



Stroke Foundation is the voice of stroke in Australia, working to prevent stroke, save lives and enhance recovery

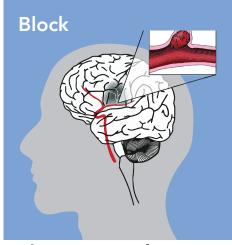
We partner with survivors of stroke, carers, health professionals, government and the community to reduce the incidence and impact of stroke for all Australians.

Stroke Foundation is the leading national organisation in Australia focused on stroke prevention, treatment and recovery.

For more than 25 years, we have championed breakthrough stroke research, successfully advocated for access to innovative treatments, increased public awareness in stroke prevention and recognition, and supported thousands of health professionals to deliver best-practice care.

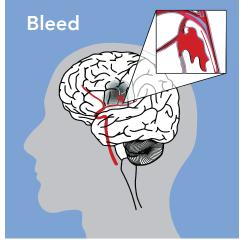
Every achievement takes a united team of stroke champions all working together with a single voice and purpose: survivors of stroke with their families and carers, health professionals, researchers, volunteers, advocacy bodies, generous donors, corporate Australia, government and philanthropic partners.

What is a stroke?



Ischaemic stroke

(Blood clot or plaque blocks artery)



Haemorrhagic stroke

(Artery breaks or bursts)

Stroke can strike anyone, at any time.

A stroke happens when blood supply to the brain is interrupted.

When this happens, brain cells do not get enough oxygen or nutrients and they immediately begin to die.

Stroke is always a medical emergency.

Importantly, we know that more than 80 percent of strokes can be prevented.

The state of stroke in the Northern Territory – why we have to act <u>now</u>

In 2023, there were 272 stroke events in the Territory,¹ and many of those survivors of stroke will be living with an ongoing disability. There are 2,559 survivors of stroke living in the Territory¹ – and their number is growing.

One of the key modifiable risk factors for stroke is high blood pressure. Importantly, 49,893 Territorians are living with high blood pressure,¹ and many don't know it. In addition, 22,009 Territorians are daily smokers and 22,596 have high cholesterol¹ – putting them at an increased risk of stroke.

Why is this happening?

Our population is growing and ageing. We are living longer, more sedentary lives. Our physical and social environments are influencing lifestyle choices and behaviours, putting us at an increased risk of stroke, and at a younger age.

At the same time, there is a clear lack of community knowledge and awareness about the common stroke risk factors, the typical signs of stroke when it happens, and the fact that stroke is a medical emergency and calling an ambulance immediately at the first sign of stroke is critical.

Our health system is also struggling to meet the needs of patients with stroke. Improvements have been made in the delivery of acute stroke treatment and care; however, time-critical treatment and best-practice care is not available to all Territorian patients. In addition, we know that for many survivors of stroke, their rehabilitation needs are not assessed and those who need rehabilitation do not always receive it. This in turn increases the impact on informal carers and social care services.

It doesn't have to be this way

Stroke can often be prevented and it can be treated. We are making progress, but there is much more to be done.

We are taking action, but we can't do this alone. It takes everyone's support, from government, community organisations, right through to individuals, to prevent stroke, save lives and enhance recovery from stroke for all Territorians.

We have an opportunity to act, to reduce the impact of stroke on survivors, their families and carers, the community, and the healthcare system. We can and must act for the health and wellbeing of future generations.

Stroke Foundation understands the significant and unique challenges the Northern Territory Government faces in delivering health services, including a dispersed and ageing population, the growing burden of chronic disease, rising healthcare costs and challenges attracting and retaining a skilled health workforce, particularly in regional, rural and remote locations. We look forward to working with the Northern Territory Government to reduce the impact of stroke on the Territory's community and health system. Significant gains can be made from a modest investment.





There were **272** stroke events in NT in 2023¹



There are **2,559 survivors of stroke**living in NT¹



Stroke can happen at **any age**. **1 in 4** first ever strokes occur in people **under 65 years**¹



More than **80 percent of strokes** can be prevented²

Lifetime costs associated with strokes that occurred in 2023 exceed

\$138 million (almost \$532,000 per person)



Costs in the first year after stroke were over

\$58 million
(almost \$222,000 per person)

\$41 million

in healthcare costs for strokes occurring in 2023 including



\$3 million

in road ambulance costs



\$32 million

in hospital costs

Summary of Stroke Foundation proposals

To meet the urgent needs of survivors of stroke, their families and carers, Stroke Foundation is seeking funding of \$2 million over four years.

1. F.A.S.T. (Face, Arms, Speech, Time) Community Education Grants Program

\$1 million (\$250,000 per year over four years)

Ensure more Territorians know how to recognise the signs of stroke and how vital it is to call triple zero (000) immediately, regardless of where they live.

2. Enhanced support for stroke recovery: My Stroke Journey for every survivor of stroke and dedicated StrokeLine support for the Northern Territory

\$1 million (\$250,000 per year over four years)

Ensure more Territorians who are impacted by stroke can access the information and support they need in a timely manner. This will benefit survivors of stroke, their families and carers, the community, as well as the Territory's health system and economy.



Proposal 1: F.A.S.T. (Face, Arms, Speech, Time) Community Education Grants Program

Investment: \$1 million (\$250,000 per year over four years).

Investment in a F.A.S.T. Community Education Grants Program will deliver:

- a community-led education program focused on raising awareness of the F.A.S.T. signs of stroke in hotspot areas and among priority groups
- **)** a suite of culturally appropriate, in-language resources highlighting the life-saving F.A.S.T. warning signs of stroke
- **)** an increase in the awareness of at least one F.A.S.T. sign of stroke in the Territory from 71 percent to 80 percent by 2027.

Stroke is a medical emergency. Faster diagnosis and treatment saves lives and results in improved quality of life. When someone suffers a stroke, every minute counts. F.A.S.T. access to treatment means a greater chance of recovery and decreased costs for our health system.

The F.A.S.T. message highlights the three most common ways to recognise a stroke (Face, Arms and Speech), and reminds us that Time is critical when seeking treatment. Stroke Foundation is the one organisation in Australia dedicated to sharing this message widely, and encouraging all Australians to learn it and share it with others.

Importantly, we know that major gains in population awareness of the F.A.S.T. message can be made over time. F.A.S.T. advertising campaigns are proven to increase awareness of the signs of stroke, and calls to emergency services, nationally³ and internationally,^{4,5} and support well established scientific findings that significant and continuous exposure to public health messages over several years leads to gradual improvement in population awareness and knowledge.

Stroke Foundation has previously partnered with the NSW Government to deliver the F.A.S.T. Community Education Program in conjunction with the roll out of the NSW Telestroke Service. Over three years (2020–2022), the Program contributed to an increase in the unprompted awareness of at least two F.A.S.T. signs of stroke in regional NSW of over 20 percent (from 22 percent in 2020 to 44 percent in 2022).6 Further to this, in Tasmania, where the State Government has been funding the F.A.S.T. Community Education Program for six years, the unprompted awareness of the F.A.S.T. signs of stroke has grown to be significantly higher than in all other states and territories.⁷

Current F.A.S.T. awareness in the Northern Territory community

The Northern Territory has the highest proportion of Aboriginal residents among its population – an estimated 32 percent (79,000 people).⁸ We know that stroke occurs more commonly, and at younger ages, in Aboriginal than non-Aboriginal Australians.⁹ Aboriginal Australians are also 1.7 times more likely to be hospitalised for stroke, and 1.6 times more likely to die from stroke, as non-Aboriginal Australians.¹⁰

Only 33 percent of Northern Territory stroke patients arrive at hospital within the 4.5-hour window for clot-dissolving treatment (thrombolysis).¹¹ In the Territory community, information about stroke, and the need for it to be treated as a medical emergency, is clearly not accessible or culturally appropriate. The 2023 Stroke Foundation F.A.S.T. Signs and Stroke Awareness Survey reported on the unprompted awareness of the F.A.S.T. signs of stroke in the Territory community, and showed that 58 percent knew speech difficulties were a sign, 21 percent knew facial drooping was a sign, and 16 percent knew an inability to lift both arms was a sign.7

We know that the unique geographical challenges in the Northern Territory also impact the ability of Territorians to access time-critical stroke treatments. Many Territorians living in rural or remote communities are unable to access road ambulance services, and in the event of a medical emergency, will call or travel to their closest clinic or health service to activate aeromedical retrieval services.

The partnership between the Northern Territory Government and the South Australian Telestroke Service is ensuring Territorians have 24/7 access to stroke specialists. In addition, Stroke Foundation is a principal partner of the Australian Stroke Alliance, which is committed to improving equity of access to stroke treatment and care for Australians in rural and remote communities, through the development of new brain imaging technologies for road and air ambulance. To maximise these significant investments, it is critical Territorians know the F.A.S.T. message.

Northern Territory Government investment in a F.A.S.T. Community Education Grants Program is needed to facilitate improved awareness of the F.A.S.T. signs of stroke and the need to call triple zero (000) immediately, and where this is not possible, to call or get to the closest clinic to activate aeromedical retrieval services.

The need for Northern Territory Government investment in hospital infrastructure

Once Territorian stroke patients arrive at hospital, it is critical they are able to access the world-class treatment we know saves lives and reduces disability.

Northern Territory Government investment in infrastructure at Royal Darwin and Alice Springs Hospitals is needed to ensure all Territorians, regardless of where they live, are able to access the treatment and care they need.

Royal Darwin Hospital currently needs:

an administration support position shared with Alice Springs Hospital, to support data entry for the Australian Stroke Clinical Registry (AuSCR).

Alice Springs Hospital currently needs:

- > a second CT scanner as a matter of priority
-) a new cardiac stroke unit
- a full-time Senior Medical Consultant role
- an administration support position shared with Royal Darwin Hospital, to support data entry for AuSCR.

The program

Stroke Foundation will provide small grants, and implementation support, for community groups representing priority communities (such as Aboriginal, culturally and linguistically diverse and regional and rural Territorians), to develop and deliver innovative, culturally appropriate, in-language communications to increase awareness of the F.A.S.T. signs of stroke. Program activities will be focused on stroke hotspot geographical areas, identified using data from sources such as the No Postcode Untouched report, and AuSCR.

Community groups and health services, including Aboriginal Medical Services, Aboriginal Community Controlled Organisations and multicultural groups, will be able to develop and deliver activities that are tailored to address the needs and preferences of their communities. These groups may choose to deliver or adapt Stroke Foundation's StrokeSafe Community Education program, to deliver F.A.S.T. education and awareness to their own communities. Raising awareness

and distributing resources within Primary Health Networks will also be a priority.

The StrokeSafe program recruits, trains, and provides support to local volunteers to raise awareness in the community about stroke, including the signs of stroke, and chronic disease prevention, through the delivery of StrokeSafe presentations. StrokeSafe speakers are embedded in their local and cultural communities, and many have lived experience of stroke. Through the compelling voice of those impacted by stroke, we increase knowledge and help to ensure patients get to hospital in the critical time window for life-saving stroke treatment.

In addition to delivering *StrokeSafe* presentations, volunteers set up displays and activities at community events and in health settings, distribute F.A.S.T. resources, and gain local workplace support, which facilitates improved awareness about the signs of stroke and dispatches of ambulances and retrieval services.

We are calling on the Northern Territory Government to invest in a F.A.S.T. Community Education Grants Program, which will increase awareness of what stroke is, how to reduce stroke risk, and how to recognise the F.A.S.T. signs of stroke, in the Northern Territory community. It will also strengthen and maximise existing Northern Territory Government initiatives, such as the partnership with the South Australian Telestroke Service. This is saving lives, enabling clinicians at the Royal Darwin Hospital and Alice Springs Hospital to connect with Adelaide-based stroke specialists via videoconference, to provide fast consultations for patients with suspected stroke.



Case study 1: F.A.S.T. in action – Jenny's story

Jenny Hellyer has an affinity with the ocean – it's where the avid surfer enjoys spending time with her family, but in January this year, a regular family day out at the beach took an unexpected turn when they got home.

"My leg felt like it had turned to rubber.

I tried to walk, but it felt like a flag flapping in the breeze, then it completely gave way.

I also felt a numbness creeping up the right side of my face."

The 43-year-old was having a stroke. Luckily she knew the F.A.S.T. acronym from Stroke Foundation's campaign, recognised the signs of stroke and called an ambulance immediately.

"I just knew I had to get to the hospital quickly."

After a month in hospital undergoing gruelling rehabilitation, the mother of two learned how to walk again and was determined to get back on her board. The former stand up paddleboard state champion's love for the water drove her recovery.

"I just told myself get out there, you can't let the stroke beat you."

And that's exactly what Jenny did. She's now back on her board, taking on the waves once again.

"It feels great to be back out there in the lineup and doing what I love."

"Everyone should know the F.A.S.T. signs of stroke. It could save their life, just like it saved mine."



Survivor of stroke, Jenny Hellyer

Proposal 2: Enhanced support for stroke recovery: My Stroke Journey for every survivor of stroke and dedicated StrokeLine support for the Northern Territory

Investment: \$1 million (\$250,000 per year over four years).

Investment in enhanced stroke recovery in the Northern Territory will ensure:

- > every survivor of stroke discharged from hospital in the Territory receives a copy of My Stroke Journey or Our Stroke Journey, a resource for Aboriginal and Torres Strait Islander peoples
- > all Territory StrokeLine callers receive a same-day priority response
- > more Territorians who are impacted by stroke are able to access the information and support they need in a timely manner, including mental health support
- **)** all Territorian survivors of stroke receive the information they need to help prevent secondary stroke.

Survivors of stroke, their families, friends and carers, need ongoing information and support as they navigate life after stroke.

Stroke Foundation delivers a suite of products and services for survivors of stroke, their families, carers and friends, and the general public, including its flagship *StrokeLine* inbound information and support service. *StrokeLine* health professionals provide expert information, advice, support and referral on stroke prevention, treatment and recovery via telephone, email, social media and Stroke Foundation's recovery website *EnableMe*.

StrokeLine is a highly regarded, trusted service:

In 2023, 89 percent of clients said they would recommend it to someone else. This was similar to 2022, indicating the service delivers a consistent and positive user experience.

- When advice was provided to clients about what they could do to resolve their issue,
 77 percent acted on this advice.
- In 2023, there was a 34 percent increase in callers to StrokeLine asking for advice on signs of stroke before calling an ambulance.

Importantly however, we know from our own existing services' data and internal evaluation of the service, that there is unfulfilled demand for the *StrokeLine* Service, with the current service unable to adequately meet the needs of specific groups within our community:

> StrokeLine provided information and support to almost 2,500 survivors of stroke, their families, friends and carers, and the public during 2023; however, this is only a small proportion of the number of Australians who experience a stroke for the first time each year, and are living with stroke in our community.

In the last three years, there has been a significant increase in the number of complex calls into StrokeLine. This includes vulnerable survivors calling the service for advice and support, who are facing challenges with issues such as anxiety, depression, suicidal ideation, loss of independence, finances, strained relationships and social isolation, in addition to trying to manage the impact of their stroke. These calls are longer in duration and often require follow-up.

Stroke Foundation's My Stroke Journey

is a resource delivered by our hospital partners in the first few days after a person's stroke, which is used throughout their admission in education and care planning. This free resource also supports the transition from hospital to the community and includes information on preparing for discharge and available supports and services.

My Stroke Journey is now a suite of resources, with versions available for **Aboriginal and Torres Strait Islander peoples** (*Our Stroke Journey*), and in both standard and easy English, Italian, Arabic, Chinese, Greek, Hindi, Korean, Vietnamese and for parents and carers of children who have had a stroke.

We know that 94 percent of those who receive *My Stroke Journey* find it useful, and over 75 percent refer to it after going home. In addition, the proportion of survivors who receive advice on (1) stroke risk factors and (2) secondary stroke prevention and recovery, at discharge, has increased by 20 percent and 13 percent, respectively, as a result of *My Stroke Journey*.

In 2023, this valuable resource was delivered to 150 Northern Territory survivors of stroke. Importantly, we know that many of the people who need this resource the most are not receiving it.

What will enhanced support for stroke recovery in the Northern Territory deliver?

Dedicated, same-day StrokeLine Service for the Northern Territory

We will deliver dedicated *StrokeLine* support and a same-day priority response for Northern Territory callers, including Aboriginal and Torres Strait Islander staff and translation services, to ensure clients are supported to access the information and services they need in a timely way. We will also facilitate GP connection and liaison for clients with complex needs.

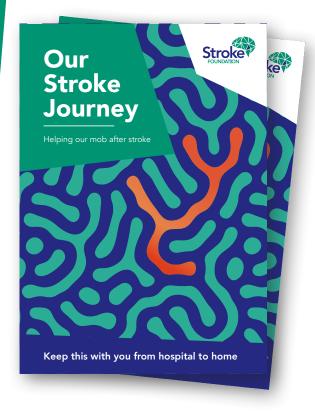
Currently, around 1 in 6 calls (17 percent) to *StrokeLine* from survivors of stroke, their families and carers are about mental ill health, including depression, anxiety and suicidal thoughts. As such, the mental health capability of *StrokeLine* will be strengthened.

A targeted community awareness campaign to raise the profile of *StrokeLine* will be delivered, with a focus on promoting the service to hospital clinicians and inpatients, primary care (GPs), multicultural organisations, Aboriginal Medical Services, Aboriginal Community Controlled Health Organisations, and survivors of stroke, their families and carers, in identified stroke hotspots.

My Stroke Journey for every Northern Territory survivor of stroke

We will directly engage with Northern Territory hospitals through educational and promotional activities, to ensure every survivor of stroke discharged from hospital in the Territory receives a copy of *My Stroke Journey* that is in the language and medium of their choice, and is culturally appropriate. The *Our Stroke Journey* resource will be available in a variety of formats, including but not limited to, audio in-language, pictorial, and video.

We are calling on the Northern Territory Government to invest in enhanced support for stroke recovery, which will deliver a dedicated, same-day StrokeLine Service for the Territory, and ensure every survivor of stroke discharged from hospital in the Territory receives a copy of My Stroke Journey. This will mean more Territorians who are impacted by stroke are able to access the information and support they need in a timely manner, which will have benefits for survivors of stroke, their families and carers, and our community, as well as the Territory's health system and economy.





Case study 2: StrokeLine in action – Greta's story

Greta rang *StrokeLine* and spoke to Siobhan, a *StrokeLine* health professional, in March 2024.

After a stroke in October 2023, Greta had changes to her vision and mood, as well as ongoing fatigue.

During the call, Siobhan worked to make Greta feel safe to talk about her concerns. Greta lived alone in Darwin, was no longer able to drive, and reported feeling socially isolated. She disclosed her previous suicide attempts and recent thoughts about ending her life. Siobhan listened, allowing Greta all the time she needed.

Greta and Siobhan talked about the role of hope in stroke recovery, and in managing depression and suicidal thoughts. Siobhan provided options for further support, referring Greta to *Lifeline*. She also encouraged Greta to make an appointment with her GP to talk about her mental health. Siobhan suggested a medication review and accessing professional support through a mental health care plan.

Siobhan understood the importance of social connection for Greta. She suggested talking to *FriendLine* for social support. She found a local stroke support group for Greta to join.

With Greta's most pressing concerns dealt with, Siobhan broadened the conversation. Greta was unsure of her stroke risk factors. She spoke about wanting to get her heart checked. Siobhan provided secondary stroke prevention education. She again encouraged Greta to make an appointment with her GP, and talked about the things Greta could do to reduce her stroke risk.

Siobhan also identified the need for further rehabilitation. She talked with Greta about accessing allied health services through a chronic disease management plan.

As Greta couldn't drive to appointments, Siobhan provided information on local transport options. She also provided details on how to access support through Centrelink.

"

Stroke Foundation's StrokeLine Service was incredibly helpful. Siobhan was able to provide me with valuable information, and connect me with the services I needed. But more than that, she gave me hope that things could get better.

Survivor of stroke, Greta



StrokeLine health professional, Siobhan McGinniss

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Will you help? We invite you to have a conversation with us today, to learn more.

 ${\bf Stroke \ Foundation}\ |\ advocacy@stroke foundation.org. au\ |\ stroke foundation.org. au$