LIVING WITH DEMENTIA: UNIQUE VULNERABILITIES AND RISKS FOR ABUSE AND NEGLECT

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DUKE FAMILY SUPPORT PROGRAM
WWW.DUKEFAMILYSUPPORT.ORG

NC Partnership to Address Adult Abuse

Raleigh, NC
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DEMENTIA IS CHANGING

Personal to public health issue

Aging to family issue

Family: beyond blood, co-housing

Pushing limits of family capacity and solidarity

DEMENTIA FAMILY CARE IS DIFFERENT

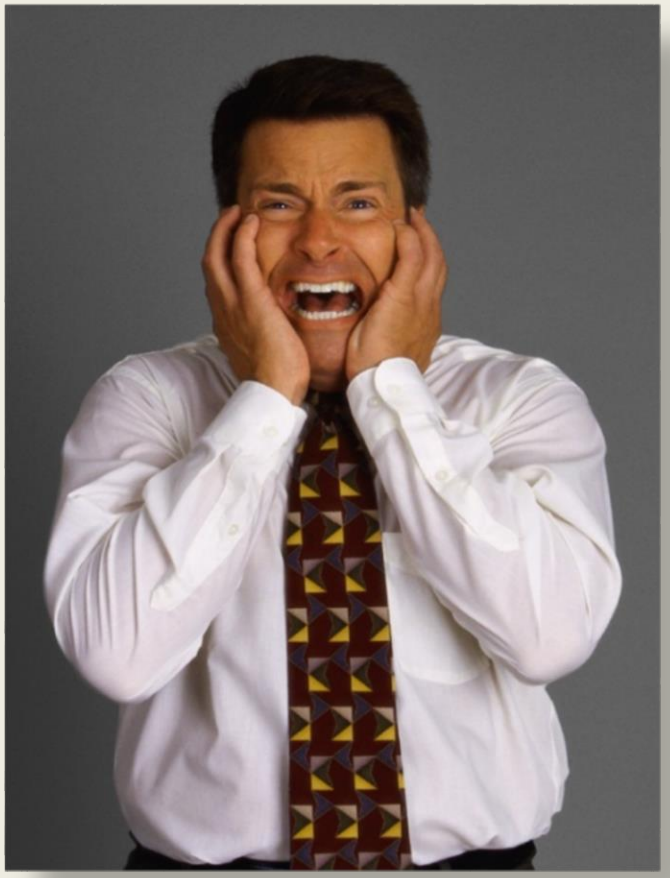
- Most intense, vigilant and longest duration care compared to other family care
- Higher incidence of depression, anxiety, burden and lower overall well-being compared to other family caregivers
- Challenging behaviors, resisting care and sleep disruptions predict risk of negative health outcomes of dementia family care

ANGER

Risk factors

- Too many responsibilities
- Unpleasant tasks
- Feeling underappreciated
- Little support
- No light at the end of the tunnel

MacNeil, et al. (2010) "The Central Role of Caregiver Anger for Mental Health and Harmful Behavior"



HOME ALONE

But she fired all the help!

THE SIX Cs OF DEMENTIA

1. Common
2. Chronic
3. Complex
4. Costly
5. Choices
6. Conflict

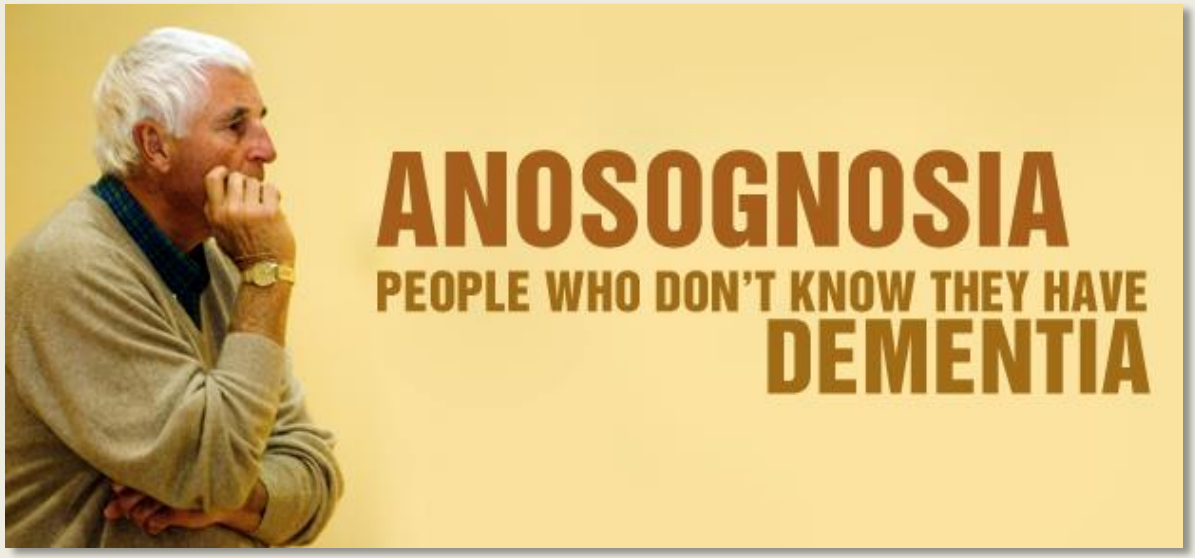
STARTING POINTS: LET'S AGREE

- Living with dementia, caring for or about a person with dementia means increased health, safety and abuse/neglect vulnerabilities and risks.
- Dementias are problems of thinking and memory. Cognitive fatigue is a real risk and vulnerability.
- Harmful health, psychosocial outcomes and abuse/neglect are a risk for individuals living with dementia, direct care staff and other residents of long-term care.
- Dementias occur with multiple chronic conditions, sensory and functional impairments and account for disproportionate mistreatment, neglect and abuse outcomes.

DEMENTIA

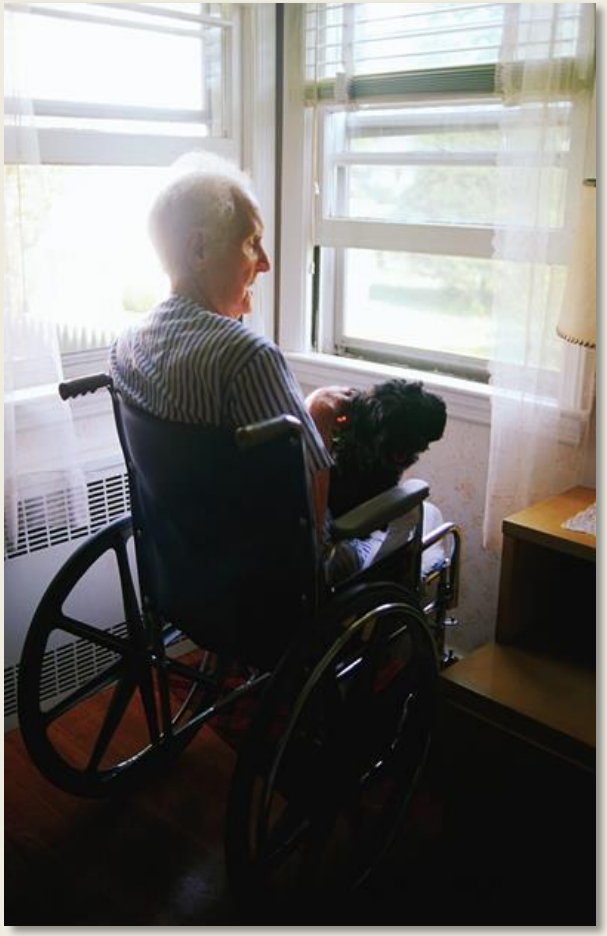
Dementia is an umbrella term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to interfere with daily life.

ANOSOGNOSIA



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

MORE THAN MEMORY LOSS

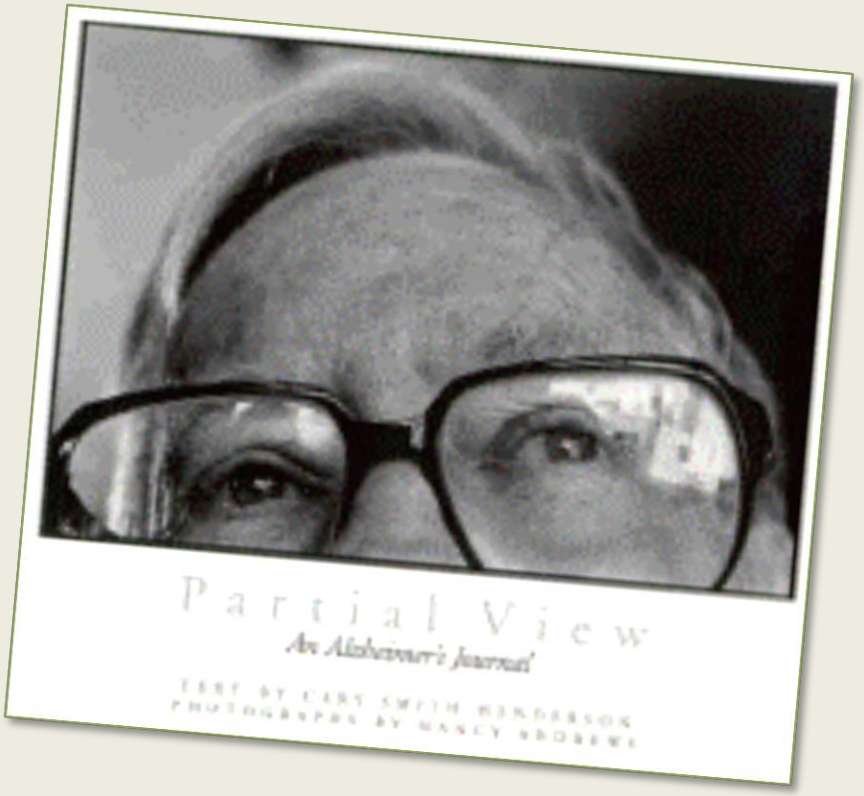


- Language
- Visual spatial
- Executive function
- Time disorientation
- Apathy/empathy
- Judgment
- Behavioral/psychiatric symptoms

THE PERSON LIVING WITH ALZHEIMER'S

I'm being overlooked… the world is cheating or out to get me when I can't think sensibly. I want to shout, raise some hell, be someone I am not.

— Cary S. Henderson, PhD, 1998



DEMENTIA IS ABOUT FEAR

Shame/stigma

Discrimination

Rejection

Social isolation

Loss of control

Change of identity

"My brain just gave up, more or less"

WHAT DO FAMILIES SAY?

- ***She never would have done that before.***
- ***He's more than I can handle.***
- ***There are no "whys" in Alzheimer's.***
- ***He seems unaware of how his behavior affects us.***
- ***She doesn't appreciate my sacrifices but my brother don't appreciate me either…***
- ***She's so nice to others and so mean to me.***

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

WHY FOCUS ON BEHAVIOR?

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

Gitlin, et al., 2010

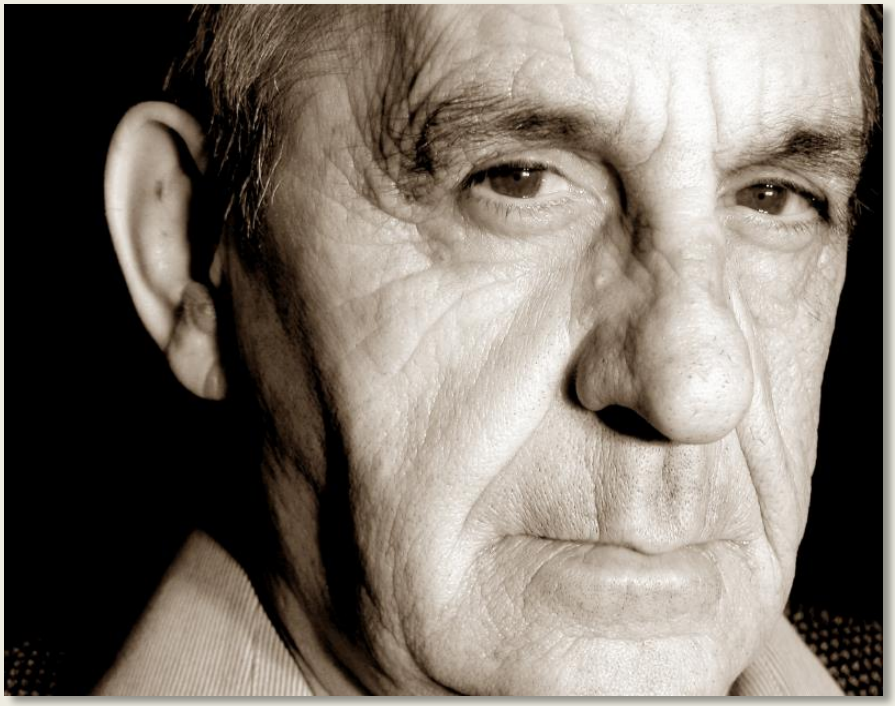
WHAT DO WE KNOW ABOUT DEMENTIA-RELATED BEHAVIORS?

- Behaviors communicate unmet need and reduced capacity to cope with stressful situations (*van der Ploeg, BMC, 2010*).
- Dementia-related behaviors may be inconsistent daily or even hourly.
- Not all behaviors respond to medicine: side effects of medication create additional problems.
- Behavior changes may be attempts to preserve identity, dignity and control in the face of frustration and unwanted threatening situations.

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

FTD: SPECIAL CONSIDERATIONS



- The blank stare
- Apathy/lack of motivation
- Loss of empathy
- Overwhelmed by sensory input
- Obsessive/compulsive behaviors

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?

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, lower stress threshold.
- Resistance may be a way to avoid embarrassment at being asked to do something too difficult or too childish.

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 or suspicious.
- 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.

WHAT IS SHE THINKING?

- *I am overwhelmed.*
- *How dare you question me!*
- *I make sense – you and events don't.*
- *Your reasoning wears me out.*
- *I must defend my turf.*

WHAT IS SHE THINKING?

- *It's gone and you are here.*
- *It's not a lie – I am filling in memory holes with something reasonable.*
- *If I could remember, I wouldn't ask or repeat questions.*
- *Waiting for me to do it myself may just frustrate both of us.*
- *Give me a clue.*

PREVENT ANGER ESCALATIONS

- Avoid conversations in loud/crowded places
- Take a breath, approach at eye level
- If he starts to walk away, don't try to stop him
- Maintain a safe distance (slightly beyond striking range)
- Speak with…not at him/her
- Be sincere, firm, direct, 1-step requests
- Listen to feelings, less to facts and respond to emotions, not behaviors

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

AGITATION: WHAT TO DO

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

AGITATION: HELPFUL TALK

- ***May I help you?***
- ***Do you have time to help me?***
- ***You are safe here.***
- ***I will get right to it.***
- ***Thanks for letting me know.***
- ***I am sorry you are upset.***
- ***This is hard - I wish things were easier for us.***
- ***I apologize*** (even if you didn't do it).

AGITATION: WHAT NOT TO DO

Do not:

- Take offense
- Raise voice
- Corner, crowd, restrain
- Rush, criticize, ignore
- Confront, argue, explain, teach
- Show alarm, make sudden movement

REMINDERS

- Being reasonable, rational, and logical will just escalate arguments.
- People with dementia do not need to be grounded in reality every minute (*Tomlin*).
- Making agreements or promises with the person with dementia doesn't work.
- Tell the doctor what's really going on and what works.

LIVING ALONE WITH DEMENTIA

- 28 – 34% of people with dementia live alone
- Less likely to be diagnosed with a dementia or to receive the same level of medical care
- Predominantly female and older
- Predominantly lower income
- More likely to have non-relative caregivers

L. Gould, Dementia Care Summit, NIH Oct 2017

LIVING ALONE WITH DEMENTIA: RISKS FOR ABUSE/NEGLECT

- Financial exploitation
- Home safety
- Unattended excursions
- Capacity to respond to emergencies

L. Gould, Dementia Care Summit, NIH Oct 2017

RISKS OF ABUSE

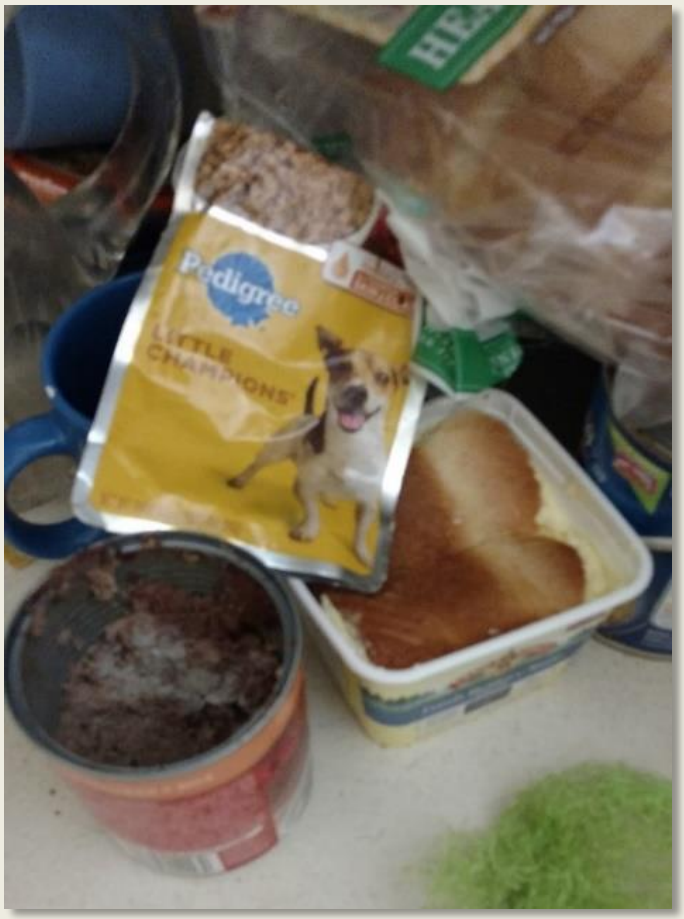
- Minor and major neurocognitive disorders create risk
- Trusting of others
- Loneliness
- Impaired judgment/reasoning
- Financial abuse
- Scams, lotteries
- Telephone, snail mail, email,
- Family, friends, charities, churches, financial advisor
- Physical abuse, including sexual

L. Mosqueda, MD. ASA 2017 Webinar

CHALLENGES FOR SERVICES PROVIDERS

- Identifying individuals with dementia who live alone
- Building trust
- Supporting safety and autonomy
- Involving family and friends
- Coordinating paid providers and formal support services
- Assisting with transition to a new setting

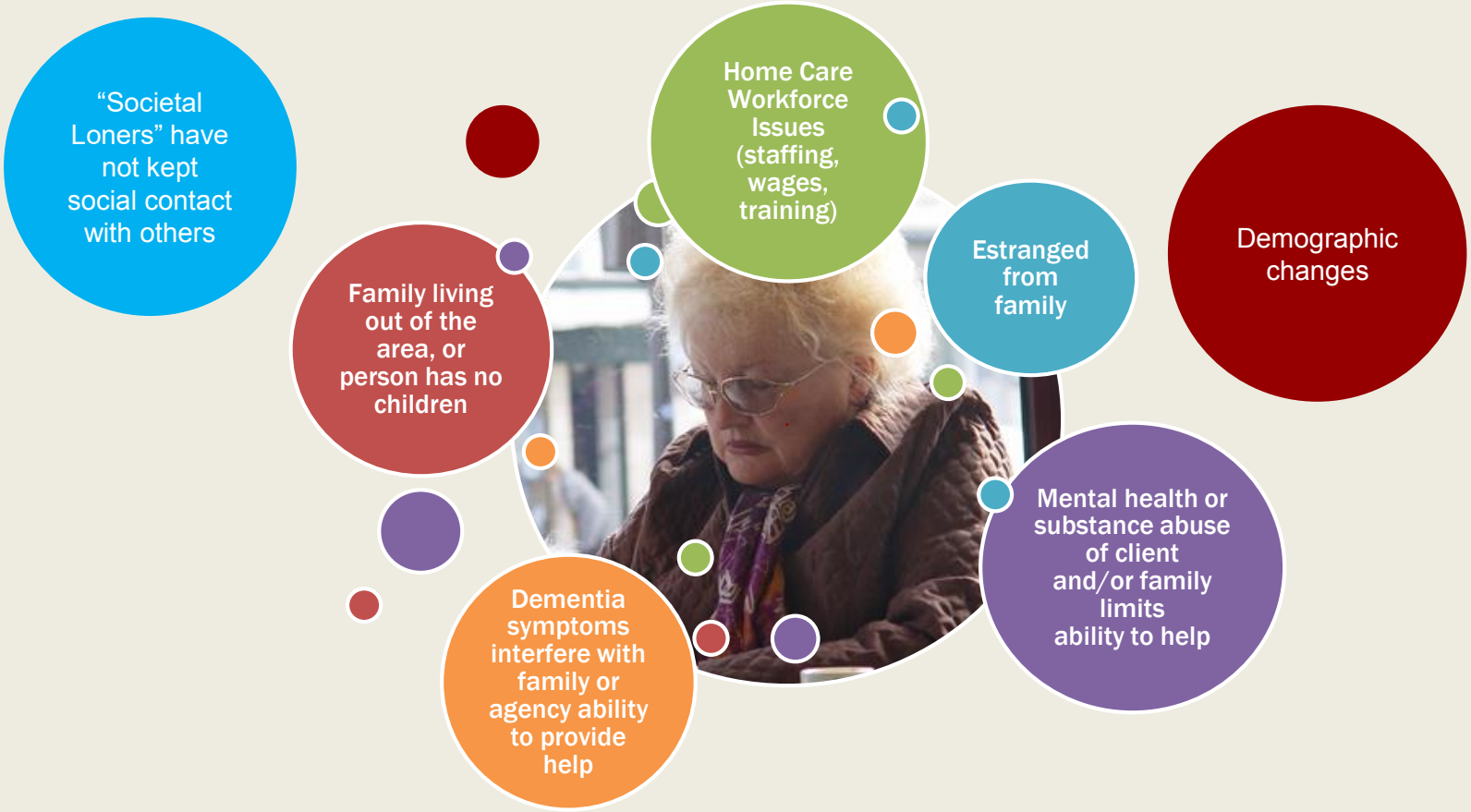
SAFETY AND AUTONOMY: ARE YOU SEEING ECCENTRIC CHOICES OR SYMPTOMS OF A SERIOUS CONDITION?



BALANCE SAFETY AND AUTONOMY

- Falls
- Medications
- Other people
- Privacy
- Judgment

INVOLVING FAMILY: AVAILABLE? ABLE? WILLING?



Duke Family Support Program, November 2017

Graphic by Sarah Harvey, LMSW-CC

COMMONLY IDENTIFIED ISSUES

L. WEAVER, SO MAINE AAA 2017

Dementia complicates every issue!

- Housing needs
- Transition to assisted living
- Death of spouse
- Isolation and loneliness
- Food shopping, prep and consumption
- Wait lists for services
- Family caregiver issues
- Co-morbid conditions and health problems
- Medication adherence
- Driving safety
- Bill paying
- Filling out applications
- Home safety
- Falls risks
- Keeping appointments
- Transportation
- Pet care
- Avoiding scams
- Decision making

COMMUNITY (DEMENTIA) SUPPORT PROGRAM:

SO. MAINE AAA, 2017

Target: living alone with dementia w/o adequate support

- Expanded MOW assessment for case finding
- Case mix: 75% “complex”
- Professional dementia specialists serving small caseloads (1.6 FTE staff)
- Average length of involvement: 8.8 months

“Building the road as we walk on it.”

FIRST STEPS: WHAT CAN WE ALL DO?

- Put people living alone on the radar for your community and organization
- Ask first responders, in-home providers, volunteers, town officials, and others if they are seeing people who worry them
- Connect the dots: Think about how easy or how hard services are to access for someone living alone with dementia

L. Weaver, So. Maine AAA, ASA Webinar 2017

RESIDENT-TO-RESIDENT AGGRESSION

"Negative, aggressive and intrusive verbal, physical, material, and sexual interactions between LTC residents that in a community setting would likely be unwelcome and potentially cause physical or psychological distress or harm in the recipient."

Rosen, Pillemer, & Lachs, 2008; McDonald et al. 2014

WHAT PRECIPITATES RESIDENT-TO-RESIDENT AGGRESSION IN DEMENTIA?

- Miscommunications, misunderstandings, misperceptions
- Frustration with lack of control and choices
- Invasion of personal space
- Problems with seating arrangements
- Intolerance of repetitive questions; unwanted touching
- Taking another's belongings
- Unwanted entry into one's bedroom or bathroom
- Racial/ethnic/LGBT comments/slurs

E. Caspi, 2016

PREVENT RESIDENT-TO-RESIDENT AGGRESSION IN DEMENTIA

- Employ the right people; train and support them
- Consistent ("*dedicated*") assignments
- Know residents' life histories
- Roommate selection and reassignment policy
- Strengthen information transfer
- Culture of blame to culture of learning

E. Caspi, 2016

RESIDENT-TO-RESIDENT AGGRESSION: WHAT TO DO

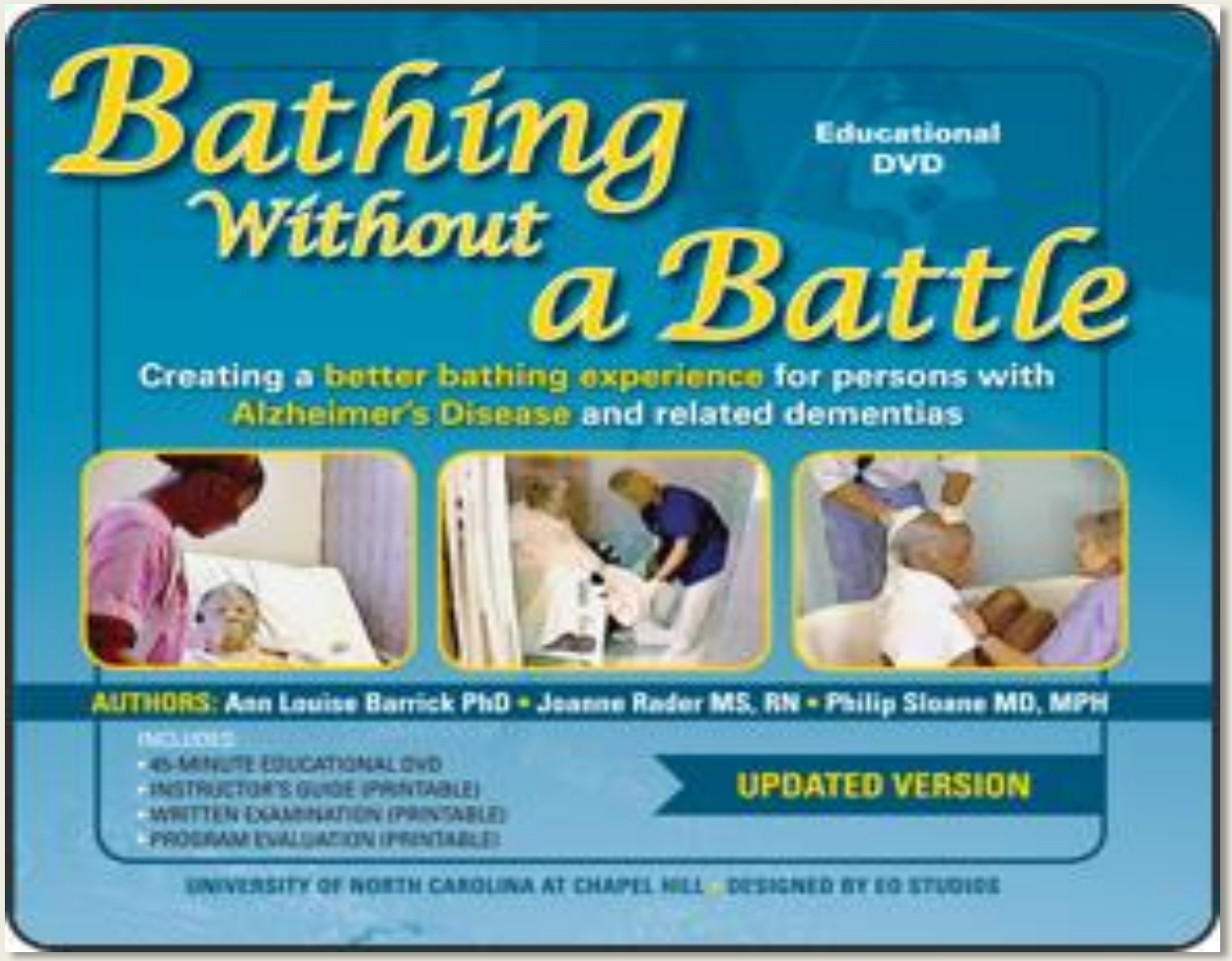
- Swift, focused, decisive, firm, and coordinated intervention
- Immediately defuse "*chain reactions*." Anxiety is contagious
- Redirect resident(s) from the area
- Avoid overcrowding resident (will strike if feels "*cornered*")
- Offer to take a walk together
- Distract/divert to a different activity
- Refocus/switch topic to his/her favorite conversation topic
- Position, reposition, or change seating arrangement

E. Caspi, 2016

TRAINING MATTERS IN DEMENTIA

1. **Habilitation Therapy**: http://www.alz.org/delval/in_my_Community_64433.asp
2. **Hand in Hand Training (CMS)**: http://www.cms-handinhandtoolkit.info/index.aspx
3. **Protect care partners (e.g., Train-the-trainer non-violent self-protection techniques – TJA PSI)**: http://www.tjapsi.com/hc_index.htm
4. **Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care**: www.caringkindnyc.org/palliativecare/
5. **ADvancing Care Newsletter**: http://www.caringkindnyc.org/advancingcare/
6. **Providing Services to Individuals with Dementia Who Live Alone: A Guide of Practical Strategies by M. Knowles**, M. Lepore, E.Gould: https://nadrc.acl.gov/sites/default/files/uploads/docs/Practical%20Strategies%20PWD%20livea%20lone%20posted%20041117.pdf

BATHING WITHOUT A BATTLE



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

Duke Family Support Program, November 2017