Advance Care Planning: Starting the Conversation

Advance Directive and MOLST

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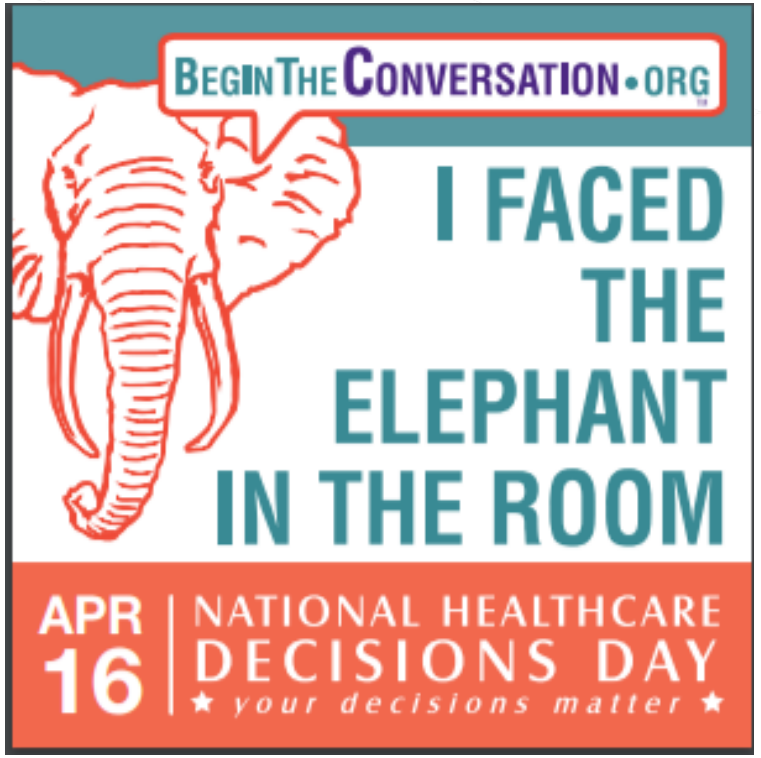
Do You Have an Advance Directive?

All adults with decision-making capacity should have the information and opportunity to communicate and document their healthcare decisions

-- **www.nhdd.org**

https://www.youtube.com/watch?v=uPDpfmdhwqs



Transition Connection Initiative (TCI)

- TCI aims to improve health care transition for clients in the REM and MW programs, their families and their providers.

- Thank you to our partners:
  - The Maryland Department of Health, Office for Genetics and people with Special Health Care Needs provides TCI with a systems development grant.
  - Frederick Memorial Hospital – "Your Life, Your Plan" materials.
  - Children's National Medical Center – Advance Directive Information Booklet.

"One of the greatest challenges we face is the need to prepare youth and families for transition to adulthood, including health care transition."

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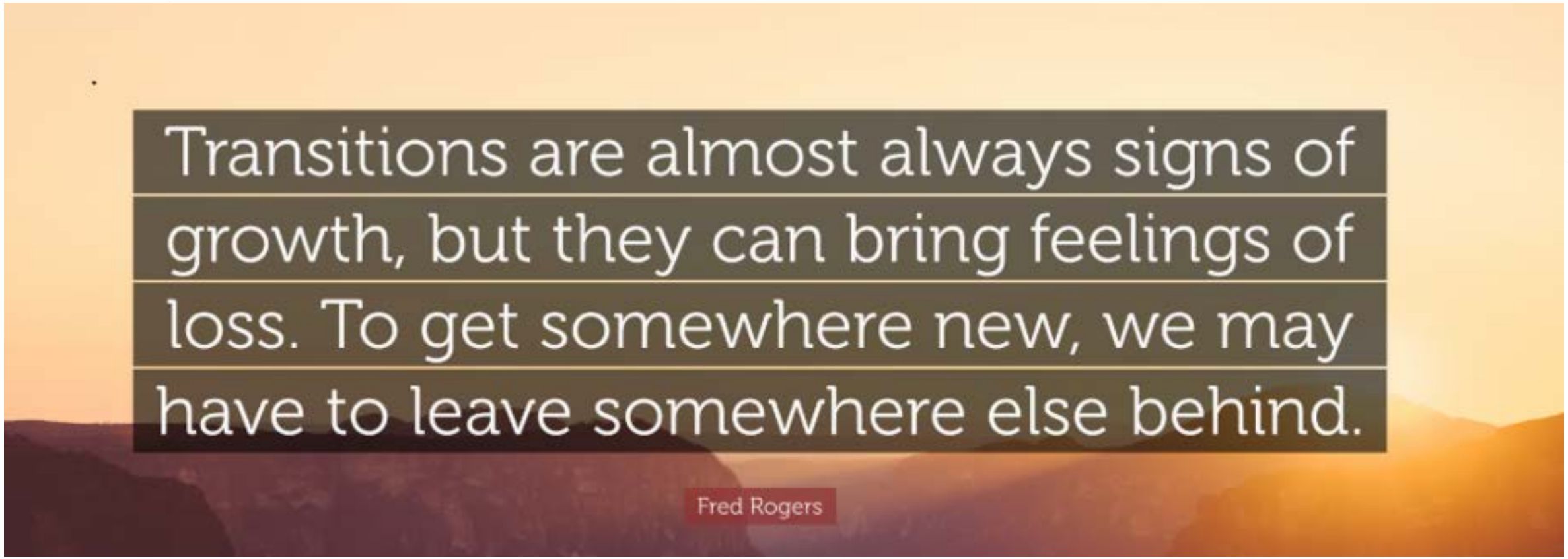
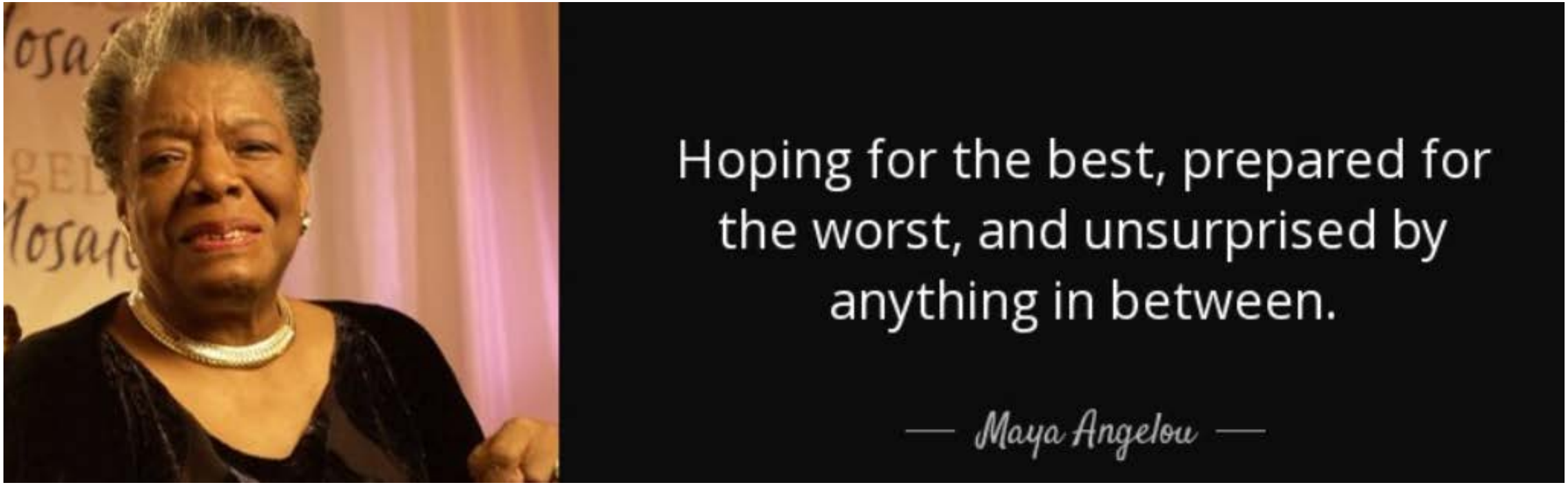

Transitions are almost always signs of growth, but they can bring feelings of loss. To get somewhere new, we may have to leave somewhere else behind.
Fred Rogers

Why is Advance Care Planning Important for People with Special Health Care Needs?

- People with complex medical conditions are at increased risk of:
  - Getting sick
  - Being hospitalized
  - Losing capacity, independence or identity
  - Dying
- Circumstances may result in the individual's inability to make or communicate decisions regarding future medical care.
- The end of life is often unpredictable.

~ National Healthcare Decisions Day 2019 Toolkit


Hoping for the best, prepared for the worst, and unsurprised by anything in between.
— Maya Angelou —

Remember the Benefits

- Advance Care Planning:
  - Gives the person a sense of control.
  - Provides for **communication** before a medical crisis occurs:
    - Decreases conflict
    - Allows parent to be a parent rather than a medical decision-maker
    - Decreases the potential for ethical dilemmas
    - Takes the burden off the family
    - Reduces anxiety of the surrogate decision maker

"You cannot make someone do what he or she is not ready or willing to do, but you can plant the seeds by pointing out that there are real advantages to early advance planning"

~ Rev. Gloria White-Hammond, Bethel AME, Boston MA

Having the Conversation

- For many people, this is not an easy discussion or question.
- Ask this question as an opportunity for further discussion.
  - **If the individual or family does not want to discuss this topic, then that is the end of the discussion.**
  - If they seem open to this topic, have the conversation.

Important Terms

- Advance directive
  - Living will
  - Medical POA (Power of Attorney)
- MOLST (Medical Order for Life-Sustaining Treatment)
- Financial POA

Advance Directive - Living Will

- **Written instructions** for care in the event that a person is not able to make medical decisions for themselves.
- Helps communicate **a person's wishes** about specific types of life-sustaining care (such as instructions for ventilator support, enteral feeding support, CPR, pain management, etc.).
- Can name a healthcare agent.
- Takes effect in the future **only when an individual becomes incapacitated.**

Advance Directive: Medical Power of Attorney

- A document that appoints a particular person (**health care agent)** to make health care decisions for an individual who is unable to do so for themselves:
  - The **healthcare agent** is bound to make decisions according to the wishes of the individual with the advance directive.
  - The healthcare agent may also be called a **health care proxy** or **health care surrogate.**

MOLST:
Maryland Order for Life-Sustaining Treatment

- **Medical orders** regarding end-of-life medical care.
- Can only be completed by a physician, nurse practitioner or physician assistant.
- Should be completed for all individuals in Maryland who are admitted to nursing homes, assisted living programs, hospices, home health agencies and dialysis centers.

More about the MOLST

- MOLST designates what will happen to the individual in an emergency situation.
- Details of the MOLST are discussed with the person's physician.
- MOLST is effective immediately once signed by a medical provider.
- **Everyone has a right to decline to discuss or make decisions about these topics.**

Financial Power of Attorney

- Appoints someone to conduct **financial business** on a individual's behalf.
- Can only be done by a person with decision-making capacity.
- Recommend legal consultation to develop.
- Must be witnessed and notarized.
- *The Financial POA is only for financial business and not for health care decision making.*

Communication

- If there is a MOLST:
  - Who knows about it?
  - How will EMS know?
  - Should travel everywhere with individual.
- If there is no MOLST, emergency responders will do everything.
- The health care provider (MD, DO, NP or PA) should be contacted if you want to discuss a MOLST.

"Anything that's human is mentionable, and anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone."

~ Fred Rogers, 1928 - 2003

Advance Care Plans – *Have the Conversation*

https://www.youtube.com/watch?v=rHZ7OHoT3MA

Why is it so hard to begin the conversation?

- We fear of making an individual or family member upset or uncomfortable.
- We think it may not be our place to discuss end of life.
- We think that the conversation should be started by medical providers or families.
- We feel uncomfortable talking about death and dying.
- When we mention advance directives, people think we have lost hope for their care and recovery.
- We do not have enough time for discuss it properly.

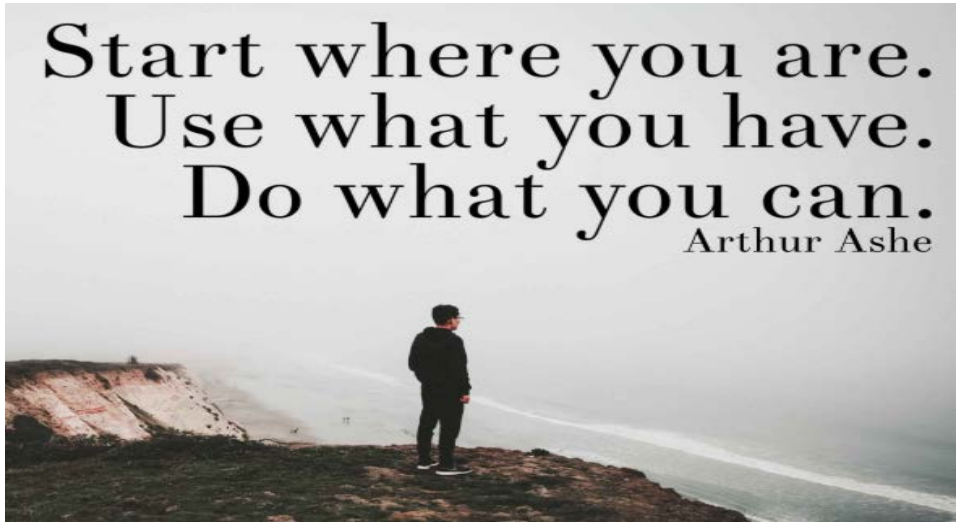
Abby and Jeanne Phillips

Sometimes the most important conversations are the most difficult to engage in

Jeanne Phillips

Before Starting the Conversation

- Remember your purpose.
- Plan what you want to say ahead of time.
- Pick a good time.
- Ask permission.



How to Start

- Ask if they have an advance directive or MOLST.
- Take small steps at first; acknowledge that advance care planning is a process.
- Find a **trigger event** to begin the conversation:
  - Turning 18 – healthcare decision-making and legal changes are already part of the transition conversation.
  - Discussing emergency care plans – what do you do **now** when there's an emergency and you can't speak for yourself?
  - When updating medical paperwork.
  - After a hospitalization or health crisis.

Conversation Techniques

- What **TO** say
  - Can we talk about advance care planning? *This doesn't mean that the person's health condition or plan of care has changed.*
  - What goals does the individual have to live their best possible future?
- What **NOT** to say
  - I'm so sorry that we have to have this discussion now.
  - What would the person want if they were dying?
  - This is what I would do if I was in your position.

Be careful not to impose your own perspectives and beliefs onto the conversation.

Advance Directive Resources

- Maryland Advance Directives
  - Guide, forms https://www.oag.state.md.us/Healthpol/adirective.pdf Guide, forms
  - Summary http://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/HCDAsummary.pdf

- Maryland Electronic Advance Directives
  - http://mhcc.maryland.gov/mhcc/pages/hit/hit_advancedirectives/hit_advancedirectives.aspx
  - https://mydirectives.com/

- "Making Medical Decisions for Someone Else: A Maryland Handbook"
  - http://www.oag.state.md.us , click on "Guidance for Health Care Proxies."

- Advance Directives for other states
  - Caring Connections (NHPCO) at 1-800-658-8898 or http://www.caringinfo.org.

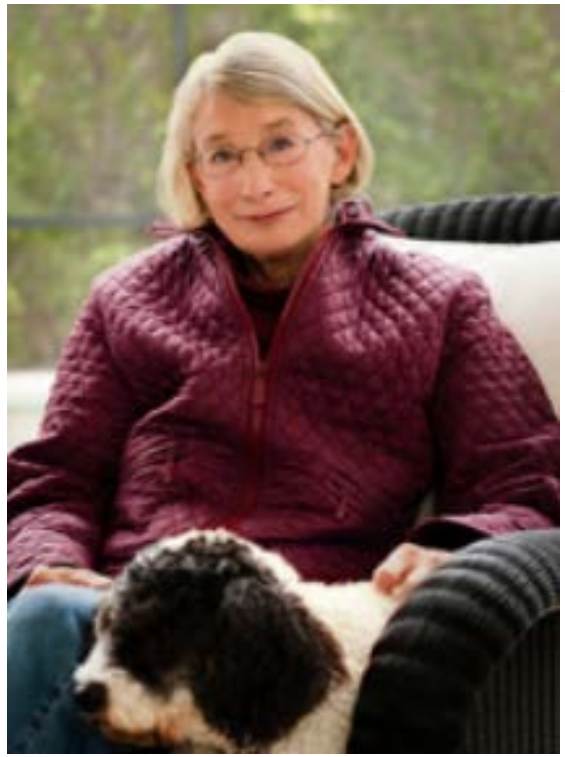
- "Five Wishes"
  - https://fivewishes.org/

- The Conversation Project
  - https://theconversationproject.org/

MOLST Resources

- Maryland MOLST forms and resources can be found here:
  - http://marylandmolst.org/

“Tell me, what is it you plan to do with your one wild and precious life?”



“to live in this world

you must be able
to do three things
to love what is mortal;
to hold it

against your bones knowing
your own life depends on it;
and, when the time comes to let it go,
to let it go”

--- **Mary Oliver (1935 – 2019)**

New and Selected Poems, Volume One

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Recommended Reading

- "Being Mortal: Medicine and What Matters in the End" by Atul Gawande
- "When Breath Becomes Air" by Paul Kalanithi
- "With the End in Mind: Dying, Death and Wisdom in an Age of Denial" by Kathryn Mannix
- "The Unwinding of the Miracle: A Memoir of Life, Death and Everything That Comes After" by Julie Yip-Williams
- "The Conversation: A Revolutionary Plan for End of Life Care" by Angelo Volandes
- "Me Before You" by JoJo Moyes (book, DVD)