

A YOUNG PERSON'S GUIDE TO EPILEPSY

INTRODUCTION

As you grow up having epilepsy, it can seem a very bad thing. Seizures can be frightening, embarrassing or painful if you injure yourself. Taking medication can be boring. You may be frightened to do things because of your epilepsy or other people want to. It can seem as if epilepsy gets in the way of everything you want to do.

It does not have to be like that.

Words and their meanings

Seizure This word means the attacks which happen to people with epilepsy. You can find details out about seizures in the section called "What type of seizures do I get".

Fit Means the same as seizure.

Convulsion Means the same as seizure. Seizure is probably the best word so we usually try and use that one.

Epilepsy The tendency to get lots of seizures.

What happens to my brain during a seizure?

Your brain controls your thinking, moving and feeling by passing electrical signals around the brain and out to the body. When you have a seizure your brain starts producing lots of abnormal electricity. These "nonsense" signals pour out of the brain to the body making the body do unwanted things. This can mean vacant spells, falling, jerking or feeling and behaving strangely.

Check what sort of seizures you get and find out more in the "What types of seizures do I get?" section.

What types of seizures do I get?

You should have been told in clinic what your seizures are called. If not, ask the doctor or the epilepsy nurse specialist. You could also find out in the letter from clinic. Once you know what sort of seizures you get check out the list below.

Tonic clonic seizures

Some people get a warning that the seizure is about to start. Others go straight into the seizure. Once the seizure starts the whole body goes stiff and you lose consciousness.

Sometimes the stiffening muscles force air out of your lungs making a loud shout!

If you are standing you will fall. You may stay stiff for up to a minute. During this time your muscles are too stiff to breathe so you may go quite blue. This can look alarming to your family or friends, but your brain is very good at self-defence. It will not let you stay stiff long enough to do you any harm.

As the stiffness settles the body then starts with irregular jerky movements of arms, legs and sometimes of the face, mouth and tongue. These are called clonic movements. These may be fine trembling movements or big jerky movements. You could get bruises to your arms and legs. As the brainwaves return to normal so the jerking movements stop. Most fits last less than five minutes. As you know, you wake up a little while after the fit and may feel rough - you may feel sick and have a bad headache. You may need to sleep for a while as the brain gets itself back to normal.

Absence seizures

The words “absence seizure” describes short vacant spells. The seizures come on quickly and make you unconscious. It does not make you move or fall over, but you do not know what is going on around you. Someone looking at you will notice that you suddenly stop what you are doing and stare blankly. The seizures are short – usually less than 10 seconds. When the seizure switches off you are quickly back to normal though it may take a second or so for you to pick up what is going on. Some people get absence seizures many times a day and they can make it difficult to concentrate on school work or other activities.

Myoclonic jerks

Myoclonic jerks are sudden, unwanted, jerky movements usually affecting your arms and quite often happening in the morning. This can make life difficult if you are cleaning your teeth, shaving, putting on make-up or eating breakfast.

Temporal lobe seizures

These are complicated seizures which can make you feel and behave strangely. The abnormal brainwaves come from deep inside your brain and you may find it very difficult to describe how you feel. Most people are familiar with how the attacks feel. They may start with an odd feeling in your abdomen or chest, strange smells, strange noises or an unpleasant feeling that is difficult to describe. As the seizure progresses you may start to behave strangely. Some people carry out purposeless actions or fiddle with their clothing. Sometimes these seizures simply get better from that stage. Sometimes they turn into tonic clonic seizures. If you get temporal lobe seizures it is a good idea to get someone to describe to you exactly what happens during the seizure.

What does it matter what sort of epilepsy I have got?

The word epilepsy just means that you are likely to get epileptic seizures of one sort or another. It includes people of all ages with lots of different illnesses. It is good to find out as much as you can about what sort of epilepsy you have. Different sorts of epilepsy produce different fits, need different treatments and can effect your life in different ways. Some sorts of epilepsy you grow out of. Other sorts of epilepsy you need to take treatment even when you are an adult. It is important when you are trying to decide what to do about treatment, employment, driving and activities to find out as much as you can about what sort of epilepsy you have and the ways it might affect you.

TREATMENT

Why start treatment?

Seizures can frighten you or others, they can stop you doing things, can be embarrassing, whether you are at home or school or out with your friends. The aim of the treatment is to control your seizures without giving you any side-effects from the treatment.

There are many medicines out there to choose from, your doctor is the best person to choose the right medication for you.

Why do I need to take the medication everyday? – can't I just take it before a seizure?

Many young people do not know when a seizure is going to happen, it just happens. To get the best control of the seizures you need to take the medication daily, usually twice a day. Breakfast time and teatime is usually fine. If you are not a breakfast person perhaps you could take your medication when you brush your teeth in the morning.

What if I forget?

We understand that remembering to take your medication can be difficult and occasionally you may forget. If you forget your morning medication and remember up to lunchtime, you can take your morning medication as usual. If it is now the afternoons just take your evening medication as normal. Never have the morning and evening medication together at the same time.

What do I do if I am sick or have an upset tummy?

Take your medication as normal, if you can. You may have a seizure because your medication is working its way through your body quicker than usual.

Will I get side-effects from my medication?

When you first start taking your medication you may feel more tired than normal. This should settle down but if it is a problem let your doctor or epilepsy nurse know. With all medications there are long lists often of side-effects, it doesn't mean that you will get them all. Generally though if you are feeling "not right" then you should discuss it with your doctor.

I take other medications as well for my asthma; will these react with my epilepsy treatment?

Always let your doctor know what other medications you are taking. Most medications do not affect your epilepsy treatment. Things like paracetamol, that you may take when you have a headache does not affect your epilepsy treatment. Antibiotics should also not affect your epilepsy treatment.

SAFETY INFORMATION

The Bathroom – This is the place where you are more likely to come to harm. Showers are safer than baths but baths can be ok if you follow some simple advice. It is not a good idea to have a bath if there is no-one in the house at the time just in case you have a seizure.

Let someone know that you are going to have a bath, don't lock the bathroom door – you could always put something on the door that will tell your family you are having a bath. Why not choose different things for each person to stick on the door when they are in the bath.

Swimming

Swimming is not a good idea if your seizures are not controlled and are a problem. If seizures are usually controlled you may want to go with your friends or family.

Public pools have a lifeguard on duty. The epilepsy nurse can give you an ID card to give to the lifeguard which tells them that you have epilepsy, and what your seizures are like. It is not a good idea to swim on your own.

Cycling

We always recommend that anyone who uses a bike wears a helmet, just in case they fall or get knocked off their bike, it helps to protect your head.

Other sports

Most sports and activities are fine for people with epilepsy. This includes almost everything you might want to do. For example: football, rugby cricket, hockey, netball, basketball, netball, rounders, baseball, athletics, cross country, judo and other martial arts, dancing (all types), golf, gymnastics, circuit training, gym workouts and so on. More difficult areas are swimming, sailing and canoeing – although these can be ok. For more information ask your epilepsy nurse or doctor.

HOLIDAYS AND TRAVELLING

Travel Insurance

You will need to let the travel insurance company know about your epilepsy, just in case you have to be admitted to hospital with your epilepsy when you are on holiday. If you don't let them know, it could cost you a lot of money not to be insured for your epilepsy. If you need more information about this ask the Epilepsy Nurse.

Taking medication and time delays

Always take your epilepsy medication in your hand luggage, sometimes suitcases can be lost or mislaid. Take more epilepsy medication with you just in case you get delayed on holiday.

If you are going abroad, check to see if there is any time delay – you will need to work out when to take your epilepsy treatment. If in doubt ask a doctor or the Epilepsy Nurse.

THINGS THAT CAN MAKE YOUR SEIZURES WORSE

Alcohol

Epilepsy treatment can make you more sensitive to alcohol – you may be affected more than your friends. It doesn't mean that you cannot drink alcohol, but you need to be aware that you cannot drink the same quantity as your friends can. Alcohol can bring your seizures on. Friends that encourage you to drink more perhaps do not realise what effect it could have on you. If you can explain this to them, we are sure that they will understand. It is not all doom and gloom !! – just take control yourself, know your limits !!

Recreational Drugs

These could trigger your seizures. Taking these drugs also can lead to not eating properly, not having enough sleep and often make you forget to take your epilepsy treatment. If you are taking these drugs do let your doctor or Epilepsy Nurse know, it could be a reason why your seizures are not controlled.

Lack of sleep

It is hard but true that late nights, lie-ins and sleepovers can increase your seizures. You have to find a midway path so that you can join your friends, without messing your sleep up too much.

Strobe lighting in clubs, cinema's etc

Very few people are affected by flashing lights or strobe lighting. Clubs are unlikely to use lights that trigger seizures. If you know that you are sensitive to these try not to look directly at the lights. You could reduce the effect of the lights by covering one of your eyes with your hand or by moving out of the light range.

DRIVING

I am 16 now will I be able to ride a moped?

If you have had no seizures for a year you should apply to the DVLA. For your provisional licence you will have to tell the DVLA about your epilepsy. They will then ask for information about your epilepsy from your doctor.

When will I be able to start driving?

You will need to be 17 and have had no seizures for a year. Again you will need to let the DVLA know and they will ask for information about your epilepsy from your doctor.

What if I pass my driving test and am driving, then I have a seizure. Who do I need to tell ?

Your doctor will need to know and also you will need to let the DVLA know. The car insurance company will also need to know. If you don't let anyone know and continue to drive, you will be putting other people's lives at risk.

I don't have "big" seizures – I only have jerks (myoclonic)– does this count ?

Yes it does, as even a myoclonic jerk means that you have lost control of the car for a short period of time.

CONTRACEPTION

If you are thinking about the need for contraception please discuss this with your doctor, Epilepsy Nurse or the Family Planning Clinic. Always let the health professional know what epilepsy treatment you are on as it could make a big difference to what contraception you choose.

The oral contraceptive pill

Some of the epilepsy treatments stop the oral contraceptive pill from working properly.

This does not mean that you cannot use it, but you may need to have a stronger oral contraceptive pill for it to work well.

Injectable contraception

This can have the same problems as the oral contraceptive pill, although you can still use this method of contraception. It may have to be given more regularly – usually after 10 weeks and not the normal 12 weeks.

The morning after pill

You may need to take a stronger morning after pill – let the person prescribing the morning after pill know that you are on epilepsy treatment.

Sex

Having epilepsy need not have any effect on your sex life. There is no evidence that epilepsy is made worse or better by sex. Epileptic seizures are very rare during sex. You should tell your partner you have epilepsy.

Periods

The anti-epileptic drugs may cause problems with your periods. Sometimes seizures can happen before your period starts. It is important to keep a diary of your seizures. Bring this along to the epilepsy clinic, and discuss this with your doctor or epilepsy nurse.

Pregnancy

You may not be thinking about becoming pregnant yet, but when you do you will need to discuss this with your doctor or Epilepsy Nurse. Anti-epilepsy drugs can have bad effects on the baby as it develops inside you so therefore pregnancy needs to be planned, if possible.

Will my children have epilepsy ?

The risk of getting epilepsy will be higher in your children. Even so, 9 out of 10 children of people who have epilepsy do not develop it.

EDUCATION, FURTHER EDUCATION AND EMPLOYMENT

Your epilepsy should not stop you from going to college or university. You may need to have some extra time during exams and this can be arranged through your school, college or university. It's nothing to be worried about, lots of young people are allowed to have extra time for lots of medical reasons.

If you are thinking about applying for a job, you will need to tell your future employer about your epilepsy for health and safety reasons. The employer may want to do a risk assessment, this is quite normal and you shouldn't think that you are different from everyone else.

What do I put on the application form about my epilepsy ?

You do not need to put it on your application form – **but** you will need to let your employer know if you get through to final interview. However many people do not understand that there are many types of epilepsy – explain to them about yours and how you are on epilepsy treatment for your seizures. If you have been seizure free for some time let them know.

If you have concerns about this, you can always discuss this with your doctor or Epilepsy Nurse. We could help you put together a response or even a letter.

Are there some jobs that you cannot do if you have epilepsy ?

Unfortunately there are, you cannot be an airline pilot or have a career in the armed forces for instance, but there are many jobs that you can do. If you want more information then you could talk to your doctor, epilepsy nurse or employment officer.

FREQUENTLY ASKED QUESTIONS

Am I the only person who has epilepsy in (Norfolk)?

No – you may feel as though you are, but we know of many young people who have epilepsy. Some young people are happy to talk about their epilepsy. If you would like them to talk to you, please ask the Epilepsy Nurse.

I don't know how to tell my friends or my boyfriend/girlfriend that I have epilepsy

This is always difficult but if they are good friends they will understand. Try to tell them that they could help you by providing some First Aid for you if you should have a seizure. The Epilepsy Nurse has First Aid information sheets and other information that could help you with this.

Who can I talk to about my epilepsy confidentiality ?

Your doctor or Epilepsy Nurse.

What should I do when my epilepsy scares me ?

It is good to talk about this. We see lots of young people and can help you with your worries. Sometimes we can give information to calm your fears- other times just talking can help.

I want to go out with my friends but my parents won't let me – what can I do?

Young people often tell us this and we often hear that parents/carers are worried about letting you go out. We can discuss this between you and your parents/carers, if you think this will help, it often does.

WEBSITES THAT WE RECOMMEND:

www.epilepsy.org.uk www.epilepsynse.org.uk

