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Understanding Palliative/Supportive Care: What Every Caregiver Should Know

Palliative care also increasingly known as **Supportive Care**, may be one of the most misunderstood terms in healthcare. Many people believe it's the same as hospice care and it means the end of life. But palliative care is different from hospice, and when put in place, palliative care can bring hope, control, and a chance at a better quality of life for seriously ill patients and their caregivers.

This Fact Sheet will summarize key features of palliative care, describe how it differs from hospice, and clarify some of the misconceptions that prevent people from considering palliative care for themselves or for loved ones.

What is palliative care and how can my family member benefit?

For individuals living with serious illness, and for their caregiving family and friends, palliative care offers medical and related treatment towards living as well and as fully as possible. Healthcare professionals embrace a patients' values, goals, and wishes when considering disease management and burden relief from pain, anxiety, fear, and other symptoms. The patients' plans and wishes are shared with family and friends who provide care, and support is provided to help relieve burdens.

Most importantly, this patient/family-centered care is appropriate at any age and at any stage in a serious or chronic illness. For example, a person with cancer may be treated for unrelenting pain and appetite loss concurrent with curative treatment; a person living with Alzheimer's disease may be treated for anxiety and sleeplessness. Care may be offered in the hospital, long-term care facility, at home, or in outpatient clinics.

First used in the 15th century, the term palliative today means to remedy or lessen without curing. Although in the past palliative care and hospice care were bound together, now they can be considered two related approaches that respond to serious illness, depending on the patient's condition and wishes. They share similar

philosophies, and a person in palliative care may transition to hospice care if they are approaching the end of life.

Looking deeper into the concept, the National Consensus Project on Palliative Care describes it this way: “Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. The goal of palliative care 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. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision making, and providing opportunities for personal growth. Palliative care can be rendered along with life-prolonging treatment or as the main focus of care.”

What is the “organized, highly structured system,” and how did it come to be so widespread now in healthcare? First, palliative care takes a collaborative, **interdisciplinary team (IDT)** approach. In addition to the patient and family, the specially trained team can consist of: doctors, registered nurses, social workers, chaplains, dieticians, pharmacists, licensed mental health professionals, physical and occupational therapists, music therapists, massage therapists, and others.

The most common health conditions addressed in palliative care include:

- Cancer
- Congestive heart failure (CHF)
- Kidney failure
- Liver failure
- Chronic obstructive pulmonary disease (COPD) or other lung diseases
- HIV/AIDS
- Spinal cord injuries
- Brain diseases such as stroke, ALS, or Parkinson’s
- Multiple sclerosis (MS)
- Alzheimer’s and other dementias

When patients choose to begin palliative care, they receive a formal assessment of their health early in the process. Symptoms most commonly addressed include:

- Pain or discomfort
- Shortness of breath

- Fatigue
- Anxiety
- Depression
- Lack of appetite
- Nausea
- Constipation
- Adjusting to and living with the diagnosis of a serious health condition
- Sleep problems

There will be discussions about the need for an Advance Directive and preferences about withholding or withdrawing life-sustaining treatments (POLST). (See *Making End-of-Life Decisions: What Are Your Important Papers?*)

The palliative approach focuses not just on difficult symptoms of an illness, but on the overall benefits and/or side effects of potential treatments, and the emotional, physical, and financial stresses for someone dealing with a serious, perhaps life-threatening, disease. Ensuring patients' dignity, coordinating care, and shared decision-making are critical components.

Palliative care is more likely to be suggested when there are:

- Frequent emergency room visits
- Three or more admissions to the hospital with the same symptoms within a year
- Serious side effects from treatments like chemotherapy
- Eating problems caused by serious illness

This is a dramatically different approach to healthcare from the fragmented care we sometimes see in standard medical practice, where treatment is not always well coordinated among primary doctors and specialists, and where time limitations and funding don't allow for an in-depth look at patients.

Physicians are trained to focus on fixing a problem(s) and charging specific fees for specific services, not necessarily offering comfort measures to patients or treating the whole person, including his or her emotional issues. Additionally, unlike a palliative program, healthcare practices too often neglect to recognize the family as part of the team, even though the family is, of course, greatly impacted by a loved one's chronic or serious illness, and is usually providing significant amounts of care.

History

The philosophy of palliative care in the US has evolved over time. It began in the hospice movement, in which a more patient-centered approach was offered when death was imminent, and where comfort, peace, pain relief, and dignity were the goals, and cure not a possibility.

Although palliative care is a natural practice in many cultures worldwide, the advancement of life-sustaining technology had charted a more cure-focused path in the United States. Life-prolonging measures such as a pacemaker early on in a condition, or a feeding tube or respirator as a disease progresses, are often assumed to be part of the treatment plan of care. Patients and their caregiver(s) can question these assumptions, opting for a plan of care that recognizes and acts on their preferences.

Palliative care became a recognized medical sub-specialty in the US fairly recently, in 2006. As with other medical specialties, physicians can become board certified in palliative care, and there is training and certification for other healthcare staff as well. Now about 80% of large US hospitals offer palliative care programs. The palliative philosophy of support, comfort, peace, and dignity is offered at any stage—even early in the diagnosis—of a chronic or serious illness that ultimately may or may not be life-threatening.

Medical professionals who practice palliative care are committed to communication, to compassion, to seeing the “whole” person, and to including the family as part of the healthcare team. Studies have indicated the benefits of palliative care:

- Better quality of life for patient and caregivers
- Help getting through difficult medical treatments
- Reductions in hospitalizations and readmissions
- At times faster recovery and longer survival rates

It's easy to understand, for example, that patients are better able to function when their pain is well managed and substantially reduced. But not all patients have access to palliative care. Hospital staff may not have the right training. A doctor may feel it would not be beneficial in a specific case. Or, because it is more time-consuming than standard medical care, facilities may have concerns about reimbursement of costs.

Paying for palliative care and hospice care

Most insurance will cover palliative services as it covers other healthcare procedures and medications, although there may be co-payments. Medicare and Medicaid (Medi-Cal in California) will likewise cover many of the costs. If questions about coverage remain, a social worker or consultant from the health care team may be able to clarify pay provisions for the service.

Comprehensive hospice coverage is available for patients with Medicare Part A. This benefit is broader than the coverage for palliative care: most services are free. This may include medical equipment such as wheelchairs and hospital beds, medications, professional fees, counseling, and more. Most private insurance programs pay for hospice programs, and state Medicaid programs cover costs as well.

How are palliative care and hospice care different?

Hospice is a specific kind of palliative care for patients approaching the end of life and focuses on death with dignity, not on seeking cure. While both palliative and hospice care deal with serious disease and offer a team approach, hospice becomes an option when there are no further treatments available, or the treatments' side effects, pain, and suffering are overwhelming and will not contribute to a cure. In contrast, palliative care can start at any stage of a serious disease, and curative treatments can continue.

With Advance Directives in place, families and healthcare professionals know that when someone is in hospice care, painful or intrusive treatments, admission to intensive care units, or frightening ambulance trips to emergency rooms, for example, may not be wanted or accepted. In fact, if a patient has a medical emergency, families or caregivers are instructed to call the hospice provider rather than 911.

Patients become eligible for hospice care when doctors have determined that they are likely to have six months or less to live. Hospice is always a voluntary program, and patients may continue in hospice if they survive longer, may be discharged from hospice if their condition improves, or may withdraw. Hospice staff are available for consultation 24 hours a day. In hospice, as in palliative care, the focus is on comfort and dignity, and spiritual concerns are addressed. Hospice also offers grief therapy and support for families, even after the death of a loved one.

How can patients access palliative and hospice care?

If it hasn't been offered, ask for it. Not all hospitals provide the services, but most do. The patient's primary physician should be able to refer families, or check the directory at www.getpalliativecare.org. There are different types of local hospice organizations—large and small, and nonprofit and for-profit. Care can be provided in the home, in assisted living or nursing home, hospital, or in a special hospice residence.

In both palliative and hospice care, patients and families are gently supported as they are asked to do deep soul-searching about their values and beliefs during a very challenging time. There is no question that the decisions are complicated and can be wrenching. Yet while most doctors are trained to do everything possible to prevent death even if treatment is painful or futile, with palliative and hospice services in place, patients have the final say.

Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

FCA CareNav: www.caregiver.org/connecting-caregivers/fca-carenav

Services by State: www.caregiver.org/connecting-caregivers/services-by-state

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers, as well as a toll-free call center for family caregivers and professionals nationwide. For San Francisco Bay Area residents, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's, and other debilitating brain disorders that strike adults.

FCA Fact Sheets

All FCA Fact Sheets are available online at www.caregiver.org/caregiver-resources/all-resources

- Advance Health Care Directives and POLST
- Making End-of-Life Decisions: What Are Your Important Papers?

Palliative Care and Hospice Organizations

Center to Advance Palliative Care (CAPC)

www.capc.org

Sponsors the website www.getpalliativecare.org with consumer information and provider directory.

National Hospice and Palliative Care Organization

www.nhpco.org

Offers information for families and caregivers through the website caringinfo.org, including downloadable Advance Directives for every state

Compassion & Choices

www.compassionandchoices.org

Works to protect and expand end-of-life options — and to ensure healthcare providers honor and enable patients' decisions about their care.

Hospice Foundation of America

www.hospicefoundation.org

(800) 854-3402

Medicare and Medicaid

www.cms.gov

(800) MEDICARE

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caregiving professionals. Leads quality education, provides compassionate caregiver planning services and works to bridge research and practice to benefit all caregivers. For more information, visit www.caregiver.org or call (800) 445-8106.

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