

GUIDE

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Clinical Guidelines for Medical Respite Care: Dementia

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Introduction

Dementia is the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people globally.¹ Dementia is not a diagnosis; it is a term used to describe a group of symptoms. Alzheimer's is the most common form of dementia, representing 60-70% of all diagnoses. About 1 in every 9 person age 65 and older has Alzheimer's dementia, and it's estimated about 200,000 Americans under the age of 65 develop a form of dementia per year; which is considered early-onset dementia.

While the greatest risk factor for developing a form of dementia is age, there are other modifiable factors, including cardiovascular health, physical activity, diet and even education level that can impact dementia risk. Other medical conditions, like a history of traumatic brain injury (TBI), even mild cases, are associated with a two-fold increase in risk of a dementia diagnosis, and those who experience TBI are more likely to get diagnosed at a younger age. New research is also beginning to analyze the impact of personal factors such as poor sleep quality, excessive alcohol use, depression and hearing impairment as possibly increasing the risk of developing dementia². Experiencing homelessness does appear to be both a risk factor for, as well as a possible consequence, of Alzheimer's Disease and related dementias (ADRD), however, this relationship also appears to be complex and connected to other co-morbidities and social determinants of health.³

This resource will provide an overview of Alzheimer's Disease and Related Dementias, how it impacts the individual, and strategies to support clients within the medical respite setting.

Key Terms and Definitions

Alzheimer's Diseases and Related Dementias (ADRD) are debilitating conditions that impair memory, thought processes, and functioning, primarily among older adults. They are not reversible.

Behavioral and Psychological Symptoms of Dementia (BPSD) also known as neuropsychiatric symptoms, represent a heterogeneous group of non-cognitive symptoms and behaviors occurring in people with dementia.

Compensatory Strategies are environmental modifications or behavioral strategies designed to bypass persistent impairment in attention, memory, executive function, and/or other cognitive skills as a means to achieve desired goals. These strategies build on the strengths and skills of the individual and can more immediately support a person in completing day to day tasks.

Dementia is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. There are five common forms of non-reversible dementia, including Alzheimer's Disease, Frontotemporal Dementia, Lewy Body dementia, Vascular dementia, and mixed dementia.

Alzheimer's Disease is a type of brain disorder that causes problems with memory, thinking and behavior. This is a gradually progressive condition.

Frontotemporal Dementia is a type of dementia that is caused by a group of disorders that gradually damage the brain's frontal and temporal lobes. These damages cause changes in thinking and behaviors. Symptoms can include unusual behaviors, emotional problems, trouble communicating, challenges with work, and difficulty with walking.

Lewy Body Dementia is also known as dementia with Lewy bodies, is the second most common type of progressive dementia after Alzheimer's disease. Protein deposits, called Lewy bodies, develop in nerve cells in the brain regions involved in thinking, memory and movement (motor control). Lewy body dementia causes a progressive decline in mental abilities. People with Lewy body dementia might have visual hallucinations and changes in alertness and attention. Other effects include Parkinson's disease signs and symptoms, such as rigid muscles, slow movement, walking difficulty and tremors.

Vascular Dementia is a general term describing problems with reasoning, planning, judgment, memory and other thought processes caused by brain damage from impaired blood flow to the brain, most commonly, but not always, caused by a stroke.

Mixed Dementia is a dementia condition characterized by symptoms and abnormalities of more than one type of dementia at once. Usually, mixed dementia entails a combination of Alzheimer's disease and vascular dementia

Harm Reduction is a philosophical approach to medical care that extends beyond substance use and, in general, establishes individual agency and self-determination as central to any health intervention or efforts towards well-being. Harm reduction approaches call for the non-judgmental, non-coercive provision of services and resources to people experiencing homelessness to assist people in reducing harms related to chronic health conditions or health behaviors. Harm reduction-based care is collaborative, provides education on available interventions, and centers the goals of the individual in care planning.

Mild cognitive impairment (MCI) is the stage between the expected decline in memory and thinking that happens with age, and the more serious decline of dementia. MCI may include problems with memory, language, or judgment.

Reversible dementia is the types of dementia that can be partially or completely cured through treatment and proper management by targeting the underlying cause

Transfer trauma is a term used to describe the stress that a person with dementia may experience when changing living environments. The length of time and severity of the transfer trauma is quite individual. For some, the stress associated with the move may be fairly significant, and for others, it may be mild or not at all. For some, the stress may last for a few days, and for others, a few weeks. This stress is usually temporary in nature and relieved as the individual builds friendships, gains trust, and develops a sense of purpose and belonging in their new community.

Trauma Informed Care (TIC) is a patient-centered approach to care that recognizes the impacts of trauma and actively works to prevent re-traumatization and promote recovery. The principles of TIC are grounded in establishing a trusting relationship and a safe physical and psychological space in which to address needs.

Clinical Considerations

Background

Both internal and modifiable risk factors can contribute to the development of dementia.

Internal Risk Factors include:

- Age
- Genetics/family history
- Traumatic brain injury
- Hearing impairment
- Cardiovascular disease
- Hypertension
- Diabetes
- Air pollution

Modifiable Risk Factors include:

- Excessive alcohol use
- Depression
- Midlife obesity
- Limited physical activity
- Low educational attainment
- Poor nutrition
- Poor sleep or sleep deprivation
- Cigarette smoking

Stages of Dementia

Early Stage: Individuals may begin to become less social than their baseline and show changes in personality and mood. Denial of symptoms, and attempts to mask symptoms, is common. At this stage people are drawn to familiar situations and people where they can rely on their long-term memories. New situations and challenges can invoke stress and anxiety.

Middle Stage: Individuals will require some assistance to carry-out basic daily activities with good quality, including showering and dressing. They will not consistently recall important information like family member's names or medications. Given the significant challenges with memory, individuals at this stage can become distressed and are more likely to show behavioral and psychological symptoms of dementia (BPSD).

Late Stage: Individuals will require excessive assistance with all activities of daily living. They still maintain the ability to walk and eat but will require 24-hour supervision.

End stage: Individuals are bedbound and require complete care.

Dementia is a progressive condition, that, at this time, has no cure. Individuals with dementia will experience a progression of symptoms that often coincide with a decline in skills. It is important to have realistic expectations for what people with dementia will be able to learn and do, especially in new environments.

For people experiencing homelessness, an onset of dementia may be confused with other conditions, such as substance use, mental health symptoms, or be identified as “difficult” behavior. It is important for providers to consider all possible causes for changes in function, including dementia. It may take additional diagnostic assessments, as the person may not be able to provide a full history, and there may not be supports who can provide a background on the person or describe changes in function.

Medical respite providers should be prepared to support an individual undergoing decline and identify an appropriate care and discharge plan where the person will receive the proper level of support. Medical respite is likely not the ideal location for someone in the middle-late stages of dementia.

Medical respite care **can** be an opportunity to:

- Provide stability where symptoms of dementia can be identified and diagnosed,
- Rule out other potential causes and conditions, and
- Transition to more appropriate services to support overall health and quality of life.

Assessment

In all assessment processes, it is important to implement a [trauma-informed](#) and harm reduction-based approach, recognizing that people may not be ready to share their entire health history in the first encounter. A good history is key to creating an appropriate plan of care and can be built over several visits. Consider that the memory center (hippocampus) and emotional center (amygdala) of the brain are closely linked, and those experiencing dementia are likely to recall traumatic past experiences or the feelings associated with the traumatic experience long into their dementia process. Furthermore, experiencing post-traumatic stress disorder puts a person at an increased risk of developing all forms of dementia.⁴ A comprehensive assessment for dementia includes the following:

Complete History and Physical, which includes:

Identify underlying or co-occurring health issues that may be causing changes in cognitive function. Information regarding medical history and all current medication should be collected and documented.

- Monitor for signs and symptoms of other conditions that might impact cognition (e.g., urinary tract infection, acquired brain injury, hydrocephalus)
- Family history (some forms of dementia are genetic)
- [Assess ability to follow medication regimens](#)
- Assess symptoms of behavioral health disorders and substance use disorders by incorporating screening tools ([PHQ9](#), [GAD-7](#), [DAST-10](#); [ASI](#); [SBIRT](#))
- Assess access to adequate nutrition and hydration
- Assess living conditions, current and where the person may discharge to, and supports available
- Assess for [history of or current interpersonal violence and/or elder abuse](#)

Assess Cognitive Status:

- Assess current cognitive status incorporating tools such as [Mini-Cog](#) or [Mini Mental Status Exam](#) [©](#)
- Assess Global Cognition using [St. Louis University Mental Status SLUMS](#)
- Assess and monitor for changes in personality or behavior
- Rule out possible delirium or other contributors to cognitive decline
- Complete [Medicare Wellness Exam](#) to determine specific indicators or risk factors for cognitive impairment

Assess for factors co-occurring with or impacting cognition:

- Assess vision, visual field of attention, and vision changes
- Assess [literacy, health literacy, and calculation skills](#)
- Assess balance and gait using the [Walking while Talking Test](#)⁵

Dementia specific assessments include:

- [Pain Assessment in Advanced Dementia Scale \(PAINAD\)](#)⁶
- [Informant Questionnaire: Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly](#) (Short IQCODE)⁷
- [The Quick Dementia Rating System](#) (QDRS)
- [Functional Assessment Staging Tool](#) (FAST)⁸
- Assess impact of dementia on communication
- Assess impact on [daily function](#)

Monitor progression of symptoms over time and assess for need for higher level of care:

- This may include comprehensive assessment of [ability to perform activities of daily living \(ADL\) independently and](#) instrumental activities of daily living (IADL). This may require a referral to occupational therapy for full evaluation, and/or a referral to speech therapy to assess communication skills.

Care Plan and Management

Strategies and treatment plans implemented should be person-centered, collaborative, and based on priorities and needs identified during the assessment process. As noted, interventions should be trauma-informed and integrate harm reduction principles to minimize risks and improve care. The below strategies are most effective for those with early and middle stages of dementia and can be used while the person is in the medical respite program and waiting for transition to a higher level of care.

Person Specific Strategies

Individual strategies for management of dementia include:

- Introduce yourself whenever you begin an interaction with the person; do not assume they will remember who you are.
- Use the person's preferred name.
- Honor individual preferences and routines whenever possible.
- Be mindful of your own body language and facial expressions that may make the person in care anxious (e.g., Crossed arms, furrowed eyebrows).
- Be mindful of the patient's body language and facial expressions. They may not have the words to communicate what they are feeling.
- Use compensatory strategies whenever possible, including pill boxes, calendars, alarms.
- Provide extra time for the patient to understand information and express any additional concerns or needs.
- Limit new learning to essential information only.
- Limit written materials (always consider health literacy) and use simple visuals/pictures when possible.
- Keep verbal communication short, specific, and clear.
- Complete daily wellness checks (at minimum) to provide support as needed and monitor symptoms.
- Avoid saying "remember when" and "you already told me that," and assume that most information or instructions presented will feel new to the patient.

Environmental Strategies

- Ensure signage is at eye level and language is simple or uses pictures.
- Ensure there is no clutter or tripping hazards in spaces where the person receiving care may be.
- Ensure hallways are well-lit to decrease fall risk.
- Provide simple, written instructions and reminders using consistent strategies.

- Check for shadows in personal space, especially bedrooms, as shadows can result in paranoia or fear.
- Offer [spaces where person can be alone with less sensory stimulation](#) to help them self-regulate and avoid becoming overwhelmed.
- Consider visual field of attention and ensure the person can actually see you (for example, the visual field of attention for someone with middle stage dementia is less than 2 feet, so ensure you are less than 2 feet away from them if you expect them to see you).

Referrals

- Behavioral health: to address impacts of changes in function related to Alzheimer’s Disease and Related Dementias (ADRD), or to address substance and alcohol use if person desires to decrease use.
- Gerontology or Geriatric Psychiatry: for assessment if presenting with conditions related to aging, even if younger than 60. This may rule out if neurological changes are related to a reversible form of dementia.
- Neurology: for diagnosis and ongoing management of neurological conditions, including ADRD.
- Neuropsychiatry: for assessment of cognition/cognitive function and impacts of ADRD.
- Occupational Therapy: for evaluation to identify underlying factors and impact of ADRD and environmental barriers on ADL and IADL performance.
- Physical Therapy: for evaluation to identify underlying physiological factors and impact of ADRD on mobility (including gait, balance, and motor skills).
- Speech and Language Therapy: for evaluation to identify impacts of dementia on memory, global cognition, communication, speech, and swallowing.

Discharge Planning

It is important to keep in mind that once a person has been diagnosed with a form of dementia, at a minimum they will require at least intermittent daily supervision. Patients with ADRD may be ready for discharge from medical respite care when:

- The patient has a support network in place to ensure they will go to all medical appointments.
- The patient has completed interventions with PT, OT, or speech therapy, and has supports in place to safely engage in daily activities.
- The patient has completed needed diagnostic and follow-up testing.
- The patient is connected with intensive ongoing community supports, such as intensive case management or local Home and Community Based Services.
- The patient transitions directly into a higher level of care as determined by need.

Advanced Training and Advocacy

- For more comprehensive overview of strategies to support individuals living with dementia, please view the webinar [Addressing Dementia in Medical Respite Programs](#)
- Additional training and resources on dementia care, as well as a 24-hour helpline, is available through the Alzheimer’s Association at Alz.org
- Resources to assist with placing individuals with dementia in senior housing can be found at the Department on Aging website [areaagencyonaging.org](#)
- Access training on [trauma-informed de-escalation and crisis prevention](#) for people with dementia.
- Understand barriers to higher [levels of care](#) and advocacy needed to increase access for people experiencing homelessness
- For more information on determining need for guardianship:
 - [Healing Hands: Strategies for Conservatorship](#)
 - [Legal Documents | Alzheimer's Association](#)
 - [Adult GuardianshipFactsheet.pdf \(alz.org\)](#)
- [NHCHC Coffee Chat focused on issues in aging and people experiencing homelessness](#)

Case Example 1

Background: Carole (she/her/hers) is an 81 year old who arrived at the city’s local shelter with several bags of belongings. Carole is unable to provide any background information on how she arrived at the shelter, whether or not she has family, and any personal history. It is unclear to staff if she is uncomfortable sharing this information or is actually unable to. Carole also has decreased mobility and an unsteady gait. After several weeks at the shelter she has become more irritable and verbally aggressive, and her ADLs have declined. Staff specifically noticed Carole more frequently smelled of urine and appeared not to be bathing or changing her clothes. During a verbal altercation with another resident, she lunged towards the resident and fell, landing on, and appearing to injure, her hip. Carole was examined by the mobile medical unit that comes to the shelter but refused additional care (such as an X-ray or the ED). However, Carole showed difficulty moving around and significant pain. Carole was referred by the mobile medical team and shelter staff to the medical respite program, located in the shelter, for rest and monitoring on her condition.

Carole presented with some difficulty transitioning to a different area of the shelter, often attempting to return to her previous shelter bed after meals. Carole also appeared to forget about her hip injury, and would try to get up or sit down quickly, resulting in a display of pain. Although Carole engaged with medical respite staff, she continued to present with irritability and difficulty remembering basic information.

Assessment: Due to Carole’s difficulty with memory, disorientation, and irritability, the medical respite provider completed the Quick Dementia Rating System based on the knowledge of the shelter and medical respite staff, indicating potential mild or moderate dementia. The provider attempted to administer the SLUMS, however, Carole became frustrated and stopped participating in the assessment, therefore it could not be scored. The provider used motivational interviewing to talk with Carole about her overall health, revealing Carole was also experiencing incontinence. A more comprehensive exam revealed the presence of a UTI and challenges with toileting due to the hip injury. Despite the rapport and trust that was built with Carole, she continued to decline any care that occurred outside of the shelter space for her hip or memory. The provider shared the findings around Carole’s likely dementia with the team, who convened to develop a comprehensive plan for her.

Intervention: Carole was prescribed treatment for her UTI, and the medical respite RN ensured Carole took her medications daily. The RN also reminded Carole when she had pain medication available for her hip, offering her the choice to take them throughout the day, especially when appearing to be in noticeable pain. Carole was referred to a home health agency equipped to work with clients with dementia for both PT and OT to address mobility and ADLs as a result of the hip injury. Carole’s bed was relocated closer to the bathroom and alongside a wall to provide a slightly calmer space and decrease the number of steps to the bathroom. A large sign with her name was posted at the edge of the bed to help her recognize her bed, and staff agreed to not relocate her during the rest of her medical respite stay. After building rapport, Carole agreed to let her case manager help her organize her belongings, in which Medicare paperwork with Carole’s name and DOB was found. The case manager was able to reconnect Carole to Medicare and apply for supplemental Medicaid. Carole had difficulty engaging in planning her discharge, stating she’d prefer to “stay here.” Her care team provided gentle reminders that medical respite was not long-term housing, and continued to present to Carole with a plan to move into long-term care where she could receive more support.

Outcomes: With treatment of her UTI and better controlled pain, Carole became less irritable and showed some improvement in her ADL management, completing regular bathing and no longer smelling of urine. Carole was referred for a long-term care placement, and intermittently stated she did not want to go. Although she declined seeking specialty care, the health center's physician was able to see Carole at the respite program to confirm the dementia diagnosis, and supplemental evaluation information from OT and PT supported the referral into long-term care. Carole remained at the medical respite program for several months until a bed became available in a long-term care facility that accepted her insurance.

Case Example 2

Background: Hector (he/him/his) is 60 years old and has been primarily living on the streets for several years. Hector has a diagnosis of schizophrenia and a long-standing history of opioid use with intermittent periods of sobriety, often in the context of hospitalization or inpatient treatment. During a snowstorm, a friend found Hector unconscious due to an overdose. Hector was taken by ambulance to the hospital where he was treated for his overdose, along with frostbite injuries from being in the storm. Hector was referred to the medical respite program for management and healing of his frostbite wounds, once stabilized.

After admission to the medical respite program, Hector expressed significant concern over his injuries caused by overdosing and being unable to seek shelter from the winter storm. He discussed being afraid of it happening again, and the potential loss of limbs and mobility from further injuries. Hector engaged well with the medical respite team, however, he presented with difficulty remembering information regarding his health, appointments, and program schedule. Hector also appeared to have difficulty verbally expressing himself, often substituting words incorrectly in sentences or taking long pauses while speaking.

Assessment: Due to his concerns around continued substance use, Hector was initially referred for, and initiated, Medication Assisted Treatment (MAT). Once more stable, Hector noticed and became more concerned with his memory. Hector's provider was able to administer the SLUMS, which indicated mild cognitive impairment, with decreased performance in the areas of recall, attention, and language. His providers completed a medication reconciliation to ensure that medications were not contributing to memory difficulties and referred Hector for a neurology evaluation. Hector's neurology appointment occurred several weeks after his transition into medical respite, and the evaluation found that although Hector did have decreased cognitive skills, it was not due to dementia. The neurologist indicated cognitive changes were likely due to his schizophrenia diagnosis, history of substance use, and extensive length of homelessness.

Intervention: While at the respite program, the case manager coordinated with the Continuum of Care and learned that Hector would soon be receiving a housing voucher. Hector was initially excited but later expressed concerns about the transition. Hector was referred for an occupational therapy assessment to determine his current functional skill level and supports needed, and how these were impacted by his health and cognition. The OT evaluation revealed Hector's strengths in accessing community resources and preparing meals for himself, but also needed supports for budgeting, medication management, and time management. Hector was referred to a permanent supportive housing team to assist with his transition into housing and help him use the strategies identified. Hector was able to continue to engage in MAT and worked with the medical respite team to use compensatory strategies (pillbox, phone alarm) to remember to take his medications. He continued to require some assistance with organizing his pillbox, but over time he showed increased ability to remember information and instructions given. Because he did not have dementia, his providers could work with him to identify and incorporate compensatory strategies.

Outcomes: Hector was able to work with the local housing navigator to find an apartment, and moved from medical respite into housing once his injuries had healed and could safely be managed in the community. Hector made the transition from the medical respite team to the PSH team. Hector also worked with his new PSH team to determine ongoing supports (e.g., rep payee services, working with the RN for weekly pillbox management) and to help Hector with his goal of maintaining participation in the MAT program. His team also supported Hector with reminders for critical appointments and supported Hector in using strategies from the OT to manage and organize his time.

References

¹ [Dementia \(who.int\)](https://www.who.int/)

² Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2022;18.

³ Babulal, G. M., Rani, R., Adkins-Jackson, P., Pearson, A. C., & Williams, M. M. (2022). Associations between Homelessness and Alzheimer's Disease and Related Dementia: A Systematic Review. *Journal of applied gerontology : the official journal of the Southern Gerontological Society*, 41(11), 2404–2413. <https://doi.org/10.1177/07334648221109747>

⁴ Günak, M., Billings, J., Carratu, E., Marchant, N., Favarato, G., & Orgeta, V. (2020). Post-traumatic stress disorder as a risk factor for dementia: Systematic review and meta-analysis. *The British Journal of Psychiatry*, 217(5), 600-608. doi:10.1192/bjp.2020.150

⁵ Verghese, J., Buschke, H., Viola, L., Katz, M., Hall, C., Kuslansky, G., & Lipton, R. (2002). Validity of divided attention tasks in predicting falls in older individuals: a preliminary study. *Journal of the American Geriatrics Society*, 50(9), 1572–1576. <https://doi.org/10.1046/j.1532-5415.2002.50415.x>

⁶ Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003;4:9-15.

⁷ Jorm, A. F. (n.d.) *Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)*. Available from https://nceph.anu.edu.au/files/English_short.pdf

⁸ Reisberg, B. (1984). *Functional Assessment Staging Tool (Fast Scale)*. Available from https://www.compassus.com/sparkle-assets/documents/functional_assessment_staging_tool_fast_scale.pdf



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