



THE RIGHT TO PULMONARY REHAB

The One in Five: Special Report



NO LIFE HALF LIVED





This report highlights what it's like to live with a chest condition in Scotland, and reveals the limited rehabilitation that is currently available. Rehabilitation that could transform people's lives. It makes recommendations for the action we believe is needed to ensure that there is no life half lived in Scotland for people with chest conditions.

There are over 129,000 people in Scotland diagnosed with chronic obstructive pulmonary disease (COPD)¹, with many more remaining undiagnosed. Yet the rehabilitation which can help people stay as well as possible is hugely variable and in some places non-existent. Pulmonary rehabilitation reduces the number of hospital admissions and halves the time spent in hospital², yet out of the estimated 69,000 people in Scotland who would benefit, between just 2% and 21% of those who might benefit are being referred to this life-changing treatment.

Scotland has one of the worst records on chest disease in Europe. It is our fifth biggest killer³ and, although there have been huge advances in tackling other major health issues (such as heart disease, stroke and cancer), the prevalence and mortality rates for chest disease remain poor.

This puts huge pressure on the NHS, with the economic burden of chest disease in Scotland estimated to be in the region of £1 billion.⁴ There are over 127,000 hospital bed days⁵ in Scotland each year due to COPD alone – a figure that could be reduced for the benefit of people with chest conditions and the NHS if good support in the community was available for everyone to help people self-manage their health conditions.

Most importantly though, chest disease can have a significant impact on every aspect of someone's life. Breathlessness and fatigue, which are common symptoms of COPD, are debilitating. Anxiety and ongoing poor health can lead to mental health problems and isolation – from work, from previously enjoyed interests, from being with and enjoying your family and friends.

In this report we bring together the latest analysis of information provided by Health Boards about the pulmonary rehabilitation they provide with the findings of our national survey of people's lived experience of long-term conditions. We want to make sure that the people behind the numbers have a voice – one which is always in the minds of Scotland's leaders whose decisions make a difference to the care, treatment and support people receive.

KEY FINDINGS

An estimated 69,000 people in Scotland would benefit from pulmonary rehabilitation.

The provision of pulmonary rehabilitation is hugely variable across Health Boards, creating a difference within our communities of the support available to people with chest conditions;

The number of people being referred to pulmonary rehabilitation is very low, and ranges from just 2% to 21% across Health Boards.

There is a significant level of unmet need; the capacity of programmes ranges from just 2% to 17% of the people estimated to benefit.

Waiting times range from four weeks to 29 weeks.

Chest conditions affect people's mental health and their ability to be physically active. This limits people's daily lives and causes isolation. Pulmonary rehabilitation improves people's outcomes and their quality of life.

Source: isdscotland.org

COPD accounts for over **127,000** hospital bed days annually



RECOMMENDATIONS

The Scottish Government should:

Establish an Improvement Fund for Health Boards to draw on, in order to deliver a universal and equal Right to Rehab for people with chest conditions.

Fund a Pulmonary Rehabilitation 'Champion' for three years who will oversee improvement and support Health Boards.

Improve referral rates by health professionals, and raise awareness among people with chest conditions about the benefits of pulmonary rehabilitation.

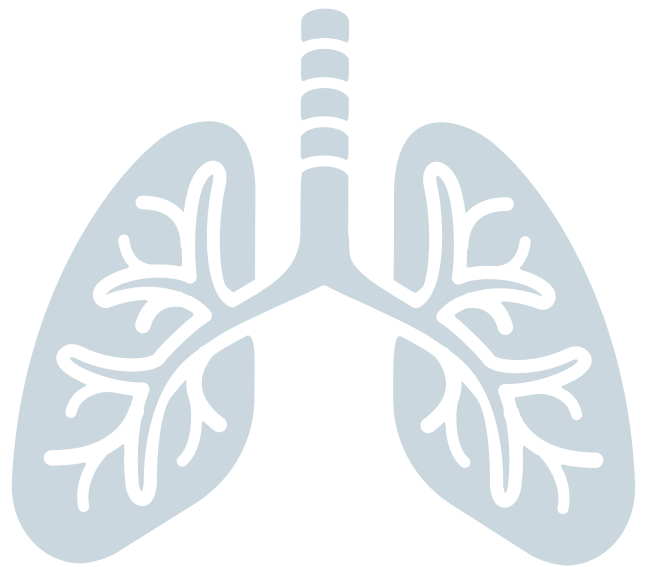
Support the development of partnership opportunities between the third sector, NHS and social care in order to provide an integrated rehabilitation pathway.

THE RIGHT TO PULMONARY REHABILITATION

WHAT IS PULMONARY REHABILITATION?

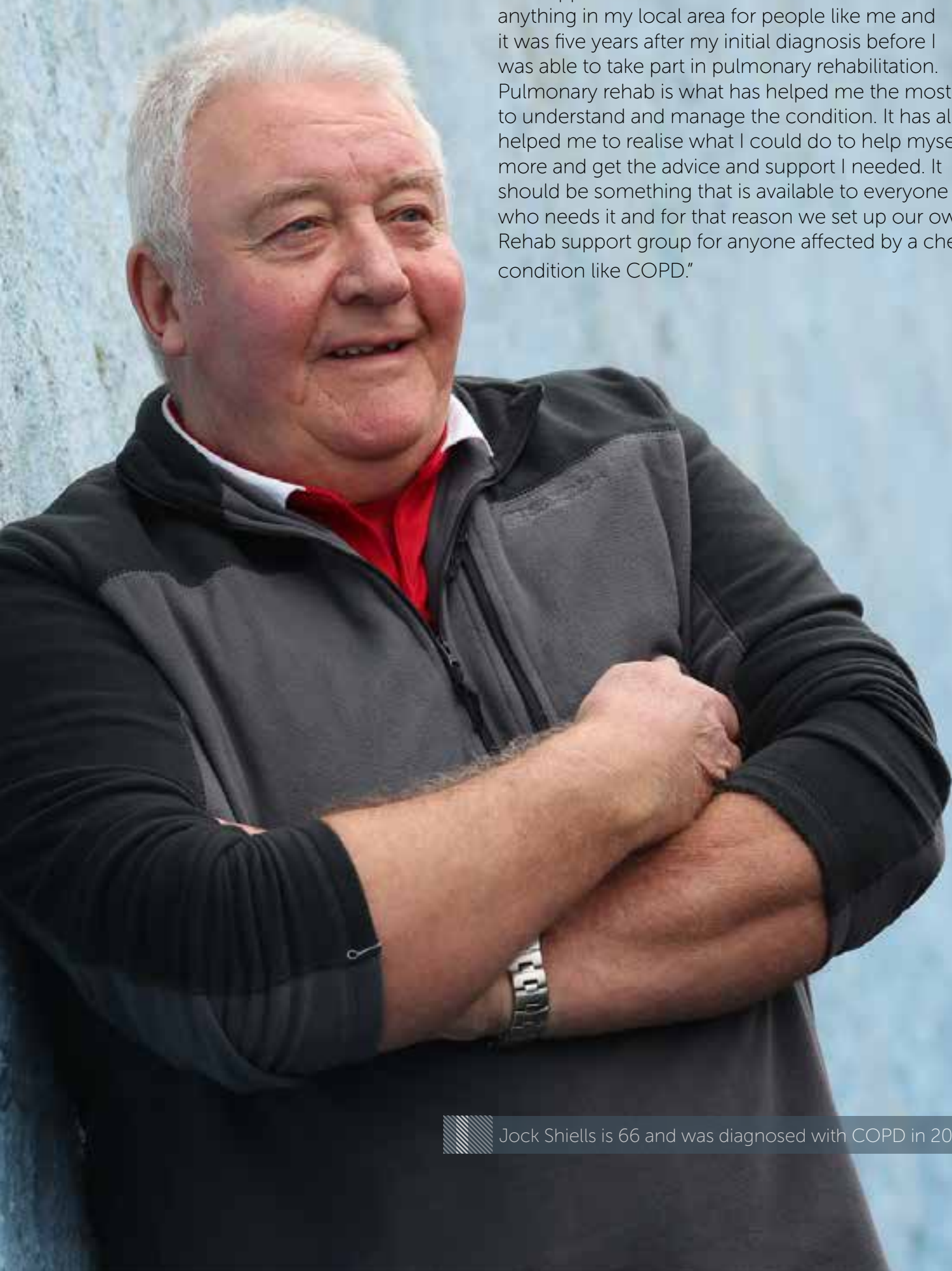
Pulmonary Rehabilitation is a treatment proven to be both clinically and cost effective in reducing hospital admissions. It is a key part of clinical guidelines for treating COPD and supports people to self-manage their conditions. It combines physical exercise with education, advice and support for people living with chest disease. It improves fitness and strength as well as supporting learning to help control symptoms like breathlessness. Through regular group activities, it builds people's confidence in their ability to get active and live as independently as they can, and helps their overall health and wellbeing.

We estimate that as many as 69,000 people with COPD would benefit from pulmonary rehabilitation, but that only a fraction of them are accessing it.⁶ The reasons for this include the capacity of programmes and sometimes a lack of awareness among health and social care professionals which means too few people are being referred to rehabilitation, and so the level of demand is lowered. People can also struggle to attend or complete a full course of rehabilitation because of their fluctuating health, or the challenge of fitting it around a working week.



“My breathing was bad and I had a severe cold that I couldn't seem to shake off. After tests, I was told that I had COPD. It was a big shock at the time. It was hard to cope with being short of breath and not being able to do everything I was used to doing.

It did take a few years to find the right treatment and support that works for me. There didn't seem anything in my local area for people like me and it was five years after my initial diagnosis before I was able to take part in pulmonary rehabilitation. Pulmonary rehab is what has helped me the most to understand and manage the condition. It has also helped me to realise what I could do to help myself more and get the advice and support I needed. It should be something that is available to everyone who needs it and for that reason we set up our own Rehab support group for anyone affected by a chest condition like COPD.”



Jock Shiells is 66 and was diagnosed with COPD in 2004



We recently asked all fourteen regional Health Boards for current data about the pulmonary rehabilitation they provide, and found a very mixed picture, with many people still missing out on this treatment:

The number of people being referred to pulmonary rehabilitation is very low, and ranges from just 2% to 21%.

There is a significant level of unmet need, with the capacity levels of programmes ranging from just 2% to 17% of people who would benefit.

There is only capacity for around 5,000 people to attend pulmonary rehabilitation programmes, though an estimated 69,000 would benefit.

Previously, one Health Board (NHS Borders) had had no rehabilitation available at all but has now identified resources and is putting plans in place to establish programmes.

The average proportion of people who are completing their rehabilitation programmes is just 31%.

Waiting times range from four weeks to 29 weeks for an assessment, and then on average a further three weeks to begin pulmonary rehabilitation.

Only one pulmonary rehabilitation programme has input from a clinical psychologist, despite the well-documented link between anxiety, depression and COPD.

The sources of referrals vary across Health Boards – in some significantly more referrals are made by consultants, and in others GPs.

HOW DOES CHEST DISEASE CHANGE PEOPLE'S LIVES?

Around a half of respondents to our national survey of people's lived experience⁷ told us that their chest condition has affected their confidence and causes them anxiety and stress. This reflects the existing evidence about the harm conditions such as COPD can cause to people's mental health, for example leaving people up to ten times more likely to experience panic attacks⁸. If left undiagnosed or untreated, anxiety and depression can worsen people's physical symptoms, and affect their use of medication.⁹

“ I It's like you're walking around on eggshells... I never used to use anti-depressants before now. I just feel my whole life has changed... it's always at the back of my mind something might happen to me.” Respondent age 51, living with heart and chest conditions

Over half of people – 53% - told us that their condition limits their ability to get out and 48% reported a loss of independence. While we know that having a long-term health condition can have this impact, the concern is that the support and help is not always there to help reduce or prevent it entirely. People with long-term health conditions can be at far greater risk of experiencing isolation and loneliness because of the limitations their conditions cause, emotionally and practically. 43% of people told us they have some problems accessing public transport, which compounds the isolation that can be caused by ill health.

“ I've got a really good friend network but I feel disjointed from them... they're all planning what they're doing in the future, looking forward to this and that... I'm looking forward to making it through another day!” Respondent age 52, living with chest and heart conditions

65%

of respondents to our survey say **their ability to be physically active is affected**



65% of people say their ability to be physically active is affected. For some people this will mean the basic things that many of us take for granted - like walking to a bus-stop or getting to the shops - are a challenge. The breathlessness and fatigue that people can experience with chest conditions can make physical activity seem impossible, although we know that it is hugely important to keeping as well as possible.

Perhaps unsurprisingly, 40% of people told us that their ability to work as before had been affected. This in turn affects people's finances and causes anxiety about getting by each day.

“The ability to pay my bills... it's soul destroying 'cos there's no way out.” Respondent age 52, living with chest and heart conditions



PEOPLE WITH COPD

are up to ten times more likely to have panic attacks

Source: kingsfund.org.uk



“When I was first diagnosed with COPD and throughout the years that I've had it, my main support has actually been my husband. I get terrible breathlessness, and that can actually cause me to go into panic which makes you ten times worse, really.

Pulmonary rehabilitation was the making of me, basically, it really was. I was six years into having COPD before I was asked if I wanted to do this. I had to then wait another eighteen months before I got into a class but it turned my life around, absolutely turned my life around.”

Dorothy Keith was diagnosed with COPD in 2009

HOW CHEST HEART & STROKE SCOTLAND IS CHANGING LIVES

PEER SUPPORT GROUPS: FORFAR AIRWAYS

Chest Heart & Stroke Scotland has support groups across Scotland offering a range of support including information, exercise and the chance to meet and talk to others. We know that support groups can make a real difference to people's recovery and quality of life. Forfar Airways is a group supported by Chest Heart & Stroke Scotland for people living with COPD. The group was founded by Ian Baxter. He said, "We have about thirty people attending the group each week taking part in physical activity and enjoying the social side. We always do something sociable and often have a sing song too as it's helpful for breathing control. It also helps give us the feel good factor and a sense of belonging. We have a great time together and support each other through good and bad times".



“

Life wouldn't be worth living if I didn't have this group. I look forward to coming each week. This is my only afternoon out a week and I really look forward to it. We are like one big family.”

Ann Tyrie, member of Forfar Airways Group

THE SUPPORT THAT PEOPLE NEED

When we asked people what their biggest concern is, managing their health condition took priority. Self-management of conditions like asthma and COPD means that people are able to take control and grow confident in being able to do so, recognising when their symptoms are worsening and knowing what action to take. There is evidence that self-management can significantly reduce the number of hospital admissions for people with COPD and asthma.¹⁰ But people need support and the right tools in order to self-manage.

Resources like Chest Heart & Stroke Scotland's 'My Lungs My Life' help people to understand their condition and make positive changes, so that they have the confidence to manage their symptoms and make informed decisions, knowing how to get help when it's needed. My Lungs My Life is a free online resource provided by Chest Heart & Stroke Scotland for anyone living with COPD or asthma, or for the parents and guardians of children with asthma. Full of advice, information and tips it covers everything from using inhalers, healthy eating, overcoming fatigue and breathlessness.

People living with chest conditions are accessing a wide range of support from health professionals. Over the last two years 70% had seen their GP, 58% a hospital doctor (such as a consultant), 52% a specialist nurse and 31% a therapist (for example a physiotherapist). But the NHS is just one part of the picture – when we asked which sources of support had the most positive impact, in addition to GPs, nurses and doctors, it is family and friends who make the most difference, with 22% also accessing a local support group.

We know that awareness about the benefits of rehabilitation for people with chest conditions like COPD is very low – partly because they are not always told about it, but also for people living with symptoms such as breathlessness and fatigue, being active can seem counter-intuitive. Seventeen percent told us they had been unable to access rehabilitation (a higher figure than respondents with heart conditions or a stroke) but because of the lack of awareness about pulmonary rehabilitation this figure is likely to be artificially very low. There are also issues with health and social care professionals not always being aware of the benefits of pulmonary rehabilitation and so not referring people to it. We think that the true picture of the number of people being unable to access rehabilitation is far higher – but that people are unaware that they are missing out.



of people with COPD are either undiagnosed or have an incorrect diagnosis



CONCLUSION

It is clear that without investment and leadership at a national level, people living with chest conditions will continue to miss out on support and treatment which help ensure no-one's life is half lived. Pulmonary rehabilitation doesn't just benefit people with chest conditions – it saves the NHS money.

We are calling on the Scottish Government to commit to and invest in a 'Right to Pulmonary Rehab', in order to ensure there is universal and equal access to rehabilitation programmes for those who could benefit. Given the huge disparity between the need for pulmonary rehabilitation and the existing capacity of programmes, this is particularly vital for people with chest conditions.

ENDNOTES

1. <http://www.isdscotland.org/health-Topics/General-Practice/Quality-And-Outcomes-Framework/2015-16/Register-and-prevalence-data.asp>
2. <https://www.rcplondon.ac.uk/projects/outputs/pulmonary-rehabilitation-beyond-breathing-better>
3. <https://www.nrscotland.gov.uk/files//statistics/rgar/2017/rgar17.pdf>
4. <https://www.blf.org.uk/policy/economic-burden>
5. <http://www.isdscotland.org/Health-Topics/Hospital-Care/Diagnoses/>
6. <https://www.chss.org.uk/documents/2017/06/2017-pulmonary-rehab-report.pdf>
7. <https://www.chss.org.uk/documents/2018/10/one-in-five-report-pdf.pdf>
8. <https://www.sciencedirect.com/science/article/pii/S0954611110001903>
9. <http://err.ersjournals.com/content/23/133/345#ref-3>
10. <https://www.kingsfund.org.uk/sites/default/files/Avoiding-Hospital-Admissions-Sarah-Purdy-December2010.pdf>



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