

Milestones for the Young Adult (18-25) Person with CF & Parent/Support Person



Below is a recommended list of CF-related milestones for the young adult with CF age (18-25) 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

SUPPORTING

- **Educates and responds to questions** about new aspects of CF care, such as:
 - Newly prescribed treatments and clinical trials
 - Impact of CF on family planning and relationships
 - Impact of lifestyle choices on the future (transplant, clinical trials, etc)
 - Insurance and financial management
 - Choosing a college or career path

ROLE OF PERSON WITH CF

OWNING

UNDERSTANDING CF

- **Understands** and learns about all adult-related CF care issues:
 - Learns about new treatments that have been prescribed
 - Understands rights in the medical system, college, and workplace
 - Understands the breadth of governmental and private programs available to someone with CF (ADA, office of disability services on the college campus, etc)
 - Fully understands impact of CF on reproduction and family planning
 - Understands coping strategies and which healthcare providers to see to help manage anxiety and depression
 - Understands the impact of unhealthy lifestyle choices on transplant and future health
 - Understands how to manage all aspects of an insurance claim
 - Understands costs associated with treatments and therapies (co-pays, etc)
 - Understands how to create a budget for managing CF-related finances

MANAGING CF CARE

- **Clinic visits:** Attends clinic visits at the request of the young adult
- **Hospital visits:** Supports young adult in preparing for hospital stays
- **Insurance & financial:** Consults with the young adult on more complex insurance and financial matters

- **Clinic visits:** Plans for and takes the lead during clinic visits and doctor's appointments (scheduling, planning transportation, answering questions, etc)
- **Health status:** Implements recommended nutrition/treatment changes after clinic and hospital visits
- **Hospital visits:** Plans and coordinates hospital visits
- **Sleep:** Maintains healthy sleep patterns
- **Exercise:** Maintains a physically active lifestyle/exercise plan
- **Nutrition:** Eats a CF-friendly diet
- **Coordination of care:** Coordinates all 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 required paperwork associated with transfer now that he/she is 18
- **Insurance & financial:**
 - Monitors medications & supplies, calls in refills
 - Owns all medication and insurance-related management, and reaches out to parent/support person if questions arise

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ROLE OF PARENT/SUPPORT PERSON

SUPPORTING

TAKING CF TREATMENTS & THERAPIES

- **Taking treatments:** Provides support, as needed, when requested by young adult

ROLE OF PERSON WITH CF

OWNING

- **Setup:** Completely responsible for setting up all equipment
- **Taking treatments:** Completely responsible for taking all treatments, with little parental/support person supervision
- **Cleaning & disinfecting:** Completely responsible for cleaning and disinfecting all equipment
- **Medicine management:** Responsible for tracking, sorting, and storing all medicines, and identifying need for refills

LIVING WITH CF

- **Planning for future:** Continues to envision a future for young adult and provide ongoing support to help reach life goals
- **Anxiety & depression:** Understands and provides emotional support if young adult has anxiety and/or depression
- **Support system:** Encourages young adult to utilize support system with their peers who have CF
- **Lifestyle:** Has an open dialogue with young adult about the impact of lifestyle on long-term health

- **Planning for future:** Actively plans for future
- **Anxiety & depression:** Can identify warning signs of anxiety and depression and work with care team/other healthcare providers to manage
- **Self-advocacy:** Able to independently 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