Fact or Fiction? PAH Myths and Truths

Pulmonary arterial hypertension (PAH) is one type of high blood pressure in the arteries that goes from your heart to your lungs. Several myths exist about PAH. Let’s explore.

PAH MYTH #1: PAH is a single disease.

PAH is a form of pulmonary hypertension, or high blood pressure in the lungs. When people say that they have PAH, they usually mean that they have a form of pulmonary hypertension that is due to scarring of the small blood vessels going into the lungs. When these vessels are blocked, it causes a strain on the part of the heart that pumps the blood (right-sided heart failure). Although PAH may be caused by other diseases, sometimes there is no apparent cause. It is very important to identify a specific cause, if possible, since choosing the best treatment will depend on it.

PAH MYTH #2: PAH and pulmonary hypertension are the same thing.

Pulmonary hypertension is a general term for any form of high pressure in the blood vessels in the lungs. There are five large categories of diseases that cause pulmonary hypertension. PAH may be seen in some diseases that have narrowing and scarring of the small blood vessels that go to the lung.

PAH MYTH #3: An echocardiogram is good enough to diagnose PAH.

The echocardiogram is a noninvasive ultrasound of the heart to find pulmonary hypertension, but it is not the best test to confirm PAH. A right-sided heart catheterization is needed to make sure that PAH is present. In this procedure, your doctor passes a narrow plastic tube through a vein and into the pulmonary artery to measure the pressure directly.

PAH MYTH #4: There is no treatment for PAH.

Although PAH is usually not curable, there are several medications that are effective in treating PAH. The choice of medicines is based on the patient, the severity of the PAH, and the cause of the PAH.

PAH MYTH #5: I have no control over my disease.

PAH tends to get worse over time, but committing to taking the right medications, dieting, exercising, and stopping smoking are also very important. Because PAH is uncommon and the medications may be complicated to prescribe, it may help to see doctors with a lot of experience with the disease.

PAH MYTH #6: There are no forms of curable pulmonary hypertension.

Most forms of pulmonary hypertension are treatable but not curable, but some can be cured. The most common of these is pulmonary hypertension caused by old blood clots. This disease may be cured with surgery but requires an experienced physician to determine if the disease is present and potentially curable.

PAH MYTH #7: If I am taking medications, I don’t have to worry about my diet.

While medications can make a tremendous difference for the patient, it is still important to follow a healthy diet. Avoiding extra salt can help to prevent water retention and swelling. Salt is hidden in many forms of food, such as premade foods and canned goods. You have to be very alert to these sources of salt.

PAH MYTH #8: My doctor said that I have PAH, so there is no need for more tests.

Since PAH is caused by many different diseases, the testing that we do for patients with pulmonary hypertension is to help us prove that you have the disease, determine what type of pulmonary hypertension that you have, and decide which medication is best for you. The testing also helps us to know how you respond to treatment.

PAH MYTH #9: I should not exercise.

Exercise is important for most patients. Doctors typically suggest that patients get some exercise every day, and your doctor can help you decide what exercise to do and how strenuously you do it. Some patients join a supervised cardiac or pulmonary rehabilitation exercise program. You should never push to the point of severe symptoms, chest pain, or near fainting. Discuss this with your doctor.

PAH MYTH #10: I should just get a lung transplant.

Transplantation is not done as often as in years past because medications are more effective. However, some patients with very severe disease despite use of medications, dieting, and exercising benefit from lung transplantation. Transplantation can cure the pulmonary disease but comes with its own risks and challenges. In general, patients who respond well to treatment for PAH may not need transplant, but others who do not respond well or who begin to decline should discuss a lung transplant with their physician.