

Life After Stroke:

Experiences of Stroke Survivors and Carers in Kirklees and Calderdale

September 2026



Summary and Key Findings.....	3
Key Findings.....	5
Introduction.....	7
What we did.....	7
Who we heard from.....	8
What we heard	10
Emergency care	10
Hospital experiences.....	11
Rehabilitation starts well but ends too soon	12
Left to find support alone	13
Living with the long-term effects of stroke.....	15
The wider impact beyond health	16
Speech and communication needs	17
Carers need more support.....	17
Gaps in follow-up and pathways	18
Which services help people most after a stroke	18
Awareness of stroke symptoms.....	19
What would improve life after stroke?	19
Conclusion	20
Recommendations	20
1. Develop a longer-term stroke support pathway.....	20
2. Introduce routine stroke reviews after discharge	21
3. Improve information and signposting following stroke.....	21
4. Strengthen emotional and psychological support	22
5. Improve support for carers and families	22

Summary and Key Findings

Healthwatch Kirklees and Healthwatch Calderdale carried out engagement to understand people's experiences of stroke care, rehabilitation and life after stroke. We heard from stroke survivors, carers, family members, healthcare professionals and community organisations through surveys, face-to-face conversations, focus groups and direct feedback.

People consistently described emergency treatment and hospital care as being of a high standard. Ambulance services, specialist stroke units and the early stages of rehabilitation were widely praised, with many people believing that the prompt care they received had saved their life or made a significant impact on their quality of life after a stroke.

However, the engagement also highlighted a clear gap in support once people returned home or were discharged from initial care pathways which were described as too time-limited. People faced a prolonged and fragmented struggle afterwards.

The recurring issue is not simply a lack of individual services, but a lack of continuity, coordination and holistic support as people adapt to life after stroke. This includes support to return to the workplace, travel and social support.

Many felt rehabilitation ended before they felt ready and described limited follow-up from specialist services and uncertainty about where to turn when new challenges arose. Stroke survivors told us that recovery continues long after formal rehabilitation ends, yet ongoing support was often difficult to access.

The long-term impact of stroke extended far beyond physical recovery or clinical need. Fatigue, communication difficulties, reduced confidence, impact on emotional wellbeing, loss of independence, financial pressures and social isolation were common themes throughout the engagement.

While some people were able to access additional support through community organisations or private therapy, others described feeling left to manage their recovery alone.

The findings suggest that while acute stroke care is working well, there is an opportunity to strengthen longer-term rehabilitation, improve follow-up and signposting, and ensure people affected by stroke receive the practical, emotional and community support they need to rebuild their lives.



Key Findings

The engagement identified six key themes:



Emergency stroke care is highly valued. People were positive about the care they received from Yorkshire Ambulance Service, and mostly positive about hospital stroke teams and inpatient services.



Support often ends too soon. Early rehabilitation was widely praised, but many people felt support stopped before they had reached their full recovery potential.



People are often left to navigate recovery alone. Many stroke survivors were unsure who to contact after discharge and found community support through chance rather than formal signposting.



Stroke has a lasting impact on everyday life. Fatigue, communication difficulties, reduced confidence, impact on emotional wellbeing, mobility and loss of independence continued long after hospital discharge.



Recovery extends beyond healthcare. People described challenges relating to transport, employment, finances, benefits, social care and maintaining social connections, highlighting the need for a more holistic approach to recovery.



Access to ongoing support is inconsistent. Differences in community services, rehabilitation and peer support meant that people's experiences varied depending on where they lived and what support they were able to access.



Life after a stroke – one man's story:

I found the medical part of having a TIA (transient ischaemic attack) was as I expected, the fast response calling 999 and into hospital care via A&E and everything was as it should be, quick, efficient and right for the purpose. I was given some information about after care too & I've had a follow up.

It's the other stuff around having a stroke that I still find difficult & feel angry about. My driving licence was suspended. I lost my independence and it's hard to come to terms with still.

I was off work for 3 months before phased back, but as I couldn't drive I struggled. No direct buses, what was a 35 minute car journey was 1 hour 25 minutes on 2 buses. I gave up recovering, working full time then 3 hours a day on buses was too much.

The battles with the Department for Work & Pensions then began and I honestly have got nowhere. I find the paperwork a struggle and using their systems are difficult as they don't work logically in my mind. They (DWP) tell me I can work, but my mind doesn't work as it did & I know I cannot do 9 5 or shifts again.

I cashed my private pensions, use foodbanks and have 3 years until my state pension when it'll feel a bit easier. The health aspect isn't my concern, it's everything else you cannot predict.



Introduction

A stroke can have a profound and lasting impact on every aspect of a person's life. While emergency treatment focuses on saving lives and reducing the immediate effects of stroke, recovery often continues for months or years afterwards.

Healthwatch Kirklees and Healthwatch Calderdale carried out engagement to understand people's experiences of stroke care, rehabilitation and life after stroke. We wanted to understand not only what happens during a stroke emergency, but also whether people receive the support they need to rebuild their lives afterwards.

This report brings together the experiences of stroke survivors, carers, family members, community organisations and healthcare professionals.

While experiences of emergency treatment and hospital care were generally positive, many people described significant challenges once they returned home.

The findings highlight the importance of longer-term rehabilitation, emotional support, community services and practical help to enable people to live well after stroke.

What we did

Unlike some Healthwatch projects, we did not undertake a large-scale social media promotion campaign. Instead, we took a more targeted and relationship-based approach to hear directly from people with lived experience of stroke and those supporting them.

Between April and June 2026, Healthwatch Kirklees and Healthwatch Calderdale gathered feedback from people affected by stroke through:

- An online survey shared with key support organisations.
- Face-to-face conversations in community settings.
- Assessed feedback shared directly with Healthwatch.
- A focus group involving stroke survivors and carers.

- Discussions with professionals working in stroke rehabilitation and recovery services.

We asked people about:

- Emergency treatment.
- Hospital care.
- Rehabilitation services.
- Life after stroke.
- Access to ongoing support.
- The impact of stroke on daily living.

We further looked at feedback to Healthwatch in Kirklees and Calderdale dating back to 2024 to see if what we were being told has remained consistent with feedback we have previously received.

Who we heard from

This report brings together the experiences of 58 people affected by stroke.

During our targeted engagement in 2026, we heard from 34 people through surveys, community conversations, focus groups and feedback shared directly with Healthwatch. This included feedback from:

- Stroke survivors.
- Family members.
- Carers.
- People supporting someone following a stroke.
- Healthcare professionals involved in stroke rehabilitation.

Seventeen people completed the survey. Of those who answered the relevant questions, 56% had experienced a stroke themselves – 66% of them within the last three years – and 43% were answering on behalf of someone who has had a stroke.

Most survey respondents had experienced a stroke within the previous three years.

We also reviewed 24 experiences shared with Healthwatch since 2024. Including this earlier feedback enabled us to compare recent findings with people's previous experiences and identify where concerns appear to be long-standing rather than isolated incidents.

Demographic information was collected through the survey. However, demographic information was not routinely collected during face-to-face conversations, focus group or feedback shared directly with Healthwatch. The demographic data presented within this report should therefore be considered representative only of survey respondents and not everyone who contributed their experiences.



What we heard

Emergency care

People consistently praised emergency stroke services.

Survey respondents rated Yorkshire Ambulance Service (YAS) extremely highly, with all respondents rating care as either good or very good. 73% of people used YAS emergency care to get to hospital.

The focus group reached a similar conclusion.

One person told us:

"Initial care excellent – excellent service from YAS, extremely responsive and paramedics have high knowledge of stroke care." (stroke patient, Kirklees)

People described:

- Rapid ambulance responses.
- Fast access to hospital.
- Prompt investigations.
- Quick diagnosis.
- Effective treatment.

One survey respondent told us:

"Fortunately, I was a lucky one with no problems after my stroke due to rapid care and treatment." (female, Calderdale)

Many people felt the emergency response had prevented more serious long-term consequences. However, some people experienced delays.

One respondent described waiting over two hours for an ambulance while their symptoms worsened:

"The anxiety of having to wait for the ambulance whilst I could feel myself deteriorating was unbearable and not helpful." (female, Kirklees)

Others highlighted practical barriers, including difficulties parking at Calderdale Royal Hospital during a stroke emergency.

Hospital experiences

Hospital care was generally viewed positively. Many people praised staff working on stroke units and inpatient wards. 72% of people told us the urgent care and treatment was very good or good.

Participants described:

- Consultant-led care.
- Regular monitoring.
- Fast access to scans.
- Good communication with families.
- Early rehabilitation support.

One focus group participant said:

"Inpatient care is generally very good, rapid scans/tests, clear information, consultant-led care, and families kept informed." (Kirklees)

Most survey respondents rated their hospital experience positively – 61%, but 38% said it was 'ok'.

The reported negative experiences included multiple ward moves, concerns about personal care and environments that made recovery difficult.

One respondent said:

"The inpatient episode at Calderdale Royal was not a pleasant one as my mum was moved between 5 wards in the 6 weeks that she was there." (female, Calderdale)

Not everyone has had a positive hospital experience, with some carers having to do basic tasks:

One carer told us: "Visitors are having to help him to drink, he has bed sores. Parkinsons information is not displayed behind his bed. Carer has

requested that he is discharged to rehabilitation home, possibly a Stroke specific unit. Hospital does not appear willing to consider this."

Rehabilitation starts well but ends too soon

The strongest theme across all engagement was the quality of rehabilitation immediately after discharge and lack of support afterwards.

40% told us that their rehabilitation was "very good" and a further 26% good, indicating overall positive feedback about it.

People consistently praised the first few weeks following discharge. They described:

- Regular physiotherapy.
- Occupational therapy.
- Speech and language support.
- Home visits.
- Intensive rehabilitation.

However, many felt support ended before recovery was complete.

At one Kirklees focus group participants described support: "[like] dropping off a cliff"

One participant said:

"It goes from 12-week high-intense support to nothing virtually overnight."

Another explained:

"Feel like just starting to make progress and support stopped – progress plateaued or regressed."

Several people felt the current model did not recognise that stroke recovery is highly individual.

As one participant put it:

"There's no personalised care... it's a one size fits all module when stroke recovery is very individualised."

A patient of Mid Yorks Hospital told us: "... there is no joined up care. After having first seizure and stroke symptoms following a fall, brain clot (subdural haematoma) I never fully recovered. I was discharged from A&E the very next day with an epilepsy drug to manage – without any first fit review with a neurology or stroke team. Despite my GP writing 3 times for urgent follow up, have been put as normal, low priority on a neurology waiting list at 49 week waiting time! It has been over 6 months and there is no one looking at what damage is going on due to brain bleed ever since. It's precariously scary to be in this situation. It's like they are waiting for things to go worse for them to take any notice."

The survey findings reflected the same concerns as only 40% of respondents rated rehabilitation support as very good, while more than a quarter rated support as just okay or poor.

A manager at Calderdale & Huddersfield NHS Foundation Trust explained that although specialist stroke rehabilitation ends after a set number of weeks, people can be referred to the Community Rehabilitation Team to continue to work towards their goals.

Left to find support alone

Many people told us that once rehabilitation services ended, they felt abandoned. 66% said 'no' or that they were 'not sure' if they were given follow-up health appointments with specialist services.

Several described uncertainties about:

- Who to contact.
- What support should be available.
- Whether further recovery was possible.
- How to access additional help.

One survey respondent said:

"I was shocked how many people have a stroke and how long it took to get any care, mine was only a mild stroke and I get no proper help or advice afterwards." (Kirklees resident).

A recurring theme was that support groups and community services were often discovered by chance rather than through formal referral pathways.

A representative from the Stroke Association explained that they are no longer commissioned to provide support for stroke survivors in Kirklees which leaves a gap in support available in this area.

In Calderdale, the Stroke Association continue to deliver community groups that provide longer-term peer support, helping people to rebuild confidence, regain independence, rediscover skills and connect with others who have had similar experiences.

This difference in available community support was reflected in the feedback we heard. Several people living in Kirklees described travelling to Calderdale to access Stroke Association groups or relying on informal support networks because there were limited local alternatives.

One Kirklees person told us:

"More support in Huddersfield area [needed] – we travel from Huddersfield to Halifax to access support from the Stroke Association and Aphasia café" [the person is aware there is now an Aphasia cafe in Huddersfield, but had already made connection with Halifax group as that was only option at the time when they needed them the most] (Female, Kirklees)

Some people told us they had been able to pay privately for additional physiotherapy, speech and language therapy or other rehabilitation to continue their recovery. However, many recognised that this is not an affordable option for everyone, creating inequalities in access to ongoing support once NHS rehabilitation has ended.

Several people felt annual stroke reviews should also be available to provide reassurance, identify emerging needs and help people reconnect with services when their circumstances change.

Living with the long-term effects of stroke

Many participants described stroke as a lifelong condition rather than a single event with more than 46% telling us they now needed some form of help for daily activities such as cooking, washing and shopping.

The most common ongoing challenge reported in the survey was fatigue, affecting over 90% of respondents.

People also reported:

- Mobility problems.
- Memory difficulties.
- Speech and language difficulties.
- Emotional challenges.
- Loss of confidence.

Many described the hidden impact of stroke. One Kirklees respondent said:

"Learning to live in a different body."

A Calderdale resident explained:

"The health aspect isn't the concern, it's everything else you cannot predict."

People described losing independence, reducing social activities, becoming reliant on others and struggling to accept changes to their lives.

One participant explained:

"Adapting to my physical changes. Managing my constant fatigue and insomnia. I am independent in some ways, but feel a loss of independence when I have to ask for help. Trying not to feel embarrassed when my loss of function/ incontinence affects my social life. I definitely go out much less than I used to. I find that I am unable to drive for longer distances, I tire easily so keep to local areas only" (female, Calderdale)

The wider impact beyond health

One of the strongest findings was that stroke affects much more than physical health for themselves and the people they live with/close family members.

The impact of stroke was rarely confined to a single health problem.

People described challenges relating to:

- Employment.
- Finances.
- Benefits.
- Driving.
- Transport.
- Housing.
- Social isolation.

Several people described difficulties navigating benefits systems after stroke, particularly where cognitive changes made paperwork and online processes difficult.

The greatest challenge after stroke was therefore not their immediate medical treatment, but adapting to a fundamentally changed everyday life.

"Support re benefits – if I am entitled to any, as I have had to cut my working hours due to a health condition – does this mean I am able to claim something? No one has discussed this with me, and it would be useful to have someone to discuss this with. (Male, Calderdale)

Transport was another major issue.

People who could no longer drive often struggled with public transport due to memory problems, fatigue or anxiety.

One Calderdale person explained:

"I use taxis now more which costs a lot more but it's less anxiety."

Professionals working in stroke services confirmed that transport remains a significant barrier to accessing healthcare, rehabilitation and community support.

Speech and communication needs

Communication difficulties were one of the most commonly reported ongoing challenges.

Over 60% of survey respondents reported speech or language difficulties.

Many people praised the speech and language therapy (SALT) they received during rehabilitation. However, several described a lack of support once they returned home.

One respondent said:

"Speech has been affected the most – had very little input from SALT."
(Calderdale stroke patient)

Another told us:

"Had input from SALT almost daily during 2-month stay in hospital, then nothing since discharge." (Calderdale stroke patient)

Participants felt access to speech and language therapy should continue beyond the initial rehabilitation period where needs remain.

We heard that reading and mixing numbers up were frequent after-stroke issues that people needed help with.

Carers need more support

Carers described significant pressures following a stroke.

Several family members felt they had become responsible for coordinating support, chasing referrals and advocating for services.

One participant described concerns that rehabilitation referrals had never been made following discharge. Physiotherapy was only arranged after family members independently sought help elsewhere.

Others described being expected to provide substantial levels of care with limited support from health and social care services.

Carers frequently told us they needed:

- Better information.
- Emotional support.
- Practical advice.
- Easier access to services.

Carer's feedback:

We "have had only very little social care involvement (for my husband). He is particularly seeking mental health and respite support plus support to get me out to groups. Neither of us are leaving the house much at the moment."

Gaps in follow-up and pathways

The engagement identified concerns about inconsistent follow-up and referral pathways.

Some people reported excellent coordination between hospital and community services.

Others described:

- No follow-up appointments.
- Unclear referral routes.
- Delays accessing rehabilitation.
- Reliance on self-referral.

Professionals also highlighted variation between areas, with some referrals reaching community stroke services promptly while others arrived months after the stroke had occurred.

Which services help people most after a stroke

Survey respondents told us they have had most benefit from physiotherapy, speech and language therapy and occupational therapy.

Others told us of the great benefit they have gained from community groups and peer support.

Awareness of stroke symptoms

Professionals raised concerns that public awareness campaigns may not fully reflect the range of stroke symptoms.

Several examples were shared where visual disturbances were the first symptom of stroke.

One family member described how her husband drove himself to a GP appointment, then to an optician and later to hospital before his stroke was recognised.

Professionals felt that symptoms such as sudden visual changes or severe headaches may be overlooked because they do not feature prominently in public awareness campaigns.

What would improve life after stroke?

Across all engagement, people consistently identified similar priorities:

- Longer-term physiotherapy support.
- Continued speech and language therapy where needed.
- Annual stroke reviews.
- Easier routes back into rehabilitation services.
- Better information about community support.
- More emotional and psychological support.
- Better support for carers.
- Benefits and welfare advice.
- Support with transport and maintaining independence.
- Improved communication between services.



Conclusion

People spoke positively about emergency stroke treatment and urgent hospital care. Many believed the care they received saved their lives or reduced the long-term effects stroke can have.

However, the engagement highlights a significant gap between surviving a stroke and learning to live well afterwards.

Stroke survivors, carers and professionals all described a system that provides intensive support immediately after discharge but often withdraws that support before recovery is complete.

People continue to experience fatigue, communication difficulties, mobility problems, emotional challenges and loss of confidence long after formal rehabilitation has ended. Many also face wider challenges relating to employment, finances, transport and independence.

The findings suggest that improving life after stroke is not only about healthcare. It requires ongoing rehabilitation, stronger community support, better information, improved follow-up and recognition that recovery continues long after people leave hospital.

Recommendations

1. Develop a longer-term stroke support pathway

Stroke survivors told us that rehabilitation support often ends while recovery is still ongoing. While early physiotherapy, occupational therapy and speech and language therapy were widely praised, many people felt support ended before they had reached their full recovery potential. Several participants described ongoing communication difficulties and felt Speech and Language Therapy ended too soon.

We recommend that providers review rehabilitation pathways to identify opportunities for longer-term support, including access to physiotherapy, occupational therapy and Speech and Language

Therapy where ongoing needs remain, and provide easier access back into services when needs change.

2. Introduce routine stroke reviews after discharge

Many people described feeling unsupported once rehabilitation ended and were unsure who to contact when new issues emerged. The barriers aren't peripheral social issues, they can directly affect access to treatment and recovery.

We recommend that all stroke survivors are offered a structured review at regular intervals following discharge, such as six months and twelve months after stroke, to identify ongoing needs and provide access to further support where appropriate.

3. Improve information and signposting following stroke

Many people found support groups, community services and specialist organisations by chance rather than through formal referral pathways. Stroke survivors also described difficulties accessing welfare rights, benefits, employment and financial advice, particularly where cognitive or communication difficulties made navigating systems more challenging.

We recommend that all stroke survivors and carers receive clear information about available support, including community groups, welfare rights and benefits advice, employment support, transport support, emotional wellbeing services and specialist stroke organisations. This support should be continuous for anyone who has had a stroke and not time-limited.

4. Strengthen emotional and psychological support

People frequently described anxiety, fear, loss of confidence and difficulties adjusting to life after stroke. Many felt emotional recovery received less attention than physical rehabilitation.

We recommend that emotional wellbeing and psychological support form a routine part of stroke recovery pathways, with clear referral routes into appropriate services.

5. Improve support for carers and families

Carers described taking on significant responsibilities following discharge, often acting as advocates, coordinators and providers of care.

We recommend that carers are routinely offered information, practical guidance and signposting to support services throughout the stroke recovery journey.

6. Raise awareness of the wider signs of stroke

Healthcare professionals highlighted concerns that public awareness campaigns do not always reflect the full range of stroke symptoms. While the FAST campaign has been successful in raising awareness of common signs, professionals shared examples where symptoms such as sudden visual disturbances were not recognised as possible indicators of stroke, resulting in delays in seeking treatment. Improving public awareness of the wider signs and symptoms of stroke could help more people access emergency care as quickly as possible

We recommend working with national and local partners to improve public awareness of the wider signs and symptoms of stroke, including visual disturbances and other less recognised symptoms.