

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.

For more information, see leaflet one in this series: **'What is epilepsy?'**.

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:

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

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?

- 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, see leaflet two in this series: **'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 sustained during seizures?
- Do you have a written eye-witness account of your seizures?

Does anything seem to trigger your seizures?

- | | |
|---|---|
| <input type="checkbox"/> Lack of sleep or disturbed sleep | <input type="checkbox"/> Flashing lights |
| <input type="checkbox"/> Missed meals | <input type="checkbox"/> Fever |
| <input type="checkbox"/> Boredom/inactivity | <input type="checkbox"/> Alcohol |
| <input type="checkbox"/> Anxiety/stress | <input type="checkbox"/> Other recreational drugs |
| <input type="checkbox"/> Menstruation | <input type="checkbox"/> 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 in this series, leaflet one: 'What is epilepsy?' and leaflet three: 'Recording seizures'.

TREATMENT OPTIONS

Do you know about the following treatment options?

- | | |
|--|---|
| <input type="checkbox"/> Anti-epileptic drugs (AEDs) | <input type="checkbox"/> Vagus nerve stimulation (VNS) |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Ketogenic diet (generally used for children) |

What treatment has been recommended for you?

See also leaflet five in this series: '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:

- | | |
|--|--|
| <input type="checkbox"/> some antibiotics | <input type="checkbox"/> some anti-allergy medications |
| <input type="checkbox"/> some antidepressants and antipsychotics | <input type="checkbox"/> some anti-malarial medications |
| <input type="checkbox"/> some oral and injectable contraceptives and hormone replacement therapy (HRT) | <input type="checkbox"/> some herbal medicines |
| | <input type="checkbox"/> 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, see leaflet six in this series: 'Anti-epileptic drugs'.

LIFESTYLE CHOICES

Lifestyle choices can affect your epilepsy.

Do you know the benefits of:

- | | |
|---|---|
| <input type="checkbox"/> a healthy diet? | <input type="checkbox"/> regular, safe exercise? |
| <input type="checkbox"/> good sleep patterns? | <input type="checkbox"/> learning to relax? |
| <input type="checkbox"/> taking a realistic approach to alcohol and other recreational drugs? | <input type="checkbox"/> balancing risk and safety? |
| | <input type="checkbox"/> learning to manage stress and anxiety? |

Are you aware of methods of managing stress?

- | | |
|--|--|
| <input type="checkbox"/> complementary therapies | <input type="checkbox"/> 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 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 or leisure activities, and when travelling?
- about the range of safety aids available for people with epilepsy, including:
 - 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?

See also in this series: leaflet seven: '**Balancing risk and safety**'; leaflet eight: '**Safety at home**'; leaflet nine: '**Safety in school, college and university**'; leaflet ten: '**Safety at work**'; leaflet eleven: '**Safety in sport**'; leaflet twelve, '**Epilepsy: leisure and pleasure – safety issues**'; and leaflet thirteen: '**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:

- | | |
|---|---|
| <input type="checkbox"/> living with epilepsy | <input type="checkbox"/> complementary therapies |
| <input type="checkbox"/> how best to manage problems posed by your epilepsy | <input type="checkbox"/> self-management methods |
| <input type="checkbox"/> epilepsy and pregnancy | <input type="checkbox"/> epilepsy and learning disability |
| <input type="checkbox"/> epilepsy in younger children | <input type="checkbox"/> epilepsy and other physical disabilities |
| <input type="checkbox"/> epilepsy in adolescence | <input type="checkbox"/> epilepsy and mental health issues |
| <input type="checkbox"/> epilepsy and sexual function | <input type="checkbox"/> epilepsy and stroke |
| <input type="checkbox"/> epilepsy and the menopause | <input type="checkbox"/> research into epilepsy? |
| <input type="checkbox"/> epilepsy in older age | |
| <input type="checkbox"/> new AEDs | |

Do you know that there are:

- opportunities to attend educational programmes, seminars, and conferences on epilepsy?
- many useful internet sites on epilepsy? See our links page http://www.epilepsyresearch.org.uk/about_epilepsy/what_is_epilepsy.htm for the most useful.

Text supplied by Epilepsy Connections. Last updated January 2008.

Epilepsy Research UK promotes and supports basic and clinical scientific research into the causes, treatment and prevention of epilepsy. The research it supports is entirely funded by donations. A contribution would be greatly appreciated.

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Registered charity No. 1100394. Company limited by guarantee (No. 4873718 – England).

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