

Empowering the Patient with Associated PH

As a patient with congenital heart disease (CHD) and pulmonary arterial hypertension (PAH), I know how hard it is to juggle two diseases. It was hard enough having one major disease growing up, but acquiring PAH in my early thirties was a whole new ballgame! I've gone through life with doctors saying things like, "We just don't know how your body will respond," and "We haven't had any patients like you." With PH and all the fancy medicines that comes with it, I hear things like this even more often than before!

That is why it is important for people like me, who have PH with an associated disease, to stay on their toes. Patients with associated diseases have to be proactive with their health management so they can help all the specialists they see coordinate with each other. Our doctors need to consider everything that's going on in our bodies and how our various diseases and symptoms interact. Here are some things you can do to become your own health advocate and help your doctors give you proper treatment:

1 Educate yourself and your medical professionals

Stay educated about your diseases. I use the PHA website, the Adult Congenital Heart Association website and the websites of the specialty pharmacies. I ask lots of questions of my doctors, nurses and pharmacists. Read what you can, pay attention to the news and talk to other patients. Use the forums on the websites, connect with local support groups and go to conferences. The key is to use your common sense because if there is one thing I've learned, it's that I'm not in the textbooks. Run new information you come across by your PH specialist as it may not apply to you.

Armed with what you've learned, be sure all your doctors understand your primary and associated illnesses. Many doctors aren't familiar with PH and how to treat it, or how associated diseases affect PH. It often falls to the PH patient to educate their non-PH specialists.

2 Get your doctors talking

Communication between patient and doctor is key. You can ask why a medication or procedure has been recommended and what it will entail. It's part of your doctor's job to answer these questions and listen to what you need. This holds true in

the hospital too. If a doctor other than your own prescribes a medication you weren't expecting, it is your right to ask who ordered it and get verification from your doctor or ask the doctor on call to come talk to you.

It is also important that your doctors communicate with each other because PH poses different risks and challenges in association with other diseases. Try to find doctors who are willing to work together. It helps to have a good primary care physician who understands your needs and is willing to work with your other doctors. It's also important that your associated disease specialists are willing to consult with your PH doctor.

Between consultations, it's up to you to take responsibility for communicating information among all of the doctors treating you. Keep up-to-date on your medicines and stay informed about side effects and interactions with other medications and foods. Be as thorough as possible when relaying your medical history and medications to new doctors or when having a procedure.

3 Listen to yourself

Having grown up with chronic illnesses, I was taught at an early age by my doctors to take cues from my body. While I always keep in mind that I'm not the expert, sometimes I have information from other doctors, from past experiences or from the way I'm feeling that is helpful in guiding my care. And remember you don't have to do it alone — look to your family members, friends and other doctors to back you up when you need support and encouragement to stand up for yourself.

As you can see, there are lots of things to consider, and honestly, my healthcare coordination truly is my second job. However, my hard work usually pays off. We, as patients, need to use all our resources and fight for what we need. ♦

By Melinda Schissel

PH Patient

"PH Plus" is devoted to patients with PH and associated illnesses. To learn more visit

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