

Our Aspirations

OUR PRIORITIES

- Creating a **supportive environment** for all Tasmanians living with or affected by epilepsy.
- Bringing epilepsy **out of the shadows**.
- Actively encouraging and facilitating the health sector to achieve **more research, better treatments and a cure**.
- **Raising awareness** of the risk of epilepsy among older Tasmanians.
- Ensuring Tasmanian children with epilepsy receive a **good education**, and adults are able to gain and maintain **regular employment**.
- Growing the **financial security and capacity** of Epilepsy Tasmania so we can continue our services.

OUR FUTURE DIRECTIONS

'Smart Schools: Educate Me, Include Me'

Partnerships with Primary Health Tasmania, General Practices & the National Disability Insurance Scheme

Older Tasmanians

Corporate Partnerships

Endowment Fund

Epilepsy Connect

Open Gardens for Epilepsy

Donate to the Lavender

Fundraising

A SNAPSHOT

20,000 Tasmanians develop epilepsy during their lifetime



80,000 family members, carers and friends are also affected

53% of Tasmanians living with epilepsy experience discrimination at some point in their life, and 51% of those within the last 12 months.



Only one third of Tasmanians with epilepsy drive their own car



An increasing number of older people are being diagnosed with epilepsy

55% are on low incomes - half below the poverty line



Epilepsy is up to **8 times more common** in people with other health conditions such as depression, dementia, heart disease and arthritis, which further affects seizure outcome and quality of life.



Epilepsy Tasmania Our Aspirations

2017



Our Aspirations

Epilepsy Tasmania recently commissioned a report - the first of its kind - to shine a spotlight on the disorder of epilepsy within the Tasmanian population.

"Epilepsy Tasmania: A Briefing Paper" (November 2016) reveals **new information that will better enable us to address the needs of the 20,000 Tasmanians who develop epilepsy during their lifetime**, and the 80,000 family members, carers and friends who are also affected in some way.

The World Health Organisation says the stigma associated with epilepsy is often more of a problem than the condition itself. Here in Tasmania, epilepsy sadly remains widely misunderstood with **53% of Tasmanians living with epilepsy experiencing discrimination at some point in their life, and 51% of those within the last 12 months**. The most common place for discrimination is the workplace, followed closely by educational environments.

We now know that **only one third of Tasmanians with epilepsy drive their own car** with the remainder forced to rely on public transport or taxis, the cost of which is often prohibitive given **55% are on low incomes - half below the poverty line** - due largely to heightened medical expenses and an inability for many to work full-time.

Tasmania is also seeing an **increasing number of older people being diagnosed with epilepsy**, and sadly it is up to **eight times more common in people with other health conditions** such as depression, dementia, heart disease and arthritis, which further affects seizure outcome and quality of life.

Despite these poor Tasmanian statistics, the positive outcome of this research is that Epilepsy Tasmania is **more committed than ever before to continuing to provide and increase our range of practical on-the-ground services to Tasmanians who are living with or affected by epilepsy**.

We are also **determined to bring epilepsy out of the shadows** and speak out against commonly held myths to ensure that community, workplace and educational institution attitudes are based on fact rather than fiction.

Please, spend a moment reading our aspirations and initiatives because we need your understanding and support to create these changes in Tasmania.

Wendy Groot
Chief Executive Officer



OUR PURPOSE

To improve the quality of life and community participation of every Tasmanian living with or affected by epilepsy.

OUR VALUES

- **Access** - Every Tasmanian living with or affected by epilepsy needs access to resources that allow them to experience the highest possible quality of life.
- **Inclusion** - Regardless of age, location or demographic, every Tasmanian living with or affected by epilepsy deserves to feel safe and connected.
- **Innovation** - We strive to improve the services available to Tasmanians living with or affected by epilepsy, and ensure that individual needs are met and assistance is provided when and where required.
- **Honesty** - Remaining a trustworthy organisation that delivers on promises, operates transparently and is sincere in its attempts to help assist Tasmanians living with or affected by epilepsy is a core value, genuinely important to us.

OUR PRIORITIES

- Creating a supportive environment in which health and community organisations can respond appropriately to the needs of all Tasmanians living with or affected by epilepsy, particularly in relation to education, employment, income, gender, transport and access to services.
- Bringing epilepsy out of the shadows by talking about epilepsy and speaking out against commonly held myths to ensure community, workplace and educational institution attitudes are based on fact rather than fiction.
- There is an urgent need for more research, better treatments and a cure. We will actively encourage and facilitate the health sector to achieve this.
- Raising awareness of the risk of epilepsy among older Tasmanians and of epilepsy as a co-morbidity to other health conditions.
- We will not be satisfied until all Tasmanian children with epilepsy are receiving a good education, and Tasmanian adults are able to gain and maintain regular employment.
- Growing the financial security and capacity of Epilepsy Tasmania so we can continue to expand the breadth and width of our services across Tasmania.

OUR FUTURE DIRECTIONS

- We are employing allied **Health Educators**, including a registered nurse, social worker and occupational therapist to work with the Education Department to further develop the **"Smart Schools: Educate Me, Include Me"** program within Tasmania.
- We are building **strong partnerships** with Primary Health Tasmania, General Practices and the National Disability Insurance Scheme to increase access to services and create more understanding and awareness of epilepsy.
- **Older Tasmanians:** We will prioritise raising awareness of the risk of epilepsy among older Tasmanians and epilepsy as a co-morbidity to other health conditions. Co-morbidity means that a person has more than one condition at the same time, which is very common in people with epilepsy.
- **Corporate partnerships:** We are prioritising the development of partnerships with corporate organisations to increase epilepsy awareness within the workplace and fundraise for Epilepsy Tasmania while further developing our 'charity of choice' model.
- **Endowment Fund:** We believe the philanthropic donations we are bequeathed should live on and continue to improve the quality of life and community participation of Tasmanians living with or affected by epilepsy. Our new Endowment Fund has been set up to preserve the donated capital and use the interest earned to provide additional Tasmanian epilepsy services.
- **Epilepsy Connect:** Our innovative free telephone service provides peer support to people living with or affected by epilepsy, reflecting current evidence that talking with others who've had similar experiences significantly and positively results in feeling more understood and less alone.
- **Open Gardens for Epilepsy:** In partnership with Blooming Tasmania, gardens across the state will publicly open throughout the year to increase epilepsy awareness and raise funds for Epilepsy Tasmania.
- **Donate to the Lavender:** Our new tagline has been designed to counteract the increasing number of national charities collecting donations in Tasmania but not necessarily providing services here. As a proud Tasmanian charity, the Donate to the Lavender logo is our assurance that funds raised in Tasmania stay in Tasmania.
- **Fundraising:** Christmas Appeal; we are selling digital Christmas e-cards online, and encouraging people to light up their homes and gardens with Christmas decorations. Purple Month; throughout March there will be a number of purple-themed events, activities and merchandise sales to increase awareness of epilepsy and raise funds for Epilepsy Tasmania.