

Choosing Hospice

a consumer's guide



MINNESOTA NETWORK OF
HOSPICE & PALLIATIVE CARE

Minnesota Network of Hospice & Palliative Care (MNHPC) promotes quality of life in Minnesota communities through education and access to resources in advance care planning, palliative care and hospice care.

Our vision is that all individuals, families and providers will understand the value of and have access to these resources.

With provider members across Minnesota, the work of MNHPC touches communities throughout the entire state.

Table of Contents

Introduction.....	2
What makes hospice care special?	4
How will hospice care provide support for me and my family?	6
What if I live alone or don't have family nearby?	7
Who is eligible for hospice care?	8
How is my care paid for?	8
How do I find a hospice program?	10
Glossary	12

Originally written in 1997 with a grant from the Allina Foundation as part of its Project DECIDE Program.

© 1997 Minnesota Hospice Organization. All rights reserved.

© 2nd Edition, Revised 1998. All rights reserved.

© 3rd Edition, Revised 2000. All rights reserved.

© 4th Edition, Revised 2009. All rights reserved.

© 5th Edition, Revised 2010. All rights reserved.

Made accessible in 2016 by funding from a Live Well at Home Grant from Minnesota Department of Human Services.

INTRODUCTION

The thought that you or someone you love is dying can be overwhelming. It may seem that all is hopeless, that there is nothing more you can do.

There is much you can do. Hospice care is available to help you live comfortably with the love and support of family and friends.

Hospice care is a special way of caring for people living with life-limiting illnesses.

Hospice care:

- » **Emphasizes living your remaining days as fully as possible;**
- » **Provides relief from the physical, spiritual and emotional pain that often accompanies a life-limiting illness;**
- » **Supports the whole individual and family;**
- » **Provides grief support to the surviving family.**

“You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”

*Dame Cicely Saunders,
founder of the first hospice*

“Thank you for being honest with me, for educating me, holding my hand, leading me, caring about me, laughing with me, helping me in any way possible and sometimes not so possible ways.”

Judy, friend of a hospice patient

According to the wife of a hospice patient, “We knew that Mark’s prognosis wasn’t good, but we also knew that we had today and that we had help from hospice. With that, we decided to do what we could for today—and for each day remaining. Our hope was to make one good memory of each day. One day it was a special lunch for just the two of us, another day we organized pictures and recorded stories for the kids. Simple things like that. When you think about it, it’s not a bad way for anybody to live.”

The purpose of this booklet is to show how hospice care can help. The quotations are from people in Minnesota who have had firsthand experiences with hospice care. Their words illustrate how hospice care helped them make the most of their loved ones’ final days.

For those facing the difficult decisions that come with a life-limiting illness, help is available and hope continues to be very much alive with hospice care.



WHAT MAKES HOSPICE CARE SPECIAL?

“The thoughtful insights and honesty of the hospice philosophy allowed us to move through this difficult time with more understanding and dignity than I thought possible.”

Rachel, daughter of a hospice patient

“Our mother was able to die under almost ideal conditions. The privacy allowed us to deal openly with our feelings and to give comfort to our mother in a much more personal way.”

George, son of a hospice patient

Hospice care is rooted in the centuries-old tradition of preparing gifts for those embarking on a long journey. Today hospice care is a special kind of care that an individual and their family or loved ones choose. Hospice care helps people with life-limiting illnesses live their final months in comfort and with dignity.

Hospice care provides physical, emotional and spiritual support for you and your family in whatever setting you are most comfortable.

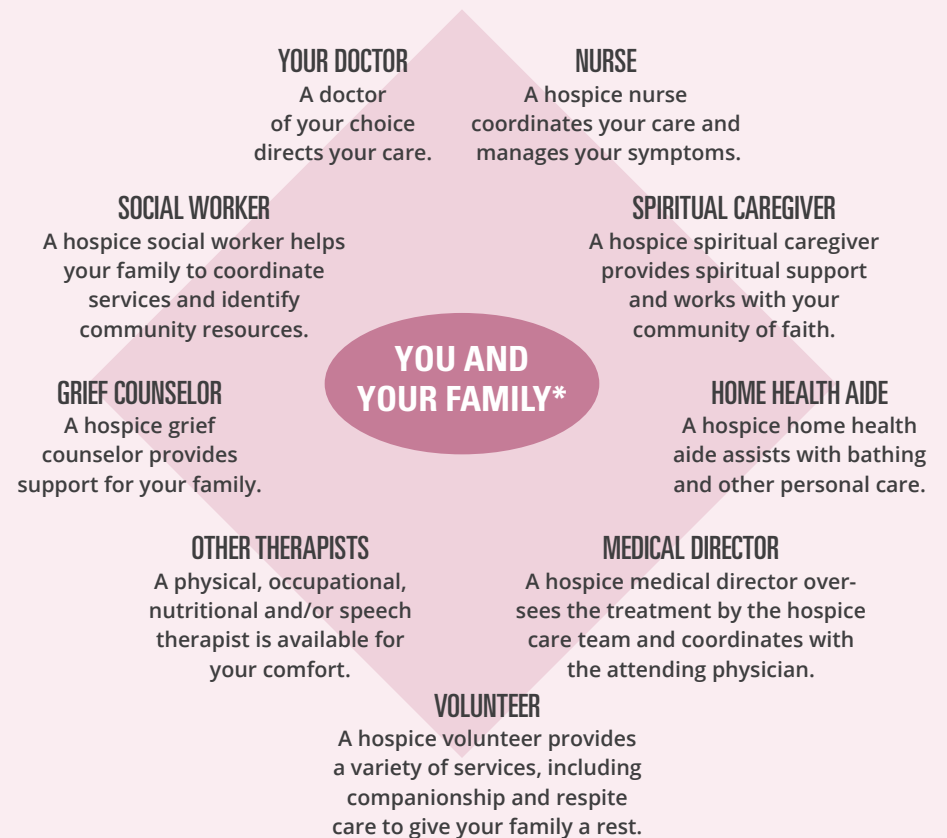
A CARE TEAM AT YOUR DOOR

Hospice brings a caring team right to your door—whether your home is a house or apartment, a nursing facility, assisted living setting or residential hospice.

Care is available from your doctor and a hospice care team of professionals that include nurses, social workers, spiritual caregivers, grief counselors, home health aides, volunteers and physical, occupational, speech and nutritional therapists. Because your needs are unique, the hospice care team works with you to develop a personalized plan for your care.

HOSPICE CARE TEAM

You and your family are the core of the hospice care team and are at the center of all decision-making.



* A family may include relatives, friends, neighbors, or extended family.

HOW WILL HOSPICE CARE PROVIDE SUPPORT FOR ME AND MY FAMILY?

Many families have little or no experience in caring for someone who is dying. This is where hospice can help.

Hospice care provides the support, the teaching and the expertise to enable your family to provide needed care.

Your family is expected, with guidance from your hospice care team, to:

- » Provide a safe, comfortable environment for your care;
- » Alert the hospice care team of changes in your condition;
- » Help with personal needs such as feeding, bathing, turning and giving medications.

The care of each person varies. Some are active and independent. Some are confined to bed and require intense care. Some require a little of both. The frequency and type of hospice services are tailored to meet the needs of you and your family.

"I felt a very heavy burden on my shoulders lighten perceptibly because I knew there would be trained people to share with our family the care of my husband."

Shirley, wife of a hospice patient

TO SUPPORT YOU AND YOUR FAMILY, THE HOSPICE CARE TEAM:

- » Provides comfort care, including medications and therapies to relieve pain and symptoms;
- » Is available 24 hours a day to answer questions;
- » Offers emotional counseling and spiritual support;
- » Teaches specific care techniques, such as turning, positioning and transferring, bathing and administering medications;
- » Arranges for necessary equipment such as hospital beds, oxygen, bedside commodes and wheelchairs;
- » Coordinates any additional help and special services needed in the home;
- » Provides information about alternative settings, such as nursing homes or residential hospices;
- » Offers grief support, which may include writing letters, making telephone and personal contacts, counseling, or providing opportunities to share experiences in organized support groups.

WHAT IF I LIVE ALONE OR DON'T HAVE FAMILY NEARBY?

The hospice care team can talk to you about choices for staying safe and comfortable in your home, even if you live alone. Hospice services may also be available in your region through nursing home facilities or residential hospices.

Covered Services Under Medicare

- » Physician services
- » Nursing care
- » Medical equipment
- » Medical supplies
- » Medications for symptom management and pain relief*
- » Short-term inpatient care
- » Respite care*
- » Home health aide and homemaker services
- » Physical, occupational, and speech therapy
- » Medical social services
- » Dietary and other counseling

** Medicare pays for the entire cost of these services. However, the hospice has the option of charging a copay of up to five dollars per prescription and a small copay for inpatient respite.*

WHO IS ELIGIBLE FOR HOSPICE CARE?

Hospice care is appropriate for people with any terminal illness, as determined by the patient's physician. Care is provided regardless of age, nationality, gender, race, creed or sexual orientation.

HOW IS MY CARE PAID FOR?

Hospice services are paid for by Medicare, Medical Assistance, MinnesotaCare, most private insurance companies, or you may pay privately. Veterans' benefits are also available. Your hospice program works with you and your family to identify ways to pay for services. However, care is provided regardless of your ability to pay.

MEDICARE

Hospice care is covered by the Medicare Hospice Benefit (Part A). You may choose this comprehensive benefit if:

- » You are eligible for Medicare Part A;
- » Your physician and the hospice medical director certify that you have a terminal illness with a life expectancy of six months or less;
- » You enroll in hospice instead of the standard Medicare benefits for care of the terminal illness; and
- » You receive care from a Medicare-certified hospice program.

Medicare pays only for services that are authorized by the hospice program. 24-hour care is paid for only in times of medical crisis. You may discontinue the hospice benefit at any time and resume your standard Medicare benefit.

While enrolled in hospice, standard Medicare benefits are still available for treatment of health problems unrelated to the terminal illness, and all Part B benefits for physician services are also available.

If the hospice you choose is not Medicare-certified, it will provide some services and work with other agencies to provide services that will be paid for by Medicare.

MEDICAL ASSISTANCE AND MINNESOTACARE

If you are eligible for Medical Assistance and MinnesotaCare, you also have a hospice benefit, which includes the same services as the Medicare Hospice Benefit.

PRIVATE INSURANCE

If you have health coverage through an insurance company, you are eligible for a hospice benefit in most cases. If you are unsure about the hospice benefit in your insurance plan, speak with your insurer or a hospice representative.

HOW DO I FIND A HOSPICE PROGRAM?

Choosing hospice care means that you have decided to pursue care focused on comfort to live your remaining days as fully as possible.

Talk to your doctor about when hospice is appropriate for you. Let him or her know you are interested in hospice care, and ask for help in making that decision. You can also talk with your nurse or directly contact a hospice program.

Hospice programs have arrangements with hospitals and nursing homes for short-term inpatient and respite care. If you prefer a particular hospital or facility, ask which hospice programs provide services there.

The Minnesota Department of Health (MDH) licenses hospice programs and conducts on-site surveys so you can be assured that the hospice meets quality guidelines.

In addition, hospice programs can choose to become Medicare-certified and comply with federal guidelines for care and survey process.

If your doctor does not have a recommendation, you may check with Minnesota Network of Hospice & Palliative Care (MNHPC) at (651) 917-4616 or toll-free at (800) 214-9597 for a list of state licensed and Medicare-certified programs that serve your community. You may also call the Minnesota Department of Health (MDH) at (651) 201-4101.

WHAT IF I HAVE CONCERNS WITH THE CARE I RECEIVE?

Hospice care is always the choice of you and your family. You have the right to discontinue hospice services at any time or transfer to another hospice program.

Your hospice care team will review with you a Hospice Patient's Bill of Rights. This document provides information on your rights as a patient and how to handle concerns you may have about your care.

You may also seek assistance through the Department of Health Office of Health Facility Complaints at (800) 369-7994 or the Office of Ombudsman for Long-Term Care at (800) 657-3591.

DO I NEED A HEALTH CARE DIRECTIVE?

Competent adults have the right to make their own health care decisions, including the right to decide what kind of medical care to accept, reject or discontinue. However, there may be times when you cannot make your wishes known. This is why it is important to express your wishes in writing through a health care directive.

You are not required to have a health care directive to enroll in hospice. However, it is a good idea to consider drafting one.

A health care directive helps your family and loved ones understand your choices about care when you are at the end of your life. It helps make sure your values, beliefs and wishes about medical care are heard if you are unable to make or communicate these decisions. It is a gift to you and your loved ones. Hospice staff is available to provide you with information on this topic.

GLOSSARY

Assisted Living

A service, not a place. Assisted living programs usually include a package of services such as meals, housekeeping, transportation, recreational activities and an emergency response system.

Comfort Care

Care that relieves pain and suffering and controls debilitating symptoms, but does not prevent dying.

Health Care Directive

A legal document for people to state their wishes regarding medical care, treatment and preferences in case they are incapacitated. Health care directives include advance directives, living wills, and medical power of attorney. The person appointed to make decisions in case of incapacitation is called the health care agent.

Hospice

A philosophy of care for dying patients that emphasizes comfort over cure. Hospice care is provided by an interdisciplinary team of health care professionals who attend to the physical, emotional and spiritual needs of the patient and family and provide grief support services for the family. Most hospice care occurs in the home, but is also available in hospitals, nursing facilities and residential hospices.

Nursing Facility

A multi-occupant facility that provides care for people needing basic or skilled services which are provided by staff employed by the facility.

Palliative Care

Care focused on relieving symptoms and designed to meet the complex needs of patients with a chronic condition. Some patients receiving palliative care continue to seek curative care, unlike hospice care.

Residential Hospice

A facility that provides 24-hour residential and support services in a home-like setting for hospice patients.

Respite Care

Short-term care that may be provided in a hospital or nursing facility to provide relief for the family from the daily care of the patient.

Terminal Illness

An illness or condition that is incurable and irreversible. When a person is diagnosed as terminally ill, death is expected in a relatively short period of time.

FOR ADDITIONAL INFORMATION OR A REFERRAL

Minnesota Network of Hospice & Palliative Care (MNHPC)

2365 McKnight Rd N Suite 2
North Saint Paul, MN 55109
(651) 917-4616 / (800) 214-9597
www.mnhpc.org

National Hospice and Palliative Care Organization (NHPCO)

(800) 658-8898
www.nhpc.org

FOR INFORMATION ON MEDICARE & LICENSURE

Minnesota Department of Health (MDH): (651) 201-4101

www.health.state.mn.us

MinnesotaCare: (651) 297-3862

www.mn.gov/dhs/minnesotacare

Medicare: 800-MEDICARE (800-633-4227)

www.medicare.gov

TO FILE A COMPLAINT ABOUT A HOSPICE AGENCY

Ombudsman for Long-Term Care

(651) 431-2555 / (800) 657-3591

Office of Health Facility Complaints

(651) 201-4201 / (800) 369-7994

FOR COMMUNITY RESOURCE INFORMATION

Senior LinkAge Line®

(800) 333-2433
www.mnaging.org/advisor/SLL



MINNESOTA NETWORK OF
HOSPICE & PALLIATIVE CARE

www.mnhpc.org