

Thriving after stroke

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

[#ThrivingAfterStroke](#)

Rebuilding lives after stroke

Stroke
Association



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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

Case study Michael Pursey

Former sports coach and teaching assistant Michael Pursey, from Wales, expected to be in a wheelchair forever after having a stroke in 2019 at the age of 24. Four years on, Michael, can walk, talk, and drive again.

I returned home after six months in hospital. I felt lonely and depressed, without any belief that I could recover. When I got home, I cried my eyes out, thinking I'd be in a wheelchair forever.

My physiotherapist recommended that I attend a stroke group in Neath Port Talbot on World Stroke Day in 2019. The coordinators I met there then came to see me at home, talked to me about what I could access, supported me to do so and helped me to re-evaluate my goals. Driving, walking, it may not happen straight away but if I gave up at the first hurdle, then that was it. Every day I walked along my hallway, supported by the wall and a banister, filming myself at least once a week to visualise progression.

If you work hard, there's no limit to your improvement. I needed that mentality, that push out of procrastination.

There's life after stroke! Four years on, I can walk, talk, I've just passed my driving assessment and I'm helping other stroke survivors in their recovery.

"The aim is to improve outcomes for people. In addition, working together frees up hospital beds and help flow through the service as people can be discharged from community rehabilitation sooner as we know they will have longer term support from life after stroke services. Stroke survivors have fed back previously that they felt lost when rehab services stopped, so by working together we have stopped people feeling this way through life after stroke support. We don't want anyone to feel like there's no hope after stroke."

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

“The value of life after stroke support is huge, and not just for survivors, but for their families and carers too. We often hear from stroke survivors and carers about how much they benefit from peer support groups – meeting other people who’ve been through a similar experience helps them feel a bit less isolated.”

Joanne McKee, Community Stroke Lead, Southern Health and Social Care Trust, Northern Ireland

“Life after stroke support provides a really important part of the person processing what’s happened to them, as they can sometimes feel they’ve been abandoned after they leave hospital. If life after stroke support was done properly, people would be in a much better place from a mental health point of view.”

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

“When a stroke happens to somebody, it just comes out of the blue and there’s not always warning. You could just be having tea or be out at work. It changes someone’s life dramatically. Post discharge, it’s vital that life after stroke support kicks in, as once people have processed everything that’s happened, there’s going to be so many questions. It’s vital for someone’s recovery. It’s vital for their mental health and wellbeing going forward.”

Vikki Pattinson, Support Coordinator, Stroke Association

“Often, when considering the stroke pathway, the primary focus gravitates towards preventive measures, acute care, and the initial phases of post-stroke rehabilitation. Sadly, we tend to neglect the subsequent phase, known as ‘life after stroke,’ which, for many stroke survivors, especially the younger ones, may endure for 20, 30, 40, or even 50 years post-stroke.

It is essential that we avoid construing ‘life after stroke’ as a fixed state. Likewise, we must not perceive it as ‘the life one is left with’ after a stroke, implying that recovery is limited within a predefined timeframe. Instead, we should perceive ‘life after stroke’ as an evolving journey – a life that can be reclaimed through post-stroke recovery, regardless of the gradual nature of progress and its duration.

It is imperative that every stroke survivor can partake in a thorough six-month review, enabling them to address the ongoing challenges they encounter. The current rate of stroke survivors accessing this review is distressingly insufficient.

At Different Strokes, we offer support to thousands of younger stroke survivors annually, empowering them to regain control of their lives. We collaborate with dedicated professionals within the NHS and fellow charitable organisations who share our commitment to these objectives. However, it is paramount that we establish comprehensive funding, systems, and a well-equipped workforce across the board. This approach will enable us to assist stroke survivors in maximising their recovery and shift our perception of ‘life after stroke’ from a mere depiction of the final stage of the stroke pathway to a life worth living.”

Austin Willett, CEO, Different Strokes

What is life after stroke support?

Life after stroke support provides a lifeline to people affected by stroke, improves quality of life for both stroke survivors and carers, and means people can live well beyond stroke.

Long term support is a vital, yet often overlooked, part of the stroke care pathway. It provides the information and support that many stroke survivors need to rebuild their lives, regain independence, reduce their risk of a further stroke, and improve their confidence, self-esteem, and physical and mental wellbeing. The voluntary sector can be commissioned to provide these services.

Life after stroke support should include:

- Personalised care and support planning and information provision by a stroke coordinator/stroke key worker.
- Psychological and emotional support.
- Peer support.
- Post-stroke reviews.
- "Return to work" support for working age stroke survivors.
- Support for carers.
- Communication support.
- Secondary prevention information and support.

A stroke key worker is a "community-facing professional who has sufficient knowledge and skills, following appropriate training, to support the practical, informational, emotional and social support needs of people affected by stroke. Stroke key workers make a unique contribution to the multidisciplinary stroke care pathway".



Support, alongside rehabilitation, allows people to rebuild their life from day one. Without long-term support, physical and mental health may avoidably deteriorate. Further benefits include:



Emotional support - level one emotional support includes active listening, goal setting, helping with adjustments and supporting and supporting people to come to terms with the impact of stroke.



Improved communication - communication support in the community offers a safe and supportive environment where people can build their communication and confidence skills so that they can live well with their communication difficulty.



Return to work support - Around a third of stroke survivors of working age have to give up their job following their stroke.¹ Despite the vast benefits of returning to work (including quality of life and general health), there is often an absence of return-to-work support.² NHS England have produced a Vocational Rehabilitation Toolkit as 'return to work support should be offered as a core component of rehabilitation from stroke'.³



Secondary stroke prevention - six-month reviews include both blood pressure and atrial fibrillation checks, to screen for risk factors for secondary stroke. This helps people understand stroke risk factors and what they can do to reduce these risks using personalised care approaches. Recurrent strokes, often a result of unsuccessful secondary prevention, account for 25–30% of all strokes.⁴ Medication for secondary prevention can reduce the risk of another stroke by between 20 and 30%.⁵



Support for carers - carer support is essential. Long-term support reduces potential feelings of isolation, by connecting carers with support networks and better understanding their needs.



Patient satisfaction - research shows that support from a professional who is dedicated to coordinating a stroke survivor's care after leaving hospital improves patient satisfaction.

"We [stroke support coordinators or key workers] can help make connections and give people the tools and information on key risk factors, such as smoking, high blood pressure and alcohol, to help prevent another stroke. It helps give the stroke survivor autonomy for their own decisions and ownership of their own lifestyle."

Karen Bellew, Support Coordinator, Stroke Association



Case study Caroline and Matt Cooke

The lives of Caroline and Matt Cooke from Northern Ireland were turned upside down when Matt had a sudden stroke in August 2020.

At only 40 years old, Matt's life had changed forever, his stroke left him with cognitive problems and left sided paralysis. He was in hospital for nearly a year and Caroline became his carer. She says, "the reality is everything has changed in my life as well as Matt's life. A stroke has a huge impact on the person who has it but also on the family. We had shared roles but now everything falls on me and that is difficult."

"When Matt had his stroke I didn't know anything about it. I was scared and worried about my husband so I looked online and found the Stroke Association website. I called the Stroke Helpline and they referred me to their local support service. It was really good and helped me with trying to deal with what was happening especially as I had limited visits due to Covid. That emotional support for not only stroke survivors but carers as well is so important to helping to rebuild a life after stroke."

"At the start, Matt couldn't remember the days of the week, tell the time or even do one plus one. He was in a wheelchair when he came out of hospital but he has regained movement in his left leg so he's come a long way. The journey hasn't been easy but positivity, belief and having hope is so important - everyone's life after a stroke is different".

Case study Dave and Jackie Parkyn

Carpenter Dave Parkyn from Cornwall had a severe stroke in August 2020, aged just 28. This devastated his life, his mother's life, and the lives of those closest to them. Dave is now blind in his right eye, partially sighted in his left and physically disabled.

For the first two years after his stroke, his family struggled with the huge emotional toll. Now, thanks to the emotional support received from Life After Stroke services, they have started to come to terms with what has happened.

Jackie (Dave's Mum) told us "It has devastated Dave's dreams. He has lost his income, his self-confidence, pride and ambition. He planned a future with a wife and family, was buying his own house, had just started his own business and absolutely everything changed.

"Dave and I were hesitant when we were offered a referral to the Stroke Association's Cornwall Emotional Support Service, but being able to talk openly about our feelings has made a real difference."

Dave said: "I didn't think it would help and I was reluctant to go through with it but I'm very pleased that I did. I spoke to them about everything, my feelings of humiliation and worthlessness, my lack of confidence and my embarrassment at how I now felt I looked. It helped me think about how to let out my anger and frustration, which is a huge part of the healing process. It was just nice to be able to talk to someone and share my feelings and not feel judged.

Jackie said: "They enabled me to think and reflect and simply talk openly and honestly, never once telling me what or how to think or feel but helping me explore my feelings and come to some sort of acceptance of them. Dave will never fully be able to do the job he loved so much, but he's recently returned to carpentry work.

"He is now beginning to accept some of what has happened and is trying to re-build a career and a life, albeit different to the one he planned."

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.⁶





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.⁷

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



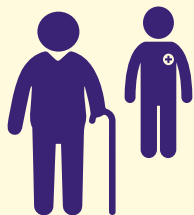
The third sector can provide vital support and help alleviate the burden on primary, secondary and social care.



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.



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

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:

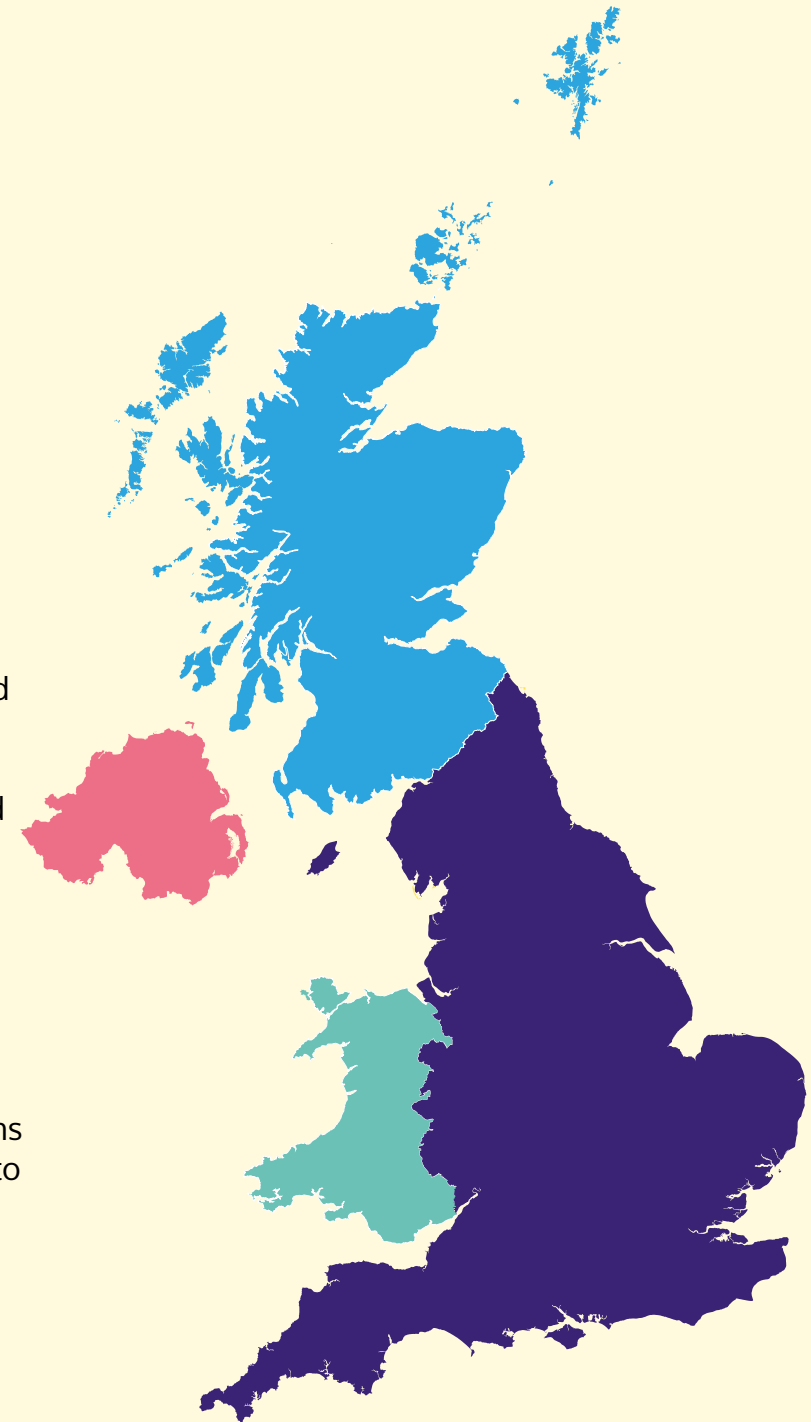
- All Scottish Health Boards should implement the National Model of Psychological Care in Stroke, as prescribed in the Stroke Improvement Plan 2023.
- Health Boards must ensure that stroke survivors in Scotland have timely, needs-based access to all levels of psychological and emotional support as a 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 current data on six-month reviews

Two thirds of stroke survivors leave hospital with a disability. The needs of stroke survivors and their families are often complex and constantly changing through the process of their recovery. It is therefore important that they receive regular reviews, including at six weeks, six months and annually following their stroke.

What is a six-month review?

A six-month post stroke review is a person-centred holistic review of a stroke survivors physical, neuropsychological and social needs. It should be used to inform the next stages of their personalised care and support plan. Where needs are identified, further support or intervention should be provided, which may include onward referral to health, social and voluntary sector support based on the individuals goals, preferences and circumstances.

Without access to a six-month review, stroke survivors will not receive access to the ongoing rehabilitation and life after stroke support they need to continue their recovery.

Access to support and to a six-month review is patchy and currently varies depending on where you are in the UK. Rates are now lower than before the pandemic. **Just 37% of stroke survivors received a six-month review in 2022-23, meaning over 40,000 people missed out.**⁸ There is large variation between hospitals, with rates ranging from 16% to 100%.⁹ There is currently no data available for Scotland; however, every Health Board should be providing reviews.

“Six-month reviews give stroke survivors and their families an important opportunity to be listened to and heard. It provides a forum to understand their needs, concerns and plan the next stages of their recovery. A greater focus on ensuring that all stroke survivors have a six-month review, on time and adequately resourced is definitely needed.”

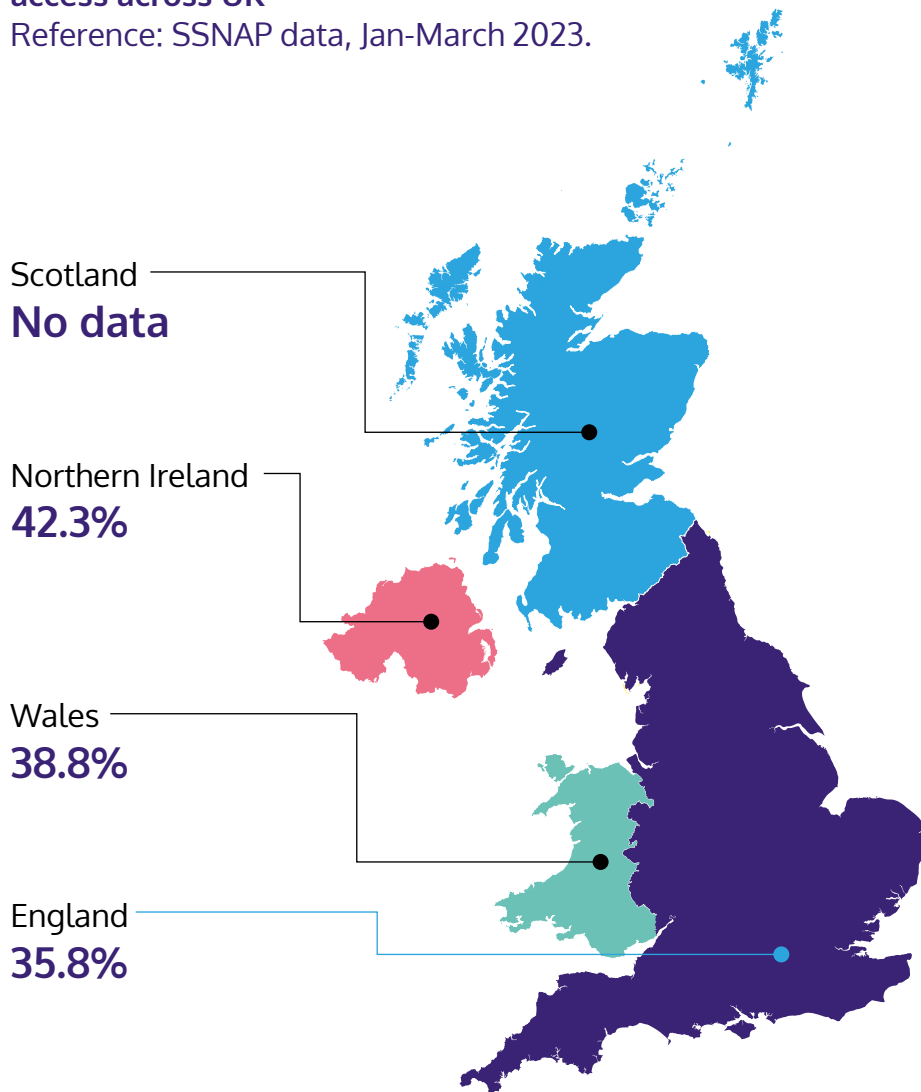
Mark Cadman, Stroke Survivor, Campaigner and Trustee, Harlow Stroke Support



Just 37% of stroke survivors received a six-month review in 2022-23, meaning over 40,000 people missed out.⁸

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 & health's Clinical and Operational
Lead for the Integrated Community Stroke Service across
Bristol, North Somerset and South Gloucestershire**



Case study Julie Lomax

Mother, Julie Lomax had an ischaemic stroke in May of this year. Julie describes being discharged home and feeling left upstream without a paddle post-stroke.

"On the day of my stroke, I felt some tingling around my lips and my left cheek. It got worse down my left side the next morning and I lost all coordination. After three days under observation in my local hospital I was blue-lighted to Oldham to have an endarterectomy. When I first came out of the surgery, I felt great, and everything was going well. I was given my medication but then simply told to go home".

"It was very odd getting home without any knowledge of what happens next. I was sure this wasn't normal process. I felt left upstream without a paddle."

The Bury Stroke Recovery Service received referral for Julie, direct from Fairfield Hospital.

"Shortly after contact with our coordinator Jo I had appointments booked with coordinators, district nurses and physiotherapists."

"Our coordinator, Jo did a home visit and told us to call anytime. She scooped me up and has been my safety net ever since. It's as if her world is revolved around my family. I had a bee's nest at the front of my house and couldn't get out. My daughter contacted Jo, who put me in touch with a local pest control and we got it sorted. It seems such a trivial issue, but not to Jo. She always goes the extra mile."

Problems with memory and cognition are very common after a stroke, recovery can continue for months or even years. Life after stroke services help stroke survivors to increase confidence in decision making and execution of tasks.

"Without her emotional support, personability and guidance, I wouldn't have the bright post-stroke outlook that I have today. I've got a life to keep living!"



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.¹⁰ 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.¹¹
- Life after stroke support cannot replace guideline levels or 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 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.¹² 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 to 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.¹³ 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.¹⁴ 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.¹⁵ 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'.¹⁶
- 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.¹⁷

“There can be a perception that life after stroke isn’t a vital part of the service; however, it cannot be overstated how much working together across health and the voluntary sector improves outcomes for individuals, improves hospital flow, helps people get back to work and have social participation and emotional support, which in turn reduces the ask of social care.”

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

“Without LAS support, it’s difficult for rehab professionals as there’s no support or service to discharge people off to. They have to keep flow and capacity in the stroke unit and within community rehabilitation teams, so without the support there it becomes about managing workload instead of doing what matters to the person.”

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

“The life after stroke service works really seamlessly with our early supportive discharge team and community teams and we have excellent communication. They are one of the key components in connecting everything together. The benefits are huge and we see them as an integral part of our pathway.”

Ruth Witham, Clinical Specialist Physiotherapy, Early Support Discharge team lead and Cheshire and Mersey ISDN Rehabilitation Lead

“I’ve been supporting stroke survivors for over 10 years. Because of stretched capacity in the NHS, people often can’t get to see their GP. I often get questions from stroke survivors that I have the skills and expertise to answer, and it reduces the reliance on GP services. Some of these questions they wouldn’t get the answers to if our support service wasn’t there for them. If we weren’t there to give people information and support about secondary stroke prevention, people would go on to have further strokes and this would cost the NHS a lot more than funding life after stroke support.”

Karen Bellew, Support Coordinator, Stroke Association

“It has been a welcome addition to have Stroke Association stroke coordinators, working closely with the team – attending MDTs, liaising with the team about any complex issues and supporting and signposting patients. The service is providing support to patients even after we have discharged patients and helping them integrate in community. We find that this has freed up our nursing and therapy time where we can provide the nursing management and therapy support and can let Stroke Association Stroke Recovery Coordinators support with understanding emotional changes, financial worries, relationship concerns and reconnecting in their local areas.”

Fatema Mullamitha, Team Lead Community Stroke team, South Manchester and Clinical Lead for Community Stroke GMNSIDN

The size of the prize in England by implementing the National Stroke Service Model (NSSM) and Integrated Community Stroke Service (ICSS) model

Life after stroke services form a key part of NHS England's Integrated Community Stroke Service (ICSS) model to support specialist community stroke rehabilitation teams.¹⁸

This Model features evidence-based policy recommendations for delivery of responsive and needs-based community stroke rehabilitation for stroke survivors. The ICSS model includes a core specialist multidisciplinary team, providing responsive and intensive Early Supported Discharge (ESD) and community stroke rehabilitation, with specialist support for vocational and psychological rehabilitation. Integrated and collaborative working with social care and the voluntary sector is also recommended to provide tailored patient centred rehabilitation care, peer support and provision of six months reviews, information, and longer-term support in the community.

NHS England, working in partnership with the Stroke Association and other organisations, have produced the Integrated Life After Stroke Support (ILASS) model. This provides best practice guidance on the provision of support services required to provide practical, emotional and social input to people affected by stroke.¹⁹ This includes access to a Key Worker; personalised care and support planning; emotional support; secondary prevention support; carer support; communication support, return to work support and a post stroke review.

The NHS Long Term Plan references out of hospital, integrated support, 'delivered in partnership with voluntary organisations including the Stroke Association, will support improved outcomes to six months and beyond'.

The National Stroke Service Model (NSSM), the blueprint for stroke services, is clear on the value of long-term support to support good outcomes post stroke.²⁰ The Model states: 'life after stroke services provide the ongoing personalised care and support that people need to rebuild their lives and minimise risk of future cardiovascular events.'²¹

Recently, the Major conditions strategy: case for change has also emphasised the need for people to live well with stroke, stating the ambition 'to make sure people living with health conditions are able to make informed choices about their care and manage their condition well'.²²

ICBs have a duty to improve 'population health and healthcare', tackle 'unequal outcomes and access', enhance productivity and value for money' and help the 'NHS to support broader social and economic development'. Supporting people, including stroke survivors, to live well by commissioning the ILASS allows ICBs to meet each of their aims.

Integrated Care Boards (ICBs) must work with their ISDNs to implement the ICSS and NSSM locally.



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."



Patient Reported Experience Measures (PREMs) survey findings

The publication of the first ever national Stroke Patient Reported Experience Measures (PREMs) survey report has provided valuable insight into the experience of stroke survivors right across England. While we already have rich data on other conditions such as cancer, this is the first time that parity of esteem has been given to stroke patient experience.

The national report, facilitated by a close partnership between the National Stroke Programme at NHS England and the Stroke Association, details experiences of treatment and care across the entire stroke pathway – from acute care through to community rehabilitation and life after stroke.

Over 6,600 responses were collected from stroke survivors.

Key findings:

- The majority of respondents reported feeling generally satisfied with the care they received along the whole stroke care pathway.
- High numbers felt they had been treated with dignity and respect, that their stroke was explained in a way they could understand, and they were made aware of how their stroke would affect their life.
- A number of respondents indicated that they would have liked support with their emotions, mood and wellbeing, but they were not offered any.
- **Many respondents would have liked more life after stroke support.**

The findings from this report are relevant to everyone in the stroke community and provide guidance on the improvements that need to be made.

To read more visit:
stroke.org.uk/prems2022-23





Case study

Rebuilding Minds after Stroke

In January 2023, we joined forces with mental health charity Mind Cymru to begin to scope out and test the first model of mental health support for people affected by stroke in Wales.

76% of stroke survivors in Wales experience depression, anxiety, a lack of confidence, mood swings or even suicidal thoughts during their recovery. Despite this, there is very little mental health support available.

A community-based project in Neath Port Talbot in 2020, saw the local Stroke Association Support Coordinator working with the local Mind to deliver an eight-week programme aimed specifically at stroke survivors, based on Mind's established My Generation scheme.

Run by Mind staff, sessions covered psychoeducation (learning about and understanding mental health and wellbeing), peer support and community activities to improve mental health and wellbeing, build resilience and reduce isolation.

The success of this project demonstrated the potential for a **strategic partnership** between Mind Cymru and the Stroke Association.

The overall aim of the partnership is to create, test and implement solutions that address the mental health needs of stroke survivors and their families in Wales.

Project activity officially began in January 2023 and we will launch the findings in January 2024. We expect that because of this project, stroke survivors and carers will:

- Feel **better able to cope** with their life after stroke.
- Feel **better supported** with their mental wellbeing.
- Feel better able to cope with their **negative emotions**.
- Feel more able to **access the support** they need.
- Feel **less isolated** and **more connected**.
- Feel **more confident** to move forward with life.

"When I had my stroke my life changed overnight and I was left suicidal. I didn't know how to deal with how the stroke had changed my life. The sessions with Mind helped me massively. They encouraged us to talk through our feelings and express how we feel. It is so important to talk to somebody about your feelings so you are not alone."

Phil, stroke survivor from Neath

Case study:

National Stroke Rehabilitation Pilot - North Central London: Stroke Buddy Role

NHS England's Stroke Quality Improvement in Rehabilitation (SQulRe) programme seeks to improve the quality of community-based stroke care as evidenced by improving clinical outcomes and patient experience.

In North Central London, the Stroke Buddy role was developed and piloted to provide a point of face to face and virtual contact for up to six months post stroke or longer if appropriate. The Stroke Buddy facilitates the identification of patient reported barriers to participation and challenges to recovery and help.

The Stroke Buddy team also introduce to the stroke patients and their carers a validated self-management intervention tool called 'Taking Charge After Stroke' which is a low cost, person-centred, self-directed rehabilitation intervention after stroke that has been shown to improve health-related quality of life and independence.

Between 1 September 2021 and 31 March 2022, the Stroke Buddy team has offered support for 390 patients (out of a total of hospital discharges since 1 September 2021 of 402) and completed a programme of support in 169.

The Stroke Buddy model has been successful and provides one solution to the perception that care falls away at the end of formal therapy input. A key learning from the pilot to date is that there is a wide spectrum of non-therapy needs amongst the patient group, so the delivered service model needs to be sufficiently flexible to identify issues and coordinate multi-disciplinary expert input that is appropriate for the patient and their family.

Appendix

Appendix A - unmet needs of people affected by stroke.

Stroke survivors tell us that it feels like falling off a cliff once discharged from hospital and that they feel abandoned.²³

Our Lived Experience of Stroke reports surveyed over 10,000 people affected by stroke finding:

- 44% of stroke survivors experienced depression after their stroke and 16% experienced suicidal thoughts, showing the clear need for psychological and emotional support.²⁴
- More than a third of working age stroke survivors gave up work following their stroke.
- Half felt they needed support for longer or more frequently.
- 22% were not involved in making choices about their recovery and support.
- The mental health of carers gets worse over time.

Appendix B - policy context

The Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of Physicians of London endorse the 2023 National Clinical Guideline for Stroke for the UK and Ireland. This evidence-based Guideline recommends all stroke survivors should have access to a six-month review and for stroke survivors and their families and carers to be 'given information and offered contact with relevant statutory and voluntary agencies (e.g. stroke key worker)'.²⁵

Despite policy commitments, commissioners often do not view life after stroke as an essential part of the stroke pathway.

Personalised, integrated and coordinated care to support people to live well is prioritised by various policies across the UK – including the Comprehensive Model for Personalised Care and goals within NHS Long Term Plan in England and the Health and Wellbeing 2026: Delivering Together plan in NI that proposes a 'new model of person-centred care focused on prevention, early intervention, supporting independence and wellbeing'.

Policy commitments across the UK

Scotland - in June 2023 the Scottish Government published Stroke Improvement Plan 2023. This plan sets out its long-term stroke support goals. Priorities 4, 5 and 6 call for Health Boards to deliver improved services related to aspects of life after stroke:

- **Priority 4: Early secondary prevention** - we will seek to prevent as many additional strokes as possible by optimising the care of those who have suffered a stroke or TIA.
- **Priority 5: Rehabilitation** - we will make the provision of high quality, holistic rehabilitation a cornerstone of stroke care in Scotland. Rehabilitation should be person-centred, re-accessible, delivered in the appropriate setting and patient outcomes and experiences measured.
- **Priority 6: Psychological care** - we will ensure that 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.

Northern Ireland - priority 4 of the Department of Health Stroke Action Plan recognizes the importance of both rehabilitation and life after stroke and commits to ensuring that stroke survivors have access to the right support at the right time for as long as they need it. As part of this work, the regional Stroke Network have developed a new specification for the provision of community and long-term stroke support which sets out the optimal support pathway for all patients once discharged from hospital. The Department of Health have also previously committed to using the Stroke Association's report "**Struggling to Recover**" "as a blueprint to improve support for stroke survivors".

Wales - the Welsh Government's Quality Statement for Stroke outlines its "recognition of the importance of rehabilitation, early therapeutic intervention, self-management, peer support and group consultations to life after stroke services". The Quality Statement identifies people affected by stroke as a clear population group and identifies the desired outcome for this group as; 'People in Wales who have a stroke have an excellent chance of surviving and returning to independence as quickly as possible.'

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About the report

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.

Personalised life after stroke support is an essential part of the recovery pathway. It must be provided alongside the other core elements of care and rehabilitation, to enable the best outcomes for stroke survivors. Life after stroke support is different, yet complimentary to rehabilitation and should not be seen as a substitute for rehabilitation, but an integral part of the core multidisciplinary team.

The National Clinical Guideline outlines this principle “rehabilitation, recovery, and adjustment are different albeit linked concepts that may take place over differing time frames and require differing levels of support” and “life after stroke services should be available to support and advise during, between, and following different phases of rehabilitation”.

Whilst we recognise that life after stroke cannot be seen in isolation from the rest of the pathway, this report is focusing on the often unrecognised the value life after stroke support.



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

Stroke
Association

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

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