

# BEARING THE **BURDEN**



The impact of the  
cost-of-living crisis  
on people with  
pulmonary  
hypertension

# BEARING THE BURDEN



## About pulmonary hypertension

Pulmonary hypertension (PH) is a rare, life-limiting health condition. It causes high blood pressure in the blood vessels connecting the heart and lungs (the pulmonary arteries), putting significant strain on the right side of the heart.

People with PH live with symptoms that are often debilitating, including severe breathlessness, chest pain, and fatigue.

Treatments for this chronic condition include oral medication, intravenous drugs, and nebulised therapy, which can all be accompanied by challenging side effects. Some people with PH must also take oxygen, for up to 24 hours a day.

## The long-term costs of living with pulmonary hypertension

Because of the high burden of symptoms, many people with PH are unable to work and therefore rely on benefits.

Plus, there are just nine specialist PH centres in the UK and Ireland – meaning patients often have to make long and costly trips for appointments and treatment.

In 2019, we conducted **this** in-depth research into the true costs of living with PH. In it, 76% of patients under the age of 60 told us their financial situation had declined since being diagnosed with PH – so the cost-of-living crisis is adding huge pressures to many already struggling with money.

## The crisis through the lens of PH

With the cost of living continuing to rise for everyone, we set out to discover how those with pulmonary hypertension are being affected – and where the biggest challenges lay. Our survey aimed to identify specific areas in which we can help, and understand how we can focus our support in the most effective way.

This survey was conducted online during October and November 2022\* and 112 responses were received. As well as answering questions we gave people the opportunity to share their own comments too, and you will see some of these words alongside the statistics throughout this report.

78%

of respondents told us **they do not work** (76% of these people told us this was because of **health reasons**)

75%

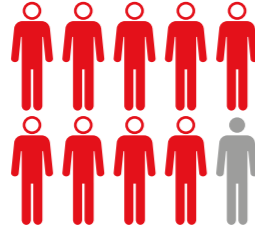
of respondents are in **receipt of benefits**

\*The survey closed on 4th November 2022, prior to the Government's Autumn Statement.

We are grateful to everyone who responded to this survey.

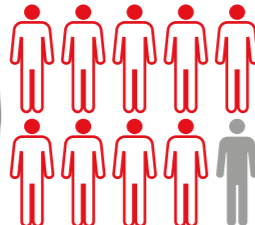


# The key findings

**93%** 

of people with PH are worried about the cost-of-living crisis having an impact on their **physical health**.

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**90%** 

of people with PH are worried about the cost-of-living crisis having an impact on their **mental health**.


**78%**


of people with PH are concerned about meeting their **rent or mortgage payments over the winter**.



**33%** 

of people who take oxygen for their PH **have reduced how much they take** because they are concerned about the costs of electricity.




**33%** 


of people with PH feel **their disease symptoms have worsened** due to the increasing costs of living.

**26%** 

of people with PH say they are **eating less healthily** in order to save money.

**51%** 

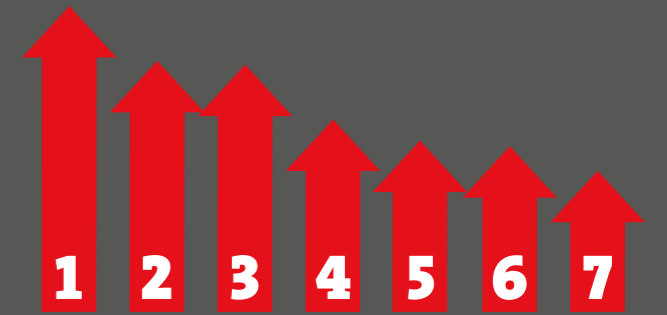
of people with PH are **worried about being able to afford prescriptions** over the next few months.

**94%** 

of people with PH have **reduced how often they have their heating on at home**, in order to save money.

**60%** say that feeling cold at home is **making their PH symptoms worse**.

## PEOPLE WITH PH ARE **MOST WORRIED ABOUT:**



- 1 > **ENERGY BILLS** meaning they will be cold
- 2 > **ENERGY BILLS** meaning they can't cook as much
- 3 > **FOOD PRICES** meaning they can't eat healthily
- 4 > Travel costs due to **FUEL PRICES**
- 5 > **ENERGY BILLS** meaning they have to use less oxygen
- 6 > Paying their **RENT OR MORTGAGE**
- 7 > **PRESCRIPTION COSTS**



# Heating



**60%**


of people who are using less heating to save money think that **feeling cold at home is making their PH symptoms worse**



“**Life is difficult enough** without having to suffer cold in your own home.”

survey respondent



**94%** 

of people with PH have **reduced how often they have their heating on at home**, in order to save money

**93%** 

say they **expect to have it on less over the winter** in order to save money

**87%** have **felt cold in their home recently**, due to using the heating less

**41%** say they have **felt cold 'often'** 

“

“When I’m cold...I have to walk slower, and sometimes increase my oxygen.”

“When the house is cold it feels damp, and it makes my breathing worse.”

**“I get very breathless especially when I am shivering.”**

“I live with my daughter who is my carer. She notices if I’m cold and makes sure I’m warm. But I know she worries about the bills.”

“When I am cold, I tend to snuggle up on the sofa and I do not move. This causes muscle pain and wastage. I don’t tend to eat as it’s warmer with the blankets on you.”

“Patients shouldn’t have to choose when they turn their heating on.”

**“It is going to be a big problem this winter and [I] will try and use public spaces but these are not easy as I need to put my feet up and you cannot do that publicly.”**

“I believe it is necessary to have a comfortable home in order to maintain health... Many people won’t be able to afford to put on their heating and will be too frightened to maintain a comfortable temperature this winter.”

**“I am really scared that I won’t be able to afford enough heating when the weather gets really cold.”**

“Disabled people with breathing issues can’t move around like a healthy person so I feel the cold more.”



“  
No patient should  
have to make a  
decision to **reduce**  
**how much oxygen**  
**they take.**”

survey respondent

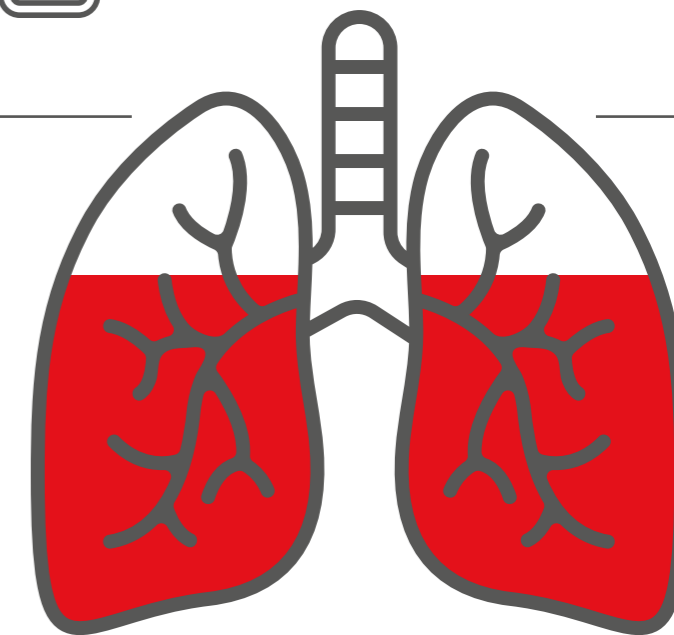
Photo posed by model

# Oxygen



**33%**

A third of people who take oxygen for their PH have **reduced how much they take** because they are concerned about the costs of electricity.



**39%**



of respondents told us they have an **oxygen concentrator installed in their home**

**85%**



of people who use an oxygen concentrator **claim a rebate for the electricity used**

“

“I worry about if there are power cuts”

**“The rate given back is low for those in financial difficulties”**

“I’m scared because I have to use it 16 hours a night and during the day”

**“We are being refunded at 28p per unit but paying much more, and the rebate is not being increased in the foreseeable future. I have therefore tried to decrease oxygen use by around 20%, the same amount as the price increase roughly. It’s not right when this is a prescribed medication.”**



## Rent & mortgage payments

“It hits the disabled **hard**”



**78%** of people with PH are concerned about meeting their **rent or mortgage payments over the winter.**

**23%** say they are ‘very concerned’



say they fear they will **lose their home** due to not being able to meet the payments.

## Food & nutrition



**26%**

of people with PH say they are **eating less healthily** in order to save money.

“Healthy eating is harder because **groceries are so expensive**”

**59%** say they have **changed the way they cook in order to save money** (for example, using the oven less)

**“I buy less and eat less”**

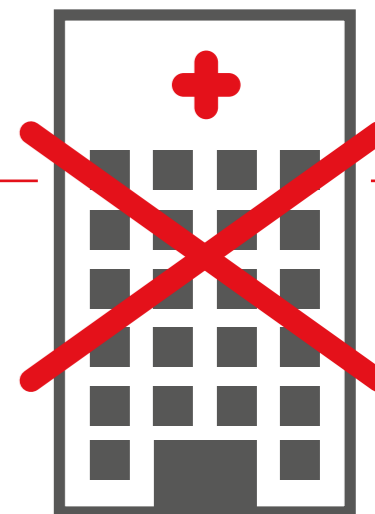
“We’ve cut down on portions to save money”

**“[I’m] having one meal a day and buying more junk food as it’s cheaper”**

## Medical appointments

“I will struggle to afford the train or petrol costs **to attend hospital appointments**”

**12%**



of people with PH have **missed a medical appointment recently** due to the cost of travelling to it

**19%** say they expect **to miss medical appointments over the coming months, because of the cost of travel**

## Prescriptions

“My medications are too important to skip or reduce, so no matter how bad it gets I will still have to find the money to continue my pre-payment certificate”

**“If I had to pay for them, I wouldn’t be able to due to benefits being so low. I miss working every day due to being so poor.”**

“Pre-payment is the **only way I can afford to pay for my prescriptions**”

**51%**



of people with PH are **worried about being able to afford prescriptions** over the next few months.



“

*The rise in fuel costs, living costs and the rise in interest payments (my mortgage has increased £270 a month this year alone!) **has made my PH significantly worse. Being cold and stressed is really not good.***

survey respondent

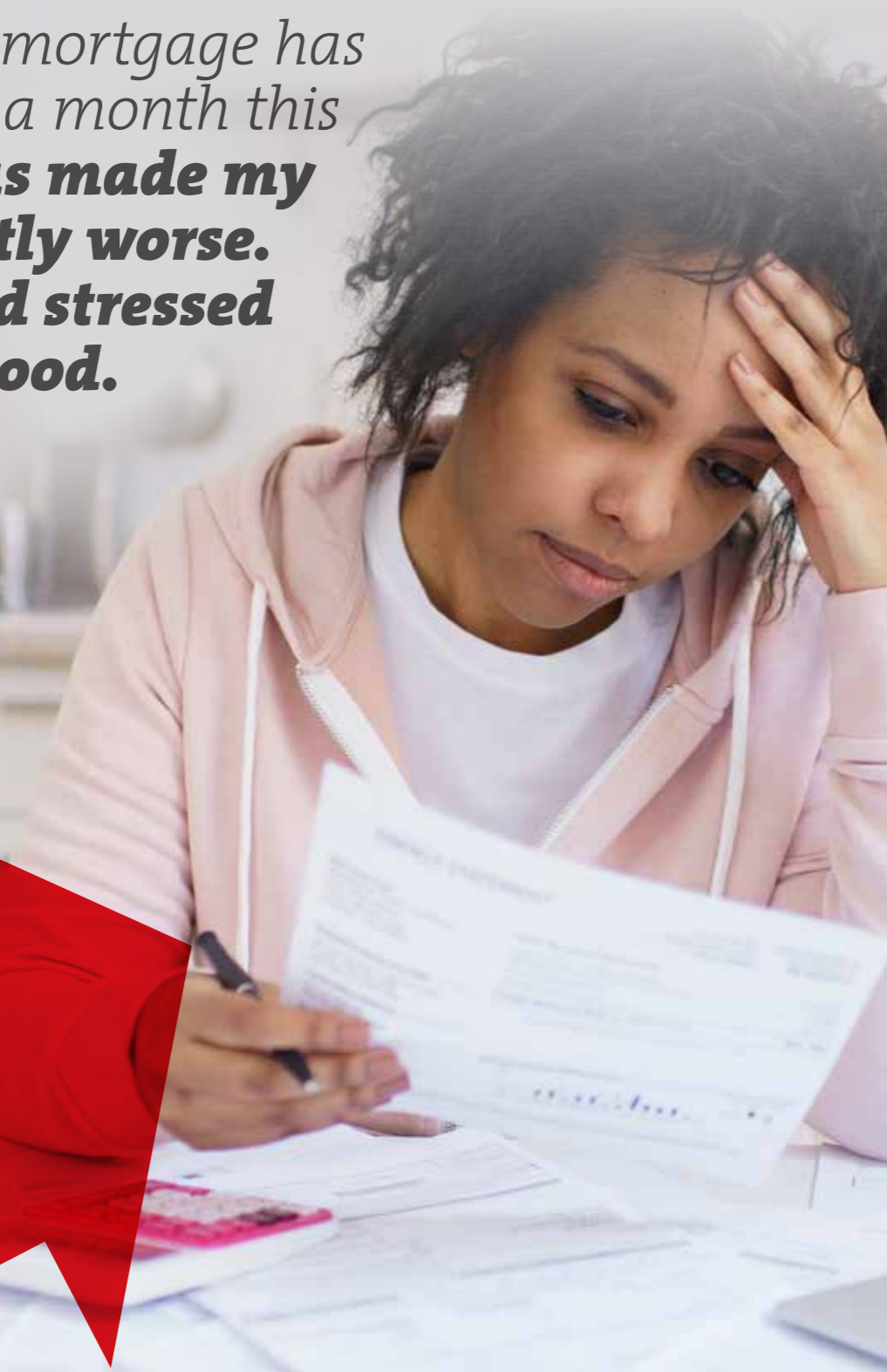


Photo posed by models

## The direct link between the crisis and the disease

**33%**

of people with PH feel **their disease symptoms have worsened** due to the increasing costs of living.

“

*“I think because I’m more anxious I feel my symptoms more”*

**“The cold and worry is affecting my health”**

*“The stress of the crisis is affecting my PH”*

*“[I’m] not being able to keep as fit because I can’t afford to go out much”*

*“More stress so more giddiness”*

**“Not being able to put the heating on as much as I’d like really affects me both physically and mentally. [I] have been staying later at work just because its warm”**

*“Anxiety and stress. Thinking more about how we will cope and feeling hopeless”*

**“The government need to see that the chronically ill need help. We are cutting heat and food and having extra stress put upon us that is making us more ill than we need to be”**

*“Decreased quality of life due to changes made to reduce costs”*

*“I do less exercise as I do not leave the house. It’s expensive to run a car and it is easy to stay in once you have got warm”*

**“Stress makes things harder for me, I have been thinking of reducing my hours to make life easier as my PH has gotten worse but now I can’t afford to as we need the money for bills”**



“

I feel this cost of living crisis will hit the most vulnerable who need to keep warm, eat well, travel to important hospital appointments and use oxygen. **There are many different sides to this crisis but as always the poorest/most vulnerable will suffer.**

survey respondent

## Fears for the future

93%



of people with PH are worried about the cost-of-living crisis having an impact on their **physical health**.

90%



of people with PH are worried about the cost-of-living crisis having an impact on their **mental health**.

“

“My outgoings far outway my incoming money. I had very little savings but I’m using them up very quickly. I don’t know what I’ll do when it runs out as things are just constantly increasing. This makes me anxious and affects my physical and mental wellbeing!”

“Increased health inequality due to higher cost means I cannot take care of myself as I did. I cannot enjoy leisure activities as I did because I need to spend more on my health [which] affects my mental health and well-being”

**“I work full time as an NHS clinician, on oxygen 24/7. My condition is reaching the point where I should consider reducing my hours as it’s getting very hard to keep going but the cost of living crisis is forcing me to continue working full time. This and all the problems associated with the cost-of-living crisis will very well shorten my limited lifespan”**

“I cannot see an end to managing as I am near retirement and fear what that will bring in the next 5 years”

**“I feel there should be more understanding about how difficult life can be for patients with life limiting/terminal illnesses. We deserve more financial support during these hard times”**





## What comes next?

The cost-of-living crisis is affecting everyone in the UK, but those with pulmonary hypertension are facing a two-fold blow to their finances.

As our **2019 research** has already shown, the diagnosis itself results in loss of income for most – regardless of the astronomical price hikes of recent months.

***This ‘double-whammy’ is causing huge distress to people already coping with a high symptom burden and navigating life with an incurable disease.***

The results of this survey demonstrate a clear correlation between the cost-of-living crisis and declining health in the PH community, and it's vital that there is change.

## A message to our members

**As a charity dedicated to supporting people affected by pulmonary hypertension, we will do all we can within our power to help you through this difficult time.**

Upon analysing the results of this survey, we have acted quickly to build an **online hub** housing advice and guidance around the areas you told us matter to you most. We will continue to expand this resource.

We have already begun meeting with other national charities with a view to using the data from this survey to add weight to their political lobbying. We will

continue to nurture these collaborations and ensure your voices are part of the calls for help and reform.

Independently, we will also work hard to support you specifically in the ways you told us are most important.

The findings of this survey highlight the extent to which the cost-of-living crisis is already impacting the PH community. The stress and anxiety associated with these times are making disease symptoms worse, and 90% of you told us you are worried about the mental impact too.

***We promise to do all we can to help.***

If you would like to discuss any aspect of this report, please email [office@phauk.org](mailto:office@phauk.org) or call **01709 761450**.



Pulmonary Hypertension Association UK

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Registered Charity No: 1120756

