### **ILLNESS ROADMAP**

### 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.

#### **HOW TO USE THIS**

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	NOTES ON MANAGING EACH STAGE
MIDDLE STAGE SIGNS	
LATE STAGE SIGNS	
LATE STAGE SIGNS	
END STAGE SIGNS	
END STACE SIGNS	

## **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
	Explore ways to slow progression and lessen	<ul> <li>Taking medications as prescribed</li> <li>Integrating good nutrition, regular physical exercise, and social engagement</li> </ul>
	symptoms.	Making time for medical visits and rehab programs
병		· Getting updated on preventative care (e.g., flu shots)
STAGE		· Learning self-management strategies to manage symptom flare-ups
		· Substitute decision-maker / lasting power of attorney for health care
	health care oversight in case	Point person(s) for communication and coordination of care
	you are unable to express consent and needs	Companion for appointments and tracking of medical information
	Settle personal affairs	· Critical account access, passwords, contacts (e.g., banks, life insurance)
	proactively, while you can	· Will and estate planning
	express preferences	· Advance care plan discussions
		• End of life wishes (e.g., legacy leaving and funeral planning)
		• Other:
	Assess needs and get support	· Cleaning, groceries, meal preparation, home affairs
	to maintain your daily	· Medication management
	routines.	Managing personal finances
STAGE		• Exercise, social interaction, and companionship, emotional support
ST/		Transportation
	Assess ability to provide care	· Assistance with feeding, bathing, hygiene care, dressing, toileting
	at home and consider professional services	Mobility aids and preventing falls (e.g., walker, cane, wheelchair)
	Assess home environment to	Making home modifications to prevent injury or enable mobility (e.g., walker,
	ensure safety and to	wheelchair, stair lift)
	maximize energy and	• Enhanced home care supports (e.g., public home care, private home care,
	independence	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:
	Discuss and make	• Returning to advance care planning discussions to inform decision-making
	decisions about end of life, with a focus on	• Do-Not-Resuscitate / Allow Natural Death designation
ш	quality-of-life	<ul><li>Stopping unnecessary medications, including antibiotics</li><li>The burdens of artificial nutrition and hydration</li></ul>
STAGE		Preparing for bedridden care
ST		Understanding what natural dying looks like for your illness
		• Seeking resources for grief and bereavement support
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		• Other: