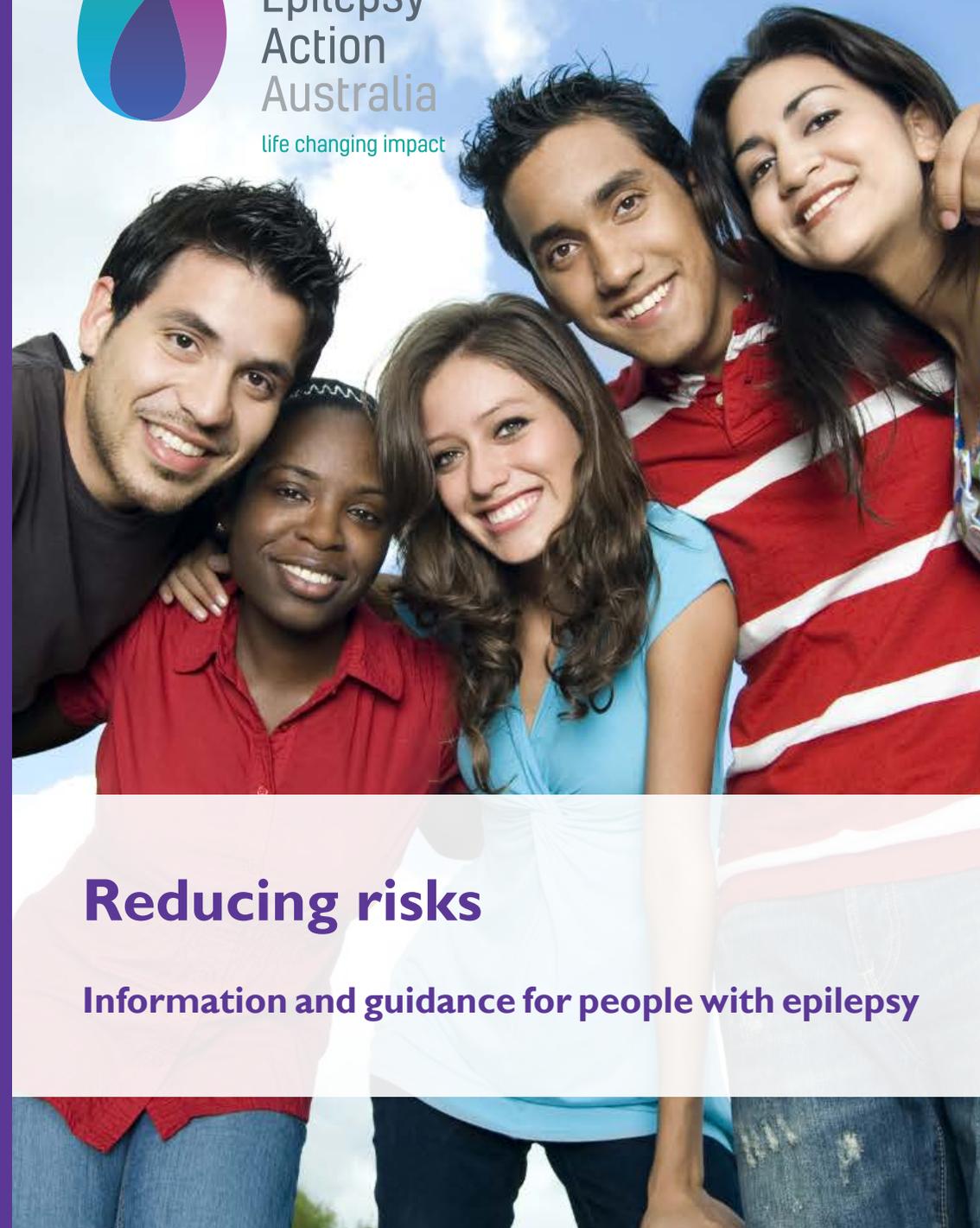




Epilepsy
Action
Australia

life changing impact



This information is not intended as medical advice. Do not make changes to treatment or medications without first discussing with your treating clinician.

Please contact us for further information:

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(Australia wide priority call)

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This leaflet has been created by SUDEP Action, a charity dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths. It is the only UK charity specialized in supporting and involving people bereaved by epilepsy.

SUDEP Action 
Making every epilepsy death count

SUDEP Action is delighted to work in collaboration with Epilepsy Action Australia to distribute this leaflet.

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Epilepsy Bereaved (founded 1995) is part of SUDEP Action

Reducing risks

Information and guidance for people with epilepsy

As someone with epilepsy, you've almost certainly had to think about risks. Simple precautions – such as taking a shower rather than a bath or changing the way you cook – can make a big difference to your safety if you have a seizure.

There is, however, another risk that you need to consider too. It's very small, but significant, and it becomes more serious if you have frequent tonic-clonic seizures. It's called Sudden Unexpected Death in Epilepsy – or SUDEP – and it's something you may want to discuss with your medical team when you've read this leaflet.



What is SUDEP?

Each year, roughly one in every thousand people with epilepsy will die suddenly with no obvious cause. This is what we call SUDEP. The risk may be greater for a small number of people, which is why it's important to talk to your doctors or nurses about your own condition. SUDEP usually occurs at night or during sleep. It's often the case that the affected person will have had a seizure just before their death, although this isn't always so.

Why does it happen?

Researchers are still investigating the causes of SUDEP and it's unlikely there's a single cause. During seizures, people may often have a change in their breathing or heart rhythm. Normally, this isn't a problem, but if more serious changes occur – a major drop in oxygen levels in the blood, for example – then this might be a trigger for SUDEP.

Seizures may also affect the brain's influence on breathing and the heart. Another possibility is that there is a genetic link between seizures and heart rhythm abnormalities. Advances in research mean that we're getting closer to identifying the critical risk factors.

HOW CAN YOU REDUCE YOUR RISK?

The strongest risk factor is a generalised tonic-clonic seizure (which some people call a 'grand mal'). The more frequent these convulsive seizures are, the higher the likelihood of SUDEP. As a result, the most important step you can take to avoid SUDEP is to minimise the number of seizures you have.

Learn about your epilepsy

Learning about: your own epilepsy - the type and pattern of your seizures; your medications; and potential seizure triggers helps you to take control and make informed choices about your lifestyle. Epilepsy Action Australia specialist epilepsy nurses are available to discuss your concerns and offer a wide range of practical information and resources.

Take your prescribed medication regularly and reliably.

Try a diary or smartphone app if you have trouble remembering.

Keep regular appointments with your doctor and attend your annual review.

Don't make adjustments to your medication or stop taking it, without talking to a doctor first. There is help available to safely look at your choices. If you're making changes in your life – moving away from home or taking contraception for the first time – see if your epilepsy care plan needs to change.

Identify the triggers for your seizures.

Do you find that your epilepsy is particularly affected by not sleeping enough, drinking too much alcohol or taking recreational drugs? If so, try to avoid the trigger.

Discuss other epilepsy treatments with your doctor.

If you feel your medication isn't doing enough to control your seizures, there may be other options such as surgery.

Confide in your friends.

Tell them that you have epilepsy and explain what they should do if you have a seizure. There is some evidence that it's safer to be with someone when you have a seizure, so it might be worth discussing sharing a room with a family member if you are affected during your sleep. Alternatively, you might want to consider, with your doctor, a monitoring device that may alert them if you have a seizure.

You can find out more about risk and epilepsy at

<https://www.epilepsy.org.au/about-epilepsy/epilepsy-and-risk>

To speak with an epilepsy specialist nurse at Epilepsy Action Australia

Call 1300 37 45 37

Email epilepsy@epilepsy.org.au

“Don't make adjustments to your medication or stop taking it, without talking to a doctor first.”

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