

**ALZHEIMER'S AND OTHER
DEMENTIAS: MORE THAN
MEMORY**


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Training
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**DUKE FAMILY SUPPORT
PROGRAM**

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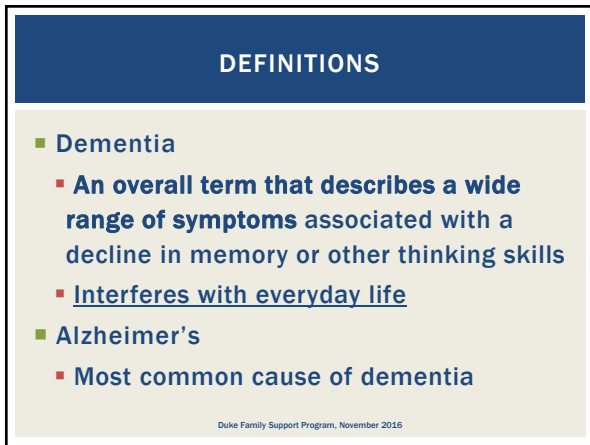
**WE ARE A BRIDGE TO UNDERSTANDING
YOUR OPTIONS**

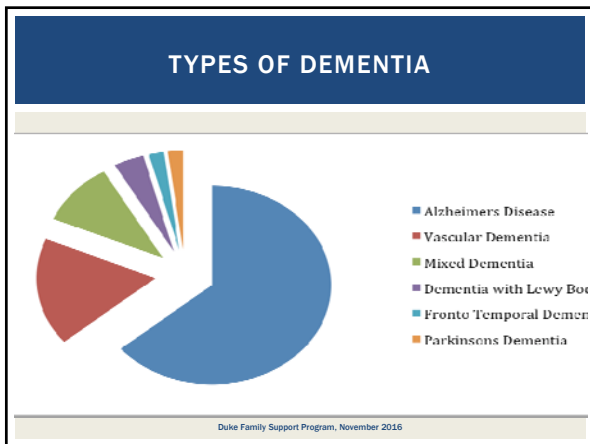


A no-cost service for all NC families and professionals
caring for someone with a memory disorder

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ALZHEIMER'S IS NOT ...

- Normal aging
- Limited to people over 65
- Diagnosed by a single test
- Contagious
- Preventable
- Curable



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CAVEATS

- When you have met one person with a memory disorder, you have met one person... Not a “look” disease.
- Language, labels and communication contribute to stigma
- Common, complex, chronic, costly, conflicts
- Insidious onset, variable progression, retained capacities
- It's about adapting human and physical environment and communication

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FACTS & FIGURES

- An estimated 5.4 Americans have Alzheimer's
- Alzheimer's is the 6th leading cause of death in the United States, 5th in NC
- 1 in 3 seniors dies with dementia
- Alzheimer's is the only disease among the top 10 causes of death in America that cannot be prevented, cured or even slowed

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RACIAL & ETHNIC DIFFERENCES

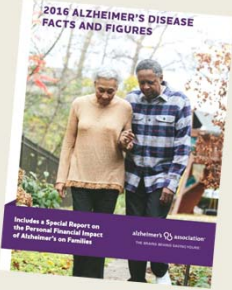
- African-Americans and Hispanics are more likely than older whites to have AD and other dementias
- Older African-Americans are about twice as likely to have AD and other dementias as older whites, and Hispanics are about one and 1 ½ times as likely to have AD and other dementias as older whites

- From 2016 Alzheimer's Disease Facts and Figures

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WHY RACIAL & ETHNIC DIFFERENCES?


Variations in health, lifestyle and socioeconomic risk factors across racial groups likely account for most of the differences



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WOMEN & ALZHEIMER'S

- Almost 2/3 of the 5.4 million Americans with Alzheimer's are women
- Women in their 60s are about twice as likely to develop AD over the rest of their lives as they are to develop breast cancer
- Of all unpaid AD and dementia caregivers, 70% are women




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WHY MORE WOMEN?



Katherine Lin, Duke Class 2016
Duke Family Support Program, November 2016

MORE THAN MEMORY LOSS



- Language
- Visual spatial
- Executive function
- Time disorientation
- Apathy
- Judgment
- Behavioral/psychiatric symptoms

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EARLY-STAGE ALZHEIMER'S

"Early-Stage" refers to people, irrespective of age, who are diagnosed with Alzheimer's disease or related disorders and are in the beginning stages of the disease.

—Alzheimer's Association

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MILD STAGE SYMPTOMS

- Significant memory loss
- Losing or misplacing things,
- Repeating things
- Hard to find the right words
- Difficulty completing routine tasks
- Visual changes

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MORE EARLY-STAGE SYMPTOMS

- Lost or disoriented in familiar settings
- Trouble handling money
- Taking longer
- Personality, Behavior and Mood changes
- Apathy, loss of initiative
- Changes in feelings of intimacy

From: Living Your Best, Lisa Snyder

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ANOSOGNOSIA

- Lack of self-awareness, or insight
- Unaware of one's own decline or difficulties
- Brain cell changes lead to a lack of self-awareness
- **Person "is not behaving in a difficult, hurtful or indifferent manner on purpose."**

From Banks & Weintraub, Brain Cognition 2008

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THE LIVED EXPERIENCE OF AD

*“Please don’t correct me ...
remember, my feelings are intact
and I get hurt easily...
I may say something that is real to me but
may not be factual.
I am not lying.
Don’t argue – it won’t solve anything.”*

Canadian Early Stage Support Group

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WHAT INFLUENCES QUALITY OF LIFE?

- Experience of connectedness in:
 - relationships together vs. alone
 - purposeful vs. aimless agency
 - well vs. ill perspective
 - located vs. unsettled sense of place

–O’Rourke et al, 2015

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BASIC HUMAN NEEDS



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MODERATE SYMPTOMS

- Language and reasoning problems
- Sensory processing problems
- Recognizing family and friends
- Difficulty with new learning, new situations
- Problems with multi-step tasks
- Hallucinations and delusions
- Impulsivity

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Home Alone



***But she fired
all the help!***

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HOME ALONE?

■ Leaving stove on	■ Calling frequently
■ Smoking	■ Opening the door to strangers
■ Responding to emergencies	
■ Wandering	– University of Michigan Geriatrics Center
■ Giving money away	
■ Falling often	

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THE HARDEST PARTS

- "I can't NOT take it personally!"
- "It's like a box of chocolates – you never know what you will find when you bite in."
- "I was told to tell the truth – I don't lie"
- "Couldn't she remember the good stuff?"
- "It only natural to try to explain rationally"

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REGRET

It wasn't that I didn't do the best for Mama; but that the best I could do wasn't as good as I wanted. I wanted to always be patient, kind and understanding; I wasn't...Sometimes, under the stress of exhaustion, emotions surface which are later regretted.

– A Daughter

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IN A SUPPORT GROUP ONE CAN

- Share difficult feelings such as anger, fatigue, regret and frustration
- Express disappointment in professionals, providers and family
- Recognize that you are not a failure
- Receive immediate, practical help

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RESPIRE: WHAT DO WE KNOW?

- Most preferred, least available, least affordable
- Families need help in how to best use respite time
- Timing, frequency, flexibility, dependability, affordability and quality affect use and outcomes
- By the time respite is needed, there is a need for many other community supports

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WHY FOCUS ON BEHAVIOR?

- Major cause of suffering for people with dementia, their families, care staff
- Common, most challenging aspect of care
- Major predictor of negative mental & physical health consequences for caregivers
- Major predictor of increased care time, nursing home admission, hospitalization, higher care costs, injury, and death
- Major contributor to problems of recruitment, retention, injuries, & burnout of direct care workers

WHAT DO WE KNOW ABOUT DEMENTIA-RELATED BEHAVIORS?

- Anxiety, suspiciousness, restless agitation are common symptoms of brain disorders despite best care (Goforth & Gwyther, 2009).
- Non-drug approaches are recommended first based on evidence and expert consensus (Lyketsos et al, 2006).
- Rejection or resistance to care in nursing homes is associated with delirium, delusions, depression or inadequately treated pain (Ishii, 2010).

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WHAT DO WE KNOW ABOUT DEMENTIA-RELATED BEHAVIORS?

- Behaviors communicate unmet need and reduced capacity to cope with stressful situations
- Dementia-related behaviors may be inconsistent daily or even hourly.
- Not all behaviors respond to medicine: Side effects of medication create additional problems.



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WHAT DO WE KNOW ABOUT DEMENTIA-RELATED BEHAVIORS?

- Behaviors may be a response to sensory overload, fear, frustration, anticipated embarrassment or physical symptoms.
- Dementia-related behaviors respond to changes in activity, routines, environment, balancing rest and stimulation and changes in communication from others.

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COMMON DEMENTIA-RELATED CHANGES




- Apathy (70%)
- Agitation (60%)
- Anxiety (50%)
- Mood blunting/ lability (40%)
- Disinhibition (40%)
- Delusions (40%)
- Aggression (20%)
- Hallucinations (15%)
- Sleep disruptions

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AGITATION TRIGGERS

- Pain
- Fatigue
- Hunger/Thirst
- Dehydration
- Constipation
- Full Bladder
- Drug Effects
- Caffeine/Alcohol
- Incontinence
- Infection




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WHICH BEHAVIORS ARE MOST CHALLENGING?

- Begging, repeated accusations
- Swearing, insulting, threatening
- Resistance to care
- Shadowing, rummaging, wandering
- Hitting, biting, scratching, pinching
- Voiding in the wrong place
- Undressing, unwanted touch or intimacy

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FTD: BEHAVIORAL VARIANT



- The blank stare
- Apathy
- Lost judgment
- Loss of empathy
- Obsessive/excess compulsive

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FTD: SPECIAL CONSIDERATIONS

- Can't resist impulses to manipulate or operate
- Ritualistic, compulsive excessive perseveration without purpose
- Impulsive disinhibition with no insight about harm to others
- Hyper-orality



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IS THE BEHAVIOR A PROBLEM?

- Causing distress to person or caregiver?
- Interferes with function or increases disability?
- Impedes delivery of necessary care?
- Limits capacity to stay in preferred setting?
- Safety risk to self or others?



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BEHAVIOR BASICS

- The person is trying as hard as s/he can. Reasoning, pleading, extracting promises or punishing won't help.
- People forget what is acceptable public behavior and lose impulse control – short fuse.
- Resistance may be a way to avoid embarrassment at being asked to do something too difficult or too childish.

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BEHAVIOR BASICS

- Brain damage makes it difficult to start, plan, organize or sequence a task.
- Overwhelmed fearful responses (catastrophic reactions) to a confusing world may be beyond her capacity to understand. She doesn't know why she is angry, suspicious or sad.
- The person sees you as security or safety in a shrinking world – He will respond in kind if you are angry, rushed or upset, yet he may not let you out of his sight.

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COMMUNICATION IS KEY

- Verbal and non-verbal
- Cueing, guiding, leading, reassuring
- Identity and social roles reminders
- Familiar predictable phrases
- Humor helps



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AGITATION: WHAT TO DO

- Slow down, soothe, structure
- Encourage, praise, be gracious and polite
- Add visual cues, adjust light
- Back off and ask permission
- Guided choices
- Reassure repeatedly



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AGITATION: WHAT TO DO

- Ask for adult-like help or “company”
- Offer security object, rest and privacy after an upset
- Limit caffeine or alcohol
- Comfort rituals
- Modify favorite social, creative or sports activities
- Avoid scary TV shows

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REMINDERS

- Avoid over- or under-estimating what the person can do.
- Be flexible and adjust timing based on energy.
- Do not change the diagnosis when she has moments of lucidity or insight.
- When you have dementia, thinking takes more energy.
- Pay attention to comfort, retained strengths, and opportunities to pamper.

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ADVANCED DEMENTIA

- Eating problems, weight loss
- Resistance to care
- Non-communicative
- Aspiration pneumonias
- Pressure ulcers, contractures with immobility
- Breathing problems or pain – 30-40%

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Almost Home

"Where Someone Cares"

Chandelier Assisted Living


"The finest in Senior Independent & Assisted Living facilities"

- Independent Living For "55 And Better"
- Nursing Staff & House Doctor
- Home Cooked Meals Available To All
- Library-Chapel-Card Room
- Bank-Beauty Shop
- Scheduled Transportation
- Lake & Beautiful Grounds
- Caring Staff & More...

821-333-2238 or 821-333-1308

She doesn't belong in a nursing home

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When I saw him coming toward me in wet socks and somebody else's shoes, I thought 'Is this what it has come to?' I work so hard to protect him and feel betrayed by those I entrusted him to. This is symbolic of the failure of their implied contract to care for this man who was so important to us ...

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WHAT DO FAMILIES WANT FROM RESIDENTIAL CARE?

- Meet basic care needs
- Safety and security
- Sense of belonging or place
- Foster dignity with respect
- Support in addressing family guilt
- Communication from physicians
- Information and guidance on difficult decisions

Ersek, 2014

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WHAT COMPLICATES ADVANCED DEMENTIA DECISIONS

- Translating comfort goal into action
- Lack of knowledge about illness trajectory
- Lack of adequate time for decisions
- Despite DNR or advance care planning, people with dementia are hospitalized and in emergency rooms frequently
- Families more often use best interest rather than substituted judgment standards.

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FAMILY COMPLAINTS ABOUT DEMENTIA END OF LIFE CARE IN FACILITIES

- Staff don't recognize new symptoms, needs
- Physicians are "missing in action"
- Staff are not well trained in palliative care
- Regulations hinder care delivery
- Hospice too late and conflicts with NH staff
- Perceived conflicts associated with family depression and staff stress and burnout.

Ersek, 2014

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YOU CATCH ON

Let me tell you, we love you all, and we're gonna keep on loving you as long as we can ... What's good about you all is you catch on, you catch on, you catch on and you know it's not going to be perfect.

— Jean Walker in her 90s
Four years before her death with Alzheimer's

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