IMPACT REPORT

2025

Epilepsy
Action
Australia

The Year in Focus

Now in its 73rd year, Epilepsy Action Australia remains a trusted companion on the journey for thousands of Australians living with epilepsy, helping them feel informed, supported, and empowered.

Our organisation is the leading national provider of specialist epilepsy services in Australia, supporting those living with epilepsy, the people who care for them, healthcare professionals, teachers, support workers, and others.

Whether it's a reassuring voice on the phone, a tailored training session, or a life-changing research breakthrough, our work is grounded in compassion, evidence, and a deep commitment to improving lives.

With an estimated 270,000 Australians living with epilepsy, our services are designed to be accessible and responsive: delivered via phone, video conference, community programs, and a growing suite of online tools and resources.

Epilepsy Action Australia exists to save and improve the lives of those affected by epilepsy. Our 'Vision', 'Mission', 'Values' and 'Key Focus Areas' as outlined below shape the way we behave and deliver our services and support.

Vision:	Inclusion, equitable access, and self-determination for people living with epilepsy.
Mission:	Epilepsy Action Australia drives positive change empowered by the collective voice of people living with epilepsy.
Values:	Client-centred, innovative, collaborative, efficient

Key Focus Areas:

1) Assistance and Support

We offer specialist information and services needed by those affected by epilepsy, their family and friends, and provide individualised support and self-management resources.

2) Education and Training

As Australia's leading provider of online epilepsy courses and resources we meet the learning and training requirements of a diverse range of audiences including children and adults affected by epilepsy, healthcare professionals, teachers, support workers and others.

3) Understanding and Awareness

Public awareness of epilepsy and its impacts is key to increasing understanding in the broader community and combating any stigma and ignorance that still exists.

4) Supporting Research

We are at the forefront of partnering and funding research into new interventions and treatments to help improve and save lives, optimising future outcomes for those with epilepsy.

A Year of Connection, Innovation, and Empowerment.

The following pages provide information about our activities and achievements over the past year.

A Heartfelt Thank You

At Epilepsy Action Australia, we are deeply grateful for the generosity and belief that fuels our work. As a not-for-profit organisation, we rely on the kindness and commitment of our community to continue delivering life-changing services.

Our funding comes from a diverse mix of sources, with around 60% made possible through individual donations, community fundraising, and philanthropic grants. A further 25% is generated through the sale of our trusted training programs. While we receive some government support, it's the passion and dedication of our supporters that truly sustains us.

To every donor, sponsor, partner, volunteer, and staff member... thank you. Your support helps us reach more people, respond to more needs, and create a more informed, inclusive, and empowered future for those living with epilepsy.

Together, we are making a real and lasting difference.

Planning for a Stronger Future

In 2024, Epilepsy Action Australia embarked on a comprehensive strategic planning process to guide our direction through to 2027. This was more than a routine exercise, it was a deliberate and inclusive effort to reflect on our achievements, respond to a changing landscape, and set a bold course for the future.

The process was informed by extensive consultation with people living with epilepsy, carers, healthcare professionals, researchers, and sector partners. We listened carefully to their insights, challenges, and aspirations. We also examined internal strengths and weaknesses, external influences, and emerging opportunities to ensure our plan was grounded in both reality and ambition.

The result is a refreshed Strategic Plan built around four key domains: Advocacy, Direct Services, Knowledge and Skills, and Research. Business Plans for each financial year during 2024-2027 focused on the four strategic domains. Each year will build on successes of the previous year, as well as identifying new opportunities and challenges that may arise, with the collective voice of people living with epilepsy at the centre of everything we do.

This plan positions Epilepsy Action Australia to be more responsive, more collaborative, and more effective in improving the lives of Australians living with epilepsy. It ensures our work remains client-centred, evidence-informed, and future-focused, because every person affected by epilepsy deserves access to the best possible support, wherever they are on their journey.

> *"This Strategic Plan reflects our deep commitment to the epilepsy community. It is bold, focused, and built on the voices of those we serve. We are proud to lead Epilepsy Action Australia into a future defined by innovation, inclusion, and impact."*
>
> **Erica Siu-Gregan, Chair of the Board**

New Initiatives

Epilepsy Action Australia constantly evolves to meet the changing needs of the epilepsy community. Our commitment to innovation is grounded in deep understanding of challenges faced by people living with epilepsy and those who support them. Every initiative we launch is designed to improve quality of life, enhance safety, and promote independence. Whether through digital tools, expanded services, or new partnerships, we continue to find smarter, more inclusive ways to deliver support, ensuring no one needs to face epilepsy alone.

This year, that spirit of innovation was reflected in initiatives like the launch of our online Epilepsy Management Plan Tool and early development of a dedicated children's service focused on supporting learning and educational outcomes for young people living with epilepsy, each designed to meet identified needs and create meaningful impact.

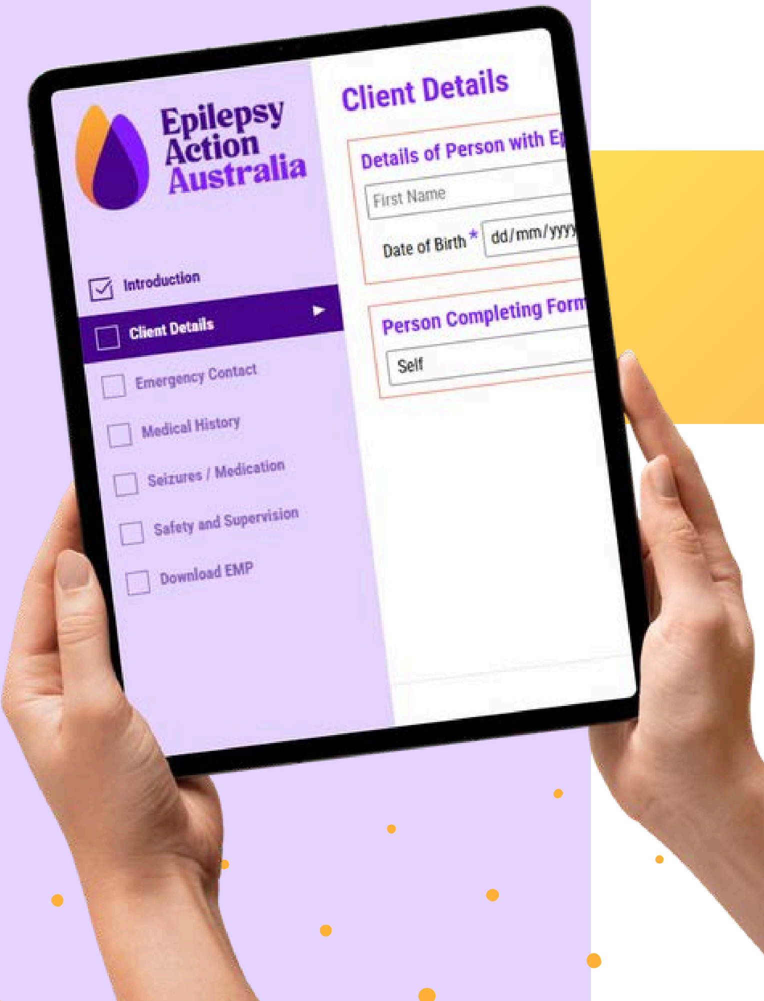
Self-Management Made Simple

We launched a new online Epilepsy Management Plan (EMP) tool, a free, interactive resource designed to help individuals take charge of their epilepsy care.

Developed in consultation with people living with epilepsy and healthcare professionals, the EMP tool guides users through a series of questions to create a tailored, downloadable management plan which can be shared with family, schools, workplaces, and healthcare providers, ensuring everyone is informed and prepared.

It is user and mobile-friendly, and designed to promote self-advocacy, safety, and confidence.

Since its launch a few months ago, the EMP tool has been embraced by over 2,000 individuals, families, and support networks across Australia, and is making a meaningful difference in how people manage and communicate their epilepsy needs.



Unlocking Potential: Helping Kids Thrive

Epilepsy Action Australia began developing its new children's service focused on addressing the educational challenges faced by children living with epilepsy. Epilepsy can affect memory, attention, language, and problem-solving, making learning more difficult and often misunderstood in classroom settings. Our emerging program takes a holistic, child-centred approach, starting with a comprehensive needs assessment and leading to an Individual Service Plan tailored to each child's goals. A key feature will be the imminent launch of an innovative Active Learning e-Tool to generate personalised strategies for classroom and home learning based on each child's unique challenges, especially valuable for families who face barriers accessing specialist support due to location, waitlists, or cost. By equipping families, educators, and children with practical tools and knowledge, we can reduce learning barriers and help every child with epilepsy thrive in their education and beyond.

CLIENT-CENTRED INNOVATION

Support when it matters most

Once again more than 10,000 people reached out to the National Epilepsy Line this past year, where our experienced specialist Epilepsy Nurses provided personalised support, reassurance, and expert guidance, often at life-changing moments.

Since its launch in 2019 and supported with funding from the Australian Government Department of Health, Disability and Ageing, the National Epilepsy Line has become a lifeline for thousands of Australians affected by epilepsy. It is the only national epilepsy telehealth service delivered by Registered Nurses with specialist training in epilepsy and continues to be the gateway to Epilepsy Action Australia's broader range of services.

Every call, email, or message is met with compassion and expertise. Whether someone is newly diagnosed, navigating the NDIS, managing medication, supporting a loved one, or simply needing to talk, our nurses are there to listen, and offer guidance and support. No question is too small, and no concern is ever dismissed.

The service is free and available nationwide, supporting not only people living with epilepsy, but also their families, teachers, employers, and healthcare professionals. In recent years, we've expanded access through digital platforms like HealthShare and BetterConsult, making it easier for GPs to access epilepsy information and resources, and connect patients with the right support at the right time.

National Epilepsy Line
1300 37 45 37

Beyond the helpline, our Epilepsy Nurses also provide more comprehensive and tailored services to individuals and families, including education around emergency medication, seizure safety planning, and navigating complex care needs. When additional support is needed, such as counselling or employment assistance, we help people connect with trusted external service providers and resources.

The National Epilepsy Line is backed by an extensive resource hub containing trusted, evidence-informed resources including fact sheets, videos, checklists, and self-management tools—all regularly reviewed by our clinical and research teams to ensure information is accurate and current.

As a registered NDIS provider, we are proud to offer services that are not only clinically sound, but also deeply human. Because when someone reaches out, they deserve to feel heard, understood, and supported.

Real Help.

Real People. Real Impact.

Building skills and confident inclusive communities

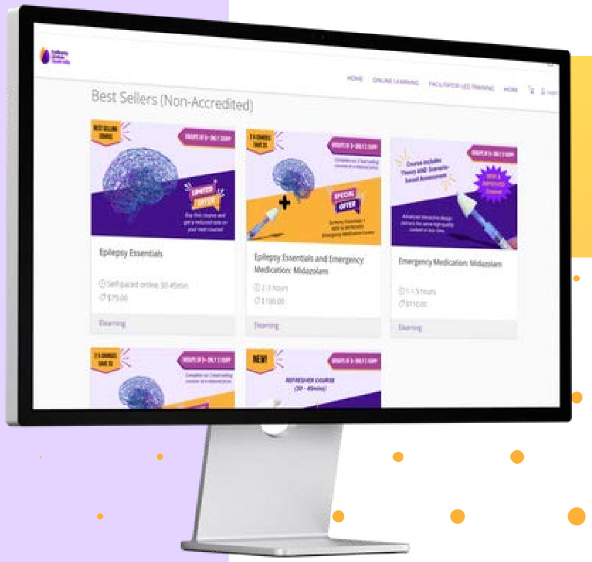
Thousands of learners participated in our epilepsy training programs, gaining the knowledge and confidence to better support people living with epilepsy. These programs continue to build skills and foster safer, more inclusive environments.

For someone living with epilepsy, the difference between being understood or misunderstood can be life changing. In schools, workplaces, and community settings, a lack of awareness can lead to isolation, fear, and even physical harm during a seizure. Education is critical, not just for safety, but for dignity, inclusion, and opportunity.

Our training programs equip people with practical skills to recognise seizures, respond appropriately, and support individuals with epilepsy in everyday life. But they also challenge outdated perceptions, reduce stigma, and build empathy. When educators, carers, and peers understand epilepsy, they help create environments where people feel safe to be themselves, where children can learn without fear, and adults can participate fully in their communities.

Epilepsy Action Australia's Online Academy offers flexible, user-friendly training options tailored to the needs of families, educators, disability support workers, and health professionals. Our accredited and non-accredited courses cover everything from foundational epilepsy knowledge to emergency medication administration, delivered online, via webinar, or in person by experienced Registered Nurse trainers.

We're proud to offer the only Vocational Education and Training (VET) Course in Epilepsy Management accredited by the Australian Skills Quality Authority (ASQA), and we continue to contribute to workforce development through partnerships with organisations such as National Disability Services (NDS) and National Disability Practitioners (NDP).



Our commitment to education is about more than knowledge; it's about creating environments where people with epilepsy feel safe, supported, and understood. This year, over 250 schools joined our Seizure Smart initiative, helping staff build the skills and awareness needed to support students with epilepsy.

These schools are working to create safer learning environments by:

- Equipping staff with practical seizure first aid knowledge
- Reducing stigma and fostering inclusion through awareness
- Supporting the development of individualised Epilepsy Management Plans
- Promoting peer understanding and empathy among students
- Ensuring educators feel confident and prepared to respond to seizure emergencies

When schools embrace epilepsy awareness, they do more than improve safety—they help children feel seen, supported, and empowered to thrive.

https://learn.epilepsy.org.au/

Driving innovation through research

Epilepsy Action Australia collaborated on more than 20 national research projects this year, partnering with leading universities, hospitals, and research institutions. These projects explored critical areas such as diagnosis, treatment, lived experience, and quality of life, ensuring that the voices of people living with epilepsy are central to shaping future care.

Our role as a community partner goes beyond recruitment. We contribute to research design, share insights from our clinical and support services, and help translate findings into practical tools and resources. This work strengthens the evidence base behind our services and advocacy and ensures that innovation is grounded in real-world needs.

We remain the major funder of the Australian Pregnancy Register (APR), which supports vital research into the effects of anti-epileptic medications on unborn babies, with this long-standing partnership reaching a significant 10-year milestone this year.

We continue our collaboration with the University of Queensland Centre for Clinical Research around the significant gender-specific health issues facing the estimated 135,000 Australian women and girls who live with epilepsy. Already living with a chronic health condition, their health complications are exacerbated by the complex interaction between epilepsy, hormones and anti-seizure medication.

We also support and promote the ground-breaking work of the Australian Epilepsy Project (AEP), which has the potential to transform how epilepsy is diagnosed and treated for thousands of Australians.

Engaging with GPs

Improving epilepsy care begins with informed, confident healthcare professionals. This year, nearly 10,000 GPs engaged with our podcast series, which tackled often overlooked but critical topics such as epilepsy and driving, pregnancy, and hormonal influences. These resources are helping to close knowledge gaps and build confidence among primary care providers, where many epilepsy journeys begin.

We also expanded our reach through platforms like HealthShare and BetterConsult, which continue to be the most cost-effective and efficient way to deliver evidence-based materials to healthcare professionals. Through our partnership with HealthShare, our resources are now directly accessible via the clinical software used by 90% of Australian GPs, making it easier than ever for them to connect patients with the right support at the right time.

> *"At Epilepsy Action Australia, we believe that meaningful progress in epilepsy care comes from listening deeply, collaborating widely, and acting boldly. Whether through pioneering research partnerships or equipping healthcare professionals with trusted resources, we remain committed to driving innovation that reflects the real-world needs of people living with epilepsy. Together, we're shaping a future where care is smarter, more connected, and more compassionate."*
>
> **Carol Ireland, CEO & Managing Director**

Where Awareness Meets Action

Trusted Information, Always Available

Our website continues to be one of our most valued assets, providing a trusted source of support for people seeking reliable, evidence-based information about epilepsy. Over the past year, it attracted more than 250,000 visits, with users accessing a wide range of practical resources, including downloadable factsheets, interactive tools, and articles tailored to different life stages and epilepsy types. From managing seizures to navigating school, work, and relationships, our online content empowers individuals and families with the knowledge they need to make informed decisions.

A Thriving Online Community

Social media continues to be a powerful tool for connection, especially for people living with epilepsy, an often-invisible condition still linked with stigma and isolation. Over the past year, more than 80,000 people engaged with us across platforms, sharing stories, raising awareness, and building a vibrant, supportive online community.

Our Facebook page remains a key hub for updates on events, programs, surveys, and studies, while our targeted online support groups offer safe spaces for peer connection and shared experience. These include:

- Oz Youth Beyond Epilepsy – for young people aged 16–24
- Epilepsy Action and Friends – for adults aged 24+
- Epilepsy and Pregnancy – for women navigating epilepsy during and after pregnancy, facilitated by a Registered Nurse

These groups help normalise experiences, reduce isolation, and empower members to exchange practical advice and emotional support, enhancing quality of life and resilience.

Public Awareness campaigns and events

As always, we focused on raising awareness and funds in the lead-up to International Purple Day, 26 March.

Epilepsy Action Australia hosted its signature fundraising Gala Dinner at Crown Barangaroo, Sydney on Friday 14 March 2025. The event welcomed 277 guests, including people living with epilepsy, supporters, researchers, and neurologists from across Australia. Hosted by our very own ambassador Lachlan Gillespie (the Purple Wiggle), the evening featured inspiring talks from Dr Kaitlyn Parratt and Matt Preston and a panel of inspiring consumers. It raised over $400,000 to support vital services and advocacy.

SUDEP Action Day

SUDEP Action Day is an international awareness day held annually in October to highlight the risks of Sudden Unexpected Death in Epilepsy (SUDEP). It encourages open conversations between people with epilepsy, their families, and healthcare professionals, promotes research, and honours those lost to SUDEP, ensuring this often-overlooked issue receives the attention it deserves. With funding support from UCB Australia, Epilepsy Action Australia led a national awareness campaign for SUDEP Action Day on 16 October 2024. The campaign achieved outstanding media reach:

- 242 pieces of coverage across TV, radio, print, online, and social media
- A combined potential reach of 105,877,803, including syndication via AAP to Daily Mail UK, which alone has a reach of over 61 million

This level of visibility is vital because increasing awareness of SUDEP can lead to more informed care, better risk management, and ultimately, lives saved.

Our work continues - with purpose, with progress, and with you.

Epilepsy Action Australia

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www.epilepsy.org.au

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