Updates in Advance Care Planning:

Making the Most of Your Medical Decisions & Knowing Your Options

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Joan Rivers' Living Will:

Melissa explained: "She had written in specifically that she was to be able to go onstage. For an hour. And be funny.

"She wasn't going to be happy wheeled in to sit in the sun, you know? It was an amazing gift to give me, knowing exactly how she wanted her life to be. Not that it's ever an easy decision, but I knew I was making the right one."

"Joan Rivers' daughter knew she was right to switch off her mother's ventilator because the 81-year-old star had a living will which explained the quality of life she wanted."

Learning objectives

- Appreciate the emotional satisfaction and legal security of putting advance care planning into place
- Understand the options for advance care planning
- Understand the newest protections for advanced care planning such as POLST and MOLST
- Appreciate the role of palliative care and hospice at the end of life

"Everyone dies.
Death is not an inherent failure.
Neglect, however, is."

--- *Atul Gawande 2016*

Advance Care Planning (ACP) is not optional !

Advance care planning for healthcare is like
other necessary elements of planning for the future:
like buying health insurance, or life insurance, or doing estate planning

It is CONSIDERATE AND LOVING
It relieves families and caregivers of the burdens of not knowing the patient's wishes

Death is not optional, but we can still have some say

- What is a good death?
- Everyone has their own idea of what this is, but usually it is NOT in the hospital
- ACP Respects our wishes for closeness, dignity, comfort
- ACP allows us to express our preferences
- ACP gives each person the control—anticipatory--to place limits, on families and physicians' desires to thwart the inevitable

Abundant Resources to Assist With Advanced Care Planning

- Documents are freely available
- Downloadable from the internet
- Interactive websites in multiple languages

RESOURCES

- http://theconversationproject.org
- https://www.nia.nih.gov/health/publication/advance-care-planning
- http://www.acpdecisions.org/
- CAPC.org
- https://www.oag.state.md.us/Healthpol/adirective.pdf

Today we are lucky to have

- State and Federal laws which require individual preferences to be respected by health care
- MOLST and POLST legislation which requires doctors, institutions, and EMTs to respect patient preferences
- Insurance reimbursement for conversations with physicians about advance care planning
- Wide availability of palliative medicine specialists and hospice care
- Wider recognition of patient choices for death with dignity

MYTHS REGARDING ACP

- Myth 1: There is only one type of power of attorney
- Myth 2: If one does not have an advance directive then the doctors must do everything
- Myth 3: An advance directive or DNR order means "don't treat"
- Myth 4: Once a person names a proxy in an advance directive they lose control of their own care
- Myth 5: A lawyer is required to complete an advance directive
- Myth 6: If someone fills out an advance directive, doctors and families don't ever have to talk to them again about end-of-life care--views can change over time!
- Myth 7: The doctor can be the durable power of attorney for health care

What are the Basic Elements of ACP?

- Designate a health care proxy
- Express your ideas of what constitutes dignity at the end of life
- Specify your preferences for comfort
- Anticipate the possibility that you will not be capable of making decisions when illness is advanced
- Specify your preferences for limiting technology and life prolonging treatment when improvement is no longer an option

THE CONVERSATION

- With your loved ones
- With your physicians
- With your caregivers
- You can help your loved ones by making your own preferences known

Palliative Care

- Care shifts from life-prolonging to comfort measures
- Relief/control of symptoms: analgesia, sedation, maintenance of dignity
- Avoiding iatrogenic effects of treatment
- Prevention of falls, pressure sores

Cause of death in PD depends on age, and other medical illnesses (comorbidities) and the severity of Parkinsonism

- Dementia
- Fractures & Falls
- Thromboses
- Infections (lung, urinary tract)
- Other medical conditions

Most doctors say that PD is not fatal—you die with it, not from it

Four Stages in Parkinson's Disease

- Diagnosis
- Maintenance
- Complex
- Palliative

- MacMahon et al. 1999

Medical Issues in Late-Stage PD

- Swallowing issues→choking (aspiration)→
- Malnutrition & Frailty*
- Frailty →Falls & Fractures
- Aspiration →Pneumonia
- Cognitive slowing &Dementia
- Cognitive Slowing & Frailty→Caregiver Burden
- Pain

In PD Palliative Care and PD care can be given CONCURRENTLY

- In late PD most treatments are symptom modifying
- Unlike with cancer, Medicare and other insurances do not compel persons with PD to choose between disease modifying treatment on the one hand , and palliative medicine and hospice on the other
- Concurrent care

How can you ensure that your wishes will be followed?

- Discuss your ACP preferences with your doctor
- Discuss your preferences with your health proxy
- Explain your preferences to your caregiver
- Have a MOLST or POLST in place
- Do these things WHILE YOU ARE MENTALLY CLEAR!

MOLST & POLST

- Designed to improve end of life care by converting treatment preferences into medical orders that are transferable throughout the health care system
- Requires a conversation with a doctor and must be signed by a health care provider
- Recommended for persons with advanced chronic progressive illness, those who might die in the next year, the frail elderly, or anyone who wants to further define preferences for treatment

The National POLST Paradigm is an approach to end-of-life planning based on conversations between patients, loved ones, and health care professionals designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and honored.

POLST (NATIONAL)
PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT
POST (VA) Physician Orders for Scope of Treatment
MOLST (MD)
MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT

MOLST/POLST ORDERS

- DESIGNED TO BE readily available to EMTs, ERs, NH staffs
- Portable and follows the person from one facility to another
- More individualization than a DNR or AD form
- May be posted in the home or registered with government agency

Resources

- http://marylandmolst.org/pages/molst_form.htm
- http://www.polst.org/
- http://virginiapost.org/

THE CONVERSATION

- Conversation is the key
- With your loved ones
- With your physicians
- With your caregivers
- You can help your loved ones by making your own preferences known