



strokeconnect
Sharing, Supporting, Connecting

Stroke Connections

Autumn Edition 2014



strokefoundation



Introducing Jack Edward Joseph Benjamin

We have started off the year with some wonderful news – stroke community members Sam and Erin Benjamin have welcomed their first child to the world (pictured above). Jack Edward Joseph Benjamin was born at 4:16pm on 20 December 2013, a healthy and happy baby boy.

The birth of Jack was a very special moment for Erin and Sam who have had a challenging time navigating life after stroke. Erin suffered a stroke in 2012 at the age of 30 during the height of her corporate career.

“Jack has brought Sam and I such happiness after what can only be described as the worst two years of our lives. We’ve embraced the happiness of Jack and let go of the sadness and fear of the stroke’s effect on our lives”, says Erin.

Erin and Sam have had their share of challenges establishing a new ‘normal’ post stroke, as many of you would have also experienced. Erin sees the change in her routine with baby Jack as an easier transition than coping with life after stroke.

“The changes to my routine all happened drastically after the stroke, coming from a very busy job and social life to the solitary life of recovery was so hard, but now I think it was a blessing in disguise because a lot of the

struggles new mums have around adjusting to motherhood, I’ve already dealt with over the past two years”, she says.

Erin likens the experience of having a newborn as a form of stroke rehabilitation saying, “I still have deficits I struggle with post stroke but strangely enough caring for a child is almost a form of rehab. Luckily babies thrive with routine and I have to have routine to survive - especially considering my fatigue and memory issues. So it seems my stroke may have happened for a reason, I was meant to be a mum not a business woman. At least I tell myself that.”

It’s wonderful to hear news of a new life, in a personal journey of life after stroke. Congratulations Sam and Erin.

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Steph, Jude and Anna



Welcome to the new-look StrokeConnections.

Within the next few pages you will find stories featuring fellow stroke community members along with handy information to help guide you through life after stroke.

If you have any feedback do not hesitate to email us at strokeconnections@strokefoundation.com.au

For information about stroke support groups, contact your local state stroke association or call StrokeLine on 1800 STROKE (787 653) or visit www.strokefoundation.com.au

Best wishes,

Jude, Steph, Simone and Anna
The StrokeConnections Team



Sharing, Supporting, Connecting

Survivor success



Image credit: Courtesy of City of Boroondara.

Jenny Cheng

Victorian-based stroke survivor Jenny Cheng (pictured above) has been awarded the Boroondara Citizen of the Year 2014.

Jenny had a stroke in 1993 which caused instant paralysis to the left side of her body. On discharge from hospital to home she found significant gaps in support services for stroke survivors. This experience prompted Jenny to form the Boroondara Stroke Support Group in 2002 to provide help and support to other stroke survivors in similar situations.

The group holds two meetings per month and provides a nurturing, inclusive, social and active environment. It has also become a platform to promote stroke awareness and prevention and to advocate for better treatment for stroke survivors following their discharge from hospital.

Jenny's dedication and enthusiasm has helped stroke survivors access peer support, a component of rehabilitation which is vital for recovery. Congratulations Jenny, what an outstanding achievement!

2014 Life After Stroke Awards

We are now accepting nominations for the 2014 Life After Stroke Awards. If you know an exceptional member of the stroke community who deserves recognition, please nominate them.

We are also launching Creative Awards in 2014. If you are a stroke survivor embarking on a creative endeavour then we want to hear from you.

For more information email media@strokefoundation.com.au or visit www.strokefoundation.com.au

Stay
connected

The National Stroke Foundation community on Facebook

Facebook, the world's most famous social networking site is about to turn 10. 728 million people check into Facebook every day, which is close to the entire population of Europe.

Who is on Facebook?

- 65 percent of Facebook users are 35 or older.
- The average Facebook user is 40 years old.
- 60 percent of users are female, 40 per cent are male.
- The fastest growing user group is aged 55 to 64 years.

One theory about the incredible popularity of Facebook is until recently, almost everyone on earth lived in small, rural, interconnected communities where our friends all knew one another. But the social and economic mobility of the past century has worn away at that interconnectedness. Facebook allows us to keep up with friendships and to connect our friends with each other so we can rebuild the kind of old rural communities where everyone knew everyone else. Welcome to the electronic village.

What is the National Stroke Foundation community on Facebook?

We have almost 6,000 people in our community, and most have either had a stroke, or are a carer or family member of someone who has.



Our community share stories, post questions about recovery and provide encouragement to each other. They also talk about activities they are doing to Fight Stroke, fundraise and spread the FAST message.

Hot topics include:

- Self-directed rehabilitation.
- New research.
- What motivates me.
- Cognitive retraining.
- Pain management.

You can look at the National Stroke Foundation Facebook page without joining Facebook. Go to www.strokefoundation.com.au and look for the Facebook icon under 'Connect With Us'.

How do I join the conversation?

If you don't have a Facebook account, you can sign up for one in a few easy steps. To sign up enter your name, birthday, gender and email address into the form at www.facebook.com and choose a password.

After you complete the sign up form, they'll send an email to the address you provided. Just click the confirmation link to complete the sign up process.

There is a help button to answer any questions you may have. Facebook can be a bit daunting if you're new to it but with 728 million daily users, there's sure to be a savvy friend or family member who can help you get started. You can also check out your local neighbourhood house or library to see if they offer any classes on getting started with social networking. Once you've joined up you can 'like' the National Stroke Foundation to keep up to date with the happenings on our page.

Chronic pain – don't go it alone

Many stroke survivors have to deal with pain caused by their stroke. Headache, hemiplegic shoulder pain and neuropathic pain can all occur within the first month as well as longer term.

When pain lasts for three months or more, it is known as 'chronic pain' and can be incredibly challenging to live with. Pain experts emphasise, even if you can't make your pain go away, it is almost always possible to reduce pain levels and, more importantly, to improve quality of life.

Some things that can help include:

Find a supportive general practitioner (GP) and tell them about your pain. Studies have shown many people with chronic pain are sometimes reluctant to discuss it with their GP. People don't want to complain, especially when they are unsure whether there is anything which can be done to help. People also worry about the risk of dependency or side effects with prescribed medication. Make sure you feel comfortable talking to your GP about your pain and your GP is willing to work with you to find the best solution.

Consider multidisciplinary care. Pain is best managed using a team approach that is tailored to the individual. This may include allied health services such as physiotherapy, occupational therapy and psychology. GPs can arrange access to allied health services under the Chronic Disease Management Medicare items. If you have private health insurance, check what allied health services are covered. If co-payment is a barrier, services from your local community health service may be an option.



Access a specialist pain clinic. A pain management clinic can provide special programs to help you learn to cope with chronic pain. Treatment is provided by a team who work together to address the variety of factors which may be contributing to your chronic pain. The clinic provides an environment for receiving treatments to restore your quality of life and levels of activity, even if the pain itself is not completely relieved. Your GP can arrange access to a pain clinic if appropriate.

Seek support. Be honest with trusted family and friends about your experiences. Ask for their help and support and take opportunities to talk about how you're feeling. It's common to worry about burdening others with your problems, but most people really do want to help. You may also find it helpful to talk to someone with similar experiences. The Australian Pain Management Association's Pain Link telephone helpline is staffed by volunteers who live with chronic pain themselves. Call 1300 340 357.

More information

For information and advice, call StrokeLine on 1800 STROKE (787 653). You can also download the Chronic pain management after stroke fact sheet at www.strokefoundation.com.au or ask StrokeLine to send you a copy.

The Australian Pain Management Association website also has useful resources and links. Visit: www.painmanagement.org.au

Survivor profile



Benefits of StrokeConnect

Heather is a volunteer host on StrokeConnect Online, a forum for stroke survivors, carers and family members.

I've always been a fit and active person so I was very shocked when I was told I'd had a stroke.

My stroke happened at the end of a month's holiday in Scotland. I'd gone over to spend time with friends and to scuba dive on the remains of the German WWI fleet that was scuttled when the armistice was declared. The photo above was taken in my first week in hospital. My t-shirt says 'Wrecked in Scarpa' and was pretty appropriate after what happened.

I was initially treated for decompression illness as I surfaced from a dive feeling fine, climbed the ladder onto the boat when I realised I was having trouble working out what people were saying. I'd started slurring my words and couldn't turn my tanks off. I was put in the recompression chamber and after two treatments I was declared fit to go home. A couple of days later I realised something was wrong when I couldn't do up a button. So back to the local hospital for recompression and monitoring. While there, I stood up to walk across the room and promptly fell over. Late night I was air lifted to a stroke specialist treatment centre. I vaguely remember being given a CT scan and the specialist telling me I'd had a stroke.

I spent a month in acute care and rehabilitation before flying back to Australia. Once home, I was surprised as the different approach in the rehab here. It was frustrating being in a rehab that would not let me have the minimal independence I'd had in rehab in Scotland. I was discharged just before Christmas 2010 at which point I was 'walking' with a single crutch. I still call my walking 'taking steps' rather than

walking, it gets me from A to B but it's neither efficient nor elegant.

Since then, I'm now working five days a week. I've got a full driving licence again. I've got my dive medical certificate so I'm looking forward to diving again. I'm back at the gym, and I've been doing yoga and pilates. I'm going strong and I'm not going to let this thing stop me doing the things I enjoy. It's going to be a long time before I'll run up a hill again but I'm not saying 'never'.

My gym goal for this year is to hop on both feet and jump. My trainer thinks it's probably achievable by Easter. I thought it would be more than that as I've got so little ankle control. But we started on it recently and I did get both feet off the floor (just) a couple of times using a stick as a balance point and to push off against. I'll keep everyone on the forum posted as to my progress.

Post stroke, previously simple things can be really, really difficult. I'm just not good at being dependant on others. I know it's low priority stuff in the real scheme of life but it still makes me cross as. It's so hard to wait for others for those simple jobs I used to do so easily.

I love the way the forum gives me a place to vent my frustrations. I think part of it is living alone, but part of it is I don't have to explain everything when it's getting to me, as I do with family and friends. It can be inspiring too – we were recently talking about finding a happy medium between not aiming too high in your goals and aiming high enough to keep your progress moving along. Sometimes I do feel like StrokeConnect Online gives me my own personal cheer squad.

StrokeConnect Online is a very useful resource and personally I love the support it gives. The National Stroke Foundation is planning some improvements to make it more user friendly this year. I just hope we can give that support to many more people in the coming year.

Why not join Heather on StrokeConnect Online?

You can explore the forum to see if it's for you, and if it is, you can register as a user to join the conversation. All that's required is an email address. Visit www.strokefoundation.com.au

Australia's **BIGGEST** Blood Pressure Check

Stop stroke

You may have noticed we have rolled out our signs of stroke FAST advertising campaign nationally.

This awareness-raising campaign was funded by the Federal Government and includes television, radio and online advertising as well as wallet cards and direct mail.

Building on the FAST campaign we are now ready to take the nation's blood pressure. Australia's Biggest Blood Pressure Check will be held on 2 April with free blood pressure checks being held in major cities across the country. The focus of this check will be on stroke prevention and highlighting stroke risk factors.

The only way to know your blood pressure is to have it checked. Our message to Australians is simple. To avoid stroke, know what your blood pressure is and if it is high, talk to your doctor and take steps to reduce it. Don't let a stroke be your first sign of high blood pressure.

We encourage all Australians to get involved. For more details on Australia's Biggest Blood Pressure Check including your nearest test location visit www.strokefoundation.com.au

Think F.A.S.T. Act FAST!

CALL 000

Join the movement to stop stroke

We are asking the Australian community to show their support of the National Stroke Foundation and the global movement to stop stroke by wearing a Stroke Solidarity String. Wearing the string shows we are united. Wear it. Show it. Share it.

The indigo string symbolises the connection between all people touched by stroke, the flow of blood and the healthy function of the brain and body. Stroke Solidarity Strings are now available from the National Stroke Foundation and Chemmart Chemists across Australia. Each string is \$5.

For further details or to purchase visit www.strokefoundation.com.au or call 1300 194 196.





Aged Care Assessment Team (ACAT)

If you or someone you care for requires access to aged care services, your local Aged Care Assessment Team (ACAT) may be able to help.

ACAT health professionals are experts in assessing the needs of older people and helping them get the care they need. An ACAT assessment can help identify the type of care services needed to help people to stay at home. It can also provide people with eligibility for respite or permanent care in a residential aged care facility.

ACAT ensure people's wishes are always listened to and considered as part of the assessment. The assessment is an opportunity to identify options and ensure people can make an informed decision once they have received the outcome of their assessment.

ACAT is referred to as the Aged Care Assessment Service (ACAS) in Victoria. Jenny Harriott (pictured above right), Community Program Manager for ACAS, Bendigo Health, explains how the service assists older people and their carers.

Who does your service target?

ACAS provides service to frail older people over 65 and their carers, people from Aboriginal backgrounds over 50 and younger people with a disability who are eligible for assessment. There is an ACAS for every part of Australia. My service, the Bendigo ACAS, provides services to a huge area – 14 per cent of Victoria, covering from Macedon to Swan Hill, and Kyabram to Maryborough.

Why should people contact the ACAS?

People should contact an ACAS to identify what level of care will best meet their needs when they are no longer able to manage at home without assistance.

What is involved in the assessment?

For an older person to access Commonwealth funded residential care, residential respite, home care packages or flexible care, they must first be assessed as eligible by ACAS. ACAS can also approve people for Transition Care, which is aimed at improving independence and confidence immediately after a hospital stay. ACAS provides a comprehensive, holistic, medically-based assessment of care needs including information, advice and referral to a range of suitable care options.

What happens after the assessment?

What happens after the assessment depends on the outcome. If the person has been assessed as eligible for residential care or respite, the team will provide them with eligibility documents and information about residential care facilities. If they have been assessed as eligible for a home care package, their documents will include information about package providers in their area.

How long have you worked on the ACAS?

I have worked with ACAS for five years. I enjoy the challenge ACAS provides and the individuality of the needs of each client and their carers.

To find your local ACAT, call My Aged Care 1800 200 422. You can also visit the My Aged Care website www.myagedcare.gov.au

Keeping
active



Secret Men's Shed business

Men's Sheds are an updated version of the shed in the backyard that has long been a part of Australian culture. The Australian Men's Shed Association (AMSA) is the largest men's representative organisation in Australia, with around 75,000 members located in over 1000 sheds across Australia.

David Helmers from AMSA is a passionate advocate for Men's Sheds. "The common theme in all Sheds is about men retaining self-esteem, feeling useful, contributing again to their communities and having a meaningful purpose in life. Learning or sharing skills, making friends, networking and accessing health support information and opportunities are all part of being in the Shed environment."

Members of Men's Sheds come from all walks of life. The bond that unites them is they are men with time on their hands and they would like something meaningful to do with their time. Becoming a member of a Men's Shed gives men access to a safe and busy environment where they can find an atmosphere of old-fashioned mateship. And, importantly, there is no pressure. Men can come to have a catch up and conversation over a cup of coffee if that is all they're looking for.

One member reflects on the benefits of the Shed saying, "The Men's Shed takes away the worry of being in my current medical state and allows me to talk to other shedders about a variety of health topics. I get time out from the family and the others who seem to run around after me all the time. Here at the Men's Shed I can have some fun, can learn new things and generally have time that is my own to accomplish work and this gives me satisfaction."

To find your nearest Men's Shed go to www.mensshed.org or contact the AMSA on 1300 550 009 or e-mail amsa@mensshed.net



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