

POSITION STATEMENT

Addressing the needs of older Australian survivors of stroke in aged care

Key points

- Well beyond their discharge from hospital, many older Australian survivors of stroke have yet to make a full recovery and continue to experience a wide range of health problems; however, many survivors in aged care face challenges accessing the services and supports required to address their assessed needs.
- Allied health professionals play a critical role in stroke rehabilitation and recovery, and optimise the function and independence of survivors of stroke. Importantly, many older Australian survivors of stroke living in the community struggle to access the allied health services they need, due to challenges with the assessment process and the way in which client budgets are managed by aged care service providers. Older survivors of stroke living in residential aged care have little to no access to allied health services specific to their needs, due to a lack of dedicated funding for these services.
- Federal Government investment is needed in a new model of aged care that survivors of stroke and their families and carers can navigate with greater ease, where survivors experience accurate assessment of need, and timely access to appropriate care and services that are person-centred, optimise their well-being and quality of life, and support their independence.

Background

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.¹ Unless action is taken, it is estimated by 2050, Australians will experience an additional 23,000 new strokes annually, and there will be an additional 374,000 survivors of stroke living in the community.¹

Ageing is the strongest non-modifiable risk factor for stroke, and older survivors of stroke have a higher mortality and morbidity, and poorer functional recovery, than their younger counterparts. In 2020, 61 percent of Australians who had a stroke for the first time, and 72 percent of survivors of stroke living in our community, were aged 65 years and over.¹

For older survivors of stroke and their families and carers, their experience of navigating the aged care service system mirrors that of the broader community. They often describe it as confusing and fragmented, requiring contact with multiple agencies, and an understanding of a system with which they have had little or no previous contact. The result is that many older survivors of stroke do not receive the services and care they need to support their independence. Survivors describe this as feeling as if they are ‘falling into a black hole’, often not receiving much needed services until their health has significantly deteriorated. More recently, these issues have been exacerbated by the COVID-19 pandemic and health professional workforce shortages.

Assessing the needs of older Australian survivors of stroke in aged care

Well beyond their discharge from hospital, many survivors of stroke have yet to make a full recovery and continue to experience a wide range of health problems. Issues with strength, sensation, range of movement and coordination are common post-stroke, and can result in loss of body control and movement, impacting an individual's ability to walk, use their hands and arms in daily tasks such as showering, as well as their speech or swallowing. Changes in communication can also occur after a stroke, with many survivors struggling to express themselves or to understand others. Other common post-stroke disabilities include 'hidden' problems, such as fatigue and changes in cognition. Some survivors have difficulties with memory, learning, or focusing on, planning or sequencing tasks, which can impact their ability to complete daily tasks such as getting dressed, or more complex activities such as driving.

Rehabilitation is a proactive, person-centred and goal-oriented process that should begin the first day after stroke. Rehabilitation should be timely, equitable and comprehensive and have as the ultimate aim that the person with stroke will maximise their function and achieve the highest possible level of independence – physically, psychologically, socially and financially.² Rehabilitation should be provided by a specialised interdisciplinary team of health professionals throughout the care continuum.² Allied health professionals, including physiotherapists, occupational therapists, speech pathologists, dietitians, social workers and psychologists, play a critical role in stroke rehabilitation and recovery, and optimise the function and independence of survivors of stroke.

Post-rehabilitation, survivors of stroke with ongoing deficits will need further allied health support in order to improve their quality of life and live well. This support will vary depending on an individual's needs, and could include things such as communication partner training for aged care staff to ensure survivors with aphasia aren't mistakenly

classified as having dementia, or therapy with a speech pathologist to ensure survivors with dysphagia are able to maintain adequate nutrition.

Currently, older Australian survivors of stroke in aged care face challenges when trying to access needs-based allied health care. Many survivors of stroke have significant disability and complex care needs. Issues such as neurological-based fatigue, and hidden cognitive problems, are often missed, while those with communication difficulties (both understanding and speaking) may have trouble communicating needs. For many older survivors of stroke and their families and carers, one of the biggest challenges they face is getting assessors to understand need, as many assessors do not have an adequate understanding of stroke, stroke-related disability, and the impact this disability has on survivors, their family members, and carers. This in turn affects their ability to determine which supports, services and assistive technologies survivors require in order to maximise their functional gains and achieve their desired goals.

An Australian study has identified the factors associated with a survivor of stroke having their need for ongoing rehabilitation assessed while in hospital, in line with clinical guidelines.³ Importantly, survivors of stroke were more likely to have their needs assessed if they were living at home before their stroke.³ For survivors living in residential aged care, their ongoing rehabilitation needs were not always assessed, increasing the risk of functional dependence and the subsequent burden on aged care services.³ Research has shown that mortality and health-related quality of life outcomes are worse for patients discharged directly to residential aged care compared with patients discharged to in-patient rehabilitation.⁴ In addition, patients discharged to in-patient rehabilitation after stroke experience disproportionately fewer hospital readmissions and problems with mobility than patients discharged directly home, despite having markers of more severe stroke.⁴

Services and supports that address the assessed needs of older Australian survivors of stroke in aged care

Currently, allied health services are available to older Australians, including survivors of stroke, through the various in-home aged care programs delivered by the Department of Health and Aged Care. Importantly however, for a variety of reasons, including challenges with the assessment process and the way in which client budgets are managed by aged care service providers, many older Australian survivors of stroke are unable to access the specialised allied health services they need, or the right amount of services, to maximise their functional gains and achieve their desired goals. For example, for older Australians who currently receive Home Care Packages, their nominated aged care provider organisation, that may provide them with a range of services including personal care, meals, and domestic assistance, also controls their budget. Importantly, these organisations generally do not provide allied health services, and in many cases, budgets are spent on the services they provide, even when older Australians require, and request, allied health services. In fact, only two percent of Home Care Package budgets are spent on allied health services.

While clinical guidelines do not recommend taking into consideration an individual's living situation prior to, or after their stroke when determining their rehabilitation needs, research has shown that Australian clinicians prioritise rehabilitation for survivors of stroke who are expected to be discharged to the community, rather than residential care.³

In addition, residential aged care facilities do not have sufficient funding to cover all of the allied health needs of survivors of stroke, and in fact, allied health professionals deliver just one percent of individual care time in residential aged care facilities. Therefore, the only option older Australian survivors of stroke living in residential aged care have if they want to access allied health services, is to pay for these services out of pocket, which is something many survivors and their families cannot afford.

Assistive technology

Currently, older Australians, including survivors of stroke, seeking access to the assistive technology they need to live a better, more independent and inclusive life, have to navigate their way through a patchwork of approximately 100 different funding streams throughout the country.⁵ Many older survivors of stroke living in the community are often forced to wait for more than 12 months to access funding for assistive technology, while others have to fund it themselves or miss out completely. For those living in residential aged care, accessing the assistive technology they need is even more challenging, with a National Aged Care Alliance Rapid Evidence Review noting that 'in residential aged care some basic care equipment may be provided, but little, if any, holistic quality of life enabling assistive technology is usually considered'.⁶



An aged care funding model that supports the long-term sustainability of service providers in the sector

The current aged care funding model does not fully capture the costs of providing services, including transport and administrative costs, as well as the cost of additional 'out of session' time that providers spend on activities such as case conferences for planning and review, which are particularly important for clients with complex needs, including many survivors of stroke. With regard to allied health services, in order to reflect the full cost of service delivery, it is important that client attributable hours that do not involve face to face interactions with a client are viewed as part of the therapeutic intervention, and are funded accordingly. Importantly, private service providers, including allied health professionals,

that deliver a wide range of services to older Australian survivors of stroke in aged care, often work across other sectors, where they are paid for time spent on travel or 'out of session'. Therefore, it may become increasingly difficult for the aged care sector to recruit and retain these providers with stroke-specific knowledge and skills, as they leave for more lucrative opportunities in the health and disability sectors.⁷



Recommendations

1. Australian Governments to work with health services to ensure all older Australian survivors of stroke in aged care have their needs assessed, regardless of where they live. The needs assessment should meet the following criteria:
 - a. **Assessor**
Have sufficient background knowledge of, and experience with, stroke, including experience working in the neurological disability sector. Trained to be sensitive and inclusive to people with both physical, as well as cognitive and communication impairments, and in the use of proxy interviewees (for those with communication difficulties).
 - b. **Assessment tool**
Evidence-based, clinically relevant, validated, and able to consider different settings and times, and determine what 'good days' and 'bad days' look like, for those with complex hidden cognitive disabilities for example.
 - c. **Assessment process**
Firstly, a clinical assessment of need is undertaken, to determine which types of allied health services they require in order to address their needs. Secondly, a discipline-specific assessment is undertaken to determine which therapeutic interventions they need, and the specific dosage (frequency, intensity, duration, and timing) of these interventions.
2. Federal Government to implement a new aged care funding model to ensure all older Australian survivors of stroke in aged care have access to services that address their assessed needs, regardless of where they live.

This includes:

- a. funding for care partners, who are independent of aged care service providers, and are able to manage individual budgets, and monitor the clinical needs of participants in in-home aged care programs, ensuring their care plans meet their needs
 - b. a new, dedicated funding stream specifically for the delivery of allied health services for older Australians living in residential aged care.
3. Federal Government to establish a national Assistive Technology Program to address the needs of all older Australians in aged care, regardless of where they live. The Program will provide funding for:
 - a. the purchase or hire of assistive technology
 - b. specialised assessment, reassessment (where required), training and support
 - c. servicing.
 4. Federal Government to support the long-term sustainability of service providers in the aged care sector, including allied health professionals, by:
 - a. implementing a new aged care funding model that acknowledges the full cost of service delivery, including the cost of 'out of session' client time spent by providers, as well as transport and administrative costs
 - b. providing career pathways and opportunities for career progression, as well as supervision and training opportunities.

Established in 2008, the Australian Stroke Coalition (ASC) is co-convened by Stroke Foundation and the Stroke Society of Australasia (SSA), and brings together representatives from groups and organisations in the field of stroke treatment and care, including clinical networks and professional associations and colleges. The ASC tackles agreed priorities to improve stroke treatment and care and raise the profile of stroke at a state and national level.

References

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