

A guide for people living with pulmonary hypertension

Empower yourself & others

Living with pulmonary hypertension can be challenging — but you're not powerless. Empowerment means gaining the knowledge, confidence, and support to take an active role in your care and live your best life. Learn, connect, and ask for help when you need it.



Understand your disease

Learn about PH, ask questions, and look for trustworthy information. Being informed helps you make better decisions.



Practice self-care & adapt your lifestyle

Focus on good nutrition, gentle exercise like walking, and energy-saving strategies. Use tools like medication trackers and symptom journals.



Connect with your community

Join patient associations and peer groups. Share experiences, learn from others, and find encouragement.



Access practical & financial support

Learn about insurance, disability benefits, and workplace rights. Don't push yourself too hard — adjust and protect your health.



Explore clinical trials

Clinical trials help improve treatments for PH. Taking part is voluntary, and your safety is always protected. Ask your healthcare team if any studies might be right for you.



Look after your mental health

Emotional well-being matters. Talk to professionals, join support groups, and practice daily stress-reduction techniques.



Work with your healthcare team

Prepare for appointments, keep health records, and use tools like the EmPHasis-10 questionnaire. Remember, you are part of the team.



Support carers & family

Include loved ones in your care, help them access resources, and remind them to care for themselves too.



Consider advocacy

If and when you're ready, your lived experience can make a difference. Patient experts help shape research, policy, and awareness.



Join awareness efforts

Take part in campaigns like World PH Day to raise awareness and promote early diagnosis.

The WHO and leading research show that empowered patients — who understand their health and actively manage their care have better outcomes, higher adherence, and improved quality of life. Patient empowerment isn't just a nice idea; it's essential for effective healthcare. For further reading on empowerment visit <https://pmc.ncbi.nlm.nih.gov/articles/PMC10463815>

pvrinstitute.org/PHpatients

Produced by the PVRi IDDI Patient Engagement & Empowerment Workstream

Pulmonary Vascular Research Institute (PVRi) is a registered charity (no. 1127115) and a company limited by guarantee (no. 05780068)