Addressing Code Status:
A Practical Guide to Difficult Conversations

Marianne M Holler, DO, FACOI
Chief Medical Officer
VNA Health Group
Holmdel, NJ
Objectives

- To Provide tools for discussing code status with patients and their families in the face of advanced illnesses

- To understand historically how we arrived at our present day end of life care philosophy

- To assist in handling patient’s care who are DNR/DNI
History Lesson

- 1916 People died at home surrounded by loved ones and supported by the family physician.
- Society pitied those who had to die in an institution (hospital or nursing home) surrounded by strangers.
- It was thought those individuals lacked family and loved ones who truly cared about them.
Dying at Home

Historically a good death
History Lesson

- People now die in institutions despite many studies showing that most individuals prefer to die at home peacefully.

- If you die at home there is an underlying cultural sentiment: “Didn’t you want everything done for your mother?”
So What Happened?

• “It is time to contemplate the unintended consequences of medical technology’s frighteningly successful war on natural death and its banishment of the “Good Death” our ancestors so prized” Butler 2013
More History

- 25% of Medicare’s $560 billion budget is spent in annual outlays covers medical care in the last year of life! (Roughly $140 billion)
End of Life Facts

- 2.5 Million deaths in the US in 2016
- 50% died in the hospital, 25% died in ECF, 25% Died at home
- 80% of patients prefer to die at home
- NJ Ranks last in the nation for the most money spent at the end of life
State of Care

Average Medicare spending during the last two years of life for chronically ill patients.

Source: Dartmouth Atlas of Health Care
SUPPORT Study
(study to understand prognosis and preferences for outcomes and risks of treatments)

- Many patients received unwanted care at the end of life
- Clinicians were not aware of patient preferences for life-sustaining treatment, even when documented in the record
- 50% of DNR orders are written within the last 48 hours of life
- Pain was often poorly controlled at the end of life
- Efforts to enhance communication were unsuccessful
- Originally conducted in 1996 and repeated 20 years later
A Little History Lesson

- 1944 a Doctor in England pulled shrapnel from pulsing hearts of more than 100 wounded soldiers, breaking a long-standing medical taboo of surgically invading the heart.
Just a little more history

- 1952 Beth Israel Hospital in Boston
History

- Paul Zoll, MD invented the Grass Physiologic Stimulator. These external pacemakers were bulky, painful and limiting for the patient.

- Modern pacemakers came from this breakthrough
History

- 1960 in Seattle doctors started to experiment with Teflon and created a non-clogging u-shaped shunt that could be left permanently in a patient’s vein, thus turning dialysis from an emergency lifesaver into a routine treatment.
1961

- Dr Robert Porter, in Kansas City took over an open ward formerly used to nurse the county’s impoverished elderly and set up 11 cubicles equipped with all the latest machinery and electronic monitors.

- Literature says first ICU may have been in North Carolina.

- CPR had arrived and the first ICU came into being.
• Primitive respirators based on the design of vacuum cleaners were used

• The nation’s first “crash carts” were developed to hold all new equipment and meds that could be rushed to the bedside. (Designed after carts in sheet-metal and auto shops)
1971

- The 911 system came into being on a national level

- Between ICUs and 911 lives of hardy people in their primes were saved who had suffered a heart attack, overdose, head-on collision, drowned, been stabbed, shot or accidentally poisoned.

- No doubt MIRACULOUS, no doubt important, no doubt transformative
History

At the same time, the units obliterated Western death rituals, reshaped the architecture of the hospital, transformed the meaning of the body, and brutally deformed the way families, doctors, nurses and even the dying themselves—behaved at the deathbed.
A New Paradigm

Because a doctor CAN do something never means they SHOULD! We have learned so much about what to do no one is spending time to discuss when we should and shouldn’t do. We need to ask ourselves what are we doing “to” patients vs what are we doing “for” them.
CMC codes 2016

- 189 Code Blue (total codes/not patients)
- 127 patients survived the initial code
- 22 patients survived to discharge (<12%)
- 122 of the codes were in ICU
- 33% were between the ages of 81-100
Discussing Code Status

• What are the two most important questions that must be asked to start the conversation?
QUESTION #1

- What is your understanding of what is happening with your (your family members) health at this time?
QUESTION #2

• Based on that information what is the GOAL?
Full Code vs DNR

- Base the discussion on the goal
- Is CPR/intubation/ACLS going to achieve a specific goal?
- Will it change the outcome for the patient? Or just how the patient experiences the outcome?
- Can it add to the quality of a patient’s life or prolong the dying process?
What not to say and do

- Threats! “We are going to break her ribs, cut a whole in her neck, hook her up to machines, send her to a facility…etc etc”

- Understate the Facts! “we are just going to put a tube down her throat to help her breathe, is that ok?”

- Readdress code status on a DNR/DNI patient in an emergent situation! “your mom/dad is not doing well, are you sure s/he wanted to be a DNR”, “i’m sure this is a situation that is temporary and can be turned around”
Do Not Change the Code Status in the Heat of the Battle
Why we do these things

- As practitioners we are taught HOW to do but not WHEN to use that HOW judiciously.
- It makes us feel better and more comfortable that we DID something.
- Realize that doing nothing in some situations is the best you can offer that particular patient and family.
When Challenged

• “We want everything done for mom!”
When Challenged

• Majority of healthcare practitioners will walk out of the room and document on the chart: “Family wishes everything to be done” and go on to the next patient.

• The vast majority of us will also shake our heads and discuss it with a colleague how ridiculous these efforts are in this patients particular situation.
When Challenged

• “What concerns you that everything hasn’t been done or isn't being done? I reviewed the records and I can assure you, in your mom’s situation, everything has been done”

• Now you have the opportunity to have a detailed discussion about what is really happening.
Still Challenged?

• “What concerns you most about your mom’s death?”
“God is Going to Heal Her”
Stop Seeing Religion and Faith as a Barrier

• What are families really saying when they say “God is Going to Heal Her?”

• This is an opportunity, not an obstacle.
“We have Hope”

- Hope is a powerful asset
- Do not take hope away
- You may need to help families re-define what they are hoping for
- Hope is not binary, not a two sided coin
What Do Patients with Serious Illnesses Want?

• Pain and symptom control
• Avoid inappropriate prolongation of the dying process
• Achieve a sense of control
• Relieve burdens on family
• Strengthen relationships with loved ones

-SINGER et al, JAMA 1999
What do family caregivers want?

- Study of 475 family members 1-2 years after bereavement
- Loved ones wishes honored
- Inclusion in the decision process
- Support/assistance at home
- Personal care needs
- TO BE LISTENED TO
There are Two Rules of Medicine

- Other than “first do no harm” what are they?
RULE #1

Patients will die
RULE #2
Doctors DO NOT get to change Rule #1
As much as we owe our patients the depth and the breadth of our skill and knowledge

We also owe them the chance for a peaceful and meaningful death
Questions
hollerma@gmail.com
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