## **StrokeConnections** Summer edition 2018/19





### A Christmas like no other

Christmas and the New Year is typically a time to slow down from the hustle and bustle, spend time with loved ones and reflect on life.

For Cairns woman Tara-Lee Henry, this could not be more true.

Tara-Lee's year has been a rollercoaster – incredibly tough and challenging, but not without the sweetest of rewards.

At the age of 28, Tara-Lee was happily making plans for the future after learning she and her husband Garry were expecting their second child. The couple was debating names and just about to share the exciting news with their toddler Evelyn. But, eight weeks into her pregnancy Tara-Lee suffered a stroke. It happened in an instant. It was incredibly frightening and overwhelming for the family.

Tara-Lee was at her obstetrician's office for a routine check-up when she began feeling unwell and experiencing intense pins and needles down the left side of her body. Tara-Lee's obstetrician recognised something was seriously wrong and she was raced to hospital. Tara-Lee was terrified for her own life and the life of her unborn child.

As she lay in a hospital bed, a million questions raced through her head. An ultrasound thankfully confirmed the baby had a strong heartbeat, but Tara-Lee's symptoms remained.

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### Welcome to the summer edition of StrokeConnections

Welcome to our favourite edition of the year, where we deliver some great holiday reading! We think you'll enjoy our story about Tara-Lee Henry, who had her stroke while pregnant with her daughter Sophia. As the Henry family prepares to celebrate Sophia's first Christmas, Tara-Lee's story will warm your heart.

This edition also features StrokeLine's 12 Days of Christmas. We have a heap of tips on enjoying the festive season and setting up for a great year ahead. We also have news of a funding boost for stroke, with investment in the stroke Clinical Guidelines and a new research package. Finally, we take a look at the work our community stroke advocates are doing to get our message to members of parliament across Australia and outline how you can be involved.

Wishing you a safe and happy Christmas from everyone at Stroke Foundation.

### Funding boost for stroke research

The Stroke Foundation is thrilled with a \$2.5 million dollar investment from the Federal Government as part of the Medical Research Future Fund.

The recently announced funding will deliver:

- \$1.5 million to pilot "living" Clinical Guidelines for Stroke Management
- \$1 million Return to Life, Return to Work research package

In a world first, the introduction of living Stroke Guidelines will mean important medical discoveries in stroke can be rapidly moved into clinical practice at our hospitals. This is a game changer because the existing system of periodic updates is slow and often leads to out-of-date treatment recommendations and care. The pilot will save lives and improve health outcomes for people with stroke and it will be supported by technologies developed by Cochrane Australia.

The Return to Life, Return to Work research package has the potential to provide new medicines to aid recovery for working-age Australians impacted by stroke. It will include Australia's first multicentred clinical trial of Perispinal Etanercept in chronic stroke. The successful applicants will be announced in February next year.

We applaud the Federal Government for investing in the future of those impacted by stroke.



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Tara-Lee felt disorientated and struggled to remain conscious.

Further tests confirmed Tara-Lee had suffered a stroke. The news came as a shock. Tara-Lee wondered how she could possibly be in this position. Tara-Lee had never heard of people in their 20s having strokes.

Even though her precious baby appeared okay, it was an incredibly emotional time. There were physical challenges too. When little Evelyn visited her in hospital, Tara-Lee couldn't even hold her because of the damage to her body from the stroke.

As the days progressed, Tara-Lee was determined to be the best mum to Evelyn and the new baby she could be. Tara-Lee had suffered a stroke but she had survived it and so had her baby so now it was time focus on recovery. She was determined to walk again and regain the use of her arm and hand. Knowing recovery would take time and patience, Tara-Lee was fully committed.

Returning home from the hospital as her recovery progressed was a big deal. It was daunting and Tara-Lee questioned how she would be able to look after her family when she needed so much help herself.

But family and friends stepped up and eased the burden. The unconditional support and love had an enormous impact on her recovery. Being pregnant can be tough enough in itself, but when you are recovering from stroke and looking after a toddler at the same time it's physically and mentally exhausting.

Tara-Lee knows how lucky she was and has so much gratitude to the people in her life who fought the recovery battle right beside her every day.

After three months of rehabilitation, Tara-Lee returned to work. It was a gradual process, but an important one for her confidence and independence. She also started driving again, which was a major accomplishment.



Towards the end of her pregnancy, doubts and fears started to grow for Tara-Lee. Tara-Lee wondered if her baby would be impacted by the stroke and whether she would have enough stamina to give birth naturally.

Then the day arrived. Tara-Lee safely delivered a healthy baby girl, Sophia. She had dreamed of this moment. It was magical.

When the doctor placed Sophia into Tara-Lee's arms for the very first time, Tara-Lee was so proud. She felt like a huge weight had been lifted. They had both survived and they were finally united.

Today, Sophia is thriving and is adored by her family – especially her big sister Evelyn.

This will be Sophia's first Christmas. While she will have no idea just how special it really is, it will be a time of celebration for Tara-Lee and Garry after the journey they have been through.

For Tara-Lee, Christmas had always been about giving. But now, the sentiment behind the gifts is stronger. The greatest gift is time spent together making memories. She can't wait to watch her girls grow and play with their older cousins at Christmas time and enjoy simple activities like building sandcastles or fishing.

Tara-Lee tries not to dwell on the past. She has found a strength she never knew she had and enjoys each day as it comes. Tara-Lee is full of hope for life with the family she and Garry created.

# StrokeLine's 12 days of Christmas

Here's some easy tips to a fabulous festive season.



### Get travelling

For many stroke survivors, having a holiday is a significant milestone in their recovery. Like many of us, you might be

travelling over Christmas, or planning an adventure in the new year.

Stroke survivors are often pleasantly surprised with the help available at the airport and on the flight. StrokeLine has a great guide to flying when you have a disability – call us for a copy.

Nothing makes or breaks a trip like your accommodation. Check websites to help eliminate places that clearly won't meet your needs before speaking directly to providers to cover off the details. When it comes to travel insurance, shop around to get the best coverage at the best price. Finally, if you have a disabled parking permit, don't forget to take it with you if travelling by car.



### Don't shop until you drop

We want to give gifts that are personal, useful and enjoyable but it can be tricky, especially as we get closer to Christmas.

The good news is some of the best gifts don't require navigating the Christmas crowd at the mall or shopping centre:

- > Subscriptions that last all year long: movie streaming, audio books, magazines.
- > Tickets that are tailor made: a movie, theatre show or sports event.
- > Vouchers for a dance, photography, meditation or cooking class.
- > The gift of a home-cooked meal, transport, cleaning around the home or garden.
- > Personal items such as framed photos, letters of gratitude and encouragement.



### Take care of yourself

The Christmas period can be full of lots of lovely times but can have its challenges too. Whatever is going on for you,

make sure to take care of yourself.

- > Be as kind to yourself as you are to others. Keep the negative self-talk in check and remind yourself you are doing your best.
- Take time out. Listen to your body. If you need a break, take a walk or find a quiet place. Practice relaxation techniques that work for you or take some time to learn some new ones (StrokeLine can help with this).
- > Celebrate your wins. Feel proud of your achievements. Write down positive things as they occur and place them in a jar. Read them back as a reminder that life comes with successes you might otherwise miss.

### Get active



Keeping active will reduce your risk of further stroke, reduce post-stroke fatigue and help to continue your recovery.

Get active for 20 to 30 minutes most days at a light to moderate intensity. A tip to check you are not working too hard is to ensure you can talk while exercising.

Your 20 to 30 minutes can be split up into smaller bursts throughout the day. It's okay to start small and build up gradually. Simple things such as walking or household chores count as activity, and will help you gradually improve your endurance and strength.

Stay motivated by setting some small goals. Think about activities you enjoy and invite family and friends to join in.

Talk to your doctor or physiotherapist before beginning or changing an exercise program.





### Love your pets

The benefits of pets go way beyond how cute they look wearing reindeer antlers!

Pets can positively impact on your

health and well-being every day of the year.

Research into the health benefits of pets shows they can help to lower blood pressure and cholesterol, as well as having a positive effect on mental health. Having an excitable companion for walking not only encourages regular exercise but helps you connect with the people in your neighbourhood. Your pet can help you feel better by pulling you (quite literally) into nature every day.





## Dip into healthy eating this Christmas

Did you know that 75 percent of the salt in our diet comes from processed and packaged foods.

Dips, crackers, sauces, ready-made meals and processed meats are some of the worst offenders. Most of us are eating twice as much salt as recommended, so these foods are worth a re-think.

Dips are a Christmas favourite but why not try making your own tasty, healthy and low-salt dips this Christmas? You can find some delicious recipes on the Unpack The Salt website (unpackthesalt.com.au). You can also call StrokeLine – we'll help you out with some ideas.



## Make Christmas celebrations a little easier to swallow

Whether you celebrate Christmas with a traditional roast or some summer seafood, there

are ways that you can make celebrations enjoyable for someone on a modified diet.

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Here are some handy ways to be inclusive of your family member with dysphagia (difficulty swallowing):

- > Put time and effort into the taste and presentation with herbs, spices, sauces and dressings.
- > Ensure there is more than one appropriate food choice available.
- > Provide an environment that feels comfortable and not rushed.

Try our **Salmon and Polenta Pikelet recipe** on page 7.

### Beat the heat



Sweltering Christmas days are an Aussie tradition.

On hot summer days, the most important thing is to keep hydrated by drinking lots of water. Limit alcoholic, sugary or caffeinated drinks which can cause dehydration. If you are on limited fluids or fluid pills you should ask your doctor how much to drink during hot weather. If you're using thickening powder, you can thicken a variety of different drinks to mix it up and encourage good fluid intake.

Temperatures above 37°C are particularly dangerous, so take note of the forecast so you don't get caught out. Make sure you have what you need before a hot day so you don't have to go out in the heat. If you don't have air-conditioning, consider heading off early to somewhere that does. Make sure you let family and friends know how you're feeling. Also, check in on anyone you know who might be at risk at least once on a hot day. If you're worried about the effects of heat:

- > See your doctor
- Call HealthDirect for 24 hour health advice on 1800 022 222
- > Call 000 in an emergency.





**Check in on your stroke risk** It's normal after a stroke to be pretty focused on improving your health and reducing your risk of having another one. Get

yourself on a good footing for the new year by checking in on your risk factors.

Speak to your doctor about medical risk factors such as high blood pressure and cholesterol, atrial fibrillation and diabetes. You can tackle these with the right medication, diet and exercise. There are lifestyle changes you can make to reduce your risk too – stopping smoking, being active and eating well.

Also, make sure you drink alcohol safely. It can be tempting to drink more than we normally do over Christmas. For healthy people, drinking no more than two standard drinks on any day reduces the risk of harm. A standard drink varies a lot, so check the label. Remember too that after a stroke or TIA, you need individual advice about what is safe for you.



### Give the gift of F.A.S.T.

This Christmas, let people know that the F.A.S.T. test is an easy way to remember the most common signs of stroke and TIA.

Visit our website **strokefoundation.org.au** to order F.A.S.T. wallet cards to spread the word, or give StrokeLine a call.





#### Take fatigue into account

Post-stroke fatigue may be invisible but it sure is real. Take your fatigue into account when planning Christmas events and

activities. Prioritise what's important to you and don't be afraid to 'drop out' if you need to.

Family and friends may need help to understand why you can't do everything or attend every event. Use our fatigue fact sheet and podcast on EnableMe.org.au to help people understand what's going on with you or give StrokeLine a call.



### Reset your recovery goals

We used to think that no further recovery could be made after the first twelve months poststroke. We now know that

improvement can continue for years and even decades after a stroke.

Keep focused on your recovery by setting new recovery goals for 2019. What's next for you? Where do you want to be and how will you get there? Our brand new goal setting tool on **EnableMe.org.au** has everything you need. Our StrokeLine goal guru, speech pathologist Melita, breaks it down into simple steps and a whole heap of stroke survivors tell their stories of goal setting and recovery.



Need more information and ideas? Call StrokeLine on **1800 787 653**. We close for the Christmas break on 21 December and will be back to take your calls on 2 January.

# Festive recipe – Salmon and polenta pikelets

These festive pikelets are safe for people on a soft diet.

You can modify this recipe for people on a minced-moist diet by:

- > Replacing the pikelets with creamy polenta
- > Pureeing the salmon.



### Ingredients

### Pikelets

- <sup>1</sup>⁄<sub>4</sub> cup polenta
- 1/2 cup boiling water
- 1 egg, lightly beaten
- 2 tablespoons reduced fat milk

### Method

### Topping

- 2 tablespoons reduced fat cottage cheese
- 1 teaspoon lemon juice
- 2 x 95g can salmon in springwater, drained
- 2 tablespoons chives, finely chopped
- 1. Combine polenta and water. Sit for 5 minutes. Stir through egg and milk. Fold in flour and mix until smooth.
- 2. Spray a non-stick fry pan with olive oil and heat over medium-low. Cook two teaspoon portions of pikelet mixture for 1 minute or until bubbles appear, allowing room for spreading. Turn and cook for a further 30 seconds or until golden brown. Remove cooked pikelet from pan and put aside to cool.
- 3. Combine cottage cheese, lemon juice and chives. Spread pikelets with cottage cheese mix and top with salmon and chives.

# Make your voice count

Every stroke survivor, their family or carer has a story. You may not know it but your story can help influence the future of stroke through community advocacy.

For example, during National Stroke Week, Stroke Foundation staff along with volunteer StrokeSafe Ambassadors hosted health checks at Victorian, New South Wales and Queensland Parliament Houses.

The checks were an excellent opportunity to chat with members of parliament (MP) and their staff about stroke and what needs to be done. We had lots of MPs get involved, with many realising there were aspects of their own health they need to look at. MPs went away with a better understanding of stroke and its impact as well as some knowledge about their personal risk.



Stroke survivor Toni Arfaras meeting with Victorian Minister for Roads; Road Safety and Ports the Hon Luke Donnellan MP

Our advocates in Victoria have been extremely busy spreading the "fight stroke" message in the lead up to the Victorian election. We have had lots of advocates writing to their local MPs and candidates. Many of these letters have led to successful meetings!

Soon we will be starting to gear up our New South Wales advocates for their state election in March 2019 and then will be diving straight into the federal election.

If you are interested in helping us advocate to government, please get in touch at fightstroke@strokefoundation.org.au



Victorian Minister for Housing, Disability & Ageing; Mental Health; Equality; Creative Industries the Hon Martin Foley MP with StrokeSafe Ambassadors and stroke survivors Jeff Ryan and Kevin English

Contact us StrokeLine 1800 STROKE (1800 787 653) strokefoundation.org.au

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