



What is Palliative Care in Cystic Fibrosis (CF)?

Palliative care is a type of care for patients and families living with chronic illnesses that focuses on reducing physical and emotional symptoms, improving other types of distress, and promoting the best quality of life possible from diagnosis onward. Palliative care for people with CF occurs alongside usual treatments and is individualized according to the unique goals, hopes, and values of each person with CF.

CF is a serious illness. Although recent advances, including CFTR modulator medications, have reduced the burden and severity of illness for many, some children, adolescents, and adults with CF continue to have problems and concerns that can cause distress, impair function, or otherwise undermine quality of life.

CF palliative care recognizes that patients and families may need help with these problems or other challenges, such as navigating the health care system and dealing with insurance or financial barriers. Palliative care must be ongoing and altered as needed to respond to unexpected and sometimes rapid changes.

Who Provides Palliative Care in CF Care?

Palliative care treatments and services may be provided by members of CF care teams. This is called primary palliative care. It also may be provided by one or more other professionals who often work in a team that may include doctors, nurses, social workers, chaplains, and others. These teams offering specialist palliative care may work in collaboration with CF care teams.

Recent guidelines from the Cystic Fibrosis Foundation suggest that primary palliative care should be provided by appropriately trained members of the CF care team, with involvement of palliative care specialists for more complicated situations, like when procedures like lung transplantation are being considered or when symptoms are severe and difficult to manage.

How Does Palliative Care Help?

Palliative care begins with a detailed assessment that determines the symptoms and other sources of distress that are particularly burdensome for the patient and family. Based on this assessment, many treatments and services may be offered. These may include medicines and other treatments for respiratory symptoms such as cough or breathing problems, for gastrointestinal symptoms such as constipation or nausea, or for pain or fatigue. Other support may be provided for emotional distress, family problems, or spiritual distress. Palliative care's focus on quality of life also includes support for treatments that promote wellness and resilience—approaches that may become more important as new treatments are emerging for CF.

One of the care team's goals in providing palliative care is to try to make sure that the patient and family understand the illness and the benefits and burdens associated with CF treatments. This helps ensure that the patient and family make informed decisions, and that the care provided is always consistent with their values and preferences. Professionals focused on palliative care also encourage adults with CF to complete advance directives, which describe how health care decisions should be made if the person becomes unable to communicate in the future.

Palliative care is often needed from the first time that a serious illness is diagnosed, but the need for palliative care treatments and services usually increases when the illness is in an advanced stage. If someone with CF is approaching the end of life, palliative care makes certain that dying happens with as little suffering as possible and in a way that respects the patient and family. Palliative care includes treatments and services that support good care at the end of a person's life, and specialists in palliative care are often helpful as an extra layer of support to the CF care team at this time.

What Is Hospice?

Hospice in the U.S. is a large government-supported health care system that is able to provide specialist palliative care to eligible patients living at home or in other settings. Hospice programs provide case management by an interdisciplinary team, many treatments and services, and interventions to support the family. All of these services are provided at no cost to the patient or family.

Patients referred to hospice have advanced illness. In most situations, a physician must state that the patient is likely to survive for six months or less. Patients who enroll in hospice can continue to receive care from their CF team, including their own physician. Hospice can be revoked by the patient at any time and for any reason, and a person can re-enroll if eligible.

How Can I Learn More About Palliative Care?

If you're interested in learning if palliative care may help you, or you would like to discuss hospice, ask your CF team.