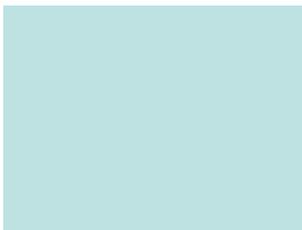


Epilepsy and later life



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Introduction

Anyone can develop epilepsy at any age. However, it is more common in childhood, teenage years and later life. As more people live longer more people will develop epilepsy when they are older.

We have written this booklet to give you information on how to cope with epilepsy in later life. We explain what epilepsy is, what causes it and how it is treated. The booklet also gives some advice on how you can live with epilepsy as safely as possible, so that you can enjoy a full life.



What is epilepsy?

People with epilepsy tend to have repeated seizures. Epilepsy is the most common serious brain (neurological) condition.

You can have one seizure but not have epilepsy. The reason could be a high temperature or a head injury. Most people will have their seizures controlled by medication.

What causes epilepsy?

In many cases there is no known reason. However, if you develop epilepsy in later life, there is more likely to be a physical cause. For example, you can develop epilepsy after a stroke. In fact, stroke is a very common cause for epilepsy in later life.

40,000 people in Scotland have epilepsy, that's one in 130.

However, the figures are much higher for older people.

Approximately one in 90 people over the age of 65 has epilepsy.

What is a seizure?

Seizures start in the brain and usually last a short time. Billions of brain cells pass messages to each other and these affect what we say and do. When there is too much electrical activity, messages can get mixed up and cause seizures.

Seizures also vary in how often they happen and the length of time they last. Everyone experiences a seizure in a unique way. In later life seizures where you fall are less common than in other age groups.

Some seizures may be frightening to watch.

Sometimes only you will know when you are having a seizure. Most seizures are short and you can recover on your own.

Some older people can take a while to recover after a seizure. They can feel confused for some time.

Are there different types of seizures?

There are over 40 different types of seizures. Your doctor or epilepsy specialist nurse will tell you what type of seizure you have. Seizures are divided into two main groups – partial and generalised.

The majority of people experiencing seizures in later life will have partial seizures.

Our Seizures leaflet explains the different types of seizures. Phone us for a free copy.



What can trigger a seizure?

If you have epilepsy you may find that certain things can trigger a seizure. Keeping a **seizure diary** can help to identify if you have triggers and avoid them where possible. However, many people have seizures for no obvious reason. Phone our Helpline for a free seizure diary.

Common seizure triggers can include (in no particular order):

Forgetting to take your medication. This is the most common cause for seizures returning after they've been controlled for a while.

Lack of sleep.

Too much alcohol.

Feeling ill or hot.

Missing meals.

Not drinking enough water (dehydration).



Taking other prescribed medication – your doctor needs to make sure that this will not increase your risk of having more seizures.

Flashing or flickering lights (photosensitive epilepsy) – this sensitivity is rare. Less than five per cent of people with epilepsy are affected by this. Your epilepsy specialist will tell you whether you have photosensitive epilepsy.

Being stressed or bored.

Other factors to bear in mind:

Bereavement

The death of someone you love can be a shattering experience. Coping with strong feelings and emotions following a bereavement is stressful. If you need to talk to someone, speak to your doctor first. They can refer you to see a counsellor. You can also phone our Helpline for contact details of organisations that can help.

Getting older/ retirement

As you get older, you may find it harder to stay active and mentally alert. Some people may feel they have no clear purpose when they retire. You may find it difficult to fill your days. Being bored can make seizures worse in some people.

However, retirement does not have to be boring or stressful. You will have more time to develop new interests, take up hobbies, and make new friends. Many older people find that retirement gives them the chance to be more physically active and become healthier.

How is epilepsy diagnosed in later life?

Older people may have a number of other medical conditions. Symptoms of a stroke or irregular heartbeat can, for example, be similar to those of epilepsy. Sometimes this makes diagnosing epilepsy in later life difficult.

If you have any kind of faint or 'funny turn' see your doctor. They may refer you to a consultant at the hospital for further tests. This consultant will be either a care of the elderly consultant or a neurologist.

During the hospital appointment, the consultant will take a full medical history. They will need to know about any other medication you currently take. It might help to take a list of all your medication with you as it can be difficult to remember drug names.

The doctor will also want to know what happened before, during and after your faint or funny turn. Give as many details as you can as this will help the consultant. Write down what happened while it's still fresh in your mind.

If someone was with you when you took this faint or funny turn, ask them to come along to the hospital appointment. If they can't make it, ask them to agree to be contacted by telephone.



Your consultant will want to know what they saw. This is very important and will help in making the right diagnosis. Without this, your consultant may still be able to make a diagnosis by doing some tests.

What kind of tests are there for epilepsy?

A number of tests can help the consultant find out what caused a seizure, the type of epilepsy you may have and the best treatment for it. These tests are painless.

An **EEG** (electroencephalogram) records the brain's electrical activity. During a seizure this activity is disrupted. The procedure usually lasts 30 – 60 minutes.

A **brain scan** lets the consultant see if there is anything which may be causing the seizure. This could be scarring on the brain or an area of damage from a stroke. The two main types of brain scan are CT (Computerised Tomography) and MRI (Magnetic Resonance Imaging) scans.

They normally last between 15 – 35 minutes. MRI scans are usually not done if you have a pacemaker or any metal implant.

Sometimes other tests can be done to check your heartbeat, if it is not clear what caused your funny turn.

Help from an Epilepsy Specialist Nurse

Once you are diagnosed with epilepsy, ask your consultant to refer you to an epilepsy specialist nurse. Most epilepsy clinics have these senior nurses who are specially trained in epilepsy. They can help answer the many questions you may have. You can discuss how best to take your medication or what to do if you forget to take it. Or you may be worried about side effects.

Being diagnosed with epilepsy in later life can be a traumatic experience.

You may worry about losing your independence and becoming a burden to loved ones.

Your epilepsy specialist nurse can give you tips and hints on how to live your life as independently and safely as possible with seizures.

How is epilepsy treated?

The most common treatment is with anti-epileptic drugs. If you have only had one seizure, a doctor will usually not prescribe anti-epileptic drugs. This is because one seizure does not necessarily mean you have epilepsy. Occasionally, a doctor may prescribe anti-epileptic drugs after one seizure to stop you hurting yourself if another happens.

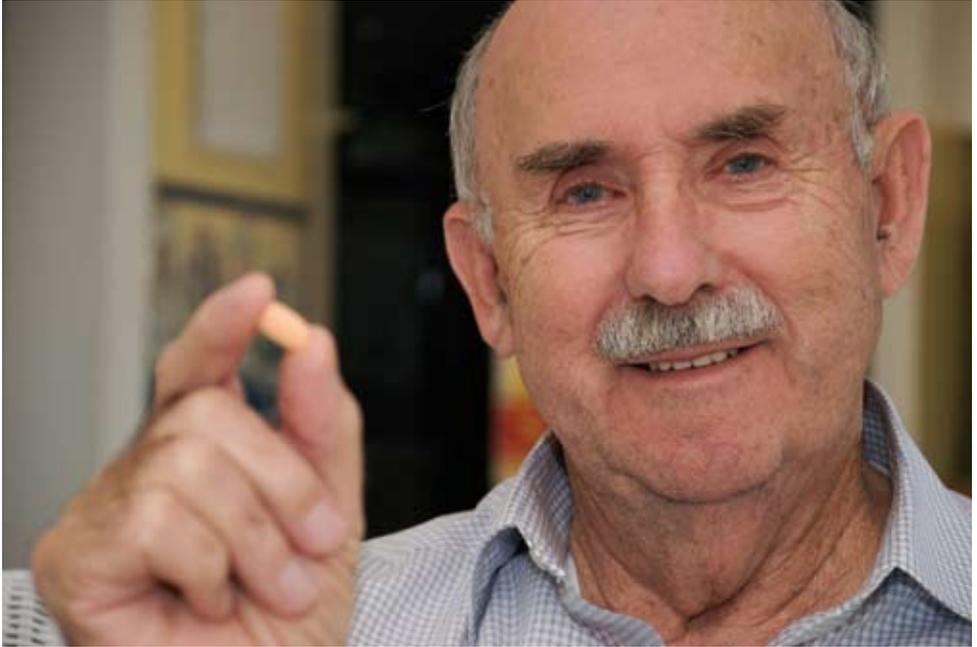
Anti-epileptic drugs do not cure epilepsy. They control your seizures.

As many as seven out of ten (up to 70%) people with epilepsy can become free of seizures with medication.

With older people, surgery is usually not an option.

What are anti-epileptic drugs (AEDs)?

Anti-epileptic drugs (AEDs) have two names - a chemical name and a brand name. The brand name is given to the drug by the manufacturer.



For example, carbamazepine is the chemical name and Tegretol the brand name.

It is important to make sure you get the same make of drug each time as there can be small differences between versions or makes of each drug. Ask your doctor to write your drug's brand

name, not its chemical name, on the prescription.

Your medication usually comes in tablet or capsule form. If you have difficulty swallowing you can sometimes get syrups or soluble tablets.

Ideally, you will only need one kind of AED to control your seizures.

However, sometimes, people may need to take two or more drugs.

Most people who develop epilepsy in later life will have their seizures controlled with just one type of medication.

There are many different medications. Your consultant will want to choose one that will give you good seizure control with as few side effects as possible.

When should I take my medication?

Always take the same amount of your medication at roughly the same time each day. Your doctor or epilepsy nurse will tell you what to do if you miss a dose or accidentally take it twice.

Never stop, reduce or increase your medication without speaking to your doctor or nurse first.

Here are some tips to help you remember to take your medication:

Ask your consultant, doctor or epilepsy specialist nurse to write down how and when to take your medication.

Link taking your medicine with something you do every day such as taking your medication with breakfast.

Buy a pill dispenser from your pharmacist to store your medication for each time slot and day of the week. Some of these have an alarm you can set to remind you to take your medication.

As you get older, you are more likely to have to take other prescribed medications for conditions such as high cholesterol or high blood pressure. It is also important to tell your doctor and pharmacist if you are taking any over-the-counter medication or supplements. Sometimes these can make your anti-epileptic drugs less effective.

If you find it difficult reading small print, ask your doctor or pharmacist to give you a copy of the medicine label in large print. Your pharmacist can also give you special pill containers which are easier to open if, for example, you have arthritis.



Are there any side effects?

As with any medication, anti-epileptic drugs can cause a number of possible side effects. This includes sleepiness, nausea, headache, dizziness and weight gain. Your doctor will tell you what to look out for. You can also read the information sheet that comes with your medication. Most people find that any side effects are mild. If not, your doctor will try and adjust the dose you take. This will normally reduce side effects.

If you notice a skin rash when you start or increase your medication tell your doctor straight away. This could be a sign that you are allergic to the medication.

Write down anything about your health that has changed since starting your medication. Let your doctor know about this. Some side effects can be missed in older people, such as problems with memory, concentration or attention. This is because these are similar to what most people expect to happen as they get older.

You may be more likely to develop osteoporosis (thinning bones) when you take some types of anti-epileptic drugs.

If you fall during a seizure, the risk of injury may be slightly greater. Your doctor or epilepsy specialist nurse will be able to suggest ways to keep you as safe as possible. They may also suggest you take medicine that protects your bones. Taking your medication regularly is important as this will reduce the risk of you having a seizure.

What is emergency medication?

If you have many seizures, or seizures that last a long time, your doctor may prescribe emergency medication. This is usually diazepam or midazolam. Diazepam is given rectally (into the back passage) using a special tube or applicator.

Midazolam is placed inside the cheek (buccal cavity) or given as nose drops. Your doctor or epilepsy specialist nurse can show someone you trust how to give this medication in an emergency.

This person must have written consent from you or your carer. They should also have had training. Epilepsy Scotland provides this training on epilepsy and the administration of emergency medication. Call our training team on 0141 427 4911 for more information.

Will I be on medication for life?

Some people will need to take their anti-epileptic drugs throughout their lives. Others may only need to take it for a limited time.



If you have not had a seizure for two or more years you can talk to your doctor about slowly coming off your medication. You should be aware that there is always a risk of seizures coming back.

This depends on:

- How long you have been seizure-free.

- The type of epilepsy you have.

- The cause of your epilepsy.

Usually, people who have been diagnosed in later life are less likely to remain seizure-free if they come off their medication. However, depending on your individual circumstances, it may still be possible. Once you have been given all the necessary information, it will be your own decision.

You may want to discuss this with those closest to you. Your doctor will need to carefully monitor you if you decide to come off your medication to ensure you remain safe.

If you stop your medication under medical supervision, DVLA (Driving Vehicle Licensing Authority) recommend that you don't drive during this period and for six months after stopping medication.

This is to make sure that your seizures don't return and you are safe on the road.

What about complementary therapies?

Complementary therapies are not an alternative to taking your medication. There are currently few scientific studies about how these therapies help someone with epilepsy. However, some people find them helpful to lower stress and help them relax. If stress is likely to trigger a seizure for you, anything that helps you to relax may reduce the amount of seizures you have. You could try yoga, for example, which is known to have a stress-reducing effect.



Some herbal medicines and aromatherapy oils could make your seizures worse. These include St Johns Wort, evening primrose oil, hyssop, rosemary, sweet fennel, sage and wormwood. Before trying any complementary treatment, talk to your doctor or epilepsy specialist nurse first. They can check if it is safe for you.

Once you've decided which complementary therapy is best for you, find a qualified therapist who is a member of a professional body. Tell them that you have epilepsy before the treatment begins.

First aid

Those looking out for you, such as your family or partner, a carer, friends or neighbours, will want to know what to do to keep you safe during a seizure. Here are the basic first aid rules. We also have a separate First aid leaflet. Phone us for a free copy. This contains a lot more information on first aid for seizures.



First aid for tonic-clonic seizures

What to do

Keep calm. Once a seizure starts it will generally stop on its own.

Check the time to see how long the seizure lasts.

Move any objects that could cause injury.

Remove glasses and loosen tight clothing around the neck.

Put something soft like a rolled up jacket or cushion under the person's head to stop injury.

Protect the person's privacy, particularly if they have emptied their bladder or bowels.

Stop other people crowding around.

Check for medical identification like a bracelet or necklace as this may have more information on the person's epilepsy.

Check the person's care plan, if they have one. This will tell you what to do.

As soon as the jerking stops, turn the person onto their side (left, if possible) into the recovery position.

Speak softly and gently when you tell the person what has happened.

Remember the person may be confused for a while after a seizure. Stay with the person until they have fully recovered. The person may want to sleep after a seizure.

What not to do

Do not move the person unless they are in danger eg on a busy road or at the top of stairs.

Do not try to stop the jerking or restrain the person.

Do not put anything into the person's mouth or between their teeth.

Do not offer the person anything to eat or drink until they are fully conscious.

Only call an ambulance if

It is the person's first seizure.

The person has badly injured themselves.

The jerking lasts for five minutes or a longer time than is usual for that person.

One seizure follows another with no recovery of consciousness between seizures.

The person is having problems breathing after the seizure has stopped.

First aid for other types of seizures

For any other types of seizures first aid guidelines are straightforward:

Stay with the person and make sure they are not putting themselves in danger, for example walking into a busy road.

It may help the person if you talk gently to them. During some seizures the person is awake but their level of consciousness is altered. They will not know what is happening.

After the seizure, tell the person what has happened and stay with them for a while. They may want to sleep after a seizure.

Living with epilepsy

Having a diagnosis of epilepsy in later life can be difficult to come to terms with. It may hit you particularly hard if you have always been healthy and active. Losing your driving licence and having to rely on others can affect your self-esteem.

Over the years you may have known people with epilepsy. You may remember some of the difficulties they have had to face. Things are changing. There are now more drugs to choose from. There is less social stigma associated with epilepsy.

And there is also legislation (Disability Discrimination Act) to protect the rights of people with epilepsy.



Many older people live alone. They can be worried about the effect epilepsy may have on their independence. Family and close friends sometimes become over-protective when they hear about your epilepsy. However, there is a good chance your seizures will be well controlled with medication. If this is the case, you should be able to do most of the things you have always done.

Never give up hope

Doreen Jobson has just turned 70. Her three adult children and six grandchildren keep her busy. Doreen is also an active member of her local church teaching in Sunday School and helping with other activities. “I always thought that once you are retired you would struggle to fill your days with things to do. But that is not my experience. There is never enough time to do all the things I would like to do!”

Her first seizure happened when she was around 50. “For a couple of years before that seizure I’d had some strange feelings, a bit like *déjà vu*. I mentioned these to my doctor and was eventually referred to hospital for some tests.



They didn’t show up anything and I was told that it probably was the menopause or ‘nerves’.” That was until she had a bad tonic-clonic seizure during her sleep. She had bitten her tongue and was unconscious. Her husband, fearing the worst when he saw the blood from her mouth, called an ambulance.

Doreen said: “I woke up in hospital and thought that I may have had a heart attack.” After a second bad seizure, again during her sleep, she was referred to a consultant neurologist who told her she had epilepsy.

“I was totally shocked. As a medical secretary, I obviously had heard of epilepsy. But I thought epilepsy meant people suddenly falling down and twitching violently. My husband pointed out that this more or less had happened to me only I was doing this in my sleep! I thought epilepsy was something you developed as a child. I didn’t realise you could suddenly develop it in later life. If I am honest, I was horrified, and even a little ashamed.

Epilepsy back then had a lot more stigma. When I telephoned my mother from hospital and told her, she was shocked and reacted quite badly. She felt the need to point out that no-one in our family ever had epilepsy. Partly because of her reaction I didn’t tell many people for a long time.” Doreen stresses that her husband and children however have always supported her.

Apart from the shock and shame she felt about her epilepsy diagnosis, Doreen’s life was further turned upside down when she started having seizures while awake. She also had to give up her driving licence. “It had a huge impact on my independence”, she said.

After her diagnosis, Doreen contacted Epilepsy Scotland for information. “I was lucky I could also talk to the doctors at my work, and they were very supportive. Had I not worked as a medical secretary I think I probably would have lost my job. Generally I kept the epilepsy to myself and didn’t talk to anyone about it.”

Doreen is a member of her Church’s Guild. They have guest speakers at their meetings on different subjects. In 2001 someone invited Epilepsy Scotland to come along. “After their talk I stood up and told everyone I had epilepsy. People were surprised and concerned to hear this. But since then, they’ve all been very supportive.



In a way, Epilepsy Scotland helped me to ‘come out’ and be open about my epilepsy!”

After her diagnosis, Doreen started treatment with anti-epileptic drugs. “I must have tried every drug that was available, in every possible combination over the next 20 years. Some of them worked better than others but my seizures were still frequent. I had practically resigned myself to the fact that I would have seizures for the rest of my life.”

However, a couple of years ago, her neurologist decided to add a new drug, Keppra, to the Epanutin she was already taking. “I was told that there may be unwanted side effects but I was willing to risk this. My seizures improved from having four or more a month to only three seizures in a year. I was obviously delighted with this progress. My neurologist decided there was still room for improvement and suggested another drug, Pregabalin, to be added. This was in May 2007.

It has had a dramatic effect, it stopped my seizures. I am so grateful to all the doctors and neurologists over the years. They’ve been wonderful.

I also feel indebted to all those who have been involved in epilepsy research.

In April 2008, having been seizure-free for one year, I applied to have my driving licence re-instated. I am now in possession of a full driving licence.”

Doreen is keen to share her experience with others. “When I still had seizures I never let it get me down. I know that a lot of people get really depressed about their epilepsy. But I always think you can either sink or swim. I am definitely a swimmer.

My story shows that even after many years it is possible to become seizure-free with the right medication. Never give up hope.”

Even if your seizures are not well controlled there are many things you can do to keep yourself as safe as possible.

We have tried to address some of the most common questions in the following chapters. If they do not answer your own questions, phone our free confidential Helpline. We will be happy to discuss anything you want to know. We are here to help you live your life as safely and as independently as possible.

What can I do about my memory problem?

When you get older, your memory can become a problem. Epilepsy and the side effects of medication sometimes make this worse.

There are many ways you can try to help your memory.

Focus on one thing at a time, don't overload your memory.

Keep a diary or calendar of events.

Write a list of things you need to do.

Notepads, post-it-notes, dictaphones, talking clocks and mobile phone alarms can all help to remind you to do something.

Keep your mind and body active.

Look after yourself. Stress can affect your ability to remember things.



If you or your family or friends become concerned about your memory, speak to your doctor. We also have a guide on Epilepsy and memory which goes into more details. Call our Helpline for a free copy.

How can I stay safe in my own home?

There is help available if you need it. Speak to your doctor first. They will refer you to your local social work department for an assessment. You or someone acting on your behalf can also contact them. Check for the number of your nearest social work department in your phone book. An occupational therapist will usually visit your home and look at any possible risks. You can talk about ways to keep as safe as possible in your own home. They can also arrange for support. For example, if you do not feel safe to cook, they can arrange for a hot meal to be delivered to you.



These tips can help you to be safe at home if your seizures are not well controlled:

Guards for open fires, radiators and cookers can reduce the risk of you burning yourself during a seizure.

Cordless kettles and irons will stop you from tripping over a cord if you have a seizure.

It's safer to grill or use a microwave. If you don't have a grill or a microwave, use the back rings of your cooker and turn pot handles in.

A shower is safer than a bath. You can also get a shower chair. If you do not have a shower you can attach a shower fitting to both taps and take a shower sitting down with the bath plug out.

If you have seizures at night, it's safer to use firm foam pillows than soft ones. Call our Helpline for details of safety pillows.

You may be worried about falling and injuring yourself during a seizure. A few simple measures can reduce the risk of injury:

Soft wool carpeting or cushioned linoleum is better than hard flooring.

Put shaped plastic pieces over sharp furniture corners.

Safety glass or a protective film on glass doors and low windows can also reduce the risk of serious injury.

Many people find it reassuring to carry a card that lets people know they have epilepsy. You can record details of who to contact and how long your seizures usually last on this card.

Phone us for your free card. You can also buy medical identification jewellery such as a bracelet or necklace.

Whether you live with someone or alone, seizure alarms can alert someone that you are having a seizure or that you need help. Phone our Helpline for details of different seizure alarms and where to buy them.

Our Safety leaflet has more information. Phone us for a free copy. You can also talk to us in confidence if you are worried about your safety.



Can I still enjoy leisure activities and hobbies?

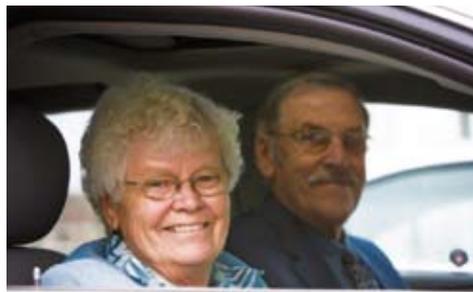
If your seizures are well controlled you will be able to do most leisure activities. Even with seizures you can still enjoy being active. However, you do need to take extra care if you have frequent or unpredictable seizures. Before you take up a new activity, talk to your doctor or epilepsy specialist nurse.

Swimming for example can be dangerous if you take a seizure. Only swim in a pool that is supervised by a qualified lifeguard. Tell the lifeguard beforehand that you have epilepsy. Take someone with you who knows what to do if you have a seizure.

Holidays

If you travel abroad, carry an extra supply of your medication in your hand luggage in case your suitcase goes missing. Flying does not usually trigger a seizure. If your seizures are frequent, let the airline know at the time of making your reservation. This will ensure that the cabin crew look after you and can help if you have a seizure.

We have many more tips like these in our Epilepsy and leisure guide. Phone our Helpline for a free copy.



What about driving?

If you have any seizure, whether awake or asleep, you will need to stop driving. You may find this sudden loss of independence difficult to cope with.

However, you may not have to give up your licence for too long. If you have not had any kind of seizures for 12 months (with or without medication) you can ask DVLA (Driving Vehicles Licencing Authority) for your licence back.

If you only have seizures when you are asleep the regulations are slightly different. If during a period of three years you don't develop seizures while awake, you can get your licence back after that time.

If you cannot drive because of your epilepsy you are entitled to a **free bus pass**. This allows you to travel free on local or long distance bus services throughout Scotland. Our Helpline can tell you how to get this pass.

If you take epilepsy medication but continue to have seizures, you are also entitled to **discounted rail fares**. A Disabled person's railcard will give you up to a third off UK train fares.

Insurance companies are not allowed to charge you more for car insurance simply because you have epilepsy. It is worth shopping around.

Our Helpline can give you details of insurance companies that offer a fair deal to people with epilepsy.

Our Epilepsy and driving leaflet has a lot more information on driving and discounted travel. Phone us for a free copy or speak to our Helpline staff in complete confidence.



Can I still drink alcohol?

Like many people, you may want to enjoy a drink when relaxing or socialising with family and friends. If you have epilepsy you need to take some extra care. Speak to your doctor or epilepsy specialist nurse first. Some doctors recommend that if you have epilepsy you should avoid alcohol completely.

This is because alcohol can make epilepsy medication less effective and also increase any side effects.

If your doctor thinks you can drink alcohol, a moderate amount is not likely to cause any problems. This is usually one to two units a day.

One unit of alcohol is equivalent to a half pint of beer, lager or cider, one small glass of wine, or one single measure of spirits.

Drinking alcohol can also make some people forget to take their medication. It's important that you take your medication regularly, as forgetting to do so may trigger a seizure.

Never drink alcohol before driving as drinking even small amounts can interfere with your epilepsy medication.

Will I get any benefits because of my epilepsy?

If you have epilepsy you may be eligible to claim Attendance Allowance if you are over 65, or Disability Living Allowance if you are under 65.

This will depend on how epilepsy affects your life, and whether you need help looking after yourself. You can contact your local Citizens Advice Bureau or the Benefits Agency for advice. It helps if someone who knows you well is with you during your appointment. They can explain how your epilepsy affects your day to day life.

If you have epilepsy, you are entitled to free prescriptions. You will also get any other prescribed medication free. From April 2011, free prescriptions for everyone will be introduced in Scotland.

Can I still look after my grand children?

It's natural for your family to be concerned and become a bit over-protective in the beginning. However, the more they know and understand about epilepsy the more likely they will want to encourage you to enjoy life as fully as possible.



Once your seizures have stabilised there is no reason why you cannot look after your grand children. If they are old enough, you can teach them how to get help if you have a seizure.

Further information

Epilepsy Scotland has information on:

A guide to epilepsy - what you need to know

A woman's guide to epilepsy

A parent's guide to epilepsy

An employer's guide to epilepsy

Caring for people with epilepsy and learning difficulties

Guidelines for teachers

Men and epilepsy

Seizures explained

... and more on:

Diagnosis

Driving

Employment

First aid for seizures

Leisure

Memory

Photosensitive epilepsy

Safety

SUDEP (jointly published with Epilepsy Bereaved)

Treatment

Triggers (includes information on alcohol)

We also have information leaflets designed for people with learning difficulties. These include:

All about epilepsy

Safety and epilepsy

Living with epilepsy

Phone us for a free copy.

If you have questions after reading this leaflet, please call our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in large print, a different format or another language, please call us.

Finally

We hope this leaflet has answered many of your questions. However, if you, a family member or carer would like more information, advice or support, our free confidential Helpline is here to help.

**Phone us on
0808 800 2200**



epilepsy scotland

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