



TALKING POINT

By Wendy Groot, CEO Epilepsy Tasmania.
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Make March Purple for Epilepsy

Every 33 minutes, someone's life is turned upside down by epilepsy.

A diagnosis of epilepsy can be life-altering, affecting the personal life, employment, education and wellbeing of that person, as well as their family members.

Epilepsy is a serious neurologic condition, diagnosed in the presence of at least two unprovoked seizures occurring more than 24 hours apart.

Seizures occur when there is a disruption to electrical activity in the brain, leading to changes in a person's movement, behaviour, level of awareness and/or feelings. They can include a loss of consciousness, a range of unusual movements, or odd feelings and sensations.

For the 305 Australians who are diagnosed with this condition every week, even just getting an epilepsy diagnosis may have taken years, because epilepsy is not as simple to diagnose as you would imagine. In the meantime, they endure unpredictable seizures - sometimes many, many each day - and grief for the life they used to live before epilepsy turned it upside down.

Epilepsy significantly affects quality of life because it 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 we see is the visible tip of the iceberg: underneath, this person can be dealing with reduced concentration, memory loss, isolation, reliance on others, anxiety, loss of income, depression and a genuine struggle to function day-to-day.

Sadly, 30% of people with epilepsy are not able to prevent their seizures with medication: more research is still needed to find better medications and one day, hopefully, a cure.

Nearly half of people with epilepsy have no idea what triggered the condition, because the causes of epilepsy are complex and dependant upon the age the first seizure was 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.

Tasmania has the highest prevalence of epilepsy than any state or territory in Australia, and this figure is expected to continue rising due to our older than average population and the increasing number of people who survive incidents that can lead to epilepsy.

Make March Purple for Epilepsy is a joint effort by epilepsy organisations around Australia to turn things around for people living with epilepsy, and their families.

By raising awareness of the condition and gathering vital funds for research, support and education, we hope to bring stability and peace of mind to the 20,000 Tasmanians diagnosed with epilepsy every year, and to the 80,000 family members, employers, colleagues, teachers, carers and friends relied upon to provide logistical, physical and emotional support.

By making all of March purple, we hope to generate lasting discussions about epilepsy and make real change for people living with the condition in Tasmania.

Changes that include greater understanding of the extra challenges people with epilepsy face, and the additional support they often require to go about their lives. Changes that include a realisation of how common epilepsy is, how it can happen to anyone at any time, and that right here in Tasmania 1 in 7 people who present to hospitals are there due to epilepsy.

So this month, when you see a building lit up with purple lighting; or visit a business with purple decorations; or walk past a purple fundraiser - take a moment to think about what it would be like to live with the unpredictability of epilepsy and how you can make life easier for the people who do.

Because epilepsy can happen to anyone, and one day it may be your life that is turned upside down.

- ENDS -

MORE INFORMATION:

Claire Burnet 0448 585 947 or www.epilepsytasmania.org.au

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, but 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 Australians experience a seizure during their life.** One in 26 of these develop epilepsy, which is two 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. In 40% of cases the cause cannot be determined.

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

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.

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.** It imposes a greater burden on Tasmania's health system than prostate cancer, and one similar to that of lung cancer and Parkinson's disease.

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.

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. The most common place for discrimination is at work and school.

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.

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.

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.**

30% of people with epilepsy cannot control their seizures with medication.

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