

Expect The Best:

How To Get The Most Out Of Your Hospice Care

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Objectives

- ❖ Describe hospice philosophy and approach to care
- ❖ Debunk misinformation and myths about end of life care
- ❖ Gain information about rights of the patient and their caregivers/decision makers
- ❖ Define the members of the hospice interdisciplinary team and their roles

Why You Need To Know About Hospice

- ❖ 80% of Americans prefer to die at home – only 20% actually do (Stanford School of Medicine, 2020*)
- ❖ For every 1 hospice patient there are 2 more who could benefit from hospice (NHPCO Facts & Figures 2020*)

Hospice Myths & Misinformation

Myth

- ❖ Hospice is just for the last few days of life
- ❖ Hospice is only for cancer patients

Fact

- ❖ Hospice is for anyone with a limited life expectancy (six months or less)
- ❖ Hospice patients have a wide variety of diagnoses (respiratory, heart, kidney, neurological diseases, & more)

Hospice Myths & Misinformation

Myth

- ❖ A patient on hospice can never come off of hospice
- ❖ Hospice is a place

Fact

- ❖ The patient or patient representative can choose to cancel hospice care and seek treatment. They can choose to return to hospice at a later time
- ❖ Hospice is a philosophy; most hospice patients receive care in private homes, nursing homes, or assisted living facilities

Hospice Myths & Misinformation

Myth

- ❖ Hospice agencies require the patient to have a Do Not Resuscitate document
- ❖ Hospice hastens death

Fact

- ❖ Not all hospice patients have a DNR; it's the patient's choice
- ❖ Hospice care does not hasten death or prolong life – it's all about improving quality of life

How To Choose A Hospice Agency

- ❖ Interview 3-4 hospice agencies – no doctor's order is needed (word of mouth recommendation helps)
- ❖ All hospice agencies provide care under the same regulations and laws (for-profit vs non-profit/small agency vs large chain)
- ❖ Search for agencies in your area on the Care Compare website (*Center for Medicare & Medicaid Services**)

Care compare from Center for Medicare & Medicaid services (medicare.gov)

Or, select a provider type to learn more:

 Doctors & clinicians	 Hospitals	 Nursing homes including rehab services	 Home health services
 Hospice care	 Inpatient rehabilitation facilities	 Long-term care hospitals	 Dialysis facilities

Questions To Ask When Shopping For A Hospice Agency

- ❖ How many patient are in a nurse's caseload?
- ❖ Are your nurses/medical director certified in hospice & palliative care?
- ❖ How often does a nurse/social worker/spiritual counselor see a patient who's stable/during the dying process?
- ❖ What disciplines of the hospice team are available on-call?
- ❖ What medications & equipment will be provided?
- ❖ How are complaints handled?

Questions To Ask When Shopping For A Hospice Agency

- ❖ Is the agency accredited? If so, by whom? (CHAP, Joint Commission, ACHC, state)
- ❖ Can a patient/caregiver attend a hospice team meeting?
- ❖ What facilities is the agency contracted with for respite care and General Inpatient Care (GIP)?
- ❖ How long has the agency been in business?
- ❖ What is a typical on-call response time?
- ❖ What bereavement care is provided after the patient dies?

Rights Of The Patient (And The Caregiver!)

- ❖ Agency choice
- ❖ Change of agency (transfer)
- ❖ What hospice disciplines see the patient
- ❖ DNR vs full code
- ❖ What medications/equipment are utilized
- ❖ Choice of doctor
- ❖ Where care is provided (home, LTCF, ALF, group home)
- ❖ Start/stop hospice care (Election vs Revocation)
- ❖ Right to make a complaint (to agency, accrediting organization, or state)

The Hospice Interdisciplinary Team (IDT) & The Care They Provide



Registered Nurse – assessments, education, symptom management



Physician – orders for the Plan of Care in collaboration with the IDT



Spiritual Counselor (Chaplain) – support of faith beliefs, counseling funeral planning



Social Worker – counseling, resources/referrals, caregiver support, patient safety

The Hospice Interdisciplinary Team (IDT) & The Care They Provide



Hospice aide – bathing, personal care, light housekeeping



Volunteer Coordinator and Hospice Volunteers – errands, companionship



Bereavement Coordinator – bereavement and grief counseling/support

The Hospice Interdisciplinary Team (IDT) & The Care They Provide



Nurse Practitioner – “Face to Face” visits required by regulation for recertification



Therapies (physical, occupational, speech) – used infrequently



Dietician – consulted for special dietary needs

References

- ❖ <https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/#:~:text=Studies%20have%20shown%20that%20approximately,and%20only%2020%25%20at%20home> Stanford School of Medicine, 2019
- ❖ <https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf>
National Hospice and Palliative Care Organization
- ❖ <https://hospicefoundation.org/>
Hospice Foundation of America
- ❖ <https://bkbooks.com/>
BK Books (Barbara Karnes, RN – End of Life Education Materials for Families & Professionals)
- ❖ <https://www.medicare.gov/care-compare/?providerType=Hospice&redirect=true>
Care Compare by CMS
- ❖ <http://www.theheartofhospice.com/>
The Heart of Hospice

The Heart of Hospice, LLC

Hospice education
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Thank you!

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About FCA

Family Caregiver Alliance offers education, services, research, and advocacy based on the real needs of caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

National Center on Caregiving (NCC) was established by FCA to advance the development of high-quality, cost effective programs and policies for caregivers in every state. NCC sponsors the Family Care Navigator, a state-by-state resource locator designed to help caregivers find support services in their communities.

Bay Area Caregiver Resource Center — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA's staff of family consultants through education programs and direct support offer effective tools to manage the complex and demanding tasks of caregiving.

Be sure to visit FCA on social media:

 facebook.com/FamilyCaregiverAlliance

 twitter.com/CaregiverAlly

 youtube.com/CAREGIVERdotORG