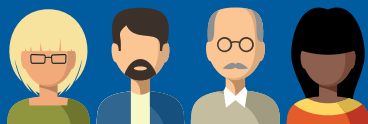


LIVE

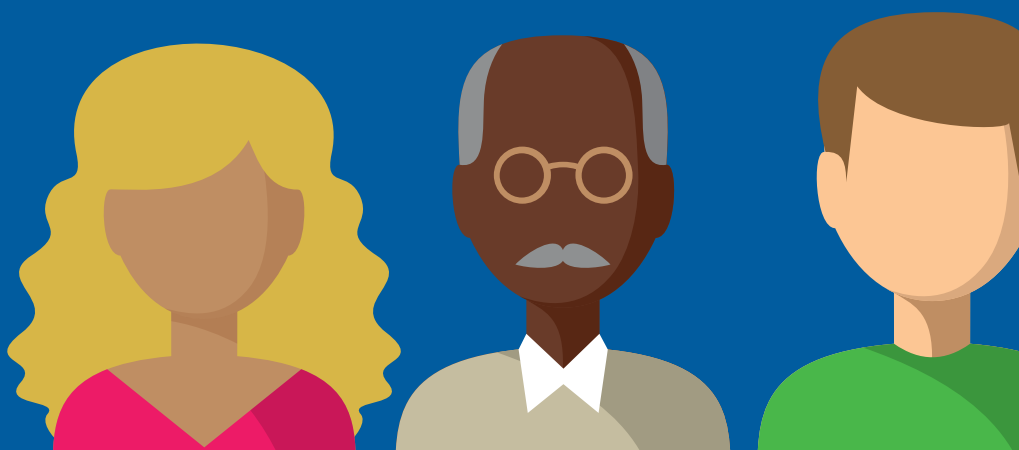


BETTER
WITH **PH**

THE EVIDENCE | 2019

Beneath the surface

*The true emotional
impact* of pulmonary
hypertension.



The true emotional impact of PH.

Pulmonary hypertension comes with many challenges, and not all are physical. Of those who responded to our 2017 Living with PH survey, 87% said the condition impacts their mental and emotional wellbeing – and we wanted to know more.

This follow-up research drew 498 responses, the second highest ever response rate to a PHA UK survey. This number in itself tells us how important the subject is.

The results we bring you in this report are powerful, but not surprising. We have always known that pulmonary hypertension affects mental and emotional wellbeing, and these findings now provide vital statistical evidence.

The survey also provided space for people to leave comments about their personal experiences, and you'll see some of them running throughout this report.

As a patient organisation the PHA UK has long recognised that our members have emotional needs too. That's why, in 2012, we partnered with Anxiety UK to provide a specialist helpline service that enables those struggling to access advice and support. You can find out more about this on page 15.

Thank you to everyone who gave their voice to this survey.

Mental health and emotional wellbeing is being talked about more and more, and the stigma is starting to lift. For people affected by PH, we hope this research will show them they are not on their own.



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



MORE THAN NUMBERS AND STATISTICS.

To bring the findings to life, we filmed interviews with five PHA UK members, and their loved ones, to highlight their personal experiences of the emotional impact of PH.

You can see the films by visiting www.PHocus2021.org or the PHA UK YouTube channel.

You can also read their stories within this report.

Knowing that our lives now have to follow a different path affects my husband and I emotionally every day.

Contents

About pulmonary hypertension and the PHA UK	04
About the research	05
The overall impact	07
Paula's story: "I feel very differently about myself since I've been diagnosed."	08
Anxiety and depression	09
Ian's story: "I struggled really hard with an uncertain future."	10
Self-confidence and socialising	11
Alysha's story: "Having PH has knocked my confidence."	12
Isolation and loneliness	13
Our partnership with Anxiety UK	15

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 and Instagram @pha_uk_insta

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.

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

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.

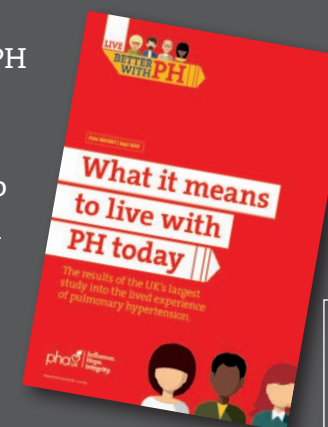


About the research

In 2017, we conducted a major piece of research into the issues affecting pulmonary hypertension patients and their loved ones.

The *Living with PH survey* showed that the effect of PH on general emotional and mental wellbeing had a major knock-on effect onto overall quality of life – and we wanted to know more.

We conducted this follow-on survey into emotional wellbeing during the summer of 2019, asking questions about anxiety, depression, self-confidence, socialising, isolation and family roles. The survey was mailed to all members of the PHA UK and it was also available online – meaning it could be accessed by anyone with pulmonary hypertension.



498

responses were received – the second biggest response to a PHA UK survey

114

people completed the survey online and the rest were sent through the post



"I feel very scared sometimes and I am self-conscious about what I have."

76%

of respondents were female

24%

of respondents were male

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
○○○○○○○○↑↑↑



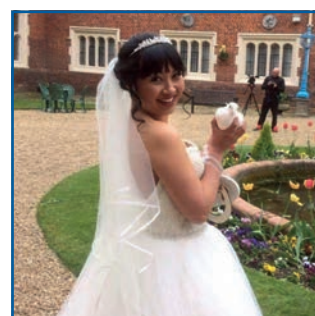
The average age
of a PH patient
in this study is
59 YEARS



The average age
at diagnosis is
53 YEARS



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

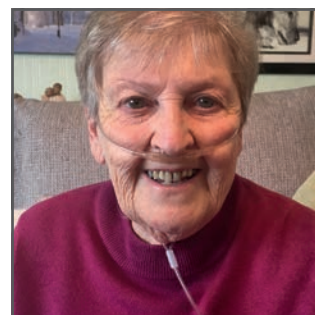
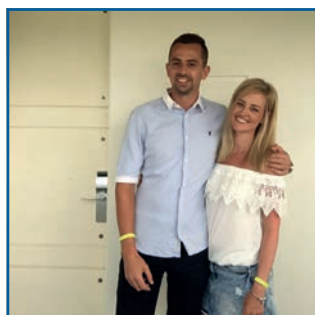


59%

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

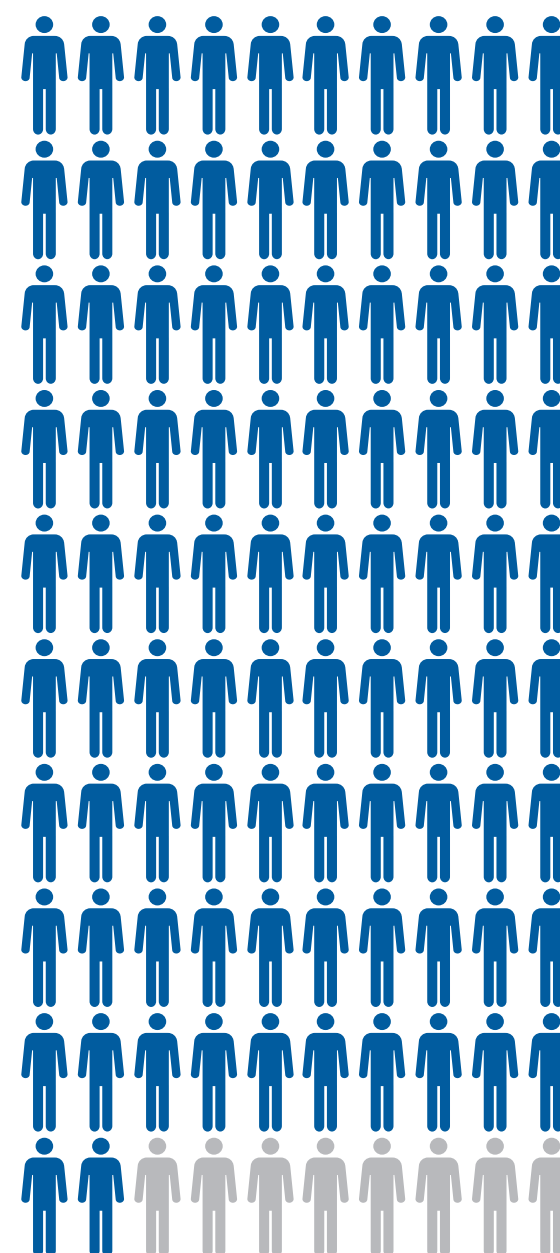
They include 15% with congenital heart disease...

...and 11% with connective tissue disease.



92%

of people with PH say the condition has affected their emotional wellbeing.



My self-esteem has gone, and my dignity has disappeared.

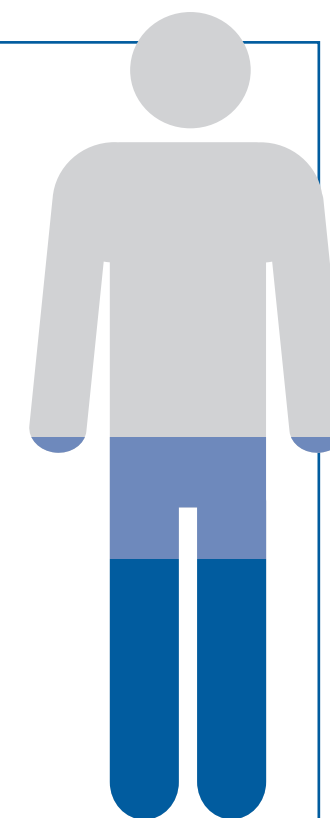


15%

said it has affected it 'drastically'

33%

said it has affected it 'a lot'



Paula Hartley

diagnosed with PH in 2007

Until you've walked in the footsteps of someone with PH, you're never going to know what it's fully like.

PH has affected me emotionally in a lot of ways. I was quite a strong person, and I still sometimes see myself as a strong person, but it did get really bad to the point where I started thinking about harming myself. That's when I got counselling, which helped tremendously.

You feel a burden to your family and to yourself. I get frustrated with myself because I can't do the things that I want to do, and it all just gets on top of me. **Sometimes I think, why bother?**

Why bother putting everyone through this? I can see it affecting other people's lives, not just mine.

PH has had a massive effect on my social life. My husband and I used to run pubs and were always going out, but now we hardly do anything.

I feel very differently about myself since I've been diagnosed. I feel that I am not the full person I was before because I would do anything and go anywhere, but I feel that has been taken away from me now.

I feel very lonely. Although people might know

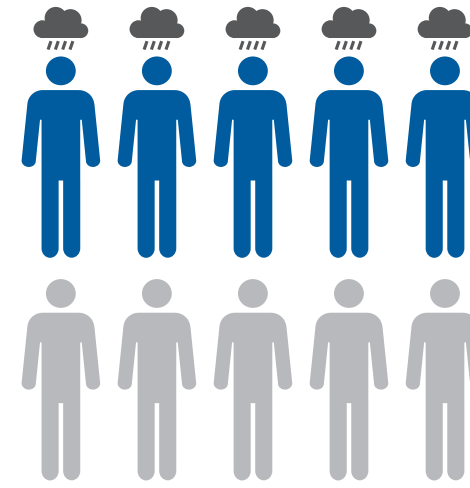
what the illness is, I don't think many know how it makes you feel. Until you've walked in the footsteps of someone with PH, you're never going to know what it's fully like.

My one-year-old granddaughter has really helped my mental health. It's an unconditional love. She obviously doesn't know anything about my condition, she just wants her Nanan, which is wonderful. **My family is so important.**

Ian Hartley, Paula's husband

"It's been really hard. Before Paula had PH we used to go out all the time; now our social life has really changed. It really gets her down sometimes and she normally cries when she talks about PH.

Sometimes I have to make her come out with me. **I get upset, and then she gets upset.** But what can I do? I can't do much, can I?"



53%

of people diagnosed with PH have experienced or been diagnosed with **anxiety or depression.**

#BreathlessNotVoiceless

I am ***anxious, depressed*** and have lost all confidence.



I have ***extreme anxiety about my prognosis*** and whether I will leave my husband and children.



58%

of those who have experienced or been diagnosed with anxiety or depression have **asked for professional help.**

Ian Briggs

diagnosed with PH in 2015

I had massive anxiety and flashbacks.

My route to diagnosis was a slow process; it took about three years and ended up with me in an intensive care unit with multiple organ failure, unable to breathe, and being told I had a 50/50 chance of survival. It was literally the toss of a coin whether I would live the next few days.

There was the prospect of my daughter growing up without a dad. And that still could happen, because it's an awful disease – **you just don't know how long you have left.**

I struggled really hard with an uncertain future and ended up having two-and-a-half years of therapy for Post-Traumatic Stress Disorder (PTSD) and anxiety, which was a direct result of everything that happened in hospital. **I had massive anxiety and flashbacks, and I was unable to sleep.** Every night for at least a year, I worried about stopping breathing in my sleep. I felt like I didn't want to burden people with all this though. Do you actually want your partner to know you're scared to sleep because you are worried you're going to die? Do you want to tell your parents or friends that?

Through the therapy I realised I was grieving, for my life before and everything I could do.

My whole world had been turned upside down, like a snow globe.

The thing I still struggle with today, even after going through all the therapy, is anxiety around my health. I also have anxiety around medical procedures; it's very easy to become overwhelmed and literally go to pieces.

Having PH has left me disappointed more than anything. **I feel cheated.** Cheated out of my life, and disappointed with how things have turned out.

#BreathlessNotVoiceless



70%

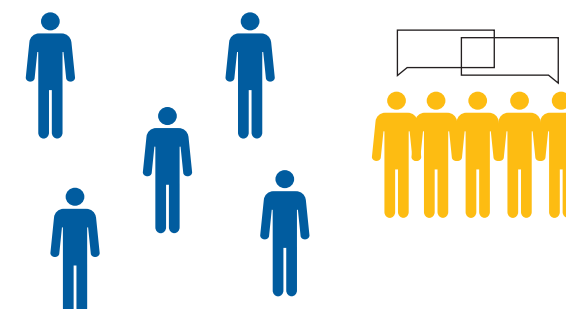
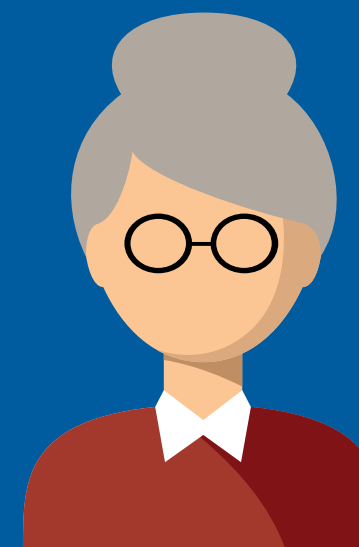
of people with PH say the condition has **lowered their self-confidence.**



PH has affected my self-confidence because I am no longer able to do everything that I used to do.



I lack confidence in doing anything or going anywhere, even with family.



53%

of people with PH say the condition makes **socialising difficult.**

Alysha Sharma

diagnosed with PH in 2018

■ ■ Having PH has knocked my confidence because I can't do as much as I could before. I get quite anxious and nervous if I'm in a big group of people. It makes me not believe as much in myself because I doubt everything I do.

I had a counsellor for quite a long time when I was diagnosed. I felt 'Why me? Did I do something really bad in a past life?' I used to play netball and go to the gym, but **within a year, everything had changed.** I don't go away on holiday with friends, like most people my age. They'd be having a good time, but I wouldn't be able to because of the tablets I'm on, so it's easier that I just don't go.

I massively worry about the future. I've been advised not to have children, which is difficult. As women we are raised to believe we will get married and have children, but I just can't see that happening to me. I'm learning to be more positive about it though; I always say everything happens for a reason, so that's what I'm going to live by.

I've learned that I'm stronger than I think. I've got no other choice but to be determined and positive because **no amount of getting upset or crying will ever take away the condition.** You have to just keep going. ■ ■

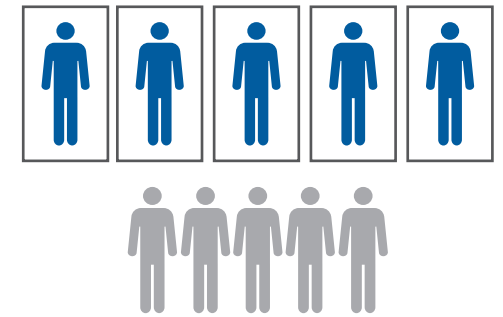
Anita Sharma, Alysha's mum

"Alysha is not as confident as she used to be, and she doesn't push herself as much. A year and half on it is getting better, and we do try and support her as much as we can, but **she's definitely a different person to who she was before she was diagnosed.** I don't feel as strong as I used to be either. I feel like I have to be around Alysha all the time. **I worry about the future and I worry about what she can do now compared to what she used to do.** I worry about when she is sick, and whether it's going to be more serious."



■ ■
I worry about the future.
■ ■

#BreathlessNotVoiceless

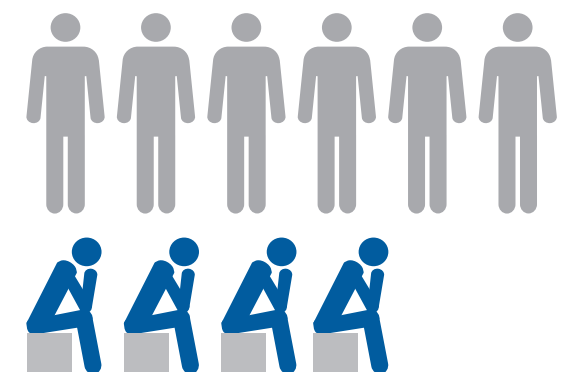


49%
of people with PH say the condition makes them **feel isolated.**

■ ■
*I feel lonely and isolated because at my age (19) my friends are out partying but **most days I'm too exhausted to even leave my bed.***
■ ■



■ ■
*I feel angry and resentful and **I find the future terrifying.***
■ ■



43%
of people with PH say the condition makes them **feel lonely.**

Catherine Makin

diagnosed with PH in 2014

“Emotionally, some days I will feel fine but other days I don’t want to get out of bed. I do have off days where I’ll sit and cry because **I don’t know what the outcome will be.**

Since being diagnosed with PH I’ve learned to toughen up and be positive when I think there is something I can’t do. I became an auntie a year ago and it upsets me that I can’t run around after my niece or walk the dog like I used to. But I’ve found hobbies, such as cross stitch and reading, that make me feel better.

My job (as a nursery nurse) is also very important to me because it gets me out of the house and socialising with colleagues at work. **It gives me something else to talk about, that’s not just my illness.**

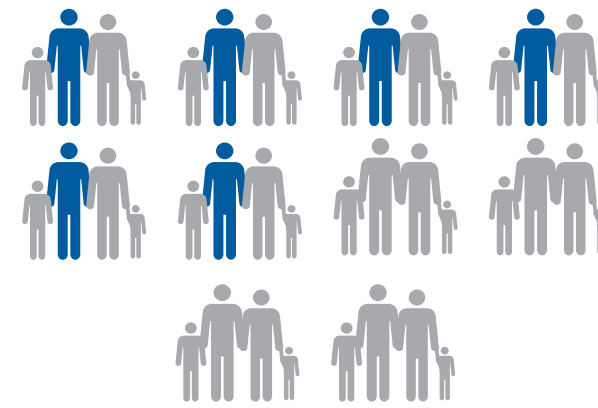


Lou Chadburn

diagnosed with Chronic Thromboembolic Pulmonary Hypertension (CTEPH) in 2012

I go through stages where I think ‘Why me? What have I done wrong in life?’ and I get **upset with myself and frustrated** that I don’t feel I am able to do what I could before. I have to rely on people more than I used to and I am a bit more vulnerable; I don’t like to push myself too much in case something happens.

I view life a lot differently since I became ill. I have good days and bad days, but when I get down, I thank my lucky stars that I am still here.



58%

of people with PH say the condition has **changed their role in the family.**

#BreathlessNotVoiceless

I feel guilty for the worry I’m causing my family,



Are you struggling with stress or anxiety?

Help is available to members of the PHA UK if you or your family have concerns about your emotional wellbeing

- Dedicated helpline service 0344 332 9010
- Email support via phauk@anxietyuk.org.uk
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

www.anxietyuk.org.uk

AnxietyUK

PHA UK
TRUSTED
Partner





*I feel so many emotions
- frustration, sadness,
confusion, devastation...*

Why me?



Copyright to the PHA UK. No part can be used without prior permission nor used without appropriate permission that the PHA UK were the originator for the data.

Pulmonary Hypertension Association UK

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

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

Registered Charity No. 1120756

Published October 2019



The PHA UK have conducted two other surveys in this series. For copies of the reports, email office@phauk.org