

Chest
Heart &
Stroke
Scotland



NO LIFE HALF LIVED

1 IN 5 CHEST & LUNG 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.

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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 people living with chest conditions are struggling with the most and the actions that are required to change this. It is clear that many people with chest conditions live in fear of relapse, exacerbation or flare ups, and are looking for support to better manage their condition particularly around breathlessness, exercise and loneliness.

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



1 in 4 (25%) people living with a long term chest condition say they weren't referred for rehab

2 in 5 (40%) said they **experienced loneliness**



52% said that they **needed support they had not been able to access**



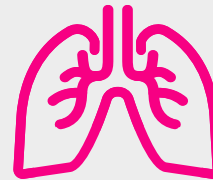
37% of people had **cut back on essentials** such as heating, due to the cost of living crisis

Context



2 in 3 people living with COPD in Scotland **are undiagnosed or have an incorrect diagnosis**

Around **477,000** people in Scotland live with Asthma or COPD



Chest conditions include Chronic Obstructive Pulmonary Disease (COPD), Asthma, Bronchiectasis, Idiopathic Pulmonary Fibrosis and obstructive sleep apnoea.



Around **1 in 14** people in Scotland are currently **receiving treatment for asthma**

What Matters to You?

We spoke to people living with chest conditions about what mattered to them – specifically, which parts of daily life they were most concerned about.

Just under a third of people living with a long-term chest condition in Scotland (30%) said that their biggest concern was further health complications. This fear was highest for those who had been diagnosed in the last six months (40%).

After this, people's biggest concerns related to how their condition impacted on the life they want to live.

- Almost a quarter (24%) were concerned about **managing their health condition**.
- Over one in five (22%) were concerned with **losing independence**.
- Nearly a third (30%) were concerned with **keeping physically active**.



“My COPD has suddenly got worse. Up until now, I have been very active. I feel I need advice on how to manage my condition as I don't want to give up my busy life. I don't know how to get help.”

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“The respiratory consultant I was seeing every six months retired last year and I was referred back to the GP practice. Since then I have had no medical communication at all apart from repeat prescriptions. I would find it so helpful if I knew that a doctor understood my condition and its progression, and was there to help me formulate my lifestyle.”



Impact

The consequences of being diagnosed with a long-term chest or lung condition can be extremely varied, and impact on lots of different areas of people's lives.

- More than 3 in 5 (63%) said it affected their ability to be **physically active**.
- More than six in ten (61%) said it caused problems with their **sleep or fatigue**.
- More than two in five (44%) said it affected their **ability to get out and about**.
- More than two in five (42%) said it affected their **personal independence**.

"Need for more healthy exercise in swimming pool or gym, or both. Help with this through being prescribed such help, rather than just paying everything myself, or missing out exercise and relying on just medication."



Mental Wellbeing

The significant impact that a long-term chest or lung condition has on people's lives means that it also affects people's mental wellbeing.

Two in five (45%) said their long-term chest or lung condition had affected their mental health or self esteem.

- Just under a half (49%) said it affected their **anxiety and stress levels**.
- More than two in five (47%) said it has affected their **self confidence**.
- Two in five (40%) said it affected their **happiness**.
- Just over a third (35%) said it affected their **self esteem**.

Our initial report, 1 in 5, also identified that people with lung conditions rated their mental wellbeing less well than people with stroke or heart conditions.

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



"I don't think there is an understanding that women who feel unwell are not just anxious. The anxiety comes from feeling so unwell and no-one helping. I feel down because it has gone on for so long."

Loneliness

A long-term chest or lung condition can impact on people's ability to get out and communicate, leading to isolation and loneliness.

- Two in five (40%) said they experienced **loneliness**.
- More than half (56%) said their **loneliness had gotten worse** over the pandemic.
- Just under a third (32%) said their **condition had gotten worse**.
- 28% of those who said they were lonely told us they had been **unable to get out much**, with 24% worrying about **going out alone**.

"I fear that I will become more isolated as my condition deteriorates and will be unable to access any support group. Once I become housebound I will have no interaction with others apart from my husband and telephone calls. It will become very lonely."



Stigma

Attitudes and understanding towards people with long-term chest or lung conditions can hold people back.

Over a quarter (27%) said they had been judged or treated negatively because of their condition.

Those who had been judged or treated negatively told us it had a significant impact on their lives.

- More than two in five (47%) say it **impacted on self esteem**.
- More than half (56%) say it made them **feel embarrassed**.
- More than half (57%) said the judgement or negative treatment **limited social life and relationships**.
- More than half (52%) said that stigma caused them to **feel overlooked and unsupported**.
- Over two in five (47%) said that stigma negatively **affected their mental health**.



Access to Services: Rehabilitation

Rehabilitation (or rehab) covers a wide variety of support, from dedicated pulmonary rehabilitation and occupational 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.

Only two in five people with long term-chest or lung conditions (42%) say they accessed NHS Rehab.

- Of these, 34% said they accessed **pulmonary rehab**.
- 41% accessed **physiotherapy**.
- 23% accessed **occupational therapy**.

A quarter (25%) of people with long-term chest or lung conditions say they **weren't referred for rehab**.

"I have been offered a pulmonary rehab programme as my health professional said that I would probably benefit from attending one again. However this programme is not currently available in my area and hasn't been for a number of years, which wasn't helped by the COVID pandemic. There is in excess of 200 people on the waiting-list."

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NO LIFE HALF LIVED

Access to Services: Cost of Living

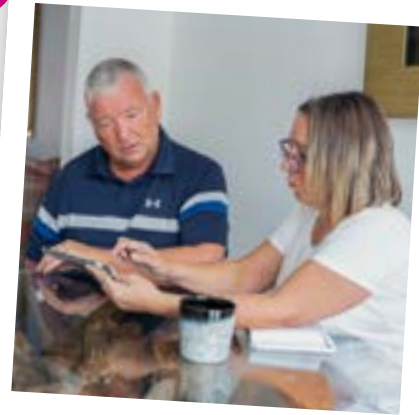
Disabled people and those with long-term health conditions are more likely to experience financial hardship. Nearly half of all people in the UK who live in poverty are either disabled or live with a disabled person (Disability Rights UK).

- One in five (19%) people with chest and lung conditions said their condition had an **impact on their finances**.
- One in five (21%) people with chest and lung conditions said their health condition **made it hard for them to work at all**.
- A quarter (23%) said their health made it **hard for them to work as before**.

Increases in the cost of living have made life hard for people with our conditions. 37% of people with long term lung or chest conditions had **cut back on essentials**, such as heating due to the cost of living crisis. For people with long-term chest or lung conditions, being able to heat their home is essential for managing their condition, staying well and avoiding future hospitalisations.

People who use medical devices such as home oxygen or CPAP machines will also not be in a position to cut back on these costs.

"Being self employed, I am unable to access benefits or any help when my asthma has led to time off work and time in hospital. I lost a previous job due to asthma being misunderstood by my employer."



Access to Services: Support

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

Of those who couldn't access support:

- **13%** couldn't get access to **pulmonary therapy**
- Over one in ten (**11%**) needed **access to physiotherapy**
- **15%** couldn't get access to **mental health support**.

"I would like to talk to a psychologist."



"I am tired of battling for a referral to a respiratory consultant. I have been told that I can only have a referral when I am on maximum medication and my condition is not controlled. This reactive approach to breathing seems to be verging on neglectful to me. It worries me very much to think about having to get so bad before I can see a consultant."

"Probably the most important unmet need I have is physical exercise. I don't know how good various classes are, and I have often overdone it.."

One in five (**20%**) people with a long-term chest or lung condition **did not know what support was available** in their area. Some respondents expressed a need for an advice phonenumber – while the CHSS Advice Line is available to all people with respiratory conditions, many were clearly unaware of this.

"I need a telephone line that I could call if I need advice on something which I am not sure of about my condition."



"I would like to have a phone service I could ring if I have worries or concern about my health and a contact to tell me if I need to contact doctors."

"I would like more information on how to help myself, what long-term prognosis is, to know if there is support out there."

17% said that they **didn't know where to find the information** on support and that was a barrier, compared to 18% who said that **waiting lists were an issue**.

Many people spoke about their need for greater peer support, or advice that would allow them to self manage their condition.

"I am on waiting lists but these are very lengthy."

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"Peer support groups are good to be in, but hard to find. Often they provide a lot of info that professionals don't have time to tell you about, plus handy tips on managing your own conditions, social contact and friendship."

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"I need communication with others suffering from similar lung condition as myself."

"I would like to join a group that caters for people with my condition, which is COPD. The group stopped with Covid and have not heard that it has started again."

Case Study

Ian Baxter, 75, is chairman of the Forfar Airways Group, a peer support group affiliated to Chest Heart & Stroke Scotland. A long-time smoker who finally quit at the age of 60, Ian was diagnosed with COPD in 2004 but had to wait until 2009 before receiving pulmonary rehab.

Ian has also been diagnosed with the long-term lung condition bronchiectasis, pleural plaques and asbestosis. In 2009, he helped set up Forfar Airways to provide exercise, activities and support for others with chest conditions.

"I was diagnosed with COPD in 2004. It was a condition I knew nothing about at the time. I didn't realise I would be living with COPD for a long time and that there were things I could do to make life easier.

"I asked at the time to get pulmonary rehab, but that didn't happen until 2009. The problem for people with our condition is there's nothing after rehab. You get two sessions a week for six weeks. It isn't long enough to make a difference.

"When I asked what was next, I was told to go to a gym and get help there. But gyms are intimidating for people and especially if you have difficulty with your breathing. You need to trust you're doing the right thing.

"That's why a support group is so important because it gives people a social side, too. Forfar Airways first met in the local community hospital and there were nine of us. But we quickly grew in numbers and outgrew the room we had. From 2011, we've been meeting in the community fire station in Forfar.

"At one point we had more than 40 members, but those numbers fell away after Covid-19. Now we have around 30 members.

"I took it upon myself to get trained to do pulmonary activities and exercises as we only have one accredited trainer at the moment. I did the Revitalise training with Angus Council, and I've been teaching some of the group to do the activities.

"We do desperately need new members, but the gateway into membership of our group is the official NHS pulmonary rehab. That way we know new people are fit to exercise because they have completed pulmonary rehab. We also take those referred by their GP. Non-members can also come and participate, but they must sign a disclosure for safety.

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"Exercise is key to the group. It's the most important element of our weekly meetings, but the social side is also important. We have a cup of tea and a chat, and that interaction is very valuable for people's mental health. They can discuss their condition or pass on information or tips.

"We also used to have a professional singer come to help us with breathing exercises. And although we no longer have that, we do sing ourselves, even if some of us aren't great singers!

"Being part of the group is really important. People go out of the door feeling happy after being with each other. Loneliness can be a terrible thing, especially when you're living with a long-term health condition. And we know there's a high instance of depression in those with chronic health conditions. I was treated for depression because I felt very low after my diagnosis.

"Today I see it as my job to keep myself fit. Years ago a nurse told me having COPD is like training for a marathon. You have to stay as fit as you can be. Everyone has different levels of fitness, so when you come to the group, you do what you can. There's no competition between us, we all want the best for ourselves and each other.



"Pulmonary rehab is absolutely essential for people with COPD. But there's more the NHS could be doing. I didn't get a CT scan until 2014, 10 years after the COPD diagnosis. I'd been coughing up blood. But the time spent having the scan and speaking to the consultant was the most valuable half-hour I had spent in years.

"The consultant was terrific and explained that as well as COPD, I also had bronchiectasis, pleural plaques and asbestosis. It's high time that the NHS gave people a CT scan when they're diagnosed with COPD so they know exactly what's wrong with their lungs.

Ian is supported by Chest Heart & Stroke Scotland, and did not take part in the research survey.

Recommendations

EMOTIONAL/MENTAL HEALTH

- Everyone with a long-term chest or respiratory condition 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 people should be shown how at discharge they can access this support in the future.
- 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, including long-term chest or respiratory conditions.

REHAB AND SERVICES

- Scottish Government must ensure that everyone who needs it has access to quality, accessible rehabilitation. Access to services should be universal and equitable, and available whenever it is needed.
- Scottish Government and NHS Scotland must work together to improve the availability of and access to pulmonary rehabilitation programmes.
- Public Health Scotland and Scottish Government must work together to effectively collect data on pulmonary rehabilitation provision and uptake, in order to support improvement.
- 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.
- Everyone with a long-term chest or respiratory condition should be able to access support to stay physically active in a way that is accessible to them. Health and social care services should be able to refer directly to local third-sector services who offer support.



THIRD SECTOR SERVICES

- Every person with a long-term chest or respiratory condition should have access to self management support to help them live life to the full.
- Scottish Government and NHS Scotland should work together to develop a Once for Scotland referrals scheme to third sector support, such as the Community Healthcare Support Services and our affiliated Peer Support Groups.
- Primary and secondary care, as well as community health and social care, should be able to refer to local third-sector support.

COST OF LIVING

- Scottish Government must consider greater financial support for people with long-term chest or respiratory conditions, including support to cover the cost of heating and running medical devices such as CPAP machines.
- More support needs to be available to help people with long-term health conditions who want to return to employment, including where they need adjustments or support to retrain.

CHSS Support

Supported self management and community recovery is increasingly recognised for helping people affected by chest and lung 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 chest and lung condition 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.

"I have been helped with everything via CHSS. 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?"



[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.



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 **502** people living with the consequences of a long term chest or lung condition, which was **27%** of the total sample.
- **61%** of respondents were living with **more than one health condition**. **28%** were **living with two**, and **8%** 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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