

Understanding adult congenital heart disease and pulmonary hypertension information needs

Report published April 2024

CAREGIVER SURVEY

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The PHA UK has teamed up with a group of specialist doctors to develop new information resources to help people living with pulmonary hypertension (PH) associated with congenital heart disease (CHD).

Some people born with heart problems (known as congenital heart disease) go on to develop PH, and at present, there are limited information resources available that are specifically aimed at these individuals.

At the end of 2023, we conducted a survey amongst both patients and caregivers to identify knowledge gaps and understand what is needed from new resources.

The questionnaire was promoted both online and within treatment centres, and it was completed by **177 patients and 33 caregivers**.

This report contains the key findings from the survey conducted amongst caregivers.

This work is being carried out by the PHA UK in collaboration with the **CHAMPION** group, which stands for **C**ongenital **H**eart disease **A**nd **pulM**onary arterial **hyP**ertension: **I**mproving **O**utcomes through education and research **N**etworks.

The group is made up of clinicians specialising in the management of pulmonary hypertension (PH) and of congenital heart disease (CHD) from a number of specialist centres in the UK. As the name suggests, their aim is to help improve the management of patients with PH due to CHD through research and education.

THE KEY FINDINGS FROM OUR SURVEY: **CAREGIVERS**

33 people who provide care for someone with PH and CHD completed our online survey.

ABOUT THOSE WHO RESPONDED

79% of respondents' loved ones have been diagnosed with PH for over 3 years

67% of respondents' loved ones are female

85% of respondents' loved ones are white

33% of respondents' loved ones have Down Syndrome

79% view their CHD and PH as a combined issue (21% view them as separate issues)

30% receive treatment at a specialist PH unit only

15% receive treatment at a CHD unit only

55% receive treatment at both a PH and a CHD unit

ADVICE FROM MEDICAL PROFESSIONALS

Only 7% of respondents said they have been told, by a medical professional, what symptoms may suggest endocarditis (an infection of the inner lining of the heart).

No respondents said they have been told, by a medical professional, what symptoms may suggest a brain abscess.

Just over half of respondents (57%) said they have been given advice, by a medical professional, regarding flying in an aeroplane.

TRUE OR FALSE?

Vigorous physical activity is recommended for all PH patients

5% answered 'true'

75% answered 'false'

21% answered 'not sure'

THE TRUTH = Many studies have shown the benefits of exercise in patients with PH, especially once established on PH medications. However, it is recommended that patients exercise to a moderate intensity. If they develop severe breathlessness or dizziness then they are exercising too much.

A sedentary lifestyle is recommended for all PH patients

4% answered 'true'

86% answered 'false'

11% answered 'not sure'

THE TRUTH = As above, a number of studies have demonstrated improved outcomes in patients who keep active.

People with PH should not drink any alcohol

14% answered 'true'

50% answered 'false'

11% answered 'not sure'

THE TRUTH = There is no specific reason why moderate alcohol intake, within the UK government recommended safe amounts, should be avoided. As is the case for all of us, excessive alcohol intake is not recommended.

It is dangerous for a woman with CHD and PH to become pregnant

61% answered 'true'

7% answered 'false'

32% answered 'not sure'

THE TRUTH = Pregnancy places extra demands on the heart and many patients with PH in association with CHD therefore do not tolerate pregnancy well. It is therefore strongly recommended that patients with PH and CHD do not become pregnant.

Approximately **92%** of respondents, who provide care to a female and of child-bearing age, said they have been advised by a medical professional about the need for effective contraception.

89% of respondents believe PH is associated with *increased pressure* in the pulmonary arteries. **11%** believe it is associated with *decreased pressure*. ('Increased pressure' is correct)

INFORMATION AND RESOURCES

Only 8% of respondents said they were given specific educational material on PH associated CHD, at the time of diagnosis. (38% said ‘can’t remember’)

93% of respondents agree there is a need for new information resources regarding PH in associated with CHD (of which 19% ‘strongly agree’)

These are the top 5 topics respondents said they would find most important (in order of importance)

- 1 - **How congenital heart disease and PH affect the body**
- 2 - **Treatment for PH, including side effects**
- 3 - **Symptoms that might suggest a problem with my PH**
- 4 - **Measures to prevent complications from my CHD**
- 5 - **Lifestyle advice to stay as well as possible with PH and CHD**

Respondents told us they would like new information resources to be produced in the form of printed booklets or leaflets, online web pages, and video or audio tools.

The next steps...

Our findings show there is a clear unmet need for information that focuses on the combined issues of PH and CHD. We'll be gathering more insight to help us shape these resources by holding an online focus group with patients and caregivers, ensuring the materials we produce fully meet the needs of those affected by these conditions.

We are grateful to everyone who completed our survey.

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