#### Epilepsy



What is Epilepsy?



Epilepsy is a common brain condition.



About 1 person in every 200 has epilepsy.



Epilepsy is when you keep having seizures.



A seizure is a sudden burst of electrical activity in the brain.



This causes the brain's messages to stop or get mixed up.



The type of seizure depends on where the activity happens in the brain.



Sometimes people use the word 'fit' for seizure.



There are about 40 different types of seizure.



- These can be short moments when a person seems to not be listening or speaking
- Or longer, like falling to the floor and having a 'convulsion' (shaking suddenly).



A convulsion is when a person's body shakes rapidly and uncontrollably.



Most seizures are over in a few minutes or less and the person recovers quickly.



As there are so many different types of seizures, it is important that your doctor knows what type of epilepsy you have, so that they can give you the right medicine.



Most people, with the help of the right medicine, can get on with their lives.



We make every effort to make sure the information is correct (right).



# There are different types of seizures...

Here are some of the more common ones:



**Auras** are simple partial seizures. They can come before bigger seizures.



If you are about to have an 'aura', you may have unexpected tastes, smells or tingling feelings.

It may feel as if your tummy is rising.



#### Typical 'absence' seizures

These begin when you are a child.



They begin quickly and finish very quickly.



If you have this sort of seizure, you will stare into 'space' for a few seconds.



Your eyelids may twitch and your fingers may jerk a little (but this is not usually noticed).



'Absences usually last 5–10 seconds. Some children can have them hundreds of times each day.



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#### **Tonic-clonic seizures:**



This sort of seizure may start by: your head turning, your lips smacking, dribbling or having convulsions (when the body jerks).



A jerking movement may begin in your face or hand, and spread to the arms and legs. Or your body might stiffen.



You may lose consciousness (like being in a heavy sleep). After the seizure, your legs and arms may feel weak or achy for a few hours.

You may feel sleepy or forgetful.



You should check to see if you bit your tongue during the seizure. You should give yourself time to get better slowly.



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#### How can people look after you if you are having a tonic-clonic seizure?



They should cushion your head with their hands or a soft material.



They should move away any objects that could harm you. If this is too difficult, they should move you out of danger.



People should NOT try and hold you down.



They should not put anything in your mouth.



When the seizure stops, they should check your mouth and throat to check nothing is blocking it.



They should then put you in the **recovery position**.

This is a special position that means you will get better in the safest way possible.



People should watch you until you feel better. They should check that you aren't hurt.



If it is your first or second seizure you should call the ambulance.



If your tonic–clonic seizure lasts more than 5 minutes, or if you have more than 3 seizures in an hour, you may need medicine.



If the medicine does not work quickly, someone should call an ambulance for you.



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#### If your doctor thinks you have epilepsy, he or she will suggest you see a 'Specialist'



A specialist is a medical person who knows all about epilepsy.



You should be able to see them within 2 weeks.



Until you see the specialist, you should not do any activities that could put you in danger.

For example, do not go swimming. If you have a fit when you are swimming you could drown.



Make sure someone is with you when you take a bath. Then there is no chance of you drowning.



Ask someone to record your next seizure by filming it on their mobile phone or in a diary.

This will help the specialist and doctor to understand more about your epilepsy.



If you have a fit during the 2 weeks before you see the specialist, it is important to go and see your doctor again.



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## **Testing for Epilepsy**

Not everyone will need the tests below.



**EEG** (Electroencephalography) finds out about the brain's activity.

It can find out if there has been any unusual activity. An EEG is the most common test.



It takes up to an hour and is not painful.



**MRI Scan** uses magnetic fields and radio waves to look at the brain.

It can find out if there are any small marks and scars.



It is very useful in cases where surgery is a possibility.



**CT or CAT scan** is when X-rays of the brain are taken.

It shows a cross-sectional view of the brain, which is stored on a computer.



Sometimes a dye (coloured liquid) is injected into a vein to make the view of the brain clearer.



**Ambulatory EEG** is when you wear a tape cassette recorder for a few days. The tape records several days' and nights' activity of your brain.



**Video telemetry** – this consists of the EEG recording (described above) and video recording of seizures.



**PET** scan is a machine that can show pictures of your brain in 3-D. It may show if you have a tumour.

A tumour is the name for a swelling which could be caused by a cancer. It is rare.



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# How often should the person have a routine epilepsy review?



The Specialist will explain to you about your epilepsy. The specialist may give you some medicine to take.



If you have a supporter or carer with you, the specialist should explain to them about how to look after you if you have a fit.



The Specialist may explain to both you and your supporter about how to take the medicine.



You should see a specialist once a year or more to check how your epilepsy is and that your medicine is working well for you.



If you have not had a seizure for 2 years, the specialist may say you don't need to take so much medicine.

Or the Specialist may stop your medicine.



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#### If you are taking medicine for your epilepsy:



Your Specialist will explain the importance of taking your medicine properly.

If you do not take your medicine properly, you could have more seizures.



Your Specialist may tell you what foods and exercise you need to do keep your bones strong and healthy.

This is because epilepsy medicine may cause Osteoporosis – a disease of the bones that makes them weak and more likely to break.



Your doctor may suggest that you take Vitamin D. This can help to keep your bones healthy.



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If you are a woman....



The Specialist should speak to you about how your medicine could affect your baby if you get pregnant.



The doctor may suggest you take 'folic acid' to keep the baby as healthy as possible, if you are pregnant.



The doctor may change your medicine, if there is a chance you could get pregnant.

This is because some medicines can be more dangerous for an unborn baby.



Your doctor may suggest you find out about benefits if you have epilepsy.



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#### Jewellery and cards that let people know you have epilepsy:



If you are told you have epilepsy, you could wear jewellery or use a card that lets people know you have epilepsy.

We cannot make any suggestions about which you should use, these are just examples:



Medic Alert can engrave your medical condition and their 24 hours emergency number on jewellery.



Call Medic Alert on 020 7833 3034 or their free number 0800 581 420.



Their email is info@medicalalert.org.uk



Their website is at www.medicalert.org.uk;



Identity cards (ID cards)



Different cards are available from Epilepsy Action for adults, young people and children.



The plastic card shows information on your medicine and health, and who to contact.

You can add extra details if you need to.



Call the Epilepsy Action helpline on 0808 800 5050.



Their email is <u>helpline@epilepsy.org.uk</u>



Their website is at www.epilepsy.org.uk



Please note:



The two organisations we have mentioned are just examples.

If you look on the internet you will find other companies that also make the cards and jewellery.



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### **Useful contacts are:**



Epilepsy Action Helpline: 0808 800 5050 www.epilepsy.org.uk



The National Society for Epilepsy Helpline: 01494 601 400 www.epilepsysociety.org.uk



Epilepsy Research Uk Telephone: 0 20 8995 4781 www.epilepsyresearch.org.uk



Joint Epilepsy Council Telephone: 01943 871852 www.jointepilepsycouncil.org.uk



If you are worried about your health it is important to speak to a health professional like a doctor.

A health professional will be able to explain it in more detail.



You can also call NHS Direct on 0845 4647.



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However, we cannot be responsible for any actions as a result of using this information.



foundation for people with learning disabilities

**PROD(†)GY** 



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www.prodigy.clarity.co.uk

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