



**Connecticut Children's Medical Center
CCCFC- Pediatric Cystic Fibrosis Program**

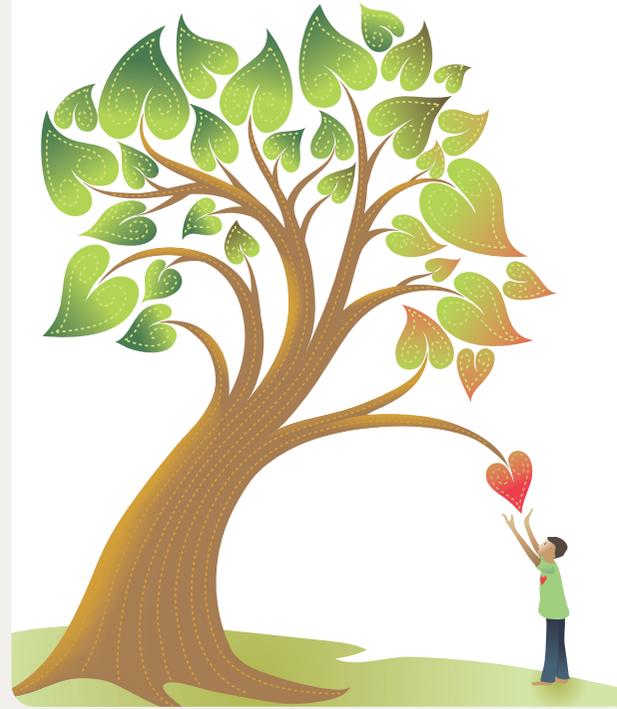
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**Hartford Hospital
CCCFC- Adult Cystic Fibrosis Program**

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TRANSITION: THE CCCFC's APPROACH

MOVING FROM THE
PEDIATRIC CF PROGRAM
TO THE ADULT CF PROGRAM



INTRODUCTION

You are being given this brochure to help you begin thinking about the change of your CF care from the Pediatric CF Program to the Adult CF Program. It will describe the steps we can take with you and your family over the next few years to prepare for the move and some basic information about the Adult CF Program.

WHAT IS "TRANSITION"? THE CCCFC'S APPROACH

Our view of **transition is that it is a change that happens over a long period of time, not overnight.** It is NOT just a "transfer" of your medical records to an adult physician when you turn 18. There are several steps involved, and we will help you get ready to take charge of your health care as one part of your transition to adulthood. Making your own decisions about your life can be exciting, but as a person with an illness that needs daily attention, you have some extra planning to do. We will work with you and your family to make a plan for as smooth a transition as possible and we want to know what you think might be the best way to do this!



A SPECIAL NOTE TO PARENTS

We know the tremendous challenges you face in raising children and how hard you have worked to get your child to this point. Soon it will be up to your child to make all his/ her own decisions, and it may be difficult to hand over the reins of healthcare management to them. But your child's increased independence does not mean that your job ends! Rather, **your job responsibilities change.** Teaching your child when, what, where and from whom to ask for help will be your biggest task now. **A good way to think about your role is that it gradually changes from that of "caregiver" to "coach".** The CF team has tremendous respect for the amazing job you have already done! Please don't hesitate to talk with us about concerns or questions you might have.

AGE OF FINAL TRANSFER:

The CCCFC's policy



The policy of our Center and of Connecticut Children's Medical Center and Hartford Hospital is that the final transfer of care must occur by age 18 years. Although this policy cannot be altered for hospitalizations, the Pediatric and Adult Teams are committed to working with families to provide some overlap of the two outpatient programs when absolutely necessary. Be assured that our Pediatric and Adult providers are in regular contact to coordinate these changes and support you and your family during this time.



TRANSITION TIMELINE

ASSESSMENT:

The timeline below was developed with the help of our patients and families. It is what we offer during the transition years, **but our goal is to make an individualized plan with you and your family tailored to your needs! You are not required to go through all of these steps at these exact ages**, but we want you to know what to expect and what we will offer.

AGE 12:

- The Pediatric Team begins transition education with you and your family during your visits. This will include information about insurance, college and employment.
- You and your parents may be asked to complete a "Transition Checklist" to figure out what you already know and what you need to learn.

AGE 15:

- The Pediatric Team will talk about meeting with you without your parents in the exam room so you can "practice" meeting with your doctors on your own.
- If you and your family agree, you may begin to meet with the Pediatric Team without your parents in the exam room. However, your parents will be included at the end of your visit to share information, ask questions and plan for your next visit.
- The Adult CF Program social worker may visit you during a Pediatric Clinic visit.

AGE 16:

- Between the ages of 16-17, you may have a "Transition Planning Meeting" at the Adult CF Center.
- At the end of the "Transition Planning Meeting" you will have a written plan describing what will happen over the next year or two. For example, it might include several Adult CF Clinic appointments, a tour of the Adult Clinic/ Hospital or a list of who will be responsible for providing education on various topics.
- We will begin to coordinate transfer of your sub-specialty care such as endocrinology, gastroenterology, etc.

AGE 17-18:

- You may have both Pediatric and Adult clinic visits during this year.
- Tour of CF Adult Clinic and Hartford Hospital if desired.

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ADULT CF PROGRAM DESCRIPTION

The Adult CF Program is similar to the Pediatric Program. Patients meet with a "Team" in Clinic, have many of the same tests and procedures, and are seen several times a year as recommended by the Cystic Fibrosis Foundation. Adult clinics are held three times per month at Hartford Hospital. The Adult Program has its own phone number for scheduling appointments, routine questions, and medication refill requests. The adult pulmonologists are available for urgent calls and there is always a physician on-call after hours and on weekends. At the age of 18, hospitalization occurs at Hartford Hospital on Bliss 11 East. This is a unit that specializes in the care of respiratory illnesses and is the usual floor for CF hospital stays.

SUMMARY

We hope the information in this brochure has given you an idea of what to expect as you get ready to move over to the Adult CF Program. We are always available to talk about questions you may have and will help you get ready for this important change. The move to the Adult Program should be a goal you look forward to as you take charge of your health...you have accomplished so much already and we want you to go on to reach all of the goals you have for your life!