Shifting goals of care towards end of life
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Objectives

• Learn strategies for having goals of care conversations
• Learn the members and roles of each person on the hospice team
• Outside-the-box goal achievement
About me

- AZCOM class of 2007
- Honor Health Osborn residency 2010
- Board-certified family medicine
- Two roles at Hospice of the Valley
  - Inpatient hospice
  - Home hospice
- The “procedure” of hospice doctors is the family meeting

Who should be facilitating?

- PCP
- Oncology
- Pulmonary
- Cardiology
- Any provider managing late-stage chronic disease or life threatening illness
- Palliative care/hospice
Would you be surprised: 1 year?

- 853 pts with breast, lung or colon cancer
- 826 patients classified by oncologist
- “No” – 131 patients
- “Yes” – 695 patients
- The “No” group had 7 times greater hazard of death in the next year

*Moss et al, J Palliative Med 2010*

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1-year survival prediction

- https://depts.washington.edu/shfm/app.php
- Seattle heart failure model
- Age, co morbid, EJF, meds, devices
- Online calculator

*Levy et al, Circulation 2006*
**COPD indicators**

- Frequent hospitalizations
- Increasing rate of exacerbations
- Reduced function
- Increasing oxygen needs
- Lack of further treatment/poor response to tx

*Janssen et al, Chest 2012*

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**Renal disease indicators**

- Dementia
- Peripheral vascular disease
- Albumin <3.5 g/dL
- Advanced age

*Allen et al, Circulation 2012*
**All patients**

- Frequent hospitalizations
- Considering major intervention/procedure
- Loss of 10% body weight in one year
- Would you be surprised by death in 1 year?
- Functional decline/change in living situation
- Change in social support/death of spouse

*Dunlay et al, Trends cardiovasc med, 2016*

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**Many tools to calculate**

- Eprognosis.ucsf.edu
- Where is patient? Home, facility, hospital or hospice
- Home: Age, BMI, co morbid conditions, ADLS
- Facility: Wounds, cognition, nutrition, ADLS
- Hospital: creat, alb, co morbids, ADLS
- Percent mortality one year in similar pts
- Can print or email

*Yourman et al, JAMA 2011*
Barriers

- Time
- Family not understanding poor prognosis
- Fear of destroying hope
- Difficulties prognosticating
- Fear patient/family is not ready to talk
- Physician lack of confidence/discomfort
- Cultural beliefs

*Dunlay et al, Trends cardiovasc med, 2016*

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Ideal situation

- Separate from bad news
- Longitudinal
- Conversation
- Trusted provider
- Office or controlled setting
- Include family, especially MPOA if possible
- Distraction free
REMAP

- Reframe
- Expect emotion
- Map out the future
- Align with values
- Plan treatment

*Childers et al, Oncol Pract. 2017*

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**Reframe**

- “Tell me what you understand about your illness.”
- “What have the doctors told you about your health?”
- Response may be accurate, if not then clarify.
- “Given these changes, we should probably talk about next steps. Is this okay with you?”
- “I think it is important to talk about what the expected course of your (medical condition) may be. How much would you like to know?”
Prognosis

- Give information clearly without medical jargon.
- “The treatment options are no longer working.”
- “Your are not a transplant candidate.”
- Give range – days, weeks or months
- Acknowledge uncertainty
- “No one can tell you for certain how long you have to live, but I am concerned you may only have ___ left.”

Expect emotion

- **Name:** “It sounds like you are feeling ____.”
- **Understanding:** “I cannot imagine what it would be like to be in this situation.”
- **Respect:** “You have been such a good advocate.” or “You have done all the right things.”
- **Support:** “I will be here when you have questions.”
- **Explore:** “Tell me more…”
Map out the future

• “Given what you understand about your situation, what is most important to you?”
• “Is there any situation you want to avoid?”
• “What are your biggest worries about the future?”

Align with values

• Repeat back what you learned.
• “What I hear you saying is that ____ is most important to you.”
• “Am I understanding correctly that you want to avoid ____ in the future?”
Plan treatment

• “Now that I understand what is important to you, would it be okay to talk about treatment options?”

• “Here are some things we could do;____.”

• “Would it be helpful if I offered a recommendation?”

• “From what I have learned about you and what is most important to you, I would recommend _____. How does that sound to you?”

Surrogate decision-maker

• Advance directives vs. MPOA vs. surrogacy laws

• Reframe to lessen burden of decision-making

• “If we could pull up a chair for your mother to join this conversation with a clear mind, what would she say?”

• “Some families tell me their loved one would not want a situation like this prolonged.”
Documentation

- Complete or update advance directives.
- Update MPOA information including phone number.
- Don’t let information get buried in visit note.
- Referral to palliative care or hospice if appropriate.

Hospice is a team sport

- Medical director
- Nurse
- Social worker
- CNA
- Chaplain
- Others
Medical director (MD or DO)

- Leading the care team
- Education of staff and families
- Management of total patient
- Guiding difficult situations
- Determining eligibility
- Term certifications
- Death certificate completion

Nurse

- Eyes and ears in the field
- Teaching family
- Support/counseling
- Medications
- DME
- Communication with other team members
- Plurex drain care
- Port maintenance
- Ostomy care
- Wound care
- Drain care
- Extubation (in patient)
- Death visits
Social work

- Support/counseling
- Placement
- Caregiver resources
- ALTCS
- Navigating LTC policies
- FMLA paperwork
- Final arrangements
- MPOA situations
- Family discord
- Traveling arrangements
- Books for the blind
- Meals on wheels
- Coordinate respite stay
- Death visit

More teammates

CNA
- Bathing
- Skin care
- Caregiver teaching
- Reports to the team

Chaplin
- Spiritual support
- Network of religious officials
- Reports to the team
- Presides over service
Other support

- Dementia team
- Physical therapy
- Respiratory therapy
- Massage
- Volunteers
- Pet therapy
- Music therapy

Big smiles
Most common goals

- Be comfortable
- Quality time with family and friends
- Make the most of each day
- Be at home
- Not wanting to burden family
- Special events

Cancer pain management

- 72 y/o male, stage IV lung cancer with malignant pleural effusions
- Oxy IR 10 mg q 4 prn with 24 hr total of 60 mg
- Son is exhausted and patient is still not comfortable
- Solution; Fentanyl patch 50 mcg q 72 hr and oxy IR 10 mg q 2 prn pain/dyspnea
- Now patient and son can get better rest
- Long acting agents are the key; adjust if needed
• Ed is 35 with renal cell cancer with invasion of spinal cord and is newly paraplegic.
• Goal? “I want to see my daughter with the princesses at Disneyland.”

Barriers to Disney
• Paraplegia
• Hygiene in the park
• Traveling to California
• Didn’t want to be a burden
• Kids would enjoy it more without him
Disney on Ice

The simple things

• 95 y/o female lives alone with CHF
• Niece in NY
• Neighbor checks in on her
• Walker about 20 ft.
• Goal?
Fourth of July pool party

“"I want to see my son.""

- 78 y/o male with COPD
- Oxygen dependent 4L
- Dyspnea with minimal exertion
- Unable to travel for months
- Son is...
Everyone’s Grandma

- 95 years old
- New dx stage IV cancer of unknown primary
- New paraplegia
- Goal: quality time and having fun
- Loves women’s basketball

News clip
As if that wasn’t enough...

Play ball!
Hot air balloon ride

News clip
Questions?
Comments?

We’re available 24/7
(602) 530-6900 hov.org

Thank you.