End-of-Life Discussions with Long-Term Care Residents & their Families

Presented by Patricia Pollina, APRN, ACHPN, NP-C
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Comagine Health

• Comagine Health, formerly Qualis Health and HealthInsight, is a national, nonprofit, health care consulting firm. We work collaboratively with patients, providers, payers and other stakeholders to reimagine, redesign and implement sustainable improvements in the health care system.

• As a trusted neutral party, we work in our communities to address key complex health and health care delivery problems.

• We serve people in Alabama, Alaska, Idaho, Mississippi, Nevada, New Mexico, Oregon, Utah, Washington, D.C., Washington State and Wyoming.
Presenter

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Patti is a Family Nurse Practitioner with Advanced Certification in Hospice and Palliative Care and has extensive experience with end of life discussions as a hospice and palliative provider. She serves on the board of Nevada POLST and by appointment to the Nevada Advisory Council on Palliative Care and Quality of Life.
Agenda

• Advance Care Planning and EOL Conversations
• Communication Tools
• Case Study
• Other Considerations: Decision-Making Capacity, Hospice Care, Spiritual Issues, Cultural Issues

Learning Objective

Know how to access, understand and use evidence-based communication tools to assist with End of Life discussions with long-term care residents and their families.
Talking About Dying Isn’t Easy

We are all born, and we all die. Because of medical advances, we can now support life for much longer than anticipated.

For some, a long life is filled with joy, wisdom and renewed spirituality, for others it may be filled with recurrent infections, dependence on ventilators and feeding tubes.

Either way, care is continuous, and conversations about dying are important.
Consider the Facts

According to a New England Journal of Medicine study, 70.3 percent of Americans over the age of 60 lost capacity for decision-making at the end-of-life. (Silveira., Kim and Langa, 2010)

But only 25 percent of Americans have an advance directive. (Maxwell, McKnight’s Long Term Care News, 2017)
What’s in Your End-of-Life Toolkit?

Could you explain the following to a resident?
• Health-care durable power of attorney (DPOA)
• Advance directives
• Physician’s order for life-sustaining treatment
• Palliative and hospice care

Have you considered?
• Using Ask-Tell-Ask and SPIKES communication tools
• Addressing spiritual, cultural differences
Advance Care Planning Meetings

Discussing advance directives in care planning meetings (or care conferences) is **REALLY** important.

**First**, prior to a care conference, residents and families should understand the role of a health-care DPOA.

**Next**, explain what happens during and after resuscitation.

**Finally**, discuss in detail a resident’s preferences and options.
It Doesn’t Have to Happen Just Once

Any acute change of condition, especially when it may lead to hospitalization, is another opportunity to bring up advance care planning.

Watch out for a resident who may be experiencing a slow decline or no longer responding to medical therapy.
Advance Care Planning Resources

For residents with decisional capacity, The Conversation Project has excellent materials for clarifying values and preferences. It can also assist with family communication.

The Conversation Project
www.theconversationproject.org
Communication Tools: Ask-Tell-Ask

**Ask-Tell-Ask** is a useful tool for any difficult conversation.

A collaborative communication tool that inquires about the resident’s expectations, delivers information and then assesses for understanding. *(Campbell et al., 2010)*
ATA Case Study No. 1: Mr. A

Mr. A is a 92-year-old male suffering from early-stage Alzheimer’s disease with a previously completed advance directive.

He is ambulatory though he has an enlarged prostate, which is agitated due to full bladder. The agitation was quelled some after a straight catheterization. He is unable to tolerate an indwelling urinary catheter, and is pending a urologist appointment. Unfortunately, he’s not a candidate for transurethral resection of the prostate (TURP). (Childers, 2015)

He often spits out medications.
ASK: What do you think is important to your father right now?

TELL: The nurse explained the resident was able to pull out another catheter after it was placed. Mr. A remains fairly strong and does not like any kind of catheter.

ASK: How do you feel about us managing his symptoms conservatively?

TELL: We can manage his symptoms and treat symptomatic urinary tract infections (UTI). We can attempt to straight catheterize if his bladder becomes much more distended and he allows us. We will continue medications for benign prostatic hyperplasia (BPH), also diuretics, if helpful in maintaining comfort.
ATA Case Study No. 1: Mr. A

His daughter agrees to the plan. Months later, Mr. A’s Alzheimer’s disease has progressed to where he is bedbound, and he has developed a chronic wound. The family has decided against artificial nutrition. He has developed several infections in the past year.

Ask: How do you feel things are going with your father?
Tell: It seems to me his disease has progressed.
Ask: How can we support his quality of life? Have you thought about hospice?
ATA Case Study No. 2: Mrs. B

Mrs. B is an 82-year-old long-term care resident with a history of multiple hospital admissions in the past year. She suffers from congestive heart failure (CHF) comorbidities, diabetes mellitus type 2 (DM II), neuropathy, and osteoarthritis.

She was recently diagnosed with pneumonia with an 89 percent pulse oximetry, which is near her baseline. Her daughter wants her to go to the hospital, but Mrs. B does not want to go. She tells her daughter, “I want God to take me when he is ready.”

Mrs. B’s advance directive is in place. Her son and a former neighbor are the DPOAs for health care.
ATA: A Conversation with Resident

**Ask:** Is there a reason you are talking about God taking you?

**Tell:** You have pneumonia, but it can be treated with an antibiotic. We can talk to the provider about your desire to be treated in the facility.

On assessment, we learn that her quality of life is good, but Mrs. B feels she is becoming frailer. She is tired of going to the hospital. She would like to have someone read the bible to her.

Would you be surprised if the resident died within a year?” If your answer is “no,” consider a physician’s order for life-sustaining treatment (POLST).
The DC MOST program provides a more comprehensive approach, empowering terminally-ill patients the right to make decisions on their end of life care options.

MOST document is appropriate for residents in fragile health. For providers, the rule of thumb is that it would not be surprising for the resident to die within the year. The preferences in this document are a medical order that is transferable between health care facilities.

The form must be completed and signed off by an authorized DC-licensed healthcare professional (Physician (MD/DO) or Advanced Practice Registered Nurse (APRN) – only) in consultation with the patient or the patient’s authorized representative.

Source: https://dchealth.dc.gov/node/1354936
All copies of the original MOST Form serve as a legal document. The patient must have a copy on their person or in the immediate visible vicinity in order for it to be honored. In addition, a copy must be kept on file in the patient’s medical record as well as with DC Health’s MOST Program. Completed Forms should be returned to DC Health via email at dc.most@dc.gov

MOST is 100% voluntary. A resident cannot be required to complete an advance directive or a MOST. See https://dchealth.dc.gov/node/1354936 for specific regulations.

For DC MOST Frequently Asked Question please see https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/DC%20MOST%20FAQs%20V072919.pdf

Source: https://dchealth.dc.gov/node/1354936)
Communication Tools: SPIKES

A Six-Step Protocol for Delivering Bad News, the SPIKES tool is also useful for one-on-one conversations or family meetings.

It can be combined with Ask-Tell-Ask.

(Peereboom and Coyle, 2012)
Communication Tools: SPIKES

- **S** is for SETUP or listening **SKILLS**. Ideally sit down together.
- **P** is for PERCEPTION. Find out the viewpoint of the resident and or family with open-ended questions.
- **I** is INVITATION. What do you want to know?
- **K** is KNOWLEDGE. Give information in lay language.
- **E** is EMPATHY. Acknowledge this is difficult news. Allow for expressions of emotion.
- **S** is for SUMMARY. Where are we at now? Assess readiness for next steps.

*(Peereboom and Coyle, 2012)*
Other Considerations: Decision-Making Capacity

• Please tell me in your own words what we have stated about your condition and the way we could treat it.

• How do you feel about this? Why? Do you think the treatment will help you? What do you see happening if we do not treat aggressively?

• Can you please repeat to me what you have decided so I am able to understand? (Clore, 2009)

• A letter is needed from a physician that states they have “decisional capacity.” (Ewald, 2018)
When should a resident or family be approached about hospice? When the resident experiences:

- Weight loss in spite of efforts to provide desired foods and appetite stimulants
- Chronic infections or infections resistant to antibiotic therapy
- Dysphagia is resulting in poor intake and aspiration risk
- Measurement tool indicates progressive decline (palliative performance scale)
- Progressing dementia, for example, Fast 7 in FAST scale for Alzheimer’s disease
- Severe non-healing or worsening wounds (Letizia, 2005)
Other Considerations: Spiritual Issues

Start with an open-ended question to determine if spirituality is an important concern. Remember that spirituality exists both inside and outside of organized religion.

Possible questions:
• “Are you comfortable in your spiritual life?”
• “Do you feel healthy spiritually?

(Taylor, Elizabeth Johnson, 2015)
Other Considerations: Cultural Issues

Members of some cultures have difficulty with the concept of stopping aggressive medical treatment, be sure to:

• Ask how they would describe “quality of life.” Some cultures may use a family-centered approach to decision-making.

• “Ask, Tell, Ask” becomes useful in this situation. What do you know and what do you want to know?

• Always answer direct questions from a resident. Direct questions evidence a readiness for understanding. (Manzanec and Panke, 2015)

• We can’t stress enough the importance of using a certified medical translator.
Other Considerations: Cultural Issues

• Some questions you can ask to learn more about someone’s culture:
  o Where is your family from?
  o Where did you grow up?
  o Do you have any special beliefs about health and illness? (*Dahlin, 2010*)

• Be patient and accept that some residents and their families will continue to pursue heroic methods that we may not see as effective.

• Be nonjudgmental and supportive.
Start the Conversation Today!

• Individuals often have preferences for end-of-life, but may not express them until it is too late.

• Use communication tools such as Ask-Tell-Ask and SPIKES, and materials from The Conversation Project.

• A person must have decisional capacity to make an advance directive or POLST/MOST.

• Spiritual issues matter at the end-of-life. Assess for spiritual needs.

• Culture impacts end-of-life decision making. Respect differences and do not stereotype.
National Healthcare Decisions Day is now a week!

April 16-22, 2020

“It always seems too early, until it’s too late.”

Visit www.nhdd.org for more details on what you can do to ensure your residents have a better understanding of advance care planning.
Resources

Conversation Project Starter Kits

https://theconversationproject.org/starter-kits/
References

- Coloradoadvanceirectives.com/most-in-colorado
- Five Wishes https://www.agingwithdignity.org/

Marie A Bakitas, Constance Dahlin, Margaret Firer Bishop and Imatullah Akyar. Palliative and End of Life Care, 14 Chapter in Buttaro et al. Primary Care. 94-108.e2 Elsevier 2017. From Mosby Clinical Key.


Nevada Secretary of State: Nevada lockbox. https://www.nvsos.gov/sos/online-services/nevada-lockbox

NevadaPOLST.org


References

• The Conversation Project http://theconversationproject.org/
• Tips for leading difficult family meetings #59. www.geriatricfastfacts.com
• Ewald, Peggy, Personal communication 2018. Peggy Ewald RN, CCM Nevada POLST Chair.
Questions

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Collaborative Tools & Resources

DHCF Nursing Facility Collaborative
Website
https://dhcf.dc.gov/node/1390591

Comagine Health DC Medicaid
Nursing Facility QI Collaborative
Website
http://www.qualishealth.org/healthcare-professionals/collaborative-dc-medicaid
Thank you!

Reminders:

• A post-event evaluation will immediately populate following this webinar. Please complete the evaluation because your feedback is very important to us.

• Attendees will receive a Certificate of Attendance, along with a copy of today’s handout, via email by the end of the business day.

• In place of the May 21st face-to-face Learning Session we will have a one-hour webinar session from 1:00 -2:00 pm. The guest speaker will be Patty Webster, Improvement Advisor from IHI. The topic will be Person-directed, Person-Centered EOL Care and Promoting Interdisciplinary Advance Care Conversations.

• April Senior Leader Report due May 10th.

• For questions, please contact: Gazelle Zeya, Comagine Health QI Consultant Email: GZeya@comagine.org | Phone: 1-800-949-2992 ext. 2992