

ADDRESSING HIDDEN DISABILITIES: SUPPORTING YOUNG STROKE SURVIVORS

CARE
DELIVERY

Project title:

Co-designing a psychoeducation package to enhance psychosocial wellbeing for young adults living with stroke

Investigators:

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Timeline:

January 2024 to 2026

Location:

Victoria

Partners:

Stroke Foundation



CONTEXT

An estimated 142,000 Australians aged 18 to 65 are living with the impact of stroke, and over half experience hidden disabilities including depression, anxiety, memory and other cognitive difficulties, and fatigue. According to the latest Stroke Foundation audit, 32% of stroke services lack access to a psychologist, so there is a need to provide other forms of information and support. Despite this, there have been no studies co-designing or evaluating psychoeducation interventions or accessible information tailored specifically for young stroke survivors. The need to address hidden disabilities in this demographic is highlighted by data from the Stroke Foundation's helpline, StrokeLine. The most frequent inquiries from callers aged 18–65 focus on fatigue (34%), followed by concerns about emotions/mood (21%) and thinking/memory/judgment (18%). Many callers seek guidance on strategies and information about available services or clinicians who can provide support.



APPROACH

To address significant service gaps, researchers and industry stakeholders have recognised the need for large-scale, easily implementable solutions specifically designed for young stroke survivors. Psychoeducation involves active communication to improve understanding of psychological, cognitive, and behavioral issues. When delivered interactively, it can enhance wellbeing, support self-management, and prevent the need for more intensive interventions. This model of care is particularly effective because it can reach large populations through online resources and telehealth sessions, making it usable for anyone with access to the internet. This project is co-designing an accessible psychoeducation package for young adult stroke survivors (aged 18–45). It includes dynamic resources like videos, podcasts, online tip sheets with chat/comment capability, and telehealth Q&A sessions to support self-management, ensuring scalability and broad accessibility. The feasibility and acceptability of these resources will then be tested in a pilot trial.



OUTCOMES

Co-designed with young stroke survivors, their support people and clinicians, this research will have both local and international impact, contributing to the evidence on the acceptability and feasibility of co-designed psychoeducation interventions. These interventions have the potential to improve client outcomes and provide additional resources for health services. By addressing the hidden challenges faced by young adults living with stroke, this project will make these invisible difficulties more visible. If it is found to be feasible and acceptable, the psychoeducation package will be made widely available to support young stroke survivors and their families.

"The psycho-social impacts of stroke are huge, not just on stroke survivors but their family members, friends and the wider community, and younger stroke survivors have unique needs."

Dr Matthew Berryman, stroke survivor

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