



StrokeConnections

Spring edition 2021

Joe, survivor of stroke and proud Kooma man with his partner Kim.

Out of a bad situation, there is always something good

Joe Miller is a survivor. In fact, the 66-year-old from Tamworth in New South Wales survived five strokes in two years. The proud Kooma man is determined to do all he can to prevent stroke – both for himself and others.

Joe had his first stroke in 2014 in a supermarket. He didn't feel right, so he grabbed a trolley to prop himself up.

"I was trying to eat a pie and I couldn't control my arm. It was flying everywhere and the pie ended up all over my face," Joe said.

"I was lucky I knew the most common signs of stroke. I knew about F.A.S.T. (Face.Arms. Speech.Time.) because I had been involved in organising health talks in Aboriginal communities. I managed to ask someone to call triple zero (000) for me.

"I remember saying I think I'm having a stroke."

continued page 4

Welcome to StrokeConnections

This edition of StrokeConnections brings you stories from Joe Miller and Emma Beesley. Joe has had five strokes and he's determined to do all he can to prevent stroke for both himself and others. Since her stroke, Emma and her family have been passionate about raising awareness of aphasia, a condition that affects our ability to speak, understand, read or write.

We hope you enjoy this edition. Wishing you all the best, Simone, Emily and everyone at Stroke Foundation.

Stroke Foundation acknowledges the ancestors and traditional custodians of the land on which our offices stand and pay respect to Elders past, present and emerging.

New partnership

Quit and Stroke Foundation have partnered to deliver training and resources for hospital stroke teams. Hospital health professionals play a vital role in helping people stop smoking after a stroke.

If you've struggled to stop smoking since your stroke, you're not alone. It's never too late to stop smoking and help is always available.

Contacting Quitline increases your chance of quitting successfully.
Call Quitline on **13 78 48** or visit **quitnow.gov.au**

Our Stroke Journey

Stroke Foundation is excited to launch a new resource specifically designed to help Aboriginal and Torres Strait Islander people navigate their journey after stroke.

Our Stroke Journey includes helpful information, tips and stories to support survivors and their families.

Call StrokeLine on **1800 787 653** for a copy of Our Stroke Journey.



New President

Professor Linda Kristjanson AO has stepped into the role of Stroke Foundation President and Chair of the Board.

Professor Kristjanson began her term in May, taking the helm from Professor James Angus AO, who was recognised for his outstanding leadership and dedicated service.

Professor Kristjanson has a distinguished career in health, education and business. She is delighted to have been given the opportunity to drive Stroke Foundation's important work in advancing treatment, care and support pathways for survivors and their loved ones.

Like thousands of people in our community, Professor Kristjanson's family has been personally impacted by stroke. She is proud to champion the cause.



Larapinta trail

Here at Stroke Foundation, we are so inspired by people who get involved in unique fundraising opportunities.

For the first time, we held Hike for Health in May – an epic 60 kilometre trekking adventure on the spectacular Larapinta Trail in the Northern Territory.

Seven people, including survivors of stroke and a stroke nurse, tackled the challenging walking tracks and took in the incredible ochre-coloured landscape by day and slept under the stars to the sounds of native wildlife.

Ashlea, Andrew, Alex, Cindy, Peter, Priya and Trina had a wonderful time every step and every kilometre they covered helped in the fight against stroke.

Together they raised more than \$18,000 for Stroke Foundation.

If you are interested in joining a trek, there is a one-day hike in the Tasmanian wilderness this November. Tickets sell out fast, so keep up to date by registering your interest at www.tasmanianiconicwalks.org



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Joe was taken to hospital in an ambulance quickly, curbing the injury to his brain.

Two weeks later, Joe was eating dinner with his partner Kim at home when stroke struck again. When Joe couldn't swallow a cup of coffee, he knew something was wrong, but it didn't feel like his first stroke. He decided to go to bed for a rest. Fortunately, Kim wasn't willing to take any chances and insisted on taking him to hospital.

Joe went on to have three more strokes and his symptoms were different each time.

"Sometimes I could not lift an arm, another time I was disorientated, another time I had a headache and vomited. My fourth stroke felt like I was on a rocky boat out at sea and I lost my peripheral vision on my left side. That was the worst," he said.

"I owe my life to my friend Rachel, who is the stroke coordinator at my local hospital. She taught me what signs to look out for with stroke. Without that knowledge, I may not have acted with the urgency needed."

Joe is now in a position where he can share his experiences candidly, but the road to recovery has been extremely challenging.

After the first stroke, Joe lost independence and positivity for around six months. He needed help to walk, became quite depressed and had some dark days. Joe's father died from stroke at an early age and that weighed heavily on him at the time.

Joe was kept awake at night with worry, asking himself questions like: "Will I ever be able to work again?" "Will I have another stroke?" "Is the next one going to be worse than the one before?" "What if I die?"

These fears continued to circle in Joe's mind and led to a lack of sleep and sheer exhaustion, which contributed to his depression.

Joe said he worked hard to pull himself out of that hole. With the love and support of Kim, he was able to come to terms with his fears.

"I would remind myself that things could be worse and that there were many people in the world doing it tougher than me," Joe said.

"I also quit smoking and drinking which really helped get my health back on track."

"I used to smoke two packets of cigarettes a day. Drinking and smoking went hand in hand, so I couldn't give up one without the other. With help from my doctor and family and friends I have been a non-drinker and a non-smoker for more than five years."



Joe is passionate about educating the Tamworth community about stroke prevention and the F.A.S.T. signs of stroke, giving a number of public talks. As a proud Aboriginal man, Joe recognises the lower health literacy, the risk factors and poorer outcomes for his people.

Joe's tips to prevent further strokes are:

- › Quit smoking, if you drink, do it only in moderation and keep your stress levels down.
- › Have health check-ups, listen to your doctors, and take your medication.
- › Ask for help. There is always help available. People are there to support you because they love you. While the journey can feel lonely, you don't need to do it alone.

Joe said he is recovering well and doesn't take life for granted.

"I have lost my peripheral vision, but I still have my speech. I am able to work, I got my driver's license back and I even won an achievement award from New South Wales Health.

"With the right treatment at the right time, the right medication and mental health support you can live well after stroke.

"I am more well now than I have ever been, and I am in a position to help others.

"Out of a bad situation, there's always something good."

The F.A.S.T. test is an easy way to remember the signs of stroke.

- › **Face** Check their face. Has their mouth drooped?
- › **Arms** Can they lift both arms?
- › **Speech** Is their speech slurred? Do they understand you?
- › **Time** is critical. If you see any of these signs call 000 straight away.

As Joe's story shows, there can be other signs, such as:

- › Numbness, clumsiness, weakness or paralysis of the face, arm or leg on one or both sides.
- › Dizziness (particularly 'head spins'), loss of balance or an unexplained fall.
- › Loss of vision in one or both eyes.
- › Headache, usually severe and sudden.
- › Difficulty swallowing.
- › Nausea or vomiting.

Remember, even if you aren't sure it's a stroke, call triple zero (000). The operator will decide what needs to happen next. Triple zero (000) operators are experts in making these decisions.

Many survivors of stroke experience depression. Depression is highly treatable and help is available. Speak with your doctor.

StrokeLine's allied health professionals provide information, advice, support and referral.

StrokeLine is available 9am – 5pm AEST. Call **1800 787 653** or email **strokeline@strokefoundation.org.au**

Beyond Blue is available 24 hours a day, 7 days a week. Call **1300 22 4636** or visit **beyondblue.org.au**



My aphasia diagnosis was a light bulb moment

Emma Beesley is the sort of person who makes you smile when you chat to her. The 38-year-old is bright, determined and driven.

Living with her parents in Bolwarra Heights, New South Wales, Emma has her eyes on the future. Emma plans to use her experience with stroke and aphasia to raise community awareness and help others.

Stroke can affect our ability to speak, understand, read or write. When these difficulties are caused by injury to the language area of the brain, it's called aphasia. People with aphasia can find:

- › It's hard to think of the right word.
- › They use the wrong word or sound.
- › They don't understand what someone is saying.
- › Words on a page don't make sense.

While one-in-three people with stroke will suffer aphasia, Emma has discovered that not many people know what aphasia is. She is passionate about changing that.

"Aphasia is loss of language, not loss of intelligence," she said.

Emma won the 2021 Stroke Awards Courage Award, for raising awareness of working-age stroke and aphasia through public speaking, social media and fundraising.



She also represents the needs of young survivors of stroke through her roles in advisory groups and research. But it took Emma many years to reach a point where she had the confidence to advocate for herself and others in this way.

Emma was fit and healthy, with no underlying conditions, when she had a stroke five years ago at the age of 33. She was working as a lawyer at the time and was engaged to be married. Her stroke turned her life upside down.

"When I first had a stroke, I had limited movement on one side of my body and everyday tasks like dressing and walking were exhausting. I lost my independence and my mental health suffered. I became very depressed and began to block out many of the people in my life."

Emma's mum Kim recalls the early days after Emma's stroke and rushing back home from a holiday in Portugal to be with her.

"When my husband and I first saw Emma in hospital, her appearance was a shock. Her mouth was still slightly drooped, and she couldn't sit up without support. But we both had to be brave and keep positive for her because she was still our beautiful, incredible daughter," Kim said.

"Emma's vocabulary consisted of mostly the words "sorry", "yeah" and "no", and often these last two were mixed up. While she recognised us immediately, she had trouble calling us by name. I was "Wednesday" to her because she had been told that Mum and Dad would arrive on Wednesday."

"Three weeks later, Emma moved from hospital to a rehabilitation facility where the main focus was to get Emma out of a wheelchair and walking independently."

When Emma could walk again she went back home, but her communication difficulties contributed to a breakup with her fiancé. It was a difficult time and she had no choice but to move back in with her parents. Emma was struggling to accept she would not have full use of her right arm and hand and would continue to walk with a limp. She also couldn't fully understand why she could not communicate. Emma felt frustrated and alone. She missed her pre-stroke life.

It took 10 months for Emma to be told she had aphasia, but it was a light bulb moment.

"To finally know that there was a name for my inability to express my thoughts and feelings was empowering," Emma said.

"This diagnosis opened the door to being able to find ways to set and achieve goals for myself. I was excited to realise that with hard work and continual therapy, gains were possible."

Emma joined the Maitland Aphasia Communication Group, where she made friends and shared stories with others. This support network helped Emma find a new purpose and strength.

The mutual support this group provides is invaluable to the health and wellbeing of members and their carers.

Emma continues to make remarkable progress in her recovery from stroke. She has adjusted well to using only her left arm and hand, she drives a modified vehicle and has a part-time job with her previous employer.

Emma's parents are a powerhouse of support. Kim joined the Stroke Foundation Consumer Council as a voice for carers in the community and is the secretary of the Australian Aphasia Association.

Currently, only seven percent of Australians can identify aphasia as a language disorder. Emma and Kim realise they have plenty of work to do to help educate the community, but they are well and truly up for the challenge.

continued page 8



Support

Stroke support groups are a great way to connect with others to share advice and support.

For a list of stroke support groups, stroke choirs and aphasia groups across Australia and online, visit **strokefoundation.org.au**

StrokeLine can help find the right group for you. Call **1800 787 653** or email **strokeline@strokefoundation.org.au**

If you would like to know more about aphasia groups, call the Australian Aphasia Association **1800 274 274** or visit **aphasia.org.au**



STRIDE⁴ STROKE

This November we invite you to Stride4Stroke! Simply pick an activity and get together with friends, colleagues or family to create a team or go solo. Do it your way wherever you are, and raise vital funds to help prevent, treat and beat stroke.

#Stride4Stroke


www.stride4stroke.org.au



Scan here to register for Stride4Stroke.



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 **StrokeLine 1800 STROKE**
(1800 787 653)

 **strokefoundation.org.au**

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