



strokefoundation

strokeconnect
Sharing, Supporting, Connecting

Stroke Connections

Spring edition 2014



Sing your way through recovery and beyond

For some stroke survivors with aphasia, communicating through speech is difficult – but singing is an entirely different thing!

Introducing stroke choirs – a wonderful outlet for survivors who want to communicate, be part of a community and just have fun. Everyone has a voice, it's just a matter of finding a way to express it. Local choir conductors are shocked at the change in members' confidence after only a few months of singing! Who knew the 'Mamas & Papas' and 'Advance Australia Fair' could make such a difference a survivor's recovery.

Self-expression is vital in a survivor's recovery journey and while some turn to art or photography, others turn to singing. Don't worry, you don't have to be the next Pavarotti or Susan Boyle to join a choir, it's not a talent show but a welcoming and fun form of group recovery - outside of a hospital setting. Members of many of the stroke choirs are now friends even after practice is over, with some organising social groups like 'Blokes with Strokes' in Melbourne.

Aphasia is often misunderstood by the general population, leading to feelings of isolation for

survivors which is why stroke choirs are so important. Offering peer support, friendship, gains in speech and self-confidence as well as improved posture and breathing – the choirs are a growing global movement. There are several currently operating around Australia with Stroke-a-Chord Ringwood's annual performance taking place on 11 October and Stroke-a-Note Geelong continue to entertain their community, most recently performing for The Australian Men's Shed Association.

Please contact StrokeLine to find out if there is a stroke choir in your area: 1800 STROKE (1800 787 653)

Pictured above is Stroke-a-Chord Ringwood, photo by Jon Osborne.

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Jude, Jess, Simone and Katherine

Welcome to the spring issue of StrokeConnections

After the harsh cold of winter, the spring season brings a little warmth and a lot of new things to Stroke Connections. The spring issue introduces the regular column *'It works for me'* where tips, hints and suggestions are sent in by helpful readers. We also talk about the *Thankful* project, the PIN or sign debate and the fantastic impact stroke choirs are having on our community in this issue.

For those readers who love the online arena, make sure you check out our Facebook page www.facebook.com/strokefoundation to keep up with the latest events, stories and research.

It's a great way to interact with other survivors and ask questions. Awareness is key.

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

Keep in touch,
Jude, Simone, Katherine, Anna, Emma and Jess

The StrokeConnections Team
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No postcode untouched by stroke

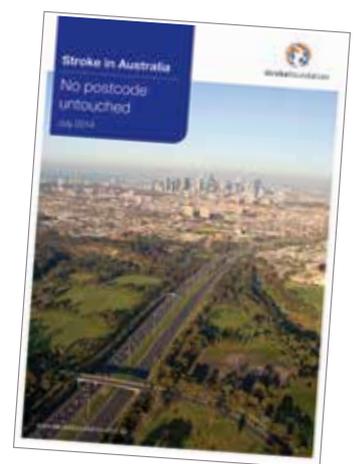
In an Australian first, the impact of stroke across the Australian landscape, its cities and towns has been mapped.

The National Stroke Foundation commissioned Deloitte Access Economics to estimate the impact of stroke across Australia. *Stroke in Australia: No postcode untouched* sheds new light on the widespread impact of stroke on local communities.

Launching the report at Parliament House in Canberra, Dr Erin Lalor said "Our report shows no postcode has been left untouched by stroke. Despite successive governments recognising stroke as a national health priority, Australia does not have a federally funded strategy or the

care services to address widespread need. The Stroke Foundation is urging national action to tackle stroke because all Australians need and deserve access to quality stroke care."

Visit www.strokefoundation.com.au to read the report and enter your postcode to see information about your local area. Once you've entered your postcode, you can click on a link to contact your member of parliament about the impact of stroke in your community.



It works
for me!

Share your tips and tricks with the community

A new column to share advice on what makes your life easier. Do you have advice for other stroke survivors, carers and family members on gadgets, apps, tricks or techniques to make life easier? Best tip published wins a \$50 Coles Myer gift card.

“I bought Dad an electronic medication organiser. He was having trouble remembering to take his medication – he knew he had to take it, but he’d forget. The really good thing about it is it talks to you. It says ‘It’s 9am Friday, it’s time to take your morning medication.’ And it doesn’t stop until you turn it off.”

Rebecca, carer

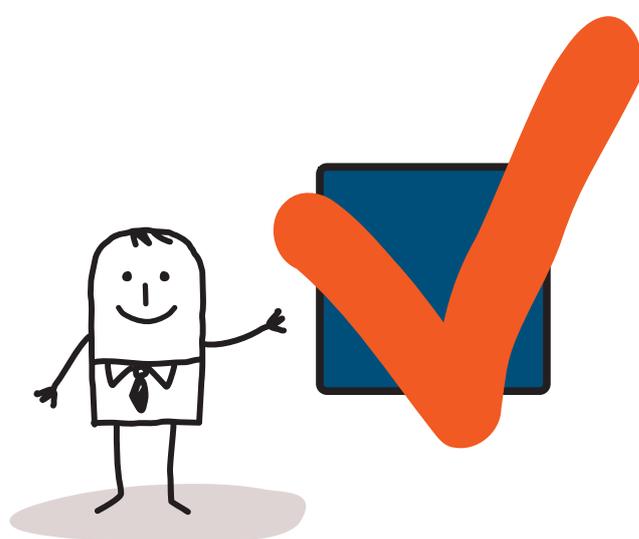
Search ‘electronic medication organiser’ online, ask your chemist or call the Independent Living Centre on 1300 885 886.

“People ask me about technology all the time. One app I really like is ‘It’s Done!’. To set it up, you choose from their task library or create your own. It then prompts you about tasks and you can check them off as you do them.”

Adrian, stroke survivor

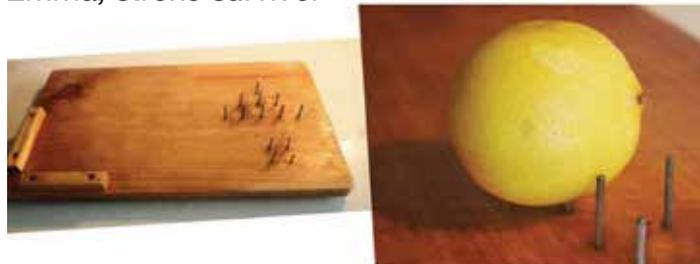
‘It’s Done!’ is available for both Apple and Android phones and costs about \$3.

Email your ideas and tips to strokeconnect@strokefoundation.com.au or call StrokeLine 1800 STROKE (1800 787 653).



“I love cooking but with hemiplegia it’s difficult. I wanted bread and chopping functions on one board. So my uncle created the Kitchen Hand for me. A very durable wooden board (a bit larger than your normal chopping board) with a raised L-shape in one corner and nails inserted into the wood on the other end for me to chop vegetables or fruit. Now I can easily make my favourite snack – peanut butter on bread with banana on top!”

Emma, stroke survivor



Emma’s customised chopping board

“I was having trouble buttoning up my shirt and I couldn’t work out why. I was doing it while looking in the mirror and my OT suggested I look down instead.

“I couldn’t understand why it worked doing it that way but my OT’s theory was that my brain was mixing up the visual signal I was getting back from the mirror. My hands had retained the ‘muscle memory’ to be able to do it so I didn’t need the mirror to do it – in fact it was making it much harder.”

Sandy, stroke survivor

“I recommend Slipon Swimsuits. They are great to get into and out of with limited mobility.”

Heather, stroke survivor

Visit www.sliponswimsuits.com or call 1800 059 114.



Fatigue - don't let it get you down

Fatigue is common after stroke, with 50 percent of survivors in one study saying tiredness was their main problem twelve months on.

The cause of fatigue after stroke remains unclear but one simple explanation is that cognitive, physical and sensory changes after stroke mean everything takes more effort. There's also the theory the neuroplasticity involved in recovery is a physical process, which is actually fatiguing.

Fatigue can present as a feeling of weariness, tiredness or a lack of energy that is not improved by rest. It can be physical, mental or psychological. Symptoms of fatigue can include headache, dizziness, blurred vision, increased pain, aching muscles and reduced coordination and balance. Other symptoms include 'brain fog', impaired memory and decision-making, moodiness or irritability, anxiety and depression or low motivation.

Despite fatigue being so prevalent after stroke, it isn't always discussed until it becomes problematic. Knowing about fatigue is essential to recognise its impact on daily life and to identify strategies to minimise the effects. Maree was completely unprepared: "I didn't know about post-stroke fatigue and so it was totally unexpected. It may have been mentioned in hospital and probably was in literature given to me at the time, however nothing and no-one seemed to emphasise the fact it can be such *extreme* tiredness."

Heather's experience of education around

fatigue was different, but still difficult to navigate. "My occupational therapist made a big deal of it when I was returning to work. Which was both helpful in that people knew what to expect and harmful in that I wasn't as badly affected by it as everyone expected me to be. So even when I was happy to push limits other people were reluctant to let me."

For some stroke survivors fatigue improves over time, whilst for others it can be persistent and debilitating. "My fatigue still gets me down. It is still present, and has never really waned or improved dramatically. I have learned to live with it, but wish other normal people would understand how quickly I can tire" John said.

Some things that can help include:

Take care of yourself. Eat a healthy diet and drink adequate amounts of water. Get adequate sleep, go to bed at the same time each night and switch off electronic devices at least an hour before bed. And avoid drinking too much alcohol. Heather says "I'm four years post stroke now. I still need more sleep than other people and I don't always wake up 'awake'. Sitting down to watch telly or read a book on the weekend will usually result in an impromptu nap."

Listen to your body and know your limits. Plan regular rest breaks and recognise any patterns of fatigue. Do tasks in a way that uses less energy, like sitting down to get dressed. Break larger tasks into several smaller tasks. Most importantly, prioritise the tasks that are most important to you. Heather's advice is to "Plan and be aware. Remember everything takes

More information

If fatigue is getting you down, speak to your doctor or rehabilitation team.

Check out the resources library at our website www.strokefoundation.com.au to download our fact sheet on fatigue.

You can also call StrokeLine on 1800 STROKE (1800 787 653) to talk it through and get the fact sheet.

energy and now you've got to conserve it. Get into a stable routine, but make space for naps as well. You can push through it but you'll pay for it later. Be especially vigilant for things like clumsiness which can be indications you've pushed too far."

Get some exercise. Move your body to stimulate good endorphins. Build up stamina and strength slowly and sensibly. John says it helps to "Establish a routine and try to stick to it. Remember to exercise, and don't sit around all day, even if you feel like it."

Ask for advice and support. Talk to your doctor, especially about your medications, as some can contribute to fatigue. Talk about it with supportive friends, family and other stroke survivors who have been through it. Finally, take up some of those offers of help: you don't have to do everything yourself.

Heather's learnt a lot about fatigue since her stroke. "I do have to watch out if it's a stressful week at work, I find that can trigger a fatigue hit, also things like colds and sunburn that put pressure on the immune system can trigger it too. Also remember it accumulates unless dealt with. Don't just ignore it." Maree's best tip? "Accepting it, first of all. Fatigue certainly has a way of making you slow down, allowing your body to heal and ultimately that's a good thing."

Research and services news

THE COMMUNICATION RESEARCH REGISTRY

The word is out

This month we spoke to Emma Leach, a speech pathologist at the Communication Research Registry to find out how they are contributing to better services for people with communication difficulties.

"The Registry was set up to provide people who experience speech and language difficulties with the opportunity to be involved in research. People from all over Australia, including those who have communication difficulties such as aphasia, dysarthria and apraxia of speech post stroke are encouraged to join the registry. Family members and carers can also join", Emma said.

If you are interested in joining the Registry, contact them on 07 3365 2089 or visit their website www.crrregistry.org.au After joining, you will get information about research that may be of interest to you as well as an annual newsletter about research outcomes.

PIN or sign?

On 1 August 2014 all financial institutions phased out the signature as a form of verification on all credit and debit cards.

Alzheimer's Australia has been in contact with the major banks to find out whether they will be offering alternative arrangements for those people with memory problems. A number of the large banks including ANZ, Commonwealth, NAB and Westpac are planning to provide sign-only cards to customers with special needs.

Eligibility criteria, as well as how the sign-only cards can be used, will differ between the banks. If you or a family member need a sign-only card, contact your financial institution to find out more. More information about the move to PIN can be obtained from www.pinwise.com.au

Calling children of stroke survivors

“When I had my stroke five years ago my primary concern was not my own survival and recovery. It was the physical and emotional well-being of my children.

“At the time I was 44 and my children were just two and nearly four. The most difficult part of my stroke was watching my children’s responses to leaving when they visited me in hospital; having outsiders come into our home to care for them because I wasn’t able to; seeing marked changes in their behaviour in response to the stress and changes within our family and thinking about the ways in which my children’s lives are altered because of my stroke.

“For a few years after my stroke I felt very alone in my grieving and that many of the people closest to me didn’t understand my experience. I had a light-bulb moment when a fellow survivor said to me ‘Why would they? They haven’t experienced it.’ I joined a number of online stroke support groups, specific to my age, interests and

stage of life. My internal fight melted away. The way I was feeling and the difficulties I was having were validated by people who understood exactly what I was talking about. They felt the same way and had experienced similar things. I didn’t have to prove or justify anything to anyone anymore. It was real.

“Which made me reflect; did my children feel similarly alone and could children of stroke survivors benefit from hearing the experiences of their peers?

“We are creating an animated video of children’s drawings and we’d love it if you and your child would like to be involved. It’s open to children of all ages; preschoolers, primary school aged children and teenagers. It’s as simple as inviting your child to do a drawing which shows some aspect of their feelings about their dad or mum’s stroke and recording a conversation with them about their feelings.”

More information

Interested? Find out more about Karen’s project website here:

www.kidstrokemotion.wordpress.com

Connect with Karen on Facebook here:

www.facebook.com/kidstrokemotion

*Stroke survivor and StrokeSafe Ambassador
Karen Bayly is pictured below with her children.*



Walk for your health

Katherine, our StrokeLine physiotherapist, is a big fan of walking. “Walking can be a fantastic way to get exercise and help recovery after stroke. Fitness levels often drop after a stroke so it is important to keep active to improve your health. Walking is free and has numerous health benefits for both mind and body.”

Regular walking can help control weight, improve blood pressure, reduce your risk of diabetes and help protect against osteoporosis. It will also do great things for your energy levels and your mood as we move into spring.

Katherine advises, “It is a good idea to speak to your doctor before starting a regular walking program if you have any health issues. Consider seeing a physiotherapist if you have difficulties walking, balance problems or a history of falls.”

Katherine’s top tips:

- Wear comfortable, supportive shoes.
- Build it up slowly. Break your walks up to two walks a day if you need to. Aim to get to at least 30 minutes every day but remember, any chance to get on your feet - even if it’s just to the letterbox - makes a difference.
- A brisk walk is great but remember you should still be able to talk comfortably while walking.
- Vary your walks by visiting somewhere new like a national park.
- Stay motivated by setting goals and tracking your progress in a diary.



Another good tip is to find a walking buddy or join a walking group. Greg, a stroke survivor, found his walking group was a great to stay motivated: “We walk and talk, everyone goes at their own pace... I’ve done well over 300 walks with different walking groups!”

To talk about walking after a stroke call StrokeLine on 1800 STROKE (1800 787 653).

Stride for Stroke

Make your walking count this November by joining us for a month-long campaign to help stop stroke, save lives and end suffering. Stride for Stroke will ask walkers and runners alike right across Australia to take on a personal challenge throughout November – pledge your kilometre target for the month, be it 25kms or 1,000kms, then get out there and pound the pavement!

Once signed up, you will receive your very own fundraising page which you can personalise, track your progress and ask your friends to support your challenge.

Sign up for Stride for Stroke this November and support stroke survivors and their families.

To find out more visit
www.strokefoundation.com.au

Community

The Thankful project

Recently we were approached by Kim McDonnell from Thankful, a new website celebrating, well, being thankful.

Kim says “The road to recovery after any health or personal crisis can be strewn with seemingly insurmountable challenges. That’s where we take inspiration from others, hearing their stories of success and aspirational achievements. When we reflect on the many things we have to be thankful for and share it with others, we start to feel better in ourselves.”

It’s this simple idea that inspires the team at Thankful and they invite you to get online and share what you’re thankful for, no matter how big or small – like the small steps you take recovering from stroke, to the wonderful people, family and friends who are there for us in recovery everyday.



Be part of a community who recognises and celebrates life’s precious moments and share your simple pleasures at www.projectthankful.com.au



strokefoundation

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www.strokefoundation.com.au

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