

Pediatric CF Updates

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CF Education Day 2014

CF R.I.S.E.

Responsibility. Independence. Self Care. Education.

Gilead Transition Advisory Council
Commenced October 2011 at NACFC
10 CF Centers participating in program
Pediatric/Adult patients reviewed program
Go Live started September, 2013

Program Background

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Defining CF Transition and Transfer

Transition: the purposeful, planned movement of adolescents and young adults with Cystic Fibrosis from pediatric CF Centers to adult CF Centers

Transfer: the point in time in which the patient moves from the pediatric CF Center to the adult CF Center

The Landscape of CF Transition and Transfer

- **A significant and growing adult CF population**
Gaps in transfer and transition-related clinical care have been studied and identified
- **The ‘Emerging Adult’ (18-25) is an at-risk group of CF patients**
- **A growing recognition that we need to “do more” to effectively address this issue**
- **Though commonly discussed, no approach to facilitate this process has been made available nationally**

Sources:

1. Cystic Fibrosis Foundation Patient Registry: 2011 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.

The Mission of the Program

- ▶ To foster patient ownership of CF care through an educational program focused on the achievement of independence

Program Objectives

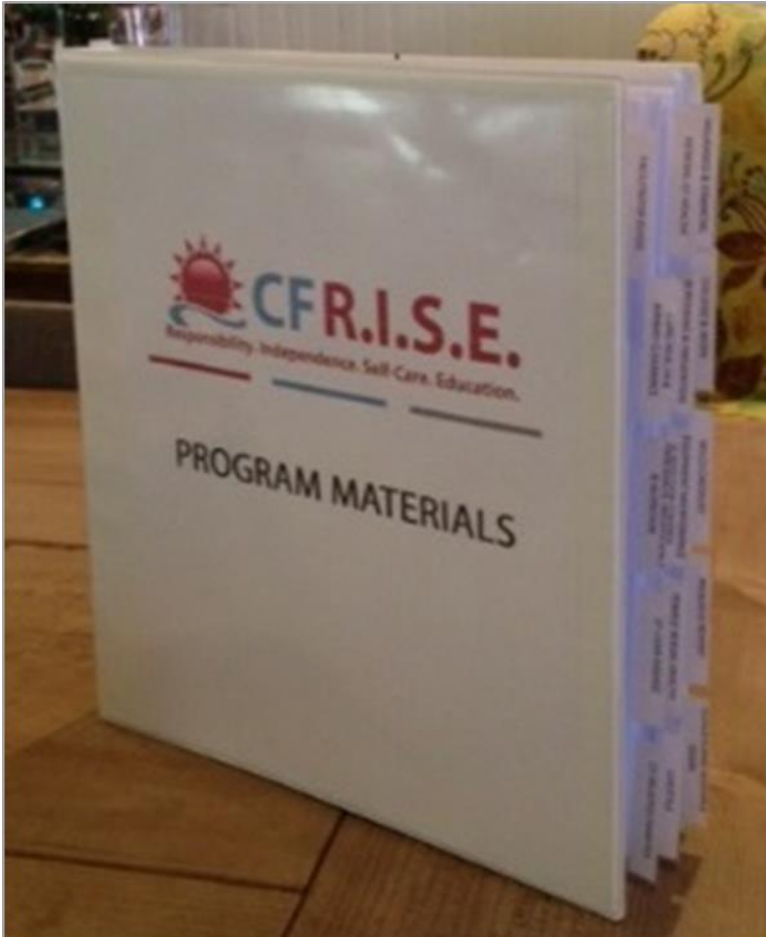
Provide CF care teams with patient tools to help manage transition and transfer

Help to facilitate communication between pediatric and adult care teams/patients and caregivers

Program Tools

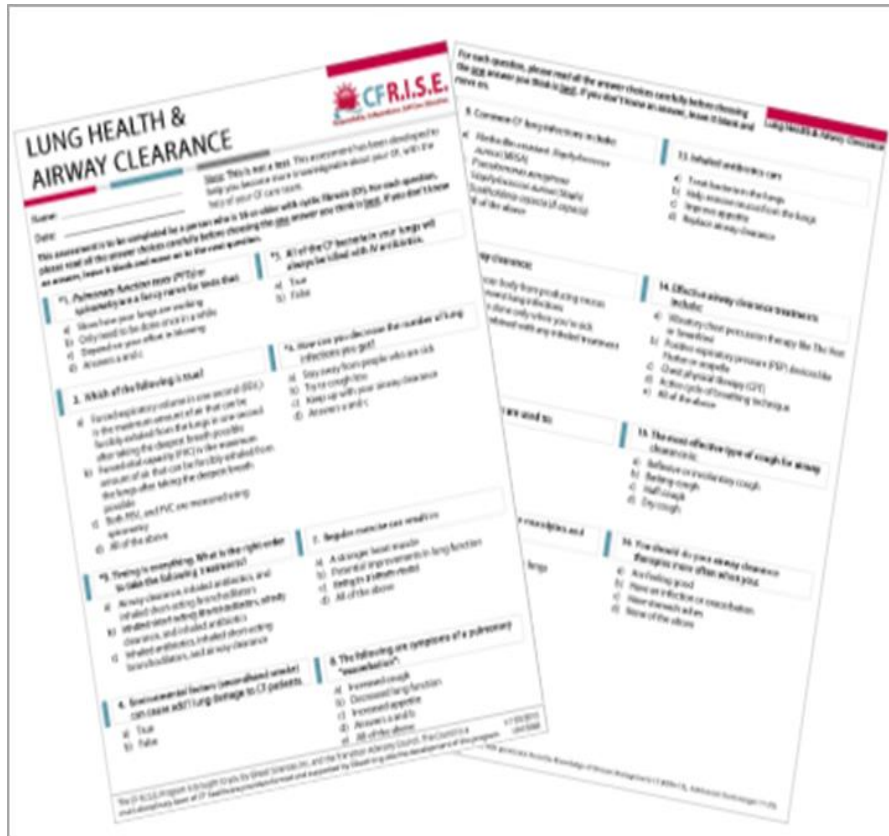
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Overview of the Tools



A resource binder for all program-related topics/tools, including printouts of the core toolset for patients in the pilot program

CF Knowledge Assessments



Objective: Help each patient identify opportunities to improve knowledge in 11 important aspects of CF care so that the patient and care team can work together to develop a personalized, focused plan

Modules developed on 11 topics:

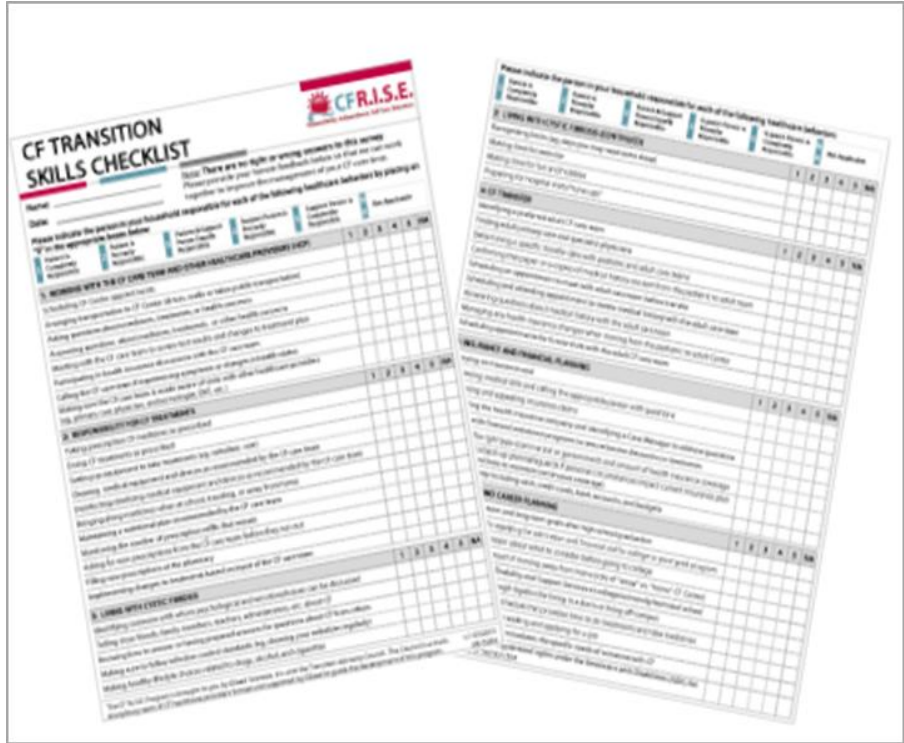
- Lung Health and Airway Clearance
- Pancreatic Insufficiency and Nutrition
- CF Liver Disease (CFLD)
- CF-Related Diabetes (CFRD)
- General CF Health
- Screening and Prevention
- Equipment Maintenance and Infection Control
- Sexual Health
- Lifestyle
- Insurance and Financial
- College and Work

Completed at: CF Center

Completed by: CF patient aged 16-25

Completed when: At every quarterly CF Center visit or at the discretion of the CF care team

CF Skills Checklist



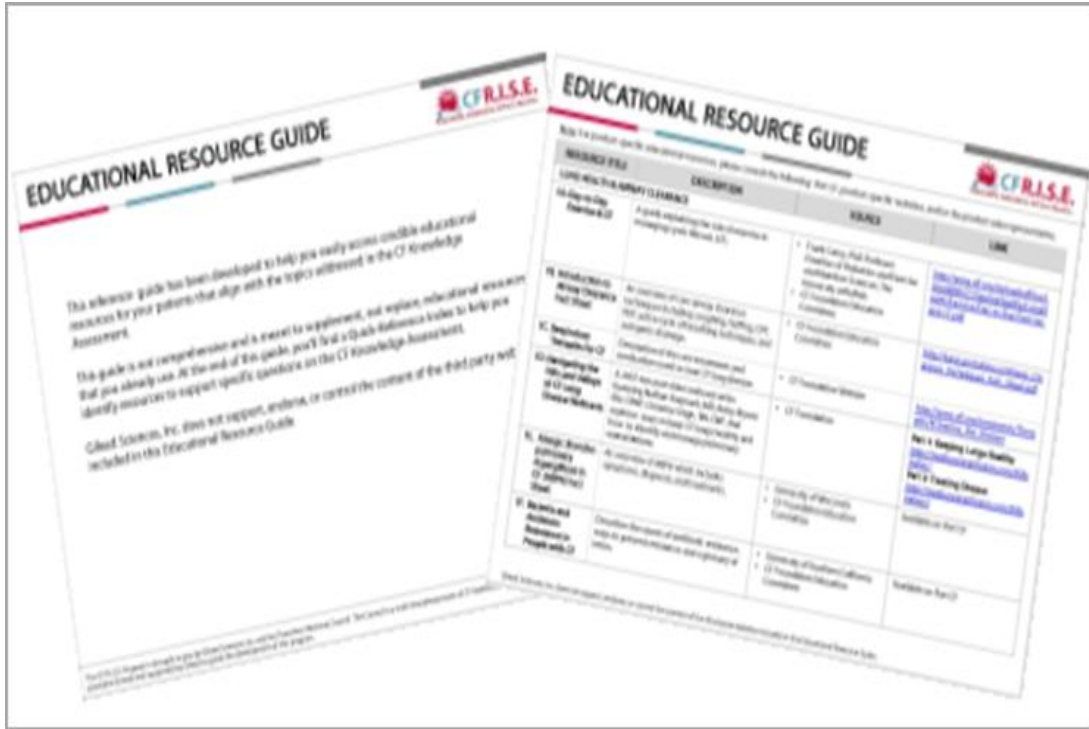
Objective: Help each patient to develop age appropriate, self-care skills by working with the CF Care Team to assess and monitor their current level of responsibility for their CF

Completed at: CF Center or Home

Completed by: CF patient aged 16-25 or Support Person (Parent, Spouse, etc.) of a CF patient

Completed when: Annually or at the discretion of the CF care team

Educational Resource Guide



Objective: Help each patient and care team member access credible educational resources to help overcome knowledge and skill gaps identified in the CF Knowledge Assessment

Completed at: CF Center or Home

Completed by: CF care team member and/or CF patient aged 16-25

Completed when: As needed

Tips for Improving Transition and Transfer Processes In General

Strive for continuous improvement

Introduce the adult CF care team to the CF patient and family before transfer

Create a Transfer Summary Form for all transitioning patients

Coordinate a formal “Transfer” meeting prior to the transfer date

Organize site visits to the adult hospital inpatient unit and adult CF center/clinic

Hold regular meetings between the pediatric and adult CF care teams

Future Goals of the Program

****Digital Portal for CF RISE**

Pilot started January, 2014

****Role out Nationally to all CF Centers with support from the CFF**

Thank you to the 5
patients and their parents
for participating in the
Pilot Program!!!!