



### Key things to consider

- Being an active listener can benefit the patient – listening and asking open questions<sup>3</sup> can help patients feel more comfortable in talking to you
- Ask them about the emotional impact PAH may be having on their life<sup>2</sup>
- Building a positive relationship with the patient can help you find out what they know and understand
- Make sure the patient understands their condition and the information you have given them. Encourage the patient to ask questions and to contact patient groups for additional support

#### 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, [www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/](http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/) (Accessed July 2013).
3. Partnerships in Caring. *Breaking bad news ... regional guidelines*. Department of Health, Social Services and Public Safety, 2003.
4. National Institute of Clinical Excellence. *Depression in adults with a chronic physical health problem*. NICE Clinical Guideline 91. NICE, 2009.
5. Pulmonary Hypertension Society. *Understanding and managing the emotional effects of pulmonary hypertension in the long term*. PHA, 2012.
6. National Institute of Clinical Excellence. *Patient experience in adult NHS Services: Improving the experience of care for people using adult NHS services*. NICE Clinical Guideline 138. NICE, 2012.

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



## Talking to patients about the emotional impact of having PAH

### Introduction

Living with a condition such as pulmonary arterial hypertension (PAH) may impose physical restrictions on patients that can affect their whole life, including socialising, family, children, intimacy and other relationships; in turn, this can have an adverse effect on patients' emotional state.<sup>1,2</sup> It is important to be aware that PAH can affect people of any age or sex, therefore the concerns of the patient may vary between individuals. This support card outlines key topics that may be useful when talking to a patient about the effects on their emotional and psychological state that may result from their condition.

### Preparing for the conversation

Review previous conversations with the patient and identify any concerns previously raised.<sup>3</sup> General principles to have in mind when talking to your patients with PAH, and especially about emotional issues, include:<sup>3</sup>

- Listen and give patients time to think
- Find out from the patient what they want to talk about and what their questions are



## Example conversation\*



**HCP** – What impact does PAH have on your life and your family life?



**Patient** – I find that there are times when I get upset and worried about things I can't do.



**HCP** – Tell me more about that.



**Patient** – Well, I feel frustrated that I can't do as much as I could when I am playing with my children. I am worried that it will get harder in the future.



**HCP** – Who helps you cope when you are upset or scared?



**Patient** – Well, I usually don't tell anyone.



**HCP** – What stops you from telling someone?



**Patient** – I don't want to upset or worry anyone.



**HCP** – What would your partner think about that?



**Patient** – They would want me to tell them.



**HCP** – If you were to talk to your partner, what help would you like from them and what is the best thing that could be done to help you?

## Having the conversation

- Be willing to discuss the psychological needs of the patient<sup>4</sup>
- Ask the patient how well they are coping with the emotional aspects of PAH<sup>2</sup>
  - Patients may have questions and concerns about their future and the future of the people they love. If they are unable to work or pick up and look after children this can be difficult or they may be upset if they think that their symptoms are deteriorating<sup>1,2,5</sup>
- Are there any areas that they find particularly difficult or where they feel they are not coping?<sup>6</sup>
- Give the patient the opportunity to talk about what it is like for them to be living with PAH<sup>1,3</sup>
- Ask what support they need or want<sup>6</sup>
- Ask what has helped them in the past and see if there is a way you or another member of the team can help them with these strategies<sup>1,2</sup>

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



- Identify potential signs and symptoms of stress and anxiety that you need to be aware of
  - They may notice that they feel tense, stressed and worried.  
They may notice their heart racing or a shortness of breath.  
These may be signs of anxiety<sup>1</sup>
- Evaluate patient psychological/emotional status on a regular basis. A variation may exist, which is sometimes associated with their physical condition and sometimes not. It is important to continually check up with the patient, as things may change.

## General principles to follow when supporting your patient

Give the patient information on the types of support available, including:

- Self-help information from recommended books and websites<sup>4</sup>
- Patient support groups and associations<sup>2</sup>
- Local counsellors and psychologists<sup>2</sup>

## Ending the conversation

Key things to consider:

- If your patient tells you they are really struggling with the emotional aspects of their PAH, then it is important to get them the right support by either referring them directly to a mental health specialist or by advising them to contact their GP/primary care physician who can refer them<sup>1,4,5</sup>
- Be aware of local protocols in identifying and referring those patients you feel may need more mental health support<sup>4</sup>
- Let the patient know they can talk to you again<sup>3,6</sup>