



What Is Hospice?

Answers to Your Questions

 **NorthShore**
University HealthSystem

Home and Hospice Services

Dear Prospective NorthShore Hospice Patients,

Welcome!

When you choose NorthShore Hospice, it means that you have surrounded yourself with an interdisciplinary team of professionals who are dedicated to helping you achieve your healthcare goals.



In addition to your family, friends and primary care physician, you are supported by palliative care physicians who specialize in pain and symptom management, pharmacists, registered nurses, certified nursing assistants, licensed social workers, chaplains, child life specialists, music therapists, counselors and volunteers. Each team member brings a unique set of skills and resources to provide you with a full spectrum of services. All of them are dedicated to providing the best quality of care for you and your family. I want to encourage you to take advantage of all the resources we have to offer.

Know that whatever difficult challenges and decisions you face, we will deal with them together. We are here when you need us.

If you have any questions or concerns, please feel free to address them with me or any member of our care team.

Sincerely,

A handwritten signature in black ink that reads "Michael Marschke". The signature is fluid and cursive, with a large loop at the end.

Michael Marschke, MD
Medical Director



Welcome to NorthShore Hospice

At NorthShore University HealthSystem (NorthShore), our hospice program is committed to providing each individual and family with the highest quality personalized care and services at a time we recognize as both stressful and unfamiliar for all involved. While a patient's physician may have recognized that curative care is no longer an available option for his or her illness, our warm and caring hospice team can offer compassionate and dignified care that continues to value each person and his or her wishes and preferences for daily living. For many individuals, hospice care provides hope and relief as the attentive services and care of staff allow patients to remain comfortable and live life to the fullest, making the most of their time now with family and friends.

NorthShore Hospice care focuses on the physical care of the person living with the disease while also being attentive to the emotional and spiritual needs of the patient and his or her loved ones. Whether a patient chooses to remain in his or her home, assisted living apartment or nursing home, our hospice team will provide care and personalized services to meet his or her individual needs and preferences. Should hospitalization be necessary at one of our NorthShore Hospital locations, our team will continue to provide care to our patients.

A Leader in Hospice Care

NorthShore Hospice is fully integrated into NorthShore's comprehensive caregiving health system. In addition to our four hospitals, we are also connected to a medical group of over 900 primary care physicians and specialists, and a research institute doing groundbreaking research in a number of fields.

NorthShore Hospice works closely with our palliative care and home health programs to ensure a seamless transition of care. This allows us to help patients and their families navigate the complex and sometimes confusing world of modern healthcare.

We are:

- Medicare-certified
- Fully licensed in the state of Illinois
- Accredited by The Joint Commission
- Magnet-recognized, a prestigious designation shared by only 6 percent of healthcare organizations in the country
- A teaching affiliate of the University of Chicago Pritzker School of Medicine
- A member of the National Hospice and Palliative Care Organization, the National Association for Home Care & Hospice, and the Illinois Homecare and Hospice Council

Answers to Your Questions About Hospice Care

What is hospice?

The term “hospice” originally referred to a place where hospitality was provided to sick and weary travelers. In the modern medical sense of the word, hospice is not a place so much as it is a philosophy of care. The hospice philosophy offers continuity of care when a shift from curative medicine to comfort-based care and symptom management is required. We do this not only by addressing the pain and symptoms of illness and disease, but also by recognizing that physical distress is compounded by the emotional and spiritual suffering of patients *and* their families. Hospice offers a community of interdisciplinary professionals who gather around a family that is struggling with how to cope with life-threatening and terminal illness. Hospice offers hope and consolation when finding a cure is no longer an option.

How will I know I need hospice care?

To make an informed and timely decision, it is never too soon to consult with your primary care physician and physician specialists about all your treatment options. Hospice may be the right choice for you when you or a designated healthcare power of attorney for medical care determines that the impact of medical treatments outweighs the benefits of extending your life, or your physician informs you that the disease has progressed to the point where finding a cure is no longer an option. **You are eligible for enrolling in hospice if your physician certifies that you have a life expectancy of six months or less were your illness to run its**

normal or predictable course. It is not uncommon for hospice patients to live longer than six months while under hospice care; however, many people wait far too long to enroll in hospice to realize all the benefits that hospice has to offer themselves and their families. If you are thinking about hospice and you have not already done so, it is time to have a frank discussion with your physicians, family and others (such as faith community leaders or close friends) who have your best interest at heart.

Who pays for hospice?

If you are currently covered by Medicare, Medicaid or private insurance¹, most if not all of your expenses related to the hospice diagnosis will be covered. **You will still be responsible to pay for private-duty caregivers and other medical expenses, such as medications not related to your hospice diagnosis.** Please refer to the *Medicare Hospice Benefit Fact Sheet* for more details (see page 10).

Paying for housing in private homes, nursing homes and other assisted living facilities is the responsibility of patients and their families. Medicare does not cover the cost of housing or room and board. However, if you qualify for Medicaid, in most situations, room and board at a nursing home will be covered under the Medicaid benefit. If you are admitted to the hospital for *general inpatient care*, your inpatient stay at the hospital is covered under the hospice benefit. Each benefit period, one *five-day respite stay at a nursing facility* is also covered under the hospice benefit.

¹ NorthShore Hospice contracts with many of the major healthcare insurance companies. Should you decide to enroll with us, we will contact your insurer to determine whether your hospice care is covered by your provider.

Does NorthShore Hospice have a hospice inpatient unit?

NorthShore Hospice has inpatient units at all four hospitals, with our primary unit at NorthShore Skokie Hospital.

What happens on evenings and weekends?

Throughout the week, your hospice nurse and other interdisciplinary team members will work with you and your family to schedule their visits. On evenings and weekends, a nurse is on duty 24 hours a day. You can feel free to call at any time. If you have any concerns about increased pain or anxiety or other symptoms need to be addressed, the on-call nurse will assess the situation, provide direction on how to deal with the problem and, if needed, come to you to help manage the problem. You can take comfort in the knowledge that we are only a phone call away.

What do I need to do to sign up for hospice right now?

If you are interested in enrolling in our hospice program, we will contact your physician to inform him or her of your intention, confirm that you meet the criteria for admission and coordinate your care. Then we will schedule an appointment for a representative from hospice to obtain your written consent and address any additional questions you may have.

What happens during the admission appointment?

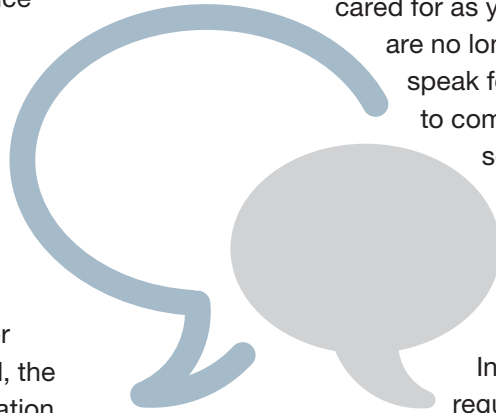
A nurse will come to you to do an “initial (physical) assessment.” In order to manage your medications, the nurse will also make a list of all the medications you are currently taking (including over-the-counter

and herbal remedies) to ensure that there are no negative drug interactions, adjust dosages or order additional medications.

The nurse will also address several important documents, the first being a written consent form to enter the hospice program, signed by you or your designated power of attorney for healthcare. The nurse will explore with you how you want to be cared for as your disease progresses and you are no longer able to make decisions or speak for yourself. You may want to complete an advance care plan, select powers of attorney, make a *Living Will* and/or sign a *Physician Orders for Life-Sustaining Treatment* (a “do not resuscitate” order).

In compliance with Medicare regulations and as part of the initial assessment, a social worker and a hospice chaplain will also contact you to assess your and your family’s social, emotional and spiritual needs. Social workers can help with transitioning between hospital and home or other assisted living facilities, connecting with community resources, hiring caregivers and making funeral arrangements. Hospice chaplains bring their own experience and resources to help you and your family manage this difficult time. They can provide spiritual and emotional support to you and your family and/or help arrange contact with your faith community or other community-based spiritual resources.

After an initial assessment is completed, the various members of the hospice team will remain available to assist you and your family during the entire time you are enrolled in the hospice program. A primary nurse will be assigned to you to coordinate your care. The other members of our interdisciplinary team will work with you to schedule their visits.



What happens if I change my mind about hospice?

If at any time you change your mind and decide you want to again pursue curative treatment, you may elect to “revoke” hospice. We hope that you would consider contacting us if at some point in the future you need hospice services again.

Does hospice pay for private caregivers in the home?

Even with the variety of hospice services in place, a time may come when additional help at home may become necessary for an individual’s safety and well-being. When this occurs, the hospice social worker will work together with you, your family and a hospice nurse to identify resources best suiting your circumstances and preferences. Unfortunately, the cost of private caregiver services is not covered by Medicare or the hospice program. However, community resources can be explored for individuals who are income-qualified.

Do I need to inform hospice if I will be out of town for a few days?

Yes, please let us know when you will be away from your home so we can make a notation in your record. If you will be away for seven days or longer, we can make arrangements for a hospice to provide services to you in the area you are visiting. Medicare rules require that hospice staff visit you a minimum of once every two weeks. Please talk to your nurse or social worker as soon as you begin to make travel plans so we can work together to ensure comfort, safety and care coordination.

When death approaches, what can I expect from the hospice team?

Your nurse can increase his or her visit to daily, and your social worker and chaplain are also available to increase their visits. We will be there to assess whether the goals of comfort are being met and to guide and support family and friends through the end-of-life journey. During the evening, nighttime and weekend hours, a hospice nurse is available 24 hours a day. Call us at **(847) 475-3002** with any questions or concerns you may have—and when needed, the nurse can make a visit.

After death, when your loved ones are emotionally ready, a nurse will make a home visit. The nurse will offer support and guidance to your family and document the time of death. With your permission, the nurse may assist with medication disposal, assist with procedural calls, and arrange to have any medical equipment removed at a time that is convenient for the family.

While discussing end-of-life preferences such as funeral arrangements can be difficult, many hospice patients and families find a burden is lifted once the discussion takes place and decisions are made together. The social worker is available if resources are needed. Please discuss your choices with your social worker so that they can be entered in the NorthShore Hospice Electronic Medical Record (EMR) system.

Who can best assist my family with funeral/cremation resources?

Your social worker will have a resource list of funeral homes, cremation resources and groups that receive bodies for advancement of science, such as medical schools. They would be glad to work with you to see that your preferences and wishes are fulfilled. Our chaplains are available to help plan and conduct a memorial service if desired.

Is there bereavement support for my family?

As part of the Medicare benefit, bereavement support is available to family members for no additional charge. NorthShore Hospice sponsors grief support groups, and individual grief counseling is also available. We can also make referrals to community resources for those family members who live outside our service area. For more information about bereavement support services, please call **(847) 982-4364**.

We realize that all of this information is a lot to take in. In times of stress, it is hard to absorb so many details. The information contained in this booklet is provided so that you and your family can revisit all of this information at your leisure. Choosing hospice is an important decision. Know that you can count on the entire NorthShore Hospice interdisciplinary team to support you and your family in your time of need.

If at any time you have a question or concern, you can call our 24-hour hospice number at (847) 475-3002.

Service Area

We are able to care for patients who currently reside in private homes, long-term care facilities or any of our four hospitals. The NorthShore Hospice service area covers parts of Cook County and all of Lake County. It extends from the Wisconsin border to North Avenue (Rt. 64) in Chicago and from Lake Michigan as far west as the Palatine area. For specific inquiries about our service area, please contact NorthShore Hospice at [\(847\) 475-3002](tel:847-475-3002).

Services Included in Hospice Care

- Coordination of care with consultation of the patient's primary care physicians and other physician specialists
- Pain and symptom management overseen by a board-certified palliative care physician
- Registered nurses on call 24 hours a day, seven days a week
- Nursing aides to assist with bathing, hygiene and skin care
- Medical equipment, including hospital beds, wheelchairs, assistive devices, oxygen concentrators, etc.
- Medications related to hospice diagnosis, including home delivery
- Volunteers to assist with light household duties or companionship
- Emotional and spiritual support provided by chaplains, licensed counselors, child life specialists, and music therapy, including ongoing bereavement support for loved ones
- Licensed clinical social workers who provide invaluable support with hospital discharge planning, funeral arrangements, transitions to home or nursing facilities, etc.



Levels of Care

Routine Care

As the name suggests, *routine care* involves the general daily care of hospice patients whose pain and other symptoms are well managed in their own homes or assisted living facilities. Routine care includes all of the services listed to the left.

Respite Care

During each benefit period, each patient is entitled to a maximum of five days of *respite care*. This five-day period is provided at a skilled nursing facility. Respite care allows the caregiver an opportunity to travel or simply take a much-needed break, feeling confident that the hospice patient will be well cared for while he or she is away.

General Inpatient Care

General inpatient care can be provided at all four NorthShore Hospitals—Evanston, Glenbrook, Highland Park and Skokie. If a patient requires procedures for pain and symptom management that cannot be managed in the home or assisted living facility, patients can be admitted and cared for at the hospital to address the crisis.

Continuous Care

Continuous care is primarily provided by a hospice nurse during brief periods of crisis to maintain the patient at home if this is the family's wish and it is determined by the hospice team that the symptoms can be resolved at home with a continuous level of care. The focus during this care is symptom management to obtain optimum comfort. If you have further questions about this level of care, please do not hesitate to ask your hospice team.

Termination of Hospice Care

Patients or their designated healthcare power of attorney may elect to terminate hospice care at any time.

- **Revoke** A patient and family may change their minds about hospice care or decide that they want to again pursue curative treatment. At that time, the patient's nurse and doctor will discuss options with the patient and his or her family.
- **Transfer** If a patient wishes to travel for a period of time, NorthShore Hospice will assist in locating another hospice in the chosen area to care for the patient while traveling. A patient may also elect to transfer to or from another hospice within this service area.
- **Discharge** There are occasions when a patient's condition stabilizes, and he or she no longer meets the Medicare criteria to stay in hospice. On those occasions, the patient or his or her designated power of attorney may appeal the decision and request to be re-evaluated.
- **Readmission** In each of these situations, a patient's condition may change or he or she may decide to be readmitted to hospice. At that time, the patient can be re-evaluated to determine whether he or she meets Medicare eligibility requirements.
- **Death** The families we serve take comfort in the knowledge that bereavement support services remain available for thirteen months following the death of a hospice patient. For more information, please contact us at **(847) 982-4364**.

Medicare Hospice Benefit Fact Sheet

- The Medicare hospice benefit (Part A) is designed to provide specialized care for Medicare-covered patients who have a terminal illness with a life expectancy of six months or less if the disease runs its normal course.
- Part B covers doctors' appointments that can include "palliative" rather than "curative" care.
- Room and board is paid for privately except under special circumstances.
- Hospice is paid on a per-day (per diem) basis. The hospice benefit includes all visits by the hospice team as well as medications and medical equipment and supplies related to the primary diagnosis.
- Hospice services include visits by registered nurses, certified nursing aides, social workers, chaplains, physical therapists, occupational therapists, speech therapists, dietitians, music therapists and child life specialists, as well as counseling and bereavement support and volunteer visits.
- Under the Medicare hospice benefit, the patient may continue to be seen by his or her personal physician. The cost of such visits will be covered by Medicare Part B—if the patient is seen by the hospice medical director.
- Hospice services are typically provided in the patient's home but may be provided in an inpatient setting or a skilled nursing facility when necessary. When care is provided in a hospital or nursing facility, there must be a contract with the hospice in order to be reimbursed under the Medicare hospice benefit.
- Under the Medicare hospice benefit, a patient may be admitted for an initial benefit period of 90 days. At admission and at the end of a benefit period, a physician must certify that the patient continues to meet the criterion for hospice—i.e., a life expectancy of six months or less if the disease runs its normal course. The second benefit period is also 90 days, followed by unlimited 60-day periods for as long as the patient meets the criterion and is enrolled in hospice.
- If a patient wishes to sign out or revoke hospice, he or she may do so at any time. The pre-existing Medicare benefit is immediately restored.
- If the patient revokes the Medicare hospice benefit, he or she loses the remaining days of coverage in that benefit period.
- For additional information about the Medicare hospice benefit, please visit [medicare.gov/forms-help-and-resources](https://www.medicare.gov/forms-help-and-resources)

Supporting Patients and Families

Dame Cicely Saunders, the founder of the modern hospice movement, used the term *total pain* to describe the pain and suffering that includes the physical, social, psychological, spiritual and practical struggles that people deal with as they face a life-threatening or terminal illness.

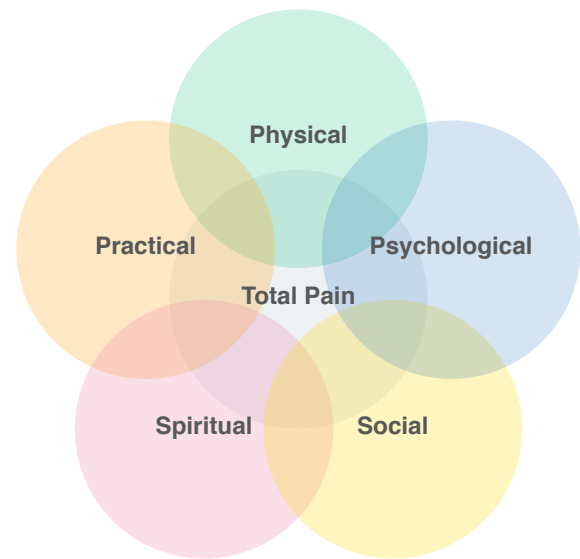
The NorthShore Hospice team remains committed to seeing you as a person, not just a patient. We will work to address the concerns and needs of you and your family in order to help you through these trying times.

Signs of Physical Pain and Symptoms

Our physicians, pharmacists, nurses and nursing aides will work with your primary care physician and other palliative care specialists to address your physical pain and symptom management.

Signs of Psychological, Social, Spiritual and Practical Pain

- You or a loved one is struggling with your diagnosis or admission into hospice.
- You or a loved one needs help finding a better way to cope with anxiety and stress.
- You are worried or have questions about the dying process.
- You need help finding community resources.
- You need help connecting with a family member separated by a great distance.
- You need help with activities like shopping, light cleaning or companionship.



- You want to explore questions about the finality of death or the existence of an afterlife.
- You begin doubting long-held beliefs.
- You need help finding ways to express deeply felt emotions.
- You are aware of unresolved family conflicts.
- You do not know how to explain illness and dying to your children or grandchildren.
- You have a desire to leave a legacy for your children and grandchildren.
- You and/or others are worried about how your family will manage after you are gone.
- You grieve the losses associated with declining health and separation from family.

These and many other concerns add to your total pain and make an already difficult situation worse.

How We Can Help

Roles of the hospice interdisciplinary care team

Hospice/Palliative Care Physicians

Our palliative care physicians can either work together with the physician of your choice or personally manage your hospice needs. The physicians provide oversight of all care, medications and treatments. They will also make any visits as required by Medicare to meet hospice criteria.

Pharmacists

Our pharmacists attend weekly meetings with the hospice team to oversee medications, watch for adverse drug interactions and side effects, and make additional recommendations. Our pharmacists will also fill any medication prescribed by the physician.

Nurses

Our nurses visit with each patient regularly to offer support, assess any changes to his or her care goals, and address treatment needs. The nurse will also support family members and caregivers by training them how to respond to your needs. The nurse facilitates the ordering of medications and supplies, provide direct care, and address pain and symptom management. The nurse also coordinates communication between patients, family members, hospice team members, physicians, hospital staff and/or nursing home staff, as needed.

Nursing Aides

Our nursing aides are available to assist with personal services such as bathing. They can also perform simple homemaker needs during their visits, such as linen changes and assisting with meals.

Allied Support Services

Our chaplains, social workers, child life specialists, music therapists, grief counselors, and volunteers can assist with all the other issues that are also troubling to you and your family during this stressful time.

Social Workers

Our social workers can help you with a variety of social, psychological and practical issues like helping you access benefits, entitlements and insurance policies; making funeral arrangements; working on family communication; and coordinating services with alternative living situations like nursing homes or senior housing. They can help arrange for professional caregivers to assist with your physical care so that you can focus all your attention on the emotional and spiritual needs of you and your family. Our social workers can also provide emotional support to you and your family during this difficult time.

Chaplains

Our chaplaine can help you and your family explore the many spiritual and emotional issues that arise when facing a life-threatening or terminal illness. They are knowledgeable about diverse religious and



cultural backgrounds, and are also respectful of those who do not identify with any religious tradition but are looking for someone who can help them explore the deeper questions of suffering or simply reminisce or reflect on the story of the patient's life. Our chaplains can offer prayers, help with rituals or sacraments, and connect you with other spiritual and religious resources in your community. They are here to offer support to the entire family.

Child Life Specialists

Our child life specialists can help provide support to children and teenagers impacted by having a loved one enrolled in hospice. They use activities to help them understand, memorialize and cope with your illness and declining health. The child life specialist remains available to help bereaved minors and to connect your family with resources available in your community.

Music Therapists

Our music therapists can promote your health and well-being by encouraging expression of emotions, decreasing isolation and facilitating life review. They use music to help you manage pain, anxiety and other symptoms.

Grief Counselors

Our grief counselors can help you with your own grief and all the thoughts and feelings about your illness, separation and loss. A grief counselor remains available to support your family for at least a year after your death by offering grief support groups, individual counseling and referrals to community services.

Volunteers

Our volunteers may provide support to you and your loved ones in a number of different ways. Though volunteers are not allowed to help with any hands-on tasks or personal care, they can sit with you while the caregiver takes a break or runs errands. Volunteers may provide companionship and emotional support to you or anyone else in the home. Volunteers may provide transportation to doctor appointments, grocery stores, the post office and more. Volunteers may run errands for you—for example, to the grocery store or library. Volunteers may be able to help with light tasks in the home such as washing or putting away dishes, doing your laundry or preparing a light meal. A volunteer may be assigned for once a week, for up to three hours per week, after an assessment has been done by the volunteer coordinator. Advance notice is required before a volunteer is assigned.

None of us can manage all end-of-life issues on our own. We need family and friends—and in times like these, the support services of NorthShore Hospice can help you find ways to deal with the challenges of total pain.

If you have any questions or would like the support of any one of these healthcare professionals, speak to any hospice team member or call [**\(847\) 475-3002**](tel:847-475-3002).

For more information about NorthShore Hospice
or to request an additional consultation, please call:

(847) 475-3002

NorthShore Hospice
4901 Searle Parkway, Suite 160
P.O. Box 1006
Skokie, IL 60076-8006

Visit us at: northshore.org/hospice

NorthShore University HealthSystem is an integrated healthcare delivery system consistently named among the nation's best. The NorthShore system, including its four hospitals—Evanston, Glenbrook, Highland Park and Skokie—is consistently ranked as a Top 15 Teaching Hospital System in the United States. NorthShore also includes a 900-physician multispecialty group practice, NorthShore Medical Group, located in 100+ offices across Chicago and many of the Northern Suburbs. NorthShore is a Magnet-recognized organization, the first in Illinois designated as an entire system to receive this prestigious honor that demonstrates excellence in nursing and high standards in patient care. The system also supports the NorthShore Research Institute; NorthShore Foundation; and NorthShore Home and Hospice Services. In addition to launching Be Well-Lake County, a community health initiative committed to providing greater access to comprehensive care, NorthShore contributes more than \$209 million in charitable care and services to the community it serves.

NorthShore Home and Hospice Services is a hospital-based, nonprofit agency that offers the full spectrum of home and hospice care, including skilled nursing, physical and occupational therapy, and home medical equipment. Our caregivers represent a wide range of medical specialties and work with the patient, family and physician to tailor home care to meet the individual needs of each patient.



Home and Hospice Services

Hospitals

Evanston Hospital
2650 Ridge Avenue
Evanston, IL 60201
(847) 570-2000

Glenbrook Hospital
2100 Pfingsten Road
Glenview, IL 60026
(847) 657-5800

Highland Park Hospital
777 Park Avenue West
Highland Park, IL 60035
(847) 432-8000

Skokie Hospital
9600 Gross Point Road
Skokie, IL 60076
(847) 677-9600