

LIVING WITH PAH: A DIALOGUE TOOL FOR CARERS

INTRODUCING THE CARER DIALOGUE TOOL

The results of a recent international survey have improved our understanding of many of the daily challenges faced by carers of 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** patients' and carers' needs. We also realized that carers (a very diverse group including partners, parents, grown-up children, siblings and friends) could benefit from a tool to help them identify issues or emotions causing concern, from interpersonal relations to social interactions.

The **Carer Dialogue Tool*** is intended to help you record, clarify and cope with caring for a patient with PAH and its impact on your emotions, overall well-being and daily life. The tool will enable you to document your thoughts, feelings and concerns in a structured way, which can help focus discussions with doctors, family, friends and others, and get the emotional support needed to cope with the patient's illness. The Dialogue Tool can be found on pages 17–24.

In addition, we are pleased to provide a summary of the results from the international survey, which prompted the development of the Carer 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 in those countries. The complete survey results are available at: <http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/>.

*This Dialogue Tool is intended for those caring for patients with a confirmed diagnosis of PAH.

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RECOGNITION OF CARING

Caring for a patient or loved-one with PAH is a huge undertaking and you may find that there are many roles you have to play, such as seeking information, coordinating care, as well as attending to other family members and your home. You may find these roles particularly challenging if you are a parent as well as a carer. You may feel that the physical tasks and chores you carry out for the patient are affecting you physically and emotionally. It is now recognized that carers have an increased need for emotional and psychological support. Support is available from a variety of sources, including healthcare professionals and patient organizations. It is important to remember that, as a carer, you don't always need to have all the answers. The survey highlighted that carers would benefit from information on many aspects of PAH. These range from the impact of PAH on the household financial situation to seeking help for yourself or the patient on the emotional consequences of PAH. Here too, you should not hesitate to seek help from professionals and learn from the experiences that patient associations provide.

Information on the prognosis of the disease and practical advice, such as healthy exercises for the patient, may also be useful to you. If you are caring for your partner, you may also require information on possible changes in sexual relations.

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, 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.

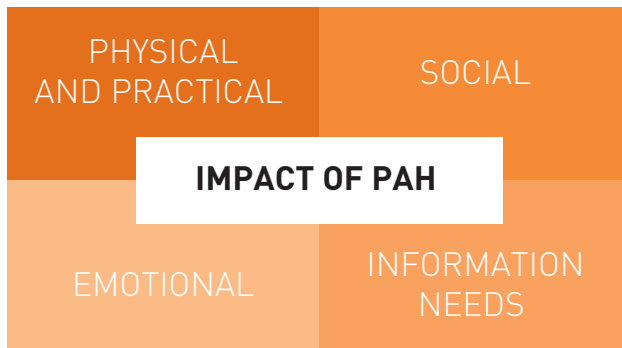
More detailed information on PAH is available on the following websites:

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 below.

Figure 1: Areas explored in the survey



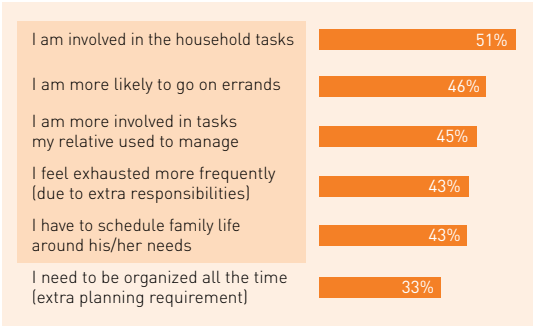
PHYSICAL AND PRACTICAL IMPACT OF PAH

*"I've taken on a lot of household chores.
I clean windows, vacuum and cook
because the person I care for
is not able to do this any longer"*

Carer

Caring for a patient with PAH can leave you physically drained, and this may be considerably worse if you are older or have health problems yourself. The survey showed that more than half of carers felt that caring for a patient with PAH had a 'very significant' impact on their daily life; for example, many felt exhausted more frequently due to their extra responsibilities. Approximately half of the carers had increased responsibilities (for instance, household tasks, or going on errands) that were previously carried out by the patient; many carers responded that they needed to be well-organized all the time (Figure 2). The survey also revealed that nearly one-third of carers reported stopping work or changing their working conditions as a result of caring for a patient with PAH. This had a major impact on carers' incomes, with more than

Figure 2. Changes to carers' lives as a result of PAH



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

one-third of carers reporting that there had been a reduction in their income. The physical impact of PAH also extended to loss of intimacy, with nearly three quarters of carers who are partners of PAH patients reporting a decrease in sexual relations. This is mainly due to the patient's lack of interest in sex since being diagnosed with PAH and the carer's fear of making the patient more ill.

Questions 1, 2, 4 and 5* of the Dialogue Tool on pages 17–22 are intended to help you clarify where you may be experiencing difficulties. This will in turn help you to prioritize what is important for you and will help you focus your discussions with healthcare providers, family members, patient organizations and other relevant parties (such as social services and local councils).

Increasing your awareness of how caring for a PAH patient affects your everyday activities is important, as it can help you find the most appropriate resources to provide the support that you need.

*Reference to question 3 of the Dialogue Tool can be found on page 19. Questions 4 and 5 are only intended for carers who are partners of patients with PAH.

SOCIAL IMPACT OF PAH

*"I no longer have hobbies as it is not feasible
with being a carer... It takes up all my time.
It takes up your whole day caring for the patient"*

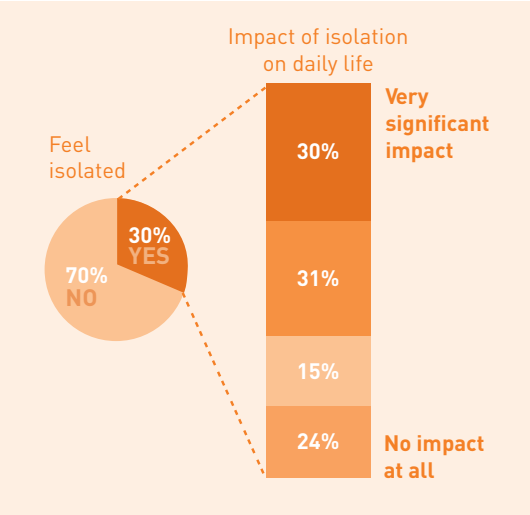
Carer

As a carer, you may feel that your world has narrowed because of the amount of time you now spend caring for someone with PAH. Feedback from the survey revealed that half of carers' time is spent caring for someone with PAH in a normal month. As a result, one-third of carers felt socially isolated or excluded and, of these, 61% found this had a significant impact on their daily life (Figure 3). Feeling isolated was greatest amongst carers who looked after patients with idiopathic PAH and in carers who had to stop working or change their working conditions. Given that PAH is often not apparent from the appearance of the patient, family, friends and the wider community often have a difficult time understanding the challenges presented by the disease. This was also found to be a major cause of carers' feelings of isolation.

By recognizing such feelings, you are already on the road to resolving many issues. Remember that you are not alone and that there are people available who fully understand how you are feeling and who are there to help and support you.

Question 6 of the Dialogue Tool on page 23 can help you to recognize if you are feeling socially isolated as a result of caring for a patient with PAH.

Figure 3. Feelings and impact of PAH on carers



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

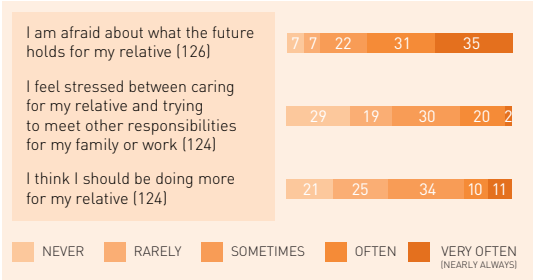
EMOTIONAL IMPACT OF PAH

*“Living with someone with PAH is like not knowing
what to expect. I don’t know how it will develop”*

Carer

The survey identified many positive aspects to being a carer, with 92% of carers feeling that they are contributing to the patient’s quality of life and nearly two-thirds feeling that caring had brought them closer as a couple or family. However, the interviews also revealed that carers tend to prioritize the patient’s emotions above their own. Two-thirds of carers reported being concerned for their relative often or very often and nearly one-quarter of carers said they felt stressed caring for their relative and trying to meet their other responsibilities (Figure 4). These feelings increased with the decline in the patient’s functional class (12% for FC II to 29% for carers of people with FC IV).

Figure 4. Carers’ feelings when caring for a patient with PAH (shown in %)



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

Question 3 of the Dialogue Tool on page 19 is intended to help you identify such feelings and will encourage and assist you in discussing such issues with health care professionals, patient organizations and those closest to you.

You may also find that the patient you care for may have signs or feelings associated with depression, which healthcare professionals might investigate, or initiate a referral to another professional. As a carer, you may be able to provide insights on these feelings and be in a position to encourage the patient to discuss these with their healthcare professional.

You may be experiencing these emotions, without being completely aware of them. It is important to address the emotional aspects so that you are in a better position to care for a patient with PAH.

As a carer, you will have a unique set of information requirements, especially relating to emotional aspects, appointments and financial consequences of caring for someone with PAH. Feedback from the survey revealed that carers are more proactive than patients in seeking information, with many actively looking up additional information from a variety of sources, which is then shared with the patient as appropriate. Overall the survey highlighted that carers were keen to receive regular updates on their relative, detailed drug information and information on the disease itself. The information requested by carers was very similar to that wanted by patients, but carers were more interested in receiving information on specialists and doctors involved in PAH care, the emotional consequences of having the condition, follow-ups (including schedules and purpose), and financial consequences.

It is important that you continue to be proactive and you are encouraged to seek advice from all available support organizations. In addition to healthcare professionals, you may find that PAH patient organizations can provide you with useful information on a broader range of topics.

The importance of patient organizations to carers was highlighted in the survey, with over two-thirds of carers having joined a patient organization, and one in four being active members.

As a carer, you will find that managing PAH is a continuous and complex process which means that you may need to repeatedly request written information.

Question 7 of the Dialogue Tool on page 24 includes a checklist of possible topics that you may wish to receive information about. As a carer, you should not be afraid or embarrassed to revisit this list with the patient's healthcare professional or patient organization as often as you need to.

Now that you have had a chance to learn more about the impact of caring for a patient with PAH on the daily lives of other carers, we encourage you to read further and to use the questions in the Dialogue Tool. This tool will help you clarify issues and emotions that, when left unaddressed, can add to the difficulties that caring for a patient with PAH entails. We hope that this Dialogue Tool will encourage you to live a full life whilst caring for a loved one with PAH.

CARER DIALOGUE TOOL

INSTRUCTIONS

The purpose of the Dialogue Tool is to help you gather your thoughts and feelings, so that you can reflect and then discuss them with your doctors, other professionals, relatives, members and staff of your patient organization and, possibly, with the person with PAH for whom you care.

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 completing this tool, please do so and continue again when you are ready.

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

PLEASE CONSIDER THE CHANGES TO YOUR DAILY LIFE FOLLOWING THE DIAGNOSIS OF PAH FOR THE PERSON WHO YOU CARE FOR.

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 YOUR LIFE	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
I have needed to make changes to my daily life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am more involved in household chores/go on errands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am more involved in taking care of our child/children (if any)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am more organized/take on planning of his or her daily life/involved in tasks my relative used to manage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I schedule our family life around her/his needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel exhausted more often (due to extra responsibilities)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am involved in administration of PAH medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>please specify:</i>	<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 you have had to make changes to your daily life, 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 carers
- ☐ Other including

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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.

Q2

HAS YOUR ABILITY TO WORK BEEN NEGATIVELY IMPACTED SINCE THE DIAGNOSIS OF PAH FOR THE PERSON YOU CARE FOR?

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 carers
- ☐ Other including

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- ☐ 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 the person I care for being diagnosed with PAH	<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.*

PEOPLE TAKING CARE OF ANOTHER PERSON OFTEN FEEL A NUMBER OF EMOTIONS. IN THE LAST MONTH, HAVE YOU EXPERIENCED ANY OF THE FOLLOWING EMOTIONS?

DATE COMPLETED: _____

EMOTIONS	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
I feel stressed caring for my relative and trying to meet other responsibilities for my family or work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my relative asks for more help than he or she needs/I feel my relative is over dependent on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that because of the time I spend with my relative, I do not have enough time for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel angry/strained when I am around my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my relative adversely affects my relationship with other family members or friends/I feel caring for my relative gives me less time to spend with my children or grandchildren <i>(if any)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am afraid about what the future holds for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel my health has suffered because I am caring for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I do not have as much privacy as I would like because of my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I will be unable to take care of my relative much longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that I have lost control of my life since my relative's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 carers
- ☐ Other including

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- ☐ Not needed/ necessary

Continued on next page ►

**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.*

Q3

PEOPLE TAKING CARE OF ANOTHER PERSON OFTEN FEEL A NUMBER OF EMOTIONS. IN THE LAST MONTH, HAVE YOU EXPERIENCED ANY OF THE FOLLOWING EMOTIONS?

EMOTIONS	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
I wish I could just leave the care of my relative to someone else/ I feel I have no choice but to look after my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel uncertain about what to do for my relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think that I should be doing more for my relative/I feel guilty that I should do more for my relative/ I feel that I could do a better job in caring for my relative	<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.*

A HAS THERE BEEN AN OVERALL REDUCTION IN YOUR SEXUAL RELATIONS SINCE THE DIAGNOSIS OF PAH FOR THE PERSON WHO YOU CARE FOR?

DATE COMPLETED: _____

SINGLE ANSWER		
Yes	<input type="checkbox"/>	▶ Go to B . You may wish to discuss this with your PAH specialist or other HCP.
No	<input type="checkbox"/>	▶ Go to Q5
I would rather not answer this question	<input type="checkbox"/>	▶ Go to Q5

B WHAT DO YOU BELIEVE ARE THE REASONS FOR THIS?

Several answers are possible. Please select all that apply.

DATE COMPLETED: _____

POSSIBLE REASONS	YES	NO
My partner has low self esteem/negative body image	<input type="checkbox"/>	<input type="checkbox"/>
I am afraid of making my partner more ill	<input type="checkbox"/>	<input type="checkbox"/>
He/she is physically not able due to PAH	<input type="checkbox"/>	<input type="checkbox"/>
I have lost interest since the PAH diagnosis	<input type="checkbox"/>	<input type="checkbox"/>
My partner has lost interest since having PAH	<input type="checkbox"/>	<input type="checkbox"/>
Afraid of pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Presence of one or more serious diseases or conditions in addition to PAH	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>please specify:</i>	<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.*

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 carers
- ☐ Other including

☐ Not needed/necessary

Q5

HAVE YOU EXPERIENCED A CHANGE IN YOUR LEVEL OF INTIMACY WITH YOUR PARTNER SINCE THEY WERE DIAGNOSED WITH PAH?

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 carers
- ☐ Other including

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- ☐ Not needed/ necessary

INTIMACY	YES	NO
I feel less close to my partner	<input type="checkbox"/>	<input type="checkbox"/>
I struggle to show my affection in other ways	<input type="checkbox"/>	<input type="checkbox"/>
I feel like my partner sees me more as a carer than a lover	<input type="checkbox"/>	<input type="checkbox"/>
I am not concerned that there has been a decrease in sexual relations and we have discussed this	<input type="checkbox"/>	<input type="checkbox"/>
I would like to find different ways of showing affection (kissing, cuddling, etc)	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>please specify:</i>	<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.*

HAVE YOU FELT ISOLATED WHILE CARING FOR ANOTHER PERSON DIAGNOSED WITH 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.

Q6

DATE COMPLETED: _____

REASONS FOR FEELINGS OF ISOLATION	NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
Lack of understanding of the disease by the person I care for who has PAH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of the disease by my/our friend/colleagues/family/children/grandchildren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of the disease by the wider society/community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My lack of empathy/compassion towards my relative's PAH condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to share my/our experience with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to share my/our experience with PAH specialists/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" (i.e., physically apparent to others)	<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 <i>please specify:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<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 carers
- ☐ Other including

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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.*

WHICH TOPICS WOULD YOU LIKE TO RECEIVE MORE INFORMATION ABOUT?

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 carers
- ☐ Other including

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- ☐ Not needed/ necessary

INFORMATION TOPICS	YES, NOW	YES, AT A LATER PERIOD	NO
The 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/drugs used for PAH therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The follow ups, including their schedules and purposes of these	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balancing work and my role as carer	<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 the 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)	<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"/>
Other <i>please specify:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Use this space for additional comments

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 doctors, 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 their carers 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 whilst caring for a patient with PAH. You can too!

[illegible]

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



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