A Patient Centered Approach

Palliative Care

Anne Front, LMFT

What is Palliative Care

World Health Organization (WHO)

- Palliative care is an approach
  - that improves quality of life
  - Focuses on prevention and relief of suffering
  - early identification
  - impeccable assessment
  - treatment of pain and other problems
  - treatment of bio-psycho-social-spiritual

What Palliative Care Does

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death

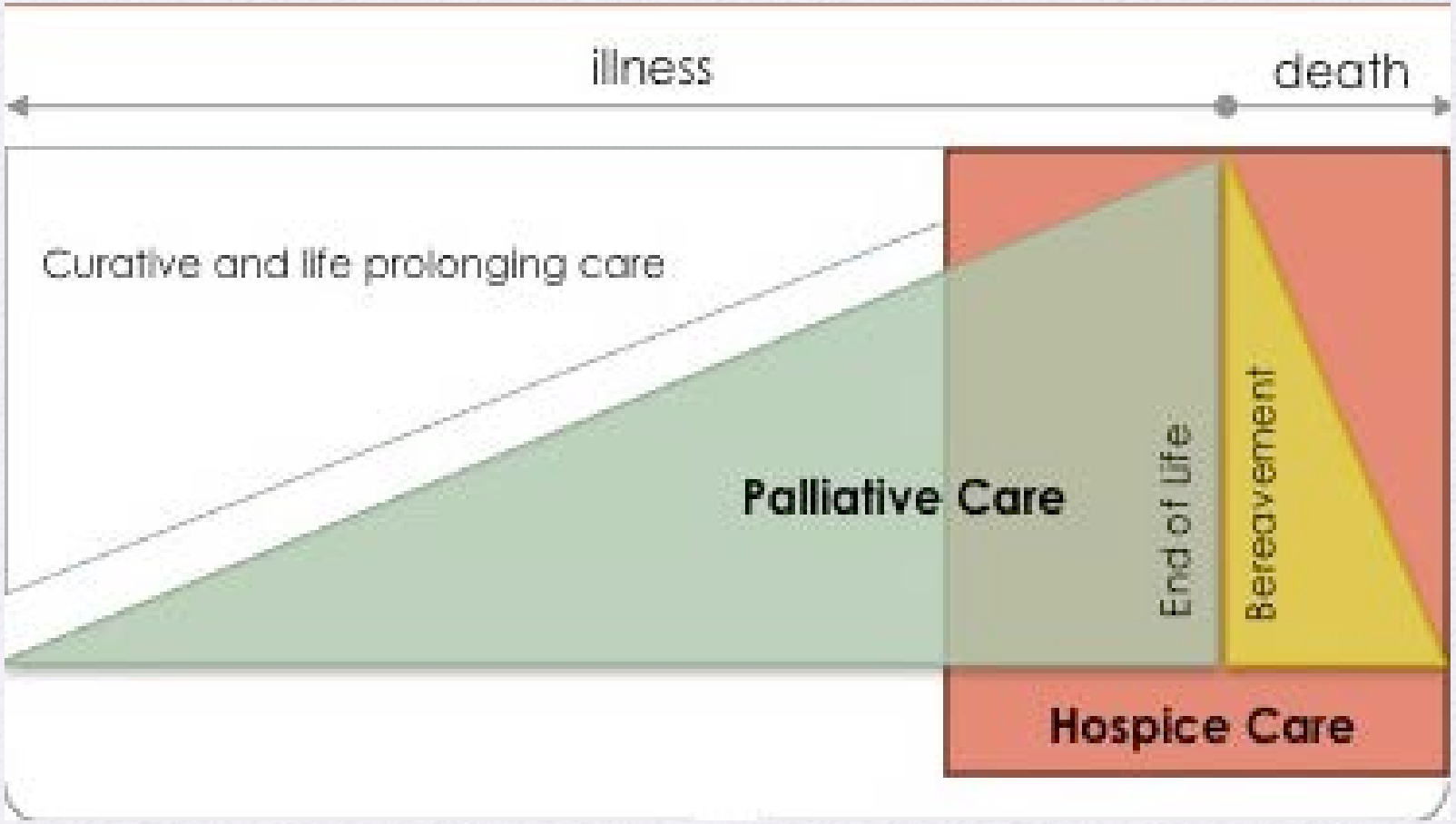
What Palliative Care Does

- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

Palliative Care Diagnosis

- Cancer
- Congestive heart failure (CHF)
- Chronic obstructive pulmonary disease (COPD), emphysema, lung disease
- Kidney failure
- Liver failure
- Neurological diseases (e.g., ALS, Parkinson's)
- Dementia

Trajectory of Illness



When to refer to Palliative Care

- Palliative Care is applicable
  - early in the course of illness
  - in conjunction with other therapies that are intended to prolong life (example chemo, radiation, dialysis)
  - When there is a need to better understand goals of care
  - Advance planning
  - Symptom management

Palliative Care – A Bridge

https://www.youtube.com/watch?v=lDHhg76tMHc

Traditional Medicine

- Traditional medicine has used a “top-down” approach to health care. Physicians diagnose problems, prescribe solutions and the patient has little say in the treatment process.

A New (Old?) Approach

- Palliative Care is patient-centered, respecting the individual as a person first and not the sum of his/her disease. The goal of Palliative Care is to understand the patient – what is important to that person and how does he/she define quality of life. When the individual is understood, and his/her goals are known, best care practice is established.

Getting to Know the Individual

- Is this a Person or a Patient? Is this a Family or Visitors?
- Get to know the person and the family – Everyone has their own unique story.
- The Individual and family are at the center of the treatment.
- Person-Centered Care is the basis of Palliative Care

Understanding What Matters

- We can do a lot of things to keep people alive.
- More treatment is sometimes at the expense of life quality.
- What matters to some, doesn't to others.
- Individuals inherently know what is best for themselves – the medical team can help provide information and guide, but the individual and family are the decision makers.
- Asking the question "What Matters" is essential to treatment planning.

Quality of Life

- Defining Quality of Life is Subjective
- Freedom, human rights, happiness, dignity
- Physical , functional, social and well-being of a person.

A Team Approach

- Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Settings

- Palliative Care is rapidly expanding
- New Programs are building every year
  - Inpatient – over 1700 hospitals in 2012
  - 90% of hospitals with 300+beds have Palliative Care teams
  - Extended Care Facilities
  - Outpatient Programs through Home Health and Hospice
- Barriers to growth include not enough **education** about services and **underdeveloped workforce** to meet the demands.

Information about Palliative Care in the Community: https://www.capc.org/topics/palliative-care-community/

Outpatient Palliative Care

- Outpatient programs are being built to meet the increasing needs of patients and families going through serious illness
- Goal is to get to know the patient and their needs.
- Rather than being a guest in the hospital, the outpatient setting is a chance to get to know who this person really is in their own environment.
- This becomes a dialogue of care to shape the treatment plan according to the needs.

Existing Supports

- Many Palliative Care patients and families already have existing supports
  - Inner Circle
  - Psychotherapists
  - Community Health
  - Support Groups
  - Senior Center
  - Faith Organizations
- Important to use these supports in the plan of care.

New Layers of Support

- As the disease prolongs or progresses, additional support may be needed:
  - Caregiver Assistance
  - In home Supports (Medical Equipment, Meals)
  - Home Health
  - Structured Palliative Care
  - Hospice
  - Other

Home Health, Palliative Care

- Focus on rehabilitation in the home
- Symptom Relief (pain, shortness of breath, fatigue, constipation, appetite, sleep)
- Understanding condition & choices
- Emotional Support
- Many programs have on-call support

Hospice

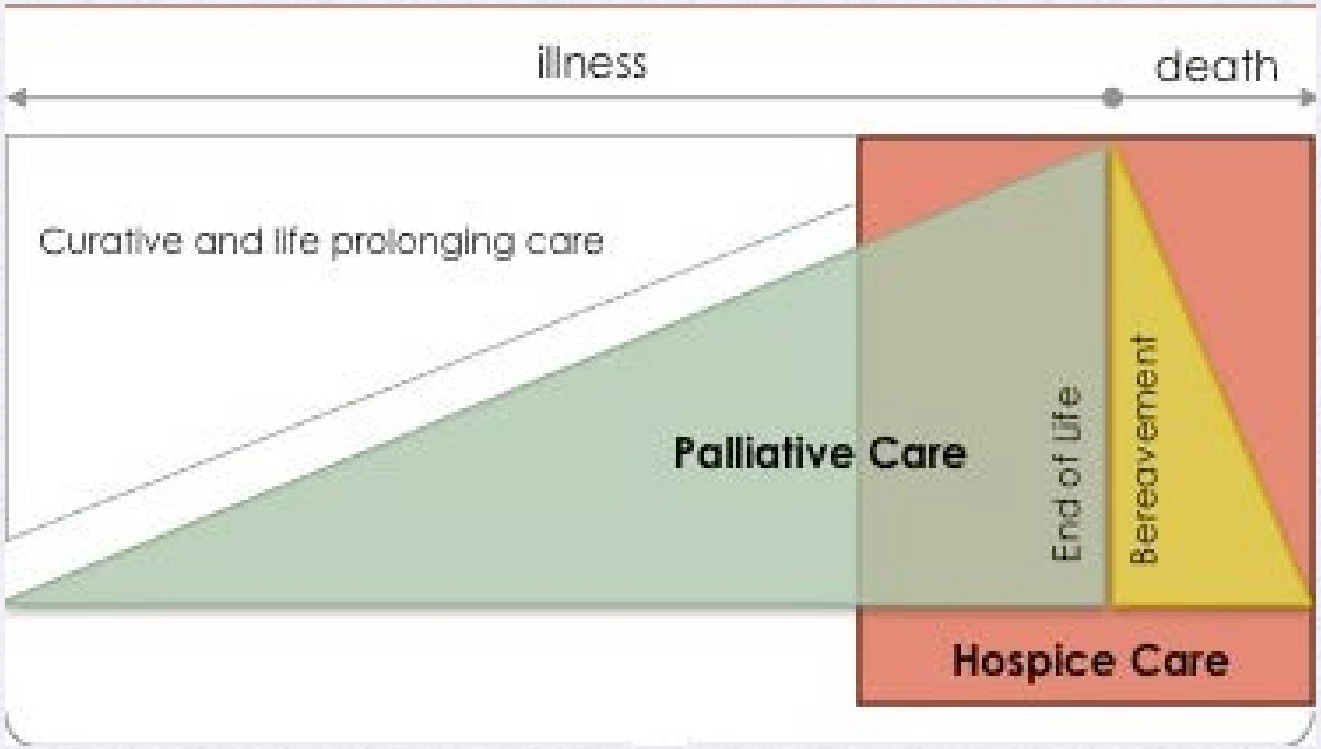
- A service that provides care for patients who are terminally ill with a life expectancy of less than six months
- Patients forgo curative treatment
- Focus is on comfort, dignity, quality of life
- Supports the patient and surviving family through the dying and bereavement processes
- Goal is to die at home or in an residential care facility.

Comfort Care

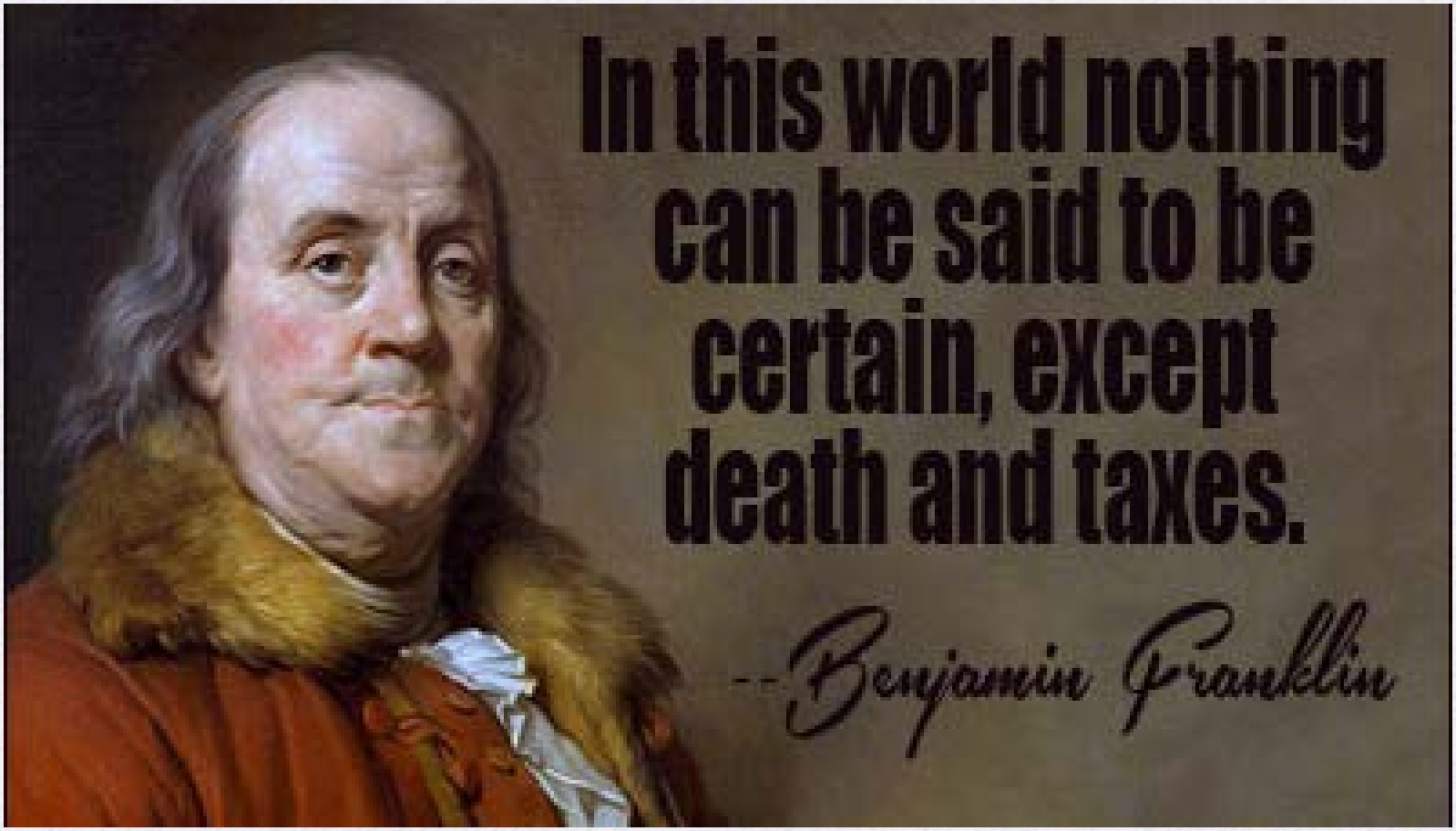
- Care of the terminally ill patient in the hospital setting.
- Patient is expected to die within a few hours to days.
- Often may include withdrawal or withholding of treatments.
- Goal is to make sure the patient is comfortable and the family is supported through the death of their loved one.

Think backwards – Illness Trajectory

Never stop hoping or believing but have a plan



Advance Health Care Planning



Do you have a Plan?

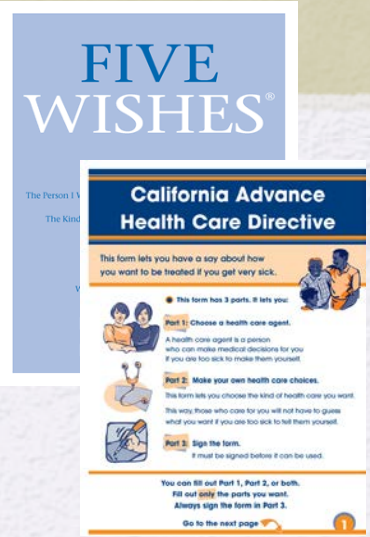
- 25% of Americans have a living will or AHCD.
- 75% of Americans DO NOT have a documented plan.
- Most people feel it is a good idea but don't feel it is urgent or that somehow the MD or family will know their wishes.

Frontline: Facing Death

- Nearly 50% of Americans die in a hospital, 70% die in a hospital or nursing home.
- 70% of Americans say they would prefer to die at home
- 25% actually die at home.
- 80% of patients with chronic diseases say they want to avoid hospitalization and intensive care when they are dying.
- The rate of hospitalizations at EOL are increasing every year.
- One Third of Americans see 10 or more Physicians in the last 6 months of their life.
- Only 25% of Physicians knew their patient had an AHCD on file.

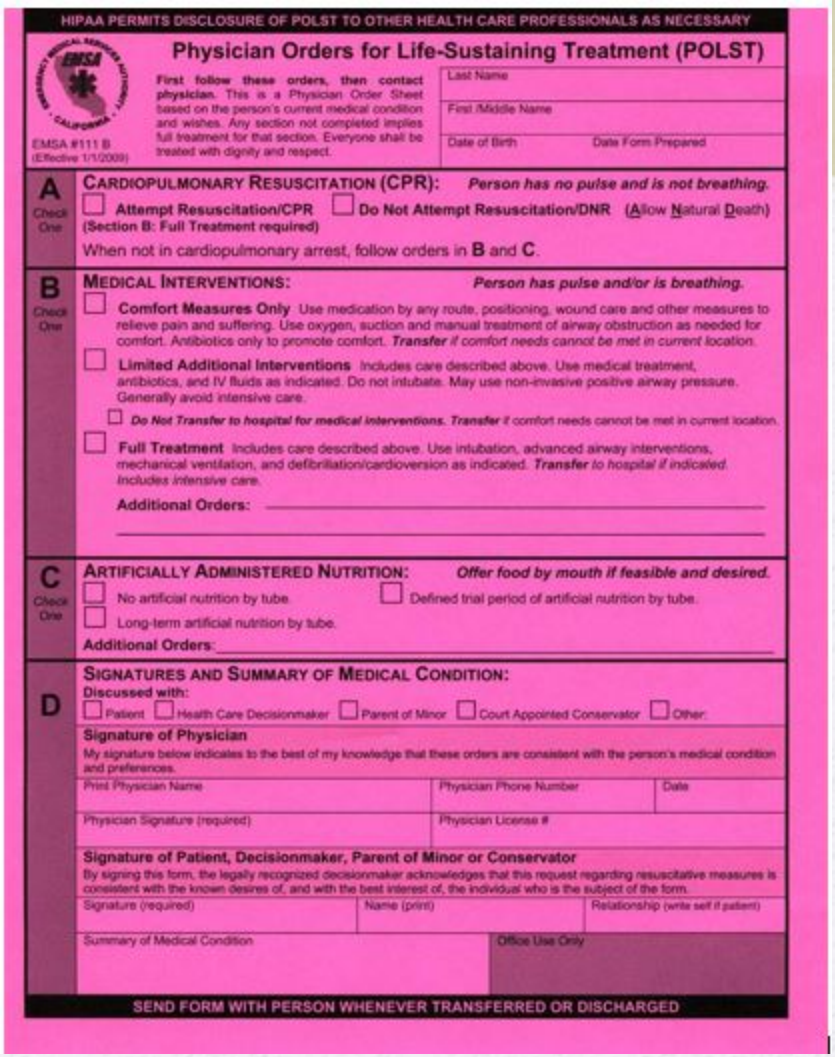
- http://www.pbs.org/wgbh/pages/frontline/facing-death/facts-and-figures/

Advance Health Care Directives



- For anyone 18 and older
- Provides instructions for **future** treatment
- Appoints a Health Care Representative
- Does not guide Emergency Medical Personnel
- Guides inpatient treatment decisions when made available

California AHCD form
http://oag.ca.gov/sites/all/files/agweb/pdfs/consumersProbateCodeAdvancedHealthCareDirectiveForm-fillable.pdf



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

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B (Effective 1/1/2009)

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. Everyone shall be treated with dignity and respect.

Last Name | First /Middle Name | Date of Birth | Date Form Prepared

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** *Person has no pulse and is not breathing.*

☐ Attempt Resuscitation/CPR ☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

(Section B: Full Treatment required)

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B Check One — **MEDICAL INTERVENTIONS:** *Person has pulse and/or is breathing.*

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Do Not Transfer to hospital for medical interventions. Transfer*** *if comfort needs cannot be met in current location.*

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: _____

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

☐ No artificial nutrition by tube ☐ Defined trial period of artificial nutrition by tube.

☐ Long-term artificial nutrition by tube.

Additional Orders: _____

D — **SIGNATURES AND SUMMARY OF MEDICAL CONDITION:**

Discussed with: ☐ Patient ☐ Health Care Decisionmaker ☐ Parent of Minor ☐ Court Appointed Conservator ☐ Other:

Signature of Physician

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Physician Name | Physician Phone Number | Date

Physician Signature (required) | Physician License #

Signature of Patient, Decisionmaker, Parent of Minor or Conservator

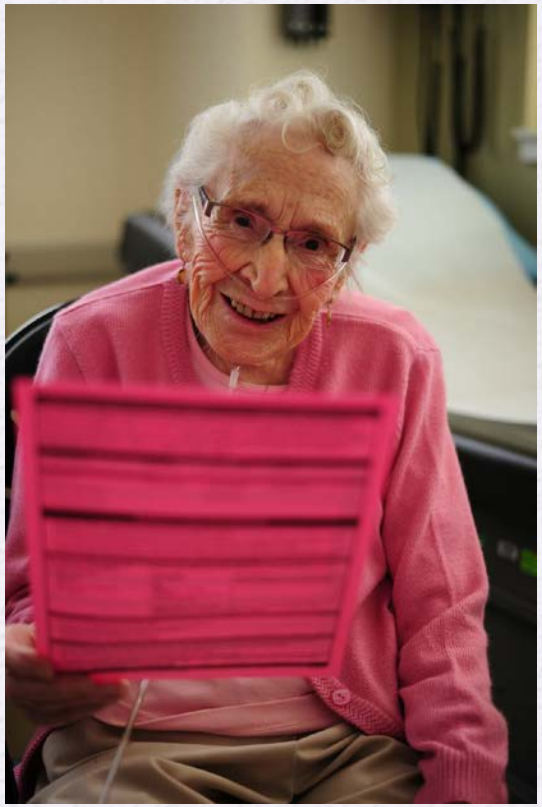
By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Signature (required) | Name (print) | Relationship (write self if patient)

Summary of Medical Condition | Office Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

California
POLST



DOWNLOAD NEW 2016 POLST

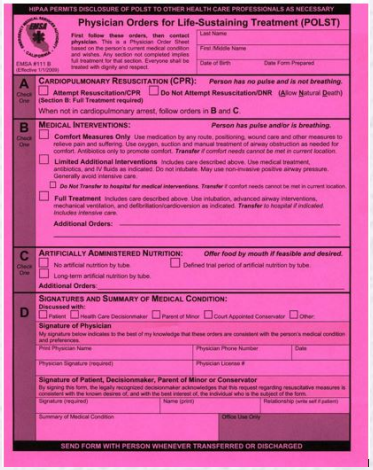
http://www.polst.org/about-the-national-polst-paradigm/what-is-polst/

POLST

- Must have two signatures to be considered valid: Physician, NP or PA and patient or healthcare decision maker.
- Healthcare professionals are mandated to follow the orders on a POLST.
- Valid facility to facility anywhere in California.

(i.e., hospital, skilled nursing facility, EMS, home)

http://www.polst.org/advance-care-planning/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(Section B: Full Treatment required)
When not in cardiopulmonary arrest, follow orders in B and C.

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

C Check One — ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*
☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.
Additional Orders:

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Discussed with:
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My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.
Print Physician Name | Physician Phone Number | Date
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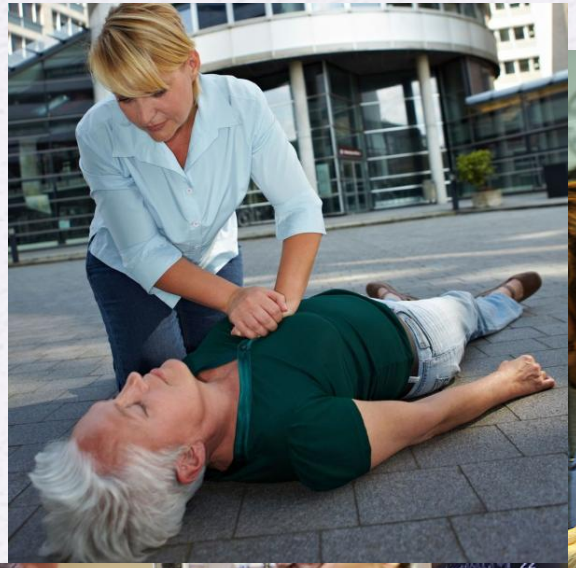
Summary of Medical Condition | Office Use Only

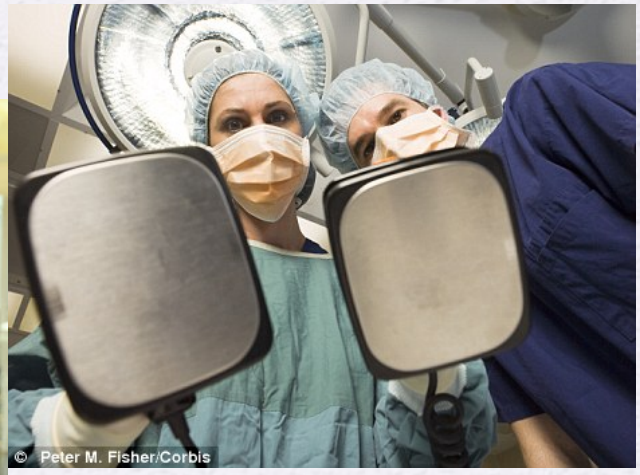
SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Guidelines for POLST

- For persons with serious illness — at any age.
- Provides medical orders for current treatment.
- Guides actions by Emergency Medical Personnel when made available.
- Guides inpatient treatment decisions when made available.
- Any incomplete means Full Treatment for that Section.

Decisions





CPR

Cardiopulmonary Resuscitation

CODE Status Section A

- “Until they die, it doesn’t apply”
- FULL CODE – Attempt Resuscitation
- DNR (Do Not Resuscitate) (Allow Natural Death)
- DNI (Do Not Intubate)

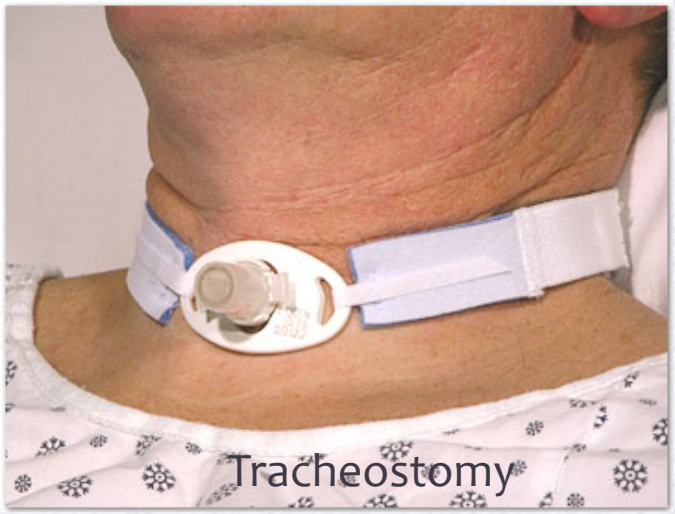
CPR

- CPR Success Rates
  - In Hollywood, 75% Successful
  - 40 – 50 year olds- less than 10% CPR Success
  - Less every decade, 80 year olds – estimated 3.3% success
- Effects of CPR
  - Broken Ribs
  - Internal Damage
  - Increased Physical Debility
  - Hypoxic Brain damage
  - Doesn’t change the underlying condition

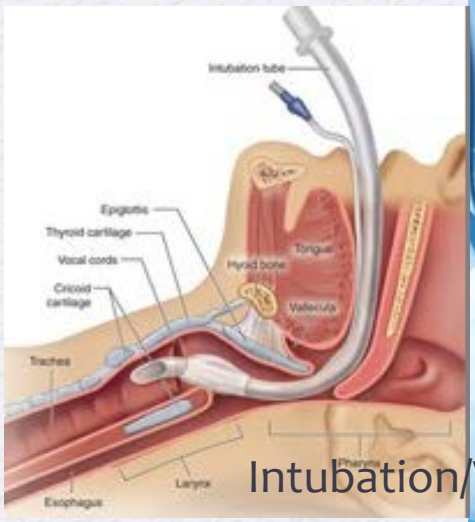
Airway Support

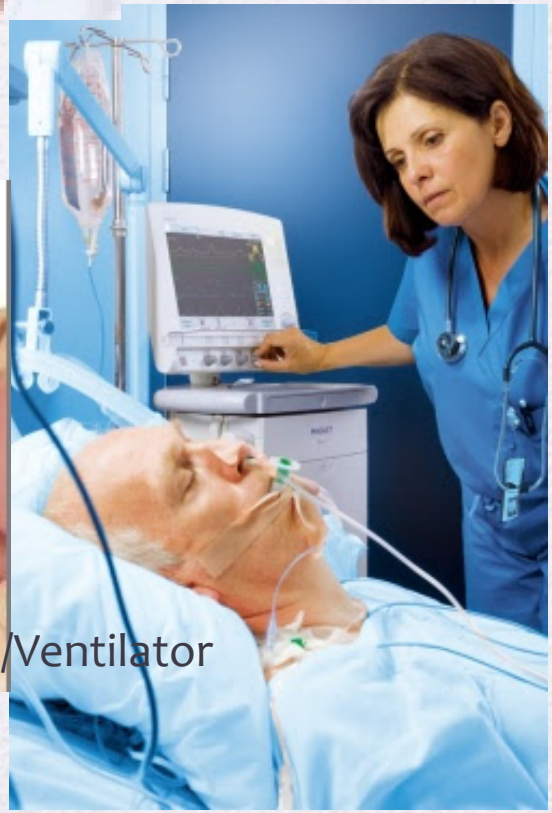
Nasal Cannula

Bi-Pap



Tracheostomy

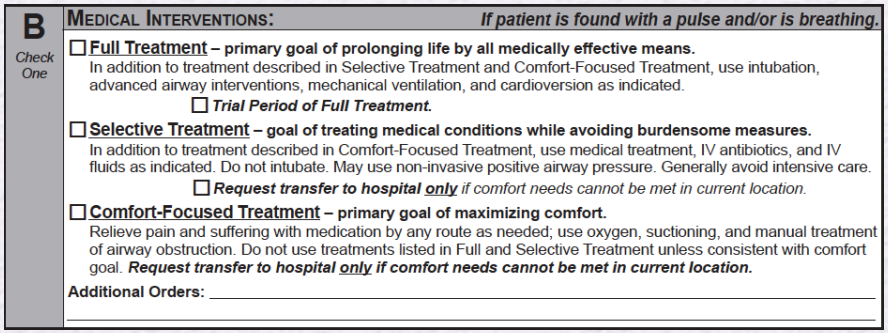




Intubation/Ventilator

Treatment Options Section B

- How Much Treatment
  - Full – Primary Goal of prolonging life by all effective means.
  - Selective – Goal of treating medical conditions while avoiding burdensome measures.
  - Comfort-Focuses – Primary Goal of maximizing comfort



B *Check One*

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

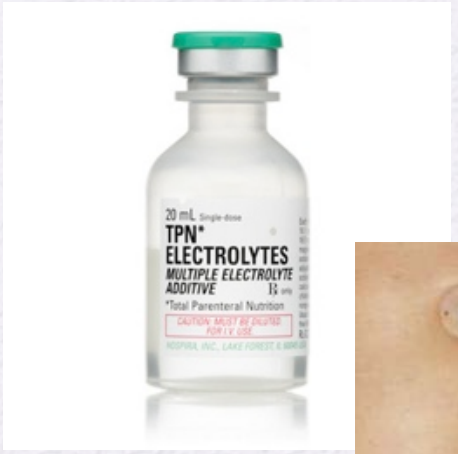
☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ ***Trial Period of Full Treatment.***

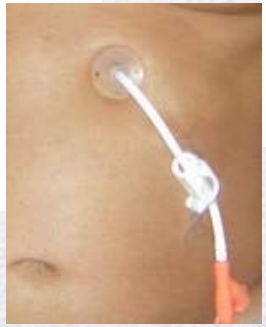
☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ ***Request transfer to hospital only** if comfort needs cannot be met in current location.*

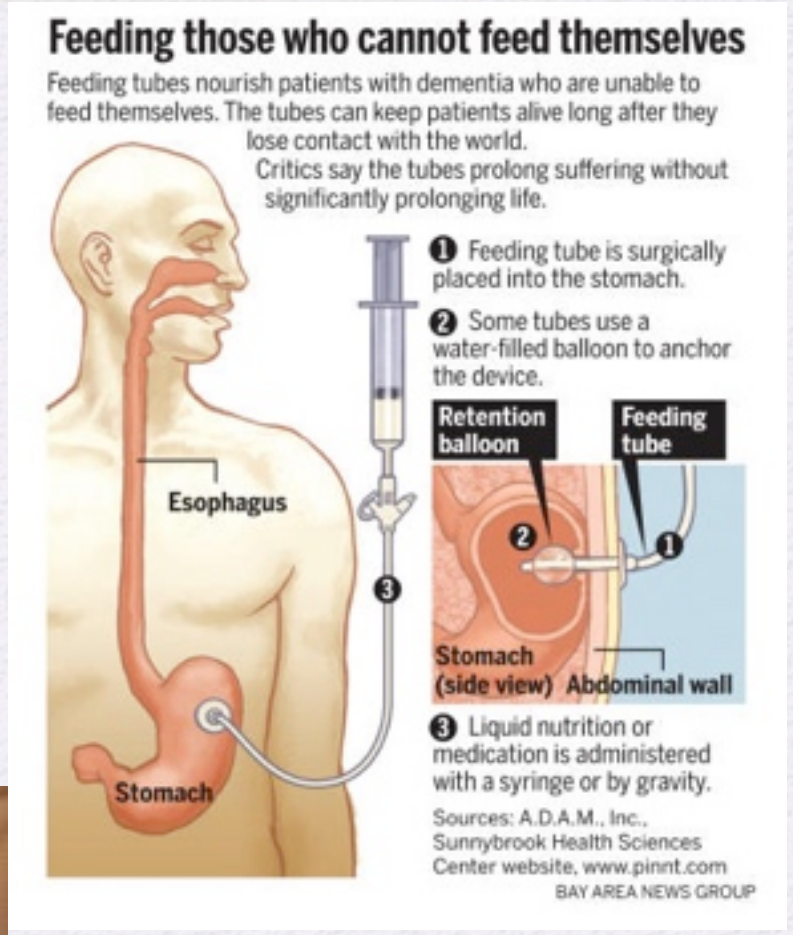
☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: _____

Artificial Nutrition
Section C







Feeding Tubes

- PEG Tube – Percutaneous Endoscopic Gastrostomy Tube – a flexible tube placed through the abdominal wall and into the stomach. (Long Term)
- NG Tube – Nasogastric Tube placed through the nose, past the throat, into the stomach. (Short Term)
- TPN – Total Parenteral Nutrition – Drips through IV or catheter for 10-12 hours 5x/week to daily. (Short or Long Term)

Emotions of Eating

- We have an emotional Attachment to food.
- Our instinct is to providing nutrition to loved ones, even at end-of-life.
- As we move closer to end-of-life, our body doesn't have the same nutrition needs.
- Many Physicians feel they cannot refuse PEG placement if a patient or family requests it.
- Physicians often perform non-beneficial PEG tube placements to avoid difficult discussions with family or patients

Difficult Discussions

End-of-Life Conversations

- End-of-Life Discussions can be difficult
- Culture, Religion, Backgrounds can diversely affect individuals and families comfort levels with EOL conversations
- Planning ahead can help make the conversations easier for individuals, families and staff.

Death is a Natural Process

- “Death rates hold steady at 100 percent.” – The Onion
- Ellen Goodman, Pulitzer Prize Journalist says, "In a highly technological society, people lose a kind of sense of the life cycle. They think we're in charge of it, and they have more trouble thinking of it as a natural part of life that should be talked about.“

Physician Perspective: Michelle Brandt

- Patients are thinking about their own mortality the moment they're given a life-threatening diagnosis. Often the doctor is trying to protect the patient, and ironically the patient is trying to protect the doctor. Usually both parties know that the disease is serious.

- I think many patients are actually glad when physicians broach the topic of end of life. It removes some of the anxiety and creates a partnership where the patients knows they have a physician who will take care of them both in good times and hard times. It also opens up the ability for both parties to talk about hard topics, rather than avoid them.

- http://scopeblog.stanford.edu/2013/09/25/communicating-with-terminally-ill-patients-a-physicians-perspective/

Physician Communication

- Most people want to talk about end-of-life issues with their Physician and Medical Team.
- Medicare is now reimbursing for these discussions.
- Most people think the Physician will initiate the discussion.
- Physicians are human. They are trained to treat, maintain and fight. Talking about death is hard.
- Palliative Care and Mental Health teams can help.

Priorities

- “A lot of these moments hinge on the fact that people do have priorities in addition to living longer. The most reliable way to know what those are is to ask, and we don’t ask. We ask less than a third of the time.”

Who Wants to Talk

- Sharing Medical Information
  - Some people don't want to talk about it.
  - Others want to know everything.
  - Family Members & Communication
- Ethics
  - It ain't always easy…

Having the Conversation

- The Human Connection of Palliative Care: 10 Steps for What to Say and What to Do.
- https://www.youtube.com/watch?v=7kQ3PUyhmPQ

Important Questions

- It is important to ask permission of the individual to ask end of life questions.
  - "I would like to talk about how you would like to be cared for if you got really sick. Is that okay?"
  - "If you ever got sick, I would be afraid of not knowing the kind of care you would like. Could we talk about this now? I would feel better if we did."

Reference: http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3282

Atul Guwande's Questions

We need to know:

1. What is your understanding of where you are and of your illness?
2. Your fears or worries for the future
3. Your goals and priorities
4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?

And later,

5. What would a good day look like?

Reference:

http://www.nextavenue.org/atul-gawandes-5-questions-ask-lifes-end/

What is your Comfort Level?

- Opening the dialogue with patients and families
- As Health Care Providers – being comfortable with talking about illness and death.
- My Gift of Grace – A conversation game for living and dying well.

http://mygiftofgrace.com/

Small Groups

1. Who haven't you talked to in 6 months who you would want to talk to before you died?
2. Who would you ask to help you in the bathroom? Who would you not want to ask?
3. What music do you want to be playing as you die?
4. If you knew you had 3 months to live, what would you do in the months 1, 2 and 3?

Questions from My Gift of Grace

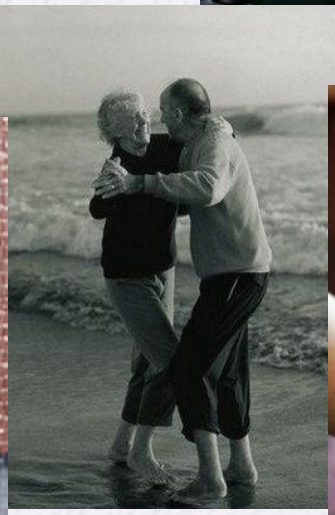
We Need You!

Within the emerging field of Palliative Care lies a need for Mental Health Professionals to provide skillful care and advocacy to patients and their families.

There is so much to discuss if only the time..

- Grief - Normal, Complex, Anticipatory, Disenfranchised, Prolonged, Chronic, Complicated, Cumulative
- PTSD – living with a chronic illness & invasive treatments
- Dual Diagnosis – Physical and Mental
- Complex Psychosocial Factors – Homeless, Frail-Elderly, Financial, etc.
- Spirituality
- And More!

When it rains, it pours. Maybe the art of life is to convert tough times to great experiences; we can choose to hate the rain or dance in it.
-Joan Marquez



With Gratitude,

Anne Front, LMFT

818-760-7725

anne@annefront.com

Facebook Group:

"Palliative Care Counseling and Social Work"

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To PEG or Not to PEG Dr. Waleed Kh. Mahrous http://www.slideshare.net/walwal99/to-peg-or-not-to-peg-30576571

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1495357/

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http://www.apa.org/monitor/2010/10/living-will.aspx

http://www.nhpco.org/press-room/press-releases/new-study-advance-directives

Book Recommendations

- The Etiquette of Illness – Susan P Halpern
- Being Mortal – Atul Gawande MD
- The Anatomy of Hope – Jerome Groopman MD
- The Better End – Dan Morheim MD
- Four Things that Matter Most – Ira Byock
- The Caregivers – Nell Lake

Book Recommendations

- The Conversation – Angelo E. Volandes
- Oxford Textbook of Palliative Care Social Work – Teri Altilio & Shirley Otis-Green
- Dignity Therapy – Final Words for Final Days – Harvey Max Chochinov
- Heal Thyself – Saki Santorelli
- Dying in America – Committee on Approaching Death