



Advising patients on how to communicate with those closest to them

■ Introduction

For people with chronic conditions such as pulmonary arterial hypertension (PAH), the support of family and friends can be very important.¹ Good communication between the patient and their family and friends is very important in making sure that the patient gets not only the physical, but also the emotional support they need.¹ This requires a certain amount of understanding from the person with PAH about how their condition affects the lives of those around them.¹ This support card has been developed to provide summary information about how healthcare professionals (HCPs) can offer help to patients in their communications with those closest to them.

■ Preparing for the conversation

Be prepared to answer questions, or to point them in the direction of more information, such as details of patient organisations that may also be able to offer support.^{2,3} Some general principles to have in mind when talking to your PAH patients include:

- Listen and give patients time to think
- Find out from the patient what they want to talk about and what their questions are³
- Encourage the patient to bring someone with them to the clinic, or join a consultation between you and the patient. This can be very helpful for both the patient and the carer in the following ways:¹
 - For the patient because the second person can take notes or help the patient in remembering extra details of the conversation¹
 - For the carer as it is a chance for them to ask their own questions and get to know the healthcare team²



■ Example conversation*



HCP – How have things been since we last met?



Patient – There are times when I find it easier to do things such as cooking, and times when it's hard to just walk down the stairs, let alone cook dinner:



HCP – Tell me more about times when it is easier or harder. Have you told someone close to you about how you feel?



Patient – Well, after work it is harder. When I am more tired, I also feel more stressed.



HCP – Can you find a different time to cook, or alternate days to do it? Tell me more about what it is like when you feel stressed.



Patient – When I find I can't do things like I used to, I get stressed.



HCP – Have you spoken to your family about this?



Patient – Well, we don't really talk about my PAH.



HCP – What help do they need to support you? Would they like to come with you to an appointment to talk to us about information and specific support that they need?



Patient – Yes, I think that might be helpful.

■ Having the conversation:

- Talk to your patient about whether and how they wish to share their news. If they do, some things they might wish to think about include:
 - Family members may experience a range of emotions and they may react differently to the news.¹ Patients may need to consider that some people will need more time to adjust to, and to think about, what they have been told, e.g.:¹
 - Family members may feel shocked, scared and even angry. They may need help and support to understand what PAH is and how it affects you

*Conversation is based on the personal communication of DrVanessa Garratt, Clinical Psychologist at the NIHS Trust UK.
HCP = Healthcare professional



- A consideration of questions that family members and close friends may have and how they would answer these, e.g.:³
 - What is PAH?
 - What is the treatment plan?
 - How will it affect the family?
 - What will happen in the future?
 - What can they do to support you?
- Does the patient need help and support from you in how to talk about PAH? The patient card *Talking about PAH with those closest to you* has some example phrases that they may wish to talk over with you
- They may want to think over how best to plan their conversations, including when and where to have them, and how to start off
- You may want to talk about how it can help the patient to develop a network of family and friends who understand how PAH affects their life and the kinds of help and support they may need or want¹

■ Ending the conversation

- Ask them about times when they have had to share news with people and to consider what worked for them and what what should be avoided
- Let the patient know they can talk to you again as well as any other member of the healthcare team^{2,3}
- Advise where they can find further sources of information both for them and their carers, friends and families^{1,2}



Key things to consider

- *Being an active listener can benefit the patient – listening and asking open questions³ can help patients feel more comfortable in talking to you*
- *Ask them about the emotional impact PAH may be having on their life²*
- *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/ (Accessed July 2013).
3. Partnerships in Caring. *Breaking bad news ... regional guidelines*. Department of Health, Social Services and Public Safety, 2003.

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

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