

Thriving after **stroke**

Thriving, not just surviving:
every stroke survivor should have the
support to live well after their stroke

[#ThrivingAfterStroke](#)

Executive Summary

Rebuilding lives after stroke

Stroke
Association



Foreword

Stroke is a leading cause of adult disability in the UK. It happens in an instant and can have a devastating impact, changing people's lives forever.

The impact of a stroke extends to all aspects of a person's life. Their needs are often constantly evolving throughout their recovery. Many of these needs go beyond the support provided through traditional health and social care services.

With the recommended levels of rehabilitation and long-term support, recovery and adjustment are possible. Yet, despite the National Clinical Guideline for Stroke being explicit on the need for life after stroke services to be available for all, thousands of stroke survivors do not have access to this vital support. They repeatedly tell us this leaves them feeling abandoned and like they are falling off a cliff edge. This is causing a catastrophic impact on people's lives and stress on the system.

We cannot afford to continue to leave stroke survivors trying to rebuild their life after stroke alone. We must think differently about long term support, much of which can be provided by the voluntary sector, which has decades of experience in delivering care and support based on what matters to people affected by stroke.

We recognise that life after stroke support cannot be seen in isolation. It must be provided as part of a whole pathway approach to deliver the best outcomes for stroke survivors. This includes stroke survivors receiving vital rehabilitation, where necessary, for as long as needed. It must, however, be given parity of esteem with other elements of stroke care and treatment and be recognised for the benefits it brings to individuals, health and care systems and the broad socio-economic system.

This report features some of the remarkable people working determinedly to improve the outcomes and wellbeing of stroke survivors. Most importantly, it shows how truly transformative life after stroke support can be for stroke survivors, carers, and their families. The Stroke Association hopes this report will spur on action across the UK at government, Integrated Care Systems (ICSs) and Health Board/Trust levels that will ensure the value of life after stroke services is recognised. **All stroke survivors should have the support in place to thrive, not just survive, after their stroke.**

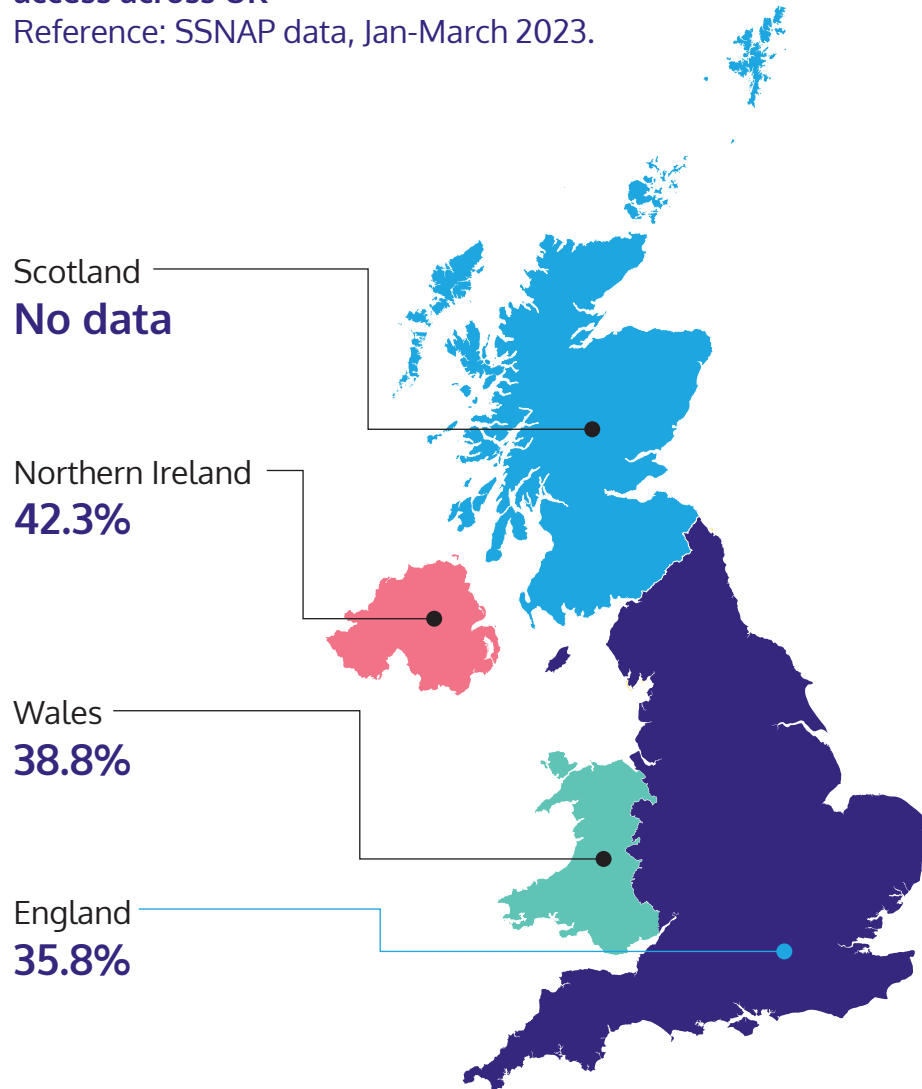


Juliet Bouverie OBE,
CEO, Stroke Association

The current data on six-month reviews

Map of the % of six-month reviews completed access across UK

Reference: SSNAP data, Jan-March 2023.



"There is currently a postcode lottery of support across the country. It is dependent on what is being funded in each place and not based on clinical need. Sometimes it's wrongly viewed as an expensive luxury and not essential."

Dr Louise Shaw, Clinical Lead for Stroke, Royal United Hospitals Bath

"We can offer a six-month review, which means that even if someone doesn't highlight problems straight away, they aren't lost in the system. These reviews are also vital for secondary prevention and for preventing people going to hospital unnecessarily."

Emma Richards, Sirona care and health's Clinical and Operational Lead for the Integrated Community Stroke Service across Bristol, North Somerset and South Gloucestershire



Just 37% of stroke survivors received a six-month review in 2022-23, meaning over 40,000 people missed out.¹

Summary and UK-wide recommendations

Summary



Life after stroke support enables people to thrive, not just survive.

Too often, support suddenly ends when a stroke survivor leaves hospital. Without long-term support, physical and mental health may avoidably deteriorate.

Life after stroke support delivers vast benefits to the system and economy.

Including freeing up time for clinical colleagues, supporting hospital flow, reducing reliance on primary care and delivering wider economic benefits by improving return to work rates.



The existing policy consensus for life after stroke is strong. This includes a focus within the National Clinical Guideline for Stroke.

There is currently unacceptable unwarranted variation in access to essential life after stroke support.

Just 37% of stroke survivors received a six-month review in 2022-23, meaning over 40,000 people missed out.²

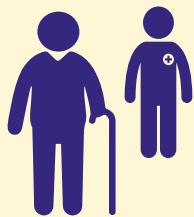




One in four strokes happen to people of working age.

One in three in this age group have to give up their job following their stroke.³

The third sector can provide vital support and help alleviate the burden on primary, secondary and social care.



We must urgently ensure all stroke survivors have access to guideline levels of long-term life after stroke support.

Life after stroke support includes vital emotional, practical, and social support. It is often an overlooked part of the pathway.



Stroke strikes every five minutes.

There are over 100,000 new strokes every year and there are over 1.3 million stroke survivors in the UK today.

These numbers are only set to grow.



Recommendations

Across the UK, life after stroke support should have parity of esteem with other parts of the stroke pathway and all stroke survivors must have access to Guideline levels of support. To realise our goal of **all stroke survivors having the support in place to be able to thrive**, we are calling for the following:

Across the UK:

- All relevant health providers and decision-makers should determine long-term pathways to implement the recommended levels and quality of support in the **2023 National Clinical Guideline for Stroke**.
- All stroke survivors should have access to a six-month review and key worker.

Northern Ireland:

- The life after stroke workforce should be included in the upcoming stroke workforce review and long-term plan so that the necessary people, skills and knowledge required to support longer-term recovery are available from all relevant providers.
- The new Northern Ireland specification for the provision of community and long-term support should be appropriately resourced and rolled-out across Health and Social Care Trusts.
- All stroke survivors should have access to effective pathways into clinical psychology and mental health services, encompassing both statutory and community and voluntary sector provision.

Scotland:

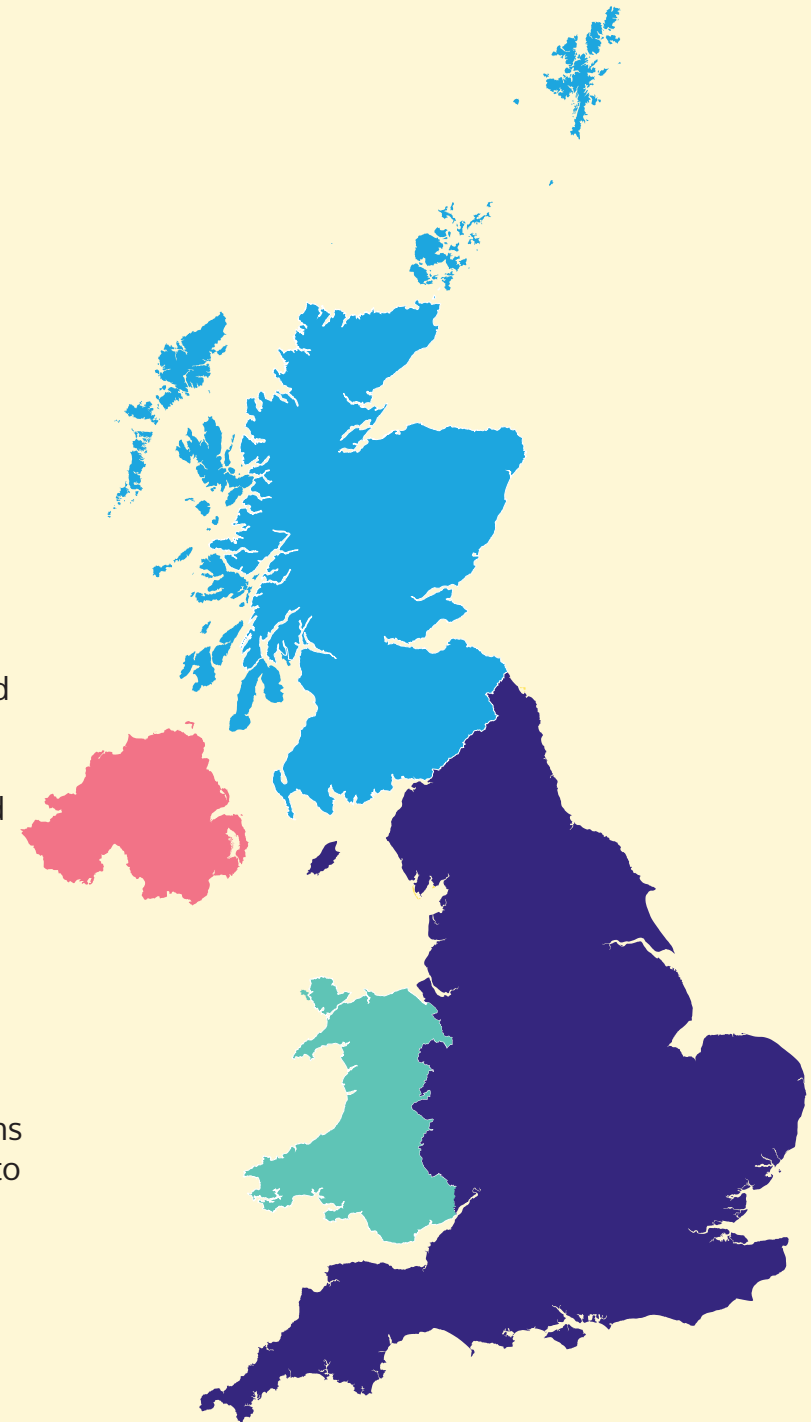
- All Scottish Health Boards should implement the National Model of Psychological Care in Stroke, as prescribed in the Stroke Improvement Plan 2023.
- Health Boards must ensure that stroke survivors in Scotland have timely, needs-based access to all levels of psychological and emotional support as a matter of course. Our vision is of a stroke service where the emotional and cognitive needs of those who have survived a stroke are given the same level of importance as their physical needs and recovery.
- To achieve this, all healthcare staff working with stroke survivors, including those providing long-term support, should be trained in psychological assessment and management.

Wales:

- The NHS Executive's work on the Transformation of Stroke Services in Wales should ensure that rehabilitation and life after stroke services are a priority in the stroke pathway.
- A service specification must be co-produced by people affected by stroke, to ensure that anyone who has a stroke in Wales has an excellent chance of surviving and returning to independence as quickly as possible.
- Welsh Government should properly resource and fund transformation work.

England:

- Working with the Integrated Stroke Delivery Networks (ISDNs), Integrated Care Boards (ICBs) should fully implement the National Stroke Service Model (NSSM) and Integrated Community Stroke Service (ICSS) model, referring to the Integrated Life After Stroke Support (ILASS) guidance for what good life after stroke should look like.
- The Department of Health and Social Care must include commitments for life after stroke in the Major Conditions Strategy, recognising the huge gains to be made across the country.



The benefits of long-term stroke support to the system

Life after stroke support not only provides huge benefits to stroke survivors, carers and their families, it also delivers vast benefits to the system and economy, through:

Freeing up time for rehabilitation and clinical colleagues

- Access to recommended levels of rehabilitation is chronically low. Staff are stretched, with less than a third of community-based rehabilitation teams meeting recommended staffing levels.⁴ Workforce challenges are persistent. As of December 2021, all three of the major therapeutic professions, as well as psychologists, were included on the UK Government's list of shortage occupations for health and care services.⁵
- Life after stroke support cannot replace guideline levels of rehabilitation; however, it can provide support for widely reported emotional, financial and social impacts of a stroke, which can prevent people engaging in their rehabilitation. Where life after stroke support is in place, clinical staff report that it is essential in freeing up their time to provide vital rehabilitation.

Frees up stroke beds and supports hospital flow

- We know that stroke patients admitted to hospital are likely to have much better outcomes if they are treated on a stroke ward. However, due to pressure on bed numbers, it is not always possible to move patients to the most appropriate place for their care. Poor patient flow is a result of wide-ranging challenges, but primarily stem from the high demand for beds combined with complexities involved in discharging medically fit patients from hospitals.⁶ Unnecessarily long stays in hospital due to delayed discharge can place patients at risk of hospital acquired infections or deterioration whilst awaiting discharge. The bottleneck at the point of discharge has a knock-on impact on emergency departments, ambulance response times, inpatient care, planned admissions and overall staff wellbeing.
- Not having any support available for staff to discharge stroke survivors delays discharge. If guideline levels of ESD, rehabilitation and life after stroke support was available everywhere, this would support better patient flow through the hospital and free up beds.

Reduced reliance on primary and community care services

- Supporting patients to care for themselves is recognised as one of the most promising interventions for generating healthcare savings.
- Stroke survivors often have multiple conditions. Only 59% of stroke survivors surveyed felt confident to manage any issues arising from their condition, in comparison to 80% of cancer patients.⁷ Universal access to a stroke key worker and life after stroke support, alongside vital rehabilitation, is essential to enable stroke survivors to feel more confident to self-manage the effects of stroke through having personalised tailored conversations about what matters to them. Thus, reducing reliance on primary care services.

Reduced unplanned hospital admissions

- The most common causes of unplanned hospital admission in the first year after a stroke are infections, heart conditions and recurrent stroke.⁸ By reducing the incidence of secondary stroke through effective secondary prevention measures, pressures placed on hospitals, at a time of increased stress on the NHS are reduced.
- Life after stroke support optimises recovery through goal setting and helping adherence to rehab and can also be helpful in identifying the need for further support with home adaptations and additional fall prevention support.

Reduced or delayed need for residential or nursing home care

- Demand for social care has reached record levels, yet financial challenges facing local authorities mean that less people are receiving it.⁹ Life after stroke support increases independence, self-management and enables people to access services in the community. It's also essential in supporting family members in their carer role, all of which promote independent living and reduce the need for residential or nursing home care.

Wider economic benefits to the system

- A single stroke avoided saves £22,175 – that is, £13,459 (NHS costs) and £8,716 (social care costs) in a year. The cost saving rises over five years to £45,232 – that is, £17,931 (NHS costs) and £27,301 (social care costs).
- As noted in the guidance for NHS England 2019/20 Commissioning for Quality and Innovation (CQUIN) policy, six-month reviews provide an opportunity to 'reduce the risk of subsequent vascular disease', 'inform future system planning' and support the 'reduction in secondary avoidable costs to health and social care through the identification of unmet/under treated patient need'.¹⁰
- Life after stroke support also benefits the wider economy. One in four strokes happen to people of working age. Improved rates of stroke survivors returning to work due to good quality vocational provision would help to boost the UK labour force, at a time when record numbers of people are out of work due to long-term illness.¹¹



Case study Marwar Uddin

Marwar Uddin, 41, from Tower Hamlets, London, had a haemorrhagic stroke aged just 40 in August 2022. A Dad of three, his stroke not only changed his physical abilities but his role in family life. He now receives life after stroke support and regular care support.

Marwar said: "Stroke is one of the worst things because of the long-term impact it has on you as a person. I need help to go to the toilet. I can't even dress myself. There is so much I can't do anymore. My voice is different now, like I'm a different person. I cry myself to sleep most days. It's difficult for me.

"My youngest daughter, she's only five, came to the hospital to see me after about six weeks. When she walked in the room, she saw me and said, 'That's not my dad.' This is my daughter who would come running into my arms when I picked her up from school and give me kisses. That was one of my most difficult days.

"After my stroke, I was contacted by several organisations. The Stroke Association was there right from the beginning and has been with me throughout my whole journey. My Stroke Support Coordinator calls me regularly to see how I'm doing. They have sent me so much information, pointed me in the right direction for obtaining a disability lanyard and helped me to get my blue badge.

"I am also set to start a phased return to work later this year.

"Without life after stroke services, my life would be massively different. I have had so much encouragement from the Stroke Association and the community stroke teams. If I didn't have any of this support, I think I would still be in a chair in my living room watching the world go by.

"It feels like the jigsaw puzzle pieces of my life are slowly taking shape again. I'm now registered disabled. I'm not the same person, and I probably never will be the same person again. But I'm determined to make things work."



When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

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To find out more about support and services available in your area, please contact campaigns@stroke.org.uk

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