

**Note to patients:**  
Should any questions arise from this material, please ask your healthcare professional for advice.




## Living with PAH


### Introduction

Life with a condition such as pulmonary arterial hypertension (PAH) can be transformed in many ways and it can sometimes take time to adjust to these changes.<sup>1,2</sup> Some people with PAH may find that talking to others is a good way of helping them with these readjustments<sup>1</sup> and this card has been developed to help you think about the people and resources you can turn to.


### Example conversation\*

 **Patient** – I'm finding it difficult to cope with my symptoms of PAH at the moment. I get very tired and I feel very upset.


 **Family/Friends** – Tell me more about what it's like.

 **Patient** – I have lots of worries about what will happen in the future and whether my symptoms will get worse.

 **Family/Friends** – Is there anyone who you can talk to?

 **Patient** – I could ask my healthcare team.

 **Family/Friends** – What can I do to help?

 **Patient** – Well, sometimes everyday tasks are difficult to do. There might be times when I'm in hospital when I need help.

 **Family/Friends** – If you let me know what you need, I might be able to help.

### Practical tips for structuring the conversation

PAH can affect people's lives in different ways<sup>2</sup> and there are ways of seeking help and support when and if it is needed, such as:

- Talking to people about how you feel<sup>1</sup>
- Work out who the best person is for you to talk to, such as friends, family, and/or colleagues and always take the advice of a member of your PAH healthcare team<sup>1</sup>
- Thinking about how much you might want to do today or this week<sup>3</sup>
- Thinking about what help or support you might need<sup>1,3</sup>

\*Conversation is based on the personal communication of Dr Vanessa Garratt, Clinical Psychologist at the NHS Trust UK.



## II Emotional wellbeing

- Think about what helps you:<sup>1</sup>
  - Keeping a diary of your feelings/symptoms
  - Talking with friends, other patients affected by the same disease
  - Distraction, e.g., hobbies
  - Going out
- There are many books and information leaflets that offer additional advice and information on living with long-term conditions such as PAH<sup>4</sup>
- There may be particular matters you should discuss with your PAH healthcare team regarding the impact PAH has or may have on your life, such as pregnancy, birth control and sexual intimacy<sup>1,5</sup>

## II Physical wellbeing

- Many people find some form of regular exercise helpful and you should talk to your doctor before considering possible options for exercise<sup>1</sup>
- Some people find yoga, meditation or other activities, such as massage, helpful<sup>1</sup>
- If there are activities that you might enjoy or have helped you in the past, you should discuss them with your PAH healthcare team

## II General wellbeing

- Finding a support network – some people find it helpful to join a group in their area so they can share experiences and help each other<sup>1</sup>
- Ask your PAH healthcare team for information regarding local support groups or patient organisations

## II Practical matters

- Consider if there are any practical matters where you may need advice from your healthcare team, such as managing housework, travel, daily tasks and shopping<sup>1,6</sup>

If you find it becomes difficult to cope with your PAH, contact your PAH healthcare team<sup>2</sup> and patient support organisation – they are there to help you.

### Key references

1. Pulmonary Hypertension Association. *A Guide for the Newly Diagnosed. Dealing with change, loss and the emotional impact of pulmonary hypertension*, PHA, 2012.
2. PHA Europe. *International-PAH-patient-and-Carer-Survey-Report*. 2013; Available from: [www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/](http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/) (Accessed November 2013)
3. Pulmonary Hypertension Association UK. *Day to day living*. [www.phassociation.org](http://www.phassociation.org) (Accessed November 2013)
4. Helping people help themselves. *A review of the evidence considering whether it is worthwhile to support self-management*. Health foundation 2011.
5. Pulmonary Hypertension Association UK. *Pregnancy and PH*. [www.phassociation.uk.com](http://www.phassociation.uk.com) (Accessed November 2013)
6. Pulmonary Hypertension Association UK. *Frequently asked questions for newly diagnosed patients*. [www.phassociation.uk.com](http://www.phassociation.uk.com) (Accessed November 2013).

**These cards have been developed and reviewed by a steering committee of PAH specialists across Europe in collaboration with Pfizer.**