

## **Cystic Fibrosis Transition Program**

Funded by a cooperative agreement  
between CMHI and MCHB/HRSA

## **Faculty**

**Dewana Carter, MSW, LGSW**  
**Adult Cystic Fibrosis Program**  
**Outpatient Social Worker**  
**University of Alabama at Birmingham**

## **Objectives**

- Name at least two elements of success for transition
- State one method of incorporating families and youth into the transition process
- Name two obstacles in current systems of care for transitioning patients with Cystic Fibrosis

## **Program Overview**

- The Cystic Fibrosis transition program has been in operation since the year 2000
- Patients enter the transition program between the ages of 16 - 17
- The pediatrics center holds a transition clinic twice a month
- Adult CF clinics held once a week

## **UAB / COA Cystic Fibrosis Care Teams**

- Nurse Clinical Coordinator
- CF Nurses
- CF Physicians
- Registered Dietitians
- Respiratory Therapists
- Social Workers

## **Transition Planning and Families**

- Each patient and family is individually educated about the transition process
- Families are active participants in the tour of the adult center
- Patients and families provide feedback about transition process

### **The Age of Transition**

- Transition is optional for our patients at age 18 and mandatory at age 21
- Discussions about transition occurs at diagnosis and continue throughout the child's life
- Patients are seen alone in clinic starting at the age of 14

### **Sample Checklist Questions**

1. Do you do your chest therapy more than 4 days a week without a reminder?
2. Can you list all of your medications and state what they do?
3. Do you, not your parents, call your pharmacy, equipment company, or CF center for refills?

### **Sample Checklist Questions**

4. Do you know how to contact your insurance company and what your plan covers?
5. Do you have a method of transportation to get to clinic?

### **Transition Program Outline**

- **Initially**
  - Transition Survey
  - Transition Score
- **Transition Quarterly Goals**
  - Nutrition
  - Insurance

### **Transition Program Outline**

- Pharmacy Review
- College / Vocational Rehab
- Risky Behavior
- Reproductive Health
- CF Research

### **Transition Program Outline**

- **Exit**
  - Parent Exit Survey
  - Patient Exit Survey

### **Transitioning to Adult Care**

- Pediatrics' team provide a “going away book”
- A tour of the adult center occurs prior to the actual transition
- One final appointment at pediatrics' clinic and the next at the adult center
- Given a transition packet, includes information about adult center

### **Medical Information Sharing**

- In the pediatrics' transition program information is shared by sending letters to all primary care physicians
- In the adult program the EMR system can fax clinic notes directly to a provider's office

### **Obstacles**

- Lack of insurance
- Inability to obtain accurate and complete records
- Patient resistance to becoming more independent
- Lack of transportation
- Lack of good social support system

### **Obstacles**

- Lack of “buy in” by parents
- Lack of “buy in” by members of medical team

### **Keys to Success**

- Discussing transition from the time of diagnosis!
- Early education by the medical team about:
  - Consequences of engaging in risky behavior

### **Keys to Success**

- Importance of adherence to all therapies
- Fundamentals about insurance coverage
- Career / education planning
- Reproductive health

### **Future Goals**

- **Pediatrics:**
  - Incorporate quarterly educational topics for patients
  - Have the adult team members attend clinic
  - Incorporate a study of transition readiness

### **Future Goals**

- **Adults:**
  - Continue QI projects for patient care
  - Add more clinic days in the distant future
  - Continue quarterly meetings with pediatrics team

### **Community Partners**

- Local CFF Chapter
- LAPS for CF
- HOPE for Alabama
- Cystic Dreams Fund
- Children's Rehabilitation Services
- Vocational Rehabilitation

### **Transition is GREAT!!!**

Transition can be a stressful and an exciting time. The care teams at both centers are highly trained in caring for transitioning patients living with Cystic Fibrosis. Our teams are committed to providing you with excellent care and we are just a phone call away if you need us.