

Taking the Fear Out of Palliative Care

Sally is 63 years old and is being treated for metastatic breast cancer and heart disease. Although her prognosis is hopeful, she is having a lot of pain and worries about what will happen if she becomes sicker. She specifically states she does not want to be a burden to her family...

In the first weeks after receiving a serious diagnosis, an overwhelming amount of information can come your way and you may have a lot of questions. Quite suddenly and unexpectedly “You enter a world of procedures, tests, and uncertainties. This world has a new language, and unpredictable roads that are not always well lit or labeled. You enter scared but hopeful and you need to be able to trust your guides.”¹ And in those first weeks, how often does one stop to ask about Palliative Care (PC)?

What is Palliative Care?

PC is a comprehensive program of services, delivered by a team of experts, to prevent and ease suffering. PC offers support to families and caregivers, and treatments to improve one’s quality of life.

PC and Hospice are often thought of as the same. Because of this, we are sometimes reluctant and maybe even fearful to have a realistic discussion with our health care providers about what are wishes are, who can help us during treatment, or what to do if our illness progresses. We don’t often feel it necessary to have this realistic discussion right away, but these conversations often become more complex when our health is deteriorating.

It is important to understand that PC and Hospice (although they complement one another) are two separate entities. It is absolutely feasible for someone with cancer or other serious illness to receive curative therapy (treatment to eliminate the disease) and PC at the same time. Early referral to the PC team offers many opportunities to improve the quality of life for both patients and their families.

Hospice

- Can **complement** Palliative Care to center on pain and symptom management
- Patient has a terminal diagnosis with life expectancy of less than six months
- Not seeking curative treatment



Palliative Care

- Concentration is on pain and symptom management with consideration to the patient’s needs as an individual
- Patient does not have to be terminal
- May still receive curative treatment²

The goals of PC are to address the multiple aspects of a patient’s needs: physical, emotional, spiritual, practical, and familial. It is meant to support patients on their journey through care. The National Consensus Project for Quality Palliative Care states that the hope for PC is “to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. PC is both a philosophy of care and an organized, highly structured system for delivering care.”³

“Health care systems are now more appropriately applying that definition to the care of people who are seriously ill, not just the dying. In other words, we have begun to recognize that anyone facing a life threatening illness deserves to have their symptoms managed (especially pain) and their non-physical needs met. Whatever the outcome, people are much more able to face illness with dignity and energy if they receive compassionate, ‘holistic’ care that addresses all of these areas.”¹



How do I get Palliative Care and what should I expect?

Ask your health care provider for a consult and they will provide a referral for PC. PC can be provided on an outpatient basis, within a hospital, at your home, or in a long-term living facility. Most insurance companies cover the costs of PC, but it is best to ask first. Often a PC care consult is done with you and your family, to help you identify what is most important to you, as well as fears and concerns you may have. Allowing you the opportunity to voice your concerns is therapeutic in and of itself, and providing you with information on what is available to assist in your journey may empower you and make you less fearful.

The PC team of trained professionals will talk to you about how to address your needs. These team members may include doctors, nurses, physical, occupational or speech therapists, chaplains, social workers, dieticians, and grief and bereavement counselors.

...Sally wasn't comfortable speaking with her family about fears of becoming a burden. The PC team helped start the conversation and Sally learned how strongly her husband and daughter felt about helping her stay at home as long as she was comfortable. The team also provided information about resources available to support Sally and her family. Now, Sally and her family can be comfortable that everyone's wishes are being taken into consideration.⁴

One of the members of your team may be a Patient Navigator. A Patient Navigator is your advocate: they are trained to help you with the complexities of cancer treatment and an array of scheduling needs and they help you navigate through the health care system. Navigators can help you get answers to your questions or offer a hand to hold. They become your point of contact through every step of your treatment and provide you support on your journey. Ask your doctor about a Patient Navigator and how you might benefit.

Making proactive decisions about your care can give you a greater sense of control and hope. By taking measures early in your treatment to ensure that your wishes are respected and to reduce or eliminate pain, you may be able to better cope with treatment and have less fear of the unknown.

NH Comprehensive Cancer Collaboration
Emerging Issues Work Group
in partnership with the New Hampshire Hospice
and Palliative Care Organization



Sources:

1. Joanne Hilden MD and Sarah Friebert MD. "Palliative or Hospice Care: Does my child need this service?" CCCF Newsletter, Fall 2001: <https://www.acco.org/Information/hospice.aspx>
2. University of Maryland Medical Center. "Palliative Care vs. Hospice Care, April 26, 2007:" http://www.umm.edu/palliative/palliative_hospice.htm
3. National Consensus Project for Quality Palliative Care. "Clinical Practice Guidelines for Quality Palliative Care." Pittsburgh, PA; 2004.
4. Case Study provided by Mary Kazanowski, APRN, PhD, ACHPN, Palliative Nurse Practitioner.

Photos:

Railroad: <http://procrastinationhub.wordpress.com/>

Holding hands: <http://www.diariodemivida.com/el-arte-de-la-espontaneidad/couple-holding-hands-on-a-railroad-track-image-by-%C2%A9-royalty-freecorbis-2/>