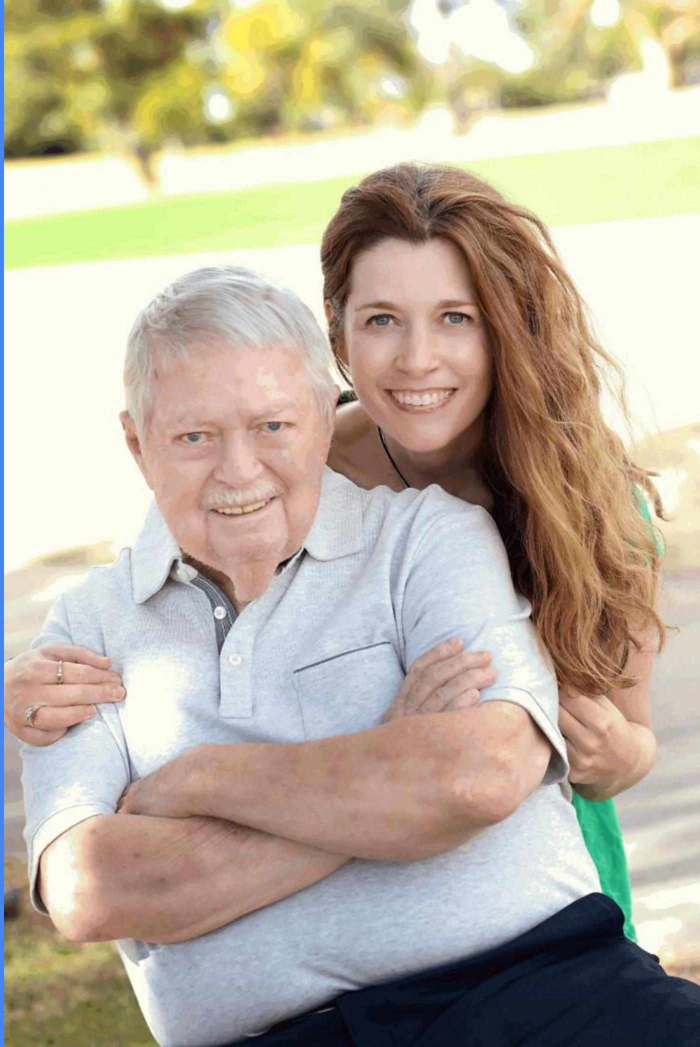
End of Life Decisions
and
Goals of Care

Julie Myers, RN, PHN, FNP-BC



End of life decisions

- End-of-life decisions are the choices an individual makes, or that are made on their behalf, regarding medical care, treatment, and quality of life when facing a terminal illness or nearing death.
- These decisions aim to honor the person's values and preferences, often documented through advance care planning, such as living wills and medical power of attorney.

(National Institute on Aging, n.d.)

Goals of Care

- Goals of care can be defined as the overarching aim of medical care
- This should be informed by patient's underlying values and priorities
- They are established within the existing clinical context, and used to guide decisions about the use of or limitation on specific medical interventions.

(Gates, n.d.)

Who should be having these conversations?

- Cancer
- Dementia
- Dialysis
- Oxygen dependent COPD
- Heart Failure
- Stroke
- Assisted Living
- Polypharmacy
- History of ICU admission
- "Surprise" question or “would you be surprised if this family member died in the next 12 months?”
- **But realistically, everyone because nothing is certain and discussing these things prior to catastrophe is helpful**

Lingo

- Advance Directives/Living will -Medical Power of Attorney/health care proxy
- Advanced care planning ACP
- Do-not-resuscitate orders DNR
- Do-not intubate orders DNI
- Chemical code
- Orders for Life Sustaining Treatment POLST
- Palliative care
- Hospice Care

No Documentation

- The medical system is designed to keep people alive without regard to the quality of life. Interventions will happen if you do not make your wishes known. If these wishes are not legally delineated, sometimes well meaning healthcare providers/ friends/family will have you treated in ways you would not want!
- Social work will attempt to identify a healthcare surrogate decision maker at some point if you are critically ill, this is sometimes a hefty challenge and can be a hefty burden for that person if requested to do so (and can be refused). If the patient has capacity to identify a person, that will be put in the record, but often times he/she is too unwell to do so

Advanced Care Planning

Advanced Care Planning includes:

- Identifying a healthcare agent/durable power of attorney.
- Discussing values, goals, and what quality of life means
  - What gives your life meaning?
  - What are your hopes for your care?
  - Who should speak for you if you cannot?
- Expressing preferences for:
  - Hospitalization
  - ICU Care
  - Ventilators
  - Tube Feeding
  - Resuscitation
  - Comfort-focused care

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

- This form has 3 parts. It lets you:

Part 1: Choose a health care agent.

A health care agent is a person who can make medical decisions for you if you are too sick to make them yourself.

Part 2: Make your own health care choices.

This form lets you choose the kind of health care you want.

This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.

Part 3: Sign the form.

It must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out only the parts you want.
Always sign the form in Part 3.

Go to the next page

FORM 3-1

Advance Health Care Directive

NOTE: This form should include taglines as required by the Affordable Care Act. *(See www.calhospital.org/taglines, for detailed information.)*

Explanation

You have the right to give instructions about your own health care. You also have the right to name someone else to make health care decisions for you. This forms lets you do either or both of these things. If you use this form, you may complete or modify all or any part of it. You are free to use a different form.

Instructions

Part 1 of this form lets you name another person as "agent" to make health care decisions for you if you become incapable of making your own decisions, or if you want someone else to make those decisions for you now even though you are still capable. You may also name a different person to act for you if your first choice is not willing, able, or reasonably available to make decisions for you.

Unless you state otherwise in this form, your agent will have the right to:

1. Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition.
2. Select or discharge health care providers and institutions.
3. Approve or disapprove diagnostic tests, surgical procedures, and programs of medication.
4. Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation.
5. Donate your organs, tissues, and parts; authorize an autopsy, and direct disposition of remains.

However, your agent will not be able to commit you to a mental health facility, or consent to convulsive treatment, psychosurgery, sterilization or abortion for you.

Part 2 of this form lets you give specific instructions about any aspect of your health care, whether or not you appoint an agent. Choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, as well as the provision of pain relief. You also can add to the choices you have made or write down any additional wishes. If you are satisfied to allow your agent to determine what is best for you in making end-of-life decisions, you need not fill out Part 2 of this form.

Give a copy of the signed and completed form to your physician, to any other health care providers you may have, to any health care institution at which you are receiving care, and to any health care agents you have named. You should talk to the person you have named as agent to make sure that he or she understands your wishes and is willing to take the responsibility.

You have the right to revoke this advance health care directive or replace this form at any time.

Name of Patient: ______________________________

Date of Birth: ______________________________

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Part 1 Choose your medical decision maker

Your medical decision maker can make health care decisions for you if you are not able to make them yourself.

A good medical decision maker is a family member or friend who:

- is 18 years of age or older
- can talk to you about your wishes
- can be there for you when you need them
- you trust to follow your wishes and do what is best for you
- you trust to know your medical information
- is not afraid to ask doctors questions and speak up about your wishes

Legally, your decision maker cannot be your doctor or someone who works at your hospital or clinic, unless they are a family member.

What will happen if I do not choose a medical decision maker?

If you are not able to make your own decisions, your doctors will turn to family and friends or a judge to make decisions for you. This person may not know what you want.

If you are not able, your medical decision maker can choose these things for you:

- doctors, nurses, social workers, caregivers
- hospitals, clinics, nursing homes
- medications, tests, or treatments
- who can look at your medical information
- what happens to your body and organs after you die

Part 1 — Power of Attorney for Health Care

Your agent may not be an operator or employee of a community care facility or a residential care facility where you are receiving care, or your supervising health care provider or an employee of the health care institution where you are receiving care, unless your agent is related to you or is a coworker.

Designation of Agent:
I designate the following person as my agent to make health care decisions for me:

Name of person you choose as agent: ______________________

Address: ______________________

____

Telephone: ______________________
(home phone) *(work phone)* *(cell)*

OPTIONAL: If I revoke my agent's authority or if my agent is not willing, able, or reasonably available to make a health care decision for me, I designate as my alternate agent:

Name of person you choose as alternate agent: ______________________

Address: ______________________

____

Telephone: ______________________
(home phone) *(work phone)* *(cell)*

Agent's Authority:
My agent is authorized to make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care to keep me alive, except as I state here:

____

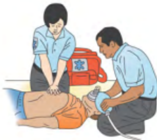
____

____

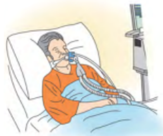
(Add additional sheets if needed.)

Here are more decisions your medical decision maker can make:

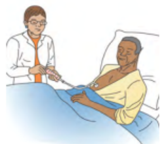
Start or stop life support or medical treatments, such as:



- **CPR or cardiopulmonary resuscitation**
  cardio = heart • pulmonary = lungs • resuscitation = try to bring back
  This may involve:
  - pressing hard on your chest to try to keep your blood pumping
  - electrical shocks to try to jump start your heart
  - medicines in your veins



- **Breathing machine or ventilator**
  The machine pumps air into your lungs and tries to breathe for you. You are not able to talk when you are on the machine.
- **Dialysis**
  A machine that tries to clean your blood if your kidneys stop working.



- **Feeding Tube**
  A tube used to try to feed you if you cannot swallow. The tube can be placed through your nose down into your throat and stomach. It can also be placed by surgery into your stomach.
- **Blood and water transfusions (IV)**
  To put blood and water into your body.
- **Surgery**
- **Medicines**

End of life decisions your medical decision maker can make:

- call in a religious or spiritual leader
- decide if you die at home or in the hospital
- decide about autopsy or organ donation
- decide about burial or cremation

Part 2 — Instructions for Health Care

If you fill out this part of the form, you may strike any wording you do not want.

End-of-Life Decisions:
I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

Choice Not To Prolong Life:
I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits. ____________

(Initial here)

OR

Choice To Prolong Life:
I want my life to be prolonged as long as possible within the limits of generally accepted health care standards. ____________

(Initial here)

Relief From Pain:
Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

____

____

(Add additional sheets if needed.)

Other Wishes:
(If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

____

____

____

____

(Add additional sheets if needed.)

POLST

Purpose of POLST

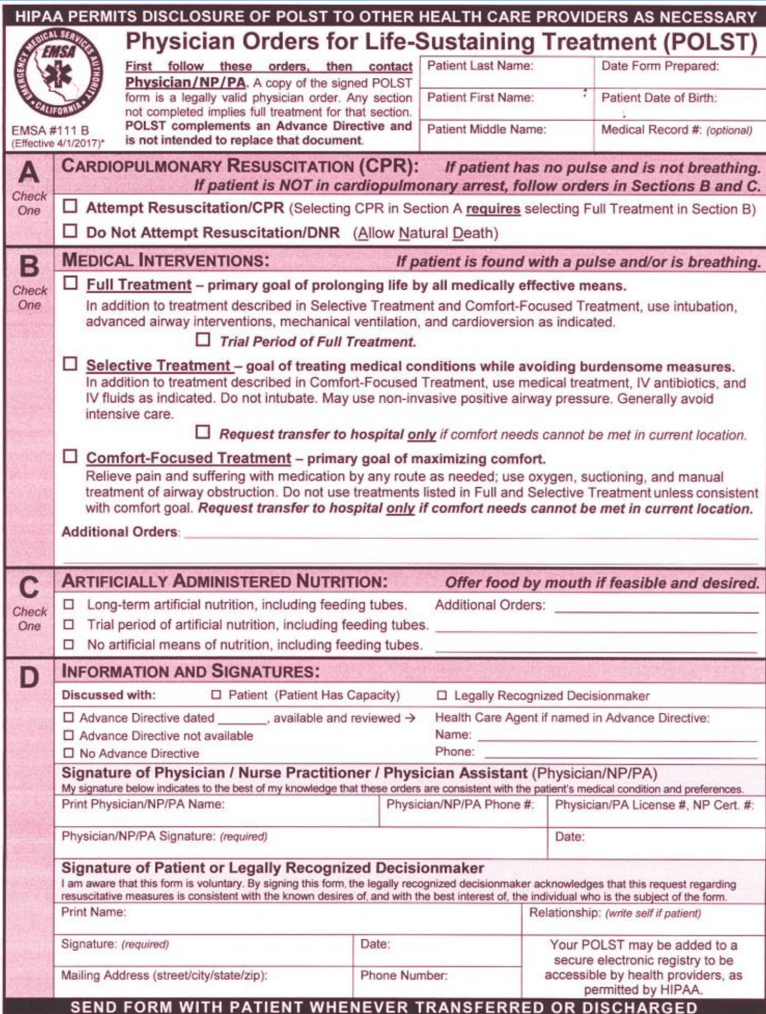
- A medical order for seriously ill or frail individuals, not a general population form.
- Converts goals into actionable medical instructions.

When POLST Is Appropriate

- Moderate-late-stage Alzheimer's/Dementia
- Frailty or multimorbidity
- When clinician believes the patient would not be surprised to die with a year (discussing prognosis)
- When the patient or surrogate wants to clarify limits on medical interventions.

What POLST Covers

- Resuscitation status (CPR vs DNR)
- Medical Interventions: full treatment, selective treatment, comfort-focused care
- Artificial Nutrition options



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

EMSA #111 B (Effective 4/1/2017)*

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

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

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** ***If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.***

- ☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A requires selecting Full Treatment in Section B)
- ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B Check One — **MEDICAL INTERVENTIONS:** ***If patient is found with a pulse and/or is breathing.***

- ☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
  In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
  ☐ ***Trial Period of Full Treatment.***
- ☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
  In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
  ☐ ***Request transfer to hospital only** if comfort needs cannot be met in current location.*
- ☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
  Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: ______

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** ***Offer food by mouth if feasible and desired.***

- ☐ Long-term artificial nutrition, including feeding tubes.
- ☐ Trial period of artificial nutrition, including feeding tubes.
- ☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: ______

D — **INFORMATION AND SIGNATURES:**

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

- ☐ Advance Directive dated ______, available and reviewed →
- ☐ Advance Directive not available
- ☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: ______
Phone: ______

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

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

Patient Information

Name (last, first, middle):	Date of Birth:	Gender: M F

NP/PA's Supervising Physician	Preparer Name (if other than signing Physician/NP/PA)	
Name:	Name/Title:	Phone #:

Additional Contact ☐ None

Name:	Relationship to Patient:	Phone #:

Directions for Health Care Provider

Completing POLST

- **Completing a POLST form is voluntary.** California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician, or a nurse practitioner (NP) or a physician assistant (PA) acting under the supervision of the physician, who will issue appropriate orders that are consistent with the patient's preferences.
- **POLST does not replace the Advance Directive.** When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician/NP/PA believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known.
- A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately.
- To be valid a POLST form must be signed by (1) a physician, or by a nurse practitioner or a physician assistant acting under the supervision of a physician and within the scope of practice authorized by law and (2) the patient or decisionmaker. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible.

Using POLST

- Any incomplete section of POLST implies full treatment for that section.

Section A:

- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation."

Section B:

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort-Focused Treatment."
- Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Modifying and Voiding POLST

- A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician/NP/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force. For more information or a copy of the form, visit **www.caPOLST.org**.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Notify Key People of Your Preferences

- Tell your doctor, family, and close friends about your end of life preferences
- If you have a local hospital, these documents should be made available to them as they will attach to your chart so if you are admitted and cannot speak for yourself they know what to do
- Do not keep the copy of the document in a safe - no one knows how to get to that, it needs to be accessible and your family/friends need to know how to access it

The Five Wishes

1. **My Healthcare Advocate**

   Choose the person you trust most to make legal healthcare decisions and carry out your wishes when you can't do so yourself.

1. **My Treatment Wishes**

   Outline in your own words the medical treatments you want or don't want if you become seriously ill.

1. **How Comfortable I Want to Be**

   Express how you want to be kept comfortable so your caregivers can help you feel at ease.

4. How I want People to Treat Me

Addresses personal dignity, such as having visitors, cleanliness

5. What I Want My Loved Ones to Know

Tell your loved ones what they should know about you and how you want to be remembered.

(Aging with Dignity, n.d.)

FIVE WISHES®

MY WISH FOR:

1. The Person I Want to Make Care Decisions for Me When I Can't
2. The Kind of Medical Treatment I Want or Don't Want
3. How Comfortable I Want to Be
4. How I Want People to Treat Me
5. What I Want My Loved Ones to Know

Print Your Name

Birthdate

CPR Statistics

- In-hospital CPR has 15-25% survival discharge rate (note, this is not necessarily discharge to home - may be another hospital, rehab, nursing home, or to hospice)
- Neurologic function of survivors shows 14% have decline
- Functional performance also declined 25%
- Factors predicting failure to survive discharge include sepsis prior to CPR event, creatinine > 1.5 mg/dl, dependency for activities of daily living, hypotension on admission, metastatic cancer, and dementia

(Palliative Care Network of Wisconsin, 2025)

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American Preference

70% of Americans would prefer to be at home with loved ones in their final days yet only 25% die at home

(NEWS, 2003)

Nonintervention

- Often in crisis in the hospital the treating MD/DO/NP/PA will order antibiotics, pressor support, oxygenation, hydration, nutrition, etc.
- If these are not in line with your goals you can also opt to do nothing and die naturally and comfortably
- It is much harder emotionally for clinicians and loved ones to take away treatments once they have been started, however, heart breaking, most times these decisions must be made and the guilt family members take on trying to figure out what is best can be tremendous
- Ask your nurses!

Palliative Care vs. Hospice Care

Similar but Different

Palliative Care

- Focuses on relief from physical suffering. The patient may be being treated for a disease or may be living with a chronic disease, and may or may not be terminally ill.
- Addresses the patient's physical, mental, social, and spiritual well-being, is appropriate for patients in all disease stages, and accompanies the patient from diagnosis to cure.
- Uses life-prolonging medications.
- Uses a multi-disciplinary approach using highly trained professionals. Is usually offered where the patient first sought treatment.

Hospice Care

- Available to terminally ill Medicaid participants. Each State decides the length of the life expectancy a patient must have to receive hospice care under Medicaid. In some States it is up to 6 months; in other States, up to 12 months. Check with your State Medicaid agency if you have questions.
- Makes the patient comfortable and prepares the patient and the patient's family for the patient's end of life when it is determined treatment for the illness will no longer be pursued.
- Does not use life-prolonging medications.
- Relies on a family caregiver and a visiting hospice nurse. Is offered at a place the patient prefers such as in their home; in a nursing home; or, occasionally, in a hospital.

Combined Care

Hospices are the largest providers of palliative care services in the country. Many organizations work together to offer the patient a seamless continuum of care over the course of a serious illness.

Follow us on Twitter #MedicaidIntegrity

Palliative Care

- Applicable across the disease spectrum with a goal of making life as comfortable as possible by controlling pain and symptoms
- Not prognosis dependent
- Not just for Cancer
- Not in place of life prolonging therapies or hospitalizations
- Not “giving up”

(Rome et al., 2011)

PALLIATIVE CARE: WHAT IS IT?

Interdisciplinary medical care aimed at optimizing:

- Enhancing quality of life
- Mitigating symptoms of serious, complex, often terminal illness
- Helping with decision making (ACP), POLST completion
- Delivered concurrently with life-prolonging care or as the focus of care

Hospice Care

- Comfort and support for patient and family when there is no longer benefit from cute-oriented therapy. Typically 6 months or less of life expectancy.
- Meets patients where they are
- Covered under Medicare Part A
- RN, Social Work, Chaplain, Home Health Agency, and Grief Support for family
- DME/durable medical equipment
- 24/7 MD support

(M. C. Reeder, personal communication, February 13, 2026)

Spiritual Guidance

In 1992 the ELCA Church Council approved a message on End of Life Decisions prepared by the Division for Church in Society.

- **Life as a Gift:** The message starts that Life is a gift from God, and that death is part of the life process to be respected
- **Refusal of Treatment:** Patients have the right to decline/withdraw medical treatment, including artificial nutrition and hydration, if it does not offer meaningful benefit.
- **Definition of Care:** The ELCA defines care as prioritizing comfort, pain relief, and emotional/spiritual support over the relentless pursuit of a cure.

- **Quality of Life:** Decisions should consider whether treatment provides a "significant extension of life" or simply prolongs the dying process.
- **Focus on Presence:** The church encourages accompanying the dying with prayer and presence, focusing on God's love.

(Evangelical Lutheran Church in America, 1992)

Bishops Letter on “End of Life Decisions” 2005

- Response to the drawn out court decision making and conflict within Terry Schiavo’s family about her right to not pursue care
- Reaffirms that “We would continue to surround the dying loved-one with the assurance of God’s love and do what is possible to relieve any suffering.”
- And that “Competent patients are always the prime decision-makers and may refuse any treatment whether recommended or not by medical professionals”

(Benoway, 2005)

When in Doubt

Call Pastor Mark!

Pastor Doolittle is associated with LightBridge Hospice too.

Questions?

Special thank you to my Scripps Colleagues in Palliative Care, some of whom provided slides to poach for this presentation: Nerissa Cruz, MSW, Patricia Wragg, RN, Mary Carol Reeder, NP, Clint Morehead, MD

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