Advance Care Planning to Establish End of Life Care Preferences

Erica Holman, LMSW, LNHA

Learner Objectives

- Define Advance Care Planning
- Describe how Advance Care Planning can reduce hospitalizations
- List ways Advance Care Planning increases control over end of life decision making

Advance Directives vs. Advance Care Planning

- Before we begin…let's clarify -

The Conversation is Not Occurring

- Most people say they would prefer to die at home, yet only about one-third of adults have an advance directive expressing their wishes for end-of-life care (Pew 2006) .
- Between 65% and 75% of physicians whose patients had an advance directive were not aware it existed (Kass-Bartelmes 2003).

Entering the Conversation

Set The Stage

- Start the discussion; research options
- Gundersen Health Systems is an international leader in advance care planning

Set The Stage

- Ensure the PHYSICIAN is involved in the Advance Care Planning process
- Many people have Advance Directives and physicians are not aware
- Sometimes things go wrong and the physician does not have quick and easy access to the most recent Advance Directive –

Talking “Fact”

- Many people do not understand the difference between Hospice and Palliative Care
  - Definitions of Palliative Care and End of Life Care vary – even among experts
- Many people do not understand their medical conditions completely as well as the mortality that may be associated with certain conditions

Defining Advance Care Planning

- Per CDC: Advance care planning is about doing what you can do to ensure that health care treatment you may receive is consistent with your wishes and preferences should you be unable to make your own decisions or speak for yourself. There are several written documents available for us to express our care wishes and/or appoint a surrogate decision-maker if we become unable to make our own decisions. Equally important is making sure that our surrogate knows and understands our care preferences.

(Tangum and Benson, 2010)

Reducing Hospitalizations through Advance Care Planning

- Reducing (unnecessary) hospitalizations and rehospitalizations is an emphasis related to quality of care initiatives in long-term care.

Reducing Hospitalizations through Advance Care Planning

- Most people say they do NOT want to die in a hospital setting.
- Many people do NOT have Advance Care Planning or Advance Directives in place to limit the likelihood of dying in a hospital.

Reducing Hospitalizations through Advance Care Planning

- What is the relationship between Advance Care Planning and Hospitalization rates?
  - When the patient has not planned for care and services, the home has limited choice but transfer to hospital.
  - If the hospital cannot provide services to improve, or stabilize, the patient's condition the transfer can be traumatic.
  - Can increase a patient, or family's, (unrealistic) expectations about the patient's prognosis.

Reducing Hospitalizations through Advance Care Planning

- What is the relationship between Advance Care Planning and Hospitalization rates?
  - Inefficiency when transfer is not necessary
  - Cost – time & financial
  - When you, and the entire team, know what the patient's expectations are and HOW they want care delivered, it can improve care delivery and change the way we provide care

Decisions Regarding Hospitalization from a Nursing Home

- Nursing home patients commonly develop new or worsening symptoms.
  - Need to know patients choices (Advance Care Planning and Advance Directives) regarding decision for remaining in community or being transferred to hospital.

- Risk & Benefits of care in hospital – many factors patients and families should be aware of.

- Research has shown some hospitalizations may be unnecessary.
  - Preventing hospitalization depends on patient's conditions, ability of staff to provide care in the SNF and preferences of the patient and family. (Interact 3.0)

Benefits of Hospital Care

Many symptoms and conditions that usually require treatment in the hospital – for example, very abnormal vital signs are (temperature, heart rate, or breathing rate), or severe symptoms that can't be controlled (such as pain or vomiting). Hospital care offers benefits in these situations, including:

- Availability of sophisticated lab tests, X-rays, and scans
- Access to doctors and specialists who are in the hospital every day
- Availability of surgery and other procedures if needed
- Intensive care units for critically ill people

(Interact 3.0)

Risks of Hospital Care

- Nursing home patients are prone to complications of care in a hospital. Complications may occur because of older age, chronic medical problems, and the condition that caused the transfer all combine with the hospital environment to put nursing home patients at high risk for complications. Complications include:
  - New or worsening confusion
  - More time spent in bed, which can increase the risk of blood clots, pressure ulcers, muscle weakness, loss of function, and other complications
  - Less sleep and rest due to tests, monitoring, and noise
  - Increased risk for:
    - Falls with injuries, such as cuts, bruises, and broken bones
    - New infections
    - Depression due to limited opportunities to socialize with friends and family, as well as being in an unfamiliar environment

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Benefits of Staying in the Nursing Home

- There are benefits of staying in the nursing home when a new symptom or condition occurs – assuming it is safe to treat the condition and staying is consistent with the preferences of the patient and her or his family. Treatment in the nursing home allows patients to:
  - Have continuity of care – this means that patients continue to receive care from staff members who know them, and who are able to respond to their individual preferences and needs
  - Remain in a familiar environment with their personal possessions, and keep their individual routines as much as possible
  - Avoid what is often an uncomfortable trip to the hospital and long delays waiting in the emergency room
  - Avoid potential problems due to miscommunication between the hospital and the nursing home
  - Avoid other hospital-related complications

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Deciding About Going to the Hospital

What Can patients and Their Families Do?

There are several things that patients and their relatives can do to make sure the right decisions about hospital care are made in their best interest, including:

- Participating in care planning (deciding on treatment preferences) with the nursing home staff and their primary care provider (doctor, nurse practitioner, or physician's assistant)
- Discussing the risks and benefits of a hospital transfer vs. treatment in the nursing home when a new symptom or condition is recognized
- Completing an Advance Directive document, such as a Durable Power of Attorney for Health Care that expresses preferences for care in emergencies and at the end of life
- Understanding the resources available in the nursing home to treat the new symptom or condition (for example, oxygen, lab tests, intravenous (IV) fluids and medications)
- Understanding the financial and other issues, such as bed-hold policies, of treatment in the hospital vs. in the nursing home

(Interact 3.0)

End of Life Care Needs

- Difficult to define end-of-life care needs because we each define this differently and it has many emotional connotations.
- Great variance in what people want at the end of their lives.

End of Life Care Needs

- Listen to the voice of the patient
  - Some focus on quality of life
  - Some want aggressive and life-prolonging treatment
  - Some want comfort care in familiar settings
  - Some seek closure

(Tangum and Benson, 2010)

End of Life Care Needs

- Steinhauser (2000)surveyed over 1,400 people involved in end-of-life care and rated their most important goals:
  - Pain and symptom management
  - Preparation for death
  - Achieving a sense of completion
  - Decisions about treatment preferences
  - Being treated as a “whole person”

End-of-Life and Hospice Care

- Hospice care is end-of-life care provided by health care professionals and volunteers.
- Provides medical, psychological and spiritual support.
- Provides medical, psychological ad spiritual support.
- The of the Hospice Care is to help people who are dying have peace, comfort and dignity

End-of-Life and Hospice Care

- Caregivers try to control pain and symptoms so the person can remain as alert and comfortable as possible.
- Hospice Care programs generally provide supportive services to the patient's family.

Palliative Care

- SNFs are not doing this as well as we should
- Palliative Care –
  - Medical specialty that helps people facing serious and chronic illness be more comfortable by alleviating pain, treating a host of other symptoms and focusing on their quality of life.
  - Appropriate at any age and any stage of a serious illness and can be provided along with curative treatment.
  - Palliative Care provides pain relief and comfort care regardless of prognosis – even if receiving Hospice Care.

(Tangum and Benson, 2010)

Identifying patients for Hospice or Palliative/Comfort Care Orders

patients with Selected Diagnoses who may be Appropriate for Hospice:

- Congestive Heart Failure
  - Symptoms of CHF at rest (New York Heart Association class IV)
  - Serum sodium level < 134 mmol/L or creatinine level > 2.0 mg/dL due to poor cardiac output
  - Intensive care unit admission for exacerbation

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Identifying patients for Hospice or Palliative/Comfort Care Orders

patients with Selected Diagnoses who may be Appropriate for Hospice:

- Chronic Obstructive Pulmonary Disease
  - Cor pulmonale (right-sided heart failure associated with COPD)
  - Intensive care unit admission for exacerbation
  - New dependence in two activities of daily living (ADLs) due to COPD symptoms
  - Chronic hypercapnia(PaCO2>50mmHg)

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Identifying patients for Hospice or Palliative/Comfort Care Orders

patients with Selected Diagnoses who may be Appropriate for Hospice:

- Dementia
  - Dependence in all ADLs, language limited to just a few words, and inability to ambulate
  - Acute hospitalization (especially for pneumonia or hip fracture)
  - Difficulty swallowing with recurrent aspiration
  - Has feeding tube due to dementia or swallowing difficulty related to dementia

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Identifying patients for Hospice or Palliative/Comfort Care Orders

patients with Selected Diagnoses who may be Appropriate for Hospice:

- Cancer
  - Poor physical performance status as a result of cancer(dependence in multiple ADLs)
  - Multiple tumor sites
  - Metastatic cancer involving liver or brain
  - Bowel obstruction due to cancer
  - Pericardial effusion due to cancer

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patients at High Risk of Actively Dying

patients that Should be Considered for Palliative or Comfort Care Orders (if not already on Hospice):

- Frequent Emergency Room visits and/or hospitalizations over the last 6 months
- Sudden,majordeclineinfunctionalstatuswithnoidentifiedreversiblecauses
- Primary diagnosis of metastatic cancer with chronic pain and/or poor ADL function, not on chemotherapy
- Semi-comatose or comatose state with no identified reversible causes
- Inability or difficulty taking oral medicines
- Minimal oral intake (or receiving continuous or intermittent IV hydration)
- Mottling of extremities related to poor oral intake or volume depletion

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Comfort Care Interventions

Some nursing home patients and/or their families are reluctant to enroll in hospice but would like a comfort care plan.

Comfort Care Interventions

These are a few examples of comfort care orders that may be helpful for patients who will not have hospice orders:

- Pain and Dyspnea:
  - Opioids usually most effective
  - Use small, frequent doses as needed for opioid-naïve patients
  - Consider stopping sustained preparations and switching to immediate release Morphine concentrate 20 mg/ml
  - Start with equivalent dose as previous regimen – at least 5 mg PO every 2 hrs
  - Offer routinely, and let the patient refuse
  - Use short-acting benzodiazepine if anxiety is present

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Comfort Care Interventions

These are a few examples of comfort care orders that may be helpful for patients who will not have hospice orders:

- "Death Rattle"
  - Keep back of throat dry by turning head to the side
  - Stop IV fluids or tube feedings
  - Use a Scopolamine patch; Atropine drops 2 - 3 in the mouth every 4 hrs. until patch is effective
    - Use glycopyrrolate, 1- 2 mg PO or 0.1- 0.2 mg IV or subcutaneous every 4 hrs.; or 0.4 -1.2 mg/day continuous infusion is an alternative
  - Avoid deep suctioning
  - Allow family to cleanse mouth with sponge sticks

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Comfort Care Interventions

These are a few examples of comfort care orders that may be helpful for patients who will not have hospice orders:

- Comfort, Counseling, Safety
  - Sit with patient and talk to avoid isolation
  - Reposition and massage regularly
  - Avoid sensory overload (e.g. loud TV); use soft music
  - Avoid use of restraints, bedrails, and alarms
  - Religious counseling should be considered if acceptable

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Comfort Care Interventions

These are a few examples of comfort care orders that may be helpful for patients who will not have hospice orders:

- Nausea and Delirium
  - Review underlying cause(s) of delirium and nausea, and eliminate if possible
  - Haloperidol 0.25 - 2 mg PO or 0.5 - 1 mg subcutaneous every 2 hrs. for 3 doses until symptoms relieved, then every 4 hours PRN

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A Few Areas of Consideration in Advance Care Planning – CPR, Tube Feeding & Mechanical Ventilation

CPR Considerations

- CPR is an attempt to re-start the heart when it has stopped beating.
  - Person is placed on a hard surface and center of chest compressed about 2”
  - Compressions must be done 100 times each minute
  - Artificial respiration may be started

(California Coalition for Compassionate Care, 2013)

CPR Considerations

- Once CPR is initiated the following may occur:
  - Emergency team may place a breathing tube for oxygen
  - Electric shocks administered with paddles to the chest
  - An IV may be started
- If person survives will taken to ER, transferred to intensive care and attached to a ventilator and heart monitor

(California Coalition for Compassionate Care, 2013)

CPR Considerations

Who is least likely to benefit from CPR?

- Most older adults do not have the type of heart rhythm that responds to CPR
- People with chronic disease affecting heart, lungs, brain and kidneys can have lower chances for survival after cardiac arrest

(California Coalition for Compassionate Care, 2013)

CPR Considerations

Who is least likely to benefit from CPR?

- People with advance dementia have 3 times lower survival rate than those without
- Various advanced stages of illness for people with full dependence for care result in low survival rate (0% - 5%) even if transferred to hospital before cardiac arrest
- Other co-morbid factors and age can impact benefits of CPR

(California Coalition for Compassionate Care, 2013)

CPR Considerations

Who is most likely to benefit from CPR?

- What is reason heart stopped?
- How long has the heart stopped?
- About 15% of those provided with CPR will survive – difficult to know who is most likely to benefit.
- Survival rate may increase for those with no major health problems or who have sudden, unexpected collapse and have CPR within minutes AND have the heart rhythm responding to electrical shocks.

(California Coalition for Compassionate Care, 2013)

CPR Considerations

- Complications can occur – these should be reviewed and discussed with the physician, the care team, patient and family members. They include, but are not limited to:
  - Up to 97% CPR attempts in the elderly result in fractures
  - Bruising
  - Burns from defibrillator
  - Permanent brain damage in 50%
  - Other complications –

(California Coalition for Compassionate Care, 2013)

CPR is the patient's Choice

- CPR is a choice, not a required treatment for every patients.
- The choice to NOT have CPR will not affect any other aspect of care & services.
- All of the care and treatments will continue if CPR is not chosen
- If CPR is NOT chosen only difference will be NO CPR if found without a pulse or heart beat

(Interact 3.0)

Tube Feeding Considerations

Making the Decision about Tube Feeding

- Many people make a decision in advance about whether or not they want tube feeding.
- You can choose between having tube feeding and asking for a 'No Tube Feeding' order.
  - You may not be able to make this decision for yourself at the time you are unable to eat or drink.
- Making the decision in advance will help make sure that your wishes are carried out.

(Interact 3.0)

Tube Feeding Considerations

Making the Decision about Tube Feeding

- Research studies indicate tube feeding does not prolong life, or improve function or quality of life.
- Research also indicates tube feeding does NOT:
  - Prevent episodes of pneumonia due to swallowing trouble
  - Prevent the development or healing of skin wounds (pressure sores) that can be caused by not moving around and not having enough nutrition or fluid

(Interact 3.0)

Tube Feeding Considerations

Benefits of Tube Feeding

- Provides nutrition and fluids temporarily or long-term when person is unable to eat or drink or has difficulty swallowing.

(Interact 3.0)

Tube Feeding Considerations

Risks of Tube Feeding can include:

- Complications of the operation place the tube in the stomach, such as bleeding, infection, and pain can occur, but they are infrequent.
- The area around the tube can become irritated, painful, or infected.
- The tube may become blocked or fall out, requiring trips to the hospital to have it replaced.

(Interact 3.0)

Mechanical Ventilation Considerations

- **Common reasons for use and benefits:**
- To deliver oxygen
- To eliminate carbon dioxide
- To ease the work of breathing
- Despite their life-saving benefits, mechanical ventilators carry many risks.
  - Therefore, the goal is to help patients recover as quickly as possible to get them off the ventilator at the earliest possible time.

(American Thoracic Society, 2013)

Mechanical Ventilation Considerations

- The main job of our lungs is to get oxygen into the body and to get rid of carbon dioxide. When a patient's lungs are no longer able to do this job completely a ventilator may be used.
- Mechanical ventilator most commonly used for patients when they are in respiratory failure.
  - Respiratory failure is the situation when the patient has a low level of oxygen in the blood, even while getting oxygen therapy and/or when the level of carbon dioxide rises too much in the blood.
  - Some patients need help from a ventilator even though they still have nearly normal levels of oxygen and carbon dioxide in the bloodstream. This can be true when breathing is very uncomfortable.
  - Sometimes patients are placed on a ventilator because of other serious injuries that require treatment, which may interfere with breathing temporarily.

(American Thoracic Society, 2013)

Mechanical Ventilation Considerations

Mechanical ventilators do not actually fix diseases, but keep the patient alive while the physician and staff members determine why the patient has difficulty breathing and treats the disease that is causing the difficulty.

(American Thoracic Society, 2013)

Mechanical Ventilation Considerations

Some of the risks of mechanical ventilation include:

- Infections
- Collapsed lung
- Lung damage
- Side Effects of Medications
- Maintenance of Life

(American Thoracic Society, 2013)

A few words to the wise -

Good Working Knowledge

- To be an effective advocate, must have good knowledge base related to medical conditions and care options, end of life care factors and palliative care delivery
  - Draw upon the Interdisciplinary Team to envelope the patient in a strong and knowledgeable resource system

Advance Care Planning Summary

- Not related to a culture of coercion – the patient's choices are paramount
- The physician must be involved and active in communication
- The Interdisciplinary Team must understand how to communicate the options for Advance Care Planning
- The conversation should be initiated prior to admission
- Reducing (unnecessary) hospitalization can result from knowing the patient’s care preferences and can create an atmosphere conducive for peaceful, dignified end-of-life care

Questions or comments?

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