

A better plan for stroke for all Australians

Federal Pre-Budget
Submission
2024–25

*Survivor of stroke Lillian Chen and
her husband Jonathan.*

strokefoundation.org.au

About Stroke Foundation

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, [Stroke Strategy 2024](#).

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Introduction

Stroke is one of the biggest killers in Australia. It kills more women than breast cancer and more men than prostate cancer.¹ Despite the enormous toll stroke takes on the Australian public and health system, initiatives to improve prevention and post-stroke rehabilitation have received insufficient investment by the Australian Government to date.

Stroke is always a medical emergency. We know for every minute that a person waits to receive medical attention, stroke attacks 1.9 million brain cells.² The longer a person waits for treatment the more likely they will face death and disability.

The ripple effect of this hits the health and National Disability Insurance Scheme's (NDIS) budgets the most, with significantly higher treatment and medical costs per individual than if they received the treatment they needed as the stroke was happening. Importantly, we know that many preventive health interventions are cost-effective, and for every dollar invested in prevention there is a \$14 return.³

For this reason, Stroke Foundation is prioritising our efforts to prevent stroke in the first place, and ensure that if Australians do suffer a stroke, they know the signs of a stroke, get the best and quickest treatment possible, and are supported with the advice they need to live well and prevent secondary stroke. **However, we can't do it alone. We urgently need the support of government, in addition to the significant donations we receive from the community.** Our programs and services are in greater demand than ever before because the health system is not meeting the needs of survivors of stroke as they return to the community post-stroke.

We know that time is everything when it comes to stroke, and this is also true of the need for greater funding for Stroke Foundation programs in the next year. We need increased government investment in our proven evidenced-based programs that prevent, treat, and beat stroke nation-wide, reaching cities and the country, and people from all walks of life.

We appeal to the government that now is the time for action and investment to deliver real and long-lasting impacts for the Australian community. This submission sets out a very clear plan of action the government can take now to change the landscape of stroke prevention, treatment, and enhanced recovery in Australia.

The facts

In 2020, 27,428 Australians experienced stroke for the first time, and there were more than 445,000 survivors of stroke living in our community – many with an ongoing disability.⁴ Unless action is taken, it is estimated by 2050, Australians will experience an additional 23,154 new strokes annually, and there will be an additional 374,849 survivors of stroke living in the community.⁴

One of the key modifiable risk factors for stroke is high blood pressure. Importantly, 4,728,100 Australians are living with high blood pressure,⁴ and many don't know it. In addition, 2,790,800 Australians are daily smokers, 2,472,000 have high cholesterol, 3,127,900 are physically inactive, and 13,775,000 are overweight or obese¹ – putting them at an increased risk of stroke.

The solutions

Stroke Foundation has identified a six-point plan that if implemented will make a significant difference to survivors of stroke and their recovery, deliver national evidence-based best-practice stroke treatment, and ensure more Australians know the signs of stroke and are able to address the risk factors to prevent stroke in the first place (Figure 1).

This plan builds on the support we have had from the Australian Government to date to deliver the successful and targeted *F.A.S.T. (Face, Arms, Speech, Time) Community Education Program and Multimedia Campaign for regional and culturally and linguistically diverse (CALD) communities*, as well as the *Living Well After Stroke Pilot Program*. We are proud of the in-roads made to date, but more needs to be done.

That's why we are calling on the government to fund the following six initiatives in the 2024–25 budget:

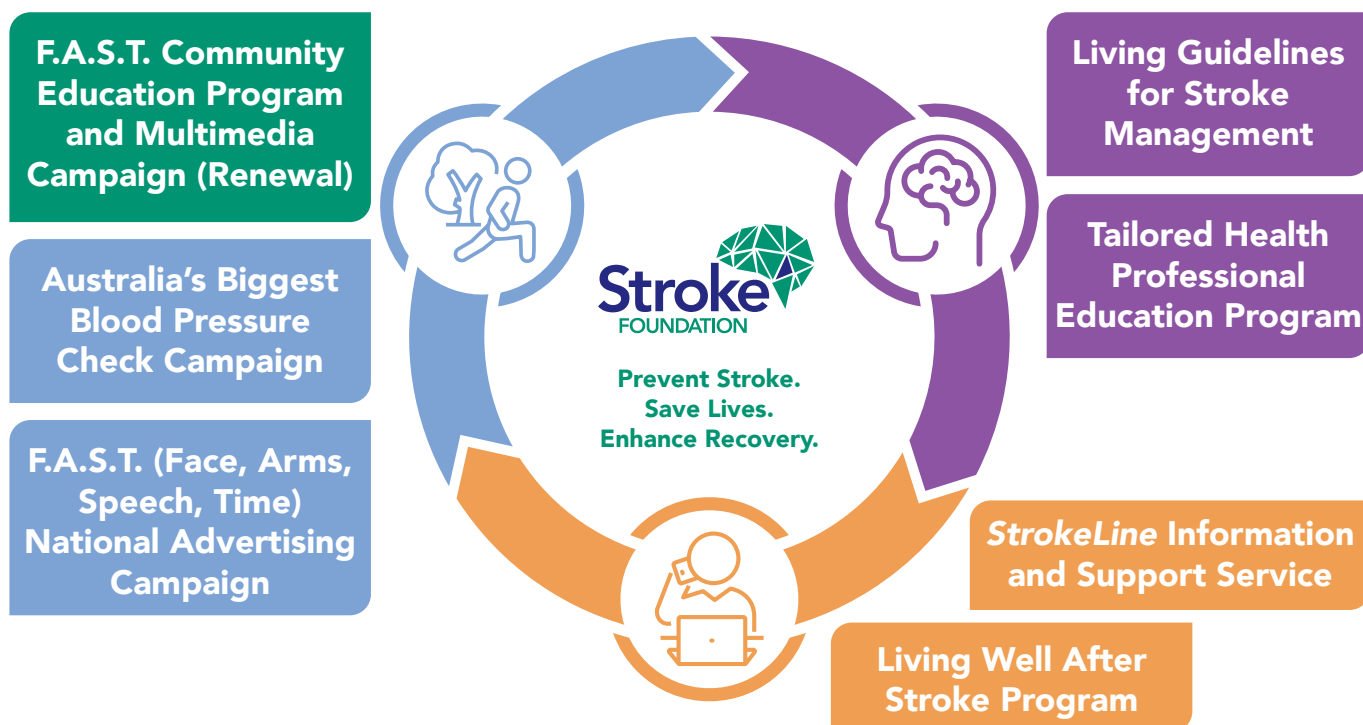
1. A game changing **F.A.S.T. (Face, Arms, Speech, Time) National Advertising Campaign** to ensure more Australians know the signs of stroke and act quickly. We know if Australians receive treatment within 4.5 hours of stroke onset they are more likely to avoid death and disability.
2. The most common risk factor for stroke is high blood pressure. For the past decade, Stroke Foundation has been delivering the annual **Australia's Biggest Blood Pressure Check** campaign to reduce the incidence of high blood pressure, but we need more support to reach more Australians. By doing this, we will be able to prevent more strokes from happening in the first place.
3. Ensure best-practice national stroke treatment standards are achieved, by investing in the **Living Guidelines for Stroke Management** (a world-first approach). This will ensure Australians continue to receive up-to-date evidence-based stroke treatment and care within the health system, no matter where they live.
4. Provide health professionals nation-wide with tailored educational resources that address their specific needs and identified practice gaps through our **Tailored Health Professional Education Program**. This will ensure they have

the knowledge and tools they need to improve the safety, quality and effectiveness of stroke care provided in Australian hospitals, which will lead to better health outcomes for stroke patients, and a reduction in the burden of stroke on our health system and community.

5. Expand the successful **Living Well After Stroke** pilot program to a national program, to provide expert advice to survivors of stroke across the country so they can be empowered to change their health behaviours, live well, and prevent secondary stroke.
6. Invest in **StrokeLine**, the national stroke helpline, which is currently over-run with calls, which provides survivors of stroke, their carers, families and friends, with critical advice and information. The donations we receive to run this service can no longer keep up with the increased demand, because the health system is failing to provide the advice and support survivors of stroke need once they are discharged from hospital.

If this person-centred approach that addresses all aspects of the health journey for survivors of stroke is funded, we will be able to more effectively support community health care and best-practice treatment, which will deliver significant long-term economic returns to the health system.

Figure 1. The six-point plan for preventing, treating and beating stroke in Australia



Summary of key budget proposals

Proposal	Investment	Page
Prevention: Fewer preventable strokes in Australia		
<p><i>F.A.S.T. National Advertising Campaign</i></p> <p>Ensure more Australians know how to recognise the signs of stroke.</p>	\$2.5 million p.a. (over four years)	7
<p><i>Australia's Biggest Blood Pressure Check Campaign</i></p> <p>Increase awareness of high blood pressure as a risk factor for stroke, as well as support GPs and pharmacists to better identify high blood pressure, in the Australian community.</p>	\$750,000 p.a. (over four years)	9
Treatment: Ensure all Australians have access to evidence-based stroke treatment		
<p><i>Living Guidelines for Stroke Management</i></p> <p>Enable the living approach for clinical guidelines to continue to evolve, ensuring Australian health professionals have access to reliable, accessible, and up-to-date clinical recommendations.</p>	\$250,000 p.a. (over four years)	13
<p><i>Tailored Health Professional Education Program</i></p> <p>Deliver tailored, web-based educational resources for Australian health professionals, which address their specific needs and identified practice gaps.</p>	\$350,000 p.a. (over four years)	15
Recovery: Enhance recovery to help Australians achieve better outcomes after stroke		
<p><i>Continue the Living Well After Stroke Program</i></p> <p>Reduce the risk of recurrent stroke through effective secondary prevention.</p>	\$625,000 p.a. (over four years)	18
<p><i>StrokeLine Information and Support Service</i></p> <p>Ensure more survivors of stroke, their families, friends and carers, and the community, have access to expert information, advice, support and referral on stroke prevention, treatment and recovery.</p>	\$800,000 p.a. (over four years)	20

Fewer preventable strokes in Australia – why we need to act now

More than 80 percent of strokes can be prevented,⁵ and stroke prevention remains the most effective means of reducing the burden of stroke in Australia.

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

The Strengthening Medicare Taskforce report, released by the Albanese Government in February 2023, calls for Australia to invest in innovative initiatives to support patient-centred care and reduce the impact of complex and chronic conditions.⁶ Through our programs, Stroke Foundation works with health professionals, researchers and the community to achieve tangible impacts across the entire stroke care spectrum, to optimise the efficiency of Australia's health workforce across the primary care sector. Our prevention, quality improvement, and recovery programs empower people to be more involved in their health care, access best-practice treatments earlier and recover better.

Stroke Foundation was commissioned by the Australian Government to co-develop the National Strategic Action Plan for Heart Disease and Stroke (the Action Plan)⁷ in 2019, under the overarching National Strategic Framework for Chronic Conditions (the Framework).⁸ The Action Plan recommends the implementation of initiatives to reduce avoidable hospital admissions, disability and premature deaths due to cardiovascular disease and stroke in Australia.⁷ Our programs are informed by, and aligned with, the vision and mission of the Action Plan, with clear goals to reduce the physical, psychosocial and economic impacts of stroke on the Australian community, survivors of stroke, their families and carers, and the health system.

A review of the Framework⁸ is currently underway, and Stroke Foundation is engaged in, and supportive of this process, to guide future sustainable and evidence-based investment in the prevention and treatment of stroke and other chronic conditions in Australia.

Stroke Foundation is committed to reducing the number of preventable strokes in our community, by empowering more Australians 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 Australians 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 with their general practitioner. 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 Australian Government to deliver the F.A.S.T. (Face, Arms, Speech, Time) Community Education Program and Multimedia Campaign for regional and CALD communities, two priority populations with an increased risk of stroke. We know that regional Australians are 17 percent more likely to suffer a stroke than those in metropolitan areas,⁴ while those in CALD communities often experience a higher burden of chronic conditions, including stroke, due to barriers which impact their ability to access health services and the information they need to make informed decisions about their health. Australians in these high risk communities have received life-saving messages about stroke, how to reduce stroke risk, how to recognise the signs of stroke and the importance of calling triple zero (000) immediately (using the F.A.S.T. test), as a result of this program; however, more must be done to increase the number of Australians who are able to receive life-saving stroke treatment sooner.

We are calling on the Australian Government to invest in a F.A.S.T. (Face, Arms, Speech, Time) National Advertising Campaign and in the Australia's Biggest Blood Pressure Check Campaign, to lift national awareness of the signs of stroke, increase awareness of high blood pressure as a risk factor for stroke, as well as support GPs and pharmacists to better identify high blood pressure in the Australian community.

1. F.A.S.T. (Face, Arms, Speech, Time) National Advertising Campaign – we need more people to know the signs of stroke now

Investment: \$2.5 million per annum over four years.

We know the Australian Government is focused on increasing awareness and understanding of stroke within the Australian community. Stroke Foundation's *F.A.S.T. (Face, Arms, Speech, Time) National Advertising Campaign* aligns strongly with this focus and will help the Government to deliver on a key action of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to implement a nation-wide, targeted education and awareness campaign for stroke.

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.

Importantly, only 38 percent of Australian stroke patients arrive at hospital within the 4.5-hour window for clot-dissolving treatment (thrombolysis).⁹ There is a clear lack of awareness in the Australian community about stroke and the need for it to be treated as a medical emergency.

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 Australian community which showed that 51 percent knew speech difficulties were a sign, 39 percent knew facial drooping was a sign, and 10 percent knew an inability to lift both arms was a sign.¹⁰ **As such, more needs to be done to improve awareness of the F.A.S.T. signs of stroke in the Australian community.**

It is critical Australians 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.

Stroke Foundation is proud to be partnering with the Australian Government to deliver the F.A.S.T. Community Education Program and Multimedia Campaign for regional and CALD communities. This initiative is delivering results; however, more must be done to increase the number of Australians who are able to receive life-saving stroke treatment sooner.

F.A.S.T. advertising campaigns are proven to increase awareness of the signs of stroke, and calls to emergency services, nationally¹¹ and internationally^{12, 13}, 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.

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 awareness of the signs of stroke increased 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.¹¹ These results are also reflected internationally. In New Zealand, calls to emergency services increased by 32 percent while the F.A.S.T. campaign was being delivered,¹² and in the United Kingdom calls increased by 78 percent.¹³

Therefore, Stroke Foundation is calling on the Australian Government to invest in a nationwide advertising campaign to lift national awareness of the signs of stroke.

We know that the use of other channels, in combination with TV, can help to reinforce and strengthen understanding of key messages. As such, this investment will deliver a **national advertising campaign that will meet people where they are at, including on TV, radio, and social media platforms**, which will be crucial for driving awareness and long-term recall of the F.A.S.T. message in the target audience. This campaign will provide nationwide coverage in all capital cities, with content showing during peak viewing times.

A formal campaign 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 F.A.S.T. Signs and Stroke Awareness Survey. Other specific outcome measures will be determined prior to the commencement of the campaign.

We are calling on the Australian Government to invest in a F.A.S.T. National Advertising Campaign, which will increase the number of Australians who understand how to recognise a stroke when it occurs, and how vital it is to call an ambulance immediately. This campaign will support and strengthen the work of Stroke Foundation's F.A.S.T. Community Education Program, which is being delivered nationally and at a state and territory level, and will ensure life-saving information on the signs of stroke reaches a broader audience, using a national platform and a single message.

Eddie's Story



Survivor of stroke, Eddie.

Eddie was 49 when he suffered a stroke.

He was at home when he began to experience the telltale F.A.S.T. (Face, Arms, Speech and Time) signs of stroke.

"I went to stand up and felt light-headed. I noticed I couldn't raise my left arm. I tried to get up again, but my legs collapsed from underneath me," said Eddie.

Thankfully, Eddie's wife Caroline was at home at the time. She had participated in a first aid course at work only the day before, where she had learnt about the signs of stroke. She knew what to do, kept Eddie calm, and called triple zero (000).

"I have no doubt she saved my life, if not my life, she was able to greatly improve my quality of life by getting me the help I needed quickly," said Eddie.

"I didn't realise younger people had strokes, but the reality is, they can happen to anyone, at any time," said Eddie.

Eddie says he's fighting stroke by facing challenges he once thought impossible.

"Being back at work was a big achievement of mine. It's been really great to have some independence."

"My next goal is to make it to the top of Mount Wellington. That would be the pinnacle of my recovery journey."

2. Australia's Biggest Blood Pressure Check Campaign –Australia has one of the lowest rates of controlled high blood pressure, it's time to change that

Investment: \$750,000 per annum over four years.

We know the Australian Government is focused on detecting and better managing Australians at risk of stroke. Stroke Foundation's *Australia's Biggest Blood Pressure Check Campaign* aligns strongly with this focus and will help the Government to deliver on a key action of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to improve the identification and management of high blood pressure. This campaign will also help the *National Hypertension Taskforce* to deliver on its goal of improving Australia's blood pressure control, doubling rates from 32 percent to 70 percent by 2030.

High blood pressure is the leading modifiable risk factor for stroke and the most preventable cause of stroke worldwide.¹⁴ **The number of strokes experienced globally would be almost halved (48% reduction) if high blood pressure was eliminated.**⁵ In Australia, it affects six million (34%) people aged 18 years and over.¹⁵

Importantly, while high blood pressure can be controlled through lifestyle modifications and the use of antihypertensive medications, the rate of uncontrolled high blood pressure in Australia remains unacceptably high, affecting 4.1 million (23%) Australians aged 18 years and over.¹⁵ Most Australians living with uncontrolled high blood pressure remain unaware, as they often do not experience symptoms. The only way to know if you are suffering from this 'silent killer' is to get your blood pressure checked regularly.

Modelling commissioned by Stroke Foundation, and undertaken by Deloitte Access Economics, has shown that if the rate of uncontrolled hypertension in the Australian population were reduced from its current rate of 23 percent to a target rate of 17 percent, then 1,217 strokes would have been avoided in 2020.¹⁶ The potential savings from meeting this benchmark in 2020 were estimated to be \$1.3 billion over five years (in net present value terms).¹⁶

Investment is needed in public education programs and campaigns that improve health literacy and awareness of high blood pressure as a risk factor for stroke, as well as support and build the capacity of primary health care professionals to better identify high blood pressure, in the Australian community.

Stroke Foundation's annual 'Australia's Biggest Blood Pressure Check (ABBPC)' campaign, that began in 2014, is central to our mission to increase awareness of the link between high blood pressure and stroke.

Initially a one-day national campaign held at outdoor activation sites and pharmacy stores, it has expanded to a month-long campaign coinciding with World Hypertension Day in May.

The activities undertaken as part of this campaign have included the delivery of free health checks in community settings across Australia, including workplaces, pharmacies, and public events. Since the beginning of ABBPC over one million Australians have had a free health check. This campaign has demonstrated that opportunistic health checks are an effective tool for increasing community awareness of stroke risk factors, by identifying those at high risk and prompting them to act.

In recent years, ABBPC has largely been a media-based campaign, which has encouraged Australians to visit pharmacies or their GP to get their blood pressure checked.

Key activities of this campaign will include:

- › Education events, including webinars, and resources, for pharmacies, GPs, and allied health practitioners regarding the identification and management of high blood pressure.
- › Blood pressure activation sites at community events (including targeted activities with priority groups such as Men's Sheds), health expos and workplaces.
- › A partnership with NACCHO and peak bodies for First Nations Health Workers (NATSIHWP) to co-design and deliver targeted health messaging in First Nations communities.
- › A media campaign, including a call to action for Australians to get their blood pressure checked at their pharmacy or GP, with specific blood pressure patient case studies.
- › Social media engagement (Facebook, Instagram, X and LinkedIn).
- › A targeted, fully integrated, multi-channel advertising campaign (including radio, Facebook and YouTube digital advertising, and other channels as appropriate).

To evaluate the progress and impact of this campaign, a mix of qualitative and quantitative performance measures will be utilised. We envisage these will include:

Quantitative performance measures

- › F.A.S.T. Awareness Survey – community awareness of blood pressure as a key risk factor for stroke (compared to baseline measurements from previous calendar years).
- › Number of Medicare health checks (MBS Items 701, 703, 705, 707 and 715) delivered nationally in the 6 months before and after the campaign (compared to baseline data from 2022 and 2021).
- › Number of education events and resources delivered.
- › Number of ABBPC online Blood Pressure Quizzes completed.
- › Number of ABBPC campaign webpage users.

Qualitative performance measures

- › Geographic distribution and gap analysis of campaign engagements – to inform future blood pressure awareness, promotion and prevention activities.
- › Survey of health practitioners and the community to identify blood pressure health literacy gaps.
- › Analysis of future language and cultural needs to develop culturally appropriate blood pressure resources to better support priority populations (e.g. First Nations, CALD, etc).

We are calling on the Australian Government to invest in Stroke Foundation's Australia's Biggest Blood Pressure Check Campaign, which will increase awareness of high blood pressure as a risk factor for stroke, as well as support GPs and pharmacists to better identify high blood pressure, in the Australian community. It will also strengthen and maximise existing Australian Government investment focused on the prevention of chronic conditions, including the National Hypertension Taskforce, and will help to shift the number of Australians with adequately controlled blood pressure from 32 percent to the target of 70 percent by 2030.



Ensure all Australians have access to evidence-based stroke treatment – every minute counts

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).¹⁶

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.¹⁶

Endovascular thrombectomy is a highly effective treatment with evidence of benefit in selected patients with large vessel occlusion,¹⁷ but it requires highly specialised teams, and is restricted to comprehensive stroke centres. This life-saving treatment is provided to 8 percent of all reported ischaemic stroke patients in Australia, while 10 percent of ischaemic stroke patients receive thrombolysis treatment.⁹

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.^{18, 19} Importantly, only 72 percent of Australian stroke patients are able to access stroke unit care.⁹ More work needs to be done to improve access to stroke unit care in Australia.

The Australian Stroke Coalition (ASC), co-chaired by Stroke Foundation and the Australian and New Zealand Stroke Organisation, has developed a voluntary system for certification of stroke units in Australian hospitals, which has now been piloted. Eleven hospitals across Australia were successful in achieving certification during this pilot. The ASC Stroke Unit Certification Program is now an ongoing initiative, with the goal of certifying all centres providing stroke care in Australia by 2030.

While many of the structural elements of good systems of care are in place, more could be done to improve processes of care in Australia. Improving the quality of stroke treatment and care provided in Australian hospitals is critical to reducing the burden of stroke on survivors, their families and carers, and our community and health system. A Learning Health System (LHS), involving ongoing cyclical processes, where practice is turned into data, which is then analysed to generate new knowledge, which in turn is implemented into practice, has been identified as an important element in improving the quality, safety and efficiency of care.²⁰ Knowledge of performance is critical to identifying gaps in care and to helping prioritise quality improvement activities.²¹ In the case of a Stroke LHS, it is critical that²¹:

- › all acute and rehabilitation stroke services routinely monitor care by collecting national acute stroke quality of care indicators, and/or agreed rehabilitation indicators
- › stroke services quality committees regularly review stroke data dashboards that monitor near real-time performance
- › stroke services compare their performance with national benchmarks and actively drive improvement.

Stroke Foundation is committed to supporting hospitals and health professionals to strengthen their capabilities in the delivery of best-practice, evidence-based stroke treatment and care, and have developed *StrokeLink*, a stroke quality improvement program focused on closing the gap between guidelines and practice. This program has been supporting hospitals across Queensland since 2007, with funding from the Queensland Government, and has contributed to substantial improvements in the delivery of best-practice stroke treatment and care.^{22, 23}

Australian stroke clinicians also 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, and are provided thanks largely to the generous support of Stroke Foundation donors and partners. 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 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.

We are calling on the Australian Government to invest in the world-first Living Guidelines for Stroke Management, and a Tailored Health Professional Education Program, which will support Australian stroke clinicians and ensure they have the knowledge and tools they need to drive quality improvement in treatment and care.

3. Living Guidelines for Stroke Management – ensuring best-practice treatment to prevent death and disability

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

We know the Australian Government is focused on developing a platform to rapidly translate research evidence into clinical practice and policy. Stroke Foundation's *Living Guidelines for Stroke Management* aligns strongly with this focus, and will help the Government to deliver on a key action of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to improve research translation and availability of evidence through 'living', continuously updated clinical guidelines.

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

Busy clinicians need robust reviews to summarise the latest research to guide their practice. Living guidelines ensure clinical recommendations are streamlined, up-to-date, and accessible when and where they are needed. **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, a formal evaluation of the Living Guidelines for Stroke Management found that clinicians have 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.²⁴

The substantial investment in health research by the Australian Government needs to be followed up by investment in tools and resources (such as guidelines), that will ensure the research investment benefits patient outcomes more rapidly.

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

Stroke Foundation is part of the Australian Living Evidence Collaboration (ALEC), which brings 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.

Over the last two years, funding from ALEC has enabled Stroke Foundation to maintain the Living Guidelines for Stroke Management, albeit in a scaled-back fashion. In order for Stroke Foundation to be able to continue to develop and maintain these guidelines in a sustainable way, and to NHMRC standards, Australian Government investment is needed.

We are calling on the Australian Government to invest in the Living Guidelines for Stroke Management, which will enable the 'living' approach to guideline development to continue to evolve in a sustainable way, equipping stroke clinicians with the most up-to-date knowledge with which to drive improvements in treatment and care across Australia.

Aaron's Story



Survivor of stroke Aaron and his family.

Aaron 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 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.

Almost 2 years after his stroke, Aaron still struggles with fatigue, and finding his words as a result of aphasia, but is almost back to full-time work, and is achieving many of the goals that he has set for himself.

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

4. Tailored Health Professional Education Program for Australian stroke clinicians – helping to close the gap between guidelines and practice

Investment: \$350,000 per annum over four years.

We know the Australian Government is focused on the provision of efficient, effective and appropriate stroke treatment and care for all Australians. Stroke Foundation's *Tailored Health Professional Education Program for Australian stroke clinicians* aligns strongly with this focus and will help the Government to deliver on a key action of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to develop a nationally consistent approach to support health professionals in the translation of clinical guidelines.

We understand that Australian health professionals involved in the delivery of stroke treatment and care receive stroke-specific professional education through a number of channels. This includes informal channels such as colleagues at their hospital, as well as formal channels such as InformMe e-Learning modules, hospital-level training programs, and annual forums or workshops delivered at national conferences, or by local health districts or networks, state stroke networks or communities of practice. Importantly however, there is little data on the number and type of stroke-specific professional education activities individual health professionals access and complete.

Stroke Foundation has a number of evidence-based education resources which have been developed with subject matter experts, and informed by the Living Guidelines for Stroke Management. We are also in the process of developing a suite of new generation education resources that cater to the needs of today's busy stroke care teams, which will facilitate on-demand:

- › tailored, individualised, learning paths
- › training packages accredited by Stroke Foundation
- › monitoring of staff training progress mobile-friendly learning modules.

The content will be customisable and intuitive, enabling adaptation to health professionals' changing needs for on-the-job expertise that seamlessly translates in real time to improved stroke patient care outcomes. This solution supports the growing shift in the health sector towards a greater emphasis on patient-centred care, and will pave the way for real-time translation of health professional education into practice.

Importantly, the program will also support country clinicians around Australia, increasing their confidence and improving their decision-making when dealing with complex neurological conditions such as stroke.

The tailored educational resources developed for, and delivered through this program could include, but not be limited to:

- › online learning modules on InformMe
- › webinars
- › podcasts
- › videos.

The number and type of educational resources delivered, and the specific clinical areas covered in these resources, will vary from hospital to hospital, depending on a number of factors including individual site circumstances and needs, and identified gaps in treatment and care at these sites.

We are calling on the Australian Government to invest in the Tailored Health Professional Education Program, which will help close the gap between guidelines and practice and empower Australian health professionals to deliver evidence-based, best-practice stroke treatment and care across the country.

Enhance recovery to help Australians achieve better outcomes after stroke – survivors tell us they need help and support now to prevent secondary 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, 30 percent of Australian survivors of stroke are discharged from hospital without a discharge care plan.⁹ As a result, they and their families and carers often do not receive critical information on secondary prevention, 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 Australians can connect with and access trustworthy information, resources, and post-stroke support. **Specifically, our goal is to ensure that by 2024, 85 percent of Australians will be connected to Stroke Foundation and enabled to navigate the ongoing support they need to achieve better outcomes after stroke.**

Stroke Foundation is proud to have partnered with the Australian Government to pilot the behaviour modification program *Living Well After Stroke* in Queensland. This program, which is focused on secondary stroke prevention, has been shown to deliver significant and sustained gains in the performance of health behaviours that reduce the risk of future stroke.

Thousands of Australians also 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, which has been co-designed with survivors of stroke and carers. This 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. In 2022, over 76,000 survivors of stroke, their families, carers and health professionals, accessed 330,000 pages of information through *EnableMe*.

- › *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 2022, 163 hospitals delivered this resource to almost 25,000 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.

We are calling on the Australian Government to continue its investment in the successful secondary stroke prevention program *Living Well After Stroke* and invest in Stroke Foundation's flagship *StrokeLine* information and support service. This will equip survivors of stroke with skills and strategies to reduce their risk of future stroke, and ensure they, and their families, friends and carers receive the information and support they need as they navigate life after stroke.

StrokeLine Manager, Katherine.



5. Continue the Living Well After Stroke Program – this program is helping survivors to develop behaviour change skills to reduce their risk of future stroke

Investment: \$625,000 per annum over four years.

We know the Australian Government is focused on supporting Australians with stroke to make the best recovery possible, to be well, and to actively engage with the community. Stroke Foundation's *Living Well After Stroke Program* aligns strongly with this focus and is helping the Government to deliver on a key objective of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to address risk factors for stroke to encourage all Australians to live healthier lives. *Australia's National Preventive Health Strategy 2021–2030* also calls for greater Government investment in prevention, as well as partnerships and community engagement, in order to support healthier lifestyles and ensure all Australians live in good health and wellbeing for as long as possible. The *Living Well After Stroke Program* was designed and implemented specifically to help achieve this goal.

Every year, more than 39,500 Australians experience a stroke event (including more than 27,000 first-time strokes), and there are more than 445,000 survivors of stroke living in our community.⁴ Importantly, four in 10 survivors of stroke will go on to have another stroke,²⁵ and secondary stroke is more likely to be fatal or cause major disability.²⁶

More than 80 percent of strokes can be prevented,⁵ and this provides a unique and urgent opportunity to support health behaviour change and prevent secondary stroke from occurring.

People are at higher risk of stroke after their first stroke, and the Living Guidelines for Stroke Management state that stroke patients should be assessed and informed of their risk factors for recurrent stroke and educated about strategies to reduce their risk.¹⁷ Despite this, once in the community, many survivors of stroke find appropriate, evidence-informed health behaviour change interventions unavailable or difficult to access.

There is a clear need for services that address behaviour modification for the reduction of stroke risk factors, to reduce further stroke.

As such, **Stroke Foundation is proud to have partnered with the Australian Government to pilot the Living Well After Stroke Program in Queensland.** This person-centred, 8-week program provided survivors of stroke who had an identified need to change health behaviours to reduce their risk of future stroke, with a clear pathway for effective, evidence-based education and intervention to support this health behaviour change.

The program targeted health behaviours such as physical activity, healthy eating, smoking cessation, consuming alcohol within safe limits, and medication adherence, and supported participants to build motivation, set goals, plan, and implement and track health behaviour change.

Key outcomes of the Living Well After Stroke pilot included:

› **Significant behavioural improvements**

The pilot evaluation demonstrated that participants were able to achieve short-term health behaviour changes, but crucially (and uniquely) also gain up to 25 percent more positive lifestyle and health behaviour modifications (e.g. reduce smoking and salt intake, and increase physical activity amongst others) in order to lower their risk of secondary stroke.

› **Adoption of self-management skills**

The Living Well After Stroke program equipped participants with transferrable skills and strategies they could apply to improve their lifestyle. Between the end of the program (8-weeks) and the 16-week follow-up, participants showed significant improvement in an additional self-identified secondary prevention behaviour. This demonstrated that the program could foster both immediate behavioural improvements, as well as equip survivors with the skills to make further positive changes on their own.

› **Boost in wellbeing**

A consistent and significant increase in participants' wellbeing between the start of the program and its completion was shown.

› **Endorsement by participants**

Participants praised the program for filling a critical support gap, by providing not only a structured roadmap for secondary prevention, but also a platform for connection and shared understanding among survivors of stroke. This fostered control, guidance, and a supportive community that enhanced recovery and empowerment.

"All-round a friendly helpful support. I was quite lost and neglected after my stroke due to COVID and being in regional areas. This helped me feel more in control and better guided to move forward in my recovery instead of being lost and stuck."

Living Well After Stroke Program participant

The Living Well After Stroke Program was funded by a one-off Federal Government grant that will end in December 2023. To build on what has already been achieved, we are calling on the Australian Government to continue its investment in this important work. This will provide more Australian survivors of stroke with a clear pathway to lifestyle risk management after discharge from hospital. Continued funding will enable the program to continue to equip survivors with a toolkit of transferrable behaviour change skills and strategies to support long-term self-management and reduce their risk of future stroke. This will reduce the burden of stroke in our community and ensure a more sustainable health system.



6. Fund *StrokeLine* – we can't meet current demand as more survivors call to seek help and support to recover from their stroke in the community

Investment: \$800,000 per annum over four years.

We know the Australian Government is focused on improving the patient and carer journey from hospital to community. Stroke Foundation's *StrokeLine Information and Support Service* aligns strongly with this focus and will help the Government to deliver on a key action of its *National Strategic Action Plan for Heart Disease and Stroke*, which is to improve post-discharge support services for people with stroke and their carers.

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

We know that 30 percent of Australian survivors of stroke leave hospital without a discharge care plan, and 28 percent leave without education on how to avoid another stroke through behaviour change for modifiable risk factors.⁹

Similarly, when people discover they are at higher risk of stroke, they need individualised advice on their risk factors and how to manage them, and support to navigate the health system and make needed changes.

Stroke Foundation delivers a variety of products and services for survivors of stroke, their families, friends and carers, 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 this practical, free, and confidential service. *StrokeLine* delivers services via telephone, email, social media and *EnableMe*. This dedicated helpline aims to equip people to take action as required; however, if the person is vulnerable or at risk, health professionals coordinate their care and follow-up as needed.

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. The *StrokeLine* health professionals who deliver this service day-to-day are a mix of allied health professionals such as occupational therapists, social workers, physiotherapists, and speech pathologists. Importantly, they understand stroke and the stroke support service network, and as such, are able to provide survivors with the support and information they need.

StrokeLine is a highly regarded service, with 88 percent of clients in 2022 saying they would recommend it to someone else. This was similar to 2021, indicating the service delivers a consistent and positive user experience.

Based on our own existing services' data, we know there is unfulfilled demand for services such as *StrokeLine*. This service provided information and support to 2,600 survivors of stroke, their families, friends and carers, and the public during 2022. 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. Since 2021, there has been an almost three-fold increase in the number of complex calls into *StrokeLine*. Specifically, there are an increasing number of vulnerable survivors calling the service for advice and support, who in addition to trying to manage the consequences of their stroke, are also facing challenges with issues such as homelessness and social isolation. These calls are longer in duration and often require follow-up.

We are calling on the Australian Government to invest in our *StrokeLine* Information and Support Service. Our primary health care system is coming under ever-increasing pressure. *StrokeLine* is helping to ensure people don't fall through the cracks. Australian Government investment will enable us to expand this inbound information and support service, by recruiting, training, and retaining more health professionals to deliver the service who have the appropriate knowledge and experience in stroke. This will ensure more Australians, regardless of where they live, are provided with the information and support they need in a timely manner. This will have benefits for survivors of stroke, their families, friends and carers, and our community, as well as our nation's health system and economy.

Siobhan's Story



StrokeLine Officer, Siobhan.

StrokeLine received a call from a survivor of stroke in October 2022. He had been trying to access the NDIS since 2021, and was now seeking support through StrokeLine as his attempts were unsuccessful.

He had major depression, suicidal ideation, difficulty managing anger post-stroke and was isolated with minimal support. He was faced with many push backs from the NDIS and other support services.

There were many times when the survivor wanted to give up, yet the StrokeLine Officer, Siobhan, never did. Siobhan continued to show resilience, patience, compassion, and support for him, contacting Local

Area Coordinators, the National Disability Insurance Agency, and the Minister for the NDIS, as well as working with other support services, including Adrian at the Physical Disability Council of NSW.

StrokeLine is here to be a safety net and to prevent survivors from falling through the cracks. With StrokeLine's support, the survivor now has access to the NDIS. Siobhan sat in on his NDIS planning meeting to ensure a thorough handover was provided. This was a successful meeting, which was evidenced by the survivor being physically relaxed by the end of the session, and having hope that he would finally get the support he needed.

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-  **Raise funds** – donate or hold a fundraising event.
-  **Speak up** – join our advocacy team.
-  **Leave a lasting legacy** – include a gift in your Will.
-  **Know your numbers** – check your health regularly.
-  **Stay informed** – keep up-to-date and share our message.