

# Caregiving Challenges throughout the Stages of Dementia

## Caregiving challenges: early stage dementia

<b>What it looks like</b>	<ul style="list-style-type: none"> <li>• Symptoms are mild, but typically noticeable to friends and family around them.</li> <li>• Denial is very common – the person doesn't recognize the problem and blames others.</li> <li>• Depression and anxiety are common as they realize they are having problems.</li> </ul>
<b>Impact on independence</b>	<ul style="list-style-type: none"> <li>• Still able to live independently, but might need help with some things.</li> <li>• May be able to manage getting support, e.g. hiring household help, coordinating with family.</li> <li>• Important to have regular care with a doctor familiar with dementia, or a neurologist.</li> <li>• Driving is very risky even in early stage dementia.</li> </ul>
<b>Things to watch out for</b>	<ul style="list-style-type: none"> <li>• Forgetfulness and memory loss.</li> <li>• Losing items, can't to retrace steps to find item.</li> <li>• Trouble managing finances: forgetting bills, unable to balance checkbook.</li> <li>• Neglect of household chores, personal hygiene.</li> <li>• Trouble managing medications.</li> <li>• Loss of concentration</li> <li>• Confusion while driving.</li> <li>• Risk of exploitation, scams.</li> </ul>
<b>What kinds of help might be needed</b>	<ul style="list-style-type: none"> <li>• Reminders and monitoring: medication dispenser system, financial checkups, auto-pay bills.</li> <li>• Advance care planning: Durable Power of Attorney (DPOA), directives, financial concerns for future care needs.</li> <li>• Connect with help at home, transportation.</li> <li>• Get help before it is needed, to get comfortable with the provider and set a routine.</li> <li>• Home safety improvements: grab bars, stove controls, lighting.</li> <li>• Doctor can order a OT Home Safety Evaluation (covered by Medicare).</li> <li>• Safety/security: Personal emergency response system/button.</li> <li>• Smart911: register online so that in an emergency, dispatchers have info and family contacts.</li> <li>• Support groups and/or counseling</li> <li>• Early-stage memory loss programs for education and support; Alzheimer's/Dementia Café</li> </ul>
<b>For Caregivers</b>	<ul style="list-style-type: none"> <li>• Make decisions about the future together: legal, financial, and long-term care planning.</li> <li>• Help your loved one to research available treatments and clinical trials.</li> <li>• Get to know local resources and support services.</li> <li>• Being able to take advantage of all these benefits can reduce anxiety about the unknown and lead to better outcomes for everyone involved.</li> </ul>

## Caregiving challenges: middle stage dementia

<p><b>What it looks like</b></p> <p><i>Can be the longest stage – maybe many years</i></p>	<ul style="list-style-type: none"> <li>• Trouble tracking time, place, situation.</li> <li>• Difficulty learning, poor short-term memory</li> <li>• May have difficulty recognizing family: “Generational confusion” – son vs. dad?</li> <li>• Problems communicating: jumbling words, sentences unclear, not understanding others.</li> <li>• Feeling moody or withdrawn in social situations or when experiencing a cognitive challenge.</li> <li>• Getting frustrated, angry, depressed, anxious, or irritable.</li> <li>• Trouble with bladder control, dressing.</li> <li>• Restless at night or changing sleep patterns.</li> <li>• Acting in unexpected ways, like refusing to bathe, physical and/or verbal outbursts.</li> <li>• Repetitive behaviors or speech.</li> <li>• Wandering.</li> </ul>
<p><b>Impact on independence</b></p>	<ul style="list-style-type: none"> <li>• Unable to manage living alone without help, but also can’t coordinate the help by themselves..</li> <li>• Can still make most decisions, but may be unable to take action.</li> </ul>
<p><b>Things to watch out for</b></p>	<ul style="list-style-type: none"> <li>• Weight loss: forgetting to eat, or how to cook.</li> <li>• Getting lost in familiar areas.</li> <li>• Anxiety and agitation</li> <li>• Financial problems, missing money.</li> <li>• Risk of exploitation, scams.</li> <li>• Skin problems due to poor hygiene.</li> <li>• Health problems due to inability to manage meds or follow directions.</li> <li>• Dramatic behavior or mood changes:</li> <li>• Check with the doctor to rule out other physical problems or medication side effects.</li> </ul>
<p><b>What kinds of help might be needed</b></p>	<ul style="list-style-type: none"> <li>• More management and support with all aspects of daily functioning.</li> <li>• Activities to reduce anxiety and agitation.</li> <li>• Alzheimer’s or Dementia Café programs.</li> <li>• Adult Day Health programs.</li> <li>• Palliative care can provide in-home support with various symptoms and is covered by Medicare.</li> <li>• May need daily in-home care, even when partner or family are providing a lot of help:</li> <li>• You need back-up, and you need breaks.</li> <li>• May need residential care: adult family home or assisted living with dementia care available.</li> <li>• You don’t want to have to move again later, so find a place that can provide care for people with later to end stage dementia.</li> </ul>
<p><b>For Caregivers</b></p>	<ul style="list-style-type: none"> <li>• Try for flexibility and patience.</li> <li>• Speak slowly, distinctly, and gently.</li> <li>• As the person’s abilities change, you will have to take on greater responsibility.</li> <li>• Daily routines will need to be adapted, and structure will become more important.</li> </ul>

## Caregiving challenges: later stage dementia

<b>What it looks like</b>	<ul style="list-style-type: none"> <li>• Extreme memory loss.</li> <li>• Not able to track time or situation.</li> <li>• Extremely limited social abilities, even with help.</li> <li>• Requiring help with all activities.</li> <li>• Wandering and becoming lost if unsupervised.</li> <li>• May not recognize family.</li> <li>• May sleep a great deal of the time.</li> </ul>
<b>Impact on independence</b>	<ul style="list-style-type: none"> <li>• Unable to live independently, need 24/7 care.</li> <li>• Eventually unable to speak, walk, eat.</li> <li>• Burden on caregivers is very high – need outside help if person is living at home or with family.</li> <li>• May need residential placement or hospice.</li> </ul>
<b>Things to watch out for</b>	<ul style="list-style-type: none"> <li>• Risk of infections, especially pneumonia.</li> <li>• Risk of skin breakdown: keep skin dry and clean.</li> <li>• Risk of constipation: monitor bowel movements.</li> </ul>
<b>What kinds of help might be needed</b>	<ul style="list-style-type: none"> <li>• Residential care may be necessary.</li> <li>• Palliative care – can be provided at home, in a residential community, or in a care facility.</li> <li>• Hospice care if they are expected to have six months left to live – covered by Medicare.</li> </ul>
<b>For Caregivers:</b>	<ul style="list-style-type: none"> <li>• Focus on preserving quality of life and dignity.</li> <li>• Connect through the senses:</li> <li>• Connect through the senses:</li> <li>• Play their favorite music</li> <li>• Read books that have meaning for them.</li> <li>• Look at old photos together</li> <li>• Prepare their favorite food</li> <li>• Rub skin with a favorite scented lotion</li> <li>• Brush their hair</li> <li>• Sit outside together on a nice day</li> </ul>