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*Celebrating 20 years of exemplary education for the public health workforce, 1999-2019*
Sex, Guns, and Driving: Considerations in Dementia Care

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Featured Speakers

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Learning Objectives

- Describe the cognitive changes that occur in dementia that impact personal and public safety
- Identify safety concerns that impact caregiver burden and stress
- Recognize the importance of screening persons living with dementia about guns and driving
- Explain issues specific to sexuality for persons living with dementia and their caregivers

What is Dementia?

- Cognitive decline that causes impairment in everyday function
- Memory impairment is only part of the equation
- Losses related to thinking skills:
  - Insight
  - Judgement
  - Planning
  - Perception
  - Understanding ‘cause and effect’ consequences of one's actions
Dementia: A Clinical Disease

- Mood & Behavior Changes
- Cognitive Decline
- Physical Decline
- Functional Decline

Alzheimer Disease (AD)

- The most common form of dementia
- An estimated 5.8 million persons in the US are living with AD
  - 400,000 in New York State alone
  - Number does not include other types of dementia
- Many never diagnosed by a doctor
- Many patients and families unaware of a documented diagnosis
Why Diagnose Dementia Early?

- Early diagnosis may improve outcomes in patients at risk
- Earlier intervention is KEY to lowering the burden of disease
- Earlier diagnosis permits decision-making and planning by patient and family while capacities are retained

Dementia-Associated Behavioral Symptoms

Important to assess behavior and psychological symptoms of dementia:

- Activity disturbances
- Mood changes
- Thought and perceptual symptoms
Consequences of Behavioral Symptoms

Presence of these symptoms leads to:

- Greater impairment in activities of daily living
- More rapid cognitive decline
- Lower quality of life
- Earlier institutionalization
- Increased incidence of caregiver depression

The Faces of Dementia

- Dementia is a socio-medical condition with consequences for the dyad – the individual with disease and the caregiver

- Critical to identify all cognitive changes that pose potential risk to the patient and others and affect caregivers
Effects on Caregivers

- Caring for someone with AD is more stressful than caring for someone with a 'medical' illness
- Stressed caregivers have higher chance of:
  - Flu and other illness
  - Heart and kidney disease
  - Being hospitalized
  - Developing dementia
  - Dying

Effects of Caregiver Stress on Persons with Dementia

- Those with dementia whose caregivers are stressed decline more quickly and have worse outcomes
- Successfully managing stress improves outcomes for both patients and caregivers
Safety Concerns that Contribute to Caregiver Stress

Guns in the Home

- Long-term gun users may lose inhibition or judgement about appropriate use
- Concerns about the presence of perceptual changes and paranoia
- Caregivers may not anticipate issues related to safety
Addressing Concerns

Talking about firearms in the home can be difficult

- Physicians may be uncomfortable asking about firearms; concern this may impact physician-patient relationship

- Belief that firearm counseling is outside the scope of practice or infringement on Second Amendment rights

- Caregiver and family may not perceive this as a true risk!

New York’s “Red Flag” Law

*Extreme Risk Protection Order (ERPO)*

- A court order issued when a person may be dangerous to themselves or others

- Prohibits a person from purchasing or possessing guns

- Process can be started by law enforcement, school officials or members of a person’s family

- No criminal charges or penalties involved

- Allows for a hearing, but once a judge rules, the order is in effect up to one year
Driving Safety

- Identify high risk drivers
- Facilitate a driving safety referral
- Assess cognitive, visual, perceptual and motor abilities

Identifying a High Risk Driver

- History of crashes
- History of moving violations
- Caregiver opinion that the driver is unsafe, reports of getting lost frequently
- Infrequent driver (e.g. low mileage exposure)
- Aggressive or impulsive driving
- Impaired higher-order activities of daily living (cooking, finances, etc.)
Provider Challenges

- Discussions of driving are time-intensive
- Caregiver might not recognize or be willing to discuss concerns
- No appropriate billing codes
- Need to start conversations early and normalize!

Driver Evaluation Referrals

- “Driver Evaluation” prescription required
- Two part assessment:
  - Clinical Assessment
  - In-Vehicle
- Medicare does not cover
Clinical Assessment

- Assesses vision, cognition, motor skills and perception
- Identifies potential “red flags” for road test
- Educates and provides resources to caregivers and families about coping with driving safety
- Assists physician in final determinations
- Takes burden away from caregivers

Evaluation Components

- Vision
- Perception
- Cognition/attention
- Problem solving for safety
- Memory function
- Reaction time
- Motor skills and strength, coordination and ROM
- Knowledge of traffic situations
Cognitive

- Visual and auditory attention and processing
- Sequencing
- Memory
- Safety judgment and problem solving
- Sign symbol identification
- Direction following and insight

Visual/Perceptual Skills

- Acuity
- Depth perception
- Peripheral fields
- Spatial relations
- Left/right discrimination
Motor Function

- Evaluate range of motion
  - Upper and lower extremities
  - Head and neck
- Test muscle strength and sensation
- Evaluate posture and coordination
- Assess reaction time
- Check motor planning and response

Finding a Driving Evaluation Program

American Occupational Therapy Association
www.aota.org
Search Driving Evaluation Specialist for programs by state

Alzheimer’s Association Dementia and Driving Resource Center
www.alz.org/driving
Reporting Unsafe Drivers

- Unsafe driving can result from any disorders that result in loss of consciousness – not only dementia
- Reporting requirements vary by state – know the laws!
- No mandatory reporting in New York State

NYS Reporting *Form DS-6*

- Physicians can advise individuals to stop driving to avoid having license suspended
- If a patient continues to drive, physician completes Form DS-6 which triggers further investigation from the Department of Motor Vehicles (DMV)
- DMV Medical Review Unit determines driving status based upon information provided by the physician
Addressing Sense of Loss

- Provide emotional support, but stick to the decision
- Discuss potential benefits (cost, reduced stress)
- Create a transportation plan
- Focus conversations on SAFETY and well-being
- Formal MD “prescription” to “DO NOT DRIVE”
- Discuss driving safety early in the disease process
- Consider a Driving Contract

Sex and Dementia

- 75 year old woman with memory loss and confusion, waking up her partner in the morning for sex. Forgets and repeatedly wakes her up later in the morning
  - Situation is consensual but partner suffers from anxiety and needs sleep

- 78 year old woman with memory decline, indicates continued desire for sexual relationship with husband
  - He needed guidance about best approaches to navigating periods of aggression, delusions or unusual behaviors that might appear
Sexuality with Dementia

- Sexuality an “adult” activity – deeply personal – that balances an understanding of benefits and risks
- Dementia impacts cognition, judgement, perception and memory
- Emotion and need for intimacy may still persist

Talking About Sexual Health

- Clinicians need to assess medical decision-making and the capacity to consent to intimate sexual activity
- Resources are available regarding how to manage sexual expression for individuals living with dementia
- Sexual intimacy should be discussed early in the disease and as an aspect of care management
- Staff attitudes about sexual activity need to be addressed
- Training of medical and health care professionals needs to normalize the discussion of sexual health
In Summary

- Behavioral symptoms in dementia associated with increased caregiver burden and reduced quality of life
- Clinicians need to assess these symptoms
- Discussions about sexual health, driving and gun safety should occur during diagnostic assessments and follow-up visits with medical providers
- Important for all to engage in conversations about driving or firearm safety when caring for individuals living with dementia, and to learn how to respond to these issues

Changing Current Practice

- Remove barriers to discussion
- Normalize the topics
- Be culturally sensitive
- Ask questions about sexual health, driving and firearms during initial visits with persons living with dementia and throughout the course of disease
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