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Sharing, Supporting, Connecting

# Stroke Connections

Winter edition 2015



strokefoundation



## Give more, live more

Jan Corcoran uses her art to help people understand the impact of her stroke. “I did a painting of a bird of paradise and after I finished I covered it in white pastel so people could see what I was seeing with my own eyes...a lot of people who’ve had a stroke will tell you, it feels like there’s a cloud or veil over your face,” Jan explains.

After suffering two consecutive strokes in 1998, Jan was robbed of her speech, her mobility and her career. On top of this, the strokes happened not long after Jan had moved to Cairns and besides her husband she didn’t know a soul. Isolated and frustrated, the emotional impact of stroke took its toll.

“After my stroke I couldn’t understand what was happening in my brain. I thought I was talking properly but I wasn’t. I had a bad habit of walking away when I got frustrated and was in tears, which happens because your brain hasn’t had time to assess it all,” she says.

It was in this vulnerable state Jan discovered the depth of her inner strength.

“You don’t give up,” Jan says. “I couldn’t talk for three years – not a sentence – now I don’t shut up! I couldn’t walk properly – I still stop-start stop-start but I’m walking,” she proudly tells.

After working hard at her own recovery, which she describes as ‘long, slow and hard’, Jan turned her mind to how she could help others.

“After my stroke I couldn’t go back to work... but I knew I had to do something,” Jan said. This ‘something’ came up unexpectedly when a friend asked her to take the minutes at the meetings of a local disability advocacy group.

Despite not being able to say a sentence and having restricted mobility, Jan used a voice recorder to tape the meetings and at home Jan doggedly typed out the minutes with two fingers, determined to help. The volunteering opportunity boosted Jan’s confidence and inspired her to get involved in the local community.

Since then, Jan has volunteered for over 17 years, dedicating countless hours to helping diverse charities such as the Royal Flying Doctors Service, Tourism Cairns and the Leukaemia Foundation.

Almost two decades of service saw Jan honoured as a recipient of an Order of Australia earlier this year, however Jan believes it should be her thanking the community.

“My volunteering has helped me to achieve so much over the last 17 years. We had only lived in Cairns for six months when I had my strokes. It is amazing how my life changed and the people I met,” she explains.

“If I can do anything to help others I’m happy to – even if it helps only one person.

“I highly recommend getting involved in the community – you need to get involved, you’ve got to give back to help yourself too.”



Rich, Di, Jude, Rachel and Jess

## Welcome to the winter issue of StrokeConnections

Welcome to our first ever email-only edition of StrokeConnections. This marks a change for us as we move to two print editions each year and two email-only editions.

This edition centres on how stroke can impact a person's identity. For many of us, our identities are so tied up in our jobs and our role within family or friendship circles. When something happens to us and we can no longer fulfil these roles as we used to, it can be incredibly tough to create a new identity.

Stroke survivors have told us about the important role volunteering work has played in their recovery, in helping establish a new identity. This got us thinking about how giving back can help people in life after stroke. We are pleased in this edition to bring you the stories of stroke survivors and National Stroke Foundation volunteers Neville Kerr (former StrokeSafe Ambassador) and Jan Corcoran. Neville and

Jan tell us how community involvement helped them in life after stroke.

In this edition, we also have a link to an interview with survivor Desney King, who explores her stroke experience with us and what life is like when your stroke recovery is not what you hoped for. We also have a review of a book that many, many stroke survivors nominate as crucial to their recovery: *Stronger after stroke* by Peter Levine.

Please, enjoy this edition of StrokeConnections. We are always pleased to receive your feedback or suggestions. Email us at [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au)

Best wishes,

**The StrokeConnections and enableme teams**

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## Rediscovering my identity after stroke: Neville Kerr

For stroke survivor Neville Kerr, watching his wife pull out of their driveway every morning to go to work is a gut-wrenching experience. It is a constant reminder of the role he used to have as business owner and breadwinner – a role Neville was forced to give up over three years ago after suffering a stroke.

“I feel the greatest amount of guilt watching Lynne go to work...watching her drive out the gate kills me. I think that’s my job, I’m the breadwinner of the house. I’m meant to be the one going to work,” Neville said.

Neville was a successful business owner and family man when out of the blue he suffered five strokes in one day. Neville’s strokes had a massive impact on his emotions. But like many stroke survivors Neville’s rehab focussed mainly on getting him physically able to get back to work and his life before stroke – there was little emotional support or a focus on helping Neville understand what had happened to him.

Once out of rehab, Neville attempted to return to his business and his old life but discovered he couldn’t cope. Forced to give up the business and work, Neville was faced with a new dilemma; discovering a sense of purpose after stroke.

“That’s the thing with stroke, your normal life is gone and there are things you have to do to compensate for and there are things you have to get on with. You have to accept this is now your life and some of the things are very difficult to accept,” Neville said.

“I still have withdrawal symptoms from that [retiring] even though it’s been three and a half years now.



“That’s something I still have to come to grips with. It’s your normal life that isn’t there anymore.”

For many working age stroke survivors getting back to ‘normal’ is a key focus of their recovery. According to research by young stroke survivor and research fellow at the Florey Institute of Neuroscience and Mental Health Barbara Wolfenden, many survivors’ identity is challenged by stroke, and time is required to recover and make necessary adjustments. Resuming their life roles and responsibilities is commonly very important to stroke survivors.

Yet for many stroke survivors like Neville, resuming their old life isn’t possible. After the loss of his business, Neville found himself sinking into depression. It was by complete chance he discovered help. Lynne was reading the paper when she spotted an ad for a local forum for stroke survivors hosted by the National Stroke Foundation. They decided to go along and Neville found himself amazed at how much he didn’t know about stroke.

“I learned more in an hour than I had in two and a half years... it was like my eyes opened up. All of a sudden there was something to be aware of, there was something to live for, there was something to understand,” Neville said.

When the Foundation approached Neville to join a group of stroke survivors travelling to Parliament House in Canberra to meet with



members of parliament, he immediately said yes. But Neville found the thought of putting himself out there incredibly daunting. Despite his years as a confident banker and business owner, the prospect of meeting with other stroke survivors terrified him.

“I lost a lot of confidence when I had my strokes. To get on a plane and go and not know anyone who was there was a big issue,” Neville said.

“It was a big learning curve, sitting down and talking to other stroke survivors and finding out what they had done to get on with their lives.

“Everyone had an issue or deficiency somewhere along the line but they weren’t obvious. And looking at how people had got on with their life and what they have done to get back with their lives was the most beneficial thing that had happened to me. All of a sudden there were people just like me, they had issues just like me.

“Meeting with the NSF people and meeting with the other stroke survivors in Canberra was the biggest learning curve I’ve ever had in my life,” he explained.

The Canberra trip unearthed a new sense of purpose in Neville. He realised how little he had known about stroke prior to having one and decided to join the Stroke Foundation in raising awareness by becoming a StrokeSafe Ambassador.

“I’d always been a public speaker – my whole life I’d always been involved in groups like Rotaract and to find out there was a way you could get out and impart the knowledge was fantastic,” Neville said.

“It’s given me a challenge, not only to help me but to get other people to understand [about stroke],” he said.

Taking on the StrokeSafe Ambassador role helped Neville develop a greater understanding of his strokes and has helped him cope with his changed life after stroke.

“You can’t stop learning with stroke – stroke is so different to everyone. I have learned so much by talking to people in the community.”

“If other people can do it you can too... there’s no incentive in life until you know and understand.”

Neville is excited to be continuing in his role as the StrokeSafe Ambassador program transitions to the new volunteer program.

## Rediscovering my identity after stroke: Desney King

Desney King describes herself as having been 'a very fit, healthy, full-on working woman of sixty' when her first stroke hit. She was highly regarded as a book editor, well known for her work on complex non-fiction and illustrated books.

Desney had three strokes over a two year period, with her last stroke happening in 2014. As a result of her strokes, Desney has experienced cognitive changes, general muscle weakness and persistent, crippling fatigue. We caught up with Desney to discuss her stroke experience, and what life is like when your stroke recovery is not what you hoped for. She discusses the practical and personal strategies she has used to create her 'new normal' and the role acceptance has played in her life after stroke.

**Jude:** Is fatigue the biggest issue for you?

**Desney:** Yes. It affects my daily life and it massively affects my quality of life. But it's also the fatigue in combination with my particular cognitive impairment – together, they prevent me from driving, working and doing any creative writing. The increased fatigue since the third stroke last July has finally stopped me from blogging which was my compromise when I could no longer work on the novels.

**Jude:** When you saw your first neurologist after your stroke, did you have a conversation about fatigue?

**Desney:** I did and he was very dismissive. He made me very angry because he decided very



early on, and I'm not sure why, that although he was picking up on my deficits with his neurological testing, that my problem was psychological and that I had had a nervous breakdown.

My experience with him caused me a great deal of additional distress so I changed neurologists. I've got a lovely young neurologist now who basically says to me, 'Look, there's just so much we don't understand.'

**Jude:** I think anything that can't be physically seen is something people really struggle with. I've heard a lot of people say people will assume that because you look normal, everything must be back to normal. So you're not only dealing with the impact of the stroke, you're also dealing with all the negative responses that you get.

**Desney:** That's true Jude. The fatigue and the right side weakness, it's still with me, so I've been walking with a walking stick. The physio early on said to avoid using a walking stick, to do everything possible to get your body to return to normal. So I really tried, I persisted with that for three or four months, until I found myself in situations where I would walk up to the shops, I'd do a little bit of shopping and I couldn't walk home.

The third stroke did something else in my brain and it's rendered me unable to sit up in a chair for more than about ten minutes at a time.

## Desney King

(continued)

I suppose that's the other thing I wanted to make clear to you in this discussion is that every kind of interaction increases my fatigue level, so it drains my energy. Whether it's emotional, doing something physical like standing, or sitting upright, or something mental, they all sap energy. I have to manage that very mindfully all the time.

**Jude:** *If you were talking to a recent stroke survivor and fatigue was an issue for them, what advice would you give them?*

**Desney:** If I was just generally giving others advice, I'd advise acceptance basically.

“ Acceptance, which is nothing to do with giving up! Acceptance allows you to work out all the energy saving strategies you can. Get really clever about energy saving strategies, so everything you do is really helpful to you. Don't waste your energy on anything, get rid of people who cause you grief. Let them fall away. ”

And a salvation I forgot to mention: crochet! A craft I learned in my teens and still love. It gives me a creative outlet, and a way of giving something to others. I order my wool online from Bendigo Woollen Mills, and mainly crochet rugs and blankets which are easy but lovely.

To read the full interview with Desney visit: [www.strokefoundation.com.au/blog/2015/07/23/interview-with-stroke-survivor-desney-king](http://www.strokefoundation.com.au/blog/2015/07/23/interview-with-stroke-survivor-desney-king)

## Foundation news

### National Stroke Week 2015

We are asking Australians to take the challenge to be aware, live healthy and get checked this September 14 - 20. The campaign is all about raising awareness to prevent stroke. With your help we will shine the spotlight on stroke, encourage Australians to know the signs of stroke and learn how to minimise their own risk of stroke.

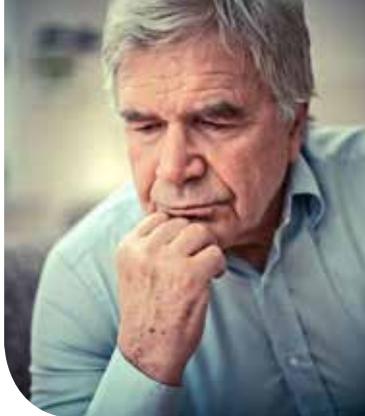
It's a great chance for workplaces, sporting or social clubs, pharmacies and health professionals to get involved and raise awareness by:

- Holding an awareness activity, display or talk.
- Setting a physical, lifestyle or food challenge.
- Organising health checks.

Registrations are open online and free resource packs will be provided to support your activity.

[Click here to find out more.](#)

The graphic features the text 'TAKE THE CHALLENGE' in orange, the 'strokefoundation' logo, and a blue banner with 'National Stroke Week' in white. Below the banner, the dates '14-20 September 2015' are shown. Three circular icons represent the campaign themes: a hand holding a red megaphone for 'Be aware', a bowl of fresh vegetables for 'Live healthy', and a doctor examining a patient for 'Get checked'. At the bottom, it says 'Get involved at www.strokefoundation.com.au' and '#strokeweek15'.



## Why am I so emotional? The impact of stroke on controlling emotions

‘Emotional lability’ refers to fast, fierce and uncontrollable changes in mood. After stroke, survivors may find themselves laughing or crying for little or no reason. Emotional responses don’t seem to make much sense or can be out of proportion. As we generally pride ourselves on keeping our emotions in check, especially in social situations, this effect of stroke can be very challenging.

Emotional lability is caused by damage to the parts of the brain that control our awareness of emotion and how our emotions are expressed and regulated. It is sometimes called the pseudobulbar affect and can last anywhere from a few weeks, to many years.

Stroke survivor Danny Furlong writes of his experience in his book *Flat Out*: “I’d cry at the drop of a hat and I felt humiliatingly ashamed at being so weak, at not being able to rise above my problems.” What made a difference for Danny was his neuropsychologist’s explanation that his emotional response was a manifestation of his brain injury. This brief discussion instantly alleviated some of his fears about being weak or worthless, and marked a turning point in his recovery.

Being aware of and managing triggers for emotional lability can help. What triggers lability will be unique to the individual, but things to be aware of include tiredness, stress, anxiety, and noisy, overcrowded environments. Being around emotional people, situations or events can also be a trigger, as can being put under pressure.

Useful strategies and tips include:

- Push through, or alternatively, take a break. You can try ignoring the emotional response. Try to get others to ignore it too and continue on with the conversation or task. Focussing on the lability can reinforce the problem. Alternatively, take a break from the situation to help regain control of emotions, and allow things to settle. Try taking a short walk or doing a different activity.
- Relaxation and cognitive techniques. Try techniques such as relaxation and breathing exercises. These are commonly described in books and on the internet. Psychologists can help with cognitive and behavioural strategies.
- Switch things up. If it’s really bothering you, you may want to consider making some changes to your routines. One-to-one, brief and pleasant activities in a quiet environment can be better than trying to constantly deal with stressful situations or environments.
- Deal with the awkwardness head on. Explain to people what’s happening. Uncontrolled crying or laughing can be upsetting and confusing for other people. Tell people about your stroke and about what works best for you, for example saying “Just ignore it and it will stop”.

As Danny Furlong notes, “I take deep breaths and try to stop my agonised sobbing, but the tears keep coming. I’m being hugged and hushed. No, I’m not crying at the utter futility of my existence, I’m crying because the radio is playing some slow and sad song! Now I know I’m far from unique in my tears and they are something I’m not responsible for, so I can take them in my stride.”

Call StrokeLine on **1800 STROKE** (1800 787 653) to obtain further support, advice or information on emotional lability or start a conversation about emotional lability on [enableme](http://enableme.org.au) [www.enableme.org.au](http://www.enableme.org.au)

## Book review

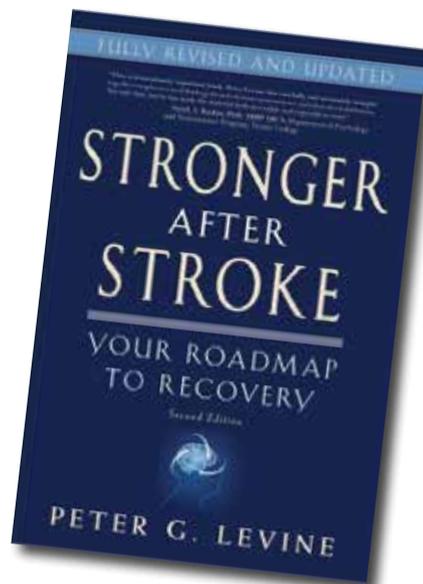
# ***Stronger after Stroke* – your roadmap to recovery by Peter Levine**

StrokeLine staffer and physiotherapist Katherine reviews our book for this edition: *Stronger after Stroke*.

This book is not a novel or a story, but instead a brilliant guide to stroke rehabilitation. It's loaded with information and advice for stroke survivors and carers wanting to take charge of their own recovery. Reading from cover to cover takes you through the various stages of stroke rehab, giving you knowledge that is invaluable in achieving the best possible recovery after a stroke.

The author, Peter Levine, provides clear explanations of the principles behind stroke recovery, discussing neuroplasticity and how 'brain rewiring' can be maximised. Major therapy techniques are described simply but in enough detail so you can understand how these therapies may benefit you. Peter does tend to focus more on the physical issues after stroke, such as problems with walking or hand function, but the description of general recovery principles will be useful for all stroke survivors and carers. As an American book, some references are American-based, however the vast majority of information is universal.

One of the best things about this book is it empowers you to take charge of your own recovery. Peter challenges the notion of the



'plateau' being the end of recovery, giving you great advice for how to continue progressing. He makes no secret of the fact that recovery after stroke is about hard work and dedication, but there's a real sense of hope throughout the book. *Stronger after Stroke* really is a must-read for any survivor and carer wanting to maximise their recovery. Keep it on the shelf and remember to refer back to it because it's chock-full of excellent information.

## **Stroke survivors recommend this book too:**

“Of the many books I have read, this was the most helpful and hopeful,” Elizabeth.

“One of the better books out there. Great if you are looking for a practical guide of what you can do and safe ways to tackle your goals,” Heather.

## Fundraising for stroke awareness



## Ida's story

Melbourne local Ida Dempsey knows a thing or two about what can be achieved by a determined stroke survivor. Ida had a near-fatal stroke when she was just 40 years old and wasn't able to walk, talk or eat for months.

Ida worked hard at her rehabilitation goals, including getting back to her beloved running. After taking on marathons at home and overseas, Ida's guts and determination have helped her build an online community of people passionate about living healthy and fighting stroke. Running under the banner 'I run FAST to promote stroke awareness' Ida's running events and online campaigning aim to raise awareness of the vital message that saved her life.

"Through the fundraising and stroke awareness events we have saved lives and will save more," Ida said.

Like many Australians Ida wasn't always so stroke aware. In fact stroke was the last thing on Ida's mind when she happily went to a Rugby League semi-final in 2011. She'd had a busy day at work and was looking forward to a fun evening with friends.

She was sitting in the stadium watching the match. Suddenly, Ida became aware of a strange sensation in her right hand.

"My hand felt really weak," she recalled. "It just didn't feel like my hand."

Ida tried to concentrate on the game, but her hand was distracting her. "I asked my friend if she thought my hand looked strange, she took one look at my face and called for the

paramedics," Ida said.

Thankfully, Ida's friend knew the signs of stroke and followed the **F.A.S.T. steps** when she recognised Ida was having a stroke. She called an ambulance straight away, saving Ida's life.

Ida still shudders to think what might have happened if her friend hadn't recognised the FAST signs.

"It's frightening to realise I could have died that night. Thankfully due to the fast actions of my friends that night, I'm a stroke survivor. I tell everyone I meet how to recognise the signs of stroke. A FAST response makes the difference," Ida said.

The fact that Ida is out there running marathons today is because she got FAST treatment.

A key part of our work at the National Stroke Foundation is educating Australians about the signs of stroke through the **F.A.S.T.** campaign. Stories like Ida's really highlight how big a difference this life-saving message has made.

A recent study revealed Australians who had seen our **F.A.S.T.** campaign were 80 percent more likely to recall two or more signs of stroke than those who hadn't seen it. This tells us what we're doing is making a difference – it also tells us we need to work harder to share this life-saving message with even more people.

Please make a gift today. Your support will help us educate more people about the signs of stroke.

Simply call us on 1300 194 196 or make a secure online donation at [www.strokefoundation.com.au](http://www.strokefoundation.com.au)

## My Stroke Journey: what do you think?

In 2013, the **National Stroke Foundation** launched **My Stroke Journey**, an information pack given to survivors and carers immediately after a stroke. We worked with hospitals to get My Stroke Journey out there and now have over 160 hospitals providing it to their patients. The pack provides information on stroke and its treatment, which we know is important as most stroke survivors and carers have little knowledge of stroke before the event. My Stroke Journey is designed to support survivors and carers through the initial crisis, as well as providing them with a road map for long-term recovery.

We are currently reviewing My Stroke Journey, and plan to launch a new version in 2016. We are looking for stroke survivors and carers to provide their views on My Stroke Journey. You may have received it during your hospital stay, but even if you didn't, we'd love to know what you think. If you are interested in being involved, please let us know by email and we will get in touch to hear your views. Email [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au)



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**StrokeLine: 1800 STROKE (1800 787 653)**  
**[www.strokefoundation.com.au](http://www.strokefoundation.com.au)**

Visit **enable *me*** – our online tool to aid stroke recovery. [www.enableme.org.au](http://www.enableme.org.au)

Sharing, Supporting, Connecting

## What's happening on *enableme* this week?

Lots of discussion on *enableme* this week about the role of acceptance in recovery, in the forum 'Is too much acceptance a bad thing?'

Adrian kicked off the conversation with the question 'Is acceptance of everything that has happened, whilst psychologically beneficial, taking away some of the fight in me?' Another hot topic is the role of diet in tackling post stroke fatigue, with survivors swapping ideas, confessing to some guilty diet secrets and aspiring to a healthier way. Also under discussion is people's experiences of being prescribed antidepressants after stroke.

Have you checked out *enableme* yet?

Visit [www.enableme.org.au](http://www.enableme.org.au)

**enable *me***  
stronger after stroke

## Sign up to receive StrokeConnections by email

To ensure you don't miss out on our digital-only edition of StrokeConnections please email [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au) with the subject **StrokeConnections** and include your full name, postal address and email to receive your copy.

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