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Dear Sir/Madam

Stroke Foundation's response to the NDIS Evidence Advisory Committee consultation

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 strokes occurred around Australia,[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-stoke 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 supporting 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 September 2025, there were 10,640 survivors of stroke receiving support through the NDIS.[2]

Therefore, as the voice of stroke in Australia, Stroke Foundation strongly supports the Australian Government's commitment to ensuring the NDIS provides safe, effective and high quality supports that maximise the benefits for people with disability, through the work of the NDIS Evidence Advisory Committee (EAC).

Stroke Foundation's world-leading *Living Guidelines for Stroke Management* (the Guidelines) are critical to ensuring Australians receive the best and most up-to-date stroke treatment and care. The Guidelines provide a series of best-practice recommendations to assist decision-making in the management of stroke and transient ischaemic attack (TIA) in adults, using the best available evidence. The Guidelines use the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) process[3] to develop recommendations for specific interventions. This process uses two categories for the strength of recommendations, based on how confident the guideline panel is that the desirable effects of an

intervention outweigh undesirable effects across the range of patients for whom the recommendation is intended:

- **Strong recommendations:** where guideline authors are certain that the evidence supports a clear balance towards either desirable or undesirable effects.
- **Weak (or conditional) recommendations:** where the guideline panel is less certain about the balance between desirable and undesirable effects, but clear enough to make a recommendation.

These strong or weak recommendations can either be for or against an intervention.

Outlined below is a brief summary of the evidence and recommendations for those supports which will be considered by the EAC in the second round of assessments, and which are currently captured in the Guidelines.

Functional electrical stimulation

The impact of functional electrical stimulation (FES) on upper or lower limb activity, subluxation (shoulder joint dislocation), and shoulder pain, post-stroke, has been evaluated. The Guidelines have grouped all electrical stimulation approaches together. A significant amount of the underlying evidence was focused on FES, where electrical stimulation combined with active training showed positive benefits.

Weak recommendation

For survivors of stroke with mild to severe arm or hand weakness, electrical stimulation in conjunction with motor training may be used to improve upper limb function.[4, 5]

In addition, electrical stimulation is recommended for survivors of stroke with shoulder pain.

Weak recommendation

For survivors of stroke with shoulder pain, electrical stimulation may be used to manage pain.[6]

A summary of the evidence regarding the impact of FES on the ability to walk independently, which is affected in approximately 46 percent of stroke patients,[7] is included below.

Walking difficulties

Survivors of stroke have identified the achievement of safe, independent, effective, and efficient walking as critical enablers of future health and quality of life[8]; however, by three months post-stroke, approximately a quarter of survivors have not achieved independent walking.[9] Even for those who achieve independent walking, issues such as reduced gait speed and endurance can result in survivors not being able to walk independently and safely in diverse, real-world environments beyond their home, such as shops, parks, and public transport, or integrate walking with complex tasks.[10, 11]

One systematic review has examined the effect of FES for improving upper and lower limb activity after stroke compared to placebo, no treatment or training alone.[4] A total of 18 trials were eligible for inclusion in the review. A subgroup analysis was undertaken of eight randomised trials of moderate quality, with a total of 203 participants, to determine the efficacy of FES for improving lower limb activity. This analysis demonstrated that the use of FES during walking training resulted in a small improvement in walking speed of .08m/s. Due to a lack of available data, it was not possible to determine if this benefit of FES on activity was long-lasting.

Weak recommendation

For survivors of stroke with difficulties walking, functional electrical stimulation may be used to improve function.[4]

We are also in the process of reviewing and incorporating an updated Cochrane review on electrical stimulation after stroke into the Guidelines.[12] This review includes 55 trials of FES (1729 participants) and appears to confirm the usefulness of FES for survivors of stroke.

Music therapy

Studies have evaluated the impact of music therapy on communication difficulties, as well as cognitive impairments related to attention, concentration and memory, post-stroke. With regard to cognitive impairments, currently it is not possible to make a statement about the impact of music therapy for stroke patients specifically, as studies have included mixed populations, including patients with other neurological conditions (e.g. Parkinson's disease and multiple sclerosis) or types of acquired brain injury. A summary of the evidence on the impact of music therapy on aphasia, a communication difficulty that affects between 26 and 34 percent of stroke patients,[7] following stroke, is included below.

Aphasia

Stroke patients who experience aphasia have difficulty talking, reading, writing or understanding other people when they speak. This can happen even if their thinking, memory and judgement are unaffected by their stroke. The most common cause of aphasia is a stroke to the left hemisphere of the brain, where the language function is situated for right-handed people.[13]

One randomised control trial,[14] one study that reviewed data pooled from two randomised controlled trials[15] and one systematic review,[16] have evaluated the effect of music therapy on post-stroke aphasia. Aravantinou-Fatorou and Fotakopoulos (2021) undertook a trial in 79 patients, comparing post-stroke aphasia standard care combined with daily traditional experiential music learning, with standard care alone, in patients with a single cerebrovascular accident.[14] Results from this study suggest that an enriched sound environment may be beneficial for patients with post-stroke aphasia, as clinical recovery was significantly higher in the music intervention group (40.5 percent) compared with the control group (24 percent).[14] Sihvonen et al (2020) used data pooled from two randomised controlled trials with a total of 83 participants, to compare the effects of daily listening to self-selected vocal music, instrumental music, and audiobooks, during the first 3 months post-stroke.[15] All intervention groups showed improvements in language skills and verbal memory; however, the highest improvement in both verbal memory and language skills occurred in the vocal music group, particularly in aphasic patients.[15] Gong and Ye (2024) reviewed nine trials, with a total of 309 participants, that compared music therapy with conventional speech and language therapy in post-stroke aphasia.[16] No significant differences were observed between the music therapy and control groups with regard to improvements in functional communication or understanding ability; however, the degree of improvement in repetitive ability of the music therapy group was significantly higher than that of the control group.[16]

For survivors of stroke with aphasia, there is currently insufficient evidence to form a recommendation regarding the use of music therapy and further studies are needed.

Hyperbaric oxygen therapy as a disability support

The impact of hyperbaric oxygen therapy (HBOT) on several secondary effects commonly experienced by stroke patients, including cognitive impairments related to attention, concentration and memory, as well as difficulties with movement and chronic pain, has been evaluated. Currently however, there is insufficient

evidence to make a statement about the effectiveness of HBOT for the treatment of these elements of chronic ischaemic stroke. HBOT has also been used to treat post-stroke depression (PSD), a common psychosocial disability following stroke which affects around one-third of stroke patients.[17] A summary of the evidence on the impact of HBOT on PSD is included below.

Depression

PSD, characterised by depressive mood, sleep disturbance, decreased energy, guilt and even suicidal tendencies, can significantly impact a survivor of stroke's ability to work, study, or interact socially, and is associated with increased mortality and poor rehabilitation results and functional outcomes.[17] Currently, the majority of PSD patients remain untreated or inadequately treated.[17]

One systematic review undertook a meta-analysis to evaluate the efficacy and safety of HBOT for PSD.[17] A total of 27 randomised control trials involving 2250 participants were identified for inclusion. HBOT was associated with a significantly higher response rate, reduced depression severity as measured by the Hamilton Rating Scale for Depression, reduced neurological deficit, improved physical function and significantly fewer adverse events, compared with the control group. A subgroup analysis demonstrated that patients who received HBOT in combination with antidepressant treatment achieved better results than patients who received antidepressant treatment alone. Due to the poor methodological quality of the included studies however, the results of this review should be interpreted with caution.

For survivors of stroke with depression, there is currently insufficient evidence to form a recommendation regarding the use of hyperbaric oxygen therapy and further studies are needed.

In summary, Stroke Foundation strongly supports the objectives of the NDIS, and believes that the scheme should empower survivors of stroke, through appropriate supports, to grow and thrive and maximise their life after stroke. The work of the NDIS EAC is critical to ensuring survivors of stroke have access to the safe, effective and high quality supports that they need to achieve their goals.

In our response to this consultation, we have provided information to inform the EAC's second round of assessments, drawing on the *Living Guidelines for Stroke Management*. Not all supports under consideration by the EAC in this round are currently captured in the Guidelines, and for those that are captured, developing strong recommendations regarding their utility for survivors of stroke is challenging, due to limitations of the published evidence.

Thank you for the opportunity to provide feedback as part of this consultation.

Yours sincerely

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