

Thriving after stroke

Scotland campaign briefing
May 2024

Rebuilding lives after stroke

Stroke
Association

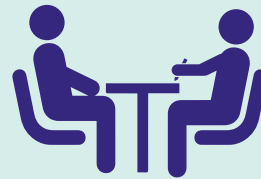


Thriving after stroke

To help everyone to thrive after stroke, every stroke survivor should:



Leave hospital with a personalised rehabilitation plan.



Have contact information for ongoing support from stroke services.



Receive a review of their progress and needs six months after their stroke.



The Stroke Association's UK 'Thriving after stroke' report includes broader evidence for life after stroke support and testimonials from healthcare professionals to its effectiveness.

stroke.org.uk/thrivingafterstroke

Introduction

Stroke is the leading cause of life-changing adult disability in Scotland. Stroke happens in an instant and can have a devastating impact.

The impact of a stroke can extend to every aspect of a person's life. Their needs are often ongoing and constantly evolving. Crucially, receiving recommended levels of rehabilitation and long-term support makes adjustment and recovery much more likely.

The Stroke Association believes every stroke survivor deserves the chance to thrive after stroke. But too many feel they don't have access to the longer-term support they need. Indeed, some say that being discharged from hospital feels like falling off a cliff... with a long, lonely climb back to a new normal.

We know that getting life after stroke support right improves outcomes for people. However, it also reduces pressure on the health and social care system by systematically treating persistent problems before they become long-term conditions.

We will therefore focus on three key actions that together help create the conditions for recovery to happen. All three are already recognised in national policy. Our 'Thriving after stroke' campaign will support and encourage the delivery of these measures on the ground.

Our goal is nothing less than a Scotland where every stroke survivor has the opportunity to thrive after stroke. We understand that making the necessary changes will take time. It will also need resourcing. But the potential win-win for the health and social care system, and the people it supports, will be more than worth the investment.

John Watson
Associate Director for Scotland

"What distinguishes stroke from other neurological conditions is the capacity for recovery. We know that getting the right support, in the right amounts, for as long as it is needed, makes all the difference.

"I want to see every stroke survivor resume their life with enhanced capacity, and with reduced need for ongoing support. This clearly benefits those who have had a stroke but also reduces their longer-term dependency on relatives, carers and health and social care services which benefits society more widely."



Dr Matt Lambert
National Clinical Lead
for Stroke and Stroke
Specialty Advisor to
Scotland's Chief
Medical Officer

What is life after stroke support?

Life after stroke support is a crucial part of the holistic stroke rehabilitation pathway. Core rehabilitation therapies, such as physiotherapy, occupational therapy and speech and language therapy, are complemented by a coordinated pipeline of support to address longer-term practical, social and emotional needs.

When practiced, this is a powerful combination that has proved successful in rebuilding lives. Stroke survivors can regain independence, reduce their risk of a further stroke, and improve their confidence, self-esteem and physical and mental wellbeing.¹

The concepts of person-centred care and supported self-management are central to life after stroke provision. People are empowered to actively engage in their recovery from the outset and achieve far better outcomes as a result.²

Life after stroke support can include signposting people to online resources and help in their community, including from charities. Where appropriate, it should also provide emotional support, return to work support and support for carers.

Scotland's Stroke Improvement Plan (2023)³ points to key pillars of holistic rehabilitation incorporating life after stroke support, including:

- Personalised care and support.
- Patients and practitioners work jointly towards agreed goals.
- Support to overcome communication and other difficulties affecting patient capacity for decision-making.
- Psychological and emotional support.
- Six-month reviews carried out by a healthcare professional knowledgeable and experienced in stroke and familiar with the patient.
- Consideration of those with caring responsibilities.

Life after stroke support achieves better outcomes for stroke survivors and reduces ongoing support needs. Getting life after stroke right is a crucial part of the prevention agenda that is needed for our health and social care system to meet the growing demands placed on it.



Rehabilitation means different things to different people... rehabilitation refers to a wide range of approaches that include activities, interventions and information resources that support individuals to recover or adjust to achieve their full potential.

Scottish Government – ‘Rehabilitation and recovery: a person-centred approach’ (2022)⁴

People who have suffered a stroke should be considered to have the potential to benefit from rehabilitation at any point after their stroke. Healthcare professionals should facilitate timely access to services that are necessary to enable people with stroke and their families to address their evolving needs over time.

National Clinical Guideline for Stroke (2023)⁵

Veronica's story

Vernonica Murphy, 70, from Wishaw is a doting Nana to seven grandchildren and loves her dog, Floyd.



I had a massive stroke in Glasgow in December 2023. At the time, I couldn't swallow or move the right side of my body. I spent 13 days at the Queen Elizabeth hospital in Glasgow.

I was then transferred to Wishaw general hospital where I was put on a clinical trial and spent 10 weeks undergoing intensive physiotherapy. At first my family couldn't see any improvement. But then one of my fingers moved, and it gave them a glimmer of hope. From then on there was no stopping me. I learnt how to stand, took my first step then gradually more with the support of a rail. My physios were amazing and put so much work into helping me.

On leaving hospital I was given a plan detailing my goals for returning home. I was assigned a community nurse who checked up on me, noted my progress, and left her phone number asking me to call with any questions at any time.

Some adaptations were made to the house on my return home. I continued to get regular home visits from the physiotherapist and occupational therapist, and achieved my initial goals of climbing the stairs, making a meal, and walking outside with help from my physio if needed.

More recently, I am thrilled to report that I am now able to walk and pick up my four-year-old grandson, Nathan, from nursery!



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.



"Veronica's experience demonstrates that even people with a poor prognosis can be hopeful of rebuilding their lives after stroke.

"Many more could be given hope with sufficient opportunity to engage with dedicated rehabilitation therapists and having an agreed plan and trusted contact for any ongoing needs and support. These are the hallmarks of best practice, based on current evidence and the voices of stroke survivors and their families who deserve nothing less."



Professor Frederike van Wijck
Neurological Rehabilitation Sciences, Glasgow Caledonian University and Co-Lead Stroke and Neurological Rehabilitation Research Group (SYNERGY)

Our campaign

There are many elements of good care after stroke. Our campaign will focus on just three key, achievable measures that will enable the identification and delivery of the particular support any individual needs.

Every stroke survivor should:



- 1. Leave hospital with a personalised rehabilitation plan.**
Every stroke survivor has different needs. So every stroke survivor should have their own rehabilitation plan. This should be agreed with the patient and their family or carers before leaving hospital.



- 2. Have contact information for ongoing support from stroke services.**
Many stroke survivors tell us they felt abandoned on leaving hospital. So that support does not suddenly end at discharge, stroke survivors, and their significant others, need to know how they can get in touch with stroke services. Every stroke survivor should have continuity of contact for their recovery from an experienced stroke professional who is familiar with them.



- 3. Receive a review of their progress and needs six months after their stroke.**
Almost two thirds of stroke survivors leave hospital with a disability⁶, with their needs evolving throughout their recovery. It is therefore vital they receive post-stroke reviews to identify these changes and plan further support or intervention. Six-month reviews are a way for stroke survivors to check-in on progress with a healthcare professional familiar with them and address ongoing needs. This may include re-referral to stroke services.



Almost two thirds of stroke survivors leave hospital with a disability⁶



These three measures are neither radical nor contentious. There is already wide agreement that they should happen. This will require leadership, commitment, determination and resourcing, from both health boards and government.



Our 'Keeping stroke recoveries in mind progress report' highlights the importance of psychological care as part of life after stroke and where Scotland's Health Boards are in delivering it. stroke.org.uk/world-stroke-day/keeping-stroke-recoveries-mind

Where are we now?

There has been genuine progress over the last two years in agreeing a national policy framework for stroke in Scotland. We now have a clear picture of what Health Boards should be doing, including for life after stroke support. Yet while clear policies are now in place, delivery on the ground is patchy.

Personalised rehabilitation plan

The Scottish Government's Stroke Improvement Plan⁷ commits Health Boards to 'demonstrate that their stroke services make use of goal-setting, where individuals are involved in setting meaningful personal goals in their rehabilitation'.

We know that Health Boards are looking at who should carry out assessments that will form the backbone of discharge plans, in consultation with the patient and their significant others. There are very different approaches here, with digital and paper records both on the table.

Continuity of contact

As part of the Stroke Improvement Plan (Annex A)⁸, Health Board annual reporting should demonstrate 'there is a clear pathway for people who have had a stroke to re-engage with stroke rehabilitation services and re-access specialist support at any stage following their discharge'.

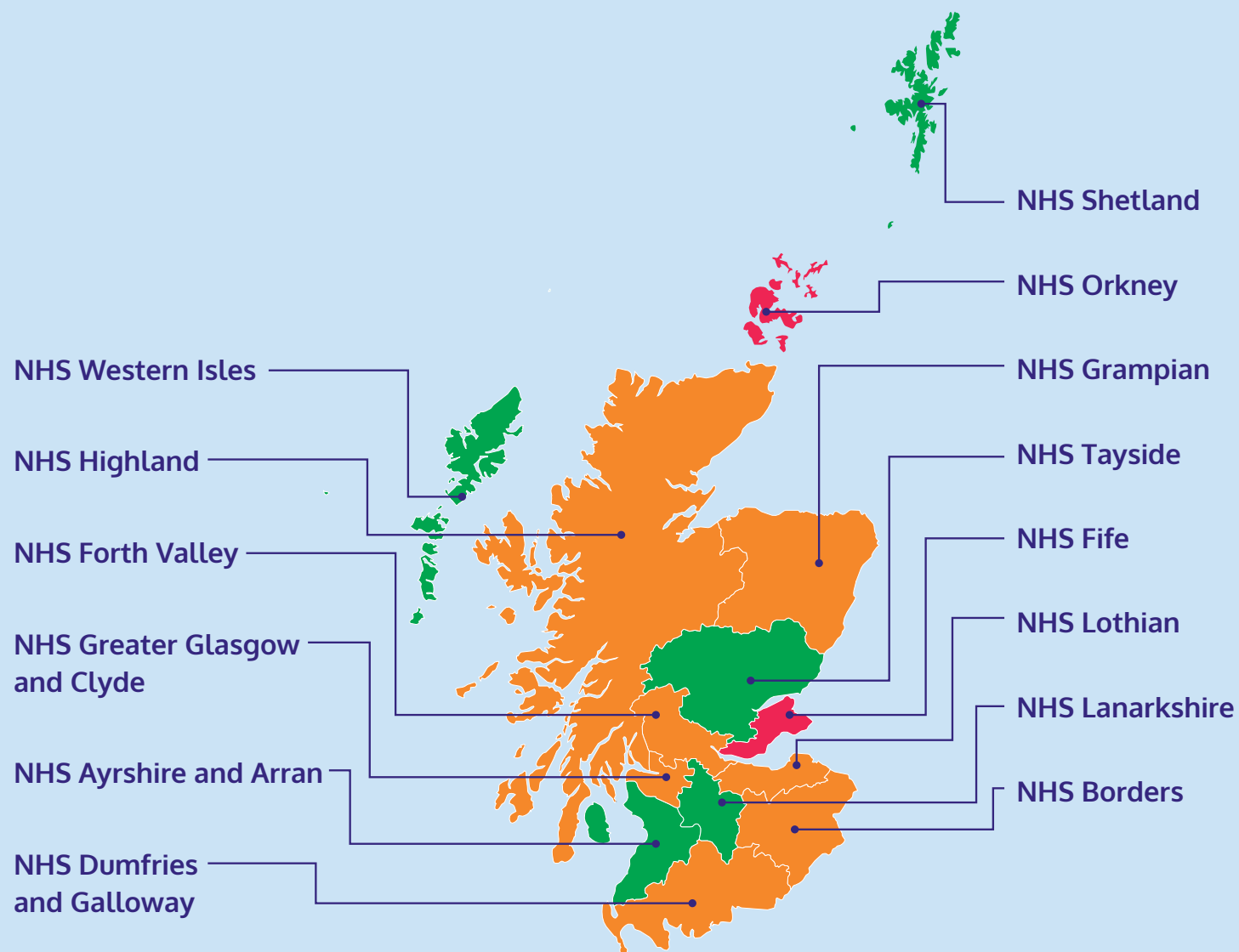
Again, progress is patchy and there is still much to do. But having continuity of contact within stroke services will be a huge help to stroke survivors whose condition may have deteriorated over time or manifested itself in a different way.

Six-month reviews

The Stroke Improvement Plan⁹ states that 'The Scottish Government is now asking stroke services in all NHS Boards to offer a formal review to everyone who has had a stroke. This should take place six months after the stroke event and allow re-referral into stroke services where required'.

Surface analysis of the position for six-month reviews is provided in the Scottish Stroke Improvement Programme annual report 2023¹⁰, which, due to the nature of annual data collection and reporting, features 2022 figures.

Six-month reviews 2022



Key

- Red:** There is no evidence six-month reviews are being carried out.
- Amber:** There is limited evidence of six-month reviews being carried and not all criteria listed is fully embedded.
- Green:** There is evidence that six-month reviews, meeting all criteria outlined, are fully embedded into stroke care and being consistently delivered.

Over and above this, we have established that Health Boards have been advancing on this front over the last year or so with some pockets of good practice. However, most are on a point between beginning to look at reviews and working through the practicalities of how they will do it.

Data from Scottish Stroke Improvement Programme annual report 2023¹⁰

What happens next?

Every year, around 10,000 people in Scotland are admitted to hospital following a stroke. The identification, treatment and rehabilitation services provided for these people need to improve. Getting stroke care right is one of the urgent reforms needed to help our health and social care system deal with the unprecedented demands it faces.

We are at the beginning of what we hope will be real change for all those people, their families and carers, with work being done in hospitals and a thorough review of what is happening in rehabilitation.

We recognise that such wholesale change takes time, but there is clearly imperative for the three things we are calling for to be put into practice urgently. They provide a framework from which almost everything in life after stroke support can flow.

This briefing is just the beginning of what we see as a long, sustained campaign where we will use policy, evidence, lived experience and analysis of Health Board performance on the ground, to press for change.

At this point, people who have had a stroke might get a personalised plan, contact continuity and a six-month review, but it is a long way from being the norm. We hear too many stories of stroke survivors who leave hospital not knowing what happens next, or where to turn.

Every stroke is different. Some effects are hidden. Everyone who has had a stroke should be offered the same three things.

We sense that the stroke community in Scotland is coming together for a period of exceptionalism. We will continue to comment and collaborate with the Scottish Government and Health Board leaders. We will work with stroke teams and researchers, politicians, third sector partners, stroke survivors, families and carers to improve lives.



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.



Stroke in Scotland



11,257

admitted to hospital with
a stroke in 2022¹¹



Around

6,754

left with a disability¹²



More than

130,000

stroke survivors
living in Scotland¹³

Someone has
a stroke in
Scotland every



53 minutes¹⁴

By 2035, the annual cost
of stroke to **Scotland's**
health and social care
system will be over



£4.5 billion¹⁵

Stroke Association
currently invests

£1.9 million

in stroke research in Scotland



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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**

Rebuilding lives after stroke

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To find out more and support our campaign, please contact
Scotland@stroke.org.uk

Updates on our work in Scotland, and how you can get involved, can be found at **stroke.org.uk/scotland**

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

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