

The hidden impact of stroke: the need for psychological and emotional support

A stroke is sudden and shocking and affects every part of your life. It can have a profound effect on survivors' mental health and emotions. Anxiety, depression and feelings of grief, anger and frustration are common after a stroke.

Around one in three stroke survivors will develop depression as a result of their stroke. Despite this, a very small proportion of survivors receive any form of psychological support due to workforce and resource shortages.

We believe that every stroke survivor should have timely access to professional support for any psychological or emotional challenge they face after their stroke, for as long as they need.

The new Stroke Action Plan must prioritise and improve access to psychological and emotional support for people affected by stroke through investment in the psychology workforce, coproduction with stakeholders, and enhanced collaboration with the voluntary sector.

What do we mean by psychological and emotional support?

- Psychological support is an intervention by a clinical psychologist or psychiatrist to manage a serious mental health issue, such as depression or anxiety, arising as a result of a stroke.
- **Emotional support** assists with more mild and transitory variations of mood that can be expected after a stroke, and can be provided by peers, stroke healthcare professionals, or specialist psychologists and/or psychiatrists.

93% of stroke survivors in Northern Ireland say they experience mental health issues following their stroke, including a lack of confidence, anxiety, depression, mood swings or suicidal thoughts.ⁱⁱ

"I was an emotional mess after my stroke. Leaving hospital and coming home was scary and I felt completely alone"



Current service provision in Northern Ireland

National guidelines for stroke care recommend that psychological care should be provided for stroke survivors both in hospital and at home in the community.ⁱⁱⁱ

Yet, stroke survivors continually tell us that they feel entirely without psychological or emotional support after their discharge from hospital.

This is supported by recent engagement with people affected by stroke where the impact of psychological problems following stroke and how to reduce them was identified as the number one priority for future stroke research and policy.^{iv}

"Stroke survivors and the research evidence base have continually highlighted the psychological and emotional effects of stroke as being 'hidden' and receiving less support than some of the more physical effects of stroke. Stroke survivors and their families often feel abandoned to deal with these difficulties alone. It is essential that more support in this area is provided to help the nearly 40,000 stroke survivors living in Northern Ireland today. Stroke is not a condition that is confined to hospital. It has a lifelong impact on stroke survivors and their families and as a result support with all aspects of stroke care needs to be provided long term"

Dr Niamh Kennedy, Lecturer in Psychology at Ulster University with specialist research interest in physical and psychological stroke rehabilitation.

A shocking 90% of stroke survivors in Northern Ireland feel that their emotional and cognitive needs are not met once they leave hospital.

A recent audit of stroke care here shows that **no Northern Ireland stroke unit meets the key performance indicator of at least one WTE qualified clinical psychologist per 30 stroke beds.** VI This was also the case in the last comparable audit in 2019.

And a recent paper by the Regional Stroke Clinical Psychology Special Interest Group for Northern Ireland estimates that only around 30-50% of stroke survivors and their families who would benefit from direct access to clinical psychology services are currently receiving any direct input from stroke psychologists. VII



"Psychological support on adjusting to life after a stroke is the thing most missing from stroke care"

The paper concludes that "in Northern Ireland, there has been a consistent shortfall in the provision of clinical psychology services which has never been appropriately resourced or prioritised".

Opportunities for improvement

The Department of Health Stroke Action Plan^{ix}_released by the Minister of Health in June 2022, recognises that *"stroke patients should have access to timely clinical psychology support"*.

The Department has therefore committed to the development of pathways for referrals to clinical psychology and mental health services by March 2023.

They have also committed to a comprehensive Stroke Workforce Plan by summer 2023. It is imperative that the role of clinical psychologists, both in the acute and community setting, is considered as part of this.

Unfortunately, budget uncertainty and financial constraints pose a challenge to the full implementation of the plan. There is currently no additional or recurrent funding committed to the delivery of the action plan, which makes strategic and necessary transformation challenging.

Recommendations for improvement

Psychological and emotional support should be viewed as an integral element of the stroke treatment pathway, closely linked to other aspects of rehabilitation. Successful rehabilitation is built on the foundation of a stroke survivor's healthy psychological and emotional wellbeing, allowing them to engage fully in different therapies, such as physiotherapy or speech and language therapy.

An excellent standard of rehabilitation, including adequate psychological and emotional support throughout the stroke pathway, is likely to reduce rates of readmission following stroke, the need for ongoing follow-ups, social care costs, longer term disability, and mortality post-stroke.^{x xi}

The new Stroke Action Plan is a golden opportunity to prioritise and improve psychological and emotional support for people affected by stroke. However, in order to fully address this long-unmet need, we need to see:



- 1. **Investment in the Action Plan**, including a commitment to recurrent funding to ensure the plan is implemented as intended over the next few years. Prioritisation should be given to ring-fenced investment in psychology resources, given the historical and consistent underfunding of this area.
- 2. A comprehensive Stroke Workforce Plan, that considers the number of psychologists that will be required in both acute and community stroke settings over the next decade.

The stroke rehabilitation workforce, including psychologists specialising in stroke care, is overworked, overstretched and undervalued.

- 3. **Co-production of services** with people affected by stroke, clinicians, researchers and the third sector.
- 4. Enhanced collaboration between the statutory and third sectors, as the community and voluntary sector are also ideally placed to support people with emotional changes after a stroke. However, it's important to note that while the third-sector should be considered a vital part of the solution to improving psychological and emotional support for people affected by stroke, we should not be seen as an alternative or substitute for statutory clinical psychology services.

Further information

In June 2022 the Association of Clinical Psychologists UK (NI) published Delivering Psychological Care to Stroke Survivors in Northern Ireland, a briefing paper on current status and future recommendations for improved care. For further information, including proposed models of care, the paper can be accessed online.

¹ Hackett, M.L. et al. (2014). 'Frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies', *International Journal of Stroke, 9,* pp. 1017-25.

ii Lived Experience of Stroke, Northern Ireland Results (2019).

iii RCP National Clinical Guidelines for Stroke, 2016.

iv James Lind Alliance Priority Setting Partnership for Stroke (2021). Available at: https://www.stroke.org.uk/research/priority-setting-partnership

^v (Struggling to Recover (2019).

vi SSNAP Acute Audit, 2021.

vii Delivering Psychological Care to Stroke Survivors in Northern Ireland, Association of Clinical Psychologists UK (Northern Ireland) (2022).

Delivering Psychological Care to Stroke Survivors in Northern Ireland, Association of Clinical Psychologists UK (Northern Ireland) (2022).



ix https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-Stroke%20Action%20Plan%20June%202022.PDF

^{*} Pollock, A. et al. (2014). 'Physical rehabilitation approaches for the recovery of function and mobility following stroke', *Cochrane Database Syst Rev, 22.*

^{xi} Legg, L. et al. (2007). 'Occupational therapy for patients with problems in personal activities of daily living after stroke: systemic review of randomised trials', *BMJ*, *3*(335).