



Stroke Connections

Winter edition 2016



Love after stroke

Len and Tania Lewis do everything together. The couple from regional New South Wales have been married for 27 years and their relationship is full of love, adventure and above all things friendship.

Although Tania was living with a serious back injury, the couple and their daughter Faith, *pictured above*, didn't let that hold them back from living life to the full. This included taking on a huge family road trip full of destinations chosen by a roll of the dice.

Then one day in 2011 everything changed. Tania had a stroke while in hospital for a routine medication rotation. Tania's severe stroke left her paralysed, unable to see, move or speak. Tania said it was one of the most frightening experiences of her life.

"When I finally come around [after the stroke] I couldn't see or anything it was so scary because I didn't know what the hell was going on. All I knew was I was in a body that wouldn't move, I couldn't speak. I could hear and I could blink you know, but I couldn't see," Tania explained. "It took about six months before my speech came back... it was the worst. I was trapped in a body that didn't work," she said.

Len said although Tania's stroke hit him hard, he was determined to try and make things work. They had been best friends since they were children and for Len there was no way a stroke was going to tear them apart.

"The stroke changed a lot, a real lot overnight.

We went everywhere together, we had done everything together and it just finished," Len said. "You can't just walk away. We'd known each other since we were five or six years old... when you get married it's for life."

Once Tania got home from hospital it became clear her family would need a lot of support, but she was told there were limited services available.

"I went to the doctors and asked and asked and asked. I couldn't get any nursing care, I got a couple of weeks of in-home care, that's all they provided but it wasn't enough," Tania said.

"I had some really bad seizures and my hubby just wouldn't sleep, he was watching me all the time. His mum was staying over too, they were taking turns looking after me and I felt so guilty it shouldn't have been that way. They were just so overprotective and wanted me to be okay."

Len was unable to sleep out of fear Tania would have a seizure, he ended up collapsing out of exhaustion.

Len was advised to take Tania to the local hospital, tell them that he couldn't look after her anymore and he wasn't taking her home.

Tania stayed in hospital for a few weeks before being admitted to a nursing home. Len said the time Tania spent in the nursing home was a nightmare for the close-knit family.

"Guilty... I just felt guilty putting her in there," Len said. "I didn't want to [place Tania in a nursing

Tania's story continues on page 4



Rachel, Katherine, Jude and Chris

Welcome to the winter edition of StrokeConnections

Welcome to the winter edition of StrokeConnections – where did the last six months go! It has been an incredibly busy time for the Stroke Foundation with the delivery of Australia's Biggest Blood Pressure Check, the opening of the 2016 Stroke Awards and our first ever stroke election forum on the Central Coast in Gosford. Just last month we also celebrated the first birthday of *enableme*, our self-directed recovery website. We're so proud of *enableme* and the way it is supporting stroke survivors all around the country. In this edition we look at the different ways *enableme* has been helping stroke survivors, their carers and families including an interview with *enableme* user Sue Bowden and a look at our latest podcast.

Our feature article shares the story of husband and wife Len and Tania Lewis from regional New South Wales. Tania had a massive stroke in 2011 which left her paralysed. In need of a high

level of care, Tania was admitted into a nursing home. This loving couple has faced incredible challenges but their love and commitment to their family has got them through the tough times. Carer Julie Collins has been through a similarly challenging situation and shares her tips on becoming a carer.

This edition we also review the fantastic autobiography, *Reinventing Emma*, written by inspirational stroke survivor Emma Gee.

Thanks for reading. If you have any feedback or suggestions for topics you'd like to see in StrokeConnections, drop us a line.

Best wishes,

The StrokeConnections team

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Falls well that ends well

Falls can be an ongoing problem for stroke survivors. Stroke Foundation Consumer Council member Adrian O'Malley, pictured, was taking the bins out a few months ago when he tripped and fell.

As he explains, "it was due to foot drop on my right foot. One minute I was vertical and the next, horizontal." After getting himself off the road and out of harm's way, he found he had broken the distal joint in his finger. Adrian is in his forties and will be managing the impact of his stroke as he ages. This fall made him think about how he can avoid breaking any more bones, and got him wondering if there is a way to 'fall well'.

After a stroke, people can fall for a variety of reasons, including:

- Impaired eyesight.
- Reduced balance.
- Reduced sensation in the feet, legs and joints.
- Slower reaction time.

If you are at increased risk, the basics of preventing falls include:

- Getting regular check-ups to manage any health conditions that might lead to falls.
- Reviewing your medications as some can have side effects that may increase your risk.
- Getting your eyesight checked regularly.
- Having a home assessment to review any hazards. An occupational therapist will highlight hazards and let you know what you can do to remedy them.



- Staying active by working with a physiotherapist, exercise physiologist or personal trainer to maintain or improve your balance, strength and coordination.
- Check your footwear to make sure your shoes are comfortable, firm-fitting and flat with a low broad heel and good grip.

If you're at risk and live on your own, or are alone for long periods, it's a good idea to have a plan in place before a fall happens. Think about carrying a mobile phone with you or wearing a personal alarm. Hip protectors can lower the risk of a broken hip, so talk to your health professional about these. Also talk to your doctor about ways to keep your bones strong to lessen the risk of a break.

If you or someone else does have a fall, here are some tips:

Keep calm: falls can give you a big shock. Take a few moments to compose yourself. This will help you think more clearly to plan what to do next.

Check for injuries: if you are in pain or badly injured, stay put and raise the alarm.

If you're not badly injured, you may be able to get up. Look for a sturdy piece of furniture nearby to help you. Don't try to stand up straight away. Just focus on getting yourself up onto the chair first.

If you're helping someone who has had a fall, don't try to lift them. Guide them gently. The person who has fallen should be doing the work to get up. If they get stuck, make them comfortable and call an ambulance.

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Never too late to seek help

Sue Bowden, *pictured*, had a stroke 24 years ago, she was pregnant with her and her husband's first baby. At 21 weeks Sue was diagnosed with pre-eclampsia – sadly resulting in the stillbirth of the young couple's baby Chelsea. Sue is now 46 and living in Bathurst, New South Wales. Sue remembers what it was like in the first stage of her recovery.

"Being someone who survived their stroke many years ago and being in an isolated rural town for my recovery... I forged ahead with my life after our loss of our baby and the life I had prior to my stroke," she explained.

As Sue recovered from the physical impact of her stroke and got back to recreating her life with her husband, dealing with her grief and loss took a backseat to her physical recovery. Sue was able to achieve her dream of becoming a mother, and as life got busier raising three children the emotional challenges of her stroke didn't go away but loomed less large.

Recently Sue was given the opportunity to share her story with others and found it helped with the underlying pain caused by her stroke. She was in a hospital waiting room when she discovered *enableme*, a support website that would connect her with other survivors.

"When I stumbled across *enableme* as I sat in a hospital waiting room in December last year, feeling alone with my worries, I became very excited at the thought that this support site was available for survivors and carers," Sue said.



Sue began using the site as a way of talking with other people who had 'been there'.

"I felt an immense relief that the ability to connect with other survivors had come so far and that it may help others not to experience the intense aloneness I had once felt during my recovery," Sue explained.

"I have made some helpful connections as I have explored this site and totally respect the courage people have to post about themselves.

"*enableme* has reminded me that self-care, no matter at what stage of recovery, is still important."

enableme has been helping thousands of stroke survivors like Sue since it launched in June last year.

It contains more than 930 resources about stroke

More than 2,300 users sharing their stories, tips and advice

Three podcasts on topics suggested by our stroke community

If you haven't signed up yet, give it a try. *enableme* is free to join and gives you access to the tools, advice and support to enable you to make the best recovery after stroke.

www.enableme.org.au

Preventing another stroke

For those who've had a stroke, the thought of having another one is a genuine concern. However, it's important this concern doesn't lead to anxiety that holds back your recovery and getting on with life. This is why we made this the topic of our second *enableme* podcast.

We sought advice from general practitioner and author Dr Bill Williams. His book, *Bleed*, is about the drama that ensued when his wife Gisela had a brain haemorrhage while camping in central Australia, and Bill's desperate mission to get her to medical care and on the road to recovery.

Although haemorrhagic stroke - caused by a bleed - is less common than ischaemic stroke, which involves a blocked blood vessel, the two types of stroke share some common, controllable risk factors. The biggest of these are high blood pressure and smoking, but they also include high cholesterol and being overweight.

Bill sees plenty of stroke survivors in his practice. "They're all concerned about what they can do to prevent having trouble like that in the future," he told us.

He shared with us his top tips for reducing the risk of another stroke:

- 1. Stop smoking.** Although, Bill says most of his patients have figured that out for themselves by the time he sees them after a stroke. If you're finding it hard, talk to your doctor - there are a wide range of strategies and products that can help.
- 2. Lower your blood pressure.** This can be done by addressing lifestyle factors, like



activity and diet, as well as taking blood pressure medication.

- 3. Take your medication for atrial fibrillation.** Many people have this irregular heart rhythm and are prescribed blood-thinning medication to prevent clotting. It's important those people maintain their medication and make sure they're safe and healthy while taking it.
- 4. Control your cholesterol** and, if you have diabetes, **keep your blood sugar in the normal range.**
- 5. Adopt a basic healthy lifestyle** in terms of diet and exercise. Physical activity is particularly important, because it also enhances your life and helps you do the things you enjoy, which is a big part of recovery.

Most of these tips would be of no surprise to stroke survivors, and Bill admits when people come to see him they already know a lot about what they need to do. Bill sees his job as working through it with them.

"I'm of the partnership view about it," Bill said. "It's helping people find their way on what is in some ways a new pathway for them, being as optimistic as possible about it, and using the knowledge we have."

To listen to the rest of our conversation with Bill, as well as advice from stroke survivor Nikki Mennel and StrokeLine's Simone Russell on coping with anxiety caused by the thought of having another stroke, go to enableme.org.au/podcasts

Pictured above: Stroke Foundation's Katherine David and Chris Lassig in the podcast studio

Love after stroke

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home], but it just got to the stage that I had to do it. If I didn't, something would've happened to me, and then there would've been no one for my daughter."

Tania describes the time she spent in a nursing home as bleak.

"The first nursing home they put me in I was the only young person there with all the older people," she said. "Then, I moved to a second nursing home and I was on a different floor to all the young people so I never got to see them."

Things seemed hopeless, until one night Tania found a way out. While chatting with her daughter on Facebook, Tania googled young people in nursing homes. That's when she found out about the National Disability Insurance Scheme (NDIS).

"I was always on Facebook but I never thought about searching for help and just one night I googled and found it. Thank god I did," she said.

Tania discovered she could apply for an NDIS support package as she lived in one of the trial sites, which meant she could come home to Len and her daughter. Tania now gets the support she needs to live at home.

"I have nursing care twice a day, a cleaner every week, respite when I need to, a physio, an occupational therapist, travel allowance, wheelchair, shower chair, hoist, beds and all that kind of stuff as well," she explained.

Although Len was ecstatic to have Tania home there are still daily challenges they face.

"If you have barbeques and if Tania can't get there, we all have to stay home because it's so hard to get respite. In respite you have to book a week in advance," Len explained.

But despite the difficulties of life after stroke, it is their strong love that keeps this couple going.

"It was no good trying to give me the ring back. There's no way I was going to leave, she had no hope," Len said. "One day if she does go or I go - if she goes first, I won't be finding no one else."

"I'm so blessed to have the husband that I do. He's my best friend. He's everything to me," Tania said.

Community tips

Julie Collins became a full-time carer after her husband Ross suffered a stroke in 2012. Ross's stroke left him wheelchair bound. He has difficulty communicating and eating, and depends on Julie and his family for most daily activities. Since then, Julie has learnt a lot about things which make a difference to life as a couple after stroke.

Document it all

Because so much was happening when Ross first had his stroke, 'the book' became my lifeline. I wrote down everything that happened, along with everyone's name and their role. The book helped me answer everyone's questions and keep track of it all. I still write everything down in my diary.



Have a plan

I developed laminated cards that go everywhere with Ross, with an emergency care plan, his medical history, medications and emergency contacts.

The cards also have information about Ross's difficulties with language and communication, with tips on how to communicate. The speech pathologist helped with this, and the occupational therapist helped with information about using Ross's wheelchair safely.

Share with friends

I emailed the information to all our friends, so if people are out with Ross without me, they are prepared with all the information they need.

I sent it out before the first time our group of friends got together again after Ross came home. It helped people be prepared for how things are now, and it helped them include Ross. It can be very confronting for people who haven't had anything to do with people with disabilities. You're trying to get across to people that Ross hasn't changed, he's still got the same wicked personality. It was important to be proactive about helping our friends to be comfortable too.



A game-changer for Darlene and for stroke

When Adelaide local Darlene McLeod collapsed on the kitchen floor, her young daughter thought it was a game. Darlene's husband Don immediately thought *stroke*.

Don's quick thinking meant it wasn't long before Darlene was in hospital getting specialist stroke treatment with a clot-busting drug.

But the clot wasn't dissolving and the outlook was grim. Two finger-widths of Darlene's brain was dying and another large area was threatened. Don was worried he could lose Darlene.

Fortunately both luck and research were on Darlene's side.

Darlene's neurologist was part of a research team led by leading stroke expert and the Chair of Stroke Foundation Clinical Council, Associate Professor Bruce Campbell. They'd been trialling a new treatment called endovascular clot retrieval in combination with the clot-busting drug. It was Darlene's best chance.

Don had to sign approval to use the new procedure. "Once the doctor said he would do it if the patient was my wife, I knew we had to go for it," Don said.

The clot was successfully removed and by the end of the day Darlene was sitting up in bed and even able to say hello to her children. Her rapid recovery was described by hospital staff as 'miraculous'.

According to Associate Professor Campbell's research, in 89 percent of patients blood flow to the brain was restored using clot retrieval, compared with 34 percent of patients who had clot-busting drugs alone.

With your support, we can continue our ground-breaking stroke research program. Together we can:

- Encourage visionary researchers to work on stroke.
- Seed new research that will help prevent stroke and improve quality of life after stroke.

Please share our appeal to help fund the next game-changer for stroke.

Visit www.strokefoundation.com.au

Falls well that ends well

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Finally, back to Adrian's question: is there a way to fall well? His mate gave him the advice he gives the young footballers he coaches: use your knee, hip and shoulder and keep your arms tucked in.

StrokeLine's physiotherapist, Katherine David advises: "There isn't much research about the safest way to fall and it will differ from person to person. I recommend seeing a physio to get personalised advice that is right for you. Falls prevention clinics can also be very helpful to conduct a thorough falls risk assessment,

correct any issues and work with you on increasing your confidence, so you may want to ask your GP for a referral."

The Australian Government has produced a handy booklet called *Don't fall for it. Falls can be prevented!* Google the title or call us on StrokeLine and we'll send you a copy.

If you need advice on falls, or any other aspect of life after stroke, call our stroke health professionals at StrokeLine on 1800 STROKE (1800 787 653).

Book corner



Reinventing Emma

At just 24, Emma Gee, *pictured above*, had her whole life ahead of her. She was an occupational therapist, an avid runner and had just climbed Borneo's Mt Kinabalu with a group of friends. But months later she was suddenly a stroke survivor, unable to move, speak or swallow.

Emma's memoir, *Reinventing Emma*, is testament to her belief that it's not what happens to you that matters - it's how you choose to deal with it. The book is a well-written, insightful, often funny and sometimes heart-breaking account of her long journey of recovery. Emma reveals how lost she felt as she let go of the 'old Emma' and slowly and painstakingly built the 'new Emma' after her stroke.

Reinventing Emma is a detailed account of how complicated this reconstruction really is. Emma's exit from inpatient rehab was not as she'd imagined it, literally running home, free from disability. Instead Emma's stay in rehab ended with her dad pushing her out the door in a wheelchair, her belongings stacked on her knees. As Emma wryly notes, she hadn't imagined herself "a dependent, disabled baby returning home, watching Gardening Australia with her parents on a Saturday night at age 25". Emma though, just keeps going. She never gives up, and Emma navigates that tricky space between what she imagined her life would be and what it is with grace and sharp intellect.

Emma notes it wasn't until she started moving beyond focusing on recovering lost function, to doing new things based on her strengths, that she found the 'new Emma'. This Emma is many things. She's a motivational speaker, an author, a favourite auntie, a swimmer and a passionate advocate for change. But really, beyond all that, she is truly and entirely herself, Emma. This is a great book – highly recommended.

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www.informme.org.au – our online tool to assist health professionals.

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