

Why Transition to Adult PH Care?

Why Am I Transitioning?

The goal of this guide is to help you and your parents prepare for your transition into adulthood and to an adult healthcare setting. Although you may want to stay with your current pediatric medical team, one that you may have known for many years, you may be required to transition to an adult team due to hospital policy. A few years before you turn 18 years old, you should discuss and create a plan for your transition with your pediatric team and your parents. If you make these preparations a few years, rather than a few months, before your transition, you won't be overwhelmed when it's finally time to move on, whether you are 18, 21, 25 years or older.

Why Am I Not Transitioning?

Some of you may not be transitioning to an adult PH clinic. There are many reasons why your pediatric medical team will continue to follow you through early adulthood. Sometimes your doctor prefers to follow you until you are 21 years of age or older. For example, if you have pulmonary hypertension associated with a congenital heart disease, there may be no adult cardiologist in your local area who is comfortable caring for you, in which case, you may remain with your current pediatric PH medical team.

Even if you are not going to transition to an adult care setting any time soon, you should still develop a plan with your current medical team and your parents to help you gain greater independence in managing your medical care.

What To Expect in an Adult Healthcare Setting

Transitioning to an adult healthcare setting will mirror much of what you will be experiencing when you turn 18 years old. That is, you will be gaining greater responsibilities as a legal adult, requiring you to be responsible for making decisions about your medical care. Your parents can still help you make these decisions and participate in your care as much as you would like, but the medical team will ultimately communicate directly with you and look to you for the final decision. For example, in a routine clinic visit, the adult team will be speaking directly to you when discussing your medical issues. They will expect that you are knowledgeable about your disease and that you are relatively independent in your day-to-day medical care.

At the first clinic visit, it is important to discuss with the team what you know, what you don't know, and how much you are doing independently. It is also important to discuss how involved you want your parents to be involved in your medical care.

Whether you remain in a pediatric PH practice through your early adult life or transition to an adult practice when you turn 18 years old, this Transition Guide will provide you with some background on pulmonary hypertension, the current available medications, and the responsibilities that you will need to gain to have a successful transition into an adult medical care setting and, more importantly, a smooth transition into your adult life.



This article was written by Michelle Ogawa, CPNC-NP, and Darci Albrecht, LCSW, as an addition to the adapted Teen Transition Guide. The Teen Transition Guide has been adapted from the Vera Moulton Wall Center for Pulmonary Vascular Disease at Lucile Packard Children's Hospital. The adaptation was reviewed by Michelle Ogawa, CPNC-AP.