# An Era of Opportunity for Stroke Care Improvement

Submission on the 2016-17 Federal Budget from the National Stroke Foundation

2016-2017



CONTACT: Scott Stirling, A/Director Policy & Advocacy, National Stroke Foundation, 03 9670 1000, sstirling@strokefoundation.com.au

### **Executive Summary**

2016 marks 20 years since stroke was made a national health priority by the Council of Australian Governments (COAG). Despite development of countless state and national strategies there has never been funding for a coordinated national plan of action.

We have seen growth in stroke unit numbers, increased coordination of clinical advice through development of state clinical networks and major breakthroughs in life-saving treatment however there remains a huge variation in care and thousands of Australians are not receiving the care we know saves lives.

A concerted and organised national approach is required to ensure that quality stroke care is provided to all parts of Australia, including often neglected regional areas.

We have a significant opportunity to reduce the impact of stroke; to improve the quality of care provided by the hospital system; to ensure equity of care across urban and regional areas; and to give all survivors the community follow-up support and information they desperately need after their stroke.

The National Stroke Foundation calls for leadership from the Australian Government and cooperative engagement from the states and territories along with injection of a modest \$44 million of initial funding. The stroke community has been united in understanding what needs to be done and with appropriate targeted resourcing and support, patient outcomes from stroke will improve rapidly.

#### Stroke Impact

In 2016, despite advances in evidence around treatment and prevention, there will be more than 50,000 strokes in Australia. The number of stroke survivors living in the community will surpass 450,000 and more than 300,000 of them live with disability.

Stroke will be responsible for a \$5 billion hit to the economy and \$3 billion of this will be a result of lost productivity. Without concerted effort to reduce its impact, huge growth in stroke is foreshadowed. By 2050 the number of survivors in the community is expected to be near 1 million.

The 2015 National Stroke Audit shows that around 20,000 stroke patients per year do not receive the full benefits of quality hospital care that Australian governments have told people they should expect. Only seven percent of patients receive life-saving clot-busting drugs; up to one-third do not get medication on discharge to stop secondary stroke and up to half of patients are discharged without a care plan.

Poor discharge care leaves patients totally unprepared and ill-equipped to deal with a life-changing event, which more often than not includes the prospect of long-term disability. While sufferers of other illnesses are often well supported through their journey to recovery there is no coordinated follow up care for stroke survivors. Need amongst survivors is extremely high - verging on universal – and without a system of follow-up, stroke survivors are literally left to fend for themselves.

#### **Call to Action**

This budget submission calls for an immediate \$44 million investment over four years to urgently address gaps in stroke treatment and care that have been identified by the 2015 National Stroke Audit<sup>1</sup>. It also calls for the Australian Government to spearhead efforts to bring all Australian

<sup>&</sup>lt;sup>1</sup> National Stroke Foundation. National Stroke Audit – Acute Services Report 2015. Melbourne, Australia.

governments together to develop detailed costings for a national plan to close gaps in stroke care permanently.

The initial \$44 million investment is detailed in this submission and includes:

- A follow up program for stroke survivors after they leave hospital to ensure they are connected to the services and people they need to make maximum recovery after stroke;
- A data collection and reporting system to regularly monitor care quality in hospitals and focus improvements in the areas that need it most;
- Support for an innovative stroke health professional education, training and quality improvement program that will lead to better health outcomes;
- Investment in expansion of current telehealth stroke pilot programs to enable better regional patient access to life-saving stroke treatment;
- Funding to raise awareness of stroke symptoms, including targeted regional efforts, to enable faster transport of patients to hospital; and
- Funding to update absolute risk cardiovascular prevention guidelines to guide better primary care prevention.

Further work that is also required immediately is:

 Cooperative effort from all Australian Governments to cost and ultimately fund national action that will close the stroke care gap in Australia permanently.

#### **Outcomes**

The initial funding called for in this submission would deliver immediate reduction in stroke suffering. Fewer people will die from stroke and fewer will be left with a lifetime of acquired disability.

All survivors of stroke will get access to vital recovery information and support they currently miss out on; more patients will get treatment that saves their lives; there will be greater access to quality stroke care in regional areas; hospitals will be empowered to improve local practice and more strokes will be prevented through better primary care prevention.

Deloitte Access Economics modelling indicates that if action were taken to address the gaps in care identified through the 2015 National Stroke Audit then significant potential savings would be realised. Following up patients is estimated to contribute to savings in the order of \$30 million per year and improving care so it meets national standards would contribute to savings of around \$50 million per year. This includes over 2000 fewer cases of disability resulting from hospital quality improvement and 1300 survivors per year regaining their independence as a result of routine follow-up. These are Australians avoiding a life of dependence and suffering.

Survivors and their spouse who - is most often a carer - are going back to work or are able to resume other practical and productive activities including better quality time with family.

#### Stroke is everybody's business

There is no single solution to improving stroke care. It is a complex problem requiring input from all levels of government. Stroke care crosses the continuum of health care services from community-based support to primary care to hospitals.

Therefore, this problem requires cooperation and commitment from all Australian Governments. There is a modest cost required to start the process of care improvement but it will deliver significantly improved outcomes for hundreds of thousands of Australians who suffer from stroke's impact. It is then imperative that governments agree to develop costings and ultimately agree to fund the ongoing efforts required to close the gaps in stroke care permanently.

#### 1. Fund national rollout of StrokeConnect

**Recommendation:** Support the StrokeConnect program to guarantee every one of the estimated 25,000 Australian stroke survivors discharged home from hospital each year is followed up, providing early intervention to prevent increasing dependency and to link them with appropriate information and services.

Investment required: \$20 million over four years.

Stroke survivors often speak of falling into a 'black hole' once they are discharged from hospital without the support of follow-up in the community.

The often profound and prolonged brain injury that results from stroke can severely impact a survivor's ability to navigate an often complex health and welfare system in order to access the support and services they need to aid and maximise their recovery.

This is made worse by inconsistent delivery of support from the hospital system prior to discharge and in discharge planning. The NSF commissioned a survey of stroke survivors to better understand their needs and relating to stroke and whether or not these needs were being met. The results showed that 96 percent of those surveyed reported having needs after their stroke. Of those, 84 percent had needs that were not fully met.

There is no comprehensive program in Australia to ensure that survivors of stroke are followed up by liaison workers or community nurses as is the case with other health conditions. This means that those who live in need and are unable to actively seek support are often left to suffer in silence. They are not supported to recover quickly from their stroke and instead live with disability and other needs that impact on their ability to actively participate in society.

Fully funded, the StrokeConnect program will provide a phone call to every stroke survivor in the period following discharge from hospital to home linking survivors with available services in the community appropriate to their needs. The program also works with hospitals to support discharge planning processes through provision of targeted information for stroke patients that prepares them for a life with stroke. Funding of this program will also support widespread availability of information resources for all survivors of stroke currently living in the community.

The National Stroke Foundation has been piloting and developing the StrokeConnect model of care in response to survivor needs since 2008. It has been partially operating in Queensland with State Government support since 2011. StrokeConnect is ideally positioned to operate with the new Primary Healthcare Networks.

Evaluation of the pilot program and the Queensland model has demonstrated improved coordination of care, increased participation in relevant programs and improved health related quality of life, mood and participation in community activities.

Investment of \$5 million per year in the StrokeConnect program will guarantee a phone call to every Australian stroke survivor discharged home from hospital (estimated at 25,000 per year), linking them up with appropriate services and supports. It will also ensure widespread availability of targeted stroke information for stroke patients and survivors living in the community. **Deloitte**Access Economics estimates for this investment StrokeConnect would result in nearly

1,300 survivors regaining their functional independence each year contributing to a cost savings of over \$30m per year<sup>2</sup>.

<sup>&</sup>lt;sup>2</sup> Deloitte Access Economics, *The economic impact of stroke in Australia*, 2013

# 2. Fund an expansion of telemedicine pilot programs for stroke

**Recommendation:** Support an expansion of current telemedicine stroke pilots to deliver 24/7 acute stroke expertise to more regional hospitals.

Investment required: \$2.2 million over two years.

Regional Australia is ageing with a high proportion of the population aged over 65 years and therefore more likely to suffer a stroke. In regional Victoria and northern New South Wales alone there are *5000 new strokes each year*. These strokes occur in areas where there is limited access to stroke specialists and therefore limited treatment options.

When someone suffers a stroke, every minute counts. The sooner treatment is provided, the better the chance of a good recovery.

National Stroke Foundation supports a proposal by the Australian Telestroke Network (ATN) to expand telemedicine stroke services to more regional areas of Australia.

Telemedicine stroke services were first trialled in the Victorian Stroke Telemedicine (VST) Program. This program piloted the ability to facilitate rapid clinical decision-making and treatment of stroke by seamlessly connecting rural and regional emergency departments to a roster of Melbourne-based neurologists.

The neurologists were accessible 24 hours a day, seven days a week, via a single 1300 telephone number (1300-TELEMED). Through new state-of-the-art mobile computing technology and software, the neurologist could remotely examine patients at the bedside, review brain imaging and provide rapid diagnosis and treatment advice, irrespective of their geographic location.

The VST is demonstrating that people living in rural and regional areas can quickly access stroke specialists so as to deliver high-impact stroke therapies such as thrombolysis (clot-dissolving drugs) and endovascular clot retrieval (catheter removal of the blood clot). It is saving lives.

Prior to VST, regional hospital emergency departments had been unable to consider these therapies as they require rapid assessment by a specialist with stroke expertise to ensure a patient is suitable for treatment. This is important because "*Time is Brain*" – therapies must be given as soon as possible after stroke symptom onset to achieve a good outcome.

A telestroke service has been well established (and working well) in Europe and North America. The VST is demonstrating the potential for effective and efficient telestroke care in Australia

There is an opportunity to expand on the work undertaken so far and further demonstrate the potential for a truly national telestroke network capable of delivering equity of stroke health care to all regional hospitals. Through this project we can continue to build regional stroke patient access to stroke specialists and best practice standards of stroke care – the quality of care that everyone deserves.

The ATN will see stroke specialists available 24/7, across state borders, and demonstrate the potential for a truly national network of acute stroke specialists.

# 3. Fund a program to monitor Australian stroke care quality and drive targeted quality improvement

**Recommendation:** Support Australian hospitals to pursue continuous quality improvement by funding a system to regularly monitor and report on stroke care standards.

Investment required: \$6.4 million over 4 years.

There is a clear and widely shared understanding of what quality stroke care looks like. It is embodied within the Commission for Safety and Quality in Health Care's Acute Stroke Clinical Care Standard and recent Federal Government funding to update stroke clinical guidelines will ensure that care recommendations rely on the most up-to-date clinical evidence.

From the data available to us we know that current stroke clinical practice falls well short of our shared definition of high-quality and alarmingly the standard has barely improved in the past two years.

Both the Commission's Australian Atlas of Health Care Variation report and the 2015 National Stroke Audit (the Audit) have found significant variation in Australian stroke care. The Audit, which reports on care against indicators from the Acute Stroke Clinical Care Standard, found up to 20,000 patients annually are not getting full benefit from stroke unit care. It also found only 7 percent of patients receive potentially life-saving thrombolysis treatment and support for patients on discharge including secondary prevention medication and care planning continues to be poorly managed. The issues vary from state to state and within states, with no jurisdiction able to claim high quality stroke care is being delivered to all or even most of their patients.

Given the significant burden of stroke in Australia – around 50,000 strokes and 440,000 survivors in the community costing the economy \$5 billion - there is significant benefit to be realised from improvement in clinical practice. In order to drive improvement however there must be a system in place to regularly monitor and report on care standards.

Other than the National Stroke Foundation National Stroke Audit, which is conducted every two years, there is no national picture of stroke care quality with extremely limited data collection confined to only some parts of the country.

While we know that hospitals use National Stroke Foundation Audit data to drive targeted improvements we also know that two years between reports is simply too much of a gap to build and sustain a culture of continuous quality improvement.

We recommend government investment in a national stroke care monitoring system that puts the power of continuous quality improvement into the hands of state governments and local hospitals.

A ready-made solution for consistent and efficient data collection exists and is ready to be implemented nationally with appropriate funding support. Implementation would lead to better quality stroke care and ultimately better health outcomes for stroke patients.

Deloitte Access Economics has found potential for 2000 fewer cases of stroke-induced disability and over \$50m in economic savings per year if best-practice acute care and rehabilitation was realised in Australia<sup>3</sup>.

<sup>&</sup>lt;sup>3</sup> Deloitte Access Economics, *The economic impact of stroke in Australia*, 2013

# 4. Increasing the number of Australians eligible to receive time-critical stroke treatment.

**Recommendation:** Increase community knowledge of stroke symptoms so that patients get to hospital in time for life-saving treatment through mass media advertising combined with targeted regional community awareness activity.

Investment required: \$10 million over 4 years.

Life-saving clot busting treatment can only be administered within 4.5 hours of a stroke and currently only 7 percent of Australian stroke patients receive this therapy. Failure to act when stroke symptoms arise is the main factor behind stroke treatment delay, accounting for around 68 percent of the total delay in time to admission for ischaemic stroke.

Many people in Australia are unable to act because they cannot recognise the symptoms. Currently, one in five people cannot recognise any signs of stroke and only a third of people can recognise three or more signs.

Additionally, many people with transient signs of stroke (transient ischaemic attack or TIA) do not act as symptoms seemingly resolve themselves. And yet up to 20% of patients having a TIA go on to have a subsequent stroke within 90 days if early preventative treatment is not instituted.

Half of those who experience stroke symptoms delay calling an ambulance; many individuals hope symptoms will alleviate; or will elect to speak to friends, family or their general practitioner.

Since 2007, the National Stroke Foundation has been successful in raising awareness of the signs of stroke by promoting the FAST test through social marketing campaign activity. Australian Government funding supported a national rollout of the campaign in early 2014 and philanthropic funding supported a regional pilot of community-based awareness activity in Wagga Wagga and Warrnambool in the same year.

The central feature of the FAST campaign is mass media advertising using a pre-existing 'Fire in the Brain' television commercial and associated print, radio and online promotion. Given the success of our regional pilot we propose to expand this into other regional areas utilising volunteers to raise awareness of stroke signs and stroke risk through community talks and community engagement.

The FAST test is an easy way to remember and recognise the signs of stroke. FAST stands for Face, Arms, Speech and Time to act. Using the FAST test involves asking these simple questions:

**Face –** Check their face. Has their mouth drooped?

**Arms –** Can they lift both arms?

**Speech –** Is their speech slurred? Do they understand you?

Time – Is critical. If you see any of these signs call Triple Zero (000) straight away.

Evaluation of the program demonstrates that FAST increases community awareness of stroke signs in all areas where it is delivered. In Victoria, where state government funding was provided for the program between 2007 and 2012, awareness of the signs of stroke is the highest in the country. Furthermore, independent analysis of Melbourne ambulance data has identified increased dispatches for stroke in the month following each FAST campaign push, demonstrating the 'call Triple Zero (000)' message gets through.

# 5. InformMe: An innovative online portal for stroke health professionals

**Recommendation:** Support the rollout of an innovative online stroke health professional portal which will improve individual health professional practice and facilitate targeted local quality improvement activities.

## Investment required: \$4 million over 4 years

The gap between best-practice clinical care and what actually happens in the Australian healthcare system is resulting in poorer health outcomes and increased costs associated with stroke.

The 2015 National Stroke Audit of Acute Services found limited improvement in stroke care and services in Australia, despite significant advancements in in the treatment and care guidelines for acute stroke and the best efforts of health professionals and hospitals.

The results demonstrate that there is enormous opportunity to improve care and deliver better outcomes for patients. Key to achieving this is the provision of direct support to stroke health professionals through information and guidance to improve their individual clinical practice.

In response to health professional feedback the National Stroke Foundation has developed an innovative online resource that will provide information and support to clinicians, administrators working in stroke. As the key stroke website for health professionals it will bring together the latest evidence, link health professionals with their peers, provide monitoring data on current practice, share success stories of sites that have improved care and also offer tools and resources to maximise the quality of stroke care delivered.

The portal will provide up-to-date education on aspects of best practice stroke care. This will be used by hospital clinicians, those working in the community and general practice.

InformMe is designed for health care professionals who work with stroke patients across the full continuum of care including in the acute and rehabilitation hospitals and community setting. Health professionals include treating physicians, neurologists, rehabilitation consultants, physiotherapists, speech pathologists, occupational therapists, social workers, psychologists, dieticians and other allied health professionals and health care administrators.

The portal has been developed with funding from the National Stroke Foundation and philanthropic partners. We are calling on government investment to support ongoing development and management of the resource so as to maximise the benefit it provides. This includes ongoing efforts to incorporate and embed contemporary and evidence education and training modules, maintenance of quality care data and engagement with health professionals who use the site.

By funding this program government will contribute directly to better health outcomes for stroke patients by ensuring health professional have access to tools and resources that will improve clinical practice and ensure better adherence to national clinical care standards.

# 6. Update absolute risk cardiovascular prevention guidelines

**Recommendation:** The Heart and Stroke Foundations, together with the National Vascular Disease Prevention Alliance, recommend funding be provided to review and update the current guidelines for the management of absolute cardiovascular disease risk, developed according to National Health and Medical Research Council requirements.

# Investment required: \$1.2 million

The NHMRC approved guidelines for the management of absolute cardiovascular disease risk (2012) support clinicians to assess risk of heart attack or stroke among the general population (45 years and over).

Absolute cardiovascular disease (CVD) risk assessment is the probability, expressed as percentage, that a person may experience a cardiovascular event within a specified period. This guideline, developed with the assistance of Australian Government funding, is a lynchpin to preventive initiatives to reduce the incidence of heart attack and stroke across Australia.

Each year, around 55,000 Australians suffer a heart attack (which equates to one heart attack every 10 minutes) and around 440,000 Australians are living with stroke. The extent of this pressing problem is illustrated by the following Australian statistics:

- Around 3.7 million Australians had a long-term cardiovascular disease (2011-12)
- There were 44,000 deaths attributed to CVD in Australia in 2012
- CVD was responsible for more deaths than any other disease group (30 percent of total)
- CVD was the main cause for more than 520,000 hospitalisations in 2011-12
- CVD has the highest level of health-care expenditure of any disease group
- Days of reduced activity for people with CVD were 1.4 times the average Australian
- Lower rates of employment and absenteeism due to CVD in 2004 were estimated to cost the economy around \$2.2 billion.

Clinical recommendations that improve detection and underpin evidence-based medicine to reduce CVD events are a priority in Australia. Emerging evidence from comparative assessment programs in New Zealand and overseas will inform new clinical guideline recommendations.

New Zealand Primary Healthcare Organisations have achieved 86 percent assessment rates of the eligible population, drawing on clinical guidelines as the basis for detection and management of risk, compared to 25 percent in Australia.34 Without updated evidence-based guidelines, patient care could be compromised, leading to increased hospitalisations, and a reduced workforce.

There is an opportunity for significant positive change with limited investment.

An investment of \$1.2 million to fully update the clinical recommendations over two years will help to establish and maintain the new online resource ensuring that health professionals are able to maintain a commitment to continuous professional quality improvement. Uptake of the new guideline will be strengthened by the support of the Improvement Foundation (Australian Primary Care Collaboratives) and colleges of general practice to ensure wide communication and to encourage broad clinical involvement. A better quality workforce delivers better outcomes for patients, more efficient care and dramatically lower health costs.