

Taking the Next Step.....

Making the Transition from the Paediatric to the Adult CF team

What is Transition??

Transition has been defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medication conditions from child-centered to adult-oriented health care systems. It is a complex process that should incorporate medical, psychosocial, educational and vocational needs.

What is our Philosophy on 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 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 there 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 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 paediatrics 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 clinic's policy on Transition??

The CF Clinic's policy on caring for young adults states that all young adults under the age of 18 will be care for by the Paediatric CF team. Once you reach the age of 18, your care will be managed by the Adult CF team. 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 paediatrics to adult care.

Stages of Transition

As you get older, you will be ready to learn new things and take on more responsibilities. We have broken down each of these times into six stages. We have provided an overview of what to expect during each stage.

We have also included a check list to help you learn more about CF. There are many skills to learn, and knowing which ones you need to focus on can help you to take charge of your life and your care.

Stage 1 Age 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 good 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:

- 1) Explain what it means to have CF
- 2) Understand why some people have CF and others do not
- 3) Begin to learn how your lungs work
- 4) Understand why airway clearance is necessary
- 5) Begin to learn how your body uses good
- 6) Help your parents remember your enzymes
- 7) Understand why salt and fluids are important when exercising
- 8) Name your medications and simple reasons for taking them (can use slang names)

Stage 2 Age 10-12

We will continue to ask you questions about your health and medications. Try to answer the questions about your health without help from your parents. We will also continue to help you understand your respiratory and digestive baseline. We can help you to see when there is a change in this.

Checklist:

- 1) Explain what it means to have CF
- 2) Continue to learn how your lungs work
- 3) Remembers to do your airway clearance on your own (most of the time)
- 4) Continue to learn how your body uses food
- 5) Remember to take more salt and fluids when exercising
- 6) Name your medications using their proper names and reasons for taking them

Stage 3 Age 13

Starting at age 13, at one clinic visit during the year we will ask you to complete the clinic patient report will allow us to see what knowledge you have of your disease and health and what else we need to teach you. These reports will continue until you get to the adult clinic. We will also start discussing having clinic visits with you alone for the first half and then having your parents join in for the last half. This will help you become more independent and to build confidence that you are able to take care of yourself.

Checklist:

- 1) understand respiratory baseline and changes that may occur
- 2) independent airway clearance
- 3) understand digestive baseline and changes that may occur
- 4) remain independent with enzymes and all other medications

- 5) list medications, that amount and times you take them
- 6) answer questions independently in clinic
- 7) understand why you come to clinic every 3 or 4 months
- 8) begin to understand the test that we do each year and why

Stage 4 Ages 14-15

If you and your parents are in agreement, the CF team will start to see you alone for the first half of the clinic visit. You should be completing the clinic patient report and review by yourself now. We get your parents to join in for the last half. This will allow you to build trust with the CF team, as well as with your parents. As you start to take an active role in the clinic visits, it helps you to be a part of the decision making process.

Checklist:

- 1) Remain independent with airway clearance
- 2) Remain independent with enzymes and all other medications
- 3) Continue to list medications and doses
- 4) Independent clinic visits
- 5) Continue to understand the tests that we do each year and why
- 6) Make choices about friends, drinking, and smoking that keep you healthy

Stage 5 Ages 16-17

This is when you (instead of your parents) begin to talk directly with the CF clinic staff over the phone when there are concerns with 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 CF team. You and your family will have an opportunity to meet with the Nurse case manager from the adult team during your last two paediatric clinic visits. This will give you time to have your questions answered and give you a face to recognize at your first adult visit.

Checklist:

- 1) remain independent with airway clearance
- 2) remain independent with enzymes and all other medications
- 3) continue to list medications and doses
- 4) continue independent clinic visits
- 5) continue to understand the tests that we do each year and why
- 6) continue to make choices about work, friends, drinking and smoking that keep you healthy
- 7) being to monitor medication and supplies
- 8) call in for refills on medications
- 9) call CF center and speak directly with staff if there are changes in your health

Stage 6 Age 18

At this point you will have had or be having your last paediatric visit. You will be given information at this visit about the adult clinic and all of the necessary appointments you must attend prior to it. We expect that at this point you will be calling the CF clinic independently if there are changes in your health. You manage your own medications

and call for refills when needed. We will talk to you about how school, work, and lifestyle choices may impact your health.

Checklist:

- 1) Remain independent with airway clearance
- 2) Remain independent with all medications
- 3) Continue to list medications and doses
- 4) Continue independent clinic visits
- 5) Continue to understand the tests that we do each year and why
- 6) Continue to make choices about work, friends, drinking and smoking that keep you healthy
- 7) Monitor medication and supplies, call pharmacy when refills are needed
- 8) Call the CF clinic directly and speak to staff when there are changes in your health
- 9) Secure financial coverage or insurance

How family members can prepare for transition.....

- 1) When your child is 8 years old, start to talk to them about the changes that will happen in clinic. Explain that the team will ask them questions directly. This allows the child to become comfortable answering questions while they have you as a safety net in the room.
- 2) Work with our child at home to take an active role in their care. You can use the checklists in this guide to do so. Take one thing at a time and encourage independence.
- 3) When your child is 14, encourage them to start seeing the CF team on their own for the first half of the clinic visit. You can join in half way through and review the information we have gone over and ask any questions that you may have. This helps create an independence and will allow your child to form a relationship with their health care providers. This will also help them learn how to form future relationships with the adult CF team.
- 4) Find out about the age limit and terms of coverage on your insurance plan.
- 5) If you would like to speak with another parent whose child has transitioned to the adult CF team please let us know and we can arrange this for you.
- 6) Remember that you are not alone and we are there to help at any time.

What adolescents/young adults can do to prepare for transition.....

- 1) As you get older take on more responsibility for your care.
- 2) Keep a list of your medications, doctors and CF team members along with other information on managing CF
- 3) Learn how to obtain and maintain an appropriate weight with proper nutrition
- 4) If you would like to talk with another young adult who recently transitioned, we would be happy to arrange this for you
- 5) Find out about health insurance
- 6) Make a list of questions to take to your first adult clinic appointment
- 7) Over time work through the checklists for each stage
- 8) Remember that you are not alone and we are here to help you at any time.

What the CF clinic team can do.....

- 1) Encourage you to meet the Nurse case manager from the Adult team
- 2) Encourage you to come to clinic prepared to talk about your health, medications and therapies
- 3) Remind you that you aren't alone and help you with the transition
- 4) Provide you with all of the information and resources you need to become independent in your care
- 5) The adult team will answer all your questions and make the transition very smooth.

Your Health Care teams*Paediatric CF Team*

Children's Hospital, London Health Sciences Centre
 800 Commissioners Rd
 London, ON
 N6A 5W9

Erin Fleischer RN BScN Nurse Case Manager 519-685-8500 ext. 52692 Erin.fleischer@lhsc.on.ca	Dr. April Price Respirologist 519-685-8500 ext 58052
Amanda Finnie Registered Dietician 519-685-8500 ext. 53598	Dr. Brian Lyttle Respirologist 519-433-2242
Natasha Nunes Physiotherapist 519-685-8500 ext 52402	Jill Tosswill Social Worker 519-685-8500 ext 56149

Adult CF Team

London Health Sciences Centre, South Street Hospital

Tracy Gooyers RN Nurse Case Manager 519-685-8500 ext 55186 Tracy.gooyers@lhsc.on.ca	Dr. Nigel Paterson Respirologist 519-685-8500 ext 76548
Pat Leggatt Registered Dietician 519-685-8500 ext 55796	Heather Roberts Physiotherapist 519-685-8500 ext 50103
Connie Shrubsole Social Worker 519-685-8500 ext 75392	