



My young daughter's stroke changed Christmas for the better

Christmas Day for the Clayton family once looked like this:

- › Early morning wake up by two extremely excited children.
- › Gathering around the Christmas tree to open gifts.
- › Racing from one location to another to visit family.
- › Food, food and more food.
- › A swim.
- › Then falling in an exhausted heap at the end of the day.

It's a familiar story for Aussie families right across the country, but it all changed for the Clayton's in August 2010 when 4 year old Sophie suffered a stroke.

Little Sophie had been playing with her cousin when she walked out of the playroom holding her leg. She collapsed and her mum Amanda rushed to her aid, recognising the FAST signs of stroke.

It was touch and go initially, but Sophie's fire-cracker spirit shone through and she was discharged from hospital 10 days later determined to make the best of life after stroke.

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Welcome to the summer edition of StrokeConnections

Welcome to our favourite edition of the year, where we deliver some excellent holiday reading! We think you'll enjoy our story about the Clayton family Christmas. Sophie Clayton was four years old when she had her stroke, and seven years later, her mum Amanda reflects on what it has meant for their family, and for their family Christmas. Like so many families of stroke survivors, it has seen them focus on what is truly important. As Amanda says, "When you experience something like your daughter having a stroke, you realise it's so important to make memories and be present in the moment."

This edition also features the continuation of our memory series, with a focus on the practical strategies that make a big difference to life with memory changes after stroke. We also have travel tips from our EnableMe community and gift ideas from our Facebook community.

The yearly audit of Australian stroke services is part of the Foundation's ongoing effort to ensure all Australians have access to best practice treatment and care for stroke. The Audit provides a snapshot of where the health system is working well and where improvements are needed. This year's audit showed improvement in the rate of Australians receiving life-saving treatment, which shows that it can be done, but there is still a long way to go.

So from the Stroke Foundation and the StrokeConnections team, we wish you a safe and happy end to 2017, and a wonderful year ahead.

Best wishes,

The StrokeConnections team
Katherine, Jude and Chris

Continued from cover

Flash forward seven years and Sophie's mum Amanda said the Christmas routine is now much quieter, calmer and family focused.

There are not mountains of gifts and obligations. It's all about appreciating a special day with loved ones.

"Don't get me wrong, the kids are still up early!" Amanda said, expecting Sophie and brother Elliot to creep into her room before 5am.

"But we pace ourselves now. We open our presents, have breakfast and play with lego – which the kids love.

"We have an allocated wind-down time in the morning and afternoon where all four of us will sit down together and put on a Christmas movie for a couple of hours.

"This quiet family time is essential for Sophie and for all of us to recharge the batteries. And there's nothing more special than snuggling with your kids on the couch at Christmas – even in the Brisbane heat!" she said.


Amanda and husband Jamie have tweaked the family Christmas Day routine over the years, as they learnt more about the impact of Sophie's post-stroke sensory issues. Sophie's environment is carefully managed to avoid sensory overload.

"Flashing Christmas lights trigger migraines for Sophie, so we have warm white lights on our tree. We avoid big busy shopping centres and we visit a 'Quiet Santa' which has no queues, low light and no background music," Amanda said.

"So many things need to be done differently now. I also ensure Sophie is cool and hydrated, minimise sugar intake and I am mindful not to let her get over-tired.

"It's common sense really."

Amanda is positive about adapting the family Christmas to better suit Sophie.



“To be honest, the changes we have made have improved the whole family’s Christmas experience,” she said.

“It’s more intimate and simple now. We’ve moved forward and created new traditions.”

Sophie and Elliot tap into the Christmas spirit by making their parents and each other gifts – whether that be a lego creation, cookies or a Christmas card.

“We encourage creative gifts. Toys can break after a while and children grow out of clothes, but you can keep a thoughtful handwritten letter forever,” Amanda said.

“Sophie can’t write, but she will record a video message for all of us. It is something personal and special that will always bring a smile to my face.”

Sophie is now 11. The stroke has left Sophie with weakness on her right side, some speech issues and she has had difficulty learning, but her close-knit family has vowed to make her journey a story of positivity.

Sophie is a determined young lady, who looks to the future. She even scaled the Sydney Harbour Bridge as part of the Stroke Foundation’s Stride4stroke campaign launch in October. This was a highlight of 2017.

“We were really delighted to be involved in that event. It was amazing to see Sophie bound up the bridge and skip down,” she said.

“She continues to inspire me.”

Sophie has also found her voice in spreading awareness about stroke. Sophie wants to help end the misconception that stroke only happens later in life and has presented at school and in her local community about stroke risks and how to spot the F.A.S.T signs of stroke.

As Sophie’s story demonstrates, stroke can strike at any age and change lives in an instant. The impact is felt not only by the individual, but their family and friends. For some, it can change their outlook on life for the better.



“Christmas can be a crazy time,” Amanda said. “There is a lot of excitement in the air, but it’s important for me not to overwhelm the kids.

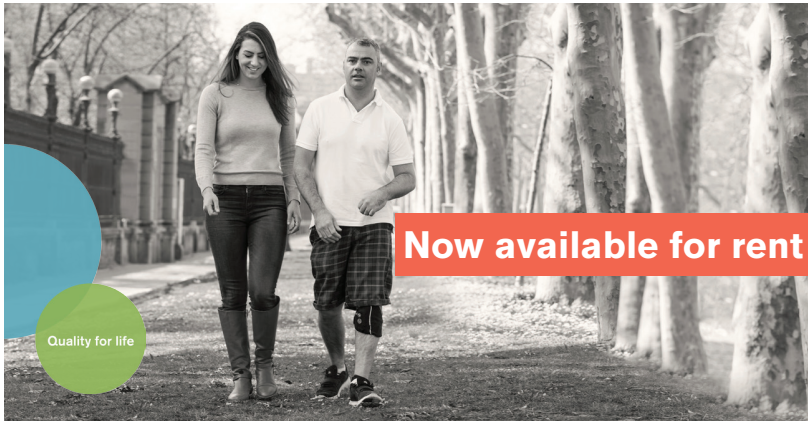
“We appreciate the opportunity it brings for family time and for treasuring each other’s company.

“Everything can wait an hour. I would rather be sharing a movie with my children than plonking them in front of the TV and racing around cooking dinner in the background.

“When you experience something like your daughter having a stroke, you realise it’s so important to make memories and be present in the moment,” she said.

Sophie’s family set up the Stroke kids Facebook page to help other families and show there is plenty of life after stroke and therapy can be creative and fun.

Visit [facebook.com/strokekid](https://www.facebook.com/strokekid)



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Christmas gift ideas for stroke survivors

The Stroke Foundation's Facebook page not only provides a platform for people who have been touched by stroke to connect, but it also generates interesting conversations.

This included a post recently about what to buy somebody who has suffered a stroke as a gift.

We thought we would share some of the ideas on this topic ahead of Christmas. It may spark some inspiration for those who haven't hit the shops yet!

'Darryl' reached out to the Facebook group for gift ideas for his father, explaining he had limited movement after his stroke, but had his speech. The suggestions from the community included:

- › Electronic photo frame loaded with pictures of his favourite people and moments.
- › Google Home – to play music, turn on the lights etc. through voice activation.
- › iPad apps that help fine motor skills.
- › Battery operated radio.
- › Good quality pillow.
- › Photo/message wall.
- › Tracksuit pants with no zips or buttons.
- › Uplifting music.
- › Jigsaws or lego.
- › But mostly, something money can't buy – love, time and support.

Join the conversation [facebook.com/strokefoundation/](https://www.facebook.com/strokefoundation/)

Tap into a new way of ordering your meds

Your Health, Your Way



National Stroke Audit

Stroke survivor Maryanne Bawden had extra reason to celebrate her birthday recently.

The Bowral resident spent the morning of her 68th birthday recalling her stroke experience at the launch of the 2017 National Acute Stroke Audit at Liverpool Hospital.

An emotional Maryanne was so grateful to husband Peter for recognising the signs of stroke and calling an ambulance straight away after he heard her drop some dishes in the kitchen at home.

From there, Maryanne received the time-critical clot busting (thrombolysis) and clot removal (endovascular thrombectomy) treatments and has made an amazing recovery.

The audit launch provided an opportunity for Maryanne to thank the stroke team who saved her life. She could not have talked more highly of them.

Maryanne's story is an example of a positive outcome as a result of the health system working well, but the audit found best practice care like this is not available to all Australians – especially those in regional areas.

There is a significant opportunity for improvements across the country to save lives and reduce disability.

The Stroke Foundation will continue to work tirelessly to achieve this.

Some of the key statistics from the audit include:

- › 36 percent of patients are reaching hospital within the 4.5 hour window for thrombolysis
- › Delivery of thrombolysis with appropriate patients has increased to 13 percent (up from 7 percent since 2015)
- › Delivery of thrombolysis within 60 minutes of hospital arrival lags internationally (Australia 30 percent, United States 59 percent, United Kingdom 62 percent)
- › 95 hospitals have a stroke unit (up from 87)
- › 77 percent of metropolitan stroke patients access a stroke unit, compared to 47 percent of regional patients

See the full report at <https://informme.org.au/en/stroke-data>



“When I was younger, if I needed a word or a fact it was at my fingertips. Now it’s like an arthritic and elderly gentleman has to sit up and go down many, many flights of stairs very slowly and go rummage in dusty drawers.”

Best-selling author Neil Gaiman.

Last edition we delved into how memory works. With so many StrokeLine callers asking us about memory loss, this edition we look at strategies you can use to compensate for memory problems.

Relying solely on memory to get through the day is tricky. It’s a bit like willpower – it can let you down. Incorporating memory compensation techniques into daily life relieves the effort of constantly trying to remember. It also reduces stress as it helps ensure fewer things go wrong because something’s been forgotten.

Memory compensation comes down to two things – the power of routine and the helpfulness of tools.

Use routine by:

- › Keep important things such as your keys or glasses in the same place so you always know where to find them.
- › As soon as you think “I need to remember to take that with me tomorrow”, get up and put it in your bag or at the front door.
- › Establish routines for preparing for days or events, doing the same thing in the same order each time. This helps ensure nothing is missed. Use checklists during tasks that require a number of steps and make a “to do” list daily.
- › “Keys, wallet, phone” is a good mantra as you leave the house. If you have particular things you need to remember, like turning something off, make up your own mantra. Start by writing it on a note on the front door until it becomes second nature.

Memory compensation comes down to two things – the power of routine and the helpfulness of tools.

Try using tools:

- › Use a calendar or diary to note every appointment so nothing is missed.
- › Make a note that you’ve done small jobs as you do them. You can use your diary, notebook, calendar or even take a photo on your phone.
- › Take notes, especially at appointments, and keep them all in one place. Use your diary or a notebook. Avoid making notes on random bits of paper and on the backs of envelopes.
- › Bring someone with you to appointments if you think that you may be receiving a lot of new information.
- › Use a dosette box for medications so you know if you’ve taken that day’s dose.
- › Use phone alarms or even your oven timer to alert you to do something at a particular time.

Stroke survivor Dean writes that he has a couple of memory compensation tips that (most times) work for him.

“If I leave a tap running to water the garden, before I start I put a picture of a water tap on my island bench. I cut pictures out of a colourful magazine and stick them

onto cardboard so they stand up. My thoughtful and crafty granddaughter stuck a picture of a battery charging onto a folding cardboard that I use to remind myself that my mobility scooter is on charge.”

“Outside I put things in front of my path like washing baskets to remind me of what I was doing, like hanging up the washing. I still forget things or look at things with a mental blank but I don’t put the picture boards away until I have worked out what I need to do.” Dean writes.

Find out more ideas or post your own tips at enableme.org.au

Holiday plans

There is usually a lively conversation going on EnableMe about travelling after a stroke. Everyone agrees that travelling after a stroke requires a lot of extra planning but is definitely worth the effort. Here are our community's top tips:

Air travel. You can fly once cleared by your doctor. There is a bit to consider when flying, and the advice from stroke survivors is not to book until you have spoken to the airline about your particular situation. Stroke survivors and carers are usually pleasantly surprised when flying for the first time. The general consensus is that there are good systems in place to assist disabled travellers at the airport and on the flight, and most staff are helpful and kind. "Prepare for take off: air travel tips for people with a disability" is a recommended guide. It provides comprehensive advice and a handy checklist. Call StrokeLine and we can send you a link or a printed copy.

Accommodation. Survivors suggest that checking websites will help you eliminate some obviously unsuitable options, but again speaking directly to accommodation providers is best. Caution is advised, with some survivors reporting that some providers having a limited understanding of what accessible accommodation really is (hint: it's more than a single handrail in the bathroom).

Go local. Survivors say they started small to rebuild confidence. One survivor and carer started with picnics in the park before trying a weekend getaway nearby. After that they felt comfortable to venture interstate. Smart planning can make life easier even when you go local. One beach might involve negotiating a lot of steps, while another around the corner is easily accessible. Check out if beach or wilderness wheelchairs are available for hire where you're heading, as these can open up new worlds. StrokeLine can help track these options down. And if you have a disabled parking permit, don't forget to take it if you are planning on hiring a car.

Try a cruise or a tour. Annie echoed many people's feelings about cruising: "I find that cruising is the way to go post stroke. There is no unpacking each day, good comfortable accommodation, all meals supplied, entertainment available and medical assistance on hand if needed." Organised tours also get the thumbs up from survivors, with many noting that tour operators are often used to catering for people with disabilities.

Insurance. Survivors suggest shopping around to get the best coverage at the best price, noting that while it will cost more after a stroke, peace of mind is worth the price paid.

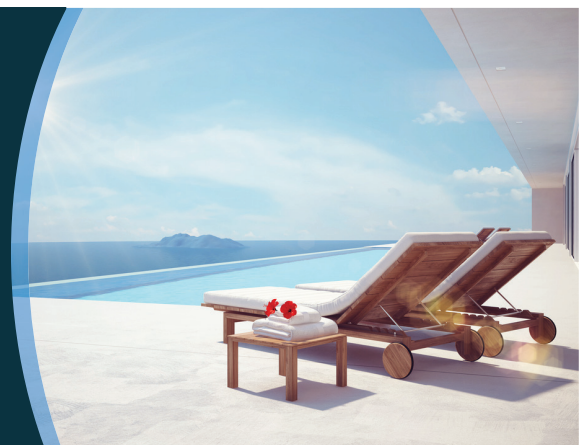
StrokeLine can help with any questions you have when making holiday plans, and EnableMe is a great source of advice too.

StrokeLine 1800 787 653 or **enableme.org.au**

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Stroke Awards – Nominations now open!



The Stroke Awards celebrate the amazing work and commitment of stroke survivors, carers, volunteers and health professionals.

If you know an unsung hero working tirelessly to make a difference for the stroke community, nominate them now.

Categories include:

- › Stroke Care Champion
- › Improving Life After Stroke
- › Creative Award
- › Courage Award
- › Fundraiser of the Year Award.

For more information call the Stroke Foundation on (03) 9670 1000.

Nominations close Friday 16 February 2018.

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enableme.org.au latest

- › Listen to the new podcast – stroke in your 20's and 30's.
- › The Photography and Recovery Group continues to post photos of daily life.
- › Katrina blogged about moving on from a job but holding on to the support of her husband.

Plus lots more...

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