and support

- Have you had the opportunity to ask questions about your epilepsy of your doctor, epilepsy specialist or epilepsy support worker?
- Do you have information about local epilepsy support services?

Have you had the opportunity to seek information about:

- living with epilepsy?
- how best to manage problems posed by your epilepsy?
- epilepsy and pregnancy?
- epilepsy in younger children?
- epilepsy in adolescence?
- epilepsy and sexual function?
- epilepsy and the menopause?
- epilepsy in older age?
- new AEDs?
- complementary therapies?
- self-management methods

- epilepsy and learning disability?
- epilepsy and other physical disabilities?
- epilepsy and mental health issues?
- epilepsy and stroke?
- research into epilepsy?

Do you know that there are:

- opportunities to attend educational programmes, seminars and conferences on epilepsy?
- many helpful internet sites on epilepsy?

See our links page: www.epilepsyresearch.org.uk/about-epilepsy/other-sources-of-information/ for the most useful.

This is one in a series of information leaflets about epilepsy.

To access the others, or to find out more about our research, please visit our website: www.epilepsyresearch.org.uk

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