

The Art of Conversations Approaching Palliative Care and End of Life

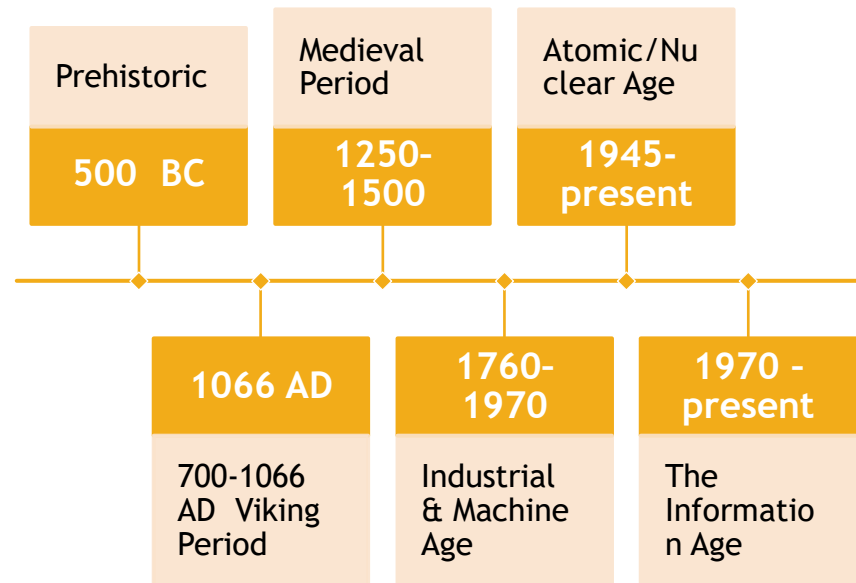
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What we know about the human mortality rate...? .



At the conclusion of this presentation, you will be able to :

Discuss Dying in Today's world

- ▶ Define Palliative care
- ▶ Recognize why palliative conversations so difficult
- ▶ Identify opportunities to initiate palliative conversations.
- ▶ Identify basic the components of palliative care conversations.
- ▶ Demonstrate an ideal way to deliver Bad News
- ▶ Reply to those most difficult comments and questions regarding palliative care and End of Life
- ▶ Know where to find resources for additional learning and tools regarding discussions regarding palliative care, hospice and End of Life.

Dying in today's
world...

Technology

What is a
“good” death?

Who is in
charge?

Patient Self
Determination
Act





Oh, when we
were young
and had no
troubles.....

How and where do we die?

- ▶ Disease Trajectories :

- ▶ Chronic illnesses
- ▶ Terminal Cancers
- ▶ Sudden Death
- ▶ Frailty

- ▶ Milestones (of Life) and Death

CHANGE IS PREDICTABLE . Change Happens!



How and where do we die?

- ▶ Where do we die?
- ▶ Hospital 35%
- ▶ Nursing Home 27%
- ▶ Home 31%
- ▶ Other 7%

(Source MMWR May 15, 2020)



Palliative Care Definition (WHO)

Patient/Family centered care that optimizes quality of life

Anticipate , prevent and treat suffering throughout the continuum of illness or injury

Provides holistic person-centered care (physical, emotional, intellectual, social, spiritual)

Support autonomy through informed decision making

Provided by interprofessional teams

So why are these conversations so difficult?

- ▶ Guilt
- ▶ Provider history with the patient
- ▶ Fear of emotions.
- ▶ Don't know the answer
- ▶ Fear to say the “wrong thing”
- ▶ Not the “best” or “right” time
- ▶ Don't have time
- ▶ Patient and /or family are resistant to discuss

How do we know when to have these conversations?

- ▶ All chronic illnesses have common signs and symptoms related to decline:
 - ▶ Increase in physical symptomology of the disease state: increased pain, dyspnea, nausea , anorexia , wt loss ,decline in cognition,
 - ▶ Exacerbations / hospitalizations/ ER visits
 - ▶ New or other complications
 - ▶ New or worsening burden of mental and emotional stressors
 - ▶ The patient or family wants to discuss a change in direct of care
- ▶ Decrease in level of FUNCTION is the most predictive indicator of a poor Prognosis.



Palliative Conversation Basics: 101

Know your patient's world

Check expectations, then understanding

Empathize

Read the Room- call out the Emotion

Align yourself with the patient

Ask before giving bad news or recommendations

Remember your Thank You's

Know your patient's world:

READ

READ the MAP - What road(s) got the patient to this place in time?

- review office visits, hospitalizations, specialists reports , diagnostics

FOLLOW

FOLLOW the MAP with the patient/ family: "This is where we WERE, and this is where we are NOW"

Know your
patient's world:

“ Tell me more “

“Anything else? ”

- ▶ These words are “*invitations*” to better understand the patient's and family perceptions of events, their values, customs, strengths and barriers.

Know your
patient's world:

“ Tell me more “

“Anything else? ”

▶ Avoid the words
WHAT and WHY

Know your
patient's world:

“ Tell me more “

“Anything else? ”

▶ “I'M LISTENING”

This information is important for me to understand in order that we can make better decisions together about the future.

Check Expectations, then Understanding

Help me understand ... About what you were told by the doctor

Tell me in your own words.... What this diagnosis means to you.

Given what we've just discussed, what concerns you most about the next few days, or months ahead?

Empathize

- ▶ Cognitive Empathy:
 - ▶ From what you've told me, I understand you know his kidneys are failing and he has a serious infection.

Empathize

- ▶ Emotional Empathy:
 - ▶ I'm sensing this conversation and new information is shocking to you"
 - ▶ I can barely imagine how hard this situation is for you

Empathize

- ▶ Empathetic Concern :
 - ▶ I'm so impressed by your resilience and determination to understand your father's condition. (shows support)
 - ▶ I can see you want to do what your mother would have wanted. (gives confirmation)

“Read the Room” - Respond to the Emotion call it out , so you can move on with the discussion.

- ▶ Emotions “puts the brakes on
“ to cognition!
- ▶ The Patient / family has “hit
a wall” and are stuck on that
strong emotion.
- ▶ I can sense/see/feel that you
are overwhelmed/sad/
frightened/ angry.....

It's ok to be SILENT for a bit!



Align yourself WITH the concerns of the patient/family

- ▶ Show the patient/ family you've been listening to what's important to him
 - ▶ “based on what you've told me.....
 - ▶ He valued his independence , never liked going to the doctor and had an attitude that “nature would take over”

Align yourself WITH the concerns of the patient/family

- ▶ Show the patient/ family you've been listening to what's important to him
 - ▶ “based on what I've heard you say...
 - ▶ That she would like to try any treatments that might give her more time and allow her to see his daughter get married.

Always ASK
permission before
giving news, your
opinion or any
recommendations

Is it ok if I give you my point of view now and make a few recommendations?

Some people like to know details and others just want me to give them the “big picture”, how would you prefer I give you my recommendations?

Some families just want me to talk to one person. If there are 1 or 2 people others you feel should be here, should we have this conversation with them tomorrow?

Is this a good time to talk about your dad? I have some information I'd like to share with you before we discuss how we can work together to find the path he would want for the future.

When the patient is ready for your recommendations...

Frame your proposals in the “POSITIVE”

What CAN be done.

- ▶ These are the things we **CAN DO** for you:
- ▶ “ **continue** the medications that **will allow** you to be comfortable and breath easier. We will carefully balance your pain medications so **you can** be awake and aware and still have good pain relief. **We can** continue to provide fluids to you with straws and syringes to **allow you** to enjoy the smell and taste of even a few bites. **We can** keep the IV’s going until your kidneys can no longer handle the stress of the extra fluid. **We can** have you be home so all your family can spend time with you.

When the patient is ready for your recommendations...

Frame your proposals in the “POSITIVE”

What CAN be done.

- ▶ I would recommend **ALLOWING** a natural death.
- ▶ There may be nothing or little I can do about your disease at this stage, but **there ARE these things I can do for you.....**
- ▶ **We can** allow you to have your last breaths without an uncomfortable tube in your throat and lungs

Remember to say

Thank You!

Thank

Thank you.....
I really appreciate your sharing such personal thoughts at this difficult time.

Thank

Thank you.....
from what I've learned from this discussion, I can better care for you in the manner you desire.

Thank

Thank you.....
It's been a very emotional discussion. One of my jobs is to help make these bad times less scary.

Thank

Thank you.....
thinking through this together has been very valuable and helpful to me.

When you are
stuck.....

Remember
You have an
Ace in the Hole
.....!!

- ▶ If your mom and dad were able to hear us talking, what would they be thinking?
- ▶ If your sister could be here with us now, what would she say?
- ▶ Imagine your mom, hearing what we just discussed, what would she add to the conversation?
- ▶ Knowing how your dad lived his life, what would you expect him to say about all this?





How do you best deliver bad news?

Give a 5th Grade Newspaper Headline.

- ▶ What's wrong?
- ▶ What does it mean?

**Severe storm coming.
Heavy damage to
people and property
expected.**

What's the
Headline?

What's wrong?

What does it
mean?

- ▶ Full Code. 66 yo John is living in a SNF for over 6 years now with Multiple Sclerosis. He is losing weight, is frail and has a deep sacral decubiti. He had a complicated hospitalization 4 months ago. He is now lethargic and confused. BP is low , he's tachycardic, with a low body temperature. What's your headline for his son in Texas?

What's wrong?

The Headline:

What does it mean?

Your dad has symptoms of a serious infection called sepsis.

I'm worried, even with hospitalization and strong antibiotics and fluids , that he may not survive.

What's the headline?

What's wrong?

What does it mean?

- ▶ DNR DNI 93 yo Ruth is a long term SNF resident with advanced dementia requiring total care. Last week, she developed a cough, fever and elevated WBC. She has a large rt pleural effusion. HCP prefers maximum treatments available in the SNF. She's had antibiotics, IV fluids and oxygen support. She is now minimally responsive. What's your headline for her daughter?

What's wrong?

The Headline:

What does it mean?

Your grandmother has pneumonia and her condition is worse and not responding to the treatments.

I'm worried she may be dying.

What's the headline?

What's wrong?

What does it mean?

- ▶ DNR DNI DNH 98 yo Kate , with multiple complex medical problems and primary diagnosis of advanced Parkinson's dementia, has fallen in your SNF. She has severe pain and deformity of her left femur. What's your headline for the daughter?

What's wrong?

The headline:

Your mom has fallen and broken her thigh/femur bone.

What does it mean?

I'm afraid she will be experiencing pain with this. We will be watching her closely and adjusting pain medications so she can be as comfortable as possible here at the SNF.

What about those impossible statements and questions?

So you're giving up on me? But there must be something else to do!

We want **EVERYTHING** done for him!

But that's not what the cardiologist told us!

You expect her to starve to death?

God's going to cure her

Use your “I wish...I worry”

“tell me more”

“what else? “

Starve to death? ...

“ Of course not! **I wish** that science had proved feeding tubes extend a good quality life for patients, but that hasn't been the case. **I worry** that the procedure and attempting to give him artificial food sources might cause him more harm than good. What we **CAN** do isCan I talk to you more about what I know of feeding tubes in this situation?

Use your “I
wish...I worry”

“tell me
more”

“what else? “

It's in God's hands, He will save her.....

I wish there would be a miracle. What kind of miracle are you hoping for? I worry that despite God's Interventions and all our best efforts, your husband may continue to lose ground/decline. What else is there?

Use your “I
wish....I worry

“tell me more”

“ What else?”

Must be something else to do for me.....

- ▶ I wish there were more/better treatments available for you. I worry that continuing the treatment or starting a new one will not likely give him more quality time. Can you tell me more about what you are thinking?
- ▶ (If you sense this is truly a cognitive question... answer in specifics)

Use your “I
wish....I worry

“tell me more”

“ What else?”

We want EVERYTHING done for him.

- ▶ Tell me more about what you are hoping for... I can see how much you love him
- ▶ I wish that is could say there are other treatments out there that could bring him back to the place he was before all this happened. I worry that looking in that direction could limit the quality time he might have left.

Use your “I
wish....I worry

“tell me more”

“ What else?”

But that’s not what the other doctor said.....

- ▶ It must be frustrating to have different opinions to deal with... [tell me more..](#)
- ▶ [I can](#) reach out to his cardiologist to better understand his point of view and discuss this further with you .

Surrogate
discussions:

Remember
You have an
Ace in the Hole
.....!!

- ▶ If your mom and dad were able to hear us talking, what would they be thinking?
- ▶ If your sister could be here with us now, what would she say?
- ▶ Imagine your mom, hearing what we just discussed, what would she add to the conversation?
- ▶ Knowing how your dad lived his life, what would you expect him to say about all this?

Think about the 1 or 2 things you will take away from this presentation

▶ Take Away #1

▶ Take Away #2

▶ Action Taken:

▶ Action Taken:



Resources

- ▶ Hospice and Palliative Care Nurse Association: www.hpna.org
- ▶ Center to Advance Palliative Care (CAPC) www.capc.org
- ▶ **Dr. Robert Arnold: Distinguished Service Professor of Medicine**
Chief, Section of Palliative Care and Medical Ethics
Director, Institute for Doctor-Patient Communication
University of Pittsburgh Department of Medicine
Medical Director, UPMC Palliative and Supportive Institute
- ▶ VITALtalk app (find in App store)
- ▶ Being Mortal by Atul Gawande

Contact me

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What's the headline?

What's wrong?

What does it mean?

- ▶ DNR DNI DNH 98 yo Kate , with multiple complex medical problems and primary diagnosis of advanced Parkinson's dementia, has fallen in your SNF. She has severe pain and deformity of her left femur. What's your headline for the daughter?

Center to Advance Palliative Care (CAPC)

New Videos: Techniques for Communicating More Effectively in the Time of COVID

▶ [Goals of Care Conversations in the Time of COVID →](#)

Learn how to have effective goals of care conversations using a structured talking map, focusing on patient-based values. Presented by Katy Hyman, MDiv, BCC, and Michael Mendez, MD.

▶ [Responding to Emotion During Difficult Conversations in the COVID Era →](#)

This video demonstrates how to respond to the emotion of patients and families when delivering serious news, in a way that can help build trust. Presented by Michael Mendez, MD, and Tessie October, MD, MPH.

▶ [Advance Care Planning Conversations in the Time of COVID →](#)

Learn a structured approach for initiating advance care planning discussions in order to help patients match their care plan with their personal values. Presented by Katy Hyman, MDiv, BCC, and Michael Mendez, MD.

Marilyn Mae



Conclusion

Thank you!!!

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