



### Key things to consider

- Being an active listener can benefit the patient – listening and asking open questions<sup>2</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>3</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. Partnerships in Caring. *Breaking bad news ... regional guidelines*. Department of Health, Social Services and Public Safety, 2003.
3. 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 September 2013].

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



## Talking with your patient about their PAH

### Introduction

There are a range of typical emotional effects that have been reported by patients with pulmonary arterial hypertension (PAH).<sup>1</sup> This support card explores these effects, and may help with the management of patients with PAH both at the time of their diagnosis and throughout the course of their disease.<sup>2,3</sup> It covers information on preparation for the discussion, the conversation itself and sources of information that may be useful for healthcare professionals (HCPs) to pass on to their patients.

### Preparing for the conversation

Recognise that having PAH can have a wide impact for many patients affecting areas, such as work, travel, social activities, role as a parent, relationships, finances and general lifestyle.<sup>1,3</sup>

There will be a lot of feelings for the patient to cope with as well as practical and medical information to take in, so providing a written summary of what you have told them at the end of the consultation may be useful in ensuring they have accurate information.<sup>2</sup>

### Example conversation\*

-  **HCP** – How have you been since I last saw you?
-  **Patient** – Well, I feel like I have had a set back and that things have got worse.
-  **HCP** – Tell me more about that.
-  **Patient** – I feel sad and depressed and I am a lot more irritable than I usually am.



 **HCP** – Can you tell me about times when you feel more irritable or sad?

 **Patient** – Actually, it's usually after having a check-up with you or before coming.

 **HCP** – What is it about the hospital appointment that makes you upset?

 **Patient** – Well, I'm confused about whether I am getting worse.

 **HCP** – Shall we start then by talking about your PAH?

## ■ Having the conversation

- Encourage the patient to talk about what living with PAH is like for them and how they cope with their feelings and emotions about PAH<sup>1,3</sup>
- Listen to how PAH affects their life<sup>2,3</sup>
- There may be an economic impact on the patient, which can lead to emotional problems<sup>1</sup>
- It is known that some patients may experience a wide range of thoughts and emotions about living with PAH.<sup>1</sup> These can include times when they feel:
  - Isolated
  - Grief for the past and loss of identity
  - Fear or worry about going out
  - Frustration
  - Low self-esteem
  - Anger – this may come and go over time

It is important to ask the patient how PAH affects them<sup>2,3</sup> – they may feel some of these emotions, or none, but may need help in finding the right support (see *Talking to patients about the emotional impact of having PAH*).

## ■ Ending the conversation

Ask the patient what has worked for them in the past.<sup>1</sup> Are there things



they can use now to help with their emotions? For example, some patients have found the following helpful:<sup>1</sup>

- Using a diary (patient log)
- Talking to family and friends
- Setting and working towards goals that are important in their life
- Relaxation and breathing techniques to cope when they are feeling anxious

You can help your patients identify who they can approach to help them cope and work towards their goals. They may need help with language and terms they can use to describe PAH<sup>2</sup> (see *Talking about PAH with those closest to you*).