

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!



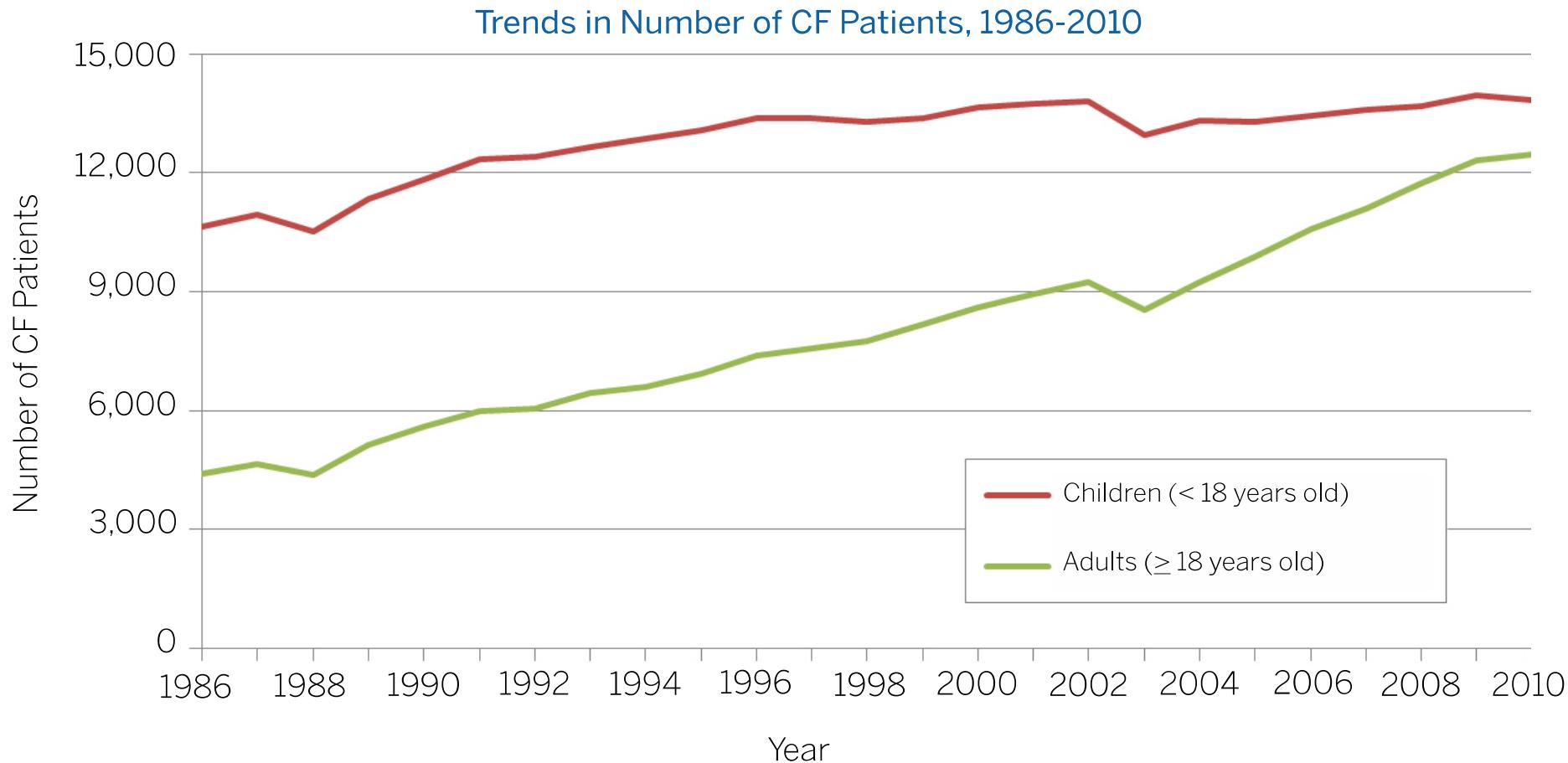
What is transition?

- 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

CF: A disease for internists



UNC
SCHOOL OF MEDICINE



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 w/ 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

Chaudhry SR et al. Ped pulm. 2013;48(7):658-65.

Nasr SZ et al. J adol health. 1992;13(8):682-5.

Blum RW. J adol health. 1995;17(1):3-5.

Flume PA. Curr opin pulm med. 2009; 15(6):611-4.

Flume PA et al. Ped pulm. 2001;31(6):443-50.

Rosen D. J adol health. 1995;17(1):10-6.

Missed opportunities

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



Nakhla M et al. Pediatrics. 2009;124(6):e1134-41.

Benefits of working towards transition

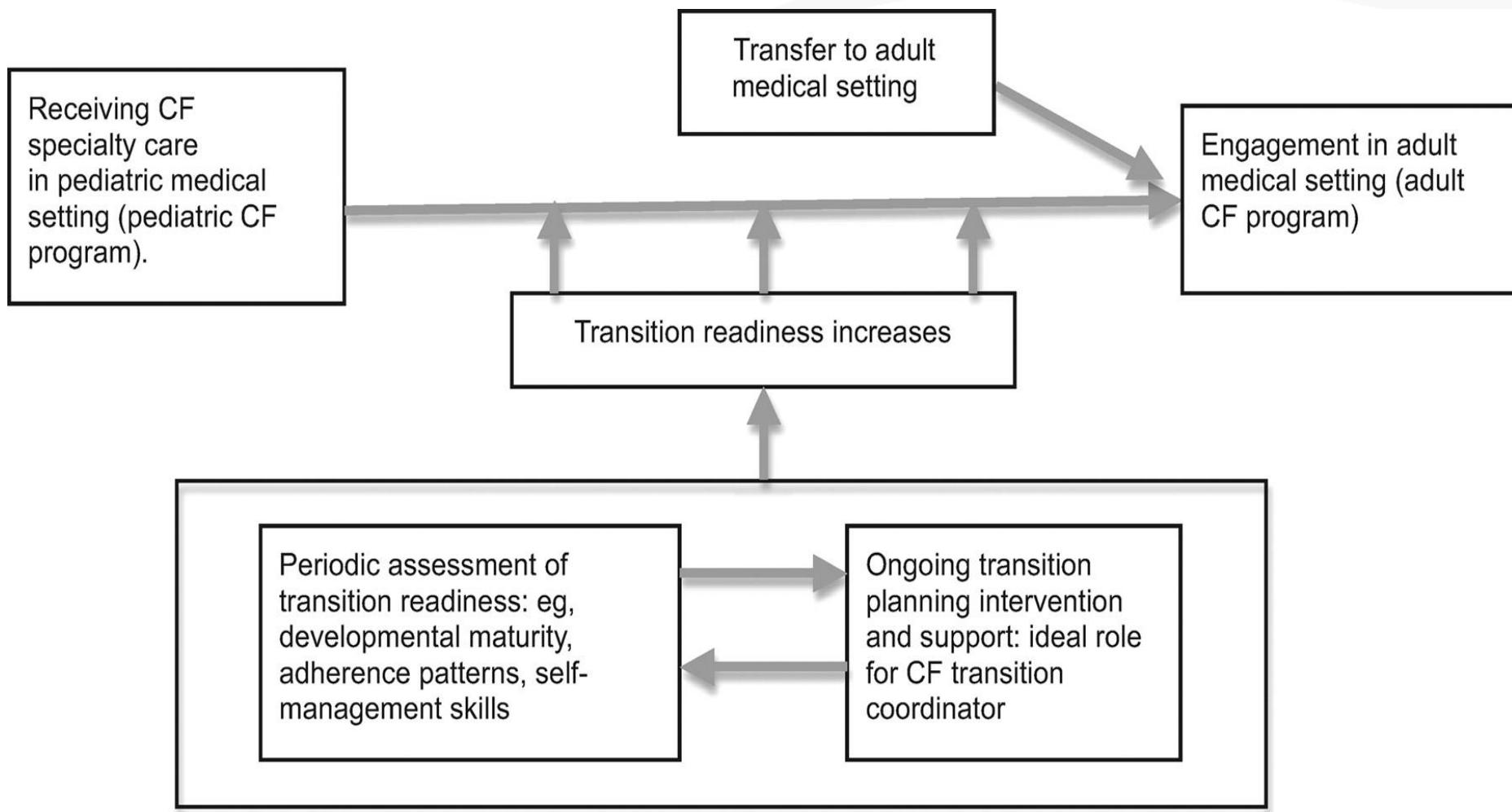
- Gives patients a sense of optimism about the future and self-worth as an adult participating in society*
- Patients indicate a higher degree of satisfaction with their pediatric center as well as a higher perception of their health status**



*Rosen DS. Cancer. 1993;71(10 Supp)

**Congleton J et al. Thorax. 1996;51(9)

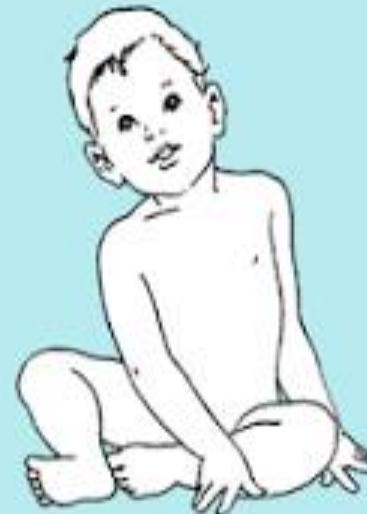
Approach to a successful transition



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

I would be more inclined to grow up if I saw that it worked out for everyone else.



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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

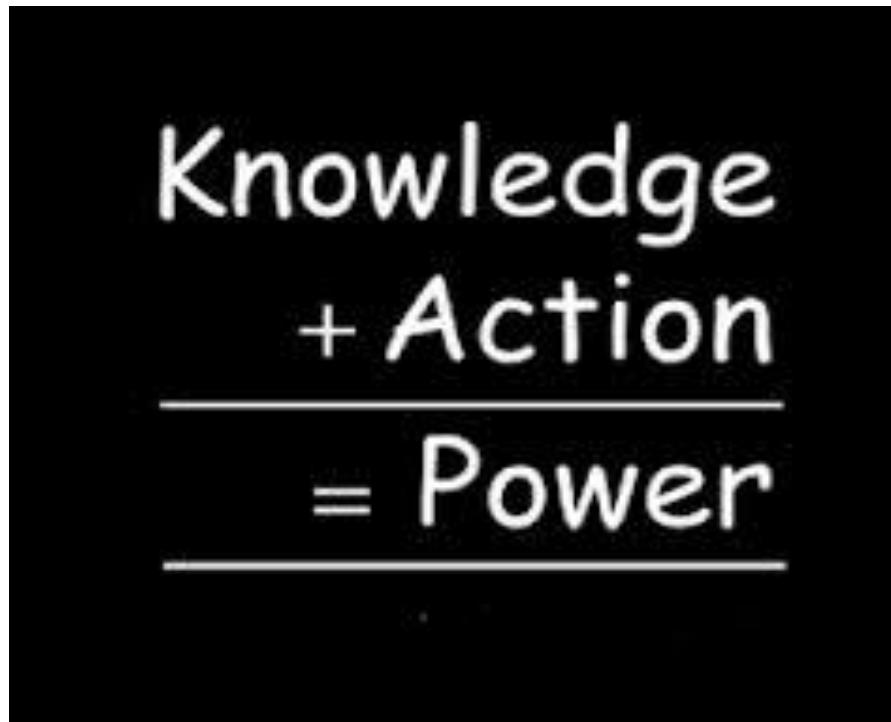
Physicians

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

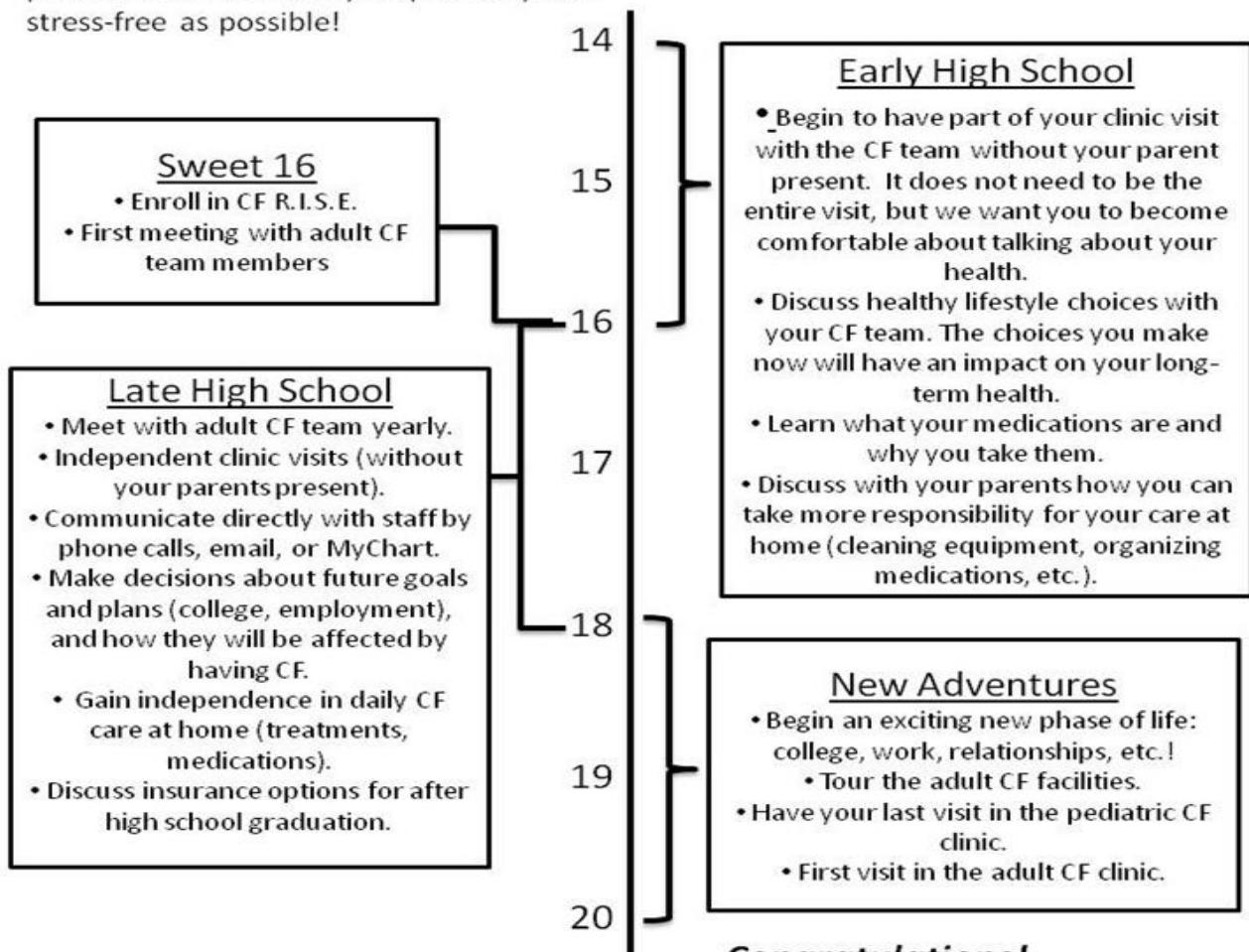


Readiness Assessments

- 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

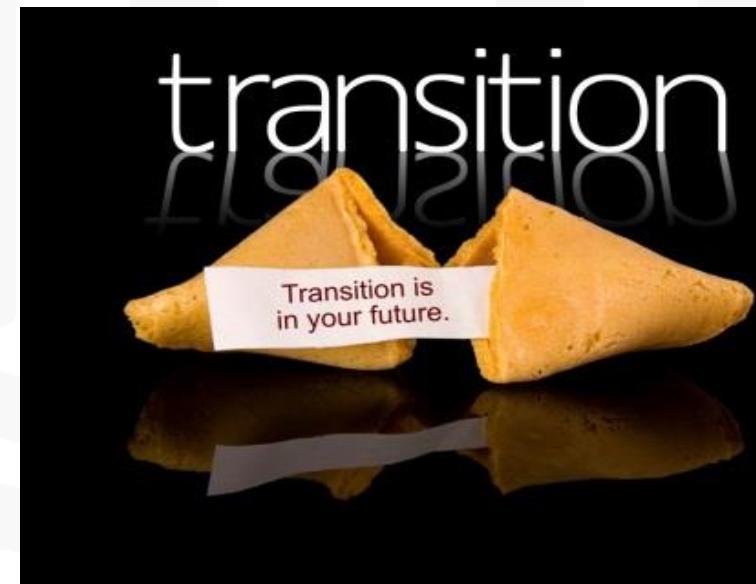
You're entering a very exciting phase of life! You have been learning a lot about what it means to have CF as you've gotten older, and we will continue to work with you to learn everything you need to know to be an adult living with CF. Part of being an adult with CF is transitioning to the adult CF 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!



“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

LUNG HEALTH & AIRWAY CLEARANCE

THIS INFORMATION MEETS THE GUIDELINES AND STANDARDS OF THE CF FOUNDATION EDUCATION COMMITTEE.

LUNG HEALTH & AIRWAY CLEARANCE

Name: _____ Date: _____

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

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

1. Pulmonary function tests (PFT) or spirometry are a fancy name for testing how well you can breathe. These tests measure how much air you can exhale from your lungs in one second. (FEV1)

a) You need to do them every day.
b) Only need to be done once in a while.
c) Depend on your effort in blowing.
d) Answers a & b.

2. Which of the following is true?

a) Forced expiratory volume in one second (FEV1) is the amount of air that can be exhaled from the lungs in one second.
b) Forced vital capacity (FVC) is the maximum amount of air that can be forcibly exhaled from the lungs in one breath.
c) Both FEV1 and FVC are measured separately.
d) All of the above.

3. Timing is everything. What is the time to take the following treatments?

a) Aromatherapy, essential oils
b) Inhaler using short acting bronchodilators
c) Inhaler using long acting bronchodilators
d) Inhaled antibiotics, inhaled short acting bronchodilators, and nebulizer clearance
e) True
f) False

CF R.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts and is sponsored by Gilead.

7. Regular exercise can result in:

- stronger heart muscle
- Potential improvements in lung function
- Being in a better mood
- All of the above

8. The following are symptoms of a pulmonary "exacerbation":

- Increased cough
- Decreased lung function
- Increased appetite
- Answers a and b
- All of the above

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



CF LIVER DISEASE (CFLD)

Name: _____

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.

Date: _____

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.

10

YOUR SCORE ON THIS ASSESSMENT: 10%

Correct answers: 1

Incorrect answers: 9

Unanswered questions: 0

[Print Score](#)

[Email Score](#)

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:*



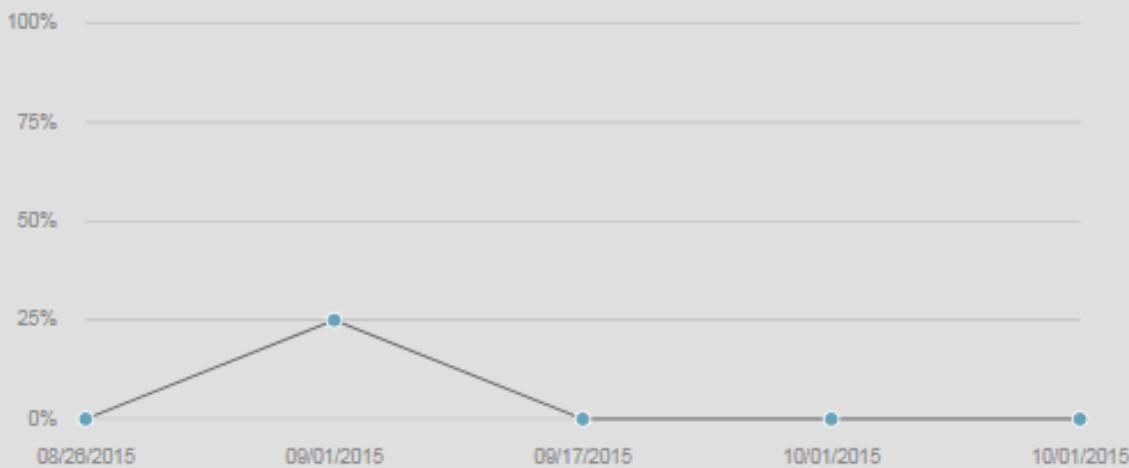
- a) Write down your questions before going to your clinic visit
- b) Ask your CF team to write down changes in your treatment plan
- c) Keep a journal or write down changes in your health
- d) Ask questions if you don't understand something
- e) Answers a and d
- f) All of the above



Screening & Prevention

YOUR AVERAGE RESULTS
FOR THIS ASSESSMENT

5



ASSESSMENT HISTORY

10/01/2015 Score: 0

10/01/2015 Score: 0

09/17/2015 Score: 0

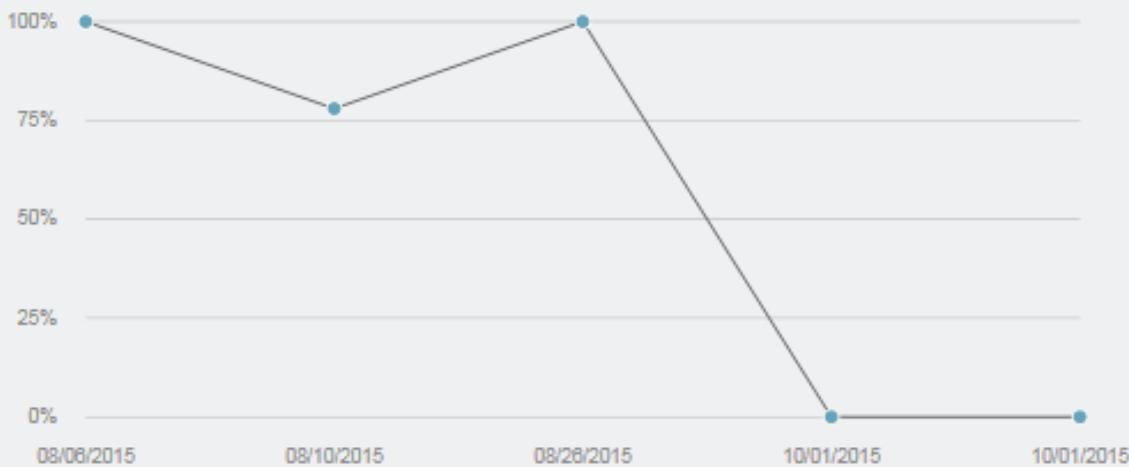
09/01/2015 Score: 25

08/26/2015 Score: 0

Equipment Maintenance & Infection Control

YOUR AVERAGE RESULTS
FOR THIS ASSESSMENT

55



ASSESSMENT HISTORY

10/01/2015 Score: 0

10/01/2015 Score: 0

08/26/2015 Score: 100

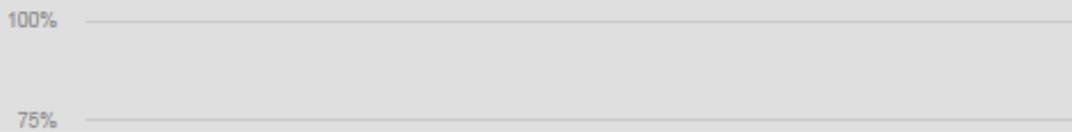
08/10/2015 Score: 78

08/06/2015 Score: 100

Lifestyle

YOUR AVERAGE RESULTS
FOR THIS ASSESSMENT

0



Responsibilities Checklist for Patient & Support Person

CF Responsibilities Checklist

CF Patient

 CFR.I.S.E.
Responsibility. Independence. Self-care. Education

2: Responsibility for CF Treatments

Name: _____ Date: _____

Note: There are no right or wrong answers to this survey. Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 I am completely responsible 2 I am primarily responsible 3 My support person and I are equally responsible 4 My support person is primarily responsible 5 My support person is completely responsible NA Not Applicable

Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Taking prescription CF medicines as prescribed	
2. Doing CF treatments as prescribed	
3. Setting up equipment to take treatments (eg, nebulizer, vest)	
4. Cleaning equipment used for treatments	

PATIENT CHECKLIST

Support Person

 CFR.I.S.E.
Responsibility. Independence. Self-care. Education

CF Responsibilities Checklist

1: Working with the CF Care Team and other Healthcare Providers (HCP)

Name: _____ Date: _____

Note: There are no right or wrong answers to this survey. Please provide your honest feedback below so that we can work together to improve the management of your CF over time.

1 CF patient is completely responsible 2 CF patient is primarily responsible 3 CF patient and I are equally responsible 4 I am primarily responsible 5 I am completely responsible NA Not Applicable

Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

1. Scheduling CF Center appointments	
2. Arranging transportation to CF Center (drives, walks or takes public transportation)	
3. Asking questions about medicines, treatments, or health concerns	
4. Answering questions from healthcare providers	

SUPPORT PERSON 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)

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