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
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End of Life Care for Patients With Dementia

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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
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
Let's Talk...
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Thank you for joining us today!

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