



Navigating Transitions Part I:

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

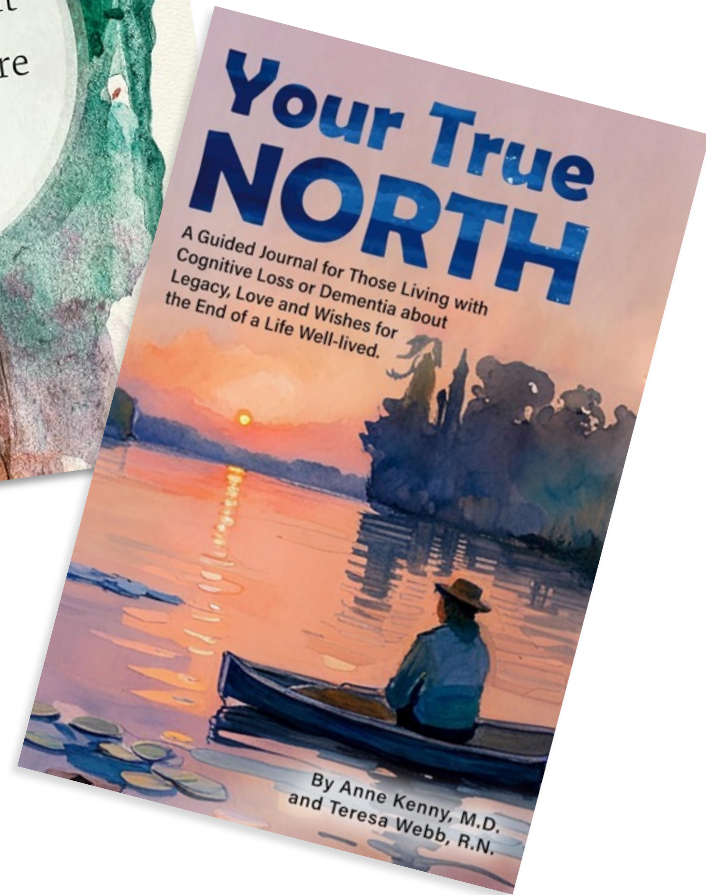
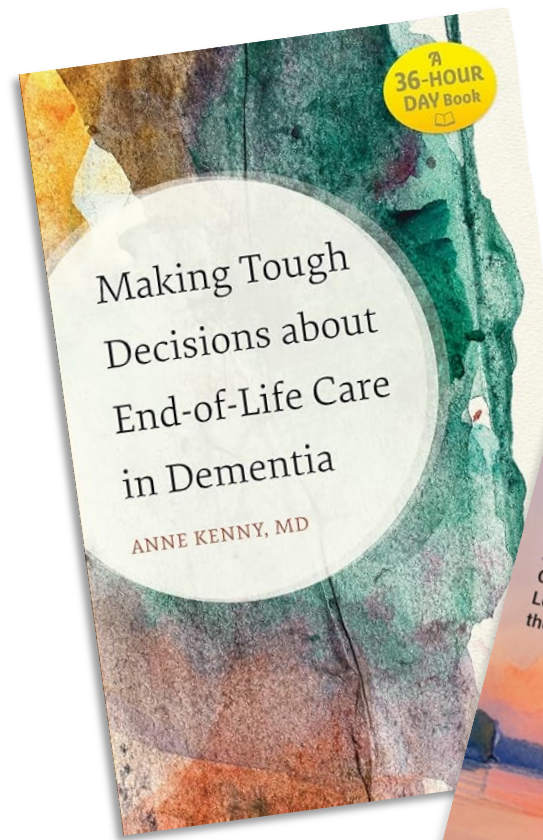
Introduction to palliative care, hospice, living-dying arc

Anne Kenny, MD
Palliative & Clinical Care Consultant

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

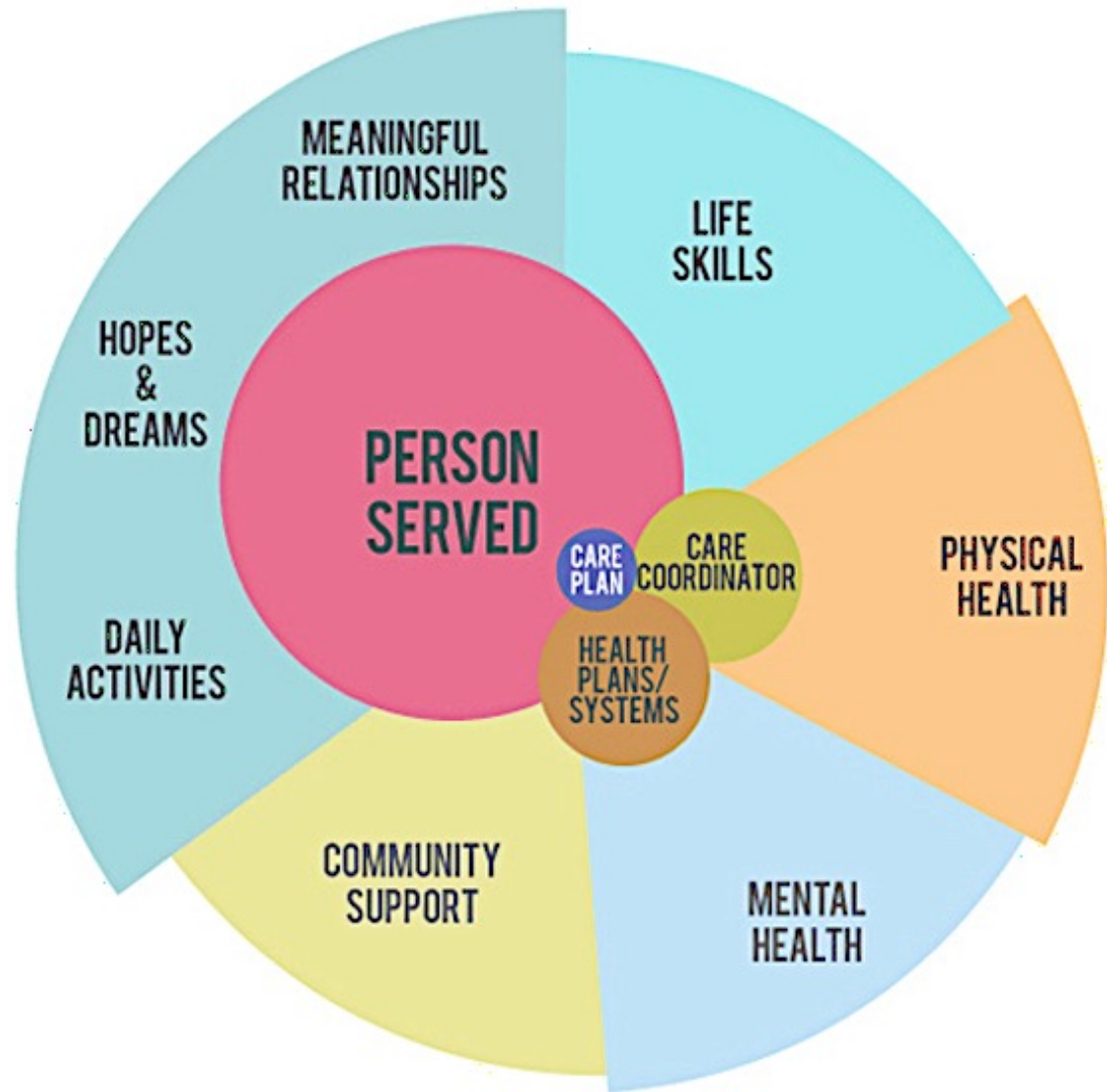
- "There is nothing they can do, take a pill and come back to see the medical community in 6 months to a year"
- "Put your affairs in order"

But.....

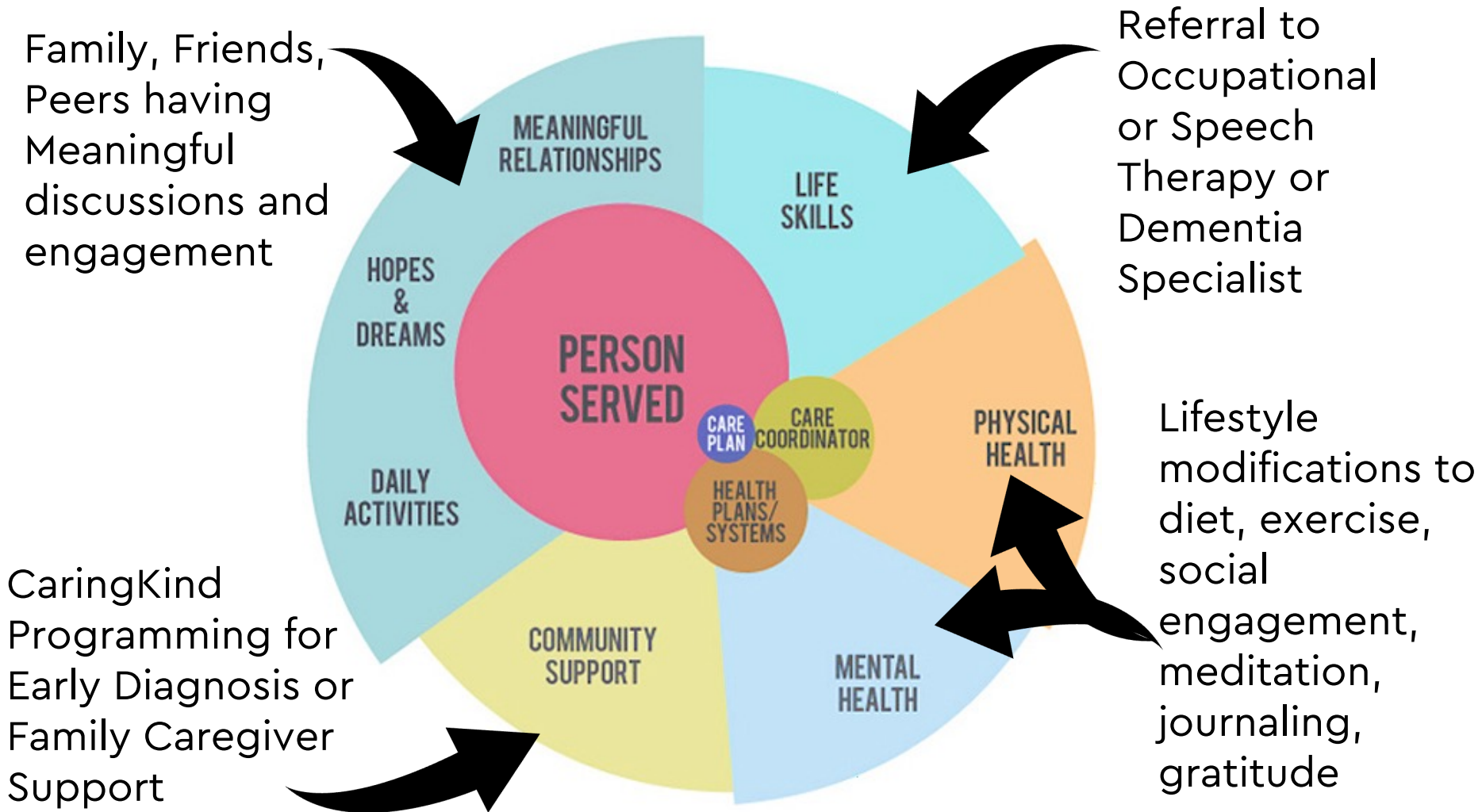
- Those who were given support (and hope) experienced markedly decreased distress (from 30% to 5%), while those who were left without support experienced psychological distress that increased from 30 to 45%

(Mazurek Clinical Interventions in Aging 2019).

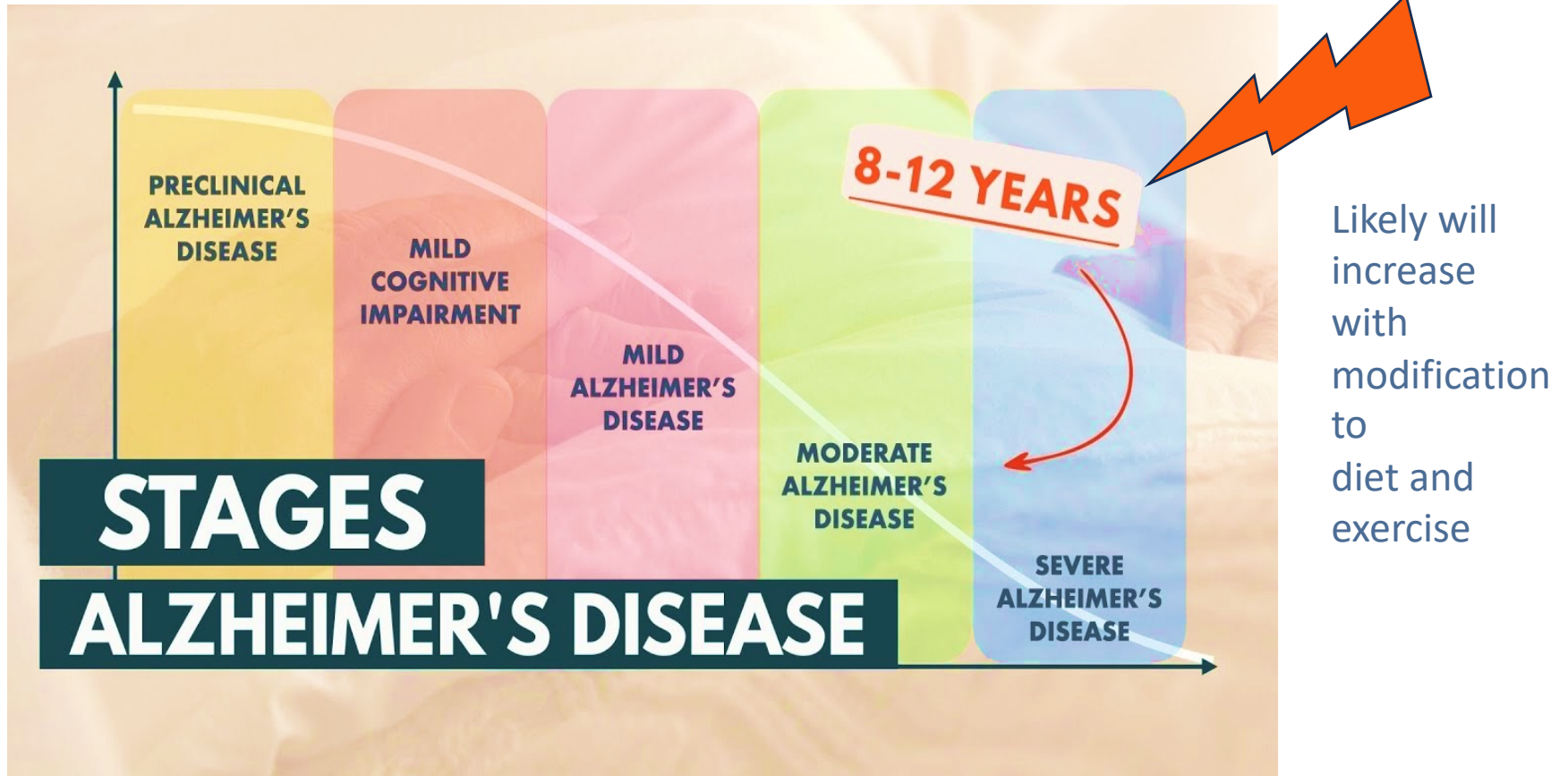
How to provide that support with person-centered care?



Examples of Interventions



Need for Information - Understanding the Disease Trajectory



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

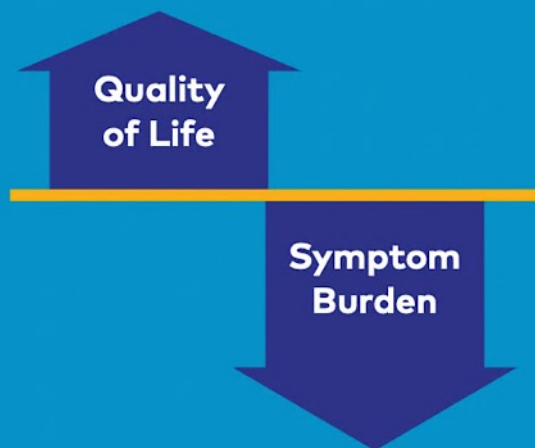
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Building Support – Consider Early Palliative Care Approach

**IMPROVES QUALITY OF LIFE
AND SYMPTOM BURDEN**



**Reduces symptom
distress by**

66%

with improvements
lasting months after
initial consultation¹

**DRIVES HIGH
SATISFACTION AND
POSITIVE PATIENT
EXPERIENCES**

93%

of people who received
palliative care are
likely to recommend it
to others²

1: Kavalieratos, D, J Corbelli, and D Zhang. JAMA 2016

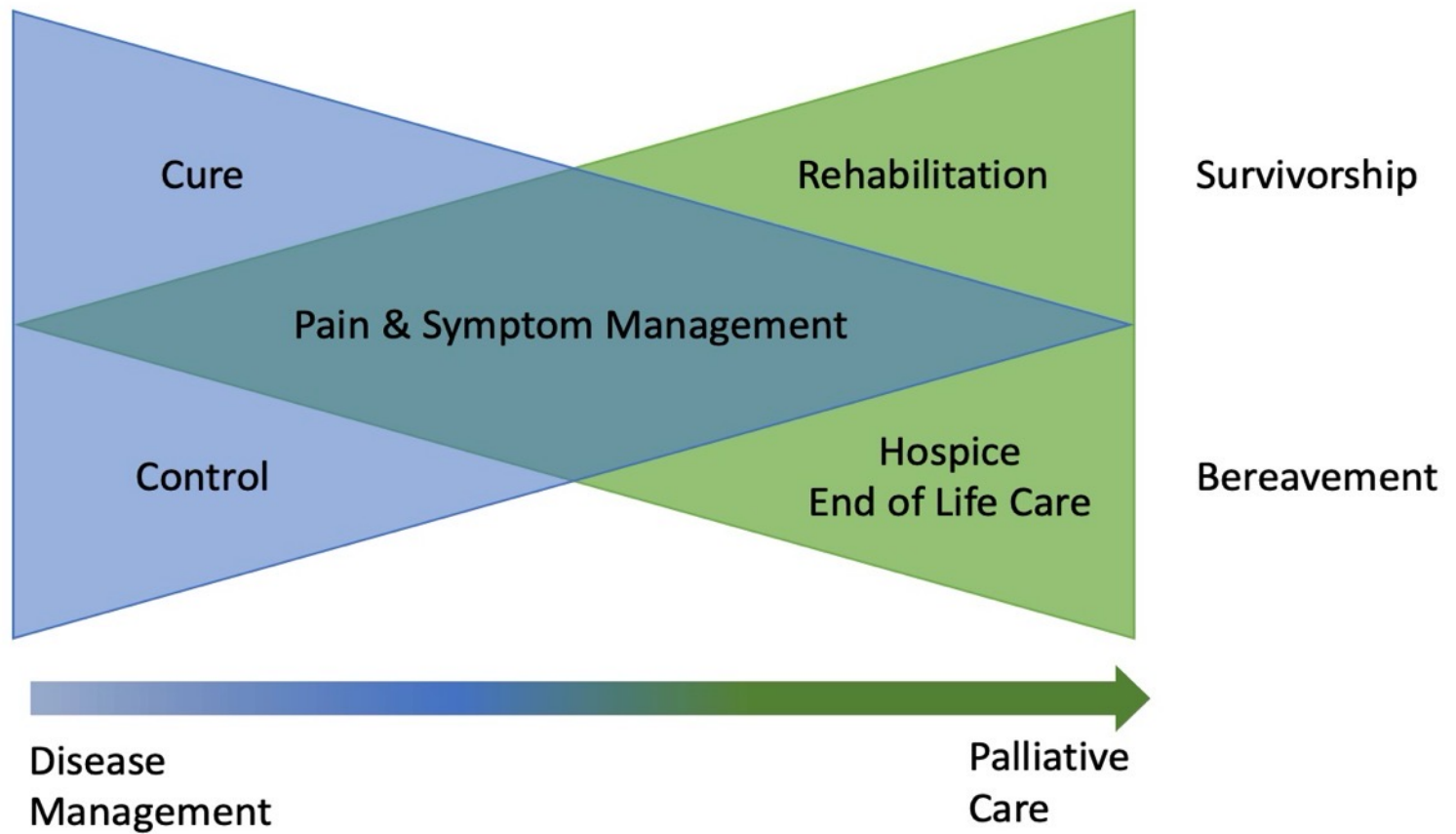
2: Boehler, A. NICHM Foundation Webinar: May 19, 2017

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.**”

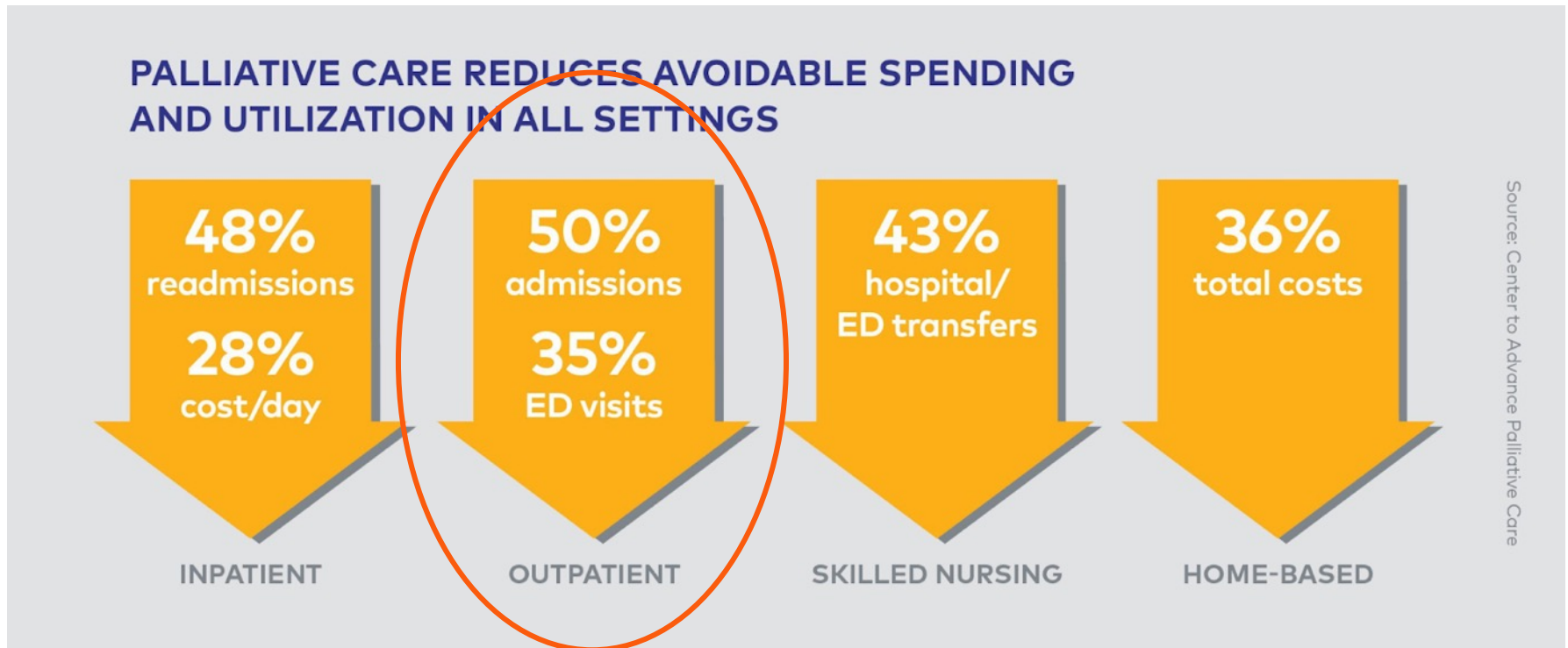
World Health Organization (WHO) definition

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?



<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

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



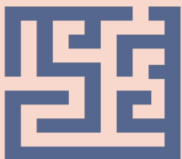
Psychological

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

<i>Palliative Care</i>	<i>Hospice</i>
Physical and psychosocial relief	Physical and psychosocial relief
Focus on quality of life	Focus on quality of life
Multidisciplinary Team Approach	Multidisciplinary Team Approach
<i>Any stage of disease</i>	Prognosis 6 months or less
<i>May be concurrent with curative treatment</i>	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 ²⁵assistance in choosing proper clothing

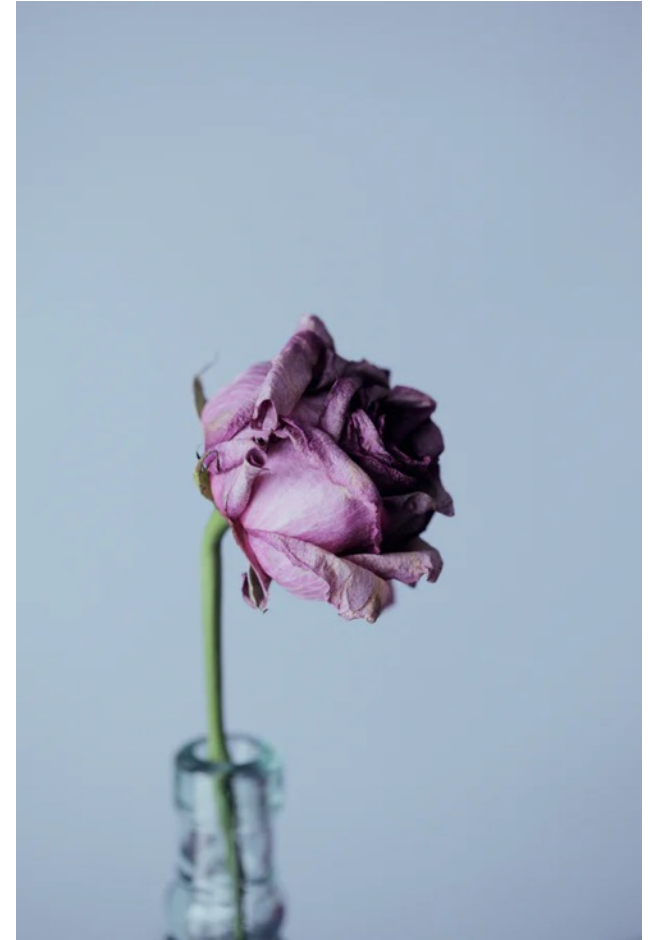
FAST SCALE 6 – Moderate Dementia



- 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 incontinence²⁶

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

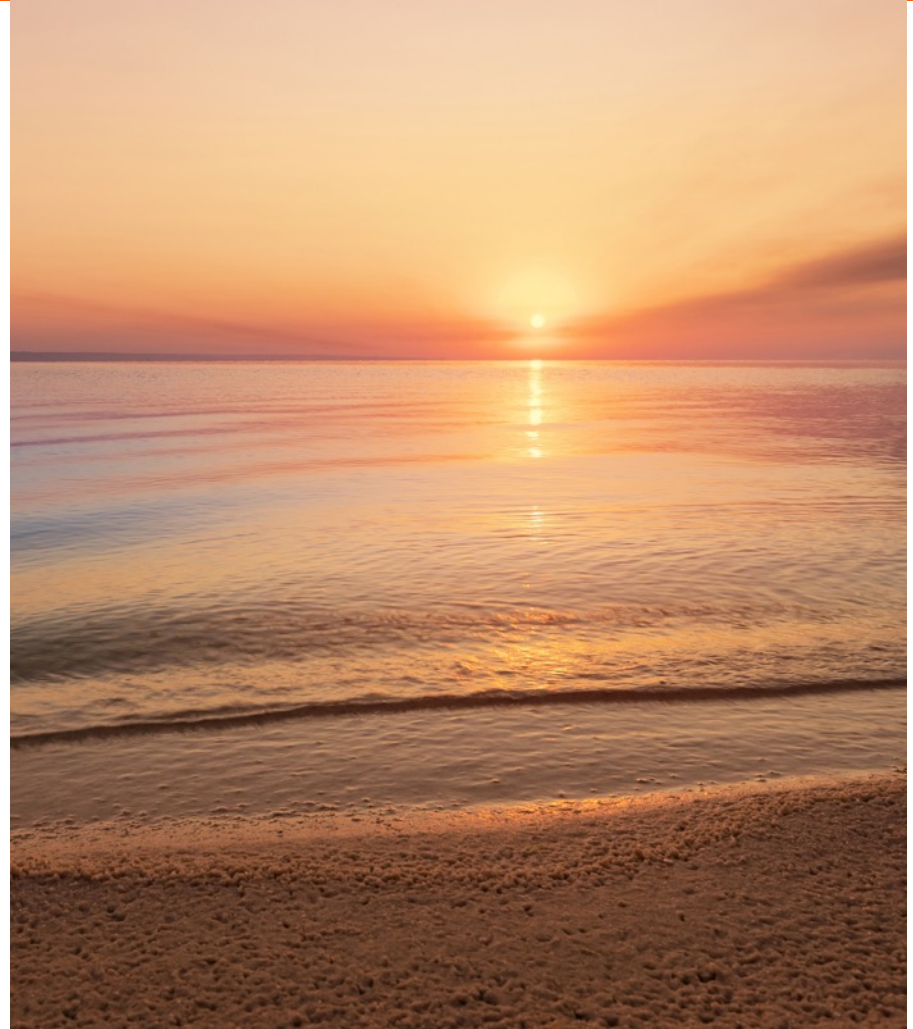
- Therefore, you will be advocating for yourself or your family member

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

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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

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QUESTIONS

WE HAVE THE ANSWER

