



A stroke of luck

Stroke treatments have come a long way over the last decade, however many patients in rural and regional areas continue to miss out on best-practice treatment. A ground-breaking program in Victoria is making headway by using video technology to take the expertise of the city to the country. Sue Mahoney, who lives in the small Victorian town of Skipton and is pictured above with her dog Rocky, was one of the first regional stroke patients to benefit from this lifesaving technology. Sue tells her remarkable story in her own words.

It was Saturday 16 June 2012 when I had my brain stem stroke.

We were about to head off to our local football match. At the time, I was the manager for the under 18s team.

It was about 7.30 am, I had finished my shower and as I was getting dressed I started feeling dizzy. I was starting to go cross eyed and I had a terrible noise in my head which sounded like a high pitched industrial fan.

I frantically yelled out to my husband Rob who rang 000 straight away. When the local ambulance arrived, the paramedics seemed to think I had gastro. I was completely unprepared for what followed – I had never been sick.

The local paramedics gave me pain relief to inhale, it did nothing to lessen the pain, and by this time I was feeling nauseated.

I was transferred to our local hospital where the territory ambulance service was ready and waiting for my arrival. Once I got there, the territory paramedics quickly realised that I may have been suffering a stroke.

The emergency department doctor in Ballarat dialled in to The Royal Melbourne Hospital neurologist more than 100 kilometres away. The neurologist assessed my case and advised the doctor to give me blood-thinning medication if a scan confirmed the stroke diagnosis. Unfortunately I crashed just before I could be scanned.

Continues on page 8

Happy New Year and welcome to the summer edition of StrokeConnections. We kick off the new year with the remarkable story of Sue Mahoney. Sue's story highlights the potential of telemedicine to improve stroke services in rural and remote areas. We have stories on recovering your conversation skills after stroke, and on accessing rehabilitation services. We also have two book reviews with giveaways so make sure you enter to win!

2016 was a big year for the Stroke Foundation, marking 20 years of working with you to fight stroke and we launched a brand new look too.

We hope you love the new-look newsletter however if you do not wish to receive these newsletters let us know.

Have a great summer, and enjoy this edition of StrokeConnections.



The StrokeConnections team
Rachel, Katherine, Jude and Chris

Twenty years of Fighting Stroke

Last year marked 20 years since the Stroke Foundation became the charity you know today, focusing our efforts on fighting stroke.

Thanks to your support there is so much to be proud of, there has been significant advancements in the prevention of stroke, its treatment and after-stroke care.

With your help, the Stroke Foundation has:

- › Supported thousands of stroke survivors and their families around the country.
- › Championed better research.
- › Increased public awareness of the signs of stroke.
- › Supported thousands of health professionals.
- › Advocated to Government vigorously for increased funding for stroke and improved access to innovative treatments.

Stroke is now recognised by the community as a top 10 health issue in Australia, however, too many people still don't associate stroke

with the brain. Over the past 20 years we have focused on building recognition for stroke and establishing the Stroke Foundation as the voice of stroke – it is now time for us to become the face of stroke as well.

As you are well aware, far too many Australians continue to be affected by stroke. It doesn't have to be this way. We need the continued support of the community to prevent, treat and beat stroke in the future. Together we can fight stroke and win.

As part of 20th Anniversary celebrations, we launched a new brand for the organisation. We feel this new look better reflects our mission to prevent, treat and beat stroke. Check out our new look throughout this newsletter.

To celebrate this significant milestone we have released a special booklet showcasing what has been achieved over the past two decades. This 20th anniversary booklet can be found on our website strokefoundation.org.au

Conversation is a big part of life, important to everything from everyday tasks to connecting with the people around us. Aphasia is common after stroke, affecting the fundamentals of conversation – listening to and understanding others, as well as expressing ourselves.

Find your voice

Alana, one of our StrokeLine speech pathologists (pictured below), advises the best way to get better at conversation is by well, conversing.

“Find communication partners, people who you can get into a routine with, and practice. Go for a coffee or a walk, use the telephone or even text. Think about getting conversation opportunities into your day, including having conversations with people working in shops and cafes,” Alana said.

You may also need to help others understand how to have conversations with you.

“Our communication fact sheet is great to use in educating family and friends. Most people don’t know anything about aphasia, so may not understand how things have and haven’t changed for you. They may mistake your difficulty speaking for a lack of understanding or interest,” she said.

Fellow StrokeLine speech pathologist, Melita, offers some tips for practicing on your own.

“Pick up an object and describe it out loud. What colour is it? What shape? How does it feel and sound? What is it for? What type of object is it?” she said.

“You can also read out loud. Make sure you slow down and say every sound in every word. It also helps to exaggerate.”

Melita also notes StrokeLine receives lots of calls from family members about supporting someone with their speech recovery.

“Practicing conversation together is an obvious way to help. While family members play an important role in speaking up for someone with aphasia, sometimes it’s important not to jump in. Watching someone struggle is tough – but it can be an important part of recovery” Melita said.

“Keep in mind that difficulty with conversation can have knock on effects. If you start to see people becoming less involved in family life, whether it’s expressing an opinion or being part of decision making, it might be time to get some professional advice.”

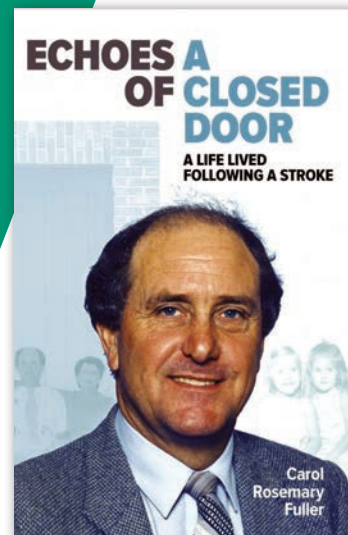
If you have questions about speech recovery, get in touch. StrokeLine’s health professionals are experienced in finding an approach to communication that works.

You can email StrokeLine, write a letter, call 1800 STROKE (1800 787 653) or visit enableme.org.au



Thanks to Carol Fuller, Kathleen Jordan and Impact Press we have copies of *Echoes of a closed door* and *Standing Up!* to give away to StrokeConnections readers.

Send an envelope with your name and address on the back to:
StrokeConnections, Stroke Foundation,
7/461 Bourke St Melbourne 3000
or email your name and address to
strokeconnections@strokefoundation.org.au
for your chance to win.



Echoes of a closed door: A life lived following a stroke by Carol Fuller

Reviewed by Rachel Murphy,
PR and Media, Stroke Foundation

Clive and Carol Fuller were living an ideal life in Adelaide, happily married and with their two daughters at university they planned to realise their long-held dream of travelling the world. But in 1991 that dream was shattered when Clive suffered a major stroke – he was only 50 years old.

Echoes of a closed door: a life lived following a stroke is Carol Fuller's account of the years after Clive's stroke and the impact it had on their lives. Carol doesn't shy away from portraying the hardships of stroke. Clive's stroke left him with aphasia, hemianopia (partial blindness), nerve pain, paralysed on one side and with bouts of severe depression. The title *Echoes of a closed door* describes Clive and Carol having to come to terms with the loss of their former lives.

Carol described the constant frustrations Clive experienced as he "was impatient with himself, and determined to be better than he was." This frustration and impatience sometimes led to Carol and Clive falling victim to 'charlatans' offering a quick-fix or miracle cure.

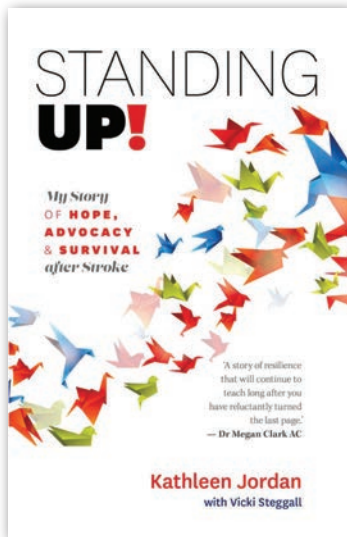
Despite the hardships, the deep love between Carol, Clive and their daughters is obvious as the family tries to make the most of their 'new

normal'. Throughout the book, Carol does her utmost to help make Clive's life as meaningful as possible. Despite Clive's disability, the couple travelled overseas and continued to socialise with family and friends.

Carol describes her many roles as wife, mother, carer and advocate. Carol had to work within a health system that was fragmented, under-resourced and unable to offer stroke patients consistent, high quality care. Clive's story highlights the importance of having someone like Carol in your corner, fighting for Clive to get access to rehabilitation and other basic services. Carol describes a system that had given up on Clive from the start, and she learned she had to demand support for Clive. Carol includes an excellent chapter on being a carer, offering tips and advice, including the importance of looking after yourself in order to be able to care for someone else.

Above all *Echoes of a closed door* is a love story. Despite the challenges of his stroke, Clive and Carol never gave up on their love for each other through good times and bad. Carol's moving account shows that despite not being able to speak, Clive touched the lives of everyone who knew him.

See more book reviews at
enableme.org.au



Standing Up! My story of hope, advocacy and survival after stroke by Kathleen Jordan

Reviewed by Chris Lassig,
Content Writer, Stroke Foundation

Kathleen Jordan's memoir *Standing Up!* is more than an inspirational tale of recovery after a brain haemorrhage: it's also a practical guide for others in similar situations.

Advocacy is a big part of this tale. Kathleen's stroke, which occurred while the successful businesswoman and leadership consultant was giving a speech to medical researchers in Melbourne, was so severe that doctors wanted to mark her 'not for resuscitation'. Kathleen's daughters and sisters fought for ongoing treatment, a fight that continued throughout her lengthy rehabilitation.

Kathleen's journey back has been difficult, with her family being struck by other tragic events, but her determination has taken her from not being able to move or communicate to walking, to mixing once again in her professional circles and, of course, writing this valuable book.

Ask StrokeLine

A common question from StrokeLine callers is how to access rehabilitation and allied health services. Stroke recovery is lifelong but access to rehabilitation isn't – so how do you make the most of what is available?

Start with your GP. Stroke is part of the Chronic Disease Management Plan scheme, which means Medicare will subsidise five allied health sessions each year. Five sessions is not a lot, so make sure your health professional makes a plan about what you can do between sessions and after your sessions have ended for the year. A home practice program will increase your activity which should in turn increase your results.

You can also ask your GP to refer you to community-based rehabilitation which is provided by local public hospitals. This is a good avenue if you need access to more than one type of allied health professional, and if things are changing for you. If you have concerns about maintaining your ability to do things or if you have new goals you want to tackle, community-based rehabilitation can be a good option.

Use your private health insurance if you have it. If you have extras cover you will be able to access allied health services. If there is an allied health practice near you that offers the different services and disciplines you need, you'll get the benefits of a multidisciplinary team communicating and planning together.

Be sure to ask your insurer about whether your hospital cover will fund outpatient rehabilitation sessions. This part of hospital cover isn't as well understood, so you may have to do some investigating into your policy. Many insurers are now also providing telephone health coaching, which can help you tackle your risk factors and avoid having another stroke, so be sure to ask about that too.

Get involved in research and check out student clinics. Research can involve testing a therapy, so check out our website for opportunities, or call StrokeLine. Universities often offer student allied health clinics and this can be a great way to access low cost or free allied health sessions.

For more information and advice on your particular situation, be sure to give our StrokeLine health professionals a call on 1800 STROKE (1800 787 653).

Monash University researcher David Lawson is passionate about using technology to improve rehabilitation offered to stroke survivors. We talk to him about what he's working on at the moment and how stroke survivors can get involved.

Q & A with researcher David Lawson

Tell us about your research

Up to 50 percent of stroke survivors experience difficulties with memory, yet many do not have access to rehabilitation. We are investigating different ways of delivering a memory rehabilitation program to allow more people to access such programs.

What motivated you to do this research?

We're in an exciting time where technology can improve treatment after stroke, but we need good research to support these opportunities. A lot of people don't have access to rehabilitation services, so conducting research that could directly benefit many people is inspiring. On a personal level, I also have a connection to the stroke community, so helping survivors on their recovery journey is something that I care about.

What's involved in participating? And what's in it for participants?

Participants receive a six-week program of memory rehabilitation, free of charge. The program consists of a two-hour session each week, one-on-one with a therapist. This occurs either at a clinic in Melbourne, or over the internet for anyone outside of Melbourne, interstate, or even overseas.

The program covers information about stroke and how memory can be affected, as well as useful strategies and tools to support everyday memory functioning.

Before and after the program, participants fill in questionnaires and complete activities to assess memory. At the end of the process, participants also receive an individualised report outlining their progress throughout the rehabilitation program.

Any advice for stroke survivors wanting to get involved in research as part of their recovery?

Research studies are vital for progress toward better treatment in the future, and may also provide great opportunities for survivors to advance their own recovery. It's usually free of charge too! If you are interested in exploring research, search for research studies on the Stroke Foundation website, or other stroke community forums and websites. Make yourself known - there is probably a researcher who is looking for you too.

What's next for you and your colleagues?

We will be recruiting for this study throughout 2017, and hope to publish results in 2018. We also have another study looking at assessing cognitive skills after stroke remotely that is also inviting participants.

If you are interested, please contact me on 0425 751 734 or david.lawson@monash.edu.au





“I didn’t recognise my stroke symptoms – then suddenly I was a stroke patient”

Janette Bingham from Queensland thought she was healthy and well. Not in her wildest dreams did Janette think she could be at risk of stroke. Stroke wasn’t even on her radar.

“I’d recently lost some weight and felt fit enough to tackle anything,” Janette said. “I was working fulltime, was busy with my grandchildren and life in general.”

Janette, pictured in the white shirt, is a qualified midwife and has worked in hospitals for years, but even she did not recognise her stroke symptoms.

Thankfully, Janette’s GP did recognise them.

Janette had not been feeling well and she’d begun to feel numb on her tongue and the side of her face.

“I honestly didn’t think it was anything,” Janette said emphatically. “But when I went to see my doctor I was sent straight off to hospital.

“I can’t change what happened, but I wish I’d recognised the signs.”

With the support of the Stroke Foundation and a committed team of health professionals Janette has come a long way in her recovery.

“I’m feeling more confident in the kitchen again after the memory-training therapy. When I first came out of hospital I sometimes couldn’t remember all the steps involved in cooking a normal family meal. It was very frustrating,” she said.

“I don’t know where I’d be without the support of the Stroke Foundation and all the specialist therapists who’ve helped me. I really have come a long way and I’m very grateful for their help.”

Stroke prevention is one of our top goals here at the Stroke Foundation. Stroke prevention saves lives. In many cases you can defuse your chances of stroke. Blood pressure is a factor, along with diet and exercise. Small changes in your life can make a big difference.

Your support helps us prevent stroke. It helps us treat stroke. And it helps survivors like Janette to recover after stroke.

Help us continue to support stroke survivors like Janette by sharing our latest appeal with your family and friends. Your support will ensure we can continue our work to prevent, treat and beat stroke. To find out more phone us on 1300 194 196 or email supporter@strokefoundation.org.au

Continues from page 1

The doctors in Ballarat and Melbourne were faced with a tough decision – administer the clot-busting drug without the scan and risk a bleed in my brain, or do nothing as the stroke killed millions of brain cells every single minute. In consultation with the Melbourne neurologist they decided to give me a chance at life and gave me the drug without the scan.

The doctors then put me into an induced coma and prepared me to be flown to Melbourne for further treatment.

My husband Rob was told the heart-wrenching news that I was having a stroke and was being prepared to be flown to the Royal Melbourne hospital.

Rob was left to tell our children Andrew and Matthew the terrible news that at best, I had a one percent chance of survival.

The neurology team at The Royal Melbourne Hospital assembled their Code Stroke team and successfully performed a new procedure that extracted the three clots from my brain stem.

Thank God this new procedure was available. I was in intensive care for three days and on the stroke ward for around a week. I was then transferred back to St John of God Ballarat Hospital, where I had daily rehabilitation for a week. After that I was able to go home and

continue my rehabilitation as an outpatient, twice a week for a number of months.

My right hand side had been impacted, however after rehabilitation it's back to about 95 percent. My speech gets slurred when I'm tired and I suffer from fatigue.

I am very grateful for The Royal Melbourne stroke team, St John's Hospital and the paramedics from Ballarat. Especially the paramedic in the back of the ambulance who was sure I was having a stroke and called ahead to the hospital. If it wasn't for them I wouldn't be here today.

The Victorian Stroke Telemedicine program links rural and regional Victorian hospitals to a network of Melbourne-based neurologists who can provide treatment advice about patients with acute stroke symptoms. Following the success of the Victorian program, the Stroke Foundation is advocating for the program to be expanded to other locations across the country so that regional stroke patients like Sue get the best possible treatment.

To join the Stroke Foundation's advocacy for telemedicine and other improvements to the stroke care system contact fightstroke@strokefoundation.org.au or sign up online at strokefoundation.org.au



Contact us

 1300 194 196

 strokefoundation.org.au

 /strokefoundation

 @strokefdn

 @strokefdn

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

enableme.org.au

enableme is your free online resource and community for stroke survivors, their families and supporters. Our quick, easy and free registration ensures you receive our regular email updates of StrokeConnections and other stories.

enableme latest

- › Listen to the new podcast – Sex after stroke.
- › Great group discussion on returning to work.
- › Emma started a forum chat about overseas travel after stroke.
- › Fact sheets and video on different aspects of life after stroke.
- › Ask a question of a StrokeLine's health professional or other stroke survivors.

Plus lots more...

Disclaimer: While care has been taken to ensure information is accurate, all information in this publication is only intended as a guide, and proper medical or professional support and information should be sought. References to other organisations and services do not imply endorsement or guarantee by the Stroke Foundation.