CF Transition

Graduating from Pediatric to Adult Care
Discussion topics

- Transition: What is it and why is it necessary?
- OneCF LLC
- Readiness Assessments/CF RISE
- Transition Pathway
- Adult Team Visits
  - Welcome Booklet
  - Tours of clinic and hospital floor
- How YOU can help!
What is transition?

• A period or process of changing from one state or condition to another
  > can occur abruptly or in a more planned process over a period of time

• Our focus as a transition team is to develop and coordinate a transition process that meets the developmental and psychosocial needs of the patient as they move through adolescence to adulthood.

• Our ultimate goal is to transition patients who are self-reliant, knowledgeable about their disease, and in charge of their healthcare
In 1996, The CF Foundation recommended that all CF Centers transition at least 90% of their patients aged ≥21 years to adult providers.
Barriers to transition

- Poor communication between pediatric and adult providers
- Logistical hospital obstacles
- Parents having difficulty relinquishing primary responsibility for disease management
- Family perceives poor quality of care by internists due to lack of familiarity with pediatric diseases
- Pediatric providers fearing a decline in the level of care provided after transition
- Family-focused care provided in pediatrics which limits education, independence, and self-management skills for the adolescent

Missed opportunities

These barriers may lead to patients not seeking care until a serious problem arises, rather than engaging in preventative care.

Benefits of working towards transition

• Gives patients a sense of optimism about the future and self-worth as an adult participating in society*

• Patients indicate a higher degree of satisfaction with their pediatric center as well as a higher perception of their health status**

*Rosen DS. Cancer. 1993;71(10 Supp
**Congleton J et al. Thorax. 1996;51(9)
Approach to a successful transition

Receiving CF specialty care in pediatric medical setting (pediatric CF program).

Transfer to adult medical setting

Transition readiness increases

Engagement in adult medical setting (adult CF program)

Periodic assessment of transition readiness: eg, developmental maturity, adherence patterns, self-management skills

Ongoing transition planning intervention and support: ideal role for CF transition coordinator

How to begin?

• Introduce the idea of transition as a normal, healthy part of becoming an adult
  » Best to start discussion prior to adolescence, potentially even right after diagnosis
OneCF LLC

- Multidisciplinary effort lead by CFF re: QI approach to transition
- Improving communication between teams
The OneCF LLC Team Includes

- Coach
- Dietitians
- Nurses
- Patient
- Parent of patient
- Physicians
- Respiratory Therapists
- Social Workers
Readiness Assessments

- Preparing for transition begins early!
  - Teaching your child responsibility, skill sets, independence
  - Readiness assessments begin age 8
  - Encouraging child to speak up for themselves

Knowledge + Action = Power
Readiness Assessments

• Questions are age-specific
  » Medications
  » Independence with treatment
  » Calling care team when sick
  » Making own appointments for doctor visits
  » And more!

• These assessments help us to know how we can better prepare patients for transition.
  » Feedback is given to individual providers about specific areas for education.
CF Transition Pathway

You’re entering a very exciting phase of life! You have been learning a lot about what it means to have CF as you’ve gotten older, and we will continue to work with you to learn everything you need to know to be an adult living with CF. Part of being an adult with CF is transitioning to the adult CF care team. Don’t panic! We’re here to usher you along in this process and make every step as easy and stress-free as possible!

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Early High School
- Begin to have part of your clinic visit with the CF team without your parent present. It does not need to be the entire visit, but we want you to become comfortable about talking about your health.
- Discuss healthy lifestyle choices with your CF team. The choices you make now will have an impact on your long-term health.
- Learn what your medications are and why you take them.
- Discuss with your parents how you can take more responsibility for your care at home (cleaning equipment, organizing medications, etc.).

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Sweet 16
- Enroll in CF R.I.S.E.
- First meeting with adult CF team members

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Late High School
- Meet with adult CF team yearly.
- Independent clinic visits (without your parents present).
- Communicate directly with staff by phone calls, email, or MyChart.
- Make decisions about future goals and plans (college, employment), and how they will be affected by having CF.
- Gain independence in daily CF care at home (treatments, medications).
- Discuss insurance options for after high school graduation.

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New Adventures
- Begin an exciting new phase of life: college, work, relationships, etc.!
- Tour the adult CF facilities.
- Have your last visit in the pediatric CF clinic.
- First visit in the adult CF clinic.

Congratulations!
“Psychological readiness” for transition

Psychological components

- Adherence
- Psychiatric conditions (e.g., depression (SI/SA), anxiety)
- Possible contraindications to transition?
- Emotional readiness for change (of patients, parents, and providers)

» All taken into account when deciding individual ideal transition time
• Patient/provider portal for transition, including knowledge assessments, responsibilities checklists, and educational tools
  » Print or digital access
• Free and secure
• Helps prepare your child for disease self-management
• Pilot program to begin January 2016
• Full roll-out anticipated Fall 2016
• Educational opportunities for adults as well!
CF Knowledge Assessments

11 Assessment Topics

- CF Liver Disease (CFLD)
- CF-Related Diabetes (CFRD)
- College & Work
- Equipment Maintenance & Infection Control
- Sexual Health
- General CF Health
- Insurance & Financial
- Lifestyle
- Lung Health & Airway Clearance
- Pancreatic Insufficiency & Nutrition
- Screening & Prevention
CFR.I.S.E.  
Responsibility, Independence, Self-care, Education

CF LIVER DISEASE (CFLD)

Note: This is not a test. This assessment has been developed to help you become more knowledgeable about your CF, with the help of your CF care team.

This assessment is to be completed by a person who is 16 or older with cystic fibrosis (CF). For each question, please read all the answer choices carefully before choosing the one answer you think is best. If you don’t know an answer, leave it blank and move on to the next question.

1. Which of the following is correct?
   a) CFLD occurs because people with CF have damaged lungs
   b) CFLD occurs because the pancreas does not secrete enough chemicals and digestive enzymes for normal digestion to occur
   c) CFLD occurs because people with CF have sticky bile which can lead to blockages in the bile ducts that cause scarring in the liver over time

4. Which of the following are symptoms of CF Liver disease?
   a) Headaches, fever, and decline in lung function
   b) Joint pain, exhaustion, and muscle spasms
   c) Fatigue, bruising, and weight gain

2. Cirrhosis is:
   a) Bleeding in the liver
   b) Scarring of the liver
   c) Build-up of bile in the liver
   d) All of the above

5. To treat CFLD, you should see a specialist called a _____, in addition to the CF care team.
   a) Podiatrist
   b) Gastroenterologist or GI doctor
   c) Gynecologist
   d) General practitioner or family doctor
General CF Health

On this page, you can review all your answers and find additional resources and information.

YOUR SCORE ON THIS ASSESSMENT: 10%
Correct answers: 1
Incorrect answers: 9
Unanswered questions: 0

Talk to your CF care team if you have questions.

Click on the "Additional Resources" links to the right to learn more about general CF health.

ADDITIONAL RESOURCES
Cystic Fibrosis: A Guide for Patient and Family
Moving On, Next Stop... Adulthood
An Introduction to Cystic Fibrosis for Patients and Their Families, 6th Edition
Building Life Skills to Manage CF Webcast
Patient Registry: Annual Data Report 2013
Hemoptysis Information Sheet

YOUR ANSWERS

1. To make the most out of your clinic visit, you should:*
   - [ ] a) Write down your questions before going to your clinic visit
   - [ ] b) Ask your CF team to write down changes in your treatment plan
   - [ ] c) Keep a journal or write down changes in your health
   - [ ] d) Ask questions if you don't understand something
   - [ ] e) Answers a and d
   - [x] f) All of the above

*This question is used with permission from the Knowledge of Disease Management-CF (KDM-CF), Adolescent Version (ages 11-20). ©Quittner AL, Marcil KK, & Marcil JA.
Responsibilities Checklist for Patient & Support Person

**PATIENT CHECKLIST**

- CF Responsibilities Checklist helps patients identify aspects of their care and where they can take more ownership
- Completed by both patient and support person (ex: parent, spouse, significant other)

**SUPPORT PERSON CHECKLIST**
Meetings with the Adult Team

- Adult Team (dietitian, nurse, respiratory therapist, social worker) meet with pediatric patients who are approaching transition
  - During clinic visit or while hospitalized
  - Introductions, names and faces
- Opportunity to ask questions, learn about the adult clinic, and build relationships with the adult team
- Clinic and hospital tours available
Welcome Booklet

- A welcome booklet is given to patients at one of their last pediatric clinic appointments.

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How Can You Help?

• Encourage your child to take an active role in their care by:
  » Answering and asking questions during their clinic visit
  » Calling to talk to their nurse when not feeling well or when refills are needed
  » Know their medications and their use
  » Begin helping them learn about their health insurance coverage
WELCOME TO THE FUTURE