

维多利亚癫痫基金会

THE EPILEPSY FOUNDATION

OF VICTORIA INCORPORATED
REG. NO. A002267 4D

Simplified Chinese

认识我们 **Who we are**

维多利亚癫痫基金会是一个以人为本的组织，为维多利亚省内受癫痫症影响的市民提供协助。

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.

本会的宗旨是为受癫痫症影响的市民提供全面及一系列针对性的服务及活动，促进病患者及其家属积极面对生活，提升生活质素，帮助他们融入社会。

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.

我们本着公平，接纳，奉献及创新的精神为市民服务。

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

我们的历史 **Where we began**

维多利亚癫痫基金会的前身是维多利亚癫痫症事务局(Victorian Bureau for Epilepsy)，由一群热心的家长于 1964 年创立，目的是为了延续在 1963 年关闭的 Talbot Colony for Epileptics 的使命，向省内受癫痫症影响的市民提供支援及有关资料。

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 年本会正式易名为维多利亚癫痫基金会。其后几年本会持续发展，包括任命专业医学人员为顾问及设立医学咨询小组。

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.

踏入二十一世纪，维多利亚癫痫基金会坚守为病患者服务的信念，致力提升他们的生活质素，唤起大众对癫痫症的关注和认识。

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.

服务 ***Our Services Include:***

资讯服务 ***Information on epilepsy***

我们拥有全面的癫痫症资讯，包括书籍，小册子及期刊，并会定期制作有关癫痫症的单张，录音带及录影带供大众参考，藉以提高社区人士对癫痫症的认识及了解。以上资料均有多种语言以供选择。

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.

辅导服务 ***Skilled Counselling – a multidisciplinary approach***

一群资深的辅导员提供适当的辅导治疗予癫痫症患者，并协助刚被诊断为癫痫症患者及其家属适应过渡期。

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.

专业辅导员会在现行驾驶条例，工作场所歧视等方面提供意见。此外，亦会替他们解决生活上和学习上的问题。

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.

资源中心 ***Library***

本会的资源中心提供各类有关癫痫症的资料，收藏超过 1500 本书籍，各种录影带及 DVD，一系列有关癫痫症的文献及期刊，大量有关如可照顾癫痫症病人及解决生活上难题等的资料。

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.

资源中心在讲座，工作坊和会议期间均会继续开放，欢迎各界人士到本会总部 (Camberwell) 阅览及索取有关资料，开放时间为星期一至五上午九时至下午五时。

书籍及录影带可供本会会员外借。

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.

可供购买书籍及报告 **Purchasing Resources**

基金会(Foundation resources shop) 供应精选书籍, 急救护身饰物(S.O.S Talisman Jewellery & iD 4 ME) 及药物分隔盒(pill dispenser)等。

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

个案跟进 **Case Management for complex & long term solutions**

本会辅导员以领导和支援的角色, 与医疗机构通力合作, 协助解决复杂的个案。

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**

为了减少癫痫症患者所面对的歧视及误解, 我们和顾主, 机构及政府合作, 增强大众人士对癫痫症的了解和对病患者的接纳, 达至社会共融。

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.

社区教育 **Community education**

我们会因应各机构的不同要求到社区中心, 医疗机构, 商业机构, 学校, 政府部门及团体, 提供相关讲座。

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

讲座 **Seminars**

举办各类型有关癫痫症的讲座, 主题包括最新的研究报告内容和癫痫症治疗方法, 迎合不同病患者及家属的需要, 以协助他们适应生活上的变化。

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.

训练课程 **Specialised training programmes**

本会与政府部门合作, 为医务人员, 病患者及家属提供认可训练课程及工作坊。课程内容围绕与他们息息相关的议题, 例如认识癫痫症, 解决生活难题, 理解手术程序和养育病童要点等。

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.

特别活动 **Special Events**

特别活动包括维多利亚省内中小学常识问答比赛 (Trivia Challenge) ， 特别筹款活动， 社区论坛及关注小组等。

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

Epilink

Epilink 是一个打破地域界限的电话网络。辅导员将已登记的会员连系在一起，让他们透过电话分享生活上的喜与悲，互相鼓励和支持。

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.

网上资源(Epinet) **An online epilepsy resource**

本会建立了全国第一个有关癫痫症资讯的网站(<http://www.epinet.org.au>)，提供全面的癫痫症资讯，网上讨论区，辅导员连络方法及连结到全球各地相关网站。

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.

康乐营 **Recreational camps for people with epilepsy & their families**

一年一度的康乐营让一群拥有相同经历的患者及其家人透过不同活动互相学习。康乐营可分为成年组和家庭组，成年组训练他们学习独立；家庭组提供一个平台让不同家庭分享照顾患者的心得，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.

住宿服务 **Accommodation**

本会提供免费的短期住宿服务予正在接受治疗或检查的患者及其家人，以方便他们到邻近医疗中心或医院诊治。

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.

门诊支援及医院探访 ***Clinic support & hospital visits***

辅导员与医疗机构紧密合作，包括在癫痫治疗及复康中心驻诊，亦会定期到医院探访病患者。

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***

为了让病患者有更好的生活，本会持续在有关议题上进行研究。希望透过提交实证研究报告予政府官员，从以改善他们的生活质素。本会欢迎各界人士参与研究和关注小组，有兴趣的人士可到本会接待处索取表格。

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.

权利与义 ***Rights & Responsibilities***

我们提供 **What you can expect from us:**

- 全天候的关怀，关爱及尊重
To be treated with care, compassion, respect and dignity at all times
- 一群专业及明白你需要的辅导员，给予你们贴身的服务
To receive a quality service from trained staff, which recognises your individual needs
- 清晰及明确的资讯
That information will be delivered in a clear & understandable manner
- 平等的服务，不分种族，宗教，政治，区域，性别，语言，年龄，残障，性别取向
or
或健康状况
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
- 一个安全的渠道予你们抒发对本会的意见
us
That you can express any concerns about the service you have received from us with no fear of disadvantage

我们期望 **What we expect from you:**

- 获得准确及完整的资料
Assist us by giving accurate & complete information about your epilepsy & other relevant issues
- 得到任何有关会面时间更改或延迟的通知
That you keep your appointment or notify us if you have been delayed or need to cancel
- 你们尊重任何与辅导员订立的协议
Respect any agreement made between you & your Client Services Counsellor
- 所有员工都得到礼貌的对待及尊重
Treat staff & others in the service with courtesy & respect

私隐声明 **Privacy & Confidentiality**

维多利亚癫痫基金会的资料保护政策是履行澳洲法律 (Commonwealth) Privacy Act 1988 和维多利亚省(Victorian) Information Privacy Act 2000 规定的责任, 严格确保所得的个人资料将受到保护, 避免未经许可或意外查阅。

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.

投诉途径 **Complaints Process**

欢迎各界人士对本会的服务提出意见或投诉, 令本会有机会客观地进行检讨并在适当的时候作出改善。

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.

任何人士如对本会的 Client Service Staff Team 服务感到不满或认为得不到充足的援助, 可与 Client Service Manager 联络。阁下可亲自或授权他人以口头或书面方式作出投诉。为了方便跟进, 请尽快联络我们的职员。假如事情仍未能解决, 个案将呈交本会行政总裁处理。

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.

假如维多利亚癫痫基金会未能解决阁下的问题，欢迎致电 9603 8323 与 Disability Services Commissioner 联络。

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

818 Burke Road, Camberwell, Victoria, Australia 3124

Tel: 03 9805 9111 or 1300 852853

Fax: 03 9882 7159

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

Grampians Regional Office:

The Coinda 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