

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



Talking about pulmonary arterial hypertension (PAH) with those closest to you

■ Introduction

Building and maintaining relationships is an extremely important feature of our lives.¹ This card has information to help you think about the things you might want to tell those who are closest to you, to help them understand how PAH affects you, and how you might do this. There are some suggestions for planning your conversation, deciding what you want to say, dealing with different reactions and ending your conversation. These are just suggestions – you may have your own style and it is important to use words and phrases that you are comfortable with. This card is a starting point to help you think about your conversations.

■ Example conversation*

- Patient** – I wondered if we could possibly talk about my diagnosis?
- Family/Friends** – That would be fine. What do you want to tell me?
- Patient** – The doctor has told me that I have a chronic condition.
- Family/Friends** – Are you going to be okay?
- Patient** – Well, some things may have to change in our lives.
- Family/Friends** – What sort of things?
- Patient** – I'll need to be put on treatment and have regular check-ups, that sort of thing.
- Family/Friends** – Does it have to do with your being breathless and more tired than usual?
- Patient** – Yes, it affects my heart and lungs, so I may need to slow down a bit.
- Family/Friends** – It's OK, we will manage, I am there to help.

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

■ Practical tips for structuring the conversation

Planning the conversation:¹

- What do you want from the conversation? Is it for the other person to have a better understanding of your PAH or would you like support when things are difficult?



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- How would you like to start the conversation?
 - Think about what time and place are right for you. Try to choose a time when you're both in a calm frame of mind, and a place where you will both be comfortable and relaxed¹
- What questions might they ask? They may well be the same questions you will have asked your doctor already

Be ready to listen to those closest to you when you share the news and to answer their questions about your condition.¹

- Let your friends and family ask about what they could do to help – for many people practical help can be their way of dealing with a situation²
- Be aware that this may be one of many conversations²
- It may be helpful if you let those closest to you know all the ways they can provide both physical and emotional support²

People can react very differently and it can be difficult to predict in advance what they will say or do.¹ Allow them plenty of time to think about what you have said and let them ask questions.¹ Talking clearly can deal with many of the reactions people may have.¹

Starting the conversation

There are some suggested words and phrases below that might help you in your conversations. The more you get to know about your own condition, the more you can share with others.

Specific topics and possible phrases you might use with family and friends when you share your diagnosis and talk about your condition.

When you are describing what PAH is:³

- A condition that affects both my heart and lungs; high blood pressure of the lungs
- A condition that affects the blood vessels running from my heart to my lungs

When you are explaining how PAH affects you:⁴

- Shortness of breath
- Extreme tiredness
- Dizziness and fainting

Ending the conversation

At the end of the conversation consider what you want to happen next.

Would you like to arrange to talk again? Does the person you are talking to have any more questions or would they like to know how they can help you? Think about whether there are others you would like to talk to or whether you have what you need at the moment. You might also suggest places where they can find more information or support. In the case of any remaining unanswered questions, you may want to arrange another conversation with those closest to you in the presence of a healthcare professional.

Key references

1. Pulmonary Hypertension Association. *Maintaining healthy relationships*. www.phassociation.org (Accessed November 2013)
2. Pulmonary Hypertension Association. *Coping with pulmonary hypertension. A guide for the newly diagnosed*. PHA, 2012.
3. Pulmonary Hypertension Association. *Types of pulmonary hypertension*. www.phassociation.org (Accessed November 2013)
4. Pulmonary Hypertension Association. *Symptoms of pulmonary hypertension*. 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.