

# Wow – ADVANCE CARE PLANNING

## The continued Frontier

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# Objectives – what we want to accomplish

- Describe the history of advance care planning
- Discuss what patients/families want
- Review the recent IOM report
- Review the recent medicare proposal (good, bad and hmmm)
- Review POLST as a tool
- Learn new tools for enhancing conversations about ACP, serious illness
- WOW

# So – a history lesson

- Me, myself and I
- Advance care planning – in the 60s and 70s
  - Paternalistic
  - Did not involve patient/family
  - My father's death
  - Capricious use of DNR order
  - No discussion about dying
  - Wave of new technology

# The late 80s and early 90s

- Nancy Cruzan – pivotal case
- Supreme Court
  - Both written and verbal reports are valid
  - Food and hydration at end of life does not equal normal medical treatment – it is a medical treatment that is known as artificial nutrition and hydration

# Patient self determination act - 1990

- PSDA
- Patients must be asked on admission to hospital, NH, HMO if they have an advance directive
- Anyone could or should ask
- No training
- Unclear follow up
- Emphasis remained on procedures

# SUPPORT study - 1996

- Looked at how we are dying in America
- We weren't doing so well
- Patients dying in pain, in the ICU, getting treatment they didn't like or want
- Physicians did not know how to address these situations
- No clear plan came out of these studies as to how to improve these things
- First IOM report about dying in America

# An embarrassment of riches

- Growth of palliative programs – Summit in Montana October 23<sup>rd</sup>
- Multiple tools – Respecting Choices, Prepareforyourcare, Vital Talk, Communication about Serious Illness
- Atul Gawande – Being Mortal
- BUT.....

# Institute of Medicine Report 2014

- Commissioned by an anonymous donor
- Task – current state of end of life care with respect to delivery, communication, ACP, financing, costs and education of professionals, patients and loved ones
- We are still dying poorly, not much different from 1996 when similar report issued
- 5 Recommendations



# 1. Delivery of care

All payers should cover palliative care and all health organizations should provide it

## 2. Communication and ACP

- Professional and quality organizations should develop standards for clinician-patient communication and advance care planning that are measurable, actionable and evidence based
  - Oh so complicated – for example
- Adherence to these standards should be tied to credentialing, licensing and reimbursement

### 3. Professional Education and Development

Establish training, certification, and licensure requirements that strengthen the palliative care knowledge and skills of ALL clinicians who care for individuals with advanced serious illness

# 4. Policies and Payment Systems

Federal, state and private insurance and health care delivery programs should integrate the financing and delivery of medical and social services;

And require public reporting of quality and costs for care near the end of life.

# 5. Public Education and Engagement

Every element of society should engage their constituents and provide factual information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals

# Public Perception

- To the best of your knowledge, would you say the new ACA does or does not allow a government panel to make decisions about end of life care for people on Medicare? – poll done in 2010 to seniors, Kaiser Family Foundation
- 36% - yes, law does this
- 48% - no. law doesn't do this
- 17% - don't know

- **WOW – Other info out there**

# Gap between what patients want and what they get

- Patients with serious illness have priorities beside living longer
  - Symptom management and quality of life
  - Sense of control and completion
  - Strengthening relationships



# Gap between what patients want and what they get

- Most people want to be at home and prefer comfort-focused care at the end of life, but that is often not the reality
  - 86% Medicare beneficiaries want to spend final days at home
  - 25-39% die in an acute hospital
  - 70% are hospitalized in the last 90 days
  - 29% receive intensive care in the last 30 days
  - Many experience care transitions and very short hospice stays

# What patients get often harms them and their families

- Aggressive care for patients with advanced illness if for harmful:
  - For patients
    - Lower quality of life
    - Greater physical and psychological distress
  - For caregivers
    - More major depression
    - Lower satisfaction

# Conversations are too little, too late and not great

- Multiple studies show patients with serious medical illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life
- Many conversations fail to address key elements of quality of discussions, especially prognosis
- Among patients with advanced cancer:
  - First EOL discussion occurred median 33 days before death
  - 55% of initial EOL discussions occurred in the hospital
  - Only 25% of these discussions were conducted by the patient's oncologist

# Clinicians and the medical system are important barriers to conversations and care planning

- Clinicians lack communication competencies, training and confidence
- Clinicians feel they do not have enough time
- Culture of medicine does not value key elements of effective care
  - Accepts late or non-existent conversations (low priority, low accountability)
  - Tolerates poor end of life care
  - Focuses on avoidance of emotions

# Palliative care is a high-value clinical intervention

- Provision of early palliative care services – with strong emphasis on communication and patient and family education – to lung cancer patients leads to:
  - Improved quality of life
  - Less use of aggressive care
  - 25% increase in survival
  - Reduced costs
  - “Palliastatin”

## Conversations are a key component of the effectiveness of palliative care interventions

- Earlier conversations about patient goals and priorities for living with serious illness are associated with:
  - Enhanced goal-concordant care
  - Improved quality of life
  - Reduced suffering
  - Better patient and family coping
  - Higher patient satisfaction
  - Less non-beneficial care and costs

# But

- We can't provide this care to all patients with serious illness
- We do not have enough palliative care physicians to provide access
- We need scalable interventions targeted at generalist physicians and other clinicians to assure universal access to key elements of palliative care

# MEDICARE STEPS UP

- 2 new codes for ACP which will be reimbursed
- 99497 – first 30 minutes (\$87.00)
- 99498 – additional 30 minutes (\$75.00)
- It's about the conversation, not about completing a document
- Local CMS entities will decide what documentation is necessary to justify payment
- Must be face-to-face



# NEW CODES

- Does not pay for family conversations which happens more often
- Does not provide for training of providers
- Does not specify what the conversation is
- Does not specify what should be documented

# And then there is POLST

- Not for everyone
- Voluntary
- Not the first part of any conversation
- Part of a conversation but not THE conversation
- Effective when used in the proper situation
- Transferable
- Quality issues

# POLST – the good news

- Continues to expand in multiple states
- Is a leader in helping promote education about advance care planning
- Is a leader in providing quality indicators for good conversations
- Is a leader in helping patients get what they want at the end of their life

# POLST in Montana

- Has wide spread use across the bigger cities
- Well recognized by EMS
- Coalition is active but difficult to get together in such a large state
- ?Quality control
- Shares some of the national issues as to how well it is used
- Controversies still exist from various sources

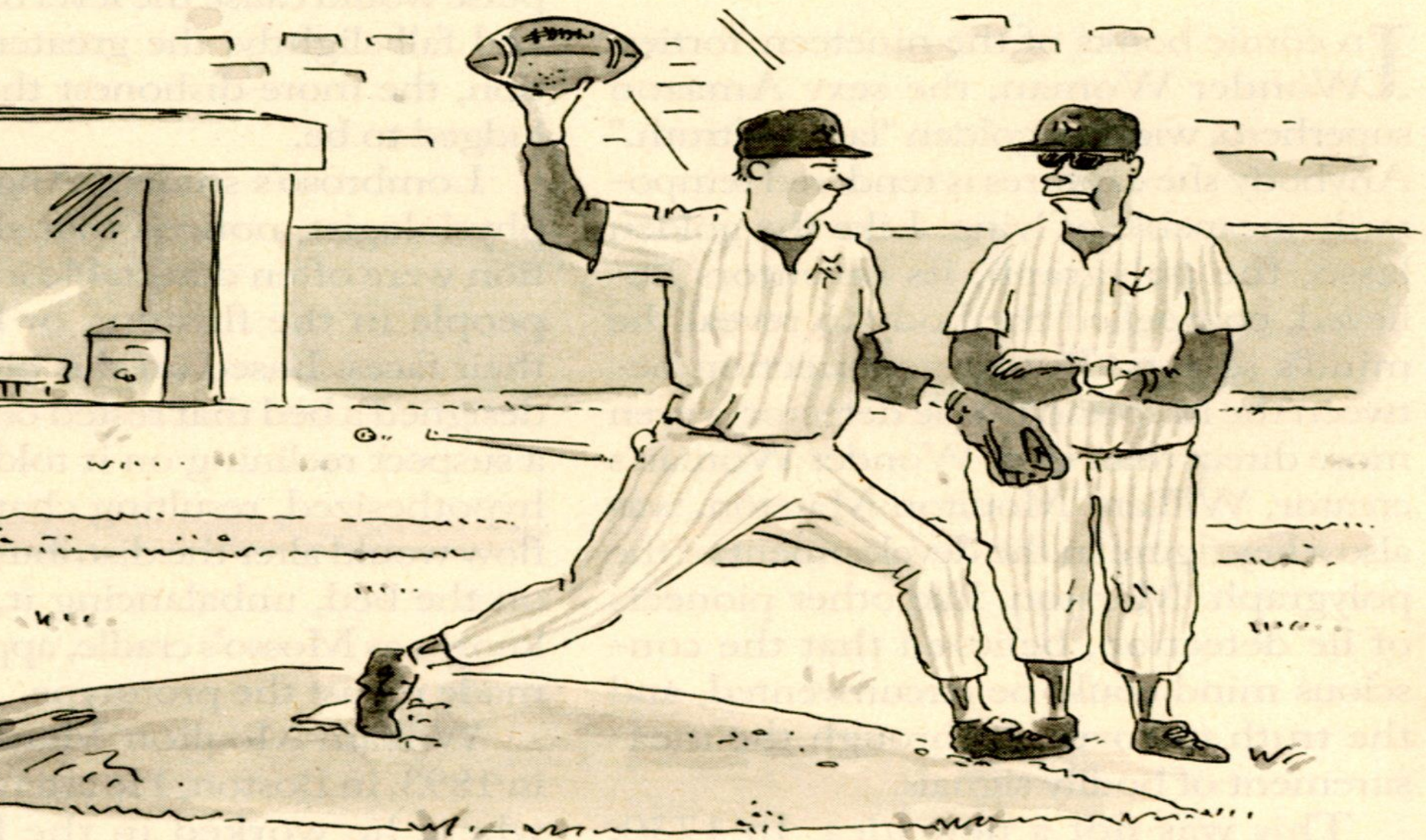
# Mr. W

- 95 yo man with CHF, on hospice for a year, fell and required stitches to his head necessitating an ER visit
- Through his hospice stay had been very clear about his POLST and desire to not be in the hospital
- Went to the ER with the hospice nurse and his POLST
- The ER MD told him he did not have to still honor his POLST wishes, that he would die in 2 weeks if he did not get IV hydration and a feeding tube
- Old POLST scanned into medical record
- Wanted to do multiple studies and evaluations



*"There's no easy way I can tell you this, so I'm sending you to someone who can."*





Shanahan

*"There's your problem."*





*"I'm right there in the room, and no one even acknowledges me."*



# WOW

- Where should we be heading
- What tools are available for the public and for providers that might facilitate these conversation
- Multiple tools out there
- Concentrate on two tools that I have found most useful

# PREPARE

- [PrepareForYourCare.org](http://PrepareForYourCare.org)
- Developed at UCSF by several palliative care docs
- Brochure available on line
- Brochure is easy to read, easy to use
- Website is very user friendly with lots of videos
- Is multilingual
- Is not procedure based
- 5 Steps

# Recent study

- Tools to Promote Shared Decision Making in Serious illness – a systematic review
  - Austin et al, JAMA Intern Med 2015;175, 1213-1221
  - Graded A for ease of use and for patients actually completing an advance directive
  - [www.PrepareForYourCare.org](http://www.PrepareForYourCare.org)

# Step 1

- Choose a medical decision maker
- This is key for any discussion about end of life or serious illness

# Step 2

- Decide what matters most in your life
- Lists 5 questions that guides you to help talk about what matters
  - What is mot important in your life
  - What experiences have you had with serious illness or death
  - Can you imagine health experiences worse than death
  - Is it most important to you to: live as long as possible, or try treatments for a period of time, or focus on quality of life and comfort
  - Have you changed your mid about what matters most in your life over time

# Step 3

- Choose flexibility for your decision maker
- Is actually a key questions as we don't have a crystal ball about what is going to happen to us
- Reflects that circumstances may change

# Step 4

- Tell others about your medical wishes
- Patients often get stumped here
- Concern about how this conversation will occur
- Gives language about how to have that conversation

# Step 5

- Ask doctors the right questions
- Probably my favorite step
- We know that doctors don't ask
- Gives control and guidance to the patient and family
- Talks about benefits and risks of treatments, options
- Talks about how treatments affect quality of life



# WOW

- But what about training providers
- Still not done in medical school – focus remains on interventions
- “Communication about Serious Illness Care Goals – A review and synthesis of Best Practices” Bernancki and Block, JAMA Internal Medicine 2014:5271, p E1-E10
- Atul Gawande as a guiding light – Being Mortal, which he is
- So what does it look like

# Education for providers

- Targeted intervention
- All patients with serious and life-threatening illness
- Solid tumor
- CHF, stage III or IV
- CKD, on dialysis age 75 or older
- COPD on home O2 with FEV1 less than 35%
- Surprise question – Would you be surprised if this patient died in the next year - if answer is “no”

# Did it work

- 2.5 hour training
- Used the Conversation Guide
- Enhanced goal concordant care
- Enhanced peacefulness
- Improved QOL, anxiety, depression
- Improved quality of communication with clinicians, family
- Enhanced family perception of patient life priorities
- Improved quality of dying death

# So what is this conversation, starts with clinician Set-up

- Thinking in advance – orient the patient
- “I’d like to talk about what is ahead with your illness and do some planning and thinking in advance. This is part of the way we care for patients at this stage of illness”
- “We like to discuss these issues when patients are doing well and we are not in a crisis”
- “Talking about it now allows all of us time and space to think these issues through, and to include your family in our discussions”

# Is this ok?

- Ask permission
- “If not ok, we certainly don’t have to do it today, but I will bring it up again for us to talk about later”

# Reassurance

- Reassure patient about continued treatment
- “The first thing I want to reassure you about is that we are going to continue to treat your illness intensively and that we will work hard in our efforts to treat and control this disease and help you feel well”
- “But we both know that this is a serious illness. And we need to do some planning in case things don’t go as well as we hope”

# Benefit for patient and family

“We want to help you stay in control of decisions about your care and to ease things in case your family has to make difficult decisions on your behalf”

# No decisions today

- “This the beginning of a conversation, and we don’t need to make any decisions today. We can keep talking about it as we see how things go.”



# The Guide

- Understanding - What is your understanding now of where you are with your illness?
- Information preferences - How much information about what is likely to be ahead with your illness would you like from me”
  - Some patients like to know about time. Others like to know what to expect, others like to know both
  - **Share prognosis as a range, tailored to information preferences**

# Checklist - cont

- Goals – if your health situation worsens, what are your most important goals
- Fears/worries – What are your biggest fears and worries about the future with your health
- Function – What abilities are so critical to your life that you can't imagine living without them
- Trade-offs – If you become sicker, how much are you willing to through for the possibility of gaining more time
- Family – How much does your family know about your priorities and wishes

# Clinician Steps - ACT

- Affirm commitment to care
- Make recommendations about next steps
  - Acknowledge medical realities
  - Summarize key goals/priorities
  - Describe treatment options that reflect both
- **DOCUMENT CONVERSATION**

# Documentation

- Advance care documents
- Conversation tickler
  - Understanding of disease
  - How much information
  - What did you communicate to patient
  - What is your most important goals
  - Fears and worries
  - Critical abilities that you cant live without
  - How much are you willing to go through for the possibility of more time
  - How much does your proxy know

# Principles

- Patients want the truth about prognosis
- You will not harm your patient by talking about end of life issues
- Anxiety is normal for both patient and clinician during these discussions
- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- Giving patients an opportunity to express fears and worries is therapeutic

# Practices - Do

- Give a direct, honest prognosis
- Provide prognostic information as a range, acknowledging uncertainty
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears and concerns
- Make a recommendation
- Document conversation

# Practices – Don't

- Talk more than half the time
- Fear silence
- Give premature reassurance – the kleenex dilemma
- Provide facts in response to strong emotions
- Focus on medical procedures

# General communication tips

- 1. 3W's: Wish (or hope), Worry and Wonder
  - Patient – will I make it to my grand-daughter's graduation in 2 years
    - I wish that things were different: I worry that that's not likely
    - I hope that you can, but I worry it may not be possible
    - I wonder if there are things you can do to prepare in the event you can't be there



# Communication tips

- 2. Explore
  - Tell me more
  - Say more about what you mean by that
- 3. Responding to emotion
  - This seems to be very sad news for you

# Finally – from one who does this for a living

- It is not easy
- I am constantly learning
- Let your patients and patience be your guide
- Keep trying
- Get a partner
- Listen and breathe
- Remember culture