

LIVE



BETTER WITH PH

The financial impact of pulmonary hypertension

Our most recent *Living with PH* survey showed that 89% of people living with pulmonary hypertension think that the financial worries linked to their condition have an impact on their lives.

We want to know more, with the ultimate goal of helping people live better with PH.

This is the first time that research has looked specifically at the financial impact of PH, and the results of this ground-breaking study will play a **vital part** in helping us push for change. All responses are **anonymous and confidential**. Please, share your voice and help us stand up for people affected by pulmonary hypertension.

About you

We would like to know a little more about you. All information will be kept confidential.

1. Are you: Male Female 2. What is your current age? _____ Years 3. What was your age at diagnosis? _____ Years

Before your diagnosis

4. What was your employment situation? (Mark all those that apply)

In full time education Working full-time Working part-time Looking for employment
Unable to work for medical reasons At home with children / caring for a loved one Retired

5. Did you live:

Alone With a spouse or partner With children under 18 years old
With children over 18 years old With parents With friends / house share

6. Approximately what **was** your monthly income? (including wages after tax and deductions, and any benefits you were entitled to at the time, eg. child allowance, working tax credit, housing benefit)

£ _____ You £ _____ Your partner*

*Partner' refers to your husband, wife, or partner who lives in the same house as you.

After your diagnosis

7. Approximately what is your monthly income now? (including wages after tax and deductions, and any benefits you are entitled to eg. child allowance, working tax credit, housing benefit)

£ _____ You

£ _____ Your partner

8. Immediately after your diagnosis, how did your working situation change?

	You	Your partner/carer
Continued working as before	<input type="checkbox"/>	<input type="checkbox"/>
Reduced your hours	<input type="checkbox"/>	<input type="checkbox"/>
Taken long-term sick leave	<input type="checkbox"/>	<input type="checkbox"/>
Had to give up work completely	<input type="checkbox"/>	<input type="checkbox"/>
I was not working	<input type="checkbox"/>	<input type="checkbox"/>

9. What is your working situation now?

	You	Your partner/carer
I have continued working as before my diagnosis	<input type="checkbox"/>	<input type="checkbox"/>
I have reduced my hours	<input type="checkbox"/>	<input type="checkbox"/>
I have taken long-term sick leave	<input type="checkbox"/>	<input type="checkbox"/>
I have had to give up work completely	<input type="checkbox"/>	<input type="checkbox"/>
I was not working and am still not working	<input type="checkbox"/>	<input type="checkbox"/>

10. Have you tried to claim any benefit support since being diagnosed with PH? (eg. DLA, PIP, ESA)

Yes No

11. How easy did you and/or your partner find applying for benefit support? (eg. DLA, PIP, ESA)

Very easy Quite easy Quite difficult Difficult Extremely difficult

12. Did the department dealing with your claim understand your diagnosis?

Yes No

13. Was your claim successful first time?

Yes No

14. If no, and you appealed, how many times did you have to appeal until you were successful?

Once Twice Three times I was never successful

15. Did you get what you applied for in the end after appealing?

Yes No

16. If you are in receipt of benefits do you feel embarrassed by it?

Not at all Slightly Embarrassed Very Extremely
embarrassed embarrassed embarrassed embarrassed

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

Yes, at the same hours as before Yes, at reduced hours No

18. If you were employed at the time of your diagnosis, have you ever been given any support from your employer to help you stay or return to work?

Yes No

Costs related to healthcare

19. How many times a month, on average, do you visit a healthcare professional for your PH?

(include visits to GPs, local and specialist hospitals to see a doctor, nurse, blood tests, heart and breathing tests, imaging etc)

GP / local hospital _____ Specialist PH Centre _____ Other _____

20. On average, approximately how much money has it cost you over the last year to visit the healthcare professionals – including travel, parking, any overnight stays (for you or your carer) if needed?

GP / local hospital £ _____ Specialist PH centre £ _____ Other £ _____

21. Since your diagnosis of PH do you spend the same, extra or less on the following items than before?

	Extra	Same	Less	N/A
Help around the house or garden (eg. cleaner / gardener)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gas / Electric	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General travel costs (eg. to get to shops, see friends, get to work – not including hospital and GP visits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Household bills (excluding gas and electric)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Childcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food costs/ special diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Insurance costs

22. Since your diagnosis, have you applied for life or travel insurance?

Yes No

23. How easy did you and/or your partner find applying for insurances?

Very easy Quite easy Quite difficult Difficult Extremely difficult

24. Since your diagnosis, have you been refused insurance?

Yes No

25. Have insurance quotes been similar / greater/ lower than before diagnosis?

Similar Greater Lower

General costs

26. Since being diagnosed, for financial reasons, have you had to... (please tick all that apply)

Take money from your savings

Cash in part or all of your pension

Borrow from your bank or building society
(loan / overdraft)

Take out a credit card

Take out a payday loan

Borrow what you consider a significant amount
from your parents

Borrow what you consider a significant amount
from your children

Borrow what you consider a significant amount
from your friends

Claim on health insurance

Sell some of your belongings to help pay for
household bills

Sell your house (for financial reasons
caused by your illness)

Visit a food bank

Miss picking up a prescription due to cost

Miss a hospital appointment due to the cost
of travel or parking

27. Overall, since being diagnosed, do you feel you have more difficulty paying bills?

No
difficulty

A little
difficulty

Some
difficulty

Much
difficulty

Extreme
difficulty

28. Overall, after being diagnosed with pulmonary hypertension my financial situation has:

Improved
a lot

Improved
a little

Remained
the same

Declined
a little

Declined
a lot

29. Has your condition caused you to fall into debt?

No

A little

Some

A lot

Worrisome amount

30. If your financial situation has declined, has this affected your mental / emotional wellbeing?

Not at all

A little

At times

A lot

Severely affected

31. Have you ever accessed or felt the need to access counselling / emotional support (eg. cognitive behavioural therapy or similar) as a result of concerns over your financial situation?

Yes

No

If you would like to add any comments relating to how pulmonary hypertension has affected your finances, please do so below (continue on an additional sheet if needed).

Please be assured that the information you provide in this survey will not be shared and will be destroyed once it has been used to input data.

Are you happy for us to contact you in order to clarify any of your responses? Yes No
If so, please provide your contact details below (there is no obligation to do this).

A THANK YOU FROM US. Would you like to enter our draw for a chance to win one of 150 £10 Love2shop vouchers? Yes No (www.highstreetvouchers.com)
If so, please provide your contact details below so we can contact all the lucky winners.

Name Telephone

Email

Thank you for your time. By sharing your experiences, you are helping us to support others affected by pulmonary hypertension.

Pulmonary Hypertension Association UK

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