



Introducing



CFR.I.S.E.

Responsibility. Independence. Self-Care. Education.

Speaker Name

Institution

Date 1, 2015

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

CF R.I.S.E. Program Overview

(Responsibility. Independence. Self-care. Education.)

- Help **prepare and empower** patients aged 16-25 to transition to adult care
- Identify areas for improvement in patient's **knowledge and ownership** of their CF care
- Help to **facilitate communication** between patients & caregivers and their pediatric & adult care teams

Transition & Transfer

- A significant and growing CF population
- Adolescence and emerging adulthood is a critical time for patients to transition to caring for themselves
- Gaps in transfer and transition-related clinical care have been studied and identified
 - No consistent or standardized approach to transition nationally
- A growing recognition that we need to “do more” to effectively transition CF patients into adulthood

Sources:

1. Cystic Fibrosis Foundation Patient Registry: 2013 Annual Data Report. Bethesda, MD: Cystic Fibrosis Foundation; 2012.
2. Flume PA, Taylor LA, Anderson DA, Gray S, Turner D. Transition programs in cystic fibrosis centers: perceptions of team members. *Pediatr Pulmonol.* 2004;37(1):4-7
3. Parker HW. Transition and transfer of patients who have cystic fibrosis to adult care. *Clin Chest Med.* 2007;28(2):423-432
4. McLaughlin, Suzanne Elizabeth, et al. Improving Transition From Pediatric to Adult Cystic Fibrosis Care: Lessons From a National Survey of Current Practices. *Journal of the American Academy of Pediatrics*, Dec 2008.
5. Tuchman, Lisa K. et al. Cystic fibrosis and transition to adult medical care. *Journal of the American Academy of Pediatrics.* 3/1/2010.

Transition Advisory Council

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



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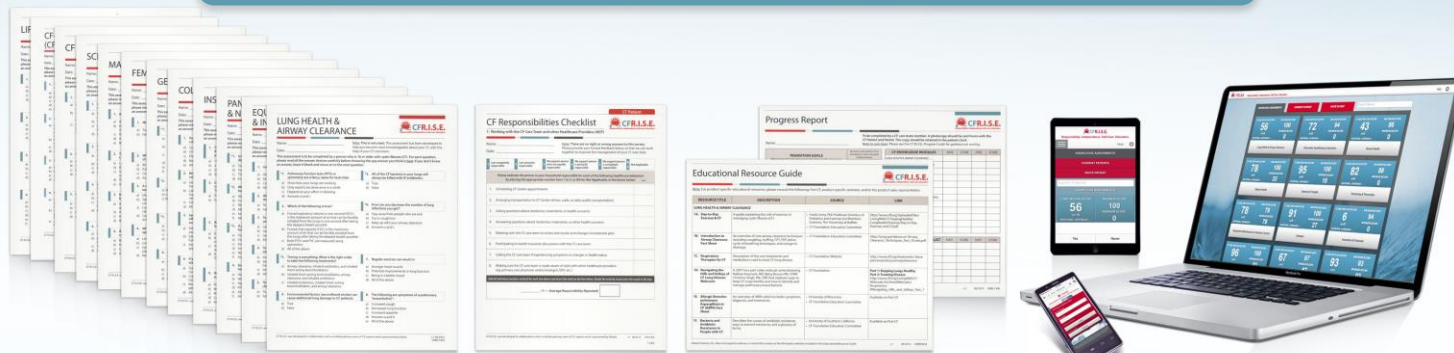
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CF R.I.S.E. Tools

THESE TOOLS MEET THE GUIDELINES AND STANDARDS OF THE OF THE CF FOUNDATION'S EDUCATION COMMITTEE.



CF Knowledge Assessments

Responsibilities
Checklists

Progress Report &
Educational Resource Guide

CFRISE.com

- Tools are available in **Print format** as well as on the **Interactive Digital Portal**
- Digital Portal can be accessed on a **desktop, tablet** or **mobile** format

CF Knowledge Assessments

LUNG HEALTH & AIRWAY CLEARANCE

THIS INFORMATION MEETS THE GUIDELINES AND STANDARDS OF THE CYSTIC FIBROSIS FOUNDATION'S EDUCATION COMMITTEE.

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Cystic Fibrosis Foundation

LUNG HEALTH & AIRWAY CLEARANCE

Name: _____ Date: _____

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. Pulmonary function tests (PFTs) or spirometry are a fancy name for the _____.

a) Show how your lungs are working
b) Only need to be done once in a while
c) Depend on your effort in blowing
d) Answers a and c

2. Which of the following is true?

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

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

a) Always clearance, inhaled antibiotics, short-acting bronchodilators
b) Inhaled short-acting bronchodilators, clearance, and inhaled antibiotics
c) Inhaled antibiotics, inhaled short-acting bronchodilators, and always clearance
d) Always clearance, inhaled antibiotics, short-acting bronchodilators

4. Environmental factors (secondhand smoke) can cause additional lung damage to CF.

a) True
b) False

5. How can you increase the amount of air that enters your lungs with each breath?

a) Breathe in through your nose
b) Breathe in through your mouth
c) Breathe in through your mouth and nose
d) Breathe in through your nose and mouth

6. How can you decrease the number of lung infections you get?

a) Stay away from people who are sick
b) Avoid crowded places
c) Avoid public places
d) Avoid public places and crowded places

7. Regular exercise can result in:

a) stronger heart muscle
b) Potential improvements in lung function
c) Being in a better mood
d) All of the above

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

a) Increased cough
b) Decreased lung function
c) Increased appetite
d) Answers a and b
e) All of the above


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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

Responsibilities Checklist for Patient & Support Person

CF Patient



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CF Responsibilities Checklist

2: Responsibility for CF Treatments

Name: _____ 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.

Date: _____


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
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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.	Cl...	

PATIENT CHECKLIST

Support Person



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CF Responsibilities Checklist

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

Name: _____ 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.

Date: _____

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
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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.	Ar...	

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)

CFRISE.com Patient Website

General CF Health

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

90 YOUR SCORE ON THIS ASSESSMENT: 90%
Correct answers: 9
Incorrect answers: 1
Unanswered questions: 0

Print Score Email Score

Talk to your CF care team if you have questions.

ADDITIONAL RESOURCES
Moving Dr... Next Stop... Adulthood

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

2. Worsening of cough, increase in volume of mucus, or decrease in energy levels means**

- a) Should be watched until the next clinic visit
- b) Can mean you're getting an infection
- c) Show that you need to eat more

3. When you might have a pulmonary exacerbation, you should**

- a) Wait a week and see if you get better
- b) Take extra vitamins
- c) Tell your CF Specialist when you call in for your clinic visit

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YOUR KNOWLEDGE ASSESSMENTS YOUR HISTORY YOUR RESPONSIBILITIES CHECKLIST DOWNLOAD PDFs

Knowledge Assessment History

In this section, you can review your assessment results. The trending chart shows your performance over time. To review your answers for each assessment, click on the dates you've taken them.

Lung Health & Airway Clearance YOUR AVERAGE RESULTS FOR THIS ASSESSMENT: **13**

ASSESSMENT HISTORY

03/23/2015	Score: 25
03/23/2015	Score: 44
03/20/2015	Score: 0
03/20/2015	Score: 0
03/20/2015	Score: 0

Pancreatic Insufficiency & Nutrition YOUR AVERAGE RESULTS FOR THIS ASSESSMENT: **20**

ASSESSMENT HISTORY

03/20/2015	Score: 0
03/11/2015	Score: 44
03/11/2015	Score: 25
03/11/2015	Score: 31

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YOUR KNOWLEDGE ASSESSMENTS YOUR HISTORY YOUR RESPONSIBILITIES CHECKLIST DOWNLOAD PDFs

Responsibilities Checklist History: Responsibility for CF Treatments

	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	N/A not applicable
Taking prescription CF medicines as prescribed	2	N/A	5	2	3	
Doing CF treatments as prescribed	2	N/A	5	2	3	
Setting up equipment to take treatments (eg, nebulizer, vest)	2	N/A	5	2	3	
Cleaning medical equipment and devices as recommended by the CF care team	2	N/A	5	2	3	
Disinfecting/sterilizing medical equipment and devices as recommended by the CF care team	2	N/A	5	2	3	
Bringing along medicines when at school, traveling, or away from home	2	N/A	5	2	3	
Maintaining a nutritional plan recommended by the CF care team	2	N/A	5	2	3	
Monitoring the number of prescription refills that remain	2	N/A	5	2	3	
Asking for new prescriptions from the CF care team before they run out	2	N/A	5	2	3	
Filling new prescriptions at the pharmacy	2	N/A	5	2	3	

KNOWLEDGE ASSESSMENTS

- Direct links to educational resources relevant to gaps
- Option to email results

HISTORY OF RESULTS

- History of knowledge assessments & responsibility checklists
- Track results over time

RESPONSIBILITIES CHECKLIST

- Identify level of responsibility around CF between patient and support person

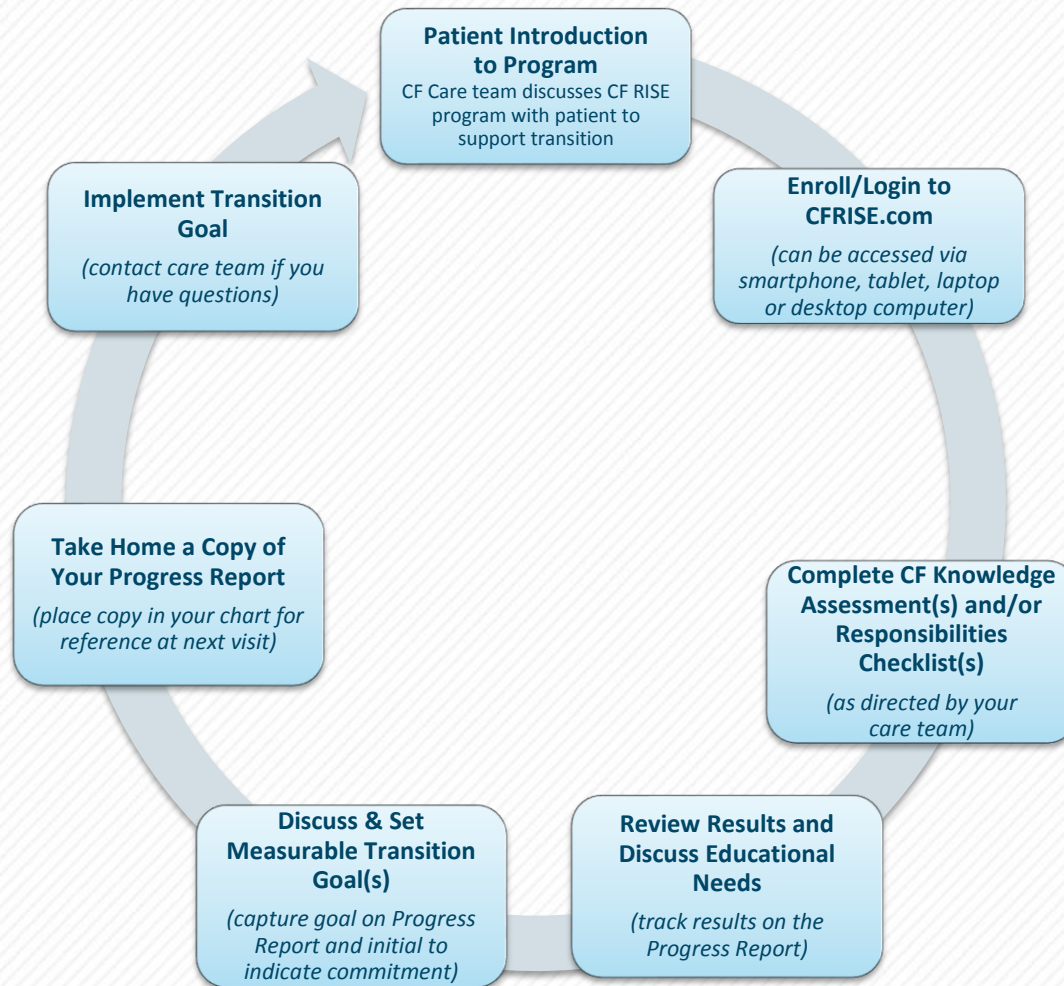
Why Go Digital?

- Access the site from your desktop, tablet or mobile format
- Log in at home after clinic
- Access your results and educational materials
- Review your history of results

Protecting Your Privacy

- Each patient personally registers for the Web site
 - First Name, gender, email address and birth date
 - Patients under 18 require a parent/guardian's consent
- Clinic code ensures that only ***you*** and ***your care team*** have access to your information
- Gilead only has access to de-identified and aggregated information
- HIPAA Compliance & Informed Consent
 - data is safeguarded with security tools including a user ID and password
 - data encryption for all personal information

CF R.I.S.E. Process



What's Next?

- **Spring 2015:** Spanish Patient Materials
- **Winter 2015/2016:** Materials for Parents & Younger Adolescent Patients

Ask your Care team for more information on how to register on **CFRise.com** today!



THANK YOU!