Community PALLIATIVE CARE of Hospice of North Idaho

DEMENTIA

Dementia is an acquired loss of memory that is substantial enough to interfere with everyday functioning. Each stage of the disease comes with a decline in cognitive and physical function that impacts the lives of both patient and caregiver. Additionally, there may be associated behavioral and psychological disturbances. The most common types of dementia are Alzheimer's Disease, Vascular, Lewy Body, and Frontotemporal. Most types of dementia have a prolonged course of decline, with additional chronic or acute illnesses impacting life expectancy. Dementia is a terminal illness.

TYPICAL PROGRESSION OF DEMENTIA

Most dementias follow a typical course of gradual deterioration punctuated by significant cognitive and functional decline, usually due to an acute illness, such as pneumonia, urinary tract infection, or hip fracture. After an acute illness, it is common for people with dementia to establish a "new normal" lower level of cognitive and physical functioning. Below are descriptors of what an individual may experience at each stage.

Mild Dementia – Short-term memory loss, personality changes, difficulty managing medications, driving, and finances.

Moderate Dementia – Marked loss of short-term memory, the decline in long-term memory; difficulty with shopping, meal preparation, housework, and may begin to have difficulty bathing.

Severe Dementia – Most memory is lost, communication is decreased, and patients have difficulty with basic activities of daily living including toileting, dressing, bathing, and transferring. Incontinent of bowel and bladder.

End Stage Dementia – May have few intelligible words, weakness, may become bedbound and develop difficulty swallowing. More prone to infection. At this point life expectancy is very limited.

Hospitalized dementia patients may experience delirium and may not return to their previous level of function or may demonstrate rapid decline.

ADVANCE CARE PLANNING

*Quality of Life – How do you define the quality of life? How does this play into decisions about medical care?

*Resuscitation Status – If heart and breathing stop (you have died), what do you want the response to be? Allowed to die a natural death or aggressive intervention? (Aggressive intervention includes chest compressions, shock, medications, ventilation.)
Would you like education on the likelihood of survival if heart and breathing stop?

*Mechanical Ventilation- If your breathing is poor, do you wish to be placed on a machine that breathes for you? (Includes a tube in your throat, and sedation.)
Do you want education on the likelihood of survival if you were placed on a ventilator?

*Feeding Tube -If you cannot swallow, do you want a feeding tube?
Decreased appetite and intake are a natural process of aging and dementia. Patients with dementia do not understand extra things on their bodies and typically pull tubes. Tubes can contribute to delirium and impact the quality of life. A feeding tube may prolong life but does not change the underlying disease process.

*Antibiotics - If you develop an infection do you want it treated with an antibiotic, or do you wish to learn about less aggressive alternatives to a curative path?
(Stage of dementia may impact this decision.)

*Hospitalization - Do you wish to be hospitalized for acute illnesses? Do you wish to have aggressive testing and imaging?
(Stage of dementia may impact this decision.)

SYMPTOM MANAGEMENT

The following are symptoms patients with dementia may experience. Once an individual has difficulty verbally communicating their needs, symptoms may be expressed in behavior, including agitation.

Pain – Ask and observe the patient. Monitor for grimacing, moaning, body language, and decreased activity. Scheduled Tylenol can sometimes be enough to manage chronic or acute pain. Discuss with your provider. Avoid opioids if possible. Try alternatives to manage pain such as ice or heat, positioning, and massage.

Constipation – Bowel movements an average of every 3 days is recommended (each person does have their own pattern). If you have difficulty with BMs, discuss a bowel regime with your provider. Also, consider how diet and activity affect the bowels. Constipation may increase agitation or behaviors.

Urinary Retention – If a patient is unable to urinate, discuss with your provider for possible interventions.

Urinary Tract Infection (UTI) – As the body becomes weaker, and an individual has less fluid intake, they are more at risk for UTIs. These can create increased confusion. Many patients with dementia experience recurrent UTIs.

Sleep – Individuals with dementia sometimes turn their days and nights around, making it difficult for the caregiver to get sleep. Sometimes a bedtime routine helps, others a medication may be recommended.

Mood - Depression frequently occurs in people with dementia. Involvement in activities of enjoyment or music may help, in the early stages of dementia cognitive therapy may be helpful. If these therapies do not help, a provider may recommend a medication.

Anxiety occurs in people with dementia, especially if they are confused, or unable to communicate their needs. Caution must be taken in prescribing medication in anxiety. Avoid sleep aids over the counter or antihistamines.

Psychosis – Consists of delusions (believing something that is not true) or visual hallucinations (seeing something that is not there). Risk vs benefit is weighed in considering medication for psychosis. Quality of life is also a consideration.

Agitation - Safety for patients and caregivers is a priority. Be aware that urinary retention, constipation, and pain can impact behaviors; all must be assessed. It may help to give the individual activity to do such as folding towels.

Delirium – People with dementia may experience hypoactive or hyperactive delirium with a change in environment, or an acute illness. Many do not return to their previous function after delirium. Attempt to orient the patient with photos, calendars, and comforting objects such as a doll or stuffed animal. Open curtains during the day and close them at night. If the patient is in a new environment, visit frequently.

Decreased Appetite and Intake – Desiring less to eat and drink or having difficulty chewing is a natural progression of dementia. Loved ones often worry that the patient is starving, this is not the case. Let the individual guide what/how much they would like to eat and drink. This is a time for pleasure eating.

Poor Swallow – As the body becomes weaker, the patient with dementia often has difficulty swallowing, this is expected. If food or fluids go to the lungs, pneumonia often develops. A feeding tube does not negate the risk of aspiration.

WHEN TO CALL PALLIATIVE CARE

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Contact your Community Palliative Care Team if you need assistance with the following concerns:

-recurrent urinary tract infections

-urinary retention

-constipation

-unmanaged pain

-respiratory infection

-poor sleep

-depression or anxiety

-increasing agitation or behaviors that are difficult to manage

-you wish to discuss goals of care

-you wish to avoid rehospitalization

-you would like to be evaluated for transition to hospice

WHEN IS IT TIME TO CONSIDER HOSPICE?

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It is often difficult to know when you are ready to transition onto hospice services. Common feedback from patient families is that they wished they had gotten their loved one onto hospice services sooner.

Consider the following:

-What is your (loved one's) cognitive functioning?

-What is your (loved one's) physical functioning?

-Are you(they) dependent on others for all care?

-What is your (loved one's) quality of life?

-How do you (your loved one) spend the day?

-Are there recurrent infections?

-Is there difficulty swallowing?

-Is there weight loss?

-Are there additional illnesses?