



The Sojourner Project

...help for the journey

Understanding Dementia and Alzheimer's disease

Brain Damage Caused by Dementia

- **Judgment & Reasoning**
 - Impairment to a person's judgment, logic, problem solving and critical thinking skill. Early warning signs include these subtle changes such as a loss of navigation skills, an inability to manage money, getting lost often, an inability to retrace steps or to follow complex directions.
- **Memory**
 - Loss of memory is more than normal forgetting, it is a not knowing, a gap in time, conversations. Forgetting recent events, conversations and are more easily confused. Becoming suspicious and even paranoid, fabricating details to explain when things are moved or missing. Memory impairment will trigger anxiety, disorientation, and making them feel lost and afraid.
- **Communication**
 - Language impairment and the inability to name things. Manifests as the inability to engage or follow conversations. Being unable to find the correct words, using nonsense words and an inability to understand when others are speaking. Eventually unable to verbally communicate their needs.
 - Needs they are trying to communicate:**
 - **Physical:** Hungry, tired, or uncomfortable, too hot or too cold or in pain, vision or hearing issues, illness, infection, drug interactions or side effects
 - **Emotional:** Frustrated, angry, sad, depressed, grieving, anxious, overwhelmed or frightened.
 - **Social:** Lonely, bored, missing family, friends, social activities or hobbies
 - **Environment:** Hot, cold, stressful, noisy, crowded, cluttered or unfamiliar

Stages of the Caregiver Journey - From disease to dementia

Early / Mild - Increasing physical difficulty and impairment but no cognitive impairment

Caregiver Role - Overseer

- Essential Task
 - Make a plan
 - Gather information
 - Get the paperwork in order
 - Adapt the physical environment to the increased disability

Middle / Moderate - Increased physical disability and the onset of dementia symptoms

Caregiver Role - Middleman

- Essential task
 - Implement Plan B - add some professional care
 - Get organized (medications, community resources, home safety)

Late / Severe - Physical disability and increased or persistent dementia

Caregiver Role - Caretaker

- Essential Tasks
 - Care for the caregiver - consider respite care
 - Reevaluate and revise care plan - time to consider moving to a professional care facility?
 - End of life preparation and planning

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The goal is to provide general information so that you can seek out professional assistance from the appropriate subject matter expert
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Stages of the Caregiver Journey - From dementia to disease

Early / Mild - Physically functions independently but have problems with memory or concentration

Symptoms:

- Problems coming up with the right word or name
- Challenges performing tasks in social or work settings.
- Getting losing or misplacing a valuable object
- Increasing trouble with planning or organizing, managing money

Caregiver Role - Overseer

- Essential Tasks
 - Get an accurate diagnosis and an education
 - Gather information - important papers access to files
 - Get the legal and financial paperwork in order
 - Begin to put safeguards in place (finances, home safety)
 - Start making a plan, preparing for the middle stage

Middle / Moderate - The longest stage requiring an increasing level of care.

Symptoms:

- Confusing words, getting frustrated or angry.
- Confusion about where they are or what day it is, may get lost or wander
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- Suspiciousness, delusions or compulsive, repetitive behavior (hand-wringing or tissue shredding)

Caregiver Role - Middleman

- Essential Tasks
 - Evaluate the situation -stay at home or move to a professional care facility?
 - Implement Plan B - expand you care team, add professional help
 - Get organized - medications, finances, resources
 - Care for the caregiver

Late / Severe - Inability to respond to their environment, communicate and control movement.

Symptoms:

- Need round-the-clock assistance with daily activities and personal care
- Lose awareness of recent experiences as well as of their surroundings
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Become vulnerable to infections, especially pneumonia

Caregiver Role - Caretaker

- Essential Tasks
 - Care for the caregiver - consider respite care
 - Reevaluate the Plan - Is it time to move to a professional care facility?
 - End of life preparation and planning

*Refer to the Alzheimer's Association website www.alz.org
for more detailed information on the stages of Alzheimer's disease.*

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