A positive life with epilepsy

Catherine Hoffman is a very down-to-earth woman who has lived a rewarding life while living with difficult epilepsy.

Her life, she says, can be described ‘in a nutshell’ in this way. She was diagnosed with epilepsy in her teenage years. She trained and worked as a nurse in the United Kingdom and came to live in Australia after her marriage to an Australian. She has raised two children, continued a successful career in nursing, while at the same time living with severe epilepsy and depression.

But that short summary disguises the very difficult journey with uncontrolled seizures that Catherine has experienced throughout her life. Born in the UK, Catherine was diagnosed with epilepsy in her early teenage years, but she suspects she was experiencing seizures long before that. “I wasn’t formally diagnosed with epilepsy until I was in my teens after having a few very long absence seizures,” says Catherine. “But before then I remember I used to fall all the time. I couldn’t explain it; I think people used to think I was some sort of idiot”.

Her greatest wish was always to be a nurse and after being rejected by one hospital, she was accepted by another hospital to do her nursing training. It was the right career choice for Catherine. From the age of 18, she has had a very successful career in nursing at all levels from general nursing to director of nursing roles, and across a range of specialisations including intensive care and mental health nursing.

It is an incredible testament to her that Catherine has achieved so much in her life while living with difficult uncontrolled epilepsy. As she explains it, life has often been a roller-coaster ride trying to find a regime of medication that would help control her epilepsy. “You’ve got no idea really just what you have to go through, not to mention the side effects, like putting on weight. And that, of course, can set off another bout of depression”.

While Catherine was holding down senior nursing positions, her seizures were becoming increasingly worse. “I’m one of those people who get no aura when they are about to have a seizure,” says Catherine. “I have tonic clonic seizures and I also have what I call ‘absence’ seizures that can last all day. I am often just wandering around not able to do anything”.

She accepts that this is the reality of her life, but she also wonders why the community does not understand more about epilepsy and the impact it has on people like her who live with seizures every day. “There’s so little understanding about epilepsy. I’ve had people just walk by, and even people who have abused me because they think I must be on drugs. I think if I lived in ages past, they would want to burn me at the stake,” she laughs.

Catherine’s severe epilepsy meant that continuing her career became increasingly difficult for her. With a touch of humour in her voice, she reflects that “now I can’t boil an egg”. But that belies the great range of interests, skills and capabilities she has, from being an excellent cook, to sewing, painting and swimming.

Catherine now lives in Geelong and finds much to enjoy in life, particularly in the arts area. She regularly attends the theatre, symphony orchestra concerts and the local film festival. “I really like where I live; it was the best move I made to come to Geelong. I have found a great specialist who listens and takes me seriously… and I have a lot of support.”

Catherine’s positive, ‘never give up’ attitude to life has not gone unnoticed by those who know her. “The thing we really admire about Catherine is that she tries not to let her epilepsy control her life,” says Linley Klopper, from the Epilepsy Foundation Barwon office. “She is faced with very difficult epilepsy but she doesn’t let it stop her getting out and doing the things she likes doing. She’s a great example to others”.

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Macedon Ranges Young Citizen of the Year

As part of the Australia Day awards, the Epilepsy Foundation was delighted to hear that Hayden Muir was awarded the Macedon Ranges Young Citizen of the Year, an award he definitely deserves.

Hayden’s award is recognition of his outstanding achievement of organising and completing a 746 kilometre mountain bike ride for epilepsy. The Foundation also takes great pride in announcing that Hayden has accepted the role as its Epilepsy Youth Ambassador.

When Hayden witnessed a school friend suffer a seizure at school, he was motivated to learn more about epilepsy and make his own contribution to raising awareness and funds for the Epilepsy Foundation and epilepsy research. And take a stand he did, in a very energetic and public way, and has raised a sensational $21,000 through donations and sponsorships.

As highlighted in our last issue of InTouch (September 2014), Hayden took to his bike and rode the Hume Highway from Woodend to Canberra over seven days. It took over 18 months of planning and training, and many people including his parents, grandparents and friends to assist.

When he reached Canberra, he was welcomed and congratulated by a group of politicians including another well-recognised cyclist, Prime Minister Tony Abbott and the ride patron, Senator for Bendigo Michael Ronaldson.

Hayden has continued to impress everyone with his dedication and interest in raising awareness and understanding about epilepsy. As the Epilepsy Foundation Youth Ambassador, Hayden will no doubt play an important part in influencing a change of attitude towards people with epilepsy.

Cranbourne Furniture Shop

Our Cranbourne furniture store opened in 2003 and relocated to its current Lurline Street location in 2012.

After moving into the larger location we have had great success in selling a wide range of products including lounge suites, dining tables, beds, wall units and electrical items. The store has really become a go-to destination for people looking for a good quality bargain and is regularly visited by antique dealer’s looking for items they can buy and re-sell.

We have 14 amazing volunteers that work in the store – some working up to three days a week. They have a good knowledge of the products and are happy to answer any questions or help customers where they can.

New stock arrives daily, and collections of donations are available in the southeast suburbs. Please call Mark to organise a collection on 0425 799 415.

Opening hours Monday to Friday 9.00am – 3.45pm | Saturday 9.00am – 3.00pm.
Address 10 Lurline Street, Cranbourne 3977 Phone 5995 2369.

A GREAT RECEPTION

Volunteers are an integral part of the Epilepsy Foundation; we just could not operate without them.

Across every area of the Foundation’s activities – administration, data processing, parent support, camps, opportunity shops to name a few – the commitment and loyalty of our volunteers is outstanding.

So with pride we introduce three volunteers who support our reception area. Meet Julie, Karen and Sarah our volunteer reception staff who regularly come in to help out with answering the many telephone calls and greeting visitors to our offices.

If you could spare a few regular hours any week, fortnight or month using your skills and experience, we would be delighted to hear from you. Please contact Karen Hansen at the Epilepsy Foundation on 03 8809 0600 for further information.

National Helpline 1300 852 853
Last October we had the great honour of announcing The Honourable Quentin Bryce, Australia’s former Governor-General, as the National Patron of the Epilepsy Foundation. Quentin is committed to making a difference to greater understanding of epilepsy, and in the following excerpts from a recent speech, you can hear the passion of her commitment come through:

Excerpts of a speech by The Honourable Quentin Bryce AD CVO

“When our little grandson, Charlie, who is four now, was diagnosed with epilepsy we were devastated. Tears, anxiety for Charlie, for his parents, Lucy and Tom. Then of course we stopped to get things into perspective, to get real –

• What can we do?
• What does this mean?
• How can we help?

I want to do all I can to learn, to understand this disease and I look forward to making a constructive contribution to this Foundation. There is a lot to be done and a record of outstanding achievement to build on.

My friends, Epilepsy Foundation research, together with experience gained from supporting people living with epilepsy, shows that the biggest issue people face, when they get a diagnosis of epilepsy is fear: fear of the future, of prejudice, discrimination, unfair treatment and fear of being alone with their epilepsy.

And one fear remains throughout their lives. It is the fear of how other Australians will treat them when they find out about their epilepsy. As a result, many people with epilepsy are living with a secret, and experience anxiety, stigma and social isolation.

The number of people who tell me that they have a family member with epilepsy but it is never talked about astounds me.

The Australian community can change this. People living with epilepsy deserve a fair go. The Epilepsy Foundation will not rest until 100% of people living with epilepsy get the best possible support to live with their condition.

The current lack of epilepsy support services is a national disgrace. Across Australia there is one epilepsy support person for every 8,200 people with epilepsy.”

We know that as a supporter, these are the things that matter to you, just as they matter to Quentin. We are delighted to have her and her family joining our work for a ‘fair go’ for people with epilepsy.

Visit us online at: www.epinet.org.au
facebook.com/epilepsyfoundation
@epilepsy_fdn
EpilepsyVictoria

The Davis Society Luncheon

In November 2014, a number of our Davis Society members were recognised for their outstanding thoughtfulness in leaving a bequest to the Epilepsy Foundation. The Davis Society, in honour of Mary and Roger Davis, was created as a way of recognising and thanking donors who have included the Epilepsy Foundation in their Will.

Mary’s third child Roger was diagnosed with epilepsy. Mary soon recognised that there was little support within the Victorian health field for people living with epilepsy. In 1964 Mary was instrumental in forming the Victorian Bureau for Epilepsy, now the Epilepsy Foundation.

The inaugural Davis Society Bequest Luncheon was held in the boardroom at Credit Suisse in Collins Street. The view from the 41st floor was breathtaking and was a wonderful back-drop for the luncheon.

Guests were presented with a Davis Society gold pin in appreciation of their generosity for including the Epilepsy Foundation in their Will. No matter how big or small, a bequest to the Foundation is such a generous and powerful thing to do.

Our sincere thanks go to Credit Suisse for their hospitality in not only providing the venue but also the delicious lunch.

Helen Smith, our Manager of Philanthropy, would be pleased to have a confidential discussion if you would like to know more about leaving a bequest to the Foundation. Contact Helen on (03) 8809 0664 or hsmith@epilepsy.asn.au.
The power of peer learning
Peer Educator pilot success

A pilot program conducted in 2014 in 13 metropolitan and regional schools through the Epilepsy Smart School (ESS) program has had outstanding success in raising awareness of epilepsy and creating a more welcoming and inclusive society.

The ESS Peer Educator pilot takes a different approach to supporting students who live with epilepsy. Typically, schools become an ESS by receiving staff training and support in the development of Epilepsy Management Plans by the Epilepsy Foundation. The teacher or student living with epilepsy (with the student’s approval) can then access resources via www.epilepsysmartschools.org.au to educate students in the school about epilepsy. For many schools and students this meets their needs well.

The approach of the ESS Peer Educator pilot is to provide additional support to schools who aim to educate other students about epilepsy. It focuses on the power of peer learning, with the Foundation training a select number of senior primary or secondary student leaders who then in turn educate their school community using the Foundation’s resources.

More than 1,000 students were trained by 107 peer leaders and over 65 identified students living with epilepsy in the pilot schools. The outcome of the pilot was extremely positive, and the comments received attest to the value of the program for teachers, students, students living with epilepsy and parents.

The ESS Peer Educator Program is a powerful way of increasing understanding of epilepsy in the community by educating young people in a supportive, peer-led program.

A successful grant through the Lord Mayor’s Charitable Foundation will enable a partnership between the Epilepsy Foundation and Mt Erin Secondary College to promote the Peer Educator program in local teacher networks in 2015.

The Epilepsy Foundation is seeking more philanthropic and individual donor support to enable more schools to participate in this successful program. Please contact Helen Smith, Manager of Philanthropy, if you would like more information on how to support the Epilepsy Smart Schools project and some of our other major projects.

Get involved in Purple Day
Thursday March 26

This year, with your help, the Epilepsy Foundation aims to raise $258,000 to fund vital support services like our National Epilepsy Helpline.

There are lots of ways you can get involved to show you care about people living with epilepsy: wear a pin, make a donation, sell our merchandise, create an online fundraising page or host your own event like a morning tea or sausage sizzle. Importantly, by promoting purple day and wearing purple, you will raise awareness of epilepsy and help break down the stigma and misunderstanding about epilepsy that still exists today.

Register your interest today at www.purpleday.com.au.

We are excited to launch a whole new range of merchandise including an all new light up epilepsy pen ($5), strawberry lip balm ($5), a USB ($8) as well as our gorgeous soft toy Gus the Gorilla ($10), t-shirts ($20), polo shirts ($25) and much more.

This year merchandise is available for sale in our online shop www.purpleday.com.au. You can also shop at our head office in Surrey Hills or our Op-Shops located in Blackburn, Parkdale, and Cranbourne. Or complete the merchandise form on the back of the coupon provided with your newsletter to get your merchandise.

Want to do more? To order a box of merchandise to sell or donate simply call us on (03) 8809 0600 or visit www.purpleday.com.au to get started. You can also find us on Facebook (www.facebook.com/epilepsyfoundation).