

Caring for Your Loved One:

A Discussion on Daily Care Needs of Individuals
with Advanced or End-Stage Dementia

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Normal Aging

- As one ages, decline in several areas may be noted as normal and expected changes of aging—without mention of dementia.

Decline in Taste

Decline in Smell

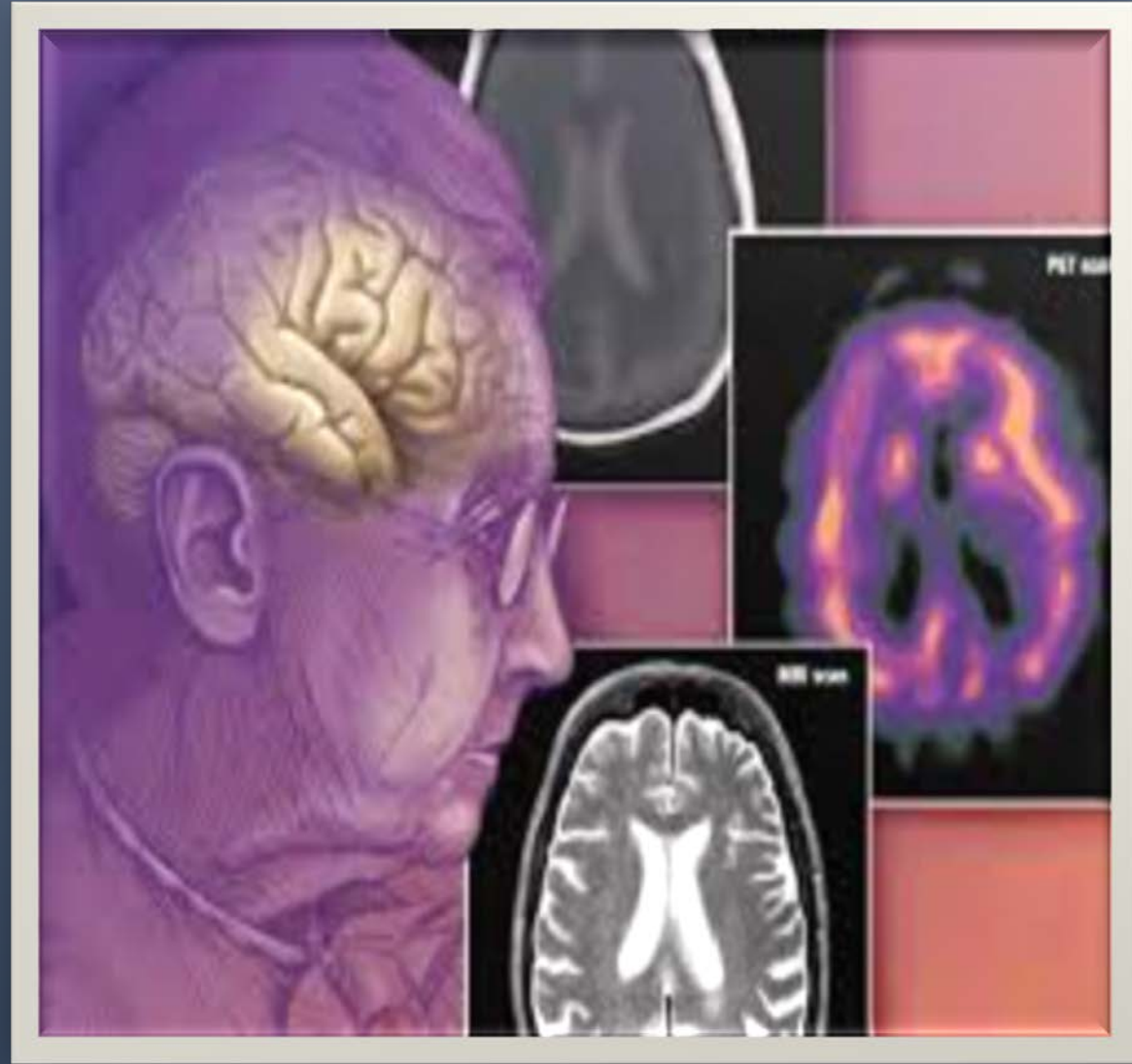
Decline in Vision

Decline in Hearing

Decline in Recall of Known Facts

Dementia

- DEMENTIA IS COGNITIVE BRAIN FAILURE !!!!
 - Individuals with dementia begin to exhibit a decline in previously obtained social and/or occupational functions.
 - They are unable to function at prior level due to developing dementia.



- They are no longer able to compensate for their deficits by writing notes or avoiding tasks they have difficulty completing on a daily basis.
- Family and friends begin to notice a change on more than one level:
 - Cognitive
 - Mobility
 - Emotional
 - Functional
 - Interpersonal relationships
- No person's journey with dementia is exactly the same as another person's journey.



Types of Dementia

- Alzheimer's Dementia (50%-65% of dementia cases)
- Lewy Body Dementia (15%-20% of dementia cases)
- Frontotemporal Dementia (15% of dementia cases)
- Vascular Dementia (10%-20% of dementia cases)
- White Matter Dementia (5% of dementia cases)

Characteristics of Each Type of Dementia

- Alzheimer's Dementia

Progressive loss of cognitive function expressed as memory loss, aphasia apraxia, agnosia, or executive functioning

- Lewy Body Dementia

Often have vivid hallucinations and Parkinson-like movements

- Frontotemporal Dementia

Often exhibit mood/ behavior/personality changes—poor hygiene, bad language, inability to stop touching/feeling/moving

- Vascular Dementia

Gradual decline in status with evidence of neurological deficits/cardiovascular disease (atherosclerosis) and falls

- White Matter Dementia

Exhibit mood disorders/apathy/depression/crying

Individuals may be affected by more than one form of dementia.

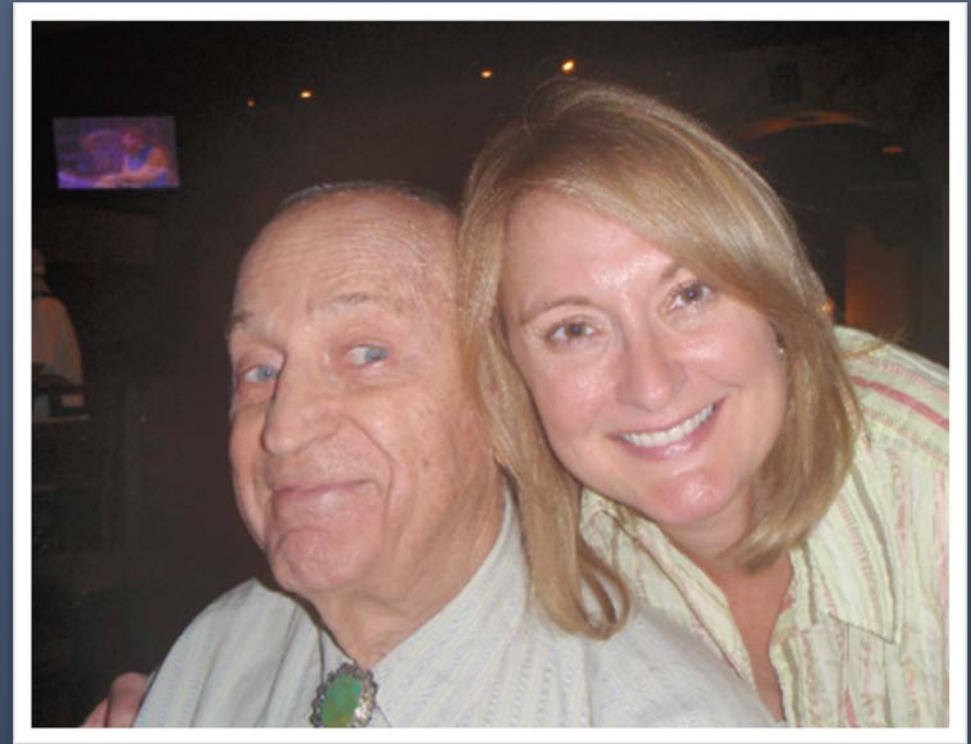
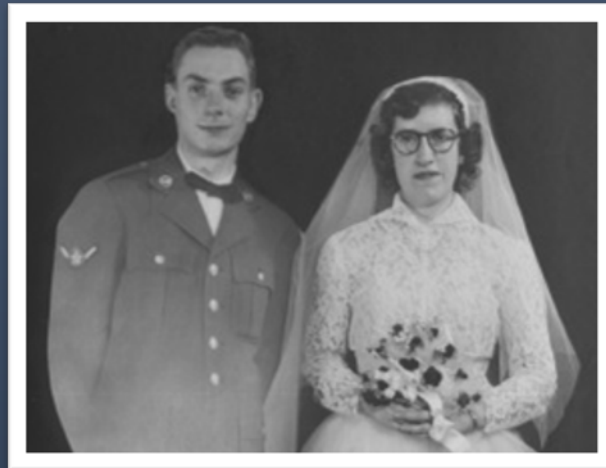
This can make treatment more challenging for both medical professionals and caregivers.

As dementia progresses, patients can display multiple symptoms.

Advanced and End-Stage Dementia

- Patients with advanced or end-stage dementia have progression of symptoms and are dependent on others for assistance in all areas.
- They are unable to function independently due to progressive brain failure.
- No two people with advanced or end-stage dementia will exhibit the exact same symptoms or level of decline.

Excellent supportive care, rather than additional medication, is often the preferred treatment for patients with advanced dementia.





Many families struggle with how to best care for their loved one with advanced dementia.

Symptoms of Advanced and End-Stage Dementia

Individuals with the following symptoms usually have a higher chance of developing advanced and end-stage dementia.

Remember: Not all individuals will have all symptoms.

Memory Loss

- Very severe in advanced dementia
- May not be able to recognize close loved ones they see daily
 - May not be able to find way from bed to bathroom
- May not be able to recognize familiar objects (apple/book/remote)
 - May believe they are living in a different time (childhood)

Difficulty with Communication

- Unable to understand what is being said to them or what they are being asked to do
 - Often unable to participate in conversations
- May lose ability to speak to others and have changes to way their words sound
 - Caregiver must look to body language for communication of needs

Loss of Mobility

- Loss of ability to ambulate
- Loss of ability to perform basic activities of daily living (ADLs)
 - Increased falls
 - Wheelchair or bedbound
- Contractures to extremities due to atrophy of muscles

Weight Loss and Decline in Appetite

- Decline in appetite and thirst contribute to multiple symptoms in patients with advanced and end-stage dementia
 - Weight loss can affect multiple body systems:
Immune/Muscular/Skeletal
 - Individuals with weight loss may not have reserves needed for:
Wound Healing after surgery/Rehabilitation after Fracture Repair

Dysphagia

- Patients with advanced or end-stage dementia often have difficulty with swallowing.
- Chewing and swallowing are tasks that require complex neuromuscular interactions. Dementia patients often lose the ability to perform these tasks as their dementia advances.
- Aspiration can develop as a result of progressive dysphagia.

Incontinence

- Loss of control of bladder and bowel is common in advanced and end-stage dementia
 - Numerous factors can contribute to the cause of incontinence
- Use of briefs are common in patients with advanced and end-stage dementia
- This can be a very devastating part of the dementia journey for many patients and their caregivers

Unusual Behaviors

- Aggressive behavior
 - Agitated behavior
 - Delirium
 - Crying/Scarred
- Repetitive behaviors (rocking/picking/constant movement of hands)
 - Hallucinations
 - Restlessness due to inactivity
- Physical inactivity (remain still/don't blink or move)
 - Remember each person is different

“Those with dementia are still people and they still have stories and they still have character and they are all individuals and they are all unique. And they just need to be interacted with on a human level.”

- Carey Mulligan



Options for Care of Advanced and End-Stage Dementia Patients

- Aggressive care
- Care of patient in home
- Nursing home or Assisted Living admission
- Hospice care

Remember:

No decision is a wrong decision if it is RIGHT for the individual patient and caregiver.



Aggressive Care

- Caregiver and patient decide to continue routine hospital visits, maximal medical therapy (medications), lab work and x-rays, supportive care measures, and doctor's visits in an effort to prolong life and enhance quality of life.
 - Patient is probably FULL code status. (CPR will be initiated.)
 - Patient can be in a variety of settings.



Care of patient in home

- Can be challenging to family/caregiver
- Will require learning new skills to provide optimal care of person
 - Good body mechanics
 - Caregiver stress/burnout
- Need to utilize community resources
- Must have adequate space for equipment in home
- Need to be open to working with others (hospice agencies/sitters/etc)



A Caregiver's Calling

- A CAREGIVER is a person, paid or unpaid, who helps another individual with an impairment complete his activities of daily living for some period of time.
 - Caregivers are often family members but can also be friends and acquaintances of the person requiring care.
- They may live in or out of the home or work for an agency. Many caregivers do not realize they are caregivers. They must have a passion and desire to help another person in their time of need. Many view this as a calling.

How many Caregivers are in this Room today ??



Avoiding Caregiver Stress and Burnout

- Find a support group and go regularly
- Have someone you can call to watch your loved one while you go shopping/get hair cut/go to bank
 - Take care of yourself
 - Go to your doctor's visits
- Take your own medications and vitamins
- Be alert for signs of isolation and depression in yourself
 - Understand it is okay to verbalize your feelings
 - Be able to enjoy the bad times
 - Remember to laugh daily

Communicating with Individuals who have Advanced and End-Stage Dementia

- Caregivers often must find other forms of communication than verbal.

Gentle touch

Eye Contact

Smiling

Meaningful Listening

Patience

Exploring Meaning of Body Language

Be alert to changes in patient response on daily basis—May signal acute illness.

The Power of Touch

- Individuals with advanced dementia are often unable to effectively communicate their needs to others verbally.
- Caregivers can use the simple, but powerful, technique of touch and exploration of the body to elicit an Automatic Autonomic Reflexive Movement/Response to identify cause of pain/anxiety/distress in individuals with advanced dementia who can no longer verbalize these needs.

Volunteer Please!!!

Get on their Level to Interact



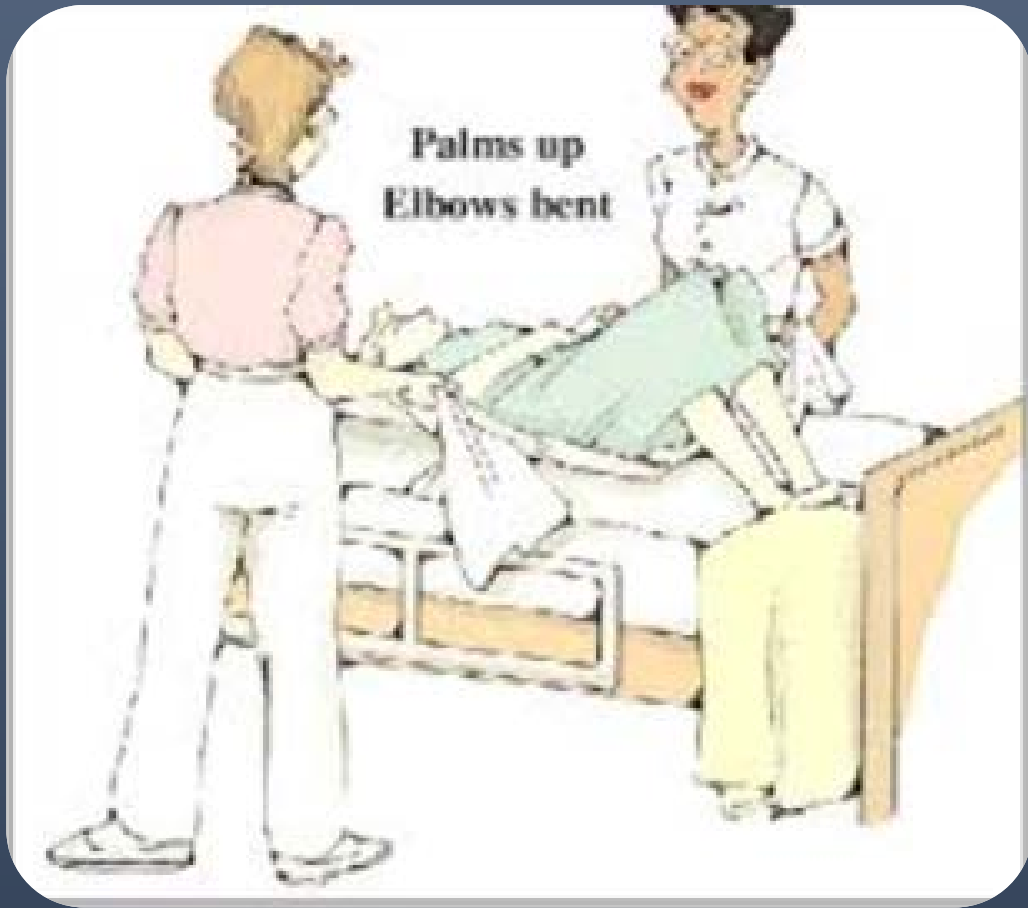
Proper Body Mechanics

- BODY MECHANICS involves moving one's body correctly as well as making the best use of one's strength to prevent injury.
- Proper Body Mechanics can be used by caregivers to transfer or reposition patients with advanced and end-stage dementia and prevent injury to either party.
 - Try to plan movements/transfers when help is present.
 - Know the limits of your body!!!

Try to Move Me!!



Pulling up in Bed



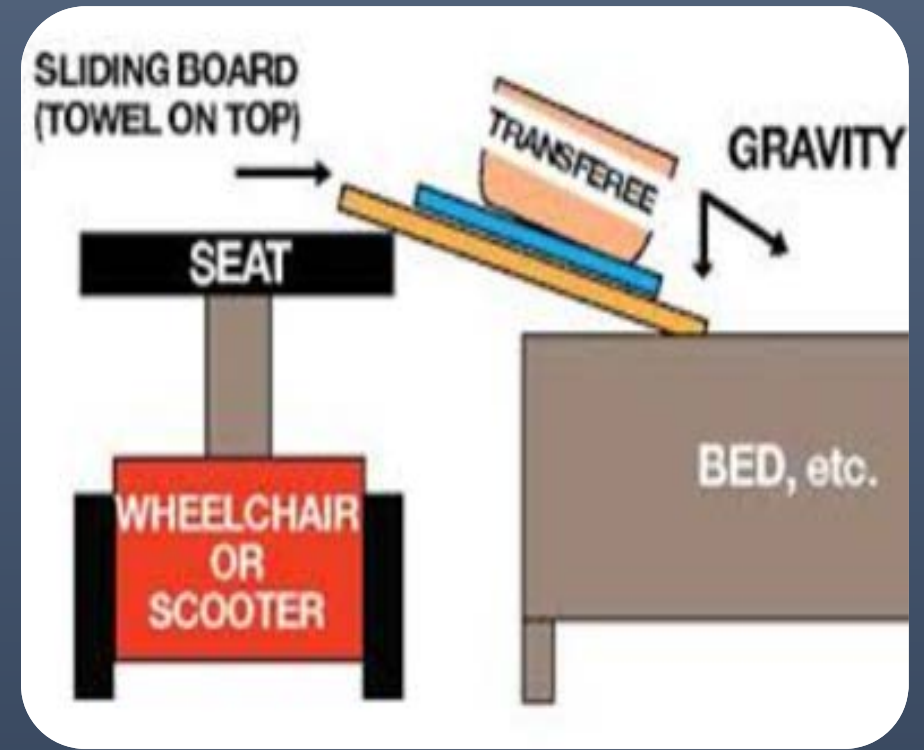
Turning on Side



Use of Bolsters, Pillows and Wedges



Dangling at Bedside and Transfers



Changing a Brief



- Have supplies within reach
- Use correct size brief
- Cleanse skin of excrement to prevent breakdown
- Roll patient from side to side with draw sheet to prevent shearing injury to skin
- Ask for help from others

Feeding and Offering Oral Fluids



Oral Care



Caregivers must realize that any activity or movement in patients with advanced dementia requires energy and strength the patient may not possess.

Goal of All Care

- Goal of all care and activities should be to better the quality of life of the individual with dementia or add to their comfort in some way.
- If an activity causes the individual distress or pain, the caregiver must stop and examine the reason why they are conducting the activity and if it is absolutely necessary to continue performing.
- Remember: Look at the individual's body language. Don't just rely on verbalization of understanding and feelings.

Nursing home or Assisted Living admission

- If individual is already in an assisted living facility, must look at change of level of care as dementia progresses to best meet care needs.
- Nursing homes offer 24/7 nursing supervision for patients with advanced and end-stage dementia. They are a good alternative for families not able to care for and individual in the home.
 - All nursing homes are different and offer different levels of care.
(Secure units/Feeding and Hydration assistance/Dementia and Fall programs)

Code Status

- FULL CODE STATUS

 - Patient will continue aggressive treatment options

 - CPR performed if unable to sustain own efforts

 - Desire to continue ER evaluation and Hospital admissions

- DNR CODE STATUS

 - Patient will seek palliative care measures

 - Comfort, not cure, is goal of treatment

 - CPR will not be performed if unable to sustain own efforts

 - May or may not seek ER/Hospital

 - Hospice appropriate

Hospice

- Individuals with advanced or end-stage dementia may qualify for hospice care if they meet certain criteria. Listed below are a few of the admission criteria for dementia patients:
 - Life expectancy of 6 months or less
 - FAST score of 7 or above
 - Inability to walk without assistance
 - Speaks less than 6-8 clear words daily
 - Inability to bathe/dress/eat/toilet self
 - Inability to turn self in bed
 - Frequent infections/UTI/sepsis
 - Multiple comorbidities contributing to gradual decline in status

Remember:

No decision is a wrong decision if it is RIGHT for the individual patient and caregiver.



Questions about Hospice Admission

- Does not mean loved one will die tomorrow
- Does offer a greater chance for comfort inside the home
- Does have potential to increase life expectancy and quality of life
 - Does not have to be DNR (but highly recommended)
 - May still be followed by PCP
 - Hospice will provide an additional layer of support and care
- Will not have a person in home 24/7 (unless meets requirements)
 - Access to on call staff 24/7

The Daily Challenges

- Caregiver and family will begin to develop professional relationship with hospice staff. Goal of this relationship is to improve quality of care and life for patient and caregiver.
- Caregiver should feel free to ask hospice staff about needed medications, patient status, dietary changes, ADLs, and their loved one's physical changes as progression occurs.
- Caregivers often communicate needs/concerns to medical staff through hospice staff at routine visits.

What to Expect when End of Life is Near

- Changes become more pronounced as death approaches. Each person's journey towards death differs; however, these are some common findings as death approaches:

Loss of appetite with inability to swallow

Excessive fatigue or sleepiness

Weakness and inability to perform basic movements

Confusion or disorientation

Change in breathing pattern

Increased oral secretions with rattle in chest

Decline in urination

Withdrawal (Desire for family to go home)

Changes to skin color or temperature

How to Cope with Withdrawal of Oral Food and Water

- This can be one of the hardest decisions a family has to make as their loved one progresses in their dementia
- Body begins to shut down and requires less “full” or food
- GI system is unable to digest food ingested due to shunting of blood to vital organs and slowing of intestines
- Natural part of aging/dementia

Remember to Use Extended Support System

- As loved one begins to decline, caregiver must call extended support system for needs. This will help prevent increased stress and burnout during this time of increased need.
- If patient is on service with hospice, be sure to communicate questions and concerns with staff.
 - Have funeral plans completed prior to this time, if possible.
- Be confident in knowing what your loved one's wishes are (code status/barial wishes/choice of minister) prior to this time so you can fulfill those wishes.

When Loved One Passes

- No movement of chest wall
 - No verbal response
- No further audible sounds of breathing
 - No blinking of eyes
- Caregiver should call hospice nurse or local authority for release of body

Continuation of the Dementia Journey

- After death of loved one, the caregiver must continue their own journey of acceptance.
- Group counseling and support are encouraged for caregivers. This offers loved ones a way to express feelings of anger, loss, denial, acceptance, and love.
- Others still on their journey with their loved one can glean wisdom from those who are now completing their journey alone.

