



Never say never

Stroke changes lives in an instant. Dealing with this can be difficult for survivors and their loved ones, especially when they hear the brutal words, “You’ll never...”

These words come in many forms – “you’ll never walk again”, “you’ll never talk again”, “you’ll never work again”... They may have been uttered by a health professional, a loved one or even your own frightened inner voice.

But as the following survivors show, “you’ll never” does not have to become part of your vocabulary. In fact, “you’ll never” can be a motivating force to live life to the fullest.

Emma Gaffey - grit and determination

Emma, pictured above, suffered a stroke in 2003 at the age of 19.

At first, Emma was told she would never return to study, drive, live independently or have a social life like other people her age. She said this reaction to her stroke confused, angered and astounded her.

“Doctors should not assume every patient has the same future ahead of them. A lot of achievements are based on strength of character and the desire to regain abilities,” Emma said.

“I have reached many, if not all of my goals. First came walking, then speaking, independent travel, two university degrees, living independently, starting my own business and the list goes on.”

Emma believes health professionals should focus on the potential positive outcomes, rather than the negatives.

“At one time I couldn’t speak – and now funnily enough - my business is in communications and I talk, write and create content for a living,” she said.

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Welcome to the winter edition of StrokeConnections

Those of us fortunate enough to work here at the Stroke Foundation have been told many stories about the words “you’ll never” after a stroke. In this edition we explore the impact those words can have. We talk to stroke survivors and ask stroke health professionals about good professional practice in conversations about recovery.

We also have an interview with Dr Annie McCluskey, an occupational therapist, educator and researcher with over 30 years experience in stroke and brain injury rehabilitation. We know 70 percent of stroke survivors will experience long-term difficulties with their hand, shoulder and arm function. Annie focuses on the most common upper limb problem after stroke, weakness. She discusses the evidence about the effectiveness of therapeutic approaches to weakness and provides advice to help progress recovery.

Finally, we begin our series on memory changes after stroke with a look at how memories are made.

We hope you enjoy StrokeConnections. You’ll notice sponsor advertisements in this edition, which are there to ensure we can keep getting this newsletter to you.

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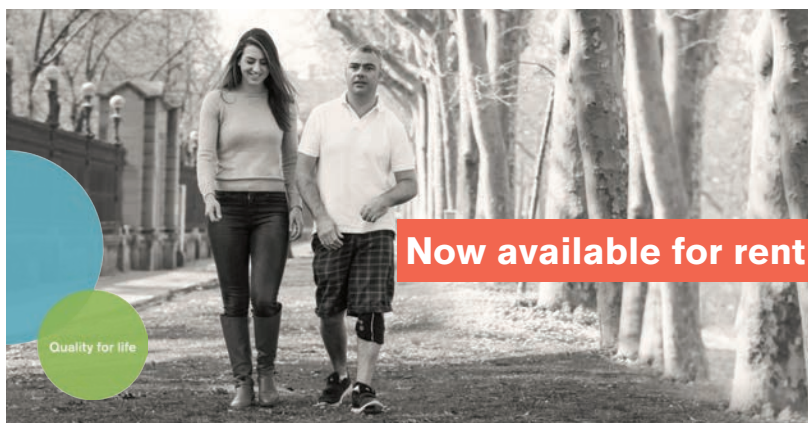
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Get the upper hand in your recovery

Many stroke survivors have long-term difficulties with their hand, arm and shoulder function.

We recently spoke to Dr Annie McCluskey, occupational therapist, educator, and researcher, about upper limb recovery after stroke. She said people can experience a range of upper limb problems, but weakness was the most common.

“After a stroke, many people find they just can’t get their muscles to work. They need to find ways to get their muscles to contract,” she said.

Dr McCluskey outlined the most effective therapies for different levels of weakness.

Severe weakness

For people with severe weakness or little or no movement, she recommended therapists focus on offering electrical stimulation, task-specific training and robotics.

“Task-specific training is where a therapist will target specific muscles like the muscles inside the thumb and try to get a particular muscle to contract,” Dr McCluskey said.

“Robotics can be difficult to access free of charge in Australia, but there are non-robotic devices that are less expensive and can be constructed at home. StrokeLine has details of a device which was made by the husband of a stroke survivor. It’s called the Strong Arm and allows the person’s arm to slide forwards in a trough to practise their shoulder movement.”

Moderate weakness

The majority of stroke survivors have moderate weakness – that’s some movement, but not effective use of the arm. Therapies which can be used in these cases also include electrical



stimulation, task-specific training and robotics. People with moderate weakness can also use mirror therapy, mental practice and games on Wii or iPad. These can be useful for promoting finger and hand movement. They can be used in a standing or sitting position.

Mild weakness

For mild weakness, constraint induced movement therapy was recommended, but Dr McCluskey said it must be intensive to make a difference.

“High intensity means at least one to two hours daily in hospital, or three to four hours daily as an outpatient, for two weeks, usually with supervision from therapists to keep the repetitions high,” she said.

Some Australian public health services and university clinics are now offering constraint therapy.

“The aim of constraint therapy is to drive the brain to get messages down to the hand, but it’s only appropriate for people who’ve got some wrist and finger movement,” Dr McCluskey said.

“This type of therapy also involves the person’s non-affected hand being ‘constrained’ which is where the name comes from. Sometimes we just use an oven glove to stop a person using their non-affected hand.

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Never say never

Shelagh Brennand – when it's okay to say 'never'

Shelagh Brennand's doctor told her there was every chance her life would return to normal after she suffered a stroke in 2013. He also thought she could probably go back to her career as a private investigator.

The company Shelagh worked for welcomed her back and gave her a small job, but the anxiety and stress was too much.

"I got so anxious because I wasn't as sharp as I was before the stroke and thought I would miss something. I was frightened I'd do a rubbish job," Shelagh said.

"I experienced fatigue and spent a week in bed after working for three days.

"In my case, I was the one who decided to say 'never'," she said.

Shelagh suffered depression and experienced a grieving process in which she felt like she was not going to be able to do anything useful. But she found poetry and learned to be grateful for what she had.

"My limbs worked. I could climb, I could run, I could cycle, so I thought life is pretty good actually," she said.



Dee Honeychurch – mission possible

The words 'can't' or 'never' are banned from Dee's household. Dee's beautiful daughter Emma suffered a stroke in utero and continues to defy the odds.

Dee said many questions raced through her mind following Emma's diagnosis – "How could this happen to my sweet Emma? How does a child survive such brain damage? Will Emma die? Will she walk? Will she have emotional intelligence?"

However, a neurosurgeon who observed Emma couldn't believe how well she was functioning; crawling, talking, pulling up to stand and taking emotional and social cues.

"He described Emma as phenomenal – something we already knew," Dee said.



Your Health, Your Way

"After having a stroke at the age of 42, I have found MedAdvisor a fantastic tool to remind me when to order medications" - Belinda R.





Shelagh Brennand pictured with her family

Emma is now two years old and is thriving. Emma can crawl, talk in sentences and is almost walking independently.

“Our goal as parents is to help Emma believe anything is possible. This is our mission.”

Dr Juan Miguel Rois-Gnecco, Rehabilitation Physician – never says never

Dr Rois-Gnecco steers clear of using the word ‘never’ with stroke survivors.

“There is clinical evidence to support the prediction of a better or worse functional outcome, but this is not always accurate and does not take into account the participation effect required for successful rehabilitation,” Dr Rois-Gnecco said.

“Stroke survivors in rehab are at their most vulnerable. You need to strike a balance between providing therapy and encouragement, but at the same time be cautious not to provide false hope.

“Focusing on function and setting realistic goals is always a good start. It’s a dynamic process and constant review of goals is mandatory.”

Dr Rois-Gnecco said it was important a survivor’s rehabilitation team is united in its goals and expectations for the patient, ensuring there were no mixed messages about recovery.

“When the time comes to have ‘the conversation’ with a patient, they often have already come to a better understanding of their functional limitations, and in most cases have been given a good go at improving their deficits,” he said.

Associate Professor Susan Hillier – what is likely and what is not so likely

A/Professor Susan Hillier said there was little evidence to support any statement that says ‘never’ and advises health professionals not to use the word.

“The language should always be about what is likely and or not so likely,” A/Professor Hillier said.

“None of us are omnipotent, none of us has a crystal ball. I have seen amazing recoveries and I have also seen people deteriorate when they give up.

“While the strongest evidence is for early and intense rehabilitation, people can make gains more than a year after their stroke.”

A/Prof Hillier encourages health professionals to help people find a balance between hope, engagement and realism for patients.

“Everyone is unique and we should help them build their own sense of self-worth and self-efficacy,” she said.

A/Professor Hillier also has some advice for stroke survivors.

“Don’t pressure health professionals to make big predictions. Find a way to accept that the future is unknowable, which can be difficult when you are looking for reassurance or clarity,” she said.

“Try to find the balance between too much hope and too little hope. Accept the stroke has happened and find a way to work with your mini goals.”

With our next EnableMe podcast focusing on memory difficulties, the StrokeLine team has been exploring how memory works.

The hippocampus is the key part of the brain responsible for memory. The hippocampus creates memories and then directs the brain where to file them. It's like a gateway through which new memories must pass before being stored.

Usually each side of people's brains are specialised. In right handers, the left side of the brain deals with numbers and words, and the right side of the brain deals with visual and spatial perception. The right and left hippocampus are similarly specialised. However, for information to reach the hippocampus the information must first be perceived, designated as being worthy of storage and then understood. For instance, if you are in a coma, you can't form memories, and if your stroke affects the language understanding part of the brain, you can't store verbal memories.

There are three stages to memory:

Registration. In this stage, you pay attention, process information and give it meaning. Most memory problems are caused during this stage. If you can't focus on what is happening, you won't be able to remember it later. For stroke survivors, it's not surprising the first few weeks after their stroke are often a bit of a blur. The impact of a sudden, life-changing event, an injured brain and a busy, noisy hospital all add up.

Storage. In this stage, a record or memory is created and stored, either working memory (short-term) or long-term.

Short-term memory is our working memory. We keep small amounts of information active and readily available for a short period of time. For instance if you are repeating a

number in your head to dial it, or someone spells out a name to you and you then go and write it down, this is 'working memory'.

If you need to remember something for a longer period, it is then moved by your hippocampus and connected areas into long-term memory. When we recollect memories we solidify their place in long-term storage. While our working memory capacity is limited, long-term memory is relatively unlimited.

Long-term memories can be about events in time and place (episodic memory), our knowledge of abstract facts (semantic

memory) or skills, procedures, and movement (procedural memory). Stroke survivors are often surprised and delighted to find their procedural memories are completely intact after their stroke.

Retrieval. The last stage of memory is accessing it. This can only happen if both registration and storage have taken place. Retrieval is based on cues that trigger your memory of how the

information was first registered. Smells, sights and sounds are often linked to memories; this is why hearing an old song can take you straight back to the past. Again, things such as stress, fatigue, anxiety or depression can interfere with this stage.

The best advice is to speak to your doctor and to seek out testing if needed. Testing can tell you about your specific memory difficulties and the specific strategies that can help you. Consideration of your overall health and the impact of your stroke, along with a medication review, will be helpful too.

Next edition we will cover strategies for compensating for memory problems.

Our memory helps make us who we are and it allows us to function in the world.

It's not surprising that noticing memory changes can panic us a little (or a lot).

Stroke treatment a cruel lottery

Regional and rural communities are bearing the brunt of Australia's stroke burden, according to an updated Stroke Foundation report. *No Postcode Untouched: Stroke in Australia 2017* was released in June with a feature on the TV show *The Project*.

The report found 12 of the country's top 20 hotspots for stroke incidence were located in regional Australia and people living in country areas were 19 percent more likely to suffer a stroke than those living in metropolitan areas. Due to limited access to best practice treatment, regional Australians are also more likely to die or be left with a significant disability as a result a stroke.

However, it doesn't have to be this way. Stroke is largely preventable. It is treatable and it can be beaten. In the wake of the report, Stroke Foundation called for a funded national action plan to address the prevention and treatment of stroke, and support for survivors living in the community. This includes:

- › A national campaign to ensure every Australian household has someone who knows the F.A.S.T. signs of stroke (Face, Arms, Speech, Time) and knows to call 000. Time saved in getting to hospital and treatments equals brain saved.
- › A nationally coordinated telemedicine network – breaking down the distance barriers to acute stroke treatment.
- › Ensuring all stroke patients have access to stroke unit care, and spend enough time on the stroke unit to receive the services and support they need to live well after stroke.

Visit strokefoundation.org.au to see how you can help us demand federal and state government action.

The *No postcode untouched: Stroke in Australia 2017* report was funded by an unrestricted educational grant from Boehringer Ingelheim.

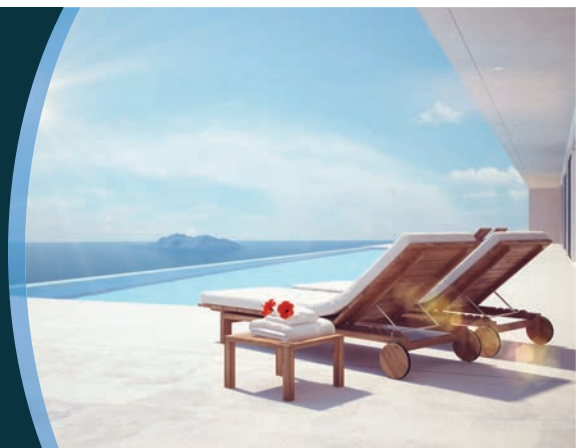


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“Upper limb problems can persist over a long period, but people should aim high and for as much recovery as early as possible. I get quite despondent, as I’m sure many stroke survivors do, when I hear somebody say, ‘Don’t worry about your arm. Just get back to walking’,” she said.

“People do need to worry about their arm. The more they try and get messages from their brain to their hand and their arm, the more likely they are to be able to get movement back.”

Dr McCluskey encouraged people to build practice into their daily routine in order to boost arm and hand recovery.

“There is a useful book called *Stronger After Stroke* by Peter Levine which gives lots of good advice,” she said.

“It has tips for different exercises, accessible information about research and good suggestions about long-term motivation. It’s a great resource.

“Think about recovery as a long journey if you really want to continue to work on your arm. Set goals and measure your progress every few months so you can see the effort has been worth it.”

StrokeLine’s health professionals provide information, advice, support and referral. StrokeLine’s practical and confidential advice will help you manage your health better and live well.

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- › Listen to the new podcast – Memory difficulties after stroke.
- › Great group discussion on explaining aphasia.
- › Carey started a forum chat about coping with the crisis of her husband’s 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...

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