

State Budget Community Consultation

Budget submission
2021-24

Submitted by Epilepsy Tasmania CEO: Wendy Groot
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Phone: 0427 044 074

Email: wendy.groot@epilepsytasmania.org.au

epilepsy
tasmania

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"I congratulate the Board of Epilepsy Tasmania on significantly building greater awareness of epilepsy in Tasmania and for delivering information and support to the Tasmanian community.

The Tasmanian Government is pleased to have supported Epilepsy Tasmania and we look forward to continuing our strong relationship over the coming years."

The Hon Peter Gutwein MP, Premier
(January 2020)

"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)

Introduction

Epilepsy Tasmania is currently receiving funding from the State Government and this additional funding request is in response to a new suite of programmes and resources developed during COVID-19 and is based on participant feedback to continue their provision. We anticipate this being done by a new part-time employee who will also operate our outbound telephone support service. Current staff are working at capacity and cannot meet the needs being met by these important new initiatives.

In this submission, we provide 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; One Health System Reforms; and Our Healthcare Future Immediate Actions and Consultation Paper 2020.

Over the last five years the organisation has commissioned two independent research documents to fully understand the condition of epilepsy within Tasmania and five statewide surveys to fully understand the gaps and needs of Tasmanians living with the condition.

Epilepsy Tasmania values Our Healthcare Future Immediate Actions and Consultation Paper 2020 and looks forward to continued collaboration to improve Tasmania's health through community ownership and grassroots solutions.

New Initiatives to Meet Changing & Increasing Demand

Since COVID-19, Epilepsy Tasmania has increased its priority of the mental health and wellbeing of Tasmanians affected by epilepsy to ensure they remain connected and supported.

In its last survey of Tasmanians who have epilepsy, 60% list feeling isolated as their second biggest challenge of the condition (after not being able to drive).

Through a Commonwealth-funded pilot project, an independent consultant was commissioned to undertake a confidential Australia-wide service gap analysis with one element being the impact of COVID-19 on service delivery. They reported that Epilepsy Tasmania was the only organisation in Australia to establish a new programme during COVID-19 to support the mental health and wellbeing of people living with epilepsy.

Specifically, it was referring to Epilepsy Tasmania's:

- ✓ implementation of an outbound mental health telephone service
- ✓ direct contact with businesses
- ✓ development and delivery of resource packs for healthcare providers
- ✓ over 214 visits to healthcare providers
- ✓ new healthcare portal with downloadable resources on the website

These initiatives are now being emulated by a number of epilepsy organisations around Australia.

Epilepsy Tasmania's response supports the recommendations and priorities outlined in the Premier's Economic & Social Recovery Advisory Council Covid-19 Response, Interim Report, July 2020 (PESRAC), page 8.

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 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.

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.

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 the primary and only epilepsy provider in Tasmania.

It 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 45 years.

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.**

Epilepsy Tasmania's **Tasmanian Health & Wellbeing Survey**⁹ emphasised 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

The organisation is seeking additional financial assistance from the Tasmanian Government to provide a professional outbound telephone support service to individuals affected by epilepsy. And to increase its support, resources, training and information to GPs and health practices.

The following recommendations will support discussed Government priorities.

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 with four particularly relevant to this additional funding request:

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.**

2. 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.¹¹ The predicted number of epilepsy-related GP visits in Tasmania during 2019-20 is estimated at 10,263.¹²

¹¹ 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.

¹² Epilepsy - A Focus On Tasmania. Epilepsy Tasmania, 2019

Government funding of Epilepsy Tasmania will achieve a 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.
- ✓ Workforce development to assist with employment and retention of Tasmanians with epilepsy.

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

In addition, the organisation has over the last 12 months:

- **developed a resource pack for healthcare providers** to ensure awareness of all services Epilepsy Tasmania can provide to them and their patients. This initiative was developed in response to the devastating death in June of a teenager with epilepsy whose paediatrician and psychologist had not referred him or his family to Epilepsy Tasmania for support and specialist epilepsy advice.

Healthcare Provider resource packs include:

- NEW Epilepsy Tasmania Service Snapshot –services available for providers and patients.
 - NEW Epilepsy Tasmania Resource list – printable and online forms and brochures for providers to give patients.
 - NEW Epilepsy Tasmania Person-Centred Support Guide.
 - Referral forms to Epilepsy Tasmania and SEER diagnostics.
 - Epilepsy Management Plans.
 - Seizure diaries.
 - Seizure first-aid posters.
- Has completed **over 214 foot in the door visits** to healthcare providers, including 164 General Practice clinics (91 South, 44 North, 29 Northwest), 7 Neurologists, 18 Paediatricians and 25 Psychologists, plus statewide out-patient clinics and allied health centres.
 - **Provide a professional development workshop to GPs** this March (invited by the Royal Australian College of General Practitioners).

3. With regards to Appendix 1 of the PESRAC, Epilepsy Tasmania believes its new initiatives are helping the State Government to address the following issues:

- ✓ **Point 12**, Restoring Demand and Jobs: The State Government is helping Epilepsy Tasmania build its organisational capacity to recover from COVID-19 by modifying the funding contract in recognition of increased performance.
- ✓ **Point 13**, Restoring Demand and Jobs: The State Government is helping Epilepsy Tasmania build its capacity to recover from COVID-19 by modifying the funding contract in recognition of its flexible service delivery and development of new models.
- ✓ **Point 50**, Starting to Address the Structural Issues: The State Government is helping people recover from COVID-19 by recognising and prioritising the work of Epilepsy Tasmania to identify, engage support vulnerable cohorts that may have ongoing disproportionate adverse impacts during recovery, including through disruption to education, training and employment.
- ✓ **Point 54**, Starting to Address the Structural Issues: The State Government is helping people recover from COVID-19 by addressing digital inclusion and equity issues. In recognition that 17 to 32% of Tasmanian households do not have internet access, Epilepsy Tasmania is contacting those affected by epilepsy via the telephone.
- ✓ **Point 60**, Staying Focused on Addressing the Social Impacts: The State Government is helping people recover from COVID-19 by supporting Epilepsy Tasmania's improved client outcomes through digital and phone call service delivery.
- ✓ **Point 60**, Staying Focused on Addressing the Social Impacts: The State Government is helping people recover from COVID-19 by supporting Epilepsy Tasmania's new mental health and wellbeing telephone support service.
- ✓ **Point 63**, How Government Delivery Needs to be Different: The State Government is helping people recover from COVID-19 by supporting Epilepsy Tasmania's regional service to engage with remote participants by telephone and visit health practitioners at their workplace, in all areas of the state.

Building participant capacity and capability

Support Services

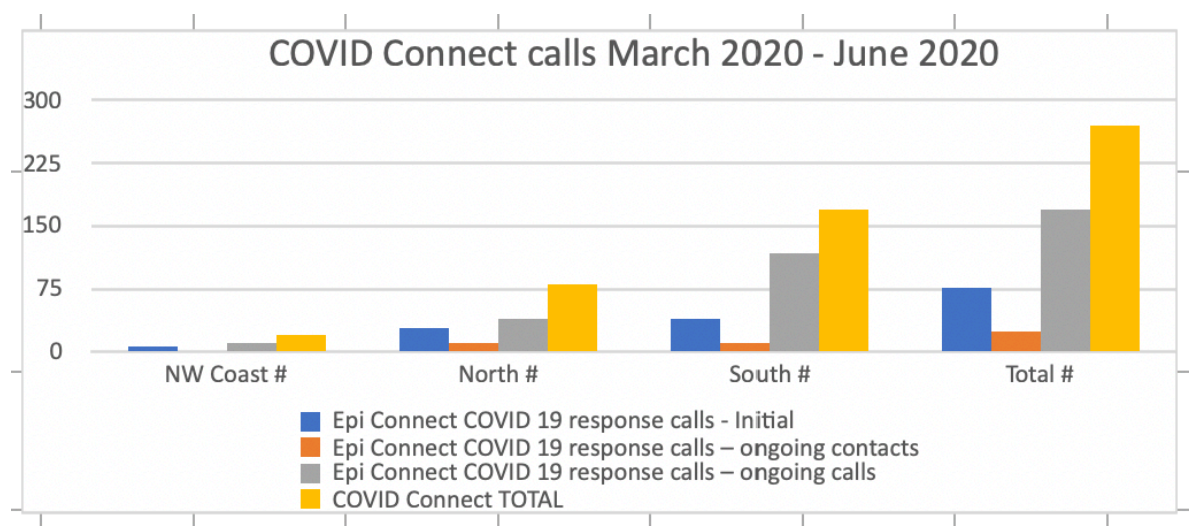
Epilepsy Tasmania has a need to recruit an additional professional social worker or suitably qualified person to make outbound telephone support calls to existing participants. This need became evident during COVID-19 lockdowns when staff called to check on the health and wellbeing and were consistently told that the calls helped reduce their sense of isolation and improve their mental health and wellbeing.

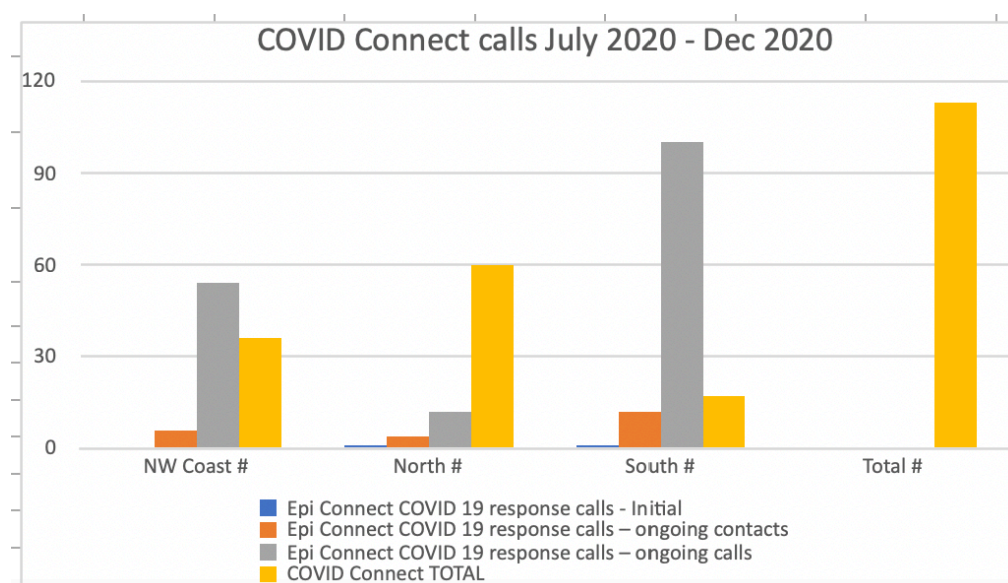
Providing a professional outbound telephone support service will help prevent poor health outcomes by providing holistic and accessible services, and ensure prevention and early intervention. It will also provide greater access and referral pathways to services.

The number of Support Services provided to individuals by Epilepsy Tasmania since July 2018 has increased dramatically by 233%

(509 services July to December 2018 to 1698 from July to December 2020).

The evidence for the need for an outbound phone-call service is based on one established during COVID-19 lockdowns. Staff made **269 phone calls** to 76 people, many of whom requested follow-up calls. This initiative was unable to continue when staff returned to normal duties, however, the need for this service remains as our current database has 970 Tasmanians who require support.





Through a Commonwealth-funded pilot project, an independent consultant was commissioned to undertake a confidential Australia-wide service gap analysis with one element being the impact of COVID-19 on service delivery. They reported that Epilepsy Tasmania was the only organisation in Australia to establish a new programme during COVID-19 to support the mental health and wellbeing of people living with epilepsy.

Epilepsy Tasmania is seeking funding support to recruit an additional part-time employee to continue providing regular support (phone and online) to Tasmanians who face isolation and health disadvantages as border uncertainty reduces access to interstate specialists and healthcare providers.

Epilepsy Tasmania conducts annual statewide surveys (five to date) 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 Survey¹³ 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.

¹³ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

Investment Required to Implement

Increased demand on Epilepsy Tasmania has meant staff have had to reduce their regular work provision in order to meet the higher service needs of the Tasmanian epilepsy community and clinical healthcare sector.

Government investment in Epilepsy Tasmania will allow the organisation to implement the identified Government goals in the fourth State of Public Health Tasmania report and the Our Healthcare Future: Immediate Actions and Consultation Paper 2020.

\$50,000 per annum will allow us to recruit an additional professional social worker or suitably person to staff the new outbound health and wellbeing telephone support service.

Total funding investment sought

\$50,000 per annum, for four years.