

Chest  
Heart &  
Stroke  
Scotland



# NO LIFE HALF LIVED

1 IN 5 REPORT 2023





# No Life Half Lived

## 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.



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# Introduction

**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 some areas, things have got worse. Compared with five years ago, more people with lung and heart conditions reported their overall health or mental health as poor. 43% of people who told us they were lonely said their loneliness became worse over the pandemic. This increases to over 50% of people with a lung condition or Long Covid.

In this report we have put a spotlight on the issues that people 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

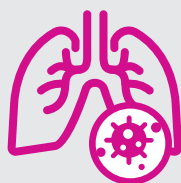


Around  
**136,000**  
people in Scotland are  
living with the impact of  
a stroke

**300,000**  
people are living  
with coronary heart  
disease, Scotland's  
biggest killer



**477,000**  
people in Scotland  
are living with  
asthma or COPD



Since 2020  
**180,000**  
people have developed  
Long Covid



More than  
**2 in 5**  
people with our conditions say  
their condition impacts their  
mental wellbeing

Less than half  
**45%**  
of people with  
our conditions get  
referred for rehab



Nearly half  
**47%**  
of people with our  
conditions say there was  
support they needed but  
couldn't access



People supported by CHSS rated their  
health and wellbeing greater than those  
who didn't get CHSS support

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## Five Years On

We wanted to see how people's experiences had changed over the last five years to support our No Life Half Lived strategy review. Many people's lives have changed significantly over the pandemic and continue to be impacted. This is true for many people with our conditions. This is the first time we've included people with Long Covid in this research, so we're not able to compare their experiences directly to five years ago.

**Compared with five years ago, more people with lung and heart conditions reported their overall health or mental health as poor.**

Loneliness was a significant problem during the pandemic period of 2020-2022 for about a third of people surveyed. Many people with our conditions felt extremely isolated, particularly those who were shielding.

**43%** of people who told us they were lonely said their loneliness became worse over the pandemic. This increases to **over 50%** of people with a lung condition or Long Covid.

## What Matters to You?

We asked people about what mattered most to them. We know that health events can be scary and traumatic, so it's no surprise that **over a third of people (37%)** said they were concerned about having another heart attack or stroke or a severe flare-up of their condition.

People tended to be most concerned about this shortly after a health event – half of people who had become ill in the last six months, and more than two in five who had become ill six months to a year ago, were worried about this. People's biggest concerns related to how their condition impacted on the life they want to live.

**More than a quarter** said their biggest concern was staying physically active – 28%.

**Around a quarter** were worried that they might lose their independence – 23%.

**One in five** people with our conditions were concerned about coping with depression or feeling down – 20%.

**One in five** people with our conditions said stress or anxiety were some of their biggest concerns – 20%.

**Just under one in five** people said their biggest concern was managing their condition – 19%.

**One in six** were concerned about rebuilding their confidence, and that they would no longer be able to pursue hobbies and interests - both 16%.

# Mental Wellbeing

Living with a chest, heart or stroke condition, including Long Covid, can have a huge impact on people's mental wellbeing.



More than  
**2 in 5**  
people with our conditions  
say that it impacts their  
mental health (43%)



**Half**  
(49%) said their condition  
impacts on their self  
confidence



**4 in 9**  
(44%) said their health condition  
caused them anxiety and stress

*"I found going home on my own after a myocardial infarction terrifying. I had dreadful anxiety symptoms including non cardiac chest pain."*

*"I feel concerned, worried about the future and as if life is on hold."*

*"Not being able to breathe is scary. It makes you anxious, and that makes breathing worse."*

*"I feel counselling would help me to deal with the grief of the person I used to be."*

Overall, women of working age and those on benefits rated their health and mental wellbeing significantly lower than other people with our conditions.

*"I was 36 when I had my stroke and feel abandoned at times as services are geared up for older people and there's little or no support if you're young."*

Many people felt that they needed additional support to deal with the mental health impact of their conditions. **One in six (16%)** had accessed specialist mental health support through the NHS. However, **one in eight (12%)** said that they needed specialist mental health support, but had not been able to access it.

*"Despite knowing I struggle a bit with my heart condition, and have generally poor mental health, I have never been able to get access to mental health teams or cognitive therapies that aren't online."*

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Our mental health can also suffer when we lose the things that support it – such as rest, exercise, and things that bring us joy.



More than **Half**  
(54%) said their sleep was affected, or that they felt fatigued



More than **Half**  
(57%) said their condition affected their ability to be physically active



More than **4 in 10**  
(45%) said their condition affected their personal independence



**4 in 10**  
(42%) said their condition affected their ability to pursue their hobbies and interests

*"I don't have energy to cook for myself. I can't do much housework as it tires me out."*

*"I cannot do my former outdoor natural history interests, I would need assistance. I need new friends and new hobbies to give a let up from struggling at home and give me something to look forward to."*

*"I want to run again in the hills but I fear I never will."*



# Access to Services

## LONELINESS

When we first asked people with our conditions about their experiences in 2018, they told us that their health condition often made them feel isolated or lonely. Five years later, that remains the reality for many people. **More than one in three (37%)** people with our conditions said they experienced loneliness as a result of their condition.

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

**38%** of those who said they were lonely said they had been unable to get out much, with **29%** worrying about going out alone.

**Nearly four in ten (38%)** of those who were lonely said feeling that they had a disability had contributed to their loneliness.

People with Long Covid and aphasia (a communication difficulty that can develop after a stroke) experienced particularly high levels of loneliness. Although older people are often highlighted as experiencing high levels of loneliness, our survey showed that those of working age and those on benefits were particularly affected.

**More than half** of these groups experienced loneliness (**55%**).

## STIGMA

Sadly, one in five people with our conditions said they been treated negatively because of their health condition. People with Long Covid and aphasia were particularly likely to report stigma.

**Three in five (62%)** of those who experienced stigma said it made them feel unsupported or overlooked. **Nearly half (48%)** said it had a negative impact on their mental health. Worryingly, **four in ten (40%)** said it made them less likely to seek help.



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## 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.

However, **under half (45%)** of people with our conditions had accessed NHS rehab.

**A quarter (24%)** of people with our conditions say they were not referred to rehab at all.

*"I would have liked the rehabilitation I read I would get in booklet on leaving hospital."*

*"Seven weeks after my stroke, I am still waiting on a OT visit."*

*"I had 6 weeks of rehab after discharge from hospital then it stopped and I had to find my own exercise classes."*

## SUPPORT

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

**Nearly half (47%)** say there was support they needed but weren't able to access.

**More than half (65%)** experienced some kind of difficulty in accessing services.

*"I have not had the support and management of my heart condition from the NHS that I would wish for. I don't know who to ask about new symptoms or if my lifestyle choices are healthy or harmful [such as exercise]. How will I know if my heart condition deteriorates to the point where I should seek help?"*

Mental health support, physiotherapy, and stroke rehab were the services people with our conditions reported they were most likely to not be able to access. **Around a quarter of people** who said they needed further support but could not access it said they needed these services (**25% mental health, physiotherapy 23%, and stroke rehab 24%**).

*"Speech therapy promised but not provided. Home needs assessment promised but never provided."*

# Access to Services

*"After my last appointment I learned that I have mitral valve disease as well as heart failure. I have no idea how the progression of this new condition will be monitored as I have no future appointment. I would just like to know that I have not been forgotten."*

*"There's no ongoing support available. I am only able to access rehab/support when health declines."*

**One in five (20%)** people with our conditions did not know what support was available in their area. While this is a slight improvement from 2018, this suggests that many local services are still not signposting or referring people to the support they need.

*"It would be helpful if when you are diagnosed with Long Covid your GP is able to give you information where you can find support. It is very hard to do all the research when you are both cognitively and physically exhausted."*

*"Peer support groups are good to be in, but hard to find."*

**One in seven people** with our conditions **(14%)** said that waiting lists were a barrier to them accessing the services they need.

*"Waiting times to be seen by a specialist are intolerable to the point I have used savings to access private healthcare."*

Some respondents highlighted a lack of follow up after discharge.

*"No meetings or discussions re stroke since it happened five years ago."*

*"I feel as if I have been abandoned after being discharged from hospital."*

*"I wasn't referred to stroke nurses on discharge. I didn't know about any support."*

There is a clear need for people with our conditions to be referred to further support when discharged from hospital, including to the support services that exist in the community.



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# CHSS Support

Supported self management and community recovery is increasingly recognised for helping people with long-term health conditions. It focuses on providing support and tools for the individual to help them manage symptoms, rather than leaving management of their condition solely to health professionals.

**Nearly eight in ten (78%)** people who responded felt that they had a key role to play in managing their condition, with support from health professionals. **Fewer than one in ten (9%)** felt that their **healthcare provider was ultimately driving management of their condition.**

When people are able to access support and advice, we know this can benefit their wellbeing. In our survey, people who had accessed CHSS support rated both their health and mental wellbeing higher than those who had not been able to access CHSS support.

*"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 it something to worry about?"*

*"I found CHSS online, and called them myself. They've been brilliant with me, inviting me to join an online Long Covid support group, as well as online activity classes."*



# Cost of Living

Disabled people 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 either disabled or live with a disabled person (Disability Rights UK).

One in five people (20%) with our conditions said their health condition affected their finances. This is unchanged since 2018.

One in five people (20%) who responded said their health condition made it hard for them to work at all. This rises to a quarter of people under 60 (25%).

*"I have gone from being a busy full time worker to now being in a wheelchair and fatigued all the time and in 3 months I will receive no income from my employer. I face losing my job."*

Increases in the cost of living have made life hard for people with our conditions. 44% of people with our conditions say the cost of living has impacted on them. This rises to nearly three in five (58%) of those claiming benefits.

People of working age are particularly hard hit financially. Nearly two thirds of all people under 60 say the cost of living has had an impact on them (63%).

Three in ten of those who said they were affected have had to cut back on essentials, including heating. This rises to four in ten people who claim benefits (39%). Ensuring people can afford food and heating is essential for managing their condition, staying well and avoiding future hospitalisations.



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# Impact of Caring

Being an unpaid carer impacts on people's mental and physical wellbeing, and is recognised as a social determinant of health.

Nearly two thirds (64%) of people who responded told us they had a carer. However, a quarter (26%) of people responding told us they were carers themselves. Three quarters of them told us that being a carer impacted on their ability to manage their own health.

*"I am a carer, and have a health condition. I get tired and frustrated and sometimes feel I have no one to talk to. My work has suffered, and it has caused problems."*

More than a third (36%) of those who took part in the survey were living with more than one health condition. People with chest, heart and stroke conditions need person-centred support that responds to their needs and considers the whole person, not just one health condition.

*"[I need to be] looked at as a whole person, not as someone with dozens of health problems that don't affect each other."*



# Andy's Story

**Andy Cudden, 60, lives in Knightswood, Glasgow, with his wife and two young children. He is an assistant museum manager at the city's Kelvingrove Art Gallery and Museum, and has been living with the symptoms of Long Covid since 2021. He has benefited from participation in Chest Heart & Stroke Scotland's online functional fitness and breathing and balance classes.**

Floored for months after contracting Covid-19 and beset by the symptoms of Long Covid, Andy began to feel he would never get better.

Then he made contact with Chest Heart & Stroke Scotland's Advice Line. Given reassurance that he was not alone and there was help and support available, Andy signed up to take part in the organisation's online functional fitness classes.

Now, almost two years after he first became ill, Andy has finally returned to work full time. And he credits the support he received from Chest Heart & Stroke Scotland for encouraging him on his road to recovery.

*"In a lot of ways, going to these classes online and in person saved my sanity. Those classes put me on a pathway that helped me get better. You were there when no one else was, and I was astounded at how lovely and caring everyone was.*

*"I cannot speak highly enough of people like Frances, the fitness instructor, and Pamela on the Advice Line. They were just so caring and supportive. They were just lovely people. They were never*

*pushy but just always there to keep me going a wee bit further, and a wee bit further."*

Along with the rest of his family, Andy developed Covid-19 in October 2021. While his wife and kids quickly recovered, he did not and began to struggle with his breathing and with severe fatigue. In his words, he was "flattened by it".

Prescribed a variety of medication that didn't seem to help, he spent weeks in bed before recovering to the point where he felt fine for a couple of days before relapsing again.

Feeling physically exhausted and wondering if he'd ever recover, he also began to feel mentally exhausted and anxious, worrying about his job – he had now run out of sick pay – and how he'd provide for his family.

He said: *"I think the worst thing about this for me was the loneliness. My wife was at work, my kids were at school, and I was alone in the house. It's difficult when you're in your own head a lot. It was stressful because I didn't know if I could get back to work, and I was worried how I would take care of the family and pay the mortgage and stuff like that.*

*"I'd joined the CHSS Facebook support group for Long Covid and someone mentioned the Advice Line. I had to make the first call*



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and I spoke to Pamela. She was so nice and helpful – it was a relief speaking to someone who understood what I was going through and was able to reassure me I wasn't alone. She called me regularly and promised me she'd stay in touch, and she did.

"I began to do some physio, but then I found out I'd actually cracked a couple of ribs because of all the coughing and sneezing. I had to wait until they healed before I could join in the functional fitness class.

"The classes gave me something to look forward to every week. Frances, who takes them, is so nice and so caring. She'd phone me after a class or before and tailor the class for me. And when she said she was going to do a class in person in Maryhill and asked if I could get there, I jumped in the car!

"It was so good to see people face to face. Frances was so good with everyone in that group, so kind. Everyone was at slightly different places, and she kept us all together. She had such good humour."

Andy progressed from the functional fitness classes to ones in strength and balance that gave him confidence to go back out again.

With some advice from Pamela, he applied for and received Employment Support Allowance, having felt unsure of how to navigate a benefits system he'd never needed before.

He said: "It was those little things that saved me. I cannot speak highly enough of Chest Heart & Stroke Scotland and what you've done for me."





# Recommendations

## REHABILITATION

- Scottish Government must ensure that the rehabilitation pathways set out in national guidance and standards is delivered. Over half of people who could benefit from this do not currently receive this support.
- Access to rehabilitation services should be universal and equitable.
- Rehabilitation should be available for as long as it is needed, and at whatever point it is needed.
- The Right to Rehab should be recognised as an essential component of the right to health, and incorporated into future human rights frameworks.
- Scottish Government must ensure proper resourcing of allied health professional staffing to support rehabilitation delivery.



## SUPPORTED SELF MANAGEMENT AND COMMUNITY RECOVERY

- Everyone with a chest, heart or stroke condition or Long Covid should be able to access quality supported self management and community recovery to help them live life to the full.
- Everyone with a chest, heart or stroke condition or Long Covid should be able to access support to stay physically active in a way that is accessible to them.
- Health and social care services should have the systems in place to be able to refer directly to third-sector services who offer support.
- Primary and secondary care, as well as community health and social care, should be able to refer to third-sector support.
- Health and social care services should have in place the data collection and monitoring of referrals to third-sector services who offer support and onward supported self management and community recovery.
- Scottish Government and NHS Scotland should work together to develop a Once for Scotland referrals scheme to third sector services (i.e. a standardised scheme operating on a Scotland wide basis).

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## EMOTIONAL/MENTAL HEALTH/ISOLATION & LONELINESS

- People with chest, heart and stroke conditions must be able to access appropriate psychological and emotional support at the time they need it.
- Emotional and psychological support needs to be easy to access, and at discharge people should be shown how they can access this support in the future.
- Local health and social care services must be able to refer and/or signpost to third sector advice line support, self directed support, and peer support groups as part of a whole system approach to psychological support.
- 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.
- Targeted peer support needs to be available for younger people and those of working age.

## COST OF LIVING

- 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.
- Scottish Government must provide greater support for people with long-term health conditions 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 with long term health conditions to access treatment, rehab, respite and other support.
- Health and social care services must ensure that adequate support is available to allow carers with long term health conditions to access treatment, rehab, respite and other support.
- Health and social care services must ensure that adequate support, including respite, is available to unpaid carers to allow them to care for loved ones with long-term health conditions.



# Methodology

The survey (offered both in paper form and online) was publicised and distributed by Chest Heart & Stroke Scotland and Scott Porter Research. It was made available to be completed over a five week period during summer 2023. Full responses were received from 1886 people from all health boards and across all conditions.

**1886** complete responses were received.

## Our Conditions

**27%** of respondents were living with a chest condition, **31%** with a heart condition, **58%** had had a stroke and **12%** were living with Long Covid.

## Multiple Conditions

**61%** of respondents were living with more than one health condition. **28%** were living with two, and **8%** were living with three or more.

## Gender

**47%** of respondents were male, **51%** were female. The number of non-binary respondents was too small to declare.

## Age

**3%** were 20 to 39, **22%** were 40 to 59, **59%** were 60 to 79, and **15%** were over 80.

## Ethnicity

**96%** of the sample were white, **1%** were Asian, and other ethnicities were too small to declare.

*Analysis of the data was carried out by Scott Porter Research & Marketing Ltd. All responses have been treated in the strictest of confidence.*



# Thank you

Thank you to the 1886 people who took the time to share their experience and views with us by taking part in this survey.



*The research was conducted by Scott Porter Research and Marketing Ltd on behalf of Chest Heart & Stroke Scotland.*

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