

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



Getting the right support: talking to your healthcare professional

■ Introduction

One of the first steps in living with pulmonary arterial hypertension (PAH) is to understand what PAH is and how to cope with the physical and emotional aspects of the condition.^{1,2} Your medical team are very important in helping to answer any questions you have, spotting problems early and helping you manage your symptoms. It can help to think about what questions and concerns you may have before going to see a healthcare professional (HCP) to make sure you get the information and help you need.³ Once you get to know your team they can be a great source of help and support. This card contains information about key topics that you might want to cover when talking to your healthcare team about PAH.

■ Example conversation*



HCP – How have you been since your last appointment?



Patient – I have noticed that I am more out of breath when I am getting around at work.



HCP – Tell me more about that. What is the impact for you of being more out of breath?



Patient – It can be different from one time to the next and can feel frustrating when I am used to being active. I have noted down times when it feels harder and easier.



HCP – Great. Let's go through that together and work out how to help you to have more days that feel easier.

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

■ Practical tips for structuring the conversation

Planning the conversation:

- Decide what questions you want to ask so that you can be comfortable talking about these queries at your visit³
- There may be things you have been wondering about with regard to your condition, for instance, what exercise would be suitable for you or whether following a healthy diet could help⁴
- Think about what information or help you need to manage your condition on a daily basis. How can your healthcare team help you with this?⁴
- Try to be as specific as possible – perhaps write down your questions or points and take the questions with you in a notepad³



Starting the conversation

Talking to your medical team about how you feel physically and emotionally can help you work together to manage your condition.¹

If your healthcare professional does not proactively discuss things that you would like to talk about then you could use this opportunity to bring up these topics yourself. It may help you to prepare notes beforehand.

Here are some specific topics you might want to cover when discussing your condition with one of your healthcare team:

What are your goals?

- Tell your healthcare professional about your hopes and goals. What is it that you feel is important to you? What would you most like to do or to continue doing?
- Discuss what goals are realistic and consider an action plan of how you can get there⁵ (See support card Making Plans)

How are you coping with your PAH and what impact has it had on your life?

- How do you manage your symptoms?⁴
- How have you been managing at work and at home so far?
 - Explain any changes that you may have made in your life or surroundings to help manage your symptoms or to make life easier⁴
- What are your support needs?
- Do the people who support you know how you feel?
- How well are you coping with your feelings and emotions about PAH?
- Do you want to know more about support groups? These can be a great benefit and source of PAH healthcare information⁶

More information and support:^{3,4}

- Are there any ways you feel your healthcare team can support you in your day-to-day living with PAH?
- Ask for any more information you feel you need

Ending the conversation

- If you can, agree possible dates and times for your next appointment
- Discuss what you would like to happen before that date
- Ask about any details and dates of any future screenings or tests you might have coming up⁷

Key references

1. PHA Europe. *International-PAH-patient-and-Carer-Survey-Report*. 2013; Available from: www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/. (Accessed November 2013)
2. Benisty. Pulmonary Hypertension. *Circulation*. 2002;106:e192-e194.
3. Pulmonary Hypertension Association. *Getting ready for your first appointment*. 2013; Available from: www.phassociation.org (Accessed November 2013)
4. National heart, lung and blood institute. *Living with pulmonary hypertension*. 2013; Available from: <http://www.nhlbi.nih.gov/health/health-topics/topics/pah/livingwith.html> (Accessed November 2013)
5. de Silva D. Evidence: *Helping people help themselves*. Health Foundation, 2011.
6. Pulmonary Hypertension Association. *Local support groups*. 2013; Available from: www.phassociation.org (Accessed November 2013)
7. Pulmonary Hypertension Association. *Empowered patient online toolkit*. 2013; Available from: www.phassociation.org (Accessed November 2013)

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