

ALZHEIMER'S SYMPTOM ROADMAP

Understand Where You Are in the Illness

WHAT IS THIS FOR

Understanding common signs and stages of how Alzheimer's evolves is key to getting the right types of support, feeling prepared, and having more choice and control.

This tool allows for open conversations between patient, family / caregivers, and health care teams to talk about **where things are at now** and what to expect later. Revisit this roadmap over time.

HOW TO USE THIS

The general pattern of Alzheimer's is typically a slow, gradual and long decline.

Use the space below to **discuss with your team and take notes** on:

1. Your current stage
2. What's unique to your experience
3. What can be done to maximize quality of life at any stage

BEGINNING STAGE SIGNS

- Repetition of questions/stories
- Difficulty processing complex information
- Confuse times/places
- Forget recent events & conversations
- Gets lost easily
- Mild personality changes
- Social withdrawal

MIDDLE STAGE SIGNS

- Forget information, meals, medication
- Wandering
- For some, resistance to personal care
- For some, agitation, anxiety, delusions, aggression, hallucinations

LATE STAGE SIGNS

- Can't recognize familiar people
- Loss of expression & emotion
- Changes in mobility
- Loss of bladder/bowel control
- Difficulty communicating

END STAGE SIGNS

- Loss of interest in food
- Difficulty swallowing
- Weight loss
- Fatigue, long periods of sleep, unresponsive

NOTES ON MANAGING EACH STAGE

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Financial contribution:

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ALZHEIMER'S PLANNING ROADMAP

Prepare for Key Life Changes

How to Use: Review this table to understand what key life changes to expect and things to do in each stage.

	Key Life Changes	Things to Think About
BEGINNING STAGE	Decline in ability to live independently	Assess needs and get support to maintain daily routines: • Cleaning, groceries, meal preparation, home affairs • Medication management • Managing personal finances • Exercise, social interaction and companionship • Transportation
	Decline in memory and cognitive function	Designate person(s) for future healthcare oversight before patient is unable to express consent and needs: • Substitute Decision Maker / Power of Attorney for health care • Point person(s) for communication and coordination of care • Companion for appointments and tracking of medical information Settle personal affairs proactively while patient can still express preferences: • Critical account access, passwords, contacts (e.g. banks, life insurance) • Will & Estate Planning • Advance Care Plan discussions • End of Life Wishes (e.g. legacy leaving & funeral planning)
MIDDLE STAGE	Increase in care needs	Assess ability to provide care at home and consider professional services to: • Assist feeding, bathing, hygiene care, dressing, toileting • Prevent wandering or getting lost • Prevent falls (walker, cane, wheelchair)
	Require full-time supervision	Assess home environment to ensure safety: • Modify home to prevent risk of injury and/or wandering • Explore alternative living arrangements (e.g. enhanced home support) • Consider need for and transition to care facility Prevent Loneliness & Isolation: • Explore ways for social interaction/companionship Identify and support family caregivers: • Find resources and strategies to prevent burnout
LATE & END STAGE	Major changes in function and significant overall decline	Discuss and make decisions with a focus on quality-of-life such as: • Recall advance care planning discussions to inform decision-making • Discuss Do-Not-Resuscitate / Allow-Natural-Death designation • Discuss pros and cons of antibiotics for infections • Seek resources for grief support Prepare for end-of-life care • Discuss stopping unnecessary medications • Understand the burdens of artificial nutrition and hydration • Prepare for bedridden care • Understand what natural dying looks like with Alzheimer's • Explore resources for bereavement support after death

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