**Patient Handout: Decision Making & Palliative Care**

**BY WENDY S. HARPHAM, MD, FACP**

In “Comfort Care for Clinicians” (Oncology Times 2019;41(13):12), I reviewed how palliative care specialists help seriously ill patients make difficult treatment decisions. Unfortunately, patient pushback presents a common challenge when recommending a consultation with a palliative care specialist. I designed this handout to dispel common myths and to reinforce that palliative care helps patients maintain control over their decision making. Feel free to edit it or use as is.

### Decision Making & Palliative Care

**Dear Patient,**

Palliative care specialists are experts in talking about difficult decisions. Even if you’ve heard of palliative care before now, please read this handout that explains why we recommend a palliative care consultation to help us continue discussing your treatment options in helpful, hopeful ways.

### What is palliative care?

Palliative (pronounced pal-lee-uh-tiv) care is a specialty focused on helping you live as fully as possible by…

- Optimizing your comfort
- Providing support for you and your family
- Helping you make the best decisions for you

Palliative care is delivered by a team of health care professionals that includes a variety of physicians (including palliative care specialists), nurses, counselors, and therapists. They have special expertise in managing symptoms that don’t respond well to usual measures prescribed by oncologists, surgeons, and primary care physicians.

[Note: This handout only deals with how palliative care helps with decision-making. A separate handout addresses the other ways palliative care helps in the care of patients.]

### Is palliative care the same as hospice?

No. This is a common source of confusion. Palliative care is an all-inclusive term for care devoted to improving comfort and helping patients live their best possible life. Palliative care is for people of any age with any medical condition, including patients we expect to make a complete recovery.

In contrast, hospice is a specialized type of palliative care for people whose life expectancy is 6 months (or less), whether due to a complete recovery.

### Do palliative care specialists push your oncologists to stop cancer treatment?

No. Palliative care specialists push for a treatment plan that respects your hopes and values. They push for whichever treatment path you determine is best for you.

### Do palliative care specialists encourage patients to give up hope?

No, they do the opposite. They help you determine which hopes can help you live your best life under the circumstances. They also teach you ways to increase your hopefulness—and find hope if you’re feeling hopeless.

### Why should you involve palliative care in your decision-making?

The decisions you’re facing today are probably more complicated and emotional than the decisions you’ve made previously. To determine the best treatment path now, we need to discuss things that are difficult for anyone to talk about—things such as “what-ifs” and “hopes” and “goals of care.”

Palliative care specialists are experts in helping people find words for discussing options and determining the best path. They help everyone (you, your loved ones, your doctors and nurses) stay on the same page while making decisions. Most important, palliative care specialists advocate for you, helping you maintain as much control as possible over your care.

### Why are some decisions more difficult?

These decisions are difficult because of the uncertainty about the future. We don’t want to give up hope of recovery too soon. At the same time, we don’t want to hold on to hope too long and then regret having continued treatments that only prolonged suffering with no benefit.

### How do palliative care specialists help you make your best decisions?

They help by…

- Describing your condition using different words than oncologists use
- Answering your questions about your condition and options
- Helping clarify your top-priority hopes and preferences
- Avoiding misunderstandings by exploring what common phrases mean to you (for example, “I want to get better” means different things to different people)
- Offering an outside perspective based on experience and expertise

### What if you and your loved ones don’t agree about treatment?

When it comes to your illness, everyone has his or her own desires and worries. Disagreements are common. It’s okay to disagree, too, unless others’ opinions keep you from making the best decisions for you. One way palliative care can help you is by helping your family.

Regarding your decisions, palliative care specialists help guide your loved ones to…

- Understand and support the decisions that are best for you
- Deal with their own desires and worries in ways that help them and don’t harm you

### What if it’s too early to discuss what you’d want if you became too ill to tell us?

It’s never too early—even if you were perfectly healthy—to discuss what you would want if you ever got too ill to say. Advances in supportive care (such as breathing machines and artificial nutrition) can keep people alive while recovery is very, very unlikely—and those treatments can cause suffering. That is why we need to know what you would want us to do.

People sometimes get very sick without warning. During a crisis, it’s much more difficult to have these discussions. By talking about these things now, you don’t risk getting very sick before you have a chance to tell us what you want (and end up having things done that you don’t want done). Once we’ve had these discussions, you can relax. You can take comfort knowing you’ve done all you can to maintain as much control as possible, whatever happens… and knowing we will work hard to honor your wishes.

### What now?

Let’s talk about asking palliative care experts to help us discuss your treatment options in helpful, hopeful ways.