

### **The Importance of Early Integration of Palliative Care**

Kathleen Lindell:

We've learned that palliative care is often instituted late in the patient's disease course. And I think the most important message for physicians and providers to take home is to integrate early in the course of the patient's disease. In yesterday's session, I talked about incorporation of palliative care.

What we've learned is that palliative care is a word that patients are often afraid of. And so, our goal is to help patients become more comfortable. And so, other words that can be substituted to include supportive care, quality of life care, and comfort care.

The goal of all of these words is that we work to improve the patient's quality of life, as well as their caregivers. The overall goal of palliative care is to improve a patient's quality of life, as well as their caregiver's. So, things that are covered in palliative care are most importantly addressing symptoms.

So, patients with interstitial lung diseases often have a great symptom burden, including cough, shortness of breath, fatigue. Often, they're anxious, they're depressed, and sometimes they're afraid because they don't know what the road ahead is like.

So, the important thing with palliative care and addressing the symptoms, is to create this dialog between the physician and the patient and the caregiver, to address this, to improve the patient's quality of life.

Another important facet of palliative care is addressing advanced care planning. And addressing it early helps put the patient in charge, and allows their decision-maker to know what their wishes are. So, both symptom management and addressing advanced care planning are two important facets of palliative care, supportive care, quality of life care, comfort care.

I know that it's concerning for providers in the community. They may not have access to secondary palliative care. But there are resources available for patients and providers to look for both, primary palliative care and specialty palliative care. And if you

take a look at these resources on these websites, they can lead you to palliative care programs in your vicinity.

It's as simple as plugging in your zip code, and it will take you to a site. As palliative care advances, we realize now that there's primary palliative care, and there is secondary or specialty palliative care. And the difference between the two is primary palliative care is delivered by the patient's primary provider. So, whoever their physician or care provider is that delivers their care. And so they can address their symptoms, and they can also introduce this concept advanced care planning.

As the disease advances, what we often know is that the symptoms worsen, and the patients have more burden. And so, that's a good time to engage secondary or specialty palliative care.

This is an interdisciplinary team of experts that their whole focus is on palliative care. So, we think that the ideal care for a patient with interstitial lung disease includes both primary and secondary palliative care. So, we've learned that often patients and providers are afraid of palliative care. They're just not sure what that word means, but they sometimes associate it with end of life or that the provider is giving up. And it's actually quite the opposite. We encourage early discussion of palliative care.

And as mentioned earlier, you can use the word supportive care, or quality of life. It's addressed in a way, we know that you will experience symptoms along this disease course, and we want to make sure that you have the best quality of life. So, we want to engage early, and bring this topic into focus, so that we can help the patient have the best quality of life.

If there was one thing that I could make a recommendation for providers to do when they care for their patient, it would be early introduction of palliative care, right at disease onset. We know that interstitial lung diseases are a serious illness, and often, some can be life-limiting, and they come with great symptom burden.

We want to help our patients have the best of quality of life. So, by introducing early palliative care at the same time as the diagnosis of whatever their interstitial lung disease, palliative

care, supportive care, quality of life care, they're all the same. But it can be delivered along with disease changing therapies.

It's important to note that a patient can still participate in research. A patient can get a lung transplant evaluation. They can take medications, but they also need to have palliative care to address their symptoms, and to make and this, early advanced care planning, because our goal is that the patient and their caregiver really should have the best care possible.