ADVANCE CARE PLANNING
WHAT MATTERS MOST

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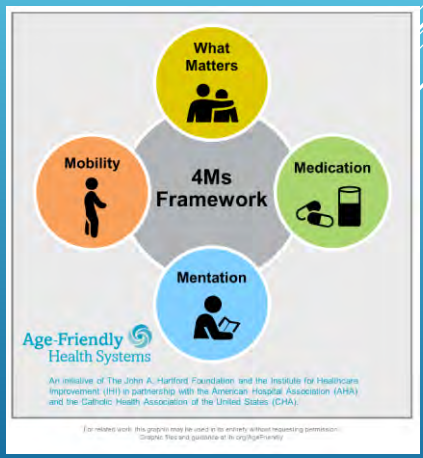


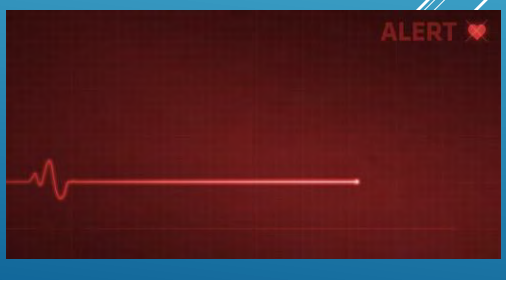
OBJECTIVES

-Understand the difference between ACP, POLST, CODE status
-realize the importance of end of life conversations, the why?
-learn tips on navigating these conversation
-digging deeper into aligning care with what matters
-resources for furthering your knowledge

- no heartbeat and no breathing, which is obvious enough, or no brain function, which requires an electroencephalogram.
- For some of us, death is reached when all other loved ones have perished, or when we can no longer think straight, or go to the bathroom by ourselves, or have some kind of sex; when we can no longer read a book, or eat pizza; when our body can no longer live without the assistance of a machine; when there is absolutely nothing left to try. Maybe the most useful answer I ever came across was the brilliant professor who instructed his daughter that death was what happened when he could no longer take in a Red Sox game.
- So, again, what *is* death? Talking about and around it may be the best we can do, and doing so out loud is finally welcome. Facts alone won't get you there. We're always left with the next biggest question, one that is answerable and more useful anyway: What is death *to you*? When do you know you're done? What are you living for in the meantime?
- We do have fuller ways of knowing. Who doubts that imagination and intuition and love hold power and capacity beyond what language can describe? You are a person with consciousness and emotions and ties. You live on in those you've touched, in hearts and minds. You affect people. Just remember those who've died before you. There's your immortality. There, in you, they live. Maybe this force wanes over time, but it is never nothing.

WHAT IS DEATH: DR. MILLER

HTTPS://WWW.NYTIMES.COM/2020/12/18/OPINION/SUNDAY/CORONAVIRUS-DEATH.HTML



Where do Americans die?

•Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
•Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
•A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.
•However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.
Still, it is clear that fewer patients are dying at home than want to do so.

Many people still die in hospitals

If most people do not want to die in hospitals, why are so many deaths in this country still occurring there? There are probably a number of reasons, including:

•Death is often unpredictable. Many inpatient deaths occur after long admissions that begin with what seems to be a treatable problem.

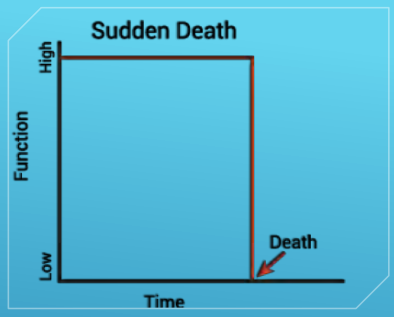
•An overestimation of the ability of medical care to cure incurable illness or reverse setbacks.

•A lack of alternatives. In many parts of the country, dying patients are stuck in the hospital because they need more care than they can get at home and have nowhere else to go.

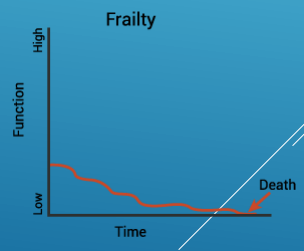
•The "culture" of medicine and availability of medical care. Medical training teaches doctors to diagnose and treat illness, but until recently, trainees learned little about when treatment is futile or how to de-escalate treatment. In addition, studies suggest that more aggressive, inpatient medical care tends to be offered in places where there are more specialists and more hospitals. Doctors may encourage patients to have inpatient treatment with little chance of changing the long-term outcome, perhaps due to an overly optimistic view of the prognosis.

•Medical error or "misadventure." Critically ill individuals have limited capacity to tolerate the downsides of medical treatment, such as side effects or medical errors.

•A healthcare system focused on the short term. For example, Medicare will cover inpatient care for a person who has had a stroke. But if that patient preferred to stay at home, care at home would not be covered even though it would be much less costly.



Majority of us will spend the last 4 years of our lives requiring help with at least 1 ADL (dressing, toileting, bathing, eating)



- Transitions of care –fragmented
- Cant make decisions when cognitive problems present
- Increased responsibility on family and caregivers
- Wishes are not honored if not documented

WHY? PATIENT EXAMPLES

HOW THE DOCUMENTS DIFFER

ADVANCE DIRECTIVE	POLST Order	DNR Order
Is a legal document	Is a medical order	Is a medical order
For anyone 18 or older.	For those who may die within 12-18 months given advanced life-limiting illness or advanced frailty	For those who are critically ill and do not want CPR attempted when close to death.
May name a decision maker	Does not name a decision maker	Does not name a decision maker
Communicates general wishes about medical treatments in future states of health. Reviewed periodically.	Communicates medical treatments specific to the current state of health. Patient has a specific diagnosis & prognosis when discussing goals of care & treatment decisions. Reviewed regularly.	Communicates specific decision about preference to attempt resuscitation in light of current state of health. Reviewed during inpatient stays and on all admissions.
Filled out by patient.	Filled out by health care professional after conversation with the patient and/or their health care decision maker.	Filled out by attending provider after discussion with patient, family or from POLST order.
Risk and benefits of particular treatments are very rarely reviewed.	Risk and benefits of particular treatments are reviewed by trained facilitator and the provider.	Risk and benefits of particular treatments are reviewed by provider.
Valid when the patient's signs in presence of two witnesses or notary.	Valid when the physician signs and is valid across all settings. Patient/agent may sign.	Valid during current admission once the physician signs. Not signed by patient/agent.

POLST FORM

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

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Physician Orders for Life-Sustaining Treatment (POLST)

FIRST follow these orders, THEN Call the appropriate medical contact. These medical orders are based on the patient's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name

Patient's First Name/Middle Initial

Patient's Date of Birth (mm/dd/yyyy)

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

☐ CPR/ATTEMPT RESUSCITATION ☐ DNR/DO NOT ATTEMPT RESUSCITATION (Allow Natural Death)

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

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

Comfort Measures always provided regardless of level of care chosen

☐ **COMFORT MEASURES ONLY** - Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.

☐ Avoid calling 911, call _____ instead (e.g. hospice)

☐ If possible, do not transport to ER (when patient can be made comfortable at residence)

☐ If possible, do not admit to the hospital from ER (e.g. when patient can be made comfortable at residence)

☐ **LIMIT INTERVENTIONS AND TREAT REVERSIBLE CONDITIONS** - Provide interventions aimed at treatment of new or reversible illness/injury or non-life threatening chronic conditions. In addition to treatment described in Comfort Measures Only, use medical treatment, IV antibiotics and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Duration of invasive or uncomfortable interventions should be limited. (Generally, avoid intensive care)

☐ **FULL TREATMENT** - Use all appropriate medical and surgical interventions as indicated to support life. Transfer to hospital if indicated. Includes intensive care.

Additional Orders: (e.g. dialysis, etc.)

C Check One — **Artificially Administered Fluids and Nutrition:** Always offer food/fluids by mouth if feasible and desired.

Check One

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube.

☐ Artificial nutrition and hydration unless it provides no benefit.

☐ Long-term artificial nutrition by tube.

Additional Orders:

D Must fill out — **DOCUMENTATION OF DISCUSSION (Required)**

☐ Patient (If patient has capacity) If patient lacks capacity:

☐ A Health Care Directive

☐ Health Care Agent

☐ Person legally authorized to provide informed consent (See reverse)

Health Care Agent/Legal Representative Name Relationship

E **PATIENT or Health Care Agent/Legal Representative (Required)**

Signature (Form Does Not Expire) Date of signature

F **ATTESTATION OF MD/DO/APRN/PA (Required)** By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.

Print Name of MD/DO/APRN/PA Name Signer Phone Number Signer License Number

MD/DO/PRN/PA Signature: required Date: required Time: required

2018 North Dakota POLST SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED 1

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

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Patient's Name Patient's Date of Birth

Health Care Agent/Legal Representative Name Relationship Phone Number Address

Name of Health Care Professional Preparing Form Preparer Title Phone Date Prepared

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

North Dakota Century Code section 23-12-13 authorizes the following persons to give informed consent for an incapacitated patient in the following order of priority:

a. A health care agent;
b. The appointed guardian or custodian of the patient, if any;
c. The patient's spouse who has maintained significant contacts with the incapacitated person;
d. Children of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;
e. Parent(s) of the patient, including a stepparent who has maintained significant contacts with the incapacitated person;
f. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
g. Grandparents of the patient who have maintained significant contacts with the incapacitated person;
h. Grandchildren of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person; or
i. A close relative or friend of the patient who is at least eighteen years of age and who has maintained significant contacts with the incapacitated person.

Completing POLST

- Must be completed by a health care professional based on patient preferences and medical indications.
- POLST must be signed and dated by a physician, advanced practice registered nurse, or physician assistant if delegated, to be valid. Verbal orders are acceptable with follow-up signature by physician, advanced practice registered nurse, or physician assistant if delegated in accordance with facility/community policy.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST

- Any section of POLST not completed implies full treatment for that section.
- A automatic external defibrillator (AED) should not be used on a patient who has chosen "Do Not Attempt Resuscitation."

Additional copies of the ND POLST are available here: www.honoringchoicesnd.org/

Faxed copies and photocopies of this form are valid.

To void this form, draw a line across Sections A - D and write "VOID" in large letters.

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort Measures Only," should be transferred to a setting able to provide comfort (e.g., pinning of a hip fracture).
- An IV medication to enhance comfort may be appropriate for a patient who has chosen "Comfort Measures Only."
- A patient with capacity or the health care agent of a patient who lacks capacity can revoke at any time and request alternative treatment.

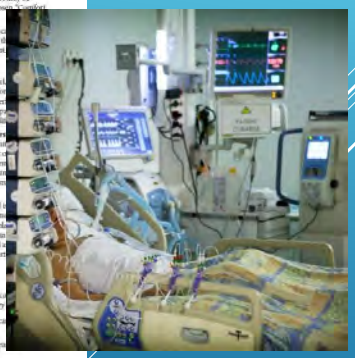
Clarifying POLST

- **Comfort Measures Only:** At this level, use palliative measures to enhance comfort. Use medications to relieve distress, avoid invasive and painful procedures, all while preserving the patient's wishes during their last moments of life.
- **Limit Interventions and Treat Reversible Conditions:** The goal at this level is to provide limited interventions aimed at the treatment of new or reversible illness or injury or managing non-life threatening chronic conditions. Treatments will be withheld and discontinued if not effective. Comfort measures will be offered.
- **Full Treatment:** The goal at this level is to prolong life by providing all available medical treatments including life support measures when reasonable. For patient's designated DNR status to be honored, medical care should be discontinued in the event of cardiac and respiratory arrest. Comfort measures will be offered.

Reviewing POLST

This POLST should be reviewed periodically and a new POLST completed if necessary.

1. The patient is transferred from one care setting or care level to another, or
2. There is a substantial change in the patient's health status, or
3. The patient's treatment preferences change.
4. The ND POLST form does not expire.



Reflect on Your Beliefs and Values

1. If you were having a really good day, what would happen on that day? Who would you talk to? What would you do?
2. What helps you face serious challenges in your life?
3. What role does religion, faith, or spirituality play in how you live your life?
4. If you have significant health problems, what are they and what do you fear in the future?
5. Considering future medical treatments, what would you not want to happen to you?
6. How does cost influence your decisions about medical care?
7. When would you want the goals of medical treatment to switch from trying to prolong your life to focusing on comfort? Describe these circumstances in as much detail as possible.
8. What would a "natural death" be like for you?

My Primary (main) Health Care Agent is:

Name: _____ Relationship: _____

Telephone numbers: (H)_____ (C)_____ (W) _____

Full address: _____

If my primary agent is not willing, able, or reasonably available to make health care decisions for me, I choose an alternate Health Care Agent.

My Alternate Health Care Agent is:

Name: _____ Relationship: _____

Telephone numbers: (H)_____ (C)_____ (W) _____

Full address: _____

Powers of my Health Care Agent:

My Health Care Agent automatically has all the following powers when I do not have the capacity to make decisions and/or I am unable to communicate for myself:

A. Agree to, refuse, or cancel decisions about my health care. This includes tests, medications, surgery, withdrawing or starting artificial nutrition and hydration (such as tube feedings or IV (intravenous) fluids), and other decisions related to treatments. If treatment has already begun, my agent can continue it or stop it based on my instructions.

B. Interpret any instruction in this document based on his or her understanding of my wishes, values and beliefs.

C. Review and release my medical records and personal files as needed for my health care, as stated in the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

D. Arrange for my health care and treatment in a location he or she thinks is appropriate.

E. Decide which health care providers and organizations provide my health care.

F. Make decisions about organ and tissue donation according to my instructions in Part 2 of this document.

Comments or limits on the above: _____

Additional Powers of my Health Care Agent:

My initials below indicate I also authorize my Health Care Agent to:

☐ Make decisions about the care of my body after death.

If I live in North Dakota or Minnesota, my initials below indicate I also authorize my Health Care Agent to:

☐ Continue as my Health Care Agent even if our marriage or domestic partnership is legally ending or has been ended.

☐ Make health care decisions for me even if I am able to decide or speak for myself, if I so choose.

Part 2: My Health Care Instructions

My choices and preferences for health care are indicated below. I ask my Health Care Agent to communicate these choices, and my health care team to honor them, if I cannot communicate or make my own choices. **I have initialed a box below for the option I prefer for each situation.**

NOTE: You do not need to write instructions about treatments to extend your life, but it is helpful to do so. If you do not have written instructions, your agent will make decisions based on your spoken wishes, or in your best interest if your wishes are unknown.

A. Cardiopulmonary Resuscitation: A Decision for the Present

This decision refers to a treatment choice I am making today based on my current health. Item 3 below **(Treatments to Prolong My Life: A Decision for the Future)** indicates treatment choices I want if my health changes in the future and I cannot communicate for myself.

CPR is a treatment used to attempt to restore heart rhythm and breathing when they have stopped. CPR may include chest compressions (forceful pushing on the chest to make the blood circulate), medications, electrical shocks, a breathing tube, and hospitalization.

I understand that CPR can save a life but does not always work. I also understand that CPR does not work as well for people who have chronic (long-term) diseases or impaired functioning, or both. I understand that recovery from CPR can be painful and difficult.

Therefore (Initial One):

☐ I want CPR attempted if my heart or breathing stops.

OR

☐ I want CPR attempted if my heart or breathing stops based on my current state of health. However, in the future if my health has changed, then my agent or I (if I am able) should discuss CPR with my health care team. My choices in **Section 2: Treatment Preferences and Section 3: Treatments to Prolong My Life** below should be considered when making this decision. Examples of when my health has changed include:

- I have an incurable illness or injury and am dying
- I have no reasonable chance of survival if my heart or breathing stops
- I have little chance of long-term survival if my heart or breathing stops and CPR would cause significant suffering

OR

☐ I do not want CPR attempted if my heart or breathing stops. I want to allow a natural death. I understand if I choose this option I should see my health care provider about writing a Do Not Resuscitate (DNR) order.

B. Treatment Choices: My Health Condition

My treatment choices for my specific health condition(s) are written here. With any treatment choice, I understand I will continue to receive pain and comfort medicines, as well as food and liquids by mouth if I am able to swallow.

_____

_____

_____

_____

_____

_____

_____

☐ My initials here indicate additional documents are attached:

C. Treatments to Prolong My Life: A Decision for the Future

If I can no longer make decisions for myself, and my health care team and agent believe I will not recover my ability to know who I am, I want (Initial One):

NOTE: With either choice, I understand I will continue to receive pain and comfort medicines, as well as food and liquids by mouth if I am able to swallow.

☐ To **stop or withhold all treatments** that may extend my life. This includes but is not limited to artificial nutrition and hydration (for example, tube feedings and IV (intravenous) fluids), respirator/ventilator (breathing machine), cardiopulmonary resuscitation (CPR), and antibiotics.

OR

☐ **All treatments recommended** by my health care team. This includes but is not limited to artificial nutrition and hydration (for example, tube feedings, IV (intravenous) fluids), respirator/ventilator (breathing machine), cardiopulmonary resuscitation (CPR), and antibiotics. I want treatments to continue until my health care team and agent agree such treatments are harmful or no longer helpful.

Comments or directions to my health care team:

_____

_____

_____

_____

D. Organ Donation (Initial One):

☐ I want to donate my eyes, tissues and/or organs, if able. My Health Care Agent may start and continue treatments or interventions needed to maintain my organs, tissues and eyes until donation has been completed. My specific wishes (if any) are:

_____

_____

_____

☐ I do not want to donate my eyes, tissues and/or organs.

OR

☐ My Health Care Agent can decide.

Part 3: My Hopes and Wishes *(Optional)*

I want my loved ones to know my following thoughts and feelings:

The things that make life most worth living to me are:

_____

_____

My beliefs about when life would be no longer worth living:

_____

_____

My thoughts about specific medical treatments, if any:

_____

_____

My thoughts and feelings about how and where I would like to die:

_____

_____

If I am nearing my death, I want my loved ones to know that I would appreciate the following for comfort and support (rituals, prayers, music, etc.):

_____

_____

Religious affiliation:

I am of the _____ faith, and am a member of _____ faith community in (city) _____.

I would like my Health Care Agent to notify my faith community of my death and arrange for them to provide my funeral/memorial/burial.

I would like my funeral to include, if possible, the following (people, music, rituals, etc.):

_____

_____

_____

Other wishes and instructions:

_____

_____

☐ My initials here indicate additional documents are attached:

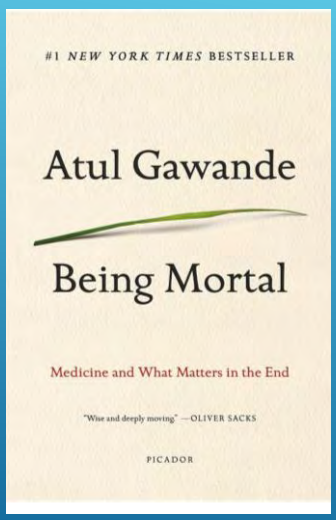
- What matters most to you?
- What makes life worth living?
- What brings you joy each day?
- What are you willing to live without, and still feel life is worth living?
- What are your biggest fears and concerns?
- What is your understanding of the current situation, and potential outcomes?
- What goals are most important to you?
- What tradeoffs are you willing to make, and which are you not?

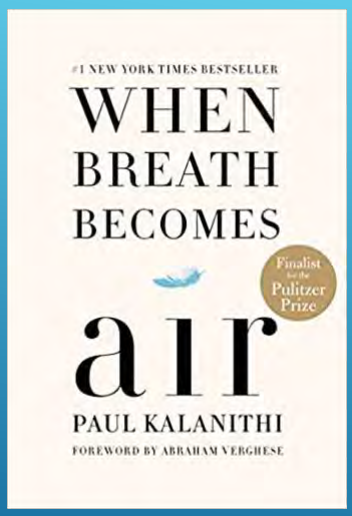
TIPS FOR CONVERSATIONS STARTERS

- Pt is 85y/o wm with h/o chf, copd, gi bleeds..
- What matters- to live for 2 years when my grandson gets back from Japan
- Still DNR/no invasive procedures but willing to push medications/treatment and not feel good now in effort to live

- Pt is 86y/o wm with h/o chf, copd, dm…
- What matters- to have energy to play cards with my buddies 2 days a week
- Weaned medications in effort to feel the best today even if may decrease length of life

PATIENT EXAMPLES





- http://www.ihi.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx
- https://www.youtube.com/watch?v=apbSsILLh28
- https://theconversationproject.org/
- Netflix: Documentaries Extremis and End Game

RESOURCES