

# Being Prepared:

## Palliative Care and the Role of Advance Care Planning in Dementia

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# What is Palliative Care?

- **Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through prevention of and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual”**

*- World Health Organization*

# Palliative Care and Dementia

- **Essential for patient and especially family support**
- **Slow progression often lends itself to caregiver burnout**
- **Medical needs become more complex as disease worsens**
- **Cognitive decline prevents patients from being their own medical decision makers**
- **Emotional decisions must be made when patients can no longer remember how to eat or drink**

# Advance Care Planning can Help...

- **Preserve autonomy**
- **Provide guidance for medical providers**
- **Support loved ones when making difficult choices**

# What is Advance Care Planning?

## ADVANCE CARE PLANNING

- General ***TERM*** used when discussing future medical choices

## ADVANCE HEALTH CARE DIRECTIVES

- Legal ***DOCUMENTS*** that record future medical choices

- **Advance Health Care Directives are health care instructions for medical providers and designated health care agent(s) to be used if a patient is ever in a situation where he/she is not able to make their own health care decisions**
  - **Plan for the “what ifs” of life**
  - **Reversible/changeable at any time**



# Potential Barriers...

- **Patient Barriers**
  - Lack of awareness, denial, confusion, and/or culture
  - Fear of not getting care that is wanted or needed
  - Yet, 97% of those polled feel the conversation is important (1)
- **Forms are often not standardized or easy to understand**
- **Providers focus on documents – not conversation**
  - Typically only discussed with the sick, dying
  - Messaging may be inappropriate
- **Social stigma**
  - Only for the old and dying

# Benefits Advance Health Care Directives:

- **Proactive approach in medicine**
- **Can be protective**
- **Can help to avoid added stress during a typically stressful time**
- **Can help prevent conflict over making medical decisions**

- **Advance Health Care Directives can help you get the medical care that you want...**
- **Or, protect you from getting care you don't want.**

# An Advance Health Care Directive often includes two parts:

## **Durable Power of Attorney for Healthcare (AKA “Health Care Agent”)**

- **The person(s) chosen to speak for the patient in the event that he/she is not able to make medical decisions**

## **Instructions for Health Care (AKA “Living Will”)**

- **Specific medical wishes about CPR, Life Support, Artificial Nutrition**

# In-Hospital CPR Statistics...

- **Research shows that about 15 percent of people who receive CPR in the hospital live to be discharged and 5 percent of those receiving CPR are alive after one year. You are less likely to benefit from CPR if you have multiple medical problems, failing organs, diseases that will not get better, or live in a nursing home where you are dependent on others (2). Of those who survive in hospital CPR, 13 out of 100 people (age 70 and younger) have little change to their mental and physical functioning; however, as a person ages these numbers fall to less than five out of 100 for people 85 years and older (3).**

# Communication is Key...

- **60% of people want their end of life wishes honored, yet less than 1/3 have Advance Directives**
- **9 out of 10 people would prefer to die at home**
  - 63% die in hospitals, another 17% in institutions
- **71% of people believe its more important to enhance the quality of life for seriously ill than prolong it**
- **62% of deaths occur yearly from the “The Big 5”** (heart disease, cancer, stroke, COPD and diabetes) (4)

Excellent Plan A...  
What's Plan B?

# Start the Conversation...

- **If you had an accident and weren't expected to wake up, what would you want your family and your health care team to do?**
- **If you were diagnosed with an illness that couldn't be cured, but could be managed for a period of time, what would be important to you?**
- **As you grow old and your body starts to get tired, what will be most important to you?**



# What is the potential impact of not talking?

- **Quality of life is compromised**
- **Patient/family satisfaction is poor**
- **Hospitals on divert**
  - CCU's full of patients receiving "inappropriate care"
- **Emergency Departments are full**
- **Health care provider distress**
- **Healthcare costs on the rise**
  - Not sustainable

# Patient Rights

- **You have a right to have your wishes respected and to be treated with dignity**
- **You have a right to know about your health condition**
- **You have a right to know about your treatment choices**
- **You have a right to say yes or no to any medical test or treatment**
- **You have a right to good pain control and symptom management**
- **You have a right to prepare advance directives**

# Our Responsibilities...

- **Understand the purpose, content and differences of “Advance Directives”**
- **Ethically bound to educate our patients, friends, relatives, neighbors**
- **Remove the stigma**
- **Have the conversation...**
  - continue the conversation**
- **Complete your own Advance Health Care Directive**

# References:

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