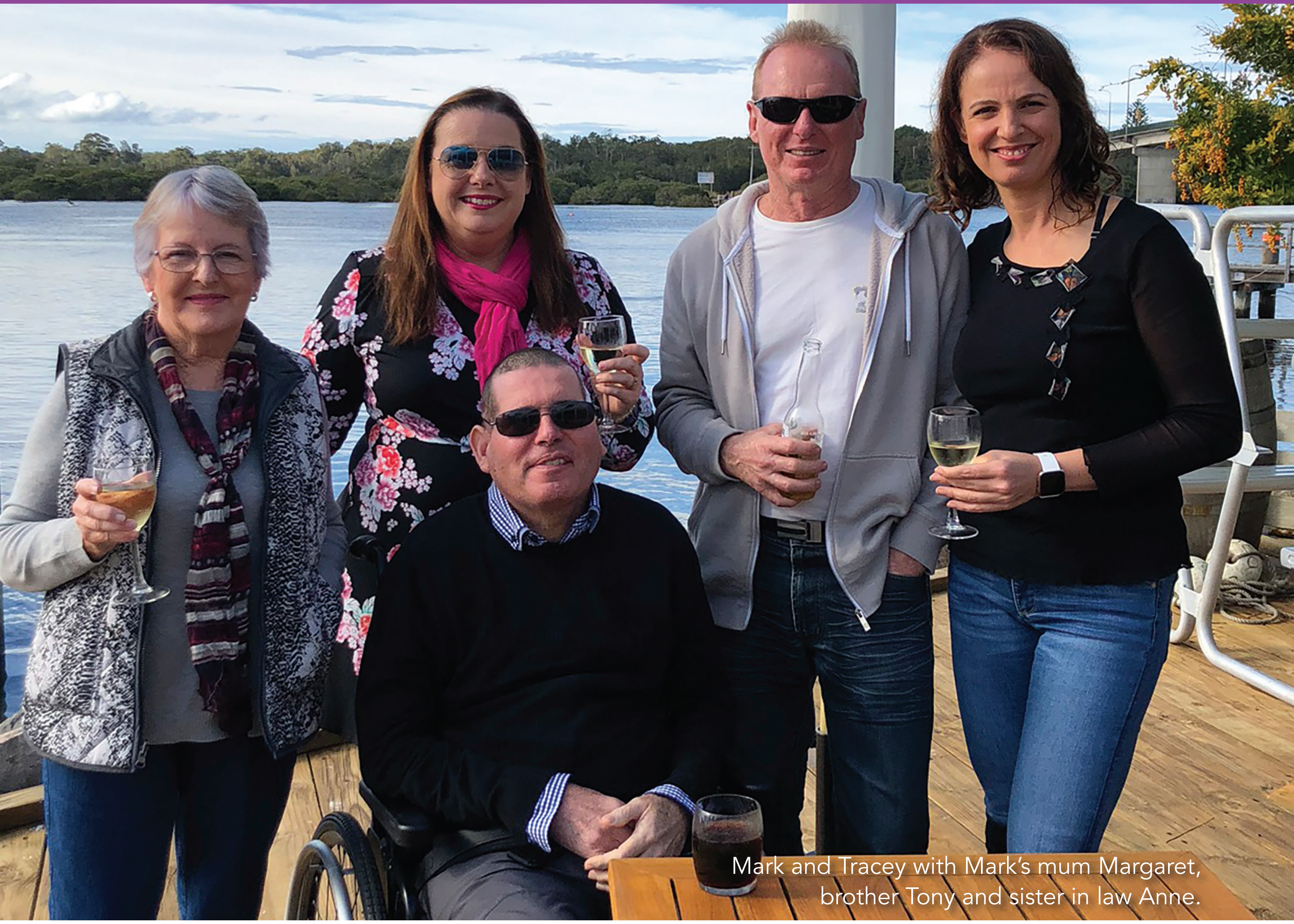
StrokeConnections
Winter 2022


Mark and Tracey with Mark's mum Margaret, brother Tony and sister in law Anne.

Caring for the love of my life

Tracey Laverick's love for her husband Mark is undeniable. You can feel the warmth of her smile when she talks about their upcoming 23rd wedding anniversary.

Tracey also knows Mark loves her endlessly and how fortunate she is they have such a beautiful bond.

But life and marriage are not how Tracey and Mark expected they would be when they exchanged rings all those years ago. Life threw a giant curveball – stroke.

Mark experienced his first stroke in 2002. He was 40 years old. It was so mild it was a week before they sought medical advice. Life carried on relatively normally, but fatigue was an issue.

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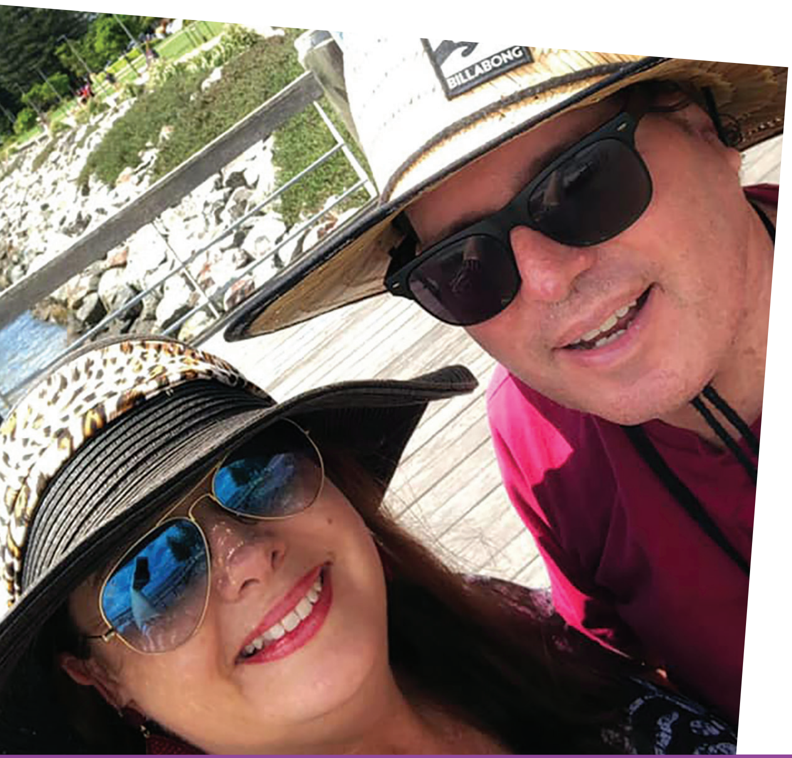
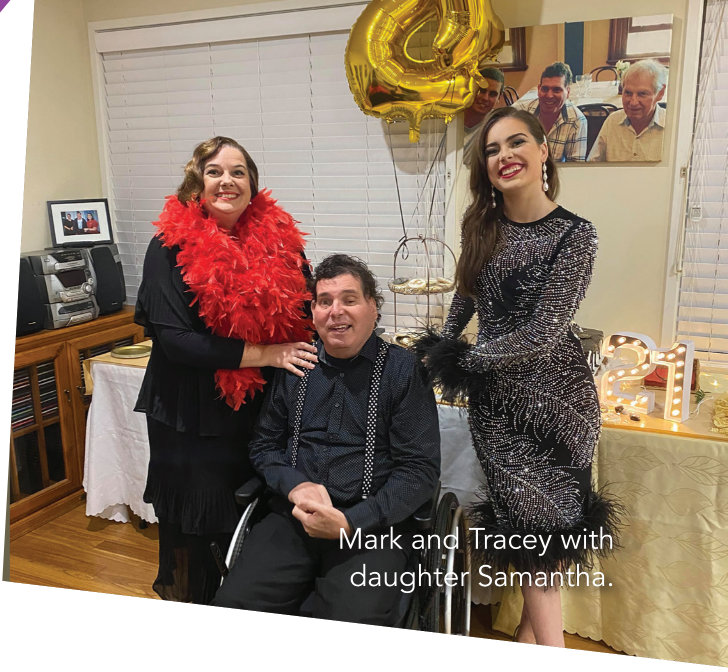
Mark's next stroke was a big one. It was New Year's Day, 2011, and he had been enjoying a break at his family's holiday house in a small coastal town in New South Wales. He was with Tracey, their daughter Samantha, Mark's parents, brother Tony and niece Chrissy. Although they welcomed in the new year in a low-key manner, some of the properties nearby were a bit rowdy, so it was a restless night.

Tracey suggested Mark stay in bed a bit longer the next morning, but when she went to check on him around 10.30, he wasn't there. To her shock, he had fallen out of bed and was lying unconscious on the floor foaming at the mouth. Everything was a bit of a blur from that moment for Tracey. Mark's mum called triple zero (000) and the ambulance crew arrived before she knew it.

Tracey said it was obvious something was seriously wrong with Mark because his head was swelling. "I rode in the ambulance with Mark, and when we arrived at hospital it was like a scene from a movie where the doors where flung open and people came from all different directions to whisk him away.





Mark and Tracey with daughter Samantha.

"I was taken to the 'family room' for a chat. This is when I was told the words nobody wants to hear. Mark's condition was very grim."

Mark had suffered a large bleed, a left-side haemorrhagic stroke. Doctors needed to operate to relieve the pressure in his head. It seemed ridiculous to Tracey that as Mark's life hung in the balance, she was told it was a public holiday and they would have to open another theatre if they were to operate.

"Has he got a chance?" Tracey asked.

When the answer was yes, Tracey wanted to scream "Well get on with it then!"

When Mark's surgery was over, his prognosis was not good. He remained in intensive care for two weeks before being moved to a stroke ward for five weeks and a rehab centre for five months. Mark was in a wheelchair, paralysed on his right side. Communication was challenging due to aphasia. Mark had to relearn to swallow and sit up among many other things.

Tracey was advised to place Mark in a nursing home but it didn't feel right. She wanted to see if they could make life work in their own home. She was determined to try. It wasn't easy at first. The transition from hospital to home after stroke was overwhelming.

"It was physically and mentally exhausting," Tracey said.

"You find yourself juggling the usual day to day tasks, with trying to work out what services are available and how to access them while also dealing with a form of grief.

"Grasping medical terminology was like learning another language. We also had therapists coming in and out, so there were times when it didn't feel like our special space anymore. We were sharing it with a lot of other people.

"But I had to trust my gut instinct that living in the family home was the best decision, and I am so glad I did."

Mark is the love of Tracey's life and while becoming his carer was a huge adjustment, there were many rays of sunshine.

"I have always considered myself a glass half full person and this attitude has certainly helped," Tracey said.

"The way I see it, I've got two choices. I can make the most of the situation or I can curl up in the foetal position, but that is no good for anyone.

"I make a choice every day to be present and smell the roses. I have learnt to adapt, and this is the way we live now."

Tracey said Mark's stroke provided them with more opportunities to spend quality time together. As time went on, he mastered walking with a quad stick and aspects of his aphasia improved. This allowed Tracey, Mark and Samantha to travel to the Great Ocean Road and on an outback holiday to Uluru, Darwin and Broome. Mark climbed into helicopters, small planes, boats, minibuses and all types of transport.

These were adventures they would not have otherwise prioritised. It was a chance to unwind, have fun and make memories.

Tracey said Mark always had an attitude of being the "best me I can be" and rarely suffered from negative thoughts.

But the challenges kept coming for the pair. Mark experienced further strokes in 2018 and 2021 which impacted his cognition, vision, and mobility. Each time, they adapted as needed, with Tracey's dedication never wavering. It has been a journey for her too. She's had ups and downs but has learnt an enormous amount along the way.

One of the integral parts of being a good carer for Tracey is self-care. She admits this did not come easy and it took time to shed feelings of guilt.

"I have a strong network of family and friends, but it was not in my nature to ask for help or accept it when it was offered," Tracey said.

"But I have learnt I am better for everyone in my household when I make time for myself."

Tracey fits a Zumba class and social tennis into her week, recognising the importance of activity for her physical and mental wellbeing. She has travelled by herself, although always wishes Mark was beside her to share the experience. Tracey has also worked out ways to spend time with friends that suits everyone.

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"Mark and I normally host gatherings at our place and everyone brings a plate," Tracey said.

"It takes the pressure off dining at restaurants. I don't have to stress about access or whether Mark is comfortable. We can relax and enjoy the company of our guests in our own space, and he can even head to bed if he feels tired."

Tracey especially enjoys the company and support of a group of friends she calls her 'stroke wives'. Kelly, Tracy and Vicki also live with their husbands, who are survivors of stroke. These connections have been crucial for her.

"We share our innermost thoughts with no judgement. While we are all different, our experiences are similar and our bonds are deep," Tracey said.

"We understand one another. We can cry on each other's shoulders, and we can lift one another up. I am so lucky to have them in my life.

"Living with someone with a brain injury can be challenging at times, but together we are a force, and we know we are not alone. I encourage other carers to find their tribe too."

The most difficult thing about being a carer for Tracey is making decisions for two people and hoping it's the right choice – particularly decisions about Mark's therapies and about parenting their daughter.

Tracey's final reflection on being Mark's wife and carer sums it all up.

"I choose to be Mark's carer and I choose for him to live at home," she said. "Mark is as beautiful and kind as he was pre-stroke. The love is the same even though our lives are different."

Lived Experience leads the way for childhood stroke

Stroke Foundation's first Childhood Stroke Lived Experience Advisory group is a big step towards better outcomes for survivors of childhood stroke.

The group is made up of six adults who had a stroke as a child, and six parents of childhood stroke survivors. Members are passionate about reducing the time taken for diagnosis of childhood stroke, improving treatment, championing research, and ensuring better support for families.

Childhood stroke survivor Tala Olins-Miller has been named as the Chair of the Lived Experience Advisory Group.

Tala, from Western Australia, had a stroke at the age of 13 however it wasn't diagnosed until two days later. Through countless hours of rehabilitation over the following two years, Tala made a full recovery. "For years, I thought about my stroke in a negative way. Then I realised I could use my experiences to raise awareness of stroke. We need to make sure children are diagnosed quickly, and that they and their families get the support and services they need."

Tala's looking forward to working with the Lived Experience Advisory Group.

"Already I can see it's a passionate and positive group of people. Together we will be unstoppable."

2022 Stroke Awards

The Stroke Awards celebrate the heroes who go above and beyond to improve the lives of Australians affected by stroke.

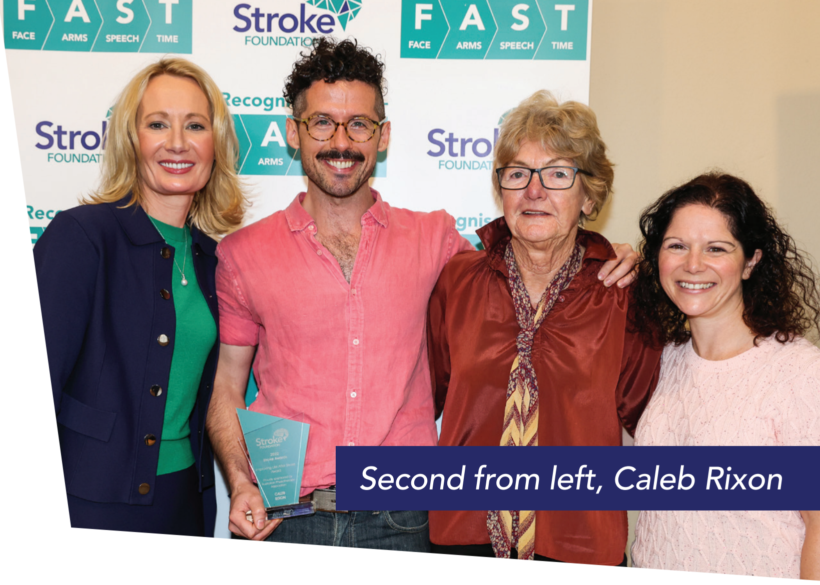
This includes the survivors of stroke, carers, volunteers, fundraisers, health professionals and researchers and members of the community.

There are seven award categories; Stroke Warrior, Improving Life after Stroke, Creative, Courage, Fundraiser of the Year, Volunteer of the Year and the President's Achievement Award.

Caleb Rixon was awarded the Improving Life After Stroke Award for his incredible work with Genyus, a global network of more than 1,500 people, including young survivors of stroke, supporters, health professionals and researchers. Caleb was singled out as a positive force for change and a fierce advocate, constantly challenging the message that those with newly acquired disabilities are somehow less than they were before.

The Courage Award category was won by Tommy Quick, the personal trainer-turned long-distance-cyclist, who is overcoming a horrific accident endured while fundraising for Stroke Foundation. Tommy had already cycled more than 3,600 kms to raise awareness of stroke and social inclusion for people with disabilities when he was hit by a car near Adelaide. After a series of operations, Tommy has had to relearn to walk, and is making excellent progress. Stroke Foundation Chief Executive Officer Sharon McGowan said Tommy's relentless courage was undeniable.

The final award of the day, the prestigious President's Achievement Award, went to Kylie Facer and Dee Banks, who founded Little Stroke Warriors.


Second from left, Caleb Rixon

Their small group has evolved into an active network of hundreds of parents.

Kylie and Dee have been instrumental in Stroke Foundation's development of new resources to help families navigate the journey ahead. And their commitment to raising awareness of childhood stroke also helped to secure $4M in research funding from Medical Research Future Fund.

Stroke Foundation President Professor Linda Kristjanson announced the award, saying that the entire community had been enriched by Dee and Kylie's willingness to roll up their sleeves and make a significant, enduring contribution.

It was a hugely emotional moment for not only Dee and Kylie, but many others in the audience.

Our thanks to 2022 Stroke Awards sponsors AFRM Claims Advocacy (ACA), Australian Physiotherapy Association, Ipsen, NAB Community, Marmalade, and Precision Fundraising.


Kylie Facer and Dee Banks

New research seeks breakthroughs in aphasia recovery

Dr Jessica Campbell will lead a new project aimed at improving the lives of people with aphasia.

The Queensland researcher has been awarded the inaugural Lady Southey Aphasia Research Grant, as part of the Stroke Foundation's 2022 Research Grant Round. The grant will support the project titled CHAT-Maintain: Maintaining language and quality of life gains with low-dose technology-delivered aphasia therapy.

Dr Campbell, from the University of Queensland, said aphasia is a common disability that affects the ability to talk, to understand what people are saying, and reading and writing.

"Aphasia is difficulty with language, not a loss of intelligence. Aphasia increases the risk of social isolation and depression. One good treatment for aphasia is intensive therapy, but for some people, that is not enough for long lasting language improvement." Dr Campbell said.

"We want to achieve long-term improvement to ultimately improve quality of life."

In the CHAT-Maintain research trial, people with aphasia will be trained to drive self-directed home therapy with technology for six months after they have completed intensive therapy. Speech therapists, volunteers and peer mentors will provide ongoing support.

The research will build on the success of CHAT and TeleCHAT intensive therapy programs at the Queensland Aphasia Research Centre which are partnered with the Speech Pathology Department at the Surgical Treatment and Rehabilitation Service (STARS) at Metro North Hospital and Health Service in Brisbane.

The Lady Marigold Southey Aphasia Research Grant was launched through the generosity of Stroke Foundation patron Lady Marigold Southey AC and Stroke Foundation supporters.

New research seeks breakthroughs in aphasia recovery

Muscle spasticity can make life after stroke difficult. In this article, the StrokeLine team covers what muscle spasticity is and what can help.

Messages travel back and forth between our brain and our muscles. These messages control how our muscles feel and move. If the part of your brain that sends and receives these messages is injured by a stroke, you may develop muscle spasticity.

Muscle spasticity can make your muscles feel stiff and tight. Your muscles may not work the way you want them to. They may resist movement.

For example, you try to move your arm, but it doesn't move easily, or as much as you expect. If someone tries to move your arm away from you, it may jerk back towards you in response. Your arm may also shake after movement.

Muscle spasticity can make it difficult to walk, affect your balance and increase your risk of falling. It can affect your ability to open your hand or reach for something. Moving may take more effort, making you more tired.

You may have a clenched fist or fingers, or a bent arm held against your chest. Spasticity can cause tightness in your knees or a pointed foot.

Muscle spasticity can cause contracture. Contracture is when muscles can become so tight that your joints have only limited movement. They may become fixed in one position. Contracture usually happens in hands, elbows, knees or ankles. If spasticity is not treated, the risk of contracture is higher.

Talk with your doctor, physiotherapist and occupational therapist about any changes to your muscles. If you need advice, get in touch with StrokeLine.

Allied health therapy

Physiotherapy and occupational therapy are allied health therapies that aim to improve movement and prevent other problems, including pain.

Your allied health therapist will recommend treatment specifically for you. This can include:

- Exercises to lengthen and strengthen your muscles.
- Casts to help stretch and lengthen tight muscles.
- Taping to improve movement.

Electrical stimulation can be used if you can't move the affected area very much or at all. A machine sends electrical currents to your muscles to get them working.

Your therapists can also tell you about:

- Protecting the affected part of your body from injury.
- Different ways of doing things.
- Aids and equipment that will help.

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Talk with your GP or StrokeLine about accessing allied health therapy for muscle spasticity.

Options include Medicare-subsidised sessions with a Chronic Disease Management Plan. If you are part of the NDIS or My Aged Care, talk with your provider about what you need.

Community-based rehabilitation may be a good option if:

- You need more than one type of allied health therapy.
- Your spasticity is getting worse.
- You have new goals.

Your GP can also refer you to a spasticity clinic for assessment and treatment.

If you're unsure, get in touch with StrokeLine – we can work out the best option with you.

Medications

If you have severe muscle spasticity, your doctor may prescribe botulinum toxin A, which is injected into the affected muscles. It's effective for about three months, giving you an opportunity to strengthen muscles and improve movement. Botulinum toxin A should always be combined with exercises set by your allied health therapist.

Getting help

StrokeLine provides advice on stroke treatment and recovery. StrokeLine is a practical, free and confidential service. StrokeLine's allied health professionals can help you manage your health and live well.

Call **1800 787 653** Monday to Friday 9am to 5pm, AEST (Australian Eastern Standard Time)

Email **strokeline@strokefoundation.org.au**

Stroke FOUNDATION

Contact us

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