

## Helping people live well with PH: *The role of palliative care*

*At the PHA UK, supporting people to live well with pulmonary hypertension is one of our main aims – so we would like to help people access palliative care if they would benefit from it.*

*At the end of 2020, we conducted an online survey to find out what PHA UK members already understand about this type of care, so we can ensure we produce the right resources and support. There were 97 responses - a good number considering the subject - and they proved there is a real need for work in this area. These findings will inform the development of resources and support systems that improve quality of life for people with PH and their loved ones too.*

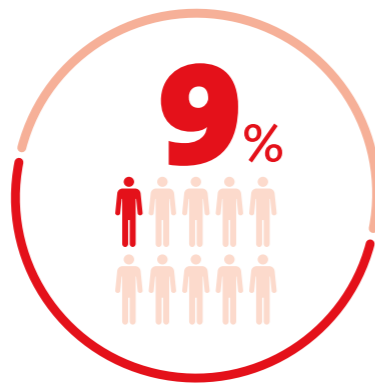
**Thank you to everyone who shared their voice in this survey.**



### TALKING ABOUT PALLIATIVE CARE

**Just 12% have had palliative care discussed with them by their medical team.**

*Those discussions have been with a mixture of GPs, consultants and nurses.*



### ACCESSING PALLIATIVE CARE

**9% of respondents said they had accessed palliative care, with 6% of that number accessing it more than a year ago.**

*This support included assessments, counselling, complementary therapies such as massage, physiotherapy, medication for pain management, home visits and an in-patient stay.*

## PERCEPTIONS OF PALLIATIVE CARE

*We asked which of the following statements respondents thought were true.*

*These results show there are misconceptions about palliative care which may be preventing some people accessing vital help and support.*

**60%** think palliative care is for **anyone with a life-limiting illness.** ✓

**1%** think palliative care is for **people with cancer only.** ✗

**55%** think palliative care is only for **those at the end of their lives.** ✗

**9%** think palliative care means **going into a hospice.** ✗

**17%** think palliative care is **only for the person with the diagnosis.** ✗



### INFORMATION NEEDS

**99%** of respondents said if the PHA UK produced information and resources about palliative care and its role in supporting people with PH they would find this useful or very useful.

### WHAT NEXT ?

*We will be using the results of this survey to create resources that meet the palliative care information needs of people affected by PH. We will also work to challenge misconceptions about this type of supportive care, and liaise with specialist PH teams to encourage more conversations and support routes – with the ultimate aim of helping patients and loved ones benefit from the care that is available.*



*Do you have something you'd like to say about palliative care and PH? We would love to hear your thoughts and experiences to help us with our work. Please contact [paul@phauk.org](mailto:paul@phauk.org) or call 01709 761450.*