

Understand Where You Are in the Illness

WHAT IS THIS FOR

Understanding common signs and stages of how your illness 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.

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HOW TO USE THIS

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

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

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BEGINNING STAGE SIGNS

MIDDLE STAGE SIGNS

LATE STAGE SIGNS

END STAGE SIGNS

NOTES ON MANAGING EACH STAGE

ILLNESS 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	Explore ways to slow progression and lessen symptoms.	• Taking medications as prescribed • Integrating good nutrition, regular physical exercise, and social engagement • Making time for medical visits and rehab programs • Getting updated on preventative care (e.g., flu shots) • Learning self-management strategies to manage symptom flare-ups
	Designate person(s) for future health care oversight in case you are unable to express consent and needs	• Substitute decision-maker / lasting 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 you can express preferences	• Critical account access, passwords, contacts (e.g., banks, life insurance) • Will and estate planning • Advance care planning discussions • End of life wishes (e.g., legacy leaving and funeral planning) • Other: _____
MIDDLE STAGE	Assess needs and get support to maintain your daily routines.	• Cleaning, groceries, meal preparation, home affairs • Medication management • Managing personal finances • Exercise, social interaction, companionship, and emotional support • Transportation
	Assess ability to provide care at home and consider professional services	• Assistance with feeding, bathing, hygiene care, dressing, toileting • Mobility aids and preventing falls (e.g., walker, cane, wheelchair)
	Assess home environment to ensure safety and to maximize energy and independence	• Making home modifications to prevent injury or enable mobility (e.g., walker, wheelchair, stair lift) • Enhanced home care supports (e.g., public home care, private home care, community supports) • Alternative living arrangements (e.g., one floor living, retirement home, institutional care)
	Prevent loneliness and isolation	• Continuing social interaction/companionship
	Identify and support family caregivers	• Find resources, supports, and strategies to prevent burnout • Other: _____
LATE & END STAGE	Discuss and make decisions about end of life, with a focus on quality-of-life	• Returning to advance care planning discussions to inform decision-making • Reviewing Do-Not-Resuscitate / Allow Natural Death designation • Stopping unnecessary medications, including antibiotics • Discussing the pros and cons of artificial nutrition and hydration • Preparing for bedridden care • Understanding what natural dying looks like for your illness • Seeking resources for grief and bereavement support • Other: _____