

**To receive the best possible treatment and the most appropriate service, it is a good idea to work co-operatively with your neurologist, paediatric neurologist or paediatrician and GP.**

**These suggestions may help you with doctors' appointments.**

### **How to choose your Doctor**

Doctors differ in their opinions of treatments and their approach to patients. If you can, choose a doctor you feel comfortable with and can relate to. Your health needs are best met when you have a true partnership with your doctor. This partnership begins with you both agreeing about your management plan - and its success depends on each person fulfilling their specific roles.



Your role as patient is to provide accurate details about your epilepsy and seizures. This is essential to getting a correct diagnosis and consequently receiving the right treatment. Do not hide information such as not taking your medication as prescribed, using illicit 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 with you clearly about treatment and any other issues that may affect you. Specialists vary in their involvement in ongoing care. If you have continuing seizures you will need closer monitoring. If your seizures are well controlled, a yearly check-up may be all that is required and your GP can manage most other things. The role of the GP is to provide day-to-day healthcare based on knowledge of your general health. While your GP often provides ongoing epilepsy care, many GPs prefer that your specialist handles or advises about 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 description or a video of your seizures can greatly assist your specialist in determining accurate diagnosis and treatment.

**Ask your specialist how much information to record about each seizure.  
Guides for recording seizures are also available from Epilepsy Action Australia.**

### **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. Retaining copies of reports of tests will also avoid them being repeated unnecessarily. Tools like My Epilepsy Diary are useful for retaining records.

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

- What happens to you during a seizure
- 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
- Anything that makes your seizures more likely to happen
- 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 visit. If you have a number of different questions, prioritise what you really want to know and consider asking them at separate visits 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 seizures or epilepsy syndrome that I have?
- What has caused my epilepsy?
- Why have I developed it now?
- Will medication cause any unwanted side effects?
- Will my epilepsy change in the future?
- Should I make any lifestyle changes?
- What side effects should I expect from my medication?
- What happens if I miss a dose?
- What if the medication doesn't work?

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

- Can I drive?
- What about my job?
- What about pregnancy or contraception?
- Does epilepsy or antiepileptic medication cause memory problems?
- Might antiepileptic medication react with my other medications?

## Note the answers

Listen carefully to the answers. If you are unsure of medical terms the doctor uses, ask for explanations until you fully understand. Take a pen and paper ready to write notes for later reference.

**Ask Epilepsy Action Australia for explanations of your doctor's medical advice and questions on social matters including employment.**

## A second opinion?

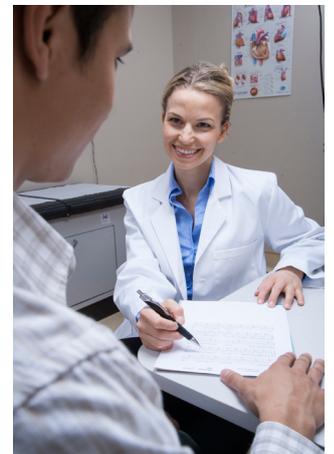
If you would like to get a second opinion, ideally you should discuss it with your current specialist. Most specialists are happy for you to seek another opinion. This is because it often confirms the first opinion, will share responsibility for your diagnosis and management, and may result in useful suggestions for your treatment.

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, simple questions such as how epilepsy is best managed and what is your future outlook. There may be medical questions that no doctor can answer such as the cause of the epilepsy, as this cannot always be determined.

Talk to Epilepsy Action Australia to obtain information or ask questions.



### 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 prior to your appointment.
- Keep your questions 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. Control of major seizures is important, but so is seizure activity such as unusual sensations, momentary lapses or twitching. It may only take an adjustment to medication to prevent these 'little episodes' if the doctor is aware that they are occurring.
- Report 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 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.