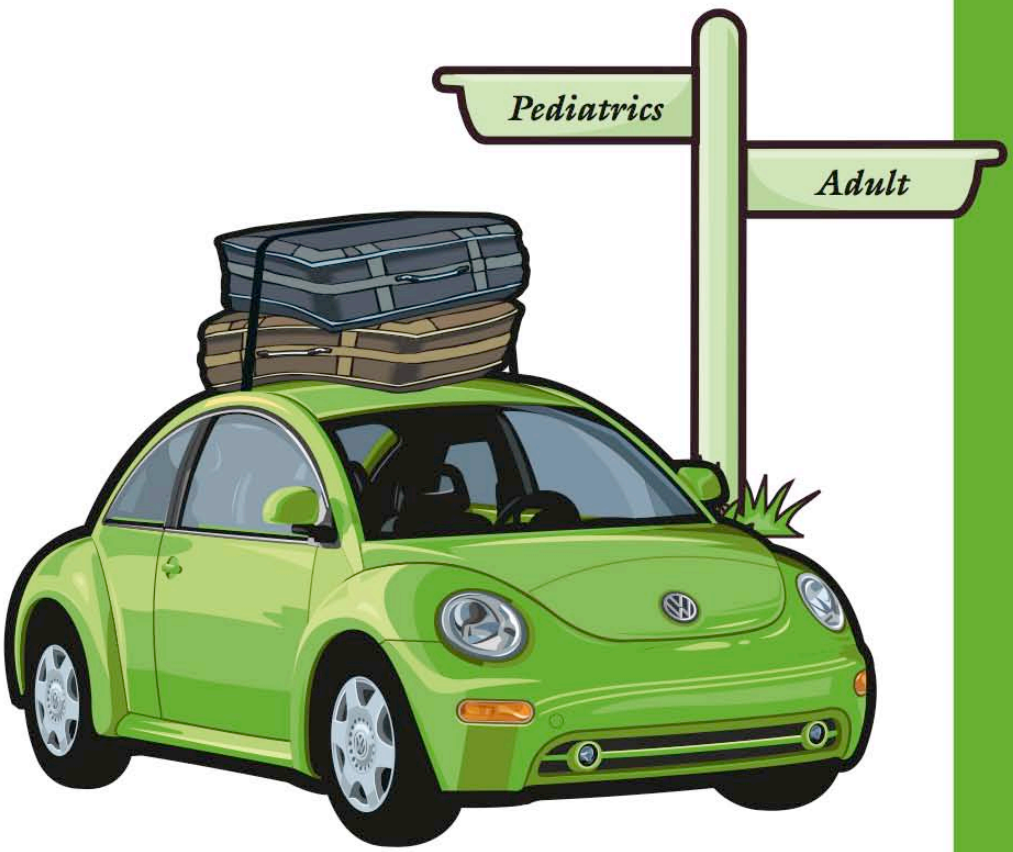
Moving On...

Transitioning from the Pediatric to the Adult Care Team



UW Health

University of Wisconsin
Children's Hospital

A Special Note To You And Your Family:

As a way to help make a smooth transition from pediatric to adult care, we created this booklet to help you learn more about CF and how to take charge of your cares. 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 let parents know that you are learning to take care of yourself. As you learn more about CF, 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 CF Center, we see it as moving from pediatric to adult 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 CF 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 right 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 CF 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 CF.

What Is The CF Center's Policy On Transition?

The CF Center's policy on caring for young adults states that all young adults under the age of 18 will be cared for in Children's Hospital. It also states that we can provide care to the age of 21. Both the pediatric and adult CF care teams expect 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 CF as you move from pediatric to adult care.

Stages Of Transition

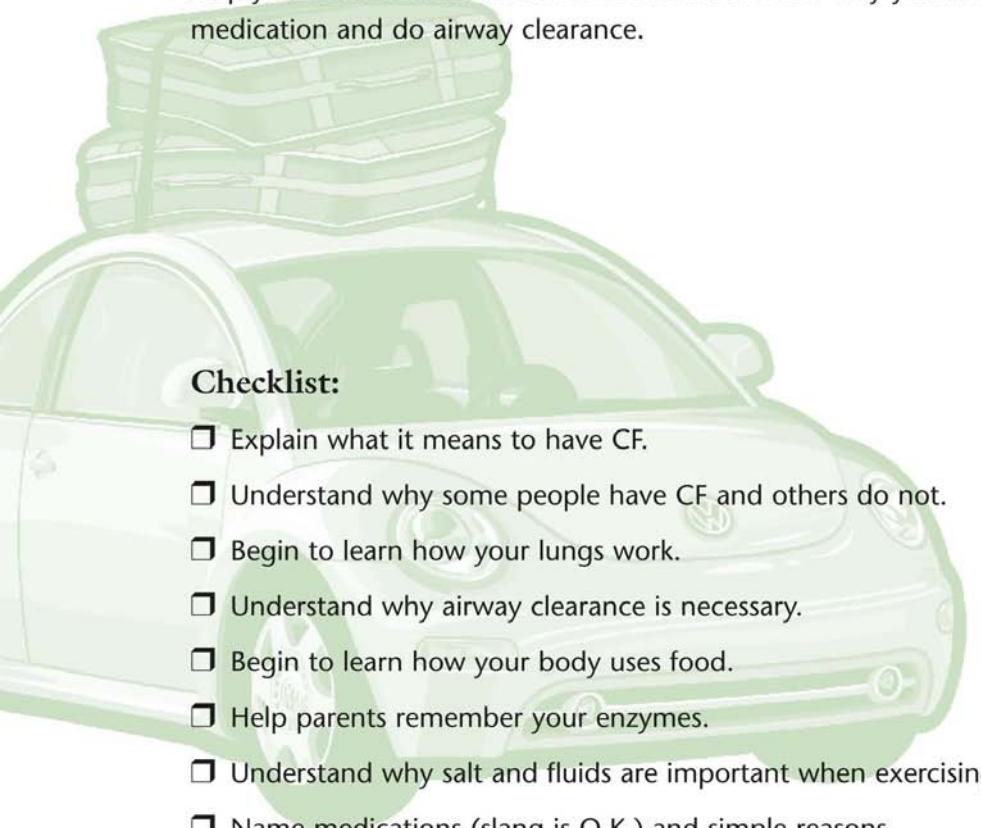
Just as you had to roll over before crawling and crawl before walking and walk before running, there are times when you are ready to learn new things and take on more responsibilities. We have broken down these times into six stages. We have given you an overview of what to expect during each stage.

We have also included a checklist to help you learn more about CF. 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 CF team begins to ask you (instead of your parents) questions about your health, medication and therapies. We help you start to understand how your lungs work and how your body uses the food you eat to grow and feel strong. This means we help you to understand what is normal for your body when you are healthy. This will help you to learn more about CF and start to know why you take medication and do airway clearance.



Checklist:

- ❒ Explain what it means to have CF.
- ❒ Understand why some people have CF and others do not.
- ❒ Begin to learn how your lungs work.
- ❒ Understand why airway clearance is necessary.
- ❒ Begin to learn how your body uses food.
- ❒ Help parents remember your enzymes.
- ❒ Understand why salt and fluids are important when exercising.
- ❒ Name 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 understand your respiratory and digestive baseline. We help you see when there is a change in your baseline. For example we help you think about if there are changes in your cough, if you are going to the bathroom more often, or if you are having stomach aches. When you begin to notice these changes, you can start to take charge of your care. This helps you to be more independent.

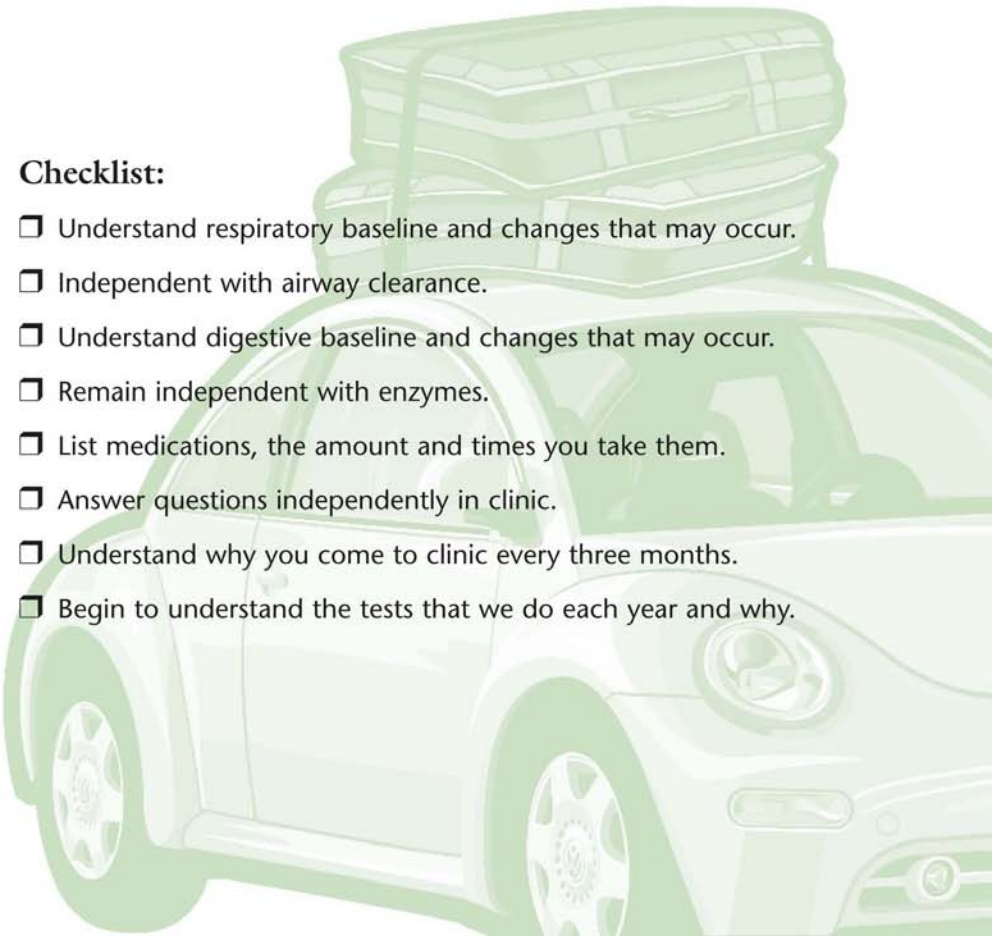
Checklist:

- ❒ Explain what it means to have CF.
- ❒ Continue to learn how your lungs work.
- ❒ Remember (most of the time) to do airway clearance on your own.
- ❒ Continue to learn how your body uses food.
- ❒ Take enzymes on your own.
- ❒ Remember to take more salt and fluids when exercising.
- ❒ Name medications (use proper names) and reasons for taking them.

Stage 3

AGE 13

The CF 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:

- ❒ Understand respiratory baseline and changes that may occur.
- ❒ Independent with airway clearance.
- ❒ Understand digestive baseline and changes that may occur.
- ❒ Remain independent with enzymes.
- ❒ List medications, the amount and times you take them.
- ❒ Answer questions independently in clinic.
- ❒ Understand why you come to clinic every three months.
- ❒ Begin to understand the tests that we do each year and why.

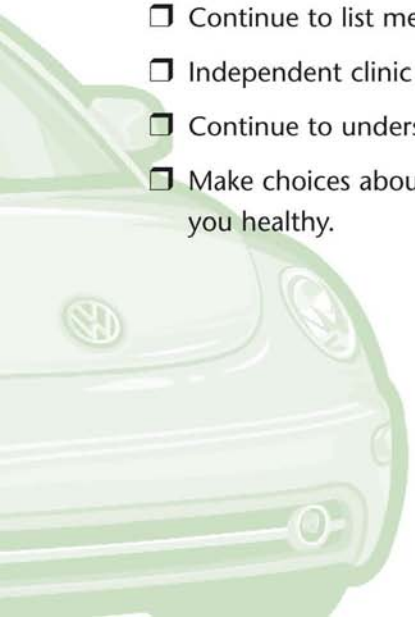
Stage 4

AGES 14-15

The CF 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 CF team, as well as between your parents and the CF team. As you start to take an active role in the clinic visits, it helps you to be 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 clearance
- ❒ Remain independent with enzymes.
- ❒ Continue to list medications and doses.
- ❒ Independent clinic visits.
- ❒ Continue to understand the tests that we do each year and why.
- ❒ Make choices about 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 CF center staff 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. (See more detail about this clinic visit under "common questions and concerns about transition…") We can also arrange for you and your family to visit the adult pulmonary inpatient unit so you can meet more adult CF team members.

Checklist:

- ❒ Remain independent with airway clearance.
- ❒ Remain independent with enzymes.
- ❒ Continue to list medications and doses.
- ❒ Continue independent clinic visits.
- ❒ Continue to understand the tests that we do each year 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 CF center and speak directly with staff if there are changes in your health.

Stage 6

AGES 18-21

We expect you call to the CF center independently if there are changes in your health. You manage your own medications and call for refills when needed. We will talk about how school, work and lifestyle choices impact your health. We will continue to talk about transition, link you with the adult CF team and may also arrange a visit to the adult pulmanary inpatient unit if you desire. You will transition care to the adult care team.

Checklist:

- ❒ Remain independent with airway clearance.
- ❒ Remain independent with enzymes.
- ❒ Continue to list medications and doses.
- ❒ Continue independent clinic visits.
- ❒ Continue to understand the tests that we do each year and why.
- ❒ Continue to make choices about work, friends, drinking and smoking that keep you healthy.
- ❒ Monitor medication and supplies. Call pharmacy when refills are needed.
- ❒ Call the CF center and speak directly with staff if there are changes in your health.
- ❒ Secure financial coverage or insurance.

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 the "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 CF 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.

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, doctors and other information about how you manage your CF.
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 health care team.
5. Find out how your health insurance coverage works.
6. Make a list of questions to ask your future health care practitioner.
7. Work through the checklists for each of the six transition stages.
8. Remember you are not alone...your parents, and the pediatric and adult care teams will help you with this change.

What the health care team can do...

1. Encourage you to meet the adult care team. (See more about this in the section "Common questions and concerns about transition")
2. Encourage you to come to clinic prepared to talk about your health, medication and therapies.
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 care system.

Common Questions And Concerns About Transition

"I don't know any of the people on the adult care team"

Enclosed in the booklet you will find a flyer entitled "Who's Who on the Adult CF Care Team". The flyer will list names, pictures and give a brief description of each team member.

"I know and trust the people in pediatrics. I know who to call and I know what to expect."

Many young adults and families know the pediatric care team and know what to expect and what is expected of them. We will help you to meet the adult care team and ease any stress about the change.

"I heard they do things different on the adult care team."

As you get older, you will be making more of the decisions about your care along with your parents. This is to help you ease into adulthood responsibilities. The adult care team assumes that young adults manage their health care on their own. They are still focused on the family, but in a different way. With your permission, any member of your family, parents, spouse, companions, or close friends can attend clinic and participate in your care. The adult care team encourages family members to remain supportive yet allow you independence when feasible.

"How will I meet the adult care team?"

You will have several opportunities to meet the adult care team. At the appropriate time, we will set up an appointment for you and your family to meet some of the members of the adult care team. They will explain to you and your family their style and what a typical clinic day may be like. The focus will be talking about transition, meeting adult care team members, and learning their approaches and philosophies. This will be a chance to have them

answer any questions you may have. A visit to the adult CF clinic can be arranged if you wish. This will give you another opportunity to meet more adult care team members, ask about their style, and how they provide care.There will be other opportunities for you to meet the adult care team if you are hospitalized. People with CF who have already transitioned can also be a good source of information.

"What can I do for healthcare coverage and insurance after the age of 18?"

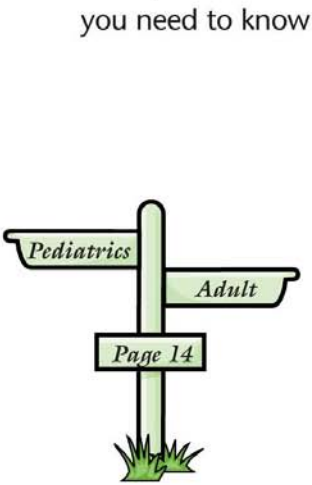
There are many different types of health care coverage and some that are specific for adults with CF in the state of Wisconsin. A visit with the adult care team is a time you can ask questions about insurance coverage. As always, social work is available on both the pediatric and adult care teams to answer insurance questions.

"Can I transition to the adult care team if I have advanced disease?"

Of course you can. Actually, we will encourage you do so particularly if you are a candidate for transplantation. The adult care team physicians are part of the Lung Transplant Program and the Intensive Care Units.

How Do You Know When It Is Time To Transition?

1. Do you take responsibility for your own care most of the time? This includes choosing and making your meals and using supplements to meet your nutritional needs.
2. When you give the CF team your health history, does it sound the same as what your parents tell the team? Does your health history match with the CF team's view of your health?
3. Do you take your medications and do your airway clearance without your parents reminding you?
4. Can you tell the CF team when you have symptoms of a respiratory infection or malabsorption? Do you know when you need antibiotics? Do you know when you need to change your enzyme dose?
5. Do you speak directly with the CF team?
6. Do you know when you need refills for your medication? Do you call the CF team or pharmacy?
7. Do you have a plan for your future, such as college or work?
8. Have you met the goals in each checklist? (This will assess what you need to know about your disease before you transition.)



If the answer to all the questions is "yes", then you are ready for transition.

If the answer to any question 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. We will also include a medical summary form (see example on the next page) as a way to provide a quick reference to your current health status. In addition, there is also a page included for you and your family to write down any specific information that you may 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." If you choose to include this information, please mail it to your CF 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.

Medical Summary Transfer Form

ATTACHMENTS:

❑ The most current history, medications and exam dictated from the most recent clinic visit.

❑ Family notes to the adult care team.

MR # _____

Name: _____

DOB: _____

Age at diagnosis: _____ State of birth: _____

Sweat test results: _____ Dx suggested by: _____

Complications at birth: _____

Genotype: _____

Current health status:

❑ Mild disease

❑ Moderate disease

❑ Severe disease

Baseline spirometry: _____

Brasfield CXR score: _____

Sputum cultures: _____

Does the patient routinely do home IV therapy?

❑ YES ❑ NO

Airway clearance:

❑ Flutter ❑ PEP ❑ Vest

❑ IPV ❑ Manual ❑ Other

Current living situation: _____

Insurance: _____

Nutritional supplements: _____

Vocational: Is the patient in school?

❑ YES ❑ NO

What is he/she studying? _____

Is he/she working? _____

Advanced directives?

❑ YES ❑ NO

Patient And Family Notes To The Adult Care Team

What would you and your family like the adult care team to know about you?