

Milestones for the Early School Age (6-9) Person with CF & Parent/Support Person

Below is a recommended list of CF-related milestones for people with CF of early school age (6-9) 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

PROVIDING & TEACHING

- **Educates** child (with the support of the CF care team) about the basics of CF:
 - What CF is and how it impacts the body (lungs, digestive system, sinuses, etc)
 - Importance and recommended amount of sleep
 - Reasons to exercise and importance of salt intake
 - Why infection control is important and reinforces proper techniques
 - Role of key staff on the CF care team
 - Names of and reasons for taking medicines and therapies
 - CF diet and nutrition
 - CF equipment and basics of care
 - Advocating for oneself (in the medical system, at school, in social situations)

ROLE OF PERSON WITH CF

DEPENDING

UNDERSTANDING CF

- **Understands** the basics of CF:
 - Knows and can provide basic explanation of CF, including how it impacts the lungs, digestive system (where food is processed in your body), and other parts of the body
 - Understands the importance of sleep on overall health and the recommended amount of sleep he/she should be getting (as recommended by the care team or current sleep guidelines)
 - Understands why exercise is important and that increased salt is needed during high levels of activity
 - Understands the basics of how to clean hands and limit the spread of infection
 - Begins to understand the roles and responsibilities of the CF care team
 - Starts to know the names of most medicines and therapies and has a basic understanding of what they do in the body
 - Understands the basics of the CF diet and can identify some CF-friendly foods
 - Starts to identify what equipment goes with each treatment and the basics of how to put it together and use it
 - Understands very basic rights in school (bathroom and water breaks, snacks, etc) and the importance of telling a parent or care team member if their needs are not being met

MANAGING CF CARE

- **Clinic visits:** Leads all aspects, including in-clinic discussion around child's health status, treatment changes, insurance changes, etc
 - Encourages child to answer a few questions during visit (how they have been feeling, current symptoms)
 - Schedules and tracks care team visits and other doctor's appointments
 - Arranges transportation to all care team visits/doctor's appointments
- **Health status:** Proactively identifies and reports changes in health/symptoms
 - Keeps track of FEV₁ and Body Mass Index (BMI) and implements recommended nutrition/treatment changes as needed
- **Hospital visits:** Prepares for hospital visits (packing, alerting school of absence, coordinating with insurance, etc)
- **Sleep:** Closely monitors sleep patterns
- **Nutrition:** Plans for CF-friendly snacks and meals
- **Coordination of care:** Complete coordination of 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 visits:** Able to answer some questions about general health status and symptoms at clinic visits, with support person's input
- **Health status:** Begins to identify and report changes in symptoms or health to a parent/support person
- **Sleep:** Has a set bedtime and wake-up time

Milestones for the Early School Age (6-9) Person with CF & Parent/Support Person

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ROLE OF PARENT/SUPPORT PERSON

PROVIDING & TEACHING

TAKING CF TREATMENTS & THERAPIES

- **Setup:** Teaches child proper way to set up equipment and allows child to do certain tasks (squirt nebulizer solution into cup, put on vest independently, etc)
- **Taking treatments:** Responsible for day-to-day management, including:
 - Being in the room while child takes treatments and medicines
 - Checking that he/she is using proper technique
 - Teaching basic strategies for remembering to take and carry pills and enzymes (giving child a pill box, counting out the number of pills needed per dose/per day, setting a timer at home for when pills/enzymes need to be taken, etc)
 - Having a plan or system for taking medicines and treatments away from home (school, vacation, etc)
- **Cleaning & disinfecting:** Responsible for cleaning and disinfecting all equipment, but encourages child to watch
- **Medicine management:** Responsible for tracking, sorting, and storing all medicines, and identifying need for refills

ROLE OF PERSON WITH CF

DEPENDING

- **Taking treatments:**
 - Begins taking steps toward remembering to take and carry pills and enzymes
 - Helps to set up nebulizer and airway clearance equipment
 - With close oversight of parent/support person, takes and participates in all treatments

LIVING WITH CF

- **Planning for future:** Pictures a future for child/encourages child to dream about the future
- **Anxiety & depression:** Understands and proactively implements strategies for managing anxiety and depression
 - Acknowledges that it is OK/normal to be sad/unhappy/anxious sometimes because of CF
 - Works with child on identifying feelings of sadness or anxiety
- **Exercise:** Creates exercise plan with care team and encourages child to participate in exercise/physical activity
- **Advocacy:** Ensures school, family, friends, and coaches are properly educated about CF
 - Speaks up for (advocates for) child's needs in the medical system, school, and other social settings
- **Support system:** Encourages child to establish support systems with their peers who have CF

- **Planning for future:** Pictures a future as an adult
- **Anxiety & depression:** Aware of anxious or sad feelings and alerts a parent/support person
- **Exercise:** Participates in sports, exercise, or other healthy activities
- **Self-advocacy:** Can answer very basic questions about CF from friends, family, and teachers
- **Support system:** Understands the importance of a support system of peers with CF

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****UNDERSTANDING CF**

- **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 FEV₁ 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**

- **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 FEV₁ 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 FEV₁ 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 FEV₁ 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)

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

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

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, FEV₁ 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 FEV₁ 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

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

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

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

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

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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

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

ROLE OF PERSON WITH CF

OWNING

UNDERSTANDING CF

- **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

- **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

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

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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