

Dementia Explained

What is Dementia?

A general term for a decline in memory, thinking, and problem-solving abilities that is severe enough to interfere with daily life.

Early-Stage

Forgetfulness, difficulty finding words, and mild confusion

Moderate-Stage

Trouble following conversations, managing finances, and completing complex tasks

Late-Stage

Significant assistance with daily activities, limited communication, may not recognize loved ones.

Communication Principles

- ✓ Dignity & Independence
- ✓ Non-Discrimination
- ✓ Full Inclusion
- ✓ Respect for Differences
- ✓ Equity for All
- ✓ Ensure Accessibility



Managing Challenging Behaviors



Cause

Identify the underlying cause of the person's behavior



Redirect

Acknowledge feelings rather than correcting; show understanding to ease distress.



Empathize

Use a gentle tone, simple language, and shift attention to another activity or topic.



Structure

Provide consistency in daily schedules to reduce confusion and increase comfort.

Caring Through Knowledge

Dementia Explained

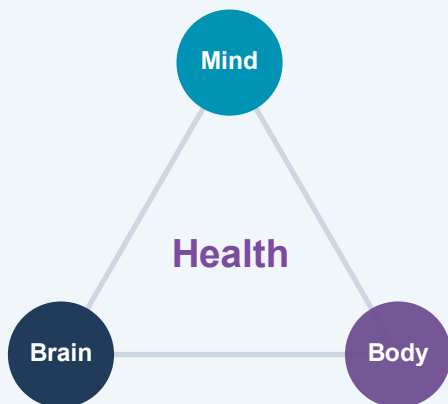
Staff Roles/Responsibilities

A multidisciplinary approach involves a team of healthcare professionals collaborating to offer comprehensive care, addressing the diverse physical, cognitive, emotional, and social needs of those affected by dementia.

Examples of Members of the Multidisciplinary Team

- Gerontologist
- Neurologist
- Psychiatrist
- Primary Care Provider
- Psychologist
- Registered Nurse/Advanced
- NP, PA
- Practice Nurse
- Case Manager
- Speech-Language Pathologist
- Physical Therapist
- Occupational Therapist
- Social Worker
- Physician

Assessments & Care plans



- ✓ Recognize emotional difficulty
- ✓ Simplify routines
- ✓ Use positive reinforcement
- ✓ Prioritize dignity, respect and choice

Safety

Abuse and neglect refer to the actions or inactions of an individual's caregiver or parent inflicting physical, sexual, or emotional harm on the individual.

Physical

Physical abuse can range from slapping or shoving to severe beatings.

Psychological

When caregivers give “the silent treatment” or intimidate the person living with Dementia, threatening them.

Neglect

Intentionally failing to meet the physical, social, or emotional needs of the older person.

Financial

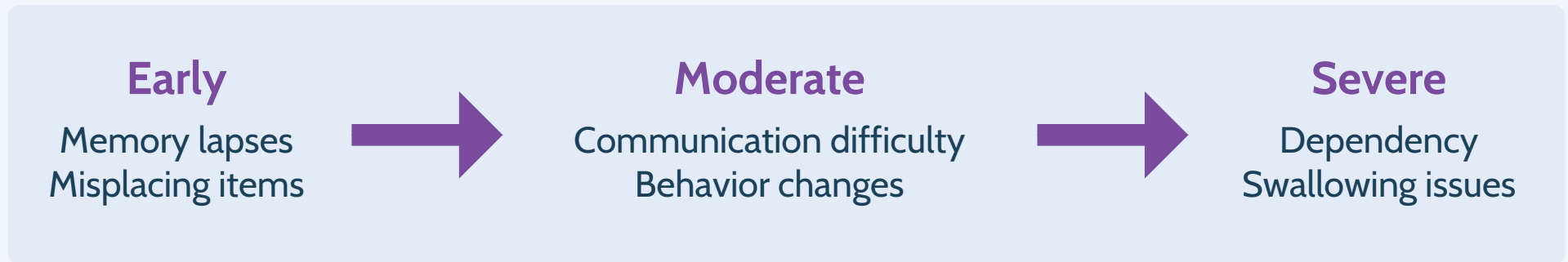
Financial abuse occurs when someone improperly uses a person's money, property, or financial accounts.

Understanding Dementia



Dementia is an umbrella term for loss of memory & other thinking abilities severe enough to interfere with daily life.

Stages & Symptom Progression



Types of Dementia

Alzheimer's Disease Vascular Dementia Lewy Body Dementia
Frontotemporal Dementia Mixed Dementia
Other, including Huntington's Disease

Transitions require coordinated care



Potential Risk Factors

Risk Factors



Education



Air
Quality



Type II
Diabetes



Unhealthy
Diet



High Blood
Pressure



Smoking



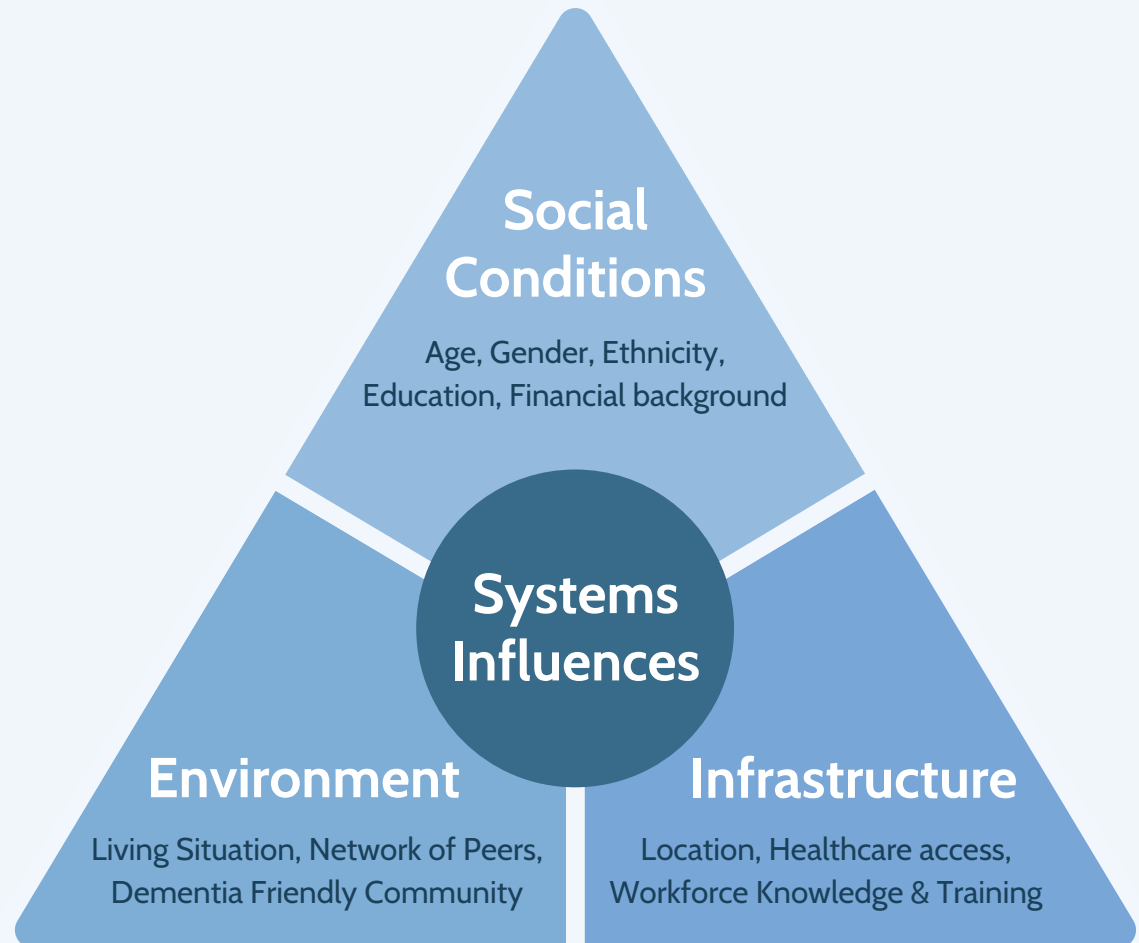
Hearing
Loss



Social
Factors

Impact

- Loss of independence
- Safety concerns
- Emotional stress
- Financial concerns



For individuals showing signs of dementia, consulting a primary care physician or neurologist is typically the initial action.

Compassionate Care

Person Centered Care

The person is at the center of their own care and are supported in contributing to the care process through shared decision-making, equality of communication, and mutual respect.

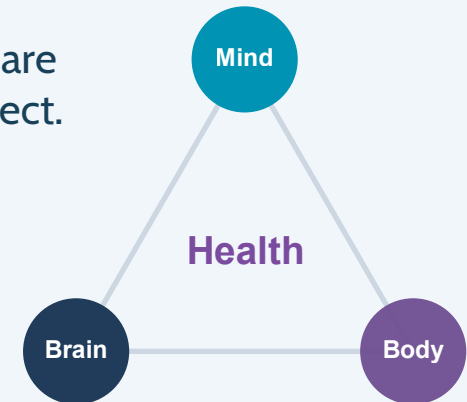
Individual needs, preferences, cultural, and spiritual backgrounds of individuals with dementia, particularly those from under-served populations, are emphasized.

Language About Dementia

The way we talk and write about dementia affects people living with dementia, their families, friends and caregivers, and public understanding of dementia.

Appropriate Language: Accurate Respectful Inclusive Empowering Non-stigmatizing

Overall health is influenced by the interaction between the mind, brain, and body, each playing an important role in how we think, feel, and function.



Encourage:

Dementia A type of dementia

Alzheimer's Disease symptoms of dementia

A form of dementia

Avoid:

Dementing illness Senile or senility

Demented Going on a journey Affliction

Strategies for Care & Support

Managing Stress

- People with dementia often have a lower threshold for handling stress
- Daily life may feel uncertain or overwhelming
- Stress can be intensified by others' emotions and reactions

Emotional Sensitivity

- Highly sensitive to the emotions of those around them
- Distress may appear as behaviors
- Behaviors are often a form of communication



Ask: What is this behavior trying to tell us?

Managing Challenging Behaviors

- Identify root causes (pain, environment, unmet needs)
- Use culturally sensitive approaches
- Avoid responses that increase distress or inequity

The DICE Framework

DESCRIBE

What is Happening?
When, where, and with whom?

INVESTIGATE

Pain, environment, unmet needs, stressors

CREATE

Person-centered strategies and supports

EVALUATE

Did it help? Adjust as needed

Supporting Everyone Involved

Emotional Support for Patients & Caregivers

- Counseling and support groups
- Respite services
- Safe, therapeutic environments
- Accessible and equitable services for all communities

Care Strategies

- Redirect rather than confront
- Empathize and validate feelings
- Structure routines to reduce confusion

Inclusive, compassionate, and culturally aware care improves quality of life for individuals with dementia and their caregivers. Be mindful of language barriers, emotional strain, and seek support for yourself when feeling overwhelmed.

Empowering Care & Support

A caregiver is someone who helps a person who needs assistance with daily activities due to illness, disability, or age.

Assess & Understand Caregiver Needs

Zarit Burden Interview

Encourage the caregiver to

- Regularly communicate your loved one's needs and preferences with staff
- Share insights about their personality to improve care
- Build relationships with other caregivers
- Visit often, Ask questions
- Document issues
- Respect their autonomy in daily choices
- Join a support group

Assess the caregivers' understanding of their current knowledge



**Scan for
Support Resources**



Be mindful of language barriers, emotional strain, and seek support for yourself when feeling overwhelmed

Social Determinants of Health

Social Determinants of Health Include

- Safe housing, transportation, and neighborhoods
- Racism, discrimination, and violence
- Education, job opportunities, and income
- Access to nutritious foods and physical activity opportunities
- Polluted air and water
- Language and literacy skills

Education Access & Quality

Healthcare Access & Quality

Social & Community Context

Neighborhood & Built Environment

Economic Stability

Barriers to Care

Patients with Alzheimer's disease

- Delays in consultation
- Comorbidities affecting the diagnosis
- Consideration of Alzheimer's disease mimics
- Safety (e.g., frailty, risk of falls, nutrition)
- Social engagement
- Access to caregivers
- Concerns related to the new diagnosis
- Legal aspects (e.g., will, power of attorney, driving)

Family & Caregivers

- Limited resources for daily management
- Limited support from specialists
- Lack of formal avenues for caregiver education
- Caregiver burnout
- Lack of male representation
- Emergency planning
- Costs and compensation
- Diagnosis stigma

What Care Teams Can Do

Caregiver Support & Resource Connection

Connect caregivers to resources
Provide information on local, regional, and national support services.

Be Aware of Community Resources

Stay up to date on programs, respite services, and cultural/community-based supports.

Collaborate with Team Members

Work across disciplines to ensure caregivers and individuals with dementia get comprehensive support.

Cultural Competence & Inclusion

Deliver care that respects cultural values, traditions, and language needs.

Mental Health Support

Address caregiver stress, burnout, and emotional well-being. Encourage use of counseling, peer support groups, and professional help when needed

Collaborative Dementia Care

Key Personnel

- The patient
- Family and caregivers
- Home health aide
- Certified nursing assistants
- Physical, occupational, and speech therapists
- Health care providers
- Social worker
- Dementia navigator
- Community and spiritual leaders

Patients with Dementia can be

- At home (on their own or with family)
- In group homes
- In assisted living facility
- In a hospital
- In an assisted living memory unit
- In a long-term care facility (LTC)

Levels of Care

	Levels of Care			
Care Facility	Skilled Care	Long Term Care	Acute/Subacute	Hospice
Hospital	x	x	x	
Skilled LTC Facility	x	x	x	
Assisted Living	x	x	x	x
Senior Group Housing	x			x
Patient's Home	x	x	x	x

“Transitions in care for persons living with dementia include movement across settings and between providers increasing the risk for fragmented care and experiencing poor outcomes such as hospital-acquired complications and excess health care expenditures.”

Considerations During Transitions



Disruptions in Care

Disruptions in routines can lead to increased anxiety or agitation.

Medication Errors

Changes in care settings increase the risk of medication errors.

Loss of Continuity of Care

Patients may have to establish relationships with new healthcare providers.

Increased Risk of Hospitalization

Care transitions can increase hospitalization risks.

Caregiver Stress

Transitions can be stressful for caregivers needing extra support.

Relocation Stress

Relocating to new settings can lead to anxiety or agitation.

Changes in Behavior

Care transitions may cause agitation or withdrawal.

Purpose of Dementia Care Plan

- Maintain or improve quality of life and daily function
- Enhance cognition, mood, and behavior
- Foster a safe environment and promote appropriate social engagement
- Respect cultural preferences and individual wishes
- Limit care transitions to prevent excess disabilities and align care plans with patient values
- Minimize risks from medical treatments, including polypharmacy

Details of Dementia Care Plan

Assessment & Goals:

Look at the person's mental, physical, and emotional needs, including their health history, and set clear goals for staying independent and happy.

Interventions & Monitoring:

Use specific actions like medicines and activities, and check regularly to see how things are going and make changes if needed.

Caregiver Support & Community Resources:

Help caregivers with education and short breaks, and connect families to local services for meals, rides, and social activities.

Advance Care Planning & Contingency Planning:

Talk about future care wishes, including end-of-life decisions, and plan for unexpected health changes with backup option.

Legal & Ethical Care



Legal Considerations

- Capacity
- Competence
- Guardianship
- Conservatorship
- Advance Care Planning
- Confidentiality and Privacy
- Neglect and Abuse

Competence refers to an individual's mental capacity to comprehend and make informed decisions regarding their affairs. It is assessed in legal situations like wills, contracts, or trials, and is determined by a court concerning one's ability to manage personal matters.

Capacity in healthcare denotes a person's ability to make informed decisions regarding their treatment, requiring understanding, communication of preferences, and consistent choices, evaluated by professionals per decision.

Health Care Power of Attorney (HCPOA)

Authorizes someone to make medical decisions on your behalf.

Activated when you are unable to make your own health care choices.

Specific to health care decisions, including treatment preferences and end-of-life care.

Guardianship – Court-appointed authority to make personal and healthcare decisions for someone unable to do so.

Conservatorship – Court-appointed authority to manage someone's finances and property.

Supported Decision-Making – The individual keeps decision-making rights but receives help from trusted supporters.

Power of Attorney (POA)

Grants authority to manage financial and legal affairs.

Can be effective immediately or upon incapacitation, depending on the document.

Covers a broad range of decisions, including property management, banking, and contracts.

Resources – Crisp DC
NIH ACP

Ethical, equitable, and culturally sensitive practices protect the rights, dignity, and safety of individuals with dementia across all communities.

Legal & Ethical Care



Physical

Physical abuse can range from slapping or shoving to severe beatings



Neglect

Intentionally failing to meet the physical, social, or emotional needs of the older person



Psychological

When caretakers give “the silent treatment” or intimidate the individual by threatening them.



Financial

Financial abuse can range from misuse of funds to embezzlement.

Observations for Safety

1. Observe interactions between seniors and their caregivers in the office setting
2. Routinely interview individuals living with dementia separately from their caregivers
3. Be attentive to body language and nonverbal cues
4. Recognize the importance of these assessments to ensure comprehensive safety evaluations.

Elder Abuse Prevention

Raise Awareness

Recognize signs of abuse and educate others.

Support Caregivers

Offer resources like respite care to reduce burnout.

Encourage Social Connections

Combat isolation by connecting with family and community.

Financial Safeguards

Help older adults protect assets and avoid scams.

Report Concerns

Help older adults protect assets and avoid scams.

Culturally appropriate dementia care means respecting each person’s background, beliefs, and practices.

Key strategies include:

- Personalized care plans
- Clear language & communication
- Familiar environments
- Safety modifications
- Staff training

Abuse and neglect refer to the actions or inactions of an individual's caregiver or parent inflicting physical, sexual, or emotional harm on the individual.

Building a High-Performing Care Team



A collaborative, high-performing care team is crucial to providing safe, dignified, and effective care to persons living with dementia. Here are key practices for strengthening your care team and ensuring quality care.

Why This Matters

People with dementia may struggle during emergencies and need extra help and clear guidance, as noises and commotion can cause fear or agitation.

Care Team Responsibilities

Follow rules and regulations, including:

- Americans with Disabilities Act
- Dementia Training for Direct Care Members Support Amendment Act (2020)
- Assisted Living Residence Regulation

Empower LTC residents and families to voice their needs and ensure quality care through ombudsman programs

Foster safety by observing individuals across settings and honoring their unique needs and preferences

During Emergencies

- Provide clear, calm guidance
- Reduce unnecessary noise and commotion
- Allow extra time for understanding and response
- Recognize signs of fear or agitation early

Care Team Reminder

Safety, dignity, and communication come first — especially across settings and during emergencies.

Care for the Caregivers



Actively Support & Communicate

- Provide coaching and growth opportunities.
- Demonstrate readiness and share essential resources.
- Clearly communicate goals and outcomes with staff.

Enhance Communication

- Identify needs early and foster trust through regular check-ins.
- Gather feedback through surveys to gain insights and drive improvements.
- Ensure patient-centered care.

Promote Well-Being Resources

- Provide resources to support staff's mental, physical, and emotional health.
- Foster resilience, engagement, and a positive work environment.

Monitor Burnout Signs

- Look for emotional exhaustion, reduced motivation, irritability, and withdrawal.
- Address burnout signs promptly to support staff well-being.

Remember

Caring for caregivers is crucial to maintaining compassionate and effective care for all.