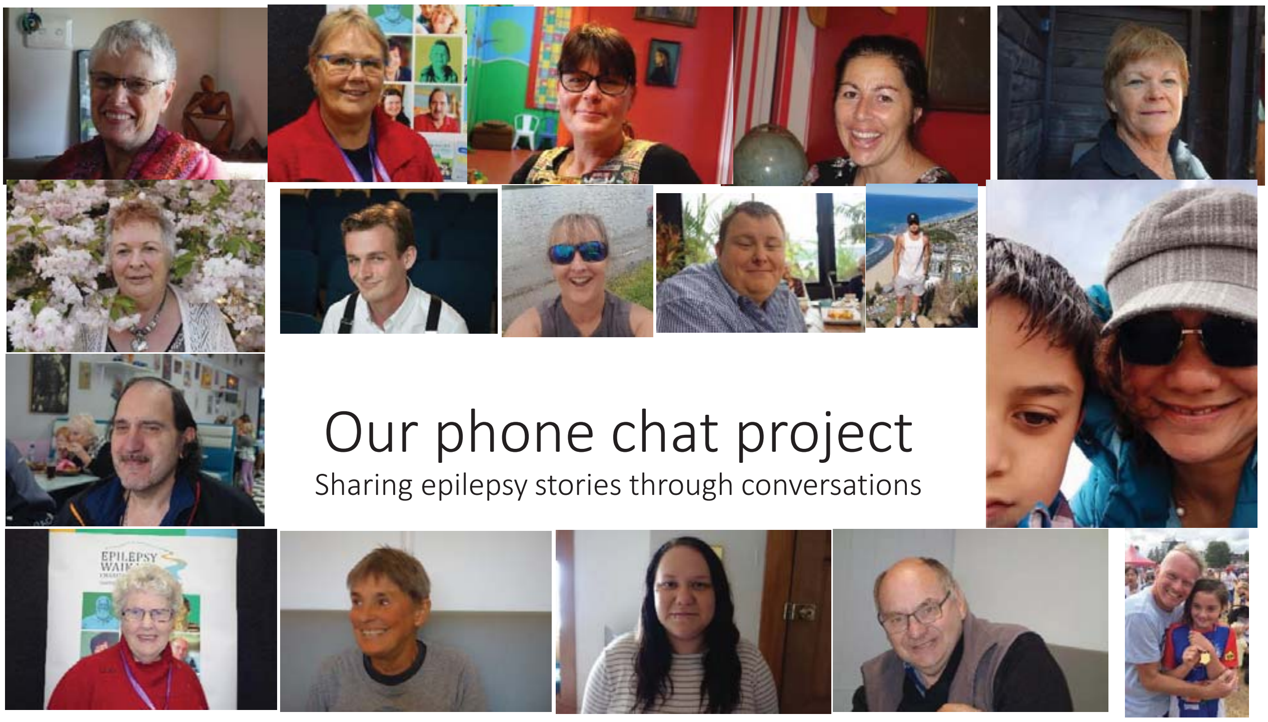

Our phone chat project

Sharing epilepsy stories through conversations

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November 2020

Our phone chat - Jan

Maria: Hi Jan, thank you for participating in our community project called "Our phone chat". Everyone has a story worthy to be told and, in this project, we are going to chat about your epilepsy story and how epilepsy has impacted on your life.

Please tell me a bit about yourself.

Jan: I was born in the Waikato to farming parents straight after the war in 1946. Growing up on the farm was hard work but I enjoyed milking the cows and helping out. It wasn't until I was 16 years old that I developed epilepsy. We couldn't work out why that happened but I grew quite quickly and there was some thought that I had grown too fast at that time. I don't know. It was quite strange.

Maria: Can you please tell me about your seizure types and how you felt about your diagnosis?

Jan: My seizures seemed to change within six months of me having my first seizure. Apparently, on my first seizure I wandered out of my bedroom in the middle of the night turning around in circles. I could hear my parents talking to me but I couldn't control what I was doing. I remember feeling quite frightened but my mother was quite a no-nonsense, calm person and this had a positive effect on me being able to cope.

About six months later I started having the so-called 'grand mal' seizures, and I was diagnosed with epilepsy and put on medications. That would have been back in 1965.

I wasn't disturbed by this epilepsy diagnosis and I immediately worked out for myself how I could be safe at all times just in case I had a seizure. I wouldn't have a bath, preferring to shower. Nor would I go swimming. I worked out that my seizures happened between 8 and 10 O'clock in the mornings so I decided that I would move into town (Hamilton) to find a job where I could go to work later in the day. I got a job in the health clinic at the YMCA, which was the first gym for ladies, working as a masseuse. I wasn't embarrassed meeting others and I never had a seizure during my time at work. I did that job until I got married.

During my early days living in Hamilton I boarded with others and that is where I met my future husband. I was married at 20 and my husband was not at all worried about my epilepsy. We have now been married for 53 years.

When we settled down together, we made sure that we chose a home somewhere near a bus stop so that I could remain independent. Being independent was really important to me, even when I became pregnant with my first child. I never saw epilepsy as a barrier for me being able to do anything in life and I think that positive attitude came from my mother. I thank her for making me strong.

Maria: How was your pregnancy with your first child?

Jan: I had more seizures! I discovered that I was okay lying down but, as soon as I stood up, I had a seizure. I ended up by having to stay in the hospital for several months in the middle of my pregnancy to be cared for. I went back to the hospital again when my GP delivered my baby son. GPs used to deliver babies in those days. Interestingly, my son was unable to speak for several years with a condition called aphasia. The doctors believe that he may have had a stroke when I was carrying him.

Maria: How did you manage with your new-born son at home?

Jan: From memory**,** I didn't have many seizures at all once my baby was born but I still put in place important safety measures just in case I had one. I had to cope on my own during the day when my husband was at work.

I never carried my baby around, especially before 10 O'clock in the mornings. I made sensible decisions because I didn't want drastic things to happen. My husband always bathed the baby when he was home.

I think that I coped really well and, less than two years later, I gave birth to a little girl, who incidentally has epilepsy. I had an easier pregnancy with her and with no seizures. With two little ones to look after I made sure I rested when they did.

Maria: Please talk about those early years at home with your children?

Jan: I had a normal busy life as a mum. I attended kindy meetings and I became involved in my community but my seizures returned and it always happened around my menstrual cycle and so I asked for a hysterectomy, which sounds rather drastic but it solved the problem. I changed for the better overnight and I haven't looked back.

Once my children were both in school, I went back to work, demonstrating sewing machines at a furniture store. I really enjoyed that job and I felt that I was achieving in life and I wasn't just a mother at home. I later went to work in a cafeteria before setting up a successful business with my husband growing vegetables.

Maria: Looking back on your life how do you feel about having epilepsy?

Jan: Over the years my seizures have become less and less. I think that my hormones have played a part in it. Could that be the reason? Every year I also have trouble adjusting to daylight saving! It really mucks me up and makes me feel tired.

I feel quite positive as I have always made a point of being sensible with my decisions. I learnt all there was to know about epilepsy when I needed information and I have had great support from my husband. We both joined the local epilepsy organisation back in the 1960s and we have been involved ever since.

I have had a lot of drive to do well in my life and I am really happy with that.

Maria: What take home message would you like to give people about epilepsy?

Jan: I would like people to be positive in their own ability to do things for themselves and not to feel disadvantaged by having epilepsy. Epilepsy need not be a barrier to a good life. Have pride in yourself and find the courage to do well. I suppose that has come from my mother's attitude towards my epilepsy. I could never give her an excuse for why I couldn't do anything!

Maria: Thank you Jan. I have appreciated our chat.

Our phone chat – Jordan

Maria: Hi Jordan, it has been a while since our last chat. Your mum proudly said that you are working hard in your job over this Covid-19 lockdown but that you would make time to share your epilepsy story with others. In these uncertain times, I believe that your story offers hope to those who are struggling with epilepsy and so thank you for agreeing to a phone chat.

Jordan: Well! You gave me hope when I felt lost and I now want to help others with epilepsy, even if it is by sharing my story. Here goes!

About eight years ago I had my very first seizure at work. I was about 18 years old and I was in a job that I loved: working on large steel ducts as an insulator. I remember being dressed up in a heavy white boiler-suit at work, high off the ground and…. That is all I remember! The next thing I was in the back of an ambulance, thinking, “What is happening to me? Why am I in the back of an ambulance?”

I went to the hospital to be told by the doctors that anyone can have one seizure in their life, but it didn’t mean that it was because of epilepsy. I was told that I had probably got too hot in my boiler suit at work. It didn’t help that I had also partied through the night. I hadn’t had much sleep before I went to work, and I had drunk a huge amount to alcohol, which I believe dehydrated me. But you know, I didn’t learn my lesson, I went back to heavy drinking, partying large and working really long hours. I worked all the hours I could because I wanted to own a house by the age of 25 years.

Maria: So, did you only have the one seizure, or were there more seizures to follow?

Jordan: The next seizure happened about a year later but, this time, I didn’t recover well. My seizure didn’t stop and so I was put into an induced coma. I believe that my seizure lasted for two days. On waking up, I felt really scared, especially to be told by the doctor that I couldn’t go back driving, do sports or continue with my wild lifestyle. If I did then I would die. One hundred percent, I would!

Maria: Goodness! How did you respond to that news?

Jordan: To be honest, I had a good cry. When I returned home it felt that my world had fallen apart and that I was in a huge hole from which I couldn’t climb out. I became unmotivated and I had bad thoughts. It didn’t help that the medications that I was put on made me feel really tired and I struggled getting out of bed to go to work but, I did, and the boss was really good to me.

I continued having seizures and I knew that, if I partied hard, that I would have a seizure the following day. Eventually, just before my 21st birthday I was diagnosed with epilepsy. But did that stop me from living wildly? No!

I knew that I couldn’t drink alcohol anymore because of my meds and so I started taking marijuana. Lots of it. Well, for the next two years I had about 30 to 40 tonic clonic seizures and I hung out with a group of turkeys who didn’t care, or worry about my epilepsy. I didn’t care either until one day, I saw the light. I had a hard look at myself and I didn’t like what I saw. I wanted better for myself. I wanted to own my house by the time I was 25 years, and so I quit my friendships with that group. You know, "you can't soar like an eagle if you hang out with turkeys"?

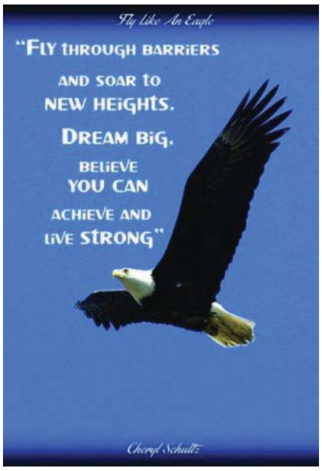
I moved back home to be with family and it is here that my life improved. My uncle offered me a job in his butchery and I was given the hard word from him. I had to work, do as I was told and stay out of trouble, and I have. I love where I work. I absolutely do! I work in a small business and I am praised for my good work. I know that I am appreciated by the others and it makes me feel important. I have now saved enough money to buy my house or, I could also buy into my uncle's business! I have much to think about.

I have also surrounded myself with good mates who are motivated and have goals in life. I go to the gym and that makes me feel really good. I have bought myself a new car and I am loving life.

On reflecting back on my life with epilepsy, I would like people to know that things could be worse than having epilepsy. I look at the brave faces of the very ill children who end up in Starship and I couldn't imagine how they must feel. They are inspirational to me.

Oh! And one last thing. You must also take your meds regularly. That is so important. Medications are there to stop seizures and, you take them without drugs and alcohol! Believe me, the combination doesn't work and you could end up having a seizure that doesn't stop. I have been there and it is not fun!

Maria: Thank you Jordan for your honest chat. Continue to soar like an eagle and enjoy life! I have found this message for you. I know that you will like it.



Our phone chat – Lisa

Maria: **Hi Lisa, thank you for asking to take part in this year's community project. You wanted to talk about the events that your son, Jordan, couldn't remember in his epilepsy story. Events that took you on a roller coaster ride of emotions and so I thank you for sharing your thoughts. I know that, as a parent, supporting our children through epilepsy can be a difficult journey in itself. Please take your time in telling us your story.**

Lisa: I will never forget the day I witnessed my son having a tonic clonic seizure at my home. It was the scariest thing that I have ever witnessed and, what I saw, will live with me forever. This was his second seizure in his life and he was put into an induced coma for two days and I imagined the worst, as any parent would. But what was worse for Jordan, was the blunt message said to him by the doctor at the time, "You can't drive. You can't work. You have a high risk of dying." The doctor then walked out of the room. My heart dropped and I felt so sad believing that my son would never be the typical 20-year-old lad out enjoying life and having fun.

Jordan was prescribed epilim, but it made him so tired that he stopped taking it after a while and he started to spiral out of control emotionally.

Over a year later, Jordan was involved in a car accident on his way to work. He drove through a large round-about whilst having a tonic clonic seizure and he was still recovering from it when the police arrived. They believed that he was drunk and so they roughly tackled him to the ground and handcuffed him. Unfortunately, he became quite aggressive and the police saw this as resisting arrest, but once the police realised that he was indeed recovering from a seizure, they took him up to the hospital to be treated.

Maria: Oh dear! If you restrain any person who is confused after a seizure, they may respond aggressively. Unfortunately, many people living with epilepsy can be mistaken for being drunk whilst having seizures which doesn't help their situation at all.

Lisa: Agreed. Jordan was angry at that time and he got angrier from taking leviteracetam once he was officially diagnosed with epilepsy. Boy, his life really did spin out of control from then on. I was aware that he was going down the wrong path in life but I couldn't stop him. Every time the phone went late at night, my heart would drop because I imagined that it was the police phoning to tell me that Jordan was either dead or injured. He was having lots of seizures and he always ended up in hospital. I started living in amber alert. I was in fear of what could happen to him.

It was about that time that I came across the EWCT sausage sizzle at Bunnings. I found your name and I asked to see you with Jordan. Jordan wasn't particularly interested in meeting you but I honestly believe that you saved his life when you met us. Jordan had hit rock bottom in his life and he felt that no one was listening to him but you understood exactly how he was feeling and you believed in him. It was the turning point in his life that he needed.

Maria: Thank you, Lisa. I feel humbled by your kind comments but thankfully Jordan was able to see that the life he was living was not the life that he wanted. As he so nicely said, "You can't soar like an eagle if you hang around with turkeys"! He also had a medication review and he was switched from leviteracetam to lamotrigine which improved his mood.

Lisa: Indeed! Shortly after meeting you, he smartened himself up, met up with his old friends and moved to another town to become a butcher working alongside my brother. Jordan takes responsibility for his epilepsy now by routinely taking his medications and he manages his seizure triggers. That means no drugs and alcohol. He has also trained our entire family in epilepsy first aid and we all know what to do if he should have a seizure, which thankfully is a very rare event these days.

Family means everything to Jordan and he is my inspiration in life. He has the unconditional love and support from all of us. He tells me that epilepsy is a part of him and not to worry about his seizures. He will be okay and I believe that he will be. I no longer live in fear. Life is great!

Our phone chat – Jackson

Maria: Hi Jackson, thank you for having a phone chat today. I see that you are really heavily into music and kung fu. Two really hard disciplines to follow. Please tell me about them and how they have helped you on your epilepsy journey.

Jackson: I grew up with epilepsy from the age of 6 years old. I was the one who sat at the back of the classroom getting into trouble from not paying attention. Apparently, I was always off in my own little world before I was diagnosed with absence seizures, and medicated for them. When I was about 8 years old, I then developed tonic clonic seizures.

I found school hard, especially as a teenager because I was trying to plan for my future, but I had to discover my own path in life and at my own pace. Between the ages of 18-20 years, I felt a bit lost but I decided that epilepsy wasn’t going to be the excuse for me not being the best that I can be and I went looking for a way forward.

It was at that time that I discovered singing and kung fu.

Music is now my passion in life. I absolutely love singing. More than anything in the world in fact, and the more I sing, the more satisfaction I have from doing it. I have now found the courage to get out into the community and brighten the lives of the people I sing to, and I am trying to build up a future for myself by performing music. I will sing to anyone such as in resthomes, at weddings, and children’s parties, and I will enjoy every minute of it too.

Maria: How has kung fu helped you?

When I discovered kung fu it helped me to mature and I developed a positive outlook towards my epilepsy. It taught me the discipline that I needed to stay safe. Today I follow a strict routine of sleeping eight hours a day, not drinking alcohol, eating healthily, taking my medications regularly 12 hours apart, and maintaining a positive attitude.

Maria: Kung fu, as a martial art, has taught you more than sparring and discipline though.

Jackson: Yes! The breathing techniques that I use are fantastic for reducing stress. Everyone should learn breathing techniques as it helps to relax people, even for those who do not have epilepsy. Kung fu has also helped me to focus on things that are positive and to push through any negative thoughts that I might have. I now hold a black belt in kung fu and I am very proud of that achievement. I can also proudly tell you that I am now teaching others in the art of kung fu. Giving back to others is really important to me.

Maria: I know that you have two very important, and wise, messages to tell.

Jackson: Yes!

Firstly, for those young people who feel bogged down by their epilepsy, I want them to find their passion in life and to work hard at it. Epilepsy won’t define who they are.

My second message is to the parents of children with epilepsy. It is okay if you don’t hold all the answers in understanding epilepsy. It is your journey, as much as your child’s, but let them grow up strong and to be the people that they want to become. Give them the skills and confidence to live well because at some point in their lives they will be old enough to evaluate things for themselves.

Maria: Thank you for sharing your story and wise words. As parents we don’t want our children coming to any harm but it is true what you say. It is important that our children are able to grow up to be themselves since having epilepsy doesn’t define who they are.

Our phone chat– Jill

Maria: Hi Jill! Thank you for the work that you do for EWCT and for also agreeing to be part of yet another of my community projects. People like you are pivotal to the success of community groups such as ours and your support has been unwavering.

Jill: Thank you Maria. It is important that people with epilepsy help others by sharing stories. For me, I would like people to understand that epilepsy is not who I am. I am Jill. A wife, mother, grandmother a volunteer and many other things that I value. Epilepsy is a small part of who I am.

Maria: Quite true! People with epilepsy are not epileptics, they are people living with epilepsy. That is an important message for people to hear right there.

In every story there is a beginning. Where does your epilepsy story start, Jill?

Jill: I had my first tonic clonic seizure at the age of 24 years when I was pregnant with my first child. I was put on Dilantin, which I absolutely hated. It made me feel so sedated but I was on this medication right through the remainder of my pregnancy to keep me safe. I seizured at the birth of my baby and I ended up by having a caesarean.

I had three more babies, with more seizures during my pregnancies and a caesarean with each one. I always had a seizure after being anesthetised, which didn’t help how I felt generally. The medical staff thought that my seizures were related to me being pregnant. My GP handled all of my pregnancies and my seizure treatment. I only had seizures during the night, and so I was able to function to some degree during the day but I always felt tired. It wasn’t until my youngest child was 5 years old, and when I was driving my car with my children in the back seat, that I actually had a daytime tonic clonic seizure and I had an accident. It was at that point in my life that I was sent to the hospital to have my seizures investigated. I was quickly diagnosed with epilepsy.

It was tough-going as I was a solo parent with four small children to look after. I couldn’t drive and I had to do the best that I could. I was put onto Tegretol and I was fairly well controlled on that medication for at least 13 years although I would occasionally have the odd night-time seizure. However, despite the tough times I was able to train as a nurse and I went to work in oncology outpatients.

Life was good for many years before I started to notice a couple of little strange things happening to me. Occasionally I would become confused at work but I didn’t put this down to seizure activity then, one day after driving home from work, I had another accident. I collided with a power pole!

Maria: Oh dear. Were you injured?

Jill: No, fortunately not but I remember trying to get out of the car and having bossy people trying to make me to stay put. I had post-ictal confusion and all I wanted was to go home. Once the police arrived, I persuaded them to take me home so that I could recover. I didn’t need hospital help. I needed to go home to sleep. The police were very kind to me. They didn't have to tell me that I would once again lose my driver's licence for a year.

After that, I consulted a private neurologist who did his best to control my seizures. Over the next 10 years he trialled me on several different antiepileptic medications but I continued to have night-time seizures. I would always wake up busting to go to the toilet and my second husband would give me frisium, which would prevent a further tonic clonic seizure from happening. My seizures generally lasted 2 minutes and I would have a headache and vomit. Sleep was the only thing that would improve my situation. One day, I can distinctly remember saying to myself "maybe this is the best control you will get, you need to accept that fact and get on with life". Reaching that point was a breakthrough for me. I stopped getting so frustrated and disappointed at myself, every time I had a seizure.

When I retired from work, I decided to go back to my neurologist to see if there were any other options. I wanted better seizure control even if it meant that I had to try a different medication. I was put on leviteracetam and that is the best medication that I have been put on. I have no side effects. No seizures! In my life I have tried epilim, lamotrigine, dilantin and tegretol and with ghastly side effects. Quite often I felt completely over-dosed. I can understand why people stop taking their meds but my advice is to continue persevering with them because eventually you may find the ones that work.

Maria: Good advice there Jill but we both know that it can be tough for 30% of people who are considered drug- resistant.

Jill: Absolutely! We all need to find hope and an enjoyment in our lives knowing that epilepsy can pose many challenges but first, we must accept our condition and find a positive path forward. Life is certainly worth living and that is possible to do with good support.

Our phone chat – Julie

Maria: Hi Julie, would you like to participate in a phone chat with me? As you know I do a community project each year and this year I am having 'phone chats' with people.

Julie: I sure would. I can talk for days about epilepsy. I also love to hear what others have to say about their own epilepsy stories. It helps me to realise that I am not a freak and that there are others just like me living with seizures. That we are all on the same planet. How exciting is that?

You know, I found out that many people with epilepsy seem to be quite spiritual or artistic, like Joan of Arc, Prince and John Lennon. A heap of famous people has epilepsy and that is really special to know as well.

Having said all of that, I really don't like the feelings that I have with my epilepsy as I don't seem to be able to completely relax. I am plagued by my own anxiety which drives my epilepsy, and then my epilepsy drives my anxiety. It is a never-ending vicious cycle and I feel quite yukky at times.

Maria: Can you describe your seizures?

Julie: I have three types of seizures: absence, tonic clonic and focal with impaired awareness. Perhaps the most interesting ones are those when I do strange things like closing all the doors and curtains without realising what I am doing. On other days I may have about a six second warning that something is about to happen and I have enough time and awareness to sit on the floor and make myself safe. When I try to speak my words come out all gobbedly gook. From then on, I have no idea what happens but apparently, I seem to blackout and look confused for several minutes before getting up, grabbing my bag, purse, phone or whatever is close to me, and I rush away. I look like I am on a mission and I don't respond to anyone. I suppose that lasts for several minutes and then I slowly recover but by then I could be crying. How embarrassing is that? I often wonder what people think of me when I do that. It is made even worse if I fall over. I know that when I have had a seizure in front of people it gives them a hell of a fright, it can't be easy for them.

I look so normal and yet I can't work as I have no seizure control. I can't trust my brain not to behave and yet I really love meeting people. It is my anxiety that holds me back to enjoying the company of others and I know that if I am feeling stressed, then I will have more seizures. I just don't want to be judged for having epilepsy and so I am really careful with the friends that I make.

Maria: What treatment options have you tried?

Julie: I have tried many different anti-epileptic medications with absolutely no success, I have even taken anti-depressants and medications for anxiety, but nothing has worked. I have been on the ketogenic diet, and lost a heap of weight, and yet the seizures still happen. I would like to try cbd but it is so expensive and I am not sure that it will work anyhow. I will ask my neurologist about his thoughts on the matter next time I see him.

Maria: Have you found any life style changes that have helped you?

Julie: Distraction works for me. Sleeping, watching tv, having the odd glass of wine, which are not good distractions, but I have found myself a voluntary job. It has given me a purpose to get out of bed in the morning and for me to put my make-up on and dress up. I have found my job fun and I am acknowledged for the work that I do.

Maria: Tell me more about your voluntary job?

Julie: I am a volunteer sorting out clothing and sewing. I love sewing. I am making dresses, skirts and trousers to give away in the Op Shop. People like what I make and some have suggested that I am good enough to put my own label on them. How does, “Lovingly created for you” sound? The money goes straight back to people living with mental illness. I feel so good knowing that I am giving back to people who are probably a lot worse off than me.

Maria: Thank you for your time, Julie. I have seen many of your creations and they are really good. Perhaps there is a market there for you. Take care and continue having fun in your life.

Our phone chat– Alicia

Maria: Hi Alicia, thank you for taking the time to have a chat with me today. I understand that having epilepsy has created many challenges for you.

Alicia: Yes, living with epilepsy has certainly been challenging, heart breaking and at times overwhelming. There are days where my brain feels as though it could explode as I have tension headaches on a daily basis.

Social occasions can cause me grief especially when I have sudden grand mal seizures in public. One day, I took my son, younger brother and friend up the sky tower and I had a seizure in the public food court and I wet myself and vomited. I required an ambulance to help me. The following days I had a support network of people who were there to look after me until I was able to look after myself and feel safe alone again.

Maria: I can imagine how you feel. Struggling with anxiety is so common with people living with uncontrolled epilepsy. It is the unpredictability of when, and where the next seizure is going to happen.

Alicia: Absolutely! The fear of being in a situation that I have no control over is terrifying. My anxiety takes over, I feel physically sick and more often than not I will choose not to go anywhere. I also feel a great deal of shame for having epilepsy because it is a hidden condition and people often say, ‘but you don’t look sick!”
I have days where inside I feel as though I am running on a fuel light and the warning bells are going off. Quite often I have to push through my anxiety.

Maria: It saddens me that there is still a lot of fear and prejudice around epilepsy and hidden conditions in general.

Alicia: Society is definitely not educated on the seriousness of hidden conditions. Apart from having epilepsy, I also have cerebral palsy and depression. I feel that I am constantly battling to keep well especially in keeping my triggers under control so that I don’t have seizures.

Maria: What are your seizure triggers?

Alicia: Being tired or having a headache are my seizure triggers. They are my yellow lights before the red light switches on and I have a seizure. It will take me anywhere between 3 days and two weeks to fully recover after a seizure.

Maria: It can’t be easy for you but I know that you have the support of someone really special in your life.

Alicia: Yes! I have a son and I want to be there for him and so I work hard in being the best I can be. I make sure that I take my medications and lead a healthy life. I try not to burden my son with my epilepsy but at the same time I know that he is there for me.

Maria: Good people in our lives are really important and I know that your son is a one of those people.

Our phone chat – Thomas

Maria: Hi Thomas! It is always a treat to catch up with you. I am sure that I am going to enjoy another lively conversation. Tell me how are we going to start our phone chat conversation?

Thomas: I am going to give our chat a title, “The economics of disability”.

Maria: Wow! Okay I am really interested to see where this leads.

Thomas: As you know I have struggled to find employment and I am really ashamed of that fact. I used to be able to run around the Waitomo hills dreaming and planning a future but those were all dashed when I developed epilepsy as a 16-year-old. Epilepsy took over my life and now I am faced with the grief of knowing that I will be unable to pursue my former dreams.

When I was growing up there was an expectation for me to get a job, get a job, get a job… and in that process buy a house and save some money. There was too much expectation for me to get a job, I dearly wanted one, and I want one now, but I feel that there are barriers to employment when you have epilepsy. Throw in mental health issues and you can be really are out of luck.

Maria: I understand the barriers around finding, and staying, in employment when you have epilepsy. It is tough and I see lots of people who would like to be employed but find their options really limited.

Thomas: I like the idea of being a blue-collar worker. I wouldn’t mind working in a factory for example, but many jobs have been packed off shore where wages are dirt cheap. Many jobs have also been automated and so people aren’t needed any more like they used to be.

Maria: Absolutely, I grew up in the olden days of the dinosaurs when there were many blue-collar jobs available. How could we improve things for people living with a disability or chronic condition today?

Thomas: I would like there to be some partnership between the government and the business sector where bosses are encouraged to employ someone with a disability or, in my case, with epilepsy, knowing that sometimes we have limitations in what we can achieve in a day. All it takes is a bit of courage, lots of empathy and some epilepsy awareness in my case.

Maria: I quite agree. From a business perspective it makes good sense to employ someone with a disability, such as epilepsy. Society’s views on a business are influenced by the people who work there, and if businesses are shown to celebrate diversity and support people with disabilities then there would be strategic, legal, social, ethical and personal benefits.

Thomas: Yes! I believe that people with any disability, including epilepsy, would make fantastic employees. We are resilient and we want to work! If only we could overcome the stigma and prejudice out there in society to make it happen. It really isn't a picnic being on a benefit and there is absolutely no quality of life when you live hand-to-mouth. By not having a job affects your mental health which then can affect your epilepsy. It is a bit of a vicious cycle of despair.

Maria: Your title "the economics and disability' is quite interesting. Many people with a disability, including epilepsy, are underemployed or unemployed simply because of their medical conditions. There is a lot of untapped potential in having these people out of the workforce.

Thomas: There is and it saddens me. I think that I will continue to dream for a better life and hope that a bit of luck, plus perseverance, will eventually find me a job.

Maria: I wish you well, Thomas.

Our phone chat - Maxine

Maxine: Hi Maria! Thank you for the invitation to participate in your phone chat project. Personal stories are always interesting.

Maria: Hi Maxine! Not a problem. It is always lovely catching up with you. Where shall we begin?

Maxine: My epilepsy story started back when I was 14 years old, just as I hit puberty. It was the end of the beginning as I felt suddenly oppressed by society. I am going back forty odd years now when there was still a lot of stigma, fear and prejudice towards epilepsy. I felt that I was handed a bad deal in life as having epilepsy had that ripple effect and I missed out on growing up. Suddenly I couldn't play sports, go to graduation, go dating. All the things that I wanted to be doing at that age.

Maria: There must have been lonely days for you. How did you manage?

Maxine: I became depressed! There were no Maria's in those days and I had to learn to cope on my own, which was really difficult and so I left home and became involved with the 'fringes of society'. I won't call them bad people but their company didn't help me as I made some really bad decisions from then on. I suppose I felt angry with the world for having epilepsy. I got involved in drugs and I fell pregnant! But I have learnt from my mistakes. I believe that it has made me a better person today.

Maria: We all make mistakes growing up, Maxine, that is life.

Maxine: It is! But it hasn't been all bad as I did get to meet some wonderful people along the way especially my Maori whanaunga who took me in when I was at my lowest. They never judged me for having epilepsy. In fact, they saw me for who I am. I owe my life to them.

Maria: There was a traumatic incidence in your life that showed the power of family love. Would you like to say what it was?

Maxine: On July 17th 1998, I will never forget that date, I fell into a scalding hot shower and had a seizure. I received third degree burns to 40% of one side of my body and I was in hospital and rehabilitation for a whole year. It was a scary time for both my young son and me, but I came through it with the help of my family and Maori whanau, my son's whanau. I found them to be very loving towards me when I needed their love. They did not judge and accepted me for who I was.

My own family and my Maori family/ Whanauga supported me to achieve my goals at that time just in showing love and kindness.

Maria: Having this horrendous injury was also a turning point in many ways for you.

Maxine. Yes! I was in survival mode for a whole year but then I was encouraged to see the bigger picture in my life. I was on a benefit for a little while, which I hated. I was told that I couldn't work and so I did quite the opposite and went back to work. Interestingly, my seizures also stopped, which was amazing. I could trust my brain to behave itself. Up until my injury I had uncontrolled epilepsy but I have only had one seizure since, and that was back in 2004, which means sixteen years of freedom!

Maria: Why do you think that this has happened?

Maxine: I am going to put it down to menopause! I still take my meds even though my seizures may have resolved but I am not taking the risk of not taking my meds and having another seizure. Hell no! I would be too frightened to have another seizure. I don't want life to stop for me. I love my job, where I am valued, I love driving my car and I love my life.

Maria: You are a strong woman; Maxine and you have a lot to offer to others facing hard times.

Maxine: I can help others, even if it to say, I understand where you are coming from as I have lived a life of hard knocks. Having epilepsy, the loss of my husband in 1993 in a drowning accident and having a serious burn injury has taught me resilience, something that we must all learn to have especially in these uncertain times post Covid. Build a positive life for yourself and be strong. Trust in the connections that our communities can provide for us using the family and friends to support and strengthen. Remembering that what we receive is given back with gratefulness, love, Mana.
Kia Kaha!

Our phone chat – Marama

Maria: Hi Marama, thank you for participating in my 'phone chat' project. I love the idea of people telling stories and I wish to thank you for telling me yours.

I understand that your little lad has quite complex epilepsy.

Marama: Indeed, he has. My son has quite a few medical, learning and behavioural challenges as a result of him having drug-resistant, left-temporal epilepsy which has been caused by a gene mutation called KCNT1. This has led to him developing encephalopathy, which is severe brain disease.

It has been a really difficult journey as my son has trialled 10 anti-epileptic drugs (AEDs) and we are still trying to get good seizure control for him.

Maria: I understand the frustrations involved here as there is no one fix magic pill and many people with epilepsy end up trying lots of different medications before they find the one (or more) that works. Unfortunately, at least 30% of all people living with epilepsy are seen to be drug-resistant. It is pure heart ache.

Marama: My son is currently being weaned off Lamictal and is trialling Phenytoin. He is also trialling CBD along with Keppra. It is quite a cocktail of medications that he takes. He is also taking Rubifen and Ritalin for his ADHD.

Maria: Please tell me about these challenging behaviours.

Marama: My son has attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), is on the autism spectrum (ASD) and has severe insomnia as a result of having clusters of nocturnal seizures. My son has seizures all through the night, usually on the hour every night, and tries to stay awake from 3 or 4 am until school starts. Due to this he is sleep deprived and at more risk of seizures during the day.

Maria: It has been a tough six-year battle getting help for your son.

Marama: It is an ongoing battle navigating various agencies to find out what respite funding is available for our son and our whānau as a whole. We have also struggled every year with meeting the criteria for HHN funding (he usually gets approved but then it is declined if he doesn't have enough daytime seizures to meet the HHN criteria) so our school is now applying for ORS for the first time. My son needs full time supervision for medication, toileting, playtime, swimming, science and technology. He needs to be safe because of his seizures. It is a real worry.

Maria: Gosh! Navigating systems are truly frustrating and so slow. The high health needs (HHN) is formulaic as minutes are counted in a child's life at school. Unfortunately, there is very little awareness of what epilepsy is and how seizures affect people generally. Epilepsy is more than a seizure. It is about how those seizures affect people and it can be lasting. It can affect mood, memory, sleep, personality. The list would go on.

How is the ORS funding application coming along?

Marama: The school is still in the process of writing that application. Once again it is going to take time. Meanwhile, my family is under pressure, as is the school, as our son's behaviour is becoming more challenging. If his mental health declines further then he will be put onto risperidone.

Maria: Children with epilepsy (and their families) carry huge burdens in life because of epilepsy.

Marama: I had to give up full time work during lockdown when we lost our previous caregiver. I hope to use the time I have off work to set up a better support network for our whānau so that we are better able to cope with the challenges of life and all that our son's condition brings with us.

We know that things happen for a reason and there are lessons to be learned here for us.

Maria: Thank you for sharing your story Marama.

Definitions for:
ORS (Ongoing Resourcing Scheme): Helps a student join in and learn alongside other students at school. Once a student is in ORS, their funding stays with them throughout their time at school. Around 1 percent of students receive this support at any one time.
More information can be found on the education.govt.nz website.

HNN (High Needs Funding): Helps a student join in and learn alongside other students at school. Once a student is in ORS, their funding stays with them throughout their time at school. Around 1 percent of students receive this support at any one time.
More information can be found on the education.govt.nz website.

Our phone chat – Mike and John

Maria: Hello you two. You have been best friends for years and I know that your sense of humour gets you into all sorts of mischief! You are so good to be around and I enjoy your company.

Mike: Well you know me. Having a sense of humour certainly helps me get through some tough days as I do feel lonely at times. Some days I sit and watch my toe nails grow! I am sure it is a bit like being on home detention, but you just have to put your nose to the grindstone and get on with life.

John: *How did you survive over lockdown, Mike? Fortunately, I had moved into a flat with three other men and I had company but I am reminded daily of my epilepsy. I have to take my medications three times a day just to keep me free from seizures.*

Mike: Oh! I don't have enough fingers and toes to count the numbers of meds that I am on. I am certainly on a cocktail of drugs. I am taking four different types of medications for my epilepsy (20/day) and 12 tablets/day, for my other medical conditions, which is over $50/script! Because of the amount of anti-epileptic medications that I have taken over the years it has caused me to have osteoporosis because the calcium has been leached from my bones. It is no wonder that I broke my femur a couple of years ago.

John: *Oh! I remember that. That slowed you down!*

Maria: I remember you both telling me that school was a bit hard for you when you were growing up.

Mike: I went to a convent school and the kids there were a bit unkind and they called me "Fits". By the time I went to secondary school, things were a bit better but I couldn't participate in many things because of my epilepsy. Having epilepsy is a bit difficult to hide. I really wanted to lead a normal life but my seizures were never controlled and so I left school at 16 years of age.

John: *I was called "Epi" at my school. I played a bit of footy but nothing fancy like the All Blacks! I left school by the age of 14 years and I went to work as a packer in Hole Proof Socks. I was there for several years, which wasn't too bad and then I worked for the Hamilton City Council for close on ten years.*

Mike: I had two jobs when I left school. I worked for Shand's Bakery grading bread and then I worked in the Huntly brick factory grading bricks. They both shut down after I left.

John: *Probably because of you Mike! I still go to work. I now work at the Cambridge Achievement Centre.*

Mike: He pretends to work!

Maria: What family support do you get to help you through the days?

Mike: I have a brother and sister who live nearby. My other two siblings live elsewhere and I haven't heard from them in ages. My brother closest to me takes me shopping every two weeks, which is kind of him. He is worried about my seizures. I seem to be having a lot more of them these days and I don't know quite what to do about it. I have travelled to Australia twice: once for an MRI and the second time for brain surgery, neither was available in New Zealand at that time. Further brain surgery was declined by me because there was an 80% chance of me losing my eyesight and no guarantee of seizure control. I wasn't prepared to take the risk.

John: *I don't have much contact with my brothers these days. People move on in their lives. It is just as well I have moved into a flat and I still go to work. I know that my boss keeps an eye on me. I don't think that I have had any seizures lately.*

Maria: It has been delightful meeting up with you both again. Until next time! Keep well and stay safe. We will keep in touch!

Our phone chat – Carl

Maria: Hi Carl, it is always lovely hearing from you and to know that you are doing well. Your epilepsy story is an interesting one because you have been experiencing unusual thoughts and feelings for a very long time now. You never imagined that you could have epilepsy but the brain is a mysterious organ and people can experience seizures other than tonic clonic, which most people instantly recognise as being epilepsy. Please tell me about your very first 'episode'?

Carl: Back in October 2015 whilst composing music, I experienced a sudden indescribable feeling that completely overwhelmed me. It felt like I was experiencing a past memory or living out something I had dreamt all at the same time and it made me very fearful. I had never experienced this before and I put it down to having a severe lack of sleep and depression. I didn't seek help at the time because I didn't think that it was anything that could be explained. Perhaps it was just that I was so tired and my brain was telling me to sleep and relax. I took up meditation, which I thought would help with my anxiety.

In 2016 I wrote in my journal of episodes in July and early December. I wrote a lot that year about feeling washed out, woozy and tired continuously. I went to my doctor in October to talk about the episodes and get my moles checked. She referred me to the Neurology Department to have a sleep-deprived EEG and a CT scan. In other news I was diagnosed with melanoma and had a malignancy removed. It was Stage 1A. This experience caused me massive amounts of anxiety and I became a hypochondriac, convinced I was going to die of cancer. This continued into 2017. I started to fear dying of a heart attack, or stroke. I didn't want to be left alone and couldn't stay by myself at night. I saw a psychiatrist.

During 2017 I also started to worry about my memory. I tried not to remember things so as to avoid the episodes. I started to worry about my memory. My doctor prescribed anti-depressants in February but I didn't take them. My sleep was consistently very poor. In March I contemplated suicide after several days of mental struggle and weird thoughts. I saw another psychiatrist over this time after talking to the Crisis Centre. I wrote a lot about feeling like I'm not awake properly, like my subconscious mind is still engaged even when my conscious mind is working. Like I'm awake and dreaming at the same time. I don't like any of the psychiatrists and don't open up to them much.

In September I am convinced I'm getting dementia. My memory is terrible. Especially short term, but I start to forget the names of people that I have known for a while. I decide to take the beta blockers and melatonin my doctor prescribed to me in July – after another bout of episodes. I get a CT scan and the psychiatrist confirms I don't have any signs of dementia but I am sleeping poorly and I constantly feel anxious.

In October I have more episodes and begin taking anti-depressants. I start talking to a male counsellor, which is helpful, although I still don't open up fully. He reckons the episodes are repressed memories trying to come back. I am getting into meditation and enjoying the effects, but I can't stay consistent. I get derailed by my anxiety over work and my daughter. I have a lot of bouts of nausea over these months. I develop appendicitis and have to have an appendectomy in December 2017.

I didn't write much in my journal in 2018, but I'm fairly certain I had some episodes at the usual periods.

Maria: In epilepsy terms, episodes like these are called focal aware seizures. A person is aware that something is happening in their brain and they can describe it. In your case it was the sense of fear, of jumbled dreams and memories. Other people can hallucinate, experience deja vue, jamais vue and a whole raft of experiences that can barely be explained. It all depends where these seizures are happening in the brain.

Carl: Interestingly, my ‘episodes’ seemed to develop a pattern of happening every three months and they would come when least expected. When I was playing football, playing music – in fact they would even wake me up from my sleep. When they happened, they created a huge degree of anxiety and I became aware that it was starting to affect my memory. This really bothered me.

Maria: Memory loss is really common in people experiencing seizures but at this stage you didn’t know if you had epilepsy. Did your GP click that something else was happening since your beta blockers appeared not to be working?

Carl: It wasn’t until the beginning of 2020 that I eventually managed to persuade my GP to refer me to the neurology department at the hospital. I had a series of tests to determine if in fact I was okay. I was starting to worry that something nasty was happening to me. Did I have early dementia? Did I have cancer?

My MRI, EEG, blood and neurology tests came back normal but the specialist was able to quickly deduce that I was having seizures in my amygdala. This region of the brain is known as the flight/fight/freeze area and it was being switched on. It somehow activated my dreams and past memories and I became fearful because the brain saw these jumbled messages as me being in danger. These seizures always leave me feeling scared. Frightened. Fearing death. And yet I have nothing to fear in my life.

Maria: How do you feel about having the epilepsy diagnosis?

Carl: I’m not convinced of the diagnosis. I need to talk to the neurologist again and get his views after this latest round of tests. I’m concerned about the T2 dots in my DWM, and want to know if this could be causing the symptoms. My main concern is still there. Am I going to get dementia, will the episodes increase or get worse and I end up having tonic clonic seizures?

Maria: Medications are designed to hopefully stop your seizures so that you can lead the life that you want. What are your thoughts on medication?

Carl: I’m still not certain of my condition. I’m really keen to know exactly what is happening there before I consider medication. It will be a bit of a journey for me but I guess that I will get there in the end.

Maria: We will stay in touch, Carl. I understand your fears. Overtime I hope that you find the answers to these horrible feelings. Take care.

Our phone chat – Kim

Maria: Hi Kim, I am really interested in hearing your story today. Your epilepsy story begins as a 12-year-old.

Kim: There were a few significant events that happened in my life when I was 12 years old that caused me to really spin out of control. Firstly, I lost my best friend in a road accident. We went everywhere together and I couldn't believe it when she died. I really mourned for her at the time. Secondly, I was kicked in the head by a horse and this led to me having seizures. The only trouble with that was being told in church one day, that I had the devil in me as I was recovering from a tonic clonic seizure. You know the sort. I was frothing at the mouth with my eyes rolled back in my head. That comment absolutely did it for me and, from then on, knowing how bad the devil was, it blew me out of the water and I was blown into a world of turmoil. I became the wild child overnight.

Maria: Oh dear! Kim. Occasionally I hear comments like this and it is tragic to know that there is still that level of misunderstanding around what epilepsy is. Epilepsy is purely a neurological condition. It is when those brain cells start misfiring and people have seizures. What happened next?

Kim: I escaped into the world of marijuana. I became a heavy marijuana user and I would escape into a 'better' world, or so I thought at the time. I liked going back into that world time and again and I had no thoughts about how dangerous it was. The only way that I could keep happy was to be totally stoned. When I wasn't stoned, I was depressed. I started wagging school and then I left at 15 years of age and I went to live in Australia with my boyfriend at the time.

Maria: What was happening with your epilepsy at this time?

Kim: Oh! My seizures simply kept coming. I would have at least three tonic clonic seizures a day and I had no idea of when, or where, I would have my next one and I didn't care. My neurologist did tell me at that time that I wasn't doing myself any favours and that my lifestyle was causing me to have all these seizures. I was completely blind to receiving any help. I blamed having dyslexia on my lack of success in life. I don't even have dyslexia! I was just too ashamed, I suppose, to say that actually I was just stoned. What an excuse?

Maria: I am afraid to say that marijuana is never going to cure epilepsy and that it can actually worsen seizures.

Kim: One day, and after 15 years of being totally wasted, I woke up to what I was doing. I was living back in New Zealand at this stage and I wanted something better for myself. I knew that my two children were terrified of my seizures. I started to feel stressed living day-by-day for my next fix and realising that my children needed more from me than what I was giving them. I had reached rock bottom and I became suicidal. One day I dropped my children off at day care and I walked away. I suppose I was trying to walk away from my life and what it had become. Eventually I fell down outside a church only to be picked up by a wonderful elderly woman. I will never forget her kindness or her name, Roma. I owe her my life. I was just 27 years old!

Maria: How is life for you today?

Kim: I am now in my 40s and I haven't touched alcohol, marijuana or tobacco for a long, long time, twenty years in fact. I still have seizures but I feel that I am getting on top of them. I am still not used to that horrible feeling of a snake writhing inside my stomach, which is the warning that I am about to have a tonic clonic seizure, but I try to distract myself and hope that it doesn’t happen. I am hoping that I will grow out of my epilepsy. I am also taking fewer medications and I feel more alert and I am happier than I have ever been.

Maria: Brilliant! Please keep in touch with your neurologist though. Any sudden withdrawal from your medications could lead to you having more seizures or even status epilepticus which is when a seizure doesn’t stop.

Kim: I want to say sorry to my neurologist. I want to tell him that I don’t have epilepsy but instead that I blew my brain cells out. I want to thank and acknowledge him because he was trying to help me for years but I didn’t want to listen.

Maria: What has been your path to recovery?

Kim: I approached the woman who told me that I had a devil within me all those years ago when I was 12 years old. She wasn’t happy to be reminded of that occasion but for me I was then able to put that past behind me. I now belong to a different church group.

I also went to polytech and I did a two-year design course. I am a successful fashion designer in New Zealand and I sell my clothes to boutique stores. I love my job. I am grateful for my family and my two wonderful children. I have less negativity in my life and less stress. I know that stress is a major seizure trigger for me and so I surround myself with good things.

I have also learnt that a story always begins at home and children live what they learn. Life is really short and it is valuable. I want people with epilepsy to look after themselves and to know that anything can be possible. I was meant to live through all of my life’s journey and I want to share my knowledge to help others.

Maria: Well done, Kim. I have seen your boutique clothing and I am in awe of your brilliance.

Thank you for your time.

Our phone chat – Mary

Maria: Hello Mary. Thank you for sharing Jake's story with me. It has been quite a journey for you all since Jake developed epilepsy as a 12-year-old.

Mary: Jacob (Jake) was born in June 1988. He was a gorgeous, healthy and a contented baby and one of five boys growing up on the outskirts of Hamilton, New Zealand.

Jake was a typical kiwi kid. He loved the outdoors and spent many weekends with friends and his brothers playing soccer, hiking, camping, rock-climbing, riding bikes and holidaying at the beach. He was shaping up to be an accomplished student, a gifted sportsman and above all else he was a loving, kind, funny, outgoing, and adventurous person.

In April 2000 when Jake was just 12 years old, we woke to hearing Jake's first epileptic seizure. He was taken to hospital and after a weekend of tests he was prescribed his first antiepileptic drug (AED) for Juvenile Myoclonic Epilepsy. Our world was turned upside down as Jake's seizures were never controlled and he lost out on enjoying the life that we imagine for our children.

Maria: I understand that sense of loss for both your family and for Jake as the normal teenage life became impossible to do.

Mary: Despite his illness, Jake had an incredible positive spirit, and through sheer determination he worked hard to lead a normal life. In his early 20s he enrolled at polytech to follow his passion for music. He managed part-time work for several years, until the frequency and severity of his seizures made it impossible to continue. Jake tried flatting, but because of how violent his seizures became, he needed more support from his family and he came back to live at home. Simple tasks became difficult for him to do and we worked hard to mitigate for any injuries should they happen as a result of his countless seizures.

Maria: Jake has drug-resistant epilepsy. What else has he tried to help control his seizures?

Mary: Jake has been seen by three different neurologists over the years who have tried every anti-epileptic medication imaginable to control his seizures. They didn't work and so we tried many avenues to get help for him. Jake is currently on the dietitian-prescribed ketogenic diet but he has tried acupuncture, homeopathic, naturopathic, osteopathic, and physio therapies.

Maria: Over the years, I believe that Jake's epilepsy diagnosis has changed.

Mary: Yes! He was diagnosed with frontal lobe epilepsy four years ago and more recently that has been changed to epileptic psychosis, a rare form of epilepsy occurring in 2-10% of people living with epilepsy. These seizures create paranoid delusions and hallucinations which are excruciatingly painful for him both mentally and physically as he is fully conscious when they happen.

Maria: What is life like for Jake today?

Mary: Initially he had been taken off all medications because of their side effects but the roller coaster of his withdrawal highs and lows, hospitals and heartache it was too much to bear and now he is back on some medications. He still has multiple seizures a week and he needs help with daily tasks like showering, shaving and eating his meals.

Maria: I believe that Jake is moving into a wonderful home where he will be looked after fulltime. It has been a long time in coming and I am cheered that he will receive the level of care that he needs. Hopefully it will also open up avenues of social interactions for him. I am sure that there have been many times when Jake has felt socially isolated.

Mary: It is so good that we now have Jake moving into what certainly looks like a great residential home and in a beautiful part of Hamilton. The staff will make all of his ketogenic meals, which is his only form of seizure treatment, and they will be given epilepsy awareness training on what Jake's seizures look like. Our hope is that Jake will have opportunities to meet others as he has certainly been socially isolated over the years. It has been a long journey, not only for Jake but, for his brothers and for us as parents. The journey isn't over but I think that Jake will have a better quality of life from now on.

Maria: I am sure that he will. Thank you for sharing Jake's story, Mary.

Our phone chat - Sally

Maria: Hello Sally. It is always lovely to hear from you. How are you?

Sally: Well you know, I have my bad days and my good. Today I am feeling a bit frustrated with myself. I used to be an intelligent person once upon a time but I think that my memory isn't quite what it used to be. What with all the seizures that I have had all my life and the hits on the head when I have fallen over, it hasn't helped me to remember things. Goodness! What a way to start a conversation. I probably need a hug!

Maria: A hug a day chases the stress away Consider yourself hugged!

Sally: Thank you. I shouldn't grumble because I am living in a place surrounded by such good people who keep an eye on me. I live in a caravan park and I am really safe here. I tell people situated close to me that I have epilepsy and I have shown a few of them my epilepsy action plan so that they are aware of what my seizures look like and how to respond if I should have one.

Maria: That is reassuring to know. You did have a seizure recently that occurred outside of the camp. What happened there?

Sally: I had one of my focal with impaired awareness seizures. I wandered outside of my caravan in the early morning wearing only but my night clothes. By the time that I had 'woken up' from my seizure two lovely young men had come to my rescue. One had phoned for the police and the other had given me his warm jacket to wear. Honestly, I was so grateful for their help.

Maria: You have a number of different seizure types.

Sally: I do! I have absence, tonic clonics, myoclonic jerks, focal and focal impaired. I have seizures most nights and I can be heard screaming in my post-ictal state. I tell those around me to bang on the door if I am making too much noise but, of course I won't hear them. Occasionally, I have a seizure when I am out and about but you know, everyone I meet are so kind to me when I need help.

I don't want to live in 'amber alert' all the time but I know that my world is smaller than most. I don't feel as free and easy as I would like and I am impacted by my epilepsy. I would really love to be normal.

Maria: Normal is boring!

Sally: Yes quite! That is what Freddy Mercury said.

Maria: I believe that you have had some interesting advice from others regarding epilepsy treatment options?

Sally: I have been told by people to take marijuana or cbd. I would be frightened of taking any substances like that. It is bad enough coping with the medications that I take without worrying about what could happen if I took something different. At least I know how my medications affect me. Taking marijuana or cbd isn't necessarily going to be the answer but many think that they are the miracle drugs that can treat most things.

Maria: There is a lot more research that has to be done on the implications of treating a person living with epilepsy with cbd. We know that it can help children living with Dravet or Lennox Gastaut syndromes but not with epilepsy generally. Neurologists and paediatricians would be quite cautious in prescribing cbd. As for marijuana, many people tend to take this drug recreationally whilst hoping to de-stress. Their belief is, 'no stress, no seizures'.

Sally: I can identify with that. Stress is my major seizure trigger. The more I stress, the more seizures I have. The more seizures that I have the more I stress, it is a vicious cycle but I still wouldn't be tempted to smoke marijuana to get out of it.

Anyhow, I best keep going as there is much to do.

Maria: Thank you for your time, Sally. Take care until we meet again.

Our phone chat – Tania

Maria: Hi Tania, thank you for sharing your epilepsy story with me today.

Tania: That is okay. I don't often speak about my epilepsy because I just accept the way things are now. My first seizure happened when I was 16 years old, straight after I had a haircut, in fact. My parents clicked that something was wrong with me and I felt upset that I didn't feel normal. I eventually ended up by going to Melbourne and being diagnosed with Rassmussens Encephalitis.

Maria: Goodness! That is a rare neurological disease. I have to give a text book answer here, Tania, straight from Dr Google. It says that Rassmussens Encephalitis is characterised by frequent and severe seizures a loss of motor skills and speech. There is also weakness on one side of the body.

Tania: All of that is true. I can't use my left arm to do the simple things like pick up a cup. My left leg drags and the neurologists say that I have Todd's paralysis.

Maria: Todd's paralysis is something that I know about. It means that there is a brief period of temporary paralysis after a seizure and it usually affects one side of the body.

Tania: That is right but they haven't explained why I still drag my leg. I need to use a walking stick to get around. There are days when I have lots of seizures. My arm shakes, my fist clenches and I feel cold. I haven't had a tonic clonic for years fortunately.

Maria: How do you manage day-to-day?

Tania: I have a team of people who come in and help me on weekdays. In the mornings I am helped with my personal cares. Someone showers me and makes sure that I have taken my meds. They come in again at lunchtime to make my lunch and to make my bed and anything else that needs doing. In the afternoon, they help to get my evening meal prepared. I really do need their help because my seizures have got worse over the years. I also lose my balance and so I fall down quite a bit. Don't let me start talking about my memory, which is like a sieve.

Maria: That is pretty tough but you do have a positive attitude towards life even if you say that epilepsy sucks!

Tania: It does rather but I am not lonely. I have lovely family and friends who keep in touch. I like to muck around on my computer and on Facebook and I talk on the phone quite a bit. I am happy in myself and I am grateful for the small things in life like my garden. My son is 13 years old and I want to be around for his 21st birthday.

Maria: That is every mother's wish. I am sure that you will be there to enjoy the day. Thank you for your time.

Our phone chat – Steph

Maria: Hi Steph. I know that you have been itching to tell me your story.

Steph: I am because I am trying to process what is happening to me with regards to my seizures and anxiety levels.

Maria: In a previous conversation you mentioned that there was an 'old you' and a 'new you'. I am interested in knowing more about that.

Steph: In my old life, I was a personal assistant to a CEO of a large insurance company in London. Life was fast, I drove a car, lived life to the full and I was in a stable relationship. Life couldn't have been better. Then something went quite wrong when I returned to New Zealand. In fact, my life spectacularly fell apart after I had my first tonic clonic seizure.

From then on, I felt my old-world crumble. Anxiety and depression took hold and my seizures became uncontrolled. The longer I had epilepsy, the more my anxiety grew and I worried what people might think of me if I had a seizure in front of them. I didn't want to ruin their day and so I started staying at home more. I became really stressed and depressed

Maria: Oh dear! I am so sorry to hear about this. In the past you have described your epilepsy experience as like playing in a game of 'snakes and ladders'. Can you explain that to me please?

Steph: I have taken lots of different anti-epileptic medications over time and, with each new medication change, I hoped to find seizure control. My life did feel like a game of 'snakes and ladders'. Some days I would feel upbeat and positive like I was winning the game but then I would slide down right to the bottom and feel quite deflated. I found it hard living with drug-resistant epilepsy and so I started having some frank discussions with my new neurologist.

Maria: Those discussions have been a turning point in how you are managing your epilepsy. Has your neurologist helped you to become a 'new you'?

Steph: He has! He has helped me to take a more positive approach in life. He is a great supporter of the ketogenic diet and so I decided to give it a go. I lost lots of weight on the diet and my seizures were starting to get under control. For the first time since developing epilepsy, I felt that I was also getting on top of my anxiety and depression.

Maria: You did marvellously well on the diet but you found that it wasn't sustainable. What happened?

Steph: Having to be so strict on the diet was hard work especially with a teenage son eating me out of house and home, and so I started looking at other options to control my seizures and I think that I have found it. Some really kind person is sponsoring me to trial cbd (cannabidiol) and so far, I think that things are working for me. I feel like I am back in the race. Life is no longer a struggle but it is still early days.

Maria: What have you noticed whilst being on cbd?

Steph: I have now been on cbd for four months and it has significantly reduced my focal seizures and they are not as intense as they once were. Every day I see a difference in my life. My confidence is coming back and I have more energy. My life is racing up those ladders and I have had very few set-backs so far. I have hope for a positive future but there is one big snag in all of this.

Maria: And what is that?

Steph: Am I going to be able to use cbd for the rest of my life if it works? The idea of it not being available scares me so much. My sponsor pays my monthly cbd costs of nearly $600/week since Pharmac does not see my need as being exceptional, as there are others like me living with drug-resistant epilepsy.

Maria: At least 30% of people living with epilepsy are drug-resistant.

Steph: Yes! And so, what options do we have in life once our medications have failed? I am sure that it is costing the healthcare system lots of money to pay for my medications, hospitalisations, in patients/outpatient care, psychologists, psychiatrists and counsellors. And I wouldn’t be the only one needing that level of support.

Maria: That is an interesting thought. Deloitte in Australia did a large study on the economic burden of epilepsy in 2019-2020 and found that people living with active epilepsy was costing their country a total of $12.3 billion a year. There are health care costs such as the use of MRIs, EEGs etc, financial costs that includes lost wages, absenteeism from work, production loss, equipment costs, welfare benefits and then of course there is the human cost.

Steph: I just want to have hope that my life is going to get better. I want to be able to have a tattoo and go sky diving. I want to have a job, get off a benefit and go on a date! Do you think any of that would be possible?

Maria: Once you choose hope then anything is possible. Thank you for sharing your thoughts with me today, Steph. You have given me lots to think about. Take care and I will watch this space as you continue your epilepsy journey.

Our phone chat – Lisa M

Maria: Hi Lisa, thank you for having a 'phone chat' with me. There is nothing better than being able to tell a story over the phone because you never know where it is going to lead. That is the beauty of using this method of story-telling.

Today we are going to talk about why your son, who lives with epilepsy, left New Zealand for Australia.

Lisa M: It is a bit of a story but, essentially, he had a great job offer there and so he decided to give it a go. He also discovered that he could stop using his anti-epileptic drugs (AEDs) in preference to using cbd (cannabidiol). Back in New Zealand he had been on Epilim, Lamotrigine, and some other drug that I can't remember the name of. In part they controlled his seizures but they lowered his mood to the point that he felt that he was walking around in a grey fuzzy cloud. The meds really took the shine off his life as he became more and more disorganised.

He would take his meds under sufferance and I would discover his bedroom drawer full of empty and half -empty pill packets. It was as if he was making a protest over what his life had become. He would ask his wonderful neurologist here, "Can I stop taking these things? Can I do ecstasy? Can I drink my energy drinks? Can I smoke weed?" The neurologist always gave a direct answer to these very direct questions but the answers were generally, "No!" Unfortunately, Jake always saw the word "no" as a challenge.

Maria: So how easy was it for Jake to switch from his anti-epilepsy meds to cbd in Australia?

Lisa M: Jake was reviewed by his Australian neurologist before he started taking cbd. He is now off his Epilim and is fully taking cbd and that is nearly two years now. And as long as he pays his taxes in Australia, he will have full access to the health system and his cbd. In fact, being able to stay on cbd is his motivation to remain in Australia but it wasn't initially his motivation to leave New Zealand.

Maria: What is your opinion of Jake taking cbd?

Lisa M: It has controlled his seizures and so I am happy for him. Believe me, seeing Jake having his massive tonic clonic seizures where he appeared to launch himself into space and end up by hurting himself was heart-breaking. As a mother, I felt pretty powerless to help him and sometimes I would just phone for the ambulance even though I knew that he would come out of his seizure and recover.

Maria: I agree. It can be really frightening watching a loved one having a tonic clonic seizure. There can be significant injuries as well but we ask that you remain calm in all of this. I understand that that is often difficult to do.

Lisa M: On recovery, I always felt so sad for Jake as I knew that he felt gutted for having had a seizure. He would have a blinding headache and need the following day off work to recover. He would say to me, “Who did I catch my epilepsy from?” He wanted to blame someone for having seizures but there is no epilepsy history in our family. Epilepsy has happened to my strongest and seemingly invincible child. As a mother I want to be able to make it better for him, but I can’t and that is why I am happy for him to be taking cbd.

Maria: I understand that need perfectly. In my role as an epilepsy advisor I get to meet many people who endure intractable epilepsy or have problems with their seizures or medications. Life is certainly challenging and I would love that there was a cure for epilepsy.

Thank you for your time, Lisa. I really appreciated our chat.

Phone chat – Ruth

Maria: Hi Ruth. Thank you for taking part in this ‘phone chat project’. I know that you will be speaking about your son’s epilepsy journey to date. It has been quite a journey and I know that there have been quite a few knock-backs from when I first met Oscar in 2016.

Ruth: Oscar has always tried to be positive about this epilepsy, but he has felt the judgement and ignorance of others on many occasions over the years, including family members whom he has chosen to distance himself from as a result. The first seizure which we experienced was in Los Angeles Airport in 1997 when we were traveling to the UK. He stopped breathing and I had to start CPR. While the ambulance officers were attending to him a woman came to me and said, “It’s just a seizure, my Uncle has epilepsy”. The word ‘just’ minimised what was happening to my son and this was unhelpful and hurtful at this time of unknown. Fortunately, we had health insurance because Oscar was admitted into a US hospital at a cost of $23,000 for a 26 hour stay.

Maria: Yes! Hospital stays overseas are certainly expensive if you don’t have medical insurance. Did you manage to get to the UK?

Ruth: We did, and we felt well supported by family and friends. I must add though that we are equally well supported here in our New Zealand community and my good friends have given Oscar, his brother (who also has epilepsy), and me the love and the manaaki to help keep us going in some tough times. The supporters have been affectionately named “Oscar’s Army”.

Unfortunately, the medical professionals have not always been supportive, or even understood Oscar’s condition. There is so much more than the actual seizures themselves. I was yelled at by a hospital GP and nurse when I had taken Oscar to the local hospital due to my concerns. They stated that I was creating Oscar’s seizures by saying out loud another one was imminent. While ambulance officers are always caring and concerned, I stopped calling them as if they could not see a seizure happening, there was nothing they could do even if Oscar was presenting virtually unresponsive. It is a difficult condition for these types of professionals to attempt to assist with due to their lack of knowledge beyond the seizure itself. In 2019 after an admission to hospital following a prolonged unresponsive period even the neurologists couldn’t agree on what they were seeing, two of which ventured to state, “he is acting” and “it is all in his head”. We, as a family, knew full well this was not the case. We were given no follow-up appointment to discuss our concerns and so we went back to our little community and essentially hid away in spite of the challenges progressing. Oscar’s life became smaller and smaller due to the increasing and daily epileptic activity he was experiencing between seizures, and the increase in multiple seizures in one given day, this affecting his interactions with the rest of the world. He could have massive falls and his breathing could be compromised needing resuscitating at times. Oscar was regularly picking himself off the floor alone, having smashed his head and teeth, amongst other serious injuries. He was often left confused and he was starting to behave in quite a strange way. The risk of death is real.

Maria: I am so sorry to hear that news. Epilepsy is a complex condition, and it is really important that medical professionals take the time to listen.

Ruth: Helping Oscar through this progression, and his determination I still work and ‘play’, was becoming unsustainable, unsafe and very high risk. In 2020 during a five-day period of being mostly unresponsive we already had a scheduled appointment with his neurologist via video call. His brother and I attended this and felt his neurologist really listened. He had a lightbulb moment stating he believed Oscar to be experiencing progressing epileptic encephalopathy. Thankfully, we have been heard for the first time in years by a neurologist. Honestly, you don’t expect any level of ignorance or judgement from professionals but when an ego is involved it gets in the way of listening and empathy; these are essential in my view to the patient AND the family who have to navigate these things with the inevitable stages of grief that occur. We have not felt heard or supported for years. I thank the neurologist for his insight, attention and understanding; this is a refreshing novelty, it has so much value in this journey and has alleviated the subconscious burden of feeling alone. We are in good stead emotionally; being peaceful, patient and living each day with some humour helps to live alongside this condition.

Maria: I understand that there is funding for Oscar to attend a wonderful residential home where there will be staff 24/7. What do you think about this new development?

Ruth: We are all delighted. I can’t believe that Oscar is still here after all that he has endured. As a family we have gone through extraordinary lengths to be heard. Oscar will live with three other young people in a safe environment and there will be trained staff who can help him make the most of the good days and support him through all the others.

Maria: I believe that there are big gaps in epilepsy awareness generally, and society as a whole can have little understanding of what epilepsy is and especially how people are affected by it. I thank you, and Oscar, for telling this story – it is much appreciated.

Phone chat – Charlie

Maria: Hello Charlie, thank you for taking part in my phone chat project. Every person with epilepsy has a special story. How shall we start yours?

Charlie: I guess that having epilepsy isn't just about me. It impacts on my entire family because of the limitations epilepsy puts on my life. I am not allowed to drive a car and so I can't just pop out to do the shopping or pick up the kids after school. I can't climb on the roof and fix the tv aerial and I can't take a chain saw to the tree that needs to come down. The things that I can't do, because of my seizures, intrude in my life and they become a burden on the family, especially for my wife.

Maria: I quite agree. The loss of a driver's licence can certainly restrict your independence and the ability to share the load within the family. And it can be a long year being seizure-free until you are able to safely drive again. Catching buses, taking taxis, relying on others for transport also takes time and organisation.

Charlie: It is the time managing my epilepsy that affects the family. It can be quite a chore. I am also not feeling quite well these days after my medications were switched from Lamotrigine to Logem. I didn't know that the medications were going to be switched until I got them home from the pharmacy and I haven't felt well since I started taking them. I am depressed, more anxious and quite irritable. I didn't feel like this on my old meds.

Maria: That is bad news, Charlie. I would recommend that your get your GP or neurologist to apply for Pharmac's exceptional circumstances application for an alternative brand of lamotrigine. When I last saw the Pharmac webpage, 2418 people had switched back to their original lamotrigine prescription. Please don't feel that you have to persist with feeling unwell. It may be that Logem doesn't suit you.

Charlie: I noticed that my GP doubled the dose of Logem just to control my seizures but it has worsened how I am feeling generally. I keep hoping for an improvement in my mood but actually things are worsening. I am also sure that I am having seizures in my sleep. I wake up feeling somewhat groggy some mornings and out of sorts. I try and tough it out at work but my lack of concentration affects my output. I have quite high standards and so I can beat myself up a bit if I know that I am not my usual self.

Maria: You work in quite a stressful environment advocating for others. That stress must be hard at times.

Charlie: It is! It also creates more seizures but I have an excellent boss. My boss appreciates what I do and I have supportive colleagues who recognise that I am having it tough at the moment. But I don't like to let the team down. I know that I am luckier than many people who have epilepsy and who work with difficult bosses. Gosh! If I had a difficult boss it would certainly be adding to my epilepsy burden right now.

Maria: It isn't easy for many people who struggle in employment whilst trying to manage seizures, or medications or even the lack of a driver's licence. There are laws governing the rights of a person with a disability and these include the rights of a person living with epilepsy. There are times when I have had to mediate for the employment rights of my clients. It can be hard work at times but I have been successful so far in helping to secure their employment.

Charlie: I am pleased that my employer is great. Do employers not realise that stress is a seizure trigger? Or do some employers create the stress to get rid of people with epilepsy?

Maria: That is an interesting thought. The employer can't openly discriminate against people with epilepsy. I can say with confidence, though, that I have met some fabulous bosses and workmates. There are times when we all have to pull together to make things work in harmony. A bit like working together in a family which is how we started our conversation.

Charlie: I enjoy our chats, Maria, and we have had many over the years. I am sure that we have righted the wrongs of the universe on many occasions. I will do as you have suggested and apply to Pharmac so that I can have my original lamotrigine prescription back and see if I can improve on my current situation. Thank you for your time and for the help that you give to others.

Our phone chat – Steve’s story

Maria: Hi Steve, thank you for wanting to share your story. You have had a bit of a rough and rocky road trying to live with epilepsy whilst not being fully supported in the community. I understand that the lack of support has been hard for you. How does your story begin?

Steve: Up until 2005 I was leading a busy life. I had my own painting and decorating business whilst being a solo dad. I played bowls professionally and I gained in total nine gold, silver and bronze medals and I was a body builder. Life was good and relatively normal until the fateful day I had a car accident. I am not sure what happened but I have vague memories of waking up to seeing the police, fire, and ambulance staff working on saving me. I know I was in the hospital for ten days recovering from whip lash and with problems with my back and neck but the right side of my head took the full brunt of the accident. You know, in a blink of an eye my life then changed forever.

Maria: It was shortly after that accident that you had your first seizure.

Steve: Yes! My daughter told me that I had a massive seizure when I was just about to take the roast chicken out of the oven! Later hospital tests showed that I had developed epilepsy as the result of the car accident and I was put on medication. Epilim it was. I hated the weight gain from taking it.

Maria: You continued to have seizures whilst on Epilim.

Steve: I did, and they terrified my daughter as I would suddenly freeze, my eyes would roll back into my head and I would drop like a fence post. I would then be frothing at the mouth and making those suffocating sounds whilst jerking. I had no warnings when those seizures were about to happen and then, afterwards, I would be as sore as the last man standing in a wrestling tournament. I would speak all gobbedly gook for hours afterwards as if I were drunk. I have broken my nose on several occasions and I have been in three induced comas because my seizures wouldn’t stop.

Maria: Gosh! This is pretty tough stuff.

Steve: I couldn’t continue working on my own as I had lost my driver’s licence and so I applied for another job. During the interview I had one of my seizures. Guess what? I didn’t get the job! I really started to struggle emotionally from then on and I felt angry with the world. The medications took a toll on my life. My weight shot up and I couldn’t sleep or I would have shingles and be emotionally low. Living with epilepsy started to make me feel like I was living a jail sentence. I became anxious and depressed and I got to the point where I couldn’t even cry anymore.

Maria: You had some really dark days but you have found yourself at peace. What has happened for you?

Steve: I found Jesus and a supportive pastor in my church! And I found a wonderful woman who has learnt to understand my epilepsy. I really need the love and support of people whilst dealing with these seizures.

Maria: It is certainly important to have that support, Steve. Having uncontrolled epilepsy is quite difficult to manage and you have had difficulties with the law when you have had break-through seizures whilst driving.

Steve: I have had three seizure-related court offences over the 15 years where I have driven a car and had a seizure. The court has seen me as a reckless driver and I have been stood down from driving for two years at a time. I was treated like a criminal each time but in fact there is a lack of understanding about what epilepsy is and how it affects people. I am not a criminal and I have been allowed to drive on occasions when I have had good seizure control. I won’t drive again though. It isn’t worth my worry.

Maria: That lack of independence is really hard when you lose a driver’s licence and it can be especially difficult when you live rurally.

Driving requires a complex array of neurological functions and skills that involve vision, thinking, attention and judgement, co-ordination, reaction time, and motor control. Any of these can be impaired by epilepsy and seizures. People who drive vehicles may present safety concerns for themselves, their passengers, and the public.

We all have to follow the strict NZTA laws and that includes those who drive drunk, drugged, or who are simply being reckless.

You are doing really well though, Steve, and I am so pleased that at long last you have found the much-needed support when tackling those difficult-to-control seizures. It may take a while for your community to recognise what epilepsy is and how it can impact on a person’s life but stories like yours will help with that awareness. Thank you for your time.

Our phone chat – Lorna

Maria: Hello Lorna. I have known you for some time now and, in that time, I have come to learn about your brave and stoic attitude towards facing your many daily challenges. You have multiple disabilities as well as having epilepsy.

Lorna: If it wasn't for my children and my dogs, I don't know how I would have kept going. I had a serious car accident 45 years ago and I lost my left arm, my spleen, and I had spinal damage. I sustained kidney failure and liver damage and I lost much of my eyesight. I had a serious brain injury which has caused me to have epilepsy. I know that there was talk of having my life support turned off at the time but my intensive care medicine specialist knew that I would survive. Sometimes, I felt guilty for surviving but I needed to keep going for my kids as there was talk of putting me in a home and having my children fostered out. I had to fight for us to stay together.

Maria: They were truly tough days for you but you recovered and, what is more, you trained horses and continued working on the farm.

Lorna: I would take horses that were destined for dog tucker or were considered too wild to tame and I would break them in kindly. One day a man saw me hopping on and off my horse with one arm and he said that I had changed his attitude to life. He became more positive. I would like to think that I have had that influence on people.

Maria: Please tell me how you started training your dogs as they have helped you with your epilepsy.

Lorna: My children left home and I needed more support and so I looked at getting a dog through an agency. Dogs have always helped me rounding up sheep on the farm and so I gathered that they could also learn to help me. It was at that stage that I got a computer and I learnt about guide dogs. But because of my multiple disabilities I couldn't get a dog through the Blind Foundation or through Epilepsy Assist Dogs.

I have numerous seizure types from absence, focal, atonic, and tonic clonics and so I needed a dog to help me deal with all of those and with me being completely helpless when I was down struggling on the floor. Not every dog can be around people with epilepsy, as they would see it as a threat, but I have chosen my dogs well.

Tara was my very first dog. She was a pig dog, a pack animal who lived outside in the kennels. I had to toilet train her and she had to get used to living inside and sleeping on a dog bed without falling out. She was so clever and she quickly learnt what I wanted from her. She was terribly intellectual, so clever, and she would alert people that I was going to have a seizure before I knew myself. I had Tara for 16 years and then one day she decided that she didn’t want to work. I then reached out to Assistance Dogs and I was given a dog but they broke my heart when they took her away. The trainers had no idea what I wanted from the dog and said that my needs were too complex.

I then trained up Faith. She was a beautiful blue-grey colour and was a border collie-kelpie cross who worked as an eye dog, a huntaway, rounding up the stock. She would round them all up, from the hills, swamps, paddocks and put them where they needed to be and then she would come back and guide me. When I took her shopping, I would leave her outside the supermarket but she seemed to sense that I was about to have a seizure and she would come bounding in and lead me back to the car where I would then have a seizure. She too lived for about 16-17 years. She was loyal to me to the day she died.

Maria: Did it take you a long time to train your dogs?

Lorna: No. I have been around animals all of my life and so I know how clever they can be. People need to give animals more credit for what they can do.

After I retired Faith, I trained up another dog called Georgia, who I have now. She is probably not as good as Tara and Faith but she gives me the love and care that I need right now. She knows when I am about to have a seizure and she will gently push me back onto my bed or chair so that I am safe. She has terrific physical strength and she will manage to get me off the ground, if I have fallen. She will wiggle herself underneath me until I am able to get myself up. I won’t even need to give her a command to help me, she just does it.

Maria: I know that Georgia is getting quite old. Will you train up another dog?

Lorna: Do I train another dog? It is a hard life for a working dog as it is 24/7 but without a dog in my life, I will be very lost. I wouldn’t last very long and so I am looking at a puppy to train up. Someone else can do the puppy training and I will do the rest.

Maria: Thank you for this wonderful conversation about the dogs that you have trained to help you with your epilepsy. I know that your epilepsy has caused you problems over the years but your faithful dogs have provided you with the love and support when you have needed them.

I look forward to meeting your new dog. I knew Tara and Faith and I know Georgia. It will be wonderful to see another dog in your life.

Our phone chat – Karl

Maria: Hi Karl, I have been chatting with people about their epilepsy stories. I understand that you would like to talk about employment and epilepsy. Have you found that having epilepsy has been a barrier to finding employment?

Karl: There is a funny sort of barrier in employment and I think that it has a lot to do with fear. Currently, I work in an organisation that looks after people with epilepsy and so the staff are always on alert to the next seizure happening. I feel comfortable knowing that my colleagues will look after me too if I had a seizure. We have yearly seizure training seminars which helps us to understand epilepsy. Interestingly, my colleagues are more inquisitive about my epilepsy rather than making assumptions about my condition. My epilepsy never comes up in conversations and I am expected to do my job just like everyone else. What I really like about where I work is the fact that there are policies around health. If I had cancer, my job would be left open for me whilst I got better. Likewise, because I have epilepsy there are accommodations made for me should I need time off work.

Maria: That is fantastic news. What did you do before this job?

Karl: I am a trained accountant and so I worked in the business world. The staff were more concerned that I would bring shame to the firm if I had a seizure.

Maria: Goodness me, how does that work in this day and age? Would they feel shame if you had a heart attack, asthmatic attack, or a stroke?

From a business perspective it makes good sense to employ a person with a disability such as epilepsy. Society's views on a business are influenced by the people who work there, and if businesses are shown to celebrate diversity and support people with disabilities then there would be strategic, commercial, legal, social, ethical and personal benefits.

Karl: I left the business world which is so stressful and draining and then I found this job, which is great. Management and staff are also able to accommodate the fact that I don't drive. Not being able to drive is a barrier to employment but, of course many of us with epilepsy can't drive. I have, however, done some amazing things in my job that hasn't required me to drive, for example, last year I took a client to America on holiday. The usual concerns were expressed about what would happen if I had a seizure, but I have good seizure control, I take my medications, and I look after myself. I didn't see travelling to America as a problem.

Maria: How was your holiday?

Karl: It was great and I never had a seizure either.

Maria: That is the interesting thing about epilepsy, you never know when the next seizure is going to happen and when it does then that is the time to take action. There are plenty of people with good first aid training out there in the community who can help with seizures.

Karl: I have found most people to be really sincere, helpful and compassionate when I have had a seizure. The odd person has got it wrong though like the time I was given CPR.

Maria: Or worse still the defibrillator comes out when you are breathing on recovery. It doesn't bear thinking about.

Maria: I have designed individual epilepsy action plans that can be shared with carers, work colleagues, schools, family members and friends etc. These plans show what types of seizures to expect and how to help. It really takes the guess work and fear out of knowing what to do in moments of stress.

Karl: That is a great idea and really helpful. Everyone with epilepsy should have one.

Maria: I am super pleased that you have found a great job where having epilepsy is not considered a liability. That speaks volumes about the organisation that you work for. I have met your employer and your colleagues and I delighted to know that they value your work.

Take care and keep up the good work.

Our phone chat – David

Maria: Hi David, it is always a pleasure spending the time chatting with you. You have had epilepsy for 45 years and so your journey has been a long one. You have medication-resistant epilepsy, which hasn't always been easy but you have remained resilient and someone who is able tell an interesting story from which we can all learn. Where shall we begin?

David: I have so much to say. Perhaps I should first mention the relationship that we have with our neurologist. I have seen neurologists for years now and I haven't always had an easy relationship with them, especially in earlier times when there was a strict egotistical medical system. Doctors were being treated as the fount of all knowledge. Of course they know a lot, but not everything. Over the years I learned to push back on what was being said to me by neurologists who continued to increase my medications to the point that I had no quality of life. Fortunately, I now have a European-trained neurologist who understands that having epilepsy is more than a seizure. It is about how I can live well with it.

Maria: Quite true. We understand the need to have seizure control in order to live safely but there is a point in our treatment when too much medication can badly affect other aspects of our lives. People living with epilepsy need to be heard.

David: Absolutely. I also believe that our New Zealand-trained neurologists should be given an opportunity to have international experience, come into contact with a wider array of conditions, and to see how things are done overseas with regard to epilepsy. That experience would be immensely valuable to them, and to us, their patients.

Maria: Cultural exchanges always work well, but I gather that there are too few neurologists in New Zealand for that to happen.

David: Possibly, but there is always room for improvement in the way that our hospital systems manage people and that is why I believe that we should push back and ask questions. It helps to form relationships with our neurologists. If they feel annoyed by that then so be it. For years I felt really dispirited by a previous neurologist's treatment of me as a person but, after 45 years of living with epilepsy, I have grown in confidence to speak out. It matters how you are treated, greeted, and communicated with. It should end up being like a partnership.

Maria: Tell me about growing up with epilepsy.

David: My parents taught me fairly early on to be mindful of my epilepsy and how I should look after myself well. I learned to manage my medications and my lifestyle and I was encouraged to live a good life. I learned to become independent, although as a teenager it felt like my mother was a 'brake' on me doing risky things such as abseiling (which I really wanted to do). Instead I cycled everywhere and had fun. I have lost count of the number of seizure-related bike accidents that I have had but you can't hide yourself away in life. You may get battered about but you have to live. I understand how parents want to protect their children who live with epilepsy, but children need to grow up and feel like they have some control. You can't cotton candy them. They don't want to be different and at the same time need to learn to manage themselves. Interestingly, I was told that I shouldn't have my own children because of having epilepsy but I proved that I could be a great father.

Maria: You have a wonderful story of when you took your child to day-care.

David: My partner and I always taught our children how to care for me (i.e. their dad) when I had a seizure. One day I woke up from having had a seizure at day-care with a pillow stuffed under my head, covered in a blanket, and with a teddy next to me while my daughter was confidently telling the creche teachers, “Daddy just had a seizure. He will be okay.” My daughter was only four years old at the time. You have to be pretty honest with children about epilepsy because they will get annoyed if you are not. I found the EWCT epilepsy children’s books great for talking about epilepsy.

Maria: There were other times when you had seizures in public.

David: That’s right. I had a seizure on a live radio show. I felt under stress being on the show and then the last thing that I remember was managing to put the music on after talking on air. Apparently, the DJ training me just simply left me to have my seizure, which is great. The show must go on! There was also another time when I was going to feature on a TV programme about epilepsy. I happened to be on set (the stage with the cameras) and felt a seizure coming on. I called out, “Move the table, now” (it was a glass one) before I went down. The next thing that I was aware of was me lying on the floor with my head in the lap the presenter. The epilepsy organisation was told never to send along anyone with epilepsy again! They did though, they just didn’t tell them.

On another occasion (when employment contracts first came in) I had just become employed but one day I had a seizure in the tearoom before work and I promptly lost my job. I now work in an organisation where I get to work with a whole variety of students, teachers, and others to find creative solutions or solve their problems through IT.

Maria: Talk about being resilient, David!

David: You can be resilient when the meds are right and you can function. I have tried so many meds, and combinations of them over the years, and I now know which meds to avoid. Some medications gave me some interesting side effects like making me porky or talking 19 to the dozen. The worst medication that I used was levetiracetam. I became the ‘crying rage monster’ with that one. If I wasn’t snapping everyone’s head off, I was crying like a baby. The worst of it all was that I was prescribed it just before the Christmas holiday and I had no neurologist to support me through that period of absolute enraged depression. It was horrible stuff. Gabapentin wasn’t good for me either and the dose controlling my seizures was enough to tranquilise a horse. It certainly slowed me down.

I am now taking a combination of four anti-seizure medications and I am still having seizures.

Maria: How do you manage the different medications that you take?

David: I use blister packs. What a great invention. Once upon a time it would take me ages sorting out my weekly medications into a pill box but now it is all done for me. I have a great pharmacist who answers all of my medication problems too. Everyone should find a good pharmacist in their life.

Maria: Pharmacists are certainly an important member of the epilepsy team.

David: Yes. As is a good neurologist who listens. My seizures have changed so much throughout the years and still are changing. I have been in status [epilepticus] several times in my life so I need to feel confident about those who are charged with looking after my medical condition.

Maria: Absolutely! Our epilepsy team must be robust in their knowledge of epilepsy and to understand the many burdens that people face living with this disease. It is only right that you are heard.

Thank you for your time, David. It is always a pleasure chatting with you.