Early Warning Signs of Cognitive Changes Outside of Normal Aging

What to expect	What to do	Resources
Warning signs of cognitive changes that may not be typical for a person's normal aging process: 1. Memory loss that disrupts daily life 2. Challenges in planning or solving problems 3. Difficulty completing familiar tasks at home, at work, or at leisure 4. Confusion with time or place 5. Trouble understanding visual images and spatial relationships 6. New problems with words in speaking or writing 7. Misplacing things and losing the ability to retrace steps 8. Decreased or poor judgment 9. Withdrawal from work or social activities 10. Changes in mood and personality	Discuss cognitive changes with a trusted family member or friend Schedule an appointment with primary care provider to discuss concerns (after assessment of symptoms, primary care provider may refer to specialty services through a memory diagnostic clinic, neurology department, or neuropsychology department for further evaluation) Prepare for the appointment • Gather appropriate paperwork (ie. advance directives) • Describe the behavioral changes that you have noticed Dementia Challenging Behavior Initiative A Waukesha County Community Response	Alzheimer's Association Online Resources: • https://www.alz.org/alzheimers-dementia/memory-loss-concerns • https://www.alz.org/alzheimers-dementia/10_signs • https://www.alz.org/alzheimers-dementia/diagnosis/medical_tests • https://www.alz.org/alzheimers-dementia/diagnosis/why-get-checked • https://www.alz.org/alzheimers-dementia/diagnosis/visiting-your-doctor • https://www.alz.org/alzheimers-dementia/diagnosis/life-after-diagnosis Education: • 10 Warning Signs Online Education (Free) Questions: • Alzheimer's Association 24/7 Helpline (800.272.3900)

Mild Neurocognitive Disorder-Mild Cognitive/Vascular Impairment

What to expect	What to do	Resources
Mild Cognitive Impairment (MCI) causes slight by noticeable and measurable decline in cognitive abilities, including memory and thinking. A person with MCI is at an increased risk of developing Alzheimer's or another dementia. People living with MCI, especially MCI involving memory problems, are more likely to develop Alzheimer's disease or other dementias. However, MCI does not always lead to dementia. In some individuals, MCI reverts to normal cognition or remains stable. Symptoms: • Amnestic MCI: MCI that primarily affects memory. A person may start to forget important information that he or she would previously have recalled easily, such as appointments, conversations or recent events. • Nonamnestic MCI: MCI that affects thinking skills other than memory, including the ability to make sound decisions, judge the time or sequence of steps needed to complete a complex task, or visual perception.	Discuss cognitive changes with a trusted family member or friend Schedule an appointment with primary care provider to discuss concerns (after assessment of symptoms, primary care provider may refer to specialty care services through a memory diagnostic clinic, neurology department, or neuropsychology department for further evaluation) Prepare for the appointment, take trusted family member of friend to appointments Schedule a care consultation with the Alzheimer's Association to learn about Early Stage Programs and Services available online and in local community Complete Advanced Directives Meet with elder law attorney and financial planner to learn about long term care planning options Schedule a meeting with the Aging and Disability Resource Center (ADRC) to discuss long term options Dementia Challenging Behavior Initiative A Waukesha County Community Response	Online Resources for persons living with MCI: • https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/mild-cognitive-impairment • https://www.alz.org/help-support/i-have-alz/live-well • https://www.alzconnected.org/ • https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials Online Resources for care partners: • https://www.alz.org/help-support/caregiving/stages-behaviors/early-stage • https://www.alz.org/help-support/caregiving/financial-legal-planning • https://www.alz.org/help-support/caregiving/safety • https://www.alzconnected.org/ • https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials Local Resources for persons living with MCI and Care Partners: • https://www.alz.org/wi Recommended Activities: • In-Person Care Consultation with Alzheimer's Association • Education Program: Living Well with Chronic Conditions; Legal & Financial Planning • Early Stage Support Groups • Memory Café's • Silver Sneakers or other exercise programs • Utilization of Assistive Technology such as GPS navigators/locators • Occupational therapy driving assessment

Major Neurocognitive Disorder-Dementia (Early Stage)

What to expect	What to do	Resources
In the early stages of dementia, most people function independently. A person may still drive, take part in social activities, volunteer and even work. It is common in the early stages of dementia for the person living with the diagnosis to experience increased episodes of confusion which cause anxiety. The person may need cues and reminders to help with memory. The person may start to need help with the following activities: • Keeping appointments • Remembering places of work or names • Recalling familiar places or people • Managing money • Keeping track of medications • Planning or organizing • Transportation Care partners often times start to feel more emotional ups and downs (feeling overwhelmed, having fear of what the future may look like, hope when a certain support provides benefit to the person living with dementia). Emotions care partners may experience as a care partner include: • Denial • Fear • Stress/Anxiety • Anger/Frustration • Grief/Depression	The care partner's primary role is to provide support and companionship, and help with planning for the future. Consider taking advantage of available treatments, participating in clinical trials, attending local early stage programs and services Begin building an informal care and support team with family members, close friends, neighbors and faith based community connections. Care partners should work to support the person living with dementia by helping them to remain healthy, active, engaged, and as independent as possible. Care partners can do this by promoting the following activities: • Encourage physical activity. Choose activities the person will enjoy. • Prepare meals that maintain a healthy diet (low in fat, high in vegetables, protein). • Create a daily routine which promotes quality sleep and social engagement with others. • Identify situations which may be too stressful for the person with dementia. • Work together with the person living with dementia to find ways to help them relax.	Online resources for persons living with dementia: • https://www.alz.org/help-support/i-have-alz • https://www.alzconnected.org/ • https://training.alz.org/ (recommended online education includes: Living with Alzheimer's for people with Alzheimer's, Living with Alzheimer's: For Younger Onset-Alzheimer's • https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials Online resources for care partners: • https://www.alz.org/alzheimers-dementia/what-is-dementia • https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia • https://www.alz.org/alzheimer_s_dementia • https://www.alz.org/help-support/caregiving/stages-behaviors/accepting_the_diagnosis • https://www.alz.org/help-support/caregiving/stages-behaviors/early-stage • https://www.alz.org/help-support/caregiving/caregiver-health • https://www.alz.org/help-support/caregiving/safety • https://www.alz.org/help-support/caregiving/financial-legal-planning • https://www.alzconnected.org/ • https://training.alz.org/ (recommended online training includes: Dementia Conversations, Legal & Financial Planning for Alzheimer's disease, Living with Alzheimer's: For Caregivers-Early Stage, Understanding Alzheimer's & Dementia)

	Care partners need to also start being mindful about their own well-being and how the help they are providing to the person with dementia may be impacting their overall health. Dementia Challenging Behavior Initiative A Waukesha County Community Response	• https://www.alzheimersnavigator.org/ • https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials Local Resources: • https://www.alz.org/wi Recommended activities for persons living with dementia and care partners: • In-Person Care Consultation for next step planning after a diagnosis • Education Programs: Living with Alzheimer's-Early Stage, Living Well with Chronic Conditions • Early Stage Support Groups • Social Engagement Activities: Memory Café's, Amazing Grace Chorus, Spark! Programs, Memories in the Making Community Events, Purple Canoe Club Events • Counseling Services (as needed) Additional recommended activities for persons living with dementia: • Brain Health Enhancement Classes • Silver Sneakers or other exercise programs Additional recommended activity for care partners: • Education Program: Understanding Dementia (3 part series, only offered locally not online)

Major Neurocognitive Disorder-Dementia (Middle Stage)

What to expect	What to do	Resources

The middle stages of dementia are typically the longest and can last for many years. As dementia progresses, the person living with the disease will require a greater level of care.
 	
During the middle stages damage to the brain can make it difficult to express thoughts and perform routine tasks. The person with dementia may jumble words, have trouble dressing, get frustrated or angry, or act in unexpected ways, such as refusing to bathe. There will be challenging days, but there also will be good days. As relationships with the person with dementia change, new ways to connect and deepened bonds are often formed.
 	
Caregiving for someone in this stage requires flexibility and patience. As the abilities of the person with dementia change and functioning independently becomes more difficult, greater responsibility is placed on the caregiver. Daily routines need to be adapted and structure becomes more important.
 	
Middle-Stage Concerns:
• Changes in behavior
• Changes in communication
• Changes in daily care needs
• Difficulty connecting to activities that provide meaning
• Inability to safely drive
• Increased safety concerns when left alone (home safety/wandering).
	Learn strategies and ways of coping that work for both the caregiver and person living with dementia.
	
	Connect with other caregivers.
	
	Create a daily routine for the person living with dementia.
	
	Focus more intently on caregiver health concerns.
	
	Meet with the local Aging and Disability Resource Center (ADRC) representative to go over long term care options, and possible funding sources
	
	Take advantage of respite programs (adult day centers, in-home care) and learn about funding options.
	
	Secure assistance with complex care needs/long distance caregiving (care management services).
	
	Transition to alternative living options (move in with family, residential care placement, 24 hour in-home care).
	
	Assistance with transitions to residential care settings (care management services, placement agencies).
	
	Connect with the Alzheimer's Association and ADRC for assistance with care plan development.
		Online Resources for Care Partners:
		• https://alz.org/help-support/caregiving/stages-behaviors/middle-stage
		• https://alz.org/help-support/caregiving/care-options/glossary
		• https://alz.org/help-support/caregiving/stages-behaviors
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/agression-anger
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/anxiety-agitation
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/depression
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/hallucinations
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/memory-loss-confusion
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/repetition
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/suspicions-delusions
		  ○ https://alz.org/help-support/caregiving/stages-behaviors/wandering

		• https://alz.org/help-support/caregiving/daily-care
		  ○ https://alz.org/help-support/caregiving/daily-care/daily-care-plan
		  ○ https://alz.org/help-support/caregiving/daily-care/activities
		  ○ https://alz.org/help-support/caregiving/daily-care/communications
		  ○ https://alz.org/help-support/caregiving/daily-care/food-eating
		  ○ https://alz.org/help-support/caregiving/daily-care/art-music
		  ○ https://alz.org/help-support/caregiving/daily-care/incontinence
		  ○ https://alz.org/help-support/caregiving/daily-care/bathing
		  ○ https://alz.org/help-support/caregiving/daily-care/dressing-grooming
		  ○ https://alz.org/help-support/caregiving/daily-care/dental-care
		  ○ https://alz.org/help-support/caregiving/daily-care/treatments
		  ○ https://alz.org/help-support/caregiving/daily-care/working-with-the-doctor
		  ○ https://alz.org/help-support/caregiving/daily-care/medication-safety_(1)
		  ○ https://alz.org/help-support/caregiving/daily-care/clinical-trials
		• https://alz.org/help-support/caregiving/care-options

		○ https://alz.org/help-support/caregiving/care-options/adult-day-centers ○ https://alz.org/help-support/caregiving/care-options/in-home-care ○ https://alz.org/help-support/caregiving/care-options/residential-care ○ https://alz.org/help-support/caregiving/care-options/respite-care ○ https://alz.org/help-support/caregiving/care-options/hospice-care ○ https://alz.org/help-support/caregiving/care-options/choosing-care-providers ○ https://alz.org/help-support/caregiving/care-options/changing-care-providers ○ https://alz.org/help-support/caregiving/care-options/working-with-care-providers ○ https://alz.org/help-support/caregiving/care-options/care-team-calendar ○ https://alz.org/help-support/caregiving/care-options/long-distance-caregiving • https://alz.org/help-support/resources/online-tools ○ https://www.alzheimersnavigator.org/ ○ https://www.alzconnected.org/ ○ https://www.communityresourcefinder.org/ ○ https://training.alz.org/ ○ https://alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials

		○ https://alz.org/help-support/resources/virtual_library • https://alz.org/help-support/caregiving/caregiver-health ○ https://alz.org/help-support/caregiving/caregiver-health/be_a_healthy_caregiver ○ https://alz.org/help-support/caregiving/caregiver-health/caregiver-stress ○ https://alz.org/help-support/caregiving/caregiver-health/caregiver-stress-check ○ https://alz.org/help-support/caregiving/caregiver-health/caregiver-depression ○ https://alz.org/help-support/caregiving/caregiver-health/relationship-changes ○ https://alz.org/help-support/caregiving/caregiver-health/grief-loss-as-alzheimers-progresses Local Resources: • https://alz.org/wi • 24/7 Helpline 800.272.3900 Recommended activities for persons living with dementia and care partners: • In-Person Care Consultation for assistance with problem solving behaviors, care plan development, and navigating long term care options and funding. • Education Programs Available In-Person and Online: Living with Alzheimer's-Moderate Stage, Effective Communication Strategies, Understanding Dementia Related Behaviors • Education Programs Available In-Person Only: Understanding Dementia for Family

		Caregivers (3 part series), Savvy Caregiver (evidence-based 6 part series), Wisconsin State Conference on Alzheimer's Disease (3 day conference, scholarships available) • Support Groups • Social Engagement Activities: Memory Café's, Amazing Grace Chorus, Spark! Programs, Memories in the Making Community Events, Purple Canoe Club Events • Counseling Services (as needed) Things to consider taking part in: • Attending State Advocacy Day • Attending Federal Forum (scholarships available) Dementia Challenging Behavior Initiative A Waukesha County Community Response

Major Neurocognitive Disorder-Dementia (Late Stage)

What to expect	What to do	Resources
The late stage of dementia may last from several weeks to several years. As the disease progresses, intensive, around-the-clock care is usually required. Late-stage decisions can be some of the hardest families face. As the disease advances, the needs of the person living with dementia will change and deepen. A person with late-stage dementia usually: • Has difficulty eating and swallowing • Needs assistance walking and eventually is unable to walk • Needs full-time help with all activities of daily living • Is vulnerable to infections, especially pneumonia. Increased attention needs to be given to the following: • Food and fluids • Bowel and bladder function • Skin and body health • Infections and pneumonia • Pain and illness	During the late stages, the caregiver's role focuses on preserving quality of life and dignity. Continue to connect with the person living with dementia throughout the late stages of this disease, especially with experiences that engage a person's senses (touch, sound, sight, taste and smell). Contact the Aging and Disability Resource Center (ADRC) Continued awareness of caregiver health concerns. Caregiver training on lifting, transfers and falls prevention of the person living with dementia. Utilize palliative care and hospice care services. Bring additional help into the home to meet increased care needs. Care needs may exceed what a caregiver is able to provide at home, even with additional assistance. Help with transitioning to alternative placement may be needed.	Alzheimer's Association Online Resources for Caregivers: https://alz.org/help-support/caregiving/daily-care • https://alz.org/help-support/caregiving/daily-care/food-eating • https://alz.org/help-support/caregiving/daily-care/incontinence • https://alz.org/help-support/caregiving/daily-care/bathing • https://alz.org/help-support/caregiving/daily-care/dental-care https://alz.org/help-support/caregiving/care-options • https://alz.org/help-support/caregiving/care-options/in-home-care • https://alz.org/help-support/caregiving/care-options/hospice-care • https://alz.org/help-support/caregiving/care-options/residential-care • https://alz.org/help-support/caregiving/care-options/long-distance-caregiving https://alz.org/help-support/caregiving/caregiver-health • https://alz.org/help-support/caregiving/caregiver-health/be_a_healthy_caregiver • https://alz.org/help-support/caregiving/caregiver-health/caregiver-stress • https://alz.org/help-support/caregiving/caregiver-health/caregiver-depression • https://alz.org/help-support/caregiving/caregiver-health/grief-loss-as-alzheimers-progresses https://alz.org/help-support/i-have-alz/ • https://alz.org/help-support/i-have-alz/plan-for-your-future/end-of-life-planning

		Additional Online Resources for Caregivers:
		• https://www.caregiver.org
		  ○ https://www.caregiver.org/alzheimers-disease-caregiving
		  ○ https://www.caregiver.org/understanding-palliativesupportive-care-what-every-caregiver-should-know
		  ○ https://www.caregiver.org/advanced-illness-holding-on-letting-go
		  ○ https://www.caregiver.org/dementia-and-pain-management-personal-story
		• https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html
		• https://www.thiscaringhome.org/helping-a-person-with-dementia-transfer-2/
		• https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease
		• https://www.caregiving.org/wp-content/uploads/2020/05/FallsPrevention_FINAL.pdf
		• https://training.mmlearn.org/caregiver-training-videos/topic/dementia#helpful-videos
		• https://www.nhpco.org/patients-and-caregivers/
		• https://www.aarp.org/content/dam/aarp/ppi/2019/02/haa-pressure-ulcers-resource-guide.pdf
		• https://www.alzu.org/blog/2015/04/23/skin-care-tips-for-those-with-alzheimer/
		• https://www.agingcare.com/articles/compulsive-skin-picking-in-the-elderly-186225.htm
		• https://www.sepsis.org/sepsisand/dementia/
		
		Education Opportunities:
		• https://training.alz.org/products/1024/living-with-alzheimers-for-caregivers-late-stage
		• https://training.alz.org/products/4036/effective-communication-strategies
		• https://training.alz.org/products/4037/understanding-and-responding-to-dementia-related-behavior_

		Recommended Care and Support Services locally: • Care Consultation Services • Support Groups • Education Programs • 24/7 Helpline Online Care and Support Services: • https://www.alzheimersnavigator.org/ • https://www.communityresourcefinder.org/ • https://www.alzconnected.org/ Dementia Challenging Behavior Initiative A Waukesha County Community Response