



Life with an invisible disability

Stroke survivor Toni Arfaras has been living with invisible disability since her stroke six years ago. Invisible or hidden disabilities are disabilities that can't be seen or aren't obvious to other people.

Many common effects of stroke can be part of an invisible disability. These can include:

- › Changes to thinking, memory and personality.
- › Changes to how you speak, understand, read or write.
- › Changes to vision and senses, including sensory overload.
- › Fatigue, pain, depression and anxiety.

After a stroke, you may find you're not only living with a disability, you are living with people's responses to your disability. Toni featured in a recent EnableMe podcast on invisible disability. For Toni, how well she can do things, and how much help she needs, depends on the day and on the situation.

continued page 2

Welcome to the winter edition of StrokeConnections

Welcome to our winter edition. We think you'll enjoy our story about Col Nelson, whose life was saved by a quick-thinking and caring stranger. Stroke is always a medical emergency, and the story of how the ambulance got to Col is amazing.

This edition also features stroke survivor Toni Arfaras' experience of living with an invisible disability. Invisible disabilities can't be seen by other people and can create challenges. Toni shares her story, along with advice from the StrokeLine team.

We also have news of a new report on the last twenty years of stroke care in Australia. The report highlights some lifesaving improvements, and some work still to be done. We take a look at the National Disability Insurance Scheme and a new edition of the essential stroke guide, *My Stroke Journey*.

Wishing you all the best from everyone at Stroke Foundation.

Continued from cover

Toni said she has faced scepticism about her disabilities.

"A lot of people don't understand unless they've actually seen me when I'm really struggling. I think that's understandable because how can you know about something if you can't see it and you haven't been educated about it?"

Toni has had both good and bad experiences. She said the worst one was when she was challenged for using a disabled parking spot.

"I had some staff at a ferry terminal have a go at me when I was getting out of my car. I said to them, 'Look, I've actually got a disabled sticker. I've had multiple strokes, so I'm entitled to use it'.

"They still didn't get it so I went to their manager, told him my situation and said 'You need to educate them.'"

"I've had some great experiences too. There's a restaurant we go to and we explained to the owner I need to sit in a quieter spot so I can stay a bit longer. As soon as we book, he puts aside a particular table for us because he knows that's where I'll be most comfortable.

Those little touches really do make a big difference to my life."

With an invisible disability, it's not obvious what your experience of disability is or what you need. Toni takes every opportunity she can to educate people.

"You can't expect people to make allowances or to be understanding if they don't know about it. So you have to decide how much you're willing to share of your story.

I think a lot of it comes down to what you've accepted about what you're going through, what you're experiencing. And once you've decided what you're willing to share, life becomes a lot easier," she said.

If you're living with invisible disability, it can help to:

Talk with your doctor. It's important to keep on discussing the impact of your stroke with those helping you look after your health. If something has changed, particularly if it's got worse, make sure you let them know. This helps them provide you with good care. It also ensures they have the full picture if you need their help with applications for a disabled parking permit or the NDIS.



Accept you are the real expert. You know what the effects of your stroke are, you know how they impact you every day and you know what you need. Being told you look and sound fine can make you doubt yourself. Remember, other people's opinions will never be as informed as yours.

Use things there to make life easier. It can feel like it's easier to hide your disability and not ask for what you need rather than risk an unhelpful or intrusive response from somebody. It may take courage to speak up, and to use the things there for people with disabilities. But these things are there to make everyday activities possible for people with a disability. If you need them, use them.

Connect with others. Sometimes when you need support, you find there is less support from some people in your life, not more. It can help to connect with other people living with invisible disability. Find them in stroke support groups or online via [EnableMe.org.au](https://www.EnableMe.org.au). Ask friends and acquaintances if they know anyone you could connect with.

Let it go. There are some people who are just not going to get it. Educating people can be hard work and it's not always up to you. It can be helpful to have a script for people you don't know well or at all. Try Toni's approach: "I've got a disabled sticker. I've had a stroke, so I'm entitled to use it."

Remember too that just because someone asks you a question, you don't have to answer it. Scripts can help close down a conversation. Try: "Why would you ask me that? Why do you want to know?" or "My doctor says I need it". You can also say "I'd rather not talk about it. Let's talk about something else."

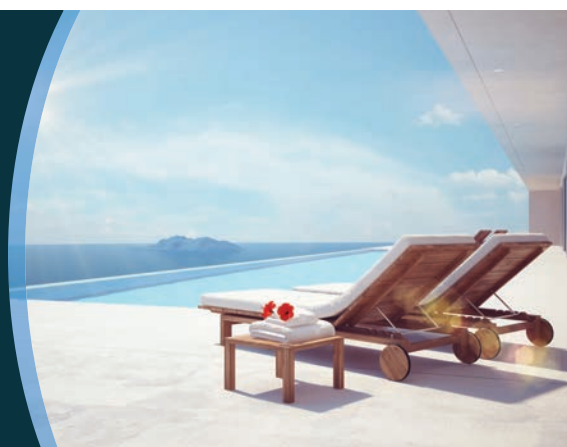


Educate people. Talk to people about your experiences when you can. Discussing how you feel is not always easy – being honest about the things that matter to us makes us vulnerable. It can take courage. Stroke Foundation has fact sheets and podcasts that you can share too.

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"I can walk on the plane and I'm perfectly fine. But as soon as other people start walking on the plane and then the plane takes off, I need assistance with walking and talking. I actually need a wheelchair to get off the plane.

"I always ask for special assistance when I book a flight. Last time, I went to the counter when they called for special assistance passengers and the crew said to me 'We don't want you, we want special assistance.' So I let them know I actually am special assistance." On the flight, the first time Toni got up to use the bathroom the crew saw how severely affected she was and stepped in to help and make the journey easier for her.

"I actually ended up spending time with all of the flight crew and explained my stroke story and all the different effects of it," Toni said.

For information and advice call **StrokeLine** 1800 787 653.

Continued from previous page

Toni's most memorable experience of educating people around happened on a recent flight.

"Flying really affects me," Toni said.

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Making the most of NDIS

The National Disability Insurance Scheme (NDIS) helps people with a disability who are under the age of 65 access the support they need. NDIS participants get funding for services to help with daily life, be involved in their community and reach their goals.

Navigating the NDIS can be a bit of a challenge. Our new video series on EnableMe is designed to make it easier. The videos feature young stroke survivors, carers, health professionals, advocates and NDIS local area coordinators. They share some of the challenges of adjusting to life after stroke and explain how to navigate the NDIS to get what you need.



To watch our video series, visit EnableMe.org.au. Go to the Resources tab and choose 'My life after stroke'.

If you are over 65 years of age and you need information about services to help you stay at home, My Aged Care may be able to help. They can tell you about different local aged care services available, assess your eligibility for services and let you know about any costs. Call **1800 200 422** or visit myagedcare.gov.au

A stranger saved my life

The thought of having a major medical emergency at home alone is an incredibly frightening concept for anybody. What if you could barely move and nobody could hear your cries for help?

Seventy-three year old grandfather Col Nelson found himself in that situation when he suffered a stroke in 2016. Thankfully, the quick thinking actions of a stranger, at the end of a random phone number, helped Col survive to share his amazing story.

When Col thinks back, there was a small clue that something was not quite right with his body in the hours leading up to his stroke.

On the day of the stroke Col was supermarket shopping, as he walked down the aisles of the store his foot scraped on the ground every now and then. It was a weird sensation and Col wondered why it kept happening, but he shrugged it off and got on with his day.

Col's wife Dianne was interstate so he went home, cooked some dinner and watched

some television and went to bed without giving his foot another thought. But when Col woke the next morning, he was almost paralysed down one side. Col couldn't control his arm and leg and he couldn't get out of bed. Col was terrified.

Col's thoughts were a jumble, but the one thing he knew was he desperately needed to get help. Col knew what a stroke was and fleetingly feared he was having one, but what could he do? Col was in the house all alone.

Col mustered up all of his strength and through sheer willpower managed to drag himself from his bedroom to the lounge room where there was a phone. Col's daughter Belinda lived nearby, and he was determined to reach her. Col was confused and didn't think to dial triple zero (000) in the moment.

"I must have called half a dozen wrong numbers [trying to call my daughter]. I just couldn't coordinate my brain and my hand," Col said.

Continued from previous page

"I don't really remember much. I was slurring my words, but I did speak to one young woman who asked if I was in trouble and needed an ambulance.

"I recall saying, no I just want my daughter."

Luckily for Col, the woman did not follow his instructions. The stranger at the end of the phone line recognised it was an emergency and dialled triple zero (000). Within minutes the ambulance service called Col's number, asked if he needed help and sent an ambulance to his address. Col was then transported to hospital for treatment and subsequent rehabilitation.

To this day, Col still doesn't know his saviour's name, where she lives or anything about her. Col wanted to find her, but her number had disappeared from his phone.

"If I ever met her, I would like to thank her very much for not hanging up on me and for her quick thinking. It's quite possible she saved my life," Col said.

Col's life has changed since his stroke. The two things Col misses the most are being able to drive and sit by a quiet river and fish. Col still has a weak side, a limp and gets confused at times, but he can walk and talk. Col considers himself extremely lucky and knows the outcome of his stroke could have been far worse if it was not for the stranger on the phone.

Col is incredibly grateful for the love and support of his family, who all rushed to his side in hospital and have helped him throughout his recovery.

"Recovery is a slow process, but I am happy," he said.

"I might not be able to climb a ladder anymore, but I am alive. I am around to cheer on my grandsons when they play football and that brings me a huge amount of joy."

Col, far left with his family.



Stroke still a significant challenge twenty years on

Stroke Foundation recently looked back on two decades of stroke data collected from hospitals and rehabilitation services, with interesting findings coming to light.

The ensuing report, *Stroke Foundation Audits – A 20 year retrospective*, highlights much has changed in stroke treatment and care in that time, largely due to medical advancements like clot dissolving (thrombolysis) and clot removal treatments (endovascular thrombectomy or endovascular clot retrieval).

The good news was the number of hospitals providing clot dissolving and clot removal treatment has risen, along with the number of patients receiving care in a specialised stroke unit. It was encouraging to see this progress.

Furthermore, the 20 year report tells us more people are surviving stroke than ever before and living well after stroke.

However, there is much more work to be done to ensure all Australians can access time-critical treatments, no matter where they live.

People in rural and regional areas continue to remain at a disadvantage due to geographical barriers to stroke specialists.



Stroke Foundation will continue to advocate for a national telestroke network to speed up diagnosis and the pathway to treatment for these patients.

The analysis also found there was not enough emphasis on mood assessment for patients, risk factor advice and psychology services to help people continue to thrive once they leave hospital.

Quality improvement programs and initiatives, to address a number of these issues have been included in the recently completed National Action Plan for Heart Disease and Stroke. The Action Plan outlines immediately achievable actions Australian governments at all levels can implement to reduce the impact of stroke and heart disease on survivors, their families and carers, the community and healthcare system.

Stroke Foundation's mission to prevent stroke, save lives and enhance recovery remains as critical as ever.

"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.



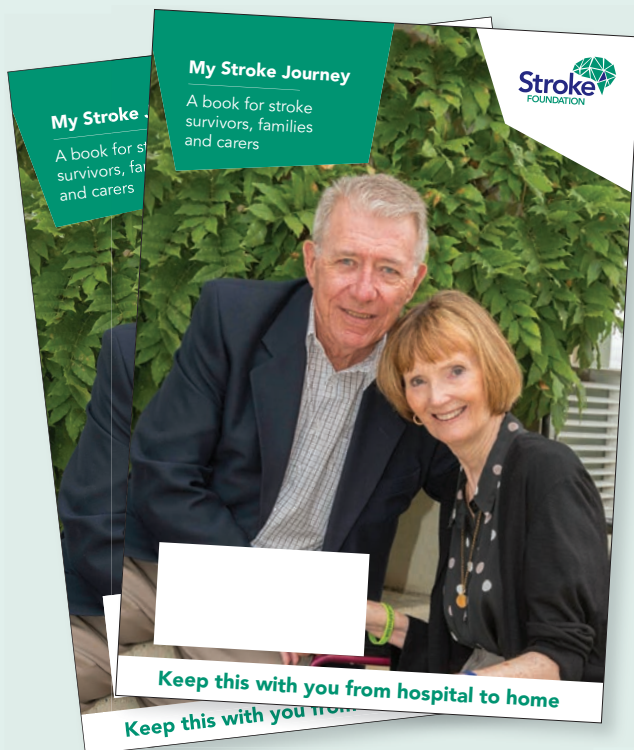

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My Stroke Journey updated for 2019

If you've had a stroke, you need a copy of *My Stroke Journey*. *My Stroke Journey* ensures every stroke survivor and their family have the information and access to the support they need.

It's been five years since we launched *My Stroke Journey*. Since then, more than 100,000 people have received a copy while in hospital.



Following feedback from survivors, their loved ones and front line health professionals we have completed an update. *My Stroke Journey* now answers more common questions, as well as being easier to read and to navigate.

My Stroke Journey has four chapters, based on these questions:

- › What is a stroke?
- › How will my stroke affect me?
- › How do I take care of my health?
- › What happens when I leave hospital?

My Stroke Journey has updated information on treatment, rehabilitation and on managing risk factors to reduce the risk of having another stroke. It also features some great new stories from stroke survivors about their stroke journey.

If you would like a copy of the updated *My Stroke Journey*, call StrokeLine on **1800 787 653**.

Contact us

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