

# Breathe: shared decision-making in pulmonary arterial hypertension

By Karolay Lorenty, Consultant, The Health Policy Partnership

**Pulmonary arterial hypertension (PAH)** is a rare, progressive condition that affects the pulmonary arteries and has a huge effect on daily life. It is characterised by high blood pressure in the pulmonary arteries, which carry blood from the heart to the lungs.

There is no cure for PAH. But new therapies can improve quality of life, extend survival and reduce health system costs. However, in many countries, people with PAH do not have access to these life-saving treatments.

To support advocates in presenting a clear case for change, The Health Policy Partnership (HPP) has published a policy toolkit, *Meeting the needs of people with pulmonary arterial hypertension*. HPP also attended the 2024 European Society of Cardiology and the European Respiratory Society congresses to discuss how to drive improved diagnosis and care for patients living with the condition.

A key theme that emerged at both congresses was that effective care for people with PAH requires healthcare professionals to listen to the perspectives of patients. This means understanding their experiences not only in regard to their symptoms, but also the impact of the condition on their mental health, social relationships, finances and other aspects of their lives.

‘Listening to the lived experiences of patients with breathlessness goes beyond understanding symptoms; it’s about seeing the person behind those symptoms. By truly hearing their stories, we can tailor care that addresses not just the physical aspects of breathlessness, but also the emotional and psychological impact it has.’

**DR IAIN ARMSTRONG, PULMONARY HYPERTENSION ASSOCIATION UK**

People with PAH describe the condition as an invisible disability that affects every aspect of their lives. For example, breathlessness is a debilitating and progressive symptom that makes it difficult to carry out daily tasks such as climbing stairs at home or taking a walk with friends. A [video](#) developed by Pulmonary Hypertension Association UK demonstrates the severe toll breathlessness takes on patients.

‘When you’re well, you can breathe without thinking about it. But when you can’t breathe, and you’re breathless, every minute and every second of every day, you’re thinking about breathlessness.’

**JULIE ROULE, PULMONARY HYPERTENSION ASSOCIATION UK**

PAH’s impact on people’s physical wellbeing also affects their financial security and their mental health. A study in Germany reported that more than half of PAH patients are not employed,



at least partly due to the impact of the condition on their physical wellbeing. These patients are also at higher risk of [mental health conditions](#), including depression and anxiety disorders.

‘You need the strength to chase away depression and the overwhelming thoughts of the worst every single day.’

**NATALIA MAEVA, BULGARIAN SOCIETY  
OF PATIENTS WITH PULMONARY HYPERTENSION**

The condition also affects fertility options; guidelines recommend that patients [avoid pregnancy](#) due to the high risk of death for both mother and baby. This can have a devastating impact, and must be handled carefully by healthcare professionals, who may provide counselling and help patients consider different options.

‘It was a surprise when the cardiologist told me, “You cannot bear a child.” It was a big shock. That was terrible. For me, it was much worse than to be ill, in fact.’

**MELANIE GALLANT, HTaPFrance**

In addition, in countries where access to effective treatment is limited, patients may experience additional obstacles to receiving the care they need. For example, Natalia Maeva, President of the Bulgarian Society of Patients with Pulmonary Hypertension, had to move to Greece to receive medication for two years before she was able to receive a double lung transplant. Other patients may only have access to outdated treatments, such as oxygen pumps, that leave them housebound.

The huge burden of PAH on patients requires effective [shared decision-making](#) to navigate the complex treatment options while improving quality of life. Clinicians and patients should discuss the advantages and disadvantages of, for example, different medications (e.g. intravenous, oral), side effects, invasive procedures and costs – as well as where treatments will be administered. Although patients want to be informed, and to accept recommendations from their clinicians, they also care about making decisions that align with their [values and needs](#).



‘I would like to stress the importance of the relationship between a patient and doctor.

A doctor’s attitude can greatly impact the patient’s treatment choices, acceptance of the disease and ultimately quality of life. Both sides need to be heard and respected – and honest and clear communication at every stage of the illness is key.’

**BARBARA BUJAR, POLISH PULMONARY  
HYPERTENSION ASSOCIATION**

By understanding patients’ perspectives, and giving them an active role in their care, clinicians foster trust and adherence to treatment, resulting in better outcomes and richer lives for people with PAH.

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