

LIVE

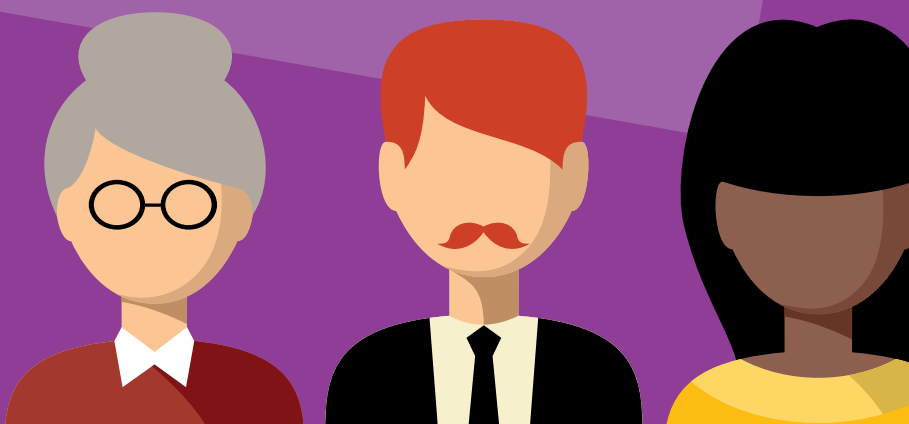


BETTER
WITH **PH**

KEY EVIDENCE | 2019

Beneath the surface

*The true financial
impact* of pulmonary
hypertension.



Looking beneath the surface

Of those who responded to our 2017 Living with PH survey, 63% said financial worries had an impact on their lives.

We wanted to know exactly which areas were impacted most, and this follow-up research has provided us with a vital evidence base upon which to target our support and campaign for change.

The statistics are quite shocking and the one-to-one interviews we carried out reveal the true emotional financial impact on people living with pulmonary hypertension – a disease which already carries a huge burden.

We are using this evidence to engage support from commissioners and key stakeholders who are duty-bound to listen and act.

Thank you to everyone who shared their voices to influence change and enable this evidence base to exist.


Iain Armstrong

Chair, PHA UK.
Nurse Consultant,
Sheffield Pulmonary Vascular Disease Unit,
Royal Hallamshire Hospital.



BRINGING THE STATISTICS TO LIFE

We've put together a special film that brings the findings of this research to life. Featuring interviews with families across the UK, the footage lays bare the true financial impact of pulmonary hypertension. You can also read some of their stories within this report.

Find the film online at www.PHocus2021.org or request a link by emailing office@phauk.org

There were 33 findings in total. This publication highlights the **key evidence**.

To view all of the findings, visit www.phauk.org or call 01709 761450

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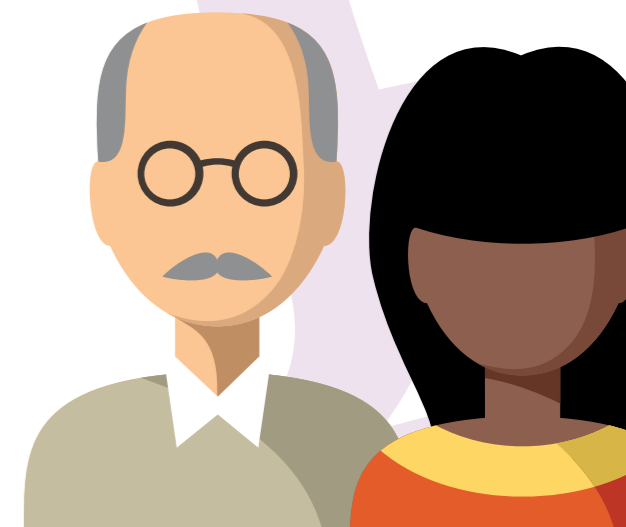
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We'd love to hear your thoughts about the research.

Please contact us on 01709 761450 or email office@phauk.org

You can also tweet us @PHA_UK or find us on Facebook @PULHAUK

Use the hashtag #BreathlessNotVoiceless to join the conversation online.



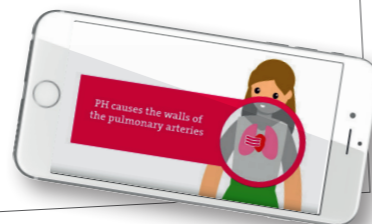
About pulmonary hypertension

Pulmonary hypertension - PH for short - is a serious condition that causes high blood pressure in the blood vessels connecting the heart and lungs (the pulmonary arteries).

In a healthy cardiovascular system, the right side to the heart pumps blood into the lungs to pick up oxygen and this oxygen-rich blood is then pumped around the body by the left side of the heart.

When a person develops PH, the walls of the pulmonary arteries become stiff and thickened, or partially blocked by chronic blood clots. This makes it difficult for them to expand; and trying to pump blood through these tightened, narrowed or scarred arteries puts increasing strain on the right side of the heart as it tries to do its job. The essential task of pumping blood into the lungs to pick up

Visit www.phauk.org to watch a short video which explains more about PH and how it affects the body.



oxygen which can then be circulated to every cell in the body becomes much harder.

PH affects people's abilities to carry out basic tasks and get around. People with this condition often look well at rest and it's only through a simple activity such as climbing the stairs, washing or dressing, that they may experience symptoms:



Pulmonary hypertension is rare. Around 7,000 people are diagnosed with PH in the UK. It can affect anyone, regardless of age or ethnic background. It affects more women than men.

NHS health professionals, PHA UK is now at the heart of a nationwide PH community, providing a network of mutual support; and a voice for those affected by the disease.

People find it hard to believe that my condition is life-limiting, because I don't look ill.



About PHA UK

The Pulmonary Hypertension Association (PHA UK) is the only charity in the UK dedicated to supporting those affected by PH. PHA UK provides information, support and advice to people with pulmonary hypertension. It funds research, educational programmes and activities to promote better understanding, diagnosis and treatment of the disease and to raise awareness.

Set up in 2000 by a small team of volunteers - patients, family members, friends and frontline

About the research

Our 2017 *Living with PH survey* gathered important statistical evidence about issues affecting PH patients and their loved ones, and made it clear that finances were an area of concern for many.

We wanted to build on these findings to find out which elements of people's financial stability are affected the most, and to understand the impact that has on their lives.

We published the results of the *Living with PH survey* in 2017, along with a commitment to discover which areas of people's finances were being affected - and use the findings to drive change.

The financial impact survey asked about changes in employment, experiences of claiming benefits, costs related to healthcare, insurance, debt, and mental and emotional wellbeing.

It was mailed to everyone who responded to the *Living with PH survey* and said they would be happy to be contacted to take part in future research.

The surveys were returned to us by post and 171 responses were received.

The future financially is really quite grim for me.



For a copy of the *Living with PH report* please email office@phauk.org or call 01709 761450. The results can also be accessed at www.phauk.org

#BreathlessNotVoiceless

63% of those surveyed said that financial worries had an impact on their lives.



26% said it had a "major impact".



63% said PH affects their ability to attend work or education.



More than just numbers

- > An important part of this research centred around interviews with patients. This qualitative research provided vital insight into the true extent of financial impact.
- > Seven interviews were conducted via telephone and quotes from these conversations are included throughout this report.



The true financial impact of PH

Key findings...

76%



of patients under the age of 60 say their financial situation has declined since being diagnosed with PH. 40% reported that their financial situation had declined 'a lot'.



On average, patients in full time work at the time of diagnosis lose a third of their income.



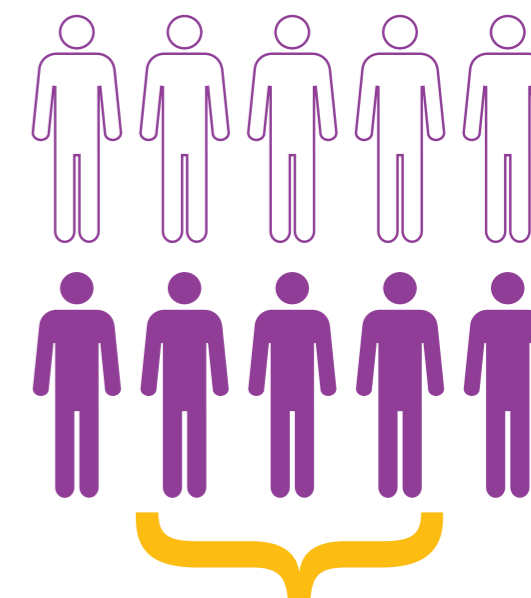
Over half of people with PH have tried to claim benefit support. Of those, 30% said it was extremely difficult, 26% said difficult, 25% said quite difficult.

£84%

say life or travel insurance quotes are more expensive since being diagnosed with PH.

52%

of applicants were turned down the first time they applied for benefits.



78%

of those who applied for benefits were eventually awarded them in the end!



60%



of people say they now have more difficulty paying bills.

59%



of people have had to take money from savings to get by.

Read on for the key evidence.

What does a PH patient look like today?

Statistics taken from our 2017 *Living with PH* Survey - the UK's largest study into the lived experience of pulmonary hypertension.



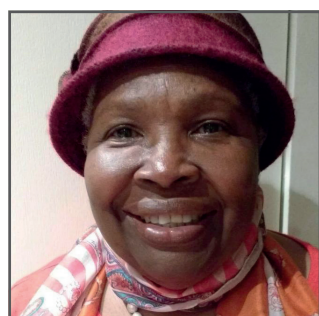
70%
of PH patients
are female
○○○○○○○○↑↑↑



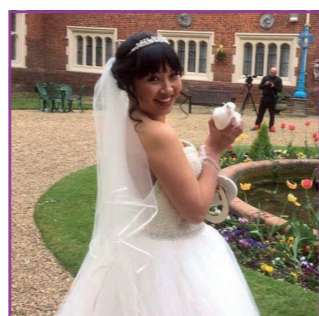
The average age
of a PH patient
in this study is
59 YEARS



The average age
at diagnosis is
53 YEARS

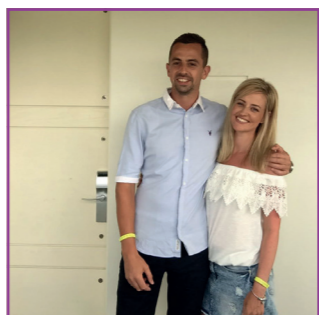


30%
of PH patients
are male
○○○○○○○○↑↑↑



59%
of patients have
conditions that may
have contributed to the
development of PH.

They include 15%
with congenital
heart disease...
...and 11% with
connective tissue
disease.



Pulmonary hypertension and...

Changes in income

Our research
shows a **significant
drop in income**
following a
diagnosis of PH.

#BreathlessNotVoiceless

“ Sometimes my two children have to take care of me financially. They're only young people, they are starting their own lives and families, **but I can tell that they are bearing the burden of what's happening to me.** ”



76%

of patients saw their **financial situation decline** since being diagnosed. (Under 60s)



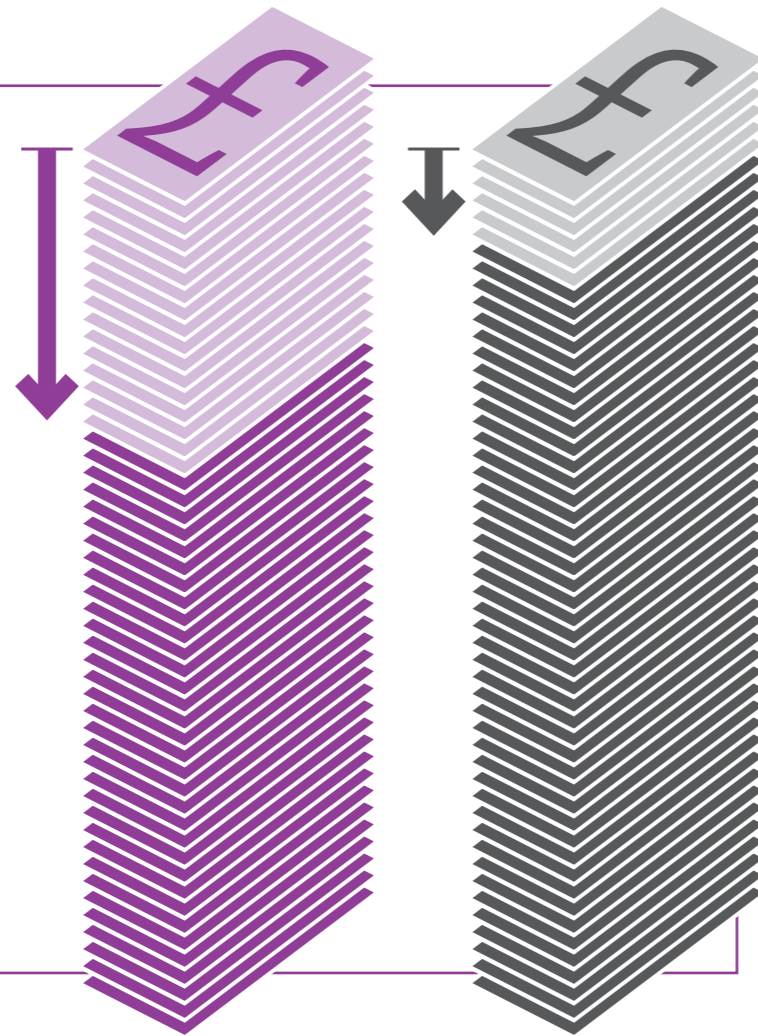
After being diagnosed with PH what was your **percentage change in income?**

-33.3%

Full time employed

-13.4%

Part time employed



I'm constantly checking my bank balance every day to check the money that isn't there.



We went from two full time incomes to living purely off benefits.



We were only living on one wage and it wasn't enough for us to cope with. And instead of leaning on one and other, we pushed each other away and sort of never spoke about it properly. I know we should have, but we didn't.



Shaun Clayton
Director of Membership Support,
PHA UK



We have lots of phone calls every day from members and it astounds me just how many of them are about finances being impacted. People are losing their jobs because of PH, through no fault of their own, and partners and loved ones are having to give up their jobs to care for them. **The statistics from this survey are extremely worrying. Can you imagine suddenly losing a third of your income, on top of being diagnosed with a devastating disease?** I'm also very concerned to see that half of people with PH who apply for welfare support are turned down at first application, but so many are then awarded it upon appeal. There is something really wrong there.



Pulmonary hypertension and...

Changes in employment

The symptom burden of PH can make it **difficult or impossible to work.**



When you work you don't ask for anything and then when you are struggling and you're dying with this illness, you lose the financial side of things.



52%

of people who were employed at time of diagnosis, **were not given support from their employer to help them stay or return to work.**



I've just been forced to take ill health retirement because there is no way I can go back to work. I feel like I've lost my identity.



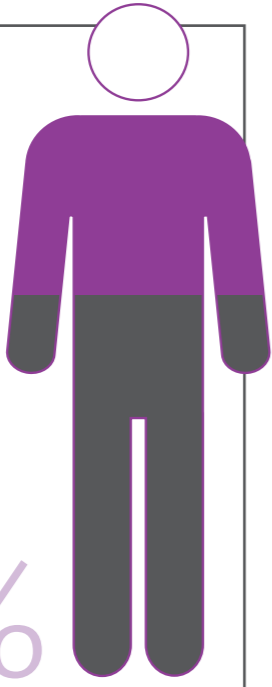
I had to give up work and retire at the age of 53. I was on something like £33,000 a year, and now I earn just my very basic pension, because I'm under state pension age. It only comes to about £7,000 per year. That's a dramatic difference.



Immediately after diagnosis

27%

had to give up work completely or reduce their working hours.
(57% were on long-term sick or already not working.)



If you had to reduce hours or stop working because of PH **were you able to return to work?**

29%
Yes, but on reduced hours

55%
No



*My husband has to focus on his work so much more because we rely on that income, **and this is putting him under pressure because obviously I cannot work.***



Breathless not voiceless...

Alysha Sharma

If I had to describe having to claim benefits at such a young age, **I'd say it's embarrassing. Really embarrassing.**

Alysha Sharma

23, Coventry, diagnosed with PH in 2018

Before diagnosis, and before my symptoms started, I was earning good money in my part time job as a carer alongside my degree. I was able to go out and see friends, but I can't imagine ever being able to do that now. **I had to cut down my hours because it was such a physical job and now, I'm not able to work at all.** I applied for PIP (Personal Independence Payments) before I had to stop working. **My assessment felt like an interrogation and the assessor, a nurse, clearly didn't understand my condition.** It was really intimidating, and I had to pour everything out to her, but I felt like she didn't really listen.

I was initially awarded the lower rate for PIP which was ok at the time, but now I'm struggling to pay my bills, so I appealed for the higher rate. I was turned down, so it's now going to a tribunal. I'm still waiting for a date for the tribunal; all I've had is an email telling me they are really busy. **I'm worried about it. There's a lot of pressure.** I'll be sitting in front of people I don't know and

pouring my heart out, but I feel like it's the only way they are going to understand how difficult this condition is to live with and how massively it affects my life.

Physically, I feel better than I did as the medication is helping. **Emotionally though, I have no confidence. I have anxiety and I don't believe in myself anymore – which is really hard.** I'm struggling. I don't want to have to rely on my parents to keep bailing me out. Waiting for a tribunal date feels like being in limbo. **I want to get in front of them and explain why I need the help, but at the same time I'm scared of being rejected.**

My message to those making decisions is this: It's easy for someone to sit and judge but not actually know anything about the person there in front of them. **Be more understanding.** You've no idea what it's like for someone who has always been well and never claimed benefits, to then have to go through all of this to justify what they need. **To hear a 'no' after it all is really hard.**

Pulmonary hypertension and...

Battling the benefits system

Too many people are having to **fight for what's fair.**

#BreathlessNotVoiceless

I just feel like I'm begging all of the time. **I'm begging for what I'm entitled to.**



81%

said they found applying for benefits difficult.

30% of these said it was 'extremely' difficult.



66%

said the department dealing with their claim didn't understand their diagnosis.

52%

of claims were
unsuccessful
first time.

NO

“
*I think that the system is stacked against people who have worked hard, then something like this comes along which is through no fault of your own, **and you're left to fall back on what you've got. It feels very unfair.***
”



“
*It's a very daunting experience applying for benefits, it's very **complicated.** The forms are overwhelming, especially when you're ill.*
”



“
*Every time they refuse you **it breaks you,** but every time you win you go a little up the ladder of victory. But every time they stop your money, you fight and they refuse you, they break you down bit by bit. **And again, your dignity is taken away completely.***
”



If you appealed, how many times did you appeal ***until you were successful?***



35%
Once

22%
Twice

11%
Three times
or more

30%
Gave up on their
claim, didn't appeal



Breathless not voiceless...

Pam & Chris Ellis

Pam

■ ■ As well as PH I also have arthritis in my hip and knee, which also affects my mobility. I was awarded Personal Independence Payments (PIP), which enabled me to get a car through the Motability scheme, before being diagnosed with PH. So, when it was time for my PIP to be reviewed, I told them all about my new diagnosis and how it affects my ability to get around.

I was devastated to be told the enhanced rate was being taken away, meaning I would lose my car. It meant I would be confined to the house, because I can't even walk as far as the shops, or the bus stop.

I was so scared and so upset, and I got so depressed. I read the report they had put together and just thought 'this is not me', because there was nothing in it of what I had said about how PH impacts me.

I was absolutely devastated. *I've not got a lot of independence left, but one thing I do have is the ability to get into a car and go somewhere on my own.*

I asked for a review of the decision and gathered supporting evidence from my GP, PH specialist, orthopaedic consultant and the PHA UK. I also contacted my local MP about it, who also sent a letter.

I was four days away from losing the car and still hadn't heard anything from the DWP. I was going out of my mind.

I couldn't sleep, I couldn't focus on anything, I was so worried. I couldn't carry on anymore without knowing the outcome, so I rang the DWP and finally managed to speak to someone - who told me I had been reinstated to the enhanced rate. I burst into tears of relief.

*PH is incurable, I'm not going to get better, so why waste money putting people like me through regular reviews? **It would be different if it was a disease like cancer.*** ■ ■

Chris

■ ■ It was a dreadful time when Pam was told she would lose her car. She was terribly upset. When we were trying to talk to the DWP to get help and ask why this had happened, we found them totally unhelpful. All we got from them was forms, which were really unclear. I've heard Pam on the phone for two hours at a time trying to get some sense out of them.

Neither of us could understand how we had gone from Pam being able to have a car because of her arthritis, to having it taken away when she now has an additional condition, that's life-threatening. It was totally incomprehensible.

I can understand that there are some people who abuse the benefits system. But there needs to be a way that people who genuinely need the help can be heard and understood. ■ ■



There is no cure for PH. I'm not going to get better, only worse. **So why must I go through this?**



Pam Ellis
62, Sheffield, diagnosed with PH in 2015

22%

of patients were
never successful,
despite appealing.



40%

felt they didn't get
what they were
entitled to *after appeal.*



61%

Feel embarrassed
about receiving benefits.



*You don't like to admit it
really that you're a family
living off benefits.*

***There is a lot of shame
in that. But we have no
other choice.***



*I had a car on the
mobility PIP and they
took it all away from
me. My money, my car,
everything. They came
one morning and seized
everything, took it all.
**I felt like my world had
fallen apart, yet again.***



Pulmonary hypertension and...

The hidden costs of PH

*Pulmonary hypertension has a **major impact** on the lives of many patients.*

*It costs me **£50 in petrol to travel to my hospital appointments** and if I'm kept in, my husband has to pay **£55 per night to stay in hospital accommodation.***



On average, approximately how much money has it cost you over the last year to visit healthcare professionals?



£50

Visiting local GP

£90

Visiting specialist centre

£35

Visiting other healthcare professionals



*Since being diagnosed with PH and giving up work I am still liable to pay prescription charges and **I've gone from needing none, to six or seven a month, at over £8 each.***



*I can't do any cleaning because I simply do not have the energy **so we have someone in to clean for us. We have to pay to have a gardener too.***



Since diagnosis, **patients spent...**



43%

more on help around the house or garden.



53%

more on gas or electric bills.



29%

more on household bills (excluding gas /electric).



44%

more on general travel costs.



26%

more on food or special diet.



58%

experienced an increase in two or more of the above.



Breathless not voiceless...

As well as being married I'm also an independent woman and it hurts me so badly having to borrow money from my husband.

Tess Jewson

28, Essex, diagnosed with PH in 2008

Tess & Terry Jewson

Tess

When I was younger, like everyone, I had dreams about what I wanted to do when I was older. My dream was to be a professional trumpet player but when I was diagnosed with PH I was told that continuing to play would put too much strain on my heart. I was devastated. I then looked at becoming a music director instead, but the hours were too long for me to cope with so I had to give up that idea too.

I ended up starting my own music teaching business. Teaching is not what I initially wanted to do, but I have learned to love it. Being self-employed means I don't need to do long hours. It can be lonely, but it means I can contribute to household finances.

I do three hours, three days a week, and spread the hours throughout the day so I can have a break between students.

Having PH affects us financially in many ways. I travel to a specialist centre two hours away. **My appointment times used to mean I had to take the peak train which cost £40 per person, every three months. That's a lot of money.** We asked to change the times which helped, but the tickets still cost over £30.

My PH medication comes free on the NHS but I have to pay for other prescriptions.

In the winter I'm prone to infections and coughs and colds and I once spent £36 on prescriptions in just one week.

Travel insurances are absolutely awful.

We were supposed to be going to Australia and I was quoted £2,500 to insure for me for three weeks - which is just crazy. We didn't go.

We went to Italy and my insurance cost £180 for under a week. My husband got the same insurance for £20. I feel like we are paying to have our condition and it's very unfair.

I think Terry feels ok financially, much more than I do. We have a joint account and I'm always borrowing from it. My husband doesn't mind but there are things I need but can't afford. It does affect me because as well as being married I'm also an independent woman and it hurts me so badly having to borrow money off my husband. **Finances are at the top of my mind and I've lost sleep over it. It's very sad.**

Terry

I never considered the financial side of things when I first met Tess. **It's hard for her to have a job because of her health**, even though all her education has provided opportunities. We have to look at our bank accounts often. **I have thought about asking family for help but feel like that would be a downward spiral.** It is hard because we have to live off one main income, but I married my wife knowing this, and I'm prepared to do whatever it takes to be financially 'happy'. **Financial stress is one of the worst things** but by putting plans in place we can see the light at the end of the tunnel.

Pulmonary hypertension and...

Inaccessible insurance

Life and travel cover is **hitting people with PH hard in the pocket** – if they can get it at all.



I got diagnosed [with PH] in the December and my life insurance policy was up for renewal in the January so I basically lost it and I ended up with no life insurance. So I haven't got any life insurance and there's nothing I can do.



I can't get life insurance now, no one will touch me with a barge pole. This left me feeling very exposed when I was really ill and I didn't know what was going to happen.



48%

of patients have been **refused insurance since diagnosis.**



Trying to find anyone who will insure you is near on impossible, and the premiums are sky high.



68%

of patients & partners have found **applying for insurance difficult since diagnosis.**

84%

of patients say their insurance quotes are **greater since diagnosis.**



Pulmonary hypertension and...

Making ends meet

*Draining savings, borrowing from family and battling bills... **this is the difficult reality for people with PH.***

The proportion of patients who, since diagnosis, have had to **take the following actions for financial reasons:**

59%



Took money from their savings.



60%

of people with PH say they have **more difficulty paying bills since diagnosis.**

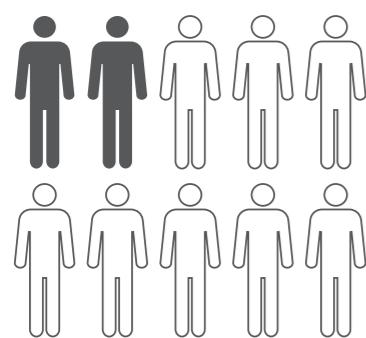
££££



42%

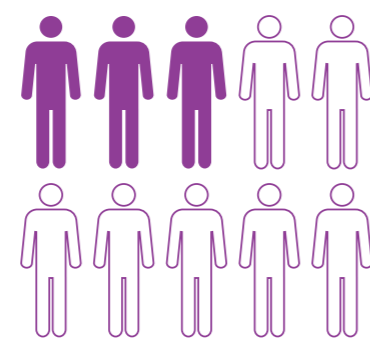
say PH has caused them **to fall into debt.**

18%



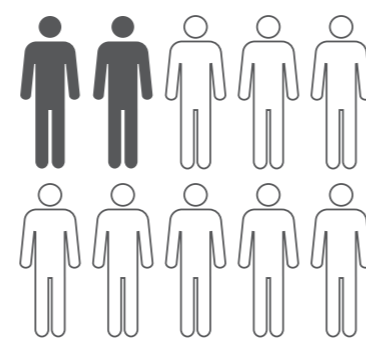
Sold belongings or their house.

30%



Borrowed from bank or on a credit card.

22%



Borrowed from family or friends.



54%

say this debt has **affected their mental/emotional well-being.**



*I've worked since coming out of school and it's now daunting that I want to live for as long as I can, **but am I going to be able to afford to live? Am I going to lose everything I've worked all my life for?***





Breathless not voiceless...

The Venables

Jayne

■ ■ I take oxygen 16 hours a day and I have IV medication with horrendous side effects that can knock me out for days. I have to use a wheelchair to leave the house. The symptoms and side effects are constant; they never go away, which is why I can't work.

When I was diagnosed with PH I was working in my parents' family business. I gave up work immediately as I was so ill I could barely walk 20 feet. I've had to claim benefits ever since. I didn't even know where to start with them. Even now, it's a minefield and I'm baffled by it half the time.

Liam is my full-time carer as well as my husband so we've gone from two incomes to living off the state.

I've had to borrow money from my parents, my sister, even my teenage kids. I don't want to borrow from anybody, but what choice do I have? We had savings, but they are gone. All credit cards are maxed out.

There are hidden costs to having PH. We have to pay more for heating as I'm at home and cold all the time. The gas bills through the winter are horrendous. Then there's the cost of prescriptions, and petrol to and from hospital appointments.

There are things you can get to help you live day-to-day, such as grabbers to pick things up of the floor, but that's another £20. It doesn't sound like much, but when you've got hardly anything coming in, it is. Even though I've been awarded benefits, I'm always aware that they could be removed at any time.

There's a real lack of understanding amongst decision-makers and assessors. They see the word 'hypertension' and think it's high blood pressure. They look surprised when I come into the interview room in a wheelchair, with an oxygen tank, and an IV line coming out of my body.

The more we can promote understanding, eventually, hopefully, we might get through to them. PH needs to be classified as a condition as serious as cancer. ■ ■

Liam

■ ■ When Jayne was diagnosed with PH I was working full time as a bus driver. Her diagnosis knocked us all sideways. My work situation changed quite drastically and very quickly as I needed so much time off to care for my wife that I was sacked.

We panicked. We had a house, a car to run, two kids, what would we do?

I tried signing on but was told I wasn't entitled to anything. In the end the only option was to become Jayne's full-time carer.

To go from two incomes to nothing in the space of a few weeks was very difficult for us all to get our heads around. It was very stressful and resulted in me having a breakdown.

We are very careful with budgeting. We provide for the kids and would rather go without ourselves to make sure they are ok. The things we used to do, we can't do now. We can't afford to go on holiday anymore. Instead we will drive to the coast and sit in the car with some chips. That's how we enjoy ourselves now.

Most of my clothes are from the charity shop, or hand-me-downs from my 16-year-old son.

If we could work, things would be a lot different. We're just trying to keep our heads above water now. ■ ■

Lucy, 14

■ ■ It's quite difficult because we can't do the things that normal families do, like going on holidays or days out. **It's difficult to explain but finances have so much to do with what we can and can't do.** Going out is so difficult now because we can't afford it. Sometimes my mum and dad ask to borrow money from me and I feel as though it shouldn't have to be like that. ■ ■

■ ■ The financial implications of the condition have brought **a lot of stress to the family.**

■ ■ Jayne Venables
50, Kent, diagnosed with PH in 2014

I've always been independent but now I'm apologising all the time because I'm a burden financially.

We are appreciative to Bayer plc for an unrestricted grant to support the production of this report and its dissemination. Bayer plc have had no participation in the initiation of the survey nor data collection or influenced the methodology of the survey.

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Pulmonary Hypertension Association UK

PHA UK Resource Centre, Unit 1, Newton Business Centre,
Newton Chambers Road, Thorncliffe Park, Chapeltown, Sheffield, S35 2PH

Tel: 01709 761450 Email: office@phauk.org Website: www.phauk.org

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To view the full financial impact report email office@phauk.org