

Community Consultation

State Budget Submission 2021-24

Submitted by Epilepsy Tasmania, CEO Wendy Groot
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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)

"Too often Tasmanians end up in hospital because it's the only care available, not because they need hospital-level care. We need to change that, with better care options in our community.

We also need better planning to ensure we are getting the best patient outcomes for every dollar we spend."

The Hon Sarah Courtney, MP, Minister for Health
Our Healthcare Future, Immediate Actions and Consultation Paper, November 2020

Introduction

This submission calls on the State Government to fund a new preventative initiative developed at the onset of coronavirus when staff were unable to provide face to face support to Tasmanians with epilepsy.

The COVID-19 pandemic continues to cause physical and psychological challenges for people with epilepsy. The Mental Health Council of Tasmania stresses that psychological distress is not a mental illness - it is a normal human response to a situation that is frightening, confusing or upsetting. For people with epilepsy and those who support them, there is concern about how coronavirus will affect people with epilepsy; worry about how epilepsy medication may compromise the immune system; significantly reduced access to interstate healthcare specialists; increased social isolation due to infection control and government lockdowns; uncertainty about the future.

To address these challenges, at the onset of the pandemic Epilepsy Tasmania created a suite of new resources to inform GPs and healthcare specialists of how it could directly support them and their patients. It also diverted staff hours into outbound calling existing registered participants to check on their mental health and physical welfare. Although this demand remains, the capacity to do this is significantly limited by existing staff commitments – Epilepsy Tasmania is seeking funding to employ additional staff who can embed the Health and Wellbeing Telephone Service into the organisation.

The success of these outbound calls resulted in many Tasmanians with epilepsy calling for ongoing similar support as they live in regional areas, are unable to drive, unemployed and socially isolated due to uncontrollable seizures.

Based on recent experience, the organisation believes there is a need for 3 types of new support:

1. **Call in** - Tasmanians can phone to receive support from a trained support worker to discuss concerns and where appropriate, be directed to a referral service.
2. **Call out** – Staff will make contact with socially isolated Tasmanians identified on its database, and their caregiving family and friends. It will also personally advise health professionals of available support options.
3. **Reach out** – through partnership with workplaces, aged care centres and schools it will reach out with support services or assistance programs.

Epilepsy Tasmania will provide this support from its office in Hobart or Launceston and if needed, by staff working on-call from home. New staff will be professionally trained to deliver the high-quality support that Epilepsy Tasmania is respected for.

The new service will address the many issues around psychological stress and will provide information on the support available for those with epilepsy who are additionally impacted by the unprecedented changes in the way Tasmanians go about their daily lives, including social isolation, loss of employment, the impact on mental health, the financial challenges and reduced access to health professionals.

Epilepsy Tasmania is seeking \$100,000 per annum for an initial three-year period in order to establish and operate this Health & Telephone support service.

We anticipate that one new part-time employee will operate this telephone support service - current staff are working at capacity and cannot meet this additional need.

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 2025. ¹

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)

What is Epilepsy

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

Tasmania has the highest prevalence of epilepsy than any other state or territory in Australia. Around four percent of Australia's population will develop epilepsy at some stage in their life and 20,000 of these people live in Tasmania.²

Epilepsy is the second most burdensome neurological condition after dementia.³

^{4, 5}

The Everyday Reality of Epilepsy

- 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

- 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. Available at: <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.

About Epilepsy Tasmania

The peak voice for epilepsy within Tasmania and the only epilepsy service provider located here.

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 45 years.

It 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 overarching priority is to keep Tasmanians well and healthy through advice and facilitated access to services and clinicians.

Epilepsy Tasmania helps people with epilepsy as well as their family, schools, workplaces and caregivers to:

- Establish new connections
- Create physical and emotional support systems
- Communicate better with their medical specialists
- Draw up personalised seizure and medication management plans
- Learn practical epilepsy first-aid training and support options

Two-thirds of Tasmanians live in inner-regional locations and one-third are outer-regional and remote⁶ so **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 helps the Government achieve its 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**⁷ highlighted 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.⁸

⁶ The State of Public Health, Tasmania 2018.

⁷ Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

⁸ Epilepsy: A Public Health Imperative, World Health Organization, 2019.

Summary of Recommendations

The organisation is seeking financial assistance from the Tasmanian Government to provide a professional Health & Wellbeing telephone support service to individuals affected by epilepsy; and to increase support and resources to GPs and health practices.

The following three recommendations support Government priorities.

1 Epilepsy Tasmania is helping the Government 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.

Epilepsy Tasmania contributes to six of these twelve priority statements with four particularly relevant to this additional funding request.

Epilepsy Tasmania Commits to 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.

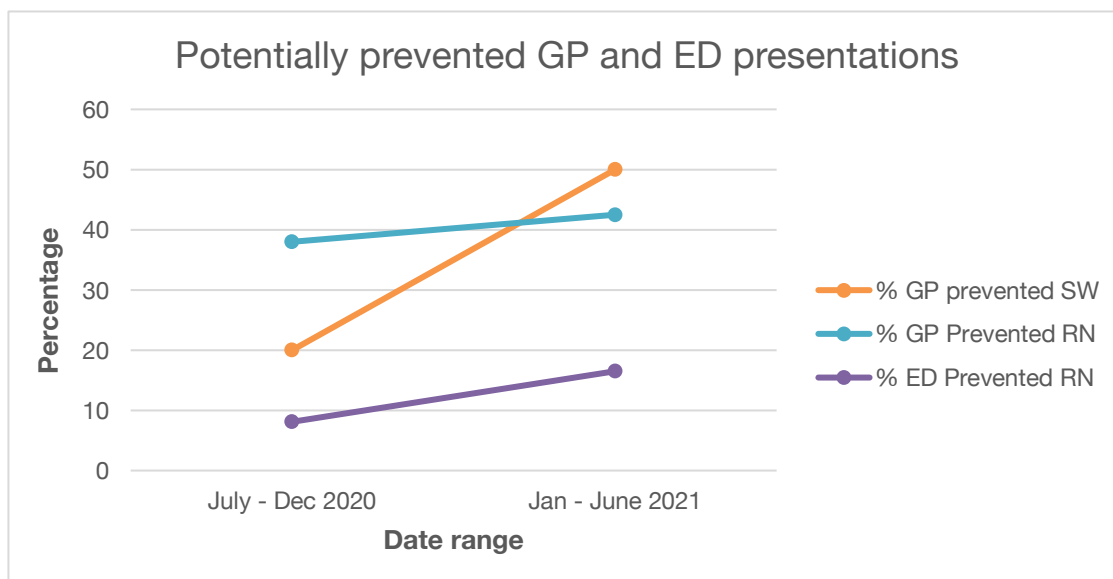
2 Epilepsy Tasmania will reduce pressure on clinical health services by decreasing the number of GP presentations and hospital emergency department admissions.

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 GPs are critical to achieving positive health outcomes, so Epilepsy Tasmania will increase GP support from its allied health team to ensure provision and delivery of resources and referral forms to help reduce their workload and keep people out of GPs and hospitals.

5% of preventable hospitalisation of acute conditions are due to convulsions and epilepsy.

The number of epilepsy-related GP visits in Tasmania during 2019-20 was 10,263. ⁹



The graph shows the percentage of General Practitioner (GP) and Emergency department (ED) presentations/hospital admissions that were potentially prevented due to contact with Epilepsy Tasmania. The percentage is calculated against the total number of people accessing services from the Epilepsy Tasmania Social Worker (SW) and Registered Nurse (RN) during the date range shown.

ED presentations to hospital in Tasmania. During the 3-year period (01/04/2017 and 30/03/2020), 3047 patients with epilepsy had 14,531 ED presentations (Primary Health Tasmania, 2021). ¹⁰

Epilepsy Tasmania's Preventative Contributions

Epilepsy Tasmania's RN potentially prevented 32 ED visits in the 12-month period from 1 July 2020 – 30 June 2021.

In this same 12-month period, Epilepsy Tasmania's RN and SW potentially prevented 184 individual GP consultations, including for Epilepsy Management Plan (EMP) development. Estimated cost per medium GP appointment is \$142 and Medicare rebates of \$75.05 per appointment, GP cost savings total \$13,809.2. Additional gap payment for patient potential \$66.95+ equals \$12,318.8

Total potential savings amount to \$26,128.

Many ambulance callouts have also been prevented through the development of EMPs as they provide details of how to manage a particular person in the event of a seizure.

⁹ 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.

¹⁰ Primary Health Tasmania. (2021). Epilepsy Review. Alex Kitsos. 28 July 2021. All data manipulation and presentation has been completed by Alex Kitsos, Health Analyst and Statistician at Primary Health Tasmania - akitsos@primaryhealthtas.com.au.

3 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 presentations.
- ✓ 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:

- **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 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.
- **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.
 - **provided professional development to GPs** (at the invitation of the Royal Australian College of General Practitioners).

Appendix 1 of the PESRAC - Epilepsy Tasmania will help the State Government address:

- ✓ **Point 12 Restoring Demand and Jobs:** With additional staff employed to implement the new Health & Wellbeing Telephone Support Service.
- ✓ **Point 13 Restoring Demand and Jobs:** With flexible service delivery and development of new models.
- ✓ **Point 50 Starting to Address the Structural Issues:** By identifying, engaging and supporting vulnerable cohorts with disproportionate adverse impacts, including through disruption to education, training and employment.
- ✓ **Point 54 Starting to Address the Structural Issues:** By addressing digital inclusion and equity issues for the 17 to 32 percent of Tasmanian households who do not have internet access.
- ✓ **Point 60 Staying Focused on Addressing the Social Impacts:** By improving client outcomes through digital and telephone service delivery.
- ✓ **Point 63 How Government Delivery Needs to be Different:** By engaging remote participants via digital and telephone options and visiting statewide health practitioners at their workplace.

4 On average, one out of 16 beds in our hospitals is occupied by someone with a potentially preventable admission – that is around two people on each and every ward.¹¹

People end up in hospital because it is the only care available, not because they need hospital-level care.¹¹ **Conservative estimates suggest this equates to a potentially avoidable cost of between approximately \$33 million and \$47million per annum.**

Epilepsy Tasmania has potentially prevented 32 Emergency Department visits and 184 individual GP consultations over 12 months from 1 July 2020 to 30 June 2021 saving the State Government a potential of **\$26,128.**

Many ambulance callouts have also potentially been prevented through the development of Epilepsy Management Plans (EMPs).

¹¹ Our Healthcare Future, Immediate Actions and Consultation Paper, November 2020

Building participant capacity and capability

Health and Wellbeing Telephone Service

The success of outbound calls during Coronavirus lockdowns resulted in many Tasmanians with epilepsy requesting ongoing similar support. This is because many reside in regional areas, are unable to drive, unemployed and socially isolated due to uncontrollable seizures.

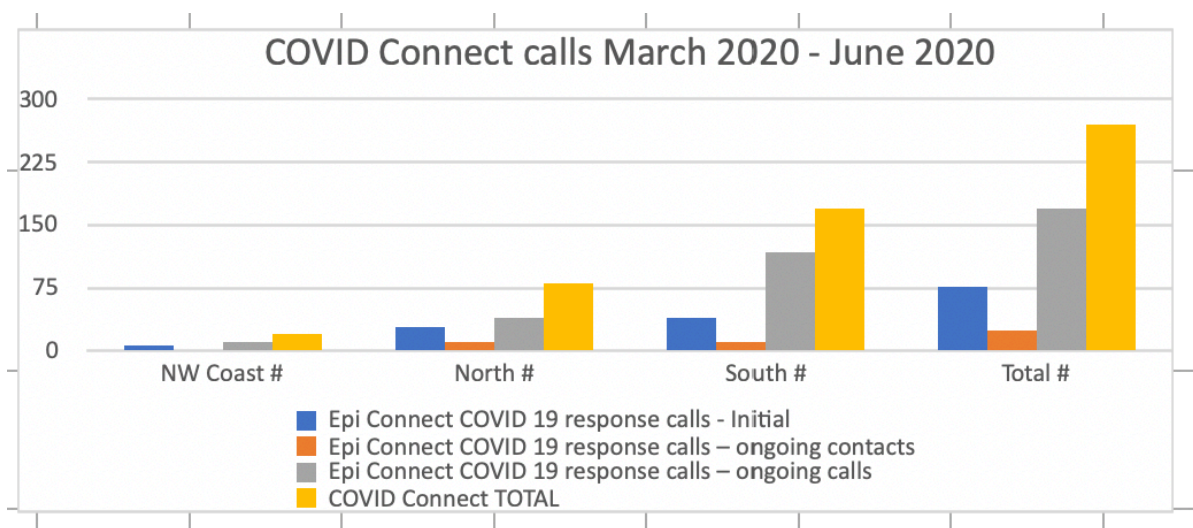
Based on recent experience, the organisation believes there is a need for 3 types of new support:

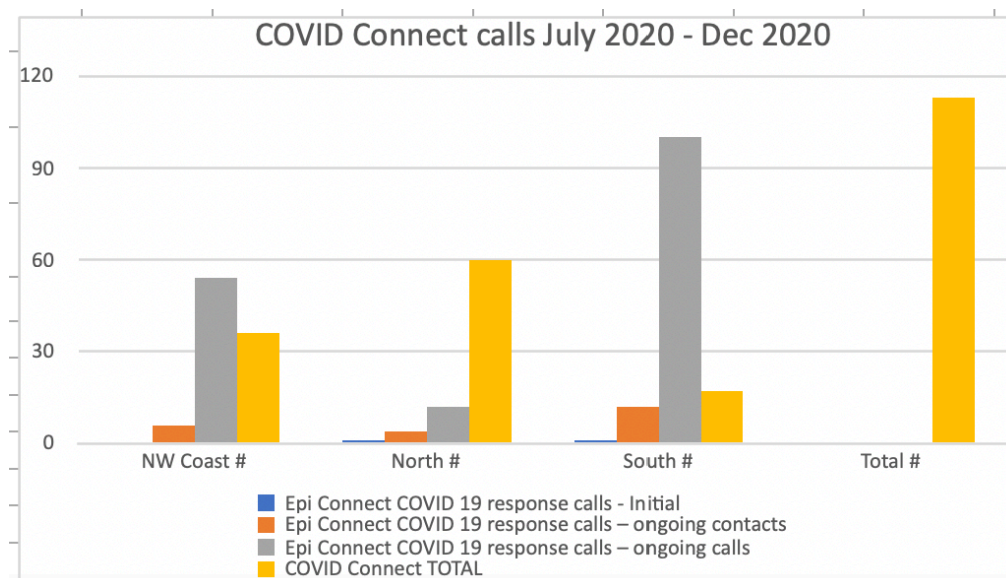
1. **Call in** - Tasmanians can phone to receive support from a trained support worker to discuss concerns and where appropriate, be directed to a referral service.
2. **Call out** – Staff will make contact with socially isolated Tasmanians identified on its database, and their caregiving family and friends. It will also personally advise health professionals of available support options.
3. **Reach out** – through partnership with workplaces, aged care centres and schools it will reach out with support services and assistance programs.

Epilepsy Tasmania has increased its number of Support Services to individuals since July 2018 by 282%

(509 between July and December 2018, up to 1946 between January and July 2021)

The evidence for the need of a Health & Wellbeing telephone support service was 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, its need remains with around 1,000 Tasmanians requiring 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 continued uncertainty reduces access to interstate specialists and healthcare providers.

Epilepsy Tasmania conducts annual statewide surveys to understand the gaps and needs of Tasmanians living with epilepsy. Based on these results it is prioritising clearer pathways and interface between community and clinical healthcare.

In the Health & Wellbeing Survey¹² 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.

¹² Epilepsy Health & Wellbeing Survey. Epilepsy Tasmania, 2019.

Investment Required

Increased demand on Epilepsy Tasmania has required staff reduce their regular work provision to meet the higher service needs of Tasmania's epilepsy community and clinical healthcare sector.

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

The organisation is seeking \$100,000 from the Tasmanian Government to provide a professional Health & Wellbeing telephone support service to individuals affected by epilepsy; and to increase support and resources to GPs and health practices.

Return on investment for the Tasmanian Government is a further reduction in the number of prevented Emergency Department (ED) visits. Epilepsy Tasmania was directly responsible for potentially preventing 32 ED visits between 1 July 2020 – 30 June 2021.

In this same 12-month period, Epilepsy Tasmania's Registered Nurse and Social Worker potentially prevented 184 individual GP consultations. Estimated cost per medium GP appointment is \$142 with Medicare rebates of \$75.05 = GP cost savings of \$13,809. Additional gap payment for patient potential is \$66.95 = \$12,318.

Potentially saving the Tasmanian Government \$26,128.

Many ambulance callouts have also been prevented through the development of EMPs as they provide details of how to manage a particular person in the event of a seizure.

**Additional funding investment request is
\$100,000 per annum, for three years.**