

LIVING WITH PAH: A DIALOGUE TOOL FOR PATIENTS

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INTRODUCING THE PATIENT DIALOGUE TOOL

The results of a recent international survey have improved our understanding of many of the daily challenges faced by patients with pulmonary arterial hypertension (PAH). The findings provide useful insights for patients, their families and carers and for patient associations, such as the need for an interdisciplinary team approach, where professionals from different specialties work closely together to address **all** patient needs – not just physical symptoms. We also realized that patients could benefit from a tool that would help them identify any issues or emotions causing concern, from interpersonal relations and personal finances to social interactions.

The **Patient Dialogue Tool*** is intended to help you record, clarify and cope with PAH and its impact on your emotions, overall wellbeing and daily life. The tool will enable you to document your thoughts, feelings, and concerns in a structured way, which can then help focus discussions with your doctor, family, friends and carers, and get the emotional support you need to cope with the disease. The Dialogue Tool can be found on pages 15–19.

In addition, we are pleased to provide you with a summary of the results from the international survey, which prompted the development of the Patient Dialogue Tool. The survey was conducted with PAH patients and carers from France, Germany, Italy, Spain and the UK, who were recruited from national patient organizations. The complete survey results are available at: <http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/>

*This Dialogue Tool is intended for patients whose diagnosis of PAH has been confirmed.

PULMONARY ARTERIAL HYPERTENSION (PAH)

PAH is a disease of high blood pressure in the blood vessels of the lungs that can lead to heart failure. In PAH, the arteries of the lungs become narrow and might have blockages, which makes it harder for your heart to pump enough blood through the lungs, and to the rest of your body. This can typically lead to symptoms such as breathlessness, tiredness, feeling faint or weak, and, in some cases, chest pains. These may become more pronounced as the disease progresses.

The term “functional class” is often used to describe how extensively these symptoms limit people with PAH. Functional class I suggests minimal limitations and proceeds to functional class II, III and IV, each signifying greater limitations in the patient’s ability to function.

Between fifteen and fifty people per million will develop PAH. PAH is more common in individuals who have certain underlying diseases, such as connective tissue disease (e.g. systemic sclerosis), liver disease, HIV infection or congenital heart disease. In very rare cases, PAH can be inherited.

Significant progress has been made in recent years in developing therapies for managing PAH with the goal of improving symptoms, enhancing the patient’s daily functioning, and creating a better quality of life. Today’s treatments enable many PAH patients to live satisfying lives.

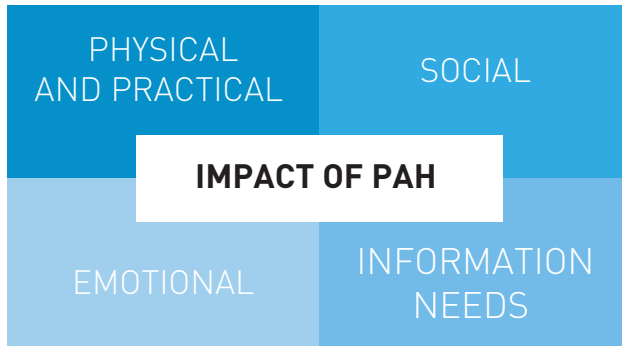
More detailed information on PAH is available on the following websites:

www.phaeurope.org | www.phassociation.uk.com | www.phassociation.org

THE IMPACT OF PAH ON DAILY LIFE: RESULTS FROM AN INTERNATIONAL SURVEY

The international survey, carried out in 2011, aimed at learning more about the ways in which PAH impacts upon the lives of patients and their carers, in areas other than their physical symptoms. As shown in Figure 1, the survey explored four main areas, the key findings of which are described on the following pages.

Figure 1: Areas explored in the survey



PHYSICAL AND PRACTICAL IMPACT OF PAH

*“I would describe PAH as like being in a car
which won’t go over 10 kph”*

Patient with PAH

The physical and practical impact of PAH can vary greatly on a daily basis, and performing everyday tasks can be physically challenging. The survey showed that 56 % of patients felt their PAH had a 'very significant' impact on their daily life, and difficulty performing everyday domestic tasks such as household chores and errands was frequently reported (Figure 2). Patients reported difficulties in climbing a flight of stairs and there was a strong negative impact on patients' ability to work, exercise, socialize and travel (Figure 2).

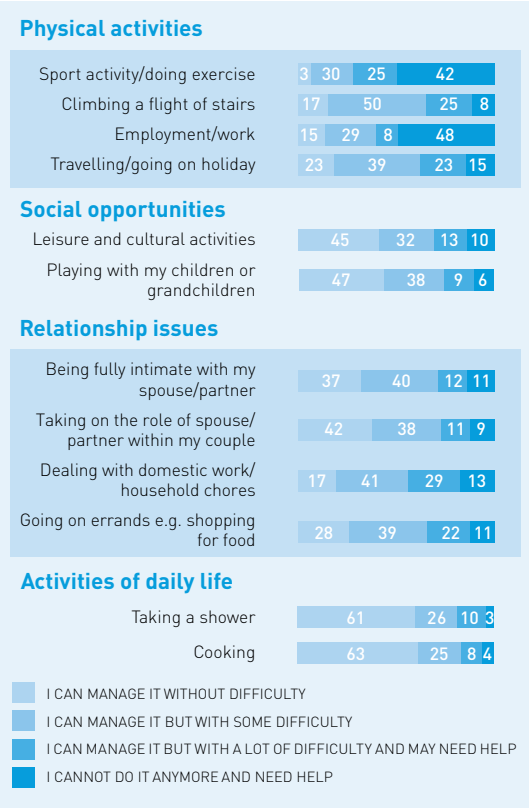
With regards to the impact on work and employment, a sizeable number of respondents reported a reduction in income. Many patients noted a loss of intimacy and diminished sexual relations, which was mainly attributed to low self-esteem and body image, feeling unable to or being physically incapable of engaging in such relations. Others reported feeling afraid of becoming more ill or getting pregnant.

Questions 1 and 2 of the Dialogue Tool (page 15/16) aim at helping you identify such difficulties so that you can discuss them in a focused way with your doctor, nurse, family/carer and patient organization.

Increasing your awareness of how PAH is affecting your everyday activities is an important step forward and can help you to find the most appropriate and accessible resources that provide you with the support that you need.

Your answers can also help in clarifying and prioritizing issues of importance to you.

Figure 2. Patients indication of ability to perform activities post diagnosis (*shown in %*)



SOCIAL IMPACT OF PAH

*“They think we’re just lazy.
They don’t understand I can’t do it,
no matter how much I want to”*

Patient with PAH

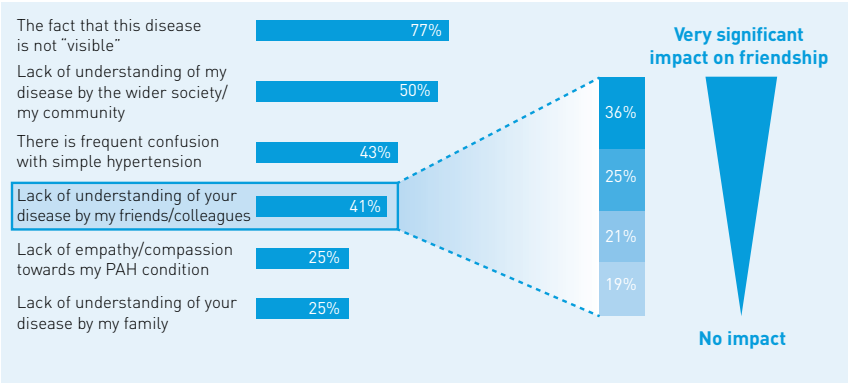
Interviews with some patients showed that their world narrowed as a result of their condition, which often requires patients to curtail their activities away from the home. For many, the social roles that they once held, for example, as a colleague, friend, or teammate, have changed and were sometimes diminished. PAH also impacted on leisure and cultural activities, as well as spending time with friends and relatives. Respondents reported feeling isolated, and for many this was the result of PAH not being “visible”, i.e., not outwardly apparent to others (Figure 3). For others who reported feeling isolated, a lack of understanding among family and friends/colleagues was the main contributing factor. Some

of the respondents reported that these feelings significantly affected their relationships.

Question 3 of the Dialogue Tool, on page 17, addresses feelings of isolation. Recognizing such feelings often helps in resolving these issues.

If you need help in dealing with these and other emotions related to your condition, you should not hesitate to approach your patient association or professionals who can support you. As the survey shows, patients suffering from emotional distress related to their conditions are not alone.

Figure 3. Causes of feeling isolated as a result of PAH



Full results of the survey are available at:
<http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/>

EMOTIONAL IMPACT OF PAH

*“It’s not a good feeling – it’s bad to be dependent
on others. It is bad to ask other people to help you.
You feel bad. You feel inferior – like a second class citizen”*

Patient with PAH

PAH is a complex disease. It is important to address the emotional aspects of PAH so that you're in a better position to deal with your disease.

The physical, practical and social changes that accompany PAH can result in a wide range of negative emotions. You may experience fear, guilt, worry and loss of libido as well as feelings of uselessness, worthlessness, embarrassment and frustration. As shown by the survey results, you are certainly not alone in experiencing such feelings.

Frustration and anger were among the most frequent emotions reported (Figure 4). These feelings can be associated with depression and, despite most patients in the survey not considering themselves as being “depressed” per se, many experienced signs that are often associated with depression, such as feelings of isolation and hopelessness, lack of enthusiasm and a feeling that everything seems meaningless. It is, therefore, important to be aware of the signs associated with depression and to get support as needed.

Emotional support (and in some cases psychological or psychiatric support) is, therefore, extremely important to help you overcome and deal with these emotions. In the survey, 42% of patients felt that emotional support was most effectively provided by their family, while 29% received this from their carer. Healthcare providers and patient organizations, particularly support groups, were also identified as positive resources when dealing with emotional stress. In the survey, 30% of patients said patient organizations provided them with emotional support. Although the physical effects of PAH are your primary

concern, feelings “beneath the surface” must also be dealt with fully and appropriately. Knowing that you are not alone in how you are feeling, and giving voice to feelings of frustration, stress, hopelessness, low mood and lack of self-worth are important steps towards getting the support that you might need.

Question 4 of the Dialogue Tool (page 18) will help you to think about such feelings and will encourage you to discuss them with health care professionals, patient organizations and those closest to you. By openly discussing how you are feeling, those around you can help identify the kind of support that would be best for you. In addition to emotional support from people close to you, counselling and, at times, medical therapy can be used to overcome depression and related problems.

Figure 4. Frequency of emotions reported by patients in the last month *(shown in %)*



Full results of the survey are available at:
<http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/>

Patients reported the need to be informed about their condition on an ongoing basis. The top information needs reported are presented in Figure 5 and focus on the disease and its treatment – topics that most patients are very keen to learn about at diagnosis.

Feedback from the patients surveyed showed that there is a lack of information on the emotional impact of the disease, and that this information is often given verbally at the time of diagnosis when physical aspects of the disease are the main focus. Consequently, emotional and other facets of living with PAH are often overlooked or forgotten.

More specifically, over one-third of the patients surveyed wanted information about depression and other potential emotional consequences of being ill with PAH. A similar proportion was interested in learning about other patients’ experiences and some wanted information on patient association contacts. The survey indicated the importance of information being presented gradually, staggered over several visits, so that the patient does not feel overwhelmed.

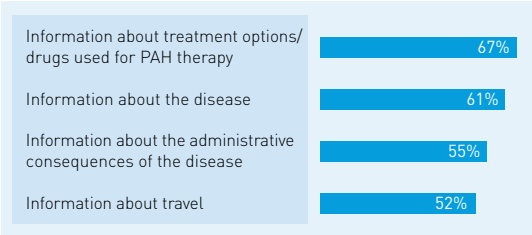
Question 5 of the Dialogue Tool (page 19) will help you to think about the areas in which you would like to receive more information, when you need certain information, as well as how you might use resources available to you.

Now that you have had a chance to learn more about the impact of PAH on the daily lives of others,

we encourage you to read further and to use the questions in the Dialogue Tool to help you clarify the impact that PAH has on your daily life. Please remember that most patients will experience some of these challenges and feelings but how they choose to manage these will differ. We hope that this Dialogue Tool will encourage you, as someone who has PAH, to live more fully and with greater satisfaction.

It is important that you do not feel embarrassed or intimidated about asking for information to be provided or repeated when you require it. In addition to your doctor and nurse, patient organizations represent an extremely important source of information.

Figure 5. Main information needs for patients with PAH



Full results of the survey are available at: <http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/>

PATIENT DIALOGUE TOOL

INSTRUCTIONS

The purpose of the Dialogue Tool is to help you gather your thoughts and feelings, so that you can reflect on them and then discuss them with your doctor, other professionals, your carer, relatives, and members and staff of your patient organization.

There are no right or wrong answers and you are not required to complete all of the questions. If you need to take a break while answering the questions, don't hesitate. You can continue again when you are ready.

You may wish to take this completed Dialogue Tool with you when visiting your nurse, doctor or patient organization to help you with your discussions.

HAS PAH HAD A NEGATIVE IMPACT ON THE FOLLOWING ACTIVITIES/ASPECTS OF YOUR LIFE?

Please tick the boxes that are relevant to you.

As your experience in these matters may change, we recommend that you continue to assess and record the ways the disease affects you (using a new copy of the Dialogue Tool).

Q1

DATE COMPLETED: _____

ACTIVITIES/ ASPECTS OF YOU LIFE	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
Getting dressed/taking a shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking a short distance/ climbing a flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure and cultural activities such as going to the movies, a museum, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with domestic work/ household chores/cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visiting relatives/friends, socializing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Playing with my children/grandchildren/ helping them do their homework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fulfilling the role of spouse/partner in my personal relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being fully intimate with my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sexual relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(If relevant) As a woman, I worry about becoming pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going on errands e.g. shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travelling/going on holiday	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being able to keep up with my hobbies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Engage in my customary religious/ spiritual practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Use this space for additional comments

If you feel that your PAH has had a negative impact, who would you consider discussing this with? *Several answers may apply; please include all those you feel relevant**

- ☐ PAH specialist
- ☐ Other specialists
- ☐ Family doctor/GP
- ☐ Counsellor/Nurse
- ☐ Patient Organization
- ☐ Other PAH Patients
- ☐ Significant other/
Life Partner
- ☐ Family/friends
- ☐ Other including

- ☐ Not needed/
necessary

*If you do not know whether you have access to some of the suggested professional help, speak to your family doctor or General Practitioner (GP) about who might be the appropriate person to speak to.

Q2

HAS YOUR ABILITY TO WORK BEEN NEGATIVELY IMPACTED SINCE DIAGNOSIS?

Again, as your experience in these matters may change, we recommend that you continue to assess and record the ways the disease affects you (using a new copy of the Dialogue Tool).

DATE COMPLETED: _____

If Yes, who would you consider discussing this with? *Several answers may apply; please include all those you feel relevant**

- ☐ PAH specialist
- ☐ Other specialists
- ☐ Family doctor/GP
- ☐ Counsellor/Nurse
- ☐ Patient Organization
- ☐ Other PAH Patients
- ☐ Significant other/
Life Partner
- ☐ Family/friends
- ☐ Other including

.....

- ☐ Not needed/
necessary

IMPACT ON YOUR ABILITY TO WORK	PLEASE TICK AS RELEVANT
Yes, totally	<input type="checkbox"/>
Yes, partially	<input type="checkbox"/>
No, but my working conditions/ occupation have changed	<input type="checkbox"/>
No	<input type="checkbox"/>
Not relevant as I was not working prior to being diagnosed with PAH	<input type="checkbox"/>

Use this space for additional comments

HAVE YOU FELT ISOLATED AS A RESULT OF PAH?
IF SO, THIS SECTION WILL HELP YOU FOCUS ON THE REASONS.

Again, continually monitoring these feelings can help prevent them from getting out of hand.

Q3

DATE COMPLETED: _____

FEELINGS OF ISOLATION	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
Lack of understanding by:					
Friends/colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner/spouse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Members of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children/grandchildren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The wider society/community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of empathy/compassion towards my PAH condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to share my experience with other patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to share my experience with PAH specialists or nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to express myself effectively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The fact that this disease is not "visible"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a frequent confusion with simple hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Use this space for additional comments

If you have experienced feelings of isolation, who would you consider discussing this with? Several answers may apply; please include all those you feel relevant*

- ☐ PAH specialist
- ☐ Other specialists
- ☐ Family doctor/GP
- ☐ Counsellor/Nurse
- ☐ Patient Organization
- ☐ Other PAH Patients
- ☐ Significant other/ Life Partner
- ☐ Family/friends
- ☐ Other including

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.....

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- ☐ Not needed/ necessary

*If you do not know whether you have access to some of the suggested professional help, speak to your family doctor or General Practitioner (GP) about who might be the appropriate person to speak to.

IN THE LAST MONTH, HAVE YOU EXPERIENCED ANY OF THE FOLLOWING EMOTIONS?

DATE COMPLETED: _____

If you have experienced any of these emotions, who would you consider discussing this with? *Several answers may apply; please include all those you feel relevant**

- ☐ PAH specialist
- ☐ Other specialists
- ☐ Family doctor/GP
- ☐ Counsellor/Nurse
- ☐ Patient Organization
- ☐ Other PAH Patients
- ☐ Significant other/ Life Partner
- ☐ Family/friends
- ☐ Other including

.....

.....

.....

- ☐ Not needed/ necessary

EMOTIONS	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
Feeling low/feeling worthless/ little pleasure in doing activities I used to enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fearful/frightened at any time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling angry/frustrated/ misunderstood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low self-esteem/confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Afraid to leave home/ no desire to socialize	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of guilt/embarrassment/ hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of libido/interest in sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite/over eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep disorders/difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of concentration/ difficulty with remembering things/ talking/thinking more slowly than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fidgety/restless/stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty in feeling positive or good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Use this space for additional comments

**If you do not know whether you have access to some of the suggested professional help, speak to your family doctor or General Practitioner (GP) about who might be the appropriate person to speak to.*

WHICH TOPICS WOULD YOU LIKE TO RECEIVE MORE INFORMATION ABOUT?

DATE COMPLETED: _____

INFORMATION TOPICS	YES, NOW	YES, AT A LATER PERIOD	NO
My disease (symptoms, prognosis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialists & doctors involved in PAH care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment options/medications used for PAH therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Follow-up/check-up appointments, including their schedules and purposes of these appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being employed while suffering from PAH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial consequences of the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Administrative consequences of the disease (disability claims, insurance coverage, travel grants for hospital appointments)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Role shifting within the family/couple	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression, anxiety risk and other emotional consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Possible consequences of sexual relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travels (tips and tricks how to make travelling possible including travel insurance issues)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Testimonials and patient stories	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient organization contacts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Use this space for additional comments

If Yes, who would you consider discussing this with? *Several answers may apply; please include all those you feel relevant**

- ☐ PAH specialist
- ☐ Other specialists
- ☐ Family doctor/GP
- ☐ Counsellor/Nurse
- ☐ Patient Organization
- ☐ Other PAH Patients
- ☐ Significant other/ Life Partner
- ☐ Family/friends
- ☐ Other including

.....

- ☐ Not needed/ necessary

**If you do not know whether you have access to some of the suggested professional help, speak to your family doctor or General Practitioner (GP) about who might be the appropriate person to speak to.*

NOTES

Please use this section to write down any feelings, questions or issues that interest or concern you. The more specific you can be about when you experience something of concern and the conditions that accompany it, the better the chance that your doctors, carer, friends and families will be able to help.

Please remember that your PH Patient Association is always there to help and support you. PAH is not a well-known disease and patients, and the people who share their lives, encounter many challenges that the general population are not aware of. Therefore, be assertive in getting answers to questions and issues that concern you. Be active in seeking help and solutions.

Remember that you are not alone and there are many people who live satisfying lives with PAH. You can too!

[illegible]

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

early diagnosis • best treatment • better quality of life • finding a cure



www.phaeurope.org



www.actelion.com

The International Patient and Carer Survey has been developed under the auspices of a Steering Committee, comprising of PAH experts and representatives of patient organizations. The development was sponsored by Actelion Pharmaceuticals Ltd, Switzerland.

This Patient Dialogue Tool has been developed by PHA Europe and was sponsored by an unrestricted grant from Actelion Pharmaceuticals Ltd, Switzerland.