

What is Palliative Care and How it Can Help Your Family

By Patrice Qualman, CFC Regional Ambassador

As the mom of a young man with CFC who was born 10 ½ weeks early, we have always been in and out of the hospital for various reasons. In March of 2021, he had surgery number 20 and 21 so we are not new to the hospital routine. But it took COVID-19 and the plethora of online trainings and webinars that became available, for me to find out about Palliative Care and wonder why no one had mentioned it to me before.

For me, as for probably most people, I assumed palliative care was the same thing as hospice, something that was available to people in an end-of-life situation, to help make their last days as comfortable as possible in the setting of their choosing. I quickly learned that I could not have been further from the truth!

www.getpalliativecare.org states, “Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.”

According to the World Health Organization (WHO), “Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals.”



I recently attended the presentation of a Palliative Care Team here in Oregon, USA. What the presenter said was, that with her organization, the Palliative Care team is made up of many different professionals but that they tailor the team according to the wishes and circumstances of each individual. Typically, each team consists of nurse(s), doctor(s), a social worker and a spiritual representative. The team is there to make sure the individual and their family are connected to any resources they may need, financial or otherwise, to help explain and provide information on medical diagnoses and what treatments are available and to help act as a liaison between the individual/family and their medical team to make sure that their preferences are clearly defined.

The WHO has been pushing since 2014 to get countries world-wide, to implement and/or improve their palliative care. According to their website

- *Palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well.*
- *Each year, an estimated 40 million people are in need of palliative care; 78% of the people live in low- and middle-income countries.*
- *Worldwide, only about 14% of people who need palliative care currently receive it.*

For my family, we can access our county palliative care team or we can access the palliative care team at the hospital of our choice. Our county team can support us any where whereas the hospital team will only provide support while we are in the hospital.

During my son's hospital stay in March, I requested access to the Palliative Care Team for the first time. They met with me as a group initially, a social worker, a doctor and a pastor. They had gone through my son's chart notes so they were versed on his past and present conditions. They made sure I knew what his current treatment plan was and that all my questions were answered. They asked about our family's spiritual beliefs and respected them. They asked me how I was doing and if there was anything I needed to help with my stress level or make our stay more comfortable. After the initial consultation, 1 of the people from the team would check in on us at least every other day. It was nice to have other people there that I felt was on my side, that I could talk to about whatever was going on.

When our kids, adult or not, are in the hospital, it is nice to know that there is a team there for us, who will take the time to make sure we understand everything that is going on, make sure that we, as parents, have the support we need, so we can function and advocate for our loved ones.

From the research I have done, and from my own personal experience, I want to urge everyone to reach out to their own Palliative Care Teams and start establishing a relationship with them. Most insurances, including Medicare and Medicaid, cover palliative care, so why not take advantage of it and see how it too, can benefit your family.

Links to Resources:

<https://getpalliativecare.org/whatis/>

<https://www.who.int/news-room/fact-sheets/detail/palliative-care>

<https://www.nhpco.org/find-a-care-provider/>

<https://champlainpalliative.ca/10-myths-palliative-care/>