

**Milestones for the Late Elementary & Middle School (10-12) Person with CF & Parent/Support Person**

Below is a recommended list of CF-related milestones for people with CF of late elementary & middle school age (10-12) 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****MANAGING**

- **Educates** pre-teen (with the support of the CF care team) on new aspects of CF care, such as:
  - Management of salt intake during exercise/hot weather
  - Ways to manage the spread of germs/infections
  - Roles and responsibilities of all members of the CF care team
  - Newly prescribed treatments and clinical trials
  - Symptoms which indicate declining health or possible exacerbations
  - Definitions of FEV<sub>1</sub> and BMI and how they measure lung and nutritional health
  - Advocating for oneself (in the medical system, at school, in social situations)
  - Meal planning/proper nutrition
  - Specifics of care and maintenance for all CF equipment
  - Other possible health issues linked to CF such as CF-Related Diabetes (CFRD), liver disease, sinus issues, etc
  - Impact of CF on body development (puberty)

**ROLE OF PERSON WITH CF****ENGAGING****UNDERSTANDING CF**

- **Understands** many aspects of CF care:
  - Understands how much additional salt is needed and ways to get additional salt if exercising or in hot weather
  - Understands ways to manage the spread of germs/infections
  - Understands the roles and responsibilities of all CF care team members
  - Learns about new treatments that have been prescribed
  - Understands that some symptoms can indicate declining health or possible exacerbations
  - Understands how FEV<sub>1</sub> and BMI help track lung and nutritional health
  - Understands basics of rights in school, like being able to have extra bathroom breaks, snacking in the classroom, and taking medicines
  - Understands the importance of telling a parent, support person, or other adult if their needs are not being met
  - Understands the importance of the CF diet and impact of nutrition on lung/overall health
  - Can identify a few high-calorie, high-fat snack and meal options
  - Understands the equipment that goes with each treatment and the specifics of its care and maintenance
  - Is aware of other possible health issues linked to CF such as CFRD, liver disease, sinus issues, etc
  - Understands what clinical trials are and participates in those that are appropriate for them
  - Begins to understand the impact of CF on body development (puberty)

**MANAGING CF CARE**

- **Clinic visits:** Oversees all aspects of the clinic visit
  - Encourages pre-teen to participate in clinic visits/allows him/her to answer questions asked by care team first
  - Schedules and tracks care team visits and other doctor's appointments
  - Arranges transportation to all care team visits and doctor's appointments
- **Health status:** Reports changes in health/symptoms to care team
  - Ensures pre-teen is aware of current FEV<sub>1</sub> and BMI, and oversees implementation of recommended nutrition/treatment changes as needed
- **Hospital visits:** Coordinates hospital visits (oversees packing, alerting school of absence, coordinating with insurance, etc)
- **Sleep:** Monitors sleep patterns and works with pre-teen to ensure that they have good sleep practices
- **Nutrition:** Plans for CF-friendly snacks and meals
- **Coordination of care:** Coordinates care with healthcare providers outside the CF center (primary care, psychologist, endocrinologist, etc)
- **Insurance & financial:** Manages all financial and insurance aspects of CF, including ensuring coverage for new treatments, coordinating refills, filling out forms, paying co-pays, etc

- **Clinic visit:** Able to independently answer more questions during the clinic visit
- **Health status:** Proactively identifies and reports changes in health and symptoms to parent or support person
  - Knows and tracks current FEV<sub>1</sub> and weight or Body Mass Index (BMI)
- **Hospital visits:** Participates in planning for hospital visits, including packing and alerting teachers and friends
- **Sleep:** Has a set bedtime and wake-up time, and starts to respond to alarm clock to wake up independently
- **Nutrition:** Participates in picking CF-friendly foods and 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)

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## ROLE OF PARENT/SUPPORT PERSON

### MANAGING

#### TAKING CF TREATMENTS & THERAPIES

- **Setup:** Delegates responsibility for treatment setup to the pre-teen
- **Taking treatments:** Directs taking of treatments and therapies:
  - Reminds pre-teen to take treatments and medicines
  - Reminds pre-teen to take enzymes and pills when leaving the house
  - Transfers responsibility, with oversight, for remembering to take enzymes and doing airway clearance
  - Closely monitors while pre-teen takes treatments and medicines
  - Educates pre-teen about plan or system for taking medicines and treatments away from home (school, vacation, etc)
- **Cleaning & disinfecting:** Partners with pre-teen to clean and disinfect equipment
- **Medicine management:** Oversees all tracking, sorting, and storing all medicines, and identifies need for refills

## ROLE OF PERSON WITH CF

### ENGAGING

- **Setup:** Able to set up nebulizer equipment
- **Taking treatments:**
  - Responsible for remembering to take and carry enzymes when leaving the house (with parental/support person oversight)
  - Independently performs airway clearance (with some parental/support person oversight)
  - Knows and sticks to treatment plan expectations when in school, away from home, on vacation (with supervision of parent/support person, school staff and doctor or providers who prescribe medications)
- **Cleaning & disinfecting:** Watches parent/support person and helps to clean and disinfect equipment
- **Medicine management:** Begins tracking and sorting all medicines, and begins to learn proper storage plan for medicines (refrigerator, pantry, bathroom cabinet, etc)

#### LIVING WITH CF

- **Planning for future:** Continues to envision a future for pre-teen and starts to lay the foundation for education and career planning
- **Anxiety & depression:** Works with pre-teen to implement strategies for managing anxiety and depression
  - Discuss impact of exercise, breathing techniques, seeking professional help, etc
- **Exercise:** Works with pre-teen to determine exercise plan
- **Advocacy:** Oversees education of school, family, friends, and coaches about CF
  - Speaks up for (advocates for) pre-teen's needs in the medical system, school, and other social settings
- **Support system:** Encourages pre-teen to establish support systems with their peers who have CF

- **Planning for future:** Pictures a future and is able to talk about hopes and dreams
- **Anxiety & depression:** Can identify feelings of sadness and anxiety and bring them to the attention of a parent/support person or other trusted adult
- **Exercise:** Maintains an exercise routine/participates in sports or other healthy activities
- **Self-advocacy:** Has a short statement to answer basic questions about CF
- **Managing germs:** Takes basic steps (hand washing, 6-foot rule) to limit the spread of germs and infections
- **Support system:** Understands the importance of a support system and starts to develop a group of peers with CF