COMFORT-FOCUSED CARE

WHAT TO EXPECT WHEN HOSPICE BEGINS

A practical first-week guide to comfort-focused care, the hospice team, coverage, equipment, medications, and family support

"Hospice is support for living as comfortably and fully as possible."

A PRACTICAL GUIDE FOR

Patients | Families | Caregivers | Senior-care teams

SECTION 1

What hospice means

A CLEARER WAY FORWARD

Hospice focuses on comfort, symptom relief, dignity, and quality of life for a person with a terminal illness. It also supports family and caregivers.

Hospice and palliative care

Palliative care can be provided at any stage of serious illness and may occur alongside treatment intended to cure or control disease. Hospice is a form of palliative care for the end of life when the plan shifts away from cure-focused treatment for the terminal illness.

Medicare eligibility

For the Medicare hospice benefit, the hospice doctor and the person's regular doctor, if there is one, certify a life expectancy of six months or less if the illness follows its usual course. The person chooses comfort care for the terminal illness and signs a hospice election statement.

Six months is not a deadline

A person may continue receiving hospice beyond six months when the hospice physician recertifies that eligibility continues. Starting hospice does not mean care stops. The goals and type of care change.

SECTION 2

What happens first

A CLEARER WAY FORWARD

The first days usually include consent and coverage discussions, a clinical assessment, medication review, equipment planning, and an individualized plan of care.

Election and coverage

- Review the hospice election statement before signing
- Identify the attending physician and start date
- Ask which illness and related conditions the hospice will cover
- Request the addendum listing items, services, or drugs considered unrelated and not covered by hospice

Assessment and plan

- Discuss symptoms, comfort goals, routines, culture, faith, caregiver ability, and safety
- Review every medication and supplement
- Plan visits, equipment, supplies, emergency instructions, and who to call after hours
- Update the plan as needs change

Keep the phone number visible

A hospice team member visits regularly, and hospice support is generally available by phone 24 hours a day, seven days a week. This does not mean a staff member remains physically at the bedside around the clock.

SECTION 3

The hospice team and services

A CLEARER WAY FORWARD

Hospice uses an interdisciplinary team. The exact visit pattern depends on the person's plan of care and changing needs.

People on the team

- Hospice physician or medical director
- Nurses and hospice aides
- Social worker and counselor or chaplain
- Volunteers, therapists, and other professionals when included in the plan
- Bereavement support for family

Possible covered services

- Nursing, physician services, and symptom management
- Medications related to pain and symptom control
- Medical equipment and supplies related to the terminal illness
- Aide and homemaker services, counseling, and therapies when ordered in the plan

Ask who supplies what

Confirm which pharmacy, equipment company, and on-call process the hospice uses. Do not buy equipment or related medications out of pocket without first asking the hospice whether it should be arranged through the benefit.

SECTION 4

What families should expect

A CLEARER WAY FORWARD

Hospice brings skilled support, teaching, and coordination. In most home settings, family or other caregivers still provide much of the day-to-day presence between scheduled visits.

The caregiver role

- Give medications only as instructed and record doses when asked
- Report symptoms and changes rather than waiting for the next visit
- Use safe techniques for transfers, skin care, mouth care, and equipment after teaching
- Tell the team honestly when the plan is no longer manageable

Call the hospice team for

- Pain, breathing changes, agitation, nausea, falls, bleeding, fever, or new symptoms
- Medication or equipment questions
- A caregiver who is exhausted, frightened, or unable to provide the planned care
- Questions about calling an ambulance or going to the hospital

Follow the individualized emergency plan

For symptoms related to the terminal illness, call hospice first when the plan directs you to do so. For immediate danger when hospice cannot be reached, follow the emergency instructions provided by the hospice and call 911 when appropriate.

SECTION 5

The four Medicare hospice levels of care

A CLEARER WAY FORWARD

All Medicare-certified hospices must be able to arrange four levels of care. The hospice determines the level based on the person's needs and Medicare rules.

Routine home care

The usual level when the person is receiving hospice where they live and is not in a crisis that requires continuous home care. Home may be a private residence, assisted living, or nursing facility.

Continuous home care

Short-term, primarily nursing care provided during a brief crisis to keep the person in the home setting. It is not ongoing round-the-clock custodial care.

Inpatient respite care

A short stay in an approved inpatient facility, generally up to five consecutive days, to give the caregiver relief.

General inpatient care

Short-term inpatient care for pain or other symptoms that cannot be managed in the current setting. It is not intended as permanent placement.

SECTION 6

Coverage, costs, and choices

A CLEARER WAY FORWARD

Coverage differs by insurer. These points describe the Medicare hospice benefit and should be confirmed with the hospice and the person's plan.

Medicare generally covers

Hospice services, medications, supplies, and equipment included in the plan of care for the terminal illness and related conditions when arranged by the chosen Medicare-approved hospice.

Possible patient costs

Medicare may require a copayment of up to $5 for each outpatient drug for pain and symptom management and 5% of the Medicare-approved amount for inpatient respite care. Normal costs may apply to care for unrelated conditions.

Usually not included

Room and board in a home, assisted living, nursing home, or hospice residence is generally not covered by the Medicare hospice benefit. Cure-focused treatment for the terminal illness and care not arranged by the hospice are also generally outside the benefit.

The person keeps choices

A person may stop hospice at any time and may return later if eligible. Medicare also permits changing the hospice provider once during each benefit period. Ask the hospice to explain how either choice affects medications, equipment, and coverage.

SECTION 7

First-week checklist and sources

A CLEARER WAY FORWARD

Write the answers where every caregiver can find them.

Know the plan

- Primary nurse and 24/7 phone number
- Visit schedule and caregiver responsibilities
- Medication list and symptom instructions
- Equipment delivery and supply process
- When to call hospice and when to call 911

Know the coverage

- Terminal diagnosis and related conditions
- Covered drugs, supplies, and equipment
- Items listed as unrelated and not covered
- Respite and inpatient arrangements
- Room-and-board responsibility

Medicare and CMS

Medicare Hospice Care Coverage
Medicare Hospice Benefits
CMS Hospice Levels of Care

National Institute on Aging

What Are Palliative Care and Hospice Care?
Hospice Frequently Asked Questions

Important

Educational information only. This guide does not replace medical advice, the hospice plan of care, insurance information, or emergency instructions. Coverage and services can vary. Ask the hospice team for guidance specific to the patient.

A note from Leah

Senior care can feel complicated, especially when decisions have to be made quickly. I created Navigating Senior Care with Leah to give families and caregivers clear information, practical questions, and a steadier next step.

Use this guide as a starting point, keep the person's voice at the center, and reach out when you need help organizing the options.

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