



Together, we can build a stronger, more informed PH community

Empower yourself & others

A guide for people living with pulmonary hypertension

Living with pulmonary hypertension (PH) can be challenging — but you are not powerless. Empowerment means gaining the knowledge, confidence, and support you need to play an active role in your care and live your best possible life. Empowered patients often experience better health, less stress, and a stronger sense of control. Empowerment takes initiative and time — learn, connect, and ask for help when needed.



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.

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



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.

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Produced by the PVRI IDDI Patient Engagement & Empowerment Workstream

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