Australian Stroke Coalition

25 November 2022

Department of Health and Aged Care
GPO Box 9848
Canberra ACT 2601
Australia

Dear Sir/Madam

Re: A New Program for In-Home Aged Care

Established in 2008, the Australian Stroke Coalition (ASC) is co-convened by the 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.

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 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 complex, 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 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 heath has significantly deteriorated. More recently, these issues have been exacerbated by the COVID-19 pandemic and health professional workforce shortages.

As the collective voice of stroke in Australia, the ASC welcomes the opportunity to provide input into the development of the ‘New Program for In-Home Aged Care’.

Please see our response below which addresses the key areas of focus for reform.

1. Assessing the needs of older Australians

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-stoke disabilities include 'hidden' problems, such as anxiety and depression, 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] For example, falls are one of the most common complications after stroke, with an incidence of up to 73 percent in the first year post-stroke, due to a range of stroke-related impairments including muscle weakness, sensory loss, and abnormalities of vision and spatial awareness.[3] After a stroke, it is recommend that older adults be offered participation in individualised exercise programs aimed at improving balance, strength, and walking, in order to prevent falls.[4] Therefore, by improving access to in-home rehabilitation programs such as these that can address the deteriorating functional status of older survivors of stroke, it is possible to reduce fall occurrence and hospital admission.

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, dieticians, social workers and psychologists, play a critical role in stroke rehabilitation and recovery, and optimise the function and independence of survivors of stroke.

The ASC understands that the Department is still developing and refining the new assessment process for the program, including an assessment tool and classification system, and as such this is not a major focus of the current consultation. However, given how critical assessment will be to the success of the program, we wanted to highlight a few issues that will be particularly important for ensuring survivors of stroke are able to access allied health services according to clinical need within the in-home aged care sector.

Currently, survivors of stroke face challenges when trying to access needs-based allied health care through in-home aged care programs. 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 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.

For those older Australians with a disability and complex care needs, including survivors of stroke, it is critical those undertaking the assessment have been trained to be sensitive and inclusive to people with both physical, as well as cognitive and communication impairments, as well as in the use of proxy interviewees (for those with communication difficulties). For survivors of stroke, it is also important that assessors have sufficient background knowledge of, and experience with, stroke, including experience working in the neurological disability sector. Assessors must be able to understand the multiplicity of challenges that an individual who has had a stroke may have to address in order to function well.

With regard to the assessment tool(s) used, it is important they are evidence-based, clinically relevant, and validated. For survivors of stroke, the assessment tools will need to be able to take into account different settings and times, and determine what 'good days' and 'bad days' look like, for those with complex hidden cognitive disabilities for example.

The assessment process will need to be flexible, and include a specific pathway for those older Australians with an acquired disability, and complex care needs, including survivors of stroke, many of whom will require access to ongoing services, including allied health. For survivors of stroke, it is critical they undergo a *clinical assessment* of need, which will determine which types of allied health services they require in order to address their needs. A discipline-specfic assessment should then be undertaken to determine which therapeutic interventions they need, and the specific dosage (frequency, intensity, duration, and timing) of these interventions. This will ensure care and services are person-centred, safe and effective, meet the older person's current needs, goals and preferences, optimise their well-being and quality of life, and support their independence, in line with the revised Aged Care Quality Standards, and the objectives of this reform process.

2. *Care partners and the management of services across multiple providers*

As mentioned earlier, for survivors of stroke and their families and carers, navigating the current aged care service system can be confusing, requiring an understanding of a system with which they have had little or no previous contact. This can be a significant burden for those who take on a caring role, most of whom are informal supports such as family and friends. Carers may accompany survivors to medical appointments, and care for them at home, playing a critical role in a survivor's recovery. In Australia, informal carers provided 39.7 million hours of care to survivors of stroke in 2020[5]; however, this support can come at a significant personal cost.

A survey undertaken by Stroke Foundation, in partnership with Monash University's Stroke and Ageing Research Centre (STARC), and the Stroke Division of the Florey Institute of Neurosciences and Mental Health, asked carers of survivors of stroke about the impact that taking on a carer role had on various aspects of their lives.[6] Of those carers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.[6] Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role reported a moderate to severe

reduction in the number or type of leisure activities in which they were able to participate. Almost a third (31 percent) of carers who were the partner or spouse of a person with stroke reported moderate to extreme changes in their relationship.[6] A significant proportion of carers reported moderate to extreme changes in their relationships with other family members (20 percent), and with other people outside the family such as friends (32 percent).[6] As a consequence of these pressures, carers of survivors of stroke commonly experience a decline in their own physical and mental health and a reduced quality of life.[7-9]

The inclusion of care partners as part of the new in-home aged care model has the potential to alleviate some of the burden currently being felt by those caring for survivors of stroke. In addition, the allocation of funding specifically for care management will provide greater transparency around how funds are being used for these activities. These roles will be focused on providing *clinical* oversight, monitoring the clinical needs of older Australians, ensuring their care plans continue to meet their needs, and supporting them with practical assistance where required. As such, for survivors of stroke, it is essential that these roles are undertaken by health professionals with sufficient background knowledge of, and experience with, stroke.

Currently, even those older Australians without disability or complex care needs are struggling to navigate the aged care service system, and would benefit from the services of a care partner. Therefore, this essential service should be made available to all older Australians, including survivors of stroke, until they (or their family or carer) state that they no longer need it.

The ASC agrees that the choice to use different service providers for different service types may help older Australians to access the care and support that best meets their needs. However, for many survivors of stroke with multiple service providers, particularly those with cognitive and communication issues, managing their own budget and ensuring they stay within their funding entitlements would be challenging. For this group of older Australians it is important that the responsibility for budget management sit with their care partner.

Regardless of whether care partners are tasked with the responsibility of managing individual budgets, it is critical they remain impartial and independent of other aged care service providers. This will avoid the conflicts of interest and lack of transparency we see in the current aged care service system. 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.

Another important function of care partners will be the role they play in coordination of care. For survivors of stroke with multiple service providers, care partners could enable the multidisciplinary, team-based care we know improves recovery outcomes. Specifically, they could facilitate direct communication between different providers, help to overcome any differences in professional cultures or terminology, and help broker agreement on care strategies. It will be important for the Department to invest in the necessary infrastructure to

enable timely and effective communication between service providers, for example by providing an online portal that all members of the multidisciplinary team are able to access to input on team care plans.

3. Support that meets assessed needs, but is responsive to changes over time

The ASC agrees that the new program must have the flexibility to adjust the service mix as older Australians' needs change over time, and support the ability of older Australians to adjust the ongoing services listed in their initial support plan as and when required within a quarterly budget. In addition, it will be critical to have a mechanism in place to review, and make significant changes to, the initial support plan in the event of major changes in the older person's needs, which may occur either because these needs were not uncovered during the assessment process, or as a result of changes in the individual's circumstances (health or other factors).

For survivors of stroke, flexibility is particularly important as recovery from stroke is a non-linear, dynamic process, and fluctuations across needs are assured. Currently, aged care assessors often fail to understand that survivors of stroke may be recovering, and this fixed deficit approach may miss the subtleties of changing function, either positive or negative.

The importance an individual survivor places on different needs may also change over the course of their recovery journey. For example, immediately after discharge from hospital, the survivor may be more focused on the basic activities of daily living and dealing with issues such as mobility, while some needs such as dealing with speech problems do not become a focus until after a certain period of time at home.

4. A funding model that supports provider viability and offers value for money

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 survivors of stroke are unable to access the allied health services they need, or the right amount of services, to maximise their functional gains and achieve their desired goals.

The ASC notes that prices for services in the proposed new funding model of the program will be evidence-based to ensure they fully capture the costs of delivering services, including transport and administrative costs. 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. For example, a survivor of stroke with aphasia would like to join an art class at their local community centre. Their treating speech pathologist facilitates this by speaking with the teacher taking the class, and giving them the education and tools they need to be able to involve the survivor in the class despite their aphasia. The speech pathologist also develops some communication aids and tools that mean the survivor will have the right vocabulary around the art class to be able to participate fully. All of these tasks will take many hours, and form part of the therapeutic intervention that enables the

survivor to achieve their goal of participating and communicating in the class, and therefore should be funded as therapy time, rather than administrative time.

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.[10] Many survivors of stroke 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. As such, the ASC is pleased to note that the proposed new funding model includes a separately funded scheme for equipment, assistive technology and home modifications.

One area that has not been included in the proposed funding model that should be considered is allied health-led group therapy. Allied health-led group therapy, where therapeutic interventions are delivered in group sessions, can be of significant value for older Australians. For example, group therapy is an effective clinical strategy for improving communication impairments such as aphasia following stroke.[11] Compared to individual therapy, group therapy can enhance socialisation and peer support, improve motivation and self-management, and encourage patient independence while under clinical supervision.[12] In addition, group therapy can be more cost-effective, reduce waiting lists for services and help patients receive care faster, and enhance the delivery of integrated multidisciplinary care.[12]

In summary, the ASC supports the move toward a model of in-home aged care that survivors of stroke and their families and carers can navigate with greater ease, and which provides for more consumer choice and flexibility. We would also welcome a model 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.

The ASC commends the Department of Health and Aged Care on its work to date to develop a new model for in-home aged care in Australia, and bring about real and long-lasting structural reform that will enable the aged care system to better meet future demands. We look forward to hearing about the outcomes of this consultation, and the finalisation of the new model.

Thank you for the opportunity to provide input into the development of the ‘New Program for In-Home Aged Care’.

Yours sincerely

Sharon McGowan
Co-chair Australian Stroke Coalition
CEO
Stroke Foundation

Professor Tim Kleinig
Co-chair Australian Stroke Coalition
President
Stroke Society of Australasia

References

1. Deloitte Access Economics. 2020. No postcode untouched, Stroke in Australia 2020.
2. Stroke Foundation. National Rehabilitation Stroke Services Framework 2022. Melbourne, Australia.
3. Denissen S, Staring W, Kunkel D et al. Interventions for preventing falls in people after stroke. Cochrane Database Syst Rev. 2019. 10:CD008728.
4. Montero-Odasso M, van der Velde N, Martin FC et al; Task Force on Global Guidelines for Falls in Older Adults. World guidelines for falls prevention and management for older adults: a global initiative. Age Ageing. 2022. 51:afac205.
5. Deloitte Access Economics. 2020. The economic impact of stroke in Australia, 2020.
6. Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.
7. Han B, Haley WE. Family caregiving for patients with stroke. Stroke. 1999. 30:1478–1485.
8. Salter K, Zettler L, Foley N et al. Impact of caring for individuals with stroke on perceived physical health of informal caregivers. Disabil Rehabil. 2010. 32:273–281.
9. Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. Int J Stroke 2009. 4:285–292.
10. Assistive Technology for All Campaign. Position Statement. Provision of GEAT (goods, equipment and assistive technology) and home modifications under Australia's new aged care system. June 2022. Available at: https://assistivetechforall.org.au/wp-content/uploads/2022/06/ATFA_Position_Statement_GEAT_and_Home_Mods_in_Aged_Care.pdf
11. Layfield CA, Ballard KJ, Robin DA. Evaluating group therapy for aphasia: what is the evidence? EBP Briefs. 2013. 7:1–17.
12. Medicare Benefits Schedule Review Taskforce. Post Consultation Report from the Allied Health Reference Group. 2019. Available at: https://www.health.gov.au/sites/default/files/documents/2021/06/final-report-from-the-allied-health-reference-group.pdf