

Chest  
Heart &  
Stroke  
Scotland



# NO LIFE HALF LIVED

1 IN 5 STROKE REPORT





# No Life Half Lived

# Introduction

## OUR VISION:

Welcome to a Scotland where people with our conditions can live their lives well. Full lives, with the right support, at the right time, and in the right place. A place where people can shape their future and live the life they want to lead.

## OUR MISSION:

Every person with our conditions should have access to quality, supported self management and community recovery. We will deliver an approach to this that is designed by people with our conditions and puts what matters to them at the heart. We will work to develop the partnerships that will enable this to be available across Scotland – for everyone, no matter where they live.



**One in five (1.1 million) people in Scotland live with one or more of our conditions. If you are not directly affected yourself, you will know someone living with a chest, heart or stroke condition or Long Covid.**

The voice of people affected by these conditions is critical to how we develop and deliver our services, and how we advocate with them on the care that matters to them.

Five years ago, we conducted the most comprehensive survey we had ever undertaken with people living with chest, heart or stroke conditions in Scotland. This helped us to set out our vision of No Life Half Lived in Scotland for the first time.

Now, five years later, we have conducted an even larger survey through an independent research company to find out how people's experiences have changed over the last five years, and to include people living with Long Covid for the first time. The 1886 responses to the survey tell us that people with our conditions are continuing to struggle with loneliness and their mental wellbeing, and that opportunities are still being missed for them to get the support they need to live their lives to the full.

The last five years have been extraordinary and unprecedented and have impacted on every part of our society and across all our communities. During this time, people with our conditions were among the most vulnerable. This is why it continues to be vital that they are given every opportunity to recover and live well after a heart attack or stroke or diagnosis of a long-term health condition.

Despite all the changes we have been through, what we found from the survey this summer is that much of what people told us five years ago is still true. Living with a long-term health condition is life-changing for the individual and the people around them. It is clear that so many people living with our conditions are not getting the support, and more specifically, the rehabilitation they want and need. Too many people in Scotland are missing out on the emotional, social and rehabilitation support that could provide them with the best possible recovery and quality of life for their futures.

In this report we have put a spotlight on the issues stroke survivors in Scotland are struggling with the most and the actions that are required to change this. By highlighting what matters most to people with our conditions, we want to inform and influence the future of support so it can make a difference to people across Scotland who are struggling to get the care they need.

Through this report, we want decision makers responsible for creating, developing and delivering services to be better informed and better understand the reality of living with a long-term health condition.

It is heartening to see that this report clearly demonstrates how the support Chest Heart & Stroke Scotland currently provides makes a difference. People supported by the charity rated their health and wellbeing greater than those who don't get support from us. This drives us forward to further develop and refine our services, and more importantly to reach more people who need us.

We remain committed to our ambition that there should be no life half lived for anyone in Scotland affected by our conditions. We want to continue to work with the Scottish Government, NHS Scotland, key partners and stakeholders to help people access the support they need from the very beginning of an acute health event or diagnosis throughout their recovery journey.

We want people in Scotland to be given the advice, information and support they need to manage their condition, live well in their community, and ultimately stay out of hospital. We will do this by providing services that are focused on a framework of supported self management and community recovery led by people with our conditions and informed by expertise and research.



## Key Findings

## Context



**1in5** (19%) stroke survivors say they weren't referred for rehab



**2in5** (41%) said their stroke had affected their mental health or state of mind



**2in5** stroke survivors (42%) say there was support they needed but weren't able to access



**NO LIFE HALF LIVED**



**136,000** people are living with the impact of a stroke



Almost **11,000** people in Scotland have a stroke every year.



Almost **TWO THIRDS** of stroke survivors leave hospital with a disability



Up to **40,000** stroke survivors in Scotland could be missing out on rehab

# What Matters to You?

We spoke to people living with the effects of a stroke about what matters to them – specifically, which parts of daily life they were most concerned about.

Half of stroke survivors (49%) said that their biggest concern was having another stroke. This fear was highest immediately after the stroke, at 57% for those who had experienced their stroke in the last six months. For those who had their stroke at least five years ago, this was still their biggest concern by a significant margin, at 46%.

- Stroke survivors were also extremely concerned by the **impact of their condition** on the life they want to live.
- Nearly three in ten (28%) were concerned with **losing independence**.
- More than a quarter (27%) were concerned with **keeping physically active**.
- A quarter of stroke survivors (24%) were concerned with **copng with memory loss, confusion, or other cognitive challenges**.
- Almost one in five (22%) were worried about **rebuilding confidence**.
- And 18% were worried about **communication challenges**.

Aphasia is a communication difficulty, and affects 1 in 3 stroke survivors. Because people with aphasia had significantly different experiences, we will be publishing a separate report going into their experiences in more detail.





# Impact

The consequences of stroke can be extremely varied, and impact on lots of different areas of people's lives.

- More than half (56%) said it **affected their ability to be physically active.**
- More than half (52%) said it **caused problems with their sleep or fatigue.** Post stroke fatigue is recognised as having a significant impact on people's lives.
- Half (49%) said it **affected their personal independence.**
- More than two in five (44%) said it **affected their ability to pursue their hobbies and interests.**
- Two in five (41%) said it **affected their ability to get out.**
- A third (34%) said it **affected their ability to drive.**

*"Fatigue is what I suffer from most. I have learned, over time, to only do a little at a time which is frustrating. I have no idea how else to manage this."*

*"I am physically very weak and feel the need to get help to build up my fitness and stamina but have no idea how or where to access help."*

# Mental Wellbeing

The significant impact that stroke has on people's lives means that it also affects people's mental wellbeing.

Two in five (41 %) said their stroke had affected their mental health or state of mind.

- More than half (53%) said their **self-confidence was affected** after their stroke.
- Two in five (41%) said their stroke caused them **anxiety and stress.**
- A third (37%) said their stroke **affected their happiness.**
- A third (35%) said their **self esteem was affected.**

*"I would have liked more mental health support after my stroke as the depression was almost as bad as the physical problems."*

*"After I got out of hospital I was scared and felt I needed to speak to my consultant to get reassurance. I understand that my consultant is very busy and needed to deal with other patients but feel there could be a support network, like an outpatient place to go to for a little longer, just for reassurance from a health professional."*

# Loneliness

Because stroke can impact on people's ability to get out and to communicate, it can lead to isolation and loneliness.

- A third (34%) said they **experienced loneliness** because of their stroke.
- A third (33%) of these said that their **loneliness had gotten worse** over the pandemic.
- 21% of those who said they were **lonely** said they had been **unable to get out much**, with 23% worrying about going out alone.

*"I have become very isolated and don't know how to change this."*

*"I miss going to the shops, swimming, going to church, meeting friends. I would find it difficult to get into an ordinary car and need assistance in getting down stairs at my front door."*



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# Stigma

Attitudes towards stroke can also have a significant impact on people's lives. 1 in 6 (17%) said they had been judged or treated differently. For people with aphasia, this was significantly higher – a third said they had felt judged or treated differently.

Those who were treated differently told us these experiences of being judged had a significant impact on their lives.

- Half (52%) say this experience **impacted their self esteem**.
- Half (49%) say it made them **feel embarrassed**.
- Half (52%) said the stigma **limited social life and relationships**.
- More than half (56%) said that stigma caused them to feel **overlooked and unsupported**.
- A third (35%) said that stigma made them **reluctant to ask for support and help**.



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# Access to Services : Rehabilitation

Rehabilitation (or rehab) covers a wide variety of support, from physiotherapy, occupational therapy, and speech and language therapy to emotional support and peer support groups. Rehab covers all the services people need to make the most of life with their condition, to be as healthy, active and independent as possible.

Despite stroke being one of Scotland's leading causes of adult disability, **only half of stroke survivors (53%) say they accessed NHS Rehab.**

- **33%** of all stroke survivors said they **accessed stroke rehab.**
- **25%** of all stroke survivors said they **accessed physiotherapy.**
- **22%** of all stroke survivors said they **accessed occupational therapy.**
- **18%** of all stroke survivors said they accessed **speech therapy.**
- One in five (**19%**) stroke survivors say they **weren't referred for rehab.**

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*“Only 12 weeks of speech therapy, not long enough.”*

*“Because of the withdrawal of community therapy, I have had to seek private resources, which is very costly.”*

*“Speech therapy promised but not provided. Home needs assessment promised but never provided. Virtually no follow up happened. It was left for my wife to offer me main support and supervision. I didn't even see GP following my stroke, had one phone consultation then nothing more.”*

*“I had support with communication help but it came to an end after one year. Whilst I was able to return to work, it was part-time and I wasn't able to do the full role required. I believe I could improve at work with more support.”*



**NO LIFE HALF LIVED**



# Access to Services : Cost of Living

People with a disability and those with long-term health conditions are more likely to experience financial hardship. Nearly half of all people in the UK who live in poverty are living with a disability or live with a person with a disability. (Disability Rights UK).

**31%** of stroke survivors said their health made it **hard for them to work as before**.

*"Having to retire due to my health, I struggle to put food on the table or heat my home."*

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*"I am financially okay, thanks to my husband, but I feel a lack of independence and am very frustrated. I need to rely on my husband to survive economically. It puts me in a very vulnerable position and it feels unfair not to be considered for financial help because my husband has a job."*

Increases in the cost of living have made life hard for people with our conditions. A quarter **25%** of stroke survivors told us they had to **cut back on essentials** such as heating.

*"Access to a local wheelchair taxi would be helpful if it was priced the same as an ordinary taxi. It would mean I could get out more often, if it was affordable."*

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Finally, many survey respondents shared how they felt CHSS services had helped them. Our 1 in 5 report found that people who had accessed CHSS support also rated their health and wellbeing higher than those who had not.

*"Everything I have achieved has been through CHSS."*

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*"Once I left hospital I felt cut adrift. I was so grateful for your helpline to just ask "is this normal or is it something to worry about?"*

*"I was very fortunate due to my psychologist referring to me to CHSS, and then locating my local stroke group. It's been the best thing for me. I've met and integrated with many fabulous people, and the volunteers are kind, thoughtful and amazing people. I can't praise it enough."*



# Access to Services : Support

Many people with our conditions are still not getting the support they need to live life to the full.

- 2 in 5 stroke survivors (42%) say there was **support they needed but weren't able to access.**
- More than half (62%) experienced some kind of **difficulty in accessing services.**

*"No help for someone under 65 years old after a stroke in this area."*

*"Mental health support not accessible. Younger stroke support group not set up in my city."*



Some stroke survivors were dissatisfied with the lack of support available to them.

*"After suffering my stroke, I was very disappointed at the lack of follow-up assistance."*

*"I have had no follow up. I had the stroke nurse visit once and nothing else since. Any support would be helpful."*



Of those who couldn't access support:

- one in eight (12%) **needed access to physiotherapy**
- **8% couldn't get access to mental health support.**

*"Wanted to talk with a clinical psychologist about my condition, but told the waiting list could be anything up to two years."*



*"Ongoing physiotherapy would be helpful. I go to local exercise classes but feel input from professionals would be of further benefit."*

*"I have not seen a community physio for more than 10 weeks, I am hoping to return to work so being able to walk would greatly help me."*

- One in five (20%) stroke survivors **did not know what support was available in their area.**
- **13%** said that having **no central place for information was a barrier** to them accessing support, compared to **11%** who said that **waiting lists were an issue.**

# Case Study

*"I have found a Stroke Support Group. If only I had found them 8 years ago."*

*"A peer support group would help, but I wasn't given any information about one, and it's hard to access services after stroke as you're not allowed to drive."*

*"I would like to meet others who have had a stroke, who may help me. I feel as if I have been abandoned after being discharged from hospital."*

*"My stroke was 7 years ago and I have recovered well. The main issue I had in the early years was having someone available to answer the hundred and one questions I had and there seemed to be no one available. Finally I sought out online forums which helped somewhat. It wasn't really counselling I was looking for – just an information source. Since then I've spoken to other stroke survivors who needed similar help."*



**Tony, 69, had two mini strokes (TIAs) followed by a major stroke in December 2021 and a third TIA in February 2022.**

"The recovery has been hard. I used to cycle around 75 miles a week and play three or four rounds of golf. I can't do that anymore because my balance has gone since the stroke. I can still walk, although I had to learn to do that by myself all over again. Now I walk four or five miles every day.

"No one tells you what to expect after a stroke. I had been in hospital with guys who had given up the ghost after a stroke, but I wouldn't let that happen. I was left to get on with it. My wife did most of the work, phoning to ask for physio, but it took eight weeks to see one.

"I saw my GP and told him I couldn't cope. He got me an appointment with the stroke psychologist, and I had eight appointments with him. My stress levels really dropped then. Now I know I get good days and bad days. I know no two people experience stroke in the same way, everyone is different.

"The psychologist suggested I contact Chest Heart & Stroke Scotland, and that has made all the difference. I go to a group that meets in Silverburn once a fortnight. One week we have a chat, the next we go for a walk. We are all sharing similar experiences. I can sit and talk to people who know what I'm going through and treat me like a human being.

"People who have had a stroke need more information about what it means. No one should be left alone like I was after they leave hospital."



# Recommendations

## REHAB AND SERVICES

- Scottish Government must ensure that all stroke survivors have access to quality, accessible rehabilitation, as outlined in the Stroke Improvement Plan. Rehabilitation should be available for as long as it is needed, and at whatever point it is needed.
- Access to services should be universal and equitable. Scottish Government must ensure proper resourcing of Allied Health Professional staffing to support rehab delivery. They should also ensure that health and social care services are able to refer stroke survivors directly to local third sector services.
- The Right to Rehab should be recognised as an essential component of the Right to Health, and incorporated into future human rights frameworks.
- Stroke survivors should be able to access support to stay physically active. Health and social care services should be able to refer stroke survivors directly to local third sector services who offer support.



## EMOTIONAL/MENTAL HEALTH

- Stroke survivors must be able to access appropriate psychological and emotional support at the time they need it, as outlined in the Scottish Government's Stroke Improvement Plan.
- Stroke survivors should be shown at discharge how they can access psychological and emotional support in the future should they need it, including through third sector support services.
- Local health and social care services must be able to refer or signpost stroke survivors to peer support groups as part of a whole system approach to psychological support.
- Targeted peer support needs to be available for younger people and those of working age.
- Specialist psychological support must be available to those who need it at the time they need it. Scottish Government and local authorities must ensure that psychological support is resourced adequately to meet demand.
- Support to address loneliness and isolation must include specific action to support people with long-term health conditions.

## TO ENABLE CHANGE

- Scottish Government and NHS Scotland should work together to develop a Once for Scotland referrals scheme to third sector support.
- Primary and secondary care, as well as community health and social care, should be able to refer patients to local third sector support.
- The Scottish Government should fund a new FAST campaign to increase awareness of the signs and symptoms of stroke, and encourage members of the public to respond to stroke as an emergency.
- The Scottish Government and health boards must ensure that acute care at the point of experiencing a stroke meets the Scottish Stroke Care Standards.



## COST OF LIVING

- Social Security Scotland should publish a detailed breakdown where possible of financial support provided by condition to ensure stroke survivors are getting access to available financial support.
- Scottish Government must consider greater financial support for people with long-term health conditions, including support to cover the cost of heating and running medical devices.
- More support needs to be available to assist stroke survivors who want to return to employment, including where they need adjustments or support to retrain.



## CARING

- Scottish Government must identify strategies to protect the health and wellbeing of carers.
- Health and social care services must ensure that adequate support is available to allow carers to access treatment, rehab, respite or other support.

# CHSS Support

**Supported self management and community recovery is increasingly recognised for helping people affected by stroke and other long-term health conditions. It focuses on support and tools for the individual to help them manage their condition.**

Our One in Five report tells us that people who received our support rate their health higher than those who have not. People living with stroke and other long-term health conditions have told us they want and need practical advice, information and support throughout their recovery journey. They want to know how to manage their condition day to day at home, work and when enjoying leisure time and hobbies.

[Our Community Healthcare Support Service model](#) is a quality supported self management and community recovery model informed by expertise and the latest research but most importantly by people affected by our conditions. It can be accessed at any time from acute health event or diagnosis throughout recovery to long-term management of a health condition.

*"I have been helped with everything via CHSS. I had follow up calls from stroke nurse and consultant then discharged. Everything I have achieved has been through CHSS."*

*"I was so grateful for your helpline to just ask is this normal or is this something to worry about?"*





# Methodology

The survey (offered both in paper form and online) was publicised and distributed by Chest Heart & Stroke Scotland, and made available to complete over a five week period during summer 2023. Full responses were received from 1886 people from all health boards and across all conditions. Analysis of the data was carried out by Scott Porter Research & Marketing Ltd. All responses have been treated in the strictest of confidence.

- **1886 complete responses were received.** This report is based on the responses of **1097** people living with the consequences of stroke, which was **58%** of the total sample.
- **48%** of respondents who **were stroke survivors were living with more than one health condition.** **36%** were living with **two**, and **12%** are living with **three or more**.
- 47% of respondents were male, 51% were female. The number of non-binary respondents was too small to declare.
- 3% were 20-39, 22% were 40 to 59, 59% were 60 to 79, and 15% were over 80.
- 96% of the sample were white, 1% were Asian, and other ethnicities were too small to declare.





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