ADVANCE DIRECTIVES & GOALS OF CARE: WHEN TO CONSIDER HOSPICE & PALLIATIVE CARE

Jo Ann Fisher, MSN, FNP-BC

ADVANCE DIRECTIVE FORMS

- Living Will
- Health Care Surrogate/Proxy (HCS/HCP)
- Power of Attorney (POA)
- Do Not Resusitate (DNR)

DEFINITION

- **Advance Directives Defined**
  - An advance directive is a written legal document that outlines the type of end-of-life medical care you desire in the event of certain medical occurrences, as well as your incapacity to communicate those desires verbally or physically.
  - These documents also state the name of the individual(s) being authorized to make medical decisions on your behalf in such a circumstance.
  - Power of Attorneys may include medical directives
  - They may be notarized
  - Terminology varies from state to state

HISTORY OF ADVANCE DIRECTIVES

- Living Will
  - Oldest form
  - First proposed by Illinois attorney Luis Kutner in a law journal in 1969 [4]
  - Based on existing estate law (Last Will and Testament)
  - Patient Self-Determination Act, part of the Omnibus Budget reconciliation Act (OBRA)of 1990 determined that healthcare providers (mainly hospitals, nursing homes and home health agencies) needed to give patients information about their rights to make advance directives under state law[7]
  - Led to what are sometimes called “second generation” “third generation” etc. advance directives
  - The basic living will, is geared more toward outlining medical preferences- “ I do/I do not wish”

Kutner L (1969). "The Living Will: a proposal". *Indiana Law Journal*. 44 (1): 539–554. 11

DESCRIPTION OF ADVANCE DIRECTIVES

- **Living Will**
  - Other versions are 5 Wishes, POLST
  - Are not always honored
  - May be referred to(activated) in a healthcare setting if a person is Terminal: deemed to have
    < 6 months to live, has an End Stage Condition or
    is in a Permanent Vegetative State
- **POA -** Power of Attorney is a document giving power to person(s) determined by the content in the POA (Power of Attorney)
- **HCS** – Health Care Surrogate (Proxy) will take over medical decision making when a person becomes incapacitated
- **DNR** - Do Not Resusitate
  - Yellow statutory form honored in a person's home, by EMS and in the Emergency Department

SECOND GENERATION ADVANCE DIRECTIVES

- Health Care Surrogate (HCS)/Proxy (HCP)
  - Surrogate and Proxy both deal with medical decision making
  - In some settings/states they are synonymous
  - Generally in Long Term Care (LTC) a HCS has been determined prior to the resident becoming incapacitated and a HCP is named after incapacity has been determined.
  - HCP
    - It will follow an order of selection
    - Spouse, child, sibling, etc.

Medical Decision Making Incapacity vs. Incompetent

- Incapable
  - This infers the lack of mental or physical capacity to sufficiently care for person and property whether temporarily, intermittently or permanently
  - This traditionally describes a medical status
  - In LTC: this can be determined by one or two physicians

MEDICAL DECISION MAKING INCAPACITY VS. INCOMPETENT

- Incompetent(no longer used in Florida as well as other states)
  - most states use the term “legally incapacitated” to describe someone who is unable to meet basic requirements to preserve physical health and safety and also their ability to make rational decisions
  - It can be limited which includes a large range of options
  - Total incapacity implies that the person is incapable of self-determination and the reasons for this finding must be stated.
  - For example you might be incapable of physically caring for yourself but are mentally capable of making decisions.
  - This may lead to Guardianship

HOW IS SOMEONE DEEMED INCAPACITATED IN FLORIDA?

- Florida Statute 744.331 outlines the legal process that must be followed in order to have an adult deemed incapacitated in Florida. Per the Florida Statute, the process begins when a concerned family member, friend, or other interested party files two separate petitions with a Florida Court. One petition is the Petition to Determine Incapacity and the second is the Petition for Appointment of Guardianship.
- A court appointed attorney is selected to represent the adults interests
- The examining committee is comprised of 3 persons from multiple different backgrounds including but not limited to psychologists, physicians, nurse practitioners and social workers.

WHO MAKES MEDICAL DECISIONS ?

- If the court has determined total incapacity, a guardian will be appointed
- Power of Attorney does not mean you are the health care decision maker (HCS/HCP)
  - Many deal with financial decision making only
- Contact Person does not signify decision maker!
  - This is frequently confused in LTC facilities
  - Many families live out of state and opt to have “someone nearby” take calls.
  - This may be a good friend of the resident or a case manager

RED FLAGS FOR POSSIBLE DIMINISHING CAPACITY

- Not just memory problems, but have difficulty learning or comprehending new tasks/ideas
- Look at executive function: can they plan, organize, i.e. plan a route with several stops
- Have difficulty making decisions and handling finances.
- Poor judgement: Are they rational or are they making bad decisions which can put them at risk
- No longer appear compliant with medical POC including medications
- Don’t give a straight answer
- Check their hearing!

COGNITIVE TESTING

- Mini Cog: Clock + three word recall 3 point test. If score is 0 recall or 1-2 with abnormal clock, there is cognitive impairment

- MMSE (Mini Mental Status Exam) Tests orientation, registration, attention and calculation, recall, and language. NOT FREE

- MOCA (Montreal Cognitive Assessment) tests attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Slightly more comprehensive

- SLUMS (Saint louis Uni. Mental Status)Tests memory, attention, orientation, and overall executive function. This includes everything from clock drawing to animal naming. It also includes tests on digit span, size differentiation, and figure recognition.

* Mini Cog was part of my Annual Medicare Exam!

SECOND GENERATION ADVANCE DIRECTIVES

- POA
  - Are completed by a person (principal) before he/she becomes incapacitated naming an attorney-in-fact (POA).
  - POAs are usually limited to financial/property
  - There are several types and with varied limitations
- Durable Power of Attorney (DPOA)
  - Drawn from business law
  - Can be utilized if the principal is not yet Incapacitated
  - Cannot be made invalid if the patient becomes incapable of making healthcare decisions
  - Includes a medical clause

GENERAL POA

- A general power of attorney is the broadest possible powers a principal can convey to an attorney-in-fact.
- General powers allow the attorney-in-fact to do anything the principal is allowed to do.
- A principal can limit the powers the attorney-in-fact receives however she/he wishes by including the limitations in the power of attorney, or POA, document.
- Some states require that in order to grant certain powers, the principal must explicitly state this in the POA document.

POA STIPULATIONS

- Regardless of the kind of power of attorney passed, the principal has to ensure compliance with all relevant state laws in order to pass a valid power of attorney.
- Some states, for example, require that the principal sign the power of attorney in front of witnesses or a notary.
- Also, if the attorney-in-fact will have the right to convey real estate, document may have to be filed with the county register or other similar agency.

SPECIAL QUALIFYING TERMS

- **Short Term or Specific**

For a short term (such as you are out of the country) or a specified situation, limited time is defined and a special POA used.

- **Springing**

A springing POA "springs" into action only under certain conditions, such as incapacitation. You should clearly define what you want "incapacitated" to mean.

- **Durable**

Durable POA can be either ongoing or springing. It allows your agent's authority to continue if you become incapacitated.

DNR: DO NOT RESUSCITATE

- It is a statutory form in Florida that is honored in your home, in ambulance and in the emergency department
- A physician's order must be written if admitted to hospital
- It is not automatically activated or re-activated after leaving the hospital
- Some Assisted Living Facilities will not honor a DNR
- Some people find this terminology offensive

AND: ALLOW A NATURAL DEATH

- There are supporters of this terminology
- **AND** is more terminology at this time than a document
- It may be terminology seen in some living wills
- It has been associated with Hospice goals of comfort care and death with dignity

WHY SHOULD WE HAVE ADVANCE DIRECTIVES?

- To ensure that your wishes are known and followed, which may not occur if you are deemed incapable of decision making
- To prevent your decision maker from having to make decisions that he/she is not prepared to make
- Last minute decisions are not always good decisions
- To ease your mind that “things are in place”
- To ensure that the “right” person is your decision maker

WHO SHOULD YOU CHOOSE?

- Someone who is willing to take on the responsibility
- **Someone who will honor your wishes**
- Someone that you trust
- This may be a family member, friend or even a lawyer or banker
- Should be reviewed intermittently
  Sometimes the HCS has died and a new one needs to be selected
- It is advisable to have an alternate selected

REMEMBER

- Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences
- Goals of Care should be discussed according to your patients overall mental and physical health, co-morbid conditions, home environment and support system

RESOURCES

AARP

Aging With Dignity

American Hospital Association

American Bar Association Advance Care Planning Toolkit

Center for Practical Bioethics

https://commonpractice.com/hello

https://www.nhdd.org

Senior Centers

Alzheimer's Association

REFERENCES

1. http://www.floridahealth.gov
2. https://en.wikipedia.org/wiki/Advance_healthcare_directive
3. info.legalzoom.com/legally-incapacitated-vs-legally-incompetent-21238.html
4. Kutner L (1969). "The Living Will: a proposal". *Indiana Law Journal*. 44 (1): 539–554. 11
5. Alexander G.J. (1991). "Time for a new law on health care advance directives". *Hastings Center Law Journal*. 42 (3): 755–778. 12
6. Patient Self-Determination Act U.S.C.A. 1395cc & 1396a, 4206-4207, 4751, Omnibus Budget Reconciliation Act of 1990, P.L:.b 101-508 (101ST Cong. 2nd Sess. Nov. 5, 1990) (West Supp., 1991). 14
7. Docker, C. Advance Directives/Living Wills in: McLean S.A.M., Contemporary Issues in Law, Medicine and Ethics," Dartmouth 1996:182.
8. American Bar Association. *Patient Self-Determination Act: State Law Guide*. American Bar Association Commission on Legal Problems of the Elderly. August 1991.
9. www.agingwithdignity.org
10. *"Living Wills, Health Care Proxies, & Advance Health Care Directives". ABA. American Bar Association. Retrieved 8 May2017.*
11. med.fsu.edu/userFiles/file/POLST%20Form%20(July%2010,%202015).pdf