Understanding the Middle Stage of Dementia for the Interprofessional Team

MODULE 6

LIGHT
LAKE ERIE INTEGRATED
GERIATRIC HEALTH TEAM

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Outline

- Clinical manifestations of middle stage of dementias
  - Overview
  - Alzheimer’s disease and related dementias
    - Alzheimer’s disease (AD)
    - Vascular dementia (VaD)
    - Lewy body dementia (LBD)
    - Frontotemporal degeneration (FTD)
- Managing common symptoms and manifestations of middle stage of dementia
  - Behavioral and psychological manifestations of dementia (BPSD)
  - DICE model or Describe, Investigate, Create, and Evaluate Model
  - Sexuality and intimacy Issues
- Safety considerations
  - Medication management
  - Driving safety
  - Home safety and environmental modifications
  - Other safety concerns
- Transitioning from home to long-term care, when needed

Learning Objectives

After completing this module, participants will be able to:

- List clinical manifestations of middle stage of dementia.
- Describe BPSD.
- Describe the DICE approach for managing BPSD.
- List safety concerns for persons living with a middle stage of dementia diagnosis.

Key Take-Home Messages

- Persons in the middle stage of dementia have progressive deterioration of cognitive abilities, executive function, and functional abilities.
- Behavioral and psychological symptoms of dementia (BPSD) are common: mood disorders, sleep disorders, psychotic symptoms, and agitation.
- Persons living with dementia (PLwD) have increasing problems with memory and overt changes in personality.
- The person in the middle stage of dementia has increasing difficulties with instrumental activities of daily living (IADL).

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Overview: Middle Stage of Dementias

- Manifestations and rate of progression of dementia depend on personal factors and underlying cause of dementia (Aubert et al., 2015; Galvin, 2012; NIA, 2015, 2017a, 2017b, 2017c; Williams, et al., 2010).
    - Middle stage is typically the longest stage of dementia.
    - There is no clear means of determining when a person transitions out of early stage for any dementia.
    - The person with middle stage of dementia may still be able to live at home, with assistance.
- There can be increasing concerns surrounding safety issues for the person in middle stage of dementia.

Progressive Deterioration of Cognitive and Executive Functioning

- Progressive deterioration of cognitive, executive function, and functional abilities
- Emergence of BPSD, such as
  - May have trouble problem-solving
  - May have difficulties completing routine tasks
  - May have difficulty concentrating or focusing
  - May have difficulty following logic
  - May have difficulties making choices
- More assistance needed with IADL (Williams et al., 2010).

Behavioral and Psychological Symptoms of Dementia (BPSD): Common Disturbances

Behavioral and psychological symptoms of dementia (BPSD) are common (Aarsland et al., 2014; Desai et al., 2012; Dodd et al., 2017; Kales et al., 2015; Lyketsos et al., 2011):

- Mood disorders:
    - Apathy, depression, and dysphoria
- Sleep disorders:
    - Insomnia, hypersomnia, and circadian rhythm disorders
    - Obstructive sleep apnea
- Psychotic symptoms:
    - Delusions and hallucinations
- Agitation:
    - Pacing, wandering, sexual disinhibition, and anxiety

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Middle Stage of Alzheimer’s Disease (AD)

- Degeneration continues throughout this often prolonged phase.
- Cognitive changes become more apparent in middle stage of dementia (Galvin, 2012).
- Increasing neurologic damage interferes with (Ortigara et al., 2013):
  - Cognitive abilities
  - Ability to perform ADL and IADL
  - Physiological functioning
- Psychiatric manifestations may begin or worsen (Horning et al., 2014).
- Cues can indicate transition to middle stage of AD (Galvin, 2012; Ortigara et al., 2013).
- Safety considerations become more prominent.
- PLwD and Down syndrome (a genetic-linked intellectual disability) have a compressed progression of Alzheimer’s and the middle stage may only last from 1 to 4 years (Prasher, 2005).

Middle Stage of Vascular Dementia (VaD)

- As VaD progresses, symptoms become more similar to those of Alzheimer's disease (Gorelick et al., 2013; Sahathevan et al., 2012):
  - Initially: cognitive impairments, physical limitations, affective changes
  - Middle stage of VaD: increasing memory and cognitive symptoms
  - Symptoms determined by location/extent of brain damage
- Different rates of progression between subcortical versus stroke-related vascular dementia (Roh & Lee, 2014)
- Shortened life expectancy: approximately 5 years after symptom onset (Wolfson et al., 2001)

Middle Stage of Lewy Body Dementia (LBD): Including DLB and PDD

- Cognitive deterioration less consistent versus Alzheimer's disease (Breitve et al., 2014)
- Manifestations: (LBDA, n.d.; Mayo Clinic, 2017)
    - Impaired thinking
    - Parkinsonian movement impairments
    - Visual hallucinations (Goldman et al., 2014)
    - Deterioration of language skills
    - Sleep disorders
    - Behavioral/mood symptoms
    - Alterations in autonomic body functions

Frontotemporal Degeneration (FTD)

- Impairments progress over time; types and rate depend on the individual.
- Characteristic manifestations include (Mioshi et al., 2010; NIA, 2017c; Piguet et al., 2011):
  - Behavioral variant FTD (bvFTD)
  - Language subtypes (primary progressive aphasia)
  - FTD with motor decline (corticobasal syndrome, progressive supranuclear palsy) (NIA, 2017c)
- Eventually, muscular deterioration from FTD results in difficulties swallowing and chewing.

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Behavioral and Psychological Symptoms of Dementia (BPSD)

- Common symptoms include (Desai et al., 2012; Kales et al., 2015):
  - Mood disorders
  - Sleep disorders
  - Psychotic symptoms
  - Agitation
- These are predominantly caused by progressive damage to brain (Desai et al., 2012; Kales et al., 2015).
- Persons living with dementia and intellectual disability experience many of same significant BPSDs as other PLwD (Dodd et al., 2017).

Assessing for BPSD

- PLwD are typically not screened for BPSD in primary care (Gitlin et al., 2012).
- Underlying cause of BPSD must be identified (Azermai, 2015; Desai et al., 2012; Kales et al., 2015).
- A comprehensive and systematic assessment approach is needed (Desai et al., 2012; Kales et al., 2015):
  - Many assessment tools are available (Azermai et al., 2015).
  - Tools include ongoing screening as part of standard comprehensive care (Cerejeira et al., 2012; Gitlin et al., 2012).
  - For persons living with dementia and intellectual disability (including Down syndrome) specialized screening tools should be used (Esralew et al., 2013; Jokinen et al., 2013)

Managing BPSD: Overview

- Few well-proven strategies or treatments are currently available for managing BPSD (Kales et al., 2014).
- Nonpharmacologic approaches serve as first-line treatment (Azermai, 2015; Kales et al., 2014:) no one intervention is ideal.
- Medication may be necessary for emergencies or when behavioral disturbances are severe and persistent (Kales et al., 2007).
- If clinically significant BPSD remain untreated, they can lead to faster progression of dementia (Gitlin et al., 2012; Gitlin & Rose, 2014).
- Goals of nonpharmacologic interventions: (Kales et al., 2014):
  - Prevention of symptoms
  - Symptom relief
  - Reduction of care partner distress
- With persons living with dementia and intellectual disability many interventions are similar; however, some specialized approaches are recommended (Dodd et al., 2017).
  - For persons living with dementia and intellectual disability it is important to differentiate expressions of BPSDs from those that have been present long-term (Dodd et al., 2017).

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A Model for Managing BPSD: The DICE Approach

DICE approach has 4 levels and requires input from both care partner and provider (Kales et al., 2014).

- **D**ESCRIBE: Care partner **describes** behavior and its context.
- **I**NVESTIGATE: Provider thoroughly **investigates** possible causes of problem behavior.
- **C**REATE: Together, care partner and provider collaborate to **create** and implement treatment plan.
- **E**VALUATE: Provider **evaluates** safety and efficacy of intervention.

General Strategies

- General strategies that a care partner can use to help manage BPSD in many dementias (Cohen-Mansfield, et al., 2015; Kales et al., 2014, 2015; Nordgren & Engstrom, 2014) include:
  - Patient engagement
  - Physical activity
  - Communication
  - Environmental changes
  - Task simplification
  - Guidance for care partner

Common Sleep Disorders in Dementia

- Different types of sleep disturbances are based on type of dementia, stage, personal factors, such as:
    - Insomnia
    - Excessive daytime sleepiness (EDS)
    - Altered circadian rhythm
    - Obstructive sleep apnea (OSA)
    - Rapid eye movement (REM) sleep behavior disorder (RBD)

Disordered Sleep: Overview

- Sleep problems are common with aging (David et al., 2010).
- Disordered sleep is a major clinical problem in dementia (Brown et al., 2014; Cipriani et al., 2015).
- There is a bidirectional relationship between sleep and AD pathology (Landry et al., 2014).
- Manifestations vary by type and stage of dementia (Cipriani et al., 2015).
- There is low recognition among health care professionals regarding assessment tools, incidence, and treatments (Brown et al., 2014).

“Sundown” Syndrome

- Term “sundown” is frequently used, despite lack of a consistent definition (Ferrazzoli et al., 2013; Yevchak et al., 2012).
- It is generally considered a clinical phenomenon that refers to worsening of disruptive behavioral symptoms in dementia (in late afternoon, early evening, nighttime) (Ferrazzoli et al., 2013; Raggi et al., 2015).
- There are many theories; data support a link with circadian rhythm changes (Ferrazzoli et al., 2013; Raggi et al., 2015).
- It may affect up to 25% of persons with AD.
- There is no approved pharmacologic treatment for sundown syndrome; nonpharmacologic approaches are preferred (Ferrazzoli et al., 2013).

Sleep Disorders in Alzheimer’s Disease

- Sleep disturbances are common in middle stage of Alzheimer’s disease and affect up to 45% of persons in clinic and community-based samples (Cipriani et al., 2015; Peter-Derex et al., 2015). Sleep problems may be directly related to the dementia or may commonly co-occur with dementia:
  - Obstructive sleep apnea
  - Circadian rhythm changes (“sundowning”) (David et al., 2010)
- Sleep problems may appear at early stage but are more often correlated with more severe cognitive decline (Peter-Derex et al., 2015).
- There are multifactorial causes (Chen et al., 2016; Peter-Derex et al., 2015).

Alzheimer’s Disease and Obstructive Sleep Apnea

- Obstructive sleep apnea (OSA) and AD share common risk factors (Bombois et al., 2010).
- The lack of oxygen associated with OSA can lead to microinfarcts in the brain and increased atrophy. OSA has not been shown to be causative of AD but may be a contributing factor (Daulatzai, 2015).
- Several pathophysiologic mechanisms in OSA are reversible.
  - Treating OSA during MCI and early AD may reduce risk for decline (Daulatzai, 2015).

Sleep Disorders: LBD

- Sleep disturbances affect up to 90% persons with LBD (Cipriani et al., 2015).
- REM sleep behavior disorder (RBD):
  - Is suggestive of LBD (Desai et al., 2012)
  - Is predictive for neurodegeneration in Parkinson’s disease (Bombois et al., 2010)
  - May precede dementia and worsen prognosis (Bombois et al., 2010; Desai et al., 2012)
- People with Parkinson’s disease may experience excessive daytime sleepiness.
- People with Parkinson’s disease–MCI (mild cognitive impairment) have poorer sleep efficiency and more nontremor features of Parkinson’s disease (Gumm et al., 2013).

Sleep Disorders: bvFTD

- Few published studies
- Sleep disruption in bvFTD vs. AD (Bonakis et al., 2014):
  - Appears at earlier stage
  - Appears more disrupted
  - Involves shorter sleep duration

Sleep Disorders: Vascular Dementia (VaD)

- Few published studies
- Substantially higher frequency of insomnia than in AD and FTD (Cipriani et al., 2015)

Treating Sleep Disorders in Dementia

- Nonpharmacologic interventions (Ferrazzoli et al., 2013):
  - Sleep hygiene (NSF, 2003)
  - Sleep restriction therapy
  - Cognitive behavioral therapy
  - Light therapy
  - Continuous positive airway pressure therapy (CPAP) for sleep apnea (OSA)
- Melatonin/melatonin agonists
- Medications (especially sedative-hypnotics or antipsychotics) can have significant adverse effects (David et al., 2010).

DICE: Addressing Circadian Rhythm Disruptions

Using DICE for Circadian rhythm disruptions (Kales et al., 2014)

- DESCRIBE: Care partner **describes** behavior and its context.
- INVESTIGATE: Provider thoroughly **investigates** possible causes of problem behavior.
- CREATE: Together, care partner and provider collaborate to **create** and implement treatment plan.
- EVALUATE: Provider **evaluates** safety and efficacy of intervention.

Psychotic Symptoms

- Psychotic symptoms: More prevalent in PLwD during the middle and later stages of dementia (Desai et al., 2012; Kales et al., 2015)
- Delusions: False beliefs that persist despite consistent evidence to the contrary
    - Generally simple and nonbizarre
- Hallucinations: Sensory experiences that cannot be verified by anyone except the person experiencing them
- Most commonly visual or auditory in dementia (Desai et al., 2012; Kales et al., 2015)

Using DICE Strategies for Addressing Delusions and Hallucinations

Using DICE for delusions and hallucinations (Kales et al., 2014):

- Care partner DESCRIBES when it happens, safety concerns, what it looks like.
- Provider INVESTIGATES possible causes of delusions/hallucinations.
- Together, they CREATE and implement treatment plan—distraction.
- Provider EVALUATES safety and efficacy of intervention.

Agitation

- Common behavioral disturbance in moderate-to-severe dementia (Desai et al., 2012; Kales et al., 2015):
  - Agitation involves feeling restless or worried, and can manifest with physically nonaggressive behaviors (wandering, pacing, anxiety).
  - Sleeplessness
  - Verbally nonaggressive behaviors (repetitive vocalizations)
  - Aggression (verbal or physical)
    - Aggression is different from agitation (Volicer et al., 2017)

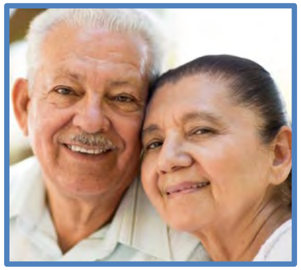
Using DICE Strategies to Address Agitation

Using DICE for agitation (Kales et al., 2014):

- DESCRIBE when PLwD becomes agitated, how it manifests, any safety concerns.
- INVESTIGATE possible causes (e.g., pain, unmet needs, illness).
- CREATE nonpharmacologic interventions for managing PLwD when agitated.
- EVALUATE effectiveness and safety of strategies.

Using DICE Strategies to Address Agitation (continued)

- Agitation often reflects unmet needs in advanced dementia (Cohen-Mansfield et al., 2015; Jacobson et al., 2015).
- Evaluate cause of agitation: illness, pain, psychiatric/psychological issues, environmental issues, medications or other medical concerns.
- Assess safety.
- Address agitation and aggression through calm and reassurance (Kales et al., 2014).
- Nonpharmacologic interventions should be matched to specific individual factors (Cohen-Mansfield et al., 2012; Jacobson et al., 2015):
    - Modify environment to elicit calm.
    - Provide reassurance.
    - Consider music therapy, art therapy, animal-assisted therapy, massage therapy .
    - Offer real or simulated social contacts.



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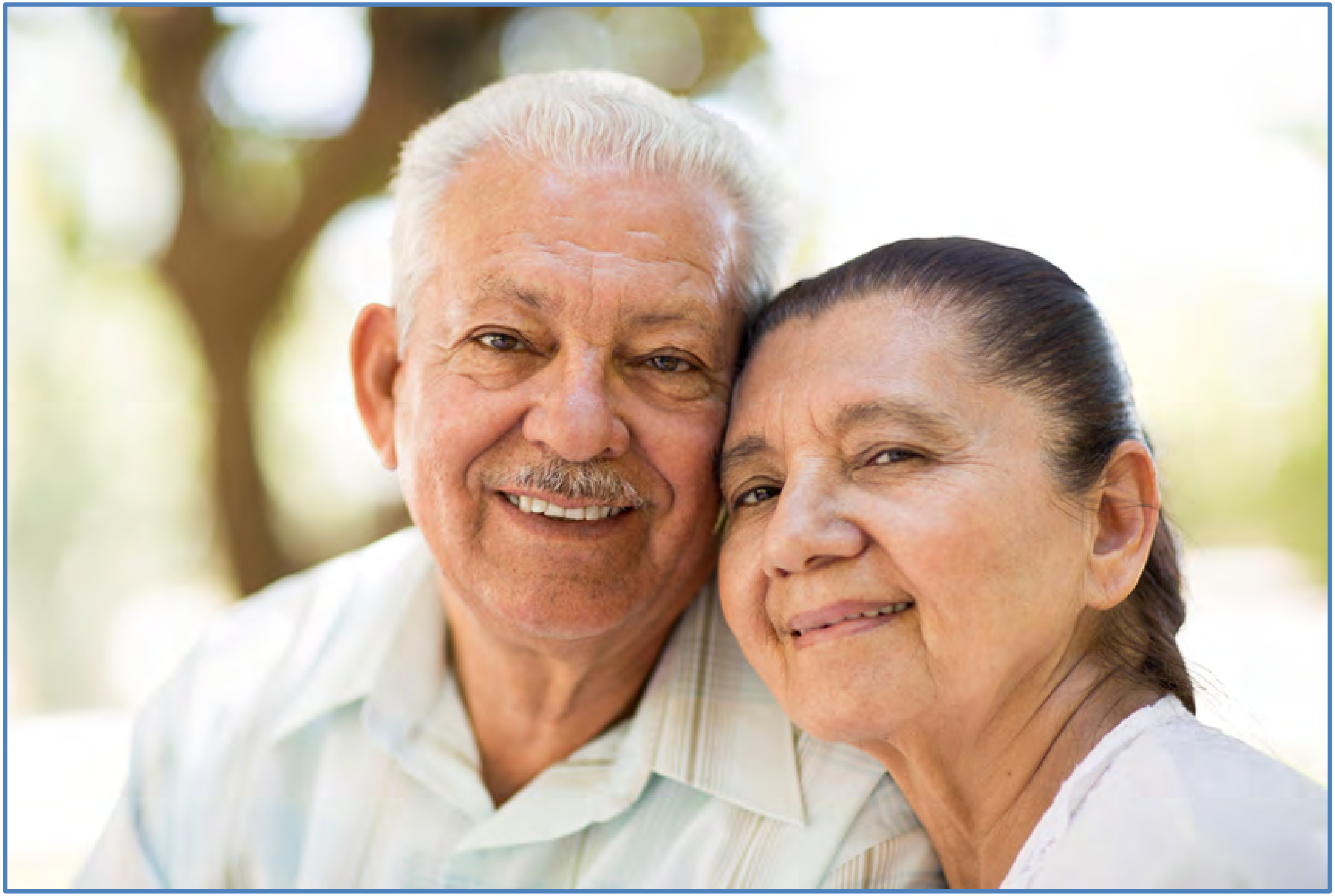
Sexuality and Physical Intimacy Issues

- Older persons are not asexual (Joller et al., 2013; Lichtenberg, 2014; Westwood, 2014).
- Decreased or increased sexual interest
- Inappropriate sexual behaviors (Murphy, 2015)
- Capacity to consent



Using DICE to Address Inappropriate Sexual Behavior

- DISCUSS what type of behavior, when it occurs, affects safety or other consequences.
- INVESTIGATE possible causes.
- CREATE strategies (Joller et al., 2013; Murphy, 2015).
  - Remain calm, provide privacy
- EVALUATE: Recommend psychotherapy or counseling for family members and other caregivers if appropriate.

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Safety Overview

- Safety concerns assume increasing importance as dementia progresses.
- Care partners must assume increasing oversight to ensure the PLwD's (and others') safety.
- Predominant concerns:
  - Medications
  - Driving
  - General home safety
  - Wandering/getting lost in the community
- Persons living with dementia and intellectual disability may be susceptive to financial abuse, if the funds provided for their care are expropriated for other uses (NTG, 2012

Medication Management

- Importance of maintaining up-to-date records, coordinating between all team members
- Need for enhanced level of oversight of medications
- Responsibilities (NIA, 2017d; Poland et al., 2014):
  - Maintaining medication records
  - Identifying adverse effects
  - Ensuring ability to take medications correctly
  - Minimizing risk of overdose


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Driving

- Recognize that all PLwD will need to stop driving eventually:
  - Be aware that when and how depends on individual situation.
  - Recognize and address consequences of driving cessation for PLwD, spouse/partner, others (Liddle et al., 2013).
- Know state-specific rules and regulations for reporting. In those states that have mandatory reporting laws for persons diagnosed with dementia, physicians are responsible.
- Be aware that there is no gold standard for assessing driving capabilities and that no one profession is responsible for driving evaluations (Bixby et al., 2015; Carr et al., 2015).
- Physicians face many challenges when evaluating older persons for driving fitness (Meuser et al., 2016).

Home Safety Concerns

- Care partner and dementia care team need to assess safety of the PLwD in the home throughout course of dementia. Problems can arise during early-stage and become more pronounced and possibly dangerous during middle stage of dementia.
  - Is PLwD able to continue living at home in middle stage of dementia?
  - Is PLwD able to be left alone?
  - What needs to be done if the answers are NO?
- PLwD and intellectual disability, who are living alone or with another adult with intellectual disability generally should not continue to live unsupervised due to home safety concerns (Jokinen et al., 2013)

Are Persons Living with Dementia Able to Live at Home?

- Home assessments focus on fall prevention, bathing/toileting safety, kitchen and laundry-room safety (Tzeng et al., 2013).
- Strategies for eliminating fall hazards include keeping floors dry and removing tripping hazards, like small toys or animals (Tzeng et al., 2013).
- Other accommodations include use of alarm bells and safety mechanisms on windows, doors and appliances, monitors.
- Guns and ammunition should be secured separately (Mertens et al., 2012; Wand et al., 2014).
- If persons living with dementia and intellectual disability are to stay in place, then on-site supervision should be provided and surveillance for functional change implemented (Joniken et al., 2013).

Are Persons with Intellectual Disability Living with Dementia Able to Live at Home?

- Home-based persons living with dementia and intellectual disability can remain living within the family home if the setting can accommodate dementia care, the family members are capable of providing continued supports, and if a disability agency is available to provide supports (NTG, 2012).
- Generally, personal supervision by someone in the home is necessary, as the persons living with dementia and intellectual disability can not be left alone (NTG, 2012).
- Most care partner time in this stage is usually devoted to supervision and personal care (aid with bathing, eating, toileting) (Janicki et al.,, 2017; McCarron et al., 2018)
- Care partners need assistance with continued assessment for decline of the person living with dementia and intellectual disability and education on care practices and handling BPSDs (Jokinen et al., 2018).

Adapting the Home Environment

- Dementia affects all 5 senses (NIA, 2017b).
- Individualized progressive deterioration in senses:
  - Decreased sense of smell (Vasavada et al., 2015)
  - Vision impairments
  - Loss of sensation (to temperature, touch)
  - Hearing impairments
  - Loss of taste sensitivity
- Alterations to address these sensory losses should be recommended.
- The federal Family Caregiver Support Program, administered by the Administration on Aging, is a source of funding and aiding with home adaptations (ACL, 2017).

Is It Safe to Leave the PLwD Alone?

- PLwD require increasing levels of supervision as the dementia progresses (NIA, 2017a).
- There should be continuous evaluation of whether it is safe to leave PLwD alone—even in the home environment (Jenkins et al., 2013; Rowe et al., 2012).
- Wandering away from home or going missing could lead to serious consequences—injury or even death.

Case Study

A primary care provider reported very contentious discussions with Mr. Smith, who was a WW2 Veteran. Despite several minor accidents, becoming so lost he had to be brought home by the police, and losing his car in a parking lot, Mr. Smith would not even entertain the possibility of not driving. His family could not even broach the subject with him without significant agitation including yelling and throwing objects. The family asked the PCP for help but, after several frustrating meetings, no progress was made.

The PCP finally decided to ask Mr. Smith to keep a daily log of where he drove. He was willing to do this task and what emerged was that there was one place he went to nearly every day: the American Legion Post that was only a few miles from his home, but too far to walk. Other uses of the car were sporadic. The PCP discussed a plan with him for getting to the American Legion Post on a daily bias, and his resistance to quitting driving disappeared. This showed Mr. Smith that he was in a loving environment where people cared for him, respected his needs and would do what was necessary to meet these needs.

Missing—Wandering—Elopement: Getting Lost in the Community

- PLwD at risk for missing and wandering incidents at almost all stages; increased risk with increasing impairment (Nakaoka et al., 2010)
- Absence of clear terminology and understanding of the concepts of missing, wandering, and elopement (Petonito et al., 2013; Rowe et al., 2011, 2012)
- Risk highest once PLwD gets lost easily (Ali et al., 2016; Nakoaka et al., 2010; Petonito et al., 2013; Rowe, 2008)
- Increased risk morbidity (falls, injuries) and mortality
- Need for increased supervision (Ali et al., 2016; Jokinen et al., 2013; Kropelin et al.,2013; Nakaoka, 2010; Petonito et al., 2013; Rowe et al., 2011, 2012)
- The PLwD should possess a “safe return” bracelet in case of incident.

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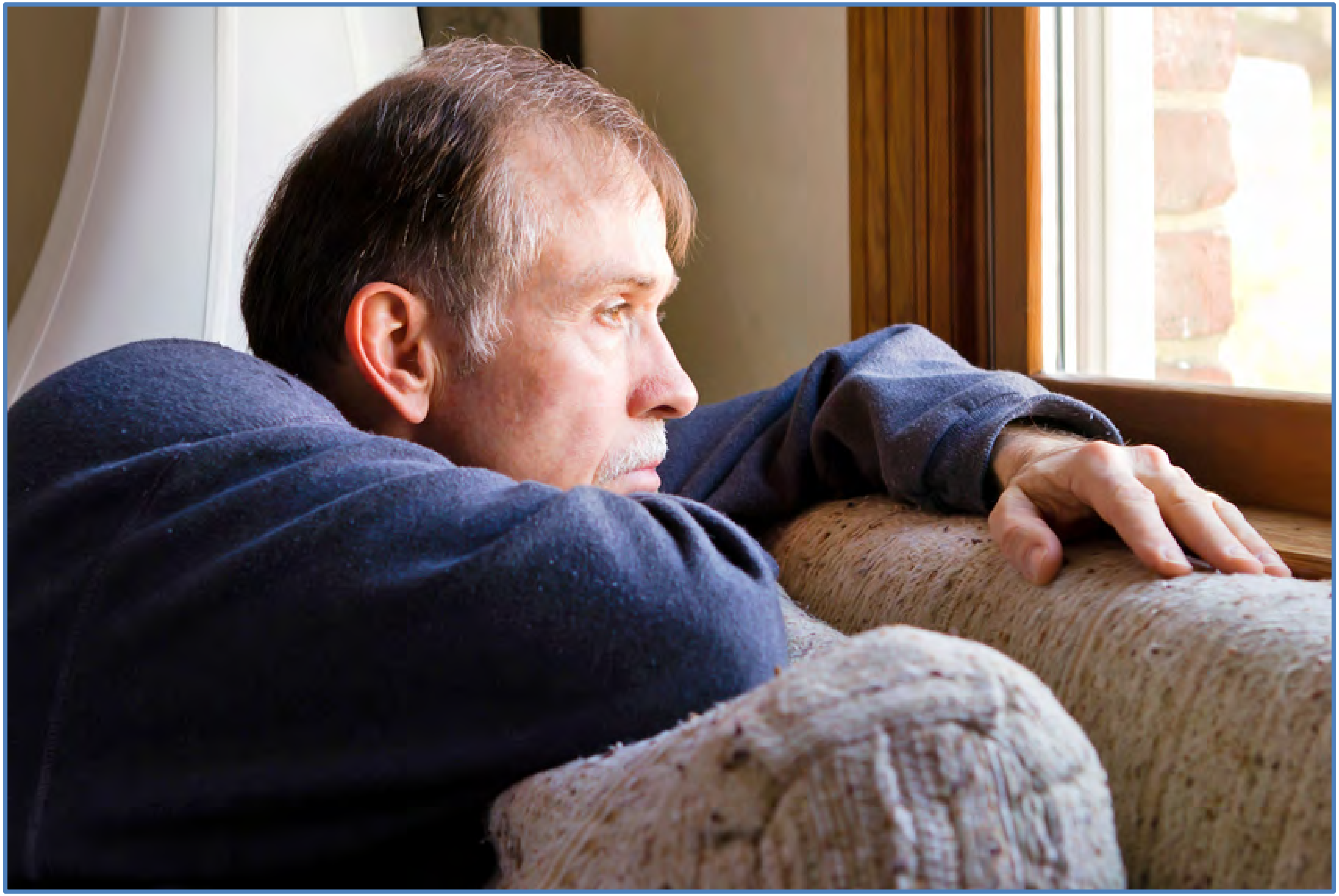
Transitioning from Home to Long-Term Care: Residential Care Options

As their condition deteriorates, PLwD may need to seek alternative services. These services are variable and include:

- Home and Community-Based Services
- Home health care services
- Adult day services
- Respite care
- Programs of All-Inclusive Care of the Elderly (PACE)
- Assisted Living
- Congregate care:
  - Nursing homes
  - Memory units
  - Other
- Care partners of persons living with dementia and intellectual disability can consult with staff at the states' developmental disabilities authority ("State Agency") about available out-of-home care options.
  - Many states fund and/or maintain dementia–capable group homes.



Evaluation

1. **The middle stage of dementia is characterized by:**
   a. Difficulties performing instrumental activities of daily living
   b. Difficulties performing basic activities of daily living
   c. Difficulties swallowing and chewing
   d. Increasing medical problems

2. **All but which of the following is a common behavioral or psychological symptom of dementia?**
   a. Pacing
   b. Obstructive sleep apnea
   c. Apathy
   d. Hyposexuality

Evaluation (continued 1)

3. When using the DICE approach to address behavioral and psychological symptoms of dementia, the provider is responsible for:

a. Identifying the symptoms that are distressing

b. Identifying the possible underlying cause(s) of the distressing symptoms

c. Describing the tactic that the care partner should take to manage the distressing symptoms

d. Determining the optimal treatment goal

Evaluation (continued 2)

4. **Which of the following is a common sleep-related concern most often observed in persons living with the middle stage of Lewy body dementia?**
   a. Sundowning
   b. Obstructive sleep apnea
   c. Rapid eye movement (REM) sleep behavior disorder (RBD)
   d. Insomnia

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