

# Transition Guide:

For Patients and Families  
Moving from the Pediatric to the  
Adult Care Team...the 5 W's of  
Transition...Who, What, Where,  
When and Why

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# Who Transitions?

- Patients who are between 18-21 years of age
- Transition formally starts at age 8
- Patients and families are given the Cystic Fibrosis Transition Guide Booklet



# What is Transition?

- According to Webster's Dictionary, transition is “the passage from one state, stage or place to another.” At Stanford CF center, transition is when our patients move from pediatric to adult care safely and smoothly.
- Transition is a normal milestone that patients and families will experience. The CF Center Care Team is committed to caring for people with CF across their lifespan. Helping young adults and their families move to the Adult care team is part of our strong commitment.

# Update on the Transition Booklet

- Breakdown of the booklet

Introduction

Defining transition

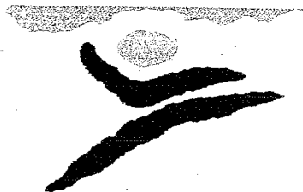
Stages 1-6

Preparing for transition

Questions/concerns about transition

When is it time to transition?

Miscellaneous forms



### **STAGE OF TRANSITION 1: Ages 8-10**

The CF team begins to ask you (instead of asking 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 medications 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.
- ☐ Understand the importance of taking enzymes before each meal and snack. Work towards independence with enzymes (remember when to take enzymes at appropriate times).
- ☐ Understand why salt and fluids are important when exercising.
- ☐ Name medications (slang is O.K.) and simple reasons for taking them.
- ☐ Understand what each CF team member does for you (respiratory therapist, nutritionist, social worker, nurse coordinator and physician).
- ☐ Understand the importance of good handwashing.

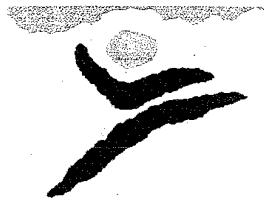


## **STAGE OF TRANSITION 2: Ages 11-12**

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 will continue to help you understand your respiratory and digestive baseline, for example: noticing a change in your cough, or change in your bathroom schedule. When you begin to notice these changes, you can start to take charge of your care. This helps you become more independent.

### **CHECKLIST**

- ☐ Continue to understand what it means to have CF and why some people have CF and others do not.
- ☐ Continue to understand how your lungs work and start to learn the name of the "bugs" that grow in them.
- ☐ Continue to understand why airway clearance is necessary. Learn how to wash your own nebulizers at home.
- ☐ Continue to learn how your body uses food (Why is important to eat meals and snacks high in calories and protein?; Why do you need to take vitamins everyday?)
- ☐ Work towards independence with enzymes.
- ☐ Understand why salt and fluids are important when exercising.
- ☐ Name medications (slang is O.K.) and simple reasons for taking them.
- ☐ Know CF team members by name. Know where to find clinic phone numbers, if you had to call.
- ☐ Start to learn the names of the different "bugs" that grow in your lungs
- ☐ Begin to understand changes in CF reproductive anatomy.
- ☐ Discuss body image: How does having CF make you feel?
- ☐ Begin to understand normal growth and development for the patient with CF.
- ☐ Begin to discuss teen issues surrounding sexuality, dating, and reproductive issues.
- ☐ Begin to think about healthy and common sense choices about hanging around with friends who might be drinking alcohol or smoking.



### STAGE OF TRANSITION 3: Ages 13-14

The CF team starts to talk with you and your parents about what will happen when you turn 15 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

- ☐ Independent with airway clearance and enzymes.
- ☐ Understand the reason for your clinic visit (Do you know why you are being seen today?).
- ☐ Understand your normal respiratory and digestive health (your "baseline")
- ☐ Describe changes in your "baseline" to your parent(s), nurse, or doctor.
- ☐ Know the names of the different "bugs" that grow in your lungs.
- ☐ List your medications: the amount and times you take them.
- ☐ Answer questions independently in clinic.
- ☐ Begin to understand the tests we do each year and why.
- ☐ Wash your nebulizers at home and prepare nebulized medications on your own.
- ☐ Begin to understand the tests that we do each year and why.
- ☐ Answer the following question: At what age do you see yourself independent during clinic visits?



#### STAGE OF TRANSITION 4: Ages 15-16

The CF team sees you alone for the first time 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 to show you that 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, you will feel like you can contribute to the decisions that are made about your care. You will be introduced to the concept of transitioning to the adult team when you are 17 years old. You will transition to adult focused CF care between the age of 18 and 21.

#### CHECKLIST

- ☐ Remain independent airway clearance and enzymes.
- ☐ Continue to independently name medications and doses.
- ☐ Semi-independent clinic visits. Learn to feel comfortable in discussions with the team about your health.  
TIP: Bring a written list with your questions/issues to each appointment.
- ☐ Understand the reason and importance of certain tests we order each year.
- ☐ Understand issues surrounding sexuality, dating, and reproductive issues.
- ☐ Make healthy and common sense choices about hanging around with friends who might be drinking alcohol or smoking.





### **STAGE OF TRANSITION 5: Age 17**

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 health care team. You and your family will have a chance to meet with the adult team pulmonologist and nurse coordinator during a clinic visit. A visit to the Stanford inpatient unit will be arranged so that you can become familiar with the adult-focused hospital setting. At this time, if you have a change in health, you (instead of your parents) will be encouraged to talk directly with the CF center staff over the phone so that we can make a plan.

#### **CHECKLIST**

- ☐ Remain independent with airway clearance and enzymes.
- ☐ Continue to list medications and doses.  
TIP: Bring your own medication list to clinic!
- ☐ Help your parent(s) monitor your medications and supplies.
- ☐ Continue semi-independent clinic visits.
- ☐ Continue to understand the tests that we do each year and why.
- ☐ Make healthy and common sense choices about friends, drinking, and smoking.
- ☐ Have a good understanding of issues surrounding sexuality and CF reproductive issues.
- ☐ Continue to make healthy and common sense choices about hanging around with friends who might be drinking alcohol or smoking.
- ☐ Begin to call the CF center and speak directly with the nurse coordinator if there are changes in your health.  
TIP: Create a binder to keep all your CF health information together.
- ☐ Work on securing financial coverage/insurance before you turn 18.
- ☐ Work on securing an adult primary care provider.

TIP: Talk to your primary care pediatrician to find out how long you can stay in their practice. Before you turn 18, ask your family, friends and primary care pediatrician to recommend an adult provider.

## STAGE 6: Ages 18 to 21

We expect you to call 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 and link you with the adult CF program. During this stage, you will transition to adult-focused CF care.

### CHECKLIST

- ☐ Attend clinic visits independently.
- ☐ Continue independence with airway clearance, enzymes, and medications.
- ☐ Continue to understand the tests we do each year and why.
- ☐ Continue to make healthy and common sense choices about friends, drinking and smoking.
- ☐ Independently monitor medications and supplies. Call pharmacy when refills are needed.
- ☐ Call the CF center and speak directly with the nurse coordinator if there are changes in your health.
- ☐ Secure financial coverage or insurance.
- ☐ Secure an adult primary care provider.
- ☐ Complete the "Medical Summary Transfer Form" before you transition to the Adult CF Program (see pocket in this guide).

# Where do you transition to?

## Stanford University Hospital



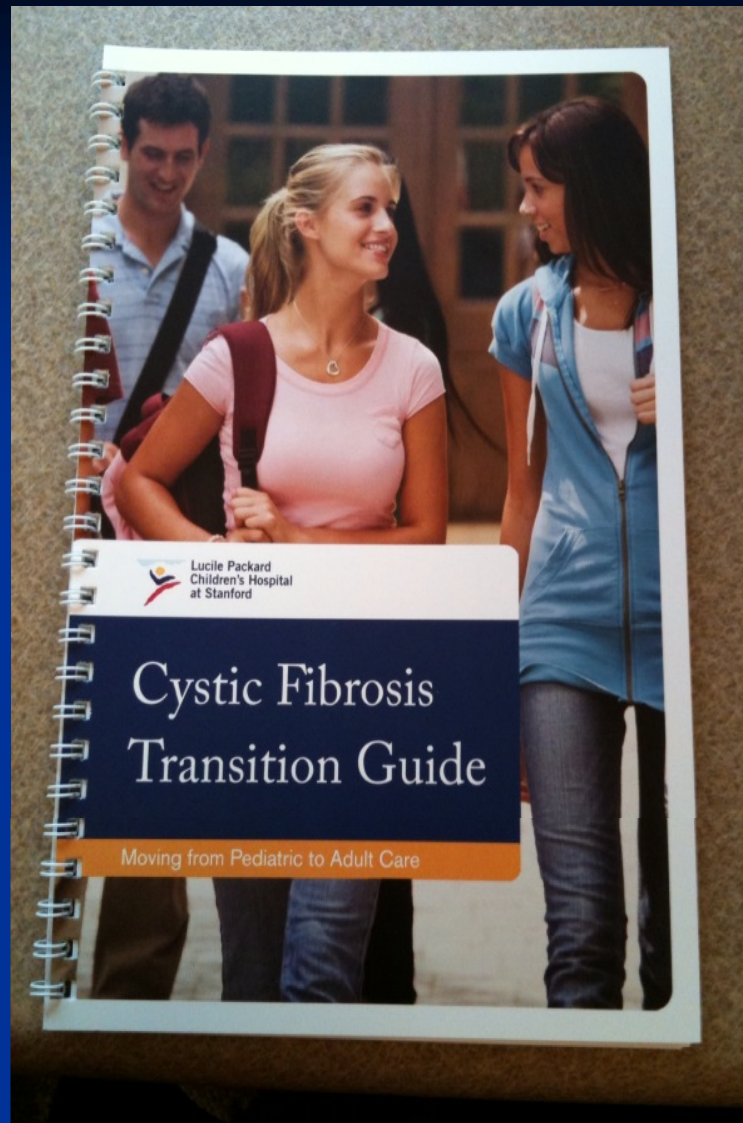
- Patients that turn 18 must be admitted to Stanford Hospital  
CF in-patients are admitted to C 3
- Outpatient clinic visits are done on the 2nd floor at SUH at the Chest Clinic

# When do you transition?

- The CF care team looks at all patients that are between 18-21 years of age to determine the readiness of the patient/family to transition
- The Pediatric and Adult CF Care Teams meet quarterly to discuss the patients that are ready to transition and a detailed outline of the patients history is discussed

# Why Transition?

- With all the advances in CF care, we have seen our young adults grow up, go to college, get jobs, get married and have families of their own. It is our hope that your time spent in the Pediatric Center prepares you and your family for life as an independent healthy adult.
- It is our goal for all young adults to learn about and eventually manage their own CF care.
- CF Adult's need adult providers!!



**Transition guides are available in clinic**