

CF R.I.S.E. PROGRAM GUIDE

*A guide to implementing CF R.I.S.E.
at your CF center*

Dear Colleague,

We are pleased to share the CF R.I.S.E. program with Cystic Fibrosis (CF) care teams across the United States. Great strides in CF care have been made over the last 15 years and have led to a steady increase in life expectancy for CF patients.¹ In addition, the number of adult CF patients now exceeds the number of children (under 18 years) in the United States.¹ While this has been a sign of progress and hope for CF healthcare providers, there has been a growing recognition in the community that we need to do more to effectively address the issue of transition from pediatric to adult care.^{2,3}

CF R.I.S.E. was developed to provide CF care teams with patient materials to educate patients about transition (the planned movement of patients from pediatric to adult care) and transfer (the point in time at which responsibility of care shifts from a pediatric CF Center to an adult CF Center) processes by:

- Providing a flexible, modular toolset that can help improve patient proficiency in CF skills and knowledge across age ranges (pre- and post-transfer)
- Helping to facilitate communication between pediatric & adult care teams and patients & caregivers

CF R.I.S.E. was developed for patients ages 10-25, and is the first program created to address transition education on a national level for CF patients and care teams in the pre-transfer and post-transfer settings. It was developed based on suggestions from CF Centers across the United States. We recognize that across CF Centers there is variability in resourcing, staffing, and degree of integration between adult and pediatric teams. As such, our goal in developing this program was to provide CF care teams with a flexible set of patient education materials that can be implemented in whole or in part, based on each CF Center's needs.

The guide that follows will provide you with suggestions for using each of the CF R.I.S.E. program tools.

We look forward to hearing about your experiences and wish you great success.

Kind regards,

The CF Transition Advisory Council

1. Cystic Fibrosis Foundation Patient Registry: 2017 Annual Data Report. Bethesda, MD: Cystic Fibrosis Foundation; 2018.

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.

MEET THE TRANSITION ADVISORY COUNCIL (TAC)



The CF Transition Advisory Council (TAC), a multidisciplinary team of CF experts, was formed to help guide the development and implementation of CF R.I.S.E.

This Council is comprised of CF healthcare providers and experts who:

- have participated in studies and/or published on the topic of CF transition
- represent both adult and pediatric CF Centers of varying geographies, sizes, and levels of integration between pediatric and adult teams
- have many years of experience implementing transition programs and transfer practices in their own CF centers
- represent the variety of disciplines of the CF care team including support persons

Physicians

- **Tara Barto, MD**, Baylor College of Medicine (pediatric & adult)
- **Patrick Flume, MD**, Medical University of South Carolina (adult)
- **Craig Lapin, MD**, Connecticut Children's Hospital (pediatric)
- **Charles McCaslin, MD**, Helen DeVos (pediatric)
- **Samya Nasr, MD, CPI**, University of Michigan (pediatric)
- **H. Worth Parker, MD**, Dartmouth-Hitchcock Medical Center (pediatric & adult)
- **Hossein Sadeghi, MD**, Cystic Fibrosis Center Columbia University Medical Center (pediatric)
- **Greg Sawicki, MD**, Boston Children's Medical Center (pediatric)
- **Jonathan Spahr, MD**, University of Pittsburgh School of Medicine (pediatric)

Center Coordinator

- **Diane Acquazzino, BS**, University of Nebraska Medical Center (pediatric)

Psychologists

- **Alexandra Quittner, PhD**, University of Miami (pediatric)
- **Kristin Riekert, PhD**, Johns Hopkins University (pediatric & adult)

Nurse Practitioner

- **Elizabeth Bryson, MSN, PPCNP-BC, CS, Nurse Practitioner**, Akron Children's Hospital (pediatric & adult)

Nurse

- **Mary Helmers, RN, BSN**, Lucile Packard Children's Hospital at Stanford University (pediatric)

Social Workers

- **Anne Daggett, MSW, LCSW**, St. Luke's Cystic Fibrosis Center of Idaho (pediatric)
- **Kecia Nelson, MSW, LCSW**, University of Missouri Children's Hospital (pediatric & adult)

Child Life Specialist

- **Carla Hart, MS Ed**, St. Luke's Cystic Fibrosis Center of Idaho (pediatric)

CF Parent

- **Lisa Greene, MA**, Certified Family Life Educator, Certified Parent Coach, Certified Positive Discipline Educator

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



CFRISE.com



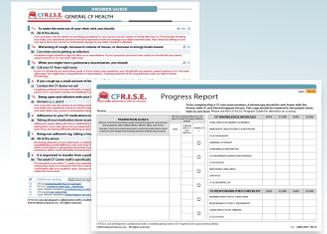
CF Milestones
by Age & Stage



CF Knowledge
Assessments



Responsibilities
Checklists



Progress Reports &
Answer Guides

The CF R.I.S.E. Program toolset was developed for people with CF and their support persons ages 10-25.

The patient toolset consists of:

1. CF Milestones by Age & Stage
2. CF Knowledge Assessments
3. CF Responsibilities Checklists
4. Progress Reports
5. Knowledge Assessment Answer Guides

All of the patient materials are available in both English and Spanish, and in digital, print, or editable PDF format. A detailed explanation of each of the tools, and their recommended implementation, can be found on the following pages.

Two sets of materials have been developed to help prepare your CF patients for transition from pediatric to adult care: one for 10-15 year olds and another for 16-25 year olds. These toolsets were developed so that the content and reading grade level are suitable for your patients, but please keep in mind that age ranges are only estimates, and your judgment should be used to determine which of the modules are most appropriate for your patients. Program materials for each age group also vary in design and question formats; a yellow key on the upper right-hand corner indicates the toolset most appropriate for 10-15 year olds.

CF R.I.S.E. has been selected by the OneCF LLC as a Smart Change Quality Improvement Initiative and is also available as a Maintenance of Certification Activity by the American Board of Pediatrics. If you would like more information on how to complete the maintenance of certification, please visit

<http://cfriseabpmoc.questionpro.com>.

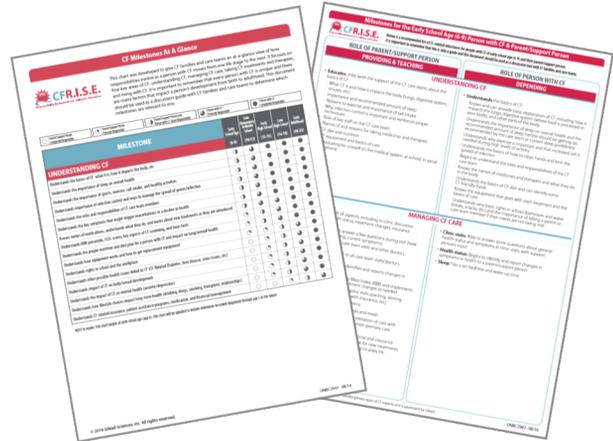
1. CF MILESTONES BY AGE AND STAGE

Objective: To introduce the need for a gradual, purposeful transition of responsibility from support person to patient over time

Completed by: CF patient, support person, and care team members ages 6 and older

Completed at: CF Center (can be administered in-patient or out-patient)

Completed when: When first introducing the concept of transition and transfer of responsibilities, and when a patient moves from one age or stage to the next



Description: This guide provides a timeline of recommended CF-related milestones that a person with CF, a parent, or a support person can work toward as the child grows up. Transfer from pediatric to adult care should be established very early on as a key milestone in the life of a person with CF. CF care team members can use the Milestones by Age & Stage brochure to introduce patients and their support persons to the concept of gradually transitioning responsibility for self-care over time. The Milestones by Age & Stage document includes an “At A Glance” chart of milestones that identifies key goals for knowledge and responsibilities in four areas of CF care:

- Understanding CF
- Managing CF Care
- Taking CF Treatments & Therapies
- Living with CF

The milestones chart indicates the level of responsibility the patient and parent should be taking during the following ages and stages of their life:

- Early School Age (ages 6-9)
- Late Elementary & Middle School (ages 10-12)
- Early High School (ages 13-15)
- Late High School (ages 16-18)
- Early Adulthood ages (18-25)

In addition to the guide, handouts have been developed that further outline the CF care responsibilities a patient and support person should own in each age and stage listed above.

2. CF KNOWLEDGE ASSESSMENTS

Objective: To help each patient identify opportunities to improve knowledge in important aspects of CF care (eg, medical, lifestyle, and financial) so that the patient and care team can work together to develop a personalized, focused plan

Completed by: CF patients ages 10-25

Completed at: CF center (can be administered in-patient or out-patient) or at home

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

Description: Knowledge Assessments have been developed to identify opportunities to improve patient knowledge on the following topics:

- General CF Health
- Lung Health & Airway Clearance
- Pancreatic Insufficiency & Nutrition
- Screening & Prevention
- Equipment & Infection Control
- Lifestyle
- Sexual Health (ages 16-25 only)
- College & Work (ages 16-25 only)

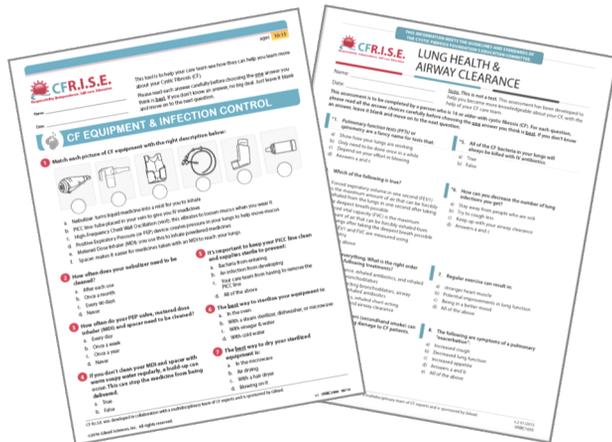
- CF & School (ages 10-15 only)
- Emotional Wellness (ages 10-15 only)
- CF & Your Body (ages 10-15 only)
- CF & Growing Up (ages 10-15 only)*
- CF Liver Disease (ages 16-25 only)
- CF-Related Diabetes (ages 16-25 only)
- Insurance & Financial (ages 16-25 only)

**recommend obtaining parental consent due to sensitive nature of content*

The CF care team should determine which Knowledge Assessments are most applicable to each patient. Knowledge Assessments should be rolled out slowly, with patients completing one to two assessments at each CF clinic visit. It is recommended, but not required, that over time all modules are administered to each patient. Each module should be completed by the CF patient independent of a parent or CF care team member to get a true gauge of specific topic areas in which patient knowledge can be improved.

Once a module is completed by the CF patient, the member of the CF care team responsible for education on this particular topic should develop a plan to help remediate the education gaps identified in the assessment. Each module should be re-administered to the patient at the next clinic visit or between 6 and 12 months later to measure progress over time.

If your center is not using CFRISE.com, use the answer key to grade the scores and then track them over time on the Progress Report. **Answer keys for the Knowledge Assessments can be found in your Program Binder in the Knowledge Assessments tab.** The TAC recommends that you consider an alternative to providing numerical scores to patients in the 10-15 year old age group. Scales such as 'Gold, Silver, and Bronze' or 'stars' are a few recommended alternatives to numerical grades.



Scoring Guidance. If a patient takes more than one assessment per visit, you may consider triaging education into high, medium, and low priority based on the highest areas of need and what the clinician, parent, and patient feel are the most important topics to address.

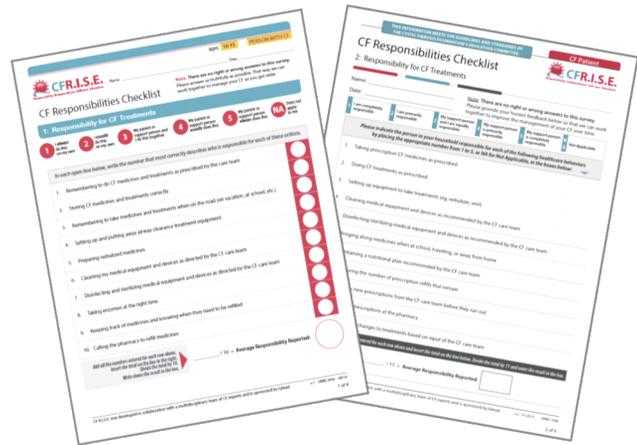
3. CF RESPONSIBILITIES CHECKLISTS

Objective: To help each patient to develop age-appropriate, self-care skills by working with their support person and CF care team to assess and monitor their current level of responsibility

Completed by: CF patients ages 10-25 and their support person(s)

Completed at: CF center (can be administered in-patient or out-patient) or at home

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



Description: These checklists have been developed to assess the degree to which a patient has taken ownership of his or her CF care in the following areas:

- Responsibility for CF Treatments
- CF Transfer (ages 16-25 only)
- Living with Cystic Fibrosis
- Education & Career Planning (ages 16-25 only)
- CF & School (ages 10-15 only)
- Insurance & Financial Planning (ages 16-25 only)
- Working with the CF Care Team and Other Healthcare Professionals

Using a 1-to-5 scale that has been developed to assess the degree of patient responsibility for a specific healthcare action, these checklists should be completed annually by the patient and the parent/support person in order to get an accurate assessment of what is happening both inside and outside the CF center.

Once the checklists are filled out, the member of the CF care team responsible for helping to improve patient skills in this area should compare the answers of the CF patient vs. the support person to evaluate the patient’s “true” level of responsibility. After a group discussion to review any discrepancies in the responses, specific and actionable transition goals should be set over the course of the coming year to facilitate the transfer of age-appropriate self-care skills to the patient. If your center is not using CFRISE.com, scores from the CF patient’s checklist should be tracked on the Progress Report to measure progress over time.

When assessing the appropriate level of responsibility a patient should have, it is important to keep in mind that each patient is unique. It is important that teen and adult patients build strong support teams to help manage the complexities of CF. This tool is an objective measure that can be used to determine a person’s readiness for transition. Over time, patients should take increasingly more responsibility for their care. Those not making progress may require more focused intervention (counseling, additional education, hands-on skill training, and/or problem solving).



Scoring Guidance. Skill levels may vary among patients. Refer to the Milestones by Age & Stage tool, but use your judgment to decide the level of progress a patient should make each year. Keep in mind that in order to achieve “independence,” most patients should be “completely” or “primarily” responsible for most healthcare actions.

4. PROGRESS REPORTS

Objective: To help each patient track improvements in CF knowledge and responsibilities over time, and develop focused and actionable transition goals for CF patients at each visit

Completed by: CF patients ages 10-25 and care team members

Completed at: CF center (can be administered in-patient or out-patient)

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

Description: The CF healthcare provider should fill out the Progress Report at every visit. The document includes space for:

- Results from the CF Knowledge Assessments and/or the CF Responsibilities Checklist taken during the most recent clinic visit
- Specific and actionable transition goal(s) based on knowledge and skill deficits identified in these assessments and the date that these goals were assigned
- The patient and healthcare provider to initial their “agreement” to work on the transition goal
- A box for the healthcare provider to “check” once a transition goal has been completed

The Transition Advisory Council recommends that a copy of the Progress Report be kept in the patient chart and updated at each visit. A copy of the Progress Report should go home with the patient to serve as a reminder of the specific transition goals that they have agreed to complete in advance of the next CF Center visit.

CFR.I.S.E. Progress Report

To be completed by a CF care team member. A photocopy should be sent home with the Person with CF and Parent/Support Person. This copy should be retained in the patient chart. Note to care team: Please see the CFR.I.S.E. Program Guide for direction on scoring.

Name: _____

TRANSITION GOALS		We have reviewed this form and agree to meet the goal outlined below.		CF KNOWLEDGE MODULES				
DATE	GOALS WITH CF INITIALS	DATE	COMPLETE	DATE	SCORE	DATE	SCORE	
			<input type="checkbox"/>	LUNG HEALTH AIRWAY CLEARANCE				
			<input type="checkbox"/>	PHARMACEUTIC RESISTENCY & NUTRITION				
			<input type="checkbox"/>	CF & YOUR BODY				
			<input type="checkbox"/>	GENERAL CF HEALTH				
			<input type="checkbox"/>	SCREENING & PREVENTION				
			<input type="checkbox"/>	CF EQUIPMENT & INFECTION CONTROL				
			<input type="checkbox"/>	CF & SCHOOL				
			<input type="checkbox"/>	EMOTIONAL WELLNESS				
			<input type="checkbox"/>	LIFESTYLE				
			<input type="checkbox"/>	CF & GROWING UP				
			<input type="checkbox"/>	CF RESPONSIBILITIES CHECKLIST	DATE	SCORE	DATE	SCORE
			<input type="checkbox"/>	MORNING WITH THE CF CARE TEAM				
			<input type="checkbox"/>	RESPONSIBILITY FOR CF TREATMENTS				
			<input type="checkbox"/>	LIVING WITH CYSTIC FIBROSIS				
			<input type="checkbox"/>	CF & SCHOOL				

CFR.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts and is sponsored by Glaxo. ©2016 Glaxo Sciences, Inc. All rights reserved. v1 UNICFRMS 08/16



When setting transition goals, be sure to set goals that are:

- Age-appropriate
- Specific
- Measurable

Transition goals should answer the questions who, what, where, why, and when. For example, a patient who is going away to college in the coming year and has little experience with managing his medications might have the following transition goals:

- Call and refill your next inhaled antibiotic prescription two weeks before you are due to start your next treatment (mm/dd/20xx) to ensure that you receive your medication in advance of your “start” date so you don’t miss a dose.
- Call the insurance company to confirm the new treatment that the doctor prescribed is covered on the formulary plan and has a manageable out-of-pocket expense. Remember to have your insurance card and policy number available during the call.

5. KNOWLEDGE ASSESSMENT ANSWER GUIDES

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

Completed by: CF care team members

Completed at: CF Center

Completed when: When remediating Knowledge Assessments and looking for related educational resources



Description: Knowledge Assessment Answer Guides have been developed for both 10-15 year olds and 16-25 year olds. Expanded explanations for all questions on each is provided, along with a list of related educational resources. The hyperlinked PDF document is meant to be a teaching tool that CF care teams can use when conducting remediation with patients. To the right of each question, you'll find a reference number that corresponds to the list of hyperlinked educational resources listed below. As knowledge and skill gaps are identified, CF care teams are encouraged to print out and/or email links to patients to help with the education process. When Knowledge Assessments are completed on the digital portal, links to the educational resources associated with questions answered incorrectly or skipped are automatically generated and displayed in a customized list of reference materials.

The Knowledge Assessment Answer Guide is not comprehensive and is meant to supplement—not replace—educational resources that you already use. The materials included in the Knowledge Assessment Answer Guide are all sourced from the Cystic Fibrosis Foundation, accredited CF Centers, and scientific publications and journals. The Cystic Fibrosis Foundation does not support, endorse, or control the content of the third party websites included in the Knowledge Assessment Answer Guide.

A number of tools have been developed to support your discussions on transition and the CF R.I.S.E. program with your patients and their families. A brief description and the location of each of the tools is provided below.

Tool	Description	Location
Introductory Letter	Template that can be sent to patients and their support persons to inform them about CF R.I.S.E.	Appendix B & CFRISE.com
Invitation Email	Email inviting them to register on CFRISE.com	CFRISE.com
Family Day Presentation	PowerPoint slides providing an overview of the CF R.I.S.E. program for use at your Family Education day	CFRISE.com
Patient Brochure	A brief overview of the CF R.I.S.E. program	Support@cfrise.com
Transition Tear Sheet	Provides discussion points on the importance of transition and an overview of how CF R.I.S.E. works	Support@cfrise.com

Ongoing Care Team Support & Feedback

Our goal is to provide you and your team with continuous support as you move forward with implementing CF R.I.S.E. at your center. We encourage you to use the following resources to overcome any obstacles that you encounter and to ensure that you have access to the latest program updates.

Resource	Description	Timing/Frequency
Support Email	Program implementation and technical support is available via email. Requests are responded to within 24-48 hours. Email support@cfrise.com	24-48 hr response
Digital Portal Starter Guide	The Digital Portal Starter Guide provides simple instructions on how to login, register, and navigate the CF R.I.S.E. digital portal.	Sent upon clinician portal set up
Training Videos	Training videos are available under the "Program Materials" tab on the clinician portal.	Available to access at anytime

TIPS FOR IMPLEMENTING CF R.I.S.E. IN YOUR CLINIC



Identify your CF R.I.S.E. Team and Appropriate CF Patients, Ages 10-25

- Use the Action Plan (Appendix A) to define your goals and assign care team member roles
- Determine “mix” of patient types
- **TIP!** *Start with a handful of patients whom you think would be receptive and eager to participate in the program*

Introduce CF R.I.S.E. to Patients and Parents

- Via email, letter (Appendix B), or in-person with the brochure, tear sheet, or at your Family Education day
- **TIP!** *Include information about the program in center newsletters or on your website*

Enroll Patients on CFRISE.com

- Patients can enroll from their smart phone, tablet, or computer
- **TIP!** *Register patients in clinic during downtime or when they are admitted, and encourage them to capture their user ID and password on their phone or somewhere they can easily find it if they forget*

Administer CF Responsibilities Checklist and/or Knowledge Assessments

- At clinic visit (patient can complete during visit or come to clinic with completed documents)
- Allow patients to choose their modules or leverage existing protocols that categorize based on age to capture consistent metrics for your center
- Assessments should be rolled out slowly, administer 1-2 per new clinic visit; Responsibilities Checklists can be completed less frequently, but goals should be reviewed at each clinic visit
- Provide younger patients with a copy of the Glossary of CF Terms for reference
- **TIP!** *Capitalize on clinic down time: have patients complete modules while waiting for test results (ex, OGTT), between clinician consults, hospitalizations*

Review Results With Patient

- Review all questions that patients got incorrect or skipped, reinforcing the correct answers
- **TIP!** *When discussing results with patients ages 15 and under, use non-numerical scales of measurement such as ‘Gold, Silver, and Bronze’ or ‘Stars’ so as to reinforce the message that the exercise is meant to measure knowledge, not obtain points or grades*

Remediate Knowledge & Responsibility Gaps

- Identify the appropriate care team member to conduct the remediation on the topic at hand in advance of the clinic visit
- **TIP!** *Keep a binder of educational resources that care team members can easily find and make copies of recommended resources to send home with patients*

Complete Progress Report

- Capture module scores and agreed-upon goals
- Have the patient initial and date their goals to encourage ownership
- Make a copy for the patient chart and send another copy home with the patient
- **TIP!** *Integrate into your EMR by scanning the Progress Report, capturing scores and goals in the AVS (After Visit Summary) or building a flow sheet into the system to track module results*

10 TIPS FOR SUPPORTING TRANSITION AND TRANSFER

The following suggestions for implementing a transition and transfer program at your CF Center have been drawn from the collective experience of the Transition Advisory Council. Below are a few ideas that you may want to consider for your practice.

1. Set Expectations That CF Transfer Will Happen and Supporting Independence Is Key to Success

CF transfer from pediatric to adult care should be established very early on as a key milestone in the life of a patient with CF, similar to the accepted practice of moving from primary school to high school or high school to college. The transition process involves all members of a CF patient's family, and it is important that the entire family works together to support the transfer of age-appropriate healthcare ownership to the patient to foster independence. Suggestions for helping to set these expectations include:

- At diagnosis, introduce this concept to your CF families in a standardized way
- Continue to reinforce the need to become more independent with parents and families as the patient gets older
- A couple of years before expected transfer (age 16 or so), carve out time for a member of the pediatric team to discuss the process of transition and transfer process in detail. This is very important because transition and transfer can be times of stress and worry for parents and patients. Explaining the process, the timeline, and the role of the parent and patient in preparing for transfer is critical

2. Identify and Address Gaps in CF Knowledge and Responsibilities

It is important that patients take on greater responsibility for their care over time. Two important contributors to poor self-care are a patient's lack of understanding of their disease and the inability to perform their treatments and therapies correctly. Suggestions for overcoming these barriers include:

- Leverage established knowledge and skill-based tools in the CF community
- Consider using programs like CF R.I.S.E. to help you educate and monitor your patient's progress and knowledge base
- Establish open lines of communication with your patients and their families so that they are comfortable asking questions about medical and emotional issues
- Spend one-on-one time with the patient at each CF Center visit to encourage independent, open dialogue between the CF care team and patient

3. Transition Is a Long-Term Process That May Require Difficult Conversations

Parents are not always comfortable giving up control and patients are not always motivated to take more responsibility for managing their CF. As a clinician, it is important to begin discussions with the family about ceding age-appropriate responsibility to the patient very early on. These conversations can be difficult, and you may be met with resistance. Suggestions you can employ include:

- Use supportive communication to begin these sometimes difficult conversations
- Have candid discussions with families about when children are developmentally able to assume certain tasks (eg, most 10 year olds can set up their medication and administer it by themselves but probably aren't ready to be independent in remembering when it is time to do it)
- Encourage the developmentally appropriate level of parental supervision and involvement given the task
- Use problem solving to overcome barriers to transferring and assuming responsibility

10 TIPS FOR SUPPORTING TRANSITION AND TRANSFER

4. Strive for Continuous Improvement

Transition is a long and involved process, and no one has cracked the code on the “best” way to effectively transition patients. Therefore, it is important that each CF care team work together to evaluate and improve this process over time. Suggestions for fostering continuous improvement include:

- Consider participating in a CFF Quality Improvement project on transition and transfer
- Foster open dialogue and communication between the pediatric and adult CF care teams. Provide continuous feedback on what you can be doing better to optimize care
- Listen to your patients: ask for honest feedback from those who have just completed or are going through the transition process. Consider conducting an anonymous survey or asking the family advisory council to provide input on how to make your program stronger

5. Introduce the Adult CF Care Team to the CF Patient and Family Before Transfer

One way to ease the anxiety associated with transfer is to ensure that the patient and family are able to gain familiarity with the adult care team well before transition. Suggestions for introducing the adult CF care team in a positive manner include:

- Have the adult care team staff attend and present at CF family days at the pediatric center
- Ensure that members of the adult CF care team attend family advisory meetings to hear and to address concerns raised in these meetings
- Schedule a private “meet and greet” between members of the adult CF care team, the parent, and the patient 1 or 2 years in advance of the goal transfer date to introduce the team, get to know the family, and deliver a message about ways in which patients can be successful during the transition process. This meeting should not include a physical exam and should remain collegial and informal so that the family is encouraged to ask questions

6. Choose a Goal Transfer Timeline

There is some variability in how a transfer timeline is set. Some CF Centers take the position that each patient should be transferred by a specific age (eg, 18th birthday). Some believe that each patient is unique and should be transferred based on emotional and physical “readiness.” Whichever you believe, it is clear that having a transfer timing “goal” set with the patient and family helps all parties prepare for this inevitability. Suggestions for choosing a goal transfer timeline include:

- Hold a meeting between the pediatric team, the patient, and parent/support person to discuss the process and determine what the transfer timeline goal will be
- Set a transfer goal with the patient 2 to 3 years in advance of transfer
- Clearly outline what is involved in CF transfer; key milestones that must be achieved to meet timeline

7. Create a Transfer Summary Form

A Transfer Summary Form is a document that allows patients, families, adult teams, and pediatric team’s access to a synopsis of the patient’s medical history to ensure this information is agreed upon by all parties.

Suggestions for the creation and handling of this form include:

- Provide a detailed copy to all healthcare providers, the patient, and the family of the CF patient
- Include any of the following fields: pre-screening results, most recent test results, key clinical stats, hospitalization history, insurance issues, vocational challenges, nutritional discussions, co-morbidities, information about family dynamics (for care teams only), etc. For those CF centers that share Electronic Medical Record (EMR) systems, you may be able to pull the requisite information directly from your internal systems

8. Coordinate a Formal “Transfer” Meeting Prior to Transfer Date

Before a patient is ready to transfer, consider holding a meeting to discuss the patient’s medical history and ongoing plan for care, and answer any questions that the care team or patient family has about moving forward. Suggestions for this meeting include:

- Meeting should be held about six months to one year prior to transfer
- Meeting attendees should include all members of the patient’s family, pediatric care team (MD, nurse, social worker), all adult CF care team members who will be working with the patient, and members of the in-patient nursing team (if the patient is a frequent in-patient)
- Use a Transfer Summary Form, which is developed PRIOR to this meeting, to drive the discussion
- Create a formal agenda for the meeting
- Depending upon the decision-making process of the full group during this meeting, the care of the patient between the pediatric and adult team is determined for the next year (eg, if the patient is or becomes clinically unstable or develops acute illness, it is determined whether it will be managed by the pediatric or adult team)
- Set a specific transfer date (eg, We will begin seeing you at the adult CF center on Thursday, August X)

9. Organize Site Visits to the Adult Hospital Ward and Adult CF Center Clinic

You can often minimize confusion and stress by de-mystifying the “unknown.” Providing patients and parents with the opportunity to become familiar with the new facilities that they will soon be utilizing can help.

Suggestions for the site visit include:

- Consider having a member from both the pediatric and adult team at the site visit to explain the differences in care/operations
- Organize the site visit within the year the patient is being transferred from pediatric to adult care
- Have the patient familiarize her- or himself with parking, check-in process, location of PFT lab, and general visit flow

10. Hold Regular Meetings Between the Pediatric and Adult CF Care Teams

Open and regular communication between pediatric and adult CF care teams is critical to the success of any transition program. A practical way to ensure that there is consistent dialogue is to establish a regular meeting schedule between the teams. Suggestions for this meeting include:

- Establish a meeting calendar (this may vary based on the size of your clinic since larger clinics may have more patients transfer throughout the year and therefore require more meetings)
- Establish a formal agenda that can include both clinical and process issues: case review of all transition-aged patients, planning for integrated meetings with the patients, coordination and process standards for transfer, gaps in transfer care, etc.
- Focus on medical and psychosocial aspects of the patient’s care, as well as nuanced issues that are important for the adult team to know (eg, parent dynamics, behavioral issues, worries and concerns)
- Hold meetings once or twice a year with the full clinic team on the adult and pediatric teams to discuss clinical care, and more regular operational meetings with support staff members to discuss operations and process issues with respect to the transfer process at your CF center
- Pediatric team should copy and provide details from all clinic visits, tests, and notes for the year prior to the transition to the adult team

APPENDIX



CF CENTER ACTION PLAN

CF Center Name: _____

Center Director: _____

Program Champion: _____

Clinical Team *(List all those responsible for administering modules and educating patients on specific topic areas.)*

Name/Position: _____

Responsibility: _____

Name/Position: _____

Responsibility: _____

Name/Position: _____

Responsibility: _____

Name/Position: _____

Responsibility: _____

Describe the type of patients you plan to have participate in the program.

Goal for Patient Enrollment *(Example: Enroll X patients within next Y months.)*

CF R.I.S.E. Planning *(Identify how and when you will plan for upcoming CF R.I.S.E. visits.)*

Implementation Milestones & Timeline

Milestone:

Example: 1. Identify five patients that meet our CF R.I.S.E. Patient Profile

2. Prepare and send an introductory email to patients/parents identified to participate in CF R.I.S.E.

Timing:

At next team meeting

Two days after team meeting

Accountable Person:

Program Champion

Social Worker

APPENDIX B

LETTER/EMAIL TEMPLATE



Directions: Below is an optional communication template that can be adapted by your care team and sent via email or letter to patients whom you would like to invite to participate in the CF R.I.S.E. program. The goal of the template is to make patients aware of CF R.I.S.E. before their next clinic visit.

[PRINT ON CLINIC LETTERHEAD AND MODIFY AS NEEDED]

[Today's Date]

John Doe
123 Main Street
Any town, ST 12345

Hello [INSERT NAME OF PATIENT AND/OR PARENT],

We invite you to participate in a unique educational program called **CF R.I.S.E. [Responsibility. Independence. Self-Care. Education.]**, which is being launched at [CLINIC NAME]. This program has been designed specifically for [CF families who have children or teenagers preparing for transition to adult care]/[young adults who have recently transferred from a pediatric to an adult CF Center].

CF R.I.S.E. is being made available to all of our CF patients between the ages of 10 and 25 and consists of the following:

- A series of **CF knowledge and responsibility assessments on various topics** to help identify areas where we, the care team, can provide you more focused education and support
- A simple tool to help **track your progress and set specific transition goals** over time
- An easy-to-access **educational resource guide** that you can consult to learn more about specific topics

Participation in this program is optional. We are excited about CF R.I.S.E. and hope that you will choose to be a part of the program. If you do choose to participate, we will review the program tools with you and administer the first assessments at your **next clinic visit**. This may extend the length of your clinic visit just a bit, but we don't anticipate any significant delays.

If you have any questions before your next clinic visit, please contact me at the number (above or below) [or name another contact and add their contact information]. We are looking forward to seeing you at your next clinic appointment scheduled for:

Date: _____ at _____.

Kind regards,

[Dr. Sally Smith or Center Staff
Director, Cystic Fibrosis Clinic
Institution Name Here]