

Useful website addresses:-

Epilepsy Connections—www.epilepsyconnections.org.uk

Epilepsy Scotland—www.epilepsyscotland.org.uk

Epilepsy Action—www.epilepsyaction.org.uk

National Society for Epilepsy—www.epilepsynse.org.uk

National Centre for Young People with Epilepsy—
www.ncype.org.uk

Joint Epilepsy Council—www.jointepilepsycouncil.org.uk

Epilepsy Research Foundation—www.erf.org.uk



Supporting people with epilepsy

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Epilepsy Checklist

Epilepsy is a common neurological disorder that affects approximately 1 person in every 200.

Epilepsy is a tendency to have recurrent seizures that originate in the brain. (See leaflet 1 'What is Epilepsy? An Introduction').

If you have a diagnosis of epilepsy this checklist will help you to access information and support in living with your condition.

The checklist will help you ask the right questions about:

1. Diagnosis and investigations
2. Seizures
3. Treatment options
4. Medication
5. Lifestyle choices
6. Accessing information and support

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1. Investigations and diagnosis

Who investigated and diagnosed your epilepsy?

- Consultant specialising in epilepsy
- Neurologist
- GP
- Accident and Emergency doctor

Have you had a full medical examination?

- 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) Scan
- CT (Computerised Tomography) Scan

N.B. Not all of these tests will 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

(See Leaflet 2 'Diagnosing Epilepsy').

2. 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 sustained during seizures?
- Do you have a written eye-witness account of your seizures?

6. Where to find more information and support

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

Have you had opportunities 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 antiepileptic drugs?
- 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 there are

- opportunities to attend educational programmes/seminars/conferences on epilepsy?
- many useful internet sites on epilepsy?

5. Lifestyle choices (cont)

Do you know

- about the range of safety aids available for people with epilepsy, including:
 - alarms?
 - epilepsy I.D. cards?
 - bracelets and pendants?
 - seizure warning dogs?
 - safety adaptations at home?
- 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, partners?
- the chance to discuss the impact of epilepsy and AEDs on sexual relationships, contraception, fertility, pregnancy, menopause?

See Leaflets

7 'Epilepsy: Balancing Risk and Safety'

7a 'Safety in the Home'

7b 'Safety in School, College and University'

7c 'Safety at Work'

7d 'Safety in Sport'

7e 'Leisure and Pleasure: Safety Issues'

8 'Epilepsy and Photosensitivity'

2. Seizures (cont)

Does anything seem to trigger your seizures?

- Lack of sleep or disturbed sleep
- Missed meals
- Anxiety/stress
- Flashing lights
- Alcohol
- Other: please state
- Boredom/inactivity
- Menstruation
- Fever
- Other recreational drugs
- Do you/your family/friends/carers know the first aid procedure for your seizure type(s)?
- Have you/your family/friends/carers had the opportunity to practice the first aid procedures for your seizure type(s)?

(See Leaflet 1 'What is epilepsy: An Introduction' and Leaflet 3 'Recording Seizures').

3. Treatment options

Do you know about the following treatment options?

- Antiepileptic drugs (AEDs)
- Surgery
- Vagal Nerve Stimulation
- Ketogenic Diet (generally used for children)

What treatment has been recommended for you?

(See Leaflet 5 'Treatment for Epilepsy')

4. Antiepileptic 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?
- the possible side effects of your AEDs 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/too little medication?
- have vomiting/diarrhoea?
- suffer a fever or infection?
- are travelling across time zones?

Do you know that drugs/preparations can reduce the effectiveness of AEDs and vice versa? These include

- some antibiotics
- some antidepressants/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

Do you need information about the possible effects of AEDs on

- sexual function, fertility, preconception, pregnancy, breastfeeding?
- infants and young children?
- older people?
- people with learning disability?
- Do you know that there is emergency medication that families/carers can use if seizures are prolonged?

4. Antiepileptic drugs (cont)

- If you have been prescribed this emergency medication do you know when and how it should be used?
- Do you know that it is potentially dangerous to stop taking AEDs without medical supervision?
- Do you know that your local pharmacist can advise on any issues relating to AEDs and other medication?

(See Leaflet 6 'Antiepileptic Drugs').

5. Lifestyle choices

Lifestyle choices can affect your epilepsy.

Do you know about the benefits of

- a healthy diet?
- regular, safe exercise?
- good sleep patterns?
- learning to relax?
- taking a realistic approach to alcohol and other recreational drugs?
- 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?
- about the driving regulations which 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 and leisure activities and when travelling?