# LIVING WELL WITH DEMENTIA: THE ROLE FOR PALLIATIVE CARE

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# **OBJECTIVES**

- Describe the specialty and concept of palliative care
- Define the differences between palliative care and hospice
- Explain the intersection of dementia and palliative care
- Identify available resources for future planning







## TO PALLIATE

"make (a disease or its symptoms) less severe or unpleasant without removing the cause"



Dictionary Definition



"Palliative care is an approach focusing on the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual."







# FUTURE PLANNING

- Advance care planning is a process that includes discussions about care preferences and what matters most
- Improves receipt of medical care that is aligned with preferences, values and goals
- Help reduce family stress and anxiety
- Formal documents can help with communicating these preferences to rest of the care team
- This does not have to be a one time choice  $\rightarrow$  As illness trajectory changes, so can your goals of care.



## WHERE CAN WE RECEIVE PALLIATIVE CARE?

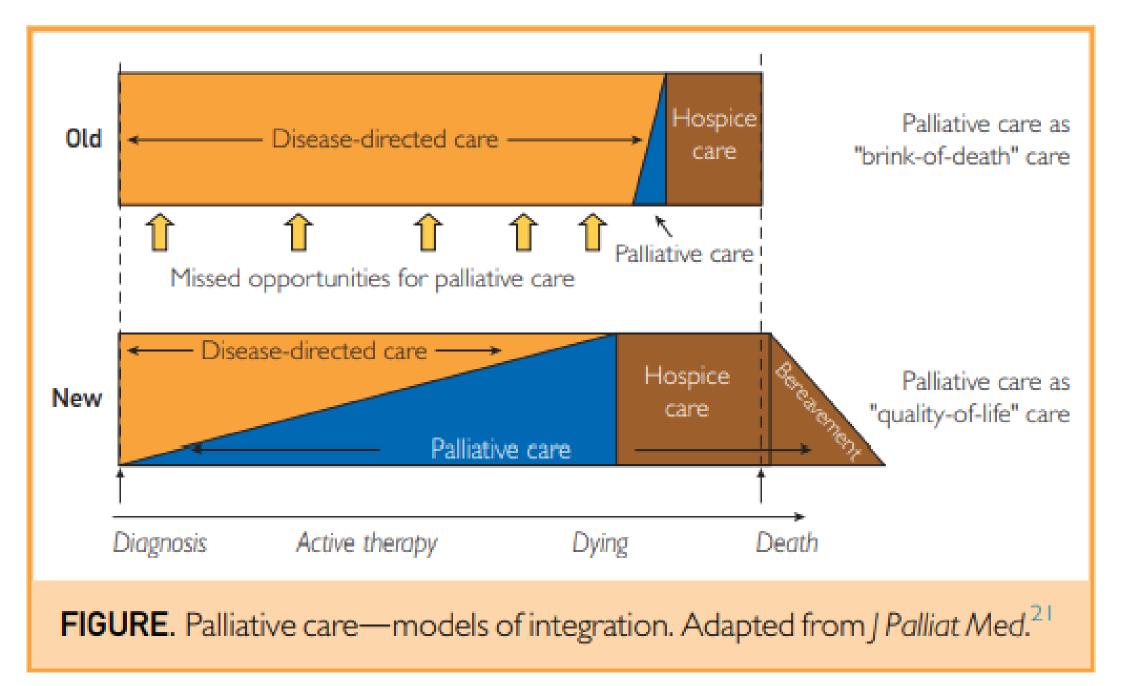
- Depends on where you live and resources available
- In Washington, can be dependent on county you live in
- There are inpatient and outpatient palliative care teams
- You can also receive this from your providers



## WHO CAN BENEFIT FROM PALLIATIVE CARE?

- Anyone living with a serious illness regardless of age, prognosis, disease stage, or treatment choice
- Ideally provided early and throughout the illness in conjunction with curative or life-prolonging treatments





# WHAT MATTERS MOST

# WHO MATTERS MOST





"It's important to understand that while all hospice is palliative care, not all palliative care is hospice"

"We are not here to help patients give up, but rather to affirm their life during serious illness."

## DR. SAGGAR

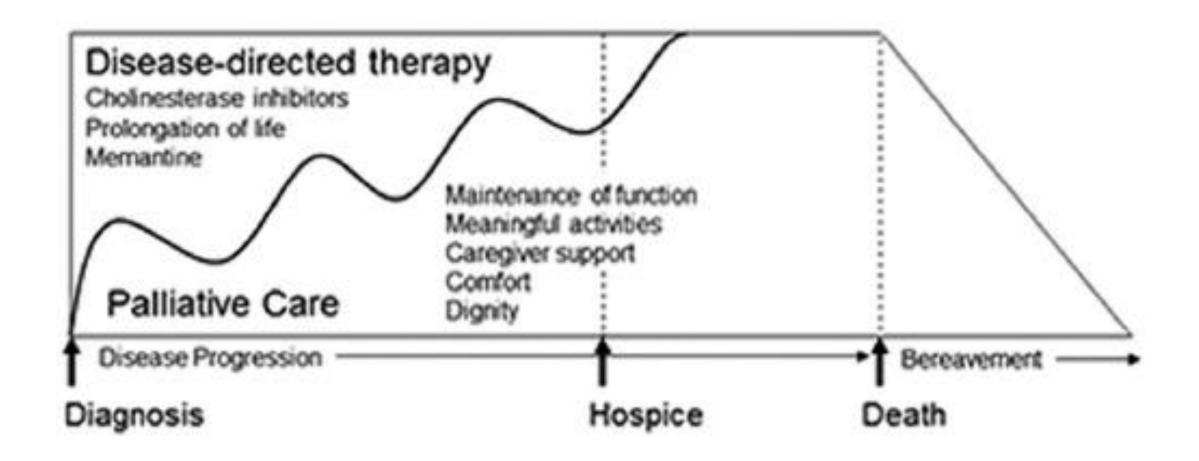
SSM Health Palliative Medicine
Division Chief for Wisconsin region



# HOSPICE

- Hospice is not a place, but a philosophy of care
- Prognosis of <6 months if disease follows its natural course</li>
- Utilizes comprehensive interdisciplinary team-based approach







## **Palliative Care**

Can receive at any stage of disease

Can occur at same time as curative treatment

Typically occurs in a medical setting

Optimize comfort

Relieve Symptoms

Provide emotional & spiritual support

Focus on quality of life

Support for caregivers and family

Holistic Care

## Hospice

Prognosis of <6 months

Not actively seeking or receive curative treatment

Typically occurs in'home' setting





## DEMENTIA CONSIDERATIONS

- Disease progression differs with dementia and does not often follow a "normal" disease trajectory
- Often a slow and steadily progressive illness considered as "chronically progressive"
- Unique challenges later in illness
  - Communication challenges
  - Increasing support for caregiver
  - Difficulty defining "terminal" phase of illness
  - Balancing the decision of medical interventions



# WHAT WOULD BE HELPFUL NOW?

- Start talking with your family and keep the conversations open, especially important when you are able to make your own decisions
  - What matters most to you?
  - Who matters most to you?
  - What is an acceptable quality of life?
- Have these conversations with your care team
- Establish with palliative care earlier on
- Bucket list items?
- Legacy work?



"All persons affected by dementia – those living with the diseases that cause it, their care partners, and their family and friends – have a right to receive the highest quality care and support possible to meet their needs. They have the human right to be treated with dignity and respect. And they are entitled to full and effective participation and inclusion in society. These rights transcend national boundaries and cultures."

## THE WORLD DEMENTIA COUNCIL

May 2017 - Global Care Statement





# HOW CAN WE GET CONNECTED WITH PALLIATIVE CARE?

- Ask your provider to make a referral to palliative care
- You can get referred at anytime in course of your illness



# ADVANCE CARE PLANNING

- Five Wishes | Make Your Wishes Known
- PREPARE (prepareforyourcare.org)
- Physicians Orders for Life Sustaining Treatment (POLST) :: Washington State
   Department of Health
- The Conversation Project Advance Care Planning
- For Caregivers of People with Alzheimer's or Other Forms of Dementia (theconversationproject.org)
- WORKBOOK A Patient's Guide to Serious Illness Conversations (theconversationproject.org)
- Durable power of attorney
- Living Wills/Healthcare directives



## **MyChart**

## Menu



Q Search the menu



- Mealth Reports
- Growth Charts
- Document Center
- End-of-Life Planning



















( Nedications Visits ( Medications )

### End-of-Life Planning





Schedule a time to meet with trained staff about End-of-Life Planning.

Schedule appointment



For my loved ones Take the time to write down what's most important to you and keep it up to date.

Start



#### For my care team

Use this space to let your care team know what your wishes are so they can provide the best care for you.

Start

#### Health Care Agents ①

You currently have no health care agents.



### Add Health Care Agent

Designate one or more health care agents who can make health care decisions for you when you cannot.

#### Planning Documents ①

If a document should be removed, send us a message.

#### Documents On File

There are no documents of this kind to display.



Common documents include Advance Directives and Living Will, a Power of Attorney, or a Physician Orders for Life-Sustaining Treatment (POLST) signed by your physician.

Back to the home page



## Helpful Resources

These resources will help you make care decisions and prepare for conversations with your family, friends, and doctors.



## Prepare for Your Care

Step-by-step program with video stories to help you have a voice in your medical care.



## Helping With Comfort and Care

Advice to cultivate comfort and happiness towards the end of life.



## Plan Your Lifespan

Help you plan for health events that may happen as you get older.



#### **Five Wishes**

Help others understand what matters most to you.



# OTHER RESOURCES

- How Palliative Care Helps Families with Dementia Focus on Quality of Life (getpalliativecare.org)
- Other team members in your care including nurses, social workers, other providers,





# THANK YOU!

# REFERENCES

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