

**MEDIA RELEASE, Monday 2 March 2020**

## **Purple Podcasts for Epilepsy**

*In their own words.*

**A new series of Pod Casts shed light on a condition that affects over 20,000 Tasmanians.**

**Epilepsy Awareness Month is a national campaign** to get more people talking about epilepsy: a neurological disorder of the brain that involves recurring seizures and can affect a person's ability to study, work, drive a vehicle and enjoy an active social life.

For the first time ever, 12 Tasmanians explain in a new Pod Cast series, what it's really like to live with epilepsy.

"Two years ago Epilepsy Tasmania created a photo-story exhibition to show people what living with epilepsy is like, but this year we decided to go a step further and let people listen for themselves," said Wendy Groot, CEO of Epilepsy Tasmania.

"Epilepsy is something most people don't talk about much," said Sam Ikin, Director of Ikin Media and creator of Epilepsy Tasmania's new Pod Cast series, My Journey.

"Epilepsy is something many of us don't understand and to be honest the thought of someone having a seizure freaks us out a little bit.

"My Journey is a series of Pod Casts that hopes to change this by helping us understand what epilepsy is really like, to demystify it and in turn make life better for people who are living with it."

My Journey Pod Cast series is being release at the start of Epilepsy Awareness Month along with a range of other events and activities people can take part in.

"Purple is the colour for epilepsy, so going purple is a way people can create their own opportunities to have conversations about epilepsy, learn about it, know what to do if we witness a seizure and let those with epilepsy know they have the support of everyday Tasmanians," said Wendy Groot, CEO of Epilepsy Tasmania.

"Some extra special activities we have created this month include a new photo-story exhibition in Launceston, an open garden event at Government House in Hobart, a finger-knitting challenge for all Tasmanian schools, and a purple bus called Miss Lila that is raising awareness of epilepsy and the 7-year-old girl with a severe form of the condition it was named after."

Throughout March, many buildings and landmarks will light up purple to remind us that one in 10 Australians experience a seizure during their life, and one in 26 of these go on to develop epilepsy, which is two or more unprovoked seizures.

"With most schools having at least one student with epilepsy, we are encouraging Tasmanian schools to join our Finger Knitting Challenge and win some great prizes," said Ms Groot.

"Schools just need to drape a school building or school item in purple finger knitting and share their results on social media using the [hashtag #FingerKnittingChallenge](#). On our YouTube channel we have a video that shows how quick and easy it is to finger knit.

- ENDS -

Watch 7-year-old Paige demonstrate how easy it is to finger knit in this short YouTube clip:

<https://youtu.be/GNomm6Brwjc> or scan the QR code to take you there.



**Register for the Finger Knitting Challenge here:**

<https://epilepsytasmania.org.au/finger-knitting-challenge/>

### Purple Month Activities

- Businesses and buildings all over Tasmania will be lighting up purple.
- Schools compete in our Purple Finger Knitting Challenge (more on this below!).
- My Journey photo-story exhibition in Launceston.
- 12 podcasts from Tasmanians about epilepsy.
- Individuals are running local awareness/fundraising events.
- Multiple social media competitions with prizes.
- Government House Open Garden for Epilepsy fundraising event.
- Bunnings BBQs.
- Cafe fundraisers.
- Television advertising campaign on WIN TV network.
- Movie advertising campaign at Hobart's State Cinema.

### MORE INFORMATION

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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**, 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 is 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