

## 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?

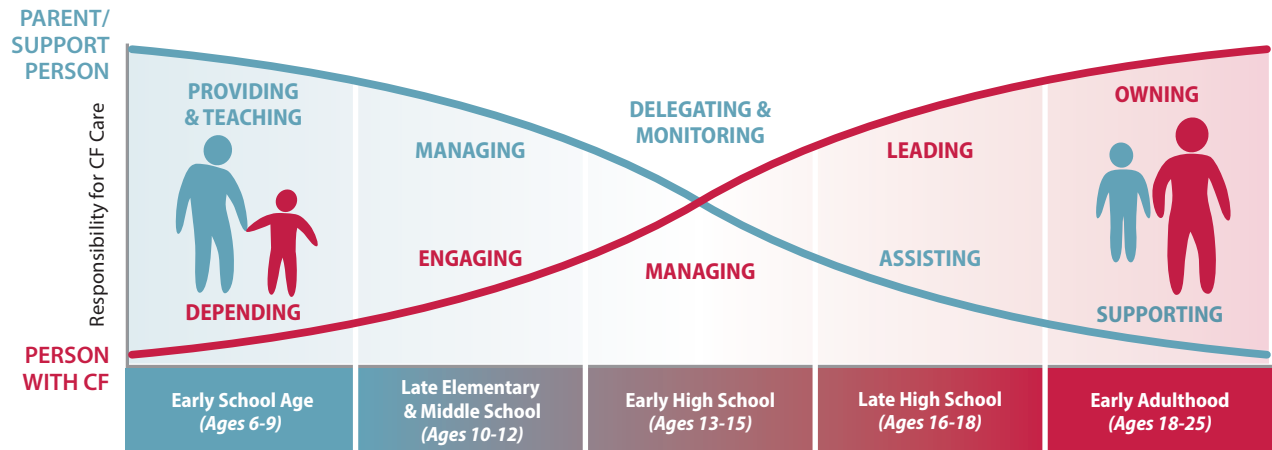
This guide provides a timeline of recommended CF-related milestones that a person with CF, a parent, or a support person can work toward as the child grows up.

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

















































































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.

 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
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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)
<b>UNDERSTANDING CF</b>					
Understands the basics of CF: what it is, how it impacts the body, etc					
Understands the importance of sleep on overall health					
Understands the importance of sports, exercise, salt intake, and healthy activities					
Understands importance of infection control and ways to manage the spread of germs/infection					
Understands the roles and responsibilities of CF care team members					
Understands the key symptoms that might trigger exacerbations or a decline in health					
Knows names of medications, understands what they do, and learns about new treatments as they are introduced					
Understands BMI percentile, FEV <sub>1</sub> scores, key aspects of CF screening, and basic tests					
Understands the proper nutrition and diet plan for a person with CF and impact on lung/overall health					
Understands how equipment works and how to get replacement equipment					
Understands rights in school and the workplace					
Understands other possible health issues linked to CF (CF-Related Diabetes, liver disease, sinus issues, etc)					
Understands impact of CF on body/sexual development					
Understands the impact of CF on mental health (anxiety/depression)					
Understands how lifestyle choices impact long-term health (drinking, drugs, smoking, transplant, relationships)					
Understands CF-related insurance, patient assistance programs, medication, and financial management					

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

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

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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