

There's Still So Much More You Can Do

Because of the outstanding support from our community, Hospice has been able to offer care and support to many individuals and their families.

Many of us will, at some time be faced with a situation that could be made easier and less painful by Hospice's specially trained and dedicated staff. There are many ways that you can help us to continue providing these valuable services to other families.

- Families can become "Hospice Ambassadors." Tell your friends about the quality of care and how helpful the support is. Someone else in need can benefit from this information.
- Later, when you are ready, become a Hospice volunteer. Some volunteers work with patients and families. Many support Hospice by performing administrative tasks, running errands, or helping with special events.
- Suggest that a speaker from Hospice make a presentation at your church, temple, school, civic organization, or place of employment.
- Set up a memorial so that family and friends can make donations to Hospice in memory of your loved one. Be sure to tell your funeral director to add this information to the obituary notice and to have Hospice envelopes available for your family and friends.
- Become a Hospice donor yourself by sending your own gift. Ask to be placed on the guest list for special events.
- Help to ensure long term security for Hospice in the community by naming Hospice as a beneficiary in your will.
- Ask your employer if he or she will make a matching gift.
- Write a letter to the local newspaper sharing your thoughts about the value that our services held for you.



Honoring Life
Giving Care
Bringing Comfort



tel: (845) 634.4974 • fax: (845) 634.7549 • 11 Stokum Lane, New City, NY 10956
info@unitedhospiceinc.org • unitedhospiceinc.org





Life... Making each day count

Hope... There's always HOPE in Hospice

Comfort... Relief from your pain and other symptoms

Dignity... Respect for you and your values

Compassion... We care about you

Support... A specialized team dedicated to meeting your needs

Family... Care and support for those who mean most to you

Choice... You have a voice in all decisions

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- Hospice Benefit Election Form
- Health Care Proxy and Living Will
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Patient/Family Bill of Rights

United Hospice, Inc. (UH) acknowledges and respects the following rights of you and your family:

1. The right to receive concerned, competent, individualized care without regard to race, creed, color, age, sex, national origins or handicap; to be treated with dignity, consideration and respect which includes respect for your privacy, property and safety.
2. The right to be informed, to the extent desired, of medical condition, prognosis, outcomes of care, treatment and services, including unanticipated or negative outcomes.
3. The right to participate to the extent desired in planning and carrying out care; (including any care that might be needed upon discharge);
4. The right to competent, appropriate and timely care for the illness which qualifies the patient for United Hospice, Inc. services;
5. The right to privacy concerning matters which have no bearing on your illness or care;
6. The right to strict confidentiality of all patient / family information including patient / family records;
7. The right to decide to change treatment course; (Note: UH reserves the right to discharge patients who decide to seek disease directed treatment)
8. The right to withdraw from the United Hospice, Inc. program at any time;
9. The right to be informed in a timely manner of significant changes in the agreed upon schedule of services;
10. The right to receive, upon admission, a statement of services available from United Hospice, Inc. and related costs;
11. The right to refuse medication and / or treatments, and the right to be informed of the possible medical consequences of such refusal;
12. The right to recommend changes and offer complaints regarding services, policies and procedures, and / or staff of United Hospice, Inc., free from restraint, interference, coercion, discrimination or reprisal. These communications can be made directly to the program's Director of Clinical Services. If a satisfactory resolution is not found, you may contact the NYS Dept. of Health, 90 Church Street, New York, NY 10007, (212) 417-4921.

13. The right to refuse release of information from United Hospice's Inc. records to any individual or agency;
14. The right to be informed of the names and function of any person/agency providing care and /or services and that personnel are qualified through education and experience;
15. The right to receive self determination information/formulate advance directives;
16. The right to be given information in a language or form that you can reasonably understand;
17. The right to choose whether or not to participate in experimental treatment, clinical trials or research and give documented voluntary consent if you so choose. All aspects of this treatment including but not limited to side effects and outcomes will be protected under the right of confidentiality;
18. The right to be referred to other organizations, services or individuals and be informed of any financial benefit to UH;
19. The right to decide to withdraw or withhold life-sustaining treatment;
20. The right to have access to, request amendment to and receive accounting of disclosures regarding your health information;
21. The right to be free from mistreatment, neglect, exploitation and any abuse including sexual, physical, including injuries of unknown source, verbal, mental and misappropriation of patient property;
22. The right to have your cultural, psychosocial, spiritual and personal values, beliefs and preferences respected;
23. The right to privately communicate with persons of your choice in the organization or the community;
24. The right to pain management.

Life... *Making each
day count*

You & Your Family's Responsibilities

Advance Care Planning

In an effort to work collaboratively, UH expects that patients and families will:

1. Be respectful of staff and their property as well as that of other patients. Do not discriminate against staff due to race, creed, color, sex, age, national origin or disability. Provide a safe environment for hospice staff to provide care.
2. To the best of your ability, share complete and accurate health information with UH staff. Inform staff of any change in your health.
3. Share information about your expectation of and satisfaction with UH. Ask questions when you do not understand or cannot follow instructions that have been given.
4. Participate in the development of a care plan to address your needs. Be responsible for the outcomes if you do not follow care, treatment and service plan.
5. Notify UH if you will not be home at the time of the scheduled visit.
6. Notify UH if you are receiving services from another agency.
7. Follow instructions about your care. Be responsible for your actions if you refuse treatment or do not follow instructions that have been given.
8. Make prompt payment if you have any financial liability for services provided.
9. Follow the organization's rules and regulations of which you have been informed.

UH respects the right of each adult to participate in health care decision making to the maximum extent of his or her ability and respects all rights consistent with New York State law. To this end, UH has instituted specific policies and procedures to ensure that your health care decisions are followed:

1. **Information to Patients** United Hospice will provide the following written information at the time of admission to the UH for care:
 - A. The following information prepared by the New York State Department of Health
 - Planning in Advance for Your Medical Treatment
 - Appointing Your Health Care Agent - New York State Proxy Law
 - Do Not Resuscitate Orders -A Guide for Patients and Families

B. An Advance Directive Form (includes Health Care Proxy, Living Will and DNR) The form is at the back of this guide.

2. Definitions. For purposes of this policy, an “advance directive” is a written instruction relating to the provision of health care when an adult is unable to make their own decisions.

Examples are:

A. Health Care Proxy. A document delegating to another adult known as a health care agent the authority to make health care decisions on behalf of the individual making the appointment if that individual in the future becomes incapable of making his or her own health care decisions.

B. Consent to or Request for the Issuance of and Order Not to Resuscitate (A “DNR” Order). Under such an order, health care providers are not to attempt cardiopulmonary resuscitation (“CPR”) in the event the patient suffers cardiac or respiratory arrest. A request for such an order can be expressed in a health care proxy or living will.

C. Living Will. A document which contains specific instructions concerning an individual’s wishes about the type of health care choices and treatments that he or she does or does not want to receive, but which does not designate an agent to make health care decisions.

3. Documentation. UH shall document in the medical record whether or not you have completed an advance directive. If made available to the agency, a copy of such advance directives shall be included in the medical record.

4. Compliance with Law. UH shall comply with all applicable New York State law regarding advance directives, including statutes and court decisions.

5. Non-Discrimination. UH shall not condition the provision of care or otherwise discriminate against you based on whether or not you have executed an advance directive.

6. Education. UH shall provide education to staff and the community on issues regarding patient decision making.

Planning in Advance for Your Medical Treatment

Your Right to Decide About Treatment

Adults in New York State have the right to accept or refuse medical treatment, including life-sustaining treatment. Our Constitution and State laws protect this right. This means that you have the right to request or consent to treatment, to refuse treatment before it has started, and to have treatment stopped once it has begun.

Sometimes because of illness or injury people are unable to talk to a doctor and decide about treatment for themselves. You may wish to plan in advance to make sure that your wishes about treatment will be followed if you become unable to decide for yourself for a short or long time period. If you don't plan ahead, family members or other people close to you may want to make decisions but may not be allowed to do so.

In New York State, appointing someone you can trust to decide about treatment if you become unable to decide for yourself is the best way to protect your treatment wishes and concerns. You have the right to appoint someone by filling out a form called a Health Care Proxy. A copy of the form and information about the Health Care Proxy are provided at the back of this guide.

If you have no one you can appoint to decide for you, or do not want to appoint someone, you can also give specific instructions about treatment in advance. Those instructions can be written, and are often referred to as a Living Will.

You should understand that general instructions about refusing treatment, even if written down, may not be effective. Your instructions must clearly cover the treatment decisions that must be made. For example, if you just write down that you do not want "heroic measures," the instructions may not be specific enough. You should specify the kind of treatment that you do not want, such as a respirator or chemotherapy, and describe the medical condition when you would refuse the treatment, such as when you are terminally ill or permanently unconscious with no hope of recovering. You can also give instructions verbally by discussing your treatment wishes with your doctor, family members or others close to you.

Putting things in writing is safer than simply speaking to people, but neither method is as effective as appointing someone to decide for you. It is often hard for people to know in advance what will happen to them or what their medical needs will be in the future. If you choose someone to make decisions for you, that person can talk to your doctor and make decisions that they believe you would have wanted or that are best for you, when needed. If you appoint someone and also leave instructions about treatment in a Living Will, in the space provided on the Health Care Proxy form itself, or in some other manner, the person you select can use these instructions as guidance to make the right decision for you.

If you do not appoint someone to make a decision for you, NYS law permits others to make decisions for you from a surrogate list. The person who is highest on the list is the one who is allowed to make decisions. The order of the list is: a MHL article 81 court appointed guardian, a spouse or domestic partner, an adult child, a parent, a sibling, or a close friend.

Deciding About Cardiopulmonary Resuscitation

Your right to decide about treatment also includes the right to decide about cardiopulmonary resuscitation (CPR). CPR is emergency treatment to restart the heart and lungs when your breathing or circulation stops. Sometimes doctors and patients decide in advance that CPR should not be provided, and the doctor gives the medical staff an order not to resuscitate (DNR order). If your physical or mental condition prevents you from deciding about CPR, someone you appoint, your family members, or others close to you can decide.

Hope...
*There's
always HOPE
in Hospice*

Appointing Your Health Care Proxy

What is a health care proxy?

The New York State Health Care Proxy Law allows you to appoint someone you trust - for example, a family member or close friend - to decide about treatment if you lose the ability to decide for yourself. You can appoint someone by signing a form called a Health Care Proxy.

You can give the person you select, your “health care agent”, as little or as much authority as you want. You can allow your health care agent to decide about all health care or only about certain treatments. You may also give your agent instructions that he or she has to follow. Your agent can then make sure that health care professionals follow your wishes and can decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent’s decisions as if they were your own.

Why should I choose a health care agent?

If you become too sick to make health care decisions, someone else must decide for you. Health care professionals often look to family members for guidance. Appointing an agent lets you control your medical treatment by:

- Allowing your agent to stop treatment when he or she decides that is what you would want or what is best for you under the circumstances;
- Choosing one family member to decide about treatment because you think that person would make the best decisions or because you want to avoid conflict or confusion about who should decide; and choosing someone outside your family to decide about treatment because no one in your family is available or because you prefer that someone other than a family member decide about your health care.

How can I appoint a health care agent?

All competent adults can appoint a health care agent by signing a form called a Health Care Proxy. You don’t need a lawyer - just two adult witnesses. You can use the form provided for you at the back of this guide.

When would my health care agent begin to make treatment decisions for me?

Your health care agent would begin to make treatment decisions after doctors decide that you are not able to make health care decisions. As long as you are able to make treatment decisions for yourself, you will have the right to do so.

What decisions can my health care agent make?

Unless you limit your health care agent's authority, your agent will be able to make any treatment decision that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments, and decide that treatments should not be provided, in accordance with your wishes and interests. If your health care agent is not aware of your wishes about artificial nutrition and hydration (nourishment and water provided by feeding tubes), he or she will not be able to make decisions about these measures. Artificial nutrition and hydration are used in many circumstances, and are often used to continue the life of patients who are irreversibly ill.

How will my health care agent make decisions?

You can write instructions on the proxy form. Your agent must follow your oral and written instructions, as well as your moral and religious beliefs. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interests.

Who will pay attention to my agent?

All hospitals, doctors and other health care facilities are legally required to obey the decisions by your agent. If a healthcare provider objects to some treatment options (such as removing certain treatment) they must tell you or your agent IN ADVANCE.

What if my health care agent is not available when decisions must be made?

You can appoint an alternate agent to decide for you if your health care agent is not available or able to act, when decisions must be made. Otherwise, health care providers will make treatment decisions for you that follow instructions you gave while you were still able to do so. Any instructions that you write on your Health Care Proxy form will guide health care providers under these circumstances.

What if I change my mind?

It is easy to cancel the proxy, to change the person you have chosen as your health care agent, or to change any treatment instructions you have written on your Health Care Proxy form. Just fill out a new form. In addition, you can require that the Health Care Proxy expire on a specified date or if certain events occur. If not, the Health Care Proxy will be valid indefinitely. If you choose your spouse as your health care agent and you get divorced or legally separated, the proxy is automatically canceled unless you have made a designation otherwise.

Can my health care agent be legally liable for decisions made on my behalf?

No. Your health care agent will not be liable for treatment decisions made in good faith on your behalf. Also, he or she cannot be held liable for costs of your care, just because he or she is your agent.

Is a health care proxy the same as a living will?

No. A living will is a document that provides specific instructions about healthcare treatment. It is generally used to declare wishes to refuse life-sustaining treatment under certain circumstances.

In contrast, the health care proxy allows you to choose someone you trust to make treatment decisions on your behalf. Unlike a living will, a health care proxy does not require that you know in advance all the decisions that may arise. Instead, your health care agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made. The health care proxy is just as useful for decisions to receive treatment as it is for decisions to stop treatment. If you complete a Health Care Proxy form, but also have a living will, the living will provides instructions for your health care agent, and will guide his or her decisions.

Where should I keep the proxy form after it is signed?

Keep the original for yourself. Give a copy to your agent, your doctor and any other family members or close friends you want. You can also keep a copy in your wallet or purse or with other important papers.

How will decisions be made if I do not complete a healthcare proxy form?

The Family Healthcare Decisions Act governs how decisions are made under this circumstance. After a variety of steps are followed to make sure you lack capacity to make a decision, the person highest on the surrogate priority list outlined in the law can make a decision.

What is a do-not-resuscitate order?

A do not resuscitate (DNR) order in the patient's medical chart instructs the medical staff not to try to revive the patient if breathing or heartbeat has stopped. This means physicians, nurses and others will not initiate such emergency procedures as mouth-to-mouth resuscitation, external chest compression, electric shock, insertion of a tube to open the patient's airway, injection of medication into the heart or open chest heart massage.

If the patient is in a nursing home a DNR order instructs the staff not to perform emergency resuscitation and not to transfer the patient to a hospital for such procedures.

Can I request a DNR order?

Yes. Under New York law, all adult patients can request a DNR order. If you are sick and incapable of deciding about resuscitation, a family member or others close to you can decide on your behalf.

What are the advantages and disadvantages of CPR?

Cardiopulmonary resuscitation (CPR), when successful, restores heartbeat and breathing and enables a patient to resume his or her previous lifestyle. In other cases, CPR may fail to restore basic life functions or only partially succeed, leaving the patient brain-damaged or otherwise impaired.

The success of CPR depends on the patient's overall medical condition and level of functioning before hospitalization. Age alone is not a predictor of success, although illnesses and frailties associated with advanced age often result in less successful outcomes.

Is my right to request or receive other treatment affected by a DNR order?

It is widely recognized by health care professionals, clergy, lawyers and others that DNR orders are medically and ethically appropriate under certain circumstances. For some patients, CPR offers more burdens than benefits, and may be contrary to the patient's wishes. The issuance of a DNR order does not affect the other treatment you wish to receive.

Is my consent required for a DNR order?

Yes, your physician must obtain your consent (or that of your healthcare agent or family member if you are unable to consent) before entering a DNR order in your record. In an emergency, it is assumed that all patients would consent to CPR unless a DNR order is in the record.

Do Not Resuscitate Orders - A Guide for Patients and Families

How can I make my wishes about a DNR known?

An adult patient can consent to a DNR order verbally, as long as a witness is present. UH staff can serve as a witness and will arrange for your MD to sign a DNR order. In the home setting, we will give you the order to keep once it is signed. A living will may be used to convey these wishes as long as it is properly witnessed. You can also request a DNR if you are at home. UH staff will assist in arranging for its issuance.

You can specify that you want a DNR order only under certain circumstances (such as if you become terminally ill or permanently unconscious) or that you wish only specific CPR procedures performed such as mouth-to-mouth breathing but not open heart massage. Before making a decision about CPR you should speak with your physician about your overall health and the benefits and burdens CPR would provide for you. A full and early discussion between you and your doctor can avoid later misunderstandings.

If I request a DNR order, is my physician bound to honor my wishes?

If you don't want to be resuscitated and you request a DNR order, your physician must either:

- issue the DNR order; or
- transfer responsibility for your care to another physician; or
- refer the matter to a dispute mediation system in the hospital or nursing home. The mediation system is only authorized to mediate disputes; it cannot overrule your decision.

If mediation has not resolved the dispute within 72 hours, your physician must enter the order or transfer you to the care of another physician.

What happens if I do not have the capacity to decide for myself?

You are presumed by law to be mentally capable of deciding about CPR unless two physicians, or a court, determines that you no longer have the capacity to make the decision. You will be informed of this determination if you are able to understand it, and no DNR order will be written if you object.

If I do not have the mental capacity to make a decision about CPR and do not leave instructions in advance, who will decide?

If you lose the capacity to decide and did not leave advance instructions, a DNR order can be entered only with the consent of someone chosen by you in advance, or by a family member or another person with a close personal relationship to you. The person highest on the following list will decide on your behalf:

- your healthcare agent;
- a court appointed guardian (if there is one);
- your closest relative;
- a close friend.

How can I select someone to decide for me?

You can appoint a person verbally, with two witnesses present. You can also appoint someone during or in advance of hospitalization by stating your wishes in writing and signing that statement with any two adults present. The adults must also sign your written statement.

Under what circumstances can a family member or close friend consent to a DNR order?

A family member or close friend can consent to a DNR order only when you are unable to decide for yourself and:

- you have a terminal condition; or
- you are permanently unconscious; or
- CPR would be medically futile; or
- CPR would impose an extraordinary burden on you given your medical condition and the expected outcome of resuscitation.

Anyone deciding for you must base the decision on your wishes, including your religious and moral beliefs, or if your wishes are not known, on your best interest.

What if members of my family disagree?

They can ask for the matter to be mediated. Your physician will request mediation if he or she is aware of any disagreement among family members.

What if I lose the capacity to decide and do not have anyone who can decide on my behalf?

A DNR order can be issued only if two physicians conclude that CPR would be medically useless or if a court approves the DNR order. It would be best if you discussed the matter with your physician and left instructions in advance.

Who can consent to a DNR order for children?

A DNR order can be entered in the record for a patient under the age of 18 only with the consent of the patient's parent or guardian. If the minor has the capacity to decide, the minor's consent is also required for a DNR order.

What happens if I change my mind after I consent to a DNR order?

You or anyone who consents to a DNR order on your behalf can withdraw that consent at any time by informing your physician/nurse of the decision.

What happens to a DNR order if I'm transferred from a nursing home to a hospital or vice-versa?

The health facility where you are sent may continue the DNR order but is not obligated to do so. If the order is not continued, you or anyone who decided on your behalf will be informed and can request that the order be entered again. A new order should be written within 24 hours of admission to the new facility.

Comfort...

*Relief from your pain
and other symptoms*

UH has a staff of caring professionals and volunteers who work as a team to bring hope and comfort to you and your family. Working with your physician and loved ones, the Hospice team focuses on the whole person: body, mind and spirit. The goal is to make every day a celebration of life...enabling you to achieve the highest, most rewarding quality of life possible.

The Hospice Nurse

Following admission to our program, a nurse will visit on a regular basis. These visits are scheduled as needed. The nurse's visits are flexible and are geared to meet your needs.

Physical changes are expected during an illness. The nurse will guide you and your family through this process, helping to ensure your comfort. Hospice works closely with your physician keeping him/her informed as to how you are doing. If your doctor orders a new medication or treatment, the nurse will give instructions concerning the change.

Hospice is aware that concerns or problems can arise at anytime. The UH office is open 8:30 am - 4:30 pm., Monday through Friday. A hospice nurse is available 24 hours a day, seven days a week. If you have a problem and need to call a nurse when the office is closed, simply call our office number. An answering service will take your message and telephone number and have a hospice nurse call you back, usually within 15 minutes. In the event that there is no response when dialing our office number after regular work hours, please call our emergency alternate number and ask that the on call nurse contact you as soon as possible. For phone number, see inside front cover. The on-call nurse will give guidance and direction over the phone. If more assistance is needed, the nurse will make a visit to your home.

Hospice's goals are to promote your independence, increase your comfort and provide support to you and your family. Please discuss any problems or concerns with your nurse during her visits or call the UH office.

At the time of any emergency or disaster situation for instance: ice/snow storm, hurricane or power failure, UH has an Emergency Disaster Preparedness Plan which will be implemented. You will be advised if the emergency situation necessitates revision of UH's staff schedules, i.e., UH staff may not be able to make a visit if there is a safety risk due to snow, etc. A UH nurse is always available for assistance by telephone to give you guidance and direction.

United
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For You

The Hospice Social Worker

The social worker is an important member of the UH team. Beginning with the initial evaluation visit, the social worker provides information, support and assessment of needs. Visits are made to explore the need for, and then provide, any of the following: assistance with planning for your care, locating community and financial resources, and counseling for you and your family to address the many issues that may arise at this stressful time. The social worker can also be very effective in helping families improve communication and in instructing you/your family in relaxation techniques to decrease anxiety and enhance pain control.

Home Health Aide and Therapy Services

The home health aide (HHA) provides direct personal care to the hospice patient under the supervision of the nurse. Personal care includes bathing, toileting, skin care, hair care, mouth care and nail care. An aide may also shave a male patient with a disposable or electric razor.

The nurse will give you a copy of the HHA care plan which is individualized for you. This care plan will tell you specifically what the aide will be doing for you.

Other care provided by the HHA may include: bedmaking, helping you from bed to chair, helping you while walking, turning you while in bed, straightening your area and changing simple, non-sterile dressings. The HHA may prepare a light meal for you, heat a can of soup, make a sandwich. Discuss specifics with the nurse.

Our home health aide coordinator will call to give you the aide's schedule for the following week. If you have a problem with the days or time scheduled, please discuss this with your nurse. We will make every effort to arrange the schedule according to your needs. If you need additional help or have any questions concerning the aide's care, please feel free to talk to a member of the team.

UH employs and/or contracts with individuals and agencies for the provision of physical, speech, occupational, nutritional, respiratory, massage and music therapies.

The Hospice Spiritual Care Coordinator

The Spiritual Care Coordinator (SCC) is available to visit you and/or speak with the clergy of your congregation. The Hospice SCC emphasizes a person-centered approach to ministry that focuses on you and your loved one's definition of spirituality. The SCC provides support to individuals with/without a religious framework.

Services provided include:

- Pastoral counseling with you and/or your loved ones based on your individual concerns.
- Sharing ritual, prayer, and pastoral ministry to those whose faith makes this a resource for them.
- Assisting in funeral planning and being available to conduct or assist in conducting funerals when appropriate.
- Helping with communication between you and your caregiver's faith community as desired.

The Hospice Volunteer

UH is fortunate to have a group of men and women who volunteer their time to help patients and families. The volunteers complete a training course and work closely with the other team members.

Volunteers can offer companionship for you as well as respite for your caregivers. Volunteers can do light shopping, run errands, baby sit, drive car pools and more. The volunteer helps in many ways where a special touch is needed. Perhaps the most valuable gift they can offer is to listen and give support.

Some individuals prefer to have scheduled visits by the volunteers as the need arises. Volunteers and staff will make every effort to visit at the convenience of you and your family.

Volunteer services are offered upon admission. If at anytime following admission volunteer assistance is needed, please call the volunteer coordinator at the Hospice office.

The Hospice Medical Director

Prior to your admission to Hospice, the medical director reviewed your medical information and history. This information is shared with the Hospice team members. Your primary physician continues to order appropriate services and medications which are periodically reviewed by the medical director. The hospice medical director is available as a consultant for your primary physician and is available to cover for your physician at such times as vacation, etc.

If you need a hospice physician, the hospice medical director will assume that role.

Equipment, Supplies & Medications

You may find, or a hospice team member may suggest, the need for medical equipment to increase your independence, comfort or safety. Equipment such as an electric bed, commode, wheelchair, oxygen, shower chair, walker or cane is provided by Hospice. Most equipment will be delivered by UH contracted vendors within 24 hours following discussion with the nurse. If equipment such as oxygen, is needed on an emergency basis, UH will make those arrangements.

When equipment is delivered, please make sure that there is space for it, i.e., your bed may need to be removed in order to have enough space for an electric bed.

When oxygen is being used continuously, Orange & Rockland Utilities must be notified in writing of the need for this equipment. Please see letter in the back of this booklet to complete and mail to O&R. In the event of a power failure, O&R will make every attempt to restore service as quickly as possible in these situations. United Hospice will also provide a portable back-up tank that does not require electricity.

Other supplies such as gloves, dressings for a wound, bedpans, urinals, and bed protectors are also provided. They are usually brought to the home by a hospice team member but can also be picked up at the UH office.

UH covers the cost of medications used to manage symptoms related to the hospice diagnosis. Our contracted pharmacies provide needed medications 24 hours a day. Please check the amount of all medications. When you have approximately a three day supply of medicine, call the hospice nurse to obtain more medicine.

If you have any questions about equipment, supplies or medications, please discuss them with your primary nurse when she visits or call the office. Please notify UH if there are any delays in delivery of the above items.

Levels of Care

Hospice care can be provided across many levels of care and settings. The levels of care provided by UH are:

1. Routine Home Care. This level of service includes the services previously described. These services are provided on an as needed basis.
2. Inpatient Care. UH contracts with area hospitals and offers care at the Joe Raso Hospice Residence to provide acute symptom management when symptoms cannot be managed in another setting. This level of care is usually for brief periods of time. Upon admission to the inpatient setting, Hospice staff will assist you in developing a plan to meet your future needs.
3. Continuous Care. In the event of an acute medical crisis in the home, Hospice will offer to provide shifts of nursing and aide services. The purpose of this level of care is to stabilize symptoms so care can be managed by family / other caregivers. Continuous care is placed for brief periods of time. Once the symptoms are controlled, patients will resume receiving routine home care.
4. Respite Care. The goal of respite care is to maintain patient comfort while providing short-term relief to caregivers from responsibilities of caring for loved ones. Respite care is provided through the utilization of varied resources.

Hope and Healing

People who experience the loss of a loved one often feel that they have no place to turn. They might feel as though the loss isn't real, or they may feel confused and forgetful. They might cry at unexpected times. They might feel angry and are very often preoccupied with thoughts about the person who died. Sometimes they experience guilt or sleeplessness. They might have a need to tell and retell stories about the life and death of the deceased. Sometimes they worry that they are losing their mind. These are all natural and normal grief responses.

Hospice recognizes that it is important to express feelings after the death of someone close. We remain available to families who grieve by offering the following bereavement support services:

- Support Groups - These groups are a professionally led journey through the grief process.
- Individual assessments, counseling, and referrals if necessary
- Healing Hearts Program - Support groups are provided for children. These groups are professionally led and are designed for children of all ages and their parent or guardian to help them acknowledge and work through their grief.
- Educational programs

Compassion...

We care about you

Support

*A specialized team dedicated
to meeting your needs*

Family...

*Care and support for those
who mean the most to you*

Choice...

You have a voice in all decisions

Home Safety Precautions

Falls are a leading cause of injury. If you fall at home, please call Hospice immediately at 845-634-4974.

1. If you have been instructed to use an assistive device, i.e. walker, cane, etc., please comply for your safety.
2. Notify Hospice if you are feeling dizzy, weak or short of breath:
 - a) Do not go up or down stairs
 - b) Sit down in the nearest chair or get back to bed
 - c) Tell us if dizziness occurs after taking a particular medication
3. Put a bell or intercom near you to use if you need to call for help.
4. Let your caregivers know when you need to use the bathroom.
5. Perhaps, placing a bed pan, urinal or commode near you, may assist you during times that you are not feeling well or that you are alone.
6. Keep a night light that illuminates by itself when it is dark by your bed and bathroom.
7. Do not use the shower or bathtub when you are home alone.
Do not lock the bathroom door.
8. Do not keep loaded firearms in the house. Unloaded firearms should be kept in a secure place out of the reach of children.

Home Fire Safety

Fire is perhaps the most dangerous and deadly of all home emergencies. Let this checklist be your guide for making sure that your home is safe from accidental fire.

1. Install and regularly check smoke detectors on each floor.
2. Post “No Smoking” signs in areas where oxygen is used.
3. Keep a fire extinguisher in areas where oxygen is used.
4. Store oxygen tanks in an upright position in a cool area.
Do not store near a heat source or in a closet.
5. Do not place anything on or over an oxygen concentrator.
6. Keep flammable materials away from heat sources such as chimneys, water-heaters, portable heaters, stoves, etc.
7. Store flammable materials away from stairways and walkways.
(If a fire did break out, they could block the exit.) Do not store, use or carry flammable liquids in open containers.
8. Clean ovens, range tops and exhaust fans to keep them free of grease.
9. Make sure that a testing lab such as Underwriters Laboratory (usually marked with a UL in a circle) has approved electrical appliances.

Controlling Infection at Home

Handwashing is the most important way that you can protect your loved ones from getting or spreading an infection. Hands should be cleaned with soap and water or an alcohol-based hand cleaner. Hands should be washed (in the bathroom):

1. Before and after giving personal care.
2. Before meal preparation, eating or drinking.
3. After toileting.
4. After sneezing, coughing or blowing your nose.
5. After removing disposable gloves.

Individuals should wear gloves in the following situations:

(Your nurse or home health aide will provide gloves for you)

1. When caring for open skin lesions or draining wounds.
2. When handling secretions or excretions such as vomit, urine, stool, blood or wound secretions.
3. When handling soiled diapers, disposable pads, linens or clothing.
4. When providing oral care, if contact with oral lesions or blood is likely.

Disinfecting Surfaces/Laundry

1. Soiled linens/clothing should be washed separately from the household wash. If they can be bleached, add one cup of bleach to washer.
2. For floor or counter surfaces soiled by secretions or excretions, clean with hot soapy water, followed by disinfecting with a 10% bleach solution (one tablespoon bleach in a quart of water or $\frac{1}{4}$ cup in a gallon of water) is adequate. The bleach solution can also be used to disinfect the toilet, tub and shower after routine cleaning.
3. Bedpans and commodes should be cleaned regularly with the bleach solution.

Disposing of Medical Waste

You can help prevent, injury, illness and pollution by following some simple steps when you dispose of sharp objects and contaminated materials that were used in the home.

Place needles, syringes and other sharp objects in a hard plastic or metal container with a screw on or tightly secured lid. Do not put objects in any container that will be recycled or returned to the store. Keep container in an upright position. Fill no more than 2/3 full. Keep containers with sharp objects out of the reach of children. If you live in Rockland County, please refer to the brochure “Rockland County Sharps Program” in the pocket at the back of this booklet.

We also recommend that **soiled bandages, disposable sheets and medical gloves** be placed in securely fastened plastic bags before you put them in the garbage with your other trash.

Gas Safety

Remember: When in doubt, get out! For gas leaks only, call Orange and Rockland utilities at 1-800-533-5325.

1. All homes should have carbon monoxide detectors.
2. When natural gas comes out of the ground it has no smell or color. An odor is added so you can smell it in case there is a leak. If you smell a strong odor:
 - Everyone should get out of the home. Call 911 if you need assistance evacuating.
 - Don't risk a fire by lighting a match, touching an electrical switch or using a flashlight or telephone unnecessarily.
 - Call your gas company from a neighbor's home to avoid using your phone.

If the smell of gas is very faint, a pilot light may be out. If so:

- Make sure the appliance is off.
- Open a window near the appliance.
- Wait five (5) minutes for the gas to clear.
- Follow manufacturer's instructions for re-lighting.
- If the pilot goes out often, have a professional check the appliance.
- Keep the area around your appliance clean and litter free. Keep flammables away.
- Make sure the pressure relief valve on the top of your water heater is not blocked. If water or steam ever comes out of the valve shut the water off and have it serviced.
- Don't install any energy saving device with a flue or vent without first contacting the gas company.

Don't use your stove as a space heater. Read instructions carefully. Learn how to shut your appliance off in case of an emergency. Have appliances installed and service by qualified professionals.

Emergency Plan Checklist

- Review the "Planning for Emergencies: Radiation, Hazardous Materials, Weather" booklet mailed to you by the NYS Preparedness Commission. If you do not have this booklet, call in Rockland County, 1-800-942-1450 or in Orange County, 1-845-615-0400.
- Post emergency telephone numbers near the phone.
- Meet with household members to discuss the dangers of fire, severe weather, earthquakes, and other emergencies. Devise a plan to respond to each.
- Identify in advance the radio station which broadcasts emergency information and tape them to radio. Turn radio on to these stations in an emergency.
- Show family members how to turn off the water, gas and electricity at main switches, if necessary.
- Pick two emergency meeting places: (a) A place near your home in case of fire (b) a place outside your neighborhood in case you cannot return home after a disaster.
- Discuss what to do if you experience power outages or personal injuries.
- Find any available safe spots in your home for different types of disasters.
- Draw a floor plan of your home. Mark two (2) escape routes from each room.
- Pick one out-of-state and one local friend or relative for family members to call if separated during a disaster. (It is often easier to call out-of-state than within the affected area.)
- Teach children your out-of-state contact's phone number.
- Replace worn or frayed cords, plugs or wiring immediately or have them repaired by a licensed electrician.
- Never overload an electrical circuit.
- Never leave an open flame unattended.
- Extinguish fireplace and barbecue flames completely before going to bed. (Even if there is no visible flame, embers can reignite.)
- Never smoke in bed or when drowsy.
- Never empty ashtrays into a wastebasket.

Safe Practices

1. Keep a multipurpose fire extinguisher on each level of your home and learn how to use it.
2. To operate a fire extinguisher, pull the pin, aim nozzle at the base of fire, squeeze the handle and sweep nozzle from side to side.
3. In the event your clothing should catch fire, stop what you are doing, drop to the floor and roll over and over until the flames are extinguished.
4. Have regular home fire drills.
5. If you do not have a fire escape, keep portable escape ladders on the upper floors of your home.
6. Make sure that all security gates and window guards can be opened from **within the home**.

Corporate Compliance Plan

United Hospice, Inc. has adopted a compliance program in order to embody its commitment to conducting business in compliance with applicable laws, rules, regulations and other directives of the federal, state and local governments and agencies. An expression of this commitment is the Code of Conduct described in the compliance manual, which is applicable to all directors, officers, employees and agents of UH. This manual is available for review on request at UH's offices. The Code of Conduct is intended to provide general guidelines to assist UH employees and agents to understand and appreciate the manner in which UH wishes to conduct its business. Although it cannot cover every situation in the daily conduct of our many and varied activities, nor substitute for common sense, individual judgement or personal integrity, it is the duty of every employee or agent of UH to adhere to the code. The code requires that UH staff members:

- Maintain high principles of business ethics and integrity. Any relationship or interest that might impede the exercise of this duty must be disclosed to UH, and examined to determine potential or actual conflict of interest.
- Establish honest communications and hold with respect all confidential, medical, and proprietary information. All reports and records must accurately reflect and clearly represent the relevant facts of the nature of the transaction.
- Refrain from conduct that violates fraud and abuse laws, tax laws, and anti-trust laws and regulations. Individual political activity by any individual employed by UH is encouraged, however, this activity may not involve the use of UH resources nor include any implication of benefit to any government official or agency.
- Avoid the appearance of impropriety by discouraging the acceptance of gifts, gratuities, and honoraria. Never use "insider knowledge" for any business activity conducted by or on behalf of UH.
- Prohibit offering, giving, soliciting or receiving any form of bribe or kickback.
- Protect the assets of UH and of the environment by conducting business in a way that is respectful of the use of all resources. Travel and entertainment expenses must be consistent with the responsibilities and UH's needs and resources for each individual. Use of UH's resources for personal benefit without express permission is prohibited.
- Treat all persons with respect. Discrimination, harassment and inequitable treatment of any person will be promptly investigated.

Reprisal shall not be taken against anyone who reports suspected violations of the Code of Conduct or any other UH policies and procedures in good faith. To anonymously report a potential violation, please call our compliance hotline at 845-634-1138 and then press 5.

United Hospice, Inc.
HOSPICE BENEFIT ELECTION FORM

Patient Name: _____

I consent to admission to United Hospice, Inc. (UH), a nonprofit corporation dedicated to emphasizing quality of life. I understand and consent to the following:

1. The hospice program is palliative (non-disease directed treatment) in its goals and care provided. The program emphasizes the management of physical symptoms and identifies and addresses the emotional and spiritual needs of the patient and family.
2. The assigned interdisciplinary hospice team will include: Primary Nurse, Medical Director, Medical Social Worker, Spiritual Care Counselor and Bereavement Counselor.
3. Additional services may be provided as deemed appropriate by UH's Interdisciplinary Team:
 - a. Home Health Aide/Homemaker
 - b. Dietary Counseling
 - c. Physical, Occupational and Speech Therapist
 - d. Volunteer services
 - e. Medical supplies, equipment, laboratory services and some prescription drugs (related to the admitting diagnosis)
4. On-call nursing services are available 24 hours/day, 7 days/week as needed.
5. There will be biweekly interdisciplinary meetings regarding my care in terms of physical, emotional and spiritual needs and discussion of my continued eligibility to receive hospice care.
6. The UH team is not intended to take the place of the family/caregiver, but to enable and support the home-based family/caregiver in caring for the patient.
7. Hospice inpatient services are available if needed for the management of acute medical symptoms associated with the diagnosis for which I have been admitted to hospice. This level of care may be provided at the Joe Raso Hospice Residence, Nyack Hospital and Good Samaritan Hospital. These services are for acute, short-term care for symptom management. **These services MUST be preapproved by UH in order to guarantee payment.**
8. Respite care is available for a maximum of 5 consecutive days for the relief of family/caregivers and will be provided at a nursing home contracted with UH. **This level of care must be preapproved and arranged by the hospice interdisciplinary team.**
9. UH accepts commercial insurance, Medicare and Medicaid assignments. I authorize UH to bill my insurance company for services provided and I assign all benefits directly to UH.
10. I designate _____ as my primary physician with whom the hospice team will consult concerning my care. **(Consultant physician services MUST be preapproved by UH in order to guarantee payment.)**
11. I can choose to receive hospice care from another hospice program at any time. To do so, I must inform UH of my wishes so a transfer can be arranged.
12. I can choose to discontinue hospice care at any time. (Medicare patients must sign a revocation statement which can be obtained from any UH employee.)
13. I give consent and approval for notations to be made on hospice records and care plans regarding medical, nursing, psychological, spiritual and personal information necessary for the hospice team to fulfill its functions. I give consent and approval for the release of information and appropriate medical records pertaining to my care to third party payors, physicians, accrediting bodies such as the Joint Commission, or community agencies requesting the information in order to verify, coordinate or offer further services. I also give consent for the release of information and medical records to Nyack Hospital or Good Samaritan Hospital, whichever provides my inpatient care.

- 14. The fiscal intermediary medical review personnel may conduct home visits and/or review charts in order to ensure that quality care is provided and that payment for the services received is appropriate. Permission can be revoked at time of request for visit.
- 15. I have received/read the UH Patient/Family Bill of Rights and Responsibilities.
- 16. I have received/read the UH Notice of Privacy Practices.
- 17. My election of hospice care goes into effect on _____, and will remain in effect unless I revoke the election in writing and/or the United Hospice Medical Director no longer considers my condition to warrant further hospice care. Discharge will occur as a result of leaving the service area.

FOR MEDICARE PATIENTS ONLY

- 1. While this election is in effect, I am waiving all other Medicare payments for the illness for which I am electing the hospice benefit.
- 2. Should I revoke this election, I may resume this waived Medicare coverage.
- 3. UH will assume the cost of pre-approved inpatient care at the Joe Raso Hospice Residence, Nyack Hospital or Good Samaritan Hospital.
- 4. My regular Medicare benefit will continue to cover the cost of care (both hospital and Part B expenses) for non-hospice related care. It will not cover services that are disease related but are not part of the hospice plan of care.
- 5. I understand that the Hospice benefit periods are as follows:
 First benefit 90 days Unlimited number of 60-day benefit periods as long as
 Second benefit 90 days the patient continues to be eligible to receive care.
- 6. Medicare Part B will continue to provide payments to my primary physician for any physician services provided.
- 7. The hospice benefit has been explained and I had the opportunity to ask questions.

A. _____
 Signature of PATIENT (if unable to sign, use X) Date

B. If patient lacks capacity and has designated Health Care Proxy:

 Signature of Health Care Proxy Date

C. If patient lacks capacity and does not have a Health Care Proxy:

 Signature of Legal Representative Date

Relationship of Legal Representative to Patient: _____

Reasons for inability to sign consent (check one or more):

Cannot understand nature of hospice election Patient physically unable to sign consent
 Is not oriented to time, place, person but agrees to elect hospice service/benefit

Additional reason(s): _____

UH Personnel: I have reviewed the hospice program with patient or legal representative and witnessed the signing of the Benefit Election Form:

UH Staff Signature _____ Date _____

United Hospice, Inc.

Advance Directives: My Health Care Proxy, Living Will and Other Wishes

I, _____, make this statement as a directive regarding my medical care.
(print name)

Part I. My Health Care Proxy

I appoint the person listed below to be my health care agent to make decisions about my medical care if there ever comes a time when I cannot make those decisions myself.

(print name) (phone #)

(address, city, state, zip)

If the person above cannot or will not be my health care agent, I appoint this person:

(print name) (phone #)

(address, city, state, zip)

I want my health care agent, my doctors, my family and others to be guided by the choices I have indicated below or as he/she otherwise knows. (In New York State, your agent **MUST KNOW** your wishes in order to make decisions about artificial nutrition and hydration).

Part II. My Living Will

Put the initials of your name by the choices you want.

These are my wishes if I am terminally ill:

Life Sustaining Treatments

_____ I do not want life-sustaining treatments (including but not limited to CPR, respirators, etc.) started.
If life sustaining treatments are started, I want them stopped.

_____ I want life sustaining treatment that my agent (or loved ones if no agent appointed) thinks is best for me.

Artificial Nutrition and Hydration

_____ I do not want artificial nutrition and hydration started. If artificial nutrition and hydration is started, I want it stopped.

_____ I want artificial nutrition and hydration, if it is necessary to keep me alive.

Comfort Care

_____ I want to be kept as comfortable and pain free as possible.

Part III. Other Wishes

You have the right to be involved in all decisions about your health care, even those not dealing with terminal conditions. If you have any wishes not covered in other parts of this document, put them here:

Organ Donation

_____ I do not want to donate any of my organs or tissues.

_____ I want to donate any usable organs and tissues.

_____ I only want to donate the organs and tissues listed below:

Autopsy

_____ I do not want an autopsy.

_____ I agree to an autopsy if my doctors/family wish it. (Please note: There may be a cost incurred if the autopsy is not felt to be medically necessary).

Signatures: You and **two (2) witnesses** must sign this advance directive in order for this to be a legal document.

a. By my signature below I show that I understand the purpose and the effect of this statement.

Signature: _____ Date: _____

Address: _____

b. Your witness' signatures: (Your witness **cannot be your agent** or alternates listed on page 1.)

I declare that the person(s) who signed this document is personally known to me and appears to be of sound mind and acting of is/her own free will. He/she signed this document in my presence. I am at least eighteen (18) years of age and NOT the person appointed as agent by this document.

1. Signature: _____ Date: _____

Address: _____

2. Signature: _____ Date: _____

Address: _____

*United Hospice is accredited by the Joint Commission on the Accreditation of Healthcare Organizations.
If you wish to file a complaint or share your concerns about the care provided by UH, you may reach them by
Phone: 800-994-6610 or by E-mail: complaint@jointcommission.org*