Epilepsy – A Focus on Tasmania



TASMANIA'S VOICE FOR EPILEPSY

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This report provides current insight into epilepsy within Tasmania in comparison to Australia and the rest of the world.

In 2019, Epilepsy Tasmania commissioned Elida Meadows Word Works¹ to research the condition of epilepsy within the state of Tasmania. This report has been written with direct reference to this Tasmanian research, the national research undertaken by Deloitte Access Economics in 2019 and global research of the World Health Organisation.²

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Epilepsy Tasmania acknowledges and pays respects to the Tasmanian Aboriginal Community as the traditional and original owners, and receives funding from the Crown, through the Department of Health.





Epilepsy Tasmania is a not-for-profit community organisation improving the quality of life of Tasmanians with epilepsy, and those around them, through education, coordination and support. It relies upon public donations and funding from the Department of Health and Human Services, Tasmania.

¹ Elida Meadows Word Works: ABN 86 558 675 749. Elida Meadows has more than 30 years' experience as a researcher across the social sciences spectrum from heritage and history to mental health, multicultural and AOD issues. She has worked in community development in the Blue Mountains region of NSW and most recently as Development Officer in the Industry Development Unit at TasCOSS. She has a strong understanding of the need to work across whole communities to achieve results for people who are often marginalised by illness, disability and difference.

² Epilepsy: a public health imperative, WHO, 2019

Introduction

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. For every person with epilepsy, there are approximately 4 others providing care and support. This means around 100,000 Tasmanians are directly affected by epilepsy.

The prevalence of epilepsy in Australia may be as high as 4% of our population. This represents 250,000 Australians who will develop epilepsy at some stage in their lives with approximately 20,000 of these located in Tasmania.³

In Australia, there is approximately a 10% population prevalence of individuals who have experienced one seizure during their lifetime.⁴ Epilepsy is generally diagnosed when an individual experiences more than two seizures, more than 24 hours apart.⁵

Epilepsy has a bimodal age distribution with peaks in the youngest individuals and those over 60 years of age.

In Tasmania in particular, the number of people with epilepsy is expected to increase further due to a number of factors:

- An older than average population.
- General rising life expectancy.
- An increasing proportion of people surviving incidents that often lead to epilepsy (birth trauma, brain injury and infections and stroke).

Epilepsy is not a single disorder. It has a variety of causes, ranging from genetic, metabolic, infectious, structural, immune and unknown. With its diversity of types and causes, its variance in severity and impact from person to person, and its range of co-existing conditions, **it is a spectrum disorder.**

Epilepsy carries neurological, cognitive, psychological and social consequences and accounts for a significant proportion of the world's burden of disease: **it is the second most burdensome neurological condition after dementia**, accounting for 14.6% of the burden of disease of all neurological conditions.⁶

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. However, in around 40% of cases the cause cannot be

³ Epilepsy Australia 2018, Epilepsy Explained. Available at: http://www.epilepsyaustralia.net/epilepsyexplained, accessed March 2019

⁴ Hauser, W.A., Annegers, J. F., & Rocca, W. A. (1996). Descriptive epidemiology of epilepsy: Contributions of population-based studies from Rochester, Minnesota. Mayo Clinic Proceedings, 71(6). 576-586

⁵ Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, H., Elger, C. E., Engel, J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D., Lee, B. I., Mathern, G., Moshe, S., Perucca, E., Scheffer, I., Tomson, T., Watanabe, M., & Wiebe, S. (2014). A practical clinical definition of epilepsy. Epilepsia, 55(4):475-482.

⁶ Australian Institute of Health and Welfare 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

determined and the individual may never understand why they have the condition.

For those who live with epilepsy, **the condition can be debilitating and have serious adverse effects on their day to day living, personal life, ability to maintain employment, and quality of sleep.** It may also pose serious dangers due to the unpredictable nature of seizure events and their related risks.

Epilepsy is associated with a number of comorbidities which can worsen the impact on people living with the condition and those who provide care to them. In particular, **epilepsy has been found to increase the likelihood of an individual experiencing depression and anxiety, fractures, motor vehicle accidents, cardiovascular disease, sleep disorders, neurodevelopmental disorders, and migraines.**

Epilepsy - A Focus on Tasmania is the second set of research to be independently commissioned by Epilepsy Tasmania. Its previous research **Epilepsy Tasmania: A Briefing Paper 2016** provided Tasmania with a benchmark from which to compare the extent that epilepsy affects Tasmanians in comparison to other Australian states and the rest of the world.

Epilepsy Tasmania concurs with the World Health Organisation that it is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

The time to act is now. Urgent actions are needed in Tasmania to:

- Promote epilepsy as a public health priority to reduce its burden.
- Improve public attitudes and promote the protection of the rights of people with epilepsy.
- Invest in health and social care systems to improve accessibility to epilepsy care.
- Prevent acquired epilepsies through improved care for common causes.
- Increase the priority of epilepsy for research agendas.

Raising epilepsy on the public health agenda and achieving these priorities cannot be done by Epilepsy Tasmania alone. This report is a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination.

Executive Summary

"...it is doubtful if any medical condition has been so universally neglected due to a combination of social stigma, low profile and lack of resources, as epilepsy."

World Health Organisation ⁷

Epilepsy Tasmania's 2016 report⁸ was the first to shine a spotlight on the disorder of epilepsy with the Tasmanian population. This 2019 report⁹ reflects on changes since then and reviews the current economic impact of epilepsy within Tasmania; our social responses; research; and the way forward. This report also voices areas of particular concern to the 20,000 Tasmanians who have epilepsy and the additional 80,000 people who are affected by it.¹⁰

Estimating the prevalence of epilepsy can be complicated due to the complex nature of epilepsy and the stigma that can skew results because respondents don't feel comfortable disclosing their epilepsy. That said, during the last four years Epilepsy Tasmania has seen an increase in the number of Tasmanians willing to disclose their condition to employers and educational institutions and we attribute this to a significant increase in public awareness campaigns. A reduction in the stigma associated with epilepsy is conversely resulting in an increase in the number of reported discrimination cases, so Epilepsy Tasmania's public awareness campaigns will now focus on reducing school and workplace discrimination.

Tasmania has the highest prevalence of epilepsy in Australia¹¹ and the condition is estimated to impose a greater burden on Australia's health system than prostate cancer, and one similar to that of lung cancer and Parkinson's disease.

The economic impact of epilepsy is high and often neglected in public health agendas:

- Epilepsy is one of the most common neurological diseases.
- Risk of premature death in people with epilepsy is three times that of the general population;
- Half of adults with epilepsy have at least one other health condition.
- Depression and anxiety from epilepsy make seizures worse and reduce quality of life;
- Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.

I hope this report will re-energize and guide government, policy-makers and stakeholders as they seek to reduce the economic and social impact of epilepsy in Tasmania.

Wendy Groot

CEO, Epilepsy Tasmania

⁷ ILAE/ IBE/ WHO (1997), Out of the shadows: A global campaign against epilepsy, Geneva: World Health Organisation.

⁸ Epilepsy Tasmania: A Briefing Paper 2016

⁹ Epilepsy - A Focus On Tasmania, 2019

^{10 (}family, carers, colleagues, friends etc.)

¹¹ Deloitte Access Economics estimates

Epidemiology

Epidemiology is the medical discipline which studies the dynamics of a medical condition in the general population. It concerns the numbers of people with the condition, those at risk and what the outcomes of the condition are. Better understanding of the epidemiology of epilepsy is a prerequisite for improving epilepsy care.

Prevalence and Incidence

The total estimated incidence of epilepsy in Australia is 14,603 new cases each year.¹²

There are many types of epilepsy. Scientific organisation, The International League Against Epilepsy (ILAE) states:

Epilepsy is more properly known as "the epilepsies", as there are dozens of different seizure disorders and syndromes in the International Classification. Most basically, however, epilepsy is classified into three main categories: Focal, Generalized or Unknown Onset. The category is determined by the location of the seizure activity within the brain at the beginning of the seizure. Seizures may also be described as either motor or nonmotor, depending on whether or not muscle movement is involved. In people younger than age 40, about 50% of new cases of epilepsy are generalized seizures, and 50% are partial.

The National Health Survey's (NHS) age and gender-specific prevalence rates were applied to the Australian Bureau of Statistics (ABS) population data to estimate the total prevalence of epilepsy in Australia during the year 2019-20: a total of **142,740 Australians will be living with active epilepsy** during this period, of which 52% are male and 48% are female. Active epilepsy is defined by the World Health Organisation (WHO) as requiring regular treatment with anti-seizure medicines or when the most recent seizure has occurred within the last 5 years.

Age group	Prevalence rate (%, males)	Prevalence (total, males)	Prevalence rate (%, females)	Prevalence (total, females)	Total
0-14	0.4	9,854	0.4	9,342	19,196
15-24	0.4	6,686	0.4	6,369	13,055
25-34	0.3	5,708	0.1	1,915	7,623
35-44	0.5	8,419	0.8	13,618	22,037
45-54	1.0	15,764	1.0	16,386	32,150
55-64	0.6	8,610	0.7	10,513	19,123
65+	1.0	18,853	0.5	10,704	29,557
Total	0.59	73,893	0.54	68,847	142,740

Table 2.1: Prevalence of epilepsy in Australia by age and gender, 2019-20

Source: Deloitte Access Economics estimates based on ABS 4364.0.55.001 - National Health Survey: First Results 2017-18 (2018) and ABS 3222.0 - Population projections, Australia, 2017-2066 (2018). Note: Figures may not sum to total due to rounding.

12 Deloitte Access Economics estimates

Epilepsy is imposing a greater burden in Tasmania than elsewhere in Australia, due to differences in population age and gender distributions.

Jurisdiction	Share of total population (%)	Implied prevalence
NSW	31.99	45,634
VIC	25.99	36,775
QLD	20.05	28,740
WA	10.32	14,727
SA	6.87	10,044
TAS	2.09	3,110
АСТ	1.69	2,344
NT	0.99	1,339
^Other territories	0.02	28
Total	100	142,740

Table 2.2: Prevalence of epilepsy in Australia by jurisdiction, 2019-20

Source: Deloitte Access Economics estimates based on ABS data (2018). Note: The prevalence differs by state due to the age and gender profiles of the various jurisdictions.

^Note: ABS population projections for Australia include Other Territories, comprising of Christmas Island, Cocos Islands, Jervis Bay Territory and Norfolk Island. While the 28 cases attributable to these territories are included in the Australia-wide estimates, they are not recognised for the purposes of the jurisdiction breakdown.

- One in 26 Australians will be diagnosed with epilepsy during their lifetime.¹³
- One in 200 school students has active epilepsy.¹⁴
- 23% of Australians with epilepsy are under 24 years of age; 56% are aged 25 to 64 years; and 21% are over 65 years of age.¹⁵
- 52% of Australians with epilepsy are male.

¹³ Estimating Risk for Developing Epilepsy, A population-based study in Rochester Minnesota, DC Hesdorffer, G Logroscino, E.K.T Benn, et al 2011.

¹⁴ Epilepsy Smart Schools, https://www.epilepsysmartschools.org.au/

¹⁵ Deloitte Access Economics

Diagnosis and Prognosis

Although commonly thought that epilepsy always and only involves convulsions, there are in fact around 40 different types of epilepsy seizures and epilepsy-syndromes and many are not convulsive. Seizures can vary from the briefest lapses of attention, confusion or unusual behaviours to falls or convulsions. Seizures can also vary in frequency, with some people having less than one per year and others having several per day.

Many people with epilepsy lead productive lives, but some will be severely impacted by their epilepsy. Although the majority of people diagnosed with epilepsy have seizures that can be controlled with drug therapies and surgery, as many as 40% have drug-resistant epilepsy.

It is important to note:

- Seizures can begin at any age, but epilepsy is most frequently diagnosed during early childhood, adolescence and people over 65 years of age.
- Epilepsy is not necessarily a lifelong disorder and many people outgrow or have a long-term remission from seizures.

Risk of Developing Epilepsy

Several known risk factors for developing epilepsy include:16

- A head injury such as in a car accident, trauma or serious fall.
- Stroke or brain haemorrhage.
- Lack of oxygen to the brain for a prolonged period (birth trauma, cardiac arrest, drowning, drug overdose).
- Brain infections (for example, meningitis, encephalitis or brain abscess).
- Brain abnormalities or malformations, particularly during childhood, prenatal development and birth.
- Brain tumours, an uncommon cause in children but more common in adults and the elderly.
- Genetic factors, such as having a parent with epilepsy.
- Degenerative conditions affecting the brain (such as dementia or Alzheimer's disease)

Seizure Triggers

There are a range of factors associated with seizure occurrence in people with epilepsy, including:

- Alcohol consumption, due to interaction with medications.
- Dietary factors, such as high levels of caffeine.
- Infections or illness, particularly in children.

16 Ibid.

- Sleep deprivation, especially due to large fluctuations in one's sleep pattern.
- Medication adherence, or lack thereof.
- Use of other medications or recreational drugs.
- Photosensitivity, severe temperature changes and high-stress levels for certain individuals.

Social and Cultural Issues

Stigma and Discrimination

In all parts of the world, people with epilepsy are the target of discrimination and human rights violations.

Discrimination and stigma still adversely affect Australians living with epilepsy, according to a new World Health Organisation report, Epilepsy: A Public Health Imperative.¹⁷ It identifies stigma and discrimination as key barriers to quality of life for Australians living with epilepsy who may fear seeking the diagnosis and care they require.

By law, people with epilepsy in Australia cannot be denied employment or access to any educational, recreational, or other activity because of their epilepsy. However, significant barriers still exist for people with epilepsy at school and at work.

Over the last four years Epilepsy Tasmania has seen an increase in the number of Tasmanians willing to disclose their condition to employers and educational institutions which it attributes to increased public awareness campaigns. Yet, despite Australia being a high-income developed nation, the WHO report revealed **47 percent of employed Australians living with epilepsy report unfair treatment in the workplace.**¹⁸ In Tasmania, this figure is 52 percent,¹⁹ anecdotally attributed to increasing awareness that epilepsy does not mean having to tolerate discrimination, rather than an increase in the actual amount of discrimination occuring.

People with hidden disabilities or conditions such as epilepsy, are among the most vulnerable in any society. While the vulnerability of people living with epilepsy can partly be attributed to the disorder itself, the stigma associated with the disorder brings a susceptibility of its own. Stigmatisation leads to discrimination and people with epilepsy experience prejudicial and discriminatory behaviour in many spheres of life and across many cultures.

In 2016 and 2019, Epilepsy Tasmania surveyed Tasmanians with epilepsy and their carers and ascertained their main challenges to be almost exclusively related to social, cultural and economic issues. Lack of public awareness and supportive environments free of stigma and discrimination are among their most pressing concerns.

¹⁷ Epilepsy, A Public health imperative, World Health Organisation, 2019.

¹⁸ Bellon M, Walker C, Peterson C, Cookson P. The "E" word: epilepsy and perceptions of unfair treatment from the 2010 Australian Epilepsy Longitudinal Survey. Epilepsy Behav. 2013;27(1):251-6.

¹⁹ Epilepsy Tasmania's Health and Wellbeing Surveys 2016 and 2019.

It is not uncommon for people with epilepsy to be denied access to education and employment. **Stigma and discrimination are significant contributors to poor physical and mental health in people with epilepsy and will not be improved with a single approach:** a multipronged strategy, which is culturally appropriate, multisectoral and collaborative, is needed. Direct investments in health care do not necessarily lead to improvements in epilepsy-related stigma. **To reduce stigma and discrimination in Tasmania**, the public awareness campaigns and training programmes of Epilepsy Tasmania's Epilepsy Smart Schools and Epilepsy Friendly Workplaces are a statewide priority during 2019-2021.

Driving

Only one-third of Tasmanians with epilepsy drive their own car, due in part to a loss of licence from uncontrolled seizures.

Relying on public transport or taxis can be prohibitive, with 55% on low incomes (half of these below the poverty line) which is heightened by medical expenses and inability of many to work full-time.²⁰

Driving is clearly an area of sensitivity for adults with epilepsy with one study finding only 1 in 10 participants willing to answer driving-related questions.²¹ Transport is particularly important for people living in rural and regional community.

Social Isolation

Social withdrawal and isolation are commonly reported among people with epilepsy.

Such isolation is frequently the product of embarrassment or anxiety about possible hostile reactions of others if a seizure should occur in a public place. Past research indicates that fear for physical safety keeps many people isolated: more than one-fifth said they were afraid to go out because of the possibility of seizures occurring that lead to accidents.

The Epilepsy Longitudinal Survey Wave 4²² in 2017 found that people with epilepsy had difficulties with everyday activities that other people engage in without problems, including the ability to drive and need for transport, engaging in social activities, undertaking domestic duties and outdoor maintenance and shopping that resulted in a significantly lower quality of life.²³

In Tasmania, there are initiatives to help people with epilepsy connect with others: Epilepsy Connect is a telephone-based peer support service that was established by Dr Simone Lee from the University of Tasmania's Centre for Rural Health and managed by Epilepsy Tasmania. This service connects people living with or affected by epilepsy with a trained peer volunteer who has had a similar experience. The phone-based service is designed to reduce isolation, especially for people living in rural and remote Tasmania and was the first of its kind for epilepsy support in Australia.

²⁰ Epilepsy Tasmania: A Briefing Paper 2016

²¹ Michael Tan ,Ray Boston ,Mark J Cook & Wendyl J D'Souza (2019), Risk factors for injury in a community treated cohort of patients with epilepsy in Australia, Epilepsia, Volume 60, issue 3, https://doi.org/10.1111/epi.14659

²² The Australian Epilepsy Longitudinal Survey takes place every three years and captures the experiences and any changes to the experiences of people with epilepsy, their families and carers. It is overseen by Epilepsy Foundation Victoria.
23 Chris Peterson, Loretta Piccenna & Christine Walker (2017), p. 5.

Building awareness

A Global Campaign Against Epilepsy is being conducted by the World Health Organization in partnership with the International League Against Epilepsy and the International Bureau for Epilepsy. Its aims are to provide better information about epilepsy and its consequences, and to assist governments and those concerned with epilepsy to reduce the burden of the disorder. **The burden of epilepsy on individuals and communities is far greater than previously realised** (in particular refer to section: Economic Impact of Epilepsy) and the problem is too complex to be solved by individual organisations. The three leading international organisations working in epilepsy have therefore joined forces to bring epilepsy out of the shadows.

Education is needed at multiple levels to reach all those involved in epilepsy management, including for the person themselves. Epilepsy organisations and support groups should be supported to increase public awareness, spread better information about the nature of epilepsy, improve the self-esteem of people living with and improve their role in society.

Australia is fortunate to have some excellent specialist care for epilepsy however; general practice is the missing link in the circle of care. GPs can each have 5-10 patients with epilepsy. The continued involvement of the GP is critical to positive outcomes. People with epilepsy need regular and personal ongoing education, risk assessment, support, monitoring, and management of comorbidities.

There are two distinct ways of working to reduce the stigma of epilepsy. The first relates to people with epilepsy who need support to counter prevailing negative stereotypes and reduce their experience of stigma. The other focuses on changing negative public attitudes aiming at specific target groups. Potential strategies encompass, amongst others, education and information provision, advocacy and increasing the level of contact between people with epilepsy and people without epilepsy.

The national **Epilepsy Awareness Month** (Purple Month) plays an important role in building awareness and understanding of epilepsy each March and is Epilepsy Tasmania's most significant awareness and fundraising event.

During October, Epilepsy Tasmania runs a public awareness campaign as part of **WorkSafe Month** to encourage employers to make their workplace **Epilepsy Smart**. October also includes **SUDEP Action Day** – a day devoted to raising awareness about sudden unexpected death in epilepsy, encouraging people with epilepsy to learn about SUDEP and their risk, and honoring the lives that have been lost to SUDEP.

Public awareness campaigns like these are successfully raising awareness and tackling the stigma and discrimination of epilepsy.

Research: Tasmanian Surveys

Surveys undertaken by Epilepsy Tasmania between 2016 and 2019 provide insight into key areas of need for Tasmanians living with epilepsy:

- 56% feel isolated and say life is difficult because they are unable to drive.
- 56% want their ability to gain and maintain regular employment prioritised.
- **53% want epilepsy brought out of the shadows** to create a more supportive environment, and suggested better education of employees at places of social gatherings (e.g. movies, shopping centre), workplaces and Centrelink.
- 51% have experienced discrimination as a result of their or someone else's epilepsy. As
 discrimination often comes from a lack of understanding more awareness and education
 about the condition is needed.
- 44% want continued financial viability of Epilepsy Tasmania.
- 44% prioritised a good education for children with epilepsy.
- 38% want better treatments and more research to find a cure.
- 37% struggle to make ends meet and 21% can't afford the medications required to manage their epilepsy.
- **32% struggle to find a suitable health professional to manage their epilepsy,** and suggested GP's need more education around epilepsy and epilepsy medication.
- 23% are unable to find work because of their epilepsy.

A common thread was the suggestion of funding for specific areas, in particular for training and education of GPs, Centrelink and general workplaces. There is a strong desire for epilepsy first aid to become well-known, and many suggestions for increased advertising to raise

awareness – this is currently being addressed by Epilepsy Tasmania with the airing of two statewide TV commercials during October 2019 (Worksafe Month) and March 2020 (Epilepsy Awareness Month).

To ensure children with epilepsy can receive a good, well-rounded education, Epilepsy Tasmania began a statewide rollout of the Epilepsy Smart School training programme in January 2019.

More than half of people surveyed want a supportive environment for all Tasmanians living with epilepsy, including those living in rural areas.

Priority Areas Identified by Tasmanians



Both surveys highlight a need for programs and support to extend to less populated area.

Research: Epileptic Seizure Prediction

A study led by scientists from IBM Research-Australia and the University of Melbourne has marked important progress in personalised seizure forecasting using an algorithm called 'Al'.

The findings present new results in epileptic seizure prediction using deep learning algorithms deployed on a brain-inspired, mobile processor. The study **Epileptic Seizure Prediction using Big Data and Deep Learning: Toward a Mobile System** was published in Lancet's EBioMedicine²⁴, and was showcased at the December 2017 Annual Meeting of the American Epilepsy Society (AES) in Washington, DC. The presentation was selected for honorable mention at AES, marking it as one of the top three at the conference.

Investigators found that the AI algorithm successfully predicted an average of 69 percent of seizures across patients, including patients who previously had no prediction indicators. The current study's tested AI algorithms also had no knowledge of future data, which allowed the researchers to simulate how the system could operate in a real-life scenario. Previous published research had not reported a forward-looking approach, meaning they weren't able to demonstrate how such systems would perform for a real patient in a clinically relevant environment.

In a survey by the American Epilepsy Society, patients selected unpredictability of seizures as a top issue, with many writing about the fear of not knowing when and what will cause a seizure. Of the 65 million people worldwide living with epilepsy, one third have uncontrollable seizures and do not respond to available treatment. These staggering numbers have not reduced in decades, even with more than 14 new treatments since 1990, making epilepsy prediction technology an important area of research which could potentially improve the lives of many patients.

Given the uncertain nature of epilepsy, there are many hurdles to creating a viable warning system for seizures, however new advances in AI offer great potential to help clinicians.

^{24 |} Kiral-Kornek, S Roy, E Nurse, B Mashford, P Karoly, T Carroll, S Harrer, (2018, Epileptic Seizure Prediction Using Big Data and Deep Learning: Toward Mobile System, EBioMedicine, Volume 27, pp. 103-111, https://doi.org/10.1016/j.ebiom.2017.11.032

Economic Impact of Epilepsy

Costs of epilepsy

The cost of epilepsy is comparable to Parkinson's disease and lung cancer and estimated to impose a greater burden on Australia's health system than prostate cancer (\$0.5 billion).^{25, 26}

The total annual cost of epilepsy in Australia during 2019–20 will be approximately **\$12.3 billion.**²⁷

For people with epilepsy, the Epilepsy Longitudinal Survey Wave 4²⁸ found a significant number of employment and financial difficulties:

- Employment and financial difficulty characterise a significant proportion despite high numbers with a university-level education.
- Less than half were in paid employment.
- Nearly one third were renting their homes.
- Most received \$250 \$499 per week in weekly individual income.
- Over a quarter could not pay their electricity, gas or telephone bills on time.
- Many are unable to afford the epilepsy equipment they feel they need such as seizure monitors and alarms.²⁹

Hospital In-Patient Costs

Approximately 50% of all hospital separations that are for seizures list epilepsy as the principal diagnosis.

A separation is defined as 'the process by which an episode of care for an admitted patient ceases'. Separations include instances whereby a patient's episode is closed and a new episode opened for a change in the type of care provided; for example, from acute to subacute care.

The number of separations is the most commonly used measure of the utilisation of hospital services. Separations, rather than admissions, are used because hospital abstracts for inpatient care are based on information gathered at the time of discharge as diagnosis is not usually known at the time of admission.

²⁵ Cancer Council 2019, Cancer costs Australian health services over \$6 billion a year: new research, available at: https://www. cancercouncil.com.au/media-release/cancer-costs-australian-health-services-6-billion-year- new-research/, accessed April 2019.

²⁶ Deloitte Access Economics 2011, Living with Parkinson's disease – update, available at:https://www2.deloitte.com/au/en/pages/ economics/articles/living-with-parkinsons-disease.html, accessed April 2019

²⁷ Deloitte Access Economics estimates

²⁸ The Australian Epilepsy Longitudinal Survey takes place every three years and captures the experiences and any changes to the experiences of people with epilepsy, their families and carers. It is overseen by Epilepsy Foundation Victoria. 2017 29 Chris Peterson, Loretta Piccenna & Christine Walker (2017), p. 7

In Tasmania, the estimated number of hospital separations related to epilepsy during 2019-20 are 652 acute separations and 38 sub-acute and non-acute separations.³⁰

In Tasmania, the total acute separation costs are \$3.6 million during 2019-20. (The average cost per weighted acute separation was \$5,569 and the average cost per acute weighted subseparation was \$19,394).³¹

Around Australia the total hospital inpatient costs related to epilepsy during 2019-20 is expected to be \$199.4 million. ³²

It has been noted that Indigenous Australians face disproportionately high rates of seizurerelated hospital admissions compared to non-Indigenous. Between 1998 and 2004, the rate of hospitalisation related to seizures for Indigenous Australians was five times more than the non-Indigenous rate. Whilst this is not a risk factor in itself, it likely reflects the health inequalities experienced by Indigenous Australians which results in poor seizure control for those living with epilepsy.

One in Nine people presenting to Australian Hospitals were Tasmanian residents

Based on the Australian Institute for Health and Welfare (AIHW) Admitted Patient Care data the ratio of hospitalisations of Tasmanian residents due to convulsions and epilepsy has been increasing over the past few years to a trajectory of one in seven by 2019.

	Convulsions & Epilepsy	Total	Percentage	Ratio	Ratio as decimal
2013-14	645	5,663	11.39%	1:9	8.78
2014-15	711	6,102	11.65%	1:9	8.58
2015-16	748	6,152	12.16%	1:8	8.22
2016-17	754	6,176	12.21%	1:8	8.20
2017-18	812	6,466	12.56%	1:8	7.96

³⁰ IPHA (2019) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices

³¹ IPHA (2019) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices

³² IPHA (2019) and AIHW (2018). A growth rate of 4.1% annually is applied to project the number of separations in 2016-17 to 2019-20. A

Hospital Out-Patient Costs

In Australia the total estimated outpatient costs related to epilepsy for 2019–20 are estimated to be \$31.5 million.³³

Outpatient or non-admitted events relate to services provided in an outpatient clinic with services typically including diagnostic testing, specialised care for complex epilepsy patients, surgical programs and telehealth services. **There are an estimated 96,838 events related to epilepsy per year.**

General Practitioner Costs

The estimated national costs related to primary care by general practitioners for people with epilepsy was \$24.9 million in 2019–20.^{34, 35, 36}

A large share of patients with epilepsy are treated exclusively by their GP for seizures and epilepsy. According to a Tasmanian study,³⁷ 78% of patients were treated only by their GP.

Fewer patients reported attending hospitals as outpatients or for specialist appointments (24.8%). Primary care, therefore, makes up an important part of patient treatment. The study also showed the mean number of GP visits specifically for the treatment of seizures and epilepsy was 3.3 over the previous 12 months of the survey period.³⁸

In Tasmania, during 2019–20 the number of epilepsy-related GP visits was 10,263. The number of imaging tests GPs ordered was 1,088 at a cost of \$119 each. The number of pathology tests GPs ordered was 4,670 at a cost of \$17 each.

Total cost for Tasmania last year for epilepsy-related imaging and pathology via GPs was \$200,000.³⁹

³³ IPHA (2019) and AIHW (2018). A growth rate of 4.1% annually is applied to project the number of events in 2016-17 to 2019-20. A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

³⁴ Department of Health Medicare Statistics (2018) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

³⁵ Department of Health Medicare Statistics (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

³⁶ Department of Health Medicare Statistics (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

³⁷ Lacey, C., Salzberg, M., Roberts, H., Trauer, T., & D'Souza, 2009, Psychiatric comorbidity and impact on health service utilization in a community sample of patients with epilepsy, Epilepsia, 50(8): 1991-1994

³⁸ Lacey, C., Salzberg, M., Roberts, H., Trauer, T., & D'Souza, 2009, Psychiatric comorbidity and impact on health service utilization in a community sample of patients with epilepsy, Epilepsia, 50(8): 1991–1994

³⁹ Department of Health Pathology and Diagnostics Imaging Statistics (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

Preventable GP and Emergency Department Presentations

Epilepsy Tasmania has been instrumental in preventing general practitioner and emergency department visits by those with epilepsy.

Enilensy Tas Data Prevented GP and ED presentations/hospital admissions (self reported)

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	Social Worker	Registered Nurse	Iotal					
July 2018 – Dec 2018	46	12	58					
Jan 2019 – June 2019	103	83	186					

Summary of Health System Costs

In Tasmania, health care expenditure on epilepsy during 2019–20 is estimated to be \$11.8 million.

Table A.8:	Estimated	healthcare	expenditure of	on epilepsy	by com	ponent.	2019-20	(\$ millions)
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State	NSW	VIC	QLD	SA	WA	TAS	NT	АСТ	Aust
Hospital	59.2	47.1	39.1	14.6	28.9	4.4	3.1	3.6	199.4
Outpatient	8.2	5.6	8.2	3.2	3.6	0.6	0.8	1.2	31.5
Primary	7.7	6.4	5.1	1.8	2.6	0.6	0.2	0.5	24.9
Pathology & imaging	3.4	2.6	2.1	0.7	1.1	0.2	0.1	0.2	10.4
Pharmaceuticals	83.8	67.5	52.8	18.4	27.0	5.7	2.5	4.3	262.1
Research	1.8	23.3	1.3	1.6	0.3	0.2	1.8	0.2	28.8
Total	164.0	152.6	108.5	40.3	63.6	11.8	8.5	9.9	557.1

The burden of these health costs fall largely on individuals and state governments.⁴⁰

Specifically, hospital costs are assumed to be borne by state and territory governments, and the majority of GP-related, diagnostics and research costs are assumed to be borne by the Commonwealth government.

Individuals bear around 41% of medication costs and the Commonwealth government bears the remainder. For GP-related costs, individuals bear approximately one-fifth of the total and the remainder is borne by the Commonwealth government.⁴¹

⁴⁰ Deloitte Access Economics estimates

⁴¹ The proportion of GP related costs borne by individuals was derived based on the mean value of the out-of- pocket rate of non-



Figure 3.1: Breakdown of annual and lifetime healthcare costs of epilepsy, by cost bearer (2019-20)

Source: Deloitte Access Economics estimates

Productivity

Productivity losses are common in people living with epilepsy due to their overall worse health outcomes relative to the general population.⁴² This is primarily due to reduced workforce participation, but may also be a result of increased absenteeism from work, reduced participation in the workforce, having to exit the labour force entirely, and reduced lifetime earning potential due to premature death.

Absenteeism as a result of epilepsy costs Australia \$259.2 million.43

In the Australian Epilepsy Longitudinal Survey (Wave 3), over a quarter were absent from work due to epilepsy during the last 12 months and for an average of 33 days.⁴⁴

The annual cost of absenteeism borne by employees is estimated to total \$145.4 million⁴⁵ and the cost to employers around \$953.0 million.⁴⁶

Reduced Workforce Participation

In addition to the temporary costs of absenteeism, there is a longer-term, human capital cost that stems from the reduced workforce participation of individuals diagnosed with epilepsy.

The Australian Epilepsy Longitudinal Study (Wave 3) reveals only 49% of individuals aged between 18 to 60 years of age were in full-time employment.⁴⁷ **This suggests difficulties for people with epilepsy in being employed full-time** as overall in Australia around 76% of employees are in full-time employment.⁴⁸

referred GP attendances from each state and territory.

⁴² Gillam, F. (2002). Optimizing health outcomes in active epilepsy. Neurology, 58(8):9-20.

⁴³ The cost of absenteeism was estimated by multiplying prevalence estimates with average weekly earnings by age and gender, the proportion of workers who take sick leave and the average number of days in a year that an individual with epilepsy would be absent from work.

⁴⁴ Epilepsy Foundation (2014), Australian Epilepsy Longitudinal Study Wave 3: The Social Impact of Epilepsy. Note that 75 individuals out of 263 respondents noted that they were absent from work due to epilepsy in the previous 12 months.

⁴⁵ The cost of absenteeism was estimated by multiplying prevalence estimates with average weekly earnings by age and gender, the proportion of workers who take sick leave and the average number of days in a year that an individual with epilepsy would be absent from work.

⁴⁶ The cost of lost productivity was assumed to be equivalent to the hourly wage of the manager, which was imputed by dividing average weekly earnings for a manager, divided by an assumed 37.5 hour work week.

⁴⁷ Of the 324 survey respondents, 128 people aged 18 to 60 years old indicated they were employed. Out of this cohort, 63 mentioned that they were employed full time, 41 were employed part time and 24 were employed on a casual basis.

⁴⁸ Australian Bureau of Statistics, 6202.0 - Labour Force, Australia, Feb 2019, accessed at http://www.abs.gov.au/ausstats/abs@.nsf/ mf/6202.0

Furthermore, one-third of respondents in this study who were unemployed were unable to work due to epilepsy or another disability.⁴⁹ **This suggests there may be significant barriers to participation in the workforce.**

In a review of Australian health and social welfare policies relating to epilepsy that was undertaken by the Epilepsy Foundation in Victoria, it was noted that **attitudes of workplaces played a role in the employability of people diagnosed with epilepsy.**⁵⁰ This is despite seizure types, severity and side effects of medications playing a role in employability.

Equipment Costs

Epilepsy can significantly impact the capacity of a person to conduct activities of daily life as the unpredictable nature of seizures can disrupt almost any day-to-day activity. As such, some individuals require equipment and devices to assist them in safely conducting daily activities, and to alert carers in the event of a seizure. These devices are used outside the health system and may need to be purchased more than once. Using data from the Longitudinal Survey of People with Epilepsy (Wave 4), the average annual cost of the most common epilepsy-specific devices was estimated to be \$60.51. Emergency ID bracelets, seizure alarms, seizure monitors and anti-suffocation pillows are the most commonly required devices for people living with epilepsy.

Type of equipment	Used by (%)	Unit cost (\$ total)	Unit cost (\$ annual)	Total cost (\$m annual)
Emergency ID bracelet	23.2	8	26.7	0.9
Seizure alarm	11.2	397	132.3	2.1
Seizure monitor	10.4	949	316.3	4.7
Anti-suffocation pillow	10.2	189	63.0	0.9
Total	-	-	-	8.6

Table 4.4: Estimated equipment and devices costs, 2019-20

Source: Epilepsy Foundation, Epilepsy Longitudinal Survey, Wave 4 (2017)

50 Epilepsy Foundation of Victoria (2008), Epilepsy in Australian policy, Available at:https://www.epilepsyfoundation.org.

au/wp-content/uploads/2016/12/Walker-Policy-and-epilepsy-in-Australia- Jan09-Final.pdf, accessed March 2019.

⁴⁹ Epilepsy Foundation (2014), Australian Epilepsy Longitudinal Study Wave 3: The Social Impact of Epilepsy

Transport Costs

In many cases, a person living with epilepsy is **unable to safely drive a motor vehicle which in Australia costs them around \$231 per year in taxis.**⁵¹ This places an additional financial burden on people living with drug-resistant epilepsy.

Support Payments for People with Epilepsy

In Australia the total annual disability support payments made to people living with epilepsy is \$392.2 million. This represents only the additional payments made as a result of epilepsy.⁵²

The most commonly received work-related welfare benefit is the Disability Support Pension (DSP). Data obtained from the Department of Social Services (DSS) through a special data request revealed there were 19,656 recipients of the DSP in December 2018 whose primary medical condition was epilepsy.

Support Payments for Carers

Many individuals are required to provide ongoing care to people living with epilepsy, particularly to those people with drug-resistant epilepsy. These individuals often have to reduce their own labour force participation or exit the workforce entirely to meet their carer requirements.

As such, epilepsy is also associated with welfare payments to these carers who cannot support themselves. The most common of these payments are the Carers Payment and the Carers Allowance. These payments are available to any person who provides constant care in the home to an individual with a physical, intellectual or psychiatric disability.

The average weekly Carer Payment and Carer Allowance were taken to be \$281.90 and \$64.90 respectively, as per the Department of Human Services.⁵³

According to 2018 data from the DSS, **10,246 individuals were caring for a person living with epilepsy and receiving the Carer Payment and 22,476 individuals were caring for a person living with epilepsy and receiving a Carer Allowance.**

⁵¹ Deloitte Access Economics estimates

⁵² Deloitte Access Economics estimates

⁵³ Department of Human Services 2019, Carer allowance: Payment rates. Available at:https://www.humanservices.gov. au/individuals/services/centrelink/carer-allowance/eligibility/payment-rates, accessed March 2019.

Management

Most epilepsy is treated successfully with medication: about 60–70% of people with epilepsy become seizure-free through medication alone, within one year.⁵⁴

Also, after 2 to 5 years of successful treatment and being seizure-free, medications can be withdrawn in about 70% of children and 60% of adults without later relapse.

A small percentage of people may be suitable for epilepsy surgery. Over half the number of people who have surgery become seizure-free long term. Many others have fewer or less severe seizures after surgery. Other treatment options for people who cannot achieve seizure control with medications include Vagus Nerve Stimulation and the Ketogenic Diet.

It is important to note that 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.

Medications

Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy.

AEDs aims to stop seizures from happening but do not stop a seizure once it has started and cannot cure epilepsy. According to the Australian Epilepsy Longitudinal Survey (Wave 3), approximately 95.5% of people surveyed took medication to control epilepsy, which results in 136,297 medicine-reliant individuals in 2019–20.⁵⁵

In Tasmania, during 2019–20 approximately 2,970 people require anti–epileptic drugs at an average cost of \$1,700 each.⁵⁶

Successful treatment of epilepsy through medication may have long term effects on quality of life with some having serious side effects such as reduced speed of information processing, memory impairment, visual disturbance or reduction in bone density. These side effects affect attention, concentration and higher cognitive functions including executive functioning. Side effects vary among different medications and between individuals

Long-Term Treatment

The primary care needs of patients with epilepsy should include a structured regular review, as is common with other chronic diseases such as asthma and diabetes.

⁵⁴ Epilepsy Australia 2018, Epilepsy Treatment. Available at: http://www.epilepsyaustralia.net/epilepsy- treatment/, accessed March 2019.

⁵⁵ Epilepsy Foundation, 2014, Australian Epilepsy Longitudinal Study, Wave 3: The Social Impact of Epilepsy

⁵⁶ Epilepsy Foundation Longitudinal Survey of People with Epilepsy Wave 3 (2014) and Pharmaceutical Benefits Scheme Statistics (2019). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices. The average annual costs was assumed to be the same across all jurisdictions.

The WA Model of Care has determined that "An annual review is recommended as a minimum, even for patients with well-controlled epilepsy, to identify potential problems, ensure discussion on issues such as withdrawal of treatment, and minimise the possibility of becoming lost to follow up. In children, review at least twice a year is recommended to monitor treatment, growth and development."⁵⁷

The annual review addresses the person's seizures and efficacy of medication, ensuring that treatment plans are followed and other issues are addressed. This can help to ensure improvements in health through recommendations for change of diet and lifestyle, referral to tests and, as knowledge increases and new medications become available, consideration of a new treatment that might deliver better outcomes for the epilepsy type. A review is also an opportunity for people to discuss the impact epilepsy may have on their lives. Even if seizures are well controlled, a regular review can be helpful in minimising risk of seizures and enabling the person to lead as full a life as possible.

Drug-Resistant Epilepsy

Dalic and Cook authored an article on drug-resistant epilepsy and noted that despite the development of new antiepileptic drugs between 20% to 30% of people with epilepsy will have drug-resistant epilepsy (DRE).

This complex condition comprises persistent seizures, neuro-biochemical changes, cognitive decline, and psychosocial dysfunction. Dalic and Cook asserted that "An ongoing challenge to both researchers and clinicians alike, DRE management is complicated by the heterogeneity among this patient group. The underlying mechanism of DRE is not completely understood."⁵⁸

They reflected that the challenge of managing patients with DRE "requires a multidisciplinary approach, involving physicians, surgeons, psychiatrists, neuropsychologists, pharmacists, dietitians, and specialist nurses. Attention to comorbid psychiatric and other diseases is paramount, given the higher prevalence in this cohort and associated poorer health outcomes."⁵⁹

Most importantly, the risk of higher mortality rates, due to comorbidities, suicide, and sudden death, emphasize the importance of seizure control.

Overall, DRE patients require a great deal of time and effort from treating physicians. Added to this, management of DRE requires a multidisciplinary and often multi-treatment approach and **significant psychosocial comorbidities and ongoing disability accumulated by ongoing seizures add up to a significant burden of disease.**

⁵⁷ WA Epilepsy Services Model of Care Prepared by the Epilepsy Review Committee Neurosciences & the Senses Health Network February 2008 Department of Health, State of Western Australia, https://ww2.health.wa.gov.au/~/media/ Files/Corporate/general%20documents/Health%20Networks/Neurosciences%20and%20the%20Senses/Epilepsy-Model-of-Care.pdf

⁵⁸ L Dalic & M J Cook (2016), Managing drug-resistant epilepsy: challenges and solutions, Neuropsychiatric Disease and Treatment, Volume 12, pp. 2605–2616, https://www.dovepress.com/managing-drug-resistant-epilepsy-challengesand-solutions-peer-reviewed-fulltext-article-NDT

⁵⁹ L Dalic & M J Cook (2016)

Surgery and Devices

Some individuals with drug-resistant epilepsy may benefit from epilepsy surgery, however, surgery is not accessible or even an option for everyone. Epilepsy surgery includes:

- Resection of an epileptic focus.
- Disconnection of an epileptic focus.
- Implantation of a device that provides electrical stimulation to the brain or a peripheral nerve.

People with drug-resistant epilepsy who are not candidates for surgery may benefit from Vagus Nerve Stimulation (VNS). The vagus nerve stimulator is implanted under the skin of the chest and attached to the vagus nerve in the lower neck. The device delivers short bursts of electrical energy to the brain via the vagus nerve. On average, this stimulation reduces seizures by about 20-40 percent. Individuals usually cannot stop taking epilepsy medication because of the stimulator, but they often experience fewer seizures and they may be able to reduce the dosage of their medication.

The Royal Children's Hospital Melbourne has noted that VNS has been extensively studied in clinical trials around the world, including in children. The hospital has summarised the available data as follows:

- About 30-50% of children gain a significant improvement in seizure control, with reduced seizure frequency or severity.
- Less than 10% of children become seizure free and most continue taking antiepileptic medication.
- Results are similar across all seizure types and syndromes, although there is some suggestion that children with Lennox-Gastaut syndrome and other severe epilepsies may respond better.
- Children with recurrent bouts of seizures that escalate to hospitalisation often benefit from VNS.
- Termination of prolonged seizures or seizure clusters is possible in some children.
- Currently there is no way to predict response to VNS.
- Many children have improvements in mood, alertness and overall quality of life, even in the absence of significant seizure improvement.
- Seizure reduction is often not evident for several months.
- Over time there may be a continued decline in seizures in many patients. 25% may have a reduction in seizure frequency at 3 months, increasing to 50% after 2 years.⁶⁰

⁶⁰ Vagus nerve stimulation, The Royal Children's Hospital Melbourne

Advances in computer software and engineering have produced a new generation of implantable devices that may hold greater promise and take a more direct approach.⁶¹ They provide electrical stimulation to the seizure focus. Deep brain stimulation using mild electrical impulses has been tried as a treatment for epilepsy in several different brain regions. It involves surgically implanting an electrode connected to an implanted pulse generator – similar to a heart pacemaker – to deliver electrical stimulation to specific areas in the brain to regulate electrical signals in neural circuits. These and other new devices are being trialled and have not yet been approved by the Therapeutic Goods Administration (Australia).

Even the successful treatment of epilepsy may have long term effects on quality of life: the implanted vagus nerve stimulator may have side effects such as fatigue, dizziness, nausea, irritability, restlessness, sleep disturbances, hyperactivity and drowsiness. These side effects affect attention, concentration and higher cognitive functions including executive functioning and vary between individuals.⁶²

Medical Cannabis

The Australian Department of Health Therapeutic Goods Administration Guidance for the use of medical cannabis in the treatment of epilepsy in paediatric and young adult patients in Australia recommended that *"Epilepsy treatment with medicinal cannabis or cannabinoids is only recommended as an adjunctive treatment – that is, in addition to existing anti-epileptic drugs."*⁶³

Results from a survey published in 2017 reveals that "Australians with epilepsy are turning to cannabis products when antiepileptic drug side-effects are intolerable and epilepsy uncontrolled. The first Australian nationwide survey on the experiences and opinions of medicinal cannabis use in people with epilepsy has revealed that 14 per cent of people with epilepsy have used cannabis products as a way to manage seizures. The study showed that of those with a history of cannabis product use, 90 per cent of adults and 71 per cent of parents of children with epilepsy reported success in managing seizures after commencing using cannabis products."⁶⁴

Tasmanians with epilepsy who meet specific criteria have been able to legally access medical cannabis since September 2017 via the Controlled Access Scheme.

⁶¹ Epilepsy Foundation (2014), Implantable Devices Could Stop Seizures in Their Tracks, https://www.epilepsy.com/ article/2014/3/read-and-react-implantable-devices-could-stop-seizures-their-tracks

⁶² NZ Department of Health (2017), Defining Epilepsy, https://www.health.govt.nz/system/files/documents/pages/epilepsy-tag-paper-1-defining-epilepsy.docx

⁶³ Australian Department of Health Therapeutic Goods Administration Guidance for the use of medicinal cannabis in the treatment of epilepsy in paediatric and young adult patients in Australia Version 1, (2017), p. 6, https://www.tga.gov.au/publication/guidance-use-medicinal-cannabis-treatment-epilepsy-paediatric-and-young-adult-patients-australia

⁶⁴ Kobi Print (2017), Insights into cannabis use to manage epileptic seizures: Survey reveals cannabis use in Australians with epilepsy, University of Sydney News, https://sydney.edu.au/news-

Support and the NDIS

The majority of people with epilepsy and their carers do NOT qualify for funding under the National Disability Insurance Scheme (NDIS).

People with severe epilepsy are eligible for the NDIS if they can show a permanent impairment which significantly affects their ability to participate in everyday activities.

These people receive funding for a range of supports and services considered reasonable and necessary, including education, employment, social participation, independence, living arrangements and health and wellbeing.

Epilepsy is a chronic condition, particularly for people with drug-resistant epilepsy. The condition on its own, or as a secondary condition to other disabilities, meets the requirements of the National Disability Insurance Scheme Act 2013, Section 24, which attributes disabilities to one more or intellectual, cognitive, neurological, sensory or physical impairments. However, the list of conditions provided in the Act that are likely to meet the disability requirements in Section 24 does not list epilepsy under conditions resulting from neurological impairments or disorders of the nervous system.

Anecdotal evidence suggests that people living with epilepsy as a secondary condition to another listed primary condition are therefore more likely to access support through the NDIS. In contrast, people whose primary condition is epilepsy may face access issues.

Data provided by the National Disability Insurance Agency, through a special data request, show that 725 participants with current NDIS plans had epilepsy as a primary disability, while 11,693 had epilepsy as a secondary disability (as at March 31, 2019).

The total committed support for these recipients was \$72,532 when epilepsy was the primary condition and \$133,057 when epilepsy was the secondary condition.

With a limited number of people with epilepsy eligible to access NDIS packages, individual state and territory governments still have a substantial role to play.

Epilepsy Tasmania's research shows that a majority of people remain confused about their ability to access the NDIS.



Eligibility for the NDIS: 2019

Morbidity, Comorbidity and Mortality

Roughly half of people with epilepsy have coexisting physical or psychiatric

conditions. Physical and psychiatric comorbidities in people with epilepsy are associated with poorer health outcomes, increased health care needs, decreased quality of life and greater social exclusion. The most prevalent psychiatric comorbidities are depression (23%) and anxiety (20%). Intellectual disability is the most common comorbidity in children with epilepsy (30–40%).

There may be an increased risk of suicidal thoughts or actions related to some antiepileptic medications that are also used to treat mania and bipolar disorder. Epilepsy is also commonly associated with neurodegenerative diseases.

Depression is common among people with epilepsy. It is estimated that one of every three persons with epilepsy will have depression in the course of his or her lifetime, often with accompanying symptoms of anxiety disorder. In adults, depression and anxiety are the two most frequent mental health-related diagnoses. Children with epilepsy also have a higher risk of developing depression and/or attention deficit hyperactivity disorder compared with their peers. Behavioural problems may precede the onset of seizures in some children.

Epilepsy carries a significantly increased risk of premature mortality, compared with the general population⁶⁵:

- People with epilepsy die at 3 times the rate of the general population.
- The mean age of death from epilepsy in Australia has been reported at 52 years (compared to the general current life expectancy of 80 84 years of age).
- The Years of Potential Life Lost (YPLL) through epilepsy-related deaths are greater than asthma (a national health priority area) and similar to prostate cancer.⁶⁶

The risk of premature death in people with epilepsy can be due to:

- Seizures in dangerous circumstances that lead to drowning, burns, head injury, car accidents, and others.
- Seizure emergencies prolonged or ongoing seizures.
- Stopping breathing during a seizure.
- Suicide.
- Sudden and unexplained causes SUDEP.

Epilepsy poses substantial individual and societal burdens that require heightened public health action. People with epilepsy often have multiple co-occurring

⁶⁵ J W Sander (2014), Epilepsy kills: stopping epilepsy-related death, J Hanna, R Panelli , T Jeffs, D Chapman, editors, Continuing the global conversation [online]. SUDEP Action, SUDEP Aware & Epilepsy Australia, www. sudepglobalconversation.com

⁶⁶ Rosemary J Panelli (2015), An opportunity to restore the missing link in Australian epilepsy care: Submission to the Inquiry into Chronic Disease Prevention and Management in Primary Health Care, https://www.aph.gov.au/ DocumentStore.ashx?id=fbb9c22d-1111-49ed-ae71-feecb68ecf3b&subId=405561

conditions (e.g. stroke, heart disease, depression, anxiety or developmental delay) that complicate their epilepsy management, impair life goals, and contribute to early mortality.⁶⁷

In addition, the risk of dying suddenly and unexpectedly in people who have epilepsy is approximately 24 times higher than in people who do not have epilepsy. Causes of death include status epilepticus, seizure related incidents such as drowning, falls and asphyxia, and negative treatment outcomes.

Diagram: Seizure-related injuries, Tasmanian Epilepsy Registry from the longitudinal epilepsy survey – Wave 4



Seizure-related injuries, Tasmanian Epilepsy Registry

The Epilepsy Foundation Victoria states that there are around 300 deaths from epilepsy in Australia each year:

- 5% of people die from a seizure that just won't stop despite medical intervention this is called Status Epilepticus.
- 45% of people die as a result of an accident caused by a seizure.

Epilepsy is ranked in the top 5 causes of avoidable mortality from ages 5 -29. This could include:

- Drowning whilst swimming, bathing or showering.
- Having a seizure whilst in a dangerous situation such as up a ladder or near operating machinery.
- Driving a vehicle.
- The other 50% of deaths from epilepsy are the result of SUDEP.68

⁶⁷ Tara Haelle (2017), Epilepsy Isn't as Rare as Many Might Think -- And Cases Are Increasing, https://www.forbes.com/ sites/tarahaelle/2017/08/14/epilepsy-not-as-rare-as-many-might-think-and-cases-are-increasing/#1aa91b037907 68 The Epilepsy Foundation, SUDEP, https://www.epilepsyfoundation.org.au/sudep/

Recent Tasmanian research surveyed⁶⁹ 819 people who were part of a communitybased registry to ask them about seizure-related injuries. Of those surveyed, 43% had a lifetime history of at least one injury and nearly 10% had an injury in the previous 12 months. The study was based on the premise that although morbidity from seizure-related injuries is common, there have been very few studies attempting to map this. Senior study author Wendyl D'Souza, epileptologist at St. Vincent's Hospital, Melbourne and associate professor at the University of Melbourne Medical School noted that a key finding was that seizure frequency was correlated with risk of injury. However, the study shows that even just one seizure a year is a risk for injury and that a person needs to be seizure-free to be safe.

The study found that, after adjusting for seizure frequency, three risk factors remained:

- Impaired awareness during seizures.
- Convulsive cluster seizures.
- Having seizures only when awake (versus during sleep).

Critically the study did not find that people who had seizure warnings (sometimes called auras) were at lower risk of injury. The study also looked at particular injuries and their likelihood and found that:

- Head injuries were common, with a lifetime incidence of 21.6% and recent incidence of 3.9%. About 1 in 4 head injuries required stitches.
- For people with epilepsy, baths and showers and swimming pose a risk of seizurerelated drowning. The risk of drowning in people with epilepsy is 15 to 19 times greater than that of the general population.
- Other types of injuries included burns, cuts, broken bones and dental injuries. 18% of the injuries were reported as occurring in public, and about 60% in the home.

Status Epilepticus

Status epilepticus is a potentially life-threatening condition in which a person either has an abnormally prolonged seizure or does not fully regain consciousness between recurring seizures. Status epilepticus can be convulsive (in which outward signs of a seizure are observed) or nonconvulsive (in which no outward signs are observed but a seizure is diagnosed by an abnormal EEG). Nonconvulsive status epilepticus may appear as a sustained episode of confusion, agitation, loss of consciousness, or even coma.

⁶⁹ Michael Tan ,Ray Boston ,Mark J Cook & Wendyl J D'Souza (2019), Risk factors for injury in a community~treated cohort of patients with epilepsy in Australia, Epilepsia, Volume 60, issue 3, https://doi.org/10.1111/epi.14659

SUDEP

For reasons that are poorly understood, **people with epilepsy have an increased risk** of dying suddenly for no discernible reason.

SUDEP is sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause of death can be found, despite thorough post mortem examination and blood tests. This does not include those who die in status epilepticus and those who die from a seizure-related accident.

To date we do not know what causes SUDEP. Current research points to respiratory or cardiac dysfunction, but the cause of this dysfunction still eludes us and we cannot predict who will be affected.

Yet risk factors only tell part of the story. Sometimes individuals with infrequent seizures die, while others with more frequent and apparently more severe seizures do not. Some may be more at risk because of social factors, lifestyle or sub-optimal management; others may have additional biological susceptibility."⁷⁰

Some studies suggest that **each year approximately one case of SUDEP occurs for every 1,000 people with epilepsy** (and 1 in 4,500 children). People with more difficult to control seizures tend to have a higher incidence of SUDEP.

It has been proposed that the burden of disease from epilepsy is higher than may seem immediately apparent. Bellona et al note that recent estimates from a Tasmanian study between 2008 and 2012 suggest the average number of deaths in Australia attributed to epilepsy was 290 per year. This figure may seem modest, however, when assessed using Years of Potential Life Lost (YPLL), a measure sensitive to premature death, **the public health burden for epilepsy is seen to be greater than the highly publicised and well-funded chronic health issue of asthma.** Although the number of deaths in 2012 from asthma (386) was higher than epilepsy (265), the number of years of potential life lost to epilepsy was 6621 compared to 3948 in asthma. **Further comparisons reveal YPLL for SUDEP is higher than other neurological conditions including amyotrophic lateral sclerosis, multiple sclerosis, Alzheimer disease and Parkinson disease.**"⁷¹

Bereavement

It is also important not to forget carers and families of people who die from epilepsyrelated issues. Epilepsy-specific information and bereavement support is needed over time. A study exploring the experiences and needs of bereaved family and

⁷⁰ Epilepsy Australia, Epilepsy & SUDEP, http://www.epilepsyaustralia.net/epilepsy-sudep/

⁷¹ Michelle Bellon, Rosemary June Panelli & Fiona Rillotta (2015), Epilepsy-related deaths: An Australian survey of the experiences and needs of people bereaved by epilepsy, Seizure, Volume 29, pp. 162–168, https://www.sciencedirect. com/science/article/pii/S1059131115001272

friends following an epilepsy-related death in Australia⁷² highlighted the need to improve community understanding and support for those affected by epilepsy and to promote informed risk assessment and communication amongst patients, families and health professionals. People bereaved by epilepsy require both immediate and long-term epilepsy-specific information and support from professionals, informal communities and peer supporters. It found that:

- Over half of respondents were unaware that epilepsy could be fatal.
- For many, the epilepsy-related death had not been adequately explained to them.
- Improved education and participation in risk-discussion is required.

The survey was completed by 101 respondents describing 90 deceased individuals. **Mean age at death was 32.1 years**, with causes of death including SUDEP, epilepsy, drowning, cardiac arrest, asphyxiation, and motor vehicle accidents. **Over half of the respondents indicated that they did not know, prior to the death, people could die of epilepsy.** In addition, 38% indicated the death had not been adequately explained to them. Comments revealed services and supports which should be available following a death, and recommendations for existing epilepsy support services which might help to prevent future deaths.

Prevention of Epilepsy

An estimated 25% of epilepsy cases are preventable. Preventing epilepsy is an urgent unmet need.

The major modifiable risk factors for 25% of all epilepsy cases are:

- **Perinatal risk factors** related to epilepsy include gestational age at delivery, birth weight, maternal health conditions such as nutritional status, pre-eclampsia, the presence and skill of birth attendants, Summary 11 method of delivery, perinatal infection (e.g. human immunodeficiency virus [HIV]), and other adverse events and conditions.
- Central nervous system infections, according to population-based studies, comprise three main categories: bacterial meningitis, viral encephalitis and neurocysticercosis. Bacterial meningitis and viral encephalitis combined account for approximately 2–3% of epilepsies in high-income countries (HIC) and about 5% of epilepsies in low to middle-income countries (LMIC). In some LMIC where the Taenia solium (pork tapeworm) is endemic, roughly one-third of epilepsies are attributed to neurocysticercosis. Malaria is one of the most common parasitic diseases worldwide. Its neurological form, known as cerebral malaria, is a

⁷² Michell Bellon, Rosemary June Panelli, & Fiona Rillotta (2015), Epilepsy-related deaths: An Australian survey of the experiences and needs of people bereaved by epilepsy, Seizure, Volume 29, , pp. 162–168, https://doi.org/10.1016/j. seizure.2015.05.007Get rights and content

potential cause of epilepsy in malaria-endemic regions of the world.

- **Traumatic brain injury** is the cause of epilepsy in 4% of LMIC and 5% of HIC. Road traffic injuries, falls and violence are the most common causes of TBI. The risk of epilepsy is higher in people with severe versus mild TBI (increased almost 20-fold).
- Stroke, including ischaemic and haemorrhagic types, is also a common potentially preventable cause of epilepsy, representing 12% of epilepsies in HIC and 2.7% in LMIC. Seizures after stroke are associated with increased premature mortality, disability, and higher resource allocation and costs. In population-based studies, stroke was identified as a common cause of status epilepticus (12–40% in HIC, 5–15% in LMIC). The primary prevention of these causes has a substantial impact on the development of epilepsies and requires improving maternal health care and obstetrical services, communicable disease control, injury prevention, and cardiovascular and cerebrovascular health with reduction of the major risk factors of NCDs. An understanding of the development of epilepsy after a brain insult or parasitic infection is critical to the development of secondary preventive strategies.

In 2009 the Joint Epilepsy Council of Australia (JECA) addressed the issue of epilepsyrelated death and concluded that **of the approximately 300 epilepsy-related deaths in Australia each year, many may have been preventable and highlighted inappropriate care as a contributing factor.**

People

Children with Epilepsy

Children are especially vulnerable to the emotional problems caused by ignorance or lack of knowledge among others about epilepsy. This often results in stigmatisation, bullying, or teasing of a child who has epilepsy. Such experiences can lead to behaviours of avoidance in school and other social settings. Counselling services and support groups can help families cope with epilepsy in a positive manner.

There is often a lack of understanding and awareness about the impact epilepsy can have on learning. Some of the neurological effects on cognition can be subtle or be misinterpreted as day-dreaming or poor behaviour. Children with epilepsy need support for learning which, if unaddressed, can have negative consequences on the student's experience of school and beyond that, their future ability to gain employment. Other issues for children with epilepsy include:

- Attention deficit hyperactivity disorder (ADHD) is more common among children with epilepsy than children in the general population.
- Evidence suggests there is a strong relationship between epilepsy which is difficult to control medically and specific learning disabilities (i.e. in literacy and numeracy). Around 15% of people with epilepsy have a learning disability while around 30% of people with learning disabilities have epilepsy.
- In addition to presenting with a higher frequency of specific learning difficulties, students with epilepsy also present with a higher rate of information processing disorders, secondary to their fluctuating attention and concentration, reduced speed of information processing and weak executive functions.

The cumulative effect of these difficulties over time is profound, often resulting in reduced educational achievement regardless of intellectual capacity.

Furthermore, epilepsy in children is often associated with increased levels of anxiety and depression which are impacted upon by issues including:

- The unpredictable nature of seizures. Many parents, children and their siblings share the fear that a life-threatening seizure could happen at any time.
- Fear of embarrassment from having a seizure in front of peers.
- Bullying or harassment as a result of the diagnosis or after having had a seizure in public.

Epilepsy Smart Schools

One in 200 students have active epilepsy and it can have a significant impact on their experience at school.

In January 2019, Epilepsy Tasmania launched the Epilepsy Smart Schools programme to help Tasmanian schools improve the academic and social outcomes of students with epilepsy. Prior to this, Tasmanian schools were unable to receive best practice accredited epilepsy-specific training.

Epilepsy can significantly impact learning in the classroom:

- Seizures can make it difficult to concentrate and remember new information.
- Memory difficulties can also be a side effect of medication.
- Some children may have a co-existing developmental condition.
- Cognitive overload can cause seizures and social isolation, and stigma is commonly experienced when having seizures at school.

Epilepsy is the third most common health condition in school-aged children (in order it is diabetes, asthma, epilepsy then anaphylaxis). **Epilepsy is also one of the top five avoidable causes of death among five to 29-year-olds.**

Each child's experience of epilepsy is different: there are numerous syndromes – over 40 different types of epilepsy seizures – each with varying symptoms, causes, methods of diagnosis and management. It is imperative that schools take an individualised approach to meet each student's needs.

The Epilepsy Smart Schools programme provides a unique combination of training that is tailored to the individual as well as the whole-of-school approach. Few other health programmes are based on a multi-system approach that seeks to benefit individual children, their families, and ultimately, the wider community.

There are 254 schools in Tasmania and it is hoped that within three years, half will have become Epilepsy Smart Schools.

Case Study

The mother of a 10 year old boy with uncontrollable epilepsy contacted Epilepsy Tasmania for advice and support. Her son is currently only enrolled on a parttime basis at school due to being sent home every time he has a seizure, which is sometimes only 30 minutes into the school day. He becomes upset when this happens and while at home just spends time on his iPad. Epilepsy Smart Schools has given teaching staff the confidence to recognise symptoms in this student and manage seizures at school so he can spend more time there. This knowledge has been shared school-wide. Students and support staff have a greater understanding of how epilepsy affects this student, resulting in a more inclusive learning environment and less anxiety.

Research

A three-year study into epidemiology and etiology of infantile developmental and epileptic encephalopathies (IEE) in Tasmania⁷³ was recently published with support from Epilepsy Tasmania through a generous bequest.

This research was trying to discover the underlying genetic causes of the IEE condition which contributes significantly to the burden and cost of care for families and health systems through frequent hospitalisation for uncontrolled seizures. Early diagnosis has positive consequences for identifying the most appropriate therapies and quality of life prognosis.

Researchers at the Epilepsy Research Centre within the University of Melbourne performed detailed bioinformatics analysis of the sequencing data from the unsolved children from the Infantile Epileptic Encaphalopathy study.

Adolescents with Epilepsy

Epilepsy can influence the behaviour and life-style of adolescents, expressed as poor performance at school, weight gain or loss, depression, suicide, drinking, smoking or substance abuse.

Adolescents can be prone to risk-taking behaviour. It is common for adolescents to assert their independence from their parents and be more influenced by their peers, often in opposition to their parents. Adolescents are more focused on socialising, going out late with friends resulting in lack of sleep, which can provoke certain seizures. A common issue that arises during this period of a person's life is that of increased experimentation with alcohol and drug use which can trigger seizures specifically, because:

- They affect the anti-epileptic medication levels in the bloodstream.
- They are often associated with late nights and sleep deprivation.
- Stimulant drugs are known to cause seizures.
- Withdrawal seizures may happen when alcohol levels drop.
- People may forget to take regular medication when they are under the influence of alcohol or other substances.

Parents therefore may tend to impose restrictions to protect their children with epilepsy. This can lead to some risk-taking behaviour – they may view the medication as a burden which obstructs their activities, and they might try to stop taking it; they might decide to not report minor seizures for fear of having to increase their medication.

⁷³ A study undertaken with support from Epilepsy Tasmania through the research grant and estate of Ms Kathleen Beulah Grace. It was published in June 2019 in leading epilepsy journal Epilepsia Open.

At a rural secondary school in central Tasmania, a 17-year-old student has photosensitive epilepsy and experiences tonic-clonic seizures. Visual stimuli such as flashing lights, bold patterns or patterns that move visually can trigger a seizure in this student, who experiences approximately one seizure per month. Before a seizure, this particular student experiences around five minutes of hot flushes and dizziness. This short warning provides a critical opportunity to reduce the student's body temperature and perhaps prevent a full tonic-clonic seizure that causes wholebody stiffening, convulsions, excess saliva and loss of body control. After a seizure, this student may experience mood changes from anger, to embarrassment, then exhaustion followed by migraines and a lack of awareness for an unspecified time. Epilepsy Smart Schools provided support to both the student and the teaching staff. All are now more aware of the triggers that can cause a seizure and look to remove or reduce them during classes. Teachers now have a greater understanding of the memory loss and lack of comprehension that can occur after a seizure, and the exhaustion and fragility that accompanies them. Their improved knowledge has led to a positive impact on the student's quality of education and health outcomes.

Men with Epilepsy

Epilepsy affects men and women equally; however, there are both biological and psychological gender differences with respect to its consequences. Sex-specific hormones affect the seizure threshold, facilitating, inhibiting or modulating the occurrence of epileptic seizures. Because of the close connections between regions of the brain that might generate seizures and regions that control hormonal activity, epilepsy itself can lead to clinically relevant sexual dysfunction, such as infertility or impaired libido. One of the possible side-effects of anti-epileptic drugs is on weight, which can cause medical problems beyond its cosmetic nature. Some of these problems can be dealt with in clinical practice, while others are poorly understood and further research is required.

Gender-related problems in men with epilepsy are less well studied than those in women. Recent research has demonstrated, however, that men with epilepsy often have various manifestations of sexual disturbance. Furthermore, reproductive function can be impaired due to decreased testosterone levels and reduced sperm quality. These abnormalities might be related to long-term use of antiepileptic drugs, and a number of studies suggest that some drugs have a stronger effect on male hormonal functions than others. Whether these problems can be avoided by using or avoiding specific medications is not yet clear.

A 49 year old male contacted Epilepsy Tasmania due to a recent increase in his seizures. After discussion, some possible causes were identified: recent commencement of new job with shift work has meant taking his medications at irregular times and sometimes missing doses; he has also recently gained weight. Epilepsy Tasmania arranged a review with his GP along with blood tests which showed he needed an increase in his medication. The organisation also introduced him to a new phone App that sends medication reminders.

Women with Epilepsy

Although most epilepsy syndromes are equally found in both genders, childhood absence epilepsy and the syndrome of photosensitive epilepsy are more common in females. In addition, some genetic disorders with associated epilepsy (e.g., Rett syndrome and Aicardi syndrome) and eclamptic seizures in pregnancy can only occur in females.⁷⁴

A particular concern for women with epilepsy is the potential teratogenic effects of antiepileptic drugs during pregnancy.

Issues of particular importance to women with epilepsy are:

- Some antiepileptic drugs can interact or mix poorly with some types of contraception (and vice versa). This could mean contraception failure or perhaps a worsening of seizures.
- It is really important that women with epilepsy plan their pregnancies to ensure that the medication they are taking is the safest possible option for when they become pregnant, and seizure control is at its best. This helps to lessen any risks to both mother and child.
- Pregnancy and having a baby may mean medications or their dosage need to change, and seizures may also change. These changes will continue once the baby is born until the woman is stabilised again post pregnancy.
- Continuing to take medication as prescribed is important at all times, but especially during pregnancy, because keeping good seizure control is one of the best ways to keep both the woman and her baby safe.
- Women with epilepsy need education and advice long before a pregnancy occurs. GPs are well-placed to provide this information and to refer to the Australian Epilepsy Pregnancy Register⁷⁵ where women with epilepsy can share information about their pregnancy to help inform future research.

 ⁷⁴ Jane G Boggs, Selim R Benbadis (2018), Women's Health and Epilepsy, MedScape, https://emedicine.medscape.com/ article/1186482-overview
 75 https://www.epilepsy.org.au/apr-registration/

A mother and daughter visited Epilepsy Tasmania to discuss their support and lifestyle. The daughter is blind and has tonic clonic seizures but wants to be independent and live by herself; her mother will live two houses away. A discussion was had about how the daughter will live, the support she can put in place, and how long she will spend alone. Epilepsy Tasmania organised a LifeMinder seizure alarm and have put in a request for a seizure dog so she is never alone.

Elderly People with Epilepsy

The prevalence of epilepsy is changing as our population ages and there is an increasing number of elderly people presenting with epilepsy. **The prevalence and demographic distribution of treated epilepsy: a community based study in Tasmania**, previously referred to in this document, found a high elderly prevalence. The authors note that "high elderly prevalence has been reported in a few recent studies in developed countries and has important clinical and public health implications in populations with similar ageing demographics."⁷⁶

Until recently, the common perception has been that seizures and epilepsies occur most often in childhood and adolescence and rarely in older persons. Today, however, it has been found that **epilepsy is the third most common neurological disorder in old age, after dementia and stroke,** mainly because of steadily increasing life expectancy and an increased likelihood of surviving concurrent medical conditions that can lead to seizures or epilepsy.

The underlying causes of seizure activity can be identified in most older patients. Seizures can recur immediately after a stroke or not for several years. **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.**

The clinical manifestations of epilepsy in the elderly are different from those in younger adults and children. The most common seizure types in the elderly are complex partial seizures, which may be shorter and less obvious than those seen in younger patients. In contrast, the elderly often have more severe, prolonged postictal symptoms. Postictal confusion with disorientation, hyperactivity, wandering and incontinence can persist for up to one week. Nonconvulsive seizures and nonconvulsive status epilepticus are quite common in the elderly and can cause sudden changes in behaviour and cognition.

⁷⁶ W J D'Souza, S J Quinn, J L Fryer, B V Taylor, D M Ficker, T J O'Brien, N Pearce & M J Cook (2012), The prevalence and demographic distribution of treated epilepsy: a community-based study in Tasmania, Australia, Acta Neurologica Scandinavica, Volume 125, Issue2, pp. 96-104, https://doi.org/10.1111/j.1600-0404.2011.01499.x

A woman who resides in a retirement village rang Epilepsy Tasmania concerned that her support person was going on holiday, She lives alone and has uncontrolled seizures and will have no support during this time. After discussion, it was decided that she needed an alert, so that if she had any seizures, up to 5 people would be alerted to go to her. This allowed peace of mind while her support person was away in knowing she would never be alone if seizures resulted.

Research

The Epilepsy Foundation Victoria has undertaken a project called **Tackling Epilepsy in the Later Years** with the National Ageing Research Institute (NARI), the Council for the Ageing (COTA) Victoria, and the Brotherhood of St Laurence (BSL). People can be diagnosed with epilepsy at any age but one of the biggest age groups to be affected by epilepsy are people aged 65 years or older. This demographic is now living longer, therefore it is vital people know how to correctly manage their epilepsy and have sufficient support available whether they are living in their own home or in residential care.

The aims of this project are to:

- 1. Evaluate the existing knowledge about epilepsy in:
 - People aged over 65 years who have epilepsy and in those who do not; and
 - Aged-care staff and carers.
- 2. Provide an evidence base of treatments, consequences/issues and the management of epilepsy in older people (65 years and older).
- 3. Improve the knowledge and understanding of epilepsy in ageing people with epilepsy and their families and aged care staff/carers through resources informed by the established evidence base.
- 4. Raise the awareness of the risk of epilepsy for older people within the community, and
- 5. Facilitate best practice in the management of epilepsy in older people.

A journal article has just been published on one of the surveys conducted as a part of the Tackling Epilepsy in the Later Years project.⁷⁷

⁷⁷ C Peterson, L Piccenna, S Williams, F Batchelor, B Dow, & G Shears (2017), Older people and knowledge of epilepsy: GPs can help, Australian Family Physician, Volume 3, pp. 132 – 136, https://www.racgp.org.au/afp/2017/march/olderpeople-and-knowledge-of-epilepsy-gps-can-help/

Family Members and Carers

Family members and carers provide valuable support to people with epilepsy and should feel justified identifying their own needs both as individuals and careproviders.

Many of the families seen by Epilepsy Tasmania are struggling with the chronic nature of epilepsy and how to manage it. Because epilepsy is a lot more than having seizures, people with epilepsy typically face an array of other challenges including cognitive, social and medical problems. These issues impact carers and family members, causing anxiety, stress and risk to their own mental health.

Diagram: What are the main challenges you face supporting someone with epilepsy? Comparison of Epilepsy Tasmania surveys of Tasmanians with epilepsy and their carers 2016–2018 and 2019.

Challenges Faced by People with Epilepsy and Their Carers



Family members and carers help in both practical and emotional ways, from help with physical and day-to-day tasks, to meeting complex emotional and support needs of the person they care for. Other issues faced by family members and carers are:

- Lack of recognition and support, including by service providers, to ensure their own quality of life.
- Reluctance to seek help and support for themselves. Others feel they would benefit from proactive offers of help and support, information and signposting, and opportunities to explore their own needs.
- Lack of knowledge about epilepsy within the services, leading to a perceived or actual lack of competency in services. This also impacts confidence in asking for, or accepting help from services. As epilepsy is often poorly understood by service-providers, it can be a challenge to demonstrate the need for support in a condition which is often invisible for much of the time.
- Many challenges facing family members and carers are epilepsy-specific and the need for care can vary greatly from one individual to another due to the variable nature of the condition. Needs can also vary within an individual at different times. For example, because the need for care can be unpredictable it cannot be planned for. For many carers the unpredictability of need for care has an impact on their employment, as employers may not understand that care cannot always be planned, and carers may need time off without notice.

The Cost of Caring

The costs of epilepsy often falls on individuals who provide informal care for people living with epilepsy, such as partners, parents, siblings and other relatives. These individuals provide care and assistance to people living with epilepsy on an unpaid basis. While the care they provide is unpaid in a financial sense, it is not free in an economic sense, as the time they spend caring cannot be directed to other productive activities such as paid work, unpaid work or leisure.

When an individual experiences a seizure event, it may lead to absenteeism from their informal carers who in severe cases may make the decision to exit the labour force to provide full-time care to the individual with epilepsy. For people with epilepsy who require informal care, the average amount of time spent on them by their carer is 28.3 hours per week.^{78 79 80 81 82}

⁷⁸ Van Andel, J., Zijlmans, K., Fischer, K., & Leijten, F. S. S. (2009). Quality of life of caregivers of patients with intractable epilepsy. Epilepsia, 50(5):1294–1296.

⁷⁹ Karakis, I., Cole, A. J., Montouris, G. D., Luciano, M. S., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. Epilepsy Research and Treatment, 2014, 808421.

⁸⁰ Helmers, S., Gupta, S., Huang, S., Berk, A., & Knoth, R. (2015). Caregiver burden: An under-recognised aspect of epilepsy care. Kantar Health.

⁸¹ Mitchell, L. A., Hirdes, J., Poss, J. W., Slegers-Boyd, C., Caldarelli, H., & Martin, L. (2015). Informal caregivers of clients with neurological conditions: Profiles, patterns and risk factors for distress from a home care prevalence study. BMC Health Services Research, 15:350.

⁸² Campbell, J. D., Whittington, M. D., Kim, C. H., VanderVeen, G. R., Knupp, K. G., Gammaitoni, A. (2018). Assessing the impact of caring for a child with Dravet syndrome: Results of a caregiver survey. Epilepsy & Behaviour, 80:152-156.

The Survey of Disability, Ageing and Carers (SDAC) was used to isolate the additional hours of care provided to Australians with epilepsy. Within this, it was found that an **average care requirement of people without disabilities caused by epilepsy and no known health conditions is 15.9 hours per week.**

In the context of epilepsy, it is assumed that only those with drug-resistant epilepsy (DRE) would require ongoing informal care. As such, 30% of people living with epilepsy are assumed to require some level of informal care.

Overall, the total cost of informal care for Australians with epilepsy is estimated to be \$438.2 million during 2019–20.

Case study

A family contacted Epilepsy Tasmania: the mother and her two adult sons each have an epilepsy diagnosis. They manage their seizures well but are experiencing stress as the sons try to develop some independence by thinking about moving out of the family home. A GP referral for a mental health plan for family psychology support and some discussion around independent living and the resources available to support this has helped the family to plan for the coming changes.

Telehealth

The Australian Department of Health define telehealth services as the use of information and communications technologies to deliver health services and transmit health information over both long and short distances.

Rather than moving the care recipients, health professionals or educators, Telehealth provides online or over-the-phone diagnosis, treatment, preventive (educational) and curative aspects of healthcare services."⁸³

The Summary of the Australian Epilepsy Longitudinal Survey – Wave 4, identified setting up and establishing telehealth services in rural and remote communities as a potential solution to the difficulty of providing services to these regions. The authors referred to evidence being available "to show that telehealth services are beneficial, particularly in improving management of chronic conditions, decreasing costs, reducing inconvenience, improving clinical outcomes and providing peer support, networking and education. A recent study has compared face-to-face consultations and telehealth with patients with epilepsy in Northern Queensland (Adamson, Smit and Costello, 2017). The results of the study were promising showing that patients who received telehealth were satisfied with the quality of care and would prefer this method instead of travelling into the city/metro for their next consultation."⁸⁴

Although patients who received face-to-face consultations reported greater satisfaction than the telehealth group, the authors concluded it is a viable model of care for people who are located within regional/remote settings and should be strongly considered to improve care and quality of life.⁸⁵

In Tasmania, Epilepsy Tasmania operates a telephone-based peer support service that is available to every Tasmanian living with or affected by epilepsy. Epilepsy Connect was the first of its kind in Australia for epilepsy support. This program was evaluated in 2018 and the evaluation report⁸⁶ found:

- **Strong support** for the program from politicians, the media and the Tasmanian community.
- **Equitable access** to peer support, with almost half of the participants living in outer regional and remote Tasmania, and a third living in the most socioeconomically disadvantaged areas of Tasmania.
- **Positive effects** on the overall wellbeing of participants, their mental health, and their ability to manage epilepsy and cope as a carer. These results reflect the original objective of the program in reducing the impact of epilepsy in Tasmania.

⁸³ Australian Department of Health, Telehealth, http://www.health.gov.au/internet/main/publishing.nsf/Content/e-health-telehealth

⁸⁴ Chris Peterson, Loretta Piccenna & Christine Walker (2017), Summary of the Australian Epilepsy Longitudinal Survey – Wave 4, Epilepsy Foundation (2017, p. 9, http://www.epilepsyaustralia.net/uploads/74689/ufiles/Wave_4_Report_ summary.pdf

⁸⁵ Chris Peterson, Loretta Piccenna & Christine Walker (2017), p. 9.

⁸⁶ Simone Lee (2018), Epilepsy Connect Evaluation Report, p. 1Centre for Rural Health, University of Tasmania.

Case Study

Featured in Tasmania's Primary Health Matters magazine (Dec 2017 Issue)

Launceston mum Skye says her daughter Savanna's epilepsy came out of the blue. Savanna was 11 years old when she had her first episode at school. "When it happened, she couldn't speak or move, she couldn't count to 10, she thought she had five brothers when she's the eldest of four. Her mind was completely shut off, she looked like she'd had a stroke. It was horrible. Initially they thought it was a one-off, something to do with migraines, but eventually they diagnosed her with absence epilepsy. The notion with epilepsy is that you drop to the floor, have a seizure and wet your pants, but not all epilepsy is like that," said Skye.

According to Epilepsy Tasmania, one in five Tasmanians are affected by epilepsy in some way, either with a personal diagnosis or in supporting a family member or friend. The impact of epilepsy is multifaceted. A lot of the families it sees are struggling with the chronic nature of epilepsy and how to manage it and anxiety and stress can affect their mental health in an ongoing way. Epilepsy is also a lot more than the seizure itself. The seizure is just the tip of the iceberg and underneath are a whole lot of symptoms that affect concentration, memory, connections and the ability to function day-to-day. For Skye, learning how to manage Savanna's condition really took a toll on her own mental health. "It was really emotional. Before this happened, Savanna was a bright, energetic, outgoing child, but she was reduced to sleeping a lot and being physically, emotionally and mentally exhausted. She was not herself so one day I rang Epilepsy Tasmania in tears, I was not coping, everything was just falling apart. They suggested I try Epilepsy Connect to connect over the phone with someone who has been in the same situation."

Epilepsy Connect is a telephone-based peer support service managed by Epilepsy Tasmania that connects people who are living with or affected by epilepsy with a trained peer volunteer who has had a similar experience. With only one in three people with epilepsy able to drive a car, the phone-based service is designed to reduce isolation, especially for people living in rural and remote Tasmania and is the first of its kind for epilepsy in Australia.

Katie is a Launceston-based peer volunteer with Epilepsy Connect. She has temporal lobe epilepsy and feels this kind of service would have been exactly what she needed when she was first diagnosed. "When I was first diagnosed I had a fabulous GP and a great neurologist and specialists, but what I really wanted was to discuss it with someone who'd had a similar experience," she says.

Katie says the Epilepsy Connect peer volunteers have a diverse range of experiences and skills, and are eager to help. "There's not a huge public understanding of epilepsy, so it can be reassuring to talk to someone and realise this is a common experience," she says. That's exactly how Skye felt when she first connected with the service. "When I spoke with the volunteer, it was like somebody had turned on a light in a dark room. The lady I spoke to had been through the same thing – she shed light on medication, on doctors, on all the emotions I was feeling, on how to cope. It was a massive relief," she says. "At the end of each conversation she'd say 'hang in there, you're doing a good job'. It might not sound like much, but when somebody who's gone through this tells you you're doing a good job, it means more and it encourages you."

For Skye, using Epilepsy Connect has made all the difference. "I think I can cope with Savanna's epilepsy a lot better because I'm aware that everything I was feeling was normal," she says. "The peer support volunteer showed me there is always a way to live a normal life as a family with epilepsy."

The Importance of Research

Epilepsy research has enabled remarkable progress in deepening our understanding of the etiologies and mechanisms leading to epilepsy and associated comorbidities. It has also brought interventions and treatments to improve the management of seizures and their comorbid conditions or consequences.

However, **investment in research for epilepsy is insufficient.** There remains a dramatic inequality in access to and utilisation of research resources and expertise across the globe.

In the United States of America, the National Institutes of Health (NIH) support for epilepsy research accounted for less than 0.09% of the total NIH budget dedicated to research and has stagnated over the last 3 years, unlike other neurological conditions which have attracted increasing research support, e.g. Alzheimer disease research, autism and rare diseases.

Whether research is preclinical, clinical or at the population level, it is important to engage and sustain the best pool of researchers in the field, at all career stages, and enrich the available resources by maintaining collaborations within and beyond the epilepsy community to facilitate this.

Developing epilepsy research priorities around the world may be a vehicle to improve research support and advocacy. Recognising the need to determine possible areas of research priority, and as a response to regional declarations on epilepsy, taskforces combining regional expertise from ILAE and IBE were established to address research priorities in their region.

The American National Institute of Neurological Disorders and Stroke (NIH) has noted that "Medical and research advances in the past two decades have led to a better understanding of epilepsy and seizures. More than 20 different medications and a variety of dietary treatments and surgical techniques (including two devices) are now available and may provide good control of seizures. Research on the underlying causes of epilepsy, including identification of genes for some forms, has led to a greatly improved understanding of these disorders that may lead to more effective treatments or even to new ways of preventing epilepsy in the future." ⁸⁷

⁸⁷ The Epilepsies and Seizures: Hope Through Research (2018), National Institute of Neurological Disorders and Stroke (NIH), modified: August 2018, https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Epilepsies-and-Seizures-Hope-Through

Australia Longitudinal Survey - Wave 4

The Australian Epilepsy Research Register (AERR) is a database of people who have epilepsy and their family or carers who have given permission to receive communication on an ongoing basis for the purpose of social and psychological research. The Register is an Australia wide project hosted by the Epilepsy Foundation Victoria with members invited to complete the Australian Epilepsy Longitudinal Survey (AELS). This survey takes place every three years and captures the experiences and any changes to the experiences of people with epilepsy, their families and carers. To date, there have been three formal research surveys from the Australian Epilepsy Longitudinal Survey. These are Wave 2 (2010), Wave 3 (2013) and Wave 4 (2017).

Registries are an important tool to obtain in-depth, high-quality information on the effectiveness and safety of medication and treatment generally. In 2017, there were a total of 1,328 eligible participants on the Australian Epilepsy Research Register. In all 393 of these completed the Wave 4 survey (response rate approximately 30%). Most were people with epilepsy (292) whilst 91 completed the survey on behalf of someone with epilepsy. There were two distinct groups in the sample. The first had well-controlled epilepsy or epilepsy in remission, and the second largely uncontrolled epilepsy with a greater need for support services.

Estimating the Economic Burden of Epilepsy in Australia

Epilepsy Australia and state members including Epilepsy Tasmania engaged Deloitte to quantify the economic burden of epilepsy in Australia. This report will be released in late 2019.

Infantile Epileptic Encephalopathies in Tasmania

A generous bequest allowed Epilepsy Tasmania to fund a three-year epidemiological study into the genetics of infantile Epileptic Encephalopathies (IEE) in Tasmania, the findings of which were recently published in the research paper in Epilepsia Open.

The purpose of the research was to discover the underlying genetic causes of the IEE condition which contributes significantly to the burden and cost of care for families and health systems through frequent hospitalisation for uncontrolled seizures.

Researchers at the Epilepsy Research Centre within the University of Melbourne performed detailed bioinformatics analysis of the sequencing data from the study and revealed that early diagnosis has positive consequences for identifying the most appropriate therapies and quality of life prognosis. The study reproduced the finding that severe epilepsies of infancy (SEI) are often caused by genetic diseases but although genetic, they are invariably new mutations in the child, rather than inherited.

The rate of SEI determined in the cohort is important due to the full capture of cases and has made an important contribution to the epidemiology.

Some of the cases have led to an expanded understanding of particular genetic conditions and for all patients, there is improved understanding of their disease, prognosis and treatment options.

The Way Forward

In Tasmania, a broad public health approach is needed to improve the care and quality of life of people with epilepsy. The implementation of policies and plans for epilepsy requires strong leadership and intersectoral collaboration. The management of comorbidities should be an essential component at all levels of care. Actions to improve access to medicines should be addressed at the international, national, district, community and individual levels.

Because the stigma of epilepsy can discourage people from seeking treatment and has consequences for the quality of life and social inclusion, **it is vital to increase knowledge and acceptance of the condition in schools, workplaces, and communities.**

Appropriate and integrated treatment of people with epilepsy requires that governments allocate sufficient funds for epilepsy care. Policy-makers need to ensure there are sufficient population and health care system data to determine the need for and evaluation of epilepsy care, identify appropriate training for providers, provide guidelines for quality health care, and allocate the required resources to ensure those living with epilepsy have access to adequate health and social services.

As the World Health Organisation states in **Epilepsy - A Public Health Imperative**, the care needs of people with epilepsy are multifaceted so comprehensive health care responses for people with epilepsy should involve providing health care and social services to decrease morbidity, premature mortality and adverse psychosocial outcomes associated with the condition. **Providing quality epilepsy care is a challenge because of its complexity, chronicity and considerable comorbidity.**

The spectrum of health care needs for people with epilepsy and their families can be viewed as a stepped model: starting with the initial diagnosis and continuing, as necessary, through to nonpharmacological therapies (e.g. surgery) for drugresistant epilepsy (see figure below). The management of comorbidities should be an essential component at all levels of care.

Multidisciplinary health care teams that emphasize person-centred care are also important in the stepped model (e.g. physicians, nurses, pharmacists, therapists and social workers). Community-based care should be emphasised to increase access to all people in need of epilepsy services. **Social and educational services should provide individualised support to people with epilepsy**, throughout the levels of care and should continue, as needed, even when the person is no longer having seizures.



Stepped model to improve quality of care for people with epilepsy

World Health Organisation - Stepped Model (Epilepsy - A Public Health Imperative)

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