

Mr Andrew Barr MLA
Chief Minister
ACT Legislative Assembly
GPO Box 1020
CANBERRA ACT 2601

Re. 2018-19 Budget Submission - Support for people with epilepsy in the ACT

Dear Chief Minister,

Please find below our submission to the ACT Government Budget Consultations 2018-19 for your consideration.

Epilepsy ACT has been assisting people diagnosed with epilepsy in Canberra for over 30 years. Epilepsy affects people in different ways and can affect people at any age. Statistics show that around 8000 Canberrans are managing one of the various forms of epilepsy.

Epilepsy ACT provides accessible support, information, education and connections for people living with epilepsy in the ACT, their families, their support network and the community. Our vision is that every person living with epilepsy in our region to feel safe, connected and able to reach their potential.

As well as supporting individuals, we aim to deliver and promote innovative community education programs to ensure that every person living with epilepsy can live, go to school, or work in a safe, supportive and understanding environment.

An epilepsy diagnosis impacts a person's whole life and independence – affecting their participation in employment, education, sport and recreation, including their ability to drive.

A recent survey of people with epilepsy living in the ACT, showed that Epilepsy ACT provided crucial and timely support for individuals and families from diagnosis through to the management of their condition. This local and personal support has a significant positive impact for families navigating a stressful diagnosis. This information and support is not able to be provided in a short GP or Specialist appointment (which often takes several months to schedule).

Current position

Epilepsy ACT funds its service delivery with a combination of fee for service training delivery, fundraising, donations and government funding. While the organisation is in a strong financial position, government funding is important to ensure the capacity of the organisation to deliver the essential services in the ACT community.

The introduction of the National Disability Insurance Scheme in the ACT has meant that Epilepsy ACT no longer receives funding through Disability ACT. It has become clear that treating epilepsy as a disability, for the purposes of funding, does not fit the new NDIS funding model. This is due to the fact that the outlook for many people with epilepsy is to live the most normal life they can as long as they have the right support and treatment in place.

Epilepsy Association ACT Inc.

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Epilepsy ACT is undertaking a strategic review which has highlighted that while all avenues to become self-sufficient, through expanded fundraising and fee for service activities, there remains a shortfall to provide the free, flexible and timely support that individuals and families touched by epilepsy rely on.

Current need

Epilepsy ACT needs to engage a paid, part-time clinical staff member to deliver some of the essential services Epilepsy ACT provides such as Epilepsy Management Plans for school students, people accessing care services, and people entering a new workplace.

This clinical professional may be a qualified Nurse, Occupational Therapist, Social Worker or Counsellor. Their understanding of the medical terminology and the system, will add value and credibility to the Epilepsy ACT service. Clients will trust their support in navigating the best possible care and management. They will also assist the organisation in accessing networks and partnerships in the health sector which are vital in providing wrap around care. They will also deliver some of the training to organisations supporting people with epilepsy.

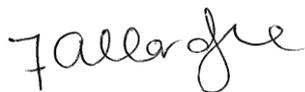
The costings below outline the additional funding needed by Epilepsy ACT to employ an appropriately qualified professional and cover a small part of the organisations administration costs. This will ensure we can continue to provide a valued local service, supplementing the health sector in the ACT.

Costings

ITEM	INDICATIVE COST
Clinical professional to provide home visits, specialised support, epilepsy management plans, training.	\$50,000
Rent and office expenses	\$25,000
Administration support	\$20,000
TOTAL	\$95,000

I appreciate your consideration and would welcome an opportunity to meet with you or your representatives to discuss this further.

Yours sincerely



Fiona Allardyce
Executive Director