

# MEDIA RELEASE

23 October, 2019.

## Difficult Conversations Needed

23 October is International SUDEP Action Day.

**For reasons that are poorly understood, people with epilepsy have an increased risk of dying suddenly for no discernible reason.**

*Epilepsy - A Focus on Tasmania*, released early this month highlighted that across Australia approximately 300 people die from epilepsy each year. The cause of these deaths can be due to having a seizure while driving or swimming, a brain injury, stroke or accidents - but half are from causes unknown.

The sudden, unexpected death of someone with epilepsy is known as SUDEP. It can occur in people who were otherwise well, and in whom no other cause of death can be found.

Epilepsy Tasmania CEO, Ms Wendy Groot, said "No one knows what causes SUDEP and we can't predict who will be affected. Today is International SUDEP Action Day and it's time to have the conversation about the heartbreaking impact epilepsy can have."

"It is confronting to know that most people with epilepsy are unaware their risk of premature death is three times that of the general population," said Ms Groot. "Or that they are less likely to live to the general life expectancy of 80 to 84 years of age; the mean life expectancy for someone with epilepsy is just 52 years old."

"It's often easier for us to avoid talking about death, to shy away from raw and potentially heartbreaking conversations," said Ms Groot.

Epilepsy Tasmania's approach today is to remind people with epilepsy and their families about the importance of taking their medications exactly as advised by their health specialists; of being extra careful around water, heat sources and vehicles; of staying in good physical health; and of trying to prevent head injuries.

"We are a good Tasmanian resource for people wanting to learn more and our nurse, social worker and support staff are all available to continue this conversation in person, over the phone or on our Facebook page," said Ms Groot.

"Only with the courage to have these difficult conversations can we begin to prioritise the importance of research and of finding a cure for epilepsy."

- ENDS -

## MORE INFORMATION:

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## SPOKESPEOPLE:

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## ABOUT EPILEPSY

**Epilepsy is a chronic disorder of the brain** that is characterised by abnormal electrical activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness.

**20,000 Tasmanians have epilepsy**, and for every person with epilepsy there are approximately 4 others providing care and support. This means **one-fifth of Tasmania's population is directly affected by the condition**.

Epilepsy can develop at any age. **One in 10 people experience a seizure during their life**. One in 26 Australians will go on to develop epilepsy (2 or more unprovoked seizures).

**The causes of epilepsy are complex** and vary depending upon the age at which the first seizure is experienced. Known risk factors include serious head injuries sustained during motor vehicle accidents, trauma or serious falls; strokes or brain haemorrhages; prolonged oxygen deprivation; brain infections and abnormalities; tumours; degenerative conditions such as dementia; and genetic factors. But in around 40% of cases the cause cannot be determined.

**60% - 70% of people diagnosed with epilepsy will gain seizure control with medication.**

**People with epilepsy die at 3 times the rate of the general population.** The mean age of death from epilepsy in Australia is 52 years (compared to the general current life expectancy of 80 - 84 years of age). The Years of Potential Life Lost through epilepsy-related deaths are greater than asthma (a national health priority) and similar to prostate cancer.

People with epilepsy have a **15 to 19 times greater risk of drowning**.

**52% of Tasmanians with epilepsy have experienced discrimination as a result of their condition.** The most common place for discrimination is at work and school.

People with epilepsy are often unable to safely drive a motor vehicle: **only one third of Tasmanians with epilepsy drive their own car**. The remainder must rely on others, public transport or taxis and imposes an additional financial burden of around \$231 per year.

**People with epilepsy are up to eight times more likely to have other health conditions** such as depression, dementia, heart disease and arthritis. Half of all adults with epilepsy have at least one other health condition. Depression and anxiety from epilepsy make seizures worse and reduce quality of life.

**Epilepsy is the second most burdensome neurological condition after dementia.**

**Epilepsy has significant economic implications** in terms of health care needs and lost productivity at work.

**1 in 7 people who present to hospitals are there due to epilepsy.**

**Advanced Alzheimer disease has been identified as a risk factor** for new-onset generalized tonic-clonic seizures in older adults and is associated with a 10% prevalence of seizures, particularly late in the illness. Increased prevalence of seizures have also been documented with other types of dementia.

**Epilepsy is a lot more than seizures** - people with epilepsy typically face an array of challenges additional to those involved in trying to prevent seizures, including cognitive, social, medical, mental health and psychosocial. **The seizure is just the tip of the iceberg: underneath are many factors affecting concentration, memory, connections and the ability to function day-to-day.**

## ABOUT EPILEPSY TASMANIA

Epilepsy Tasmania is a not-for-profit community organisation that has been improving the quality of life of Tasmanians with epilepsy, and those around them, through education, coordination and support for over 40 years.

CEO, Wendy Groot, is Chair of the national Epilepsy Australia coalition.

Epilepsy Tasmania is committed to bringing epilepsy out of the shadows, and breaking down the stigma and discrimination associated with epilepsy in Tasmania.

Its vision is to ensure all Tasmanians who have epilepsy have the same opportunities as the broader community. Its statewide services and support includes:



Workplace training



School training.



Peer support.



Fundraising and awareness.