

# Family Caregiver Education Series



## ***End-of-Life Issues***

May 13, 2021

10 – 11:30 a.m.; followed by Q and A

**Theresa Marcelo, L.V.N.**, Hope Hospice Clinical Liaison  
**Debbie Emerson, M.S.**, Hope Hospice Community Health Educator



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# Upcoming Events

**June 5:**



*Your participation in the Hike for Hope supports  
 Hope Hospice patient care, grief services,  
 and family caregiver resources.*

*Register today at [TheHikeForHope.com](http://TheHikeForHope.com).*

**June 11 :**

**Webinar: Living with Dementia – Self-Care**

10:00 am – noon

**Presenters:** **Gia Barsell**, Hope Hospice

Manager of Dementia Services  
 PACT™ Certified Trainer and Consultant

**Debbie Emerson**, Hope Hospice

Community Health Educator  
 CARES® Dementia Specialist

**Register online:** [www.HopeHospice.com/family](http://www.HopeHospice.com/family)



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## Session Agenda

- Palliative/Comfort Care (review)
- Hospice Services
- When Death Occurs
- Pre-need Funeral Planning



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## Three Goals of Medical Care

- Cure.
- Stabilization of functioning.
- Preparation for a comfortable and dignified death.



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## What is Palliative (Comfort) Care?

- An **approach to care** with the goal of preventing and relieving suffering regardless of stage of disease.
- 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.
- Palliative care team works with patient and family to respect goals, preferences, and choices.



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## Palliative care and hospice care share the same philosophy. . .

“ . . . 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



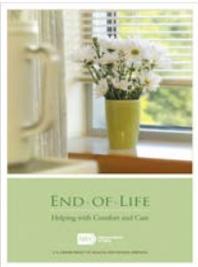
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## Hospice vs. Palliative Care

The difference can be confusing:

- Hospice provides palliative care, which is a method of administering comfort care.
- Where palliative care and hospice care differ greatly is in:
  - eligibility for services;
  - timing, and
  - payment.




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## Hospice vs. Palliative Care

**Hospice:**

- Patients must have an end-stage illness with a **prognosis of six months or less** (curative measures are no longer an option) to be considered and eligible for most hospice programs and to receive insurance benefits.

**Palliative Care:**

- There are currently no restrictions. Patients can opt for palliative care at any time and at any stage of the illness, whether terminal or not.



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## What is Hospice?

- Quality compassionate care for those facing a life-limiting illness.
- A holistic team approach to specialized medical care:
  - pain and symptom management; and
  - emotional, psychosocial, and spiritual support for patients and their families.
- Individualized plan of care based on patient and family preferences.
- A plan of care to keep patients comfortable wherever they reside.



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## Services Provided by Hospice

- Care provided *wherever* the patient resides: home, residential care facility, hospital, hospice facility.
- Care provided by nurses, physicians, home health aides, medical social workers, spiritual counselors.
- On-call 24/7.



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## Services Provided by Hospice (cont.)

- 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.
- Trained volunteers provide wide variety of services.
- Family support.
- Grief counseling for up to 13 months after death.



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## The Care Team Approach

<p>Home Health Aide</p> <p>Grief Support Counselor</p> <p>Medical Director</p> <p>Nurse Practitioner</p>		<p>Spiritual Counselor</p> <p>Medical Social Worker</p> <p>RN Case Manager</p> <p>Dietitian</p>
<p>Volunteers</p>		



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## Services Provided by Hospice (cont.)

- Some hospices offer transitions programs.
- Patients have the right to stop hospice care at any time to pursue medical treatment; can resume when circumstances change, as long as they still meet hospice criteria.
- Patients can be discharged from hospice if condition improves.
- Benefits may be extended beyond 6 months if patient lives longer than expected.



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## What's included in hospice care?

- Medications related to the primary diagnosis and for pain and symptom relief/comfort measures.
- Equipment (bed, wheelchair, oxygen, etc.).
- All visits from the care team.
- Physician services related to the primary diagnosis.
- **Grief Support Services** for up to 13 months – for adults, teens, and children.



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## Who pays for hospice?

- Medicare and Medi-Cal (Medicaid) Benefit.
- Private insurance.
- HMOs, such as Kaiser.
- Charitable donations.
- Patients and families have no out-of-pocket expense.



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## Medicare's Hospice Benefit

**Eligibility Requirements:**

- Be eligible for Medicare Part A;
- 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.



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## Types of Hospice Agencies

- **Profit** • **Not-for-profit** • **Affiliated with a hospital**
- Most insurances, including Medicare and Medicaid (Medi-Cal), pay for all hospice care.
- Not all hospices provide the same degree of services or level of care.
- Patients and their families have the right to select a hospice agency.
- Important to do research & check reviews before choosing.



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## How to Choose a Hospice Provider

- Check for accreditations and licensure.
  - Medicare and Medi-Cal (Medicaid) approved.
  - National Hospice and Palliative Care Organization.
  - Licensed by your state.
- Check the Medicare Care Compare site:  
<https://www.medicare.gov/care-compare/>
- Ask people you know.
- Review the document: *Choosing a Quality Hospice for You or Your Loved One.*



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## When is it time to consider hospice care?

- Death is a strong possibility; life-limiting illness.
- 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 & suffering.
- Desire to stop aggressive treatment and/or multiple trips to the hospital.

[HOPE video](#)



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## What are comfort measures?

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



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## 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 end-of-life care.
- Legal document (actionable medical order) that must be signed by both the physician and patient. May also be signed by nurse practitioners and physician assistants within their scope of practice.
- Prevents unwanted or ineffective treatments.
- Reduces patient and family suffering.
- Ensures a patient's wishes are honored.



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## Primary Diagnoses for Hospice Care

- Cancer
- Lung/heart disease
- Alzheimer's disease & related disorders/Dementia
- HIV/AIDS
- Liver/kidney failure
- COPD (ex. emphysema)
- ALS & multiple sclerosis
- Stroke & coma
- CHF (congestive heart failure)



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## Having "The Conversation"

- Plan for what you will say. Choose a good time & place.
- Seriously ill individuals need to feel they have choices.
- Assure that they can change their mind at any time; hospice is not an irreversible commitment.
- Focus on:
  - Additional level of care; more support & services.
  - Benefits of stopping aggressive treatment and hospitalizations.
  - Many patients actually improve on hospice care.



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## Patient Rights

### **Patients have the right to:**

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



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## How to refer a patient to Hope Hospice

- Referral from:
  - self
  - family member
  - friend
  - physician
  - health care agency/hospital
  - care facility (nursing home, board & care, etc.)
  - hospital
- Online application at [www.HopeHospice.com](http://www.HopeHospice.com)
- Call: (925) 829-8770

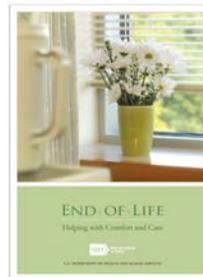


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## Family's Role in Providing Comfort and Relieving Symptoms

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



### REMEMBER:

*You are an important part of the care team!*



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## 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 Booklet *End-of-Life: Helping with comfort and care.*



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## Spiritual Issues

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

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



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## Physical Discomfort

- Digestive problems.
- Breathing problems.
- Dry/irritated/fragile skin.
- Temperature sensitivity.
- Fatigue.
- May not be able to articulate pain – watch for non-verbal indications of discomfort and pain.



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## Myths & Facts About Morphine

**MYTH:** Morphine hastens death.

**FACT:** *If used appropriately, it may, in fact, increase life expectancy due to effective pain control.*

**MYTH:** Morphine addiction is a serious problem in those with chronic illnesses.

**FACT:** *Morphine abuse is rarely seen in patients with cancer or those with severe pain, nor does it lead to addiction in terminally ill.*

**MYTH:** Morphine lowers breathing function.

**FACT:** *Reduced breathing function rarely occurs in patients with pain whose initial doses of morphine are appropriately chosen.*



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## Myths & Facts About Morphine

**MYTH:** Unacceptable sleepiness, confusion, and reduced attention span are frequent side effects.

**FACT:** *When correctly prescribed and taken, it does not often produce these side effects. Sleepiness is common, but usually temporary.*

**MYTH:** Morphine cannot be used with other meds for pain control

**FACT:** *A combination of medications for pain may be used, as well as other meds to control anxiety, constipation, etc.*

**MYTH:** If morphine is prescribed too soon, nothing else is left to help pain.

**FACT:** *As pain increases, the morphine dose can be adjusted. There is no maximum amount.*



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## Practical Considerations at End of Life

- Advance Planning.
  - Hospice?
  - Care location.
  - Wills/Advance directives/POLSTs.
  - Funeral arrangements.
- Visits from family and friends.
- Impact on everyday life.

[www.verywellhealth.com/end-of-life-4014730](http://www.verywellhealth.com/end-of-life-4014730)

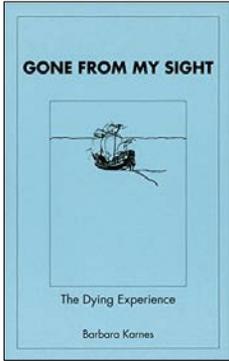


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## Signs of Dying

- *Gone from My Sight: The Dying Experience*  
- Barbara Karnes, R.N.
- *The Journey Towards Death*  
- [www.verywellhealth.com](http://www.verywellhealth.com)




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## 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.



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## 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 info.
- **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 police (non-emergency number or 911); be sure to tell them that death was expected and have the DNR and/or POLST available.



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## First Steps When a Death Occurs (cont.)

- Death must be pronounced by someone in authority: doctor, hospice nurse, coroner/medical examiner.
- Doctor or hospice nurse will complete forms necessary 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.



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## Contact the Funeral Home or Mortuary

- Funeral home vs. Mortuary?
- Arrange transportation of the deceased to the funeral home (nursing home or hospice staff will do this).
- Sign a release form to allow funeral home to transfer deceased.
- Make an appointment to make funeral arrangements – this needs to be done by the person with power of attorney.
- If pre-need and/or pre-paid funeral plan in place, be sure to review all details with funeral home.



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## Pre-need Funeral Arrangements

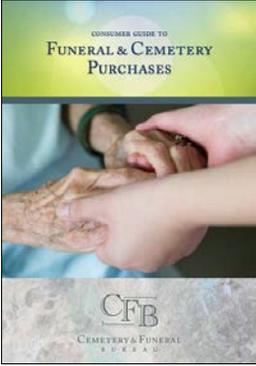
- Importance of advance planning.
- Purchasing a pre-need plan: Do your research!
  - Review Federal Trade Commission booklets online.
  - Compare plans and prices; are quoted prices guaranteed?
  - What happens to the pre-paid money and interest accrued?
  - What happens if the firm goes out of business?
  - What if you change your mind? Full refund?
  - What happens if you move? Or die away from home?
- Pre-need funeral plans exempt from Medi-Cal assets.
- State and federal regulations to protect the consumer.



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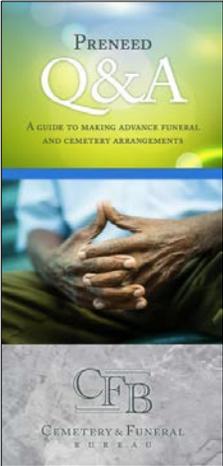
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## Resources for Advance Planning



CONSUMER GUIDE TO  
FUNERAL & CEMETERY  
PURCHASES

CFB  
CEMETERY & FUNERAL  
BUREAU



PRENEED  
Q&A  
A GUIDE TO MAKING ADVANCE FUNERAL  
AND CEMETERY ARRANGEMENTS

CFB  
CEMETERY & FUNERAL  
BUREAU



Shopping for  
Funeral Services

Federal Trade Commission | consumer.ftc.gov



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## Tips from the Trenches

- Don't set a date, time, or place for services until you've 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 can provide options for those in financial need.
- If cremated, ashes may be placed in separate containers.
- Save all receipts.
- 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.
- *A funeral is not a day in a lifetime, it's a lifetime in a day.*



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THANK YOU!



Don't forget to complete the online evaluation upon leaving the webinar – or when you get the link in the follow-up email tomorrow.

**THANK YOU!**

