

Moving On...

*Transitioning from the Pediatric
to the Adult Care Team*



Authors

Darci Pfeil, CPNP and Craig Becker, MSSW in collaboration with the University of Wisconsin Pediatric and Adult Pulmonary Teams.

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For copies of this booklet contact

The Department of Pediatrics
Division of Pediatric Pulmonology
American Family Children's Hospital
600 Highland Avenue K4/938
Madison, WI 53792-9988
608•263•8555

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A Special Note To You And Your Family:

As a way to help make a smooth transition from pediatric to adult care, we have created this booklet to help you learn more about your pulmonary diagnosis and how to take charge of your cares and health.

We understand that at first, your parents will probably help you to read this and reach your goals. As time goes on, we hope that you will start to use this booklet on your own. This is a great way to build confidence in yourself, and also to let your parents know that you are learning to take care of yourself.

As you learn more about your pulmonary diagnosis, you can take charge of your life and your cares.

We wish you well on your journey...



What Is Transition?

To get started, we look to our “old friend” Webster’s dictionary. According to Webster, transition is “the passage from one state, stage, or place to another.” At the University of Wisconsin pulmonary clinic, we see it as moving from pediatric to adult health care in a way that feels safe and smooth to you and your family.

What Is Our Philosophy Regarding Transition?

We are committed to caring for people with pulmonary disease across their lifespan. Helping young adults and their families move to the adult care team is a big part of our commitment. We believe transition is a rite of passage or a milestone that you and your family will experience. This is a big change. We want you to know that you are not alone and we will be here to help you with this change. We’ll help you throughout your journey and promise to take good care of you along the way.

With all of the advances in pulmonary care, we are seeing our young adults grow up... get jobs, go to college, get married and have their own families. Just like school prepares children for the future, we hope that your time in pediatrics prepares you and your family for life as an independent, healthy adult. Our goal for all young adults is to learn about and manage their pulmonary diagnosis.



What Is the Pulmonary Team's Policy On Transition?

The pulmonary team has a policy that states that all young adults under the age of 18 will be cared for in the Children's Hospital. It also states that we can provide care to the age of 21. Both the pediatric and adult pulmonary teams expect that the majority of the patients will transition between 18 and 19 years of age. To help you make a smooth transition, we have developed a program to help you learn more about how to manage your pulmonary diagnosis as you move from pediatric to adult care.

Stages Of Transition

Just as you had to roll over before crawling and crawl before walking and walk before running, there are times when you are ready to learn new things and take on more responsibilities. We have broken down these times into six stages. We have given you an overview of what to expect during each stage.

Our philosophy is that you will be as active as possible in the decision making and management of your pulmonary diagnosis. We have also included a checklist to help you learn more about your pulmonary diagnosis. Learning the specific skills in each list will help you to take charge of your life and your cares.



Stage 1

Ages 8-10

The pulmonary team begins to ask you (instead of your parents) questions about your health, medication and therapies.

We help you to start to understand how your body uses the food you eat to grow and stay healthy. This means we help you to understand what is normal for your body. This will help you to learn more about your pulmonary diagnosis and start to know why you take medications and do airway treatments.

Checklist:

- Explain what it means to have your pulmonary diagnosis.
- Understand why some people have your pulmonary diagnosis and others do not.
- Begin to learn how your lungs work.
- Understand why airway treatments are necessary.
- Begin to learn why good nutrition is important.
- Help parents remember your medications.
- Name your medications (slang is O.K.) and simple reasons for taking them.



Stage 2

Ages 10-12

We continue to ask you questions about your health and medications. Try to answer questions about your health without help from your parents. We also continue to help you to understand your body's respiratory baseline. We help you to see when there is a change in your baseline. For example, we help you think about if there are changes in your breathing. When you begin to notice these changes, you can start to take charge of your own care. This helps you to be more independent.

Checklist:

- Explain what it means to have your pulmonary diagnosis.
- Continue to learn how your lungs work.
- Remember (most of the time) to do your airway treatments on your own.
- Continue to learn why good nutrition is important.
- Take medications on your own.
- Name medications (use proper names) and reasons for taking them.
- Begin to answer questions in clinic.



Stage 3

Age 13

The pulmonary team starts to talk with you and your parents about what will happen when you turn 14 years old. At that time, we will start to see you alone for the first half of the visit. We will ask your parents to join you for the last half of the visit to review information, talk about the health care plan and answer any questions or concerns. This helps you to be more independent and to start to build confidence that you can take care of your health.

Checklist:

- Answer questions independently in clinic.
- Understand *respiratory baseline* and changes that may occur.
- Independent with airway treatments.
- Remain independent with medications.
- List medications, the amount you take, how you take them, when you take them, and why you take them.
- Understand why you come to clinic on a regular basis.
- Begin to understand the tests you that we do and why.



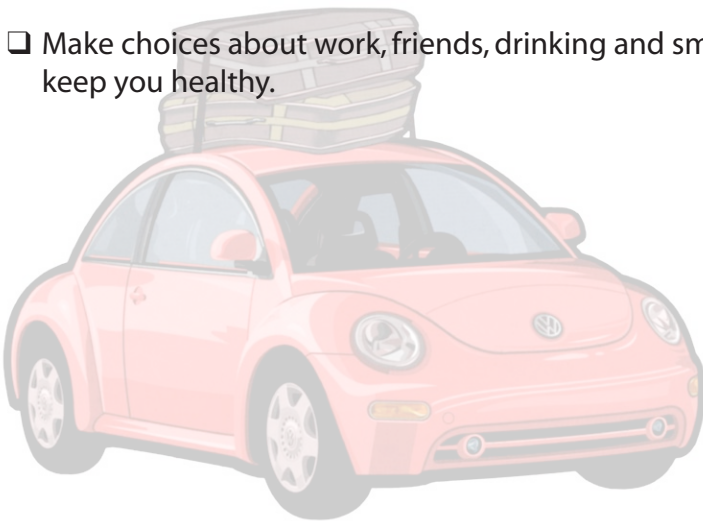
Stage 4

Ages 14-15

The pulmonary team sees you alone for the first half of the clinic visit. We will ask your parents to join you for the last half of the visit. When your parents join you and we talk about the clinic visit, it helps show what you understand. This builds trust between you and the pulmonary team, as well as between your parents and the pulmonary team. As you start to take an active role in the clinic visits, it helps you to be a part of the decisions that are made about your care. You will be introduced to the concept of transition to the adult care team when you are 16-17 years old.

Checklist:

- Remain independent with airway treatments.
- Remain independent with your medications.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits.
- Continue to understand the tests that we do and why.
- Make choices about work, friends, drinking and smoking that keep you healthy.



Stage 5

Ages 16-17

This is a time when you (instead of your parents) begin to talk directly with the pulmonary team over the phone when there are changes in your health. We will talk about plans after you finish high school and how job and career choices may impact you and your health. **We will talk about when to transition to the adult care team.** You and your family will have a chance to meet with adult team members during a clinic visit. We can also arrange for you and your family to visit the adult pulmonary inpatient unit so you can meet more adult team members.

Checklist:

- Remain independent with airway treatments.
- Remain independent with medications.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits.
- Continue to understand the tests that we do and why.
- Continue to make choices about work, friends, drinking and smoking that keep you healthy.
- Begin to monitor medication and supplies.
- Begin to call the pulmonary center and speak directly with staff if there are changes in your health.
- Begin to schedule follow up clinic appointments.
- Begin to understand reproductive choices and the impact on your overall health.



Stage 6

Ages 18-21

This is the stage when transition to adult care takes place. We expect you to contact the pulmonary center independently if there are changes in your health. You manage your own medications and supplies and contact the pharmacy or equipment provider when refills are needed. We will talk about how school, work and lifestyles choices impact your health. We will continue to talk about transition, link you with the adult pulmonary team and may also arrange a visit to the adult pulmonary inpatient unit if you desire.

Checklist:

- Remain independent with airway treatments.
- Remain independent with medications.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits.
- Continue to understand the tests that we do and why.
- Continue to make choices about work, friends, drinking and smoking that keep you healthy
- Monitor medications and supplies. Contact the pharmacy or equipment provider when refills or additional supplies are needed.
- Call the pulmonary center and speak directly with staff if there are changes in your health.
- Continue to schedule follow up appointments.
- Continue to understand reproductive choices and the impact they have on your health.
- Secure financial coverage or insurance.
- Identify a person to make health care decisions for you if you become unable to do so
- Begin to identify possible adult care providers



How To Prepare For Transition

What adult family members can do...

1. When your child is age 8, begin talking to him/her about the changes that will happen in clinic. Explain that we will start to ask questions directly to him/her. This will allow your child to get comfortable answering questions while they have a “safety net” of a parent in the room.
2. Work with your child at home to take an active role in his/her care. You can use the checklist that we have provided as a guide. Gently encourage independence, but know that it will take time.
3. When your child is 14, encourage him/her to see the pulmonary team independently for the majority of the visit. You can join your child and care providers at the end of the visit to review information and ask any questions or concerns you may have. This will help your child become independent and form a relationship with his/her health care providers. This can also help him/her learn how to form future relationships with the adult care team.
4. Find out about the age limit and terms of coverage under your health insurance policy.
5. Find out how your insurance company handles referrals to the adult health care team.
6. If it would be helpful to you, ask to speak to another parent who has a child who has transitioned to the adult care team.
7. Remember, you are not alone and we will be here to help you with this change.



How To Prepare For Transition

What adolescents / young adults can do...

1. As you get older, take on more responsibility for your care.
2. Keep a list of your medications, health care providers and other information about how you manage your pulmonary diagnosis.
3. Learn how to obtain and maintain an appropriate weight through good nutrition.
4. If it would be helpful to you, ask to speak to another young adult who has recently transitioned to the adult care team.
5. Find out how your health insurance coverage works.
6. Identify a person to make healthcare decisions for you if you become unable to do so.
7. Make a list of questions to ask your future health care provider.
8. Work through the checklists for each of the six transition stages.
9. Remember you are not alone... your parents, and the pediatric and adult care teams will help you with this change.



How to Prepare for Transition

What the health care team can do...

1. Encourage you to meet the adult care team.
2. Encourage you to come to clinic prepared to talk about your health, medication and supplies.
3. Remind you that you are not alone and promise to help you with the move to the adult care team.
4. The adult care team will answer your questions and ease you into their system.



How Do You Know When It Is Time to Transition?

1. Do you take responsibility for your own care most of the time?
2. When you give the pulmonary team your health history, does it sound the same as what your parents tell the team? Does your health history match with the pulmonary team's view of your health?
3. Do you take your medications and do your airway treatments without your parents reminding you?
4. Do you communicate directly with the pulmonary team?
5. Do you know when you need refills for your medication or supplies? Do you contact the pharmacy or equipment provider?
6. Do you have a plan for your future, such as college or work?
7. Have you met the goals in each checklist?



If the answer to all the questions is “YES”, then you are ready for transition.

If the answer to any of the questions is “NO”, then a plan will be made to help you be more independent with that part of your care. However, answering no to any of the above does not stop you from transitioning to adult care. The adult care team is experienced in helping young adults become independent.



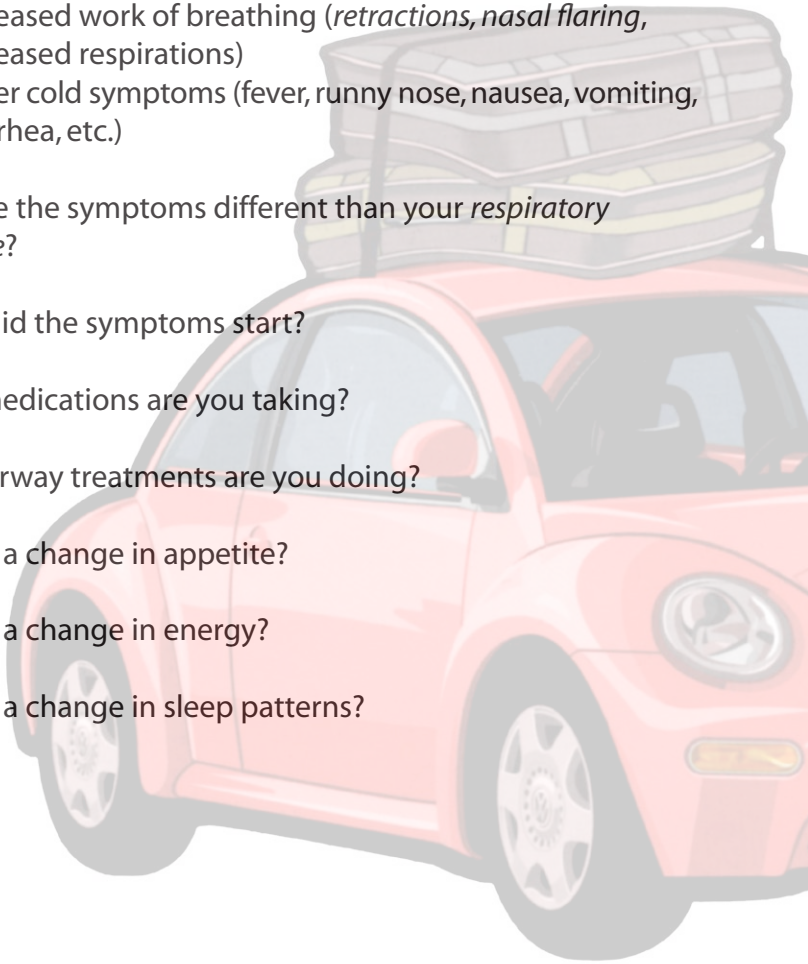
How Does Your Information Transfer To The Adult Care Team?

When you transition from the pediatric to the adult care team, your *medical records* will be transferred as well. In addition, there is also a page included for you and your family to write down any specific information that you want the adult care team to know. You can use the page in your booklet titled, "Patient and Family Notes to the Adult Care Team" or you can create your own. If you choose to include this information, please mail it to the pulmonary center or bring it to a clinic visit and we will make sure it is included in your file. By putting all of your medical information together, we believe it will make for a smooth and organized transition.



Common Questions You Will Be Asked When Calling The Pulmonary Center:

1. What are your symptoms?
 - a. Cough (wet or dry) (day or night)
 - b. Wheeze
 - c. Shortness of breath
 - d. Increased work of breathing (*retractions, nasal flaring, increased respirations*)
 - e. Other cold symptoms (fever, runny nose, nausea, vomiting, diarrhea, etc.)
2. How are the symptoms different than your *respiratory baseline*?
3. When did the symptoms start?
4. What medications are you taking?
5. What airway treatments are you doing?
6. Is there a change in appetite?
7. Is there a change in energy?
8. Is there a change in sleep patterns?



Glossary:

Medical Records: documents that contain one's health history, medical diagnoses, and treatments; cannot be shared without the individual's written permission.

Nasal Flaring: occurs with working harder to breathe and is shown by opening the nostrils wider during breathing.

PFTs or Pulmonary Function Tests: breathing tests that measure how much air your lungs hold.

Respiratory Baseline: the level of respiratory symptoms you have when you feel well.

Retractions: an increased work of breathing displayed by drawing in of the neck muscles, chest muscles or rib muscles.









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