

OPINION PIECE

20 March, 2019

epilepsy
tasmania

TASMANIA'S VOICE FOR EPILEPSY

26th March is Purple Day March is Epilepsy Awareness Month

Purple Day is a worldwide grassroots campaign started in 2008 by nine-year-old Cassidy Megan from Canada to get more people talking about epilepsy.

For the past 11 years, Epilepsy Tasmania through its affiliation with Epilepsy Australia has been a proud official partner of Purple Day, using it to educate Tasmanians about epilepsy and challenge myths that still exist.

Epilepsy is a neurological disorder of the brain that involves recurring seizures. A seizure is a sudden and temporary change in the electrical activity in the brain, which can alter and impair awareness, thought, movement, sensation or behaviour. Every person's experience of a seizure is different. Following a seizure, the person may feel tired, confused, angry, sad or worried, and some may have been physically injured during the seizure.

The impact of epilepsy can be far greater than seizures alone. Epilepsy can affect a person's ability to study, work, drive a vehicle and enjoy an active social life, which can have negative financial and emotional consequences.

Sadly, around 300 Australians die annually as a direct result of their epilepsy due either to Sudden Unexpected Death in Epilepsy (the cause of SUDEP remains unknown), seizure-precipitated drowning or other accidents.

Misunderstanding in the community has also led to people with epilepsy feeling stigmatised, discriminated against and socially isolated. Although one-fifth of Tasmania's population is touched by epilepsy, the condition still has an unfortunate stigma that causes much hurt and frustration: 51% of Tasmanians with epilepsy have experienced discrimination as a result of their condition during the last year.

As a result of this stigma, it is largely a hidden condition and many people may not even realise they know someone with epilepsy. It is not uncommon for people to hide their epilepsy diagnosis or only disclose it reluctantly, because of fear of discrimination from employers, colleagues and even family.



This month the Minister for Education launched our nationally accredited training program, Epilepsy Smart Schools, to help schools better help students with epilepsy achieve their academic potential and develop positive social relationships. And we are working on a similar package to better support Tasmania's ageing population - a demographic that is increasingly developing epilepsy, due in part to head injuries sustained during falls.

Purple Day (26 March) is a chance for us to have a conversation 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.

More information is available on Epilepsy Tasmania's Facebook page or website www.epilepsytasmania.org.au

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MORE INFORMATION:

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ABOUT EPILEPSY

Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterised by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalised), and are sometimes accompanied by loss of consciousness and even incontinence. Characteristics of seizures vary and depend on where in the brain the disturbance first starts, and how far it spreads.

Epilepsy can develop at any age regardless of ethnicity or gender. One in 10 people experience a seizure during their life. One in 25 Australians will go on to develop epilepsy (2 or more unprovoked seizures).

20,000 Tasmanians have epilepsy and an additional 80,000 family members, colleagues and friends are affected in some way.

One-fifth of Tasmania's population is touched by epilepsy, yet the condition still has an unfortunate stigma that causes much hurt and frustration: **51% of Tasmanians with epilepsy have experienced discrimination as a result of their condition during the last year.** The most common place for discrimination is the workplace, followed closely by educational environments.

Epilepsy is not contagious. The most common type of epilepsy (affecting 6 out of 10 people with the disorder) is called idiopathic epilepsy and has no identifiable cause. The known causes of secondary epilepsy include a severe head injury, a stroke, an infection of the brain, or a brain tumour.

Epilepsy is generally successfully treated with anti-epileptic medications. **60%-70% of people diagnosed with epilepsy will gain seizure control with medication.** Others may continue to have seizures, but less frequently.

Epilepsy is one of the world's oldest recognised conditions, with written records dating back to 4000 BC. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disorder and their families.

Only one third of Tasmanians with epilepsy drive their own car. The remainder are forced to rely on public transport or taxis, the cost of which is often prohibitive given that **55% are on low incomes (half of these below the poverty line),** due in part to heightened medical expenses, and an inability of many to work full-time.

People with seizures tend to have more physical problems such as fractures and bruising from injuries related to seizures and epilepsy is **up to eight times more common in people with other health conditions** such as depression, dementia, heart disease and arthritis - further affecting seizure outcome and quality of life.

The risk of premature death in people with epilepsy is up to 3 times higher than the general population, with the highest rates found in low and middle-income countries and rural versus urban areas.

ABOUT EPILEPSY TASMANIA

Epilepsy Tasmania is a not-for-profit community-based organisation that has been improving the quality of life and community participation of Tasmanians affected by epilepsy for over 40 years. It is part of the national Epilepsy Australia coalition with members in every state and territory.

Epilepsy Tasmania is committed to bringing epilepsy out of the shadows, and break down the stigma and discrimination associated with epilepsy in Tasmania. Its overarching aim is to increase opportunities for those living with or affected by epilepsy and it will not be satisfied until Tasmanian children with epilepsy are receiving a good education, and Tasmanian adults are able to gain and maintain regular employment.

Its statewide services and support includes:



Workplace training



Smart Schools training.



Peer support service.



Raising awareness of epilepsy within a relaxed environments, in partnership with Blooming Tasmania.