Pulmonary Fibrosis Foundation™

Symptom Management for PF:
How Palliative Care Can Improve Quality of Life



Patients with pulmonary fibrosis (PF) and other forms of interstitial lung disease (ILD) may experience different symptoms throughout their disease course, including shortness of breath, cough, and fatigue. Both patients and their caregivers may also experience anxiety, depression, problems with sleep, and fear of the unknown.

But palliative care can help.

WHAT IS PALLIATIVE CARE?

Palliative care is specialized medical care for anyone living with a serious illness like PF or ILD. The goal of palliative care is to improve quality of life by providing relief from the symptoms and stress of a serious illness. Simply put, palliative care focuses on symptom relief and improving a patient's quality of life.

IS PALLIATIVE CARE THE SAME AS HOSPICE CARE?

No, palliative care and hospice care are not the same thing, but they both focus on symptom relief and improving a patient's quality of life. Palliative care can begin at diagnosis or any time after that and occur at the same time as all other treatments, including pulmonary rehabilitation, lung transplant evaluation, and research participation. Many palliative care providers also offer hospice care, helping to ease the transition to hospice care when it is needed.

Hospice care typically begins after disease treatment is no longer effective and the patient is thought to have less than six months to live. Hospice care continues to focus on symptom relief, but also addresses end-of-life care.

WHAT SERVICES ARE INCLUDED IN PALLIATIVE CARE?

Palliative care treatment is usually symptom-focused (shortness of breath, cough, low oxygen levels, fatigue, anxiety, and depression), and helps patients function better in their day-to-day activities. Your pulmonary care team can also help you with many of these issues, of course. But the palliative care team can add extra resources to deal with all aspects of coping with the disease for both you and your caregiver.

IS PALLIATIVE CARE ONLY TO ADDRESS PHYSICAL ISSUES?

No. Palliative care treats the whole person and can help with many issues that affect a patient's quality of life. This means that palliative care can also address emotional, social, and spiritual needs. Palliative care teams can help patients understand their options as the disease progresses and help patients and families make decisions about what type of care they may wish to have in the future. This may include decisions about advance directives and health care power of attorney, as well as end-of-life care.

WHO IS ELIGIBLE FOR PALLIATIVE CARE?

Every patient with a serious illness has a right to palliative care, and every patient has the right to make decisions about their care at all times.

WHEN SHOULD I CONSIDER PALLIATIVE CARE?

Palliative care can be helpful at any stage of an illness. You can start receiving palliative care if at any time your symptoms cause discomfort, become burdensome, or affect your quality of life. Two common times for a referral for palliative care services are after a hospitalization or when starting supplemental oxygen therapy.

HOW DO I ASK FOR PALLIATIVE CARE?

Your pulmonologist may discuss palliative care with you soon after you receive your diagnosis. This is so that you understand all your symptom management options and does not mean anything about your prognosis. You also don't have to wait for your doctor to suggest palliative care. You can ask about symptom management and referral to a palliative care specialist at any time.

WHAT KIND OF MEDICAL PROFESSIONALS CAN PROVIDE PALLIATIVE CARE?

Your pulmonologist can provide primary palliative care by working with you on symptom management and advanced care planning. Specialty palliative care is delivered by a team of specially trained doctors, nurses, social workers, and other care team members who work together with your existing care team to provide an extra layer of support.

Importantly, your pulmonologist will continue to manage your PF or ILD. Other specialists, like a rheumatologist or cardiologist, will stay involved in your care, too.

HOW CAN PALLIATIVE CARE HELP CAREGIVERS?

It is very difficult to watch a loved one experience a disease that can cause debilitating symptoms and can affect their ability to do the activities they enjoy. At times, a caregiver may feel powerless to relieve their loved one's suffering. As the disease gets worse, the palliative care team offers family members and caregivers support and resources to help them manage the emotional and physical burdens of caring for a loved one. The palliative care team addresses quality-of-life issues for caregivers by providing counseling and resources to help them remain mentally and physically healthy.

WHERE CAN I RECEIVE PALLIATIVE CARE?

Palliative care can be given in many settings, including in the clinic, in the hospital, virtually, or in your home.

WHO PAYS FOR PALLIATIVE CARE?

Medicare, Medicaid, and many private insurance plans may cover the medical portions of palliative care. Veterans may be eligible for palliative care through the VA. Check with your insurance plan to see what it will cover.

HOW LONG CAN I RECEIVE PALLIATIVE CARE?

You can receive palliative care for as long as you need it.

WHERE CAN I LEARN MORE ABOUT PALLIATIVE CARE?

A number of hospice organizations have shared high-quality resources online. These include:

Center to Advance Palliative Care
www.getpalliativecare.org

National Hospice and Palliative Care Organization
www.caringinfo.org

American Academy of Hospice and Palliative Medicine
www.palliativedoctors.org/

National Institute on Aging, "What are Palliative Care and Hospice Care?"
www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

World Health Organization,
www.who.int/news-room/fact-sheets/detail/palliative-care

