Epilepsy Connect: establishing a telephone-based peer support service for Tasmanians

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**Introduction**

Epilepsy is a common neurological condition in which a person has a tendency to have recurring seizures. It comprises many seizure types and can develop at any age regardless of gender or background.¹

As many as one in every 100 Australians will have epilepsy at any given time² but the burden of epilepsy is much more than the seizure itself. People with epilepsy report increased levels of anxiety, depression and poor self-esteem.³,⁴ In Tasmania, high to very high levels of psychological distress have been observed in patients with epilepsy compared to the general population.⁵

Self-management of epilepsy is also known to be challenging.⁶,⁷ Stress⁸, alcohol use⁹, sleep deprivation¹⁰ and poor medication adherence¹¹ are all known to increase the risk of seizures in people with epilepsy. Good self-management is key to ensuring these risk factors are minimised.¹²

Peer-support has been shown to improve psychosocial wellbeing and self-management for a range of health conditions and issues including depression¹³, type 2 diabetes¹⁴,¹⁵, multiple sclerosis¹⁶, smoking during pregnancy¹⁷ and breastfeeding.¹⁸ Peer-support has also been shown to reduce the stigma of epilepsy.¹⁹

Furthermore, research has specifically demonstrated the benefits of telephone-based peer support for a variety of health conditions and issues including:

- reduced distress among women diagnosed with a breast cancer gene mutation²⁰
- improved antipsychotic medication adherence in people with schizophrenia²¹
- increased uptake of mammography screening²²,²³
- increased duration of exclusive breast feeding²⁴

Telephone-based peer support therefore has the potential to address psychosocial needs and self-management behaviours for people living with or affected by epilepsy.

Currently in Tasmania there is limited peer-support for people with epilepsy. There is a well-established face-to-face support group in Hobart and face-to-face support groups have recently been initiated in Launceston, Devonport and Burnie. Barriers to community members accessing these face-to-face groups are numerous and include geographical distance, lack of driver’s license or transport, stigma, time and comfort level engaging with groups.

Epilepsy Connect has therefore been established as a pilot project to assist in reducing the burden of epilepsy in Tasmania by providing equitable access to peer support for people living with, or affected by the condition.

This paper describes the process for establishing Epilepsy Connect, and associated learnings.
Methods

Epilepsy Connect is a pilot program developed in partnership with Epilepsy Tasmania and funded by the Tasmanian Community Fund. It is a telephone-based peer support service for Tasmanians living with or affected by epilepsy, including family members, partners and carers. The program is based on the well-established Cancer Council Australia model known as Cancer Connect and is a free and confidential service that connects someone who is affected by epilepsy with a trained volunteer who has had a similar epilepsy experience. Volunteers can offer practical information and emotional support to people living with or affected by epilepsy. Clients can receive up to six phone calls within a 3-month period. Anyone requiring more than this is referred to a professional counselling service.

The key steps involved in establishing Epilepsy Connect are described below.

Funding

The Tasmanian Community Fund (TCF) provides grants to “community organisations that make a difference by improving the social, environmental and economic wellbeing of the Tasmanian community.”

The Centre for Rural Health, University of Tasmania in partnership with Epilepsy Tasmania, applied for a medium TCF grant in March 2015.

Funding was sought for:

- project management/coordination
- project evaluation
- training package development
- workshop facilitation
- post-training clinical supervision of volunteers
- design and printing of training materials
- design and printing of marketing materials
- training workshop catering
- travel, accommodation and meals for training 10 volunteers
- public launch
- volunteer phone call reimbursement.

Consultation

Key stakeholders were identified during the application phase, and invited to take on an advisory role throughout the implementation of the project.

Community feedback was sought via three consultations conducted in the South, North and North West regions of Tasmania respectively. These consultations took place during regular face-to-face peer support group meetings, to ensure representative communities were engaged. Discussion focussed on perceived benefits and challenges of Epilepsy Connect; possible client issues/questions; barriers to and enablers of using Epilepsy Connect; peer support volunteer attributes; the Epilepsy Connect model; and promotion.

Evaluation design

A study protocol and low risk ethics application were developed to evaluate the program.
The evaluation was designed to assess:

- the effect of Epilepsy Connect on psychosocial wellbeing
- the effect of Epilepsy Connect on self-management behaviours that reduce the risk of seizures (eg, getting enough sleep, reducing stress, limiting alcohol consumption, taking medication as prescribed)
- the experience of Epilepsy Connect from a client’s perspective.

A 34-question pre- and post- peer support survey was designed to measured anxiety, depression, positive affect/well-being and epilepsy self-management, based on four validated instruments:\(^26,27\):

- NeuroQoL – Anxiety – Short Form
- NeuroQoL – Depression – Short Form
- NeuroQoL – Positive Affect and Well-Being – Short Form
- Epilepsy Self-Management Scale.

In addition to the survey, a semi-structured telephone interview schedule was developed to gain an in-depth understanding of a client’s Epilepsy Connect ‘experience’.

In order to publish the results in a peer-reviewed journal, ethics approval was sought from the Tasmanian Health and Medical Human Research Ethics Committee (project number H15803).

**Volunteer recruitment**

Once ethics approval was received, an advertisement calling for peer support volunteers was circulated via social media and through Epilepsy Tasmania’s email distribution list. Interested individuals were sent a Peer Support Volunteer Information and Application Pack, detailing the scope of the position and eligibility criteria. The pack was adapted from the Orygen Youth Health Peer Support Worker Information and Application Pack 2015.\(^{28}\)

All applicants were invited to attend an interview. The purpose of the interview was to gauge an applicant’s suitability as a peer and to ensure they fully understood the role. It was made clear during the interview that training formed part of the recruitment process and did not automatically guarantee them a position as a peer support volunteer.

This 3-step recruitment strategy was based on advice from Cancer Council South Australia (Hygonnet C 2015, oral communication, 23 February) to ensure volunteers were in a sound position to provide peer support, given that they were also living with epilepsy or caring for someone with the condition.

Funding was available for up to ten volunteers; the first round of recruitment saw four volunteers apply and complete the training.

**Volunteer training**

Training took place over two and a half days and comprised a day of epilepsy management education, and one and a half days on peer support and communication. The latter was delivered by a clinical psychologist, and designed to provide volunteers with practical experience in providing peer support over the phone using role-plays.

Information within the training manual was adapted from Epilepsy Australia\(^{29}\) and the Cancer Council Victoria BRCA 1/2 Peer Support Program Volunteer Training Manual.\(^{30}\)
**Marketing and promotion**

Promotion of Epilepsy Connect commenced with a public launch of the program in September 2016 and continued via unpaid media, social media, direct emails and word-of-mouth. Due to the finite capacity of the volunteers, promotional activities were rolled out gradually in order to keep potential demand for the service in-check.

**Results**

**Funding**

The proposed project plan outlined in the grant application included applying for ethics before the project could commence. As a result, the TCF agreement included a provision that funding would only be available once ethics was approved. The ethics process is often a long one and in this case was only relevant to the evaluation component of the plan. To ensure timely progress of the project, this provision was renegotiated to allow a third of the funds to be made available immediately.

**Consultation**

Eighteen people living with or affected by epilepsy (including carers) attended the community consultation workshops held around the state. Hobart had the largest attendance due to the epilepsy support group having been established for several years. Workshops in the North and North West of the state were linked to newly established epilepsy support groups and as such, attendance was relatively low.

Common responses emerged amongst all three groups and overall, the feedback about Epilepsy Connect was positive, with many commenting that they wished they had such a service when they were first diagnosed. Most concerns raised were around the logistics of the service.

**Evaluation design**

The original evaluation design aimed to measure the effect of Epilepsy Connect on psychosocial wellbeing; self-management behaviours that reduce the risk of seizures; and the experience of Epilepsy Connect from a client’s perspective, using a combination of pre and post validated surveys and follow-up interviews. On commencement of the service, the pre and post surveys were deemed too onerous for clients, and so a simpler evaluation questionnaire was devised. Although less rigorous in terms of methodology, a simple post-program questionnaire and follow-up interview will provide sufficient information to evaluate the program and is likely to be more acceptable to clients.

**Recruitment**

The first call for volunteers received several expressions of interest but no applications. The main reason was because training was scheduled to take place over three weekdays and most volunteers were unavailable due to work or family commitments.

Subsequently, the volunteer positions were readvertised and those who had expressed some interest were contacted directly to determine preferred days and dates. Training was re-scheduled for a Friday, Saturday and Sunday and four applications were received.

Three of the applicants had epilepsy themselves and one had a partner and two children with epilepsy. All were women aged over 30 years, and in all cases, their or their family’s epilepsy was well managed. Three of the women had completed University degrees and worked in their chosen profession.

All applicants were interviewed and subsequently invited to participate in training.
**Training**

Training took place in Launceston and was well attended by volunteers and Epilepsy Tasmania staff.

General feedback from volunteers was overwhelmingly positive, with the opportunity to meet others and learn new skills seen as the ‘best things’ about training.

Evaluation showed volunteers agreed or strongly agreed that as a result of the training they:

- had a better understanding of epilepsy and its impact on lifestyle and wellbeing
- had a better understanding of the volunteer role and its boundaries
- felt confident in providing first aid for any type of seizure;
- felt confident in their ability to provide basic information about epilepsy to a peer
- felt confident in their ability to reflect the content and feelings of a conversation
- felt confident in their ability to validate how a person is feeling
- felt confident in the use of open ended questions
- felt comfortable acknowledging when they don’t know the answer
- felt confident in providing peer support over the phone.

Although the number of volunteers was much less than originally planned (four vs ten), the small group size was seen as a positive by volunteers, staff and trainers alike. This was especially the case during role-plays, allowing plenty of time for constructive feedback and opportunity for continuous improvement over the two and a half days.

**Marketing, promotion and uptake**

The public Launch of Epilepsy Connect in September 2016 resulted in two television news stories, one radio news story, two printed articles and four online articles.

After some teething problems with the online referral system, nine registrations for the service were received in the 6 months following the launch; seven on-line self-referrals and two referrals from within Epilepsy Tasmania. This averages out to around one client per volunteer per 3-month peer support allocation period. Although a seemingly low uptake of the service, nine clients is deemed a manageable load for the volunteers as they begin to implement their skills and knowledge learnt in training.

**Discussion and future directions**

Epilepsy Connect was established as a pilot project to help reduce the burden of epilepsy in Tasmania. It aims to provide equitable access to peer support for people living with or affected by the condition. It is especially relevant for people who:

- live in rural and remote Tasmania;
- have limited access to peer support groups;
- prefer to maintain a sense of anonymity; or
- prefer one-on-one support over group support.
The process for establishing Epilepsy Connect as a new telephone-based peer support service resulted in some challenges around the recruitment of volunteers, community uptake and evaluation design. Good communication and strong commitment from all partners ensured these challenges were minimised.

Future recruitment will focus on including men, more carers, and a broader range of epilepsy types, as part of the peer support volunteer mix. This will ensure a more inclusive service and allow for better matching of clients to volunteers.

There will also be a focus on increasing the volume of people who use the service in line with the number and capacity of volunteers. In particular, General Practitioners, Epilepsy Specialists and Pharmacies will be targeted as key points for client referral.

Finally, the value and impact of the service will be measured based on the revised evaluation design, with a view to conducting a subsequent study using the original pre- and post- peer support questionnaire. The results from these evaluations will provide the foundations for extending the service nationally.

Conclusion

To our knowledge, there are currently no organisations nationally or internationally that provide a formal telephone-based peer support service for people living with or affected by epilepsy. This paper has described the process for establishing Epilepsy Connect, challenges encountered and future directions.

Presenter

Simone Lee is a lecturer at the Centre for Rural Health, University of Tasmania, and has a background in health promotion, public health, nutrition, health literacy and chronic disease prevention and management. Simone completed a Master of Nutrition and Dietetics at the Flinders University of South Australia and went on to complete her PhD in medicine in 2005. Her passion for health equity lead to an 18-year career in public heath, working in the not-for-profit sector in both South Australia and Tasmania. As a result, she has developed expertise in the areas of cancer prevention, asthma management, workplace health and wellbeing, and epilepsy management. She has recently joined the University of Tasmania as an academic in rural health, and her current research interests include health literacy, bowel cancer screening participation, and access to health services and support for people living with or affected by epilepsy.

References


29 Epilepsy Australia, 2006 [cited 1 April 2017]. Available from URL: http://www.epilepsyaustralia.net/epilepsy-explained/