

StrokeConnections

Winter edition 2018

The Stroke Ambulance saved my life

It was the day after Valentine's Day when Felix Schibeci almost lost his life.

The 72 year old from Altona Meadows, in Melbourne's west, had risen early after a lovely dinner out with his wife Ina the night before. He got himself breakfast and then started fixing some carpet in his bedroom. As Felix was on his knees with a hammer in his hand, an odd feeling came over him like a flash. Felix had the presence of mind to scream out and Ina came running.

When Ina reached Felix he had collapsed. Felix was paralysed down one side and could no longer talk. In that moment, he feared he may be having a stroke. He tried to mouth the word 'stroke'. Luckily Ina had the same thought and called Triple Zero (000) straight away.

"I sat with him until the ambulance arrived. It only took five or six minutes," Ina said.

"I was in shock, but the crew was wonderful. I stood back and let them do their job."

The Mobile Stroke Unit or Stroke Ambulance then arrived. Felix had heard about the Stroke Ambulance in a recent television news story, but had no idea he would ever need it.

The Stroke Ambulance crew moved Felix into the ambulance. By this point, Felix was in and out of consciousness.

"I remember being strapped down and told to keep still," Felix said as he was moved into the brain or CT scanner on board.

The scan allowed the on-board neurologist to immediately diagnose Felix's stroke was caused by a large blood clot. Clot busting treatment was given in his driveway, saving time and precious brain cells.

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Welcome to the winter edition of StrokeConnections

One thing stroke survivors share is a wish for everyone to receive the very best treatment after stroke. If your experience was not a good one, you most likely want to help ensure the outcome is better for others. Whereas, if you had a good experience, like Felix Schibeci, you want to make sure that happens for everyone, no matter who or where they are.

Felix's recovery is nothing short of amazing. Fortunately his wife Ina knew the signs of stroke, his treatment began in the specialised stroke ambulance and he was given life-saving clot retrieval on arrival to hospital. We are so pleased to bring you Felix's story in this edition.



Inside this edition, you'll also find a wrap of our 2018 Stroke Awards, along with advice on muscle spasticity after stroke and on the benefits of goal setting in recovery. We hope you enjoy this edition of StrokeConnections.

Best wishes,

The StrokeConnections team

Jude and Emily

Powerful campaign highlights the link between smoking and stroke

You may have seen Quit Victoria's latest powerful campaign on television, online or billboards. The slogan is "Smokes can lead to strokes". The campaign was launched on World No Tobacco Day on May 31.

While the video and images used are confronting, the campaign highlights the reality of smoking as one of the preventable causes of stroke. Smoking doubles the risk of stroke.

Smoking can increase your risk of stroke by increasing blood pressure and reducing

oxygen in the blood. Some of the chemicals in nicotine damage blood vessel walls and increase the chance of blood clots forming.

Three stroke survivors – Bill Gasiamis, Jayson Killick and Mandy Bowler generously shared their stories as part of the campaign.

See the campaign at strokefoundation.org.au
For information and support to stop smoking, visit quit.org.au or call the QUIT line on 13 18 48.

EVERY STEP COUNTS TOWARDS A HEALTHY LIFE

**3 – 9
SEPT
2018** **NATIONAL
STROKE
WEEK**

strokefoundation.org.au/strokeweek

This National Stroke Week, discover how easy it is to fit a few healthy habits into your daily routine, and do your part to prevent stroke.



Continued from cover

"I don't remember much after that – other than fleeting visions of the Bolte Bridge during the journey," Felix said.

"I was frightened, but a nurse held my hand and talked to me gently. This gave me great comfort."

Once at hospital, a specialist stroke medical team was ready and waiting for Felix's arrival. Felix went straight into surgery and the blood clot in his brain was removed.

Just five hours after the onset of Felix's stroke, the father of six and grandfather of 11 was awake in the hospital recovery room.

A nurse asked for his name and Felix was amazed he was able to speak again clearly. He truly believed it was a miracle.

"The nurse asked me to squeeze her hand and I could do this too. I could function perfectly!" he said.

Ina and a number of members of Felix's family were anxiously waiting for word at the hospital. They were expecting the worst, but were shocked and thrilled to hear Felix had such a positive outcome.

"I consider myself very lucky," Felix said.

"I thought I was gone. I have known other people who have had strokes, and I know the damage they can do, but my recovery has been remarkable."



Given stroke treatment is time-critical, Felix is grateful for two things. He knows how fortunate he is Ina recognised the F.A.S.T. (Face, Arms, Speech, Time) signs of stroke and called an ambulance immediately.

"Ina's quick thinking saved my life," he said.

Felix is also forever grateful the Stroke Ambulance exists, and has described it as a wonderful innovation. Felix is now home, enjoying his second chance at life.

Since his stroke, Felix has made a conscious decision not to rush around as much anymore. He is also determined to make the most of his life. He gets joy out of his family, cooking, socialising and gardening – and telling the tale of his amazing stroke survival.

The **Mobile Stroke Unit** has been operating as a trial since November 2017. It is the only Stroke Ambulance in Australia. It provides stroke patients in Melbourne, like Felix, with access to faster diagnosis and treatment, boosting their chances of survival and recovery.

While the data is preliminary, it currently shows the ambulance is being called out six or seven times a day.

Stroke Foundation is proud to be a partner in delivering this game-changing, life saving innovation.

Stroke Foundation is eagerly watching the progress of the Stroke Ambulance trial and is advocating for more units to be rolled out nationally.





Young stroke survivors struggling to return to work

According to international evidence, the prevalence of young stroke is increasing. With this, comes a huge issue for stroke survivors of working age – they are not getting the support they need to return to work.

A recent systematic review, published in the *International Journal of Stroke*, found just 66 percent of working age stroke survivors had re-entered the workforce up to four years post-stroke.

This includes 33 year old Luke Richardson who suffered a stroke in 2011.

Luke's recovery journey has been long and tough. He went back to work a couple of years ago, but in a reduced capacity. He can no longer operate as an electrician, but makes deliveries and works in the office. His employer has been incredibly supportive, but unfortunately this is not always the case.

Stroke Foundation's StrokeLine service (1800 787 653) receives many calls from people who want to return to work after a stroke, like Luke, but do not know how to go about it.

StrokeLine team member Kirsty Cole said there were many issues which could make it difficult to re-enter the workforce.

"This includes changes to walking or balance, arm or hand use and perceptual abilities like vision. Hidden issues like fatigue, anxiety and depression are also common," Kirsty said.

"Some employers require a more immediate return to work, while the stroke survivor might need more time to manage an issue like fatigue."

In the wake of the report, the Stroke Foundation called on Federal and State Governments to invest in vital rehabilitation research, and promote greater access to innovative and cutting edge recovery treatments for stroke survivors of working age.

Better services and support will reduce stroke's burden on individuals, their families, the community and the health system.

We are calling for:

- › Support for the survivor during the job hunting process. It's a tough journey and one you don't want to do on your own.
- › Support for employers who hire a stroke survivor to educate them about issues like fatigue and cognitive deficits.
- › More research into rehabilitation for young stroke survivors to improve processes and reconnect them to their work and communities as soon as possible.

If you're planning a return to work, the StrokeLine team can help by offering advice on ways to tackle obstacles, along with information about services and support. Kirsty notes that "Everyone's pathway is unique to them, so getting individualised advice is really important. At the end of the conversation with StrokeLine, you'll have a clear plan that will work for you."

She also encourages stroke survivors to find out more about other survivor's experiences. "Join the stroke survivor community and connect via support groups. There are some groups that cater for people who are younger, plus there's the online EnableMe community too," she said.

Muscle spasticity: get moving

After a stroke, about 30 percent of people will experience some form of muscle spasticity. Our muscles have a certain amount of 'tone' or activity. The tone of muscles is controlled by signals from the brain. If the part of your brain that sends these control signals is damaged by a stroke, then the muscle may become too active. This is called muscle spasticity.

Some people experience muscle spasticity immediately after their stroke, but it can start at any time.

"When I look back at photos of my hand eight years ago, I can see it was very tight. It was to the point where it was like a fist – it was not a useful hand." – Adrian O'Malley, stroke survivor

Adrian's experience is common. Stroke survivors experiencing muscle spasticity may have a clenched fist, a bent elbow and arm pressed against their chest, a stiff knee or a pointed foot. This can also result in contracture, which is when the muscles get shorter due to being kept too tight and can become fixed in one position.

If you experience muscle spasticity at any time after your stroke, it's important to get advice and to put in place the right treatment plan for you. For many people, physiotherapy and occupational therapy are the most effective treatments.

StrokeLine physiotherapist Katherine David says "Neuroplasticity is the brain's ability to change so unaffected parts of the brain can take over the job of affected areas. Repeated and challenging exercises related to every day tasks can promote this change, reducing muscle spasticity and restoring the brain's control over muscles. Your therapists will recommend exercises and strategies to improve the quality of movement and the control of your muscles."

They may also recommend therapies such as casting, taping and electrical stimulation (often when you have little or no movement in the affected area).

Your therapists will also recommend you keep moving. "Muscle spasticity will tend to get worse the less you move. This is especially true if the muscles become weaker. Moving less can also contribute to developing contracture. It's important to move as much as possible," Katherine said.

For severe muscle spasticity, your doctor may prescribe medication. The most common medication is botulinum toxin A, which is injected into the muscles that are too active. These injections are effective for approximately three months, and they should always be combined with physiotherapy or occupational therapy. They give you a window of opportunity to work with your therapists to strengthen muscles and to improve your range of movement.

For Adrian, all these strategies used in combination have been vital. "When I received the injections, my treating team asked me for three simple functional goals. I wanted to turn on a tap and to turn a door handle. My third goal was to hold my daughter Eve's hand when we're crossing the road walking home from day care. It's a very simple but very pleasurable thing to do."

"They were my three goals, and they were all achieved."

This month we launched new resources on muscle spasticity, thanks to the generous support of Allergan. For a copy of our new fact sheet, visit our website or call StrokeLine on 1800 787 653. You can also watch a video on muscle spasticity at EnableMe.org.au



Ask StrokeLine

Q. How do I set workable goals for my recovery?

For many people, recovery from stroke is a lifelong journey. Like any long journey, it can be hard to know where to start, and sometimes it can be hard to keep going. Wherever you are in your recovery, setting goals can help you figure out how to get where you want to be.

Setting goals helps you turn a wish into a plan, providing structure to your recovery. Goals focus your attention on yourself, not on what other people are doing, or on what others think you should be doing.

If you've never set goals before, it can be hard to know how to get started. So how do you set goals? How do you make sure setting goals will help, not hinder, your recovery?

Believe in your brain's amazing ability to change

We used to think that no further recovery could be made after the first 12 months post-stroke. We now know that stroke survivors can continue to improve for years and even decades after their stroke.

In the initial phase of recovery, your brain is trying to repair damaged cells and start working again. Some people have spontaneous recovery, where the damaged cells just start working. For other people, it is a case of 'use it or lose it'. Activities exercising the damaged area of the brain help it to repair itself.

In the later stages of recovery, if the damaged area has not started working again, the brain may use a new area to take responsibility for the tasks that the damaged area used to do. This is called **neuroplasticity**, meaning that the brain has the ability to physically change itself – amazing right!

Pick an area that you want to improve on

Ask yourself, "What is it I can't do now that I want to do?" Imagine your stroke is no longer stopping you from doing something you really want to do. What is that thing?

Focus on what's important to you

Sometimes, other people may suggest goals that they think will help you with your recovery. While their intentions may be good, the goal becomes a 'should do' and may be less meaningful to you.

Just remember, when it comes to your life, you are the expert. There is no friend, family member, doctor or therapist who is in a better position to control your recovery. When you direct your own recovery, your goals mean more, and you are likely to work harder and achieve greater success.

Involve your significant others

Having said that, it can help to include your family and friends in your recovery. If people have told you they want to help, think about taking them up on their offer. Tackling recovery with a loved one can provide some powerful support and encouragement.

Make it practical

When goals have practical outcomes, they mean more. Working on your grip strength, for the sake of it may not be that inspiring. However, working on your grip strength so you can use cutlery to eat your meal and feel comfortable going out to a restaurant may give you the inspiration you need.

Break it down into small steps

One of the biggest challenges of creating a goal is breaking it down into steps. But unless you do, you'll never know exactly what you need to do to achieve your goal. It also means you can celebrate your achievements as you go. Consider the goal below:

"I want to enjoy spending time with my grandchildren again."

First, think about what's stopping you. Perhaps you're worried about having another stroke while you're with your grandkids. What could help you overcome this worry?

Step 1: Get the facts. **Action:** call StrokeLine to talk to a stroke health professional about your risk factors and how to lower them. This may give rise to a new goal of getting back on track with making lifestyle changes.

Step 2: Talk to your doctor about your worry and how it's impacting you. **Action:** call your GP and make an appointment. This may give rise to a new goal of attending counselling.

Dealing with setbacks or changes

Goal setting is not a one-off thing. Your plan will need to grow and change over time. As you achieve goals, new goals will emerge. You might also have setbacks or hit road blocks. It's okay not to achieve what you set out to achieve. You can adjust your goal and try again. Is there another method you can try? Can you break your goal into smaller steps? If the goal is important to you, then keep working towards it. You may achieve it, you may adjust it or you may decide it is no longer important to you and that's fine too.

Fatigue can be a major hurdle for many stroke survivors working on their recovery. You can help manage fatigue by getting some exercise, staying hydrated and well-nourished, reducing stress and asking your doctor to review your medications. Most importantly, know your limits, listen to your body and take a break when needed. Pushing yourself too far can make you go backwards instead of forwards.

Enjoy the ride

Remember to be kind to yourself along the way. Maybe you have partly achieved your goal and that is enough to allow you to get back to an activity that you enjoy. In that case, you may decide to stop working on it or to work on it less intensely.

You have a right to decide if the effort and time it would take to achieve a goal is worth it to you. Maybe doing four hours of physiotherapy each day would improve your walking significantly, but reduce your ability to do other things you want to do. You may decide you don't want to work on a particular goal right now and return to it later.

There is no right or wrong, just the best path for you and there is no-one better to choose that path than you.

You will find a wealth of information on goal setting on **EnableMe**, including a tool that walks you through all the steps to setting good goals. Visit enableme.org.au.

StrokeLine's health professionals can provide free, individualised advice to get you where you want to be. Call **1800 STROKE** (1800 787 653).

Stroke Foundation Consumer Council member Julie Davey talks about goal setting and recovery in a new set of videos on EnableMe available in August.



Meet the 2018 Stroke Award Winners

Thank you to everyone who nominated someone in this year's Stroke Awards. We received around 80 nominations and the calibre of applicants was outstanding. See the nominees and read their stories at strokefoundation.org.au

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**President's
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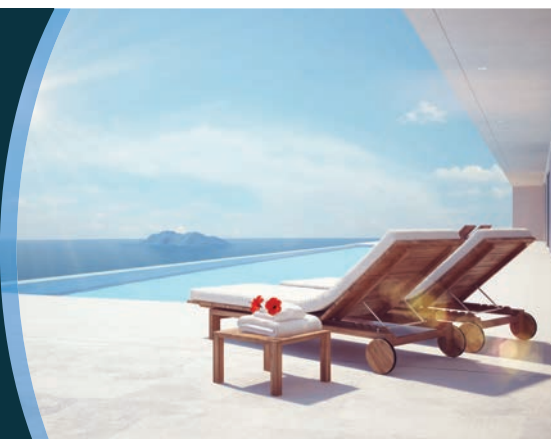


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