



Key things to consider

- Being an active listener can benefit the patient – listening and asking open questions² can help patients feel more comfortable in talking to you
- Ask them about the emotional impact PAH may be having on their life¹
- Building a positive relationship with the patient can help you to find out what they know and understand
- Make sure that 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. 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.
2. Partnerships in Caring. *Breaking bad news ... regional guidelines*. Department of Health, Social Services and Public Safety, 2003.
3. PHA Europe. *The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey, 2013*; Available from: http://www.phaeurope.org/wp-content/uploads/PAH_Survey_FINAL.pdf. [Accessed November 2013]
4. De Silva D. *Evidence: Helping people help themselves*. London: Health Foundation, 2011.
5. Galie N, Hoeper MM, Humbert M, et al. Guidelines for the diagnosis and treatment of pulmonary hypertension. *European Heart Journal* 2009;30:2493–2537.
6. Pulmonary Hypertension Association. *A Guide for the Newly Diagnosed. Dealing with change, loss and the emotional impact of pulmonary hypertension*. PHA, 2012.

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



Communicating effectively with your patient

Introduction

Creating an environment where patients feel supported to talk about matters that are important to them is key for people with long-term conditions.¹ This card contains information on what to consider when talking to your patient at the time of delivering a diagnosis or during regular follow up visits.

Example conversation*

- HCP** – We now have all the results of the tests and it looks like PAH is confirmed.
- Patient** – I don't really know what PAH is. I have never heard of it before.
- HCP** – It's a complex condition but there are many efficient treatments available now.
- Patient** – How can I find out more about how it will affect me?
- HCP** – I can help you find all the information you need.
- Patient** – How will my life change?
- HCP** – Some changes may be necessary but we can discuss these as we go along.
- Patient** – Do I have to come back?
- HCP** – Yes, we will have to see you quite often to check how you are and discuss your ongoing treatment.

*Conversation is based on the personal communication of Dr Vanessa Garratt, Clinical Psychologist at the NHS Trust and Pisana Ferrari, Vice President of PAH Europe and President of the AIPI (Associazione Iperensione Polmonare Italiana).

HCP = Healthcare professional



■ Preparing for the conversation:

General principles to have in mind when talking to your patients with pulmonary arterial hypertension (PAH):

- Listen, and give patients time to think²
- Find out from the patient what they want to talk about and what their questions are²

Consider providing a written summary of what you have told them at the end of the consultation, to make sure they have accurate information.²

■ Having the conversation:

When discussing PAH with a patient, think about where they are in their journey. Is the patient newly diagnosed or here for a check up? This can help guide what you say and how you say it.

The first conversation with the patient is very important. You may want to plan this meeting as you could be delivering a difficult diagnosis.

What

- Ask if they've heard of PAH and what they know about it²

Perhaps suggest terms or diagrams that they can use to help them explain what PAH is to their family and friends (such as those in 'Talking about PAH with those closest to you')

Information may need to be repeated and spread out over a number of consultations³

- Think about the language you plan to use²
- Give the patient time to take in the information you have given and to ask any questions²
- Ask them what information they need or would like at this point in time²
- Let patients know who they can contact if they have any questions¹

Informed decision-making

- Explain how you will manage their ongoing care²



- Consider ways of involving the patient in the decisions about their care⁴

Helping patients live with PAH

- Find out about the patients' preferred activities and goals to achieve, in order to maintain a good quality of life
- Support patients by working out with them how you can help in setting and achieving their goals and put together an action plan to help manage their symptoms⁴
- Suggest activities they might do, depending on their wellbeing⁵

Are there things the patient believes might help them? How can you support them in achieving these? Examples include:

- Seeking support from family and friends⁶
- Exploring the support available from patient organisations¹

Patient activation measures

- Help the patient to recognise any early signs that things are changing to help them manage their condition⁴

It can help patients if they view their consultations as a two-way process. Listen to any problems they have in communicating with others about their PAH.

■ Ending the conversation

- Let the patient know they can talk to you again^{2,3}
- Encourage the patient to think about any support they might need from family or friends⁶