

# Hospice Care Guide

## Introduction: A Philosophy of Compassionate Care

Hospice is a specialized approach to care for individuals facing a life-limiting illness. It is not a physical location, but rather a philosophy centered on providing comfort, managing pain, and offering emotional and spiritual support to patients and their families. The core belief of hospice is that every person has the right to live their final days with dignity, peace, and the highest possible quality of life, surrounded by those they love.<sup>1</sup>

When curative treatments are no longer effective or desired, the focus of care shifts from curing the illness to caring for the person.<sup>1</sup> This is not about giving up; it is about redefining hope and focusing on living as fully and comfortably as possible. Hospice care affirms life but does not seek to hasten or postpone death. Instead, it provides comprehensive, holistic support to the patient and their family, ensuring their wishes are honored and their needs are met.<sup>2</sup>

This guide is designed to provide clear, practical information about hospice services to help you and your family navigate this journey with confidence and support.

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## Understanding Hospice Care

### What is Hospice?

Hospice is a compassionate, patient-centered approach to medical care and support for people who are in the last phases of a life-limiting illness.<sup>2</sup> The goal is to enable patients to live their final days with respect and dignity, free from pain, and in an environment that is comfortable and familiar. It is a holistic philosophy that treats the whole person—addressing their medical, emotional, psychosocial, and spiritual

needs.<sup>2</sup>

## **Who is Eligible for Hospice?**

Generally, an individual is eligible for hospice care if they have a life-limiting illness and a physician has certified a life expectancy of six months or less, should the disease follow its natural course.<sup>1</sup> Hospice is for people who are no longer seeking curative treatment and instead want to focus on quality of life.

Common conditions that may qualify for hospice care include:

- Late-stage cancer
- Heart and circulatory system diseases (e.g., congestive heart failure)
- Advanced dementia or Alzheimer's disease
- Advanced respiratory diseases (e.g., COPD, respiratory failure)
- Advanced kidney failure
- Stroke and other neurological conditions
- A general decline in health in elderly patients

## **Who Makes the Decision to Start Hospice?**

The decision to begin hospice care is a personal one, typically made through a collaborative discussion between the patient, their family, and their physician or medical provider. The patient's wishes are always the priority. If a patient is unable to communicate their decisions, a designated healthcare proxy or family member can make choices on their behalf, guided by the patient's previously expressed wishes or advance directives.<sup>3</sup>

## **Where is Hospice Care Provided?**

Hospice is not a place, but a service that comes to the patient. Care is provided wherever the patient calls home, allowing them to remain in a familiar and comforting

environment.<sup>2</sup> This can include:

- A private residence
  - A skilled nursing facility
  - An assisted living or residential care facility
  - A hospital or dedicated inpatient hospice unit
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## The Hospice Care Team: Your Circle of Support

Hospice care is delivered by a dedicated interdisciplinary team that works together to address the patient's physical, emotional, and spiritual needs. This team acts as a circle of support for both the patient and their family, providing comprehensive, coordinated care.<sup>1</sup>

Your care team will typically include:

- **Physician / Nurse Practitioner:** A doctor or nurse practitioner oversees the patient's plan of care, manages complex medical issues, and collaborates with the patient's primary physician.
- **Skilled Nurse (RN/LVN):** A registered or licensed vocational nurse makes regular visits to manage pain and other symptoms, provide treatments, and educate the family on how to care for their loved one. Nurses are available 24/7 for on-call support and to handle urgent needs.
- **Hospice Aide:** Aides are trained to assist with personal care needs, such as bathing, dressing, changing linens, and light meal preparation. Their support helps reduce the physical demands on family caregivers and ensures the patient's comfort and hygiene.
- **Clinical Social Worker:** A social worker provides emotional support, counseling, and assistance with navigating practical and financial challenges. They can connect families with community resources, help with advance care planning, and offer guidance on coping with the emotional stress of caregiving.
- **Spiritual Counselor or Chaplain:** This team member offers spiritual support that is respectful of the patient's and family's personal beliefs and values. They can help address questions of meaning, hope, and life closure, providing comfort to people of all faiths and backgrounds.
- **Volunteers:** Trained volunteers can provide companionship for the patient, read to them, or simply offer a comforting presence. They can also offer short breaks for caregivers, known as respite.<sup>1</sup>

- **Bereavement Counselor:** This professional provides grief support and counseling to the family for up to a year after their loved one has passed, helping them navigate the grieving process.<sup>2</sup>
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## Comprehensive Hospice Services

Hospice provides a wide range of services designed to manage symptoms and enhance comfort. The patient's customized care plan is developed by the hospice team in collaboration with the patient and family, ensuring it aligns with their specific needs and goals.<sup>4</sup>

### Key services include:

- **Pain and Symptom Management:** The primary goal of hospice is to manage pain and other distressing symptoms like shortness of breath, fatigue, nausea, and anxiety, allowing the patient to be as comfortable and alert as possible.<sup>2</sup>
  - **Medical Equipment and Supplies:** Hospice arranges for and typically covers the cost of necessary medical equipment (such as a hospital bed, wheelchair, or oxygen) and supplies (like bandages and catheters) related to the terminal illness.
  - **Medications:** Medications for pain relief and symptom management related to the hospice diagnosis are typically covered by the hospice benefit.
  - **Personal Care Assistance:** Hospice aides provide hands-on assistance with daily activities like bathing, dressing, and personal hygiene, helping to maintain the patient's dignity and comfort.<sup>5</sup>
  - **Caregiver Education and Support:** The hospice team teaches family members how to provide care, administer medications, and recognize changes in their loved one's condition. This support empowers caregivers and helps alleviate their stress.<sup>6</sup>
  - **Emotional and Spiritual Counseling:** Support is available for both the patient and family to help them cope with the emotional and spiritual challenges of this journey.<sup>2</sup>
  - **Additional Therapies and Dietary Counseling:** Some hospice programs may offer other services, such as physical or occupational therapy to maximize comfort and mobility, or dietary counseling to address changing nutritional needs.
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## The Four Levels of Hospice Care

Hospice care is flexible and adapts to the patient's changing condition. As defined by Medicare, there are four distinct levels of care. The hospice team will determine the appropriate level based on ongoing assessments of the patient's and family's needs.<sup>1</sup>

1. **Routine Home Care:** This is the most common level of hospice care. The patient receives care in the place they call home. The interdisciplinary team makes regular, scheduled visits to manage symptoms and provide support to the patient and family.<sup>1</sup>
2. **Continuous Home Care:** During a period of medical crisis, when a patient's symptoms become acute and require more intensive management, this level of care may be initiated. It involves a nurse or aide remaining in the home for an extended period (8 to 24 hours) to control symptoms and avoid hospitalization.<sup>1</sup>
3. **General Inpatient Care:** If a patient's symptoms become too severe to be managed at home (such as uncontrolled pain), they may be transferred to a hospital, skilled nursing facility, or inpatient hospice unit for a short period. The goal is to control the acute symptoms so the patient can return to routine care at home as soon as possible.<sup>1</sup>
4. **Inpatient Respite Care:** To provide a much-needed break for family caregivers, this level of care allows the patient to be temporarily placed in a Medicare-approved facility (like a nursing home or hospital) for up to five consecutive days. This helps prevent caregiver burnout and ensures they can continue to provide care effectively.<sup>1</sup>

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## The Family Caregiver: Your Vital Role & Its Challenges

The family caregiver is the heart of hospice care at home. You provide the constant, loving presence and day-to-day support that allows your loved one to remain in a familiar environment. We recognize that this role, while deeply rewarding, comes with profound challenges.<sup>7</sup>

### The Many Hats of a Caregiver

As a caregiver, you often take on multiple roles, many of which may be new to you. This work is often equivalent to a full-time job.<sup>8</sup> Your responsibilities may include <sup>6</sup>:

- **Practical Tasks:** Preparing meals, managing household chores, shopping.
- **Personal Care:** Assisting with bathing, dressing, and toileting.
- **Clinical Tasks:** Managing complex medication schedules, monitoring symptoms, and operating medical equipment.
- **Emotional Support:** Providing companionship, listening to fears, and offering comfort.
- **Coordination:** Scheduling appointments and communicating with the hospice team.

## Common Emotional Challenges

It is normal to experience a wide and often conflicting range of emotions.

Acknowledging these feelings is a sign of strength, not weakness.<sup>10</sup>

- **Sadness and Grief:** A deep sadness is natural as you witness your loved one's decline. This grief often begins long before the actual loss (see Anticipatory Grief, Page 8).<sup>6</sup>
- **Guilt:** You may feel you aren't doing enough, or feel guilty for needing a break or feeling impatient. You might even feel guilty for a sense of relief when your loved one's suffering ends. These feelings are common.<sup>10</sup>
- **Anger and Resentment:** It is normal to feel angry at the illness, the situation, or the loss of freedom that caregiving entails. These feelings do not diminish your love; they are a reaction to intense stress.<sup>6</sup>
- **Fear and Anxiety:** Fear of the future, of being alone, or of not knowing what to do can be overwhelming. The constant state of alertness can lead to significant anxiety.<sup>10</sup>
- **Isolation:** The demands of caregiving can leave you feeling lonely and cut off from friends, hobbies, and your previous life.<sup>6</sup>

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## Caring for the Caregiver: A Guide to Self-Care

To provide the best care for your loved one, you must first take care of yourself. This is not selfish; it is essential. Just as you are instructed on an airplane to put on your own oxygen mask first, you must attend to your own needs to avoid burnout and continue your vital role.<sup>7</sup>

## Practical Self-Care Strategies

### Physical Health<sup>12</sup>

- **Eat a Healthy Diet:** Focus on nutrient-dense foods that provide sustained energy. Preparing simple meals or snacks in advance can help you avoid unhealthy, quick options.
- **Get Enough Sleep:** Aim for 7-9 hours of sleep. A relaxing bedtime routine can help you wind down. If your loved one requires nighttime care, try to nap when they do.
- **Exercise Regularly:** Even 15 minutes of walking, stretching, or yoga can reduce stress and boost your mood.
- **Schedule Checkups:** Don't neglect your own health appointments.

### Emotional & Mental Health<sup>10</sup>

- **Acknowledge Your Feelings:** Give yourself permission to feel angry, sad, or frustrated. Talk to a trusted friend, write in a journal, or simply allow yourself a moment to cry.
- **Practice Mindfulness:** Simple deep breathing exercises or meditation can calm your mind and reduce anxiety. Focus on the present moment rather than worrying about the future.
- **Set Boundaries:** It is okay to say "no." Be realistic about what you can do and communicate your limits to others. Protecting your energy is crucial.
- **Practice Self-Compassion:** Treat yourself with the same kindness you would offer a friend. Remind yourself that you are doing the best you can, and that is enough.

### Building a Support System<sup>13</sup>

- **Ask for and Accept Help:** People often want to help but don't know how. Create a specific list of tasks (e.g., "pick up groceries," "sit with my loved one for an hour

so I can take a walk"). When someone offers, say yes and give them a task from your list.

- **Use Respite Care:** Take advantage of the respite care offered by your hospice team. A short break can make a world of difference.
  - **Stay Connected:** Make time for a quick phone call with a friend or join a caregiver support group. Connecting with others who understand can combat feelings of isolation.
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## Navigating Grief and Bereavement

Grief is a natural response to loss. The hospice journey involves grieving not only after a death but also in anticipation of it. The hospice team is there to support you through every stage.

### Anticipatory Grief: Grieving an Impending Loss

Anticipatory grief is the grief that begins *before* a death occurs.<sup>15</sup> It is a normal process of preparing for the emotional and practical changes that come with a life-limiting illness.<sup>16</sup>

**Common Feelings:** This experience can involve a complex mix of emotions, including sadness, anger, anxiety, and forgetfulness.<sup>18</sup> It is also common to feel a sense of relief that your loved one's suffering will end, which can be accompanied by feelings of guilt. All of these reactions are normal.<sup>16</sup>

**An Opportunity for Connection:** This period, while painful, offers a precious opportunity to address unfinished business, say "I love you" and "thank you," and find meaningful closure.<sup>18</sup>

### Coping with Anticipatory Grief <sup>15</sup>:

- **Talk About Your Feelings:** Share what you're going through with a friend, family member, or a member of the hospice team.
- **Practice Self-Care:** Get enough rest, eat well, and engage in gentle exercise.
- **Live in the Moment:** Focus on creating meaningful moments with your loved one



now, rather than dwelling on the future. Play their favorite music, look at old photos, or simply hold their hand.

- **Seek Support:** Join a support group or speak with a counselor to help process your emotions in a safe space.

## Grief After a Loss

Grief is a unique and personal journey; there is no right or wrong way to experience it.<sup>19</sup> It is not a linear process with set stages, but often feels like waves that come and go, lessening in intensity over time.<sup>20</sup> The bereavement support provided by your hospice team can be a vital resource during this time.

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## Page 9: Understanding Bereavement Support

Hospice care for the family does not end when a loved one dies. Bereavement support is an integral part of the hospice philosophy and is typically available for up to 13 months following a loss.<sup>2</sup> This support can take several forms.

### Grief Support Groups

A grief support group provides a safe, non-judgmental environment where you can connect with others who have experienced a similar loss.<sup>21</sup> Participating in a group can:

- **Reduce Isolation:** It helps you realize you are not alone in your feelings.<sup>21</sup>
- **Normalize Your Grief:** Hearing others share similar experiences can validate your emotions and reassure you that what you are feeling is a normal part of grief.<sup>22</sup>
- **Provide a Safe Space to Share:** You can tell your story and express your feelings freely to an audience that truly understands.<sup>21</sup>
- **Offer Hope and Coping Strategies:** You can learn from the experiences of others who are further along in their grief journey, which can provide hope and

practical advice.<sup>23</sup>

Groups may be general or focused on a specific type of loss, such as the loss of a spouse, parent, or child.<sup>21</sup>

## Bereavement Counseling

Bereavement counseling is one-on-one therapy with a professional trained in grief and loss.<sup>25</sup> This may be a good option if your grief feels overwhelming, prolonged, or complicated by other issues like trauma or depression.<sup>26</sup>

The goals of bereavement counseling are to <sup>27</sup>:

- **Help You Work Through the Pain:** A counselor provides a safe space to explore and process the most difficult emotions associated with your loss.
  - **Develop Healthy Coping Skills:** You can learn strategies to manage anxiety, guilt, and sadness, and build resilience.
  - **Adjust to Life After Loss:** Counseling can help you navigate the practical and emotional adjustments of life without your loved one, such as finding a new routine or redefining your sense of self.
  - **Maintain a Healthy Connection:** It helps you find ways to honor the memory of your loved one while still moving forward with your own life.
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## Practical Information & FAQ

### Preparing the Home Environment

Creating a safe and comforting space is essential for hospice care at home.

**For Safety** <sup>29</sup>:

- **Clear Pathways:** Remove clutter, loose rugs, and electrical cords from walkways to prevent falls.

- **Ensure Good Lighting:** Use nightlights in hallways, bedrooms, and bathrooms.
- **Arrange for a Hospital Bed:** These beds can be adjusted for comfort and safety.
- **Install Bathroom Safety Aids:** Consider a raised toilet seat, grab bars, and a non-skid shower seat.

#### For Comfort <sup>30</sup>:

- **Keep Items Within Reach:** Place frequently used items like the phone, water, tissues, and lip balm on a bedside table.
- **Create a Soothing Atmosphere:** Play your loved one's favorite music or have familiar shows on at a low volume.
- **Add Personal Touches:** Surround them with cherished photos, blankets, and meaningful objects.
- **Manage Visitors:** A visitor log can be helpful, and it's okay to set guidelines to ensure your loved one is not overwhelmed.

#### Frequently Asked Questions

- How is hospice paid for?  
Hospice care is covered by Medicare Part A, Medicaid (Medi-Cal in California), and most private insurance plans and HMOs. This benefit typically covers the services of the care team, medications related to the hospice diagnosis, and all necessary medical equipment and supplies.
- Can a patient stop receiving hospice care?  
Yes. A patient has the right to stop hospice care at any time and for any reason. If their condition improves or they decide to pursue curative treatment again, they can be discharged from hospice. They can re-enroll later if needed.
- What should we do in an emergency?  
The hospice team is on call 24 hours a day, 7 days a week. In case of a medical issue or emergency related to the terminal illness, you should call the hospice team first, not 911. The team is prepared to handle crises at home, often preventing unnecessary and stressful trips to the hospital.<sup>30</sup>
- What is the family's role in hospice care?  
The family is a central part of the care team. While the hospice team provides expert medical and emotional support, the day-to-day care is typically provided by family and friends. The hospice team's role is to coach and empower the family, giving them the skills and confidence they need to provide loving care at

home.