Effective Strategies for Supporting Elder Abuse Survivors Living with Dementia

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RAFT DEMENTIA EDUCATION AND OUTREACH COORDINATOR

Objectives

- The RAFT program
- Dementia and the increased risk for abuse, neglect and financial exploitation
- An overview of dementia
- Communication
- Screening and interviewing
- Safety planning

The RAFT Clinical Program

- The **R**egional Older **A**dults **F**acility Mental Health Support **T**eam
- Serving Northern Virginia
- Providing services since 2008
- Supports older adults with serious mental illness and dementia with challenging behaviors
- Discharges / diverts older adults from state psychiatric hospitals to nursing homes and assisted living
- Intensive mental health services in nursing homes and assisted living
- 98% success rate in preventing rehospitalization at state psychiatric hospitals

RAFT Clinical Eligibility and Referrals

- Eligibility criteria
  - 65 years of age or older
  - Resident of City of Alexandria, Fairfax-Falls Church, Loudoun, or Prince William Counties
  - In state psychiatric hospital or at risk of hospitalization
  - Diagnosis of SMI or Dementia with challenging behaviors
- Referrals
  - from the 5 CSBs
  - from Long Term Care partner facilities

The RAFT Dementia Support Program

- Launched January 2023
- Short-term, FREE program
- Supporting individuals living with dementia and their families in their homes
- Providing individualized education and support to families
- Building caregiver resilience and reducing stress

Dementia Support Program Eligibility and Eligibility

Eligibility:

- Resident of the City of Alexandria, Arlington, Fairfax-Falls Church, Loudoun, or Prince William Counties
- 65+ years old (July1 – 55+)
- Diagnosis of dementia or exhibiting symptoms of dementia with behaviors
- Living in the community in their homes, or the homes of family members or other caregivers

Referrals: Anyone can make a referral!

Dementia Increases Risk for Abuse

Prevalence rates for abuse and neglect in people with dementia vary from study to study, ranging from 27.5% to 55%. Estimates are likely to be very underreported.

- A 2010 study found that 47% of participants with dementia had been mistreated by their caregivers.
  - 88.5% experienced psychological abuse
  - 29.5% experienced neglect
  - 19.7% experienced physical abuse
- A 2009 study revealed that close to 50% of people with dementia experience some kind of abuse.
- A 2009 study based in the UK found that 52% of caregivers reported some abusive behavior towards family members with dementia.

A literature review of 28 studies focused on elder abuse and dementia

- Psychological abuse was found to be the most common form of abuse, with estimates of its prevalence ranging from 27.9% to 62.3% of people living with dementia affected.
- Physical abuse was estimated to affect 3.5 – 23.1% of older adults living with dementia.
- A study of elder sexual abuse found that 60% of the survivors had dementia.
- In a study of family caregivers for older adults with dementia, 20.2% of caregivers admitted that they had neglected the person they cared for.
- Individuals with dementia are likely to experience multiple forms of abuse.

How does dementia increase the risk for abuse?

- Isolation
- Unable to report due to impairments in memory, communication skills, and judgment
- Reports not believed due to dementia
- Fear of retaliation
- Fear of losing their caregiver
- Symptoms of abuse and dementia may overlap making screening difficult

Dementia, Abuse, & Caregiver Stress

- Family caregivers experience high rates of stress.
- Caregiver stress often leads to caregivers neglecting their own care, using substances, experiencing financial stress, etc.
- Caregiver stress is part of the picture. Not the cause of abuse. It is a factor to consider just like mental illness or substance use.


And I would want to start by
talking to her separately.

Case Example - Ted

Ted is a 75-year-old man with mid-stage Alzheimer's Disease living in his own apartment. He has several children and grandchildren. His granddaughter, Sherry, offers to handle his finances and manage his care. Sherry becomes his rep payee. Sherry decides to fire the home health aide that supports Ted and says she will provide care for him herself.

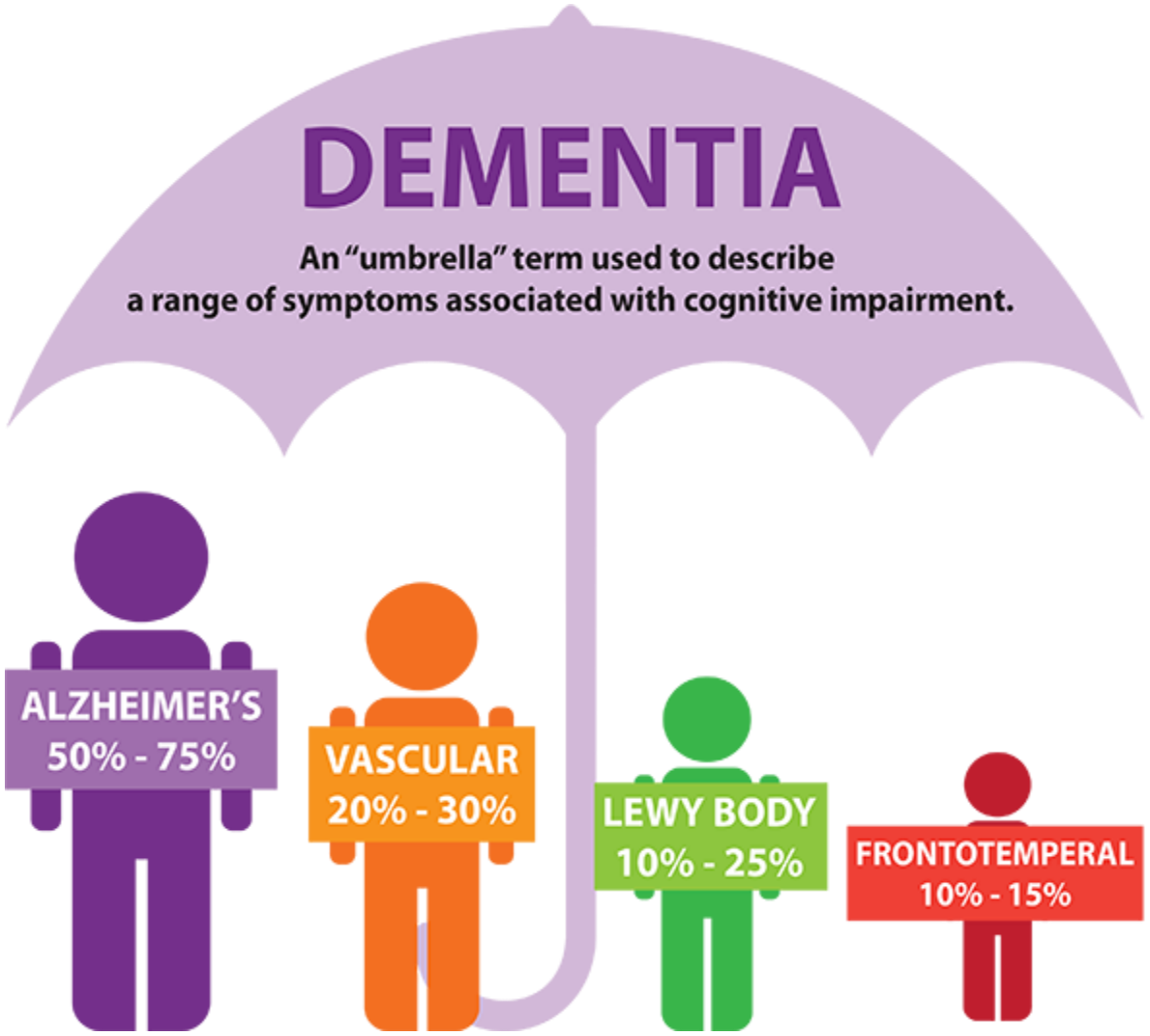
Ted's rent is no longer being paid on-time. When his family visits, it is clear that Ted is not being properly cared for. He is unkempt and there is little food in the kitchen. Sherry had claimed she was using money to buy Ted a new mattress. His family reported the mattress was clearly old and very stained.

After reporting the case to APS, Ted was brought to an elder abuse shelter in a long-term care community.

Because Ted was being left alone for long periods of time without support, he now experiences significant anxiety when he thinks he will be alone.

Dementia Overview

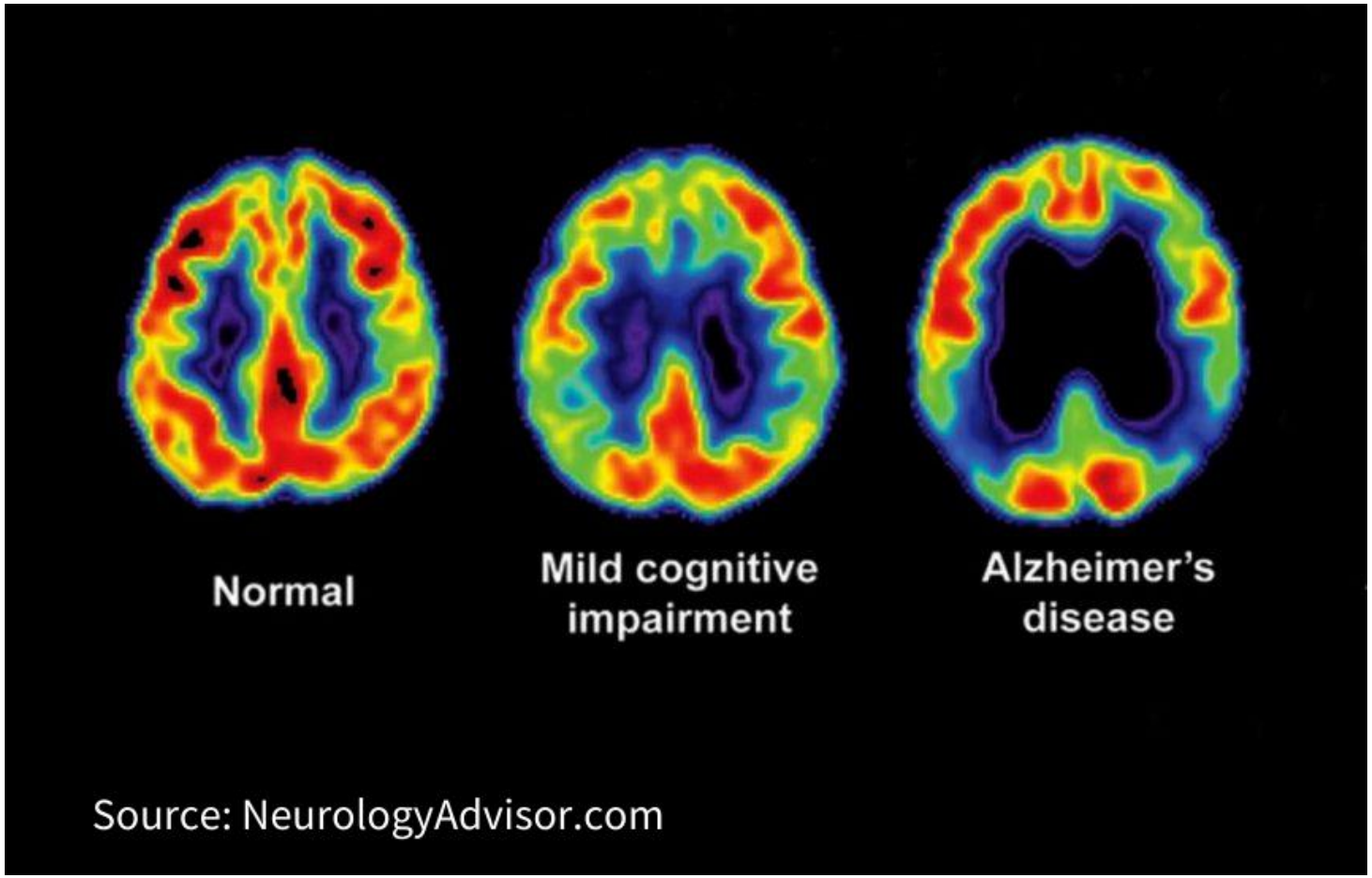
WHAT DO YOU THINK OF?


DEMENTIA
An "umbrella" term used to describe
a range of symptoms associated with cognitive impairment.
ALZHEIMER'S
50% - 75%
VASCULAR
20% - 30%
LEWY BODY
10% - 25%
FRONTOTEMPERAL
10% - 15%

What is Dementia?

- Not a disease, but a syndrome. Its symptoms are common to several brain diseases and conditions.
- More common with advanced age
- Not a normal part of aging
- Loss of cognitive functioning: thinking, remembering, and reasoning—behavioral abilities to such an extent that it interferes with a person's daily life and activities
- Impairment in memory, language skills, visual perception, problem solving, self-management, ability to focus and pay attention
- Ranges in severity from the mildest stage just beginning to affect a person's functioning - most severe stage, when the person must depend completely on others for basic activities of living

(National Institute On Aging)

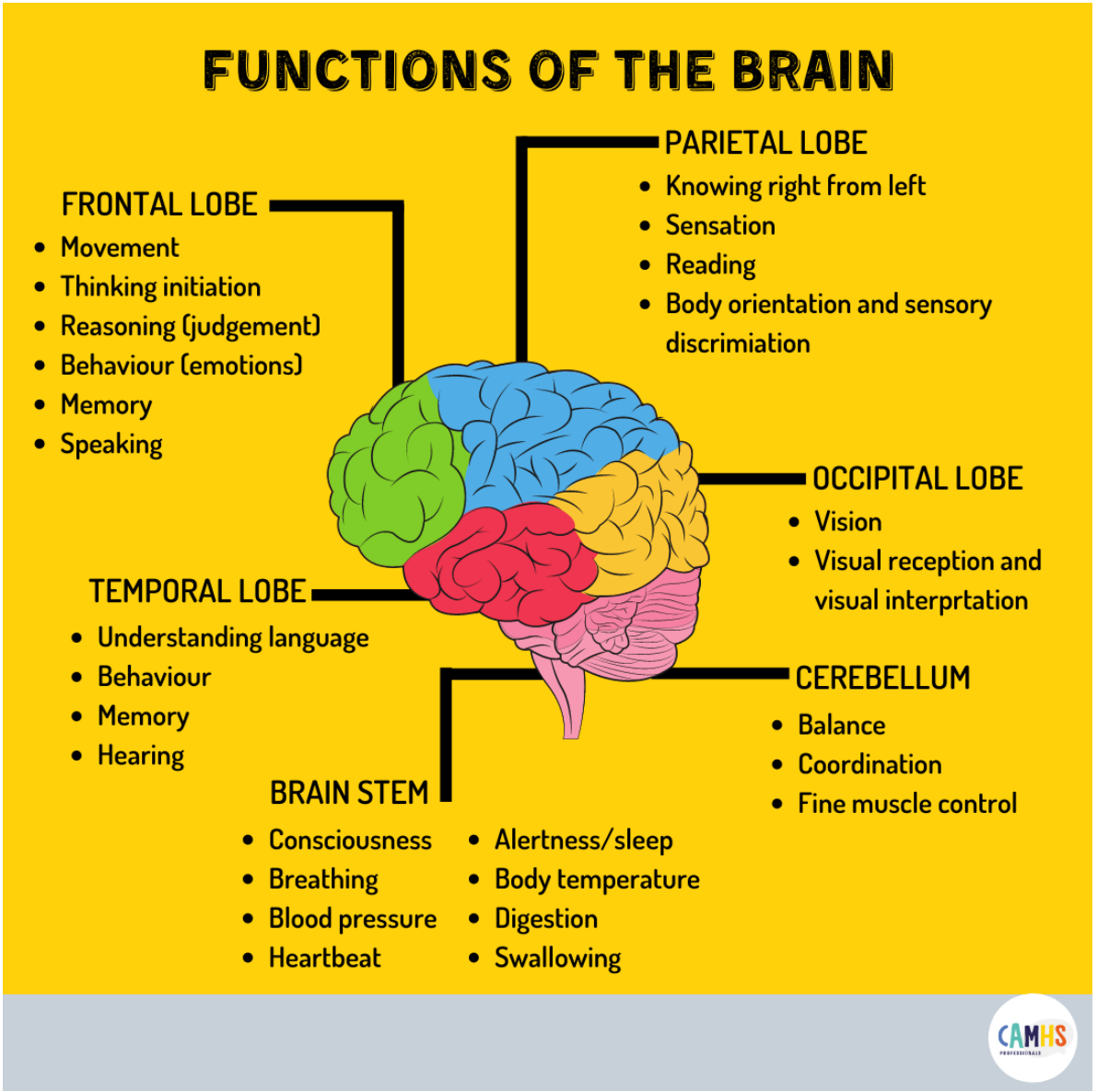


Mild Cognitive Impairment

- Between normal cognitive changes related to aging and dementia
- MCI does NOT always develop into dementia
- Trouble with thinking, judgment, memory, and language
- Doesn't significantly interfere with daily life

Reversible Dementia-like Conditions

- Normal pressure hydrocephalus: abnormal buildup of cerebrospinal fluid in the brain
- Vitamin B1 (thiamine) deficiency caused by chronic alcohol use
- Medication side effects
- Subdural hematoma (brain bleed)
- Depression
- Delirium

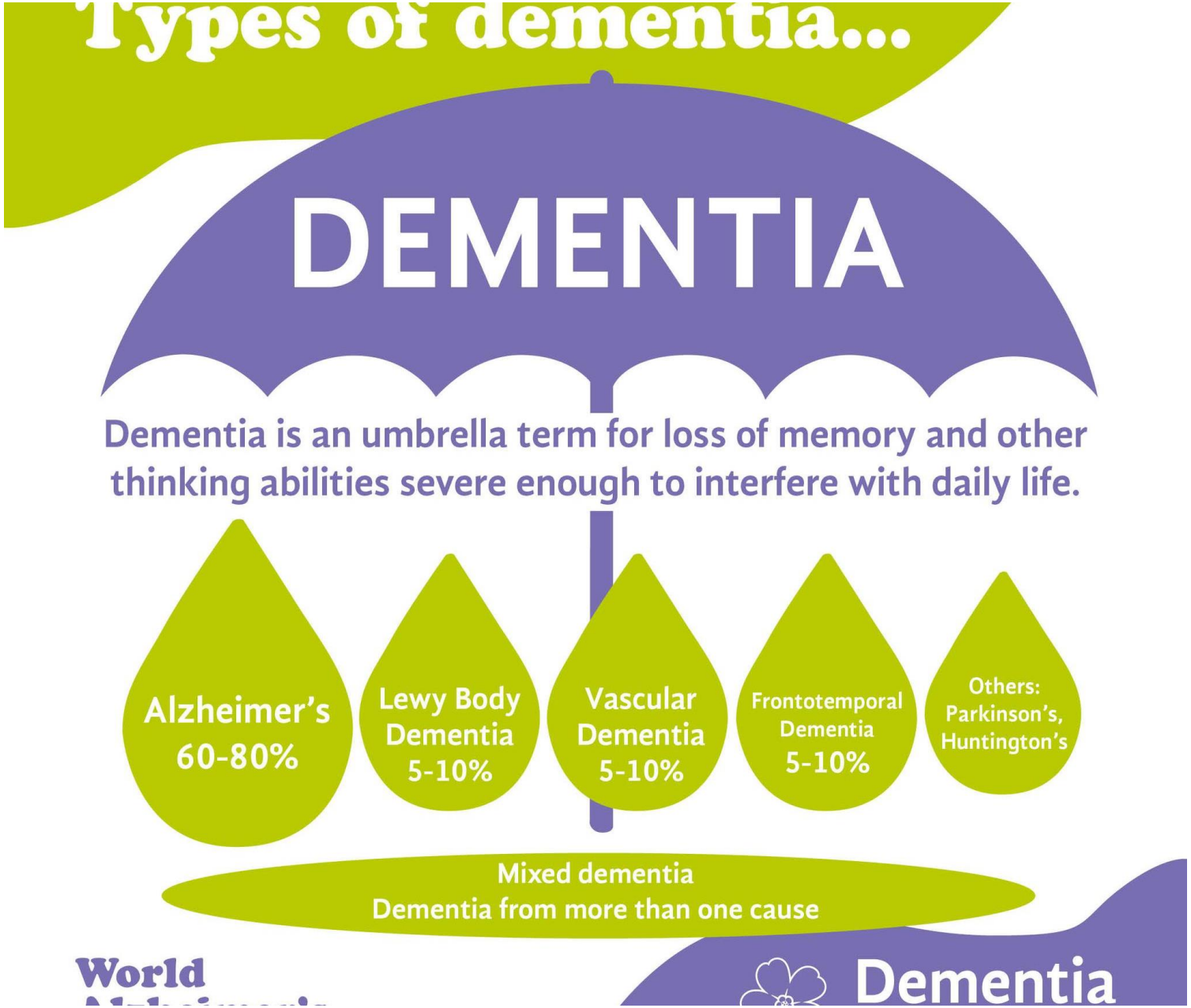


Dementia affects…

5 Main Types of Dementia

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Parkinson's Disease Dementia
- Frontotemporal Dementia

*Multiple forms of dementia is common



Alzheimer's Disease

- The most common form of dementia.
- It is a progressive disease - impacting thought, memory, and language.
- Plaques and tangles stop the neurons in the brain from communicating and ultimately causing the brain's nerve cells to die.
- Symptoms may include:
  - Memory lapses --> Significant memory loss
  - Forgetting appointments and anniversaries --> Unable to recognize close family
  - Getting lost --> Significant confusion over time and place
  - Struggling to find right word --> Difficulty speaking or understanding
  - Losing items --> Loss of wayfinding
  - Mood swings --> Paranoia, hallucinations, suspiciousness

Vascular Dementia

- The second most common form of dementia.
- Caused by brain damage from impaired blood flow to the brain - mini strokes, hypertension, smoking, diabetes mellitus, cardiac arrest, cardiovascular diseases, and lupus.
- Symptoms may come on suddenly following a cardiac event or may be gradual.
- Symptoms may include:
  - Confusion and memory issues
  - Trouble paying attention and concentrating
  - Reduced ability to organize thoughts or actions, difficulty deciding on next steps
  - Decline in ability to analyze a situation, develop an effective plan and communicate that plan to others
  - Slowed thinking
  - Difficulty with organization
  - Restlessness and agitation
  - Unsteady gait
  - Depression or apathy

Dementia with Lewy Bodies

- Protein deposits, called Lewy bodies, develop in nerve cells in the brain regions involved in thinking, memory and movement (motor control).
- Causes a progressive decline in functioning.
- Symptoms may include:
  - Visual and / or auditory hallucinations
  - Delusions
  - Stiff, rigid movement, balance, falls
  - Parkinsonism
  - Sleep disturbance, nightmares
  - Loss of smell
  - Depression and apathy
  - Decline in alertness and attention

Parkinson's Disease Dementia

- 25% - 80% of individuals with Parkinson's have dementia.
- Slow progression
- Can be a form of Lewy Body Dementia
- Symptoms may include:
  - Slowness
  - Rigidity, stooped posture, shuffling gait
  - Muffled speech
  - Difficulty speaking and communicating with others
  - Depression, anxiety, paranoia
  - Irritability
  - Sleep disturbance

Frontotemporal Dementia

- A progressive form of dementia that is generally diagnosed between ages 45 and 65.
- Decline within 2-3 years
- A group of different disorders, affecting the frontal and temporal lobes of the brain. (Behavior, language, motor)
  - Behavioral Variant Frontotemporal Dementia (Pick's Disease) : changes in personality, behaviors and judgement
  - Primary Progressive Aphasia: changes in our ability to communicate
    - Semantic Aphasia: loses ability to understand words
    - Nonfluent Aphasia: trouble producing speech
    - Logopenic Aphasia: trouble finding the right words but can understand

Frontotemporal Dementia

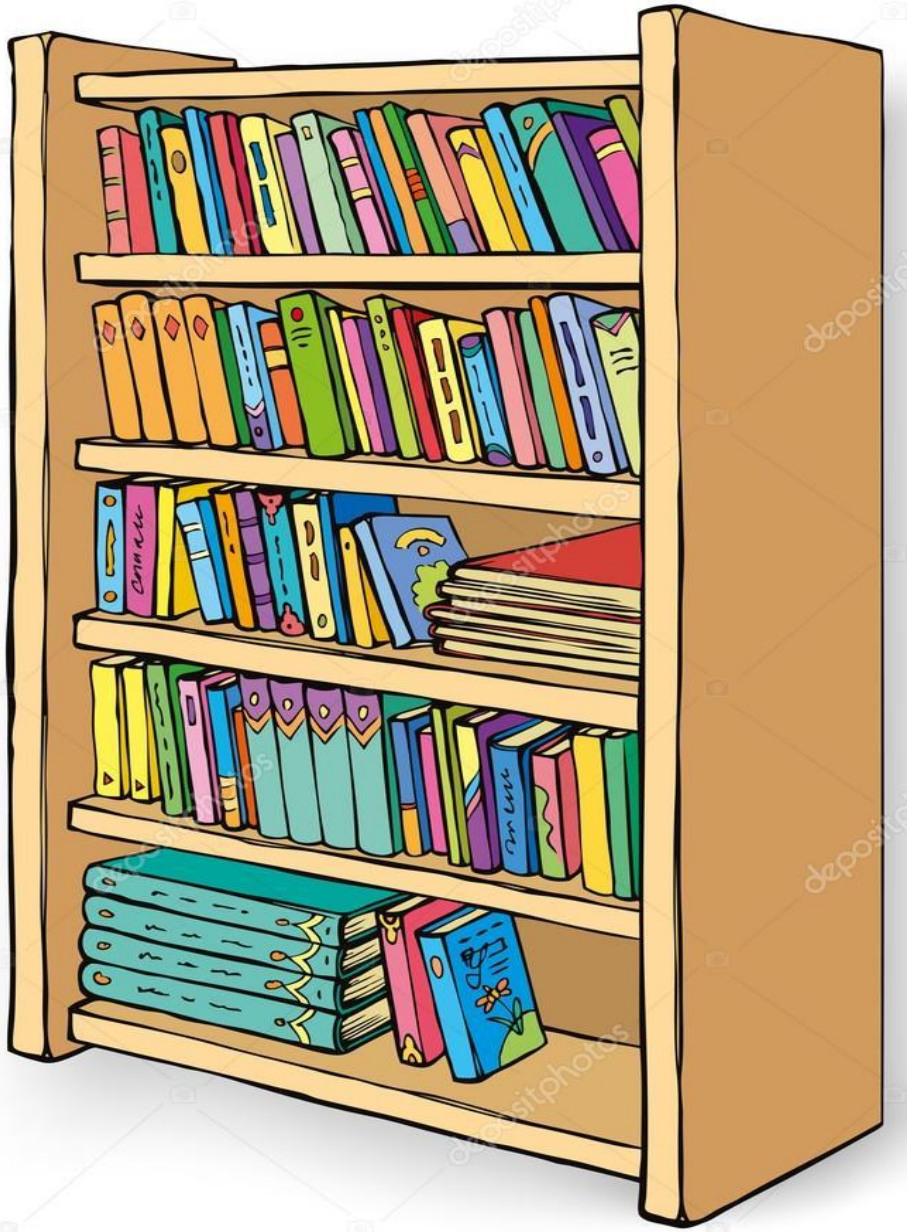
- Symptoms may include:
  - Significant changes to personality and behavior
  - Loss of empathy
  - Loss of inhabitations, socially inappropriate behavior
  - Lack of judgment
  - Difficulty with communication
  - Difficulty setting goals or making plans
  - Repetitive, compulsive, ritualized
  - Decline in motor skills – trouble walking, tremors

LET'S LOOK AT COMMON CHANGES SEEN WITH DEMENTIA.

Dementia is about more than memory loss.

Changes in Memory

- Short-term memory may be lost, while long-term memory is retained for longer.
- General forgetfulness, losing items, leaving things on stove, etc.
- Eventually may not recognize close family members or their own image in the mirror
- Unable to remember where they live, how old they are, etc.
- May lose sense of time



Changes in Language and Communication

- Difficulty finding the right words – particularly nouns
- Substituting words
- Repetition
- Disorganized speech
- Reverting to first language
- Will take longer to process what was said
- May rely more on hand gestures than verbal language
- May speak less
- Rhythm is retained (music, chit chat, bad words)

Changes in Judgement and Problem Solving

- May lose the ability to do complicated tasks that require critical thinking.
- May lose the ability to process information, make a decision, and begin a task.
- May lose impulse control.
- May lose the ability to assess for risk or safety.
- Unable to wayfind or retrace steps.

Changes in Spatial and Visual Abilities

- Difficulty with depth perception and spatial awareness
- Narrowing of peripheral vision
- Misidentifying objects or people

Changes in Emotions and Behaviors

- Mood swings with episodes of crying and agitation
- Disinterest in activities, withdrawal
- Irritability, easily overwhelmed
- Some individuals experience paranoia, hallucinations, and suspiciousness
- Restlessness, sleep disturbances, night terrors
- Still able to experience and recognize a broad range of emotions

Changes in Motor Skills

- Difficulty with fine motor skills, such as buttoning shirt
- Difficulty with gross motor skills, such as getting into bed
- Needs assistance with activities of daily living (showering, eating, dressing)
- Trouble with gait, stooped, shuffling
- While skill is lost, strength is often retained

Communicating with Someone Living with Dementia

- Don't make assumptions about someone's language abilities based solely on their dementia diagnosis.
- Do not exclude them from conversations.
- Talk **with** them not about them.
- Give plenty of time to respond.
- Do not interrupt.
- Stick to one topic at a time to avoid confusion.
- Use music to connect.

Communicating with Someone Living with Dementia

- Be aware of your body language and tone of voice.
- Avoid arguing, criticizing, or correcting.
- Speak slowly and clearly.
- Avoid multi-step instructions or multi-part questions.
- Have 1-1 conversations in quiet places with minimal distractions.
- Approach the person from the front and introduce yourself.
- Come down to their eye level.

Considerations When Screening for Abuse with Someone Living with Dementia

- Do not discount disclosures just because someone has dementia
- A dementia diagnosis does not equal incapacitation
- Consider past trauma
- Look beyond specific facts to feelings / emotions
- Ask questions about feelings as opposed to facts – Do you ever feel unsafe, uncomfortable, scared? Does anyone ever make you feel sad, worthless, or in pain?
- Allow for extra time for interviews
- Use / look for hand gestures or non-verbal cues
- Avoid interviewing the older adult in the evening
- Remember that challenging behaviors are about someone expressing an unmet need
- Talk with other family, friends, and neighbors
- Consider warning signs in the environment and alleged perpetrator

A 2010 study on screening for elder abuse among individuals with dementia found…

- Most elder abuse screening tools are designed for older adults who are cognitively intact.
- Perpetrator characteristics associated with abuse: poor health, social isolation, mental health issues, perception of high caregiver burden, and poor relationship with older adult before dementia.
- Victim characteristics associated with abuse: more severe cognitive impairment and behavioral challenges, including aggression
- 95% of caregivers who were found to be have physically mistreated, stated at least one of the following statements:
  - The patient threw something at me that could hurt.
  - The patient pushed or shoved me.
  - The patient grabbed me.

  The study found success in asking the caregiver if they themselves had ever done the following actions.

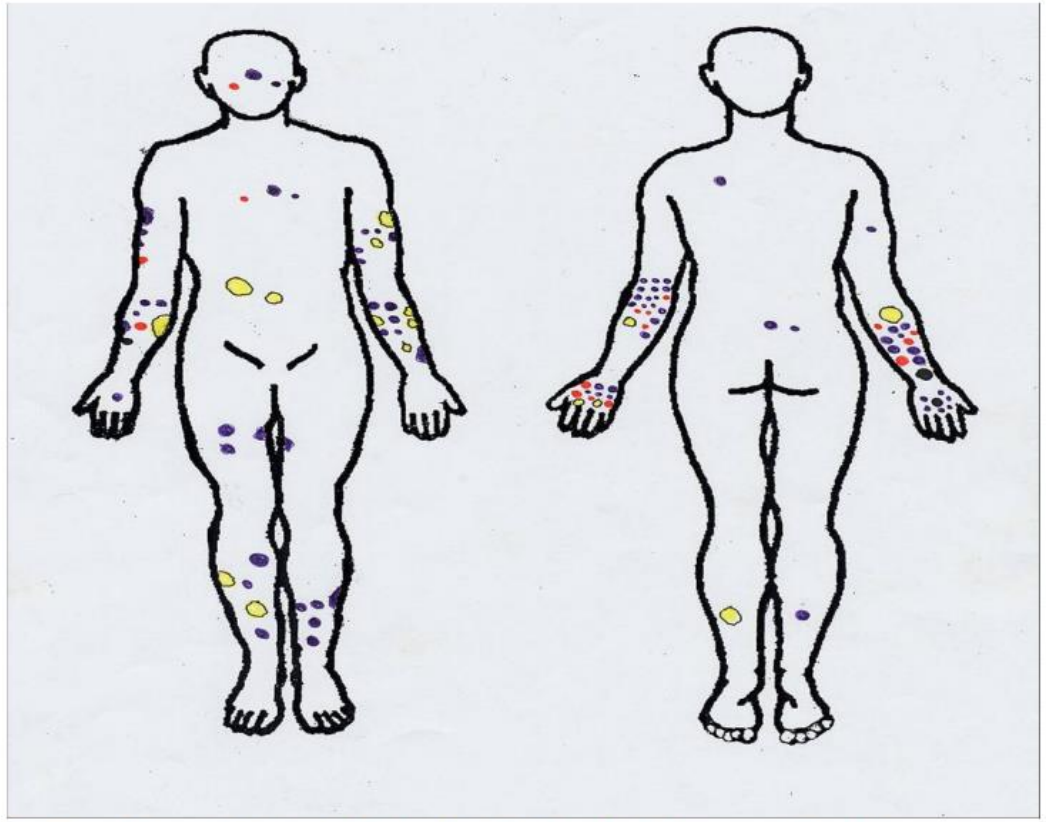
PART I: Accidental Bruising in Older Adults

Color of a bruise did not indicate its age. A bruise could have any color from day one.

- **90% of accidental bruises were on the extremities** rather than the trunk, neck, or head.

- **Less than a quarter of older adults with accidental bruises remembered** how they got them.

- **Older adults taking medications** that interfere with coagulation pathways were more likely to have **multiple bruises**, but the bruises **did not last any longer**.



Citation: Mosqueda L, Burnight K, Liao S. The life cycle of bruises in older adults. J Am Geriatr Soc. 2005 Aug;53(8):1339-43.

This project was funded by Grant 2001-IJ-CX-KO14 from the Department of Justice (DOJ),

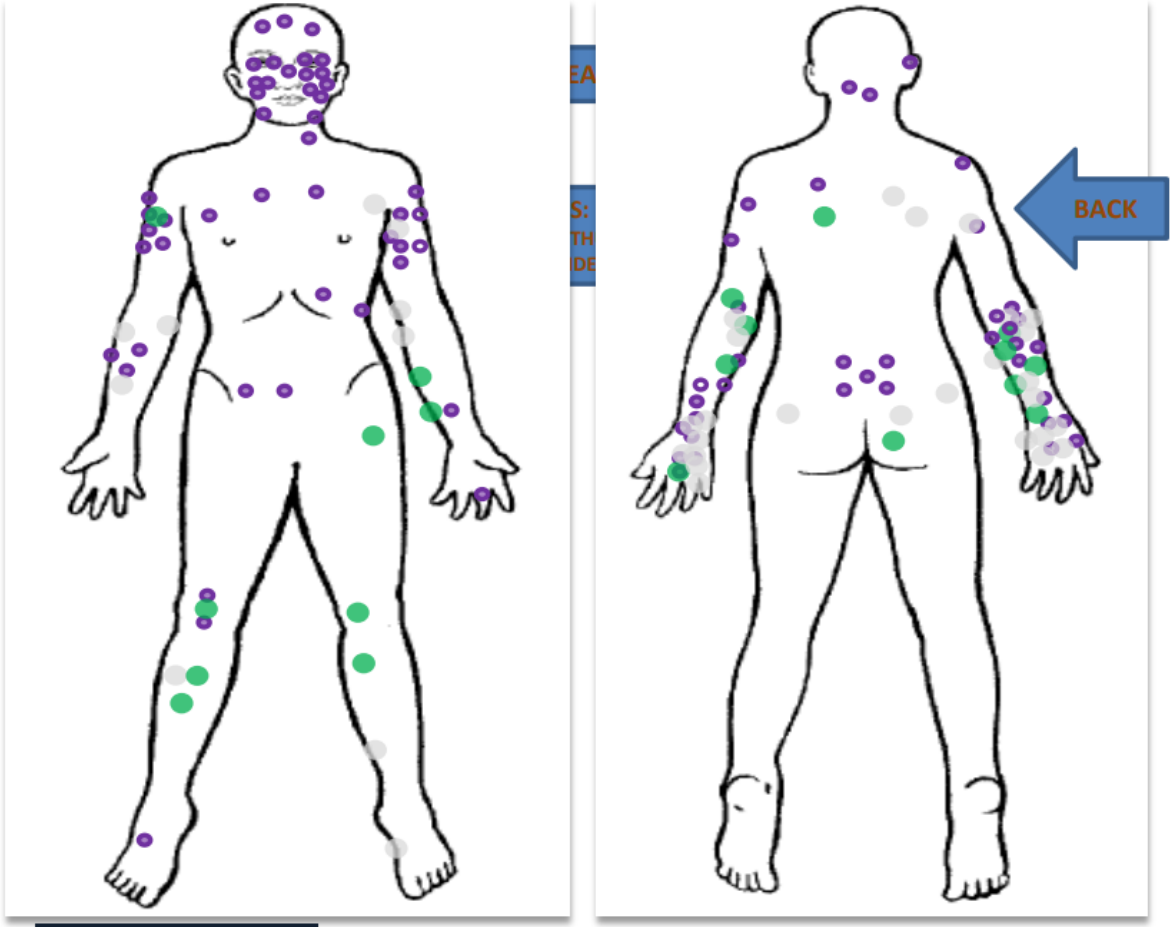
PART II: Bruising in Older Adults as Reported by Abused Elders

Key findings from this study:

- **Bruises were large.** More than half of older adults with bruises who had been physically abused had at least one bruise **5 cm (about 2 inches) in diameter or larger.**

- Older adults with bruises who had been abused had **more bruises in areas indicated in blue** than older adults whose bruises were accidental.

- **90%** of older adults with bruises who have been physically abused **can tell you how they got their bruises**, and **this includes many older adults with memory problems and dementia.**



This project was funded by Grant 2005-IJ-CX-0048 from the Department of Justice (DOJ), Office of Justice Programs

Citation: Wiglesworth A, Austin R, Corona M, Schneider D, Liao S, Gibbs L, Mosqueda L. Bruising as a marker of physical elder abuse. J Am Geriatr Soc. 2009 Jul;57(7):1191-6.

When screening for abuse with individuals with dementia, we must be good detectives!

Safety Planning Considerations

- Changing POA or guardianship
- Engage the older adult in the discussions as much as possible – supportive decision making
- Involve safe family, caregivers, and professionals
- Holistic therapy to address trauma
- Elder abuse shelter movement

Ending Thoughts

- Individuals living with dementia are experiencing high rates of abuse, neglect, and financial exploitation.
- More research is needed on screening / assessment tools that can be used with those with cognitive impairments.
- More training is needed for professionals on dementia.

Questions

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