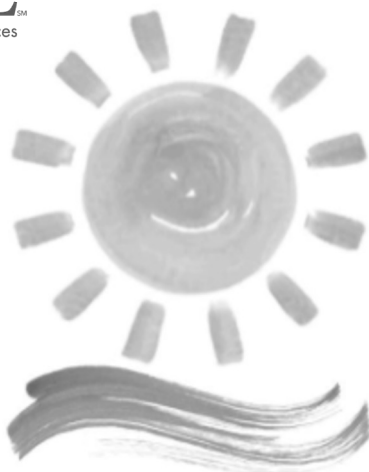


Family Caregiver Education Series



Facing End-of Life Issues:
Hospice and Palliative Care
May 11, 2023 • 10:00 a.m.

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Agenda

- Philosophy of Comfort Care
- Palliative Care
- Hospice Care
- Family's Role
- When Death Occurs
- Q and A

Three Goals of Medical Care



- Cure
- Stabilization of functioning
- Preparation for a comfortable and dignified death:
Palliative and/or hospice care



Philosophy of Care



Hospice and
Palliative Care

“ . . . the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to do so.”

- National Hospice and Palliative Care Organization



Similar, yet different

- ❑ Both provide **comfort care**
- ❑ Both employ a **care team approach**
- ❑ Palliative care and hospice care differ regarding:
 - eligibility for services
 - timing
 - payment
- ❑ Hospice care is always palliative, but not all palliative care is hospice care



Palliative or Hospice Care?

Palliative Care

- There are **no eligibility restrictions**. Patient can opt for palliative care at **any time** and at **any stage** of the illness, whether terminal or not. Patient may continue with curative treatments.

Hospice

- Patient must have an **end-stage illness** with a **life-expectancy of six months or less** – curative measures no longer an option.



Having the conversation about hospice or palliative care

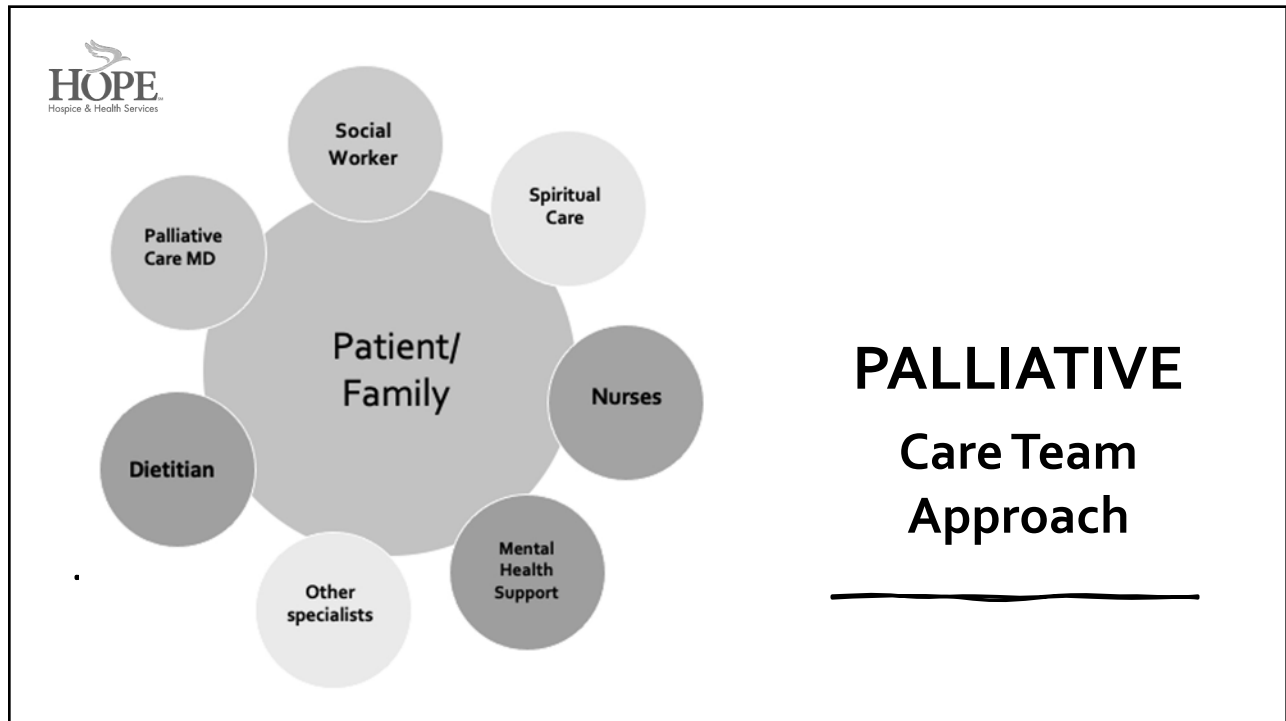
- Choose a good time and place
- Reassure that the individual has a choice in the matter
- Stress that decisions do not have to be permanent
- Focus on additional layers of care; benefits of stopping aggressive treatment and hospitalizations



What is Palliative Care?

- An **approach to care** with the goal of preventing & relieving suffering regardless of stage of disease and regardless of whether the disease can be cured
- Symptom management (ex. pain, nausea, shortness of breath, constipation, dry skin, depression, etc.)
- Medical treatment and therapies available, depending on wishes/needs of patient
- Care for the whole person: physical, emotional, social, spiritual
- Care team works with patient and family to develop a treatment plan that respects goals, preferences, and choices





When is it time to consider palliative care?

- New diagnosis of life-limiting illness
- Declining ability to function independently
- Repeated hospitalizations
- Unexplained weight loss
- Patient is struggling with after-effects of curative therapies
- When quality of life becomes more important than fighting for more time



Typical Diagnoses



Examples:

- Cancer
- Advanced lung/heart disease
- Advanced renal (kidney) disease
- Neurodegenerative diseases (dementias)
- Stroke (life-limiting)
- Catastrophic trauma



Obtaining Services

- Referral from health care provider
- Palliative care providers
 - Hospitals; clinics
 - Private agencies
- Costs covered by
 - Medicare (deductibles and copayments apply)
 - Medi-Cal (Medicaid)
 - Most health insurances
 - Patient



What is Hospice?

- Quality compassionate care for those facing a life-limiting illness
- Individual care plans based on wishes of patients and their families
- Geared toward keeping patients comfortable wherever they reside (home, facility, hospital, etc.)
- A holistic team approach to specialized medical care:
 - Pain and symptom management
 - Emotional, psychosocial, and spiritual support for patients and their families



Who pays for hospice?

- Private Insurance
- Medicare and Medi-Cal (Medicaid) Benefit
- HMOs such as Kaiser
- Non-profits rely on charitable donations



What's included in hospice care?

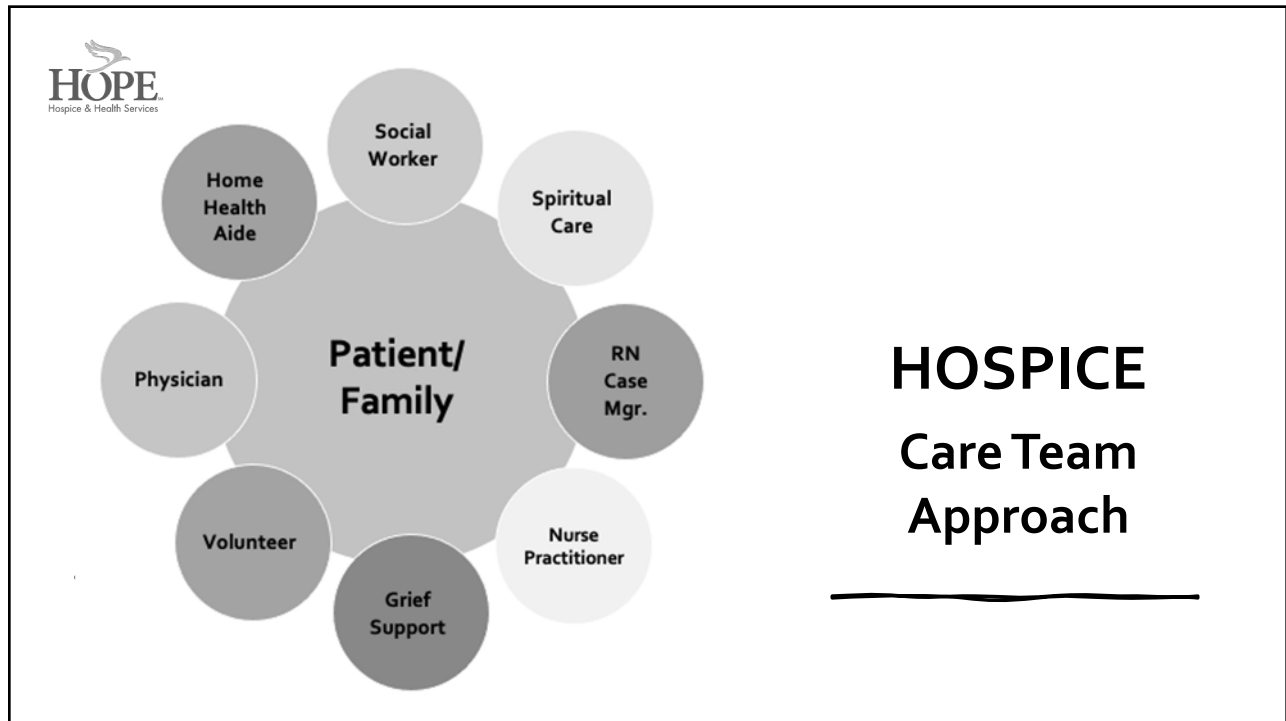
- Physician services related to the primary diagnosis
- All visits from the care team; on-call 24/7
- Medications related to the primary diagnosis and for pain and symptom relief (comfort measures)
- Equipment/supplies (bed, wheelchair, oxygen, incontinence supplies, etc.)
- Respite services (Medicare benefit)



Other Services

- Physical, occupational, and/or speech therapies as needed for symptom/pain control or to enable individual to maintain basic functional skills and activities of daily living
- Some hospice agencies offer transition programs
- Benefits may extend beyond 6 months if patient lives longer than expected
- Grief counseling for up to 13 months after death for adults, teens, children





Medicare's Hospice Benefit



Eligibility Requirements:

- Eligible for Medicare Part A (hospital benefit)
- Two physicians must certify that the patient has a life-limiting illness
- Patient (or proxy) must sign a consent form stating wishes to receive hospice care in place of regular Medicare benefits
- Receive hospice care from a Medicare-approved provider



Primary Diagnoses for Hospice Eligibility



- Cancer
- Advanced lung/heart disease
- Alzheimer's disease & related disorders/Dementia
- HIV/AIDS
- Liver/kidney failure
- COPD (ex., emphysema)
- ALS and multiple sclerosis
- Congestive heart failure
- Stroke



Patient Rights

Hospice patients have the right to:

- self-determined life closure
- be informed and participate in their own care
- stop hospice care at any time to pursue aggressive treatment and resume hospice care when they are ready
- discharge from hospice care when and if their condition improves
- continue to be seen by their own physician



When is it time to consider hospice care?

- Death is a strong possibility
- Patient has expressed a desire for a "peaceful" death
- Patient has had multiple trips to hospital, repeated infections, refuses meals and medications, difficulty swallowing, and/or weight loss
- Available treatments will likely extend pain and suffering
- Desire to stop aggressive treatment and/or multiple trips to the hospital



From Hope Hospice's website . . .

A common misconception about hospice care is that a referral can be premature. Hospice care is the most effective over a period of months, yet most hospice patients die within a month of referral based on the reluctance to refer patients earlier or at all.

An early referral can provide patients with extra attention and focused hospice care that relieves symptoms and manages pain. It also offers patients and families a vital opportunity to deal with their loss and say goodbye.



Comfort Measures

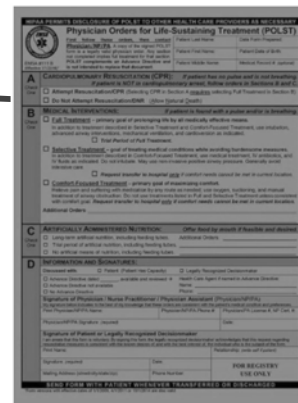
- Eliminate any diagnostic tests or medical procedures/treatments that may do more harm than good
- Avoid hospitalizations, especially ICU/CCU
- No radiation or chemo, unless necessary for pain relief
- Surgery, only if needed for pain relief
- Antibiotics, if needed
- No feeding tubes, unless already in place



POLST

Physician Orders for Life-Sustaining Treatment

- Comprehensive approach to end-of-life planning
- Gives seriously ill patients and their families more control over their care; ensures patient wishes are honored
- Legal document (actionable medical order) that must be signed by both the physician and patient (or proxy). May also be signed by nurse practitioner (NP) and physician assistants (PA) within their scope of practice
- Prevents unwanted or ineffective treatments
- Reduces patient and family suffering



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B (Effective 4/1/2011)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. A copy of the signed POLST form is legal and valid. POLST complements an Advance Directive and is not intended to replace that document. Everyone shall be treated with dignity and respect.



Patient Last Name: _____ Date Form Prepared: _____
 Patient First Name: _____ Patient Date of Birth: _____
 Patient Middle Name: _____ Medical Record #: (optional) _____

A CARDIOPULMONARY RESUSCITATION (CPR): *If person has no pulse and is not breathing. When NOT in cardiopulmonary arrest, follow orders in Sections B and C.*
 Check One
 Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)
 Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B MEDICAL INTERVENTIONS: *If person has pulse and/or is breathing.*
 Check One
 Comfort Measures Only Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Transfer to hospital only if comfort needs cannot be met in current location.**
 Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
 Transfer to hospital only if comfort needs cannot be met in current location.
 Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. **Transfer to hospital if indicated. Includes intensive care.**
 Additional Orders: _____

C ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*
 Check One
 No artificial means of nutrition, including feeding tubes. Additional Orders: _____
 Trial period of artificial nutrition, including feeding tubes. _____
 Long-term artificial nutrition, including feeding tubes. _____

D INFORMATION AND SIGNATURES:
 Discussed with: Patient (Patient Has Capacity) Legally Recognized Decisionmaker
 Advance Directive dated _____ available and reviewed by _____ Health Care Agent if named in Advance Directive: _____

Selecting a Hospice Provider

- It is your right to choose a hospice agency
- Ask those you trust: Family, friends, physician
- Use Medicare's Care Compare site
www.medicare.gov/care-compare/
- Check accreditation and licensure:
 - Medicare and Med-Cal (Medicaid) approved
 - National Palliative and Hospice Care Organization
 - Licensed by your state
- Review document on resource list:
How to Choose a Hospice Provider



Obtaining Hospice Services



- Referral
 - Self
 - Family member; health care proxy
 - Physician (need signatures from two physicians)
 - Hospital; care facility
- Phone call to hospice agency to request services/evaluation
- Online application



Family's Role in Providing Comfort & Relieving Symptoms

- Practical Considerations
- Mental and Emotional Needs
- Spiritual Issues
- Physical Comfort

REMEMBER: You are an important member of the care team!



NIH/NIA Booklet (online)
End-of-Life: Helping with comfort and care.



Practical Considerations



- Legal Documents
 - Will/Living Trust
 - Advance Healthcare Directives
 - POLST (Physician Orders for Life-Sustaining Treatment)
- Care location: Home? Facility?
- Visits from family and friends
- Impact on everyday life
- Pre-need funeral planning

www.verywellhealth.com/end-of-life-4014730



Mental and Emotional Distress



- Signs and symptoms
 - Depression and/or anxiety
 - Confusion
 - Fear
 - Isolation
- Ways to help
 - Physical contact
 - Comforting environment
 - The gift of presence

NIH/NIA Booklet *End-of-Life: Helping with comfort and care.*



Spiritual Issues



- Finding meaning
 - Reflecting on one's life and legacy
 - Resolving unsettled issues with friends & family
 - Faith
- Ways to help
 - Prayer
 - Conversation
 - Connecting with others

NIH/NIA Booklet *End-of-Life: Helping with comfort and care.*



Physical Discomfort



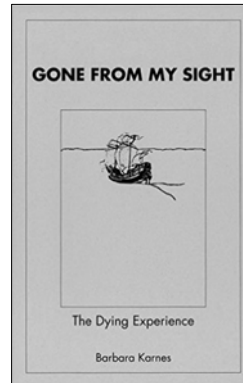
- Digestive problems
- Breathing problems
- Dry/irritated/fragile skin
- Sensitivity to temperatures
- Fatigue
- May not be able to articulate pain – watch for non-verbal indicators

NIH/NIA Booklet *End-of-Life: Helping with comfort and care.*



Signs of Dying

- Gone from My Sight: The Dying Experience*
- Barbara Karnes, R.N.
- The Journey Towards Death*
- www.verywellhealth.com



When Death Occurs

- Regardless of how prepared you are, it will still be a shock
- Should there always be someone in the room with a dying person?
- Give yourself and your family time to say good-bye; take as much time as you need to be alone with your loved one
- Remember that everyone reacts to death differently; respect each other's grieving process



First Steps When a Death Occurs



- In hospital or nursing home:** Ask the staff or hospice nurse to call the funeral home. Be sure they have the correct information.
- If at home on hospice care:** Ask the hospice RN case manager to contact the funeral home.
- If at home and NOT on hospice:** Call the local non-emergency police number or 911. Be sure to tell them that death was expected and have the DNR and/or POLST available. If death was expected, you can call the physician.



First Steps When a Death Occurs



- Death must be pronounced by one in authority: Doctor, hospice nurse, coroner/med examiner
- Doctor or hospice nurse will complete forms to issue death certificate; must be signed by attending physician; funeral home will arrange for official death certificate
- Autopsy? Physician determines if necessary; be sure everyone is aware of any cultural or religious issues
- Organ donation considerations, if appropriate



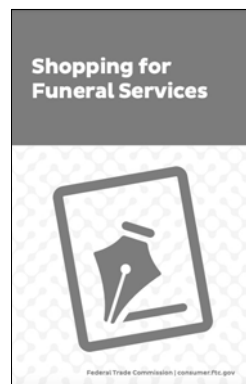
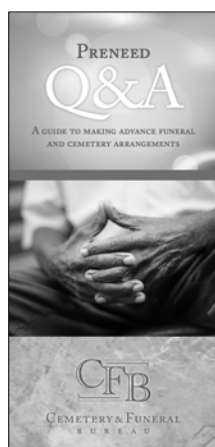
Tips from the Trenches

- ❑ Don't set a date, time, or place for services until you have confirmed with funeral director, church, and clergy . . . then notify family and friends.
- ❑ Funerals are expensive! \$6,000 – 10,000+
 - Comparison shop; don't overspend due to emotions
 - Hospice agency may be able to provide options
 - If cremated, ashes may be separated
- ❑ It's ok to do some advance planning and preparation; delegate!
- ❑ Remember: This is a stressful time; be sure to take care of yourself before, during, and after.



HOPE
Hospice & Health Services

Resources for Funeral Planning



www.va.gov

HOPE
Hospice & Health Services