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Pulmonary Fibrosis Foundation Palliative Care Position Statement: Patient

Introduction:

Palliative care delivered early in a patient's treatment journey can significantly improve health and quality of life for both the patient and their caregivers as they deal with a life changing diagnosis. Patients with pulmonary fibrosis and their caregivers experience many symptoms throughout their disease course. These symptoms can include shortness of breath, cough, fatigue, anxiety, depression, problems with sleep, and fear of the unknown, to name a few. The goal of palliative care is to improve quality of life and provide relief from the symptoms and stress of a serious illness. While there are more than 200 types of interstitial lung diseases (ILD), which can cause Pulmonary fibrosis (PF), palliative care can support patients living with PF or ILD and their caregivers by treating symptoms, and providing comfort and assistance.

1. What is palliative care?

Palliative care is specialized care for people living with any serious illness that causes a high burden of symptoms such as pulmonary fibrosis. Palliative care focuses on providing relief from the symptoms and stress that pulmonary fibrosis can cause. The goal is to improve your and your caregiver's ability to enjoy life. A palliative care team usually consists of 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.

2. What are the differences between palliative care and hospice?

Both palliative care and hospice can help provide comfort and improve symptoms for a patient with serious illness. Palliative care can begin at any time in the patient's disease course and occur at the same time as all other treatments, including participating in research studies, pulmonary rehabilitation, and lung transplant evaluation. In one study, patients with serious illness who received palliative care lived longer than those who did not. Hospice care typically begins after treatment of the disease is no longer effective and when it is known that the patient is thought to have less than six months to live. Hospice care focuses on both symptom relief as well as end-of-life care.

3. Why might a patient with pulmonary fibrosis need palliative care?

Palliative care relieves symptoms and suffering and promotes the best possible quality of life for patients and their families. If you are having symptoms that are limiting your ability to do the things that bring you joy and comfort, then palliative care teams can help provide relief. 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. While your pulmonary care team may help you with many of these issues, the palliative care team can add resources to deal with all aspects of facing the disease for both the patient and the caregiver.

While palliative care teams help patients and families throughout the disease journey, they can also provide guidance for patients whose disease is worsening despite therapy. 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 as the end of life approaches. This may include decisions about advanced directives and health care power of attorney, if not already addressed, as well as end of life care. It is always possible to provide care and symptom control, even if the disease is progressive.

Every patient with a serious illness has a right to palliative care, and every patient has the right to make decisions about their care, including care at the end of life.

4. How are caregivers needs addressed with palliative care?

It is very difficult to watch a loved one experience a disease that affects their ability to do the activities they enjoy and to, at times, feel powerless to relieve their suffering. As the disease gets worse, it is important that family members and caregivers of patients with lung disease receive support and resources to help them manage the emotional and physical burdens of caring for a loved one. The palliative care team not only attends to physical, emotional, social, and spiritual quality of life for the patient, but addresses these issues for caregivers as well by providing counseling and resources to help caregivers remain mentally and physically healthy and better support patients.

5. What resources are available and where can a pulmonary fibrosis patient find more information about palliative care?

Palliative care can be given in many settings, including in the hospital, in the clinic, virtually or in the home. If you feel that you or your loved one could benefit from more support in managing symptoms and concerns about your disease, it is important to ask your provider or care team for a palliative care referral. Most major insurances cover palliative care (including Medicare and Medicaid).

Additional Resources

getpalliativecare.org

pulmonaryfibrosis.org

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