

# Are You Ready?

## How to Receive the Care You Wish

---

Vivian Argento, MD, AGS-F

Yale New Haven Health System- Bridgeport Hospital/NEMG

# Are You Ready?

---

- If you have a sudden illness or accident, and you cannot express your wishes, do your family and physicians know your feelings about the intensity of care you wish to receive?
- Have you considered this issue?
- Have you outlined your wishes for care under a variety of circumstances?
- Have you appointed a health care representative?
- Have you made sure that your wishes are:
  - Known to your family
  - Documented
  - Available in your medical records for all clinicians to see?

# What if You Knew Time Was Short?

---

- What is important to you?
- How would you want to spend that time?
- How much would you be willing to go through for how much more time?
  
- The last months of life can be
  - a time of comfort with family and friends, or
  - a series of hospitalizations, nursing home stays, and medical interventions.
- If the length of your life is your holy grail, and you want aggressive care without limits – so be it.
- But if you would prefer to avoid aggressive interventions, and focus on the quality, not the quantity, of life, it is best to make these wishes known to family and clinicians.

# Why Is Advance Care Planning Important?

---

- You want to receive the care you wish if you become seriously ill.
- You may not be able to express your wishes should you be unresponsive or confused.

# How to Receive the Care That You Wish

---

- Think about your “goals of care”
  - What is most important in your life?
  - What abilities are so crucial to your life that you can’t imagine living without them?

# Sending a Message

---

- What intensity of medical care do you wish to receive if you become seriously ill?
- Usually – it depends:
  - Do you have an acute process which stands a good chance of resolving with aggressive treatment?
    - For example severe pneumonia in a healthy patient
  - Do you have a progressive disease with a poor prognosis?
- The answer to the first question, therefore, is complicated, varies with the medical circumstances and probable outcomes of care, and needs to be conveyed clearly and completely.

# Conveying the Message

---

- 1960's – Primary care physicians came to the hospital to oversee your care. They knew your “goals of care” and could work with you and your family to provide the intensity of care you desire.
- 2017 – Your doctors no longer come to the hospital. CPR is the default. Your goals of care may not be known
  - If you cannot communicate your wishes for care, the electronic medical record is the best place to document your goals of care and treatment preferences.
  - This record can outline your wishes to acute care and specialty physicians and surgeons throughout the health system.

# Electronic Medical Record

---

- Contains full information on your care including all of your clinicians' notes, laboratory and x-ray findings, hospitalizations, procedures, vaccinations and other health maintenance information, allergies and medications.
- Information obtained outside the system can be scanned into the record.
- All physicians practicing in your health care system have access to all of your information in the electronic medical record.

# Electronic Medical Record (continued)

---

- Health care systems usually have one electronic medical record which provides information to all care givers within this system.
- For example, the Yale New Haven Health System uses the Epic electronic medical record. If you are cared for by a physician affiliated with the System, all of your information will be available if you are seen in a Health System hospital such as
  - Yale New Haven Hospital
  - St. Raphael's campus of Yale New Haven Hospital
  - Bridgeport Hospital
  - Greenwich Hospital
  - Lawrence and Memorial Hospital
  - Westerly Rhode Island Hospital
  - NEMG
- If you are seen in another health system which also uses the Epic electronic medical record (e.g. Hartford), information from this system can be obtained with your permission

# Why Is the Electronic Medical Record So Important to Your Care?

---

- You may not be alert enough to express your wishes to your acute care clinicians when you are ill.
- If you have not appointed and documented a health care representative, there may be some confusion about the level of care you wish.
- Physicians have to proceed with aggressive care including cardiac resuscitation, intubation, and placing you on a respirator if there are no clear instructions not to do so.
- The electronic medical record is the most effective method of documenting your treatment preferences.
  - Transmits the patient-provider relationship to the next site of care

# How It Works

---

- If you decide to fill out a “appointment of a health care representative” document, you sign it, have it witnessed, and your physician scans it directly into your electronic medical record or faxes it to the hospital medical records department to be scanned into your record.
- The same process occurs with a “living will” or “treatment preference” document.

## How It Works (continued)

---

- Given the complexity of medical circumstances, it is best that your “treatment preference” document outlines your wishes in a number of different clinical situations.
- When you come to the hospital, the acute care clinician can click on the “advance care” section on the first page of your chart, and immediately see your preferences for care and your health care representative.

# Advantages of Advance Care Planning

---

- You can make sure that your wishes are followed if you were to get very sick.
- You can take control of your health care.
- You will take the burden off your loved ones, helping them make decisions without feeling guilty.
- You should have peace of mind, knowing that you have made plans for the future.

# Response to Common Concerns of Patients

---

- I'll always be able to make my own decisions
  - Acute unresponsiveness, delirium and dementia
- My family knows my wishes
  - Most studies show that families and patients often have very different opinions about health care decisions
- Doctors wouldn't put me on a machine if I'm old and dying
  - Unfortunately, the legal position in this country is that physicians must perform cardio-pulmonary resuscitation and place patient on a respirator if there are not clear instructions not to do so

# Responses to Patients' Concerns (continued)

---

- Advance care planning is only for people who are older and sicker than I am
  - Advance care planning is for everyone, because we can't predict unexpected occurrences in the future
- I might change my mind
  - You can change what you have written on these forms at any time
- I have religious objections to doing advance care planning
  - There is no inherent barrier between religious faith and doing advance care planning. Most religious leaders recommend advance care planning

# Advance Care Discussions

---

- What is most important to you in life?
- What do you want to avoid following medical interventions?
  - Being a burden, living in a nursing home, not being able to communicate...
- What are your goals of medical care?
  - Cure, function, comfort?
- How do you want your priorities to be implemented by your clinician?

# Advance Care Planning Discussion (continued)

---

- What things or abilities are so important to you that you can't imagine living without them?
- Can you imagine a condition that you would feel might be worse than death?
- If your health situation worsens, what are your most important goals?
- What are your biggest fears and worries about the future with your health?
- If you become sicker, how much are you willing to go through for the possibility of gaining some time?

# Future Health Situations

---

- When you think about health situations you may experience in the future, how do you feel?
  - Life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing.
  - There may be some health situations that would make my life not worth living.
  - I am not sure.

# In the Event of Serious Illness

---

- How do you balance quality of life with medical care? If you had serious illness, what would be important to you?
  - I want medical treatments to try to live as long as possible. I would not want to stop treatment even if I were in pain, could not feed or care for myself, or needed machines to live.
  - I want to try treatments for a period of time, but I don't want to suffer. If after a period of time the treatments do not help or I am suffering, I want to stop.
  - I want to focus on my quality of life and being comfortable, even if it means having a shorter life.
  - I am not sure.

# Interventions in Late Life

---

- Most people are most interested in the outcomes of interventions in late life, not the nature of the intervention.
- Patients should consider these outcomes, or functional states, which might cause them to decline an intervention.

# Outcomes Which Would Cause the Patient to Decline an Intervention

---

- Unable to recognize family members
- Being bedbound and unable to care for oneself
- Unable to participate in family and community activities
- Severe daily pain, only controlled by medications which cause a great deal of confusion and lethargy

# Function

---

- What abilities are so critical to your life that you can't imagine living without them? For example: ability to eat, recognize or interact with others, be aware or care for yourself
  - Being conscious
  - Being able to interact with others
  - Being without pain or great discomfort
  - Being able to talk
  - Being able to care for myself, such as toileting and feeding
  - Being able to be myself

# Preferences

---

- If I were not able to recognize my loved ones,
  - I would not want to receive treatment to keep me alive.
  - I would want to receive treatment to keep me alive.
  - I'm not sure about my answer to this question.
- If I were bedbound and unable to care for myself, requiring help from others for bathing, dressing, and feeding myself,
  - I would not want to receive treatment to keep me alive.
  - I would want to receive treatment to keep me alive.
  - I' not sure about my answer to this question.

# Preferences

---

- If I were dependent on breathing machines to continue living,
  - I would not want to receive treatment designed to keep me alive.
  - I would want to receive treatment designed to keep me alive.
  - I'm not sure about my answer to this question.
- If I were in severe daily pain, and this pain could only be controlled by medications which cause confusion and the inability to recognize loved ones,
  - I would not want to receive treatment to keep me alive.
  - I would want to receive treatment to keep me alive.
  - I'm not sure about my answer to this question.

# Next Steps

---

- Inform yourself about advance care processes with such resources as:
  - Conversation Starter kit
  - How to Talk to Your Doctor
  - How to Choose a Health Care Proxy
  - Five Wishes
  - PREPARE web site
  - EMMI video “Who Speaks for You?”

# Talk to Your Family

---

- Pick a health care representative
- Make sure that this representative
  - Knows that she/he is your representative
  - Knows your “goals of care”
  - Knows your treatment preferences

# Talk to Your Doctor

---

- After reading brochures and visiting web sites, schedule a visit with your doctor to discuss advance care planning.
- Medicare will compensate your doctor for this visit.
- Go over your treatment preferences and goals of care with doctor.
- Determine whether you want to document your treatment preferences in your medical record.
- If you do fill out documents, make sure that they are sent to the hospital's medical records department to be scanned in to your electronic medical record.

# Document your wishes

---

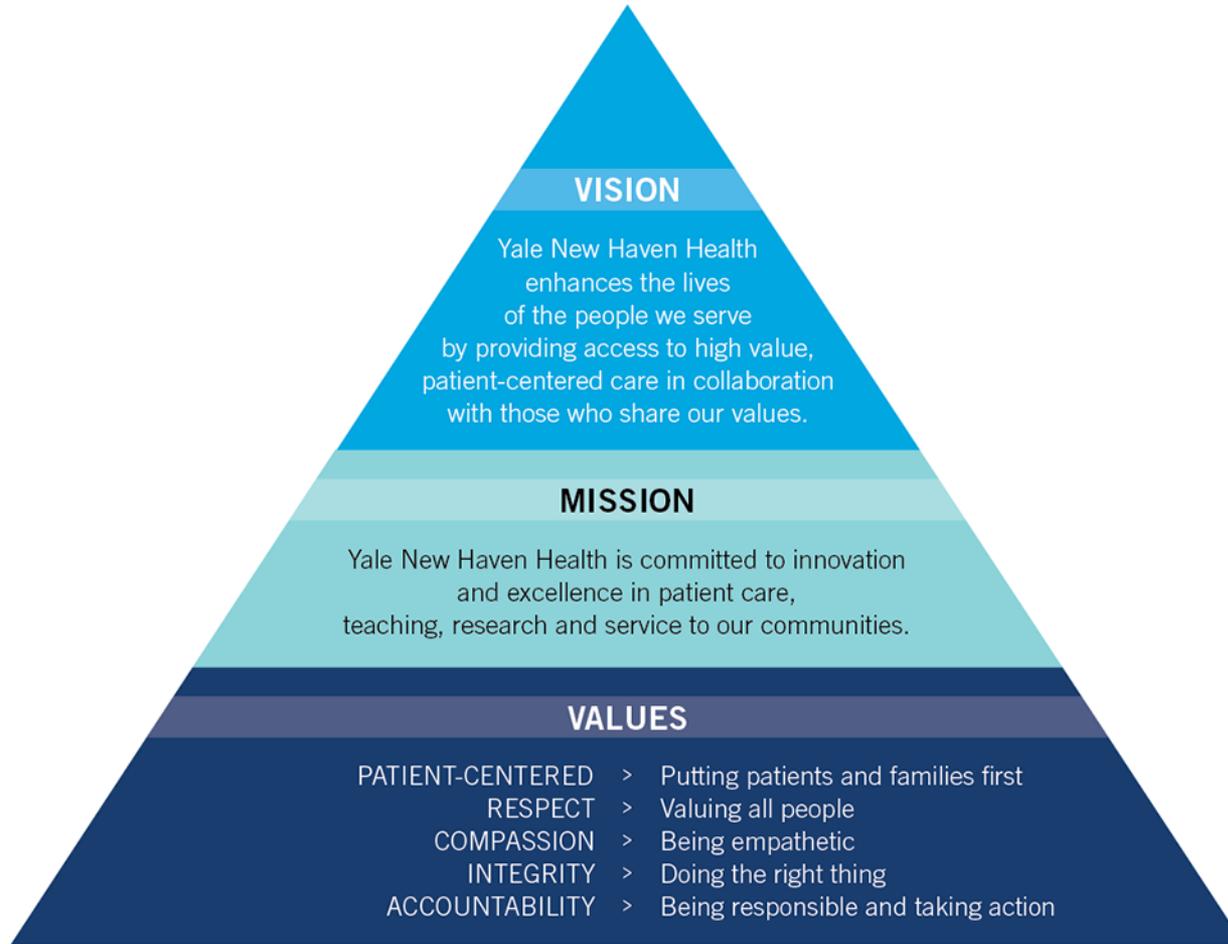
- Complete an “Appointment of Health Care Representative” document
  - Sign with 2 witnesses
  - Make copies
    - Yourself
    - Your representative
    - Your clergy, friends, anyone you trust
    - Your doctor
- Complete a “Treatment Preferences and Living Will” document
  - Sign with 2 witnesses
  - Make copies
    - Yourself
    - Your representative
    - Your clergy, friends, anyone you trust
    - Your doctor

# Get the Care you Wish

---

- When the time comes, you will get care that is consistent with your goals and preferences

# VISION, MISSION AND VALUES



YaleNewHaven**Health**