

State Budget Community Consultation

Budget submission
2020-21 to 2021-24

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epilepsy
tasmania

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"Health promotion and illness prevention activities, and the delivery of care within health and social systems, can each benefit from coordinated and synergistic approaches.

Tasmania's relatively small geographic scale and the family, social and organisation connections within and between communities provide a good environment to support change. In doing so, we must ensure that the processes of change incorporate personal and community values including equity, choice, control and resilience, and engender trust and optimism."

Dr Mark Veitch, Director of Public Health

The Fourth State of Public Health Tasmania (April 2019)

"I note the tremendous work Epilepsy Tasmania undertakes to educate, train and also provide support leading up to and at the conclusion of appointments with doctors. This is in addition to programs and initiatives that can be implemented in schools or workplaces and assist people with epilepsy and those directly affected with returning to a normal life.

I am thankful to the amazing staff, volunteers and supporters who ensure Epilepsy Tasmania change lives and provide hope to those dealing with the wide-ranging challenges epilepsy brings. Importantly, these resources extend to parents, family, friends, carers, employers, medical researchers and healthcare professionals.

These valuable services are not always appreciated and it is an amazing privilege as Minister to witness a not-for-profit organisation genuinely impacting lives through the support and services they offer.

Once again, I want to acknowledge and thank all the wonderful supporters including staff and volunteers of Epilepsy Tasmania for all the work they do."

Past Minister for Health, The Hon. Michael Ferguson MP

Foreword to Epilepsy Tasmania's Annual Report, 2018

Introduction

This 2020-21 budget submission provides evidence of Epilepsy Tasmania's contribution to the State Government's agenda to create positive impacts on Tasmania's social determinants of health and recommends additional ways the organisation can support the goal of achieving a healthy Tasmania by 2025¹.

This submission is based on the fourth State of Public Health Report 2019, the Healthy Tasmania Five Year Strategic Plan; Rethink Mental Health - Better Mental Health and Wellbeing - A Long-Term Plan for Mental Health in Tasmania 2015-25; One Health System Reforms; and Tasmania's Active Ageing Plan 2017-2022.

Epilepsy Tasmania was previously funded within **Disability Services: Advocacy, Information, Communication**, however with the introduction of the NDIS and exclusion of epilepsy as a condition for NDIS support, the organisation lobbied for and received additional funding on 1 July 2018 from the Department of Health for a two-year initial agreement within **Planning Purchasing and Performance: Workforce, Recruitment & Support**.

Activities in Epilepsy Tasmania's initial funding agreement arose from the action plan **Stakeholder Engagement Framework: Engaging with the Tasmanian Epilepsy Community** which was an outcome of the independently commissioned report **Epilepsy Tasmania: A Briefing Paper (2016)**. Since then, Epilepsy Tasmania has invested in further research to provide even more Tasmanian-specific data **Epilepsy - A Focus on Tasmania (2019)** and is the only organisation in Australia to have undertaken such detailed state-specific research.

The funding it received has enabled the organisation to achieve more positive health outcomes than ever before and to significantly reduce pressure on Tasmania's clinical health services.

Over the last four years the organisation has commissioned two independent research documents to fully understand the condition of epilepsy within Tasmania and four statewide surveys to fully understand the gaps and needs of Tasmanians living with the condition. Attached to this submission are six significant and robust documents of evidence.

Epilepsy Tasmania welcomes the new Health & Wellbeing Minister and the Premier's Health and Wellbeing Advisory Council Work Plan 2018 - 2020 and looks forward to continued collaboration to improve Tasmania's health through community ownership and grassroots solutions.

¹ The Fourth State of Public Health Tasmania (April 2019)

About Epilepsy

2,3,4,5

Epilepsy is a chronic disorder of the brain characterised by abnormal electrical activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness.

Around four percent of Australia's population will develop epilepsy at some stage in their life, with 20,000 of these people living in Tasmania.^{6,7} Every person with epilepsy has approximately four more people providing care and support - **one fifth of the population.**

The Economic Impact of Epilepsy:^{3,4}

- Epilepsy is imposing a greater burden in Tasmania than elsewhere in Australia with expenditure during 2019-20 estimated at \$11.8 million.
- Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.
- Tasmania has the highest prevalence of epilepsy in Australia 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.
- 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.

The Everyday Reality of Epilepsy:^{2,5}

- Epilepsy is one of the most common neurological diseases (1 in 26 Australians are diagnosed with epilepsy during their life).
- Epilepsy is the third most common health condition in school-aged children.
- Risk of premature death for people with epilepsy is three times greater.
- People with epilepsy have increased risk of social isolation.
- Epilepsy is in the top five causes of avoidable death in the 5 to 29 age group.
- Half of people with epilepsy have coexisting physical or psychiatric conditions which are associated with poorer health outcomes, increased health care needs, decreased quality of life and greater social exclusion. The most prevalent co-morbidities are depression (23%), anxiety (20%), intellectual disability (30–40%).
- Seizures can affect memory, learning ability and health literacy levels.

² Epilepsy Australia 2018, *Epilepsy Explained*. <http://www.epilepsyaustralia.net/epilepsy-explained>, accessed March 2019

³ The Economic Burden of Epilepsy in Australia 2019-2020, Deloitte Access Economics for Epilepsy Australia June 2019

⁴ 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.

⁵ Epilepsy - A Focus On Tasmania. Epilepsy Tasmania, 2019.

⁶ Epilepsy Australia 2018, *Epilepsy Explained*. Available at: <http://www.epilepsyaustralia.net/epilepsy-explained>, accessed March 2019

⁷ The Economic Burden of Epilepsy in Australia 2019-2020, Deloitte Access Economics for Epilepsy Australia June 2019

About Epilepsy Tasmania

Epilepsy Tasmania is a not-for-profit community organisation that has been improving the quality of life and community participation of Tasmanians affected by epilepsy for over 40 years. **It is the only epilepsy organisation based in Tasmania delivering local services and support to Tasmanians.**

The organisation provides community-based holistic liaison between families and the healthcare sector (GPs, hospitals, specialists etc.), provides individualised support, and supplies resources, equipment, training and referral pathways.

Its priority is to keep Tasmanians well and healthy through advice and facilitated access to services and clinicians. Specifically, the organisation helps people establish new connections and support systems, communicate better with their medical specialists, draw up personal epilepsy and medication management plans, provides epilepsy first-aid training, physical and emotional support and advice.

With two-thirds of Tasmanians living in inner-regional locations and one-third living in outer-regional and remote locations,⁸ **Epilepsy Tasmania's allied health team travel statewide to bridge healthcare gaps** and increase the capacity and independence of Tasmanians who have epilepsy.

Epilepsy Tasmania prioritises achieving the Government's goal of ensuring all Tasmanians benefit from the equitable distribution of resources to fairly achieve and **maintain health and wellbeing of people with and at risk of the common chronic disease of epilepsy.**

In 2019, Epilepsy Tasmania conducted a **Tasmanian Health & Wellbeing Survey**⁹ with the results emphasising the need for more localised support in rural and urban areas. Respondents believed advertising campaigns, epilepsy ambassadors, education in schools and workplaces, and easier access to health care services were important to increase community awareness, understanding and acceptance of epilepsy. When asked what health providers can do for them, respondents said they want services to be more accessible and for health providers to be more understanding and educated about epilepsy.

The **World Health Organisation** recently announced 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.¹⁰

⁸ The State of Public Health, Tasmania 2018.

⁹ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

¹⁰ Epilepsy: a Public Health Imperative, World Health Organization, 2019.

Summary of Recommendations

Epilepsy Tasmania has been diligent and innovative in meeting and exceeding KPIs in the initial two-year funding agreement and it proposes to continue meeting current reforms outlined in the introduction of this submission.

The organisation is seeking ongoing financial assistance from the Tasmanian Government to enable it to continue providing support and services to the healthcare sector and individuals affected by epilepsy.

1. Epilepsy Tasmania will support the Government to create a healthy Tasmania by 2025.

The fourth State of Public Health Tasmania report suggests what a healthy Tasmanian population will look like by 2025 and Epilepsy Tasmania is able to contribute to six of its twelve priority statements:

Epilepsy Tasmania's Commitments To Creating a Healthy Tasmania:

1. We will all understand our health and wellbeing and how people can be and stay well.
2. We will share a strong sense of personal and community agency, connectedness and wellbeing.
3. All Tasmanians will benefit from the equitable distribution of resources to fairly achieve and maintain health and wellbeing.
4. Tasmanians whose mental health is poorer or at risk will bear no stigma. They will easily engage with accessible services to manage and avert progression of mental illness, and to restore good mental health. There will be fewer deaths by suicide.
5. Harmful and fatal misuse of prescription medications will be rare.
6. We will maintain the health of people with and at risk of common chronic diseases.

(This recommendation is embedded within all current KPIs).

2. Epilepsy Tasmania will support the Government's goal of reducing premature death from chronic disease by twenty five percent by 2025.

Epilepsy is in the top five causes of avoidable death within the 5 to 29 age group and the risk of premature death among people with epilepsy is three times higher than the general population. Of the approximate 342 epilepsy-related deaths in Australia each year around half can be prevented.¹¹

The major causes of death for people with epilepsy include accidents, drowning, status epilepticus, suicide and sudden unexpected death in epilepsy (SUDEP).

Epilepsy Tasmania will develop and implement a public awareness campaign that advises Tasmanians and their health specialists how to reduce the risk of premature death from epilepsy.

(This recommendation is additional to KPI numbers 2 and 3).

¹¹ The Economic Burden of Epilepsy in Australia 2019-2020, Deloitte Access Economics for Epilepsy Australia June 2019

3. Epilepsy Tasmania will reduce pressure on Tasmania's clinical health services by decreasing GP presentations and hospital emergency department admissions.

Tasmania is fortunate to have some excellent specialist care for epilepsy, however, general practice is the missing link in the circle of care. **GPs each have between 5 and 10 patients with epilepsy**, each one needing ongoing and regular care (personalised education, risk assessments, support, monitoring, management of co-morbidities, etc.). The continued involvement of the GP is critical to achieving positive health outcomes so Epilepsy Tasmania will increase support from its allied health team to general practices and ensure that provision and delivery of resources and referral forms will help reduce their workload and ultimately keep people out of hospitals.

Five percent of potentially preventable hospitalisations for acute-conditions are due to convulsions and epilepsy.¹² Government funding of Epilepsy Tasmania will achieve a very strong focus on prevention, promotion and early intervention with the following outcomes:

- Reduced number of epilepsy-related hospital emergency department admissions.
- Reduced number of epilepsy-related GP presentations.
- Increased health and wellbeing of Tasmanians affected by epilepsy.
- Increased community participation by people with epilepsy.

(This recommendation is additional to KPI number 3).

4. Epilepsy Tasmania will educate Tasmanians how to reduce their risk of developing epilepsy.

An estimated **25% of epilepsy cases are preventable** with several known and avoidable risk factors¹³:

- 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 brain conditions (dementia, Alzheimer's disease, etc.).

(This recommendation is additional to KPI number 2).

¹² Australian Institute of Health and Welfare. Potentially preventable hospitalisations in Australia by small geographic areas. Reporting years 2013-14. 2014-15. 2015-16. 2016-17. AIHW. 2018.

¹³ The Economic Burden of Epilepsy in Australia 2019-2020, Deloitte Access Economics for Epilepsy Australia, 2019

5. Epilepsy Tasmania will educate older Tasmanians and GPs how to reduce the risk of developing epilepsy as we age and why it is harder to diagnose and manage.

'Understand Me, Support Me: Epilepsy In Later Years' is a national suite of resources being developed to improve awareness of preventable risks and create better health outcomes for older people with epilepsy.

(This recommendation is additional to KPI numbers 2 and 3).

6. Epilepsy Tasmania will promote and support the health and wellbeing of Tasmanians affected by epilepsy.

Epilepsy Tasmania supports people with chronic conditions such as epilepsy which reduces the impact on individuals, families, community and economy.

It is known that when people are healthy and well they require less support from health services, are likely to have higher rates of workforce participation and be more productive at work.

Increased health and wellbeing includes mental health and Epilepsy Tasmania has allied health staff that incorporate a social worker and registered nurse.

Anti-stigma campaigns play a role in improving mental health outcomes as **24% of people with epilepsy have depression and 20% have anxiety.**

(This recommendation is embedded within all current KPIs).

KPI 1

Accessibility of the service

- New referrals to Epilepsy Tasmania
- Direct contact with Epilepsy Tasmania

Since 2018 Epilepsy Tasmania now has **accessible offices in both Hobart and Launceston** and regularly operates **outreach programs in other locations** across Tasmania.

People receive support and services from Epilepsy Tasmania through direct contact by walking into the offices, phoning, website contact form or emailing.

Health professionals and the healthcare sector refer people to the organisation over the phone, via online form or letter, and individuals can refer themselves or a family member.

To ensure everyone, regardless of income or location, can access support and advice the organisation provides a free **telephone-based peer support service** called Epilepsy Connect. The organisation is active on multiple social media platforms and facilitates two private Facebook support groups for Families & Carers and for young Tasmanians aged 13 to 24 years.

Epilepsy Tasmania has experienced a **dramatic 273% increase in the number of people referred to it** from 52 (pre-funding agreement) to 751 from July 2018 to June 2019 (post-funding agreement).

Referrals have increased by an additional 195 in the current reporting period, with December's month of uncollected data still to come.

Direct contact with Epilepsy Tasmania has nearly doubled since July 2018. 660 contacts were received during the six-months prior to 31 Dec 2018 compared to 1131 in the six-months prior to 30 Jun 2019.

Direct contact has since increased by an additional 788 in the current reporting period, with two months of uncollected data still to come.

KPI 2

Building client and community capacity and capability

2.1 Epilepsy Education Provided

A vital outcome of providing education is to ensure equity, access and inclusion, and to help reduce the stigma of epilepsy and discrimination that is endured by 52% of Tasmanians with the condition.¹⁴

More epilepsy-related education was a common request in the 2019 Health & Wellbeing Survey,¹⁵ in particular for increased training and education of GPs, Centrelink staff and other general workplaces.

Epilepsy Tasmania's education and training improves understanding of the condition of epilepsy and level of first-aid required during a seizure. Its allied health educators work with organisations of all sizes and across all sectors.

96% of Epilepsy Tasmania's training participants feel the educators are effective in facilitating their learning, and 100% are more confident supporting a person with epilepsy.

Provision of Epilepsy Education increased by 57% between 1 July 2018 and 30 June 2019 (71 in the six-months prior to 31 Dec 2018 and 112 in the six-months prior to 30 Jun 2019).

This has increased by an additional 83 provisions in the current reporting period, with December's month of uncollected data still to come.

Educate Me, Include Me: Epilepsy Smart Schools was launched in Tasmania by the Minister for Education, Mr Jeremy Rockcliff MP, in February 2019.

One in 200 school students has active epilepsy¹⁶ and around 15% of people with epilepsy have a learning disability and 30% of people with learning disabilities have epilepsy. Epilepsy Smart Schools aims to increase educational outcomes, ensure all students and teachers know what is required during a seizure, and decrease stigma and discrimination within the wider school community.

Epilepsy is the **third most common health condition in school-aged children** (in order it is diabetes, asthma, epilepsy then anaphylaxis) and one of the top five avoidable causes

¹⁴ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

¹⁵ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

¹⁶ Epilepsy Smart Schools, <https://www.epilepsysmartschools.org.au/>

of death among five to 29-year-olds.¹⁷

Since February, 49 schools have prioritised epilepsy training with five already achieving Epilepsy Smart accreditation and 44 currently undertaking the programme. Epilepsy Tasmania is committed to supporting the remaining 205 schools in the state.

Epilepsy Smart Workplaces is a Tasmanian education and training initiative that encourages workplaces to become more inclusive for staff, customers and visitors by creating understanding around the impact epilepsy has on people's lives and the level of workplace support they require. During October's WorkSafe Month, Epilepsy Tasmania's television and cinema advertising campaign resulted in a number of workplaces committing to becoming Epilepsy Smart.

2.2 Support Services Provided

One of the values of providing support services is to prevent poor health outcomes by providing holistic and accessible services, and ensuring prevention and early intervention.

Epilepsy Tasmania's allied health staff work with individuals and families to identify and avoid their personal seizure triggers, which is reducing GP presentations and hospital emergency department admissions.

The number of Support Services provided to individuals by Epilepsy Tasmania since 1 July 2018 has increased by 103% (509 in the six-months prior to 31 Dec 2018 to 1,034 in the six-months prior to 30 Jun 2019).

Provision of support services has increased to 1,553 in the current reporting period, with December's month of uncollected data still to come.

Allied health staff consult with healthcare providers, specialists, GPs, hospital and neuro-clinic staff and based on their feedback recently created a suite of online forms and downloadable resources specifically for Health Professionals. **Feedback for this time-saving portal is positive** and recognises it to be tailored for specific clinical needs and improved health outcomes.

2.3 and 2.4 Impact of Epilepsy Awareness & Anti-Stigma Campaigns

Stigma and discrimination are significant contributors to poor physical and mental health in people with epilepsy, and reduced access to education and employment.

¹⁷ Epilepsy - A Focus On Tasmania. Epilepsy Tasmania, 2019.

In four years Epilepsy Tasmania has seen an increased number of Tasmanians disclosing their condition to employers and schools and attributes this to a significant increase in its awareness and anti-stigma campaigns. However, a reduction in the stigma of epilepsy is conversely resulting in an **increase of reported discrimination, affecting 52% of Tasmanians with the condition** and most commonly at work and school.¹⁸

Epilepsy Tasmania is therefore now focused on reducing school and workplace discrimination in Tasmania and has a public relations and communication strategy in place to help achieve this.

Reducing Stigma & Discrimination

Epilepsy Tasmania is reducing the stigma and discrimination that surround epilepsy in two distinct ways:

- Supporting people with epilepsy to counter prevailing negative attitudes.
- Changing negative public attitudes through public awareness campaigns

Epilepsy Tasmania's e-Newsletter - Brainwaves - is read by over 800 people each month and its database of Friends increased by 39% during the twelve months up to 30 June 2019.

The organisation is active on multiple social media platforms and facilitates two private Facebook support groups. It achieved a 24% increase in Facebook followers during the twelve months up to 30 June 2019 and the number of people it reached through its posts was 207,383.

Epilepsy Tasmania is **proactive in creating media opportunities and achieved 45 instances of media coverage** during the twelve months up to 30 June 2019 that reached over 400,000 people.

The organisation has strong evidence of the combined positive impact these initiatives are having on awareness and stigma: increasing numbers are seeking out epilepsy advice and services; people are disclosing their condition to employers and teachers; people are willing to talk publicly about their condition; volunteer participation has increased; and an unprecedented number of applications for its Board of Governance were recently received.

¹⁸ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

KPI 3

Effectiveness and appropriateness of the service

- Prevented GP presentations
- Prevented hospital emergency department admissions
- Satisfied clients

Five percent of potentially preventable hospitalisations for acute-conditions are due to convulsions and epilepsy.¹⁹ The predicted number of epilepsy-related GP visits in Tasmania during 2019-20 is estimated at 10,263.²⁰

Early intervention from Epilepsy Tasmania's allied health team is successfully reducing pressure on Tasmania's clinical services by preventing an increasing number of these GP presentations and hospital emergency department admissions:

GP presentations that were prevented have increased 207% from 57 in the six month reporting period up to 31 Dec 2018 to 175 in the six month reporting period up to 30 Jun 2019.

Preventions have further increased to 274 in the current reporting period, and December's month of uncollected data is still to come.

Hospital emergency department admissions that were prevented have increased from 1 in the six month reporting period up to 31 Dec 2018 to 11 in the six month reporting period up to 30 Jun 2019.

Preventions have further increased to 12 in the current reporting period, and December's month of uncollected data is still to come.

Epilepsy Tasmania has conducted four statewide surveys to fully understand the gaps and needs of Tasmanians living with the condition and based on these results has prioritised its focus to ensure clearer pathways and interface between community and clinical healthcare.

In the Health & Wellbeing Survey²¹ respondents emphasised the importance of listening to people with epilepsy, giving them a proactive voice and of providing greater awareness of epilepsy-related services, with many respondents congratulating Epilepsy Tasmania on already achieving this.

¹⁹ Australian Institute of Health and Welfare. Potentially preventable hospitalisations in Australia by small geographic areas. Reporting years 2013-14. 2014-15. 2015-16. 2016-17. AIHW. 2018.

²⁰ Epilepsy - A Focus On Tasmania. Epilepsy Tasmania, 2019

²¹ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

Investment Required to Implement

This document provides evidence of how Epilepsy Tasmania is exceeding the KPIs in its current funding agreement, improving the health and wellbeing of Tasmanians and keeping people out of hospitals and GP waiting rooms.

Increasing demand on the organisation has seen it need to employ additional staff to meet the needs of the Tasmanian epilepsy community and clinical healthcare sector, which will continue to increase as evidenced in this submission.

Government investment in Epilepsy Tasmania will allow the organisation to continue meeting its KPIs and additionally to implement the identified Government goals in the fourth State of Public Health Tasmania report to achieve a healthy Tasmanian population by 2025.

\$480,000 per annum, for four years.

Appendices

Evidence to support submission

1. Epilepsy - A Focus on Tasmania. Epilepsy Tasmania, 2019.
2. Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.
3. Epilepsy Tasmania's Strategic Framework 2018 - 2021.
4. Epilepsy Tasmania - A Briefing Paper, 2016
5. The Economic Burden of Epilepsy in Australia 2019-2020. Deloitte Access Economics for Epilepsy Australia, 2019. *(not for public use until official release in early 2020)*
6. Epilepsy: A Public Health Imperative (Summary). World Health Organisation, 2019.