

**Milestones for the Early High School (13-15) Person with CF & Parent/Support Person**

Below is a recommended list of CF-related milestones for people with CF of early high school age (13-15) and their parent/support person. It is important to remember that this is only a guide and this document should be used as a discussion tool with CF families and care teams.

**ROLE OF PARENT/SUPPORT PERSON****DELEGATING & MONITORING**

- **Educates** early teen (with the support of the CF care team) on new aspects of CF care, such as:
  - Newly prescribed treatments and clinical trials
  - BMI percentile, FEV<sub>1</sub> scores, key aspects of CF screening, and basic tests
  - Advocating for oneself (in the medical system, at school, in social situations)
  - Managing proper diet/nutrition intake in social situations (taking enzymes in front of friends, sticking to a high-fat diet when eating out, etc)
  - Where and how to access replacement equipment
  - Signs of other possible health issues related to CF (CFRD, liver disease, sinus issues, etc)
  - Impact of CF on body development (puberty and fertility)
  - Impact of anxiety/depression on a person with a chronic disease, triggers for identifying anxiety/depression
  - Healthy lifestyle choices (smoking, drinking, drugs)
  - Basics of medication management (refills, ordering new medications, etc)

**ROLE OF PERSON WITH CF****MANAGING****UNDERSTANDING CF**

- **Understands** most aspects of CF:
  - Learns about new treatments that have been prescribed
  - Understands why basic CF tests and screenings are done
  - Understands how FEV<sub>1</sub> and BMI help track lung and nutritional health
  - Understands rights in school and begin to learn aspects of learning plans (like IEP or 504 plan)
  - Begins to understand rights in the hospital
  - Understands snack and meal options should be high in calories and fat
  - Knows the signs of other possible health issues linked to CF (CFRD, liver disease, sinus issues, etc)
  - Knows how long each piece of equipment should last, can identify when it is not working right and tells parent/support person or CF care team
  - Fully understands impact of CF on body development (puberty and fertility)
  - Understands triggers of anxiety and depression
  - Understands the negative impact of smoking, drinking, and drugs on overall health
  - Begins to understand the basics of ordering and managing medications

**MANAGING CF CARE**

- **Clinic visits:** Supports the teen during the clinic visit and fills in information gaps as necessary
  - Encourages teen to independently answer questions at clinic visits and in the hospital
  - Oversees scheduling and tracking of doctor's appointments and CF clinic visits
  - Empowers teen to track doctor's appointments on family calendar and call clinic to follow-up on basic appointment questions
  - Arranges transportation to all care team visits and doctor's appointments
- **Health status:** Encourages teen to take the lead when reporting changes in health/symptoms to care team (via phone or during care team visit)
- **Hospital visits:** Oversees preparation for hospital visits (develops packing list with child, works with child to alert school of absence, owns coordination with insurance, etc)
  - Works with teen to create a plan to implement recommended nutrition/treatment changes after clinic/hospital visit
- **Sleep:** Monitors sleep patterns
- **Nutrition:** Helps teen plan for and select CF-friendly snacks and meals
- **Coordination of care:** Oversees coordination of care with healthcare providers outside the CF center (primary care, psychologist, endocrinologist, etc)
- **Insurance & financial:** Manages most financial and insurance aspects of CF, including ensuring coverage for new treatments, coordinating refills, filling forms, paying co-pays, etc
  - Teaches child about how to order and manage medications (call pharmacy, tracking system, etc)

- **Clinic visits:** Independently answers most questions during clinic and hospital visits
  - Works with parent/support person to identify times that work within his/her schedule for clinic visits
  - Tracks doctor's appointments on family calendar, and calls clinic to follow-up on basic appointment questions
- **Health status:** Reports health/symptom changes to parents and care teams
- **Hospital visits:** Plans for hospital visits, including packing and alerting teachers and friends
  - Works with parent on creating a plan to implement recommended nutrition/treatment changes after clinic/hospital visit
- **Sleep:** Has a set bedtime and wake-up time, and gets the minimum required amount of sleep most nights
- **Nutrition:** Chooses CF-friendly foods for snacks and meals, and assists in meal planning
- **Coordination of care:** Can report to care team all of the healthcare providers seen outside the CF center (primary care, psychologist, endocrinologist, etc), reasons for and outcomes from those appointments
- **Insurance & financial:** Begins to watch parent/support person order medication and supplies, and starts to call for their own refills when needed

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## ROLE OF PARENT/SUPPORT PERSON

### DELEGATING & MONITORING

#### TAKING CF TREATMENTS & THERAPIES

- **Taking treatments:** Oversees responsibility for administration of treatments
  - Confirms administration of all treatments, including enzymes, airway clearance, nebulized treatments, and pills
  - Oversees plan or system for taking medicines and treatments away from home
- **Cleaning & disinfecting:** Transfers ownership of equipment maintenance, cleaning and disinfecting with oversight and support, as needed
- **Medicine management:** Monitors tracking, sorting, and storing all medicines, and calls in most refills

## ROLE OF PERSON WITH CF

### MANAGING

- **Setup:** Has a routine for setting up maintenance medications and taking as prescribed
- **Taking treatments:**
  - Independently administer enzymes and airway clearance
  - Responsible for following treatment plan in school or while on vacation (with some supervision of parent and adults at school)
- **Cleaning & disinfecting:** Begins to own cleaning and disinfecting of equipment, and asks for parental support as needed
- **Medicine management:** Tracks and sorts all medicines, and tells parent when medicine is running low

#### LIVING WITH CF

- **Planning for future:** Continues to envision a future for child/ starts to lay the foundation for education and career planning
- **Anxiety & depression:** Works with teen to identify and proactively implement strategies for managing anxiety and depression
  - Discuss impact of exercise, breathing techniques, seeking professional help, etc
- **Exercise:** Encourages participation in sports and healthy activities
- **Advocacy:** Ensures that teen is proactively raising health concerns and proactively educating school, family, friends, and coaches about CF, as needed
- **Support system:** Encourages teen to establish support systems with their peers who have CF
- **Lifestyle:** Has an age-appropriate discussion with teen about the impact of lifestyle on long-term health (smoking, drinking, drugs, sexuality, and dating)

- **Planning for future:** By age 15, begins to plan for future (big picture plan for college, work, timing of moving out of parents house) and plan for how CF may impact future life plan and adulthood
- **Anxiety & depression:** Can identify warning signs of anxiety and depression and alert parent/support person/care team
  - Can apply coping strategies to address anxiety/depression
- **Exercise:** Maintains an exercise routine/participates in sports or other healthy activities
- **Self-advocacy:** Is more comfortable independently answering common questions from peers/others about CF
  - Understands rights in school (IEP or 504 plans) and is able to raise concerns
- **Managing germs:** Takes steps to minimize the spread of germs and infections
- **Support system:** Understands the importance of, and starts to develop a support system of peers with CF
- **Lifestyle:** Makes healthy lifestyle choices about smoking, drinking, drugs, sexuality, and dating