

# MEDIA RELEASE

30 September, 2019

## Tasmania's real cost of epilepsy

Research released today by Epilepsy Tasmania reveals startling new health statistics and the significant burden that epilepsy places on Tasmanians.

The report ***Epilepsy - A Focus on Tasmania*** provides new insights into epilepsy and compares the situation in Tasmania against national and international data.

"This is the most comprehensive epilepsy research ever undertaken in Tasmania and provides a strong mandate from which to call for sustained and coordinated action to ensure every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination," said Epilepsy Tasmania CEO, Ms Wendy Groot.

"The research shows Tasmania has the highest prevalence of epilepsy than any other state or territory in Australia, with the figure expected to rise due to our older than average population, general rising life expectancy and an increasing proportion of people surviving incidents that often lead to epilepsy," she said.

The economic burden of epilepsy in Tasmania is shared mainly between individuals and the State Government at a cost of \$11.8 million per year.

"This means epilepsy imposes a greater burden on Tasmania's health system than prostate cancer, and one similar to that of lung cancer and Parkinson's disease," said Ms Groot.

The report lists epilepsy as the second-most burdensome neurological condition to live with, after dementia. It also documents that people with epilepsy die at 3 times the rate of the general population, at the much younger mean age of 52 compared to current the life expectancy of 80 - 84 years of age.

In schools, epilepsy is now the third most common health condition (in the order of diabetes, asthma, epilepsy then anaphylaxis) and one of the top five avoidable causes of death among five to 29-year-olds.

The World Health Organisation reports that 47 per cent of employed Australians with epilepsy report unfair treatment in the workplace. But the Tasmanian statistic is worse, at 52 per cent.



“But we feel this could be good news,” said Ms Groot.

“The increase in reported discrimination cases is a sign that our public awareness campaigns are working to reduce the stigma of epilepsy and are giving people more confidence to disclose their condition and report discrimination - rather than an increasing amount of discrimination occurring.”

Epilepsy Tasmania's next campaign will run during October for WorkSafe Month to remind Tasmanian workplaces of their responsibility to provide staff and customers with a safe environment, to learn seizure first-aid and to prevent discrimination. Workplaces can take advantage of a 15% discount on all training booked during October.

Ms Groot said this new research shows urgent actions are needed across Tasmania to:

- Promote epilepsy as a public health priority to reduce its burden;
- Improve public attitudes and promote the protection of the rights of people with epilepsy;
- Invest in health and social care systems to improve accessibility to epilepsy care;
- Prevent acquired epilepsies through improved care for common causes;
- Increase the priority of epilepsy for research agendas.

“I hope this report will re-energise and guide government, policy-makers and stakeholders to reduce the economic and social impact of epilepsy in Tasmania,” she said.

- ENDS -

## MORE INFORMATION:

Claire Burnet 0448 585 947 or [www.epilepsytasmania.org.au](http://www.epilepsytasmania.org.au)

## SPOKESPEOPLE:

- Wendy Groot, CEO, Epilepsy Tasmania: 0427 044 074

## 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 generalised 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.