



How to make the most
of your dialogue tools

For Patients

Time to Talk: How to make the most of your Patient Dialogue Tool

Why has the *Time to Talk Patient and Carer Pack* been developed?

Discovering that you have pulmonary arterial hypertension (PAH) can come as quite a shock for many and can place a huge burden on your life from physical and emotional well-being to employment, social activities and relationships. As a patient with PAH, you will be well aware that PAH is a complex and challenging condition. It can also place heavy physical and mental demands on carers, who often have to manage multiple roles.

You may find it difficult to discuss your condition with your loved ones through fear of worrying them. It is however important for your wellbeing that you do speak to someone about how you're feeling and share any concerns you may have. Some people can turn to a family member for support while others prefer to talk to their healthcare professional for example. Either way, take some time to think about who you feel most comfortable talking to, when you are ready to do so. Understandably, you may not be ready to talk about your feelings yet and there is no need to push yourself to do so. Simply return to this pack whenever it feels right for you.

In order to enjoy the best possible quality of life, PAH patients and their carers need ready access to the right support and information. However, the results of the *International Patient and Carer Survey (IPCS)* reveal that patients seldom receive the information they need, either at the time of diagnosis or as the disease progresses.

What does the pack contain?

The *Time to Talk Patient and Carer Pack* has been developed in response to these survey findings and is intended for use by people who have been diagnosed with PAH. It contains materials for patients and carers specifically designed to help you analyze how you are feeling, keep track of your information needs and encourage open, honest discussion about PAH with your doctor or nurse.

The *Time to Talk Patient and Carer Pack* comprises:

- A summary of the results of the International Patient and Carer Survey
- Living with PAH, a dialogue tool for patients
- Living with PAH, a dialogue tool for carers
- A DVD/video guide showing you how to use the dialogue tool

What is the patient dialogue tool designed to do?

Patients with PAH can experience a whole range of emotions, from fear and frustration to isolation and embarrassment. The Patient Dialogue Tool is simply a way of noting down your thoughts and emotions in a structured way so you can get a clearer perspective of how you are feeling. Taking the time to sit down and analyze your emotions can help to give a sense of clarity and can make it easier to explain your feelings to other people. Your notes and observations can also provide a focus for discussion with family and friends and can help you to have a more productive consultation with your doctor.

The pack also contains a version of the dialogue tool for carers.

How do I use the patient dialogue tool?

The tool includes a series of questions on different aspects of PAH from physical and practical issues to the emotional impact and information needs, with tick boxes for your answers. The questions are summarized overleaf. Simply read the questions and tick the box that relates most closely to your experience. If a question is not relevant to you, ignore it and move on to the next. You may think of other issues or comments that are not covered in the questions and there is space to make a note of these.

It is entirely up to you whether you use the dialogue tool or not, and how often you use it. As your experience may change over time, it can be helpful to repeat the exercise on a regular basis (using a new copy of the tool or the summary sheet overleaf) to track how things have altered. You do not need to complete every section – just focus on the ones that are most relevant to you. There is no right or wrong way of using it – it is not a test!

You may wish to take the completed Dialogue Tool or the summary sheet with you to your medical appointments with your doctor, nurse or other healthcare professional or when visiting your patient organization so that you can discuss some of the issues highlighted.

For further guidance on how to use the dialogue tool, please refer to the DVD included in this pack. We hope you find these materials helpful and would welcome your feedback and experiences using them. Please send your comments to p.ferrari@phaeurope.org.

Remember that your PH patient association is always there to help and support you.

Summary of Questions

You can either complete the full dialogue tool or use this summary of questions as a reminder of the key points to consider or to note down changes since your last appointment.

1 Which aspects of your life has PAH had a negative impact on and how much have they been affected?

Eg: walking, getting dressed, exercise, social outings, domestic chores, relationships and travelling.

2 (If relevant) to what extent has your ability to work been affected since your diagnosis with PAH?

3 Have you felt isolated as a result of having PAH and if so, what do you think the reasons might be?

Eg: lack of understanding or compassion from other people, finding it difficult to share your experience with other people, the fact that PAH is not 'visible', people not understanding the difference between PAH and simple hypertension.


4 Have you had negative feelings in the last month and how often?

Eg: feeling low, fearful, angry, low self-esteem, afraid to leave home, guilty, loss of interest in sex, poor appetite/over eating, problems sleeping, lack of concentration or feeling restless.

5 Which topics would you like to receive more information about?

Eg: PAH symptoms and prognosis, specialists in PAH, treatment options, purpose of appointments, impact on employment and finances, disability benefits, how to cope with changing role, impact on emotions and sexual relationships, advice on travelling, patient stories, patient organizations.

Use the space below to note down any other questions or issues that occur to you – be as specific as you can.

A large, empty rectangular area with a light blue gradient background, intended for the user to write their responses to the questions above.