I got epilepsy in 2003. I was in year 7. When I got back to school I could only remember 2 people. I’d lost all my friends because I couldn’t remember them.

Rohan Knowles, 25

Read Rohan’s story inside about the help and support he has found with the Epilepsy Foundation.
Education and Training update

Epilepsy training and resources for schools, families and students go online.

2017 will see students, families and schools have access to epilepsy information, support and training through the new Epilepsy Smart Schools website (www.epilepsysmartschools.org.au). The new website will put teacher’s resources, student Peer Support Program resources and family information within easy reach of everyone no matter where they live.

This Epilepsy Smart Schools website provides resources and information for families, students and schools; to better understand what good practice could look like in a primary, secondary and special school setting for a student living with epilepsy. The website also provides resources and information on what the potential impacts of living with epilepsy are and the resources available to support schools and students to become more knowledgeable or ‘epilepsy smart’.

At the Epilepsy Foundation we believe education can be an engine of change, driving the future that we want to see for people living with epilepsy. Our evidence based person-centred education and training programs seek to raise awareness and improve understanding of epilepsy in the community.

Epilepsy Champions Club

The Epilepsy Champions Club is a regular giving program that provides the option to arrange pre-authorised payments that are made, monthly, quarterly, half-yearly or even yearly.

For as little as $10 a month, your regular support will enable the Epilepsy Foundation to steadily build its capacity to support people living with epilepsy.

Many donors believe in our work but their circumstances don’t allow them to make a gift as large as they would like to make. Regular giving can really change this and if you think about the possibilities it can be a very powerful option.

Think of what just $1 per day could do - a monthly donation of $31 is an incredible gift of $372 per year!

Monthly gifts can be made by credit card or direct debit and are automatically processed in the same week of each month. Why not join the Epilepsy Champions Club now and help people living with epilepsy to achieve their goals for a better life?

Further information
For further information on the Epilepsy Champions Club, please call the Epilepsy Foundation (Melbourne metropolitan) on 03 8809 0655 or 1300 437 453 for the cost of a local call. Alternatively, you can email the Epilepsy Foundation.
While growing up, Rohan loved to play sport. He especially loved playing football, basketball and cricket. It wasn’t just the games themselves: he loved the social side. Year 7 should have been the time to explore these passions and all the new challenges that come with being a teenager.

Suddenly Rohan found himself dealing with a challenge that changed his life forever: viral encephalitis - which left him unable to walk. Playing sport was not possible. He missed most of the school year spending three and a half months in hospital followed by exhausting rehabilitation, learning to walk again. He also had to deal with something else the doctors believed had been caused by the illness: epilepsy.

After re-learning to walk, Rohan tried to play cricket again. But he had lost his hand/eye co-ordination and couldn’t hit the ball. Basketball and football were out of the question. Rohan was devastated.

He returned to school in the final term of Year 7 – but he felt like a stranger – apart from his brother, there was only one friend he could remember. But the friend had made new friends who didn’t want him to talk to Rohan. He was left feeling isolated and at times very scared, especially when kids laughed at him during an epileptic seizure. His search for belonging led him to join the school chess club so he wouldn’t be alone at lunchtimes, but it was pretty much all he had.

The last thing Rohan’s parents wanted was for him to feel alone.

They discovered the Epilepsy Foundation support groups that meant he had social activities to look forward to. One of the groups was the Youth Epilepsy Support (YES) Group, a peer group for 12-24 year olds.

Now 25, Rohan is a peer leader for YES, and it’s clear he’s revelling in his role.

“The activities are fun but what I mostly enjoy are the friendships and meeting up with people I’ve now known for years as well as making new friends. It’s wonderful to be among people who understand and accept you.”

The Epilepsy Foundation isn’t just about helping people live with the condition: it’s about making sure they don’t have to go it alone.
News from the Research Unit

The Epilepsy Foundation has been undertaking a project for the last couple of years on ‘Tackling Epilepsy in the Later Years’ with the National Ageing Research Institute (NARI), the Council for the Ageing (COTA) Victoria, and the Brotherhood of St Laurence (BSL).

Two surveys were performed to explore knowledge about epilepsy in older people and aged care staff. This information was recently analysed and has been written up for publication. In summary:

Who and what did it involve?

One study involved 100 people with epilepsy and 472 older people without epilepsy. The other study involved 85 aged care staff/carers. In each study the participants were presented with a list of 23 true/false statements to explore their knowledge about epilepsy and the use of Epilepsy Management Plans (EMPs).

What were the results?

- People without epilepsy did not answer very many questions correctly indicating a poor level of knowledge.

- People with epilepsy answered more questions correctly than people without epilepsy, however they still had a poor level of knowledge.

- Sixty-six people saw a GP about their epilepsy. Only 18 people had an individual EMP despite their importance and only 9 were directly involved in writing the plan.

- Aged Care Managers recorded the most correct responses overall (followed by nurses and lastly personal care attendants), however their level of knowledge about epilepsy was modest.

- Only one third of staff surveyed worked at facilities where EMPs were used.

- Greater work experience, having a family or a friend with epilepsy and having provided support to someone with epilepsy resulted in significantly increasing correct answers.

What does this mean?

GPs need to provide older people with more information including the increased risk of developing epilepsy as a result of ageing. They also need to develop EMPs with older patients as a part of best practice and person-centred care.

The care and management of older people with epilepsy needs to be better understood by aged care staff through education initiatives and training programs to ensure that care of older people does not suffer or is not limited.

- Peterson, C, Williams, S, Batchelor, F and Shears, G. Older people and knowledge about epilepsy: GPs can help. Australian Family Physician, 2016 (in submission)

- Peterson, C, Williams, S, Batchelor, F and Shears, G. What do aged care staff/carers know about epilepsy? Australian Journal of Primary Health, 2016 (in submission)

Research information is being used to produce educational resources for older people with epilepsy and their family/carers and for aged care staff to increase their knowledge and awareness. This is very important as older people (who are 65 years or older) are the biggest age group to be affected by epilepsy. Older people are living longer and increasing age is a major risk factor for developing epilepsy. Keep an eye out for these resources in the Research part of our website.
Your Bequest – Our Future

Our day to day activities are funded through individual donations, philanthropic support and some government funding. However, long-term financial viability is dependent on the generosity of people who leave a bequest to the Foundation. Leaving a bequest is an investment in the lives of people living with epilepsy now and in the future.

A bequest is simply another term for a gift left in a Will. Including a gift in your Will is one of the most special and powerful things you can do in your lifetime. After providing for family and friends and other important needs, we would be delighted and so grateful if you would consider including the Foundation in your Will.

Your bequest will help change lives for the better. You can call 03 8809 0600 or 1300 437 453 for a confidential discussion with Helen Smith, Head of Fundraising.

In Memory Giving

When someone close to us dies, we experience grief, sadness and, ultimately, an appreciation of all memories we have of that special person.

An In Memory donation to the Epilepsy Foundation is a special way to remember someone, at the same time help give hope and life to those who remain.

If you would like to ask family and friends to give a donation to the Epilepsy Foundation in lieu of flowers, special envelopes are available. Please call 03 8809 0600 or 1300 437 453.

A Letter Expressing Condolences and Appreciation will be sent to the next of kin or nearest family member of the person who has died along with the names of all those who kindly made memorial donations (the dollar amount is not mentioned).

Receipts for All - everyone who makes a memorial donation is sent a letter of thanks and receipt, which can be used for tax purposes.

Top: Two generous donors who have left a gift in their Will
Right: WEN group enjoy their weekend at Queenscliff

WEN goes to Queenscliff

In early November a group of 20 women with epilepsy attended the Women’s Epilepsy Network (WEN) Weekend in Queenscliff. Over the three nights they were supported by Epilepsy Foundation staff and volunteers. The program for the weekend provided opportunities to tour the Fort, visit Sorrento by ferry, be involved in art and craft workshops, learn to belly dance, cook with a chef and to join a discussion on epilepsy.

The weekend enabled women to meet others in similar situations and to experience a break in an environment where they would be accepted and cared for in the event of having seizures (and there were many incidents over the weekend that required intervention and support from staff and volunteers).

Feedback was generally positive from the women and has provided valuable insights for future events. Many of the women who attended this weekend away also attended the end of year mystery bus tour to Max Brenner Chocolate Bar, followed by a coffee and afternoon snack at Middle Park Beach.
Partner up for Purple Day Sunday March 26th

This year with your help, the Epilepsy Foundation has set a goal to raise over $200,000! This will fund various support programmes, like the highly anticipated Smart Schools initiative.

There are many ways to get involved. Partner up with friends, family or your local community and start fundraising.

**PARTNER FOR PURPLE!** Buddy up with your bestie and host a fundraiser BBQ, morning tea or Purple dress up day

**GET PRETTY FOR PURPLE!** Visit one of our op shops, find a great purple outfit and wear it with pride on Purple Day!

**PEDAL FOR PURPLE!** Ride, walk, swim or dance to raise funds for Purple Day

**POWER FOR PURPLE!** Use the power of social media! Set up a fundraising page and get your whole social network involved with the click of a button!

**PURCHASE FOR PURPLE**
Check out our new range of Purple merchandise

You can also find us on Facebook: facebook.com/epilepsyfoundation

You can also find us on Instagram: instagram.com/epilepsyfoundation_opshops/supportepilepsy.com.au/event/purpleday2017

Visit www.purpleday.com.au
Or simply donate! Call us on 03 8809 0600 or 1300 437 453

Top: Joffa Corfe on Purple Day Middle: Purple Party Bottom: Masterchef 2015 contestants Jacqui and Ashleigh raised $3,000

Epilepsy Helpline 1300 852 853