

YOU AND YOUR DOCTOR

FACT SHEET



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To receive the best possible care, it's important to build a good relationship with your healthcare team.

Clear, honest communication helps you work together to manage your epilepsy effectively. These tips can help you prepare for and get the most out of your appointments.

Choosing a doctor



Doctors vary in their approach to treatment and communication.

If you can, choose a doctor you feel comfortable with and who listens to your concerns.

This isn't always possible due to location or availability, but your care will be most effective when you and your doctor can plan and agree on your epilepsy management together.

Your healthcare team's role

Your specialist will confirm your diagnosis, discuss treatment options, and help manage ongoing issues.

If your seizures continue, you may need to see them more often. If your epilepsy is well controlled, a yearly review may be enough.

Your GP can coordinate your general health care and liaise with other specialists.

Many GPs prefer that your neurologist or epilepsy specialist manages any changes to your medication.

Your role as a patient

You play a vital role in your care.

Be honest and provide accurate information about your seizures and lifestyle. This includes:

- Any recent or breakthrough seizures
- Medication side effects, missed medication doses
- Use of alcohol or recreational drugs

This information is confidential and helps your doctor make the best decisions for your treatment. Hiding details can lead to incorrect or unnecessary treatment.

Considering a second opinion

Sometimes you may feel you need a second opinion. If you'd like a second opinion:

- It's best to discuss this with your current specialist — most are supportive.
- If you're uncomfortable doing so, speak with your GP, who can refer you to another specialist.
- After your second opinion, you and your GP can decide whether to stay with your current specialist or transfer care.

The more you understand about your epilepsy, the more confident you will feel managing it.

PREPARING FOR AN APPOINTMENT

Keeping track of your seizures

Seizures can vary widely between individuals. Keeping a record helps your doctor understand your condition better.

Ask someone who has seen your seizures to describe what happens — or get them to record a video if possible.

Keep a seizure diary noting:

- When seizures happen and how long they last
- How you feel before, during, and after
- Any known seizure triggers
- How long it takes to recover

Asking questions



Write down any questions before your appointment. If you have a lot, prioritise the most important ones first. Some examples include:

- What type of epilepsy do I have?
- Do we know what caused it?
- Will it change over time?
- Can my seizures be controlled?
- What should I do if a seizure lasts longer than usual?
- What lifestyle changes might help?
- What side effects should I expect from my medication?
- What happens if the medication doesn't work?
- What should I do if I miss a dose?
- Could my medication interact with other medication I take?

Depending on your situation, you might also ask about:

- Driving and licence restrictions
- Related memory or learning challenges
- Work and your rights
- Birth control or family planning

Helpful notes to bring

If you can, you may also want to jot down:

- How you know a seizure is coming (if you do)
- What happens during a seizure
- Contact details for your GP and other relevant healthcare professionals

Understanding the answers

Don't walk away confused. Make sure you:

- Ask your doctor to explain anything you don't understand - especially medical terms.
- Take notes or bring someone with you to help remember what was said.
- Ask for referral to appropriate services if the doctor can't help, e.g. psychology, genetic counselling, employment help.

You can also contact our epilepsy nurses for further explanation or support.



Take someone with you to the appointment to help remember what was said.

APPOINTMENT CHECKLIST



- Know how your doctor's appointment system works – you don't want to be late or miss an appointment as it can be a long wait until the next one
- Ask how long appointments usually last – ask to book extra time if needed
- Write down your questions in advance, starting with the most important
- Keep your seizure diary up to date and bring it with you
- Bring someone who has seen your seizures, especially for first visits, to explain what they saw
- Be honest about all symptoms or seizure activity, even if it seems minor or embarrassing
- Record any seizure changes or side effects from your medication
- Make sure you understand your treatment plan and medication instructions
- Ask about the cost of any tests or treatments
- Ensure that your doctor clearly understands all that you have said.
- Take notes during the appointment for later reference



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

Epilepsy Clinics

It is recommended you be referred to a comprehensive epilepsy centre if your seizures continue, to gain a clearer diagnosis, and review of your treatment.

These centres are best equipped to offer a better chance at finding the most appropriate treatment.

Most states in Australia have a comprehensive epilepsy centre.

Contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

[Book a telehealth appointment with an epilepsy nurse](#)

Visit our website



Disclaimer: This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice, and you should not make any medication or treatment changes without consulting your doctor.