

# LIFTING THE LID ON NUTRITION AND PH:

*What people with pulmonary  
hypertension told us about  
their food habits, choices,  
and challenges...*

**FULL SURVEY FINDINGS**

*Report produced April 2024*

**607**

responses received

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## LIFTING THE LID ON NUTRITION AND PH:

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Pulmonary  
Hypertension  
Association UK

## An appetite for sharing thoughts and experiences...

We were unsure of the response to expect when we launched our survey into nutrition and PH. Would people be interested in telling us about their eating habits, food preferences, and cooking or weight management challenges? Would they be willing to share the areas they feel they need support in?

It turned out that many were, with a total of over 600 responses to our questionnaire – which was the first of its kind in the UK.

As well as statistics, this report shares some of the comments left by respondents, painting an enlightening picture of PH and nutrition in the UK.

The high response number shows how much people with PH care about this topic, and how much appetite there is for support.

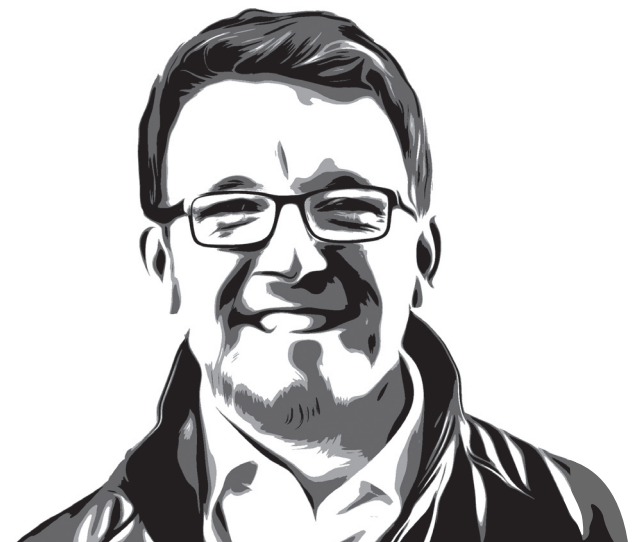
***“I’m glad you are doing this survey and I’m glad to help.”***

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*“Thank you to everyone who shared their thoughts and experiences in this first-of-its-kind research. We responded quickly to the findings and we will continue to build upon our work to support people with PH to enjoy the benefits of good nutrition. We understand the challenges that people face in this area, and we’re here to help. Watch this space!”*

### **SHAUN CLAYTON**

*Certified Nutritionist,  
Director of Finance and Operations,  
PHA UK*



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## ABOUT THE RESEARCH

The PHA UK developed the survey in collaboration with Registered Dietician Chermaine Kwant, and Professor David Kiely, Director of the Sheffield Pulmonary Vascular Disease Unit.

It aimed to understand the eating habits, food choices, and challenges facing people living with pulmonary hypertension in the UK, to inform the development of supportive tools and resources.

Responses were collected between March and June 2023. The survey was available to complete online, and paper copies were included in the Spring 2023 issue of our member magazine.

**607** responses were received

**331** people completed the survey online, and **276** people filled out the paper questionnaire

***“Food is one of my few pleasures left, if I don’t follow dietary rules it’s because I choose not to.”***

*“It was a pleasure to support the development of this pioneering survey, which has produced really interesting results. As someone who has lived with pulmonary hypertension, I’ve experienced first-hand the difference that good nutrition can make. I’m looking forward to continuing my partnership with the PHA UK to support people with PH to live well, using these survey results as the foundation.”*



### **CHERMAINE KWANT**

*Registered Dietician, researcher, and former PH patient (Chermaine underwent a double lung transplant in 2016, five years after being diagnosed with pulmonary arterial hypertension).*

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## ABOUT THOSE WHO COMPLETED THE SURVEY

### Respondents have the following types of PH:

Idiopathic Pulmonary Arterial Hypertension (IPAH) - **29%**

Heritable Pulmonary Arterial Hypertension (HPAH) - **2%**

Pulmonary Arterial Hypertension in association with Systemic Sclerosis - **11%**

Pulmonary Hypertension in association with congenital heart disease - **16%**

Pulmonary Hypertension due to lung diseases - **8%**

Chronic Thromboembolic Pulmonary Hypertension (CTEPH) - **26%**

Other - **2%**

*"I don't know what type of PH I have"* - **5%**

### Ages of respondents:

**74%** identify as female

**26%** identify as male

## EATING DISORDERS

**4%** of respondents say they have been diagnosed with, or suspect they may have, an eating disorder.

*The eating disorders identified included binge eating and emotional eating, anorexia, and bulimia.*

## DIETARY HABITS

The vast majority of people with PH do not have dietary restrictions.

### Respondents follow these specific diets:

Vegetarian - **3%**

Pescetarian (eat fish, but not meat) - **2%**

Vegan / plant-based - **1%**

Coeliac / gluten-free - **4%**

Lactose intolerant - **2%**

Other - **5%**

**82%** say they don't follow any specific diet

### **How does this compare with the general population?**

*According to YouGov data\*, 5-7% of the UK's population are vegetarian and 2-3% are vegan.*

\* <https://yougov.co.uk/topics/society/trackers/dietary-choices-of-brits-eg-vegetarian-flexitarian-meat-eater-etc>

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**This is how often respondents eat processed meat (eg. sausages, burgers, chicken nuggets):**

Daily - **4%**

3 times a week or more - **10%**

Once or twice a week or less - **72%**

Never - **13%**

**This is how many meals respondents eat per day:**

1 - **7%**

2 - **28%**

3 - **63%**

4 - **2%**

**This is how many unhealthy snacks (eg. crisps, chocolate, biscuits, cereal bars) respondents typically eat per day:**

0 - **2%**

1 - **45%**

2 - **33%**

3 - **11%**

4 - **2%**

**This is how many portions of fruit respondents typically eat per day:**

0 - **12%**

1 - **28%**

2 - **35%**

3 - **15%**

4 - **6%**

5 or more - **4%**

**This is how many portions of vegetables respondents typically eat per day:**

0 - **4%**

1 - **19%**

2 - **31%**

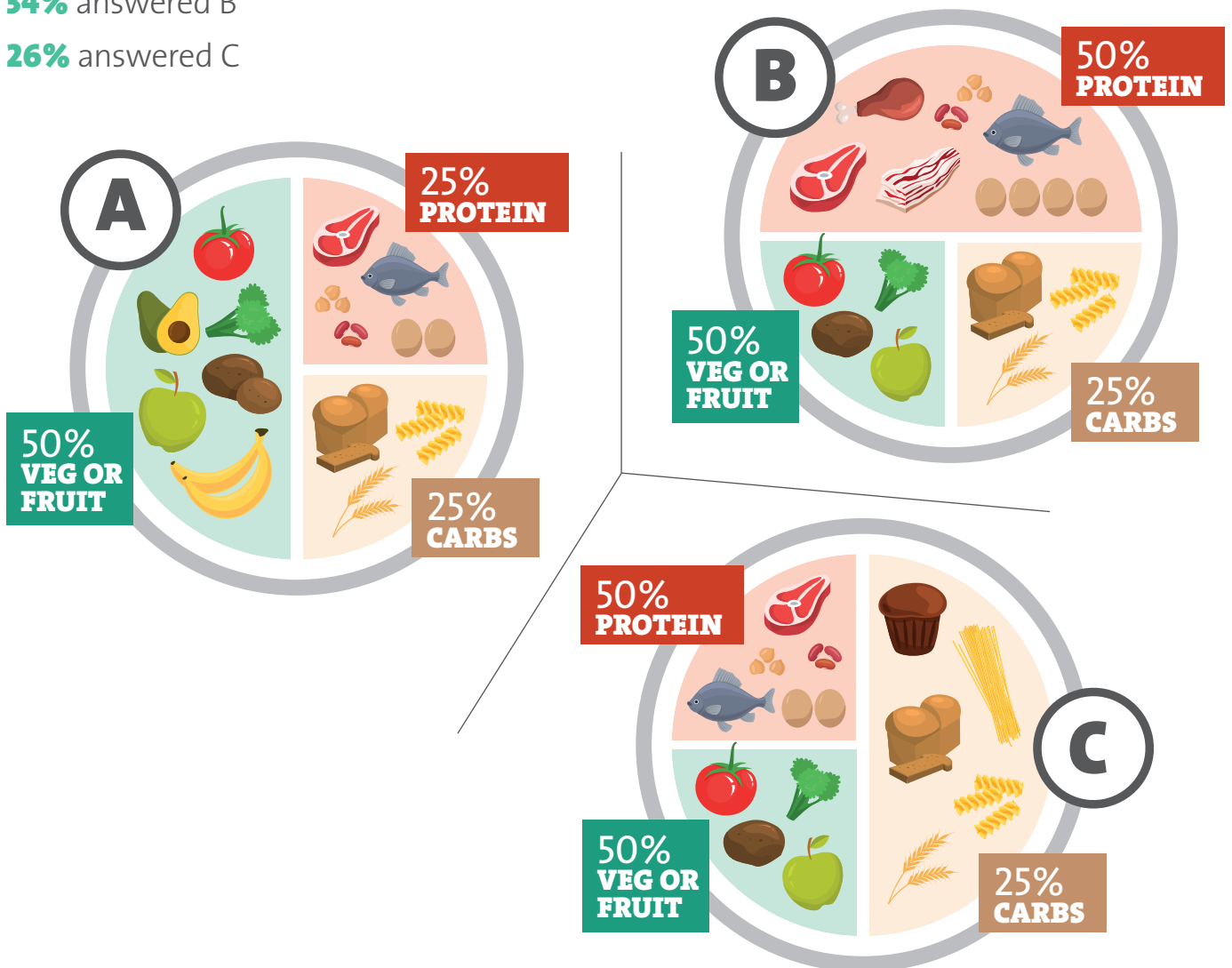
3 - **28%**

4 - **9%**

5 or more - **9%**

## The plate respondents said looks most like theirs when having a main meal:

- 40%** answered A
- 34%** answered B
- 26%** answered C



## ALCOHOL CONSUMPTION

Over a third of people with PH never drink alcohol.

### This is how often respondents have an alcoholic drink:

Never - **35%**

Once a month or less - **22%**

2 to 4 times a month - **16%**

2 to 3 times a week - **18%**

4 or more times a week - **9%**

### This is how many units of alcohol respondents consume in a typical week:

*(Large glass of wine = 3 units,  
pint of lager = 3 units,  
single measure of gin = 1.4 units)*

Never - **45%**

3 or less - **22%**

4-6 - **9%**

7-14 - **11%**

15-21 - **4%**

22-30 - **3%**

Over 30 - **1%**

### *How does this compare with the general population?*

*A 2021 NHS Digital survey\* showed that 21% of adults had not drunk alcohol in the last 12 months. 49% reported that they drank alcohol at least once a week.*

*\*<https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2021/part-3-drinking-alcohol>*

***“I could do with reducing alcohol intake but I don’t.”***

***“Ticking ‘healthy’ doesn’t take account of the daily red wine in the evening.”***

## COOKING / FOOD PREPARATION HABITS

### This is how often respondents eat pre-packaged foods:

Daily - **4%**

A few times a week - **19%**

Once a week - **23%**

Less than once a week - **55%**

### This is how often respondents eat home-cooked meals:

Daily - **63%**

A few times a week - **24%**

Once a week - **4%**

Less than once a week - **9%**

### This is how often respondents eat takeaway ('fast food' like pizza and burgers)

Daily - **0.5%**

A few times a week - **5%**

Once a week - **20%**

Less than once a week - **39%**

Monthly - **36%**

### This is how often respondents eat out in a restaurant or café:

Daily - **0.2%**

A few times a week - **5%**

Once a week - **16%**

Less than once a week - **38%**

Monthly - **41%**

### This is who usually does the cooking or meal preparation in their home:

The person with PH - **60%**

Someone they live with - **35%**

Someone else - **6%**

### At mealtimes in your home, does everyone usually eat the same meal, or do different ones need to be prepared for different people?

We both / all tend to eat the same - **63%**

Different people have different meals - **18%**

Other - **2%**

N/A - **18%**

*21% of people with PH told us they live alone, which may influence the statistics in the section above.*



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## FOOD SHOPPING HABITS

**68%** of people with PH buy most of the food in their household (16% said 'someone I live with does', 16% said 'someone else does')

**22%** do the food shopping mostly or always online

**58%** do the food shopping mostly or always in person

**20%** buy food as a mixture of both online and in-person

**88%** of people with PH buy most of their food from supermarkets. 9% buy most of it from markets

**2%** of households with PH buy food daily

**36%** buy food a few times a week

**55%** buy food weekly

**7%** other

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## THOUGHTS ON DIET

The majority of people with PH think changes need to be made to their diet.

**63%** of people with PH say they generally eat well but they could make some improvements

**24%** of people with PH say they have a healthy diet

**13%** of people with PH say they need to make significant changes to their diet

➤ This shows that there is a need for help and support in this area.

***“I’m a believer in food as a cure, but I don’t have time, money or motivation.”***

***“I’m capable of cooking but by the end of the day exhaustion can prevent me doing it.”***

## LIFTING THE LID ON NUTRITION AND PH:

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## THE CHALLENGES FACED

We asked people with PH what stops them from eating as well as they would like to. 375 people replied to this question, and of these...

**37%** cited 'The cost of healthy food'

**5%** cited 'Cooking skills'

**26%** cited 'PH symptoms (*eg. fatigue or strength limitations*) preventing me from cooking'

**8%** cited 'Lack of interest in cooking and nutrition'

**26%** cited 'Motivation or willpower to make changes'

...as the main cause of them not eating well

## More free text comments about what is stopping people with PH eating as well as they would like to:

***"I feel full after eating small amounts, swallowing issues. Fatigue and breathless issues so expend less energy, eat less."***

***"Too tired at the end of working day to try new recipes."***

***"I'm severely visually impaired, it prevents me from cooking."***

***"Loss of appetite when I see the food on the plate."***

***"Limitations due to PAH and age for cooking."***

***"Complete lack of interest in food or cooking. Side effect of PH drugs. What goes in comes out fast, diarrhea and sickness."***

***"I'm capable of cooking but by the end of the day exhaustion can prevent me doing it."***

***“Sometimes fatigue makes standing and cooking difficult.”***

***“When I’ve eaten I need to be nearer a toilet so if I’m going out I postpone eating.”***

***“Laziness”***

***“Multiple health issues severely limit my ability to cook.”***

***“I’m not interested to cook as I live alone.”***

***“I cook in stages due to fatigue. Prepare, rest then cook.”***

***“I have to prepare food then rest, then finish cooking. Prefer to cook myself with fresh food.”***

***“Rewarded as child with sweets. Lack of willpower now, completely ashamed of myself.”***

***“I have complete lack of taste and smell, loss of appetite, no enjoyment.”***

***“It’s difficult to be motivated to cook for one.”***

***“Sometimes I have no energy to cook but I actually love cooking.”***

***“When CTEPH is bad I am too fatigued to cook.”***

***“Acid tummy, hernia reflux.”***

***“I have digestive issues due to systemic sclerosis, so knowing which foods to eat without being near a toilet is difficult.”***

***“Working long hours, no motivation to eat well, just want quick access to food.”***

***“I like a few treats now and again. Not concerned that they may affect health.”***

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### What people feel they eat too much of:

**32%** of people with PH feel they eat too much sugar

**17%** of people with PH feel they eat too much salt

**13%** of people with PH feel they eat too much fatty foods

**30%** of people with PH feel they eat too many snacks / processed food

**8%** people with PH feel they eat too much red meat

**18%** of people with PH feel they eat too many dairy products

### What people feel they don't eat enough of:

**41%** of people with PH feel they should eat more fruit

**32%** of people with PH feel they should eat more vegetables

**18%** of people with PH feel they should eat more fibre

**3%** of people with PH feel they should eat more dairy products

**5%** of people with PH feel they should eat more calcium-enriched products (non-dairy)

**14%** of people with PH feel they should eat more protein (fish, meat, eggs)

**8%** of people with PH feel they should eat more vegetarian or vegan protein

### The connection between nutrition and physical and mental wellbeing is recognised by some people with PH:

**39%** of people with PH agree that when they eat well, they have more energy / feel happier

**18%** of people with PH agree that when they eat badly, they notice they feel worse

**24%** of people with PH agree that when they don't eat enough, they lack energy

**29%** of people with PH agree that when they eat too much, they feel bad

***"I turn to comfort food on a sad day."***

➤ Our work will aim to help people feel better by eating well.

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## THOUGHTS ON WEIGHT

Almost half of those with PH want to reduce their weight.

**41%** of people with PH would like to lose weight

**15%** of people with PH have been advised to lose weight by a healthcare professional in the last 12 months

**7%** of people with PH would like to gain weight

**6%** of people with PH have been advised to gain weight by a healthcare professional in the last 12 months

**47%** of people with PH are generally happy with their weight

➤ Our resources and support will address both of these goals.

## AREAS THAT PEOPLE FEEL THEY NEED THE MOST HELP OR SUPPORT WITH

We asked people with PH to rank the following in order of what they feel they need the most help or support with, and this is the order of importance they chose:

- 1.** Understanding how nutrition can influence my PH symptoms  
**(53% put this top)**
- 2.** Weight management (gaining, losing, or maintaining weight)  
**(24% put this top)**
- 3.** How to prepare nutritious food without using too much energy  
**(10% put this top)**
- 4.** How to eat well on a budget  
**(8% put this top)**
- 5.** How nutrition can improve my quality of life  
**(7% put this top)**
- 6.** Understanding more about nutrition in general  
**(5% put this top)**

## **Other areas people told us they need help with: (free text)**

***“I need more ideas for different meals.”***

***“Anything available to stop me eating when full would transform my life.”***

***“I would like more information on diet and how it affects my breathing.”***

***“The willpower, skill and energy to cook.”***

***“Making nutritious meals on a budget.”***

***“It would be great to know what foods should be avoided with PH.”***

***“I would like to know if meds make a difference to weight loss.”***

➤ These responses will help us to prioritise the subject matter of our support materials.

## **HEALTHCARE AND DIET**

**Do your PH medications, or their side effects, influence your food choices or meal timings?**

A selection of the answers to this question...

***“Diuretics interrupt mealtimes.”***

***“Digestive issues, need to take meds with/after food.”***

***“Meds dictate when I eat and drink.”***

***“Meds influence timings and choices. Soft food for digestion, quantity.”***

***“I’m more dairy intolerant due to mycophenelate. Reflux is an issue.”***

***“PH meds have an impact on digestive issues.”***

***“Need to take meds with food. I restrict dietary intake as can give me upset stomach.”***

***“Need meds on full stomach, which means a bigger breakfast than I like.”***

***“IV can give me an upset stomach and make me nauseous, making eating difficult at times.”***

***“I need anti sickness tabs due to PH meds.”***

***“Meds and copious amounts of water make me lose my appetite.”***

***“Meds cause nausea and bloating. Foods tastes bland, even curry.”***

***“Heartburn is an issue, I need to eat with meds.”***

***“I can digest smaller meals better and prefer to eat slower.”***

***“Water retention.”***

***“Frusemide effects have to be considered when scheduling meals away from home.”***

***“Digestive issues and water retention. I don’t eat after 6pm.”***

***“Digestive issues. I no longer have good appetite.”***

***“I try to take main combinations of drugs at mealtimes. Diuretics between meals...”***

➤ Our support and advice will take all of these things into account, to help people overcome challenges posed by medications in order to enjoy good nutrition.

## ACCESSING HELP AND SUPPORT

**52%** of people with PH said they **would like to receive** nutrition guidance or advice as part of their PH care from their hospital / specialist centre, but **only 10% have received it.**

➤ Here at the PHA UK, our aim is to fulfil this unmet need by providing resources and advice in the areas people told us they need it most.

### Some more of the comments left in response to this survey...

***“I eat balanced meals as I’m conscious what I feed my child. But I eat unhealthy between meals.”***

***“Scleroderma means my mouth is dry and foods get stuck.”***

***“Food has to be soft and digestible.”***

***“I have lost over 4 stone since diagnosis so I could get to transplant weight.”***

***“With trying to work, take meds etc, food comes low in priority.”***

***“Depression around PH means no motivation to eat.”***

***“I’m trying to keep weight on. IBS from meds is exacerbated by fruit and veg.”***

***“I already have a good understanding of what should be done, it’s having motivation and energy to do it.”***

***“I’ve been going to Slimming World to reduce weight, I hope it will help my PH.”***

***“I’m on oxygen 24/7 so not allowed to cook due to fire risk. I use the microwave.”***



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***“I’m almost housebound now so rely on my daughter and good neighbour.”***

***“We know about eating well, we sometimes just can’t be bothered following arbitrary rules.”***

***“Cannot cook for myself due to mobility. Rarely eat out due to mobility and cost.”***

***“Just can’t get excited about food, wish there were 3 pills – breakfast, lunch and tea.”***

***“My energy levels drop after meals.”***

## WHAT HAVE WE DONE WITH THE RESULTS OF THIS SURVEY?

People with PH sharing their thoughts and experiences has already made a big difference!

We acted quickly on the findings of this research by producing advice materials that address the things people told us you need the most support with.

We now have a dedicated nutrition area on our website, housing videos and articles on topics including cooking with fatigue, eating to manage the common side effects of medication, and understanding the basics of energy balance and good nutrition. This valuable online hub will continue to expand.



Access it at

**[www.phocusonlifestyle.org](http://www.phocusonlifestyle.org)**

or scan this code with your mobile phone.



We have introduced a regular 4-page nutrition feature in every issue of Emphasis, our member magazine, and our monthly e-newsletters now include recommended recipes that take into account the specific needs of people with PH.

Work has begun on the production of a series of printed publications addressing the areas people told us they need the most help with, and we will continue to build a library of printed and online resources.

The findings of this survey were presented at the Pulmonary Vascular Research Institute Global Congress, reaching PH researchers and scientists from all over the world.

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## **DO YOU HAVE A QUESTION ABOUT NUTRITION?**

We now have a dedicated email support service for any queries relating to food or nutrition.

Email ***nutrition@phauk.org*** and a Certified Nutritionist or Registered Dietician, experienced in the field of PH, will respond.

*“Good nutrition is not about ‘curing’ PH, but every opportunity to make yourself feel better is a win.”*

**CHERMAINE KWANT**

*Registered Dietician with lived experience of PH*