2019 Dementia Education Conference: Review of Advanced Care Planning

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Objectives

- Dementia at End of Life Overview
- Hospice or Palliative Care?
- Hospice FAST Scale for Dementia
- Facilitate better understanding of Advance care documents:
Objectives

- Living Will / Healthcare power of Attorney / Medical Orders for Scope of Treatment (MOST) / Golden Rod
- Understanding North Carolina Hierarchy for surrogate decision makers
- Do Not Resuscitate (DNR) vs. Do Not Intubate (DNI) status
Case Example

Alma had been forgetful for years, but even after her family knew that Alzheimer's disease was the cause of her forgetfulness, they never talked about what the future would bring. As time passed and the disease eroded Alma’s memory and ability to think and speak, she became less and less able to share her concerns and wishes with those close to her.

• This made it harder for her daughter Sylvia to know what Alma needed or wanted. When the doctors asked about feeding tubes or antibiotics to treat pneumonia, Sylvia did not know how to best reflect her mother's wishes. Her decisions had to be based on what she knew about her mom's values, rather than on what Alma actually said she wanted.
People can live with Alzheimer's or Parkinson's dementia for several years.

However, these are considered incurable, terminal diseases that eventually result in death.

Dementia causes the gradual loss of thinking, remembering, and reasoning abilities.

Limits loved ones who want to provide supportive care at the end of life to know what is needed.
Dementia at End of Life Overview

- Quality of life is an important issue when making healthcare decisions for people with dementia.

- Some medicines may help to control some of the behavioral symptoms associated with the disease or to delay the progression in cases especially to mild to moderate Alzheimer's dementia.
Dementia at End of Life Overview

• When making decisions for someone else near the end of life, consider the goals of care and weigh the benefits, risks, and side effects of the treatment.

• Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease.
Dementia at End of Life Overview

• “Legal and medical experts encourage people recently diagnosed with a serious illness—particularly one that is expected to cause declining mental and physical health—to examine and update their financial and health care arrangement as soon as possible!”
• Basic legal and financial instruments, such as a Living Will, a living trust, and Advanced Directives documents are available to ensure that the persons late stage or end-of-life healthcare and financial decisions are carried out.
Palliative Care

• Treatments that support alleviating symptoms of chronic, life-threatening diseases. (Heart failure, COPD, Parkinson's, and dementias)

• Patient's health approach is a curative plan
Hospice or Palliative Care?

Hospice Care

- Treatments that support and facilitate comfort and transitioning from life to death.

- When conventional treatments have failed, illness remain incurable, or the progression of a disease has not slowed down
Hospice Care

• Hospice can be offered in the home, skilled nursing or assisted living facilities, or Hospice Houses.

• Many patients and families wait too long to consider hospice care services.
Hospice or Palliative Care?

Hospice Care

• The FAST Scale is a 16-item scale designed to parallel the progressive activity limitations associated with Alzheimer’s disease.

• Stage 7 identifies the threshold of activity limitation that would support six-month prognosis; however all sub stage FAST Scale indicators under stage 7 must be present.
Advance Care Planning

- Process by which patients and their clinicians engage in discussions about future goals of care and preferences at the end of life

- Patients should be encouraged to discuss their care preferences with not only their clinician but also their loved ones

- Fully informed patients with decisional capacity have the right to forgo or terminate life-sustaining treatments
Care Alignment Tool (CAT)

- Guide for GOC Discussions
- Complete on admission, ED encounters, SNFs, or with changes in advance directives
- Obtain permission to talk about goals
- Document goal comments
- Designate Code Status
- Complete MOST or DNR if appropriate
* Final Report *

Care Alignment Tool Entered On: 2/1/2019 13:10 EST
Performed On: 2/1/2019 10:54 EST by WILLIAMS, MELISSA V NP

Care Alignment Tool

Have you listed out any papers that name a person who can make health choices for you if you are unable to make those choices yourself? No

What does the patient/decision maker understand about their medical condition and the natural course of their disease? Patient verbalizes understanding of her overall health, and she states compliance with medications and follow-up PCP appointments. Her daughter at bedside also understands the patient’s past medical history. She assists the patient with transportation to appointments.

Biggest Fear/Concern: No fears or concerns
Agree to Goals of Care Discussion: Yes
CAT Discussion Time: 20 minute(s)
Most Important Goal: Care focused on comfort
Patient Desires: No Intubation. No CPR. No Dialysis. No PEG

Most Important Goal Comments: Patient states that her primary goal is to maintain her current level of independence and to be comfortable. She states that at this juncture of her life, that she would decline resuscitative interventions to prolong her life in the event of cardiac arrest. She desires to experience a natural death. Extended discussion regarding MOST form which was completed at bedside. The original document was scanned into the patient’s EMR and then return to the daughter at bedside with instructions for maintenance and renewal.

Take the above information into consideration, what is the current code status for the patient? Allow Natural Death (DNR)

WILLIAMS, MELISSA V NP - 2/1/2019 13:08 EST
Advance Directives – Living Will

• Living Will:
  • Provides information about an individual’s end-of-life care preferences to help guide surrogate decision makers
  • Comes into effect when patient has a terminal illness with no chance of recovery
  • Signed by declarant, with 2 witnesses and notary
  • Can be completed by Pastoral Care in the hospital
Living Will

3. Exceptions — "Artificial Nutrition or Hydration"

NOTE: INITIAL ONLY IF YOU WANT TO MAKE EXCEPTIONS TO YOUR INSTRUCTIONS IN PARAGRAPH 2.

Even though I do not want my life prolonged in those situations I have initiated in Section 1:

   I DO want to receive BOTH artificial hydration and artificial nutrition (for example, through tubes) in those situations:

   NOTE: DO NOT INITIAL THIS BLOCK IF ONE OF THE BLOCKS BELOW IS INITIATED.

   [Initial]

   I DO want to receive ONLY artificial hydration (for example, through tubes) in those situations:

   NOTE: DO NOT INITIAL THE BLOCK ABOVE OR BELOW IF THIS BLOCK IS INITIATED.

   [Initial]

   I DO want to receive ONLY artificial nutrition (for example, through tubes) in those situations:

   NOTE: DO NOT INITIAL EITHER OF THE TWO BLOCKS ABOVE IF THIS BLOCK IS INITIATED.

4. I wish to be made as comfortable as possible

I direct that my health care providers take reasonable steps to keep me as clean, comfortable, and free of pain as possible so that my dignity is maintained, even though this care may hasten my death.

5. I understand my advance directive

I am aware and understand that this document directs certain life-prolonging measures to be withheld or discontinued in accordance with my advance instructions.

6. If I have an available health care agent

If I have appointed a health care agent by executing a health care power of attorney or similar instrument, and that health care agent is acting and available and gives instructions that differ from this advance directive, then I direct that:

Follow advance directive: This advance directive will override instructions

[Initial]

[Initial]

Follow health care agent: My health care agent has authority to override this advance directive

[Initial]
7. My Health Care Providers May Rely on this Directive
My health care providers shall not be liable to me or to my family, my estate, my heirs, or my personal representative for following the instructions I give in this instrument. Following my directions shall not be considered suicide, or the cause of my death, or malpractice or unprofessional conduct. If I have revoked this instrument but my health care providers do not know that I have done so, and they follow the instructions in this instrument in good faith, they shall be entitled to the same protections to which they would have been entitled if this instrument had not been revoked.

8. I Want this Directive to be Effective Anywhere
I intend that this Advance Directive be followed by any health care provider in any place.

9. I have the Right to Revoke this Direction
I understand that at any time I may revoke this Advance Directive in a writing signed by or communicating in any clear and consistent manner my intent to revoke it to my attending physician. I understand that if I revoke this instrument I should try to destroy all copies of it.

This the __________ day of ____________.

Signature of Declant ____________________________

Typeprint name ____________________________

I hereby state that the declarant, being of sound mind, signed (or directed another to sign or declarant’s behalf) the foregoing Advance Directive for a Natural Death in my presence, and that I am not related to the declarant by blood or marriage, and I would not be entitled to any portion of the estate of the declarant under any existing will or codicil of the declarant or as an heir under the Intestate Succession Act. If the declarant died on this date without a will, I also state that I am not the declarant’s attending physician, nor a licensed health care provider who is (1) an employee of the declarant’s attending physician, (2) an employee of the health facility in which the declarant is a patient, or (3) an employee of a nursing home of any adult care home where the declarant resides. I further state that I do not have any claim against the declarant or the estate of the declarant.

Date: ____________________________
Witness: ____________________________

COUNTY ____________ STATE ____________

Sworn to (or affirmed) and subscribed before me this day by ____________________________
(typeprint name of declarant)

Signature of Notary Public ______________________________________
(Printed or typed name) ____________________________

Notary Public

My commission expires: ____________________________
Living Will

FIVE WISHES®

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

Type your name:

Sign today:

FIVE WISHES STATE:

Who Should Use Five Wishes:

Five Wishes is for anyone 18 or older—married, single, person, adult children, and friends. Over 12 million Americans of all ages have already used it. See become!

Five Wishes States:

If you live in one of the 49 states listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state's requirements under the law:


If your state is not one of the 49 states listed here, Five Wishes does not meet the legal requirements in the state of your origin. To some doctors in your care may be eligible to use Five Wishes. However, many people find that it is already used in other parts of their health care. Five Wishes helps them express their feelings and provide a helpful guide to family members, friends, and others.

How to Change Five Wishes:

You can already have a living will in a different state and change your health care. If you want to use Five Wishes instead, you need to fill it out and sign a new Five Wishes in advance. As soon as you sign, it takes effect on the date you signed. Please fill in the following:

- Make sure that the form is filled out and signed by the person who completed it.
- Tell your health care agent, family members, and doctor that you have signed a new Five Wishes.
- Make sure they understand your wishes.

Here's What People Are Saying About Five Wishes:

"It will be a year since my mother passed on. We knew what she wanted because she had the Five Wishes living will. When it came down to the end, my brother and I had no trouble on what we needed to do. We had peace of mind."

C. N. Longwood, Florida

"I want my friends to know that I love my Five Wishes. It's a great way to unintended, and I don't know on the common terms of medical care, but on the terms of medical care. I used it for myself and my husband."

Susan W. Kingsman, Arizona

"My children have to make the decisions. I am leaving the order for my daughter. I have children that were in so many medical options to be considered. Thank you for such a sensible and useful form. I am deeply flattered and have it on file for my children."

Debra W. Kramer, Champion

To Order: Call 800-835-5703 or purchase online at www.fivewishes.org. For information about the program, call 1-888-756-5549. This program is made possible by the Aging with Dignity Foundation.

www.fivewishes.org or (888) 756-5549

Aging with Dignity

P.O. Box 33111

To learn more about how to use Five Wishes, sign up for the free, interactive course at www.fivewishes.org.
HEALTH CARE POWER OF ATTORNEY

NOTE: YOU SHOULD USE THIS DOCUMENT TO NAME A PERSON AS YOUR HEALTH CARE AGENT IF YOU ARE COMFORTABLE GIVING THAT PERSON BROAD AND WIDESPREAD POWERS TO MAKE HEALTH CARE DECISIONS FOR YOU. THERE IS NO LEGAL REQUIREMENT THAT ANYONE EXECUTE A HEALTH CARE POWER OF ATTORNEY.

EXPLANATION: You have the right to name someone to make health care decisions for you when you cannot make or communicate those decisions. This form may be used to create a health care power of attorney, and meets the requirements of North Carolina law. However, you are not required to use this form, and North Carolina law allows the use of other forms that meet certain requirements. If you prepare your own health care power of attorney, you should be very careful to make sure it is consistent with North Carolina law.

This document gives the person you designate as your health care agent broad powers to make health care decisions for you when you cannot make the decisions yourself or cannot communicate your decisions to other people. You should discuss your wishes concerning life-prolonging measures, mental health treatment, and other health care decisions with your health care agent. Except to the extent that you express specific limitations or restrictions in this form, your health care agent may make any health care decision you could make yourself.

This form does not impose a duty on your health care agent to exercise granted powers, but when a power is exercised, your health care agent will be obligated to use due care to act in your best interests and in accordance with this document.

The Health Care Power of Attorney form is intended to be valid in any jurisdiction in which it is presented, but places outside North Carolina may impose requirements that this form does not meet.

If you want to use this form, you must complete it, sign it, and have your signature witnessed by two qualified witnesses and proved by a notary public. Follow the instructions about whom choices you can initially very carefully. Do not sign this form until two witnesses and a notary public are present to watch you sign it. You then should give a copy to your health care agent and to any alternate you name. You should consider filing it with the Advance Health Care Directive Registry maintained by the North Carolina Secretary of State. http://www.nccoregistry.org/arco/

1. Designation of Health Care Agent.

I. (being of sound mind, hereby appoint the following person(s) to serve as my health care agent(s) to act for me and in my name (in any way I could act in person) to make health care decisions for me as authorized in this document. My designated health care agent(s) shall serve alone, in the order named.

A. Name: 
   Home Address: 
   Home Telephone: 
   Work Telephone: 
   Cellular Telephone: 

B. Name: 
   Home Address: 
   Home Telephone: 
   Work Telephone: 
   Cellular Telephone: 

C. Name: 
   Home Address: 
   Home Telephone: 
   Work Telephone: 
   Cellular Telephone: 

Any successor health care agent designated shall be vested with the same power and duties as if originally named as my health care agent, and shall serve any time his or her predecessor is not reasonably available or is unwilling or unable to serve in that capacity.

2. Effectiveness of Appointment.

My designation of a health care agent expires only when I revoke it. Absent revocation, the authority granted in this document shall be effective when and if one of the physician(s) listed below determines that I lack capacity to make or communicate decisions relating to my health care, and will continue in effect during that incapacity, or until my death, except if I authorize my health care agent to exercise my rights with respect to anatomical gifts, autopsy, or disposition of my remains, this authority will continue after my death to the extent necessary to exercise that authority.

Physician

If I have not designated a physician, or no physician(s) named above is reasonably available, the determination that I lack capacity to make or communicate decisions relating to my health care shall be made by my attending physician.

3. Revocation.

Any time while I am competent, I may revoke this power of attorney in a writing signed by or communicating my intent to revoke, in any clear and consistent manner, to my health care agent or my health care provider.


Subject to any restrictions set forth in Section 5 below, I grant to my health care agent full power and authority to make and carry out all health care decisions for me. These decisions include, but are not limited to:

- A. Requesting, receiving, and delivering any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records, and to consent to the disclosure of this information.
- B. Employing or discharging my health care providers.
- C. Consenting to and authorizing my admission to and discharge from a hospital, nursing or convalescent home, hospice, long-term care facility, or other health care facility.
- D. Authorizing any health care provider to act in my behalf as a substitute decision-maker.
- E. Authorizing any health care provider to consent to any proposed health care decisions, including but not limited to, admissions, placements, discharges, and transfers to other facilities.
- F. Authorizing any health care provider to give consent to any proposed medication, treatment, and any other procedures ordered by or under the administration of a licensed physician, dentist, podiatrist, or other health care provider. This authorization specifically includes the power to consent to measures for resit obtain.
- G. Authorizing the withholding or withdrawal of life-prolonging measures.

A. Revocation of Prior Powers of Attorney. I revoke any prior health care power of attorney. The preceding sentence is not intended to revoke any general powers of attorney, some of the provisions of which may relate to health care; however, this power of attorney shall take precedence over any health care provisions in any valid general power of attorney I have not revoked.

B. Jurisdiction, Severability and Durability. This Health Care Power of Attorney is intended to be valid in any jurisdiction in which it is presented. The powers delegated under this power of attorney are severable, so that the invalidity of one or more powers shall not affect any others. This power of attorney shall not be affected or revoked by my incapacity or mental incompetence.

C. Health Care Agent Not Liable. My health care agent and my health care agent’s estate, heirs, successors, and assigns are hereby released and forever discharged by me, my estate, my heirs, successors, assigns and personal representatives from all liability and from all claims or demands of all kinds arising out of my health care agent’s acts or omissions, except for my health care agent’s willful misconduct or gross negligence.

D. No Civil or Criminal Liability. No act or omission of my health care agent, or of any other person, entity, institution, or facility acting in good faith in reliance on the authority of my health care agent pursuant to this Health Care Power of Attorney shall be considered suicide, nor the cause of my death for any civil or criminal purposes, nor shall it be considered unprofessional conduct or as lack of professional competence. Any person, entity, institution, or facility against whom criminal or civil liability is asserted because of conduct authorized by this Health Care Power of Attorney may interpose this document as a defense.

E. Reimbursement. My health care agent shall be entitled to reimbursement for all reasonable expenses incurred as a result of carrying out any provision of this directive.

By signing here, I indicate that I am mentally alert and competent, fully informed as to the contents of this document, and understand the full import of this grant of powers to my health care agent.

This the ______ day of __________, 20___.

(SEAL)

I hereby state that the principal, ______, being of sound mind, signed (or directed another to sign on the principal’s behalf) the foregoing Health Care Power of Attorney in my presence, and that I am not related to the principal by blood or marriage, and I would not be entitled to any portion of the estate of the principal under any existing will or codicil of the principal or as an heir under the intestate succession act, if the principal died on this date without a will. I also state that I am not the principal’s attending physician or mental health treatment provider who is (1) an employee of the principal’s attending physician or mental health treatment provider; (2) an employee of the health facility in which the principal is a patient; or (3) an employee of a nursing home or any adult care home where the principal resides. I further state that I do not have any claim against the principal or the estate of the principal.

Date: ____________________________ Witness: ____________________________

Date: ____________________________ Witness: ____________________________
Surrogate decision maker

• Most states and the VA have laws or policies designating a hierarchy of legal surrogate decision makers for patients who lack decision making capacity

• Surrogate decision makers should also have the mental capacity to serve in this role

• Frail elderly couples often choose their adult children instead of spouses
Surrogate decision maker

- If the patient does not have family to fill the role of health care surrogate, the clinician can petition the court to appoint a legal guardian.
- Surrogate decision makers are expected to make decisions they believe the patient would have made through applying substituted judgement/based on the patient’s best interests.
# North Carolina Hierarchy

## ORDER OF HEALTHCARE DECISION-MAKING

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td></td>
</tr>
<tr>
<td>Healthcare Power of Attorney</td>
<td></td>
</tr>
<tr>
<td>Legal Guardian</td>
<td></td>
</tr>
<tr>
<td>General POA with Healthcare Power</td>
<td>Reasonably Available: Able to be contacted without undue effort and be willing and able to act in a timely manner</td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
</tr>
<tr>
<td>Majority of reasonably available parents and children over 18</td>
<td></td>
</tr>
<tr>
<td>Majority of reasonably available siblings over 18</td>
<td></td>
</tr>
<tr>
<td>Individual with established relationship with patient who is acting in good faith and can reliably convey patient's wishes</td>
<td></td>
</tr>
<tr>
<td>If none of the above, then Attending Physician</td>
<td></td>
</tr>
</tbody>
</table>
POLST (Physician Orders for Life-Sustaining Treatment)

- Helps to identify patient’s preferences about treatments such as resuscitation, feeding tubes and antibiotics
- Serve as physician orders that are active outside the hospital and are honored by paramedics
Medical Orders

• Names of these forms can vary across states
  • MOLST (Medical Orders for Life Sustaining Treatment)
  • MOST (Medical Orders for Scope of Treatment)
  • POST (Physician Orders for Scope of Treatment)
• Signed medical order indicating no attempts should be made to resuscitate
  • Honored by EMTs
  • Medical Order
  • Issued by MD/ACP
• Not hypothetical; immediately “in effect”
  • No interpretation
• Immediately directs care in the event of a cardiac arrest
“DNR ≠ DO NOT TREAT!”
Medical Orders for Scope of Treatment: (MOST)

- Specifies wishes for end of life
- Portable
- Medical Order, Condenses Living Will
- Effective in non-arrest scenarios
- Option to receive or withhold treatment
- Requires patient or proxy signature
- Includes specifics on other medical interventions, not just code status
MOST Form: Components

- Code Status
- Medical Interventions
- Antibiotics
- Medically administered fluids and nutrition
- Discussed with and agreed to by...
Section A: Cardiopulmonary Resuscitation

- Attempt Resuscitation (CPR)
- Do not attempt resuscitation (DNR/No CPR)
- Only one should be selected
- Only if no pulse and no breathing (Cardiopulmonary arrest)
Section B: Medical Interventions

- Patient is not experiencing cardiopulmonary arrest (no indication for CPR); has pulse and/or is breathing
- Note all mention “provide comfort measures”
Section B: Medical Interventions

- Full Scope of Treatment
- Intubation/mechanical ventilation
- Cardioversion
- ICU admission
- Transport to hospital
- All other appropriate treatment

“Goal is usually longevity”
Section B: Medical Interventions

Limited Additional Interventions

• No intubation/mechanical ventilation
• No cardioversion
• No ICU admission; avoid
• Transport to hospital if indication

“Goals: not usually longevity, more function”
Section B: Medical Interventions

Comfort Measures

• No intubation/mechanical ventilation
• No cardioversion
• No ICU admission
• Transport to hospital ONLY if comfort can’t be met in current location

• “Goals: Comfort/Hospice”
Section C: Antibiotics

• Antibiotics
• If life can be prolonged
• Determine use or limitation of antibiotics when infection occurs
• No antibiotics (Use other measures to relieve symptoms)
Section D: MEDICALLY ADMINISTERED FLUIDS AND NUTRITION

- IV fluid options
  - To receive long-term if indicated
  - To receive for defined trial
  - No IV (provide other measures for comfort)

- Feeding tube options
  - To receive long-term if indicated
  - To receive for defined trial period
Section E: DISCUSSED WITH AND AGREED TO BY:

- Patient
- Healthcare agent
- Legal guardian
- Attorney in fact (DPOA) with power to make healthcare decisions
- Spouse
Section E: DISCUSSED WITH AND AGREED TO BY:

- Majority of reasonably available parents and adult children
- Majority of reasonably available adult siblings
- An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient
Validation Signatures: Provider, Patient/Proxy, and Renewal Signatures
Questions
References

GRS 9 Teaching slides

ACP power point Cindy Stafford, ACP


http://compassionatecarenc.org/ncpcc-provider-resources/
References

http://www.agingwithdignity.org
