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
WHAT IS PALLIATIVE CARE?
TO PALLIATE

“make (a disease or its symptoms) less severe or unpleasant without removing the cause”
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.

The specialty that focuses on this approach is called Palliative Medicine.
Palliative Care is specialized care for people with serious illness

**PHYSICAL**
Understanding Disease
Symptoms
Function
Medications

**EMOTIONAL**
Mood
Coping Mechanisms
Support
Hope

**SOCIAL**
Relationships
Work – Hobbies
Resources
Finances

**SPIRITUAL**
Source of Strength
Source of Meaning
Religion – Faith Community
Legacy

**FUTURE PLANNING**
Advance Directives
Decisions

What is the impact of serious illness on all parts of your life?
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 → 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
FIGURE. Palliative care—models of integration. Adapted from J Palliat Med.21
WHAT MATTERS MOST

WHO MATTERS MOST
PALLIATIVE CARE VS HOSPICE?
“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.”
HOSPICE

- Hospice is not a place, but a philosophy of care
- Prognosis of <6 months if disease follows its natural course
- Utilizes comprehensive interdisciplinary team-based approach
Disease-directed therapy
Cholinesterase inhibitors
Prolongation of life
Memantine

Palliative Care
Maintenance of function
Meaningful activities
Caregiver support
Comfort
Dignity

Disease Progression
Diagnosis
Hospice
Bereavement
Death
Palliative Care

- Can receive at any stage of disease
- Can occur at same time as curative treatment
- Typically occurs in a medical setting

Hospice

- Prognosis of <6 months
- Not actively seeking or receive curative treatment
- Typically occurs in ‘home’ setting

Optimize comfort
Relieve Symptoms
Provide emotional & spiritual support
Focus on quality of life
Support for caregivers and family
Holistic Care

Support for caregivers and family
Typically occurs in ‘home’ setting
DEMENTIA AND PALLIATIVE CARE
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.”
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
End-of-Life Planning

Having a plan is one of the best gifts you can give to those you care about.

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

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.

Health Care Agents
You currently have no health care agents.

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

Documents On File
There are no documents of this kind to display.

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

Add a document
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.

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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.
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

- “What is Hospice?” Hospice Foundation of America, Health and Medical Research, 2018. https://hospicefoundation.org/Hospice-Care/Hospice-Services