

# Thoughts for the day

Our epilepsy community postcard project  
November 2018



# Epilepsy

- Epilepsy is a complex neurological pathway disorder which causes seizures
- There are at least 40 different seizure types and many ways in which they affect people living with the condition
- We invited 32 people from around the Waikato to share their thoughts, in only a few words, on what it is like living, both directly and indirectly, with epilepsy
- This has become known as our epilepsy community postcard project
- The postcards for November 2018 are given in the following pages
- For more information, go to our web page: [www.ewct.org.nz](http://www.ewct.org.nz)



Maria Lowe, epilepsy advisor for  
Epilepsy Waikato Charitable Trust (EWCT)

# Post Card



"It's not important how many times we fall over during seizures, it's the number of times we have tenacity and resilience to pick ourselves up. Fall over seven times, pick ourselves up eight - epilepsy warriors!!"

- Adele 2018

[www.ewct.org.nz](http://www.ewct.org.nz)

#1epilepsyawarenessmonth

# Post Card



“It is heart-breaking seeing my husband’s frustrations when he has had a seizure but, we work hard as a couple to find solutions to those frustrations. The key is to never give up.”

*-Alison 2018*

#2epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“Having epilepsy has drawn me closer to my wife and to my son because of what they do every time I have a seizure. They handle it well and it gives me confidence and reassurance that I am in good hands. Having epilepsy is certainly a humbling experience.”

- Andrew 2018

#3epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



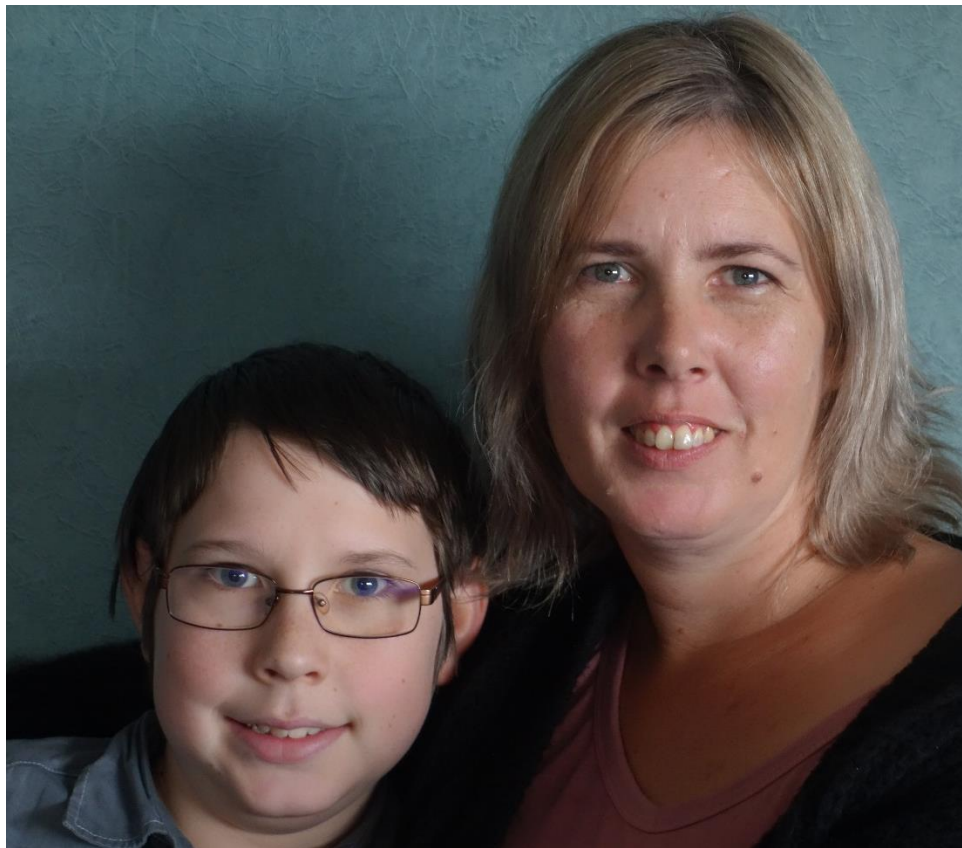
“Please meet my daughter before you judge her for having epilepsy.”

*Jenny 2018*

[www.ewct.org.nz](http://www.ewct.org.nz)

#4epilepsyawarenessmonth

# Post Card



“Life changed when my son developed epilepsy. What seemed scary at the beginning is not scary now as we have learnt to understand epilepsy and how to deal with seizures.”

*Chanelle - 2018*

#5epilepsyawarenessmonth

# Post Card



“Having epilepsy hasn’t stopped me from accomplishing things. I am a mother now and it is the best job in the world.”

*Erica- 2018*

#6epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)



# Post Card



“As a parent who has had to watch their child endure more than any child should ever have to, I have realised that my daughter’s battle is my own. I will support her until she wins.”

- Rebekah 2018

#7epilepsyawarenessmonth

# Post Card



“Sometimes, living with epilepsy has been like a roller coaster of a ride as I have coped with medication changes and their effects, and the loss of my driver’s licence on many occasions. But I am more than my condition.

I am a great wife, mother, grandma and friend and I have lots to give and enjoy in this life. That is the real me.”

Jill -2018

[www.ewct.org.nz](http://www.ewct.org.nz)

#8epilepsyawarenessmonth

# Post Card



“I have epilepsy but I feel supported at work by the best team of people who watch out for me.”

- Justitia 2018

#9epilepsyawarenessmonth

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# Post Card



“Epilepsy hasn't stopped me living life to the full. I go to work and I am learning to drive. There are goals in my life yet to achieve.”

*Kayley- 2018*

#10epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“My EWCT advisor, Maria Lowe, is always there for me when I need help. She has never let me down. Getting that support and advice helps me day-to-day in my epilepsy journey.”

*Lola- 2018*

#11epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



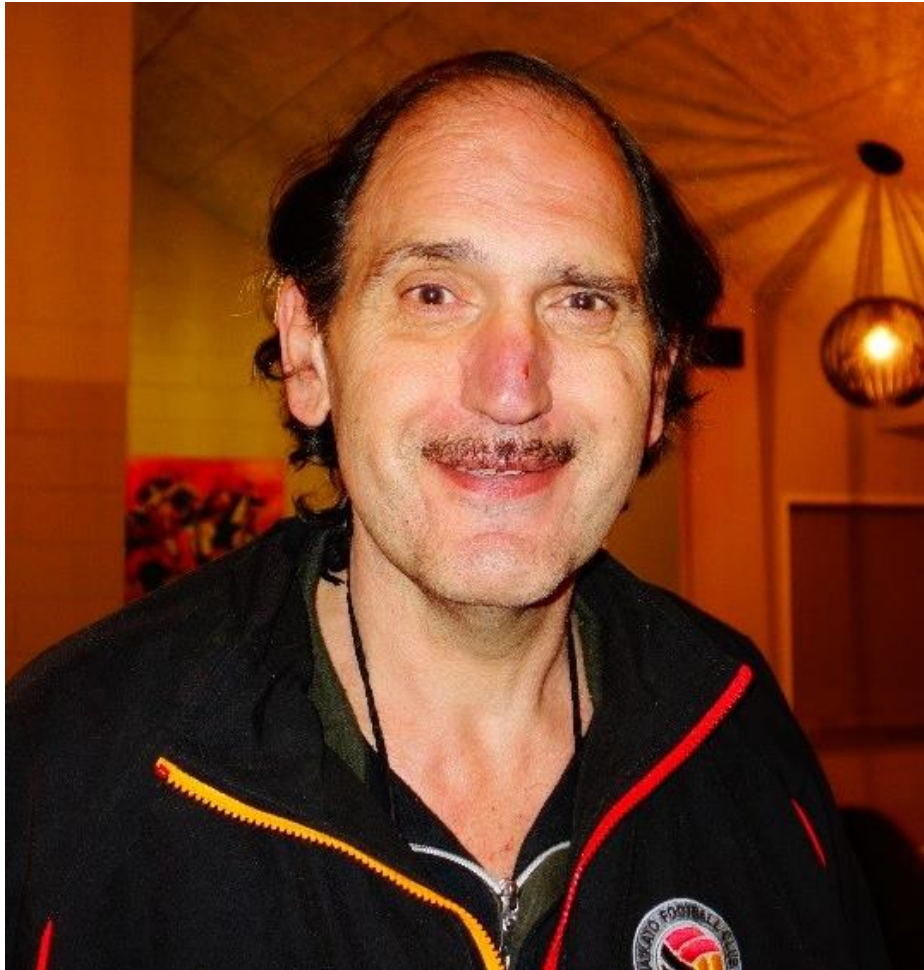
“It hasn’t always been easy having epilepsy but I accept that I have it. Having a good sense of humour has helped me and I know how to keep moving on in my life.”

-Luke 2018

#12epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



I have uncontrolled epilepsy which has been quite challenging at times, especially as I don't have the same level of independence that I would like. However, I belong to the Epilepsy Waikato Charitable Trust social group and I am a wood worker, which are two activities that I enjoy."

*Mike- 2018*

#13epilepsyawarenessmonth

# Post Card



“My normal self is having epilepsy. I wouldn’t know what it would be like not to have it as I have had it all my life.”

*Pam-2018*

#14epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)



# Post Card



“I would like to be heard. I often feel that people don’t hear how epilepsy affects me.”

*Sally-2018*

#15epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“I have epilepsy and I am fine. It doesn’t bother me at all.”

*Seth*- 2018

#16epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“Parenting this darling girl's epilepsy is a bit like living in an earthquake-prone region. We are never quite sure when they're going to strike, or what the fall out will be, and so we tend to be a bit on edge. But we're well prepared and appreciate Epilepsy Waikato Charitable Trust's (EWCT) support.”

*Susie 2018*

[www.ewct.org.nz](http://www.ewct.org.nz)

#17epilepsyawarenessmonth

# Post Card



“Epilepsy is not a disability that is easy to overcome but it is something that you learn to live with”.

*Thomas- 2018*

#18epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“It has been an uphill epilepsy battle as nothing can stop my seizures but, with the support of family and friends I am still doing the things that I want to in my life.”

*Tracey- 2018*

#19epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

“Because I have needed help at times, I know how to help others.

Focus on the good things in life.”

- Philip 2018

#20epilepsyawarenessmonth

# Post Card



“Imagine that your child with epilepsy wants to climb a tree. Is it better that they climb that tree and fall and break their arm, or sit under it, wishing they were allowed to climb it like other children?”

Help your child lead as normal a life as possible.”

*Faith- 2018*

[www.ewct.org.nz](http://www.ewct.org.nz)

#21epilepsyawarenessmonth

# Post Card



“Get some sound advice from a trusted mentor about your epilepsy and your anti-epileptic medications. Someone who will give you continuity of care and have loads of empathy as you walk along your epilepsy path.”

- Debra 2018

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#22epilepsyawarenessmonth



# Post Card



“It is important to educate others about epilepsy to help to break down barriers.”

*Barry- 2018*

[www.ewct.org.nz](http://www.ewct.org.nz)

#23epilepsyawarenessmonth

# Post Card



“Epilepsy is something that I have had all my life and I have learned to live with it.”

- John 2018

#24epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“Having epilepsy has opened up a brand-new world to me and my family. By becoming involved in this postcard project it gives me a sense of belonging to a community of people with epilepsy. It is also important for me to get involved in an event that highlights the condition so that it helps others living with it.”

- Sarah 2018

[www.ewct.org.nz](http://www.ewct.org.nz)

#25epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

“From the time my seizures first started, it terrified us all.

The empathy that came was zero to nil. Did that stop my goals? Did that stop my heart?

Never in my life will I let it break me into parts.

Keep standing on your feet, what is there to fear?

We all shall live strong, help and hope is always here.”

- John 2018

#26epilepsyawarenessmonth

# Post Card



“Over time my Juvenile Myoclonic Epilepsy has become much more manageable. I am lucky that making positive lifestyle changes has meant that I could go off medication and continue doing the things I love. Epilepsy is a part of who I am, but it in no way defines me.”

- Erin 2018

[www.ewct.org.nz](http://www.ewct.org.nz)

#27epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

“I developed epilepsy late in life for no apparent reason and with no family history.

I have appreciated the support of Maria Lowe, the epilepsy advisor of EWCT, and from family and friends.”

- Jeanette 2018

#28epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

“Reach for the moon.

If you fall short you will land on a star.”

- Jan 2018

#29epilepsyawarenessmonth

# Post Card



“Every seizure is different. Understand what your seizures looks like and educate your family and friends on how to help you when you have one.

It is not that difficult to help someone with epilepsy.”

- Julie 2018

#30epilepsyawarenessmonth



# Post Card



I have epilepsy but please don't worry about me. I can look after myself with your support.”

-Ray

[www.ewct.org.nz](http://www.ewct.org.nz)

#31epilepsyawarenessmonth

# Post Card



My son.... My hero!

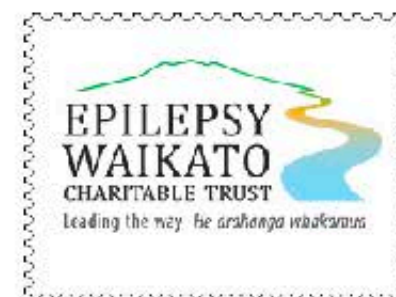
An ordinary individual who finds the strength to persevere and endure, loving life in spite of overwhelming obstacles of living with epilepsy.

Sharron-November 2018

#32epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



“I have had a brain injury and I have epilepsy.  
Life can get tough but I am a survivor.”

- Lorna -2018

#29epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

The key to a better understanding of what to do when a person has a seizure is to, educate and to advocate, since epilepsy is both visible and invisible.

Learn more here in my book:

Epilepsy First Aid: [www.epilepsyfirstaid.com](http://www.epilepsyfirstaid.com)

Krystle -November 2018

#33epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

Please do not give a person CPR or use an artificial defibrillator during a tonic clonic seizure, because people usually start breathing again on their own after their seizure has stopped.

Ingrid -November 2018

#34epilepsyawarenessmonth

# Post Card



"Finding a passion that you truly love in life, will help you to forget about your fears around epilepsy. For me it is about enjoying art!"

Amanda-November 2018

[www.ewct.org.nz](http://www.ewct.org.nz)

#35epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

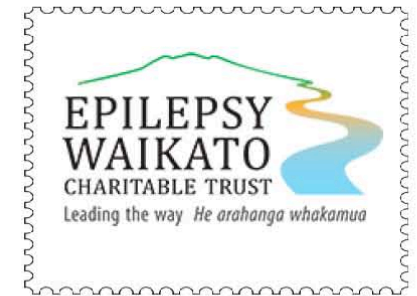
Having epilepsy can be difficult at times but, until you have had to face uncertainty, then you don't know what you are made of. It can make you a stronger person than before.

Never give up!

Matthew-November 2018

#36epilepsyawarenessmonth

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

I had Lennox-Gastaut Syndrome as a child and I had lots of difficult seizures to manage.

Today I am seizure-free and I am living well.

Jenni -November 2018

#37epilepsyawarenessmonth



# Post Card



Stroke is the most common cause of seizures in older people and you will be prescribed anti-epileptic medications if you are diagnosed with epilepsy.

(<https://www.stroke.org.nz/> ph 0800 78 76 53)

Debbie- 2018

#36epilepsyawarenessmonth

[www.ewct.org.nz](http://www.ewct.org.nz)

# Post Card



[www.ewct.org.nz](http://www.ewct.org.nz)

Know about antiepileptic medicines and how it can affect your baby if exposed during pregnancy. Feel empowered, get informed consent and develop a positive partnership with your neurologist. It could save your baby's life!

[www.facsnz.com](http://www.facsnz.com)

Denise -November 2018

#39epilepsyawarenessmonth