

To receive the best possible treatment, it is important to have a good relationship with your health care team to be able to communicate and work co-operatively with them. These suggestions may help you with doctors' appointments.

## How to choose your doctor

Doctors differ in their opinions of treatment and their approach to patients. If you are able, choose a doctor you feel comfortable with and can relate to. Sometimes this is not always possible due to location, but your health needs are best met when you can plan and agree about your epilepsy management.

Your role as patient is to provide accurate details about your epilepsy and seizures. This is essential for accurate diagnosis and treatment. Do not hide information such as breakthrough seizures, forgetting your medication, using drugs or drinking alcohol. This information remains confidential and hiding it may lead to incorrect or unnecessary treatment.

The specialist's role is to confirm your diagnosis and to discuss treatment options and any other issues that may affect you. If you have continuing seizures, you will need to see specialist more often. If your seizures are well controlled, a yearly check-up may be all that is necessary, and your GP can coordinate and manage most other things. While your GP can provide ongoing epilepsy care, many prefer that your specialist manages any changes to medication. Your GP serves a pivotal role in liaising with your other specialists and health providers.

## Recording your seizures

There are many different seizure types and what happens during a seizure is quite individual.

An accurate eyewitness description or a video of your seizures can greatly help your specialist with diagnosis and treatment.

## Keep treatment records

Record the medications you have tried, dosages and any unwanted effects. This will be useful if you are seeing a new doctor. It also helps to keep a list of your current medications and doses just in case you need to go to hospital. Keeping copies of reports of tests will also avoid them being repeated unnecessarily. Tools like [EpiDiary](#) are useful for keeping records.

It may be useful to you and your doctor if you make a note of things such as:

- Do you know if a seizure is going to happen and how do you know?
- What happens to you during a seizure, and how do you feel?
- How long your seizures normally last
- How long you take to recover from a seizure
- What to do if your seizures last longer than usual
- Is there anything that makes your seizures more likely to happen, triggers?
- Which epilepsy medication you take
- What to do if you miss a dose
- The contact details of your doctor(s)



### **Ask questions**

Write down any questions you have before your doctor's appointment. If you have a number of different questions, prioritise what you really want to know and consider asking the others at the next appointment if time is limited. This will give you time to think about the doctor's answers. You may want to ask the doctor:

- What is the name for the type of epilepsy that I have?
- Do you know what has caused my epilepsy?
- Why have I developed it now?
- Will my epilepsy change and is it likely my seizures will be controlled?
- What lifestyle changes can I make to help control my seizures?
- What side effects should I expect from my medication?
- What do I do if I miss a dose?
- What if the medication doesn't work?
- Might antiseizure medication react with my other medications?

Depending on your needs, you may also require a clear explanation about other important issues including:

- Can I drive? How long will my license be suspended for if I have a seizure?
- What about my job? Can my employer sack me?
- What about pregnancy or contraception? Are there any specific issues?
- Does epilepsy or antiseizure medication cause memory problems?

### **Note the answers**

Listen carefully to the answers. If you are unsure of medical terms the doctor uses, ask for a clearer explanation.. Take someone with you or a pen and paper ready to write notes for later reference.

### **Ask our epilepsy nurses for further explanations or questions you may have**

#### **A second opinion?**

If you would like to get a second opinion, ideally you should discuss it with your current specialist. Most specialists are happy for you to seek another opinion.

If you feel uneasy expressing your need for a second opinion with your current specialist, do so with your GP who will refer you to another specialist. If you obtain a second opinion, you should decide with your GP whether to transfer to the second specialist or stay with the first.

#### **Learn about your epilepsy**

Be curious and learn all you can about epilepsy. Understanding your epilepsy will give you the confidence to ask your doctor clear, relevant questions and enhance your ability to be involved in managing your seizures..



### **Appointment checklist**

- Be familiar with your doctor's practice and appointment system.
- Ask the receptionist the time usually allocated for each patient. You may need to make separate appointments if you have a lot of questions that need answers.
- Write down questions that you have about your epilepsy, treatment or seizure management before your appointment. Keep them simple and to the point, and make sure you have the most important ones to you listed first.
- Keep your seizure diary up-to-date and take it to all appointments.
- If possible, especially if this is your first visit, take along someone who has seen your seizures and can give the doctor an eyewitness account.
- Answer your doctor's questions honestly. Seizure control is important, but so is seizure activity such as unusual sensations, behaviour or movements or momentary lapses.. It may only take minor changes to prevent seizures if the doctor is aware that they are occurring.
- Report and record all reactions to your medication including seizure frequency or change.
- Make sure you fully understand the details of your treatment and medication.
- Discuss the costs of proposed medical treatment or tests with your doctor.
- Ask your doctor for clear explanations if you feel you do not understand.
- Ensure that your doctor clearly understands all that you have said.
- Take pen and paper and make notes for later reference.

