

# A better plan for stroke for all Queenslanders

Pre-Budget Submission 2023–24 Neville Kerr, Queensland survivor of stroke and Stroke Foundation StrokeSafe speaker.

strokefoundation.org.au

# **About Stroke Foundation**

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside survivors of stroke and their families, healthcare professionals and researchers. We build community awareness and foster new thinking and innovative treatments. We support survivors on their journey to live the best possible life after stroke. We are the trusted voice of stroke in Australia, and we work to:

- Raise awareness of the risk factors and signs of stroke, and promote healthy lifestyles.
- > Improve treatment for stroke to save lives and reduce disability.
- Improve life after stroke for survivors.
- > Encourage and facilitate stroke research.
- > Advocate for initiatives to prevent, treat and beat stroke.
- Raise funds from the community, corporate sector and government to continue our mission.

Our work aligns with three key pillars, Prevention, Treatment and Recovery, as outlined in our strategic plan, <u>Stroke Strategy 2024</u>.

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## Introduction

In 2020, more than 5,000 Queenslanders experienced stroke for the first time, and there were more than 87,000 survivors of stroke living in our community - many with an ongoing disability.<sup>1</sup> Unless action is taken, it is estimated by 2050, Queenslanders will experience an additional 5,000 new strokes annually, and there will be an additional 83,000 survivors of stroke living in the community.<sup>1</sup>

One of the key modifiable risk factors for stroke is high blood pressure. Importantly, more than 897,000 Queenslanders are living with high blood pressure<sup>1</sup>, and many don't know it. In addition, 586,500 Queenslanders are daily smokers, 422,300 have high cholesterol, 796,700 are physically inactive, and 2,698,600 are overweight or obese<sup>1</sup> – putting them at an increased risk of stroke.

Stroke Foundation is proud to be partnering with the Queensland Government to deliver the successful *StrokeLink* and *My Health for Life* programs. This submission outlines a number of proposals that provide further opportunities for Stroke Foundation to work with the State Government to strengthen stroke prevention, treatment and recovery, so more Queenslanders are able to avoid, survive, and recover from stroke.





# Summary of key budget proposals

Proposal	Investment	Page
Pillar 1 Prevention: Fewer preventable strokes in Queensland		
<i>F.A.S.T. (Face, Arms, Speech, Time) Community</i> <i>Education Program and Multimedia Campaign.</i> Ensure more Queenslanders know how to reduce their stroke risk, and recognise the signs of stroke.	\$250,000 p.a. (over three years)	7
Pillar 2 Treatment: Ensure all Queenslanders have access to evidence-based stroke treatment		
<ul> <li>Phase Two of the world-leading Living Evidence initiative.</li> <li>Enable the living approach for clinical guidelines to continue to evolve, ensuring Queensland health professionals have access to reliable, accessible, and up-to-date clinical recommendations.</li> </ul>	\$1.75 million (over three years)	16
Pillar 3 Recovery: Enhance recovery to help Queenslanders live well after stroke		
StrokeConnect Navigator Program. Facilitate improved continuity of care, and ensure Queensland survivors of stroke are connected to the services, supports, and information they need to achieve their best possible recovery and avoid hospital readmission.	\$304,000 p.a. (over three years)	21

## Fewer preventable strokes in Queensland

Eighty percent of strokes can be prevented<sup>2</sup>, and stroke prevention remains the most effective means of reducing the burden of stroke in Queensland.

Importantly, we know that many preventive health interventions are cost-effective, and for every dollar invested in prevention there is a \$14 return.<sup>3</sup>

Stroke Foundation is committed to reducing the number of preventable strokes in our community, by empowering more Queenslanders to recognise the risk factors for stroke that can be changed, and in doing so increase their chances of preventing stroke. Specifically, our goal is to ensure that by 2024, 65 percent of adult Queenslanders will know the stroke risks they can change.

Stroke Foundation delivers campaigns and programs to raise awareness of important modifiable risk factors for stroke such as high blood pressure. Stroke Foundation's annual 'Australia's Biggest Blood Pressure Check (ABBPC)' campaign raises public awareness of the link between high blood pressure and stroke, and empowers Australians to know their stroke risk and understand how to manage it by getting a free health check at a pharmacy or their general practice. Since the beginning of ABBPC in 2014, over one million Australians have received a free health check.

Stroke Foundation is proud to be partnering with the Queensland Government and the Healthier Queensland Alliance to deliver the successful *My Health for Life* program. This free, evidence-based, behaviour modification program is helping Queenslanders to reduce their risk of stroke, type 2 diabetes, heart disease, high cholesterol and high blood pressure, and avoid unnecessary hospital admissions, delivering savings to the health system. To date, over 250,000 Queenslanders have been engaged in a conversation about their health by undergoing a chronic disease health assessment, more than 16,000 are currently enrolled in the program, and over 13,000 have completed the program. Program participants have demonstrated sustained improvements in outcomes such as a reduction in waist circumference (66 percent) and ability to meet Australian physical activity guidelines (70 percent).

Stroke Foundation has developed a similar behaviour modification program aimed at secondary stroke prevention, called *Living Well After Stroke*. This program is currently being piloted in Queensland with funding from the Federal Government, and in Tasmania with funding from the State Government.

Stroke Foundation's StrokeSafe Speaker program, which is funded largely through public donations, delivers presentations across Australia to community groups, workplaces, and as part of special events. Talks are delivered by trained volunteers to raise awareness of what stroke is, how to reduce stroke risk, and how to recognise the signs of stroke (using the F.A.S.T. test). Thousands of Queenslanders have received life-saving messages about stroke through these presentations, delivered by volunteer speakers who have had a stroke themselves or are close to someone who has. StrokeSafe presentations are a key component of Stroke Foundation's highly effective F.A.S.T. Community Education Program, that is currently being delivered in Tasmania, Western Australia, New South Wales and the Australian Capital Territory, with funding from governments in each of these jurisdictions. In these states and territories, where governments provide funding, we are able to train more

StrokeSafe speakers, deliver more presentations, and reach a much larger number of people.

We are calling on the Queensland Government to invest in Stroke Foundation's evidence-based F.A.S.T. (Face, Arms, Speech, Time) Community Education Program and Multimedia Campaign, to reduce the number of preventable strokes in our community, and ensure more Queenslanders know the life-saving F.A.S.T. signs of stroke.

This program will help to realise the vision of the *My health, Queensland's future: Advancing health 2026* strategy, that Queenslanders will be among the healthiest people in the world by 2026, by improving their health and wellbeing through concerted action to promote healthy behaviours and prevent illness.

# F.A.S.T. (Face, Arms, Speech, Time) Community Education Program and Multimedia Campaign.

Investment: \$250,000 per annum over three years.



#### Background

Stroke is a time-critical illness, and 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.

Importantly, only 37 percent of Queensland stroke patients arrive at hospital within the 4.5 hour window for clot-dissolving treatment (thrombolysis).<sup>4</sup>

There is a clear lack of awareness in the Queensland community about stroke and the need for it to be treated as a medical emergency.

The results of the 2022 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 Queensland community<sup>5</sup>:

- > 35 percent knew none of the signs of stroke.
- > 43 percent knew facial drooping was a sign.
- > 10 percent knew an inability to lift both arms was a sign.
- > 54 percent knew speech difficulties were a sign.

It is critical Queenslanders understand that if they or someone they know experience the signs of stroke, including facial drooping, arm weakness, or speech changes, they must call triple zero (000) immediately.

#### The Program

Stroke Foundation's F.A.S.T. (Face, Arms, Speech, and Time) Community Education Program establishes awareness and increases people's knowledge of the signs of stroke. We recruit, train, and provide 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. 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 will set up displays and activities at community events and in health settings, distribute F.A.S.T. resources, and gain local workplace support, which will facilitate improved awareness about the signs of stroke and dispatches of ambulances.

A F.A.S.T. Multimedia Campaign will be rolled out across the state, which will include an integrated multi-channel advertising campaign, as well as F.A.S.T. stories delivered via a mainstream media campaign.

Stroke Foundation currently has 16 volunteer StrokeSafe speakers in Queensland, including four in regional areas, who are trained and ready to deliver community presentations. In the last 12 months, this group has delivered 66 StrokeSafe presentations, which have reached 2,100 people across our state. With the support of the Queensland Government, this pool of volunteers will be expanded, enabling more targeted presentations to be delivered across the state, including in regional areas, and more community members to be empowered to live well.

This program will also strengthen and maximise existing Queensland Government investments in stroke quality improvement activities, treatment pathways and protocols, and infrastructure.

#### Proven success

# F.A.S.T. advertising campaigns are proven to increase awareness of the signs of stroke, and calls to emergency services, nationally<sup>6</sup> and internationally.<sup>7, 8</sup>

At the end of Stroke Foundation's last F.A.S.T. national advertising campaign in 2013–14, which was funded by the Australian Government, it was found that among the target audience<sup>6</sup>:

- there was an increase in the awareness of the signs of stroke, from 35 percent to 39 percent, which equated to almost one million people, and was reflected as an immediate 0.5 percent increase in calls to ambulance services for stroke emergencies
- > 87 percent of people could recognise one or more signs of stroke
- the number of people who said they would call an ambulance if a stroke was suspected increased from 70 percent to 76 percent.

F.A.S.T. advertising and marketing campaigns 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. However, analysis shows that a campaign's impact is not sustained long-term, unless it is in market. The use of local

volunteers to build on advertising and marketing campaigns, and reinforce key stroke messages, has proven to be highly successful.

Stroke Foundation's F.A.S.T. Community Education Program is currently being delivered in Tasmania, Western Australia, New South Wales, and the Australian Capital Territory, funded by respective state governments, and has been shown to be highly effective.

In Tasmania, where the State Government has been funding the F.A.S.T. Community Education Program for four years, the unprompted community awareness of the F.A.S.T. signs of stroke is significantly higher than in all other states and territories<sup>5</sup>:

- > 54 percent knew facial drooping was a sign, compared with 40 percent nationally.
- 12 percent knew an inability to lift both arms was a sign, compared with 10 percent nationally.
- > 64 percent knew speech difficulties were a sign, compared with 51 percent nationally.

In New South Wales, where the State Government has been funding the F.A.S.T. Community Education Program in regional areas since 2020, to support the roll out of the Statewide Telestroke Service, the unprompted community awareness of the F.A.S.T. signs of stroke in regional areas has been higher than in metropolitan areas<sup>5</sup>:

- 53 percent knew facial drooping was a sign, compared with 33 percent in metropolitan areas.
- 14 percent knew an inability to lift both arms was a sign, compared with 9 percent in metropolitan areas.
- 61 percent knew speech difficulties were a sign, compared with 43 percent in metropolitan areas.

#### Key deliverables

- > F.A.S.T. Community Education Program
  - Recruitment and training of StrokeSafe speakers to deliver presentations at Queensland community organisations, community centres and libraries, local councils and businesses, and workplaces.
  - There will be a focus on building partnerships with Queensland community organisations and local leaders, and attendance at community events, where information booths and displays will be set up to raise awareness of what stroke is, how to reduce stroke risk, and how to recognise the signs of stroke (using the F.A.S.T. test).
  - Distribution of F.A.S.T. collateral (including bookmarks, fridge magnets, wallet cards, posters, and 'Understand and Prevent Stroke' booklets) to Queensland community-based health professionals, hospitals, medical centres, community organisations, workplaces and homes.

- Multimedia Campaign
  - Advertising Campaign: An integrated, multi-channel advertising campaign to promote the F.A.S.T. message in Queensland will be delivered. This may include high reach, high impact broadcast channels, Outdoor (OOH) or transit media, supported by digital advertising using a screens-based approach such as digital video on YouTube or catch-up TV.
  - Media Campaign: Mainstream media coverage in metropolitan news outlets emphasising the F.A.S.T. message through stories told by survivors of stroke. News stories will include a call to action for all residents and workplaces to get behind the campaign, as well as announcements of annual F.A.S.T. awareness levels.

#### Evaluation

A formal evaluation plan will be developed. The key outcome measure will be awareness of the F.A.S.T. signs of stroke (unprompted and prompted), as measured in Stroke Foundation's annual F.A.S.T. Signs and Stroke Awareness Survey. Other specific outcome measures will be determined at the commencement of the program, and could include, but not be limited to:

- > F.A.S.T. Community Education Program
  - Awareness of key stroke risk factors, measured in Stroke Foundation's annual F.A.S.T. Signs and Stroke Awareness Survey.
  - Awareness of what actions to take in the event of a stroke, measured in Stroke Foundation's annual F.A.S.T. Signs and Stroke Awareness Survey.
  - Number of StrokeSafe presentations delivered, and number of people reached through these presentations (broken down by Social Economic Indexes for Areas, SEIFA).
  - Number of community events where information booths and displays were set up.
  - Number and type of community partnerships established.
  - Number of community-based health professionals, hospitals, medical centres, community organisations, workplaces and homes where F.A.S.T. resources were distributed, and number of resources distributed.
- Multimedia Campaign
  - Advertising Campaign: Key performance indicators to be determined with media agency, dependent on the target audience, objectives and media channels selected.
  - Media Campaign: Number of news stories promoting the F.A.S.T. message published or broadcast in metropolitan news outlets.

Queensland Government investment in Stroke Foundation's F.A.S.T. Community Education Program and Multimedia Campaign 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 Queensland community. It will also strengthen and maximise existing Queensland Government investments in stroke quality improvement activities, treatment pathways and protocols, and infrastructure.

#### Jake's Story

Jake Vincent was just 22 when he suffered a stroke in March 2020.

"It had been a great night. I'd been to a concert and then hung out with my mates in town afterwards. It was late, so I decided to call it a night and head back to my girlfriend Sidney's house with her," said Jake.

As Jake was getting ready for bed, he experienced a sudden, throbbing headache. Thinking little of it, he got up to get some paracetamol from the other side of the room, and fell over. Jake picked himself up, thinking he'd had a little too much to drink, but fell over again, this time onto the bed.

Sidney woke, and saw that Jake had a facial droop, was unable to move the left-side of his body, and was slurring his words. She remembered the F.A.S.T. signs of stroke that her Grandma Dot had taught her as a child, and called an ambulance immediately.

The paramedics arrived within 10 minutes. Jake was seen immediately upon arrival at hospital, where a brain scan confirmed he had suffered a stroke, and he was given a blood clot busting drug.

Jake spent two days in hospital, including one day in the Intensive Care Unit, before being discharged.

"Jake still has issues with fatigue and anxiety, but we know the outcome could have been far worse if we delayed seeking medical treatment," said Sidney.

Jake is now back at work full-time.

"Stroke doesn't discriminate. It doesn't matter what age you are. I'm grateful beyond words to Sidney, and I urge everyone to know the F.A.S.T. (Face, Arms, Speech, Time) signs of stroke, as the knowledge could save someone's life one day."



Survivor of stroke Jake Vincent and his girlfriend Sidney.

# Ensure all Queenslanders have access to evidencebased stroke treatment

Stroke is a medical emergency, requiring urgent medical attention; however, with the right treatment at the right time, many people can recover from stroke. 'Time is brain' stroke treatments, including thrombolysis (clot-dissolving treatment) and endovascular thrombectomy (blood clot removal treatment), are saving lives and reducing disability in survivors of stroke.

Modelling commissioned by Stroke Foundation, and undertaken by Deloitte Access Economics, has shown that if the endovascular thrombectomy rate in the Australian population was increased from its current rate of 3 percent to a target rate of 10 percent, the potential savings from meeting this benchmark in 2020 were estimated to be \$455 million over five years (in net present value terms).<sup>9</sup>

An increase in the endovascular thrombectomy rate would mean more patients who might otherwise require a lifetime of disability support being able to live independently, return to work, and resume social and community participation. These benefits and the accompanying cost savings would accrue to individual survivors of stroke and their families and carers, as well as Federal and State and Territory governments, employers, and society more broadly.<sup>9</sup>

Endovascular thrombectomy is a highly effective treatment with evidence of benefit in selected patients with large vessel occlusion<sup>10</sup>, but it requires highly specialised teams, and is restricted to comprehensive stroke centres. In Queensland, endovascular thrombectomy is provided to 7 percent of all reported ischaemic stroke patients, while thrombolysis is provided to 11 percent of all reported ischaemic stroke patients.<sup>4</sup> Stroke Foundation applauds the Queensland Government's investment in the 24/7 Endovascular Thrombectomy Service for North Queensland, which represents a huge step forward in reducing the number of patients from North and North West Queensland that require long-distance transfers to the South East of the state in order to access endovascular thrombectomy. However, more needs to be done to increase access to time-critical stroke reperfusion treatments in our state.

We know that regional Australians are 17 percent more likely to suffer a stroke than those in metropolitan areas.<sup>1</sup> In Queensland, 34 percent of the population live outside the South East corner of the state, and almost 18 percent live in areas classified as outer regional, remote or very remote<sup>11</sup>; however, for those living in these areas, access to time-critical acute stroke treatment is limited. Importantly, Queensland remains the only state without a statewide telestroke service, and State Government investment in the Queensland Virtual Stroke Service is critical in order to ensure all Queenslanders are able to access emergency stroke treatment when they need it, regardless of where they live.

Building on time-critical treatment, access to stroke unit care, characterised by provision of care in one location by a multidisciplinary team including medical, nursing and allied health professionals with expertise in stroke, is proven to make the biggest difference to patient outcomes following stroke, both in hospital and after.<sup>12, 13</sup> In Queensland, 76 percent of stroke patients are able to access stroke unit care<sup>4</sup>; however, this should be improved to over 80 percent.

Stroke Foundation is proud to be partnering with the Queensland Government to deliver the successful *StrokeLink* quality improvement program, which is focused on closing the gap between guidelines and practice. Queensland Government investment in this program (including the collection of data as part of the Australian Stroke Clinical Registry), which has been supporting hospitals across the state since 2007, has contributed to substantial improvements in the delivery of best-practice stroke treatment and care.<sup>14, 15</sup>

While many of the structural elements of good systems of care are in place, more could be done to improve processes of care. Improving the quality of stroke treatment and care provided in Queensland hospitals is critical to reducing the burden of stroke on survivors, their families and carers, and our community and health system. Stroke Foundation is committed to continuing to support hospitals and health professionals across the state to strengthen their capabilities in the delivery of best-practice, evidence-based stroke treatment and care.

#### Queensland stroke clinicians benefit from a variety of Stroke Foundation resources and initiatives which are designed to support them to improve the quality of stroke treatment and care. These include:

- The National Stroke Audit, which commenced in 2007, and provides longitudinal data on the clinical performance of Australian hospitals. Data is provided in an accessible format to help hospitals identify where improvements are required, lobby for change and celebrate success.
- Clinical Guidelines for Stroke Management, which provide recommendations for best-practice stroke treatment and care, based on the latest research. Technology and processes developed and piloted during a federal government funded research project (Phase One) have enabled the Guidelines to evolve into a 'living' model, where individual recommendations are updated as soon as new relevant evidence becomes available.
- InformMe, Stroke Foundation's dedicated website for health professionals working in stroke treatment and care, which in addition to housing the Clinical Guidelines for Stroke Management and National Stroke Audit data, includes over 50 e-Learning professional development modules covering a wide variety of topics.
- The National Webinar Series, which provides web-based education on a range of topics for health professionals working in stroke treatment and care across Australia, including in regional and remote areas. Over 90 percent of clinicians who participated in the webinars reported feeling more confident in identifying their current practice gaps after the sessions.

State Government investment in Phase Two of the world-leading Living Evidence initiative will enable the living approach for clinical guidelines to continue to evolve, ensuring Queensland health professionals have access to reliable, accessible, and up-to-date clinical recommendations.

Funding of this initiative will strengthen and maximise existing Queensland Government investments in stroke quality improvement activities, treatment pathways and protocols, and infrastructure. This initiative will also deliver on a key objective of the *My health, Queensland's future: Advancing health 2026* strategy, pursuing innovation, and promoting research and its translation, to facilitate better decisionmaking by health professionals, providing them with the tools to identify and embed new evidence-based practices into day-to-day care.

### Phase Two of the world-leading Living Evidence initiative.

**Investment:** \$1.75 million over three years.

#### Background

In 2018, Stroke Foundation and Cochrane Australia were awarded funding by the Medical Research Future Fund, for a pilot project to develop world-first 'living' stroke guidelines. Technology and processes Stroke Foundation has developed and piloted (Phase One) with Cochrane Australia, as part of the Living Guidelines for Stroke Management, have enabled the Cochrane team to pivot quickly to establish a National Taskforce supporting Australian clinicians with accessible, evidence-based living guidelines for the clinical management of patients with COVID-19.

Living guidelines ensure clinical recommendations are streamlined, up-to-date, and accessible when and where they are needed. During Phase One of this initiative, the world's first living guidelines for stroke and COVID-19 led to a 99 percent reduction in time from research to point-of-care. In addition, clinicians had higher levels of trust in the living guidelines compared with the traditional guidelines model, resulting in increased use of guideline recommendations in their daily practice.

We know that the net societal benefit of implementing new guidance within the first year of practice-changing evidence becoming available (rather than five years later), for just two interventions in stroke and diabetes, is more than \$1.2 billion.<sup>16</sup>

The living guidelines model has the potential for worldwide adaptation and paves the way for future innovation for a range of health conditions.

#### The project

Stroke Foundation is part of the Australian Living Evidence Consortium (The Consortium), a collaboration bringing together experts in evidence synthesis, guideline development and digital technologies, to build a revolutionary new system for delivering reliable, accessible, up-to-date evidence in health.

The Consortium has developed a business case to deliver Phase Two of the Living Evidence initiative and continue to evolve the 'living' approach for the Clinical Guidelines for Stroke Management.

Phase Two of the program will be comprised of the following four pillars:

- Pillar 1 Establishing a national Living Evidence support hub: Develop bestpractice methods and processes, train, support, build quality and capacity and coordinate and standardise approaches.
- Pillar 2 Building a Living Evidence digital technologies platform: Further develop, enhance and integrate technical systems and digital solutions, reducing unit costs and time.

- Pillar 3 Producing Living Guidelines: Develop and maintain living guidelines (to NHMRC standards) for five of Australia's most high-burden diseases.
- Pillar 4 Getting the latest evidence to where it's needed: Optimise the dissemination and utility of evidence-based guidance and partner with Australia's leaders in knowledge translation to drive practice and policy change.

The Consortium is seeking \$24.5 million in contributions from federal and state and territory governments, and philanthropic organisations, with proposed contributions of: \$10 million from the Federal Government; \$8 million from state and territory governments; \$4.5 million from philanthropic organisations. The Consortium will dedicate significant in-kind contributions, existing capabilities, and existing research funding and partnerships.

To date, the following commitments have been secured:

- Financial commitments from the Victorian and Western Australian governments, and philanthropic organisations (The Ian Potter Foundation, Gandel Foundation, and Lord Mayor's Charitable Foundation).
- > Self-generated funding through service contracts and leveraged research grants.
- > In-kind contributions from NSW Health and Consortium partners.

#### Evaluation

The Consortium will measure, and report on, key performance indicators across specific benefit domains to be delivered through this project:

- Rapidly bringing health and medical research discoveries to point-of-care and decision-making, targeting:
  - an 80 percent reduction in the time from publication of relevant new research to incorporation in evidence-based guideline recommendations.
- Driving health system value through accelerated co-production of best-practice recommendations based on the latest evidence, targeting:
  - a 50 percent reduction in time to complete key tasks for systematic review
  - a 25 percent reduction in time to update guideline recommendations to NHMRC standards
  - a 300 percent increase in the number of patients and healthcare professionals involved in living guideline development.
- Giving patients more opportunities and resources to be active participants in their healthcare, targeting:
  - a 300 percent increase in the number of individuals accessing living guideline recommendations
  - 30,000 monthly users of patient decision aids and clinical decision support tools.

State Government investment in Phase Two of the Living Evidence initiative will enable the 'living' approach for the Clinical Guidelines for Stroke Management to continue to evolve, equipping stroke clinicians with the knowledge to drive quality improvement in treatment and care across Queensland.

#### **Aaron's Story**

Aaron Zadow was just 30 when he suffered a major stroke.

Aaron lives in a regional town, so when a brain scan at the local hospital showed that he had suffered a stroke, he was still hours away from specialised stroke services.

Fortunately, new research had been rapidly included in the Living Clinical Guidelines for Stroke Management. This extended the time window for life-saving endovascular thrombectomy (blood clot removal) treatment from 6 to 16 hours after the start of a stroke.

Aaron was rushed to the nearest major hospital that delivers this specialised stroke therapy, and was treated 7 hours after the onset of his stroke. He survived and is making a steady recovery.

As a result of this change in practice, Aaron will see his kids grow up and will not have to spend the rest of his life in a nursing home.

Aaron is one of more than 300 Australians to date who have been saved from death, or severe disability, as a result of this one 'living' guideline recommendation.



Survivor of stroke Aaron Zadow and his family.

# Enhance recovery to help Queenslanders live well after stroke

The impact of stroke is far reaching, and well beyond discharge from hospital a significant proportion of survivors of stroke have yet to make a full recovery. Many survivors speak of falling into a 'black hole' once they are discharged from hospital. The often profound and prolonged brain injury resulting from stroke can severely impact a survivor's ability to navigate an often-complex health and welfare system. This can add time and frustration to their recovery, and lead to poorer health outcomes, and hospital readmissions.

Continuity of care is an issue for survivors of stroke once discharged from hospital, and one of the major challenges to improving continuity of care is inconsistent discharge planning from the hospital system.

Importantly, 26 percent of Queensland survivors of stroke are discharged from hospital without a discharge care plan.<sup>4</sup> As a result, they and their families and carers often do not receive critical information on secondary prevention, follow-up, rehabilitation, and relevant supports and services which exist in the community.

Stroke Foundation is committed to reaching out to those impacted by stroke to ensure more Queenslanders can connect with and access trustworthy information, resources, and poststroke support. Specifically, our goal is to ensure that by 2024, 85 percent of Queenslanders will be connected to Stroke Foundation and enabled to navigate the ongoing support they need to live well after stroke.

Thousands of Queenslanders benefit from Stroke Foundation's suite of resources and services which are designed to support survivors of stroke, their families and carers following discharge from hospital, and are provided thanks to the generous support of Stroke Foundation donors and partners. These include:

- EnableMe, Stroke Foundation's recovery website with over 11,000 registered users. This online resource, co-designed with survivors of stroke and carers, provides videos, podcasts and fact sheets on a wide range of topics impacting daily life after stroke, a community forum to ask questions and share experiences, a tool to set and track personal goals for recovery, and an online helpdesk to ask questions of Stroke Foundation health professionals.
- My Stroke Journey, 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. In 2021, 147 hospitals delivered this resource to more than 23,000 Australians. My Stroke Journey is now a suite of resources, with versions available in both standard and easy English, and for Aboriginal and Torres Strait Islander peoples, and parents and carers of children who have had a stroke.
- StrokeLine, a service that provides free expert information, advice, support and referral on stroke prevention, treatment and recovery to the general public and to survivors of stroke, their families, and carers. StrokeLine delivers services via telephone, email, social media and EnableMe, and aims to equip people to take

action as required; however, if the individual contacting the service is vulnerable or at risk, StrokeLine's health professionals coordinate their care and follow-up as needed.

Stroke Foundation is expanding its inbound StrokeLine service, building on existing capabilities to deliver a digitally enabled and enhanced, equitable, and accessible StrokeConnect Navigator Program with outreach capabilities. State Government investment in this program will mean more Queensland survivors of stroke, their families, and carers will be able to access the information, advice, support, referral, and care coordination they need to achieve their best possible recovery.

The StrokeConnect Navigator Program will deliver on a key objective of the *My health, Queensland's future: Advancing health 2026* strategy, making the health system work better for consumers and their families, through all levels of the system working together for better coordinated and connected healthcare, with a focus on reducing preventable hospitalisations.

### StrokeConnect Navigator Program.

**Investment:** \$304,000 per annum over three years.

#### Background

Navigating the complex health system after leaving hospital is often one of the greatest barriers to success that Queensland survivors of stroke face in their recovery journey.

We know that 26 percent of Queensland survivors of stroke leave hospital without a discharge care plan, and 18 percent leave hospital without education on how to avoid another stroke through behaviour change for modifiable risk factors.<sup>4</sup>

This leaves many Queenslanders unable to achieve their best possible recovery, manage their health, and live well after stroke.

Stroke Foundation delivers a variety of products and services for survivors of stroke, their families and carers, including the *My Stroke Journey* suite of resources, *EnableMe*, and *StrokeLine* service; however, based on our own existing services' data, we know there is unfulfilled demand for services from survivors of stroke who cannot easily navigate the health system after leaving hospital. For example, since January 2022, only 623 survivors of stroke have received an outreach service (outbound), and 2,457 self-referred to the StrokeLine (inbound) service. This is only a small percentage of the nearly 450,000 Australians living with stroke, and the more than 27,000 having a stroke for the first time this year, suggesting that a significant number of survivors are not accessing the support services available that could assist in their recovery after stroke.

This highlights a clear need for State Government investment in a program that reaches out to all Queenslanders impacted by stroke, and their families and carers, after their return home from hospital, and ensures survivors of stroke have a smooth transition from hospital into the community. This program should facilitate improved continuity of care, and ensure survivors are connected to the appropriate services and supports, and have the information they need to achieve their best possible recovery and avoid hospital readmission due to complications or recurrent stroke. This is particularly important for vulnerable survivors, and those with poor outcomes following their stroke.

#### The Program

Queensland Government investment will enable us to extend our flagship *StrokeLine* inbound information and support service, and implement our new outbound, continuity of care service, under the StrokeConnect Navigator Program. This will include technological upgrades, increased digital health capabilities, and additional health professional 'Stroke Navigators', who will:

- Ensure the inbound service manages all enquiries in a timely and appropriate way, increasing the capacity of hospital teams as they prepare survivors for discharge.
- Deliver an equitable, proactive outreach service to provide continuity of care and connection.

The development of this program has been informed by learnings gained from evaluations of current state-based outreach services delivered by Stroke Foundation in Tasmania and the Australian Capital Territory. The program will facilitate care coordination, including referrals to other service providers and outpatient appointments, as well as improved survivor knowledge, self-efficacy, health literacy and social connection. The StrokeConnect Navigator Program will also be focused on reducing the burden on family members and carers of survivors of stroke and improving their quality of life and wellbeing.

Stoke Foundation has allocated internal funding to enable a limited roll-out of this program, but is seeking support from the State Government to enable it to be scaled-up, and therefore reach more of the estimated 5,952 stroke patients admitted to Queensland hospitals each year, as well as their families and carers.

#### Referrals

Currently, Stroke Foundation's state-based outreach programs in Tasmania and the Australian Capital Territory rely on referrals from hospital-based stroke nurses. Stroke Foundation *StrokeLink* Hospital Engagement Coordinators have strong, long-standing relationships with hospitals and stroke units across the country, including in Queensland; however, the current approach relies on hospital teams providing the right information to every survivor of stroke, and puts the responsibility on survivors, their family members and carers, to make contact with the programs.

The goal of Stroke Foundation's StrokeConnect Navigator Program will be to ensure every Queensland survivor of stroke is contacted following their discharge from hospital, and provided with the appropriate level of information and support. Therefore, in order to make certain no survivor falls through the cracks, we propose to work with Queensland Health to ensure that the appropriate notification systems are in place, and Stroke Foundation is automatically notified each time a survivor of stroke is discharged from hospital. Survivors will be able to opt out of referral to the program if they so choose. In addition, Stroke Foundation will continue to promote the *StrokeLine* inbound service through Queensland hospitals and stroke units, community partners, and social media.

#### Staffing and delivery

Patients with chronic and complex conditions such as stroke are likely to require treatment and care from several different health professionals. The skills and knowledge of multidisciplinary health professional teams are critical in helping survivors of stroke manage their condition and maximise their level of functioning. Therefore, the 'Stroke Navigators' who will be responsible for delivering the program day-to-day will be a mix of nurses and allied health professionals such as occupational therapists, social workers, physiotherapists, and speech pathologists. As we have learned through the many years of delivering the *StrokeLine* service, it is critical for all 'Stroke Navigators' to understand stroke and the stroke support service network, in order to be able to connect survivors with the supports they need.

Queensland Government funding is critical to enabling Stroke Foundation to recruit, train, and retain health professionals to deliver the program who have the appropriate knowledge and experience in stroke, in what is an extremely competitive employment market.

The StrokeConnect Navigator Program will offer a personalised, two-tier service, depending on the participant's level of need:

- For those at low risk of hospital readmission and poor physical, social, and mental health outcomes, there will be two 'lighter touch' options:
  - A tailored, self-directed digital solution.
  - A peer support solution, where survivors of stroke are matched in a structured, supportive relationship with a trained, more experienced survivor of stroke peer mentor. Interactions will be either face-to-face, online, and/or by phone, depending on individual preferences.
- For those at medium to high risk of hospital readmission and poor physical, social, and mental health outcomes, there will be an intensive, health professional-led solution.

While some participants may only require one consultation with the program, others may require one or more follow-up consultations, depending on the complexity of their needs.

#### Evaluation

A formal evaluation plan will be developed, and the program will be monitored throughout for continuous improvement. Specific outcomes to be measured will be determined at the commencement of the program, and could include, but not be limited to:

- > Number of outbound client referrals made and actioned.
- > Number of inbound client contacts made and actioned.
- Client satisfaction with the service.
- Number and type of supports provided by the service (e.g. referrals to other service providers, or provision of information on secondary stroke prevention).
- > Knowledge, self-efficacy, and health literacy, of survivors of stroke using the service.
- Health-related quality of life, emotional wellbeing, levels of distress, and rates of anxiety and depression, of survivors of stroke using the service.
- Social connection and return to work, of survivors of stroke using the service.
- Quality of life, physical and emotional wellbeing, and involvement in recovery and rehabilitation, for family members or carers using the service.
- Rates of secondary stroke and hospital readmission, in survivors of stroke using the service.

Queensland Government investment in the StrokeConnect Navigator Program will ensure more Queenslanders, regardless of where they live, are supported to manage their stroke recovery, live well, return to work (where possible), and resume social and community participation. This will have benefits for survivors of stroke, their families and carers, and our community, as well as our state's health system and economy.

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#### Contact us

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- How to get more involved
- **(i)** Give time become a volunteer.
- **Raise funds** donate or hold a fundraising event.
- Speak up join our advocacy team.
- Y Leave a lasting legacy include a gift in your Will.
- **H** Know your numbers check your health regularly.
- **Stay informed** keep up-to-date and share our message.