

維多利亞癲癇基金會

THE EPILEPSY FOUNDATION

OF VICTORIA INCORPORATED
REG. NO. A002267 4D

認識我們 *Who we are*

維多利亞癲癇基金會是一個以人為本的組織，為維多利亞省內受癲癇症影響的市民提供協助。

The Epilepsy Foundation of Victoria is a consumer-based organisation, which aims to take every opportunity to enhance the quality of the lives of people living with epilepsy.

本會的宗旨是為受癲癇症影響的市民提供全面及一系列針對性的服務及活動，促進病患者及其家屬積極面對生活，提升生活質素，幫助他們融入社會。

Our mission is to provide a comprehensive and responsive range of services and programmes to meet the personal, interpersonal, socio-economic and cultural needs of people living with epilepsy.

我們本著公平，接納，奉獻及創新的精神為市民服務。

We strongly believe in the values of equity, access, participation, ownership, commitment, leadership and innovation.

我們的歷史 *Where we began*

維多利亞癲癇基金會的前身是維多利亞癲癇症事務局(Victorian Bureau for Epilepsy)，由一群熱心的家長于 1964 年創立，目的是為了延續在 1963 年關閉的 Talbot Colony for Epileptics 的使命，向省內受癲癇症影響的市民提供支援及有關資料。

The Epilepsy Foundation of Victoria was formed by a group of concerned parents in May 1964 to provide support and information to all Victorians affected by epilepsy. Initially called the Victorian Bureau for Epilepsy, one of the first priorities was accommodation following the closure in 1963 of what was known as the Talbot Colony for Epileptics.

1978 年本會正式易名為維多利亞癲癇基金會。其後幾年本會持續發展，包括任命專業醫學人員為顧問及設立醫學諮詢小組。

The organisation's name changed to the Epilepsy Foundation of Victoria in 1978 and the next few years saw its continued rapid development including the appointment of a consultant medical officer and the establishment of a medical advisory panel.

踏入二十一世紀，維多利亞癲癇基金會堅守為病患者服務的信念，致力提升他們的生活質素，喚起大眾對癲癇症的關注和認識。

Throughout the 1990s and into the 21st century, the Foundation will continue to work towards the aims of enhancing the quality of life for people living with epilepsy, and improving community awareness and understanding.

服務 *Our Services Include:*

資訊服務 ***Information on epilepsy***

我們擁有全面的癲癇症資訊，包括書籍，小冊子及期刊，並會定期製作有關癲癇症的單張，錄音帶及錄影帶供大眾參考，藉以提高社區人士對癲癇症的認識及瞭解。以上資料均有多種語言以供選擇。

We offer Australia's most extensive information services including a wide range of books, pamphlets and information sheets. Videos, DVD's and other items are available for individuals with epilepsy, families, friends, carers, service providers, employers and the general community. Information is also available in community languages.

輔導服務 ***Skilled Counselling – a multidisciplinary approach***

一群資深的輔導員提供適當的輔導治療予癲癇症患者，並協助剛被診斷為癲癇症患者及其家屬適應過渡期。

Our team of counsellors understand epilepsy as a medical condition and are able to provide a range of effective counselling therapies. Newly diagnosed individuals, parents and families can receive ongoing support during this period of adjustment.

專業輔導員會在現行駕駛條例，工作場所歧視等方面提供意見。此外，亦會替他們解決生活上和學習上的問題。

Professional staff members are also available to assist with issues such as the current policy on driving, workplace discrimination, life-style strategies, assistance in the classroom and support for parents and carers.

資源中心 ***Library***

本會的資源中心提供各類有關癲癇症的資料，收藏超過 1500 本書籍，各種錄影帶及 DVD，一系列有關癲癇症的文獻及期刊，大量有關如可照顧癲癇症病人及解決生活上難題等的資料。

The Foundation's library boasts the best epilepsy-specific collection in Australia. There are over 1500 book titles, a variety of videos & DVD's, a complete collection of journals on epilepsy and extensive current information files dealing with epilepsy & issues related to living with epilepsy.

資源中心在講座，工作坊和會議期間均會繼續開放，歡迎各界人士到本會總部(Camberwell) 閱覽及索取有關資料，開放時間為星期一至五上午九時至下午五時。

書籍及錄影帶可供本會會員外借。

During library open hours (9.00am – 5.00pm Monday – Friday) you are welcome to come to the Foundation's head office in Camberwell and to seek information from our collection of materials. The library is also accessible during seminars, workshops and group meetings at the Foundation and our range caters for all levels from children to adults. Foundation members are eligible to borrow books and videos.

可供購買書籍及報告 ***Purchasing Resources***

基金合作社(Foundation resources shop) 供應精選書籍，急救護身飾物(S.O.S Talisman Jewellery & iD 4 ME) 及藥物分隔盒(pill dispenser)等。

A selected number of books are available through the Foundation resources shop, which also stocks medical ID jewellery, pill dispensers, etc.

個案跟進 ***Case Management for complex & long term solutions***

本會輔導員以領導和支援的角色，與醫療機構通力合作，協助解決復習的個案。

Our counsellors are involved either as lead or support counsellors with other agencies and medical personnel in the management of some very complex conditions.

提倡者 ***Advocacy – personal, state & national***

為了減少癲癇症患者所面對的歧視及誤解，我們和顧主，機構及政府合作，增強大眾人士對癲癇症的瞭解和對病患者的接納，達至社會共融。

Many people with epilepsy have to cope with prejudice and misunderstanding in their daily lives. We work with employers, organisations, governments and individuals to change these situations.

社區教育 ***Community education***

我們會因應各機構的不同要求到社區中心，醫療機構，商業機構，學校，政府部門及團體，提供相關講座。

We provide responsive, often tailored information services including talks to community organisations, health & welfare groups, business, education providers, students, state institutions and other groups.

講座 ***Seminars***

舉辦各類型有關癲癇症的講座，主題包括最新的研究報告內容和癲癇症治療方法，迎合不同病患者及家屬的需要，以協助他們適應生活上的變化。

The needs of people with epilepsy and their families differ according to their circumstances and their type of epilepsy. We conduct seminars with specialist speakers to assist those living and caring for people with epilepsy as well as keeping them informed about the ongoing research into the understanding and treatment of epilepsy.

訓練課程 ***Specialised training programmes***

本會與政府部門合作，為醫務人員，病患者及家屬提供認可訓練課程及工作坊。課程內容圍繞與他們息息相關的議題，例如認識癲癇症，解決生活難題，理解手術程式和養育病童要點等。

The Foundation has developed accredited training programmes, modules and workshops, often in conjunction with government agencies, for delivery to health professionals, people with epilepsy and their carers. The seminars aim to cover a range of issues relevant to people with epilepsy & their families such as understanding epilepsy, lifestyle factors, surgery, parenting a child with epilepsy, & gender specific issues.

特別活動 ***Special Events***

特別活動包括維多利亞省內中小學常識問答比賽 (Trivia Challenge) ，特別籌款活動，社區論壇及關注小組等。

These include the very popular Trivia Challenge quiz for Victorian schools, special fundraising and social events, community forums & discussion groups.

Epilink

Epilink 是一個打破地域界限的電話網絡。輔導員將已登記的會員連系在一起，讓他們透過電話分享生活上的喜與悲，互相鼓勵和支持。

Often restricted by an inability to travel, this telephone link programme allows clients to provide mutual support and fellowship to each other under the professional guidance of counsellors.

網上資源(Epinet) ***An online epilepsy resource***

本會建立了全國第一個有關癲癇症資訊的網站(<http://www.epinet.org.au>)，提供全面的癲癇症資訊，網上討論區，輔導員連絡方法及連結到全球各地相關網站。

The Foundation developed Australia's first epilepsy website (www.epinet.org.au). It has extensive epilepsy information, hosts internet discussion groups, email contact with counsellors and ranks many worldwide epilepsy links.

康樂營 ***Recreational camps for people with epilepsy & their families***

一年一度的康樂營讓一群擁有相同經歷的患者及其家人透過不同活動互相學習。康樂營可分為成年組和家庭組，成年組訓練他們學習獨立；家庭組提供一個平臺讓不同家庭分享照顧患者的心得，互相扶持。

These annual camps provide each person with the chance to experience activities that for many of us are commonplace. For some attending the Adult Camp, it is their first time of being away from their families. The Family Camp provides an environment where parents, siblings and children with epilepsy can enjoy their time away from home with others who understand what it is like to live with epilepsy in the family.

住宿服務 **Accommodation**

本會提供免費的短期住宿服務予正在接受治療或檢查的病者及其家人，以方便他們到鄰近醫療中心或醫院診治。

Central to all major epilepsy clinics, the Foundation provides short term accommodation for partners and families who are in hospital undergoing extensive testing, seizure monitoring, brain surgery and other procedures.

門診支援及醫院探訪 **Clinic support & hospital visits**

輔導員與醫療機構緊密合作，包括在癲癇治療及複康中心駐診，亦會定期到醫院探訪病患者。

Our counsellors work closely with health professionals, including attendance at epilepsy clinics and first seizure clinics. They also visit patients in major hospitals.

研究 **Research**

為了讓病患者有更好的生活，本會持續在有關議題上進行研究。希望透過提交實證研究報告予政府官員，從以改善他們的生活質素。本會歡迎各界人士參與研究和關注小組，有興趣的人士可到本會接待處索取表格。

The EFV undertakes applied research into the issues that most affect the lives of people with epilepsy and their families. Our aim is to improve the lives of people with epilepsy by providing evidence-based research to policymakers & health professionals. People interested in participating in research such as surveys & focus groups can join our research register by obtaining a form from the Epilepsy Foundation reception.

權利與義務 Rights & Responsibilities

我們提供 What you can expect from us:

- 全天候的關懷，關愛及尊重
To be treated with care, compassion, respect and dignity at all times
- 一群專業及明白你需要的輔導員，給予你們貼身的服務
To receive a quality service from trained staff, which recognises your individual needs
- 清晰及明確的資訊
That information will be delivered in a clear & understandable manner
- 平等的服務，不分種族，宗教，政治，區域，性別，語言，年齡，殘障，性別取向或健康狀況
That you will receive a service which does not discriminate on the basis of race, religion, political beliefs, gender, age, sexuality, disability, location, language, or health status

- 一個安全的管道予你們抒發對本會的意見
That you can express any concerns about the service you have received from us with no fear of disadvantage

我們期望 What we expect from you:

- 獲得準確及完整的資料
Assist us by giving accurate & complete information about your epilepsy & other relevant issues
- 得到任何有關會面時間更改或延遲的通知
That you keep your appointment or notify us if you have been delayed or need to cancel
- 你們尊重任何與輔導員訂立的協議
Respect any agreement made between you & your Client Services Counsellor
- 所有員工都得到禮貌的對待及尊重
Treat staff & others in the service with courtesy & respect

私隱聲明 *Privacy & Confidentiality*

維多利亞癲癇基金會的資料保護政策是履行澳洲法律 (Commonwealth) Privacy Act 1988 和維多利亞省(Victorian) Information Privacy Act 2000 規定的責任，嚴格確保所得的個人資料將受到保護，避免未經許可或意外查閱。

As a registered disability service provider we will do our utmost to ensure that any information we collect from you is secured and accessed respectfully in line with the (Commonwealth) Privacy Act 1988 & the (Victorian) Information Privacy Act 2000.

投訴途徑 *Complaints Process*

歡迎各界人士對本會的服務提出意見或投訴，令本會有機會客觀地進行檢討並在適當的時候作出改善。

The Epilepsy Foundation of Victoria welcomes feedback from people who might have an issue, concern or complaint about the service they have received from us. This gives us an opportunity to objectively review our service and implement improvements where necessary.

任何人士如對本會的 Client Service Staff Team 服務感到不滿或認為得不到充足的援助，可與 Client Service Manager 聯絡。閣下可親自或授權他人以口頭或書面方式作出投訴。為了方便跟進，請儘快聯絡我們的職員。假如事情仍未能解決，個案將呈交本會行政總裁處理。

If any person with epilepsy, family member, carer or service provider feels that they have received less than an adequate level of service from any member of our Client Services staff team, we encourage them to bring the matter to the attention of the Client Services Manager. The complaint can be verbal or written and can be made by the person who has the concern or by someone nominated by that person. It is preferable to make contact with us as soon as possible after the event. If the matter cannot be resolved at this level, it will be referred to the Chief Executive Officer.

假如維多利亞癲癇基金會未能解決閣下的問題，歡迎致電 9603 8323 與 Disability Services Commissioner 聯絡。

If the Epilepsy Foundation of Victoria is not able to resolve your complaint then you may choose to contact the Disability Services Commissioner at Level 3, 456 Lonsdale Street, Melbourne, 3000. Telephone: 1800 677 342 or 1300 728 187 (local call) TTY: 1300 726 563

Fax: 03 9603 8310 Website: <http://www.odsc.vic.gov.au>

THE EPILEPSY FOUNDATION OF VICTORIA INCORPORATED

The Victorian member of *Epilepsy Australia* – Australia's peak consumer-led
Epilepsy organization

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Email: epilepsy@epilepsy.asn.au Website: <http://www.epinet.org.au>

Grampians Regional Office: The Cooina Centre, 10 Learmouth Road, Wendouree, Ballarat, 3355
Tel: 03 5338 1277

Barwon / South West Regional Office: Barwon Design Park, 400 Pakington Street, Newtown, Geelong, 3220
Tel: 03 5223 1645