



230 East Ohio Street Suite 500 Chicago Illinois 60611 **844.TalkPFF** | **844.825.5733** PHONE  
**866.587.9158** FAX

## **Pulmonary Fibrosis Foundation Position Statement on Palliative Care: Provider**

### **Introduction**

Palliative care is defined as specialized care for people living with a serious illness that improves quality of life by providing relief from symptoms and stress of illness. Pulmonary Fibrosis (PF), whether idiopathic or resulting from one of the numerous other interstitial lung diseases, may have a progressive, often unpredictable and terminal course, with significant symptom burden including dyspnea, cough, fatigue, depression, and anxiety. Palliative care can augment the management of patients with pulmonary fibrosis by addressing symptoms, supporting caregivers, and aiding in end-of-life planning. Studies have shown that only a minority of patients who die from pulmonary fibrosis receive palliative care services and most of these services are delivered in the last month of life. In other serious illnesses, palliative care has been found to increase quality of life and survival. This position paper will provide guidance for healthcare providers on incorporating palliative care services into the ongoing management of Pulmonary Fibrosis.

### **1. How do I introduce the topic of palliative care to my patients?**

It's never too early to ask the patient "What's important to you?" A number of studies have shown that palliative care (PC) is under-utilized in patients with lung disease, generally, and with pulmonary fibrosis (PF) specifically. In fact, the majority of patients with PF never receive a formal referral for PC evaluation and services, despite the significant symptom burden as well as the poor prognosis from the outset.

There are many barriers to the introduction of PC. Initially, patients are coming to terms with facing an uncertain future due to a disease they may have never heard of before. Decisions regarding drug therapy, pulmonary rehabilitation, clinical trials, or lung transplantation take considerable time and effort to discuss and plan. This may leave little time for addressing what some providers may see as an option only for end of life. **Despite these obstacles, this Task**

**Force recommends broaching the subject of PC early in the disease course, as most patients want to know what the future might hold and how they might face it.**

Since PC encompasses all aspects of improving the well-being of patients living with serious illness, it is important to emphasize to patients the comprehensive nature of PC. Palliative care provides an extra layer of support for physical (symptoms), spiritual, emotional/psychological and social needs. Importantly in PF, palliation includes not only treating cough and dyspnea, which pulmonologists may feel comfortable managing, but also addressing anxiety, depression, insomnia, and other conditions commonly afflicting our patients. Studies have shown that PF patients and caregivers often do not understand what PC entails and what resources it can offer.

## **2. When should I refer a patient to Palliative Care?**

We recommend addressing the concept of PC early in the medical journeys with our patients. Screening tools exist to identify needs that we may not recognize in the course of a typical clinic visit. Patients may not even understand their own needs, and might confuse “normal aging” with the burdens of PF. Furthermore, they may not realize that there may be treatments to help ease symptom burden that are outside the expertise of their pulmonologist. Identifying these needs early can prompt referral for counseling, cognitive behavioral therapy, more formal psychiatric help, and other measures to improve emotional and spiritual well-being. Home assessments can identify potential hazards in the home and measures to mitigate them. Finally, early referral for PC can connect patients to organizations that will partner with them for the rest of their illness.

Significant changes in health should prompt referral (or re-referral) to PC. Starting supplemental oxygen therapy or hospitalizations are obvious events, but more subtle changes, such as identifying new limitations in caregiver support, may also be quite important.

## **3. What does Palliative care offer to patients who are early in disease? Later in disease?**

Early in disease, discussions of PC may offer reassurance that resources are available for managing symptoms and for future advance care planning. Providers may fail to recognize the peace of mind this can offer patients as they face uncertain futures.

Later in disease, PC focuses more specifically on features of disease that are more apparent: treating dyspnea, anxiety, cough, pain and depression. Studies have shown patients with

end-stage PF report worse dyspnea yet receive fewer opioids than do end-stage cancer patients.

#### **4. What are the differences between Palliative care and Hospice?**

Palliative care is comprehensive care focused on the well-being of the patient. It does not replace the medical decision-making of the primary pulmonologist, but rather aims to improve quality of life at any stage of illness, so that patients may live as fully as possible, even as disease limits them.

Hospice is end-of-life care; its focus is to alleviate suffering when the patient is thought to have less than 6 months to live and the focus is on comfort. *Advance care planning* may begin earlier. It is important for many patients to consider, for example, whether they prefer to die at home rather than in a hospital or other facility. In this sense, advance care planning discussions may be relevant as early as the time of diagnosis.

#### **5. What resources are available regarding symptoms management**

There are a number of resources available for providers addressing these issues. Many institutions have Palliative Care consult services, both for inpatients and outpatients. Various “Bridge” programs offer a spectrum of services over the course of illness, progressing from assistance in various aspects of basic needs such as home medical equipment, to anxiolytics in more moderate illness, to opioids in progressive disease, to full Hospice Care at the end of life. We advise that pulmonologists who treat patients with pulmonary fibrosis explore palliative care resources available in their own communities to facilitate early referral.

#### **References**

[www.capc.org](http://www.capc.org)

<http://www.getpalliativecare.org/>

[www.mayoclinic.org](http://www.mayoclinic.org)

[www.who.int](http://www.who.int)

[www.nia.nih.gov](http://www.nia.nih.gov)

[www.cms.gov](http://www.cms.gov)

[www.nhpco.org](http://www.nhpco.org)

[www.crossroadhospice.com](http://www.crossroadhospice.com)

[www.medlineplus.gov](http://www.medlineplus.gov)

[www.npcrc.org](http://www.npcrc.org)

[www.hospicecare.com](http://www.hospicecare.com)

[www.palliative.stanford.edu](http://www.palliative.stanford.edu)

[www.cdc.gov](http://www.cdc.gov)

### **Committee Membership**

#### *Chairs*

Sonye Karen Danoff, MD, PhD, Johns Hopkins Medicine

Kathleen Oare Lindell, PhD, RN, ATSF, FAAN, Medical University of South Carolina

#### *Literature Review Chairs*

Anna Gersten, MD, Johns Hopkins University

Divya Patel, DO, MBA, University of Florida Health

Timothy P.M. Whelan, MD, Medical University of South Carolina

#### *Literature Review Committee Members*

Traci Adams, MD, University of Texas Southwestern Medical Center

Janell Reichuber, MSN, RN, University of Kansas Health System

Tonya Russell, MD, Washington University School of Medicine

#### *Survey Chairs*

Lanier O'Hare, CRNP, University of Alabama at Birmingham

Nina Patel, MD, Columbia University Medical Center/ Boehringer Ingelheim

Zeenat Safdar, MD, MS, Houston Methodist Hospital

#### *Committee Members*

Darlene Cochran, Patient / Caregiver

Rachana Krishna, MD, Medical University of South Carolina

Yolanda Mageto, MD, MPH, Baylor University Medical Center

#### *Writing Chairs*

Heather Bachert, MSN, ANP-BC, Henry Ford Health System

Tracy R. Luckhardt, MD, MS, University of Alabama at Birmingham

Lake Morrison, MD, Duke University Medical Center

#### *Committee Members*

Jane E. Dematte, MD MBA, Northwestern Memorial Hospital

Ria Edwina Gripaldo, MD, Emory University

Michael Henderson, Patient and Portland PF Support Group Leader

Jessica E. Shore, PhD, RN, PFF  
Krishna Thavarajah, MD, Henry Ford Health System  
Rade Tomic, MD, Northwestern Memorial Hospital