



# Stroke Connections

Spring edition 2016



## Meet our 2016 Stroke Awards winners

A poet, a paramedic and a paediatrician were just some of the finalists recognised in our annual **2016 Stroke Awards**, hailing Australia's unsung heroes of stroke.

These awards celebrate the amazing work and commitment of stroke survivors, carers, volunteers and health professionals in our community and the difference they make towards improving the lives of people affected by stroke.

In a record year, more than 120 people were nominated for our 2016 awards across five diverse categories: Improving Life After Stroke, Creative, Courage, Fundraiser of the Year and Stroke Care Champion.

Our judging panels for each category faced the challenging task of sifting through the nominations and selecting our winners.

For the first time we recognised the indomitable courage and hope shown by survivors and carers in facing stroke recovery, through our Courage award. This new category was open to survivors and carers, celebrating individual recovery and resilience.

As the inaugural winner of our **Courage award**, Brisbane's Sarah-Jane Gapp suffered a rare, catastrophic brain stem stroke that left her trapped in her own body. Although she lost her physical independence, this determined young woman recovered partial movement and has since returned home.

"I may not represent the majority of stroke sufferers, as spontaneous brain stem stroke is uncommon, but I represent the extreme impact stroke can have. Stroke knows no boundaries and I want to create awareness that stroke can happen to anyone, of any age, at any time," Sarah-Jane said.

Our **Creative award** recognises stroke survivors who actively engage in creative pursuits. Melbourne author and inspirational speaker, Emma Gee was awarded for her memoir *Reinventing Emma* detailing her own stroke journey.

"The process of writing *Reinventing Emma* was both extremely gruelling and therapeutic. But in relaying both the good and difficult experiences I've had, I do hope it helps other people. In being recognised, I feel I am supported in my endeavour to make a difference," Emma said.

Our **Fundraiser of the Year award** recognises our tireless supporters who go above and beyond to raise money to help promote stroke awareness.

West Australian sisters, Rebecca Clarke and Katie Sippe took out top honours after raising an incredible \$12,000 for the Stroke Foundation with support from their local Mukinbudin community.

*Our Stroke Awards story continues on page 2*

*Pictured above are our Stroke Awards winners and finalists from Queensland at their Awards ceremony in early September.*

## Stroke Awards 2016

*continued*

Their beloved mother, Annie suffered several strokes before she was moved into aged care and it's been a tough road for the family. The sisters decided to raise funds to fight stroke by participating in Perth's HBF Run for a Reason in May this year.

"We set out to raise as much money as we could for the Stroke Foundation in order to fund more research and awareness, but also to make those people around us and in our community more aware of stroke and the devastating effect it can have on families," Rebecca said.

"Living in a small country community we received overwhelming help and support which certainly helped lift our family's spirit," Katie said.

Our [Improving Life After Stroke award](#) celebrates stroke survivors, carers and volunteers who dedicate their time to improving the lives of stroke survivors.

Noosa local Christopher Kay was only 43 when he suffered a stroke. As he struggled to get his life back, Chris realised there were no support groups for young stroke survivors like himself in his region. So he took matters into his own hands and established the [Young Queensland Stroke Support Group](#). Chris' tireless efforts have seen him named the Improving Life After Stroke winner for 2016.

"My stroke left an invisible mark, a brain injury, and I felt very alone even though family and friends were around me," Chris said.

"I just needed to talk to other survivors, hence I started the Young Queensland Stroke Support Group. There is a comfort in talking to others."

In conjunction with the Stroke Society of Australasia, our [Stroke Care Champion](#) winner was announced at Brisbane's Asia Pacific Stroke Conference in July.

## Winners 2016



Sarah-Jane Gapp



Chris Kay



Dr Mark Mackay



Rebecca Clarke & Katie Sippe



Emma Gee

Paediatric neurologist based at Melbourne's Royal Children's Hospital, Dr Mark Mackay has worked tirelessly to increase the awareness of childhood stroke and improve the quality of care child stroke patients receive.

Dr Mackay said he was "honoured to receive this award as it acknowledges the importance of my work to improve outcomes for children and families affected by stroke.

"It is vital we ensure children receive the same benefits of advances in stroke care that have transformed outcomes for adults, and to ensure families receive appropriate information about causes of stroke and potential consequences of stroke for their child."

You can read more about our incredible winners and finalists by [visiting our website](#).

Nominations will open for our 2017 Stroke Awards next year. So now is the time to start thinking about who in your community you would like to nominate.



Rachel, Katherine, Jude and Chris

## Welcome to the spring edition of StrokeConnections

Welcome to our spring edition of StrokeConnections. It has been an incredibly busy time for the Stroke Foundation with Stroke Week now underway. We encourage you to participate and help spread the message about recognising the signs of stroke and the importance of acting FAST.

Our feature article highlights the incredible efforts of our 2016 Stroke Award winners towards improving the state of stroke in Australia. This year we had a record 120 nominations from around the country for our five categories: Courage, Creative, Improving Life After Stroke, Fundraiser of the Year and Stroke Care Champion. A big thank you to everyone who nominated an unsung hero of stroke in their community.

We also explore the link between post-traumatic stress and post-traumatic growth. Studies have found that people who had distressing reactions to the trauma of their illness also experienced more positive growth and change.

In this edition we get under the covers with a blog from *enableme* discussing sex after stroke. We also highlight the story of Julie Collins who became a full-time carer after her husband Ross' stroke and what they've learnt as a couple.

We review stroke survivor and award-winning writer, Susan Varga's first book of poetry, *Rupture*. We also have a book giveaway for a lucky reader so read on for details.

And finally get ready to put on your walking boots and start fundraising for Stride4stroke in November. Only with your help can we stop stroke, save lives and end suffering.

We hope you enjoy reading this edition and if you have any feedback or suggestions for topics you'd like to see in StrokeConnections drop us a line at [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au)

Best wishes,

**The StrokeConnections team**

[strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au)

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**NATIONAL  
STROKE  
WEEK** | **12-18  
SEPT  
2016**  
#fightstroke



**SPEED SAVES**

**THINK**



## National Stroke Week is the Stroke Foundation's annual awareness campaign taking place this week.

This Stroke Week we want all Australians to know the signs of stroke and act FAST to get to treatment. Time has a huge impact on stroke and we need your help to spread this message. A speedy reaction not only influences the treatment available to a person having a stroke but also their recovery. Most treatments for stroke are time sensitive so it is important we **think F.A.S.T. and act FAST.**

Taking part in Stroke Week is a great chance to engage in a fun and educational way with your workplace, friends, sporting or community group. Last year, over 2,300 people registered to participate in Stroke Week and it attracted significant media coverage reaching more

than 12 million people. This year is set to be bigger and better and the Stroke Foundation is encouraging all Australians to get involved.

### Five reasons speed matters with stroke

1. A stroke is a medical emergency. Act FAST.
2. Stroke attacks the brain at an alarming rate. ONE minute = 1.9 million brain cells lost.
3. Call an ambulance. Don't risk driving yourself.
4. Most treatments for stroke are time sensitive and can improve a person's chance of survival and recovery.
5. The F.A.S.T. test is the easiest way to recognise the signs of stroke.

As part of National Stroke Week 2016 the Stroke Foundation is encouraging all Australians to:

- Organise an awareness activity
- Fundraise for the Stroke Foundation
- Host a health check

Registrants are supported with a free Stroke Week kit including posters, campaign booklet and resources as well as social media kits and PR support.

If you would like to get involved in National Stroke Week 2016 visit

[www.strokefoundation.com.au](http://www.strokefoundation.com.au)

Know the **signs of stroke**

**FACE** – drooped?

**ARMS** – Can't be raised?

**SPEECH** – slurred?

**TIME** – Call **000** NOW!

*Show you care – please share*

**NATIONAL  
STROKE  
WEEK** | **12-18  
SEPT  
2016**

**SPEED  
SAVES**





## Help us share the FAST message

### Debbie to the rescue

Every stroke is different, of course, and in the suburb of Ashfield in Sydney's south-west, Garry is an example of someone who benefited from **F.A.S.T.**

It was early in the morning and Garry (*pictured top right*) had cycled to his local train station. Hopping off his bike Garry tried to lock it in the usual way but for some reason he could not work the lock.

Then Garry walked across the road and suddenly his right leg gave way. After falling on the road, thankfully he dragged himself to a bench on the footpath and phoned home.

Garry's wife, Debbie, appeared in the car in about 10 minutes and immediately thought 'stroke'. Having recently completed first aid training Debbie remembered the F.A.S.T. message and called 000 immediately.

Because Debbie acted quickly, Garry was in Sydney's Royal Prince Alfred Hospital within 45 minutes of his stroke.

The medical team sprang into action and Garry was taken for an urgent CT scan. Soon the team confirmed he had suffered a stroke and acted quickly to administer the clot-busting drug. Garry and Debbie did not know it at that point, but he was already on the start of his journey towards recovery.

All because Debbie knew the signs of stroke. She knew F.A.S.T.

Garry worked very hard to regain his life and is now back at work leading an active life. Since his stroke, Garry has even been able to get back to competing in triathlons.

Australia urgently needs F.A.S.T.

We want to get every Australian up to speed like Debbie.

You can help us to spread the F.A.S.T. message even further by encouraging your family, friends and local communities to make a donation now to stop stroke and save lives. For more information please call Stroke Foundation Supporter Relations on 1300 194 196 or visit [www.strokefoundation.com.au/donate](http://www.strokefoundation.com.au/donate)

## Get moving Australia and Stride4stroke

The countdown is on! This November we're calling on all Australians to get moving for Stride4stroke.

This month-long annual fundraiser is all about getting active, having fun and raising funds and awareness to #fightstroke. We're asking the community to set a kilometre and fundraising target in an Australia-wide effort to stop stroke, save lives and end suffering. Anyone can take part no matter what your fitness level. You can ride your bike, swim a few laps of the pool or run a marathon. Every step you stride and every dollar you raise will make a difference. Last year we had more than 1,100 phenomenal Australians hit their stride for stroke, including many stroke survivors and carers.

*Stride4stroke continues next page...*

## Fundraising news

continued

*Stride4stroke continued...*

We encourage everyone to register now to help #fightstroke via [www.stride4stroke.org.au](http://www.stride4stroke.org.au)

**Need inspiration? Check out some of our super stroke survivors who took part last year.**

### Holli Bryceland

Seven-year-old stroke survivor Holli Bryceland together with her mum Kristi strode over 100 kilometres and raised more than \$3,000 for the Stroke Foundation.



### Louisa Reid

It had been just over a year since Louisa's stroke when she decided to walk 80 kilometres as part of Stride4stroke. Louisa well and truly met her kilometre target and raised more than \$130 for the Stroke Foundation – a fantastic effort!



### Scott Thornton

When Scott had his stroke he was fortunate to get to hospital quickly and he made a great recovery. Scott decided to run 150 kilometres as part of Stride4stroke in honour of the stroke survivors who aren't as fortunate as he was. Not only did Scott reach his goal but he also raised more than \$3,600 for the Stroke Foundation.



## Where there's a Will, there's a way

The Stroke Foundation is joining more than 100 of Australia's most-loved charities for one week in September to ask one single question – *“Would you ever think about including your favourite charities in your Will?”*

From 5-11 September, *Include a Charity Week* aims to raise awareness of just how important charitable gifts in Wills are to the work of Australia's favourite charities.

Ross Anderson, Stroke Foundation's Gifts in Wills Manager, said the week highlights the fact that bequest gifts in Wills are absolutely vital in helping continue the great work that just like the Stroke Foundation are doing.

“Many of Australia's most-loved charities rely on gifts in Wills to help them carry out their essential work in the community,” Ross said.

A common myth is people think they have to be wealthy to leave gifts in Wills, but Ross says this isn't true.

“Absolutely anyone can include a gift to a charity in their Will. Many of the gifts we receive from Stroke Foundation supporters are modest. Each and every gift we receive means we can continue to support stroke survivors long into the future and stop the suffering that stroke causes.”

You can find out more about *Include a Charity Week*, including stories of Stroke Foundation supporters at

[www.strokefoundation.com.au/giftsinwills](http://www.strokefoundation.com.au/giftsinwills)

include *a charity*  
Help the work live on.



## Let's talk about sex

While everyone's experience of sex is personal, there are some issues that are common after stroke. It is important to know stroke survivors can enjoy sex after stroke. You might need to work on getting back to enjoying intimacy, masturbation and partnered sex as part of your recovery - and you can!

### How stroke can affect your sex life

Everyone's different, but a life-changing and often traumatic experience such as stroke can have a big impact on you. After a stroke, getting back to sex might be a big priority for you, or it may be way down on the 'to do' list. Stroke can also change how your body feels and works and how you feel about yourself. Some things you may face include:

**Emotion and mood changes:** It's common to feel angry, irritable, low or depressed and you may lose interest in sex as a result. It may also change how you feel about yourself and your sexuality. Simply put, you just may not feel very sexy after stroke.

**Physical challenges:** Sexual activities can be impacted by physical changes caused by the stroke. Muscle weakness, stiffness, spasticity, pain, altered sensation, mobility, fatigue and incontinence can have a big impact.

**Relationship issues:** Relationship changes can also have a big impact. Interest in sex and your feelings about it can be very different for you and your partner. As in all relationships, interest in and openness to sex can shift and change.

**Medications:** Some medications such as anti-depressants, anti-hypertensives and sleeping

tablets can cause sexual dysfunction. Your doctor may be able to make adjustments if this is the cause of the problem but make sure you do not stop taking any medication without medical advice.

### Things that may help:

**Begin slowly:** Start your 'sex rehab' when you are ready. You may wish to begin with connecting again through touching, cuddling, massage or other ways of being intimate.

**Rest up and plan ahead for sex:** Plan for a time you are well rested and have uninterrupted time.

**Know the medications you are taking:** Be aware that some medications can cause problems. Speak to your doctor for advice about your medications.

**Talk about it:** Just having a conversation can help, although this takes some courage if you are new to this. Talk about any changes, the things you're finding difficult and the things you are enjoying and how you are feeling.

**Adapt to any changes:** You may need to find new positions and ways of doing things to bring you or your partner pleasure.

**Talk to a health professional:** Talk to your doctor or health professional about your concerns. Like all of us, health professionals have varying levels of comfort in talking about sex. Pick someone you feel comfortable with, and remember that while they may not have thought to ask you about sex, they may be perfectly happy to discuss it once you bring it up. If they aren't helpful, try someone else.

If you want to start with a completely private telephone conversation, call StrokeLine on **1800 STROKE** (1800 787 653).

You can read [the full article](#), including advice and the most common questions we receive about sex on [enableme](#).



## The upside: post stroke growth

Back in our Summer 2014 edition, we wrote about the trauma of stroke. The word trauma is defined as a serious injury or shock to the body, as well as an event that causes distress and disruption. The experience of trauma often involves a sudden, unexpected crisis, especially where we believe the person at the centre of the crisis may die.

Sounds like a stroke, doesn't it? And like any trauma, it will take a toll. The concept of post-traumatic stress was first recognised in survivors of wars and natural disasters, but in recent years we have come to understand the traumatic potential of a life-threatening or life-changing illness. What's interesting is that our responses are often similar even if our experiences differ. Just as studies focusing on disasters have seen similar responses to those that looked at life-threatening illness, studies across different diseases and illness events have found similar things.

The flipside is that humankind has always understood that traumatic events can potentially yield positive personal change. The positive psychology movement has fueled our interest, as the idea that we should pay more attention to the factors that see us thrive as human beings has gained traction. So having written about the downside, we thought it only right to pay some attention to the potential upside.

The idea of post-traumatic growth will make sense to many stroke survivors. In looking at

the illness experience, studies have consistently found a few main themes. We feel like we are better people, our relationships are better, and we develop new meanings and beliefs. Our perspective shifts, with one survivor of life-threatening illness noting, "once you worry about whether you are going to die, nothing else seems quite as significant to worry about".

A review of research studies conducted in 2009 found that people who had survived or were living with long-term illness reported closer, more open, and better relationships with the people around them. People reported making major changes to how and with whom they decided to spend their days, they were less concerned with possessions and appearance, and looked after themselves and their loved ones with more care. Finally, post-traumatic growth also allows us to develop compassion for those experiencing difficulties, and gives us more confidence in our ability to help others.

While post-traumatic stress and post-traumatic growth seem like very different experiences, they are closely linked. Surprisingly, studies have found a positive relationship between the two, implying that people who had distressing reactions to the trauma of their illness also experienced more positive growth and change.

While there are some common themes, our responses to all life events are unique to us. Both post-traumatic stress and post-traumatic growth are by no means universal experiences.

*The upside... continues next page*



## The upside: post stroke growth

*Continued from previous page*

There are some demographics – like being younger, and female – that are connected with the likelihood of experiencing post-traumatic growth, but the connection is pretty weak. What matters more are our personal characteristics. Our belief in our own agency is particularly significant – consider Stroke Award winning author and stroke survivor Emma Gee’s insistence that ‘it’s not what happens to you, it’s how you choose to deal with it that matters’. The esteem we hold ourselves in, and our general level of optimism, makes a difference.

As do the people around us. It’s not the number of people who surround us, but rather the quality of the support that we receive from them that matters. That talk you had with a family member or friend, that you will always remember because

it marked a moment of profound personal change – yep, that’s it. Having people who are able to have open and sometimes difficult conversations, who allow us to say the things we need to test new ways of thinking and feeling... this generates change.

All this points to how tough illness can be: tough to experience and tough to work through the impact. The potential benefit is that our humanity grows, and we have the positive experience of knowing we are profoundly better and hopefully even happier. The effect of this grows as the changes become fundamental to the person you are as you move through the remainder of your life. This gives us the potential to ‘jump the tracks’ entirely, becoming better and happier than we might otherwise ever have been.

Stroke survivor and author David Roland explores these issues in his excellent blog [www.davidroland.com.au](http://www.davidroland.com.au)

## What’s happening on *enableme*?

Julie Collins became a full-time carer after her husband Ross’ stroke. Ross was left wheelchair-bound and had difficulties with communicating and eating. Since then, Julie has learnt a lot about the things that make a difference to life as a couple after stroke. From the planning and negotiation required to get Ross home, through to maintaining friendships and a social life, Julie shares her story on *enableme*. An honest, in-depth look at life as a carer and a profound exploration of love and connection, Julie and Ross’ story is not to be missed.

Watch their story on [enableme](http://enableme.com.au).



## Speak your mind: Free advocacy course for stroke survivors

Deakin University and VALID invite people with acquired brain injury (ABI) to undertake ‘Speaking Your Mind’ – A rights and self-advocacy program for people with acquired brain injury.

Learn about your rights and responsibilities, and how to speak up for yourself.

For more information, or to register your interest in this training, please contact:

Jenny Crosbie  
Phone: 03 9251 7887  
Email: [jcrosbie@deakin.edu.au](mailto:jcrosbie@deakin.edu.au)



## Book corner



### Rupture

Having always considered herself a prose writer, poetry took over completely for award-winning author, Susan Varga after she suffered a stroke.

Her bright new book of poetry *Rupture* is very personal in a kind, luminous way. The poems, organised into life-stages; from rupture to wellness and a new place, ultimately reflect a positive life process, ending in 'Contentment'.

The 'Masterstroke' poems reflect the initial shock of stroke and its aftermath that many stroke survivors will find familiar. 'In Spaceship ICU' and 'Different Strokes' the sense of disconnect from one's self is palpable, yet safety exists in care.

A sadness pervades the 'Ward Quartet' poems that all of us who have spent time on the ward will feel... "the terrifying future ticks."

'The New House Poems' perfectly capture the adjustment of returning home and learning again

the spaces that are so known to us, yet seem unfamiliar now.

A sense of uncertainty tinged with fight pervades the 'Night' poems; whether it is finding a truce with pain or calming the chattering mind on the road to recovery.

We know what Susan gets up to in the 'Alone in the City' poems as she returns to her second home 'Sydney', asking it to "make me feel alive again." Where 'Brunswick Heads' is a welcome holiday, 'Refuge' takes the personal, political process to the street proclaiming "You are NOT Powerless."

From reading this collection, you get a poignant feeling that stroke strikes hard for a person like Susan, one with a passion and talent for words. But new opportunities emerge as we see a life reclaimed through poetry.

This is a lovely little volume that will touch your thoughts gently, but firmly.

We have a copy of *Rupture* to give away to StrokeConnections readers.

Email your name and address to [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au) for your chance to win.

*Reviewed by Debora McInnes, PR and Media, Stroke Foundation.*

### Book giveaway

#### *Bleed* by Bill Williams

Thanks to Wild Man Press and Bill Williams we have a copy of *Bleed* to give away. This is a compelling story about Bill's wife Gisela Williams who suffered a devastating stroke while camping in the desert 150 kilometres away from Alice Springs. As a general practitioner, Bill instantly

knew something was wrong. Knowing he needed to act FAST, Bill bundled Gisela into their van and drove to Alice Springs for help.

Email your name and address to [strokeconnections@strokefoundation.com.au](mailto:strokeconnections@strokefoundation.com.au) for your chance to win.



Focus  
on...

## Talking young stroke

On 15 August the Stroke Foundation teamed up with Brain Injury Australia to launch Brain Injury Awareness Week. The theme this year was Young Stroke, overturning the misconception that stroke only happens to older people.

To celebrate the launch, the Stroke Foundation co-hosted an event in Melbourne, featuring unstoppable young stroke survivors Terry Kennedy, Emma Gee and Emma Gaffy. The event also featured presentations from leading



stroke expert Associate Professor Bruce Campbell and CEO of National Disability Services, Dr Ken Baker AM.

The launch highlighted the particular challenges working age survivors face such as a lack of age-appropriate services, limited allied health sessions, and little focus on emotional and social recovery. Thank you to everyone who came along to support the event. If you missed it we livestreamed the event on our [Facebook page](#) so be sure to check it out.



strokefoundation

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

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

**[www.informme.org.au](http://www.informme.org.au)** – our online tool to assist health professionals.

## Sign up to receive StrokeConnections by email

To ensure you don't miss out on our digital-only editions 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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