



Navigating Transitions Part II:

*Understanding a Person-Centered Approach
to the Dementia Journey*

Planning care choices and actions

Anne Kenny, MD

Palliative & Clinical Care Consultant

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



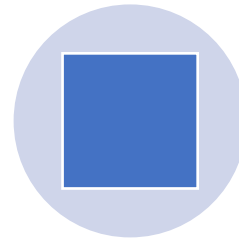
Thoughts of dependence and fear physical/ cognitive decline



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 caregivers 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 caregivers 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 caregivers 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



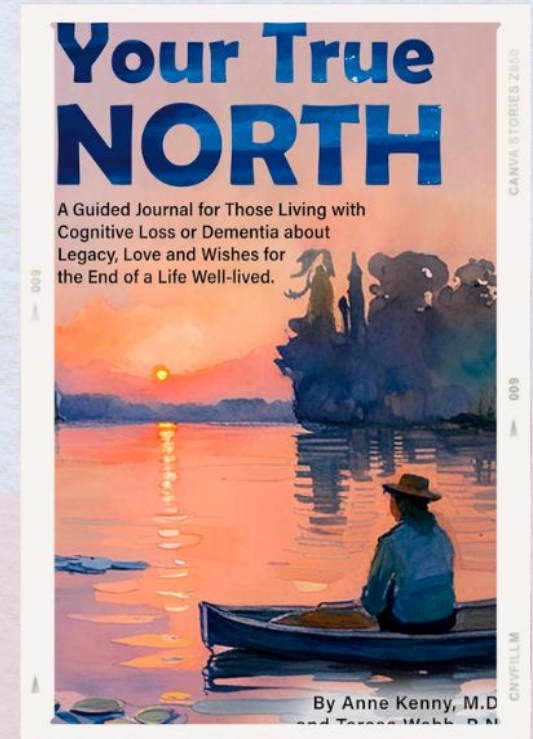
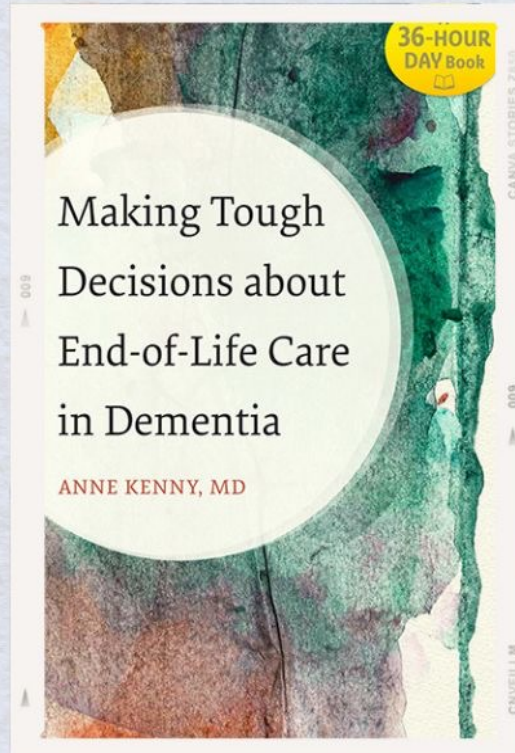
Ask for what they need

-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

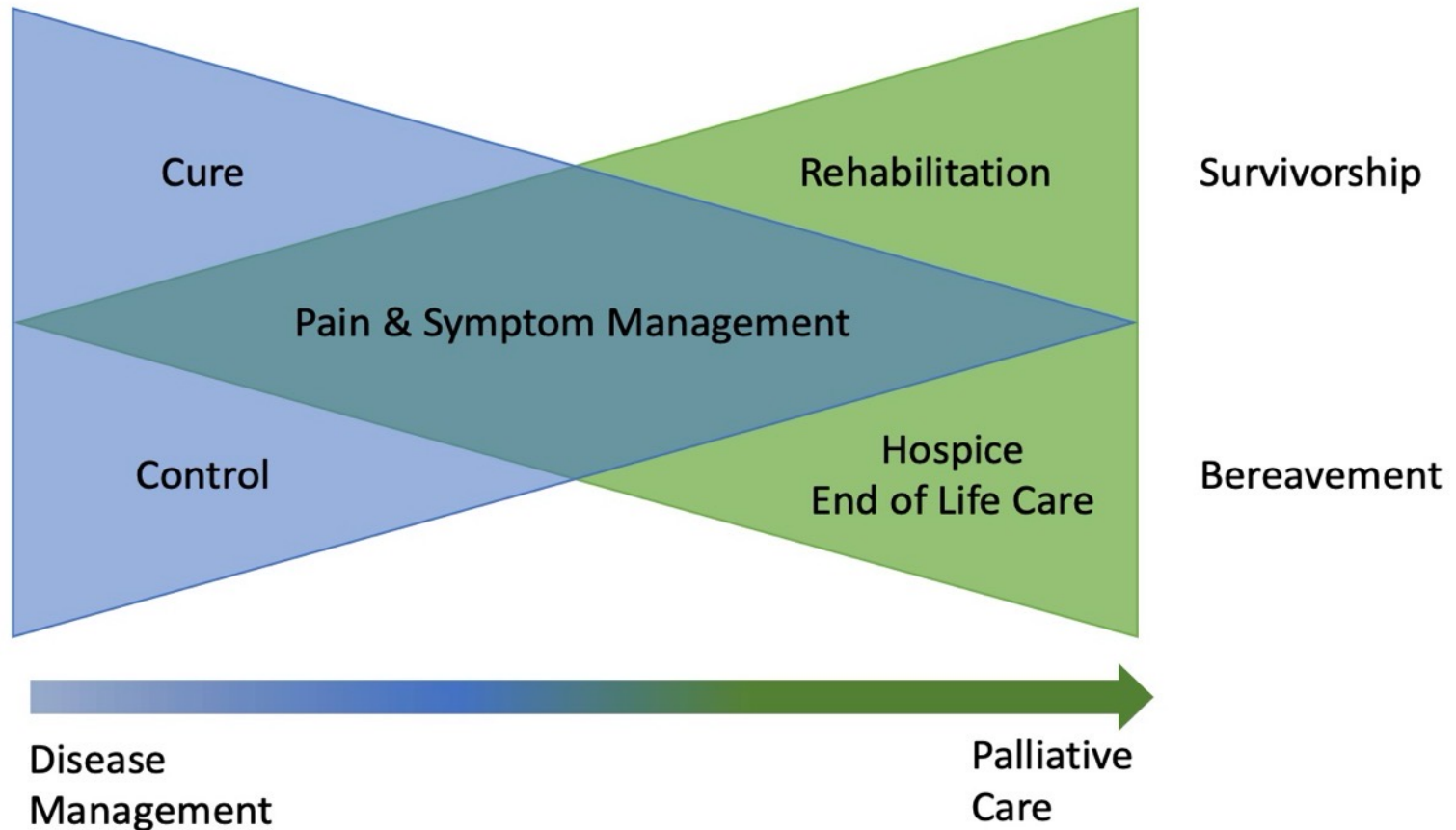
Sellers et al. Perspectives of people with dementia and their caregivers on advance care planning and end-of-life care: Palliative Medicine 2019



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*.

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

Advance Care Planning Tools




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



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)

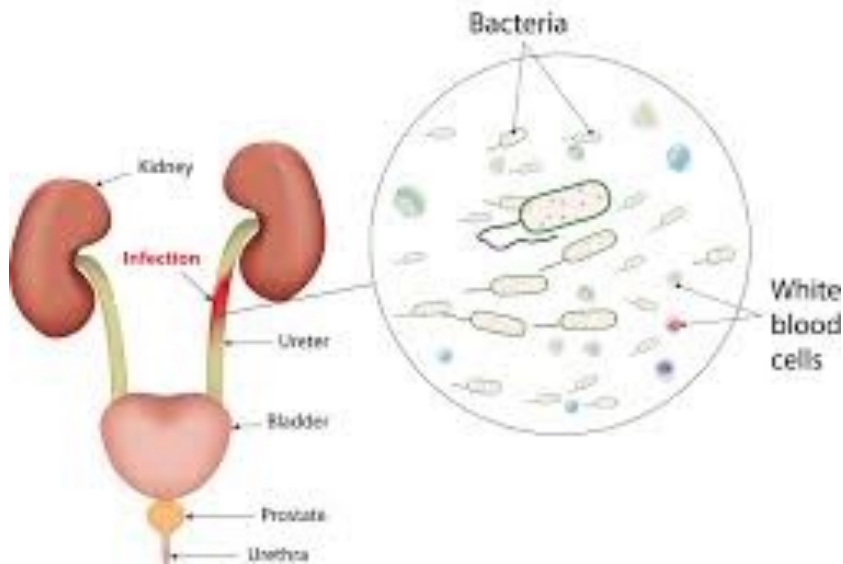
Changes or Limitations to Medical Care in Middle Stage of Dementia

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



Limitations to Medical Care in Late Stage Dementia

Urinary Tract Infection



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

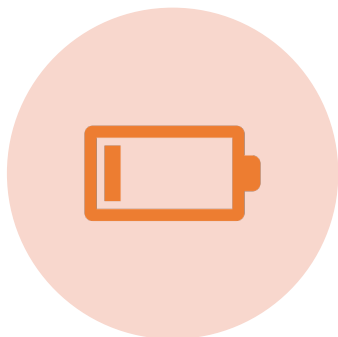
The provisions of this column are selected (initial)

OPTION B

The provisions of this column are selected (initial)



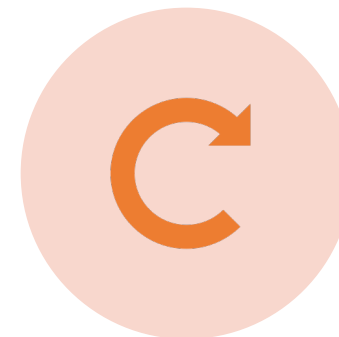
Your life, your choices



*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

caringkind

Talk to a
Navigator

646-744-2900



www.caringkindnyc.org

646-744-2900

Info@cknyc.org

www.caringkindnyc.org

Anne Kenny, MD
Palliative & Clinical Care
Consultant

akenny@cknyc.org

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



caringkind *Walk* New York City Alzheimer's

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](https://www.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**

360 Lexington Avenue, 3rd Floor
New York, NY 10017
Helpline: 646-744-2900





QUESTIONS

WE HAVE THE ANSWER