

## Milestones for the Late High School (16-18) Person with CF & Parent/Support Person



Below is a recommended list of CF-related milestones for people with CF of late high school age (16-18) 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

#### ASSISTING

- **Educates** older teen (with the support of the CF care team) on new aspects of CF care, such as:
  - Newly prescribed treatments and clinical trials
  - Advocating for oneself in the medical system
  - Rights and available services (governmental and other) in college and the workplace
  - Impact of CF on reproduction
  - Strategies for managing anxiety and depression
  - Healthy lifestyle choices (smoking, drinking, drugs)
  - Basics of insurance management
  - Impact of CF when choosing a college or career path

### ROLE OF PERSON WITH CF

#### LEADING

#### UNDERSTANDING CF

- **Understands** all aspects of CF:
  - Learns about new treatments that have been prescribed
  - Knows and proactively looks for the signs of other possible health issues linked to CF (CFRD, liver disease, sinus issues, etc)
  - Begins to learn about rights in the medical system, college, and workplace
  - Understands basics of governmental and private programs available to someone with CF as he/she is planning for college and work (ADA, office of disability services on the college campus, etc)
  - Understands basics of CF impact on reproduction
  - Understands strategies for managing anxiety and depression
  - Understands the negative impact of smoking, drinking, and drugs on overall health
  - Understands how to order and manage medicines, and replace equipment
  - Understands the basics of insurance management (insurer details, names of common forms, definitions of common terms, etc)

#### MANAGING CF CARE

- **Clinic visits:** Supports independent one-on-one teen visits with care team and plays a support role at the visit
  - Shares ownership of tracking and scheduling appointments with teen
  - Partners with teen to coordinate transportation to all care team visits and doctor's appointments (if teen has driver's license or public transport is available)
- **Health status:** Ensures teen is implementing recommended nutrition/treatment changes after clinic/hospital visit
- **Hospital visits:** Supports teen in preparing for hospital stays and manages most insurance and financial matters
- **Sleep:** Monitors sleep patterns
- **Exercise:** Encourages teen to follow an exercise plan
- **Nutrition:** Encourages teen to eat a CF-friendly diet
- **Coordination of care:** Works with teen to coordinate all care with healthcare providers outside the CF center (primary care, psychologist, endocrinologist, OB/GYN, etc)
- **Transfer to adult care:** Supports teen in navigating transfer process at clinic: asking to meet adult care providers, ensuring proper insurance, filing medical and legal paperwork, etc
- **Insurance & financial:** Oversees financial and insurance management
  - Empowers teen to order medication, call pharmacy, begin to engage with insurance company

- **Clinic visits:** Independently takes the lead during clinic visits, including answering questions
  - Schedules appointments with parent input and tracks doctor's visits
  - Partners with parent to coordinate transportation to all care team visits and doctor's appointments (if teen has driver's license or public transport is available)
- **Health status:** Implements recommended nutrition/treatment changes after clinic and hospital visits
- **Hospital visits:** Plans for hospital visits, including packing and alerting teachers and friends, and coordinating homework assignments, etc
- **Sleep:** Identifies issues with sleep patterns and raises concerns
- **Exercise:** Maintains a physically active lifestyle/exercise plan
- **Nutrition:** Can maintain a CF-friendly diet whether at home or out of the house
- **Coordination of care:** Works with parent to coordinate care with healthcare providers outside the CF center (primary care, psychologist, endocrinologist, OB/GYN, etc)
- **Transfer to adult care:** Participates in key meetings and fills out paperwork associated with transfer
- **Insurance & financial:** Monitors medications & supplies and calls in refills
  - Actively participates in discussions about insurance

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## ROLE OF PARENT/SUPPORT PERSON

### ASSISTING

#### TAKING CF TREATMENTS & THERAPIES

- **Taking treatments:** Trains and sets up teen for success to take responsibility for all treatments and equipment management, and provides support as the teen demonstrates need or as requested

## ROLE OF PERSON WITH CF

### LEADING

- **Setup:** Primarily responsible for setting up all equipment
- **Taking treatments:** Primarily responsible for taking all treatments, with little parental supervision
  - Responsible for following treatment plan in school and while on vacation
- **Cleaning & disinfecting:** Able to demonstrate and perform cleaning and disinfecting of all equipment and have a routine for getting them completed
- **Medicine management:**
  - Tracks and sorts all medicines
  - Demonstrates and calls for refills when medicine is running low

#### LIVING WITH CF

- **Planning for future:** Continues to envision a future for teen/continues to discuss education and career planning
- **Anxiety & depression:** Understands and provides emotional support if teen has anxiety and depression
  - Discuss impact of exercise, breathing techniques, seeking professional help, etc
- **Exercise:** Encourages participation in sports and healthy activities
- **Advocacy:** Supports teen in disclosing their CF in a confident and comfortable manner/works with them to ensure any new teachers, peers, etc are properly informed about CF
- **Support System:** Encourages teen to establish support system with their peers who have CF
- **Lifestyle:** Has an open dialogue with teen about the impact of lifestyle on long-term health (smoking, drinking, drugs, sexuality, and dating)

- **Planning for future:** Actively plans for future including college life (living on campus, creating a class schedule that works within treatment schedule, disability support services on campus, etc), work, and/or living independently
- **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:** Works with the care team to develop an exercise routine
- **Self-advocacy:** Able to answer questions from peers/others about CF
- **Managing germs:** Implements best practices to prevent the spread of germs and infections
- **Support System:** Understands the importance of, and utilizes a support system of peers with CF
- **Lifestyle:** Makes healthy lifestyle choices about smoking, drinking, drugs, sexuality, and dating