



Epic endurance adventure awaits young stroke survivor

There is no stopping Tommy Quick.

The 27-year-old university student, who had a stroke at the age of 12, has made defying the odds his specialty.

Tommy is in the process of planning his grandest challenge to date – riding a three-wheel bicycle, called a recumbent trike, to the four furthest points of mainland Australia.

Setting off in August 2021, Tommy will tackle the 9,000 kilometre journey from Steep Point in Western Australia to Cape York in Far North Queensland.

As Tommy travels around Australia, he wants people to know that stroke can happen at any age, but it does not mean your life is over.

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Welcome to StrokeConnections

We hope you enjoy our stories about stroke survivors Tommy Quick and Desney King, both of whom have defied the odds to achieve great things. For Tommy, this means a 9,000 kilometre bicycle ride – in his words, “not a quick ride to the shops”. For Desney, the publication of her first novel is a hard-won moment of joy.

This edition also features a story on touch and sensation from our StrokeLine team. Feeling touch differently and having strange sensations can be an unexpected affect of stroke. Our StrokeLine team provide advice on why these changes can happen, and what can help.

We have news of a F.A.S.T. campaign for Greek, Italian, Mandarin, Vietnamese, Arabic, Cantonese, Hindi and Korean speakers, and we look to the skies to improved stroke treatment for regional Australia. Young stroke survivor, William Lo, lets us know why a new project to meet the needs of younger survivors is so important.

We wish you all the very best for the holiday season, and a wonderful new year.

Emily, Jude and everyone at Stroke Foundation.

Stroke is an emergency in any language

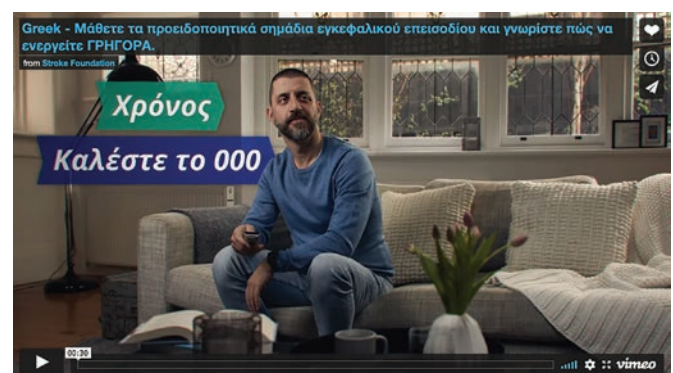
Stroke Foundation was thrilled to recently launch an in-language F.A.S.T. (Face. Arms. Speech. Time.) signs of stroke awareness campaign.

The new campaign targets eight language groups; Greek, Italian, Mandarin, Vietnamese, Arabic, Cantonese, Hindi and Korean.

Funded by the Federal Government, it takes potentially life-saving stroke information to people who may not have been able to access it otherwise because English was not their first language.

We hope this initiative will pave the way for translation and distribution of other important public health information.

The F.A.S.T. Community Education campaign involves translated marketing materials across print, digital and radio as well as online and in-person community talks. In addition to targeting eight vulnerable language groups, Stroke Foundation will also deliver activities in vulnerable regional communities.



The F.A.S.T. signs of stroke video in Greek

Continued from cover

"When I first had a stroke, I was just a school kid. I spent five weeks in an induced coma, which was pretty frightening for my family," Tommy said.

"I had to re-learn the basics, like how to swallow and to talk. I was told I would not be able to walk or run again, but I proved the doctors wrong."

"While my life had changed dramatically, I adopted a positive mindset and looked at my situation like my life was just beginning."

The sports lover has limited movement in his right arm and mobility challenges. However, Tommy played table tennis in high school, is a qualified personal trainer and completed the gruelling Kokoda Track in 2014.

Tommy said next year's Four Points of Australia adventure may be his toughest yet.

"This is not a quick ride to the shops. This is an epic adventure and a test of my resilience," Tommy said.

"I don't believe anyone has completed this challenge before and I am keen to be the first."



"I don't like the word disabled. Anyone can set themselves a goal to do something – no matter how big or small it seems. I would like to empower other stroke survivors to strive to do something they love."

Tommy plans to ride up to 80 kilometres a day and hopes other riders, joggers and ultra-marathon runners will join him along the journey.

As well as increasing awareness of stroke, Tommy will raise funds for Stroke Foundation.

"I plan to stop along the way, wherever people will listen – in towns and at schools and community groups to share my story and break-down preconceived ideas about what disability looks like," he said.

For more on Tommy's journey and how you can support his fundraising visit www.fundraise4stroke.org.au/fundraisers/tommyquick/the-4-points-australia or www.the4points.org

From editor to novelist – Desney's big achievement

Desney King has always had a deep love of literature. Desney's mum introduced her to books from an early age and, amazingly, she was able to read when she was three years old.

A highly regarded book editor, Desney's career spanned more than three decades.

Then in 2012, Desney had a stroke. The 69 year old year old can reel off the precise moment a stroke changed her life – 10am on Thursday the 23rd of February.

The impact of Desney's stroke was significant. As a result of the stroke, Desney experienced changes to her cognitive ability, muscle weakness and crippling fatigue. But Desney still had her voice and her words.

Before the stroke, Desney had been quietly working on a rough draft of a novel for several years. It was a heart-warming story about how to keep living after total devastation – and it was almost complete. When the stroke struck, Desney thought the novel would remain as a file on her computer forever.

However, 12 years after she began writing it, *Transit of Angels* has just been published.

An excited Desney has described this as a major achievement.

"I never thought *Transit of Angels* would make it to print, but I am so happy and proud it did," Desney said.

"It was a joyous moment when I got to hold a copy in my hands for the first time." Desney's novel found its way off her computer with a lot of hard work.

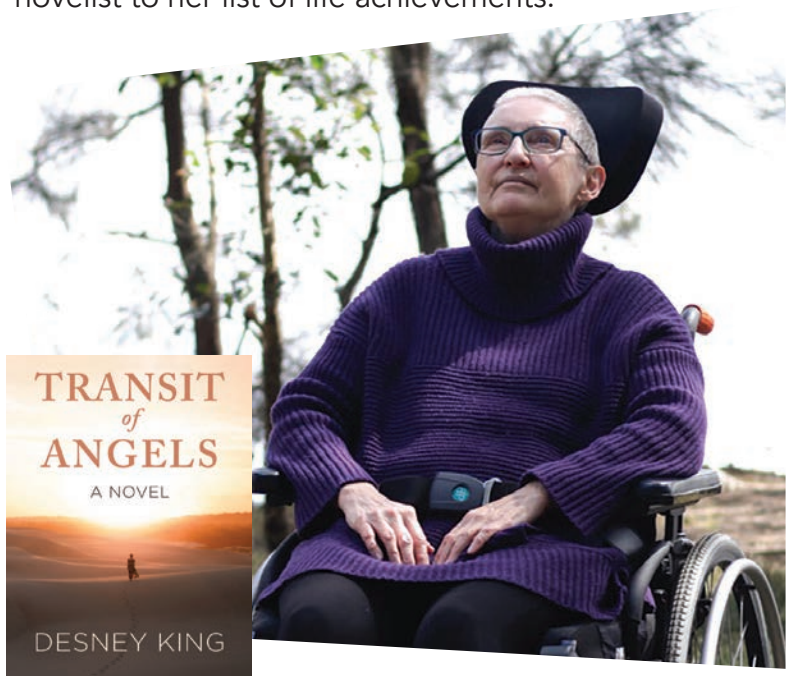
"The editing process usually lasts a couple of months, but it was much slower for me. I am unable to sit or stand unsupported and suffer from fatigue. This was taken into account by my editors and publisher," she said.

"I wrote and re-wrote sections of the book in 30 minute blocks from my bed. Some days I was able to manage a couple of stints, while others were a write-off. The edits took just over one year to complete."

Desney said she struggled with the concept of goal setting for many years due to her fatigue but managed by setting many small, achievable goals along the way. The impossible became possible. She was also buoyed by the love and support of family, friends, and a team of support workers.

Transit of Angels has received excellent reviews leaving Desney contemplating what's next. She is not short of ideas for her next book.

Desney has experienced eight strokes since 2012. While her recovery is not what she originally hoped for, she has reached a deep acceptance. Excitingly, Desney can now add novelist to her list of life achievements.



Looking to the skies to improve stroke treatment for regional Australia

Progress is well underway on research to revolutionise access to emergency stroke treatment for Australians living in rural and remote communities.

The Australian Stroke Alliance is developing lightweight mobile brain imaging scanners to be built into planes and helicopters, creating the world's first stroke air ambulances. A brain scan is essential so doctors can identify the type of stroke before deciding the best treatment to be given.

This research program, led by Professors Geoffrey Donnan and Stephen Davis at

The University of Melbourne and the Royal Melbourne Hospital, targets the crucial first hour after stroke onset, known as the 'golden hour' to give patients the best chance of survival.

Early stages of the work have been funded by a \$1 million grant as part of the Australian Government's Medical Research Future Fund Frontiers Initiative.

The Australian Stroke Alliance includes experts from more than 30 of Australia's leading health and academic institutes and charities.



Changes to touch and sensation

Feeling touch differently and having strange sensations can be a surprising change after a stroke. In this article, the StrokeLine team covers why this can happen and what can help.

We have touch receptors in our skin. When we are touched, the receptors send out signals. Mostly, it's up to our brains to make sense of these signals. All being well, we know where we are being touched, and what kind of touch it is. We know if something is hot or cold, rough or smooth, sharp or blunt. If things are working as they should, when we experience a sensation, there's a reason. We have pins and needles, for example, because a part of our body has been in an awkward position.

We also have sensations that come from our muscles. These sensations tell us if we are moving or resting, and what position we are in.

After a stroke, all this can be disrupted. Stroke can change your brain's ability to process and understand information from your senses.

Parts of your body may feel touch less or be numb. If you have a loss of sensation in your hands, you may drop things or have trouble brushing your teeth. Getting back to a craft or hobby may be difficult. Less sensation may mean you don't notice things like shoes being tight.

It can also affect relationships. You may not know if someone has touched you affectionately as they walk by, and sex may feel very different.

You can also feel touch more. A light touch can feel like much more than it is, to the point of being irritating or painful.

Again, this can affect you throughout your day, and it can change how you experience affection and sex too.

You may feel hot and cold less. This is an important one, as feeling temperature accurately keeps us safe. You may not know water is too hot, or that you are sitting too close to a heater.

You may have pins and needles, tingling or other strange sensations. Some sensations can be unpleasant, like burning or feeling like something is running over your skin.

Finally, you may not always know where your hand or foot is. You may not know it is in a funny position or you may feel like it is heavy or stiff when it actually isn't.

So, what can be done? First, remember sudden changes such as numbness or paralysis in the face can be signs of stroke, so if it's come on suddenly, call triple zero (000).



If you're experiencing sensation changes, speak with your doctor. Your doctor can:

- › Make sure you have a diagnosis.
- › Make sure there are no health or medication issues causing the changes.
- › Refer you to specialists and allied health therapists if needed.

Therapy aims to improve sensation, and to help you adapt to changes.

Improvement relies on neuroplasticity, which is our brain's ability to change and adapt. After a stroke, pathways in the brain can change so that undamaged parts of the brain can take over the jobs of damaged areas. Repetitive training is needed to help the brain build new pathways.

Sensory retraining is a therapy that aims to retrain sensory pathways and get unused pathways working. Exercises create an association between seeing and feeling touch, or between seeing and sensing where your limbs are. They can include:

- › Touching differently textured objects.
- › Having someone touch you in the same spot with your eyes closed and then open.
- › Applying a cold face-washer and then a warm one to your skin.
- › Practising sensing where your hand or foot is with your eyes closed and then open.

These training sessions need to be specifically prescribed to you by an occupational therapist or physiotherapist. For sensory retraining, you will need to see a therapist who has experience working with people with neurological conditions, including stroke. Some therapists have special training in sensory retraining.

Working with a therapist will make sure the exercises you are doing are safe and effective. You will also need to do them repeatedly to help the brain build new pathways. Your therapist will give you exercises to do between sessions.



Ask your doctor about the best way to access an appropriate therapist. Community rehabilitation may be a good option for you. You may also be able to see a therapist using Medicare-subsidised sessions. In this case, Occupational Therapy Australia or the Australian Physiotherapy Association can help you find one. StrokeLine can also help with finding a therapist.

Adapting to changed sensation is also best discussed with your therapist. Again, this needs to be specifically tailored to you to be effective.

Occupational Therapy Australia:

Visit otaus.com.au or call 1300 682 878.

Australian Physiotherapy Association:

Visit australian.physio or call 03 9092 0888.

StrokeLine's health professionals provide information and advice on stroke prevention, treatment and recovery. Our StrokeLine team can help you find the support and services you need, whether you are a stroke survivor, carer or family member.

Call **StrokeLine** on **1800 787 653**, Monday to Friday 9am to 5pm, Eastern Standard Time.

Helping younger stroke survivors live a good life after stroke

Stroke Foundation's Young Stroke Project will empower, connect and support stroke survivors aged 18 to 65 years.

Funded by the National Disability Insurance Agency, the project will deliver new information like podcasts, videos and webinars designed for and by young stroke survivors and their support crew.

William Lo, 26, has joined the project's Lived Experience Working Group to help younger stroke survivors to rebuild their lives.

"I was only a teenager when I had a stroke. I lost 80 percent of my motor skills, which was a huge life-changer," William said.



Young stroke survivor William Lo.
Photo credit Mark Sherborne.

"I spent three months in hospital and had to learn to walk again."

William said "Back then, there was a lack of information about life after stroke. I had to be proactive and ask therapists to explain what was happening so I could understand my situation."

Getting younger people involved in the project will be vital to its success. William noted "With hard work and dedication, along with a supportive environment advocating for a recovery and independence, I was able to get to where I am. I can now use both hands and drive. I hope this project will deliver more clarity about recovery, giving people something more than just hope for the future."



YoungStroke
PROJECT

To find out more and
get involved, visit
youngstrokeproject.org.au

Contact us

📞 **StrokeLine 1800 STROKE**
(1800 787 653)

💻 strokefoundation.org.au

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