

AUTUMN 2025

TAKING ACTION

Optimal outcomes for those living with epilepsy



DON'T LET EPILEPSY HOLD YOU BACK

Ella Sharman from Victoria shares her story after completing the New York Marathon and raising funds for Epilepsy Action Australia. She hopes that her story inspires others to not let epilepsy hold them back.

Ella was first diagnosed with epilepsy at just two years old. As a child, she didn't fully understand her condition, apart from the fact that she needed to take medication when it seemed nobody else did. She always felt different but couldn't quite put her finger on why. By the time she reached high school, Ella had 'grown out' of her epilepsy and stopped taking medication altogether.

As a teenager living in Victoria, Ella had aspirations like every young woman. She was working towards getting her driver's license so she could be more independent, and she had a job as a swim and sailing instructor, something she was very passionate about.

But it all changed just 2 months before her 18th birthday. She had a seizure, leaving her brother to find her unconscious and not breathing. Just five days later, another seizure struck, this time in a car park while she was with her mum.

This marked the beginning of a challenging period. Ella's seizures became more frequent, occurring weekly at some points. Her tonic-clonic seizures were particularly severe, lasting up

to 10 minutes, during which she would stop breathing and turn blue. Safety concerns meant she was constantly supervised and unable to be alone.

This put a pause on so many of the things Ella was looking forward to. She was told she could no longer teach as a swim and sailing instructor and her university asked her to withdraw due to the frequency of her seizures on campus. In what felt like an instant, Ella lost so much of what she valued, and decisions about her life were being made by others.

Continued...



CEO MESSAGE



As we welcome the new year, I am filled with a deep sense of gratitude for the unwavering commitment and passion shown by our community throughout 2024 in supporting people living with epilepsy across Australia. Thanks to your support, it was a year of meaningful progress despite the economic challenges across the country. Together with my fellow Board Members, most of whom have a direct connection with epilepsy, and building on our enduring presence of 72 years supporting people with epilepsy, we have set further goals in raising awareness, investing in research, and providing the best possible services and support.

We continue to work towards better outcomes for the estimated 270,000 Australians living with epilepsy. Our new strategic plan for the next three years focuses on inclusion, equitable access and self-determination for people living with epilepsy, with our mission being to drive positive change empowered by the collective voice of the epilepsy community.

Thanks to the incredible efforts of our supporters, volunteers, partners and dedicated staff, we have provided tens of thousands of Australians living with epilepsy, their loved ones and healthcare professionals vital services and support. And through the National Epilepsy Line, education courses, and online connections we hope to reach even more people in need in 2025.

Looking ahead, we are joined by our ambassadors Lachlan Gillespie (aka the Purple Wiggle) and Matt Preston (award winning food journalist and international TV personality) for our upcoming Make March Purple campaign. As you may know, every year in March, we raise much needed awareness and funds for epilepsy. We've left you more details about the campaign on the last page.

None of this would be possible without your support, and I extend my heartfelt thanks to each of you for your ongoing dedication and belief in our cause. Here's to a year of hope and progress.

Warmest Regards,

A handwritten signature in black ink that reads "Carol Ireland".

Carol Ireland
CEO & Managing Director

For over two years, Ella struggled deeply. She felt isolated, and many around her didn't fully grasp what she was going through. Despite this, she put on a brave face. It was during this difficult time that she discovered Epilepsy Action Australia. Reading stories of others living with epilepsy gave her comfort and a sense of connection.

"...the seizures weren't the hard part (my family might disagree with that). It was all the other side effects that come with having epilepsy. People often refer to epilepsy as the invisible disease because you can't physically see the illness. The isolation from friends and loss of control I had within my life was the hard part."

Four years later, Ella made the bold decision to move to New York for a fresh start. She wanted to redefine herself beyond her epilepsy, and it turned out to be the best decision she ever made.

Trying new things, meeting new people and to top it off, last November she completed the New York city marathon, raising \$3,410 for Epilepsy Action Australia.

Today, Ella is an advocate for those with epilepsy. She says:

"I run for those who can't, for those who have been told not to, and for those who wish they could, because years ago, that was me. I had no control. To anyone living with epilepsy, especially young people, please know that your life is so much more than your diagnosis. It's your life, your journey, and your choice. Don't ever stop fighting."



Living with epilepsy can be challenging...



Teenage years and early adulthood are a time of change and transition. Learning to drive, finishing school, finding a job, navigating relationships and exploring alcohol are some examples of these. It can be a hard for anyone, but when you have epilepsy there can be extra challenges.

It is also a time when you start becoming more independent in managing your epilepsy and transitioning into adult health services.

Did you know that to support young people through this period, Epilepsy Action Australia have developed resources specifically for this on our website? <https://www.epilepsy.org.au/about-epilepsy/living-with-epilepsy/teens-and-youth/>

Just to name a few of the resources available...

Oz Youth Beyond Epilepsy

– EAA youth Facebook group. This is a great place to connect, share experiences and support each other. With weekly topics and competitions, this is a fun and safe space where you can be comfortable to ask anything.



Transition to Adult Services – Moving from the children's health care system can be stressful. EAA have developed resources to help young people plan and prepare for this, to reduce anxiety and make the shift smoother. You can find useful resources such as tips, checklists and recorded conversations between people living with epilepsy and specialist neurologists.

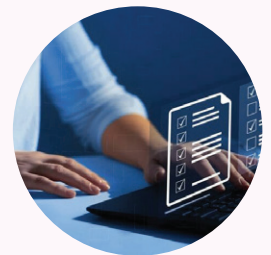


Information on additional risks as a young adult

– Adolescence is often a time of taking more risks, exploring, resisting and experimenting. A common issue that comes up is parties and alcohol. Alcohol and seizures don't mix well so it is wise to know about the risks. We have resources on this topic as well as driving, mental health, pregnancy and employment.



Seizure management plan – Taking an active role in managing your epilepsy through the use of readily available practical tools and resources can help you feel more confident and allow you to better control your symptoms and overall well-being. The Seizure management plan is a key document to help you lessen the impact of seizures especially at school or work.



Scan the QR Code to see the resources available to support young people living with epilepsy.



MAKE MARCH PURPLE FOR EPILEPSY

**NOT ALL
HEROES
WEAR CAPES**

PURPLE HEROES

As we celebrate international Purple Day (March 26th) and commit to 'making March purple', our theme this year is 'Purple Heroes', recognising the courage, resilience and strength of people living with epilepsy and the unsung heroes of those in the community supporting them (including family, friends, teachers, doctors and nurses)

We are asking people this March to be a Purple Hero and take on a Purple Challenge to raise funds and awareness as we celebrate International Purple Day on March 26th.

Led by our inspiring ambassadors, we celebrate the bravery of the estimated 270,000 Australians and their loved ones who face the challenges of epilepsy every day.

PURPLE HERO CHALLENGE

Ambassador: Neurologist Dr Emma Foster

The purple hero challenge is completed by incorporating something purple into your appearance. This could be for a day or even for the month. It could be purple nails, purple wig, purple clothing accessories etc. Ask people to support your purple efforts with a donation to your fundraising page.



PURPLE GRILL CHALLENGE

Ambassador: Matt Preston

The purple grill challenge is completed by hosting a BBQ (or grill inside) for colleagues, friends or family. There could be purple themed foods or purple decorations. People are asked to make a contribution and raise vital funds for people living with epilepsy.

PURPLE MUCK CHALLENGE

Ambassador: Wally Lewis and Brett Ratten

The purple muck challenge is completed by setting a fundraising target and encouraging as many people as possible to donate. If participants reach their target, they must pour purple muck over themselves on Purple Day (26th March).



PURPLE SCHOOLS CHALLENGE

Ambassador: Lachlan Gillespie

Schools are encouraged to host a gold coin donation day. Kids can come dressed up in purple or as their favourite superhero