

5 December 2024



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Dear Sir/Madam

Re: Consultation on Foundational Supports for people with disability aged under 65, their families and carers

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, empowering health professionals to deliver high quality, best-practice care to stroke patients, facilitating research, and supporting survivors of stroke. We advocate for better systems, processes and resources to help health professionals deliver world class stroke care.

In 2023, an estimated 45,785 Australians experienced stroke,¹ and there were more than 440,000 survivors of stroke living in our community.¹ Unless action is taken, it is estimated by 2050, Australians will experience almost 72,000 strokes annually.¹

For many survivors of stroke, the physical, emotional and psychosocial impacts of stroke persist well beyond their discharge from hospital. Importantly, recovery after stroke can occur over several months, and even years, with many survivors reporting that adjusting to the impacts of stroke is a life-long journey. Issues with strength, sensation, range of movement and coordination are common after stroke, and may result in loss of bodily control and/or movement dexterity, impacting an individual's ability to walk, use their hands and arms in daily tasks such as showering or personal grooming, as well as their speech or swallowing. Changes in communication are also common after stroke, with many survivors struggling to express themselves or to understand others (aphasia). Other common post-stroke disabilities include 'hidden' impairments, such as mood disorders, 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.

The National Disability Insurance Scheme (NDIS) is one of the most significant social policy reforms in Australian history and is facilitating hundreds of thousands of Australians with disabilities, their families, and carers to participate more fully in society and the economy. This includes thousands of Australian survivors of stroke. As of 30 September 2024, there were 9,822 survivors of stroke receiving support through the NDIS.² Importantly, however, many other survivors of stroke with disabilities are either ineligible for the NDIS, or face challenges accessing, or fully participating in the scheme.³

Therefore, as the voice of stroke in Australia, Stroke Foundation welcomes the commitment of the Australian Government, and state and territory governments, to implement additional supports to those delivered through the NDIS and mainstream services (Foundational Supports), to ensure people with disability aged under 65, their families and carers, do not fall between the cracks.

General Foundational Supports

Many survivors of stroke live with significant disability and complex needs, and for most types of Foundational Supports targeted at the stroke community, it is critical they are developed and delivered by organisations and individuals that have a strong understanding of stroke, stroke-related disability, and the impact this disability has on survivors, families and carers.

Foundational Supports should be offered through a variety of channels where possible, including online, phone and in-person (groups or one-on-one), in order to accommodate the wide range of needs, preferences and accessibility requirements of those in the stroke community. A survivor of stroke's decision to use a particular channel may be determined by a number of factors, including:

- their geographical location
- whether they have the support of a family member(s) or carer
- whether their stroke has impacted their ability to drive
- whether they are dealing with communication difficulties as a consequence of their stroke
- the availability of suitable providers of supports.

For example, for survivors of stroke in certain rural or remote communities, limited access to high-quality mobile and internet services may impact their ability to utilise online supports.

Outlined below are the types of information, advice, referral and capacity-building supports that survivors of stroke, families and carers need, some of which are delivered by **Stroke Foundation, which as the leading national organisation focused on stroke prevention, treatment and recovery, is a trusted source of information and advice and provider of services.**

Information, advice and referral supports

As discussed above, 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 the complex health, disability and welfare systems.

Stroke Foundation is committed to ensuring more Australians impacted by stroke can connect with and access trustworthy information, resources, and post-stroke support.

Thousands of Australians benefit from Stroke Foundation's suite of resources and services which are designed to support survivors of stroke, families and carers, and are provided thanks to the generous support of Stroke Foundation donors and partners.

EnableMe is 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 2023, almost 70,000 survivors of stroke, families, carers and health professionals accessed 262,000 pages of information through *EnableMe*.

My Stroke Journey is a printed (and online) 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 2023, almost 26,000 Australians received this resource. *My Stroke Journey* is now a suite of resources, with versions available in both standard and easy English, Italian, Greek, Chinese, Korean, Arabic,

Hindi, Vietnamese, and for Aboriginal and Torres Strait Islander peoples, and parents and carers of children who have had a stroke.

StrokeLine is 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, 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.

StrokeLine is a highly regarded, trusted service:

- In 2023, 89 percent of clients said they would recommend it to someone else. This was similar to 2022, indicating the service delivers a consistent and positive user experience.
- When advice was provided to clients about what they could do to resolve their issue, 77 percent acted on this advice.
- In 2023, there was a 34 percent increase in callers to *StrokeLine* asking for advice on signs of stroke before calling an ambulance.

We know from existing services' data and internal evaluation of the service, that **there is unfulfilled demand for StrokeLine**, with the current service unable to adequately meet the needs of specific groups within our community:

- *StrokeLine* provided information and support to almost 2,500 survivors of stroke, families, carers, and the public during 2023; however, this is only a small proportion of the number of Australians who experience a stroke for the first time each year, and are living with stroke in our community.
- In the last three years, there has been a significant increase in the number of complex calls to *StrokeLine*. This includes vulnerable survivors calling the service for advice and support, who are facing challenges with issues such as mental ill health, homelessness and social isolation, in addition to trying to manage the impact of their stroke. These calls are longer in duration and often require follow-up.

Importantly, Stroke Foundation can no longer deliver StrokeLine from donations alone, and we are calling on the Australian Government to invest in this highly valued service. This will ensure more survivors of stroke, families and carers, regardless of where they live, are provided with the information, advice and referral supports they need in a timely manner.

Capacity-building supports

Findings from a survey of Australian survivors of stroke and their carers reported that of the survivors who were working prior to their stroke, almost three quarters (71 percent) experienced a change in their work activities since their stroke, and over half (57 percent) reported that the change was moderate to extreme.⁴ More than one third (36 percent) of respondents experienced a loss in income since having their stroke and almost half (48 percent) were receiving some form of benefit.⁴ Over half (57 percent) of survivors who had a partner or spouse reported that their stroke had a negative impact on their relationship, and a third (34 percent) reported that this change was moderate to extreme.⁵

The survey results also provided evidence there was a significant impact experienced by carers of people with stroke.⁵ Carers may accompany survivors to medical appointments, and care for them at home, playing a critical role in a survivor's recovery; however, this support can come at a significant personal cost.

Of those carers who were working prior to taking on a carer role, 40 percent experienced a moderate to extreme reduction in the amount of work they were able to perform.⁵ Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role experienced 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.⁵ 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).⁵ 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.⁶⁻⁸

Capacity-building supports, including peer support and supports that help survivors of stroke, families and carers better understand their rights, and develop the skills they need to advocate for themselves, can help in dealing with these challenges post-stroke.

Peer support

For many survivors of stroke, families and carers, the emotional impact of stroke is often the hardest to deal with, and connecting with others affected by stroke can be an important step in helping to rebuild their life. A positive relationship has been demonstrated between perceived social support and the health-related quality of life of survivors of stroke,⁹ and there is growing evidence that peer-led interventions may be an effective way of helping survivors of stroke cope with the devastating consequences of stroke.^{10, 11}

Peer support groups for survivors of stroke and carers can offer therapeutic benefits including empowerment and inspiration, a sense of belonging, learning new ways to cope, feeling helpful, feeling secure, being able to express feelings, and a sense of increased agency and independence.⁹

There are stroke support groups across Australia, powered by survivors of stroke, and families and carers, who want to see the benefits of peer support made available to as many people as possible. Some groups cater for people in a local area, while others are focused on particular age groups or interests. These groups provide a safe and supportive space where survivors of stroke, families and carers are able to come together to share experiences, build friendships, learn more about stroke and self-care, try new things and build confidence, as they embark on their journey post-stroke.

In addition to facilitating social connection with peers, these groups also deliver a range of recreational activities, including mindfulness, meditation and cooking classes, art therapy, singing, and low-impact sports, as well as skill development activities and educational talks on topics of interest to their members. Some groups offer vocational support for working-age survivors of stroke, focused on increasing post-stroke employment.

Australian and state and territory government investment is needed to ensure the benefits of peer support are available to as many Australian survivors of stroke, family members and carers, as possible.

Self-advocacy and rights awareness

Unfortunately, many survivors of stroke, families and carers regularly face a variety of attitudinal, physical, communication, social and policy barriers, which make it challenging for them to participate in everyday life, access the services they need, and grow and succeed in their chosen career. There are many national and state and territory based organisations that are focused on supporting and advocating for the rights of people with disability, including survivors of stroke. Stroke Foundation advocates to Australian governments for policy and system change improvements to better serve the needs of the stroke community. **We have also worked closely**

with other advocacy organisations in the disability sector to successfully support individual survivors of stroke with a range of issues, including access to the NDIS.

There are survivors of stroke, families and carers, for whom self-advocacy, the ability to articulate their needs and make informed decisions about the support necessary to meet those needs, is vitally important. A number of organisations in the disability sector provide workshops and other modes of training, which equip individuals with the skills and knowledge about their own legal and human rights, to enable them to effectively advocate for themselves or others in a variety of contexts, such as the health system or the workplace.

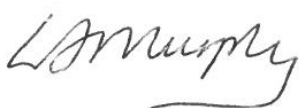
Australian and state and territory government investment in disability organisations with a strong track record and expertise in self-advocacy training and mentoring is needed, to ensure survivors of stroke, families and carers who want to develop the requisite skills and rights awareness to advocate for themselves, are able to receive the training and support they need.

In summary, there are many national and state and territory-based organisations, including Stroke Foundation, that are delivering quality information, advice, referral and capacity building supports to meet the needs of people with disability aged under 65, families and carers. It is critical that the Australian and state and territory governments ensure that:

- these organisations have access to long-term funding, which will ensure they are able to deliver these supports in a sustainable way
- there are mechanisms in place to enable people with a lived experience of disability to participate in the design and implementation of these supports
- there is an effective process for disseminating and promoting information about these supports widely in the community, so that the greatest number of people are aware of, and are able to utilise and benefit from them.

Thank you for the opportunity to provide input into this consultation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lisa Murphy', with a stylized flourish at the end.

**Dr Lisa Murphy
Chief Executive Officer
Stroke Foundation**

References

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