

MEDIA RELEASE

Tuesday 23rd October, 2018

Sudden Unexpected Death in Epilepsy

Today is International SUDEP Action Day.

Sudden Unexpected Death in Epilepsy (SUDEP) occurs when a person with epilepsy dies suddenly and prematurely - and no other cause of death is found.

Each year, **more than 1 in 1,000 adults and 1 in 4,500 children with epilepsy die from SUDEP.** It is the 'cause' of around half of all epilepsy-related deaths with the remaining 50% related to drowning, accidents, status epilepticus (a continuous seizure lasting more than 30 minutes), or suicide.

Epilepsy Tasmania ambassador, Shaun Smith, sadly has a personal story of SUDEP:

"(When my wife, Tamieka, was diagnosed with epilepsy) we didn't consider the potential for SUDEP. We didn't really know much about it... but it happened."

"The loss of my wife, and the mother of our two young daughters, Lily and Harper, was shocking, devastating, unbelievable, unfair..."

"Our hope, as a family, is that we can inspire optimism and a positive outlook for those affected by epilepsy by continuing to raise awareness of epilepsy itself and the supports available to the broader Tasmanian community."

People with poorly controlled seizures are at a greater risk of dying from SUDEP, but we don't yet know what causes it. SUDEP occurs most often at night or during sleep when the death is not witnessed, leaving many questions unanswered. Current research into the possible causes of SUDEP focuses on problems with breathing, heart rhythm and brain function that occur with a seizure. More funded research is needed.

Epilepsy Tasmania CEO, Wendy Groot, said "While there is much we don't know about SUDEP, there are things that can be done to reduce the risks for people with epilepsy."

"The most important known way to lessen the risk of SUDEP is for people with epilepsy to try to ensure they have as few seizures as possible (particularly Generalised Tonic Clonic Seizures).

"This can include taking prescribed seizure medications consistently, identifying and avoiding seizure triggers, keeping regular appointments with your doctors and considering other epilepsy treatments, such as surgery, when medications are not working to control seizures," said Ms Groot.

"To reduce the risk of non-SUDEP epilepsy-related deaths, we encourage people to be as healthy as they can (diet, exercise, stress-reduction etc.), create a supportive network and be aware of potentially risky situations."

If you or someone you know has suffered a bereavement, please call Lifeline on 13 11 14 or Beyond Blue on 1300 22 4636.

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MORE INFORMATION:

Wendy Groot, CEO, Epilepsy Tasmania: 0427 044 074

www.epilepsytasmania.org.au

SPOKESPEOPLE:

- Wendy Groot, CEO, Epilepsy Tasmania: 0427 044 074
- Shaun Smith, Ambassador with a family experience of SUDEP.

ABOUT EPILEPSY

What is the Goal of SUDEP Action Day?

- Encourage people with epilepsy to learn about SUDEP and their individual risk
- Show what is currently being done to tackle SUDEP
- Promote ways people can manage their epilepsy to reduce their risk
- Highlight the need for more research into SUDEP to help save lives
- Raise awareness of SUDEP amongst the general public
- Honor the lives of all those who have died from the condition

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, and one in 25 Australians (20,000 Tasmanians) will go on to develop epilepsy (2 or more unprovoked seizures).

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.

Up to 70% of people with epilepsy can be successfully treated (i.e. their seizures completely controlled) with anti-epileptic drugs.

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.

In Tasmania, epilepsy remains widely misunderstood with **51% of Tasmanians experiencing discrimination as a result of their condition within the last 12 months**. The most common place for discrimination is the workplace, followed closely by educational environments.

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.

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.



Telephone-based peer support service.



Assurance that your donation will help Tasmanians affected by epilepsy.



In partnership with Blooming Tasmania to raise awareness of epilepsy within a relaxed environment.

Smart Schools resources and training.