

Support and empower carers & family members

Carers are key partners

- Involve them in care conversations and decisions
- Help them access resources through patient associations
- Remind them to look after their own health and well-being

Empowering carers helps everyone cope better.

Find financial & practical support

Practical support protects health and stability

- Ask about insurance, benefits, and financial aid
- Know your workplace rights – flexible schedules, accommodations, or medical leave.
- Adjust expectations – pushing yourself too hard can worsen health
- Look into programs to help with medication, travel, or home modifications

Asking for help is a strength, not a weakness.

Become a patient expert & advocate

Some patients feel called to help improve care beyond their own lives

- Join advisory boards or steering groups
- Advise pharmaceutical companies on patient priorities
- Speak at conferences or in media interviews
- Collaborate with researchers, regulators, and healthcare teams

Becoming a patient expert takes time – don't rush. When you're ready, your experience has unique power no professional can match.

Patient associations are the heart of the PH community. They:

- provide information, support, and connection
- organise campaigns like World PH Day (May 5th) to raise awareness and improve early diagnosis
- influence policy and healthcare improvements

By joining, you can access support – and one day, help shape the future of PH care.

Steps to build an empowerment plan

Empowerment is a journey

- Set personal health goals
- Create an action plan – learning, connecting, and caring for yourself
- Build a network – healthcare providers, family, peers
- Track progress – and celebrate your successes!

Resources and support networks

- Patient organisations: PH associations in your country or region
- Trusted websites: PHA Europe, PHA US, AfPH, PVRI
- Books, webinars, and courses
- Healthcare teams and mental health professionals.

You don't have to face pulmonary hypertension alone – and you don't have to do it all at once.

Take small, steady steps. Ask for help when you need it. Stay curious, stay connected, and remember: you have the power to shape your journey, and in doing so, you strengthen the entire PH community.

Pulmonary Vascular Research Institute (PVRI) is the only charity (UK charity no. 1127115) fighting pulmonary hypertension on a global scale.



Empower yourself & others

A comprehensive guide for people living with pulmonary hypertension, their families, & carers

“Together, we can build a stronger, more informed pulmonary hypertension community”

PVRI IDDI Patient Engagement & Empowerment Workstream

pvrinstitute.org/PHpatients

Living with pulmonary hypertension (PH) is a major challenge, but you are not alone – and you are not powerless.

Empowerment means gaining the knowledge, skills, and confidence to actively shape your healthcare journey, improve your quality of life, and, when ready, help others. This booklet provides practical advice, encouragement, and resources for patients, families, and carers.

Why is empowerment important?

Empowerment transforms patients from passive recipients of care into active participants. It helps you to:



understand your disease & treatment options



participate in decisions about your care



reduce stress and feel more in control



improve communication with your healthcare team and family



choose to help others as a patient expert or advocate, influencing research, policy, and care improvements

Key areas of empowerment

Understand the disease & treatment

Knowledge is power

- Ask questions during appointments. Write them down beforehand
- Find reliable information – through patient associations, trusted websites, and medical experts
- Explore clinical trials if you're interested – ask your doctor what's right for you

When you understand your disease, you can make informed decisions and advocate for yourself confidently.

Access psychological support & mental wellbeing resources

Living with PH can bring anxiety, sadness, or frustration

- Talk to professionals like psychologists or counsellors who understand chronic illness
- Join support groups to connect with others who “get it.”
- Practice coping strategies like mindfulness, meditation, and relaxation exercises
- Include your family – they need support too

Caring for your mental health makes you stronger, calmer, and better able to handle challenges.

Practice self-care & make lifestyle adaptations

Small, daily actions add up

- Eat a balanced diet suited to your needs.
- Engage in gentle exercise, such as walking, with your doctor's approval
- Conserve energy – pace yourself, plan rest, and adapt your home if needed
- Use trackers or journals for medications and symptoms

Remember: self-care is not selfish – it's essential.

Engage in shared decision-making in healthcare

You are part of your healthcare team

- Prepare for appointments with a list of concerns
- Know your rights as a patient, and don't hesitate to ask for explanations

- Use tools like EmPHasis-10 to communicate how you're doing
- Understand the team roles – specialist, nurse, pharmacist, therapist
- Ask for second opinions if something doesn't feel right

Partnership leads to better, more personalised care.

Connect with peer-to-peer support and community engagement

Community strengthens resilience

- Join patient associations or local groups.
- Share experiences, tips, and encouragement
- Start a group or online forum if none exist in your area
- Become a peer mentor when you feel ready

You are not alone – and you can help others feel less alone too.

Explore clinical trials & research participation

Clinical trials can improve future treatments and your own care. Participation is always voluntary and strictly regulated

- Ask your doctor what studies are available
- Learn what's involved, including risks and benefits
- Understand your rights and how your safety is protected
- Decide what feels right for you or your child

Taking part in research is a personal choice – being informed helps you feel confident.