

Join the NSE Associate Membership to receive regular information about epilepsy. Please contact the Associate Membership Co-ordinator for details.

For other information please write to the Information and Education Department.

The National Society for Epilepsy

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National Helpline

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epilepsy

Developing epilepsy after 60

later life



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Questions I might ask

These are just some suggestions. You may want to add your own questions or write these ones on a separate sheet, where you can write the answers as well.

- What does this medicine do?
- How long will I need to use it?
- How and when should I take this medicine?
- How do I know this medicine is helping?
- How can I be sure it's safe for me to take it?
- What side effects are most likely from this medicine?
- What should I do if I get any of these side effects?
- What if I stopped taking it, or took a lower dose?
- Can I drink alcohol with this medicine?
- Why do I need to carry on with this medicine if I am seizure-free?
- Are there any other alternatives, such as a different medicine or another type of treatment?
- Is there anything that can help to remind me to take my medicines?

These questions were taken from the leaflets "Focus on your medicines" and "Focus on your health for people with epilepsy" from Medicines Partnership.



EasyLink Electronics

Factory 7, Grange Road, Industrial Estate, Geddington
Northamptonshire NN14 1AL
Tel: 01536 744 788
Web: www.easylinkuk.co.uk

Sensorium

Sybrig House, Donibristle Industrial Park, Dalgety Bay
Fife KY11 9JN
Tel: 0800 056 5454
Web: www.sensorium.co.uk

Technology For Care (TFC)

8 Lynhurst Avenue, Barnstaple, Devon EX31 2EP
Tel: 01271 327 207
Web: www.fallcall.co.uk

Tunstall Group Ltd

Whitley Lodge, Whitley Bridge, Yorkshire DN14 0HR
Tel: 01977 661 234
Web: www.tunstallgroup.com

For information on various safety equipment including personal alarms.

Ricability

30 Angel Gate, City Road, London EC1V 2PT
Tel: 020 7427 2460
Web: www.ricability.org.uk

Introduction- developing epilepsy after 60

Epilepsy can happen to anyone and can start at any age. It tends to be more common in children and adolescents, and in older adults. In fact one in every four people who develop epilepsy is over the age of 60.

Epilepsy can affect different people in different ways. Some things about epilepsy may be the same whatever your age, but some things can be different if you are over the age of 60.

This leaflet

If you have epilepsy, you may have questions about your epilepsy and how it affects you. This leaflet looks at different aspects of epilepsy including what it is, why it happens and how it is diagnosed. It looks at treatment and who is usually involved in epilepsy care. It also looks at issues that may be more important to you if you develop epilepsy after the age of 60.

There are many different words used for seizures, such as 'fits' or 'funny turns'. When we use the word 'seizure' we mean epileptic seizure. In this leaflet we use the terms 'later life' and 'older people' to refer to people aged 60 or over.

What is epilepsy?

Epilepsy is a neurological condition, which means it affects the brain. If you have epilepsy it means that you tend to have epileptic seizures.

Epilepsy is not something you can catch from another person. It is not a mental health problem and it does not cause dementia.

What is a seizure?

To understand more about seizures, it helps to know how our brains work. Our brain has a right and left half (hemisphere), each with four areas (lobes). Each area has a different role. For example, one area controls memory and another area controls our sense of taste.

Our brains work by sending electrical messages from one brain cell (or neurone) to another. If you have epilepsy, your brain sometimes sends unusual messages. These messages may get disrupted, or too many are sent at one time. When this happens it causes a seizure.

Are there different types of seizures?

There are different types of epileptic seizures but they all start in the brain. When we think of epilepsy, we often think of a convulsive seizure (when someone falls down and their body jerks). But there are many other types of seizure. What happens in a seizure depends on where in the brain the unusual activity happens and what this part of the brain normally does. Seizures can affect our memory, movement, consciousness and the way we feel.

Seizures can be divided into two groups called partial (or focal) seizures and generalised seizures.

Useful contacts

Medical jewellery

The following companies make identity bracelets and necklaces.

MedicAlert Foundation

1 Bridge Wharf, 156 Caledonian Road, London N1 9UU

Tel: 0800 581 420

Web: www.medicalert.org.uk.

Meditag

Hoopers, 37 Northampton Street, Hockley

Birmingham B18 6DU

Tel: 0121 200 1616

Web: www.hoopers.org

SOS Talisman

Web: www.sostalisman.com

Safety alarms

There are many companies that make safety alarms. Each can give you details of the types of alarms they produce.

Aid-Call Alarms

Linhay House, Linhay Business Park, Ashburton

Devon TQ13 7UP

Tel: 0800 772 266

Web: www.aidcall-alarms.co.uk

Aremco

Grove House, Old Ashford Road, Lenham, Maidstone

Kent ME17 2PX

Tel: 01622 858 502

Where can I find out more about epilepsy?

If you would like more information about epilepsy, some of the topics in this leaflet are covered in more detail in other NSE leaflets. These leaflets are available free of charge from NSE and can be printed out in larger size on request. You can contact the NSE Information and Education Department on 01494 601 392 for more details.

NSE also has an epilepsy helpline. This is a confidential helpline for anyone wanting to know more about epilepsy or to talk to someone about epilepsy. The number is 01494 601 400 and the lines are open from 10am to 4pm, Monday to Friday.

Other organisations

The following organisations have information about issues that might be useful for older people.

Age Concern

Astral House, 1268 London Road, London SW16 4ER

Tel: 0800 00 99 66

Web: www.ageconcern.org.uk

Age Concern has leaflets on work, leisure, money, care and benefits. They also have local groups and an information line.

Help the Aged

207-221 Pentonville Road, London N1 9UZ

SeniorLine 0808 800 6565 (0808 808 7575 in NI)

Web: www.helptheaged.org.uk

Help the Aged gives advice on benefits, care, housing options and general welfare rights through their information service and freephone advice line, SeniorLine.

Partial seizures

In partial seizures, the unusual activity affects just part of the brain. There are two types of partial seizures:

- **simple partial seizures** when a small part of the brain is affected and you will be aware of what is happening. For example, you may get a feeling of pins and needles or a funny taste in your mouth; and
- **complex partial seizures** when more of the brain is affected than in a simple partial seizure. This usually means that your awareness (consciousness) is affected, and you may be confused and not fully know what is happening. For example if you have complex partial seizures you might wander around, make chewing movements with your mouth, keep picking up objects or pull at your clothes.

Generalised seizures

In generalised seizures, the unusual activity affects the whole of the brain. There are different types of generalised seizures but they all affect consciousness. They include:

- **absences** where there is just a short break in awareness; and
- **tonic clonic seizures** (sometimes called grand mal seizures) where the person makes jerking movements.

Secondarily generalised seizures

A **secondarily generalised seizure** starts as a partial seizure, but the unusual activity spreads and the seizure becomes a generalised one. Sometimes the partial seizure at the start is called an 'aura' or 'warning', as it warns that the seizure will become generalised.

After a seizure

It can take some time to recover after a seizure. You may have a headache or feel very tired and want to sleep. You may have a 'post-ictal' or 'after seizure' stage when you feel disorientated for a while. You could have a brief paralysis or numbness in part of your body (called Todd's paralysis), or you may feel more active after a seizure. You could feel back to normal again after a short time, but for some people it can take hours or even a day or two to feel fully recovered.

How can someone help me if I have a seizure?

What someone can do to help you depends on the type of seizure you have. Knowing what to do means people often feel more confident that they can help you if you have a seizure.

If you have a simple partial seizure, such as a strange sensation or funny taste in your mouth, you may just want reassurance from the person with you. If you have a seizure where you get confused, wander about or fiddle with your clothes (complex partial seizure), they can stay with you and keep you safe and away from any dangers like walking into the road. It might help if they speak gently and calmly to you, until you start to feel back to normal again.

If you have an absence seizure, where you just 'blank out' for a few seconds, they may just want to stay with you and guide you away from any danger.

If you have a tonic clonic seizure, when you fall to the ground and shake or make jerking movements, they can:

- put something soft under your head to protect it;
- only move you if you are in a dangerous place, like in the road. Instead they can move things, like furniture, away from you so you do not get hurt;
- let the seizure happen - don't restrain or hold you down;

Epilepsy and leisure

If you still have seizures, many leisure and social activities can be made safer by taking simple measures. What might be useful for you depends on the type of seizures you have and what the activity is. For example if you are going walking, cycling or swimming, taking someone along with you who knows about your epilepsy means that if you have a seizure, help is at hand.

What about driving?

Often the first impact of having seizures is that you have to stop driving.

If your seizures are controlled and you are seizure free for 12 months, you can apply to get your car license back. Until then, you may be able to apply for help with travel costs.

The Disabled Persons Railcard gives you, and someone travelling with you, up to a third off train fares. You can get a booklet about this card and an application form from railway stations or from the Disabled Persons Railcard Office on 0191 218 8103. Local bus travel is usually free for older people. Your local council will know what help is available in your area. If you live in London you can apply for an Older Persons Freedom Pass. This gives you free travel around London. For more details contact your local London borough council.

Benefits

If you have epilepsy you may be able to claim disability benefits. This depends on what your epilepsy is like and how it affects you. If you have a carer looking after you, they may be able to claim benefits too. To find out if you might be entitled to any disability benefits, contact the Benefits Enquiry Line on 0800 882 200 or your local Citizen's Advice Bureau. If you're a carer, contact the Carer's Allowance Unit on 01772 899 729.

Epilepsy and safety

One reason to try and stop seizures happening is to reduce the risk of injury from accidents during a seizure. What might help to make things safer depends on what your seizures are like.

Sometimes simple safety measures can make it safer if you have a seizure. For example using a guard on the cooker so that you can't touch hot surfaces, having a shower rather than a bath, or having a bath when you're not on your own.

You can get help and support from your local social services or the NHS. If you do need help you can ask your local social services for an assessment. This could involve an occupational therapist visiting you at home to see what might help you. For example providing safety equipment. You can also ask your GP for help. They may be able to arrange for a community nurse to visit you or find out about other services in your community.

Alarms

There are many types of alarm that can let someone know if you have a seizure. You can press some alarms if you feel a seizure coming on. Others pick up when a seizure happens, for example if you fall. The alarms may go through to a call centre or will call someone you know such as a family member or neighbour. Some of the companies who make alarms are listed on page 25.

Medical jewellery

You may like to wear or carry with you something that says you have epilepsy. This might be an ID card, a bracelet or necklace. This means that if you have a seizure, people will know that you have epilepsy. Some of the companies that make identity bracelets and necklaces are listed on page 25. ID cards are available from NSE, (see back page for contact details).

- **don't put anything in your mouth - you will not swallow your tongue;** and
- keep an eye on the time to make sure the seizure is not too long (see the box at the bottom of this page).

After the seizure, they can:

- roll you on to your side into the recovery position;
- check that your breathing is ok and that you don't have anything in your mouth to block your throat;
- if you have been incontinent (wet yourself) they can deal with this, or cover you with a blanket; and
- stay with you until you have come round. You may feel very tired and want to sleep.

You might find it helps to tell someone if there is anything else you would like them to do if you have a seizure, like call a friend or relative for you.

Should someone call an ambulance for me?

Most seizures happen without any warning, last for a short time and stop without needing any special treatment. Usually you won't need to have an ambulance called for you, but there are some times when an ambulance should be called.

An ambulance should be called for you if:

- you have injured yourself badly;
- you have trouble breathing after the seizure has stopped;
- you have one seizure after another without recovering in between;
- your seizure lasts 2 minutes longer than is usual for you; or
- your seizure lasts for 5 minutes if they do not know how long your seizures normally last.

What causes epilepsy?

For some people, a cause can be found for their epilepsy. For example, a head injury or a stroke may cause epilepsy. But sometimes a cause cannot be found and seizures might start out of the blue.

What might have caused my epilepsy?

There are many causes of epilepsy, although some causes are more common in later life. As we get older our bodies start to change. For example, the blood vessels that supply blood to our brain sometimes become narrower and harder, which can affect the flow of blood to the brain. For many people who start to have seizures in later life, their epilepsy is due to this cause.

Doctors will usually talk to you about what they think may have caused your epilepsy and explain what type of seizures you have. This can be a good opportunity for your doctor to try to prevent any further problems if a cause is found. It also gives you the chance to ask any questions you have about your epilepsy and what has caused it. Whether a cause is found or not, seizures are usually treated in the same way.



It may help to find out a bit more about epilepsy, think about some simple safety measures or find out what support there is. Finding ways of doing what you would like to do, and keeping as mentally and physically active as you can, might help to make epilepsy just part of your life and not the most important part.

How might my family and friends react?

When you are diagnosed with epilepsy, the reaction of family and friends can vary. They may feel concerned and want to offer help and support. Some may not understand what epilepsy is like, or may become overprotective. Sometimes it can feel like family and friends are interfering or making decisions about what you can and can't do.

Having epilepsy does not affect your ability to make your own decisions any more than before you had epilepsy. It may help if your family or friends understand what epilepsy is, what your epilepsy is like for you, and that epilepsy may change very little of your life. If you know what you feel comfortable doing, you can show them how they can best help and support you.

Will this affect my living arrangements?

Most people with epilepsy live in their own homes, many on their own. It is very rare that epilepsy means that you are less able to look after yourself than before, or that you are unable to carry on living where you are. What is 'best' for you will depend on how your epilepsy affects you and what you would like to do. For example you may want to find out about any extra support that will help you to live where you are. Or very occasionally people prefer to move to somewhere with extra support, such as sheltered housing. You may find that your seizures become fewer or stop, and have less impact on your life so it is often important not to make quick decisions.

Epilepsy and you

We know and understand more about epilepsy nowadays. We know that the misunderstandings about epilepsy that used to be common are not true. We know that epilepsy is a condition that affects the brain, that it can have many different causes and that you cannot catch it from another person.

How will epilepsy affect my life?

If you have been diagnosed with epilepsy, you might go through many different emotions. Epilepsy varies from one person to another. It can affect your life in many different ways and this can be very different to how it affects someone else. You might feel shocked and angry, or perhaps numbness and disbelief. You may remember a time when epilepsy was not as well managed as it is today. It could be a relief to know what is causing the events that brought you to your doctor.

Coming to terms with epilepsy

If your AEDs stop your seizures, you may live your life just the same as before you had epilepsy.

What effect epilepsy has on your life depends on what your seizures are like and how well the medication works. If you have just been diagnosed with epilepsy, you may still be having seizures. This may change over time - if your medication stops your seizures, the effect they have on your life may get less.

Some people find it very difficult to come to terms with having epilepsy. **Most people carry on a normal life with epilepsy.** But you might not want to go out and do the things you would normally do in case you have a seizure, even if they don't happen very often. This is understandable. Some people feel isolated or depressed because of their epilepsy, and this can affect their self-confidence and quality of life.

How is epilepsy diagnosed?

Not all 'funny turns' are due to epilepsy and epileptic seizures themselves can vary. This means epilepsy can sometimes be difficult to diagnose. If you have other conditions, which you take medication for, this also makes it difficult to see what is happening and what might be causing the problem.

Epilepsy is a tendency to have seizures, so a single seizure is not classed as epilepsy. Often a diagnosis of epilepsy is not considered after a single seizure. But in some cases it may be worth investigating and looking for a cause, even after one seizure.

If you have had a seizure, and your GP thinks that you might have epilepsy, they will usually refer you to a specialist who has an interest in epilepsy. This will usually be a neurologist (a doctor who specialises in conditions that affect the brain) but may sometimes be a geriatrician (a doctor who specialises in the medical care of older people).

Epilepsy and other conditions

There are other medical conditions that can look like seizures, so as part of the diagnosis, your specialist may look at other possible causes besides epilepsy.

For example, if you have diabetes you may have a hypoglycaemic episode (when your blood sugar level is very low), which can be hard to tell apart from an epileptic seizure. It is possible to faint if the blood supply to the brain drops (say if you stand up too quickly). This can look like a seizure too. Problems with blood circulation and the heart can also look like epilepsy. The symptoms of a transient ischaemic attack (TIA) can be similar to a seizure, including a feeling of weakness down one side of the body or temporarily being unable to speak.

Your specialist may try and rule out causes like diabetes, fainting, heart problems or a cerebrovascular condition (CV condition) which affects the blood vessels of the brain. They may ask you to have a blood test, check how your heart is working using a heart monitor (an Electrocardiogram or ECG), or check your blood pressure or cholesterol levels. By doing tests for other conditions, your specialist may be able to avoid any future problems caused by these conditions, such as finding a CV condition at an early stage.

Because seizures can look similar to other conditions, it can be really useful to tell your specialist as much as possible about what happened. This can help them to tell the difference between a seizure and another condition. You will then be less likely to have a 'misdiagnosis' (when you are told you have epilepsy but you don't) or a missed diagnosis (when you have got epilepsy but your doctor thinks it is something else).

What will the specialist ask about?

A diagnosis of epilepsy is based on what happens during your seizures as well as results from any tests your specialist asks for. Often finding out about what happens during the seizures can be the most important thing to help with diagnosis. This is why your specialist will ask about what you were doing at the time and how you felt afterwards.

You may be able to remember what happens during your seizures, or you may have no memory of them. If someone else has seen your seizures, they may be able to tell the specialist about what happened to you before, during and after the seizure. For this reason, it can be really helpful for the person who has seen your seizures to come to the specialist's appointments with you.

What are epilepsy reviews?

Your GP may invite you to have a review of your epilepsy every 6 or 12 months, even if your seizures are well controlled. You can also ask for one at any point if you would like to. Your review looks at things like whether you are still having seizures, how many and what they are like. It also looks at your AEDs, how well they are working, how you feel and if you are having any side effects. Your review can also be a time to look at any other issues such as your leisure activities, work, driving or relationships. It also gives you a chance to ask any questions you have about your epilepsy, its treatment or talk about anything else. You may find it useful to make a list of the things you want to talk about before you see your doctor for a review. There is a list of possible questions on page 27.

Working in partnership with your doctor.

GPs and specialists often encourage people to become more involved in their own healthcare. This means that they help you to be fully involved in making decisions about your health, and how it is treated. Doctors understand and expect that you might have questions about your condition, how it affects you and how it is treated. In this way you can understand more about your condition and make your own choices about the treatment you want. It is important that you feel you have enough information to help you decide what you would like to do.

Who will look after my epilepsy care?

There may be a number of people who are involved in your epilepsy care. Everyone who has epilepsy should be seen by a specialist. Your specialist will diagnose your epilepsy and talk to you about things like starting AEDs and putting together a treatment plan. You might see your specialist once or twice a year after this. In between seeing your specialist, you will probably see your GP. Your GP will give you your prescriptions, help you with any drug dose changes and see you if you have any concerns about your epilepsy or its treatment. They can then refer you back to your specialist if this would be helpful, for example if the medication does not seem to be the right one for you.

Working alongside your GP and specialist may be an epilepsy specialist nurse (ESN). ESNs can talk to you about your epilepsy, and answer any questions you have. In some cases an ESN can visit you at home, where you might feel more comfortable talking about these things. Your specialist will know if there is an ESN working at the hospital that you could see.

There may be other people who can provide help or support depending on what would be useful. This might be a health visitor, an occupational therapist or a social worker. Your GP or specialist might also be able to give you contacts for support groups, epilepsy organisations or local sources of help.

If you have any questions or concerns about any part of your epilepsy care, you can talk to any of these people. You can also contact one of the epilepsy helplines. The details of NSE's epilepsy helpline are on the back of this leaflet.

By asking about what happened, this may help the specialist to see if this was a seizure, and to understand what may have caused it. If you do not remember what happens during your seizures, or if no one else can describe them, your specialist may suggest a short stay in hospital. Then the hospital staff can see what happens if you have a seizure.

The specialist may ask you, or the person who was with you, about the following things.

- How were you feeling before the seizure? Did you feel tired or had you slept well? Had you eaten or drunk anything? Had you been unwell? Had you been stressed or worried about anything?
- What happened during the seizure? Did you feel strange? Did you move in an unusual way? How long did it last?
- How did you feel afterwards? Were you confused? Did you feel tired? Did you have a headache or need to sleep?

Tests to help diagnose epilepsy

There are tests that can help to diagnose epilepsy. Which tests you have depends on what information the specialist has, and what they feel might be useful. The tests might include an EEG or brain scan, which involve a visit to hospital. The test results are looked at along with the information the specialist gets from you, and from people who have seen your seizures.

Electroencephalogram (EEG)

An EEG looks at brain activity to show how your brain is working. EEGs use small electrodes, which are put onto your head. They pick up the electrical signals from your brain as it sends messages around your body. The electrodes only record electrical signals; they do not give out electricity.

Epileptic seizures are caused by a disruption in the way the brain works, sometimes called 'ictal' activity. This can be picked up on an EEG if you have a seizure. Between seizures 'epileptiform activity' may be picked up - this is unusual activity that happens between seizures in some people. It is worth doing an EEG even if you don't have seizures very often.

EEGs show how your brain is working while the test is happening. If you do not have a seizure, and if you have no epileptiform activity, your test may be 'negative' or 'normal'. This means that there was no unusual activity seen during the test; but it does not mean that you do not have epilepsy.

Sometimes the results of an EEG are not clear because our brains work differently as we get older. Also, some medical conditions and medicines can affect an EEG recording.

Brain scans

Brain scans produce a picture of the brain. They are used to see if the cause of your epilepsy can be found. Many people have a 'structural' reason for their epilepsy - which is a physical cause that can be seen on a scan. For example this might be a scar or injury from an accident, or the area affected by a low supply of blood. Sometimes the cause of epilepsy can't be found.

You may have a computerised tomography (CT) scan or a magnetic resonance imaging (MRI) scan. The CT scan uses X-rays and an MRI uses strong magnetic fields to produce pictures of your brain. Your specialist will explain to you what happens during the scan itself. They will also tell you what the scan shows, and what this means.

Some people, quite naturally, worry about the cause of their epilepsy. But the cause may have no other effects than the seizures which brought you to the doctor. If your doctor finds a cause, it may help them to decide the best way to treat it.

Your doctors may give you a chart to help you remember when to take your tablets. You may also find a pill box or drug wallet helpful to remind you which tablets to take and when. These usually have compartments for each day of the week that are divided into sections for the morning, afternoon and evening. You can get drug wallets from many pharmacies and from NSE (see back page for contact details).

AEDs come in different forms, such as tablets that you swallow, tablets that can be crushed or mixed with water, or as a syrup. If you find the type of AED you have is hard to take, you can ask your specialist or pharmacist if there are other options.

What happens if AEDs don't work?

If your AEDs do not stop your seizures, your specialist will do various things to find out why they are not working. They will check your diagnosis again to make sure that you have got epilepsy, and find out as much as possible about your seizures. They may look to see if they can find any more information about the cause of your epilepsy, which could affect how it is treated. They will also check that you have not started medication for another condition since you started your AEDs.

The specialist may also look over your treatment plan again to check that it is easy to follow. They might ask you about your lifestyle to see if the plan fits in with it and ask you if you find it easy to remember to take your medication. They may also ask about other things that could affect your seizures, such as alcohol and your sleep patterns.

Whether you have side effects or not depends on how you, as an individual, respond to the drug. If you have side effects with one AED, it does not mean that you will have side effects with them all. If you think you might be having side effects from your AED, it is often useful to talk to your GP or specialist about what is happening.

Are AEDs taken everyday?

To work best, AEDs need to be taken regularly as prescribed, as this keeps them at a constant level in the body. Some drugs can be taken once a day and others need to be taken twice or three times. Missing a tablet does not usually cause a seizure. But if AEDs are not taken regularly the level in the body varies and you are more likely to have one. The way to get the best results from the AEDs is to follow the instructions on the prescription or to ask your doctor if you have any questions.

AEDs are not usually taken as an emergency treatment for seizures as they do not usually stop a seizure once it starts.

How long will I need to take medication?

How long you will need to take AEDs varies from person to person. For some people their epilepsy may stop of its own accord, but it may not be possible to say if this will happen for you. But because AEDs do not 'cure' epilepsy, if they are stopped, the seizures may come back. This is why people often take AEDs just to be sure that seizures do not happen.

What might help me take my drugs?

Your specialist or GP will help put together a treatment plan that is simple and easy for you to follow. Taking different drugs at different times can be hard to remember, so your plan might include a way of taking your AEDs at a time that will suit you.

How is epilepsy treated?

Managing epilepsy is all about making seizures the least important thing in your life. Part of this management is treatment with anti-epileptic drugs, or AEDs for short.

What are the aims of treating epilepsy?

The aim of drug treatment is to stop your seizures from happening, using the lowest dose of the fewest number of drugs, and without having any side effects. Most older people see their seizures stop once the right AED is found. This is often called being 'seizure free'. For some people though, their seizures will not be stopped completely, so the aim is to keep their seizures to a minimum.

Starting treatment

Your specialist will usually wait until you have been diagnosed with epilepsy before starting treatment. They might talk to you about starting treatment after a single seizure, before epilepsy is diagnosed, if they feel there is a high chance that you might have more seizures.

If you have been diagnosed with epilepsy, your specialist will talk to you about when the right time would be for you to think about starting treatment. They will discuss the risks and benefits of starting or not starting treatment, which will be different for each person. Once you and your specialist have decided on your treatment, it is usually written down in a treatment plan for you to follow. This plan shows what AED you are taking, at what dose, and what to do if you feel unwell or if the AED does not work for you. Your specialist will pass this information to your GP as well. Because everyone is individual, your treatment plan will be tailor-made for you.

When you start taking your AED, it is usually in a very low dose so your body can get used to it. It takes about a week for the AED to get into your system. AEDs do not usually stop seizures at these very low doses. So your doctor will gradually increase the dose until it does stop your seizures. While the dose is increasing, your specialist will look at how well it stops your seizures and how you feel taking it. The dose at which the AED will stop seizures varies from one person to another and will depend on how your body responds to it.

How are AEDs chosen?

Different AEDs work in different ways. They do not cure the cause of epilepsy but they make the brain less likely to have a seizure. Different AEDs work for different types of seizures, so which AED you take depends on the type of seizures you have.

Your specialist will try to stop your seizures using one type of AED - this is called 'monotherapy'. If the first AED chosen does not work, or it causes you any problems, then your specialist will change it to another one. If this does not work, they may try adding another - sometimes called 'polytherapy'.

The older, well-known AEDs are usually tried first because they work well for most people with epilepsy, and for most types of seizure. These AEDs include Carbamazepine (also called Tegretol) or Sodium Valproate (also called Epilim). If these drugs do not work for you, or you feel unwell taking them, your specialist may try a newer drug. Some newer drugs have less side effects, so they might be better for you.

The aim is to stop your seizures without the AEDs having too much effect on your everyday life. This can sometimes be a difficult balance to get right. It can take time to find the right AED at the right dose. And it can be worth trying different AEDs, or different combinations, to get the best seizure control.

What is considered when choosing AEDs?

When choosing AEDs the following things are important, and will vary from person to person.

What type of seizures do you have?

Because different AEDs work for different types of seizures, which AEDs your specialist chooses will depend on the type of seizures you have.

Do you take drugs for any other medical conditions?

Some drugs interact and affect how well other drugs work. If you take other drugs, your specialist can check if these might interact with AEDs.

What side effects might the drugs have?

Side effects are the unwanted effects that the drugs have. Like all drugs, AEDs can cause side effects in some people, and these vary from one AED to another and one person to another.

Because AEDs work on the brain to stop seizures, some can occasionally affect memory and your ability to think quickly. If you already have memory problems, some AEDs can make this worse. AEDs can have a sedative effect which can make you feel sleepy, (which may also affect your memory). Some AEDs may increase your risk of osteoporosis (when bones lose calcium, become thinner and can break more easily). So you could be more likely to break bones in a fall, for example during a seizure.

Your specialist may talk to you about what to look out for, as some people have more unusual side effects. A list of possible side effects is included on the patient information leaflet that comes with each prescription. You may be able to get a copy in large print from your pharmacist if you need to. You can also find information on the website: www.medguides.medicines.org.uk