



How to make the most
of your dialogue tools

For Carers

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

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

Caring for a patient or loved one with Pulmonary Arterial hypertension (PAH) can be very rewarding but can also be demanding and draining. Carers often have to manage multiple roles, taking on physical chores and administrative tasks as well as providing emotional support, while coping with their own anxieties. Employment, leisure activities and social life can all be affected, with the result that one in three carers feel isolated as a result of looking after somebody with PAH.

You may find it difficult to discuss your emotions with your loved ones, or the person you are caring for, through fear of upsetting 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, patients with PAH and their carers need ready access to the right support and information. Unfortunately, the results of the *International Patient and Carer Survey* (IPCS) reveal that in many cases, carers receive little or no information.

What does the pack contain?

The *Time to Talk Patient and Carer Pack* has been developed in response to these survey findings. It contains a range of materials for PAH patients and their carers designed to help you analyze how you are feeling, keep track of your information needs and encourage open, honest discussion about PAH with healthcare professionals and the person you're caring for.

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 carer dialogue tool designed to do?

The Carer 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 review 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 provide a focus for discussion with family and friends and can help to ensure that you receive the information and support that you need.

There is also a dialogue tool developed specifically for patients and you may wish to help the person you are caring for to complete this on a regular basis.

How do I use the carer dialogue tool?

The tool includes a series of questions on different aspects of how your life has been affected by caring for somebody with PAH, with tick boxes for your answers. These range from practical issues such as employment to the emotional impact of being a carer, and information that you would find helpful. 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 or 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 when visiting nurses, doctors or 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 How has your life changed since the person you are caring for was diagnosed with PAH?

Eg: taking on more household chores, childcare, planning patient's daily life, feeling more tired, being involved in helping patient to take medication

2 (If relevant) to what extent has your ability to work been affected since the diagnosis of the person you care for?

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

Eg: feeling stressed, burdened with responsibility, not enough time to yourself, angry, feeling that family life is affected, afraid for the future, health has suffered, lack of privacy, uncertain what to do or feeling that you could be doing more for the person you are caring for

4 If you are caring for your partner, has PAH had an impact on your sexual relations and what do you think are the reasons for this?

Eg: partner has low self-esteem/body image, fear of making partner more ill, partner is physically incapable of sexual relations, loss of interest in sex (by you or your partner), fear of pregnancy, partner is suffering from other diseases in addition to PAH

5 If you are caring for your partner, has your level of intimacy with them changed since their diagnosis and how do you feel about this?

Eg: feeling less close, struggling to show affection, feeling that partner views you as a carer rather than lover, not concerned about decrease in sexual relations, would like to find different ways of showing affection

6 Have you felt isolated as a carer for somebody with PAH and why do you think this might be?

Eg: Lack of understanding of the disease by the person you care for, by other family members or friends or by the wider community, finding it difficult to feel empathy for the person you are caring for, finding it difficult to share your experience or express yourself with others including medical staff, the fact that the disease is not obvious to others, the fact that people confuse PAH with simple hypertension

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

Eg: PAH symptoms and prognosis, specialists in PAH, treatment options, purpose of appointments, balancing work and being a carer, impact on finances, disability benefits, how to cope with changing role, impact on emotions and sexual relationships, advice on traveling, 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.