

Recommended Cystic Fibrosis (CF) Milestones by Age & Stage



This guide was developed in partnership with the Transition Advisory Council and supported through a survey of people with CF, their parents/support persons, and healthcare providers.

There are many phases and stages in life. With each new stage, you learn a different set of responsibilities. As you master each task, one by one, your confidence grows, getting you ready to tackle the next level of skills. Do you remember your first day of school? How about learning to ride a bike? These are all great life milestones!

As a person grows older, it's time to start planning for a new set of milestones. For people with CF, these should include health-related milestones as they are an important part of becoming an independent adult. But how do we know which CF milestones a person should begin to master at each life stage?

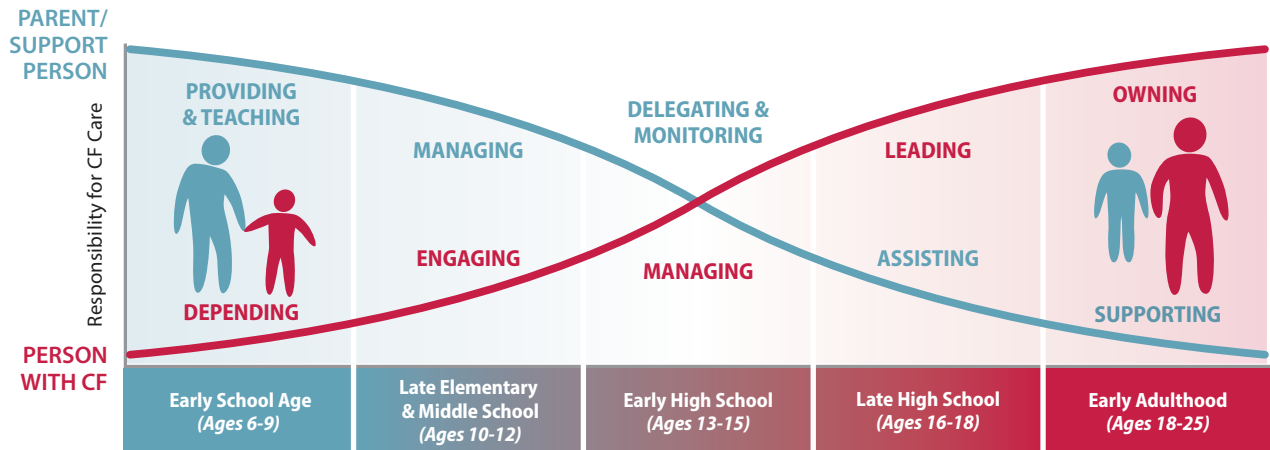
This guide provides a timeline of recommended CF-related milestones that a person with CF, a parent, or a support person can work toward as the child grows up.

Note to reader: It is important to remember that every person with CF is unique and there are many factors that impact a person's development from birth to adulthood. This recommendation is to be used as a discussion guide with CF families and care teams to determine which milestones are relevant to you.

A Transfer of Leadership

In the early years of life, parents are the leaders in their child's care. They take on almost the entire burden of CF care responsibilities to ensure that their young child remains as healthy as possible. As a child grows, it is important that a parent transfer these CF care responsibilities to their child. While this can be understandably scary and worrisome, transferring the ownership of care in a structured and carefully managed way, over time, can help ensure the development of a successful, independent young adult living with CF.

The chart below outlines the evolving role that a parent or support person might play in transferring responsibility of care to their child. It also provides an overview of the increasing responsibility a person with CF will take on for their care as they age. Remember, these skills should be transferred very slowly, over time. And, while this chart represents the role most people with CF should have for their care by a given stage, it is perfectly normal for some to take on these responsibilities earlier or later than the timing indicated below.



ROLE OF PARENT/SUPPORT PERSON		ROLE OF PERSON WITH CF
PROVIDING & TEACHING <ul style="list-style-type: none"> Owner of care Responsible for managing care & educating child 	Early School Age (Ages 6-9)	DEPENDING <ul style="list-style-type: none"> Depends on Parent/Support Person for care Responsible for learning the basics of CF care
MANAGING <ul style="list-style-type: none"> Main provider of care Responsible for managing care & educating pre-teen Provide opportunities for self-care 	Late Elementary & Middle School (Ages 10-12)	ENGAGING <ul style="list-style-type: none"> Looks to Parent/Support Person for direction on self-care Responsible for actively engaging in self-care
DELEGATING & MONITORING <ul style="list-style-type: none"> Partner in care with teen Responsible for monitoring care & educating teen 	Early High School (Ages 13-15)	MANAGING <ul style="list-style-type: none"> Partner in care with Parent/Support Person Responsible for owning some aspects of self-care/ asking questions of Parent/Support Person
ASSISTING <ul style="list-style-type: none"> Provides oversight of care Responsible for assisting in care & educating teen 	Late High School (Ages 16-18)	LEADING <ul style="list-style-type: none"> Primary owner of care Responsible for owning most aspects of self-care/ asking questions of Parent/Support Person
SUPPORTING <ul style="list-style-type: none"> Provides support at the request of young adult Responsible for supporting care and providing emotional support 	Early Adulthood (Ages 18-25)	OWNING <ul style="list-style-type: none"> Ownership & oversight of care Primarily responsible for self-care

Adapted with permission from: Kieckhefer G, Trahms C. Supporting development of children with chronic conditions: from compliance toward shared management. *Pediatr Nurs.* 2000;26(4):354-363.

CF Milestones At A Glance



This chart was developed to give CF families and care teams an at-a-glance view of how responsibilities evolve as a person with CF moves from one life stage to the next. It focuses on four key areas of CF: understanding CF, managing CF care, taking CF treatments and therapies, and living with CF. It is important to remember that every person with CF is unique and there are many factors that impact a person's development from birth to adulthood. This document should be used as a discussion guide with CF families and care teams to determine which milestones are relevant to you.

<input type="radio"/> Parent/Support Person Completely Responsible	<input type="radio"/> Parent/Support Person Primarily Responsible	<input type="radio"/> Parent/Support Person and Person with CF Share Responsibility	<input type="radio"/> Person with CF Primarily Responsible	<input type="radio"/> Person with CF Completely Responsible
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MILESTONE	Early School Age	Late Elementary & Middle School	Early High School	Late High School	Early Adulthood
	(6-9)	(10-12)	(13-15)	(16-18)	(18-25)
UNDERSTANDING CF					
Understands the basics of CF: what it is, how it impacts the body, etc	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the importance of sleep on overall health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the importance of sports, exercise, salt intake, and healthy activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands importance of infection control and ways to manage the spread of germs/infection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the roles and responsibilities of CF care team members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the key symptoms that might trigger exacerbations or a decline in health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knows names of medications, understands what they do, and learns about new treatments as they are introduced	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands BMI percentile, FEV ₁ scores, key aspects of CF screening, and basic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the proper nutrition and diet plan for a person with CF and impact on lung/overall health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands how equipment works and how to get replacement equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands rights in school and the workplace	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands other possible health issues linked to CF (CF-Related Diabetes, liver disease, sinus issues, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands impact of CF on body/sexual development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands the impact of CF on mental health (anxiety/depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands how lifestyle choices impact long-term health (drinking, drugs, smoking, transplant, relationships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understands CF-related insurance, patient assistance programs, medication, and financial management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

NOTE to reader: This chart begins at early school age (age 6). This chart will be updated to include milestones for newly diagnosed through age 5 in the future.

CF Milestones At A Glance

	Parent/Support Person Completely Responsible	Parent/Support Person Primarily Responsible	Parent/Support Person and Person with CF Share Responsibility	Person with CF Primarily Responsible	Person with CF Completely Responsible
MILESTONE					
	Early School Age	Late Elementary & Middle School	Early High School	Late High School	Early Adulthood
	(6-9)	(10-12)	(13-15)	(16-18)	(18-25)
MANAGING CF CARE					
Leads all aspects of clinic visit—asks/answers questions about health status, treatment changes, insurance, etc					
Proactively identifies and reports changes in health/symptoms and alerts parent or care team					
Keeps track of FEV ₁ and BMI and implements recommended nutrition/treatment changes, as needed					
Monitors and maintains appropriate sleep schedule					
Creates and maintains proper diet and nutrition plan					
Prepares for hospital visits (packing, alerting school/work, etc)					
Coordinates care with healthcare providers outside the CF center (primary care, psychologist, OB/GYN)					
Person with CF is open to and ready for transfer to adult center					
Schedules appointments and tracks all doctor's appointments/clinic visits					
Manages all insurance and financial aspects of CF care (ordering new treatments, coordinating refills, co-pays, etc)					
Arranges transportation to all doctor's appointments/clinic visits					
TAKING CF TREATMENTS & THERAPIES					
Sets up all equipment and treatments					
Remembers to take and carry pills and enzymes					
Remembers and takes medicines and treatments as prescribed by doctor					
Cleans and disinfects equipment					
Sorts and tracks medications, identifies need for refills, and informs care team/pharmacy if running low					
Stores medication properly					
Has a plan or system for taking medicines and treatments when on the road (on vacation, at school, at work)					
LIVING WITH CF					
Pictures and openly talks about a future for the person with CF					
Able to identify warning signs and apply strategies for managing anxiety and depression					
Maintains and monitors exercise plan					
Educates school, family, friends, and coaches about CF					
Able to speak up/advocate for the person with CF in the medical system, school, or other social settings					
Makes healthy lifestyle choices (drinking, drugs, infection control, etc)					
Understands the importance of—and utilizes—a support system of peers with CF					

NOTE to reader: This chart begins at early school age (age 6). This chart will be updated to include milestones for newly diagnosed through age 5 in the future.

This guide was adapted from "Ages & Stages Living and Growing with Cystic Fibrosis Developmental Education for use with Parents & Patients living with CF" by Kecia Nelson, MSW, LCSW