

Medications and epilepsy



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Anti-epileptic drugs (AEDs) are the main form of treatment for people with epilepsy. These medications aim to stop seizures from occurring but they do not cure epilepsy.

The AED chosen will depend on the seizure type/s, age, gender, medication side effects, and other lifestyle factors.

It is important that those who care for or work with a person living with epilepsy and a cognitive disability gain an understanding of epilepsy medications so that the person can be safely supported.

Medications and epilepsy

Most people diagnosed with epilepsy are prescribed medication to control or reduce seizure activity. Medication should always be taken in line with the doctor's instructions to maximise the benefits of the medication and reduce the possibility of unwanted side effects.

Around 70% of people with epilepsy experience good seizure control through the use of medication. However, as people living with epilepsy and a cognitive disability tend to have more severe and difficult to control seizures, they can have lower levels of medication success than the general population.

There are two types of medications that are prescribed for epilepsy:

1. Anti-epileptic drugs (AEDs). Most people diagnosed with epilepsy are prescribed one or more anti-epileptic drugs (AEDs), which are generally taken one or more times per day. AEDs are the most common treatment for people living with epilepsy. While AEDs will not cure epilepsy, they can control seizure activity. AEDs are usually selected on the basis of:

- the person's seizure type/s
- how well the person can tolerate them
- what other health-related conditions the person may have

- other medications already being taken by the person
- how seriously the seizures are affecting the person's life.

There are many different types of AEDs available. A seizure free outcome is the optimal result sought by the person and by their doctor.

2. Emergency Medication. For epilepsy, emergency medication works by stopping or reducing acute seizure activity. Some people with difficult to control seizures are prescribed this type of medication. Emergency medication is generally prescribed to stop a seizure and/or allow time for an ambulance to arrive and transport the person to hospital for further assistance.

What does this mean for the person?

Commencing medication does not always mean the person will always have to take it. Sometimes medication may be changed or even stopped. When it comes to medication some common matters to consider include:

- Understanding why the medication has been prescribed.
- Attending regular medical reviews as medication may need to be adjusted, changed or stopped.
- Always taking medication at the dosage and at the time recommended by the doctor. General advice is that if a dose is missed it should be taken as soon as possible. However, do not double up on doses, and it is advisable not to take the missed dose if it is close in timing to the next one. Keep a record of doses that have been missed.
- Noting any changes in general health or seizure activity after starting medication.

If the medication is not managing seizure activity the doctor should be advised as soon as possible as the medication or dose may need to be changed.

- Withdrawing from medication should always occur under medical supervision as stopping medication suddenly can provoke seizures and may create a medical emergency.

Using other medications

Some people living with epilepsy and a cognitive disability may also be taking other non-epilepsy related medications. This may impact on what type of AED can be prescribed.

It is important to know that the contraceptive pill may be less effective when taking an AED, so discussing alternative birth control methods with a treating doctor is important.

Medication side effects

An AED, like any medication, can sometimes cause unwanted side effects. It is good practice to ask the doctor to discuss the risks and benefits of all prescribed medications.

The doctor will describe common medication side effects however it is also a good idea to discuss any possible side effects with the pharmacist also. This helps to ensure the person, family and support worker understand and can look out for any potential side effect symptoms.

- Some common side effects that may occur in the first few weeks of taking one or more AED can include sedation, slowed thinking, fatigue/tiredness, dizziness, shaking hands, blurred vision and mood problems. Most of the time side effects are mild, don't last long and can be treated by changing the medication or reducing the dose.

- Information about potential unwanted side effects are included in the medication packaging. But remember, just because a medication may list side effects doesn't mean the person will experience them. However, it is important to let the doctor know of any side effects as they may need to assess the situation and decide whether to change or adjust medications.
- AEDs can contribute to osteoporosis, a condition of decreased bone strength (thinning of the bones) which increases the risk of a broken bone. If taking AEDs for an extended period bone density assessments may be necessary.

Emergency medication

In addition to being prescribed an AED, some people with severe, long or difficult to control seizures may find that their doctor also prescribes emergency medication.

- The doctor will advise how and when the emergency medication is to be administered, and how it is to be stored.
- Emergency medication will be recorded in an Emergency Medication Management Plan (EMMP).

Only trained practitioners or people who have been trained to administer emergency medication in accordance with the EMMP should do so. These people may include family, carers or support workers.

What can you do to help?

Some people living with epilepsy and a cognitive disability may find it difficult to understand how and why they need to take their AEDs and sometimes even resist taking these because of fears and concerns. The person may need assistance from family, carers and support workers to understand not only their epilepsy, but also why they need to take their AED as prescribed. Caregivers should also understand the medication treatment plan, particularly those people who play a role in supporting the person to take their AED.

It is highly recommended that the person and key caregivers understand the role of medication as outlined in their Epilepsy Management Plan (EMP) and participate in medical review meetings so that medication questions and concerns can be raised.

It is important that a person-centred approach is taken, ensuring that the person is at the centre of decisions which relate to their life.

A person-centred approach places the person at the centre of all discussions, plans and choices taking into account their life experiences, values, culture, interests, beliefs and goals. Taking this approach demonstrates respect for the individual, improves the quality of care and allows the person to make informed decisions.

A person over the age of 18 and living with epilepsy and a cognitive disability is presumed to be able to give informed consent to medical treatment, and equally the person can also refuse treatment. If a person refuses treatment and you are concerned about their welfare, discuss the impact that not taking medication may have. If, after doing this, the person still does not consent, you may want to consider a capacity assessment or applying for guardianship.

What can you do to help? (continued)

Being consistent in how AEDs are taken is essential. It can be easy to forget to take medication at the appropriate time. If a person lives in supported accommodation, the administering of medication is likely to be under the control of staff. However if a person lives with family, carers or by themselves some strategies may assist in reducing the risk of missing medication.

- Use of a pill box or Webster Pack. This is useful particularly if taking multiple medications. It also reduces the chance of double dosing. Encourage the person to establish a routine and combine taking of medication with a daily task such as brushing teeth or eating meals.
- Keep medication in an easy to see place so they cannot be missed.
- Encourage mindfulness – discuss the importance of pausing and being present when taking medication, to ensure the correct dose is taken.
- When supporting a person who has been prescribed emergency medication it is important to receive training in Administration of Emergency Medication.
- Use technology. Set up reminders on the person's phone, watch or electronic calendar. There is also a range of apps available for smart phones.
- Encourage the person to complete or assist in completing the Medication Summary Form on the next page.

Where to go for further information?

Epilepsy Foundation www.epilepsyfoundation.org.au

Epilepsy Learning www.learning.epilepsyfoundation.org.au

Victorian Government, Better Health Channel www.betterhealth.vic.gov.au
(Search: epilepsy medication)

Australian Government, Department of Social Services www.dss.gov.au
(Search: National Standards for Disability Services)

This information sheet is part of a suite of resources that are targeted to family members, carers and support workers, to assist with caring for people living with epilepsy and a cognitive disability.

The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from an appropriately qualified health professional.

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