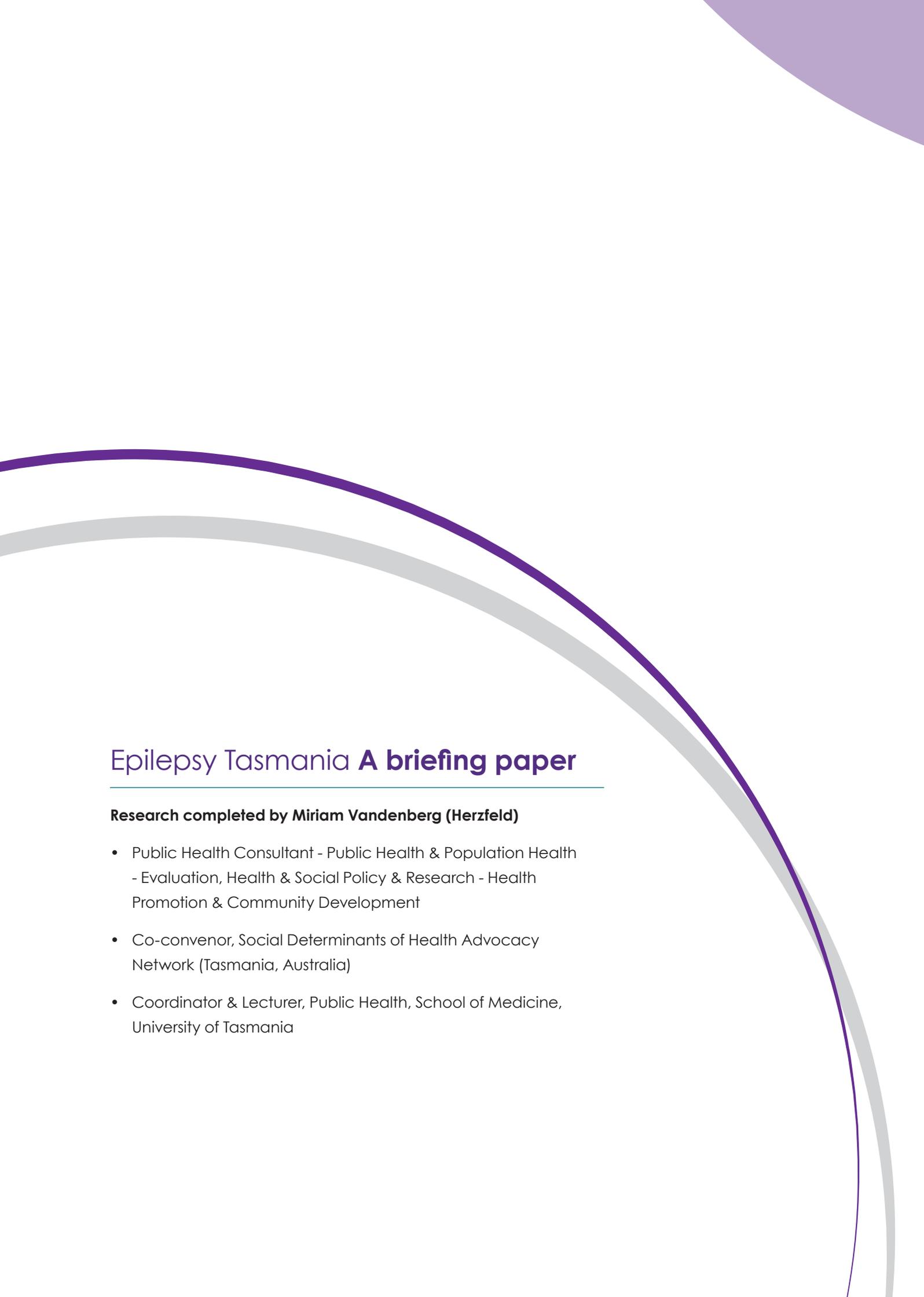




# Epilepsy Tasmania A briefing paper

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epilepsy  
tasmania



## Epilepsy Tasmania **A briefing paper**

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# A briefing paper

## Executive Summary

Commissioned by Epilepsy Tasmania, this report is the first of its kind to shine a spotlight on the disorder of epilepsy within the Tasmanian population.

The findings of this report will enable Epilepsy Tasmania to better address the needs of the 20,000 Tasmanians who will develop epilepsy during their lifetime, as well as the four-times this number of people who are affected in some way such as family, carers and friends.

For instance, we can now confirm the World Health Organisation's statement that the stigma associated with epilepsy can be more of a problem than the condition itself. Here in Tasmania epilepsy remains widely misunderstood, with 53% of Tasmanians living with epilepsy experiencing discrimination at some point in their life, and of those, 51% in 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 with half of these below the poverty line, due in part to an inability of many to work full-time and with heightened medical expenses.

Interestingly, we are now seeing an increasing number of older people being diagnosed with epilepsy. Epilepsy Tasmania would like to see further research into the cause/s of this shift given Tasmania's large ageing population. Epilepsy is also 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.

A direct result of this report will be our focus on raising awareness of the risk of epilepsy among older Tasmanians and of epilepsy as a co-morbidity to other health conditions. There is an urgent need for more research, better treatments and a cure, and we will actively encourage and facilitate the health sector to achieve this.

Epilepsy Tasmania is committed to bringing epilepsy out of the shadows, and our new strategic plan and mission statement reflect our determination to break down the stigma and discrimination associated with epilepsy in Tasmania.

Our overarching aim is to increase opportunities for those living with or affected by epilepsy and we 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.

Wendy Groot  
Chief Executive Officer

# A briefing paper about **Epilepsy in Tasmania**

**This paper was prepared for Epilepsy Tasmania in August 2016. It provides a brief scan of some of the public information, research findings and data that are relevant to epilepsy in the Tasmanian context. It is designed to provide Epilepsy Tasmania with a starting point for further discussion and planning action.**

## **What is epilepsy?**

Epilepsy is a very common and serious condition that affects nerve cell activity in the brain. This results in unpredictable, recurring episodes known as *seizures*.<sup>1</sup>

A seizure is a disturbance of movement, feeling or consciousness and involves sudden, inappropriate and excessive electrical discharges in the brain.<sup>2,3</sup> Seizures manifest differently for different people.

For more information visit the Epilepsy Foundation website: <http://www.epilepsy.com/learn/epilepsy-101/what-seizure> and <http://www.epilepsy.com/learn/epilepsy-101/what-happens-during-seizure>.

Epilepsy is a chronic condition. This means people generally live with epilepsy for a period of time or for their entire lives, and it affects quality of life.<sup>4</sup>

The World Health Organisation (WHO) has recognised epilepsy is one of the world's most common serious disorders of the brain.<sup>5</sup>

With appropriate treatment, in most instances, epilepsy can be managed and long-term harm can be prevented. Epilepsy responds to medication in approximately 60-70% of people so they no longer experience seizures.<sup>6</sup>

## **How many Tasmanians have epilepsy?**

Based on figures provided by a number of studies and research papers<sup>7,8,9,10</sup> the number of Tasmanians with epilepsy at any one time is estimated to be 5,000 (1% of the population).

It has been further estimated that as many as four times this many Tasmanians (4% of the population) will have epilepsy at some time in their lives (up to 20,000 Tasmanians).<sup>11,12</sup> This correlates to the figure quoted on the Epilepsy Tasmania website: 1 in 25 Australians will develop epilepsy during their lifetime (<http://www.epilepsytasmania.org.au/>).

It is estimated that between 260-360 Tasmanians are diagnosed with epilepsy each year.<sup>1</sup>

Non-epileptic seizures can result from a range of other health conditions. 10% of Australians will have a seizure during their lifetime.<sup>13</sup>

Research has shown that almost 60% of people living with epilepsy (in a study involving Tasmanian participants) had their first seizure under 12 years of age and that the likelihood of experiencing seizures decreased with age.<sup>14</sup> This study also found that 1 in 10 people with epilepsy experienced more than 25 seizures a month.<sup>15</sup>

People who are diagnosed with epilepsy vary with age, with high rates in early childhood, low levels in early adult life and a second peak in people aged over 65 years. In recent years, there has been a fall in the number of children affected as well as a sharp rise in epilepsy in the elderly.<sup>16</sup> The over 65-years age group is now most at risk of epilepsy.<sup>17,18</sup> Research in the Tasmanian community supports this finding.<sup>19</sup> The researchers suggest that their findings have important clinical and public health implications for populations with aging demographics.

<sup>1</sup> Based on annual incidence in developed countries of 50-70 cases per 100,000 of the population (Brodie MJ, Schachter SC and Kwan P, 2009, Op-Cit, pg 9).

# What causes epilepsy?

Both the Epilepsy Foundation and Epilepsy Australia provide information on their websites about what causes epilepsy.

In summary it is known that:

- Structural abnormalities in a developing brain, lack of oxygen during birth or a stroke, brain tumours, head injuries, and infections such as meningitis or encephalitis can cause epilepsy;
- Diabetes and Alzheimer's disease can lead to epilepsy; and
- It can be hereditary however the risk of passing on epilepsy to children is low.<sup>20, 21, 22</sup>

We don't, however, yet know what causes epilepsy in 50% of people with the condition.<sup>23, 24</sup>

## Prevention, diagnosis, treatment, co-morbidity, mortality

### Prevention

For many people living with epilepsy the condition could not have been prevented - though it can be successfully managed. However, sometimes there are ways to prevent epilepsy. For example,

- Preventing traumatic brain injuries;
- Lowering the chances of stroke and heart disease by living a healthy life;
- Getting vaccinated to lower the chances of infection that can sometimes lead to epilepsy; and
- Staying healthy during pregnancy.<sup>25, 26, 27</sup>

Seizures may be triggered by a range of factors including alcohol, diet, infections and illness, lack of sleep, menstruation, missed medication, other drugs, unusual stimuli, severe changes in temperature and stress.<sup>28</sup>

### Diagnosis

Diagnosis of epilepsy can be a drawn out process, although the presence of recurring seizures is often the determining factor.<sup>29</sup> The Australian Chapter of the International Bureau of Epilepsy in reporting on a study (involving Tasmanian participants) stated that 51% of cases were diagnosed within 3 months of their first seizure but 42% took anywhere between 3 months and over 5 years to be diagnosed with epilepsy.<sup>30</sup>

Generally, seizures fall into two categories: primary generalised seizures and focal seizures. The difference between these two types is in how they begin. There are many types of generalised seizures, some convulsive, others non-convulsive.<sup>31</sup>

There are numerous epilepsy syndromes and each has its own symptoms, seizure types, causes, methods of diagnosis, outcomes and management. Accurate identification of the epilepsy syndrome will ensure the most appropriate treatment.<sup>32</sup>

### Treatment

Epilepsy can't be cured but most types of epilepsy can be controlled through anti-epileptic medication.

It can take time and the trial of a number of medications in order to find the right one/s to provide seizure control for a person with epilepsy.

Research is being conducted to find better and more cost effective treatments for epilepsy, including clinical research into the impact of cannabinoid (CBD) use in children with severe and medication resistant epilepsy.<sup>33, 34, 35</sup>

A study of the prevalence and demographic distribution of treated epilepsy in Tasmania, found that 86% of the estimated total possible cases in Tasmania were treated; that treatment was lower in women, greater with increasing age, similar in the three main geographic regions, and similar with socioeconomic status of postcode of residence.<sup>36</sup>



## Co-morbidity

Co-morbidity means that a person has more than one condition at the same time. This is very common in people with epilepsy.

Research has found that conditions and illnesses including depression, anxiety, dementia, migraine, heart disease, peptic ulcers, and arthritis are up to eight times more common in people with epilepsy than in the general population.<sup>37</sup>

The presence of co-morbidity can negatively affect seizure outcome and quality of life. More research is needed to better understand and treat people with co-morbidities.<sup>38</sup>

## Mortality

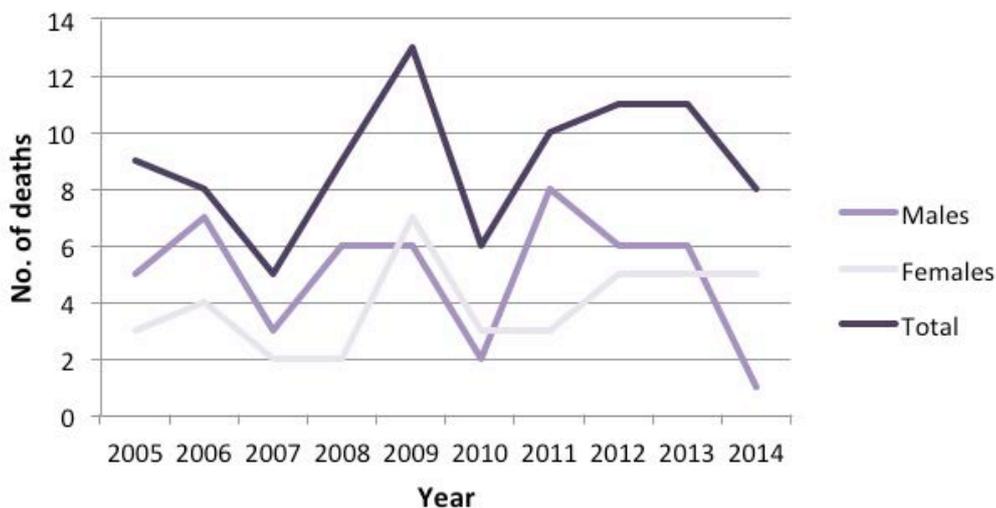
Studies suggest that mortality (death) rates among people with epilepsy are 2–3 times higher than the general population.<sup>39, 40</sup>

A report on avoidable mortality in Victoria found that epilepsy was ranked in the top five causes of avoidable deaths in the 5–29 age group.<sup>41</sup>

It is widely reported that around 300 Australians die from epilepsy each year.<sup>42, 43</sup>

**Figure 1** illustrates the number of epilepsy deaths in Tasmania from 2005-2014.<sup>44</sup>

**Figure 1: Epilepsy deaths in Tasmania (2005-2014)**



Epilepsy-related causes of death account for 40% of mortality in persons with epilepsy and include the following:

- Death due to the underlying neurologic disorder in symptomatic epilepsy;
- Sudden unexpected death in epilepsy (SUDEP);
- Accidents during epileptic attack (i.e. trauma, drowning, burning, choking);
- Status epilepticus - when a seizure lasts too long or when seizures occur close together and the person doesn't recover between seizures;
- Suicide; and
- Treatment-related death.<sup>45</sup>

The most common cause of death for people with epilepsy is SUDEP or Sudden Unexpected Death in Epilepsy. It occurs in 1 out of every 1,000 people with epilepsy and is more common among people with poorly controlled epilepsy. SUDEP rarely occurs in children. No one is sure about the cause of death in SUDEP.<sup>46</sup>

One study reported that the risk of drowning in people with epilepsy is raised 15- to 19-fold compared with people in the general population.<sup>47</sup>

## Social determinants of epilepsy

A paper on this topic that is worth reading is: Szafarski M, 2014, 'Social determinants of health in epilepsy', *Epilepsy & Behaviour*, 41: 283-289.

A summary of some of the key points from this paper, with supporting research from elsewhere, is provided below.

The key social determinants of health relevant to epilepsy are:

- Socio-economic variables
- Race/ethnicity
- Age
- Gender
- Contextual factors such as epilepsy-related public policy, that may lead, for example, to poverty, social stigma and discrimination
- Other social and psychosocial factors, such as living and employment situation, treatment adherence, social support, or health system factors.<sup>48</sup>

**Low socioeconomic status** and **disadvantaged social status** have been associated with a higher risk of epilepsy, more hospitalizations and emergency room visits (versus neurology services), antiepileptic drug non-adherence, and a lower rate of epilepsy surgery.<sup>49</sup>

**Age** is not only a demographic variable but it is also associated with social roles and social position, which in turn is related to access to resources. A young or older person's ability to engage in society (e.g. school, workforce, community) can be negatively impacted by epilepsy.<sup>50</sup>

**Women** appear to have more problems with seizure recurrence and have a higher utilization of neurology versus general services and a higher rate of hospitalization compared with men. However, children with epilepsy have similar rates of surgery regardless of gender.<sup>51</sup>

The WHO reported that **stigma** associated with epilepsy is more of a problem than the condition itself.<sup>52</sup> "Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows."<sup>53</sup> Epilepsy is widely misunderstood and has been shown to lead to fear, secrecy, stigmatisation and the risk of social exclusion.<sup>54, 55, 56</sup>

In a 2007 study involving Tasmanians living with epilepsy, 53% of participants had experienced discrimination at some point and of those, 51% had experienced discrimination in the last 12 months.<sup>57</sup> The most common place for discrimination was the **workplace**, followed closely by **education institutions**.<sup>58</sup> In addition, 48% of respondents reported perceptions of unfair treatment as a result of their epilepsy.<sup>59</sup>

Discrimination in the workplace has been identified as a key issue of concern,<sup>60, 61</sup> particularly because **labour force participation** among people with epilepsy is lower than the general population.<sup>62, 63</sup> Epilepsy can have significant impact on a person's **quality of life** and ability to undertake day-to-day activities such as working or **studying**. The Joint Epilepsy Council of Australia, in reporting on the findings of a study involving Tasmanians, found that only 12% of study participants were working full time.<sup>64</sup> For over 33% of those with epilepsy, the condition also had a significant impact on their ability to participate in education, play sport, exercise and socialise.<sup>65</sup> The Australian Epilepsy Longitudinal Study found that more than one quarter of research participants had less than Year 11 education.<sup>66</sup>

The same study found that the majority of people with epilepsy were of working age but 55% were on **low incomes** and half of them were on incomes below the **poverty** line.<sup>67</sup> These income levels created high levels of financial distress. It is worth noting that having a good income did not necessarily help people with epilepsy to deal better with the social and emotional impact of their condition.<sup>68</sup>

People with epilepsy live with significantly higher levels of **psychological distress** than the general population.<sup>69, 70</sup> An Australian study involving Tasmanians living with epilepsy found that



67% of study participants reported living with high and very high levels of psychological distress.<sup>71</sup>

As a comparison, the 2014-15 National Health Survey reported that 13.5% of persons aged 18 years and over in Tasmania reported experiencing high or very high levels of psychological distress.<sup>72</sup> High rates of psychological distress has been associated with higher rates of **health service utilization**.<sup>73</sup>

**Access to services** can be challenging for people living with epilepsy. In 2007, the Joint Epilepsy Council of Australia (in a study involving Tasmanians) found that respondents living in metropolitan areas had better access to both specialists and GPs compared to their regional peers. 41% of respondents living in regional areas had either no or poor access to a specialist. Nearly the same amount (36%) of respondents living in regional areas also reported no or poor access to a GP.<sup>74</sup> The Australian Epilepsy Longitudinal Study found that a substantial proportion (32%) of people with epilepsy reported that they had experienced a lack of understanding from Government bodies that they had turned to for assistance.<sup>75</sup>

Research involving Tasmanians living with epilepsy has found that only one third of people with epilepsy **drive their own car** and of this group, over half had their driving license suspended at some time.<sup>76</sup> People living with epilepsy are often forced to use **public transport or taxis**. The cost of taxis in particular can be a cause of concern for people with epilepsy. Australian research involving Tasmanians has found that 40% of people with epilepsy avoided public transport either occasionally, sometimes or always.<sup>77</sup> The researchers state that "this is doubtless due to a number of factors from the inability of many people with epilepsy to work full time and their consequently lower incomes, the generally heightened costs of living with chronic illness, fear of having a seizure while on public transport, and the inadequacy [as well as the national inconsistency] in travel assistance for people with epilepsy."<sup>78</sup>

There are complex relationships among social determinants of health in epilepsy, which remain poorly understood and hamper efforts to address and eliminate disparities in epilepsy care and outcomes.<sup>79</sup>

## How should we be talking about epilepsy?

There are numerous websites that provide information about commonly held myths and how to respond to these including:

- <http://www.epilepsy.org.au/sites/default/files/Seizure%20Smart%20-%20Exploding%20Myths%20About%20Epilepsy.pdf>
- <http://www.epilepsy.com/learn/epilepsy-101/facts-about-seizures-and-epilepsy>  
<http://www.epilepsy-ohio.org/about-epilepsy/characteristics/myths-about-epilepsy/>
- <http://www.epilepsy.ca/myths--misconceptions.html>

## We should talk about epilepsy and speak out against commonly held myths.

- Epilepsy is a common neurological condition that affects people from all walks of life.
- Epilepsy is not a mental health condition and does not cause mental illness, and it is not a disability.
- Epilepsy is not due to the effects of drugs or alcohol.
- Epilepsy is not contagious.
- All age groups can be affected by epilepsy but the young and elderly are most at risk. The incidence of epilepsy in older people is higher than in children.
- Even with today's medication, epilepsy cannot be cured. There is still an urgent need for more research, better treatments and a cure.
- Most people with epilepsy can do the same things that people without epilepsy can do.
- The correct first aid is simple:
  - Just gently roll the person on one side, support their head, protect from injury, and make sure their breathing is okay.
  - A seizure will run its course and restraint will not stop it or slow it down – so don't restrain a person having a seizure.

- It isn't possible to swallow your own tongue.
- There is nothing you can do to stop a seizure. The best thing to do is stay with the person and talk to them calmly. Ensure they are safe and be supportive and reassuring once they are aware of their surroundings.
- You can die from epilepsy. While death in epilepsy doesn't happen frequently, epilepsy is a very serious condition and individuals do die from seizures.
- Most women with epilepsy do not have any problems with conception or pregnancy and the majority of babies are born healthy. However, women considering pregnancy should discuss this with their neurologist.

## Public perceptions

Myths, misinformation and misperceptions regarding epilepsy have a long history and are still prevalent throughout society. A recently published systematic review concluded that while intervention studies were generally effective in improving attitudes, many were targeted to healthcare and education settings, were time-intensive, and impractical for broad general population implementation.<sup>80</sup>

A paper that is worth reading on this topic is *Epilepsy Across the Spectrum: Promoting Health and Understanding* (<http://www.ncbi.nlm.nih.gov/books/NBK100609/>). It states:

*"Although some surveys suggest that attitudes toward people with epilepsy have improved over time, it is not certain how contemporary attitudes compare and whether the overall improvements have affected behavior. People acquire information about epilepsy from many sources, including family and friends, entertainment and news media, the Internet, and social media. However, the accuracy of these sources is variable... Actions needed to improve public awareness and knowledge include informing journalists as well as writers and producers in the entertainment industry; engaging people with epilepsy and their families in public awareness efforts; coordinating public awareness efforts and developing shared messaging; and ensuring that all campaigns include rigorous formative research, considerations for health literacy and audience demographics, and mechanisms for evaluation and sustainability."*

## Suggested priority areas for Epilepsy Tasmania

Based on the above summary of information, it is suggested that the following issues be further considered by Epilepsy Tasmania:

- How to bring epilepsy 'out of the shadows', engage with Tasmanians living epilepsy and break down stigma and discrimination;
- How to generate further research to better understand the needs of Tasmanians who are living with epilepsy;
- How to translate research findings from interstate and overseas to the Tasmanian context;
- How to act on the social determinants of epilepsy particularly in relation to education, employment, income, gender, transport and access to services; and
- How best to raise awareness of the risk of epilepsy in older Tasmanians and for those with related co-morbidities, with a focus on preventative action.



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- <sup>76</sup> Epilepsy Council of Australia, 2007, Op-Cit.
- <sup>77</sup> Ibid.
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