

Chest
Heart &
Stroke
Scotland



NO LIFE HALF LIVED

1 IN 5 LONG COVID 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 our conditions. 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 with Long Covid for the first time. The 1886 responses to this 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.

Despite all the changes we have been through over the last five years, what we have found from this survey 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 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. This is especially true for people living with Long Covid. It is clear that they are continuing to lack the medical support and treatment that they need to be able to effectively self manage their condition.

In this 1 in 5 Long Covid Report, we have put a spotlight on the issues that people living with Long Covid are struggling with the most, and the actions required to change things for them. By highlighting what matters most to people with our conditions, we want to inform and influence the future of support available to them, so it can make a difference to people across Scotland who are struggling to get the care they need.

It is clear that many people who are affected by Long Covid are frustrated that they are not getting the support 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.

People living with Long Covid are desperate for more support and we are calling on Scottish Government and our partners to help us to make sure they get what they need to live their lives well.

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 and throughout their recovery journey.

We want people in Scotland to be given the advice, information and better 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



Nearly
THREE QUARTERS
(71%) said their condition
affects their
mental health



Nearly
HALF (47%)
have experienced stigma

More than
HALF (54%)
said their condition
has affected their
ability to work as
before



2 in 5 (41%)
have cut back
on essential costs

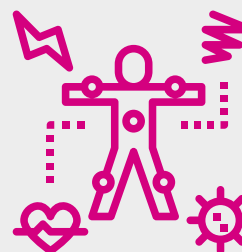


TWO THIRDS (65%)
have experienced
loneliness because
of their condition

Context

Long Covid is a condition
that develops after
someone has Covid

Since 2020, over **180,000**
people in Scotland have
developed Long Covid*



Long Covid is a multi-system
condition, meaning it affects
different systems in the body

Symptoms are varied
and include:

- Weakness and tiredness
- Shortness of breath
- Trouble sleeping
- Difficulty concentrating
- Headaches



4 in 5 (79%)
of people with
Long Covid say
their symptoms
affect their day to
day lives †

* Scottish Health Survey 2022 † Office For National Statistics, July 2023

The Impact of Long Covid

We asked people what impact their condition had on them, including on their mental health and their social life.

The vast majority of people with Long Covid told us their symptoms impacted on their day-to-day lives.

- 3 in 4 (76%) said their condition affected their **ability to be physically active**.
- 3 in 4 (75%) said their condition affected their **sleep and fatigue**.
- 2 in 5 (40%) said their condition affected their **ability to work**.



People with Long Covid rated both their physical health and their mental health as lower than people with heart conditions, people with lung conditions and stroke survivors.

"I am still struggling with Long Covid symptoms. It affects my ability to be active. That affects my weight, leads to more breathing issues and self-esteem is at rock bottom. I am constantly tired. Anxiety is a real struggle just now."

"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 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."

What Matters to You?

We asked people with Long Covid what mattered most to them – specifically, which parts of daily life they were most concerned about.

- 3 in 10 (29%) said **staying physically active** was one of their biggest concerns.
- 1 in 4 (26%) said **dealing with pain** was one of their biggest concerns.
- 1 in 5 (21%) said **managing their condition** was one of their biggest concerns.
- 1 in 5 (21%) said their condition **led to cognitive challenges**.
- 1 in 5 (19%) people were **concerned about coping with depression** or feeling down.
- Nearly 1 in 5 (18%) were **concerned about stress or anxiety**.



NO LIFE HALF LIVED

Mental Wellbeing

Living with a long-term health condition, including Long Covid, can have a huge impact on people's mental wellbeing.

- Nearly three quarters (71%) of people with Long Covid said their condition **impacted on their mental health**.
- More people with Long Covid reported **poor mental health** than those living with a chest, heart or stroke condition. For example, 30% fewer stroke survivors said their condition **impacted on their mental health**.
- 3 in 10 (29%) of people we spoke to said that they **needed specialist mental health support**, but had **not been able to access it**.
- 2 in 3 (66%) said their condition **impacted on their self confidence**.
- 2 in 3 (66%) said their condition **impacted on their happiness**.
- Over 2 in 3 (68%) said their health condition **caused them anxiety and stress**.

"Women who feel unwell are not just anxious – the anxiety comes from feeling so unwell and no-one helping. Yes, I feel down because it has gone on for so long – not because depression is the main health issue."

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"I feel as though the pandemic affected us in the worst way possible and although I have had amazing support from all quarters, especially my GP, I still feel very alone. I'm not physically or mentally strong enough to go to a group, but maybe an acknowledgement that there are people like me still suffering and grieving whilst everyone is getting back to normal would have me feel more included."

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Many people with Long Covid said their condition impaired their ability to do things that can help sustain mental wellbeing, such as socialising, relationships and pursuing interests.

- More than half **(55%)** said their condition **affected their ability to get out.**
- Two thirds **(65%)** said their condition had an impact on their **ability to pursue their hobbies and interests.**
- More than half **(56%)** said their condition **impacted on their ability to see family and friends.**

"I have had Long Covid (since March 2020) on top of COPD. It has severely limited what I can do and I have had to adjust to my new reality."

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"I live in a rural area which is beautiful but due to difficulties walking caused by Long Covid, I am unable to go and spend time in the outdoors now. I can occasionally walk short distances but pay for it in post exertional malaise which sets the spiral downwards again. I am dreading when winter comes as there will be limited opportunities to lift my spirits then."

"At the moment I feel I barely function some days, I work my hours, (22.5 hours a week) eat, sleep, wash, do very minimal housework and gardening. I have no energy for a social life, I have lost contact with friends and have no energy to retain friendships or make new ones. My relationship with partner has suffered, they also have Long Covid and I feel a lot of guilt I can't support them very well. On bad days I feel like I'm just existing."



Employment & Cost of Living

Many people who responded to the survey said that employment was a concern for them.

- One in six (16%) said **cop**ing with work was one of their **big**gest concerns.
- More than one in two (54%) said their condition **affected their ability to work as before**.
- Two in five (40%) said Long Covid **affected their ability to work at all**.

"It has been difficult to get speciality referrals and work have not been supportive, ending in a change of career."



"I have had no support to stay in work. Brain fog, memory loss and confusion are major barriers to me performing well and staying in work, but there is absolutely no help at all with these."

"My job is stressful and I feel my capacity has been impaired but I don't get any support from my team leader or manager with this."

It is therefore not surprising that more than two in five (43%) of people with Long Covid say their **condition has affected their finances**.

Increases in the cost of living have made life harder for people with our conditions, and people with Long Covid have been particularly affected.

- 2 in 3 people with Long Covid (65%) said they were **affected by the cost of living crisis**.
- 2 in 5 (41%) said they had **cut back on essentials, including heating**.
- 1 in 4 (24%) sought **government assistance**.
- 1 in 5 (20%) sought **assistance from friends and family**.

Some people shared their difficulties in accessing benefits and financial support.

"No access to benefits after months of trying."



"I feel, because Long Covid is a somewhat invisible and fluctuating illness, we are hugely forgotten and not taken seriously by many – including DWP. Because I am currently unable to work, I will lose my job. Filling in the horrendous forms for ESA and PIP or ADP, is not only mind boggling and energy sapping, it's degrading and humiliating."

Some people had sought private medical support, which in turn had a financial implication.



"I've been unable to work for over a year now and having to pay for private doctors / medication and mobility aids is financially crippling me."

"I would like occupational / physical therapy sessions so I can discuss and better learn how to manage my condition. I don't feel I have spare funds at the moment to pay for this. The majority of practical help I have got for conditions in the last 2 years has been paid for privately."

Loneliness

Nearly two thirds (65%) of people with Long Covid said they experienced loneliness as a result of their condition.

While loneliness is common among people with long-term health conditions, More people with Long Covid said they were lonely than people with other conditions'. For example, this **65%** compares to **40%** of people with lung conditions and **34%** of stroke survivors.

Stigma

Sadly, almost half (47%) of people with Long Covid said they have been treated negatively because of their health condition.

Our main 1 in 5 Report, which looked at the experiences of people with chest, heart, stroke conditions and Long Covid, found that around half of those who said they experienced stigma said this affected their self esteem or mental health. Worryingly, four in ten **(40%)** said it made them less likely to seek help.

Access to Services & Support

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

Seven in ten (72%) people with Long Covid said **there was support they needed but weren't able to access**. More than 4 in 5 (82%) **encountered some kind of difficulty in accessing services**, with some **struggling to access any medical support**.

"I am unable to access any medical help because simply told 'we can't do anything for Long Covid' and to just follow the online advice."

"I can get the support for my heart condition but Long Covid help doesn't exist."

"I have Long Covid so there is no support whatsoever. My health is deteriorating."

"Doctors don't know anything about Long Covid. I get no help from them, there are no clinics that you could go to with people who know about Long Covid."

Nearly two in five (38%) said their **doctor wasn't able to provide guidance on available support**. Many people spoke about a lack of information to support their self management.

Although Chest Heart & Stroke Scotland's Long Covid Support Service can provide advice from trained health professionals and peer support to anyone in Scotland, it is clear that many people are not being signposted or referred to this by health professionals.

"I have been diagnosed with Long Covid and told there is no cure and we don't have a Covid centre, so I've been left with a leaflet and no idea how to self manage my pain etc."

"I have Long Covid but feel completely left alone to deal with it, the GP has not signposted me to any resources or referred me to anywhere. They just said I had to sit it out. I would find it helpful to have someone to talk to about managing my fatigue and keeping me positive, like a mentor to help me monitor my energy levels and plan activities. I know I'm supposed to monitor levels but I find it difficult to do this."



Rehabilitation

Some were frustrated about the lack of coordination involved in their care.

"There is no general Long Covid expert available through the NHS. Each symptom has been treated individually, when this is a system-wide illness and each element is related to the others. There is nobody managing or coordinating my care."

"I would like a straightforward referral to a local clinic that would then take a holistic, multidisciplinary approach to my health needs."

A third of people (35%) said there was **no central source of information** for them, and 31% **didn't know what was available in their area**. 32% said there was **no support available for them locally**.

"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."

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.

As there are very few treatments available for Long Covid, much of the NHS support currently available is rehab based. Despite this, over a third (37%) of people with Long Covid **had accessed NHS rehab services**, including those who had other conditions.

43% of people with Long Covid say they **were not referred to rehab services at all**.

"I tried to access cardiac rehabilitation but was told they don't deal with POTS or IST*. Told there was no physiotherapist who deals with ME* or Chronic Fatigue Syndrome."*

"I have had to train myself to keep calm and to pace myself because if I try to do more than I am capable of it takes days to recover. It really would help to talk to someone that understands the issues and what might help."

* POTS: postural (orthostatic) tachycardia syndrome; IST: inappropriate sinus tachycardia; ME myalgic encephalomyelitis.

Caring

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

Nearly three quarters (71%) of people with Long Covid who responded told us **they received care, the majority of which was unpaid care from family.**

However, more than a third (39%) of people responding told us they **were carers themselves.**

More than a third (36%) 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.



Case Study

Craig Anderson is 57 and lives in Edinburgh with his wife. He first contracted Covid-19 in February 2021 and has been living with the symptoms of Long Covid, including fatigue, breathing difficulties and depression since. Craig, a storeman in a factory, is currently on long-term sick leave and is part of the Chest Heart & Stroke Scotland Long Covid Support Group.

Life was quiet but good for Craig. A keen Hearts fan, he'd rarely miss a game at his beloved Tynecastle, and when he wasn't watching the Jambos, Craig loved growing vegetables in his garden and going out and about on his motorbike.

Craig said: *"The best day of the week for me now is a Tuesday. I see my counsellor at 12, then I have the Zoom meeting with the support group at 2. It has made all the difference to me being part of this group – it's amazing to be able to talk to people who understand exactly what you're going through because they're going through it, too."*

"I feel I have been very lucky in how supportive my GP has been and the help I've got from the NHS. And I know from the group that not everyone has had that experience."

"That needs to change. There shouldn't be any kind of postcode lottery on help for people with Long Covid or you having to rely on a doctor who takes you seriously. Everyone deserves the very best care and understanding."

His main symptoms are overwhelming fatigue and he has also developed asthma and now uses an inhaler. He has also been prescribed antidepressants because he had become depressed over his health.

Craig spent seven months on sick leave in 2021 before returning to his job for four hours a day. On the advice of his GP and an occupational therapist, Craig stayed on those reduced hours for the whole of 2022, but he was "toiling", in his own words.

He had been referred to a counsellor and, after just one appointment, the counsellor recommended he see his GP again because he was clearly struggling to cope.

Craig recalled: "I was reluctant to go on antidepressants and I refused at first. But my wife told me I needed help, so I went back to the GP, and she spent a lot of time going over what they would do and how they could help me.

"I'm glad I did, but no one wants to be on long-term medication like this. I lived a quiet life before, but I was happy with my lot – my football, my garden, my bike. I just want to go back to that."



Craig spent most of 2023 on long-term sick leave and fears he will not be able to return to work at all. He says he takes each day as it comes, pottering in his garden when he feels able to or taking the bus to and from Tynecastle for a match – previously he'd have walked to the ground, but that's not an option now.

What helps to keep his spirits up is the weekly meeting of the Long Covid Support Group, together with support from his wife and friends.

He said: "My counsellor had got in touch with Chest Heart & Stroke Scotland to see if I could join, and I was very excited to join the first meeting. My wife had gone to the shops and when she came back, I was waiting in the front garden, absolutely hyper because I couldn't wait to share what had happened with her.

"It just felt like such a relief to be with people who understand. I'd like more understanding of Long Covid because people like me just want our lives back – no one would choose this."

Impact of CHSS Support

When people are able to access support and advice, we know this can hugely benefit their wellbeing. Our 1 in 5 survey found that 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 given digital booklets on Long Covid by my GP, but she was not able to refer me to health professionals who specialise in Long Covid as she didn't know of any, or any support groups. Fortunately, 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."



Supported self management and community recovery is increasingly recognised for helping people affected by Long Covid. It focuses on the support and tools for the individual to help them manage their condition. People living with Long Covid and other long-term health conditions have told us that 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 social and leisure activities.

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 with our conditions. It can be accessed from the acute health event or diagnosis, throughout the recovery journey, to long-term management of a health condition.



Recommendations

SERVICES AND SUPPORT

- Scottish Government must implement their Long Covid Service plans in full, ensuring access to rehab services and self management support.
- Scottish Government must work with NHS Scotland and the Royal College of General Practitioners to ensure every primary care practitioner can signpost or refer to Long Covid self management support, including those provided by CHSS.
- Scottish Government and NHS Scotland must improve care pathways to offer a coordinated, multidisciplinary Long Covid service across all health boards, ensuring that people living with Long Covid can speak to someone who is coordinating their care.
- NHS should provide direct referral pathways to CHSS support so anyone with Long Covid can be referred directly to the dedicated Long Covid Support Service.
- NHS should ensure that health and social care services can refer directly to organisations that provide peer support services.



- Scottish Government and NHS Scotland must develop a strategy for funding Long Covid services beyond the initial three-year period.
- The Chief Scientist Office must prioritise funding for research into Long Covid and treatments.
- People seeking support for Long Covid should be made aware of opportunities to participate in clinical trials.

REHAB

- Scottish Government must ensure that people with Long Covid have access to quality, accessible rehabilitation. They should be offered the correct rehab for their needs, in line with standards of person-centred care.
- Rehabilitation should be available for as long as it is needed, and at whatever point it is needed.
- Scottish Government should embed the Right to Rehab in human rights legislation, to ensure everyone can access rehab services.
- People with Long Covid should be able to access appropriate and accessible support to stay physically active. Health and social care services should be able to refer directly to local third sector services who offer support.

EMOTIONAL/MENTAL HEALTH

- People with Long Covid must be able to access appropriate psychological and emotional support at the time they need it.
- Local health and social care services must be able to signpost to 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.



SOCIAL SECURITY AND FINANCIAL SUPPORT

- Scottish Government must consider greater financial support for people with long-term health conditions navigating the cost of living crisis, such as support to cover the cost of heating or social tariffs for energy.
- Social Security Scotland must produce guidance for people with Long Covid to provide clarity and reassurance around eligibility for Adult Disability Payment.
- Social Security Scotland must provide more detailed breakdowns of applicant data in order to report on support available to people with Long Covid.
- Social Security Scotland and NHS Scotland must work together to ensure that all claimant cases of Long Covid are appropriately coded, in order to ensure better data collection.
- Scottish Government and UK Government must work together to help people with Long Covid 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.

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.** 12% of the total sample (234) were living with Long Covid. This report represents their responses.
- **46%** of the sample **lived with Long Covid and one or more other health condition.** 34% were living with two, and 12% were living with three or more conditions.
- 65% of those who responded were women, and 32% were men. The number of non-binary respondents is too small to declare.
- 8% were ages 20 to 39, 49% were ages 40-59, 40% were ages 60-79, and 3% were over 80.
- 97% of the sample were white, 1% were Asian, and other ethnicities were too small to declare.





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