

A better plan for stroke – helping Victorians avoid, survive, and live well after stroke.

- › **Impact of stroke on Australian survivors of stroke, their families and carers**
 - › Stroke is a leading cause of disability in Australia. The impact of stroke on survivors and carers is significant with survivors of stroke more likely to have profound limitations relating to self-care, movement and communication than other people with disability.¹
 - › Two years after a stroke, most survivors have reduced quality of life, with many survivors of stroke rating their quality of life as poor.²
 - › Depression and anxiety are common after stroke,³ with 50 percent of survivors reporting feeling overwhelmed after hospital discharge.⁴
 - › The cost of ongoing care, rehabilitation and equipment, as well as the emotional and social impact, and lost earnings, can be overwhelming. In addition, survivors and their families and carers often live with the fear of recurrent stroke.⁵
- › **Impact of stroke on the Australian health system**
 - › In 2020, almost 70,000 Australians were hospitalised for stroke.⁶
 - › The total cost due to the direct care for Australian stroke patients in 2020 was estimated to be \$806.0 million.⁶ Meanwhile, an additional \$466.3 million in health costs brought the total health system costs attributable to stroke in Australia to an estimated \$1.3 billion in 2020.⁶

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- › These health system costs were primarily borne by the Federal Government (\$587.0 million), followed by State and Territory Governments (\$350.2 million), individuals and their families (\$151.4 million) and other payers (\$183.7 million).⁶
- › **Impact of stroke on the Australian economy and community**
- › The total economic cost of stroke in Australia was estimated to be \$6.2 billion in 2020.⁶
- › Productivity losses were the largest (\$2.9 billion) resulting largely from premature mortality, time off from work and lower employment (compared with general community) as a result of stroke.⁶
- › The biggest impact of stroke is not the economic costs it causes, but the loss of healthy life. Of the total burden of stroke, loss of healthy life and wellbeing accounted for the majority at \$26.0 billion.⁶
- › **The Victorian Government has an opportunity to strengthen its plan for better stroke prevention, treatment and support, so more Victorians are able to avoid, survive, and recover from, stroke.**
- › This year there will be more than 7,000 first-time strokes in Victoria.⁵ There are more than 113,000 survivors of stroke living in the Victorian community, many with an ongoing disability.⁵ Yet more than 80 percent of strokes can be prevented.⁷
- › Investment is needed in the implementation of proven preventive health programs that help Victorians with risk factors for stroke, and other chronic diseases, to change their health behaviours in relation to physical activity, diet, consumption of alcohol and smoking, and reduce their stroke and chronic disease risk.
- › Victorian stroke patients have access to the best emergency stroke treatment in the country. Victorian researchers and clinicians have played a critical role in the development of a number of these game-changing treatments. In addition, the Victorian Mobile Stroke Unit (Stroke Ambulance) trial, the first of its kind in Australia, which is being delivered by the State Government in partnership with a number of organisations, including Stroke Foundation, is slashing treatment times for patients, while the Victorian Stroke Telemedicine Program, run by Ambulance Victoria, is ensuring Victorians in regional and rural communities have 24/7 access to stroke specialists. Now we must ensure these investments are maximised, and all Victorians know the F.A.S.T. message and to call triple zero (000) immediately, at the first sign of stroke.
- › State Government investment, and advancements in treatment, mean more Victorians are surviving stroke, but for survivors and their family's stroke's

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impact is far reaching. Recovery from stroke can be a difficult experience, and more investment is needed in initiatives that help survivors of stroke, their families, and carers, navigate the complex health system after they leave hospital, and empower them to live well.

- Stroke Foundation applauds the Victorian Government's \$4 million funding commitment for Living Evidence Phase Two, a four-year program to develop a world-leading, end-to-end evidence system to enable busy frontline clinicians to stay continually up to date with the latest research so they can provide the best possible care, including for stroke.
- **Together we can build on the solid foundation that has been established, maximising the value of the Government's investment, and delivering a better health plan for all Victorians.**

Proposal 1

F.A.S.T. (Face, Arms, Speech, Time) Community Education Program, and implement a F.A.S.T. Multimedia Education Campaign, to reduce stroke and speed up treatment.

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 talks. 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. We aim to roll out a media focussed initiative that is driven by multi-media platforms.

Investment: \$185,000 per annum over four years.



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.

Internationally, a dramatic reduction (as much as 80 percent in some countries) in the number of acute stroke admissions during the current COVID-19 pandemic, compared to the same period in 2019, has been observed.⁸ Anecdotal evidence indicates a similar pattern in Australia. This is likely due to patients not wishing to overburden the hospital system or fearing infection with COVID-19 if they are referred to hospital.

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

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The F.A.S.T. Community Education Program has been developed and is ready to be rolled out in Victoria.

Central to the program is recruiting, training and providing support to local volunteers to raise awareness in the community about stroke, including the signs of stroke, and chronic disease prevention. Through the compelling voice of those impacted by stroke, we will increase knowledge and help to ensure patients get to hospital in the critical time window for life-saving stroke treatment.

Rationale

Only 38 percent of Victorian stroke patients arrive at hospital within the 4.5 hour window for clot-dissolving treatment (thrombolysis).⁹

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

A recent Stroke Foundation study of awareness of the signs of stroke among Victorians, found that unprompted¹⁰:

- 38 percent knew facial drooping was a sign.
- 10 percent knew an inability to lift both arms was a sign.
- 49 percent knew speech difficulties were a sign.

The program

Stroke Foundation currently has 36 volunteer speakers in Victoria who are trained and ready to deliver community talks. In the last 12 months, this group has delivered 34 StrokeSafe talks across the state. Importantly, in 2020 and 2021, StrokeSafe talks in Victoria were greatly affected by lockdowns due to COVID-19. In the last year pre-COVID-19, 2019, 132 StrokeSafe talks were delivered in Victoria.

With the support of the Victorian Government, this pool of volunteers will be expanded, enabling more targeted talks to be delivered across the state, and more community members to be empowered to live well.

In addition to delivering StrokeSafe talks, volunteers will set up displays and activities at community events and in health settings across Greater Melbourne, and in some regional areas, distribute F.A.S.T. collateral (bookmarks, fridge magnets, wallet cards and 'Understand and Prevent Stroke' booklets), gain local workplace support, and engage local media, which will facilitate improved awareness about the signs of stroke and dispatches of ambulances.

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An online community education campaign will also be run, and F.A.S.T. digital marketing resources will be created for roll-out on YouTube, and other social media channels, including Facebook and Instagram. We know that Victoria has areas of significant disadvantage, where a high proportion of residents suffer from key risk factors for many chronic diseases, including stroke. As such, we will be able to specifically geo-target these vulnerable populations in our online campaign, using the Social Economic Indexes for Areas (SEIFA) measure.

Evaluation

An evaluation plan will be developed to produce a report on the outcomes at the end of the project, with monitoring throughout for continuous improvement. Precise measures will be devised at the commencement of the project, and could include:

- › Improved recall of the signs of stroke test – F.A.S.T.
- › Number of people reached by the program broken down SEIFA.
- › Improved health literacy, and awareness of healthy behaviours for stroke, and other chronic disease prevention.
- › Number of F.A.S.T. resources delivered.
- › Number of StrokeSafe presentations delivered, events attended, and audience size.

Proven success

F.A.S.T. community education campaigns are proven to directly result in increased awareness of the signs of stroke and calls to emergency services nationally¹¹ and internationally.¹²

Evaluation of volunteer stroke education programs demonstrate they have a significant impact. These programs also aim to encourage people to be more motivated to change their behaviour with regard to stroke health, and to visit their GP in relation to any concerns about stroke risk factors.

Similar programs funded by State Governments are currently being delivered in Tasmania, Western Australia, and New South Wales, and are showing positive results. For example, a recent Stroke Foundation study of awareness of the signs of stroke found that Tasmania, where the F.A.S.T. Community Education Program has been delivered since 2019, had the highest unprompted awareness of the signs of stroke, compared with all other states and territories.¹⁰ Similarly, in New South Wales, where the F.A.S.T. Community Education Program is being delivered in regional communities,

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42 percent of participants from regional areas knew at least two of the F.A.S.T. signs of stroke, compared with only 24 percent of participants from Sydney.¹⁰

At the end of the Federal Government funded F.A.S.T. campaign in 2013–14, delivered by the Stroke Foundation, it was found that among the target audience¹¹:

- **39 percent** of people recognised F.A.S.T. in relation to stroke (up from 35 percent) among the target audience.
- **87 percent** of people could recognise one or more signs of stroke.
- **Three in four people (76 percent)** would call an ambulance if a stroke was suspected.

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 delivered¹², and in the United Kingdom calls increased by 78 percent.¹³

There is a social and economic benefit to be derived from increased awareness of stroke signs. Better awareness means more people getting to hospital in time for life saving treatment, and ultimately less death and disability from stroke. A systematic review and meta-analysis published in *The Lancet* has found for every 1,000 patients who receive clot-dissolving treatment up to six hours after stroke, approximately 100 more will be alive and independent than if they had not received treatment.¹⁴

Proposal 2

StrokeConnect Navigator Program - Outreach after stroke

Investment: \$120,000 per annum over four years.

Based on Stroke Foundation's 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, describing it as 'falling into a black hole'. Investment in a StrokeConnect Navigator Program will ensure more Victorians are supported to manage their stroke recovery, and live well, which will have benefits for both the health system and economy.

Rationale

Navigating the complex health system after leaving hospital is often one of the greatest barriers to success that Victorian survivors of stroke face in their recovery journey. 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 acute care, which has become more profound during the pandemic, as a result of increased pressure on the Victorian health system. We know that 26 percent of Victorian survivors of stroke leave hospital without a care plan, and 32 percent leave hospital without education about behaviour change for modifiable stroke risk factors.⁹ This leaves many Victorians 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 carers and families, including the My Stroke Journey suite of resources, StrokeLine, and EnableMe. However, only 750 people who experienced a stroke received an outreach service (outbound), and 2,444 self-referred to the helpline (inbound) over a six-month period in 2020. This is only a small percentage of the nearly 450,000 people living with stroke, and the nearly 27,000 having a stroke for the first time in 2020 in Australia, suggesting that a significant number are not accessing the support services available that could assist in recovery after stroke. **This highlights the need to develop a targeted outreach service that will enhance continuity of care through improved access to, and use of, supportive services provided by the Stroke Foundation and other community services. This will support the health system and reduce the demand for hospital beds.**

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The Program

Stroke Foundation's new StrokeConnect Navigator program addresses the current health service delivery gap in continuity of care and health navigation for survivors of stroke, their carers and families. The program is an evidence-based, individualised, equitable, digitally enabled and centralised Stroke Foundation outbound service, that will proactively provide information, support, and health service navigation to survivors of stroke, their carers and family members. The program has been developed from learnings gained from evaluations of current state-based Stroke Foundation outreach services, and in partnership with research organisations.

The StrokeConnect Navigator program will offer a personalised, two-tier service delivered by Stroke Foundation health professionals, depending on the level of need:

- › a **tailored, self-directed digital solution** for those at low risk of hospital readmission and poor physical, social, and mental health outcomes; and
- › a **guided, intensive solution** for those at medium-high risk of hospital readmission and poor physical, social, and mental health outcomes.

The program will rely on referrals from hospital-based stroke nurses, and Stroke Foundation's strong, long-standing relationships with Victorian hospitals, will be key to the program's success.

Evaluation

An evaluation plan will be developed to produce a report on the outcomes at the end of the project. Precise measures will be devised at the commencement of the project, and could include the following elements, measured 12 months after implementation:

- › Number of Victorian hospitals referring to the program, number of referrals to the program, and number of survivors of stroke and their families benefiting from the program, annually.
- › Referrer and participant satisfaction with the program.
- › Number of survivors of stroke receiving care coordination, including referrals to other service providers and outpatient appointments, annually.
- › Degree of disability, or dependence, in activities of daily living, in survivors of stroke.
- › Knowledge, self-efficacy, and health literacy, in survivors of stroke.
- › Health related quality of life, emotional wellbeing, levels of distress, and rates of anxiety and depression, in survivors of stroke.
- › Social connection and return to work, in survivors of stroke.

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- › Family and carers' quality of life and physical and emotional wellbeing, and family involvement in recovery and rehabilitation.
- › Rates of secondary stroke and hospital readmission.

Proposal 3

‘Living Well After Stroke’– a stroke secondary prevention behaviour change program, empowering Victorians to stay well and lessen their risk of developing further strokes.

Investment: \$202,000 per annum over four years.

The ‘Living Well After Stroke’ program will improve post-discharge support, by delivering education and support for sustainable behaviour change, as well as better coordinated care. The program will focus on Victorian survivors of stroke who have experienced a mild stroke, with no referral for ongoing rehabilitation, and an identified need to change health behaviours to reduce their risk of future stroke.

The rationale

This year there will be more than 7,000 first-time strokes in Victoria, and there are more than 113,000 survivors of stroke living in our community.⁵ However, more than 80 percent of strokes can be prevented⁷, providing a unique opportunity to support health behaviour change and prevent subsequent strokes.

People are at higher risk after their first stroke, yet many don’t receive effective intervention for health behaviour change. In the community, many people find appropriate evidence-informed interventions unavailable or difficult to access. The ‘Living Well After Stroke’ program will address this healthcare gap and support Victorians to improve their health outcomes.

The Clinical 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.¹⁵ **In Victoria, there is a need for services that address behaviour modification for the reduction of stroke risk factors, to reduce further stroke or transient ischaemic attack (TIA).**

For those with mild stroke, and no rehabilitation admission, short lengths of stay in hospital reduce opportunities for health behaviour education and intervention. After discharge, there is no clear pathway for effective, evidence-based education and intervention to support health behaviour change. This underserved group is at risk of falling through the gaps after experiencing a first stroke.

The program

To reduce the risk of subsequent stroke, the ‘Living Well After Stroke’ program will target health behaviours related to physical activity, diet, consumption of alcohol and

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smoking. This will be done through an evidence-based, person-centred, Health Action Process Approach (HAPA), that supports people to build motivation, set goals, plan, and implement and track health behaviour change. HAPA has been shown to be an effective model for people with chronic illness and disability.¹⁶ A focus on mental health, and accessing treatment and support when needed, underpins the program.

Table 1 Overview of sessions with an allied health professional as part of the 'Living Well After Stroke' program

Session 1	Engagement, education, and choosing health behaviours to focus on.
Session 2	Motivation, intention setting and development of SMART (specific, measurable, achievable, relevant, and time-bound) goals.
Session 3	Individualised action plan.
Session 4	Monitoring progress.
Session 5	Tackling setbacks.
Session 6	Celebrating and setting new goals.
Session 7	Online resources to maintain and build on change.

Acute and primary care settings can identify individuals with risk factors for further stroke and refer them to the 'Living Well After Stroke' program. Participants' GPs (with their consent) will be provided with information about the participant's goals and activities, supporting effective medical management of risk factors, including increased prescribing of, and adherence to, medication, and improved continuity of care.

Participants will receive a mix of individual and group assessments and interventions, delivered face-to-face and/or via telehealth. Education and interventions will be tailored to each individual, in line with their needs and preferences. Existing Stroke Foundation products and services will deliver ongoing information and support to participants after they complete the program.

Stroke Foundation is well placed to lead the translation of an evidence-based, person-centred approach into practice in Victoria. We have existing, effective relationships with acute and rehabilitation stroke services that are delivering our products and referring to our services such as StrokeLine.

Evaluation

An evaluation plan will be developed to produce a report on the outcomes at the end of the project. Precise measures will be devised at the commencement of the project, and evaluation of the 'Living Well After Stroke' program will focus on its impact on health behaviours, stroke risk and coordination of care. If successful, this approach could be utilised for people who have experienced TIA, as well as for other disease groups.

Proven success of similar behavioural change programs for chronic conditions

In Queensland, Stroke Foundation is part of an alliance of organisations that delivers *My health for life (MH4L)*, a similar chronic condition prevention program, that has also been developed using the HAPA model.

Since the program was rolled out in Queensland, over 210,000 Queenslanders have been engaged in a conversation about their health through undertaking a chronic disease risk assessment, more than 16,000 are currently enrolled in the program, and over 10,000 have completed *MH4L*, exceeding the program targets. Examples of the results include:

- More than 200 locally based healthcare organisations are actively involved in delivering the program in their communities, targeting prevention as a key activity.
- More than 97 percent of participants that completed the program were satisfied or very satisfied with it.
- 97 percent of participants retained their intention to change at the end of the program.
- 60 percent of participants increased their vegetable consumption by the end of the program.
- 70 percent of participants reduced their waist circumference by the end of the program, and at 6-months post-completion, 48 percent further decreased their waist circumference.
- 49 percent of participants met physical activity guidelines by the end of the program, and by 6-months post-completion, 83 percent were active for 150 minutes or more each week.
- By 6-months post-completion, 53 percent of participants did not drink sugar sweetened beverages.
- By 6-months post-completion, 43 percent of participants were eating two serves of fruit a day.

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About the Stroke Foundation

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We do this through raising awareness, facilitating research and supporting stroke survivors.

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