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Stroke Connections

Spring edition 2015



strokefoundation



A stroke of creativity

Blues musician and former psychologist Damian Coen credits music as the driving force behind his incredible recovery from stroke.

On an ordinary Monday morning in 2012, Damian woke up to the frightening discovery he couldn't speak – even more terrifying he didn't know who he was and couldn't recognise his family.

"I woke up at 8.30am and my wife came in to wake me up but I wasn't able to speak and I just got up and sat on the back steps and stared," Damian explained.

Realising something was seriously wrong, Damian's wife rushed him to Moruya hospital where he was bundled into an ambulance and taken to the neurology department at Canberra hospital.

Scans at the hospital revealed the cause of Damian's strange behaviour. A massive stroke had wiped out the language centre of his brain. Damian was admitted to the stroke unit unable to speak and the right side of his body didn't seem to work as it should have.

"I was told I had a stroke but I couldn't process it," Damian said.

With no speech and impaired movement, Damian's situation seemed practically hopeless to the couple and their three daughters. Until ten days after his stroke when the unexpected happened.

"My wife handed me a harmonica and I couldn't believe it but I could play," Damian said. "I have played the harmonica since my teenage years and it was part of my soul. I was scared I wouldn't know how to play, but I put it in my mouth and discovered the right side of my brain was not messed up - I could play twelve bar blues.

"I realised I could do it, which was really good as it planted in my brain that I'm not so messed up after all."

From that moment Damian understood his passion for music was the key to unlocking his brain.

Six months following Damian's stroke, he could only pronounce sounds. The neurologist told him there was a chance his speech wouldn't improve any further, however Damian refused to give up.

"In terms of recovering it took me six months to get my thoughts together – it was proof to me that my brain could get in touch with things," Damian said. "One speech pathologist prioritised my music in therapy. Because she could understand that I could pronounce the words I had trouble with by singing.

"I only had her alongside me for around four months so I took it upon myself to continue with it. So I practiced, practiced, practiced [music] every day for one hour. Music was an introduction to me speaking.

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Rich, Di, Jude, Rachel and Jess

Welcome to the spring issue of StrokeConnections

We cannot believe this is the final edition of StrokeConnections for 2015 – the year has well and truly flown! As we approach the end of the year, we thought it was a great time to celebrate the creativity of the stroke community. We hear from so many of you the positive impact music and the arts has had on your recoveries. In our feature article we hear from stroke survivors Damian Coen, Ross Waldron and Antonio Iannella on how they used creativity to aid their recovery from stroke.

Also featured in this edition is Angus Campbell, who shares what he's learnt after a stroke that hit him with 'a big bamboo stick'.

We are pleased, as always this time of year, to introduce the winners of the 2015 Stroke

Awards. In addition, we review a great new book that has hit the stores, *Bleed* by Bill Williams. We're giving away a free copy of *Bleed*, along with David Roland's new audiobook to lucky readers so make sure to enter our competitions to be in the running!

Thanks for reading, and have a great festive season and an even better 2016!

Best wishes,

The StrokeConnections and enableme teams

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Survivor story

Angus and the ‘bamboo stick’

Angus Campbell was 81-years-old when he had a stroke that hit him “like a bamboo stick”.

During his working life, Angus marketed technical products and was responsible for planning major projects. Upon retirement he wrote two educational books, and he also delivered the local newspaper, walking up to five miles a day.

After his stroke, with his left arm and leg fully paralysed, his fingers tangled, his face drooping and dribbling, Angus realised the only thing working was his thoughts. Angus had survived and his recovery had begun. “After my stroke, my mind was trapped in a broken body, and I realised that I needed determination to cope,” Angus said.

Rather than calling himself a stroke survivor, Angus refers to himself as a “stroke recoverer”. A slightly clunky turn of phrase, but as Angus says, recovery itself can also be clunky.

Angus never had an easy run. As he would say, the strength of a stroke from low to high is relative to being bashed on the head with a feather duster, a wet rolled-up newspaper, a dry rolled-up newspaper, a half full cereal box, a bamboo stick, a broom handle or a cricket bat. Angus reckons he got the bamboo stick. Adding insult to injury, Angus’s rehabilitation was disrupted when he fell and broke his leg.

Extensive physiotherapy at the gym and at home, in conjunction with Botulinum Toxin injections, saw Angus make significant progress and gave him back some independence.

No stroke is the same as another, so all stroke recoverers have their own journey to recovery. Angus’s experience led him to believe that there are six elements to recovery: hope, determination,



opportunities, goals, work and time. Angus suggests following the plan below:

Hope is the one thing you need after stroke.

Determination is needed to keep this plan moving to recovery.

Opportunities open the way to goals. Determine to use the smallest opportunity.

Short and long term **goals** are central to recovery. Determine to concentrate on goals that can be easily met first.

Work should be professionally structured with multiple repetitions. Determine to build up limb strength which will be needed to bring goals to fruition.

Structured and efficient use of **time** is essential. Determine to control timetable, set priorities.

For Angus treating his recovery from stroke as an occupation helped him immensely. He believes determination works for us in two ways – it makes us measure all of our actions against the goal of recovery and it makes us seek expert therapy that will help us improve our recovery.

Three years on and Angus is still working on his recovery.

“It’s generally accepted that the largest increases in recovery take place within the first six months, tapering off to negligible after four years. I think it’s nonsense to suggest that variable strokes follow a fixed recovery course. Anyway, I don’t mind, I just keep working. Time can take care of itself.”



Music saved my life

In addition to its positive impact on speech and communication, music has been shown to have positive effects on the mental health of stroke survivors.

Antonio Iannella from Melton in Victoria was devastated when he discovered he could barely move his left hand after his stroke. Antonio could not imagine a life without playing his beloved guitar.

“Music has been a lifelong passion. I was devastated at the prospect of not playing guitar again after my stroke.”

Determined to make music again, Antonio taught himself to play piano one-handed and went on to form musical group The Lion Tamers, the group recorded its debut album last year.

“Writing [music] has been my voice – I have been able to draw on the emotions that my stroke experience caused. I totally believe I would have been completely lost after my stroke if it wasn’t for music. Music saved my life,” Antonio explained.

“Creativity triggers different brain networks associated with euphoric emotions, such as love, joy and happiness. Having to concentrate and think logically can be very fatiguing for people with brain injuries, creativity can be a therapeutic option helping to manage brain fatigue.”

Antonio is now working on a new musical project called The Braves. You can listen to Antonio’s music at [youtube.com/user/MrAntonioIannella/](https://www.youtube.com/user/MrAntonioIannella/)



Creative outlet delivers a new career

Although music can be hugely beneficial to stroke recovery, sometimes the impact of stroke makes playing music impossible.

Sydney musician Ross Waldron’s stroke took away his ability to play guitar. Ross’ stroke left him paralysed on the right side of his body with virtually no sense of feeling. Additionally his sense of rhythm and the way he perceived the world was dramatically affected making playing music practically impossible.

“I tried my best to recover as quickly as I could. I took up meditation, cycling and reading absolutely everything I could about neurology but learning to play guitar again proved to be a difficult task both then and now,” Ross explained.

“Because I couldn’t play or hear music the same way anymore, I still needed a creative outlet.”

Ross started taking photos with his girlfriend’s camera, a distraction from his tough recovery. Ross discovered he had a natural talent behind the lens and started taking photos at every opportunity. It wasn’t long before professional jobs came up and Ross found himself with an unexpected new career.

“Photography gave me an outlet to focus my recovery on and has now also given me a career,” Ross said.

In addition to photography Ross has also taken on video production, audio engineering and web design following his stroke. You can check out Ross’ work at www.rosswaldron.com

A stroke of creativity

Continued from page 1

“I had a lot of songs I had written before my stroke but hadn’t recorded yet. I had my singing to get back to. I taught myself to play guitar after my stroke – my left hand was okay but I had to learn, learn, learn to do my right hand but I did it.

“My wife helped me to set up a concert in my own home for 25 people one year after my stroke. I was playing on the guitar and singing on the microphone and playing my own song. It wasn’t perfect, but 80 percent of the words were correct.”

According to Hunter Medical Research Institute neurologist Professor Michael Nilsson, music and the creative arts can have a powerful impact on stroke recovery.

“Through the process of creating art, stroke survivors develop respect for self and others and increased confidence, empowerment and personal connections. Music performance is also inherently social – music can be played together, creating an emotionally uplifting experience,” Professor Nilsson explained.

Certainly in Damian’s case, by accessing his love of music he was able to not only forge new pathways to speaking but to regaining his confidence.

“It’s three and a half years since my stroke and it’s getting easier to speak now because my neuroplasticity has worked on my brain,” Damian explained.

“In speaking to me now you can tell I’m disabled but two years ago I was more disabled. I couldn’t put words into a narrative. I had aphasia because I could say ‘bread’ and I could say ‘chicken’ but I couldn’t put bread and chicken into a sentence.

“Now I’ve given talks to 600 people in the last two months on my stroke, neuroplasticity and resilience. Speaking is my new career! I’ve also been re-registered to practice as a clinical psychologist, but only for 12 hours a week as I still get tired each day”

Damian continues to rehabilitate his brain through music and performs in a duo in his local area and at music festivals. He has also has joined

a local choir where he is one of three ‘blokes’. The choir’s repertoire is mainly African songs which poses another challenge for the talented musician who was told he might never speak again.

“African songs are hard for me to get – pronouncing English language is hard for me let alone African songs but I manage though not perfectly. It’s a good challenge for the brain,” he said. “We performed for 230 people. I played the harmonica in two songs – I’m good at playing the harmonica – I sung as well and it’s good.”

To find out more about Damian’s recovery and to listen to his music, visit his website www.damiancoen.com

Share our Christmas appeal and save lives

When five-year-old Isaac had a stroke at school, no one knew what was happening.

“Isaac kept putting his fingers in his ears and screaming in pain. I knew something was terribly wrong,” his mum Emily said.

Neither paramedics at the school nor staff at two different hospitals could tell Isaac’s parents what was wrong. Finally at the children’s hospital, Isaac received the correct diagnosis and treatment.

Isaac and Emily’s experience shows how critical it is to improve stroke care. We’re building InformMe a service to empower health professionals to deliver the best possible stroke treatment and care.

This Christmas we’re featuring Isaac’s story in our appeal to help build InformMe. You can help by making a secure online donation at www.strokefoundation.com.au/donate by calling 1300 194 196 or sharing our appeal with your friends.

Meet the 2015 Stroke Champions

Thank you to everyone who nominated someone in this year's Stroke Awards. We received more than 60 nominations from around the country and the calibre of applicants was outstanding. We are proud to share with you the four incredible winners:

Michael Scott, VIC *Fundraiser of the Year*

Michael said it was the thought of his two-year-old daughter Olive's courageous fight against stroke that kept him going through the gruelling 1,600 kilometre bike ride from his hometown of Sale in Victoria to Byron Bay in New South Wales.

In taking on the challenging ride, Michael raised more than \$11,000 for the National Stroke Foundation as a way of saying thanks for the support it provided to his family after Olive's stroke.



Wendy Lyons, VIC *Improving Life After Stroke*

Doncaster East stroke survivor Wendy Lyons was at a local stroke support group meeting when she discovered something unusual. During a singalong she noticed support group members who could not speak due to having aphasia could sing beautifully.

Inspired, Wendy set up a choir to give a voice to aphasic stroke survivors. The **Strokeachord Choir**, formed in 2010, has gone from strength to strength with performances at large public events and on national television and radio.



Dr Rohan Grimley, QLD *Stroke Care Champion*

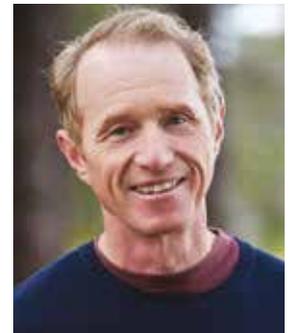
Dr Rohan Grimley, (pictured at left) the head of the Queensland Clinical Stroke Network and passionate geriatrician and stroke physician, has driven astonishing improvements in access to stroke unit care in the state.



In a period of less than ten years, stroke unit access in Queensland has increased from 40 percent to over 80 percent with countless people being saved from death or severe disability as a result.

David Roland, NSW *Creative Award*

When Byron Bay author David Roland looks back at the stroke that shook him to the core he doesn't see a disaster – he sees a new beginning.



Faced with the daunting impact of his stroke, David drew on his training as a psychologist to devise his own rehabilitation program to 'rescue his brain'.

David wrote about his experience in his first memoir *How I rescued my brain: a psychologist's remarkable recovery from stroke and trauma*. The book published last year has given hope to countless stroke survivors around Australia.

Find out more about our incredible winners and finalists by visiting www.strokefoundation.com.au

How I rescued my brain giveaway!

Thanks to David Roland and Bolinda Publishing we have a free audiobook copy of *How I rescued my brain* to give away to one lucky reader! Send your name and address on the back of an envelope to: StrokeConnections, National Stroke Foundation, 7/461 Bourke St, Melbourne 3000, or email strokeconnections@strokefoundation.com.au We'll draw a winner on Monday 14 December and publish the results in our next edition.

Helping you grow stronger after stroke



Setting goals and planning your recovery

Setting individual goals and developing a plan to achieve them is an increasingly common part of formal rehabilitation after stroke. But what happens when you get home? Stroke recovery continues, so shouldn't goal setting and planning?

Peter Levine, stroke rehabilitation researcher and author, wrote his highly-regarded book *Stronger after stroke* to help stroke survivors develop their own plan once they get home. His book begins with the mantra: 'Plan your work and work your plan.' He writes that a successful recovery plan will include long and short term goals. It will be measurable, flexible and be driven by the survivor and their family and friends. Peter's approach is designed to create what he calls an 'upward spiral of recovery' – a solid plan that will build on successes to inspire new goals and more success.

When the National Stroke Foundation asked how we could support stroke survivors to drive their own recovery, we found stroke survivors, carers and health professionals all agreed goal-setting was important. Stroke survivor Frank said it best:

"The stroke took away all the things that defined me as a person. I was a guitarist, singer and teacher. The stroke put an end to these interests. Following my stroke I became very depressed... it took me some time to focus on my therapy. Once I established my goals and saw improvement I was away and my progress has been great."

David, whose wife Joy had a stroke ten years-ago, pointed out that setting goals helps carers too. "We've been married 44 years and when she had her stroke, it really affected me too. I shared her stroke. Setting goals helped me as a carer too," David explained.

Stroke survivors and carers wanted a simple tool that would take their goals and break them down. This led to the creation of the goal-setting tool on *enableme*. It helps you set a goal, then think about your timeframe, outline the steps, as well as any obstacles you need to tackle.

So far there have been over 50 goals set on *enableme*. Many of them are about getting back to work or study, while others focus on family goals, like being able to walk a child to school or travel to Disneyland with grandchildren. Goals don't have to be major achievements – people have used the tool to help them achieve daily tasks like being able to make a coffee in the morning.

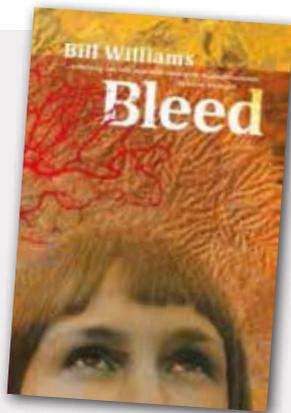
Just as every stroke is different, so is every recovery plan. While goal setting comes naturally to some, for others it can be a bit challenging. Once you have set a goal, it can be difficult to see a path from where you are now to where you want to be. This is particularly the case when there are obstacles in the way. This is where we can help.

If you'd like to work on your goals and your plan, our health professionals on StrokeLine are here to help. They have extensive experience in assisting stroke survivors to set goals and a plan to achieve them.

Call StrokeLine on **1800 STROKE** (1800 787 653) or send an email to strokeline@strokefoundation.com.au We'll make a time with you to set your recovery goal as well as plan how to get there. Life's messy and so is stroke recovery. If you haven't already, check out our goal-setting tool on enableme.org.au

Setting goals will create structure, and setting milestones will allow you to see (and celebrate) your progress. As stroke survivor Adrian O'Malley puts it: "You cannot fail, you are just not there yet."

Book review



Bleed by Bill Williams

Husband and wife Bill and Gisela Williams were camping in the desert about 150 kilometres from Alice Springs when disaster struck. Gisela woke up with a thunderclap headache and started vomiting violently. Bill knew something was seriously wrong and as a general practitioner, he immediately began a process of elimination in trying to work out what was happening. Bill dismissed possible causes one by one before coming to a devastating conclusion – Gisela was having a stroke. Bill bundled Gisela into their van and headed to Alice Springs, all the while knowing that while they must get help as quickly as possible, even then nothing is guaranteed.

Bleed is a cracking book - the rarest of things, an excellent story, very well told. Bill's worst case scenario thinking is correct, Gisela has had a subarachnoid haemorrhage, and throughout this book, her survival is uncertain, her path rocky and her future quality of life unknown.

Throughout their harrowing experience, Bill was able to use his medical knowledge to advocate effectively for Gisela.

Bill's medical expertise enables him to read his fellow health professionals and this is fascinating stuff. He can tell when a doctor's confidence in his own diagnostic powers is not to be trusted, and can read the tension between the different teams treating Gisela. He works the system, but as with anyone suddenly compelled to become the decision maker and advocate for someone, there is self-doubt and guilt at times.

The love between Bill and Gisela shines through this book, as does the love of their daughters. *Bleed* beautifully explores the connections between this family, of their love and care for each other, which make *Bleed* such a compelling read.

Bleed giveaway!

Thanks to Wild Man Press and Bill Williams, we have a hard copy of *Bleed* to give away. Send your name and address on the back of an envelope to: StrokeConnections, National Stroke Foundation, 7/461 Bourke St, Melbourne 3000, or email strokeconnections@strokefoundation.com.au We'll draw a winner on Monday 14 December and publish the results in our next edition.



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