Stroke in Australia: long term survivors have fallen into a black hole

People with long term disability after stroke should have access to the services they need, when they require them

Over recent years, the management of stroke has undergone major changes in Australia, including the introduction of stroke-equipped ambulances, improved delivery of thrombolysis, and the formation of acute stroke units.[1] However, despite more people surviving, many people after stroke are left with lifelong disability.[2] Furthermore, ongoing services and support are perceived to be inadequate by people after stroke.[3] This means that people living with ongoing disability after stroke may not have the opportunity to achieve their preferred life goals. It is time to focus on the individual burden of disease and how we can best support people with stroke in the long term.

Stroke is a chronic, lifelong health condition, but it is managed like an acute condition in Australia. Typically, a person after stroke is admitted to an acute hospital for early management; they then receive inpatient rehabilitation if they meet the selection criteria, followed by outpatient rehabilitation.[4] In reality, the amount of rehabilitation provided by the hospital sector is limited. Recent moves towards early discharge and rehabilitation in the home have been shown to be less effective in maximising function than inpatient rehabilitation,[5] whereas functional gain is possible with investment in subacute and community rehabilitation (eg, Council of Australian Governments national partnership agreements).[6] After hospitalisation, 64% of people after stroke are referred for community rehabilitation; however, the actual amount of community rehabilitation that occurs is profoundly low.[7,8]

People after stroke are caught between the health, disability and ageing sectors. In the health sector, resources are prioritised in the acute phase of care, and once in the community, funding is via the general practitioner Chronic Disease Management Plan that is limited to five annual subsidised allied health sessions (https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement). Furthermore, it is hard for people after stroke to access funding from the disability sector. People after stroke report feeling forgotten and neglected once their allotted rehabilitation quota has finished.[9]

Stroke cost the Australian health and disability sectors an estimated $1.3 billion in 2020.[1] Having a disjointed and inequitable system cannot ensure value for money. One of the costs is the National Disability Insurance Scheme (NDIS), Australia's disability funding model. In 2020, the NDIS supported 5160 people who nominated stroke as their primary disability — approximately 1% of people after stroke living in Australia at that time.[1] The NDIS does not readily accept people after stroke for two reasons. First, you must be aged 65 years or younger when you acquire your disability. In Australia, 61% of people who had a stroke in 2020 were aged over 65 years.[1] Second, the disability must have a permanent and significant impact on function or participation in life roles (https://www.ndis.gov.au/applying-access-ndis/am-i-eligible). It can be incorrectly assumed that people after stroke recover and therefore will not have ongoing disability, especially people with initial mild to moderate symptoms. While people typically have some recovery after stroke, it is usually partial and plateaus after the first 6 months.[10] A significant proportion of people also deteriorate over time, creating greater levels of disability.[10] If not eligible for the NDIS, people after stroke may need to wait until they are eligible for aged care services, which are currently not only inadequate but do not optimise participation and quality of life.[11]

Other chronic health conditions such as heart disease receive ongoing support aimed at preventing recurrence.[12] After stroke, exercise and the promotion of physical activity as secondary prevention strategies are also important but are rarely accessible. Further, participation in such programs can be limited by the complexity and severity of post-stroke impairments, such as muscle weakness and cognitive/language deficits.[1] It is time for people with long term disability after stroke to have access to the services they need, when they require them.

We suggest a new model of long term support for people after stroke who experience ongoing disability. The cornerstone of the model is a deliberate move to

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the disability sector from the health sector. This article is a call for people with ongoing disability after stroke to be able to access ongoing services regardless of age or disability. The current system is disjointed with multiple funding sources, leading to inequality in who receives which services and when. People after stroke need the ability to have regular ongoing check-ups with services implemented where required, more support for ongoing lifestyle changes such as text reminders, person-centred tools such as self-management, habit-forming exercise, ongoing gym memberships, and strategies for meaningful social interactions.[13,14] These issues are applicable not only for people after stroke but also for many others with ongoing disability. We support the urgency for a national rehabilitation strategy to move the rehabilitation focus from the hospital to the community.[15]

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