

# Navigating the road to recovery after stroke

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This article considers the patient experience of rehabilitation after stroke, the current situation and how things might be in the future. It draws on presentations given at the European Stroke Organisation's conference this year in Switzerland, and draws conclusions about unmet needs, and health and social care services.

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The impact of stroke is sudden and life changing and is associated with a range of disabilities, responsible for 143 million disability-adjusted life years (Feigin et al, 2023). Approximately, half of survivors are dependent on others for everyday activities. Long-term effects can be physical, psychological and social resulting in a range of concerns or needs that may be stroke-specific, generic, can present at different times post-stroke and will differ for each individual. There is evidence to show that in at least half of people living with stroke, these needs are inadequately identified or managed in the longer term (McKevitt et al, 2011; Andrew et al, 2014; Chen et al, 2019).

It is recommended that people with stroke have their needs assessed at least annually. In the UK, patients who have had a stroke should have a stroke review/follow-up at 6 months, one year and then annually (National Clinical Stroke

Guideline, 2023), although this does not always happen. However, the diversity and number of concerns makes identification a challenge for healthcare professionals. Currently, there is no comprehensive, standardised model for stroke care post-discharge, so identification and management of stroke survivors' longer-term concerns varies (Aziz et al, 2016). At least half of patients with stroke will have cognitive or communication difficulties (O'Halloran et al, 2012; Milosevich et al, 2024), which may result in concerns such as their overall health, participation in everyday activities, finances, social relationships and can make the process of identifying and managing concerns difficult. Patients may be anxious about being a burden, or be unsure whether the problems they feel are important, fit the remit of the consultation and so may not mention the needs that most concern them. Long-term unmet need post-stroke is associated with reduced quality of life

(Andrew et al, 2016) and greater caregiver burden (Ekstam et al, 2015; Andrew et al, 2015).

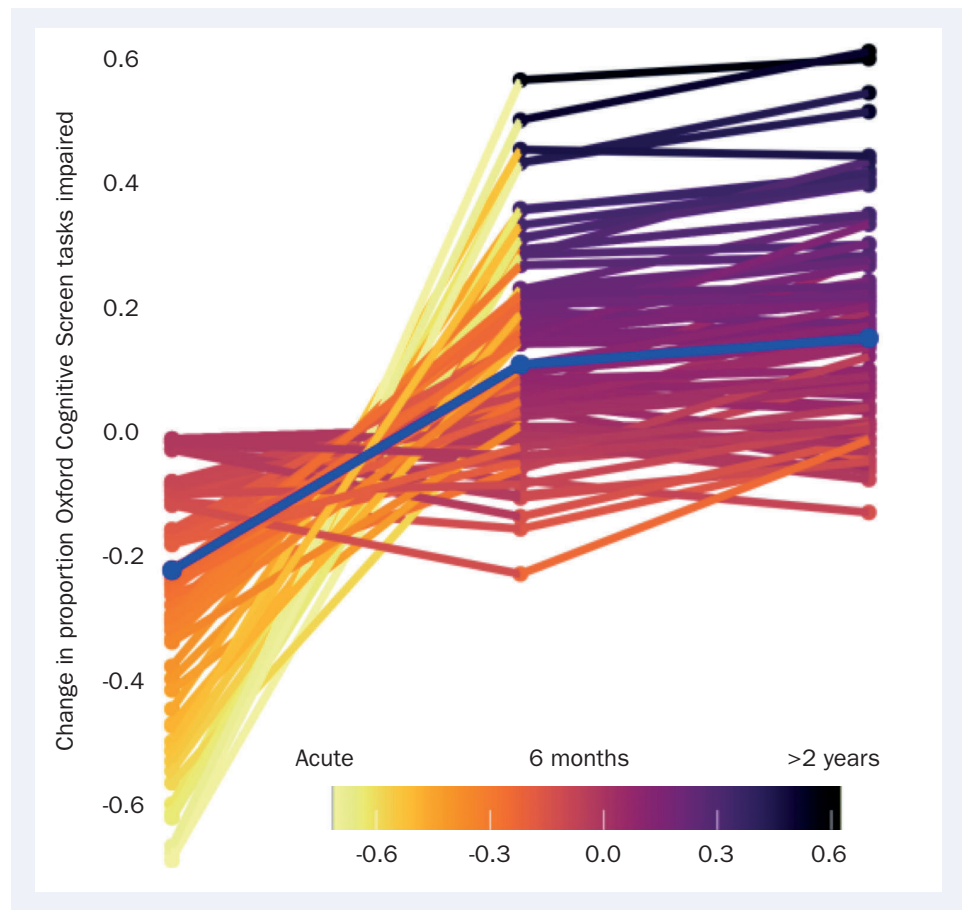
Identifying and managing concerns and unmet needs would benefit stroke survivors and their caregivers. One approach to discussing concerns could be the use of a prompt list for patients, such as the Stroke Patient Concerns Inventory, which aims to provide a holistic approach to identifying concerns in stroke clinic settings (Chesworth et al, 2023). If successful, clinicians should consider implementing interventions such as iVERVE an electronic tailored self-management support program aligned to person-centred goals (Cadilhac et al, 2018; Cameron et al, 2022) being assessed in the REcovery-focused Community support to Avoid readmissions and improve Participation after Stroke (ReCAPS) trial (Cadilhac et al, 2022) and multimodal individualised intervention being assessed in the LAST-long trial (Long-term follow-up After STroke) (Askim et al, 2023). Both randomised controlled trials are due to be reported later this year.

At the European Stroke Organisation Conference 2024 in Basel, Switzerland, in the summer, clinicians discussed studies, trials and evidence around rehabilitation post-stroke. This included a session aimed at nurses and allied health professionals on how to facilitate and support stroke recovery by addressing concerns and helping survivors to navigate life after a stroke. The session highlighted important messages about recovery from cognitive impairments, dose and intensity of therapy in relation to recovery of aphasia, as well as the value of comprehensive discharge planning that addresses the individual's needs and supports self-efficacy after discharge from hospital.

## Cognitive and mood changes

A systematic review found the most frequently reported unmet needs to be managed were cognitive and mood changes (Lin et al, 2021). Indeed, one of the most hidden but crucial components of stroke recovery is post-stroke cognitive impairment. While the reporting in the literature is focused on post-stroke dementia, implying potential decline, the evidence for different trajectories covering stability and improvement, alongside a minority proportion demonstrating cognitive decline, is growing (del Ser et al, 2005; Demeyere et al, 2019; Buvarp et al, 2021). With most studies lacking long-term follow up, beyond 1 year post-stroke, the recently completed OX-CHRONIC study aimed to better understand domain-specific cognitive changes over the long term (attention, language, praxis, executive functioning) (Kusec et al, 2023). The OX-CHRONIC study followed up 105 stroke survivors (average age 73 years, average acute NIH Stroke Score (NIHSS) 7.4) who were at least 2 years post-stroke (range 2–9, average 4.5 years) and had previously completed the Oxford Cognitive Screen (OCS) (Demeyere et al, 2015) acutely and at 6 months, providing long-term trajectory data. While this long-term sample demonstrated a high prevalence of impairments both in terms of overall cognition (46% demonstrating an impairment on the OCS, 65% scoring below a Montreal Cognitive Assessment (MoCA) cut-off of 26; 31% if using a MoCA cut-off of 22 as previously recommended in stroke), as well as demonstrating a range of different specific cognitive domain impairments on an extensive neuropsychological assessment. Importantly though, when modelling individual trajectories over time using latent class growth modelling, four distinct global cognitive impairment trajectories were identified with a majority of patients falling in the two growth classes, demonstrating cognitive improvement over time. This work will be published soon.

This study demonstrates that alongside risks of decline, there can be ongoing recovery past 6 months in domain-specific cognitive impairments, in parallel to known findings in motor recovery and aphasia. The message that



**Figure 1.** Descriptive data presented at European Stroke Organisation Conference 2024 on cognitive trajectories from the OX-CHRONIC study

cognition does not necessarily always decline is likely to be an important one for stroke survivors to hear. Indeed, recent qualitative research has found that stroke survivors want clear explanations about the purpose and outcomes of post-stroke cognitive assessments (Hobden et al, 2023). Discussions around cognitive trajectories would be welcomed, particularly where they maintain hope, with any discussions around potential decline requiring selectivity and sensitivity, on a person-by-person basis (Hobden et al, 2024).

### Aphasia

Aphasia affects about a third of stroke survivors and 20% have aphasia in the longer term. People with aphasia have worse functional, psychosocial and wellbeing outcomes than stroke survivors without aphasia (Gialanella et al, 2011; Hilari and Northcott, 2017; Zanella et al, 2023). Professor Katerina Hilari, from City St George's, University of London presented findings from the

new European Stroke Organisation's rehabilitation guideline, which is chaired/co-chaired by Professors Marian Brady and Katerina Hilari. The guideline addresses 10 questions on dose, intensity, frequency, as well as modes of delivery (digital vs in person; group vs one to one) of aphasia speech and language therapy (SLT). It also addresses transcranial direct current brain stimulation + SLT vs sham brain stimulation + SLT, which involved six separate comparisons based on location and polarity of stimulation. The presentation covered functional communication and quality of life outcomes and highlighted, among other things, the benefits of higher dose and higher intensity SLT.

### Intimacy

In terms of identifying concerns after discharge, stigma factors may reduce reporting of issues around sexual functioning, mood and emotional problems (Corrigan, 2004). Mrs Diana Wong Ramos, a former journalist and

patient advocate from Portugal, had her stroke at the age of 34 years and talked about sex and intimacy following a stroke. She wanted to rebuild an intimate relationship with her husband. The stroke had impacted her body image, she described not feeling like a woman or sexually attractive, she was unsure how to be intimate again and struggled to find the support she needed. Stroke can change how patients feel about themselves and relationships. A survey by the Stroke Association stated that over half of stroke survivors report that their sex life had changed since their stroke, while one third were too afraid to have sex at all (Stroke Association, 2024). Problems may be directly related to where in the brain the stroke occurred (for example, frontal lobe stroke leading to a loss of desire), physical changes or the patients' and/or partners' reaction to the stroke (Calabrò et al, 2011; Grenier-Genest et al, 2017; Latella et al, 2024). Despite being a fundamental aspect of post-stroke recovery, sexuality remains a taboo that is poorly addressed. Diana challenged the audience to not ignore intimacy as an important aspect of reconnecting and feeling whole. She challenged clinicians to adjust their needs assessment and to incorporate this component during their care.

### Depression

In terms of mood, following a stroke a third of survivors will be depressed at any one time (Hackett and Pickles, 2014). Depression (including depressive symptoms) leads to poorer outcomes: increased disability, longer hospital stays, reduced quality of life, higher levels of tobacco and alcohol use and higher rates of suicide (Stenager et al, 1998; Donnellan et al, 2010; Bartoli et al, 2013). Depression impacts on the management of symptoms and treatment following a stroke, reducing adherence to secondary prevention, lowering physical activity, and increasing cardiovascular-related morbidity and mortality (Ayerbe et al, 2014), yet it still remains inadequately addressed.

A national survey reported that two-thirds of stroke survivors felt they did not receive the psychological support needed (Stroke Association, 2013). This may be a result of staff not identifying or screening

for depression, perhaps led by the lack of robust evidence on how to treat and prevent depression (Allida et al, 2023)

One study exploring this is CONfirming the Mechanism of Motivational Interviewing Therapy after Stroke: a multi-centre randomised controlled trial (COMMITTS), which aims to randomise over 1200 participants from over 16 sites in the UK. Motivational interviewing (MI) is a brief psychological intervention that can be delivered by trained non-specialist staff to prevent and treat mild-moderate depression. The MI-based intervention comprising four 45-minute weekly individual sessions could easily be incorporated into a stepped-care model, freeing mental health staff to deliver complex interventions to those with major depression. During the sessions the patient is encouraged to talk about their adjustment to stroke and current concerns. This study has currently recruited 819 participants and will report study findings next year.

### Holistic approach to concerns

In terms of providing a holistic approach to identifying concerns, several randomised controlled trials are ongoing. The Recovery-focused Community Support to Avoid readmissions and improve Participation after Stroke (ReCAPS) presented by Professor Dominique Cadilhac from Monash University, Australia, aims to test the effectiveness of a 12-week intervention intended to support self-management through personalised goal setting and educational or motivational messages (Cadilhac et al, 2018; Cameron et al, 2022; ). Using aggregated data from 465 participants in the ReCAPS trial, factors associated with unmet needs 7–14 days after discharge following acute stroke were described, goals to address unmet needs were identified and if these were achieved by 90 days. The discharge satisfaction (PREPARED survey) (Grimmer and Moss, 2001) and the Long-term Unmet Needs Survey (LUNS) (Forster et al, 2013) were obtained by phone 7–14 days after discharge. At 90 days, the LUNS and goal attainment were re-assessed. Overall, the participants (mean age 65 years, 33% women) reported a mean

2.6 unmet needs at baseline compared with 1.5 at 90 days; frequency at baseline differed by age, sex, length of stay, level of dependency, confidence to manage at home or feeling prepared to return home. Various unmet needs were reported although most improved significantly by 90 days. For example, 80% of health-related goals and 78% of everyday activities goals were partially or fully met by 90 days. These results highlight the importance of preparing patients for discharge.

Issues experienced by patients with stroke who require support up to 18 months after stroke because of ongoing or new symptoms were presented by Professor Torunn Askim, from the Norwegian University of Science and Technology in her session on Life After STroke – Multimodal approaches to long-term follow up after stroke. The LAST-long trial (Long term follow-up After STroke) is aiming to investigate the benefit of regular meetings with a community-based stroke coordinator, who is delivering a multimodal individualised intervention to prevent functional decline, for 18 months. Furthermore, the stroke coordinators use the LAST-long checklist as a guide for a structured interview to assess risk-factors and shared decision making to agree on goals and action points for the next month (Askim et al, 2023). A total of 301 participants have been included and the final follow-up assessments were completed by the end of August 2024. The main results will be revealed early next year (in 2025).

Multiple factors impact life after a stroke. Recovery and adjustment to life after a stroke is a complex process. Stroke survivors have to navigate changed relationships with their body, family and friends. Stroke survivors have numerous concerns and significant unmet need, which is diverse in terms of type and frequency. More research is required to identify the best ways to identify unmet need and if more organised patient-centred health and social care services can result in better outcomes for stroke survivors and are cost-effective.

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