caringkind

Navigating Transitions Part II:

Understanding a Person-Centered Approach to the Dementia Journey

Planning care choices and actions

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Transition

Willingness to consider the end, learning about the late stage but with hope for it improving the current living

Fear…. But don't discuss

Thoughts of dependence and fear physical/ cognitive decline

Expect primary care physician to initiate discussion

75% of hospitalized patients thought about desired care 90% discussed with family, only 30% with physician.

92% of people over 50 discussed EOL with family, only 18% with doctor

Positive aspects of death?

- Possibilities for deeper meaning and inspiration to life
- Death literally gives us life
- Death enables evolution
- Sensitivity reveals appreciation – how fragile life is
- Reminder of the common human condition
- Healthy adjustment - may influence adaption to other losses
- Emotional hurt reminds us we care
- Possibility of death may serve life
- Brings an end to suffering
- Triggers memories of the collective dead

John Abraham *How to Get the Death You Want*

Beginning Dialogue about Death

- Begin with yourself – understand self before asking others to converse
- Common remarks
  - Something I'm reconciled with and have prepared
  - Rude surprise
  - Tragic event
  - Grim Reaper
  - Release and relief
  - A defeat – not uncommon in the healthcare system

Societal Reluctance to "Death"

When avoid...

Challenges arise

Not prepared

Emotional and psychological toll

Families and Providers

Unneeded and unwanted medical interventions

Miss out on available supports

e.g. Hospice

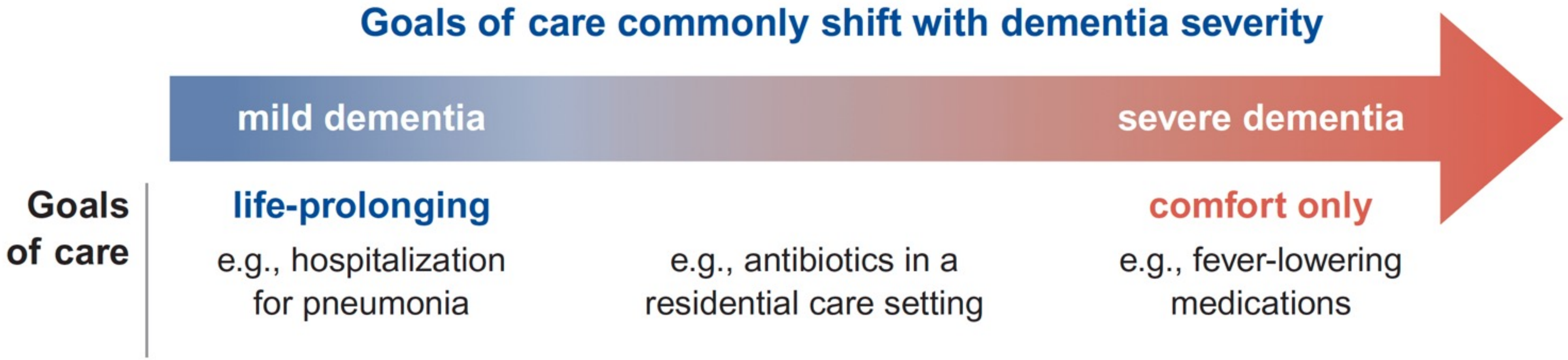
Practical Framework

Is it the right time to begin discussions?

- Hint – it's always the right time
- Small frequent discussions are best

Are there signs? Should we shift from curative to palliative?

- Know the disease
- Ask your team
- Do some simple research
- Trust your intuition



Goals of care commonly shift with dementia severity

mild dementia → severe dementia

Goals of care

life-prolonging
e.g., hospitalization for pneumonia

e.g., antibiotics in a residential care setting

comfort only
e.g., fever-lowering medications

Kenny Family Journey

- Early Goal – Independence
- Changes Needed
- Stroke
- Further Functional Decline

Transition

Understand and consider common perspectives about end-of-life contemplation regarding cognitive loss

Five Themes

- Avoiding dehumanizing treatment and care
- Confronting emotionally difficult conversations
- Navigating existential tensions
- Defining personal autonomy
- Lacking confidence in healthcare setting

Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

Avoiding Dehumanizing Treatment and Care

- Remaining connected
- Delaying institutionalization
- Rejecting burdens of futile treatment

Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

Things to Contemplate

- *Remaining connected?*
- *Communication severely impaired?*
- *Dehumanizing?*

Confronting Emotionally Difficult Conversations

- Cause of dying
- Cognitive decline too frightening to think about in advance
- Locked into pathway (ticking boxes)

Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

Things to Contemplate

- *Facilitate conversations?*
- *Tools?*

Navigating Existential Tensions

- Accepting inevitable incapacity and death
- Fear of being responsible for death
- Alleviating decisional responsibility

Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

Things to Contemplate

- *What supports exist to tolerate existential tension?*
- *What could be started or improved?*

Defining Personal Autonomy

- Care partners struggle with unknown preferences
- Individuals depend on care partner advocacy
- Justifying treatments for health deterioration

Sellars et al. Perspectives of people with dementia and their careers
on advance care planning and end-of-life care: Palliative Medicine 2019

Things to Contemplate

Ask for what they need

- ……from healthcare?
- from family?
- from their advocates?

Lacking Confidence in Healthcare Setting

- Distrusting clinician's mastery and knowledge of dementia
- Making uninformed choices
- Deprived of access to hospice care and support at end of life

36-HOUR DAY Book

Making Tough Decisions about End-of-Life Care in Dementia

ANNE KENNY, MD

Your True NORTH

A Guided Journal for Those Living with Cognitive Loss or Dementia about Legacy, Love and Wishes for the End of a Life Well-lived.

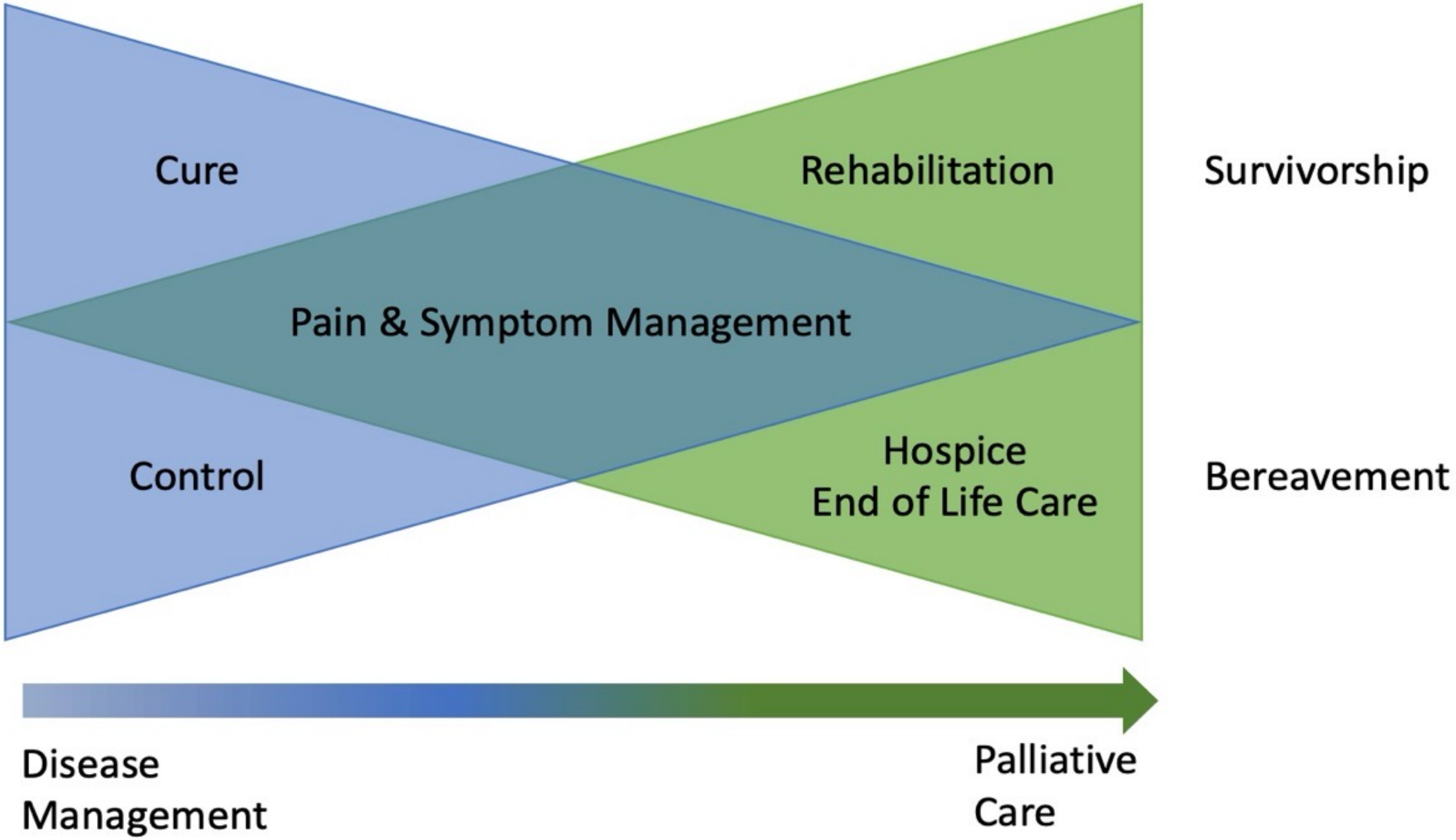
By Anne Kenny, M.D

Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

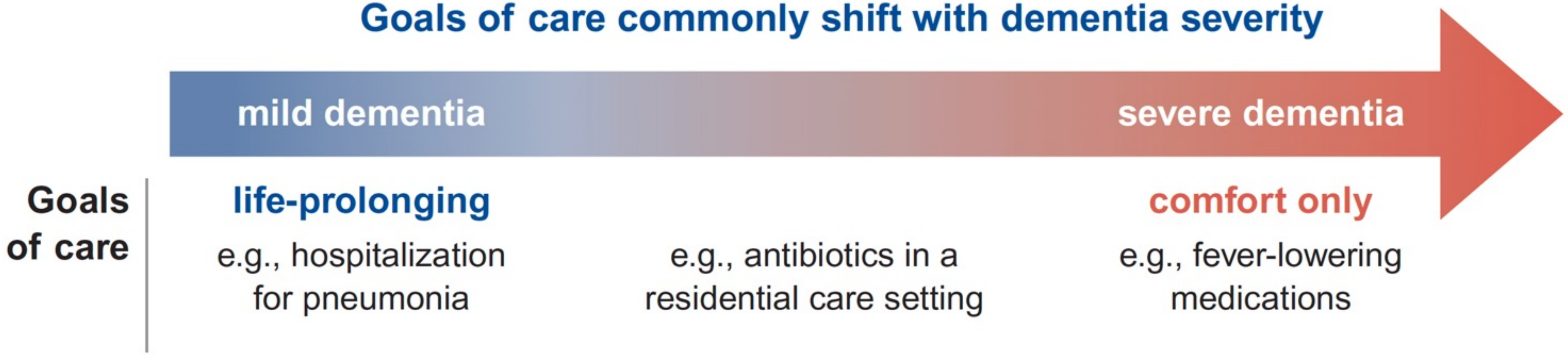
Transition

Develop and document a plan for end-of-life choices

Palliative Care Framework



Hawley, P,H. (2014). The Bow Tie Model of 21st Century Palliative Care. Journal of Pain and Symptom Management.



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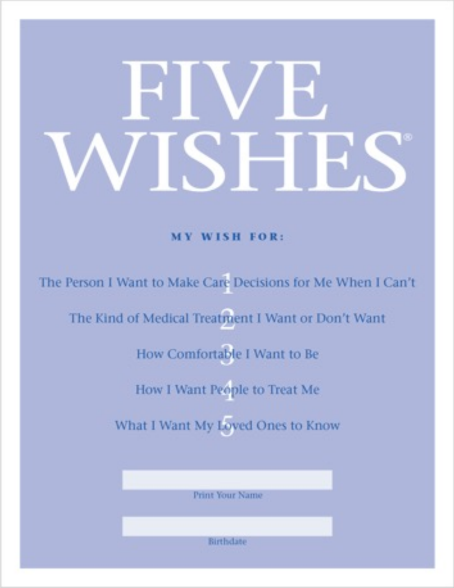
Advance Care Planning Tools


PREPARE™
for YOUR care


FIVE WISHES®

MY WISH FOR:

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

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

3 How Comfortable I Want to Be

4 How I Want People to Treat Me

5 What I Want My Loved Ones to Know

Print Your Name

Birthdate


Dementia Values and Priorities Tool®

START

compassion & choices
Care and Choice at the End of Life


Your Conversation Starter Guide

For Caregivers of People with Alzheimer's or Other Forms of Dementia

How to understand what matters most to someone living with Alzheimer's or another form of dementia, and help them have a say in their health care.

Institute for Healthcare Improvement

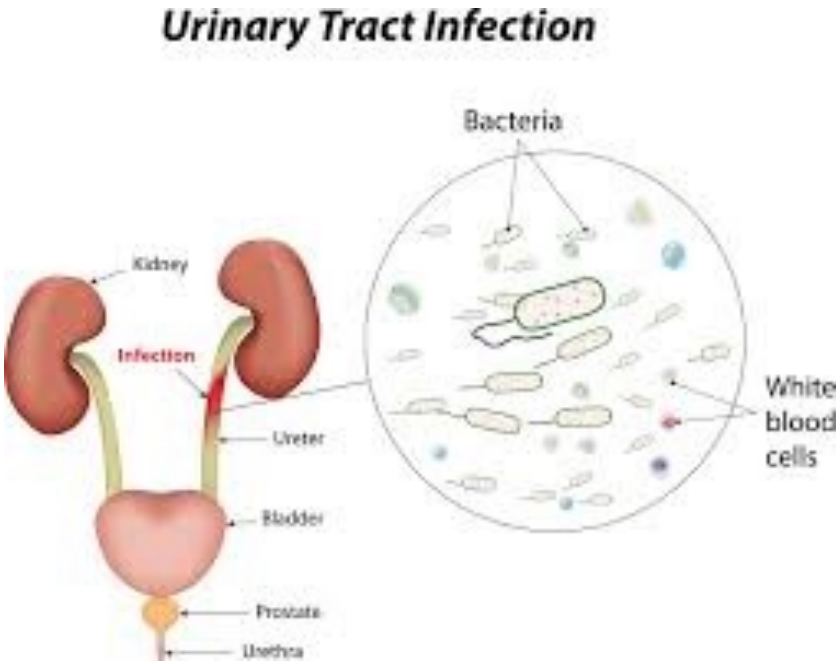
the conversation project

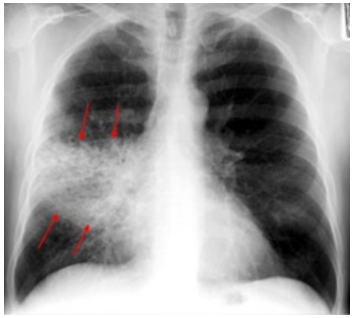
©2023 The Conversation Project, an initiative of the Institute for Healthcare Improvement (IHI)

Changes or Limitations to Medical Care in Middle Stage of Dementia

- Medications
- Nutrition/Hydration
- Exercise
- Hospitalization
- Medical interventions
- Engagement vs. rest

Limitations to Medical Care in Late Stage Dementia

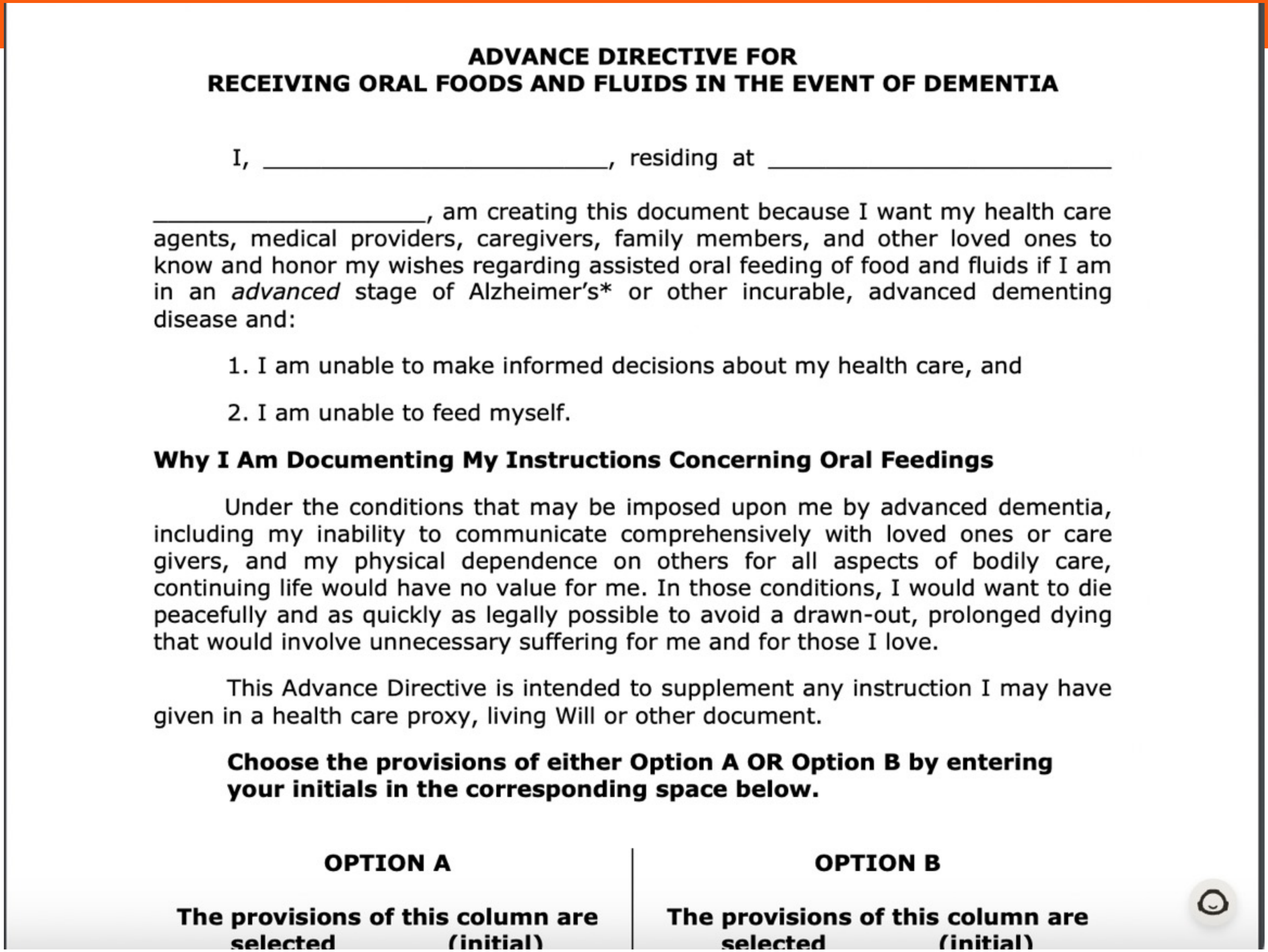




Research does not warrant the treatment of:

- Urinary tract infections
- Pneumonia due to aspiration
- Hydration
- Feeding tubes
- Hospitalizations

Comprehensive Advanced Care Planning in Dementia



ADVANCE DIRECTIVE FOR
RECEIVING ORAL FOODS AND FLUIDS IN THE EVENT OF DEMENTIA

I, ______________________________, residing at ______________________________

________________________, am creating this document because I want my health care agents, medical providers, caregivers, family members, and other loved ones to know and honor my wishes regarding assisted oral feeding of food and fluids if I am in an *advanced* stage of Alzheimer's* or other incurable, advanced dementing disease and:

1. I am unable to make informed decisions about my health care, and
2. I am unable to feed myself.

Why I Am Documenting My Instructions Concerning Oral Feedings

Under the conditions that may be imposed upon me by advanced dementia, including my inability to communicate comprehensively with loved ones or care givers, and my physical dependence on others for all aspects of bodily care, continuing life would have no value for me. In those conditions, I would want to die peacefully and as quickly as legally possible to avoid a drawn-out, prolonged dying that would involve unnecessary suffering for me and for those I love.

This Advance Directive is intended to supplement any instruction I may have given in a health care proxy, living Will or other document.

Choose the provisions of either Option A OR Option B by entering your initials in the corresponding space below.

OPTION A	**OPTION B**
The provisions of this column are selected (initial)	**The provisions of this column are selected (initial)**

https://endoflifechoicesny.org/wp-content/uploads/2018/03/3_24_18-Dementia-adv-dir.pdf

Your life, your choices

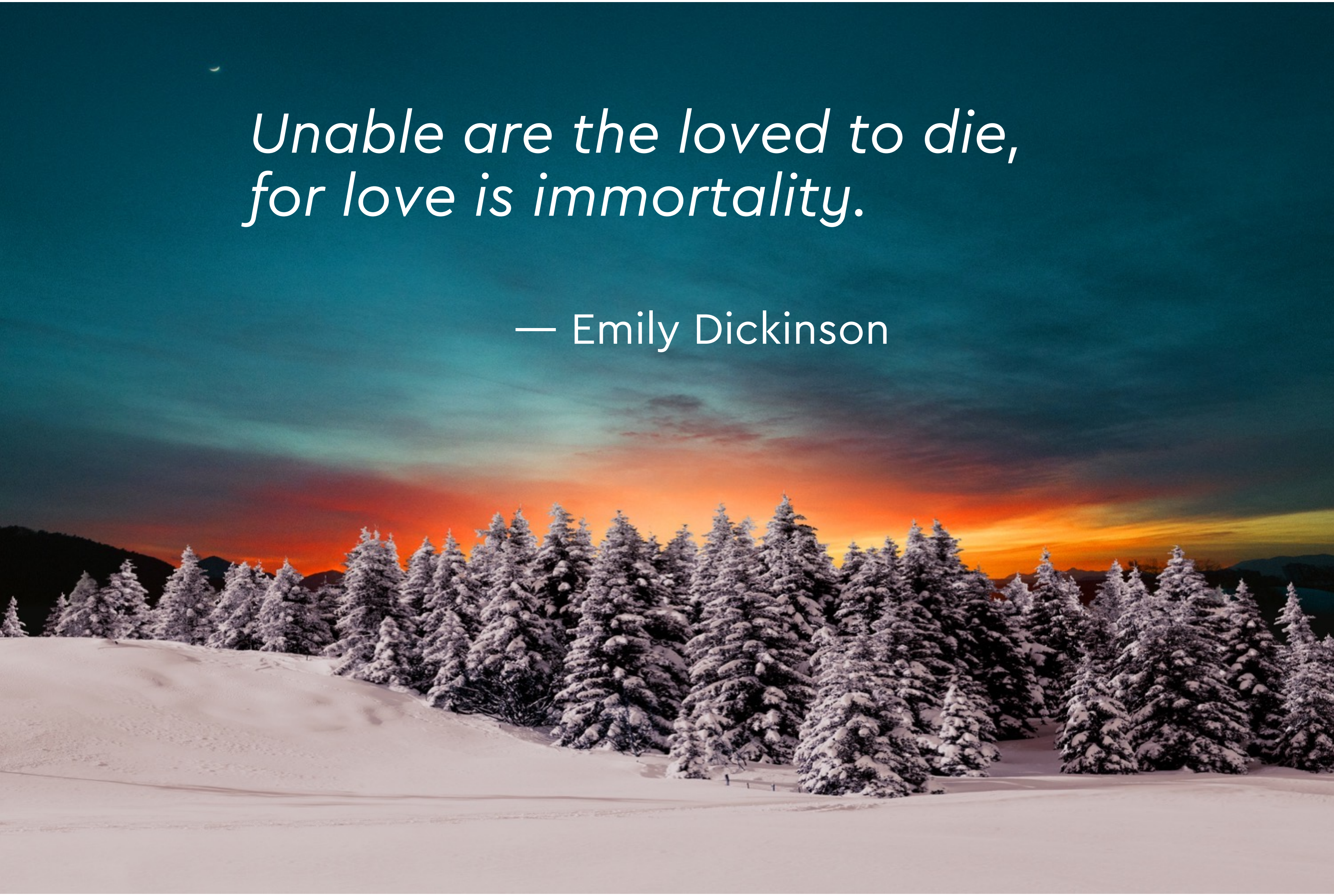
Consider that you are in charge –

Healthcare providers are trained in a medical approach and to save lives, not create comfort –

Does this change your view on planning?

Your life, your plans

- Advance Directives
- Add riders to be more comprehensive
- Use tools such as The Conversation Project Toolkit, Compassion and Choices, Prepare for Your Care, or 5Wishes to help guide more value-based discussions
- Document and communicate via paper or video



Unable are the loved to die,
for love is immortality.

— Emily Dickinson

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Talk to a Navigator

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Serving:
Brooklyn, Bronx,
Manhattan, Queens,
Staten Island...
and beyond!

caringkind New York City Alzheimer's Walk

Saturday, October 19, 2024 • 10 am
Central Park Naumburg Bandshell

Join Us at
New York City's
Longest-Standing
Alzheimer's
Awareness Walk and
Brain Health Day
in Central Park!

REGISTER VOLUNTEER CKWALK.ORG

For over 45 years CaringKind has been your Trusted Partner in Alzheimer's and related dementia care. Our mission is to be a compassionate ally for everyone, ensuring no one faces this journey alone.

For more information,
contact Samantha Vaccaro
at walk@cknyc.org or **646-744-2979**

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QUESTIONS
WE HAVE THE ANSWER