

# Duke Dementia Family Support Program

## **Caregiver Connections**

**An Educational Webinar Series With The Experts**

**The presentation will begin shortly.  
Thank you for your patience!**

**[dukefamilysupport.org](http://dukefamilysupport.org)**

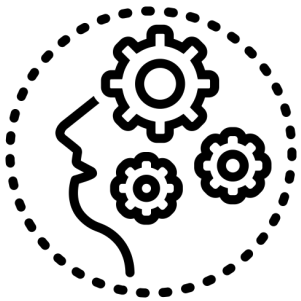
**919-660-7510**

# End of Life Care for Patients With Dementia

Jennifer Gentry DNP, ANP-BC, GNP, ACHPN, FPCN

Duke Palliative Care

Duke University School of Nursing



# Goals/Outcomes

- Describe palliative care and hospice
- Discuss signs of the terminal phase of dementia
- Common symptoms at the end-of-life
- Discuss end-of-life and bereavement resources for family caregivers

# Why is Dementia a Life-limiting Condition?

- Often not recognized as a terminal illness
- Limited access to palliative care resources
- Overall decline in functional abilities leading to incontinence, inability to move around, swallowing problems
- Risk for complications: skin breakdown, infections, weight loss, fall-related injuries, stroke
- Worsening of other illnesses

# What is Palliative Care?

“Specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for both the patient and the family... work with a patient’s medical team to provide an extra layer of support...”

- Palliative care can be provided at any point during a serious illness and combined with treatments with curative/disease-modifying intent

# What is Hospice Care?

- Hospice is a specialized form of palliative care that focuses on care, comfort and managing symptoms during the last months of life



# When is it Time for Hospice Care?

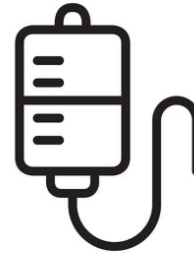
- Weight loss
- Decreasing ability to eat and drink
- Complications such as pneumonia, urinary infections, skin sores
- Hospital admissions
- Loss of ability to walk or talk
- Needs help for all self-care
- +/- other medical conditions
- Goals are comfort-oriented



# Having Conversations Early

- How does the person wish to be cared for?
- Medical treatments to pursue or avoid?
- Addressing issues of resuscitation, life support
- Decision making
- Should the person return to the hospital?
- Labs, diagnostic tests?
- Routine medications for other conditions?

# Medically Assisted Nutrition and Hydration



- Careful hand-feeding has equal or better outcomes than medically assisted nutrition and hydration
- Inability to eat and drink is a sign of dying rather than the cause of it
- Many persons that have been able to self-report at the end of life do NOT report hunger or thirst
- Tube feeding is NOT recommended for persons with advanced dementia

# Signs of End of Life

- Sleeping more
- Eating and drinking little to nothing
- Irregular breathing
- Long pauses between breaths
- Incomplete eyelid closure
- Cooling of the hands, legs and feet
- Skin color changes



# Common Symptoms

- Delirium/acute confusion with agitation
- Pain
- Shortness of breath
- Muscle twitches, seizures
- Moist breathing

# What Can Be Done About Symptoms?

- Medications
- Positioning
- Mouth care
- Oxygen
- Presence/human touch and contact
- Music
- Fans

# How Can Hospice Help?

- Support caregivers with team-based approach
- Expert symptom management
- Provide practical assistance with medical equipment, limited personal care assistance, medications for symptoms
- On call telephone support from a registered nurse
- Respite care
- Can be provided in most places where the person lives

# Care for Caregivers

- Hospice/Palliative care resources
- Bereavement support available through hospice, faith communities, private counseling, support groups
- Advance decisions about funeral or memorial plans
- Planning resources such as “Empathy” APP, Funeral Consumer Alliance, Federal Trade Commission, Dept of Justice, AARP, Alzheimer’s Association

<https://consumer.ftc.gov/articles/shopping-funeral-services>

<https://www.doj.nh.gov/consumer/sourcebook/funerals.htm>

[https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end\\_of\\_life\\_planning](https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning)

# Summary

- Early conversations and planning
- Talk to your healthcare team about goals and wishes
- Use available palliative care and hospice resources
- Most symptoms CAN be managed
- Bereavement support



Lets Talk...

# Duke Dementia Family Support Program

## **Caregiver Connections**

**An Educational Webinar Series With The Experts**

**Thank you for joining us today!**

**[dukefamilysupport.org](http://dukefamilysupport.org)**

**919-660-7510**