

**epilepsy** *action*

# Epilepsy information for prisoners

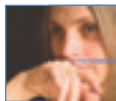
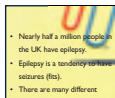


# Contents

This book has been designed with you in mind. It is full of information to help you.

At the back of the book there is a feedback form for you to complete and return.

The centre section of this book can be pulled out if you wish.



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# Epilepsy facts

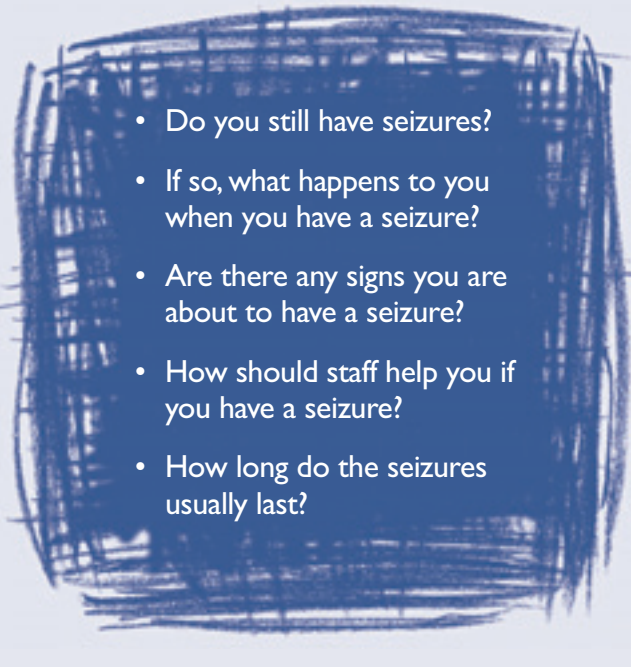
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- Nearly half a million people in the UK have epilepsy.
  - Epilepsy is a tendency to have seizures (fits).
  - There are many different types of seizures.
  - You don't have to be born with epilepsy. It can start at any time.
  - Some people lose consciousness in a seizure but not everybody does.
  - In some types of seizure, the person knows what's happening.

# Telling staff about your epilepsy

A faint, blue-toned line drawing of a person's head and shoulders, facing left. The person has short hair and is wearing a collared shirt. The drawing is composed of many fine, parallel lines, giving it a textured, sketchy appearance. It is positioned in the upper left and center of the page, behind the main title and the central text box.

If you have epilepsy, you should tell prison staff. This is so that they can help you. Think about your answers to the questions on pages 6–7, to give to staff.

# Tell staff about your epilepsy

- 
- Do you still have seizures?
  - If so, what happens to you when you have a seizure?
  - Are there any signs you are about to have a seizure?
  - How should staff help you if you have a seizure?
  - How long do the seizures usually last?

- Is there a time your seizures usually happen? For example, first thing in the morning or during your sleep? (Although most people don't have a particular pattern to their seizures.)
- How long does it usually take you to get back to normal after a seizure?
- Do the seizures stop on their own or do you need emergency treatment?





# Tell staff about your treatment

- What are the names of any medicines you take?
- When do you have to take them?
- How much do you have to take at a time?
- Who has been treating you?





# Some of these people may be able to help you

- **Personal Officer**

If you have one, this is the first person to ask for help and advice. Not all prisoners are given a Personal Officer.

- **Wing or Landing Officer**

If you don't have a Personal Officer there will be an officer in charge of the wing or landing you are on.

- **Disability Liaison Officer (DLO)**

They know a lot about how to look after disabled prisoners. Epilepsy is counted as a disability. You can ask your Personal Officer or the Wing or Landing Officer if you can see the DLO.

- **Prison nurse or the doctor**

- **Epilepsy nurse**

Some prisons have visits from epilepsy nurses. You can ask the prison nurse about this.

- **Listeners or buddies**

These are inmates who are specially trained to give support to other inmates.

- **Epilepsy Action**

Prisoners can write to us for advice about their epilepsy. Our address is FREEPOST LS0 995, Leeds LS19 7YY.

# Diagnosing epilepsy

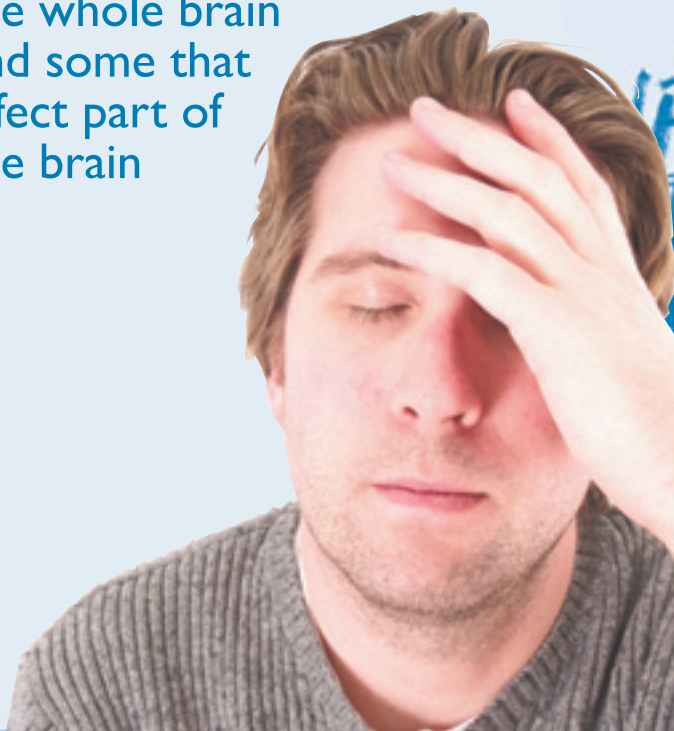
Questions the doctor might ask when they are finding out if someone has epilepsy

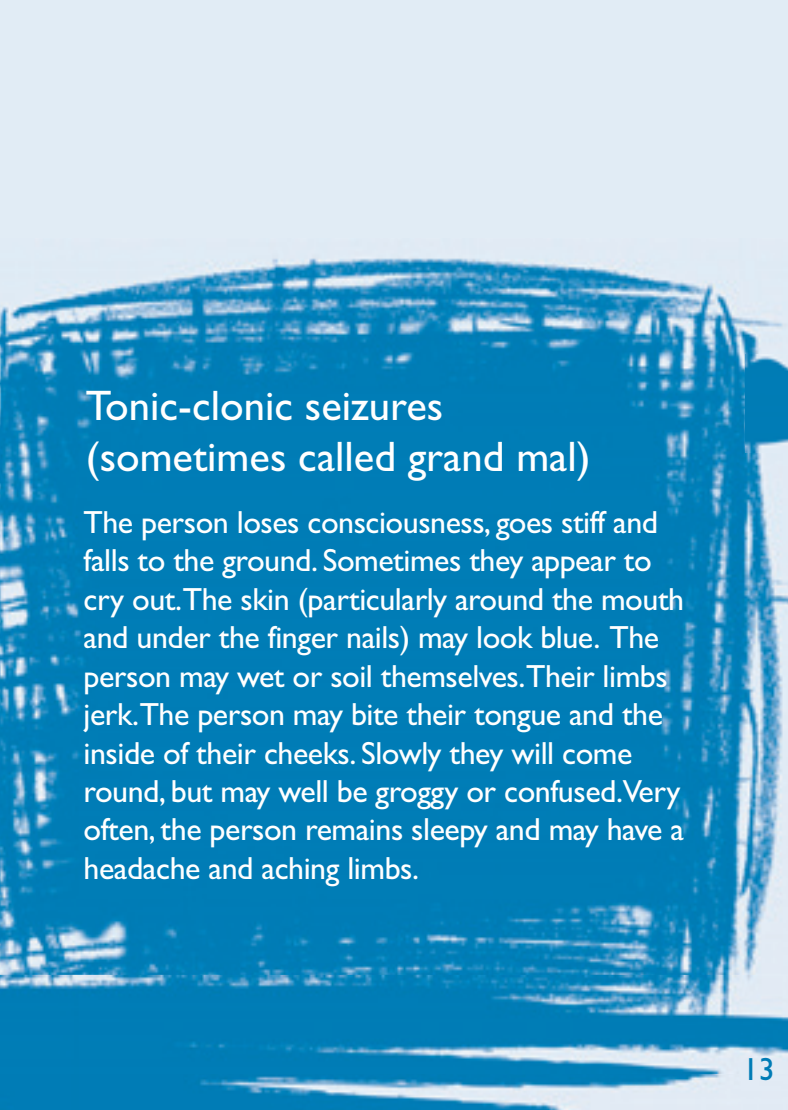


- Can you remember how you felt before the seizure (fit)?
- Did you have any unusual symptoms before the seizure?
- Had you drunk alcohol or taken drugs recently?
- Did anyone see you have the seizure? If so, can they describe what happened?
- Do you know how long the seizure lasted?
- Do you remember anything about the seizure or how you felt when you came round?
- Have you had a seizure before?
- Has anything happened to you in the past that could cause you to have a seizure? For example, a head injury?

# Types of seizures (fits)

There are many different types of seizures, some that affect the whole brain and some that affect part of the brain





## Tonic-clonic seizures (sometimes called grand mal)

The person loses consciousness, goes stiff and falls to the ground. Sometimes they appear to cry out. The skin (particularly around the mouth and under the finger nails) may look blue. The person may wet or soil themselves. Their limbs jerk. The person may bite their tongue and the inside of their cheeks. Slowly they will come round, but may well be groggy or confused. Very often, the person remains sleepy and may have a headache and aching limbs.

## Absence seizures (sometimes called petit mal)

During an absence seizure the person is unconscious for a few seconds. It may look as if they are daydreaming or switching off. However, they won't know what is happening around them and they cannot be woken up. Absence seizures are most common in childhood.



## Myoclonic seizures

These are sudden jerks. They can affect the whole body, but are usually just in one or both arms and sometimes the head. The person is not conscious, but the seizure is so brief that they look as if they are fully conscious.

## Complex partial seizures

The person is only partly conscious and although it may look as if they are fully aware of what they are doing, they're not.

Examples of what can happen are chewing and swallowing, fumbling with buttons, scratching the head or searching for an object. Some people may remove items of clothing, or keep doing the same thing over and over again.



## Simple partial seizures

The person remains fully conscious, but they are unable to stop or control the seizure.

Examples of what can happen are:

- the movement of a limb
- tingling
- smelling or tasting something that isn't there
- going pale
- sweating
- a churning feeling in the stomach
- feelings of fear, panic, sadness, happiness
- feeling that what you are doing you have already done before – even if you haven't.

When seizures occur in the part of the brain responsible for seeing things, people can see flashing or balls of light, or lose their sight for a short time.

## Secondary generalisation

Sometimes, a simple partial or complex partial seizure can spread to the whole brain resulting in a tonic-clonic (grand mal) seizure.

# Women with epilepsy

Some important facts for  
women with epilepsy



This section of the book is designed so you can  
pull it out, if you wish.

# Contraception

- Some medicines for epilepsy can make some types of contraception work less well. This means you could become pregnant.
- Some types of contraception can interfere with epilepsy medicines. This could cause you to have a seizure.
- To make sure you have the right contraception tell medical staff about your epilepsy medicine and **any other treatment you are taking.**



# Having a baby

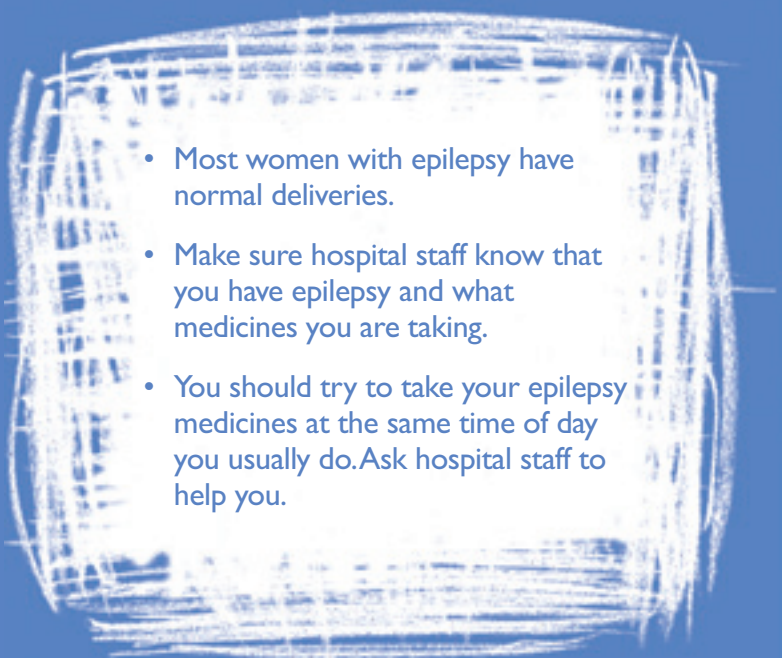
## Pregnancy

- Most women with epilepsy give birth to healthy babies.
- Having epilepsy and taking medicine for epilepsy can increase the risk of a health problem for the baby. If you can, get medical advice before you get pregnant, because there are lots of ways of reducing this risk.
- Never just stop taking your epilepsy medicine. This could be dangerous for you and for your baby.





# Childbirth

- 
- Most women with epilepsy have normal deliveries.
  - Make sure hospital staff know that you have epilepsy and what medicines you are taking.
  - You should try to take your epilepsy medicines at the same time of day you usually do. Ask hospital staff to help you.

# Breastfeeding

- Lots of women with epilepsy can breastfeed their baby. Ask your midwife or doctor for advice.





## Inheriting epilepsy

- Just because you have epilepsy it doesn't mean your children will have it But they will have a slightly greater chance of developing epilepsy than children in general.





## Menopause (the change)

- If you are going through the menopause your epilepsy could change. If you notice a difference, talk to your doctor or nurse.
- You could be at risk of developing brittle or softening bones. Some epilepsy medicines increase this risk. Treatment is available – so ask your doctor or nurse if they think you are likely to be at risk.

# Periods

Some women tend to have seizures around their periods. If you think this is the case for you, keep a note of the dates of your period and when you have seizures. Your doctor may be able to give you some treatment to help.

British Epilepsy Association  
New Anstey House, Gate Way Drive,  
Yeadon, Leeds LS19 7XY  
tel. 0113 210 8800 fax 0113 391 0300  
Email: [epilepsy@epilepsy.org.uk](mailto:epilepsy@epilepsy.org.uk) [www.epilepsy.org.uk](http://www.epilepsy.org.uk)


# Important things to know about epilepsy medicine

- Epilepsy medicine is designed to stop seizures *before they happen*. It doesn't cure epilepsy. And it doesn't stop a seizure once it's happening.
- There are lots of different medicines for epilepsy.
- If one medicine doesn't control seizures, another might.
- Sometimes it's just a matter of changing the amount you take.
- Sometimes it's necessary to change the medicine completely.
- Sometimes people might need more than one medicine.

# Important things to know about epilepsy medicine

## The rules!

- Never give your epilepsy medicine to anyone else. It could be dangerous for them.
- Tell your doctor or nurse if you are taking medicine for anything else.
- Take your epilepsy medicine exactly as your doctor or nurse tell you to.
- Take only the amount prescribed. Taking more than this can be dangerous.
- If you miss a dose, ask your doctor or nurse what you should do as soon as you can – don't take double at the time for your next dose.

- 
- Never suddenly stop taking your medicine. This could cause you to have a seizure.
  - If you think your medicine is making you unwell in any way – talk to your doctor or nurse.
  - If your medicine isn't stopping you having seizures, tell your doctor or nurse. They may be able to do something about it.

# Why epileptic seizures can happen



Sometimes there is no obvious cause. They just happen out of the blue. But sometimes there can be a reason, or 'trigger'. If you know what triggers your seizures, you might be able to avoid that trigger.

On the next page are some possible triggers. But not everyone has a trigger for their seizures.

## Possible triggers

- Not taking epilepsy medicine as prescribed
- Not eating regularly
- Not getting enough sleep
- Getting stressed or excited
- Being bored
- Some types of flashing or flickering light
- Alcohol
- Some street drugs

Drinking a lot of alcohol or taking street drugs can cause someone to have seizures (fits) for the first time. They might then go on to develop epilepsy.



# First aid for seizures (fits) with full loss of consciousness



## **This is what you should do**

- Call for help
- Protect the person from injury
- Remove harmful objects from nearby
- Cushion their head with something like a pillow, or your hands
- Turn them on their side once the seizure has finished
- Stay with them until they have fully recovered

## And this is what you should not do

- Don't try to stop the seizure or hold the person down
- Don't put anything in their mouth
- Don't try to move them unless they are in danger
- Don't give them anything to eat or drink until they are fully recovered
- Don't try to bring them round



# First aid for seizures (fits)

without full loss of consciousness

## This is what you should do

- Stay calm
- Guide the person from danger
- Remember that they might not know what's going on
- Stay with them until they have fully recovered





## **And this is what you should not do**

- Don't try to stop the seizure or hold the person down
- Don't act in a way that could frighten them
- Don't give them anything to eat or drink until they are fully recovered
- Don't try to bring them round

# When you should call for emergency medical care

- If one seizure follows another without the person gaining awareness between seizures
- If the person is injured during the seizure



# Epilepsy information for prisoners

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

☐ Very useful    ☐ Useful    ☐ Quite useful    ☐ Not at all useful

Is the language clear and easy to understand?

☐ Very clear and easy to understand  
☐ Clear and easy to understand  
☐ Quite clear and easy to understand  
☐ Not at all clear or easy to understand

Does this publication cover all you want to know about the topic?

☐ Completely    ☐ Mostly    ☐ Not quite    ☐ Not at all

What do you think of the design and general layout of this publication?

☐ Excellent    ☐ Good    ☐ OK    ☐ Poor

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Date: 

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Please return the completed form to:

**Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY**

**Epilepsy Action  
FREEPOST LS0995  
LEEDS  
LS9 7YY**

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March 2009

Review date: March 2011

Epilepsy Action makes every effort to ensure the accuracy of  
information in its publications but cannot be held liable for any  
actions taken based on this information.

# Organisations or people that give help and advice

## Epilepsy Action

### Head office:

New Anstey House, Gate Way Drive, Yeadon,  
Leeds LS19 7XY. Tel. 0113 210 8800

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

### Helpline:

freephone 0808 800 5050;

text 07797 805390

[helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

Gives information and advice on anything to do with epilepsy

## NHS Direct and NHS 24

### England and Wales

NHS Direct: 0845 4647

### Scotland

NHS 24: 08454 242424

Gives information and advice about anything to do with health and the NHS

## Epilepsy Helpline:

freephone 0808 800 5050 text 07797 805 390

helpline@epilepsy.org.uk

www.epilepsy.org.uk

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**email** epilepsy@epilepsy.org.uk **text** 07797 805 390 **www.epilepsy.org.uk**

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