

Your PAH Management, Your Voice

Living With PAH Can Be Hard

Pulmonary arterial hypertension (PAH) is a rare disease, which means that not a lot of people have it. It is also a progressive disease, which means that it can get worse over time, demanding more energy and time from you, as well as your doctors and healthcare team members. You have to deal with a lot – symptoms from PAH, taking your medicines on time, side effects from those medicines, if they happen, sometimes you may need help from a family member or friend to do a task or activity -- all of this can affect your mental and physical health. The good thing is, you are not alone in your PAH journey.

It Takes a Team to Manage PAH

There will be many healthcare team members helping you throughout your PAH journey. Your PAH healthcare team can include experienced and specialized doctors, such as a pulmonologist and cardiologist, nurses, pharmacists, and others. There are also professionals who can help with any practical, social, financial, and emotional needs that you may have.

For example, doctors will monitor how well your heart and lungs are functioning. They will adjust, or even add medicines, to prevent your PAH from getting worse. Nurses can help answer your questions about the disease, pharmacists can answer your questions about your medicines, a nutritionist can help you with a diet and exercise plan, and a social worker can help you with work or family life issues.



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You have an important role in the management of your PAH. You may be working closely with your doctors and healthcare team so it is important that you feel comfortable and trust your team and have good, open communication with them so that they can help you achieve the best outcomes possible with your PAH.



It is possible to have a long, healthy life with PAH. By being more informed, you can be more motivated and empowered to take better care of yourself. By having open communication with your healthcare team, they may be able to find a way to help you, for example, if you are experiencing symptoms from PAH or side effects from a medicine.

Do your part to improve your PAH:

- Be informed about PAH, the disease and how it is treated
- Take your medicines as directed (for PAH and for any other health conditions that you have)
- Make sure to go to all of your doctor visits
- Get the recommended tests done
- Be willing to change or add more medicines to treat your PAH
- Work with your healthcare team -- ask questions and communicate any problems that you're having

Questions to Ask Your PAH Healthcare Team

Here are some questions you can ask to get the conversation started:

- What is PAH?
- What medicines do I take to treat PAH?
- When do I take the medicines?
- How are they taken?
- What else should I do to stay healthy?