caringkind

Navigating Transitions Part I:

Understanding a Person-Centered Approach to the Dementia Journey

Introduction to palliative care, hospice, living-dying arc

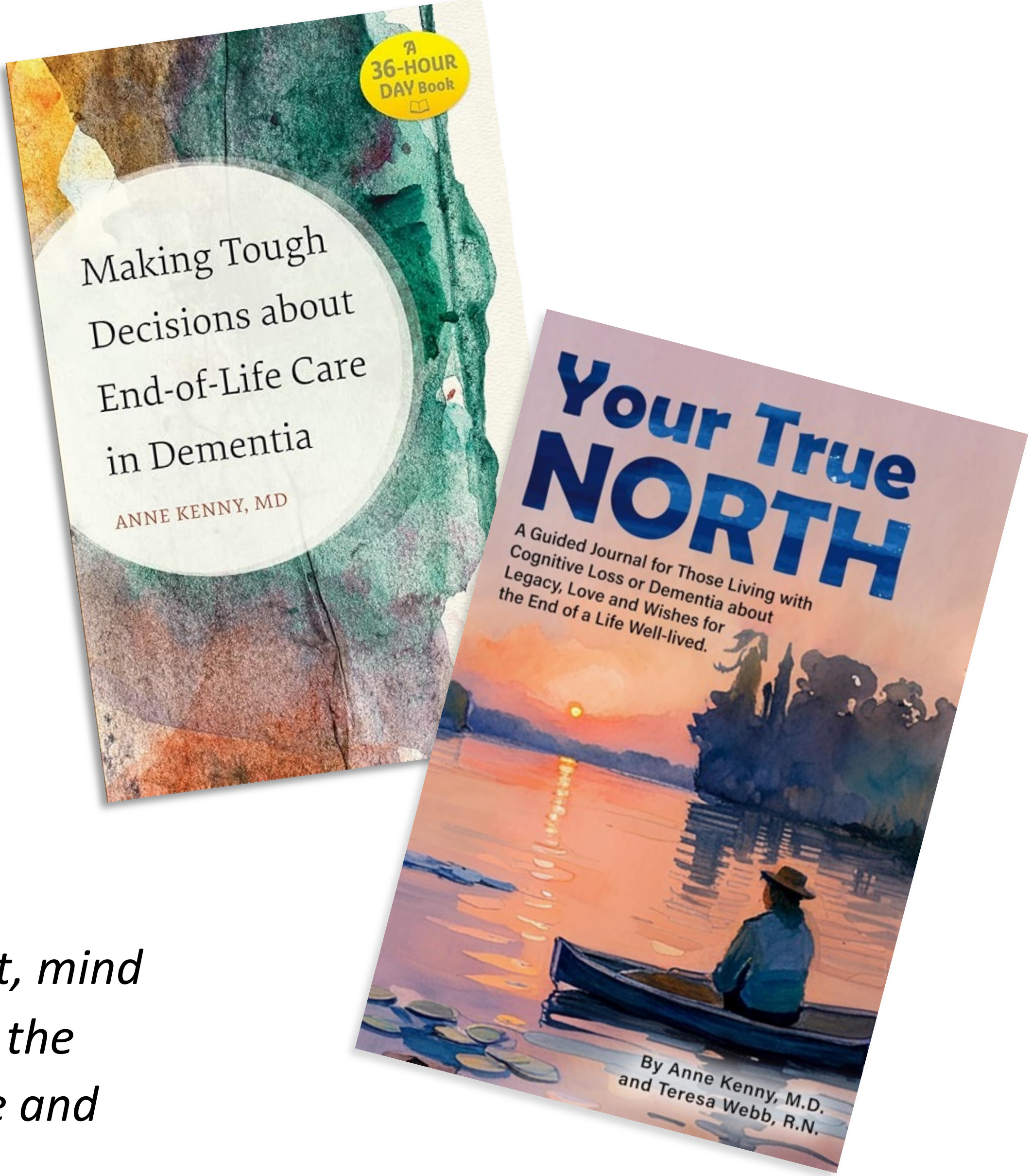
Anne Kenny, MD
Palliative & Clinical Care Consultant

360 Lexington Avenue
New York, NY

646-744-2900
www.caringkindnyc.org

Anne Kenny, MD

- Physician
- Caregiver
- Author
- Advocate



"Death isn't just about health and medicine, but the merging of spirit, mind and body – we need to take back *the complexity of choosing how to live and choosing how to die." p 20*

Transition

Getting a diagnosis, building knowledge and support

Common scenario when given diagnosis of dementia – need for support

- "There is nothing they can do, take a pill and come back to see the medical community in 6 months to a year"

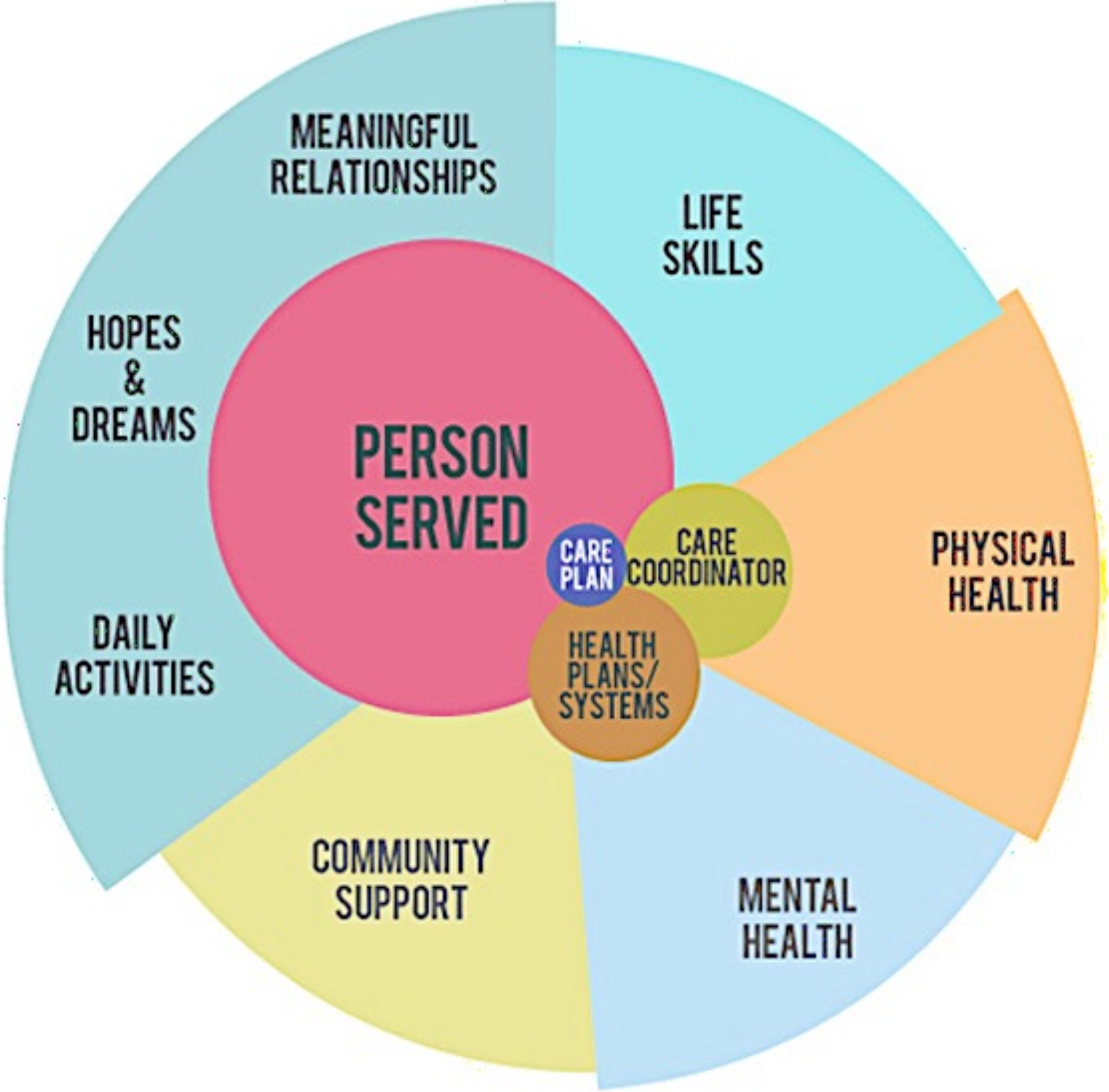
- "Put your affairs in order"

But.....

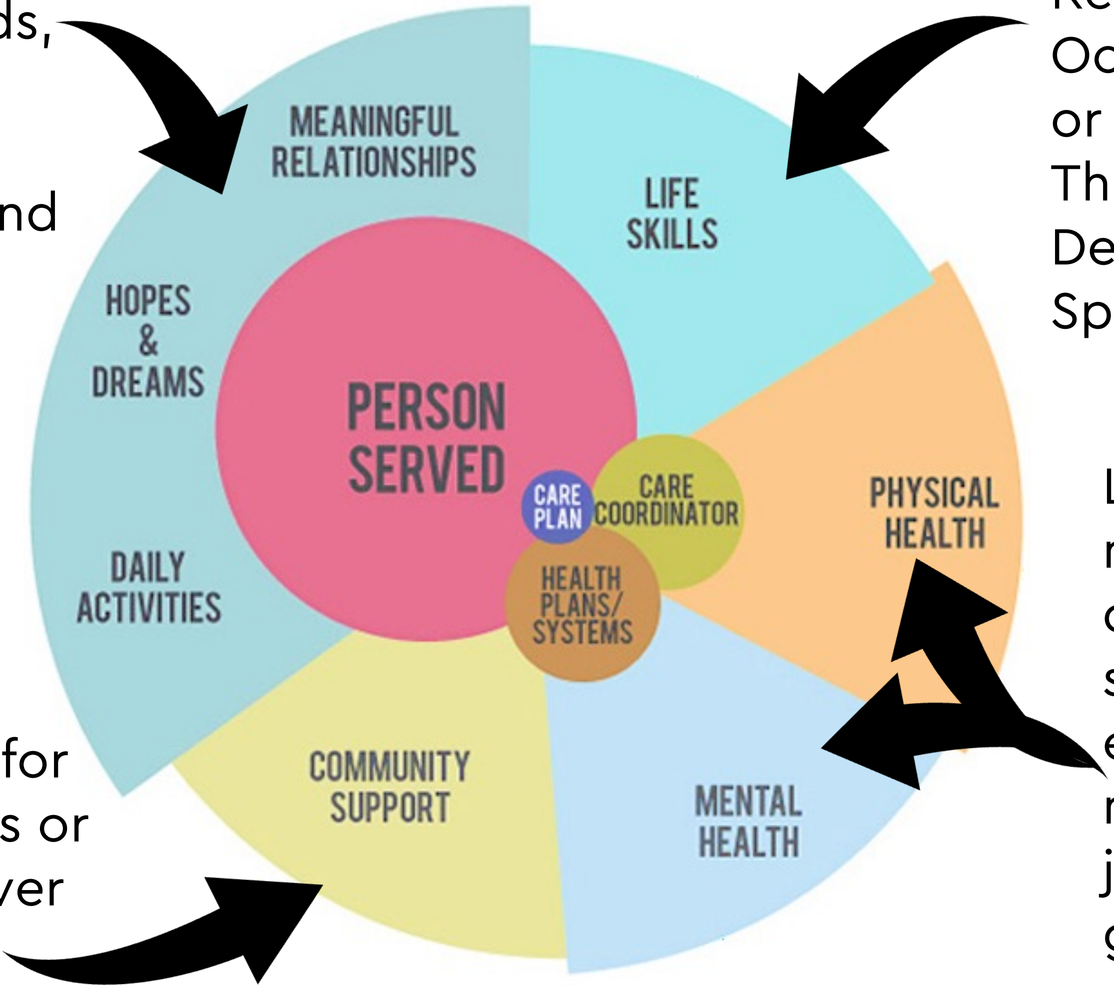
- Those who were given support (and hope) experienced markedly decreased distress (from 30% to 5%), while those who were left without support experienced psychological distress that increased from 30 to 45%

(Mazurek Clinical Interventions in Aging 2019).

How to provide that support with person-centered care?



Examples of Interventions



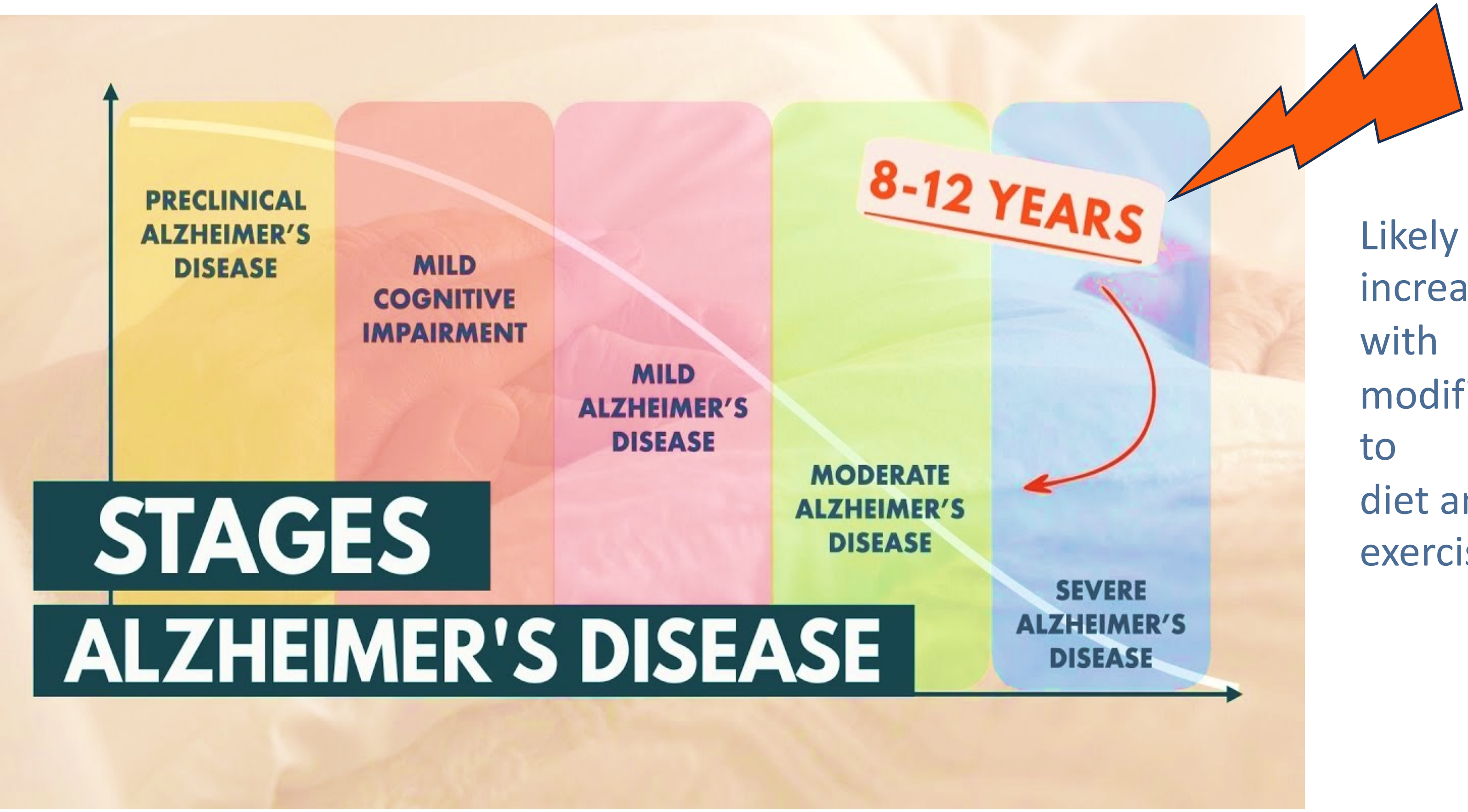
Family, Friends, Peers having Meaningful discussions and engagement

Referral to Occupational or Speech Therapy or Dementia Specialist

Lifestyle modifications to diet, exercise, social engagement, meditation, journaling, gratitude

CaringKind Programming for Early Diagnosis or Family Caregiver Support

Need for Information - Understanding the Disease Trajectory



Likely will increase with modification to diet and exercise

Building Knowledge – Understanding the Basics

You've been diagnosed.

What's next?

Stephani Shivers
Chief Innovation Officer
CaringKind

caringkind

www.caringkindnyc.org

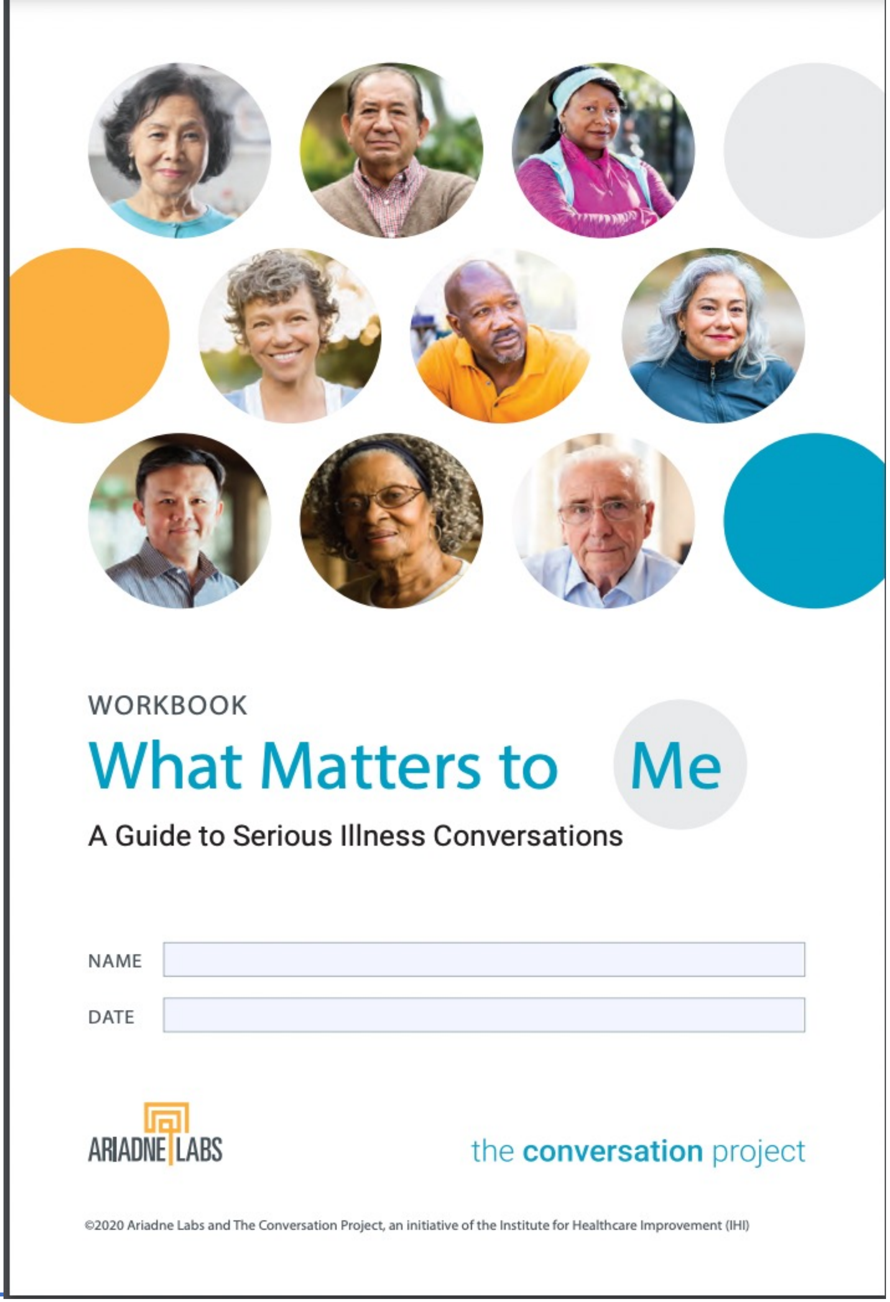
https://www.youtube.com/watch?v=gt2So9RLzZc

Transition

Contemplating goals, communicating goals, exploring choices for later transitions

Need for Communication and Planning - Preparing for the Discussion

theconversationproject.org/



WORKBOOK

What Matters to Me

A Guide to Serious Illness Conversations

NAME

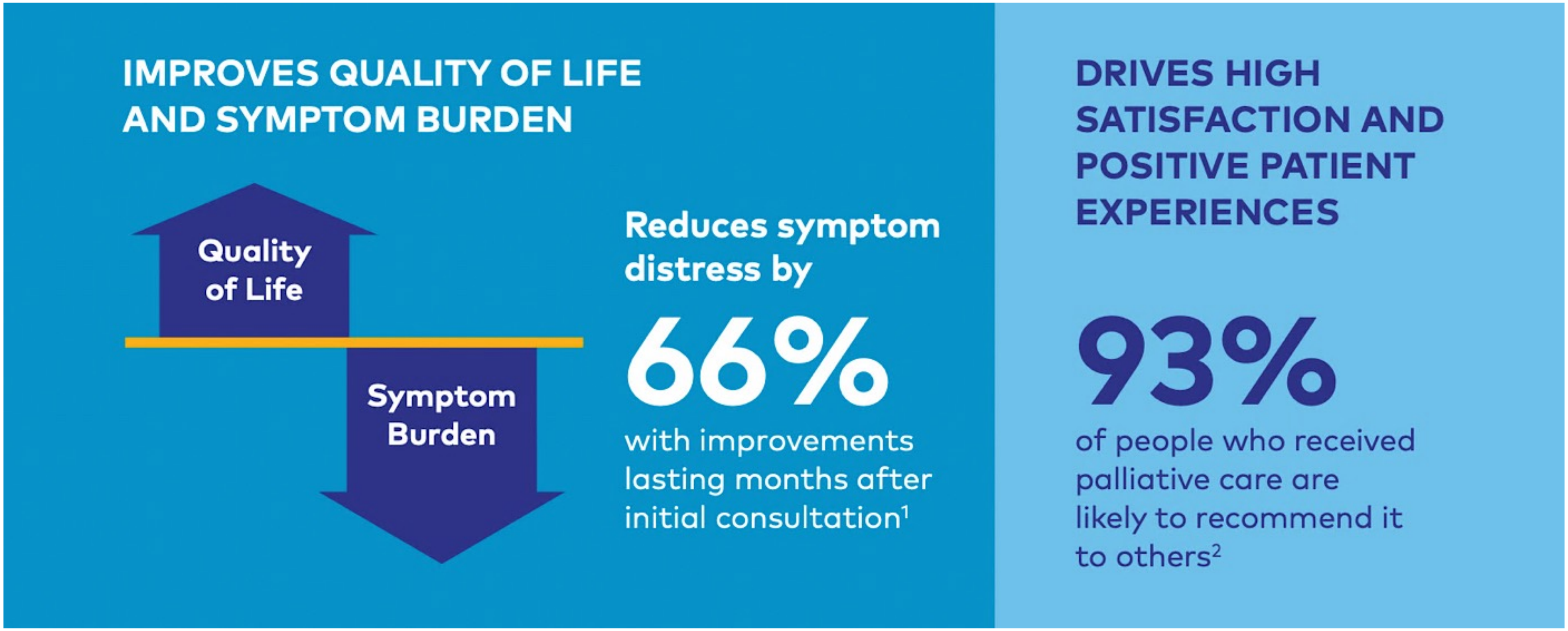
DATE

ARIADNE LABS

the **conversation** project

©2020 Ariadne Labs and The Conversation Project, an initiative of the Institute for Healthcare Improvement (IHI)

Building Support – Consider Early Palliative Care Approach



IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN

Quality of Life

Symptom Burden

Reduces symptom distress by

66%

with improvements lasting months after initial consultation[1]

DRIVES HIGH SATISFACTION AND POSITIVE PATIENT EXPERIENCES

93%

of people who received palliative care are likely to recommend it to others[2]

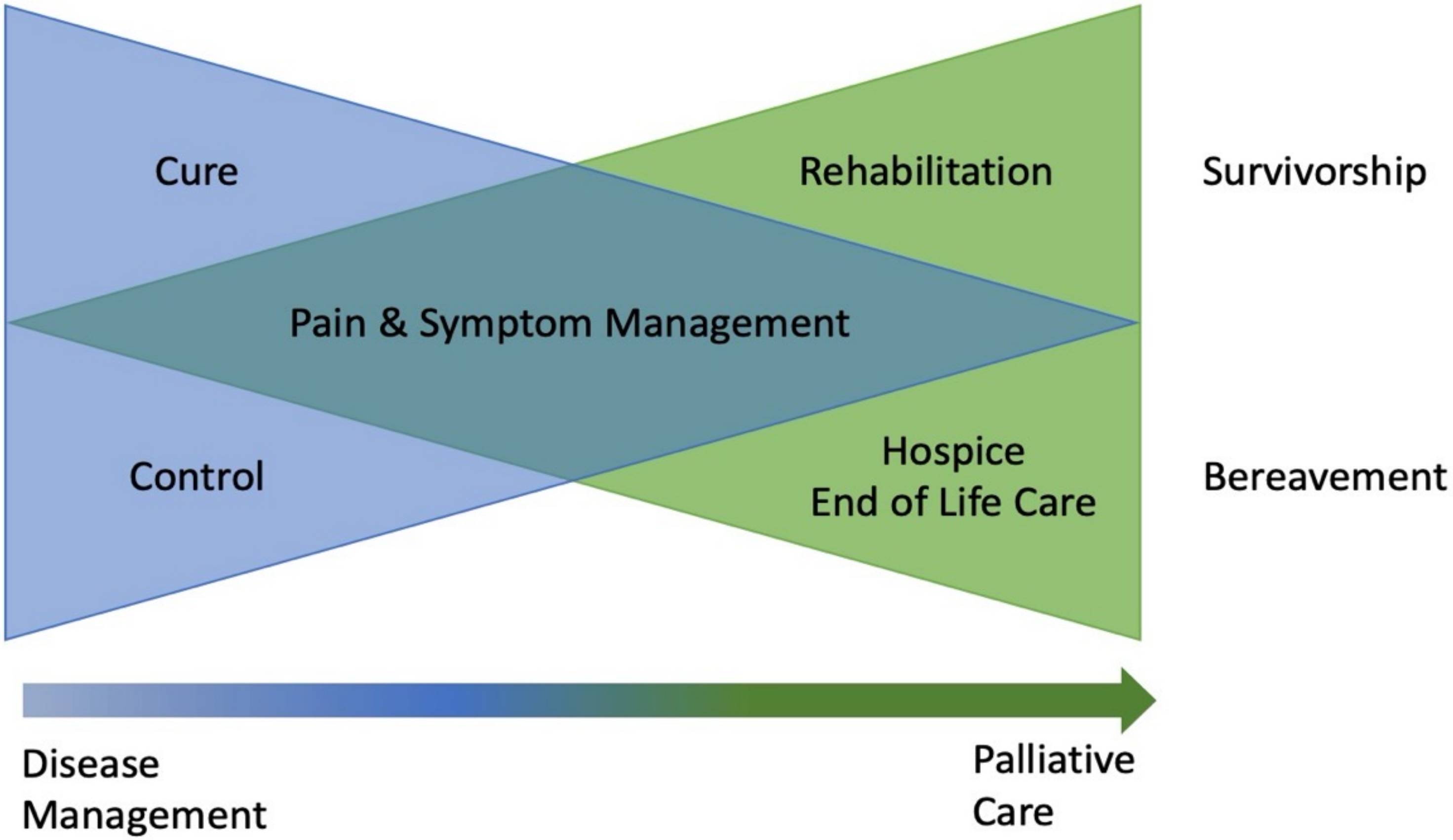
1:Kavalieratos, D, J Corbelli, and D Zhang. JAMA 2016
2: Boehler, A. NICHM Foundation Webinar: May 19, 2017

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 the *prevention and relief of suffering* by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

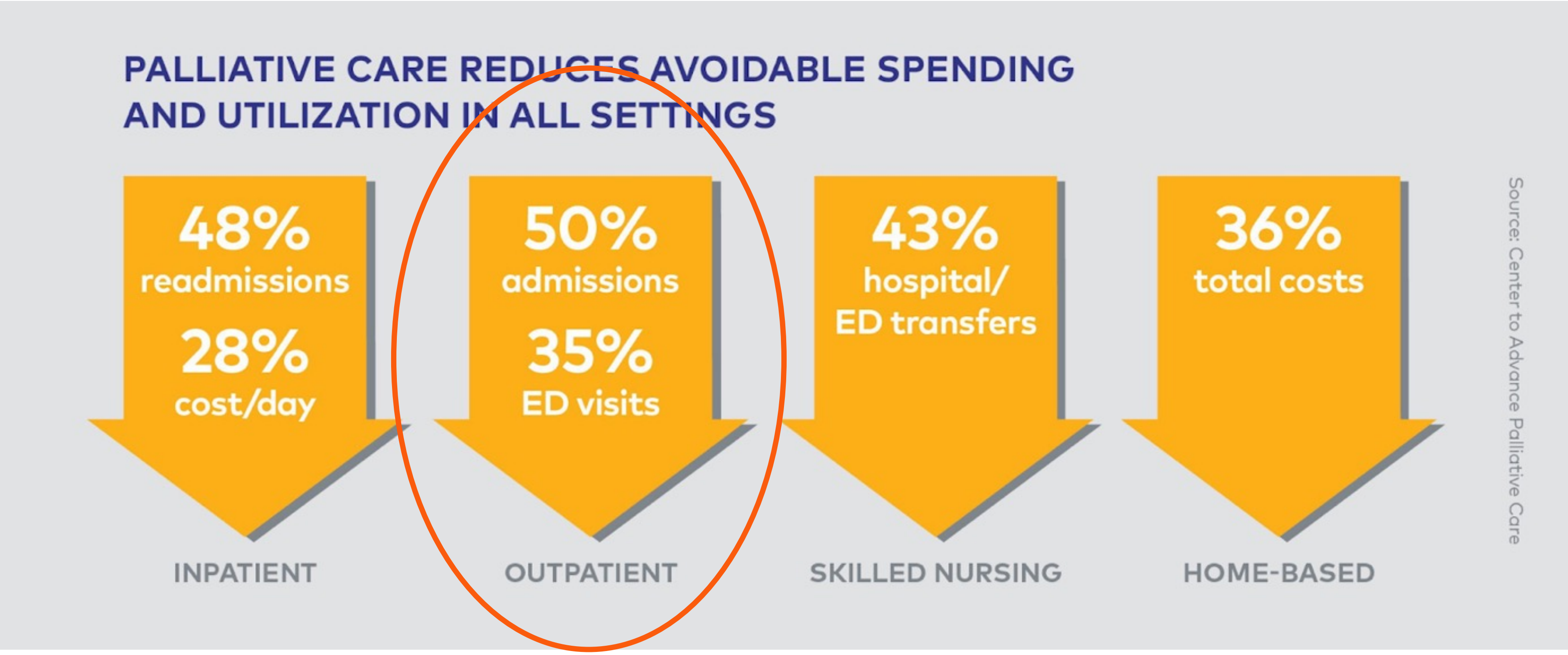
World Health Organization (WHO) definition

What is palliative care?



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

Palliative Care – How Does It Help?



PALLIATIVE CARE REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS

48%
readmissions
28%
cost/day
INPATIENT

50%
admissions
35%
ED visits
OUTPATIENT

43%
hospital/
ED transfers
SKILLED NURSING

36%
total costs
HOME-BASED

Source: Center to Advance Palliative Care

https://www.capc.org/the-case-for-palliative-care/

But really?

How does palliative care help from a person-centered approach?

Advance Care Planning: patient and family treatment goals are clearly documented - all the goals, not just medical checkboxes

The primary non-medical needs expressed most frequently include:

- need to express emotional pain
- a need to explore spiritual pain
- a need for practical financial and legal help

Domains of Palliative Care

- Structure and Processes of Care
- Physical Aspects of Care
- Psychological Aspects of Care
- Social Aspects of Care Spiritual counselors
- Spiritual Aspects of Care
- Cultural Aspects of Care
- Care of Imminently Dying
- Ethical & Legal Aspects of Care

Members of the Multidisciplinary Team

- Palliative doctors
- Palliative nurses
- Social workers
- Spiritual counselors
- Nutritionists
- Pharmacist
- Allied health (PT/OT/Speech)
- Self/Family
- Legal and financial experts as necessary

A few examples:

Medical	Medication that are likely causing harm rather than helping
Psychological	Facilitating discussions among family – discovering behaviors that mask fear of loss or control
Spiritual/Existential	Examining meaning and making sure important aspects of love and legacy are addressed
Functional/Adaptive	Focus on solutions – no matter how odd the solution may be

Palliative Care – getpalliativecare.org

- For any time in the disease trajectory
- For the entire family
- For the whole person
- Offered in any site – home, outpatient, skilled nursing, hospital
- Can still be receiving curative care

- How do I find palliative care?????

https://getpalliativecare.org/provider-directory/

Comparing Palliative Care v Hospice Care

Palliative Care	*Hospice*
Physical and psychosocial relief	Physical and psychosocial relief
Focus on quality of life	Focus on quality of life
Multidisciplinary Team Approach	Multidisciplinary Team Approach
Any stage of disease	Prognosis 6 months or less
May be concurrent with curative treatment	Excludes curative treatment

https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf

How does hospice differ compared to palliative care?

- Hospice is a Medicare benefit
- Philosophy is same
- Forgo curative care
- Not a commitment – can change your mind at any time
- Benefits to invoking hospice
  - Covers end-of-life medications
  - Provides for durable medical equipment such as hospital bed, wheelchair, commode (and will take them away when no longer needed)
  - Full multidisciplinary team
  - 1-year post-death bereavement support for family

Myths about hospice care

Only for the last few days or weeks of life

It is just for the person who is dying

It is costly

The medications hasten death

Transition

Facing the changes that accompany late dementia…
so that plans can be made sooner

Recognizing Signs of Transitions to Late-Stage Disease

Symptoms and Indicators	• Severe cognitive decline • Physical immobility • Frailty
Medical Signs	• Frequent infections • Difficulty walking • Difficulty swallowing
Emotional Signs	• Withdrawal or difficulty with alertness • Decreased engagement

Functional Assessment Staging (FAST)
FAST SCALE – Normal to Moderate

- **Stage 1**: No difficulty, either subjectively or objectively
- **Stage 2**: Complains of forgetting location of objects; subjective work difficulties
- **Stage 3**: Decrease job functioning evident to coworkers; difficulty in traveling to new locations
- **Stage 4**: Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances)
- **Stage 5**: Requires assistance in choosing proper clothing

FAST SCALE 6 – Moderate Dementia

A. Improperly putting on clothes without assistance or cueing
B. Unable to bathe properly (not able to choose proper water temp)
C. Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue)
D. Urinary incontinence
E. Fecal incontinence

FAST SCALE (7) for Severe Dementia

A. Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview

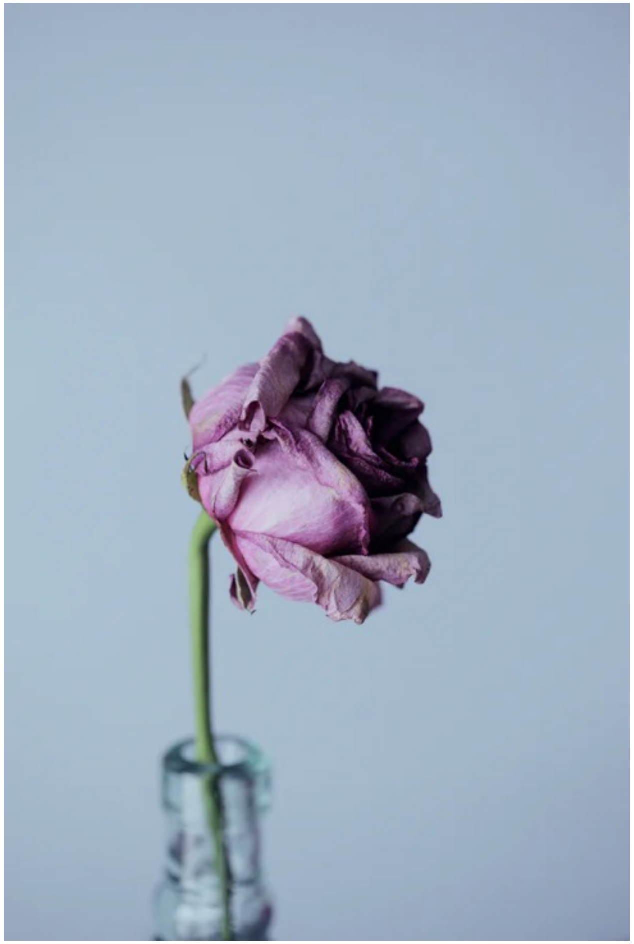
B. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview

C. Ambulatory ability is lost (cannot walk without personal assistance)

D. Cannot sit up without assistance (e.g., the individual will fall over if there are no lateral rests [arms] on the chair.)

E. Loss of ability to smile

F. Loss of ability to hold head up



Caregiving often calls us to lean into love we didn't know possible.

Tia Walker, The Inspired Caregiver: Finding Joy While Caring for Those You Love

Preparing for the Transition

Living with dementia may become dying from dementia

- When this happens… remember that a shift to supportive care will often ease the care and the dying process

Understanding and being informed about changes is important

- Then you can plan for for changes

You will likely have more understanding and be ahead of many healthcare people

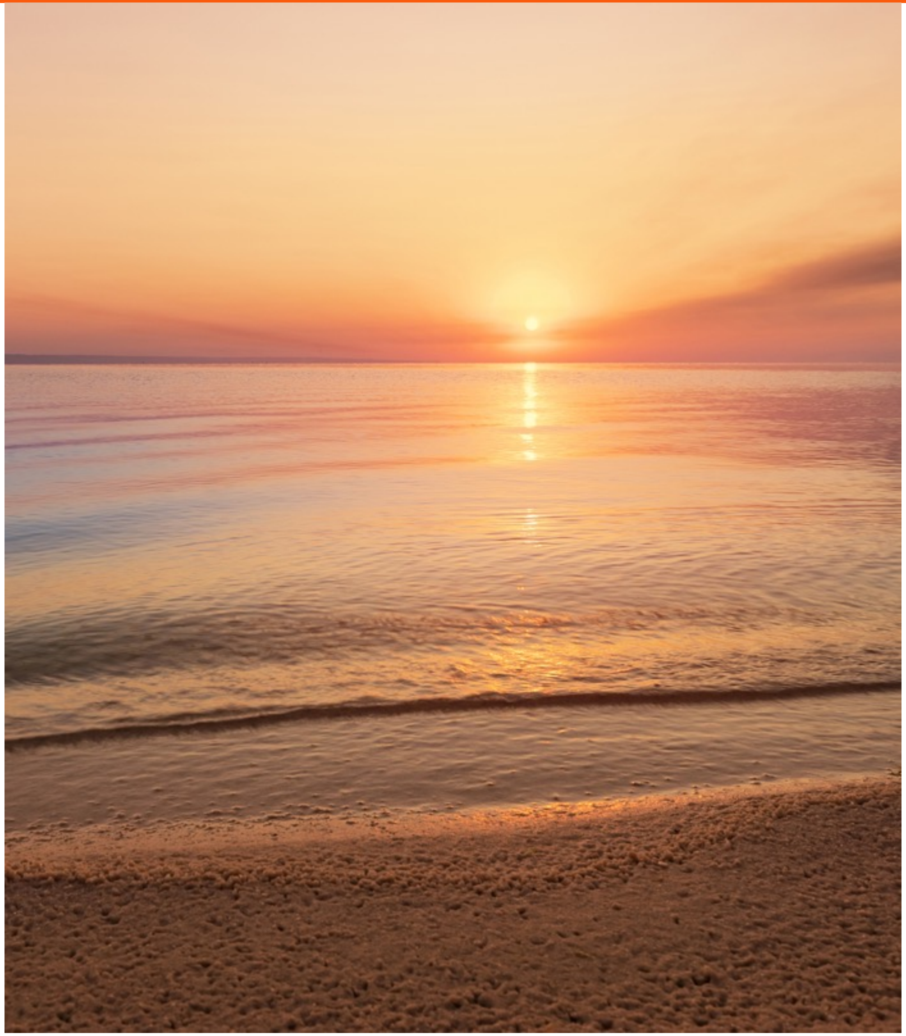
- Therefore, you will be advocating for yourself or your family member

Preparing for the Transition

Know what to expect with palliative care and hospice care

- Then when the need arises, you won't be surprised or resistant

You are amazing in your compassionate care and thoughtful decision-making in dementia.



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 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**

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


QUESTIONS
WE HAVE THE ANSWER

caringkind

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

360 Lexington Avenue
New York, NY

646-744-2900
www.caringkindnyc.org

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

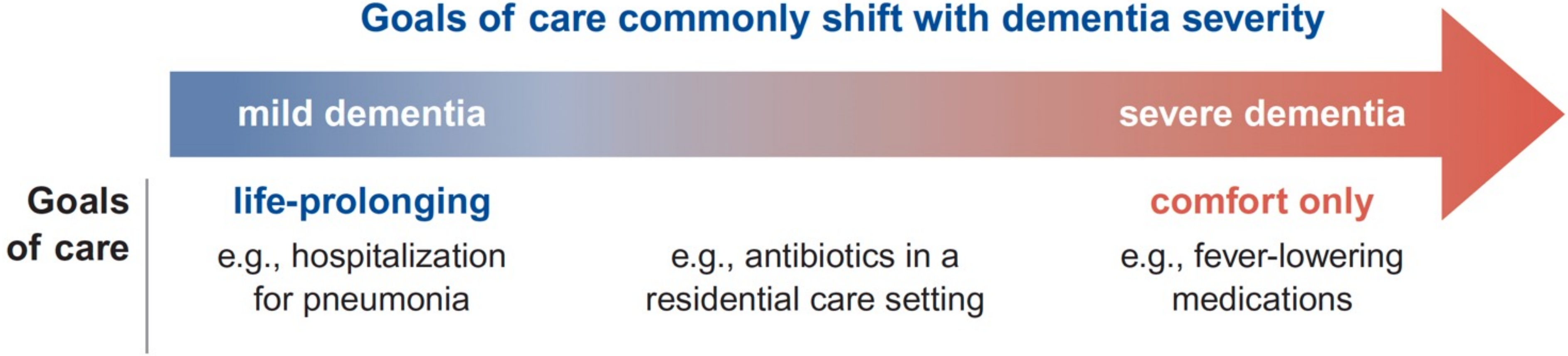
Practical Framework

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		comfort only
e.g., hospitalization for pneumonia	e.g., antibiotics in a residential care setting	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

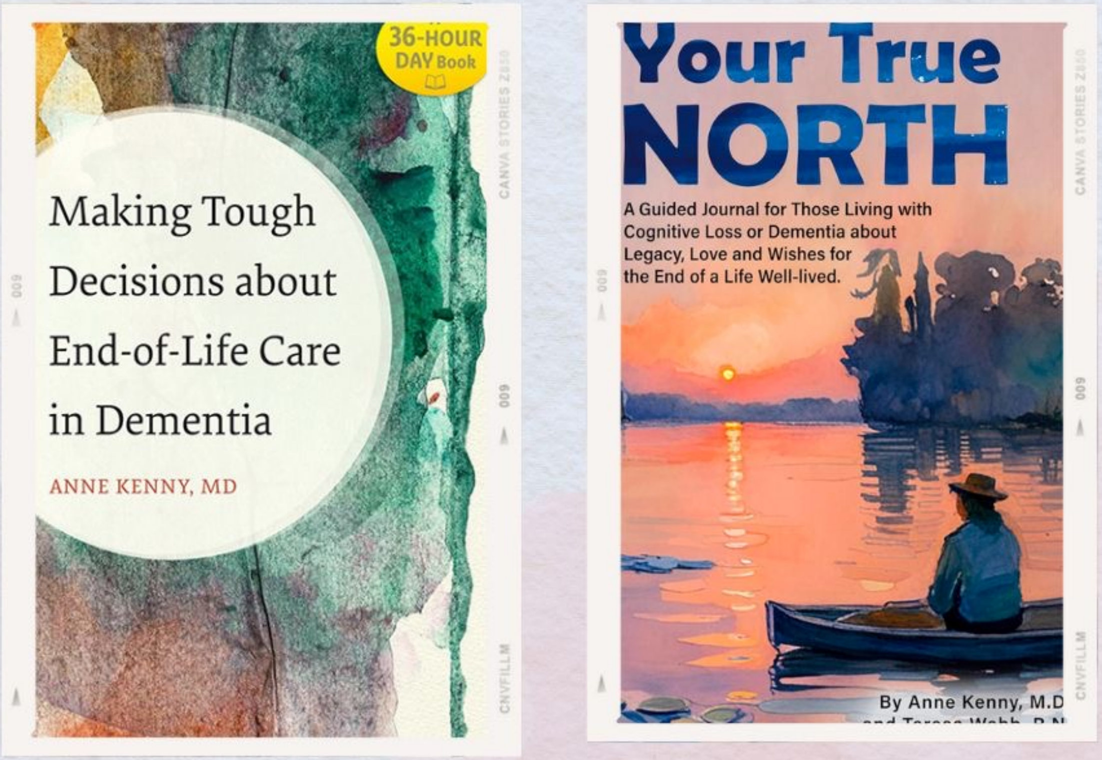
Things to Contemplate

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

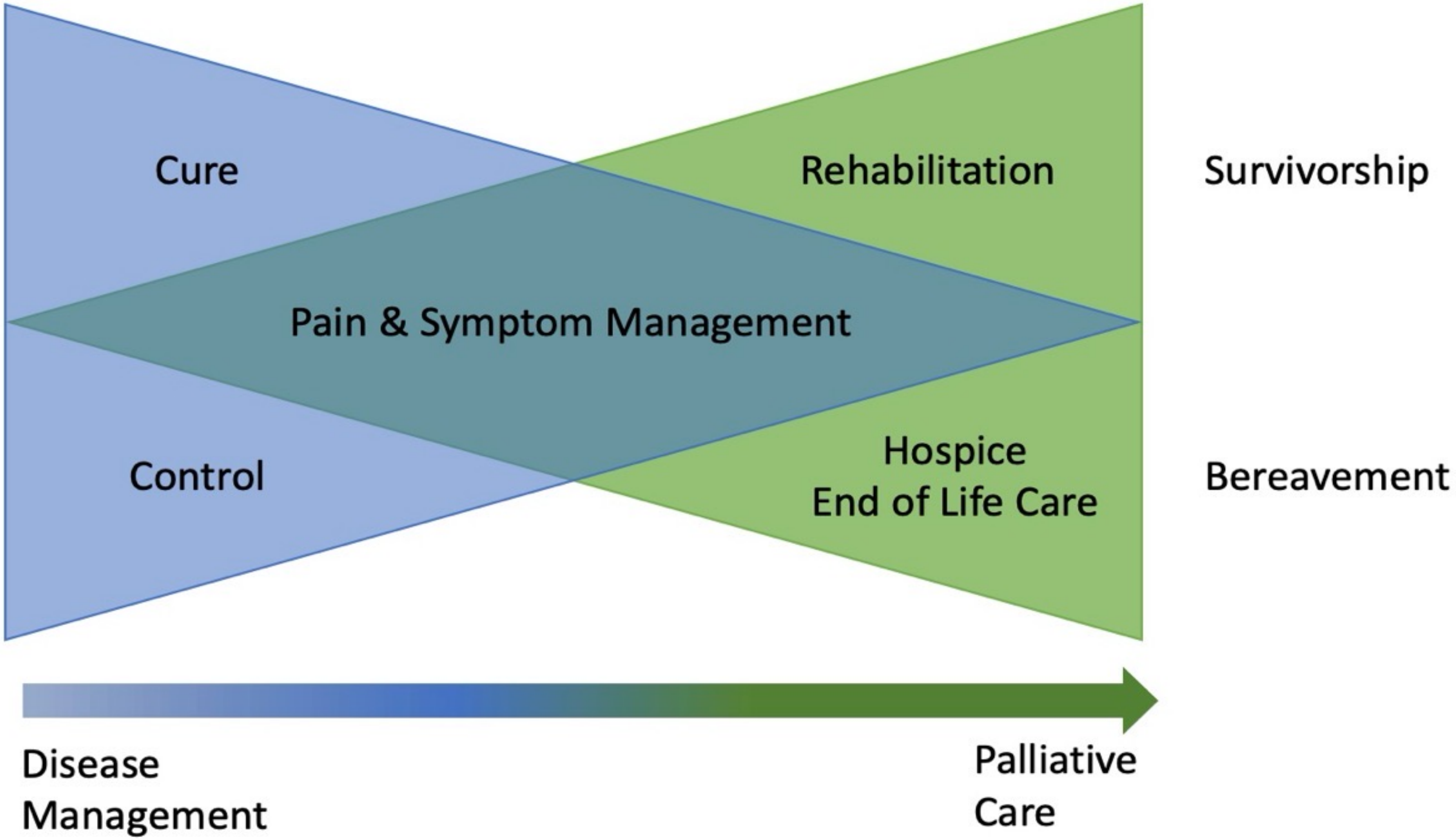


Sellars et al. Perspectives of people with dementia and their careers on advance care planning and end-of-life care: Palliative Medicine 2019

Transition

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

Palliative Care Framework



Cure

Rehabilitation

Survivorship

Pain & Symptom Management

Control

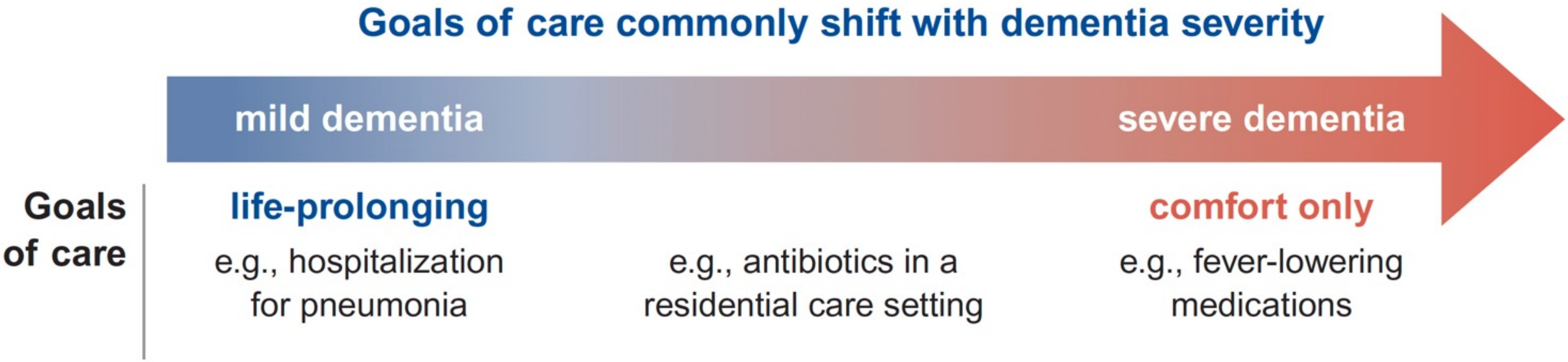
Hospice
End of Life Care

Bereavement

Disease
Management

Palliative
Care

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

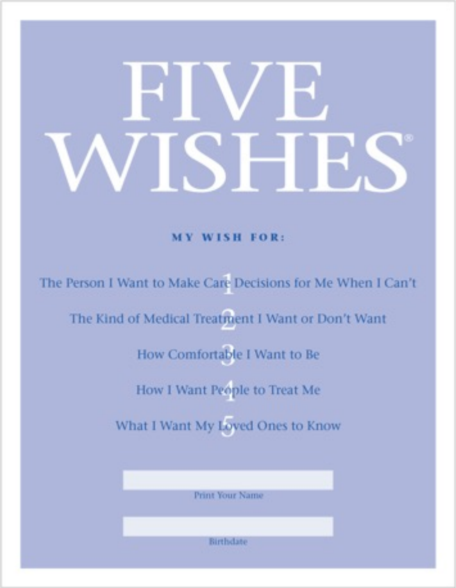
comfort only

e.g., fever-lowering medications

Advance Care Planning Tools

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

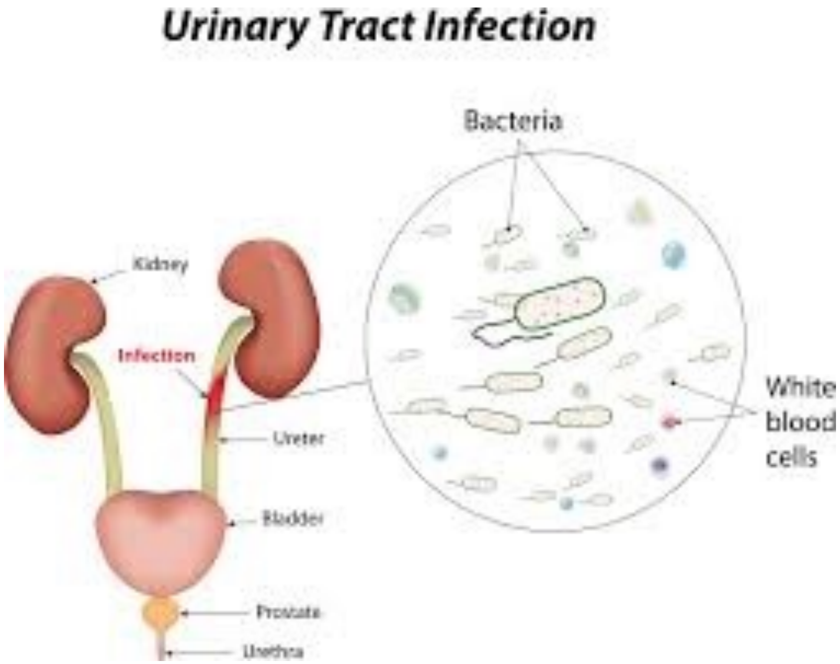
the **conversation** project

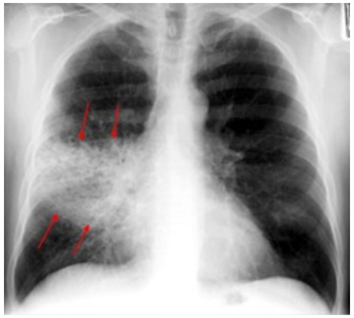
©2023 The Conversation Project, an initiative of the Institute for Healthcare Improvement (IHI)

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

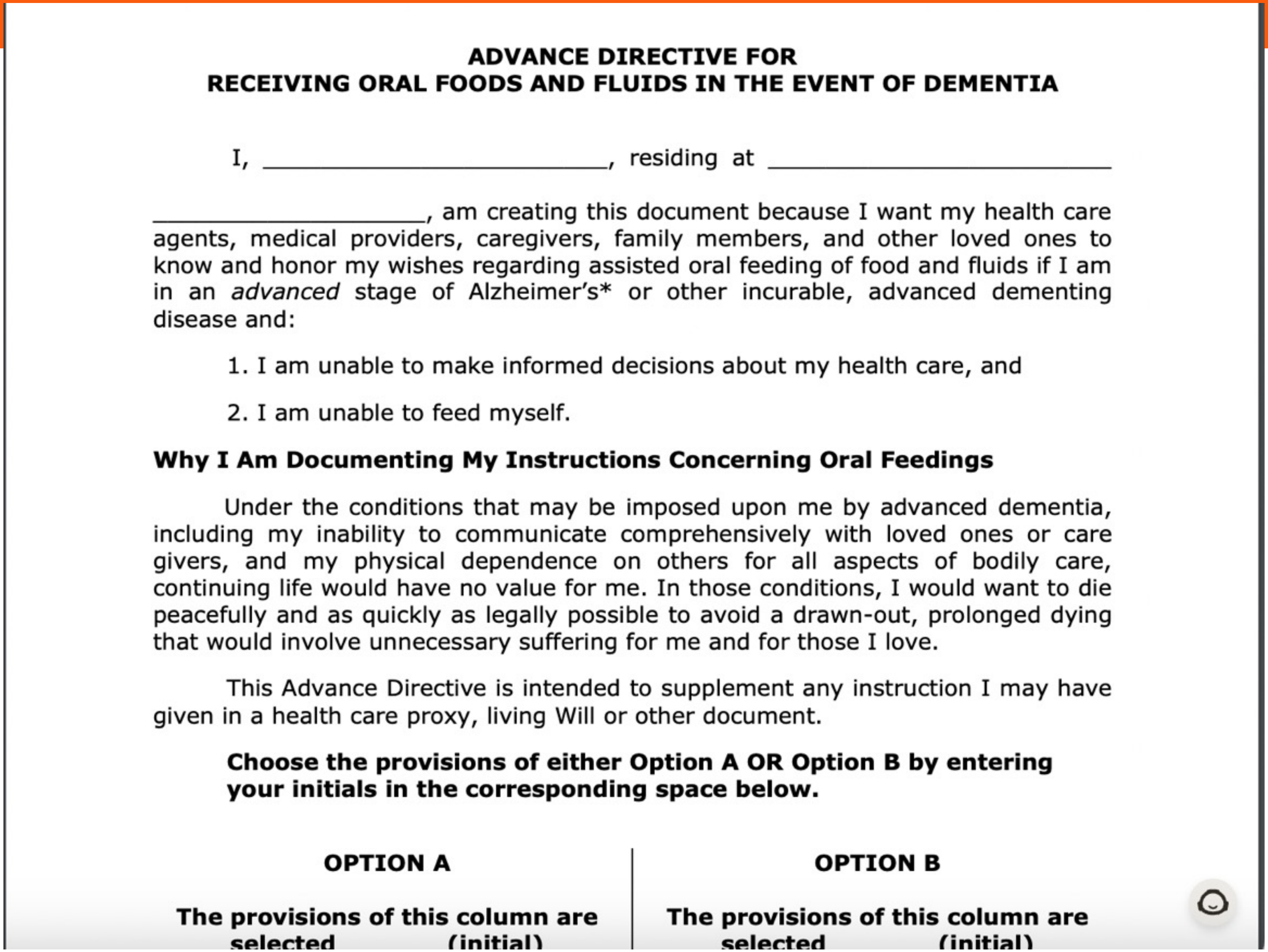




Research does not warrant the treatment of:

- 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

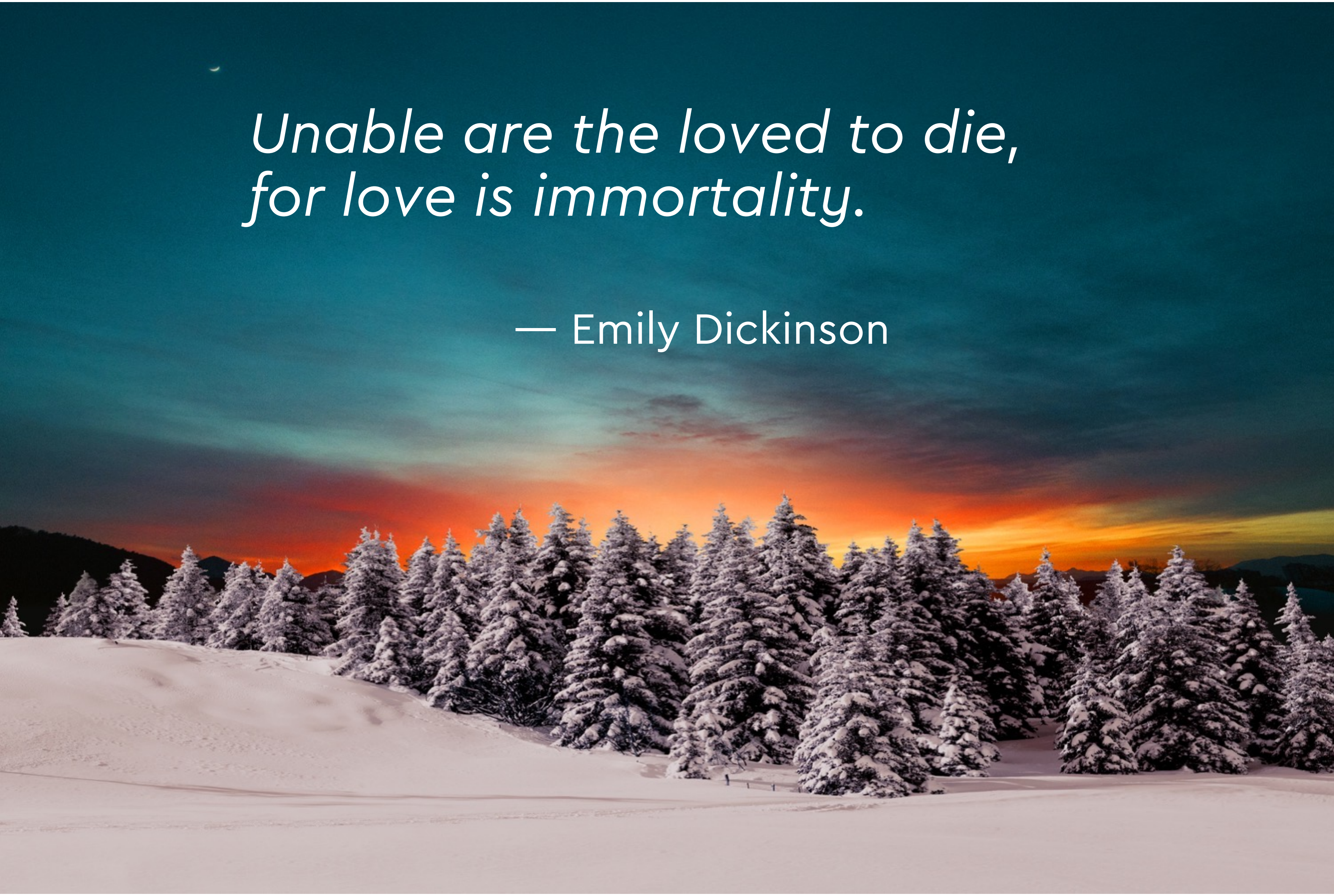
Consider that you are in charge –

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

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
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**

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


QUESTIONS
WE HAVE THE ANSWER

Navigating Transitions Part III:

Understanding a Person-Centered Approach to the Dementia Journey

Adapting relationships and grief during transitions

Anne Kenny, MD

Societal Reluctance to Address Death

Euphemisms for death

Likely originated in superstition to speak of death would draw death’s attention

But, there are consequences to avoidance

- Challenges faced by being unprepared
- Emotional and psychological toll on families and providers
- Unneeded and unwanted medical interventions
- Poor use of supports, such as hospice