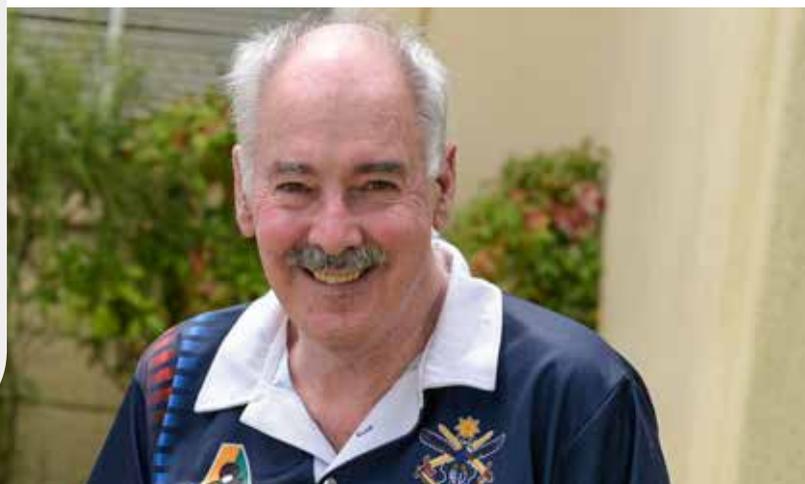




Stroke Connections

Autumn edition 2016



What I learned after my stroke

We've heard from many different stroke survivors that the first few weeks in hospital after stroke is an overwhelming, scary and confusing time.

Part of our mission at the Stroke Foundation is to make that time a little bit easier. It is why we created the **My Stroke Journey** resource to help connect stroke survivors and their families with the information and support they need in the initial period after their stroke. One of the key things stroke survivors have said made a difference for them was hearing hopeful but realistic stories from other stroke survivors who have been there.

We have just launched an update of this vital resource featuring more stories of hope, resilience and survival. Here is what six stroke survivors and carers further along their recovery journey would share with someone who had just had a stroke and their family members.



Tony Finneran, stroke survivor New South Wales

"It was the last thing on my mind, that I'd have a stroke. I was reasonably fit, although I did have an underlying blood condition that increased my risk of stroke. I hate to think of the traumatic effect on my wife, my two girls, my friends and family, looking at me fully paralysed in the intensive care unit. I was very fortunate – that unit saved my life, and the staff at rehab [rehabilitation service] gave me that life back.

"If anyone was asking how to cope with life after a stroke, I'd say to focus on the things you do well.

"The old Tony could stop locomotives and jump tall buildings. The new Tony is a new and exciting guy that I'm very surprised that I have found. Without the stroke I'd still be doing the same routines. Since my stroke, I've become a public speaker and a fundraiser, and I've written two books. So while you feel that you have been struck a devastating blow, there is a new person that you can find." (Tony is pictured above).

Stories continue on page 3



Rachel, Katherine, Jude and Chris

Welcome to the autumn issue of StrokeConnections

Welcome to the first issue of StrokeConnections for 2016. This year is shaping up to be an exciting and busy time for the Stroke Foundation. Last week we launched an updated version of the My Stroke Journey pack to better support stroke survivors and their families through the tough first weeks after stroke. As part of the update we've included more stories from real stroke survivors on what they learned after stroke. Our feature article this edition brings you their important stories of hope and realism.

We are about to kick off Australia's Biggest Blood Pressure Check with the aim of delivering 50,000 health checks throughout April. In addition, the Stroke Awards will open next week, so if there is an inspirational person you think deserves recognition read on for more information about making a nomination.

We also review a great new book that has hit the stores, *Who's Afraid* by young stroke

survivor Maria Lewis. It's been a fantastic month for new books, with stroke survivor Emma Gee also releasing her autobiography *Reinventing Emma*.

We're giving away free copies of *Who's Afraid* and *Reinventing Emma* to lucky readers so make sure to enter our competitions to be in the running. We also have a brand spanking new podcast series for you and an opportunity to take part in new research projects.

Thanks for reading and have a happy and safe Easter

Best wishes,

The StrokeConnections and *enableme* teams

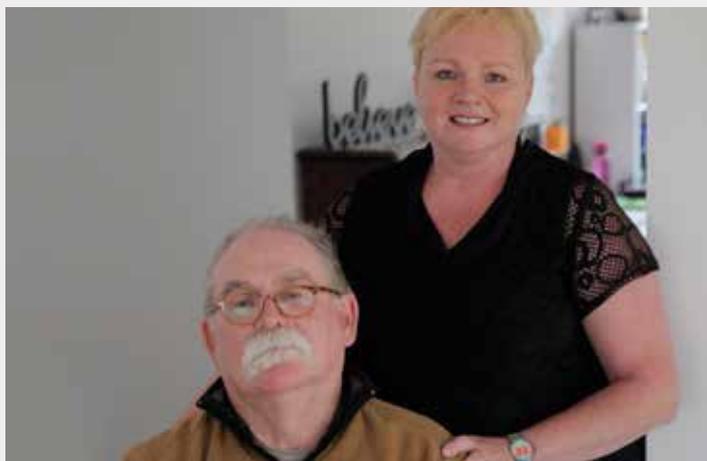
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What I learned after my stroke

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**Julie Collins, carer
Victoria**

“My husband Ross was in hospital for a long time and the entire focus was on getting him well enough to come home. You always put yourself last, you put your spouse and your children first. It’s a difficult thing for carers, to find that balance. That’s been one of the benefits of the carer’s group, to talk to people who understand what you’re going through.

“My advice is to try to do one thing at a time, not to try to do everything at once. For me it’s one day at a time, one thing at a time. I work at what I can do and I get help for the things that I can’t. Finding out where to get that help can be difficult, it takes a lot of persistence.

“Make sure you say yes to everything. If someone says ‘would you like a follow up appointment?’ the answer is always yes. Don’t say no to anything. If it doesn’t fit in later on, or you find you don’t need that service, you can say no then.

“I learnt that I’m tougher than I think. Our family is pretty tough too and we have a great group of friends. I’m an emotional wreck sometimes and that comes with being tired. Sometimes you think about all the things that you’ve lost, but then you think about all the things you’ve got. I’ve got my health, and I’ve got Ross – between us we can work through things. Being a carer is a challenge, but I wouldn’t be anywhere else.”



**Jenny Ferrier, stroke survivor
Tasmania**

“The first three months after I went home was the hardest time. I lost my independence as I could no longer drive, and my husband had to become my carer as well as my taxi driver. I also found that my moods were up and down and my reactions to things felt out of proportion. I was bewildered as I’d never felt like this before my stroke.

“I first read about [enableme](#) in the Stroke Foundation newsletter – I thought that could really help me with post-stroke information. The idea of connecting with other survivors also really appealed to me.

“As a senior I wanted to enter the world of technology - a big learning curve - and after my stroke I wanted to challenge my brain. It was certainly worth doing as [enableme](#) is wonderful. I would advise senior stroke survivors to take on the challenge of technology as there is so much to learn and enjoy.

What I learned after my stroke

Continued from page 4



**Emma Gee, stroke survivor
Victoria**

“I felt extremely lost after my stroke – I couldn’t go backwards to my old life but there was nothing to go forward to. Despite being physically impacted by my stroke, over time the emotional toll became quite evident. It was especially hard for me hearing people say, ‘Oh I saw a glimpse of the old Em’ because I knew she was gone. We all had to accept that as difficult as it was, she wasn’t going to come back.

“It wasn’t until I started to do new things, things that highlighted my strengths and not my weaknesses, that I found the ‘new Em’. I had a new direction.

“For me it was about being open to different opportunities along the way. There’s not one thing I do the same way as before, but I still live by my values, by what matters to me.

“I found being with my friends was very important. Most of my friends had never been around someone who had survived a stroke. I needed to tell them that it was okay for them to open up to me. I found it was my role to make it easier for them – I wanted to help them to grieve too.”



**Claire Hanney stroke survivor
Queensland**

“Imagine waking up and finding you can’t utter one word. A few weeks after the stroke I managed to say ‘hello’. Finding the word I wanted to say was challenging enough, but working out how to pronounce it was even more testing. When I did manage to speak the words, the ones in my head were often different from those I was verbalising. I couldn’t trust what I was saying.

“I made good progress to begin with. Before long I could get by, despite some mistakes, however I became self-conscious and fearful. I retreated, speaking less and less until I felt like a mouse in the corner with nothing to say. As my confidence diminished, my life became smaller until I felt as if I was locked in a world of my own. Nothing was tremendous or amazing, at best it was just ‘good’. I had lost all my confidence and enthusiasm, and no-one knew how I felt.

“I realised I had to move out of my comfort zone. This meant being vulnerable, embarrassed, as well as being afraid and scared of what people might think, say or do. I continued to push the boundaries. I found that increasing my vocabulary improved my imagination, my thinking and how I felt, which changed and expanded my world.

“My speech is mostly automatic, although I still have my moments when I have to pause and search for words or ponder how to pronounce them. Best of all, I have gained the confidence to speak in public.”

2016 April
campaign

Australia's **BIGGEST** Blood Pressure Check

The Stroke Foundation is partnering with Priceline Pharmacy this April to deliver Australia's Biggest Blood Pressure Check. And in 2016 it is certain to be bigger than ever before!

Free blood pressure checks will be available in more than 300 locations across Australia including Priceline Pharmacies and Westfield shopping centres, plus *Know your numbers* sites in Queensland. The aim of Australia's Biggest Blood Pressure Check is to raise awareness of high blood pressure and other risk factors for stroke and cardiovascular disease.

High blood pressure is a key risk factor for stroke but too many people don't even know they have it. We're helping Australians to be more aware of their blood pressure and stroke risk by offering free, quick and non-invasive checks nationwide.

We know Australia's Biggest Blood Pressure Check saves lives – on average 25 percent of participants discover they have high blood pressure and receive a potentially life-saving referral to their doctor.

Find out how you can get involved by visiting www.strokefoundation.com.au



strokefoundation



Many strokes are preventable. Help us conduct free health checks and save lives.

Jim Mead knew he had high blood pressure, but because he felt well he thought everything was okay. When stroke hit Jim at age 62, it was a shock.

The disability caused by stroke was devastating for Jim and his family. He can't walk far, and cannot use his left hand or arm. The worst thing for Jim has been losing his independence, and having to rely on his wife Sherry (pictured with Jim, above) to do so much for him.

Many strokes could be prevented if people were more aware of their risk. Knowing your blood pressure and managing it, if it is high, can reduce your risk of stroke. That's why we are delivering free health checks across the country as part of Australia's Biggest Blood Pressure Check this April. It's the best and most practical way to help prevent stroke.

Stroke Foundation would love to deliver health checks all year round – not just during Australia's Biggest Blood Pressure Check – but we can't do it on our own. You can help by spreading the word about our latest appeal. If you know of someone who would like to help or if you'd like to make a donation yourself call 1300 194 196, or visit www.strokefoundation.com.au



Fight Stroke in Canberra

Earlier this month, the Stroke Foundation led a delegation of 16 amazing stroke survivors, carers and health professionals to Canberra to put stroke on the national health agenda. These courageous men and women shared their personal stories with a range of key Federal Members of Parliament and Senators calling for urgent action on stroke.

We've had feedback from politicians that this visit has had a HUGE impact on their appreciation and understanding of the massive impact of stroke.

The Fight Stroke delegation in Canberra was the first step in a long fight to get the Government to take action. It will take all of us banding together to fight stroke and win. Which is where you come in. Join our movement by signing up as a **Fight Stroke member** today.

National Disability Insurance Scheme

Navigating the NDIS

The National Disability Insurance Scheme (NDIS) is one of the most significant government reforms in recent memory. It's also very new. We've done some research to provide you with a broad overview of the NDIS as it currently

stands. For information direct from the source, be sure to visit the **NDIS website** or to give them a call.

What is the NDIS?

The National Disability Insurance Scheme (NDIS) is the new way of providing support for people with disability, their families and carers. Its purpose is to maximise the social and economic participation of people with disability in the community. Under the NDIS, funding is managed through one uniform national scheme. This means that your needs, rather than where you live, determine what type and level of services and supports you receive.

The aim of the NDIS is to work with people to assess their individual needs, eligibility and provide more choice and control about the support received.

As the transition to NDIS happens, existing services and supports will continue to be available until eligible people start their plans with the NDIS.

To read more about the NDIS including eligibility criteria, where the NDIS is currently available, and what support might be available to you, read the full article on [enableme](#).

2016 Stroke Awards open

Do you know someone going above and beyond to improve the lives of stroke survivors, their families and carers? Or a stroke survivor who is inspiring others in their recovery? Show your appreciation by nominating them for a 2016 Stroke Award.

Nominations for the 2016 Stroke Awards open on Tuesday 29 March. The Awards aim to recognise the amazing work and commitment of stroke survivors, carers and health professionals in our community.

This year there will be five award categories, each highlighting an area where people are working to improve the lives of people affected by stroke:

Stroke Care Champion – recognising stroke health professionals and researchers.



Improving Life After Stroke Award – recognising individuals' contribution to improving the lives of stroke survivors, their families and carers.

Fundraiser of the Year – recognising the efforts of fundraisers for the Stroke Foundation.

Creative Award – celebrating the creative achievements of stroke survivors.

Courage Award (new category) – celebrating the indomitable courage of stroke survivors and their carers in facing stroke recovery.

So if you know someone inspirational who is making a difference in the face of stroke, make sure you keep an eye on www.strokefoundation.com.au for more information about the Awards or [email us](mailto:info@strokefoundation.com.au) to find out more.

Vale Danny Furlong

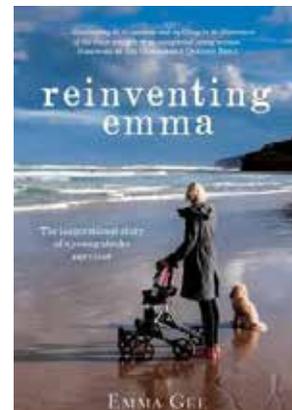
We were saddened to hear from Danny Furlong's daughters Gemma, Bedou and Jezabel that Danny passed away a few weeks ago. An accomplished fantasy, young adult fiction and poetry author, Danny was a finalist in last year's **Creative Stroke Awards** for his deeply personal autobiography *Flatout*.

Danny had a massive stroke as a young man and lived with significant disability for the rest of his life. However nothing has ever been able to stop him from telling a good story. *Flatout* tells of his transformation from an active 'ex-commando and sky diver' to awakening from a coma to discover he had lost everything except his mind. It is an extraordinary book, just as Danny was an extraordinary man.

You can read our review of *Flatout* at www.strokefoundation.com.au

Danny's books are available on **Amazon** or at www.dannyfurlong.com





Who's Afraid – Maria Lewis

Review by Rachel Murphy, Stroke Foundation.

Tommi Grayson is certainly not your average heroine. Blue haired, creative, confident, and gutsy Tommi also happens to be a werewolf.

Who's Afraid, written by debut novelist Maria Lewis, tells the story of Tommi, a young Scottish woman whose world is suddenly turned upside down when she discovers her hidden werewolf heritage. Throughout the book Tommi must learn to deal with her new found 'wolf' powers, fight off some vicious enemies and cope with the fact her life will never be the same again.

Who's Afraid is a compelling tale made all the more compelling by the character of Tommi. Maria has created a strong, female lead who's not afraid to tackle what they world throws at her.

Having met Maria it's pretty hard to avoid drawing comparisons between the character of Tommi and the author herself. With her bright coloured hair – I think it's purple at the moment – and infectious energy Maria, like Tommi has also had to fight her own battles including surviving a mini-stroke. You could perhaps read into Tommi's experience of an excruciatingly painful transformation, dealing with the impact of her changed life as a representation of coping with a traumatic experience like a stroke.

If you enjoy fantasy fiction this is a book for you. If you're not a fantasy fan but like your heroines strong and feisty give this one a go.

Maria Lewis, author and journalist at SBS The Feed, is a staunch supporter of the Stroke Foundation and the stroke community.

Maria and publisher Hachette have generously donated copies of *Who's Afraid* to give away to StrokeConnections readers. Email your name and address to strokeconnections@strokefoundation.com.au for your chance to win.

Reinventing Emma: The inspirational story of a young stroke survivor, by Emma Gee

At just 24, Emma Gee had her whole future ahead of her. She was an occupational therapist, an avid runner and had just climbed Borneo's Mt Kinabalu with a group of friends. But months later she was suddenly a stroke victim, unable to move, speak or swallow and dependent on the medical system she had worked within.

Emma's debut novel, *Reinventing Emma*, launched earlier in the month, tells of her harrowing experience of surviving a debilitating stroke. As a former health professional Emma has a rare insight into life as a patient, and emerges with a very different perspective on person-centred care and what it takes to live with resilience. Emma's story shows how, with love, support and a positive mindset, a life can still be incredible, even though not to the plan previously envisaged, and entailing a daily battle with poor vision, balance and mobility.

Emma is now a loving auntie to a brood of nieces and nephews and has an amazing support network. Working as an inspirational speaker she is determined to benefit others by drawing on her own experience and deeper insights. She has a sharp eye for detail and a sense of humour that, understandably, becomes quite black at times. This is not only the story of a young stroke survivor, but also a valuable observational memoir for health professionals, written by one of their own who has travelled to 'the other side'.

Thanks to Emma Gee and publisher Dennis Jones and Associates we have a copy of Emma's book to give away. Email your name and address to strokeconnections@strokefoundation.com.au for your chance to win.

Get involved



Join our team

The Stroke Foundation is currently seeking volunteers for a number of roles across the organisation. Would you like to play an important role in helping us stop stroke, save lives and end suffering? It could be as the face of our organisation in our national office reception area, helping at events, calling our donors to thank them for their support or helping with administrative tasks. We strongly encourage stroke survivors and their family and friends to join us. Roles are available in various locations across the country.

Visit www.strokefoundation.com.au, **email us** or call Suzanne or Megan in the volunteer team on 03 9670 1000 to find out more about these exciting opportunities!

Share your hobbies with the world

Have you taken up a hobby after stroke that has helped with your recovery? The World Stroke Organization wants to know all about it and is planning an exhibition to be displayed at the next World Stroke Congress in Hyderabad, India in October, 2016.

You might have started to paint, have written or are writing a book, or have taken up dancing, yoga or singing. Whatever it is the World Stroke Organization is keen to share it with the global stroke community to inspire others in their recovery.

To submit your story and to find out more visit the [World Stroke Organization website](#).

Research participation opportunities

Optimal Health Program

The Optimal Health Program is a nine week support program for stroke survivors and their carers. It's designed to enhance independence, includes personalised sessions with a health professional and is available nationwide. This program is a part of a collaborative evidence-based research program run by St Vincent's Hospital, the Australian Catholic University and the University of Melbourne.

For more information on how you can get involved **email the Optimal Health Program team** or give them a call on 03 9231 3779.

COMPARE aphasia study

COMPARE is a national research study which compares the outcomes of different treatments for people with aphasia. This study will determine if two contrasting treatments will result in better outcomes for people with aphasia, compared with the usual speech pathology treatments. The trial will be running in various locations in Victoria, Western Australia, New South Wales, Queensland and Tasmania.

For further details visit [this information page](#).

Podcasting

enableme podcast series

Stroke survivors and carers will have a new source of information each month with the launch of a podcast series on *enableme*. The podcasts feature survivors, health professionals and other experts being interviewed on topics central to living well after stroke.

As you know, *enableme* launched last year and brings together information, tools and community in one, accessible place. *enableme* started with a very simple idea: recovery is a lifelong journey and survivors need to be able to direct their own rehabilitation for as long as they can get better. Podcasts are an effective, portable, convenient and intimate way to deliver information to help in this journey.

The podcast series began with an episode on neuroplasticity, featuring physiotherapy lecturer Michelle McDonnell, neuroscientist



Dr Lavinia Codd, stroke survivor Karen Bayly and occupational therapist Simone Russell about their experience in retraining the brain.

Future topics will include secondary prevention, fatigue, communication, spasticity, exercise, pain, childhood stroke and navigating the health system. We're also planning a podcast on finding reliable health information, called 'show me the evidence'. Transcripts are available for each podcast. If you're interested in sharing your story, or know someone who might be perfect for one of the topics above, please [email us](#).

The *enableme* podcast series is proudly sponsored by Allergan.



strokefoundation

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www.strokefoundation.com.au

www.enableme.org.au – our online tool to aid stroke recovery.

www.informme.org.au – our online tool to assist health professionals.

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