

## **Palliative Care ~ Morgan Bell, LMSW**

When people find out that I work in palliative medicine, they tend to respond with “oh, I could never do that,” “what is that,” or “oh, so you work in hospice.” In a similar manner, there is often a fear when our team is introduced to patients and families, because the assumption is that palliative is involved in their care because “there's nothing else they can do for me,” and our team is simply there to deliver bad news. Palliative medicine is consulted when a patient has a life-limiting illness, such as cancer, heart failure, COPD, Alzheimer's disease and other forms of dementia. This list is by no means comprehensive, but is a good sample of the patients we serve.

First, let's dispel one myth: palliative medicine is *not* the same as hospice. Palliative medicine is a sub-specialty of medicine focused on managing symptoms of a life-limiting illness. Hospice is a small part of palliative medicine and is utilized when a patient no longer wants to focus on life-sustaining treatments, such as chemotherapy. In a perfect world, palliative medicine is involved at the onset of a diagnosis of a life-limiting - yet curable - illness, palliative follows along with the patient and manages symptoms during treatments, the patient goes into remission, then the patient gets to “graduate” from palliative medicine. Hospice is only enacted when 2 physicians state that a person is likely to have 6 months or less to live and if it meets the patient's goals. In cases where palliative patients are terminal, we will work alongside a hospice team to ensure patients are taken care of at the end of their life.

Palliative medicine takes a “whole person” approach, utilizing an interdisciplinary team to tackle every issue that patients face when they are treating a life-limiting illness. The team consists of physicians, nurse practitioners, social workers, dietitians, physical and occupational therapists, and chaplains. Palliative medicine takes place in hospital, clinic, and residential settings. Palliative care is based on the needs of the patient, not on the patient's prognosis. The goal of palliative care is to improve the lives of patients (and caregivers) living with a serious illness – which sounds simplistic, but many of the patients are complex and benefit from a multidisciplinary team approach. Palliative medicine focuses on management of symptoms including complex pain, dehydration, constipation, diarrhea, fatigue, sleep interruption, shortness of breath, and/or loss of appetite. We also address the symptoms that arise from serious illness, but are frequently overlooked in the medical setting, such as social and emotional pain, financial concerns, spirituality, sexual health and wellness, anxiety, depression, and grief.

Palliative medicine takes a unique approach to healthcare and incorporates modalities often not present in the current medical model. On our particular team, some of the most obvious differences are present in the specialized training of our social work team. One of our social workers has training in mindfulness-based stress reduction (MBSR), a past social worker had training in clinical hypnotherapy, I have specialized training in sexual health and intimacy, specifically related to oncology and am receiving further training to address sexual health and intimacy with dementia. We also have a licensed clinical social worker dedicated to our team with years of experience with oncology and grief and loss. Our medical director is trained in medical acupuncture, while another physician has training in eye movement desensitization and reprocessing (EMDR). Everyone on our team completes specialized training with Center to Advance Palliative Care.

In our healthcare system, the assumption is that patients want any and all treatments to sustain life, regardless of the quality of life. The main goal of palliative medicine is to meet the patients' healthcare goals, which do not always align with this “do everything” mentality. In order to do this, we are often the ambassadors for healthcare durable power of attorney and living will paperwork. In my family, it was standard practice to discuss my grandparents' healthcare wishes with them at the dinner table. Then again, I was raised by a home health and hospice nurse, so our dinner table conversations may have been different than most. As it turns out, most people tend to avoid discussing this topic. Unfortunately, most of the medical system is set up in a way that does not allow for a trained staff member to sit down and explain this paperwork to patients. With a discharge plan being the end goal in a hospital setting, discussion of durable power of attorney or living will is generally not the top priority. In the clinic setting, advance planning documents are available at registration, but are generally not mentioned past the standard questions at check-in and appointments are usually not long enough to allow for a full conversation about healthcare wishes. In the hospital setting, our team's first objective is to help establish goals and, when appropriate, one of the social workers on our team will come back and write these goals down with the patient in the form of advance directives and healthcare power of attorney. In the clinic, the medical provider and social worker devote the 3<sup>rd</sup> visit to discussing goals and putting them on paper with the patient.

Ultimately, palliative medicine puts the patient back in charge of their own healthcare decision making and helps to gather the information from all other specialties and present it to the patient and family in a way that helps them make educated decisions for themselves. Palliative teams are there to help families honor the wishes of patients who are unable to speak for themselves. If the patient does not have any known wishes, the team is skilled at helping families parse out what would or would not have been an acceptable quality of life to the patient. We are also able to get to know the patient through the family, even if we have never had a conversation with the patient, due to medical limitations. On the reverse, we are able to advocate with the patient if they *are* able to speak for themselves, but their voice cannot be heard above the noise – the noise of their own family, the medical staff, or of their own worries. We can sometimes be seen as a roadblock, because we will ask the rest of the medical staff or the patient's family to put on the brakes until the patient is ready to make a decision. Deciding between fighting their disease or focusing on quality of life is a ***huge*** decision we are asking someone to make and sometimes a patient just needs a minute to think. I would hope I would be afforded the same courtesy if I were in that situation.

For additional information on palliative medicine, please go to Center to Advance Palliative Care at [www.capc.org](http://www.capc.org).

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