

# GUIDE TO HOSPICE AND PALLIATIVE CARE

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# ABOUT THIS GUIDE

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You should know three things about the *Guide* you're holding:

*First*, this is a new, expanded edition of a booklet that has served families and hospice organizations for many years, the *Patient and Family Guide to Hospice Care*.

*Second*, its goals are the same as those of its parent publication, the healthy aging guide, *Aging in Stride – Plan Ahead, Stay Connected, Keep Moving*. Those goals, simply put, are to inform and empower – to help you understand what's involved in hospice and palliative care and be in a position to take full advantage of the services and support they offer.

*Third*, like *Aging in Stride*, this *Guide* starts as a printed publication – something you can pick up when you have a question, jot notes in, and share with others. But it doesn't stop there. It also includes an extensive online supplement, with factsheets you can read or listen to, forms and checklists, and video demonstrations. For example, the online supplement contains:

## **Factsheets and Podcasts:**

*Spirituality and Pastoral Care Near the End of Life*

*Handwashing – the Key to Preventing Infection*

*Keeping a Care Log*

*Advance Directives – Your Right to Decide*

## **Forms and Checklists:**

*Care Log Form*

*Personal Information Organizer Form*

*Home Safety Checklist*

*Emergency Readiness Checklist*

*Form for Planning a Funeral or Memorial Service*

## **Video:**

*Handwashing Demonstration*

*Just in Case (Emergency Readiness for Older Adults)*

**For information on how to access the online supplement, please turn to page 49 (inside of back cover).**

# INFORMATION FOR GETTING STARTED

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## Understanding Hospice and Palliative Care

Centuries ago, the word “hospice” described a place where weary pilgrims could stop, rest, and refresh themselves before continuing on their journey. In 1967, a British physician, Dr. Cicely Saunders, began using the term to mean a new kind of care for patients who were dying. She founded St. Christopher’s Hospice in a London suburb.

Patients did not come to St. Christopher’s with the idea of finding a cure. They came for support in managing pain. Their goal was to maintain their quality of life as much as possible, even in the face of a terminal illness.

Since Dr. Saunders founded that first hospice, the hospice movement has spread around the world. Today, patients and their families turn to community-based hospice programs for supportive, quality care near the end of life. Hospice care is provided wherever a patient lives – their private residence, adult family home, assisted living facility, or nursing facility.

## What We Mean By Hospice Care and Palliative Care

Hospice care refers to end-of-life care in which the goal is comfort, symptom management, and quality of life, as opposed to finding a cure. It is coordinated and provided by an interdisciplinary care team – one that includes the patient’s physician, plus professionals in nursing, social work, pastoral care, and so on. Hospice care generally isn’t considered an option until a person is terminally ill, with a probable life expectancy of six months or less. Hospice care is intentional in serving not just the patient, but the patient’s family as well.

Palliative care, like hospice care, has as its goal the patient’s comfort, pain and symptom management, and quality of life. Unlike hospice, it is not related to prognosis, and a patient may be seeking curative or life-prolonging treatment and still benefit from palliative care. Palliative care may be appropriate at an earlier point in a prolonged illness; whereas hospice care is the care provided nearer the end of the patient’s life.

**Think of it this way:**

Palliative Care = Comfort Care

Hospice Care = Comfort Care at the End of Life

## What Services and Support Does Hospice Care Include?

Hospice programs come in all sizes – large, small, and in between. But they all share a commitment to a basic range of services that includes:

- Care that focuses not just on the patient’s medical condition, but also on the emotional, social, and spiritual needs of both the patient and the patient’s family
- Care that is directed, as much as possible, by the patient, working together with the family and the hospice staff
- Care provided by an interdisciplinary team that includes physician, nurse, social worker, therapists, chaplain, and trained volunteers
- Nursing support available for patients and primary caregivers on an on-call basis, 24 hours-a-day, seven days a week
- Care directed at effective pain and symptom management
- Care at home, wherever that may be for the patient
- Bereavement support.



## When Should Hospice Care Begin?

It is important for someone entering hospice care to have four things:

*First*, an understanding of their disease prognosis – that they have been diagnosed with a terminal illness;

*Second*, an understanding of the services hospice does and does not provide, and that the goal of hospice care is comfort and quality of life, rather than seeking a cure;

*Third*, the cooperation of the person’s personal physician who is willing to work with the hospice team to provide care; and

*Fourth*, someone to serve as primary caregiver, if hospice care is to be provided at home.

To get the most out of hospice care, it should not be put off until a point at which much of the opportunity to benefit from a focus on comfort care and quality of life has passed. However, even when death is imminent, there is still benefit in hospice support.

## The Role of Family and Caregiver

Not so long ago, it was commonplace for people to die at home, surrounded by loved ones and familiar possessions. Now, many people die in hospitals, surrounded by tubes and monitors and other high-tech equipment. One goal of hospice care is to give patients who are terminally ill an alternative to this institutional setting that is more home- and family-focused.

Families who have been supported by a hospice program in caring for a dying loved one most often consider it a positive, empowering experience. Hospice team members are trained to be sensitive to the needs of patient and family. If your mother wants to die at home and you're able to support her in this, but are worried about the skills and support you'll need, hospice will give both you and your mother the training and help you.

Hospice programs also offer options for respite care. Respite care is having someone else care for the patient for a few hours or a few days so that the caregiver can have a break. It provides much-needed time for rest and renewal.

If you are considering taking on the role of family caregiver for a loved one in hospice care, talk with hospice staff. Find out what the expectations would be and what kinds of help and support are available. If you can, talk with others who have made this commitment. What were the challenges they faced? What suggestions would they have? Would they do it again?

Becoming a caregiver is a big, personal commitment. It is not for everyone. But for those who choose it, it can be an incredible gift, as well as a personal experience unlike most any other. Take time to make a good decision for yourself and for your loved one.

If your loved one is not living with you or needs to move to an alternate living arrangement, remember that your love and care remain important. Let the hospice team know how they can best communicate with you and provide support.

## The Hospice Team

Hospice care is patient centered, which means that the patient makes care decisions and participates in care planning as much as possible. The patient's primary home caregiver is also an important part of the hospice team. So is the patient's physician, who continues to direct

medical aspects of the patient's care. In addition, a hospice team typically includes:

**Hospice nurse** – who will visit with you and your family to determine your individualized needs and work out what services you are interested in receiving. The nurse's primary goal is to provide symptom management and comfort. Responsibilities include:

- assessing comfort level and any symptoms which may need attention, such as pain, nausea, etc.
- working with the physician to manage symptoms
- performing procedures, such as placing and maintaining catheters, wound care, blood draws, etc.
- teaching the caregiver proper procedures for catheters, dressing changes, medications, etc.
- helping coordinate needed equipment, supplies, and services
- explaining the effects of illness and treatment, answering your questions, and offering support.

**Social worker** – who is often the first person you will meet from the hospice team. The social worker will explain the hospice philosophy, goals, and services. A hospice social worker works closely with the patient and family to create and maintain a supportive, in-home care setting that will work in terms of the patient's safety and comfort. The social worker is also available to help patient and family deal with personal, financial, emotional and care planning issues that come up. A hospice social worker may also help by:

- identifying available resources in the community
- determining eligibility for state and local assistance programs
- providing information on advance directives (living will, health care directive, health care proxy, etc.)
- listening to concerns, answering questions, and providing emotional support.

**Chaplain or spiritual counselor** – who is available to visit, listen, and provide support to both patient and family. Chaplains (or spiritual or pastoral care counselors, as they are often called too) take a non-denominational approach, and can also connect you or your loved one with someone representing a preferred religious faith or tradition. The hospice chaplain can:

- meet with you or your loved one to share hopes, fears, dreams and concerns