



**FOR REFERRALS
AND INFORMATION
CALL
718-472-1999**

Hospice of New York

SERVING MANHATTAN, THE BRONX, BROOKLYN, QUEENS AND NASSAU

ADMISSION HANDBOOK

Hospice of New York

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NOTIFICATION OF SERVICES

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The Hospice of New York Plan of Care is developed with your input and assistance. You can expect services from the following disciplines—the exact number of visits will vary based upon your needs:

SERVICE	EMPLOYEE NAME	PROJECTED FREQUENCY OF VISITS	PHONE
<input type="checkbox"/> COMMUNITY HOSPICE NURSE	_____	_____	- -
<input type="checkbox"/> MEDICAL SOCIAL WORKER	_____	_____	- -
<input type="checkbox"/> HOSPICE AIDE	_____	_____	- -
<input type="checkbox"/> SPIRITUAL CARE COUNSELOR	_____	_____	- -
<input type="checkbox"/> VOLUNTEER	_____	_____	- -
<input type="checkbox"/> OTHER _____	_____	_____	- -

THE PATIENT CARE COORDINATOR OF YOUR HOSPICE TEAM IS: _____

PHONE: - -

On-going Care Plan review and revision will be provided by the Interdisciplinary Team with your input, and you will notified of any changes.

Regular staff hours are from 8:30am–5:00pm, Monday through Friday.
We are available 24 hours/day – 7 days/week for emergencies.

24 HOUR HOSPICE PHONE NUMBERS FOR EMERGENCIES

718.472.1999 OR 516.222.1211

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**PATIENT AND FAMILY
INFORMATION**

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INTRODUCTION TO HOSPICE

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The word *hospice* comes from ancient times meaning “a place of shelter for travelers on a difficult journey.” Today, hospice has come to mean a program of care for patients on life’s final journey. The hospice team of professionals and volunteers is committed to providing the resources and support needed to ensure comfort.

In an era of specialized medicine, hospice is the specialty health care program that is uniquely equipped to treat and manage the difficult needs and circumstances of a patient with a life-threatening illness. It is the “something else that can always be done” for the patient and family when they have been told “there is nothing else we can do.”

With the support of the hospice team, most patients can be cared for in their own homes. When inpatient care becomes necessary, Hospice of New York has home-like inpatient units available in medical facilities to ensure continuity of care.

The main concern of the hospice team is to optimize the quality of life for our patients and their loved ones. While hope of remission and cure is never abandoned, the focus of hospice care is on creating an environment where pain and symptoms are expertly treated so that life can be lived to its fullest.

Hospice physicians, nurses, social workers and spiritual care counselors compose the core of the hospice team. Our team works together with patients, families and their doctors to provide care and support.

Hospice of New York

To Comfort Always...



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PHILOSOPHY AND GOALS

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Hospice care is about choices. At a time when choices seem few and challenges seem many, Hospice works side by side with our patients and families. Our goal is to alleviate pain and symptoms. Hospice recognizes dying as an integral part of living. Hospice advocates for and respects the rights of the patient to live fully, including:

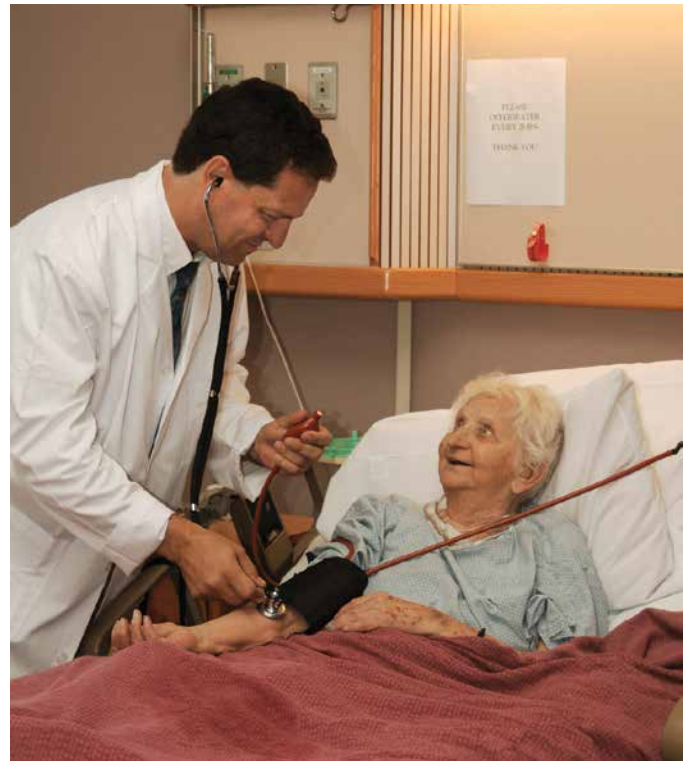
- The right to enjoy the highest possible quality of life.
- The right to die with dignity.
- The right to actively participate in the management of his/her care.
- The right to remain in the environment of his/her choice.
- The right to have their needs and the needs of their family members considered and met on an individual basis.
- The right to have support for themselves and their loved ones throughout the entire grieving process, from the time of diagnosis to more than one year following death.

LEVELS OF CARE

There are four levels of hospice care available.

1 Routine Home Care

Care and treatment are provided in the residential setting—usually a patient’s home assisted living facility or a long-term care skilled nursing facility with a focus on patient comfort in the familiar surroundings of their home environment. The Hospice team evaluates the needs of the patient and family to develop a personalized plan of care. Hospice services are then provided according to the needs identified in that plan. Hospice team members make regularly scheduled visits to coordinate care with the patient and primary caregiver. A Hospice Nurse and Nursing Administrator are on call 24 hours a day, 7 days a week for emergency needs.



Routine Home Care in the Skilled Nursing Facility

For nursing home residents who choose hospice care, the nursing home is considered the patient’s residence and the nursing home staff continues to provide daily care. Hospice provides additional supportive services, just as would be provided in a private house or apartment.

Hospice nurses offer their expertise in pain and symptom management. Home health aides supplement the personal care already offered by the nursing home. Counselors and volunteers provide additional support to families, residents, and nursing home staff. Additionally, the hospice bereavement counselor continues to work with the family, other residents and staff during both the resident’s illness and after death.

Finances and the Skilled Nursing Facility

- If the resident of the skilled nursing facility qualifies for and is approved for Medicaid payment of long-term care, Medicaid will continue to pay for room and board while the resident receives hospice care.
- If the patient or family is privately paying for long-term care, they will likewise be expected to continue paying room and board while the resident receives hospice care. Hospice services are covered by Medicare, Medicaid and most private insurance, including most HMOs.
- If the resident’s stay at the nursing home is paid through Medicare’s short-term skilled care benefit, Hospice services may only commence once the skilled care benefit ends.

2 General Inpatient Care

Short-term care can be provided in a specialized Hospice unit at a hospital or skilled nursing facility when a patient's symptoms cannot be managed at home. This includes 24-hour nursing and acute medical care to meet the patient's needs. Once a patient's condition stabilizes, he or she is expected to return home or to the skilled nursing facility for continued care by Hospice of New York.

3 Respite Inpatient Care

This is short-term inpatient care provided in a hospital or skilled nursing facility to relieve the patient's primary caregiver and family members for up to five days.

4 Continuous Home Care

Continuous care may be implemented as an alternative to admission to an inpatient facility in the rare circumstance when the patient's symptoms cannot be managed with routine home care. This level of care is utilized during a patient's crisis when symptoms are such that professional care is required for at least eight hours per day. Care may be provided for up to 24 hours, 7 days a week, on a time-limited basis for those patients whose conditions meet established guidelines for active symptom management. The Hospice team will need to approve this level of care in advance. Continuous home care is covered only as necessary to maintain the terminally ill individual at home as per Medicare guidelines.



CRITERIA FOR ADMISSION

The criteria for admission to Hospice is the following:

- The patient and/or legal representative must elect hospice.
- The patient's physician must certify hospice eligibility.
- The patient must have a limited prognosis.
- The patient must reside in The Bronx, Brooklyn, Manhattan, Queens or Nassau County.

The patient will not be denied hospice services because of race, color, creed, age, national origin, gender, handicap, religion, diagnosis, sexual orientation or ability to pay.

Patients can usually be admitted within 24 hours after Hospice has received the initial referral and physician certification.

Call Hospice of New York at 718.472.1999 or 516.222.1211 to discuss any questions you might have regarding services or admission. You may also contact us at info@hospice.nyc.

FINANCIAL CONCERNS

Medicare, Medicaid and most private health insurance, including most HMOs, provide a hospice benefit. This hospice benefit covers all of the services of the hospice team, plus the cost of medication, medical equipment, ancillary therapies and supplies related to the symptom management of the terminal illness. Hospice relieves the financial burden from patients and families.

With most plans, there are NO co-payments, exclusions, deductibles or add-on costs. Most patients will NOT receive a bill from Hospice. Please feel free to contact the Hospice office to clarify any financial concerns.

If the patient chooses hospice care for a life-limiting illness but later changes his or her mind, that patient can cancel or revoke hospice services at any time and immediately resume traditional medical care. The patient may resume hospice care in the future, should he or she so choose.

HOSPICE SERVICE AVAILABILITY AND COST

Services

The services available for all patients/families may include but are not limited to: nursing care; social services; spiritual and bereavement counseling; pharmacy supplies and medications; medical equipment; physical, occupational and speech therapies; dietary counseling; physician services; and volunteer services.

HMO or Private Insurance Rates

Most commercial insurance or managed care plans also cover hospice care. Services are provided as described above. Your rates, deductibles and co-pays are explained by the hospice staff.

Medicare Daily Rates

Medicare/Medicaid-funded patients are not responsible for any payments for treatments, supplies, patient care and/or interventions or support services that are directly related to the patient’s terminal illness and deemed necessary by the Hospice team.

For current Medicare reimbursement rates for hospice services please check our web site at www.hospice.nyc or call 718.472.1999.

SERVICES

Hospice provides all of the reasonable and necessary medical and non-medical support services for patient and family care, including:

- Hospice physician
- Nurse
- Home health aide or homemaker services
- Medical social services
- Spiritual counselor
- Volunteer
- Bereavement counselor
- Dietary counseling
- Medications for pain relief and symptom management
- Medical supplies and equipment related to the terminal illness
- Physical, occupational and speech therapy
- On-call services available 24 hours a day / 7 days a week
- Music, art and other specialized therapies



THE HOSPICE TEAM

Attending Physician

The patient's own physician continues to provide for the medical needs of the hospice patient. The hospice team will provide clinical updates every two weeks and upon any significant changes in patient status. More frequent updates from the nurse or hospice Medical Director can be requested.

Hospice Medical Director

The Hospice medical director is available for consultation, provides medical guidance for the hospice interdisciplinary team and participates in patient or family care planning. He/she may make home visits as needed, and upon request can assume the role of primary care physician.

Community Hospice Nurse

Registered nurses assess the patient's physical needs, perform skilled procedures and teach family members and other caregivers the skills needed for patient care at home. They coordinate the provision of medical equipment, supplies, and medications; communicate with the attending physician; and respond to patient and family emergencies. A hospice nurse is on call 24 hours a day, 7 days a week. Licensed practical nurses supplement the care provided by the nurse case manager.

Medical Social Workers

Certified social workers offer emotional support through individual and/or group counseling to patients and families to assist with financial concerns, and by arranging for social service assistance, including guidance in making funeral arrangements.

Hospice Aides

Specially trained aides assist patients in activities of daily living such as bathing, dressing and skin care, as well as light housekeeping and meal preparation, according to the plan of care.

Spiritual Care Coordinators

An ordained member of the clergy provides support to patients and families of all faiths through visits, prayer and counseling, often engaging local clergy, when requested.

Bereavement Counselors

Grief counselors offer support to involved family and friends through individual and group counseling for up to 13 months to help them cope following the patient's death.

Therapists

Physical, occupational, speech and respiratory therapy, as well as therapy by way of the arts, are available to patients, according to their plan of care.

Nutritionists

A registered dietitian is available to help with the dietary needs of the patients. Specialized diets and cultural factors are considered in dietary planning.

Patient Care Coordinators

Experienced nurse managers handle patient and family concerns. They also offer guidance and support to the hospice team members to assure adherence to quality standards.

Volunteers

Volunteers are the foundation upon which hospice was built. Hospice of New York offers trained volunteers for companionship, support and respite. Volunteers can stay with patients to allow caregivers to attend to personal needs. They are also available to run errands or to help prepare a simple meal. Specially trained vigil volunteers are also available for extended periods of support. Volunteers develop meaningful relationships with patients and families by simply being there during a critical time. All Hospice of New York volunteers have participated in an extensive training program and attend hospice volunteer in-service meetings. We strive to accommodate all requests for volunteers. Please call 718.472.1999 or 516.222.1211 and ask to speak with the Volunteer Department.

PATIENT AND FAMILY RIGHTS

As a patient of Hospice of New York, you have a right to be notified in writing of your rights and obligations before care is provided. Hospice must protect and promote the exercise of these rights. Your family or guardian may exercise your rights if you lack the capacity to do so.

You have the right:

- 1** To be fully informed, prior to or at the time of admission, of your rights as a patient to choose this agency from among all care providers and to choose your attending physician.
- 2** To be fully informed in terms that you can understand, at the time of admission, of your diagnosis and prognosis, treatment, alternatives to care, and plan of care; and to be presented choices about Advance Directives.
- 3** To be fully informed of:

<ul style="list-style-type: none"> ■ The types of services and service frequencies available from Hospice of New York and the services, disciplines, and service frequencies that you are to receive. ■ Any risks involved. 	<ul style="list-style-type: none"> ■ Related charges, including any charges for services not covered by third-party payers and the Hospice of New York basic rate. ■ How to manage emergencies.
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- 4** To fully participate in the development and revisions of your plan of care.
- 5** To adequate, appropriate and timely care and services, and to receive effective pain management and symptom control from Hospice of New York for conditions related to the terminal illness.
- 6** To refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal. To refuse involvement in a clinical training program or experimental research.
- 7** To be assured of confidential treatment of personal and medical records and to approve or refuse their release to any individual outside the Hospice, except in the case of transfer to another health facility or as required by law or third-party payment contract. To review all health records with your physician.
- 8** To be treated with consideration, respect and full recognition of dignity and individuality, including privacy in treatment and personal care. To have your privacy considered so that all discussions, consultations, examinations and treatments will be conducted in a confidential and discreet manner.
- 9** To be free from mistreatment, including neglect or verbal, mental, physical or sexual abuse, including injuries of unknown origin. To be free from physical or chemical restraint or seclusion, unless it is part of a physician's order for your protection or the protection of others.
- 10** To have property treated with respect by Hospice of New York personnel, including reasonable protection from damage and theft.
- 11** To be assured of the identity and professional status of Hospice of New York and agency staff and that the staff who provide care are qualified through education and experience and are duly licensed to carry out the services for which they are responsible.
- 12** For your family to receive bereavement services and assistance from the Hospice of New York team.
- 13** To be assured the right to voice complaints including grievances regarding care and treatment that do not amount to change in scope or duration of service. To be free from interference, coercion, discrimination or reprisal for exercising your rights.

- 14** To be served without regard to source of payment, race, religion, color, creed, national origin, gender, handicap, age, disease or sexual orientation/identity.
- 15** To be admitted for service only if Hospice of New York has the ability to provide safe, professional care at the level of intensity needed. You have the right to reasonable continuity of care.

To file a complaint or grievance with Hospice of New York, please contact the Clinical Director. Your complaint or grievance can be reported verbally by calling 718.472.1999 or in writing to Hospice of New York, 45-18 Court Square, Suite 500, LIC, NY 11101. The Clinical Director, or designee, upon receiving a complaint will date and log the complaint. A brief (but complete) factual statement of the complaint will be recorded. The Clinical Director, or designee, will then initiate a complaint investigation. The Clinical Director, or designee, is responsible to answer each written complaint with a written response. Oral complaints will be answered verbally or in writing, if requested. All complaints and grievances will be responded to within 15 days of receipt of such complaint, explaining the investigation findings and resolution by the program.

The complainant who is dissatisfied with an initial grievance determination may request a second review by filing a grievance appeal to the Administrator of Hospice of New York. An appeal can be requested verbally by calling 718.472.1999 or in writing to Hospice of New York, 45-18 Court Square, Suite 500, LIC, NY 11101. Appeal determinations are made by the Administrator within 30 days of receipt of the appeal. The appeal determination notice includes an explanation of the reasons for the decision, including the clinical rationale, as appropriate.

To file a complaint with the New York State Department of Health, call 800.628.5972.

In addition, the Community Health Accreditation Program (CHAP) operates a hotline for questions or complaints and is available Monday through Friday from 8:00 AM–5:30 AM ET by calling 800.656.9656.

On the initial evaluation visit a Hospice team member will present the patient and/or caregiver with a copy of these rights. The nurse will inform the patient and/or caregiver that the administrative nurse on call can be reached 24 hours a day, 7 days a week by calling Hospice of New York for questions or emergencies. **Call 718.472.1999 or 516.222.1211.**

PATIENT AND FAMILY RESPONSIBILITIES

The patient/family has the responsibility to:

- 1** Provide accurate and complete information about present concerns, past illnesses, previous hospice admissions, hospitalizations, medications, health care professionals and agencies currently involved in patient care and other matters relating to the patient's health.
- 2** Ask questions about care or services.
- 3** Follow instructions and comply with the agreed upon plan of care or accept the outcomes if they choose not to follow the plan of care.
- 4** Show respect and consideration for Hospice of New York's personnel and property.
- 5** Notify Hospice of New York personnel of the need to reschedule visit times or dates.
- 6** Meet financial commitments, including informing Hospice of New York about any changes in the patient's insurance coverage.
- 7** Inform Hospice of New York about any changes in the patient's condition, living situation, attending physician or other health care professionals involved in the patient's care, including providing advance notification of visits to medical specialists, hospitals or emergency rooms.



LANGUAGE ASSISTANCE TO PERSONS WITH LIMITED ENGLISH PROFICIENCY

To ensure that persons with limited English skills can effectively access Hospice care and services, Hospice of New York provides for a range of oral language assistance options and translated written materials.

Hospice of New York employs a diverse staff with bilingual abilities to assist patients and their families in making critical health care choices. From our referral coordinators to our volunteers, Hospice of New York is able to educate and support current and prospective patients, representatives and caregivers. Our program makes every effort to provide for effective communication between Hospice staff and those with limited English skills to facilitate meaningful participation in, and meaningful access to, services.

Title VI of the Civil Rights Act of 1964 provides that no person shall be subjected to discrimination on the basis of race, color or national origin under any program or activity that receives Federal financial assistance. The Office of Civil Rights (OCR) enforces program compliance to allow persons with limited English skills to overcome language barriers and participate meaningfully in programs, services and benefits.

Anyone who believes that he or she has been discriminated against because of race, color or national origin may file a complaint with the OCR within 180 days of the date on which the discrimination took place. Contact information for OCR Regional Office for New York is:

Region II – New York	Phone:	212.264.3313
Regional Manger, OCR	Fax:	212.264.3039
U.S. Department of Health and Human Services	TDD:	212.264.2355
Jacob Javits Federal Building		
26 Federal Plaza – Suite 3312		
New York, NY 10278		





**NOTICE OF
PRIVACY PRACTICES**

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY.

USE AND DISCLOSURE OF HEALTH INFORMATION

Hospice of New York may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. However, the Hospice has established policies to guard against unnecessary disclosure of your health information. The Hospice will limit its own uses and disclosures of your health information to the minimum amount necessary to accomplish the purpose at hand.



The following is a summary of the circumstances under which and purposes for which your health information may be used and disclosed without your specific, written authorization:

To Provide Treatment

The Hospice may use your health information to coordinate care within the Hospice and with others involved in your care, such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist the Hospice in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Hospice also may disclose your health care information to pharmacists, suppliers of medical equipment or other health care professionals.

To Obtain Payment

The Hospice may include your health information in invoices to collect payment from third parties for the care you receive from the Hospice. For example, the Hospice may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or the Hospice. The Hospice also may need to obtain prior approval from your insurer and so need to explain to the insurer your need for hospice care and the services that will be provided to you.

To Conduct Health Care Operations

The Hospice may use and disclose health information for its own operations in order to facilitate the function of the Hospice and as necessary to provide quality care to all of the Hospice's patients. Health care operations include such activities as:

- Quality assessment and improvement activities.
- Patient safety activities
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.



- Training programs, including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development, including cost management and planning-related analyses and formulary development.
- Business management and general administrative activities of the Hospice.

For example, the Hospice may use your health information with that of other Hospice patients in evaluating how to more effectively serve all Hospice patients, disclose your health information to Hospice staff and contracted personnel for training purposes or use your health information to contact you as a reminder regarding a visit to you.

For Informational Purposes in Hospice Inpatient Facility

The Hospice may disclose certain information about you, including your name, your general health status, your religious affiliation and where you are in the Hospice's facility in a Hospice directory while you are in the Hospice inpatient facility. The Hospice may disclose this information to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.

When Legally Required

The Hospice will disclose your health information when it is required to do so by any federal, state or local law.

When There Are Risks to Public Health

The Hospice may disclose your health information in order to:

- Prevent or control disease, injury or disability by reporting the incidence of disease, injury, vital events such as birth or death and assisting with the execution of public health surveillance, investigations and interventions.
- Report adverse events and product defects to help track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance in compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an at-risk individual who is a member of their workforce, as legally required.

To Report Abuse, Neglect or Domestic Violence

The Hospice is allowed to notify government authorities if it is believed a patient is the victim of abuse, neglect or domestic violence. The Hospice will make this disclosure only when specifically required or authorized by law, or when the patient agrees to the disclosure.

To Conduct Health Oversight Activities

The Hospice may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. The Hospice, however, may not disclose your health information if you are the subject of an investigation or your health information is not directly related to your receipt of health care or public benefits.

In Connection With Judicial and Administrative Proceedings

The Hospice may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when the Hospice makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.



For Law Enforcement Purposes

As permitted or required by state law, the Hospice may disclose your health information to a law enforcement agency for certain purposes, as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to a court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are or are suspected to be the victim of a crime.
- If the Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at the Hospice.
- In an emergency in order to report a crime.

To Coroners and Medical Examiners

The Hospice may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other reasons, as authorized by law.

To Funeral Directors

The Hospice may disclose your health information to funeral directors, consistent with applicable law, so that they may carry out their duties with respect to your funeral arrangements. If necessary, the Hospice may disclose your health information prior to and in reasonable anticipation of your death.

For Organ, Eye or Tissue Donation

The Hospice may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating donation and/or transplantation.

For Research Purposes

The Hospice may, under very select circumstances, use or disclose your health information for research. Before the Hospice discloses any of your health information for such purposes, the project will be subject to an extensive approval process.

In the Event of a Serious Threat to Health or Safety

The Hospice may, consistent with applicable law and ethical standards of conduct, disclose your health information if the Hospice, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety, or to the health and safety of the public.

For Specified Government Functions

In certain circumstances, federal regulations authorize the Hospice to use or disclose your health information to facilitate specified government functions relating to those in the military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and others in law enforcement custody.

For Worker's Compensation

The Hospice may release your health information for worker's compensation or similar programs.

Disclosures to Our Business Associates

The Hospice may share your health information with third party "business associates" that perform various activities (e.g., billing, transcription services) for the Hospice. Whenever an arrangement between the Hospice and a business associate involves the use or disclosure of your health information, the Hospice will have a written contract that contains terms that will protect the privacy of your health information.

Others Involved in Your Healthcare

Unless you object, we may disclose to a member of your family, a relative, your clergy, a close friend or any other person you identify, your health information that directly relates to that person's involvement in your health care. If you are unable to agree or object to such a disclosure, the Hospice may disclose such information as necessary if the Hospice determines that it is in your best interest based on our professional judgment. The Hospice may use or disclose your health information to notify or assist in notifying a family member, personal representative or any other person that is responsible for your care of your location, general condition or death. Finally, the Hospice may use or disclose your health information to an authorized public or private entity to assist in disaster relief efforts and to coordinate uses and disclosures to family or other individuals involved in your health care.

Fundraising

The Hospice may use your health information to raise funds for the Hospice. You have the right, at any time, to elect not to receive any such fundraising communications.

AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

Any other uses and disclosures of your health information not otherwise described in this Notice of Privacy Practices, including the sale of your health information or the use of your health information for marketing purposes, will only be made with your written authorization.

If you or your representative authorizes the Hospice to use or disclose your health information, you may revoke that authorization in writing at any time.

YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information that the Hospice maintains:

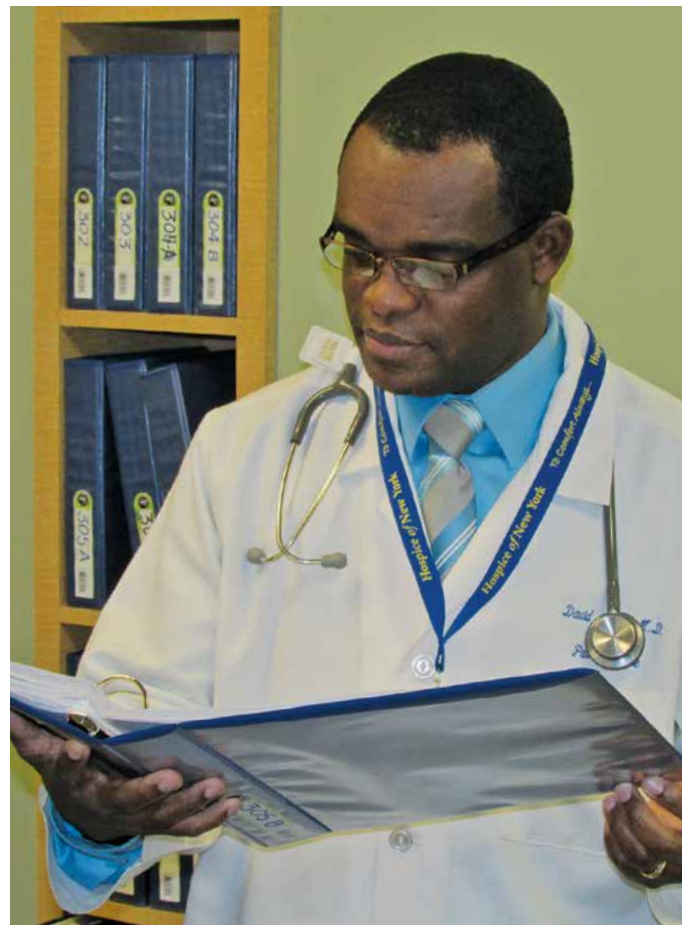
Right to Request Restrictions

You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice's disclosure of your health information to someone who is involved in your care or the payment of your care. For the most part, the Hospice is not required to agree to your request. However, the Hospice must agree to your restriction request related to disclosures of your health information to health plans for payment or health care operations if the health information which is the subject of your request relates solely to a health care item or service for which you or a third party, other than your health plan, have paid the Hospice for in full.

If you wish to make a request for restrictions, please contact the Hospice of New York Privacy Official at 718.472.1999.

Right to Receive Confidential Communications

You have the right to request that the Hospice communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately, with no other family members present. If you wish to receive confidential commu-



nications, please contact the Hospice of New York Privacy Official at 718.472.1999. The Hospice will not request that you provide any reasons for your request and will attempt to honor all reasonable requests for confidential communications.

Right to Inspect and Copy Your Health Information

You have the right to inspect and copy your health information, including billing records. If your health information is maintained electronically, you have a right to request your health information in a readable electronic format. A request to inspect and copy records containing your health information may be made to the Privacy Official at 718.472.1999. If you request a copy of your health information, the Hospice may charge a reasonable cost-based fee for copying and assembling costs associated with your request.

Right to Amend Health Care Information

You or your representatives have the right to request that the Hospice amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long

as the information is maintained by the Hospice. A request for an amendment of records must be made in writing to the Hospice of New York Privacy Official at 45-18 Court Square, Suite 500, Long Island City, NY 11101. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Hospice, if the records you are requesting are not part of the Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Hospice, the records containing your health information are accurate and complete.

Right to Accounting

You or your representative have the right to request an accounting of disclosures of your health information made by the Hospice for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to the Hospice of New York Privacy Official at 45-18 Court Square, Suite 500, Long Island City, NY 11101. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. The Hospice would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

Right to a Paper Copy of This Notice

You or your representatives have a right to a separate paper copy of this Notice at any time, even if you or your representatives have received this Notice previously or have agreed to receive this Notice electronically previously. To obtain a separate paper copy, please contact the Hospice of New York Privacy Official at 718.472.1999. The patient or a patient's representative may also obtain a copy of the current version of the Hospice's Notice of Privacy Practices at its website, www.hospice.nyc.

DUTIES OF THE HOSPICE

The Hospice is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. In addition, the Hospice is required to notify you in the event the security of your

health information has been breached. The Hospice is required to abide by the terms of this Notice as is currently in effect. The Hospice reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If the Hospice changes its Notice, the Hospice will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to the Hospice and to the Department of Health and Human Services if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to:

The Privacy Official
Hospice of New York
45-18 Court Square, Suite 500
Long Island City, NY 11101

Complaints to the Department of Health and Human Services may be made to:

Linda Colon, Regional Manager- Region II
Office for Civil Rights
U.S. Department of Health and Human Services
Jacob Javits Federal Building
26 Federal Plaza - Suite 3312
New York, NY 10278
Voice Phone 800.368.1019
FAX 212.264.3039

The Hospice encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

CONTACT PERSON

The Hospice has designated the Privacy Official as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at Hospice of New York 45-18 Court Square, Suite 500, Long Island City, NY 11101 — 718.472.1999.

EFFECTIVE DATE

This Notice is effective March 1, 2013.

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE, PLEASE CONTACT:

Privacy Official
Hospice of New York
45-18 Court Square, Suite 500
Long Island City, NY 11101
718.472.1999



What I can say is that although those were his last days, it was the best service we could have found.

— Margarita Núñez
PATIENT'S WIFE



ADVANCE DIRECTIVES

INFORMED CONSENT INFORMATION ON ADVANCE DIRECTIVES

Background

The laws of this state ensure that you have a right to decide about your health care if you are a competent adult (18 years or older). You have a right to accept or refuse medical or surgical treatment. You have a right to have an explanation about medical or surgical treatment before you receive it.

If you are too ill or injured to decide about your health care options, others *will* choose for you. The issue you have to decide is how much influence you want to exert when others choose for you.

Advance Medical Directives assist you in protecting your right to choose if you become physically or mentally unable to communicate your choices, due to an accident or illness.

An Advance Directive could relieve your family and physician of the responsibility and stress of making difficult health care decisions without knowing clearly what you would have wanted.

Advance Directives are of critical importance in light of the capacity of modern medical technology to extend life where formerly an individual might have died. The major concern with the use of medical technology to extend life is the *quality of life!*

Advance Directives Can Help You Choose:

- Who will be your doctor or other health care provider.
- Who can have access to your medical records.
- What type of treatment you will or will not receive.
- Who will make decisions for you when you are unable to do so.

Advance Directives Can Help You Make Your Feelings and Wishes Known Regarding:

- Cardiopulmonary Resuscitation (CPR)—used to restore breathing and/or a heartbeat.
- Respirators—used to keep you breathing.
- Dialysis—used to clean your blood when kidneys fail.
- Intravenous (IV) Therapy—used to provide nutrients and medication through a vein when you can no longer swallow.

- Feeding Tubes—used to provide nutrition through a nose tube when you can no longer eat.

There are Generally Five Types of Advance Directives

Living Will

A living will is a written statement directing your health care provider to withhold or withdraw life-prolonging procedures if you should be diagnosed with a terminal condition and you lack the capacity to make a decision. A living will is limited to withholding or withdrawing life-prolonging measures only when your condition is terminal; it does not apply to other health care decisions. It is wise to name a person (agent, guardian, etc.) to serve as your proxy when you sign your living will. Your proxy must carry out your wishes.

Durable Power of Attorney

A durable power of attorney is a legally enforceable, formal document in which you authorize another person to be your “attorney-in-fact” to make health care decisions when you are not able to do so. A power of attorney document must be prepared and signed when you are competent. It will not be affected by your later disability or incapacity. It can address treatments you wish to withhold or receive. It can authorize your attorney-in-fact to make limited health care decisions on your behalf. A power of attorney statement is only operable when you *cannot* make your own health care decisions. It is not recognized in every state.

Health Care Representative or Agent

Some states allow you to name the person who will make your health care decisions when you are unable to make choices about them. This measure does not require court intervention. If you are competent you can make an oral (before two witnesses) or written statement declaring whom you want to be your agent. You can instruct your agent in as much or as little detail as you like about your wishes. You can give your agent limited or complete authority to make health care decisions on your behalf.

Advance Directives can limit life-prolonging measures when there is little or no chance of recovery.

Guardian or Conservator

In some states a court will appoint a decision maker for you when you are unable to make health care choices. You have a right to nominate (name) the person you want to serve as your guardian or conservator. Most often the court will appoint the person you name. A guardianship or conservatorship becomes effective when you are unable to make decisions for yourself and after the court has appointed a person to serve as your guardian or conservator. If at any time you regain your ability to make decisions, you can ask the court to restore your rights and end the guardianship or conservatorship.

Whom shall I tell?

...Tell your family, friends, physician, proxy and attorney about your Advance Directives

Mental Health Advance Directive

A few states allow you to sign an Advance Directive explaining your wishes about “intrusive” mental health treatment such as electroshock therapy or neuroleptic medication. You can declare the types of treatment that you do or do not want. You can name a proxy to decide for you. A Mental Health Advance Directive becomes effective only when you are not capable of giving your consent to treatment.

In New York there are three ways to make an Advance Directive: choosing a proxy, writing directions or writing instructions to a proxy.



Statement of Policy

It is the policy of this Hospice to implement your Advance Directives without exception. We will not discriminate against you whether you do or do not make Advance Directives.

If you have made Advance Directives, your specific instructions will be recorded in your medical record. A note will be made in your medical record if you have not made Advance Directives.

This Hospice will provide you with a form to make Advance Directives and for you to appoint an agent. If you wish to sign a living will or give the power of attorney to someone, our social worker will assist you in this.

Our philosophy is to help you clarify your wishes related to health care decisions. Once you know what you would want, you can develop clear instructions for others who would carry out your wishes if you should become incapacitated and could no longer choose for yourself.

HEALTH CARE PROXY

Appointing Your Health Care Agent in New York State

The New York Health Care Proxy Law allows you to appoint someone you trust—for example, a family member or close friend—to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also 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. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions or only certain ones. You may also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ and/or tissue donation.

About the Health Care Proxy Form

This is an important legal document. Before signing, you should understand the following facts:

- 1** This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. “Health care” means any treatment, service or procedure to diagnose or treat your physical or mental condition.
- 2** Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
- 3** Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
- 4** You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.
- 5** You do not need a lawyer to fill out this form.
- 6** You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor, because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental health facility, there are special restrictions about naming someone who works for that facility to explain those restrictions.
- 7** Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.
- 8** If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.
- 9** Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
- 10** You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.
- 11** Appointing a health care agent is voluntary. No one can require you to appoint one.
- 12** You may express your wishes or instructions regarding organ and/or tissue donation on this form.

Frequently Asked Questions

A. Why should I choose a health care agent?

If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Health care providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. However, in New York State, only a health care agent you appoint has the legal authority to make treatment decisions if you are unable to decide for yourself. Appointing an agent lets you control your medical treatment by:

- Allowing your agent to make health care decisions on your behalf as you would want them decided.
- Choosing one person to make health care decisions because you think that person would make the best decisions.
- Choosing one person to avoid conflict or confusion among family members and/or significant others.

B. Who can be a health care agent?

Anyone 18 years of age or older can be a health care agent. The person you are appointing as your agent or your alternate agent cannot sign as a witness on your Health Care Proxy form.

C. How do I appoint a health care agent?

All competent adults, 18 years of age or older, can appoint a health care agent by signing a form called a Health Care Proxy. You don't need a lawyer or a notary, just two adult witnesses. Your agent cannot sign as a witness. You can use the form provided by Hospice of New York, but you can also use your own.

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

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

E. 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 health care 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. However, your agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she knows your wishes from what you have said or what you have written. The Health Care Proxy form does not give your agent the power to make non-health care decisions for you, such as financial decisions.

F. Why do I need to appoint a health care agent if I'm young and healthy?

Appointing a health care agent is a good idea even though you are not elderly or terminally ill. A health care agent can act on your behalf if you become even temporarily unable to make your own health care decisions (such as might occur if you are under general anesthesia or have become comatose because of an accident). When you again become able to make your own health care decisions, your health care agent will no longer be authorized to act.

G. How will my health care agent make decisions?

Your agent must follow your wishes, as well as your moral and religious beliefs. You may write instructions on your Health Care Proxy form or simply discuss them with your agent.

H. How will my health care agent know my wishes?

Having an open and frank discussion about your wishes with your health care agent will put him or her in a better position to serve your interests. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interests. Because this is a major responsibility for the person you appoint as your health care agent, you should have a discussion with the person about what types of treatments you would or would not want under different types of circumstances, such as:

- Whether you would want life support initiated/continued/removed if you are in a permanent coma.
- Whether you would want treatments initiated/continued/removed if you have a terminal illness.
- Whether you would want artificial nutrition and hydration initiated/withheld or continued/withdrawn and under what types of circumstances.

I. Can my health care agent overrule my wishes or prior treatment instructions?

No. Your agent is obligated to make decisions based on your wishes. If you clearly expressed particular wishes, or gave particular treatment instructions, your agent has a duty to follow those wishes or instructions unless he or she has a good faith basis for believing that your wishes changed or do not apply to the circumstances.

J. Who will pay attention to my agent?

All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor the decisions of your agent as if they were made by you. If a hospital or nursing home objects to some treatment options (such as removing certain treatments), they must tell you or your agent BEFORE or upon admission, if reasonably possible.

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

You may appoint an alternate agent to decide for you if your health care agent is unavailable, unable or unwilling to act when decisions must be made. Otherwise, health care providers will make health care 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.

L. What if I change my mind?

It is easy to cancel your Health Care Proxy form, to change the person you have chosen as your health care agent or to change any instructions or limitations you have included on the form. Simply fill out a new form. In addition, you may indicate that your Health Care Proxy form expires on a specified date or if certain events occur. Otherwise, the Health Care Proxy form will be valid indefinitely. If you choose your spouse as your health care agent or as your alternate, and you get divorced or legally separated, the appointment is automatically cancelled. However, if you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.

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

No. Your health care agent will not be liable for your health care 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.

N. Is a Health Care Proxy form the same as a living will?

No. A living will is a document that provides specific instructions about health care decisions. You may put such instructions on your Health Care Proxy form. The form allows you to choose someone you trust to make health care decisions on your behalf. Unlike a living will, a Health Care Proxy form 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.

O. Where should I keep my Health Care Proxy form after it is signed?

Give a copy to your agent, your doctor, your attorney and any other family members or close friends you want. Keep a copy in your wallet or purse or with other important papers, but not in a location where no one can access it, like a safe deposit box. Bring a copy if you are admitted to the hospital, even for minor surgery, or if you undergo outpatient surgery.

P. May I use the Health Care Proxy form to express my wishes about organ and/or tissue donation?

Yes. Use the optional organ and tissue donation section on the form and be sure to have the section witnessed by two people. You may specify that your organs and/or tissues be used for transplantation, research or educational purposes. Any limitation(s) associated with your wishes should be noted in this section of the form. **Failure to include your wishes and instructions on your Health Care Proxy form will not be taken to mean that you do not want to be an organ and/or tissue donor.**

Q. Can my health care agent make decisions for me about organ and/or tissue donation?

No. The power of a health care agent to make health care decisions on your behalf ends upon your death. Noting your wishes on your Health Care Proxy form allows you to clearly state your intentions regarding organ and/or tissue donation.

R. Who can consent to a donation if I choose not to state my wishes at this time?

It is important to note your wishes about organ and/or tissue donation, so that family members who will be approached about donation after your death are aware of what you intended. However, New York law provides a list of individuals who are authorized to consent to organ and/or tissue donation on your behalf. They are listed in order of priority: your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death or any other legally authorized person.



HEALTH CARE PROXY FORM INSTRUCTIONS

Item (1)

Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)

If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)

Your Health Care Proxy form will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy form to expire.

Item (4)

If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write:

I have discussed my wishes with my health care agent and alternate and they know my wishes, including those about artificial nutrition and hydration.

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatment...

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following type of treatments...

If I have brain damage or a brain disease that makes me unable to recognize people or speak, and there is no hope that my condition will improve, I do/don't want the following types of treatment...

I have discussed with my agent my wishes about _____, and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- Artificial respiration
- Artificial nutrition and hydration (nourishment and water provided by feeding tube)
- CPR
- Antipsychotic medication
- Electroshock therapy
- Antibiotics
- Surgical procedures
- Dialysis
- Organ or tissue transplantation
- Blood transplantation
- Blood transfusions
- Abortion
- Sterilization

Item (5)

You must date and sign your Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (6)

You may state wishes or instructions about organ and/or tissue donation on this part of the form. A health care agent cannot make a decision about organ and/or tissue donation because the agent's authority ends upon your death. The law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death or any other legally authorized person.

Item (7)

Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.

MAKING HEALTH CARE DECISIONS

This information is distributed in compliance with a federal law, the Patient Self-Determination Act. This law is designed, along with New York State law, to protect your rights to make decisions about your own medical care, including the right to accept or refuse treatment. You also have the right to appoint someone to make decisions for you if you cannot make them yourself.

The Family Health Care Decisions Act protects individuals' rights to make decisions about their own medical care, including the right to accept or refuse treatment.

By law, individuals are assumed to be capable of making their own health care decisions unless an individual's doctor determines that the individual is not capable of understanding the specific medical options and the risks and benefits of those options.

The Family Health Care Decisions Act

The Family Health Care Decisions Act provides for the appointment of a surrogate decision maker in cases when a person lacks capacity to make decisions and does not have a health care proxy.*

The surrogates are listed here in order of priority:

- 1 Court-appointed guardian
- 2 Spouse or domestic partner
- 3 Child over 18 years old
- 4 Parent
- 5 Sibling over 18 years old
- 6 Close friend or relative (not listed above) who has maintained such regular contact with the patient as to be familiar with the patient's activities, health and religious or moral beliefs, and who presents a signed statement to the attending physician attesting to that

■ **SURROGATE LIABILITY:** The surrogate has no financial responsibility for the medical care they determine is in the best interests of the incapacitated patient unless they have an independent obligation under law, such as a spouse. A surrogate, health-care provider or its employee will not be subject to criminal or civil liability for action taken in good faith under the Family Health Care Decisions Act.

■ **THE SURROGATE DECISION-MAKING PROCESS:** The highest ranking surrogate who accepts the position will have the authority to make all health care decisions, including whether or not to initiate, withdraw or withhold life-sustaining treatment. In order to make these decisions, hospitals must give surrogates access to the patient's medical information, medical records, diagnosis, prognosis, the nature and consequences of the health care, and the benefits and risks of the treatment.

The surrogate is also required, after review of the medical information, to base decisions on the patient's known religious and moral beliefs. If the those are not known, the decisions are required to be made according to the patient's "best interests," those defined as a combination of the following:

- A consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life.
- The potential preservation, improvement or restoration of the patient's health or function.
- The possibility for relief of the patient's suffering.
- Any other coexisting medical conditions or those concerns relating to and values that a reasonable person in the patient's circumstances would wish to consider.

■ **STRINGENT RULES ON END-OF-LIFE CARE:** Should a surrogate face the difficult decision of whether to withhold or withdraw life-sustaining treatment, stringent additional conditions must be met. The law requires that the surrogate can make this decision only if the treatment would be an extraordinary burden to the patient and an attending physician determines, with independent concurrence of another physician, that, to a reasonable degree of medical certainty and in accord with accepted medical standards:

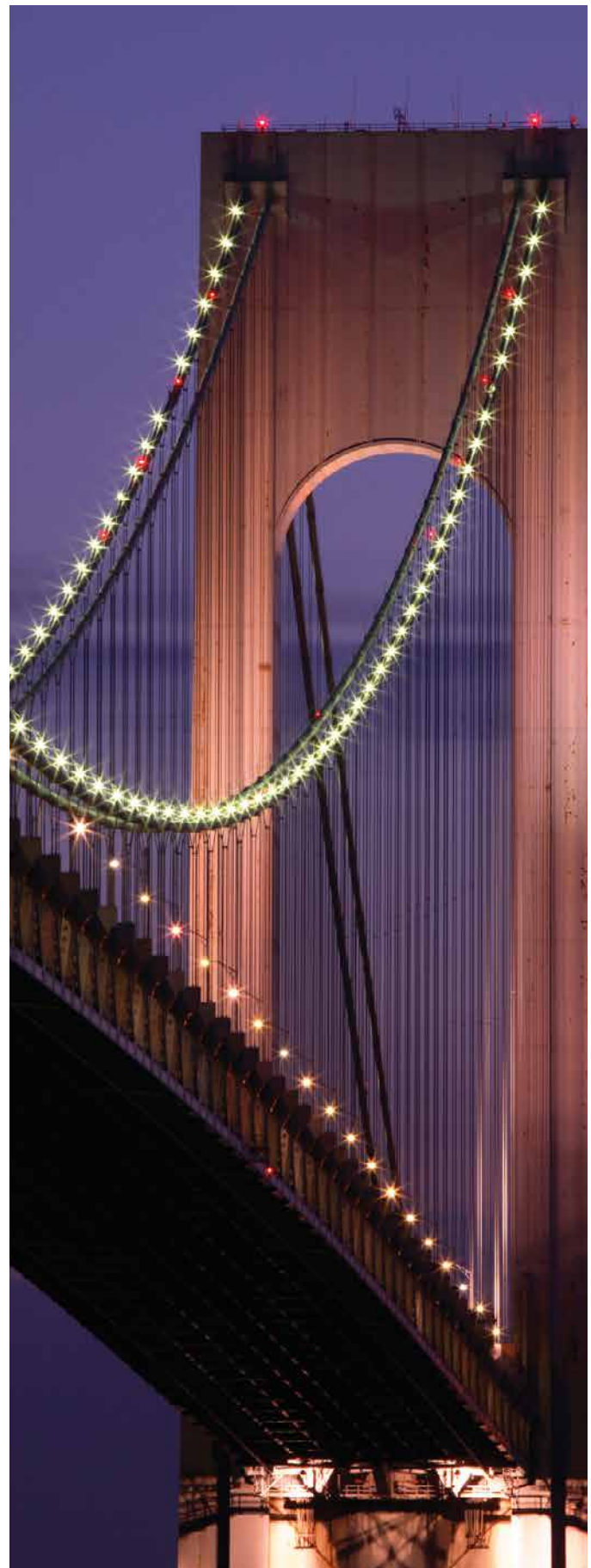
- The patient has an illness/injury expected to cause death within six months, whether or not treatment is provided.
- the patient is permanently unconscious.
- the provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances; and the patient has an irreversible or incurable condition, as determined by the attending physician with the independent concurrence of another physician.

Before any surrogate makes a decision to withdraw life-sustaining treatment, the attending physician plus an independent concurring physician must, for a second time, determine that the patient remains incapacitated and unable to make his or her own decision. Only if the incapacity is found to still exist will the surrogate's decision be honored.

- **RULES WHEN MEDICAL OPINION IS DIVIDED:** If there is a conflict of opinions between physicians on determinations of capacity, the case will be referred to an interdisciplinary Ethics Review Committee, which is required by law to exist within each hospital and nursing home. This committee will decide whether the patient is incapacitated and whether a surrogate can make the decisions on the patient's behalf.
- **THE LAW PROVIDES FOR LEGAL CHALLENGES TO THE APPOINTMENT OF A SURROGATE OR THE SURROGATE'S DECISIONS:** A person with a relationship to the patient and any member of the hospital Ethics Review Committee who has objections to the incapacity determination, the choice of surrogate, or the surrogate's decisions may go before a court for a further review in an expedited court proceeding, called a "special proceeding." The court will then review the issues to ensure all steps required under law have been taken and the decisions were factually based.
- **IF NO SURROGATE CAN BE FOUND:** For patients with no surrogate, the Family Health Care Decisions Act requires the medical facility to make health care decisions under the same guidelines as required for surrogates. The law forbids making medical decisions based on financial considerations.

*This form enables an individual to appoint an agent on their behalf to make medical decisions should the individual become incapacitated due to illness or a debilitating accident. Even after the passage of the Family Health Care Decisions Act, signing a Health Care Proxy form in advance remains very important and clearly is the best way to ensure that health care is provided in accordance with an individual's wishes.

This information is distributed in accordance with the Patient Self-Determination Act (42 USC Sections 1395cc and 1396a [a]). It also complies with the requirements of New York law.



DECIDING ABOUT CPR: DO-NOT-RESUSCITATE (DNR) ORDERS: A GUIDE FOR PATIENTS AND FAMILIES

A. What do CPR and DNR orders mean?

CPR—cardiopulmonary resuscitation—refers to the medical procedures used to restart a patient’s heart and breathing when the patient suffers heart failure. CPR may involve simple efforts, such as mouth-to-mouth resuscitation and external chest compression. Advanced CPR may involve electric shock, insertion of a tube to open the patient’s airway, injection of medication into the heart, and in extreme cases, open chest heart massage.

A DNR order tells medical professionals not to perform CPR. This means that doctors, nurses and emergency medical personnel will not attempt emergency CPR if the patient’s breathing or heartbeat stops.

DNR orders may be written for patients in a hospital or nursing home, or for patients at home. Hospital DNR orders tell the medical staff not to revive the patient if cardiac arrest occurs. If the patient is in the nursing home or at home, a DNR order tells the staff and emergency medical personnel not to perform emergency resuscitation and not to transfer the patient to a hospital for CPR.

B. Why are DNR orders issued?

CPR, when successful, restores heartbeat and breathing and allows patients to resume their previous lifestyle. The success of CPR depends on the patient’s overall medical condition. Age alone does not determine whether CPR will be successful, although illnesses and frailties that often accompany aging can make CPR less successful.

When patients are seriously ill or terminally ill, CPR may not work or may only partially work, leaving the patient brain damaged or in a worse medical state than before the heart stopped. In these cases, some patients prefer to be cared for without aggressive efforts at resuscitation.

C. Can I request a DNR order?

Yes. All adult patients can request a DNR order. If you are sick and unable to tell your doctor that you want a DNR order written, a family member or close friend can decide for you.

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

No. A DNR order is only a decision about CPR and does not relate to any other treatment.

E. Are DNR orders ethically acceptable?

Health care professionals, clergy, lawyers and others widely agree 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.

F. Is my consent required for a DNR order?

If you are able to decide, your doctor must speak to you before entering a DNR order unless he or she believes that discussing CPR with you would cause you severe harm. In an emergency, it is assumed that all patients would consent to CPR. However, if a doctor decides that CPR will not work, it is not provided.

G. How can I make my wishes about DNR known?

An adult patient (aged eighteen or older) may consent to a DNR order orally by informing a physician, or in writing, such as a living will, if two witnesses are present. In addition, the Health Care Proxy Law allows you to appoint someone you trust to make decisions about CPR and other treatments, if you become unable to decide for yourself. Before deciding about CPR, you should speak with your doctor

about your overall health and the benefits and burdens CPR would provide for you. A full and early discussion between you and your doctor will assure that your wishes will be known.

H. What do CPR and DNR orders mean?

If you don't want CPR and you request a DNR order, your doctor must follow your wishes or do one of the following:

- Transfer your care to another doctor who will follow your wishes.
- Begin a process to settle the dispute if you are in a hospital or nursing home.

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

I. If I am not able to decide about CPR for myself, who will decide?

First, two doctors must determine that you are unable to decide about CPR. You will be told of this determination and have the right to object.

If you become unable to decide about CPR, and you did not tell your doctor or others about your wishes in advance, a DNR order can be written with the consent of someone chosen by you, by a family member or by a close friend. The person highest on the following list will decide about CPR for you:

- The person chosen by you to make health care decisions under New York's Health Care Proxy Law.
- A court-appointed guardian (if there is one).
- Your closest relative (spouse, child, parent, sibling).
- A close friend.

J. How can I select someone to decide for me?

The Health Care Proxy Law allows adults to select someone they trust to make all health care decisions for them when they are no longer able to do so themselves, including decisions about CPR. You can name someone by filling out a Health Care Proxy form, which you can get from your physician or other health care professionals.

K. Under what circumstances can a family member or close friend decide that a DNR order should be written?

A family member or close friend can consent to a DNR order only when you are unable to decide for yourself and you have not appointed someone to decide for you. Your family member or friend can consent to a DNR order in any of the following circumstances:

- You are terminally ill.
- You are permanently unconscious.
- CPR will not work (would be medically futile).
- CPR would impose an extraordinary burden on you, given your medical condition and the expected outcome of CPR.

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

L. What if members of my family disagree?

In a hospital or nursing home, your family can ask that the disagreement be mediated. Your doctor can request mediation if he or she is aware of any disagreement among your family members.

M. What if I lose the ability to make decisions about CPR and do not have anyone who can decide for me?

A DNR order can be written if two doctors decide that CPR would not work or if a court approves of the DNR order. It would be best if you discussed your wishes about CPR with your doctor in advance.

N. Who can consent to a DNR order for children?

A DNR order can be entered for a child with the consent of the child's parent or guardian. If the child is old enough to understand and decide about CPR, the child's consent is also required for a DNR order.

O. What happens if I change my mind after a DNR order has been written?

You or anyone who consents to a DNR order for you can remove the order by telling your doctor, nurses or others of the decision.

P. What happens to a DNR order if I am transferred from a nursing home to a hospital or vice versa?

The DNR order will continue until a doctor examines you and decides whether the order should remain or be cancelled. If the doctor decides to cancel the DNR order, you or anyone who decided for you will be told and can ask that the DNR order be entered again.

Q. If I am at home with a DNR order, what happens if a family member or friend panics and calls an ambulance to resuscitate me?

If you have a DNR order and family members show it to emergency personnel, they will not try to resuscitate you or take you to a hospital emergency room for CPR. It is a good idea to speak to friends and family members in advance, allowing them to see the DNR order, to ensure that they understand your wishes in the event of an emergency in which CPR would be otherwise appropriate.

R. What happens to my DNR order if I am transferred from a hospital or nursing home to home care?

The order issued for you in a hospital or nursing home will not apply at home. You, your health care agent or a family member must specifically consent to a home DNR order. If you leave a hospital or nursing home without a home DNR order, a DNR order can be issued by a doctor for you at home.

Hospitals must provide patients with a brochure developed by the New York State Department of Health that describes the state's Do-Not-Resuscitate law. The brochure must be furnished to the patient at or prior to the time of admission. It must also be furnished to each member of the hospital's staff involved in the provision of medical care, and it must be posted in a public place in each hospital.

This is in accordance with the Patient Self-Determination Act in OBRA 1990 amending 1902 (a) (58) of Social Security Act Public Health Law 2929.



IMPORTANT PATIENT/FAMILY INFORMATION ON IMPLANTED CARDIAC DEFIBRILLATORS

What is an implanted cardiac defibrillator?

This is a device about the size of a pager that monitors your heart rate. It uses batteries to send electric signals to a heart that's beating too slowly, the same as a pacemaker. It can also deliver an electric shock to help restore a normal heartbeat to a heart that's beating erratically and much too fast. Cardiac defibrillation is a way to return an abnormally fast or disorganized heartbeat to normal.

An implanted cardiac defibrillator is considered a lifesaving device.

The above information is important for patients and families to know when electing hospice care. It is the recommendation of Hospice of New York that these devices be deactivated as soon as possible following admission to the Hospice program. Patients or families who elect not to deactivate the defibrillator will still be eligible for admission and will continue to be treated by Hospice of New York.

It is our policy to inform the patient and family of possible untoward effects resulting from the build-up of electrical charges of the defibrillator. Hospice of New York will coordinate the deactivation of the device, or continue the monitoring and palliative care of the patient should he or she elect not to deactivate the defibrillator. This procedure will not deactivate the active pacemaker which is unlikely to interfere with peaceful dying.

It is possible that electrical shocks, both to the patient and their caregivers, may occur when the patient's heartbeat becomes slowed or erratic, as death approaches.

While there have been no long-term consequences to patients or caregivers in such instances, the electric shocks may be painful for the patient and distressing for the family. This is inconsistent with the Hospice philosophy to provide dignity and comfort during the dying process.

If the patient or family agrees to deactivation, the Hospice nurse, in consultation with the medical director and the attending physician, will make all necessary arrangements to have the procedure done, including transportation. Patients residing in contracted facilities will have their defibrillator deactivated in accordance with that facility's policy. The cost of deactivation is determined on a case-by-case basis (depending on the Hospice diagnosis), but is generally the responsibility of the Hospice.

If the patient and family decide to maintain the defibrillator, the patient will be asked to sign a release form indicating that he or she understands the potential for discomfort and/or minor shocks to their caregivers.



PATIENT CARE AND SAFETY

CONTACT INFORMATION

AFTER HOURS EMERGENCY SERVICES

New York City: 718.472.1999

Nassau County: 516.222.1211

24-HOUR AVAILABILITY

Hospice services are available
24 hours a day, 7 days a week

After Hours Services and Emergencies

Your Hospice nurse is generally available from 8:30 AM to 5:00 PM, Monday through Friday (office hours). For routine matters such as ordering equipment, medication refills, changes in home health aide service and for questions about scheduled staff visits, please contact your Hospice nurse. If you are unable to reach him or her during these hours, please call the numbers above.

When should I call the Hospice after hours on-call team?

- Call when there is a significant patient change, such as increased pain, breathing problems or worsening symptom(s) that are making the patient uncomfortable, or for problems that are worrisome to you.
- Call if you have questions about medications, treatments or equipment that need a prompt answer.

What can I expect from the Hospice after hours on-call team?

- The on-call team can assist with symptom management.
- The on-call team has access to patient information, but may ask additional questions. Please remain calm and speak clearly about your concerns.
- The on-call nurse will call the patient's doctor or the Hospice Physician as needed and get back to you with the doctor's instructions.

- The Hospice on-call nurse will determine if an emergency home visit is needed and, if so, will make the arrangements.

How long will it take for a Hospice on-call nurse to arrive?

- The average amount of time for our staff to arrive to your home is 1 to 2 hours. This may seem like a long time, but please be assured that we have the expertise to help you when we arrive.

What happens when I call after hours?

- A registered nurse is available to patients and families for medical necessities on a 24-hour, 7 day-a-week basis. The above on-call numbers are answered by a service after business hours and on weekends and holidays. At those times, please leave your name and number with the service operator.

The on-call nurse should return your call within 15 minutes. If for any reason you do not receive a call back within that time, please do not hesitate to call again. The on-call nurse is available to assist when problems arise that patients and families are uncomfortable managing without advice or guidance. Frequently, the nurse will be able to assess the situation and recommend a course of action without visiting. It is not unusual for families caring for a patient at home to simply need reassurance that what they are doing is the right thing. The on-call nurse will notify the physician as needed and may visit if necessary.

A Hospice social worker and a spiritual counselor are also available for after hours emergencies. The on-call nurse will be able to access these services for you if needed.

PLEASE NOTE: To ensure that the on-call nurse is available for all medical necessities, we ask that routine concerns and questions be directed to your regular Hospice nurse or the Hospice office. Arrangements for prescription refills and supply deliveries should be made during routine visits. If emergency medications are needed after hours, the on-call nurse will make arrangements. We do ask that you please check the supply of medications prior to weekends and holidays.

Please call the Hospice of New York office at any time to ask questions. During regular business hours, there is always a registered nurse in the office. Messages can be left for your primary nurse at any time.

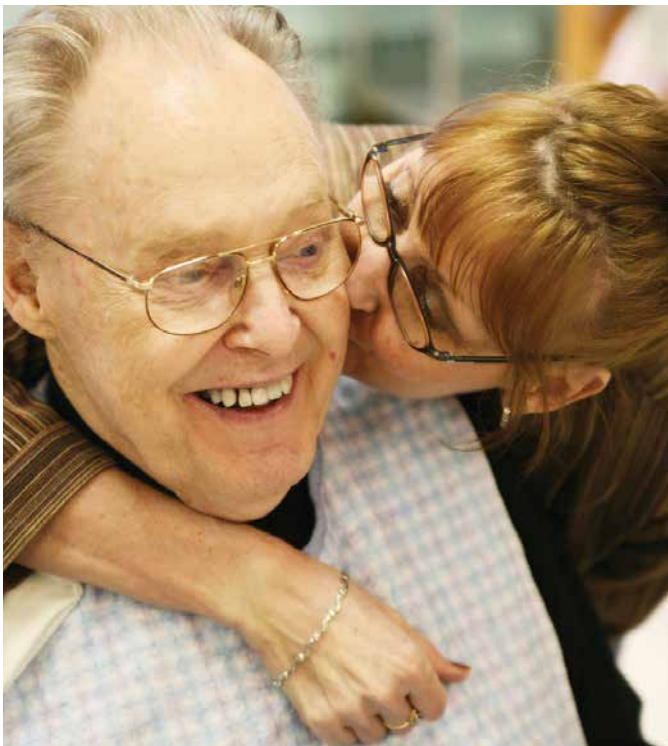
PAIN AND SYMPTOM MANAGEMENT

Hospice physicians and nurses are highly skilled in the assessment and management of pain and other symptoms. Their goal is to keep patients comfortable and prevent unnecessary hospitalization. Many of the physical difficulties that face patients can be prevented or minimized by anticipation, prevention and timely intervention.

Hospice treats pain as an emergency and works to alleviate any physical, emotional, spiritual or social discomfort. The Hospice medical staff constantly assess, monitors and treats all aspects of pain. Effective pain management allows patients to participate in an individually designed plan of care to help improve their quality of life.

Patients taking pain medicine are frequently started on a “bowel regimen” to prevent constipation. While this side effect is common, it is indeed uncomfortable. It is extremely important that patients taking pain medications adhere to this regimen if ordered.

Nausea is another common side effect experienced when pain medicines are started. This symptom usually resolves in a few days. During this time, medication can be prescribed to relieve nausea so that the medications to treat pain are not interrupted.



Constipation

Constipation is a frequent symptom that can result from decreased activity, changes in diet and use of pain medications. Prevention of constipation is key to avoiding discomfort and unpleasant treatments, such as enemas. An effective plan to promote bowel elimination must be started early by increasing fluids and dietary fiber, if tolerated. Stool softeners and/or laxatives will need to be ordered by the physician. Patients should move their bowels at least once every three days. Contact your nurse immediately if constipation occurs.

Urinary Symptoms

A catheter may be inserted, if needed, to relieve urinary incontinence or retention. Urinary retention can be caused by medication side effects or be related to disease progression. A catheter should only be inserted to relieve discomfort or to aid in wound healing by keeping the patient clean and dry. The Hospice nurse or physician will perform an examination and determine if catheter placement is required. The Hospice nurse will educate caregivers in catheter care and management.

Respiratory Difficulty

Many times, hospice patients experience some degree of breathing difficulty. This feeling of “breathlessness” can be very distressing to patients and family members. Our Hospice nurses are specially trained in treatment modalities to help alleviate breathing difficulties. Oxygen, nebulizer treatments and respiratory therapists are available when needed. Narcotics, especially morphine, are often very effective in easing respiratory distress and may be used in combination with medications to reduce subsequent anxiety. Other techniques that assist in minimizing shortness of breath are energy conservation, circulation of air by opening windows or by using fans and air conditioning, elevating the head of the bed and pursed lip breathing.

Skin Care

The skin requires extra care to prevent breakdown when a patient spends a lot of time in bed. Hospice staff will instruct caregivers in the proper positioning and turning of their loved one to prevent skin breakdown. When possible, change the patient’s position every two hours. If reddened areas or skin breaks appear, notify the Hospice nurse immediately. The lower back, hips, heels and elbows are fre-

quent points of pressure. An air mattress or other pressure-relieving device may be ordered by your Hospice nurse.

Remember to keep bed linens clean, dry and smooth. Avoid causing friction of the skin when lifting or moving a patient. Patients who are incontinent of bowel and/or bladder require special care, with application of moisture barrier creams and frequent changing. Your Hospice nurse will educate you in the use of a draw sheet to easily move the patient in a gentle manner.

Sometimes pressure sores cannot be prevented or healed, but warrant treatment. The Hospice nurse will ask the doctor for orders to begin a wound care regimen that should help to eliminate or minimize the sore, or help provide comfort to the area. Patients can be given pain medication prior to wound care and repositioning to prevent discomfort.

Mouth Care

Dry mouth can be caused by certain medications, decreased fluid intake and mouth breathing. Keeping your loved one's mouth clean and moist will add to their comfort. Avoid mouth swabs containing alcohol, as they will further dry the mouth. Clean and moisten the mouth with a Toothette® (ordered by your Hospice nurse) dipped in plain water or diluted mouth wash. Apply lip moisturizer frequently.



HYDRATION AND NUTRITION OF THE TERMINALLY ILL

As a person's body begins to slow down, the need for food and fluid may be decreased. Well-meaning family members sometimes encourage the person to continue to take nutrition. This act is customarily seen as a normal part of taking care of someone. However, at this time, it does not necessarily improve the patient's quality of life. It may, in fact, worsen it.

It is normal for people to reduce their intake of food as they begin the process of dying. Loss of appetite and lack of hunger are part of the slowing down of the body as death approaches. Some people simply refuse to eat. There is evidence that a person's body knows when nutrition is no longer needed, and the loss of appetite is a sign that the person is preparing to die.

While it may be difficult to watch a person go without eating, it is important to respect their wishes and to allow the end to come naturally.

There are many reasons for diminished thirst and appetite in terminal illness, including the disease process, medications, swallowing difficulties and compression of the bowel. Forcing nutrition and hydration on a person who is dying imposes a burden of food and water that the person's body cannot adequately process and negatively impacts his or her quality of life.

Artificial nutrition does not contribute to the relief of symptoms. In many cases it causes increased discomfort, does not prolong life, and may exacerbate the dying process. IV hydration provides very little clinically significant benefit to a person who is dying, and the *adverse* effects of hydration include swelling, fluid in the lungs and tissue and skin breakdown.

Please let your loved one be the guide. He or she will let you know if food or fluid is needed or wanted.

To Comfort Always...

MEDICATION INFORMATION/FAMILY INSTRUCTIONS

This Medication Instruction form is provided to each family member to ensure optimal safety in the handling, storage and/or destruction of all unused Hospice patient medications. Your nurse has given you verbal instructions and is leaving this form as a continuing reminder.

Storage and Handling of Medications

- Store in high, out-of-reach places that are safe from children.
- Never leave medications unattended in open areas.
- Always keep medications secured or locked within a cabinet.
- Identify household members who may be at risk for possible medication abuse.
- Assign one family member to oversee all issues regarding medications.
- Observe the “four rights” of medication administration: 1) the right medication, 2) the right time, 3) the right route and 4) the right dose (amount).
- Follow the individual instructions given for each medication.
- Call the Hospice immediately if the patient has an unexpected reaction to a medicine.
- Call the Hospice with any concerns about medication supply.

Destruction of Medications

- The Hospice nurse will assist you to destroy unused medications by helping you to follow this method: First, add a small amount of water to pills or capsules in order to partially dissolve them into a slurry. Then mix the slurry with enough cat litter, detergent, vinegar, used coffee grounds, charcoal, or non-toxic powder or spice to create a distasteful, pungent mixture. This mixture is enclosed in a sealed container (such as a sealable plastic bag or coffee can) and placed in trash (not recycling).
- If there is a risk for ingestion, medications may also be flushed down the sewer system. The Food and Drug Administration (FDA) requires that certain medications on the attached “flush list” be flushed because FDA has determined those medication to be especially harmful if they are used by someone other than the person for whom they were prescribed. Immediately flushing these types of medicines down the toilet helps keep children, pets, and other individuals safe by making sure these powerful and potentially dangerous drugs are not accidentally ingested, touched, or misused.
- When flushing, avoid flushing large quantities of medications. Flushing of smaller amounts is a safer form of disposal. Careful observation is required to ensure that the medications are completely flushed.
- When the nurse assists with disposal, the nurse will ask a witness to observe the count and actual disposal/flushing of the medications during this procedure and will request that the witness sign a form detailing which medications were destroyed. In this case, the nurse will document detailing all medication destroyed.
- Medications should be handled while wearing gloves to protect the skin from caustic substances or possible absorption.
- Protected Health Information should be removed from medication bottles/containers prior to disposal of these containers.
- State and federal law prohibit the use of any medication by anyone other than the person for whom the medication was prescribed.

What about the impact of the flushed medications on the environment and the contamination of surface and drinking water supplies?

FDA conducted research regarding the impact on the environment of flushing the medications on the flush list and concluded that flushing these medications presents negligible risk to the environment. FDA believes that the known risk of harm to humans from accidental, and sometimes fatal, exposure to medicines on the flush list far outweighs any potential risk to human health and the environment from flushing

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COMFORT PACK INSTRUCTIONS FOR HOME CARE PATIENTS ONLY

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The Hospice of New York Comfort Pack contains emergency medications that may be necessary to manage a patient's pain or other uncomfortable symptoms that may be experienced at the end of one's life. Use of the comfort pack contents should be at the direction of the Hospice nurse or Hospice physician. Your Hospice nurse will review the following medications with you so that you are prepared in the event that administration of these medications is necessary.

HALDOL (Haloperidol) is prescribed for agitation, confusion and/or restlessness. May also be prescribed to manage symptoms of nausea and vomiting. Rapid dissolve tablets are placed under the tongue.

MORPHINE SULFATE is prescribed for the relief of pain and/or relief of difficulty breathing. Rapid dissolve tablets are placed under the tongue.

LORAZEPAM (Ativan) is prescribed to ease anxiety and/or restlessness. Rapid dissolve tablets are placed under the tongue.

ACETAMINOPHEN (Tylenol) Rectal Suppositories are used for fever reduction and relief of mild pain.

HYOSCYAMINE is prescribed to reduce oral secretions and relieve congestion. May also be used as a gastrointestinal anti-spasmodic. Rapid dissolve tablets are placed under the tongue.

PROCHLORPERAZINE (Compazine) is prescribed to control symptoms of nausea and vomiting. Rapid dissolve tablets are placed under the tongue.

Our pharmacy provider will deliver your comfort pack once ordered by the physician.

Please follow the instructions for refrigeration.

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HOSPICE AIDE INFORMATION

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The Services a Hospice Aide May Provide Are as Follows:

- Assist patient with bath (tub, shower, sponge) and personal hygiene.
- Assist with transfer from bed to wheelchair, walker, toilet, etc.
- Change bed linens for patient.
- Assist with meal preparation and special diets ordered for the patient.
- Launder personal clothing and linens of patient only.
- Limited grocery shopping at the nearest store for patient's needs only.
- Light housekeeping of patient use areas.

The Hospice Aide May Not Provide the Following Services:

- Give medications.
- Scrub or wax floors.
- Wash walls or windows.
- Remain in the home if the patient is not in the home.
- Handle finances.
- Transport patient in their car.
- Move heavy furniture.

The time required for the above duties will be under the direction and supervision of your assigned Hospice nurse.

We will try our best to assign the Hospice aide to you at the time most needed for your care. However, we do care for many patients daily and the assigned times must be made according to patient priorities.

Please feel free to discuss this with your nurse at the time of his or her visits with you.

TIPS ON PREVENTING FALLS IN THE HOME

Falls are the leading cause of home injury and death among adults aged 65 and older. Each year, more than 4,700 Americans in that age group die as a result of falls, and more than a million elderly Americans are admitted to hospital emergency rooms to treat injuries related to falls, according to the Home Safety Council.

How to Prevent Falls in the Home:

- Conduct a safety check all around your home.
- Make sure all stairs and steps have a secure banister or handrail.
- Make sure all porches, hallways and stairwells are well lit.
- Use nightlights to help light hallways and bathrooms during nighttime hours.
- Keep stairs, steps, landings and all floors clear. Reduce clutter and safely tuck away telephone and electrical cords out of walkways.
- In homes with children, make sure toys and games are not left on steps or landings. When very young children are present, use safety gates at the tops and bottoms of stairs.
- Use a non-slip mat or install adhesive safety strips or decals in bathtubs and showers. If you use a bath mat, choose one that has a non-skid bottom.
- Install grab bars in bath and shower stalls. Don't use towel racks or wall-mounted soap dishes as grab bars; they can easily come loose, causing a fall.
- Keep the floor clean. Promptly clean up grease, water and other spills.
- If you use throw rugs in your home, place them over a rug liner or choose rugs with non-skid backs to reduce your chance of slipping.
- Use a sturdy stepstool with handrails when climbing is necessary.
- Follow medication instructions closely. Using multiple medications and/or using medications incorrectly may cause dizziness, weakness and other side effects that can lead to a dangerous fall.

For more information on preventing falls and on safety in the home, visit www.cdc.gov/HomeandRecreationalSafety/Falls/pubs.html.

HOME CARE INFECTION CONTROL

How to Prevent Infection in the Home:

- Wash your hands after contact with bodily fluids, such as blood, urine, stool, respiratory secretions and drainage from wounds.
- Clean, disposable (not sterile) gloves should be available in the home to assist with care when body fluids will be contacted.
- Gowns may be worn if drainage is expected to soil clothes. The wearing of gowns is to protect clothing from soiling, not to prevent the spread of infectious organisms.
- Masks are not necessary unless you are specifically instructed to use them.
- Soiled linens or clothing can be cleaned in the washing machine with hot water, detergent and one cup of bleach. (Detergent and bleach should be added to water before washing linens to minimize fading).
- Soiled tabletops, toilets, showers or floors can be cleaned by washing spills with hot, soapy water, then disinfecting with a solution of one part bleach to ten parts water.
- Separate eating or cooking utensils are unnecessary. Eating utensils should be washed in hot, soapy water after each use.
- Toothbrushes and razors should not be shared, since bleeding may occur during their use.
- If needles are used in the care of the patient, a puncture-proof disposal container (i.e., detergent container) should be kept in the house. Gloves, soiled underpads or dressings, or other items that may contain body fluids of the patient should be placed in a heavy duty plastic bag and secured firmly at the top to prevent spillage.
- These containers and heavy duty plastic bags should be disposed of in accordance with local regulations for the disposal of solid wastes.



SAFE DISPOSAL OF HOUSEHOLD SHARPS

Millions of people use needles, syringes and lancets at home to care for their health. These items are called sharps. Used household sharps must be stored safely and disposed of properly to protect people from diseases. Used sharps may hold blood infected by HIV (the virus that causes AIDS) or hepatitis C. Someone who accidentally gets cut by a used sharp could get infected by the blood.

Safe Disposal of Used Sharps:

- Protects children, pets and workers who come into contact with trash and recyclables from illness and injury.
- Prevents sharps from being re-used or shared, which can spread disease.
- Protects the environment.

How to Store Your Used Sharps:

Here are the best ways to store used sharps until you can safely dispose of them:

DO...

- Put used sharps (needles, syringes, lancets) in a sharps container. You can buy containers at your local drugstore. If you do not have a sharps container, use a plastic bottle that cannot be broken or punctured, such as a bleach bottle. Close the screw-on cap tightly. Put tape over the cap and write, "CONTAINS SHARPS" on the bottle.
- Put sharps into your container as soon as you use them. Keep the container closed and away from children and pets.
- Bring your container with you when you travel.



DON'T...

- Recycle used sharps.
- Put your used sharps container in the trash.
- Flush used sharps down the toilet or drop them into a sewer drain.
- Clip, bend or put the cap back on used sharps.
- Put loose used sharps or your used sharps container in with the recyclables.
- Put used sharps in soda cans, milk cartons, glass bottles or containers that can be broken or punctured. Coffee cans are not safe because the plastic lids come off easily or may leak.



Safe Disposal of Your Used Sharps Container

When your container is almost full with used sharps, bring it to a safe disposal site. Here are some ways to find safe disposal sites near you:

- You can bring used sharps to any hospital or nursing home in New York State. Call first to find out hours, days and a location where you can bring used sharps.
- Call the New York State Department of Health at 800.522.5006 (Growing Up Healthy hotline) to find sharps disposal sites in your area. TTY: 800.655.1789.
- Some drugstores, health clinics, and community service agencies have large metal boxes (called kiosks) for sharps disposal. Call the New York State HIV / AIDS Information Service at 800.541.2437 to find places with sharps disposal kiosks.



- The American Diabetes Association sells a container that safely holds used sharps. When it is full, you mail it back to the American Diabetes Association. Call 1-888-232-2737 for information. Or, ask your diabetes educator or local American Diabetes Association office about this program and other sharps disposal programs in your area.
- The place where you live may have special hazardous waste collection days or drop-off days. Get the number of your local public works department from the blue pages of your phone book.

Learn More About Safe Sharps Disposal:

Here are the best ways to store used sharps until you can safely dispose of them:

New York State Department of Health

- To find out the days and times for sharps disposal in your area, call 800.522.5006. TTY: 800.655.1789.
- Call the New York State HIV / AIDS Information Service at 800.541.2437 to find places with sharps disposal kiosks.
- For a list of disposal sites and kiosks by county, visit: http://www.health.ny.gov/diseases/aids/harm_reduction/needles_syringes/sharps/directory_sharpscollection.htm

Centers for Disease Control and Prevention (CDC)

- Visit: www.cdc.gov/needledisposal to learn about sharps disposal in New York State.

American Diabetes Association

- Call 888.232.2737 or visit www.BDdiabetes.com to learn about their mail-in sharps disposal program.



OXYGEN SAFETY AT HOME

Oxygen can be used safely in the home. Here are some rules for oxygen safety:

- Oxygen is a medical treatment. Too much or too little oxygen may be harmful.
- Use the amount ordered by your doctor.

FIRE SAFETY

Oxygen itself does not burn. Oxygen can feed a spark and cause it to become a large fire in seconds.

Follow These Rules to Prevent Fire:



NO SMOKING Do not allow anyone to smoke in the room where there is oxygen. Your oxygen home care company will provide “no smoking” signs to hang in your home.



NO OPEN FLAMES Do not use oxygen within 10 feet of open flames. This includes matches, fireplaces, candles, wood-burning stoves, gas stoves and any other sources of fire or flame.



DO NOT USE EQUIPMENT WITH FRAYED CORDS OR ELECTRICAL SHORTS They could cause a spark.



AVOID USING ELECTRIC RAZORS AND HAIR DRYERS WHILE USING OXYGEN Battery-operated razors and hair dryers under 10 volts can be used.



DO NOT USE AN APPLIANCE WITH A “CONTROL BOX” Heating pads are a good example. Control boxes can throw sparks.



AVOID NYLON OR WOOLEN CLOTHING These types of fabrics are more likely to generate static electricity.



USE A HUMIDIFIER IN WINTER Humidifiers add moisture to dry air in your home.

Proper Storage and Handling of Oxygen

- Store liquid and other cylinder oxygen away from heat and direct sunlight.
- Secure cylinders with chains as arranged by your home care therapist. Place cylinders in a secure holder and in an upright position.
- Never apply any oily substance (petroleum-based lip products such as Vaseline, Blistex®, Chap Stick®) to your nose, lips or the lower part of your face.



HELPFUL HINTS FOR CAREGIVERS

Consistency

Develop a routine in giving care. Performing tasks in the same way and at the same time each day helps the patient's sense of security and is more efficient for you.

Records

Days are often alike and remembering details can be difficult. Write down what you need to remember such as medications, bowel movements, pain, nausea, vomiting or other complaints or symptoms.

Meals

If chewing and swallowing food become difficult for the patient, you can use a food processor or blender to purée most meals. Most foods adapt well to being chopped or puréed by adding small amounts of broth or juice to make them smoother. Clear foods like Jell-O®, popsicles, ginger ale, apple juice and watery ice are often recommended. Many patients respond well to salty foods such as canned soups or saltine crackers. Also, it is essential to pay attention to your own nutritional needs as a caregiver. Even if the patient eats poorly, it is essential that you regularly eat well-balanced meals.

Rest

Take a break at least twice a day. When the patient rests, you should rest. Remember, what you are doing is important, but very often tiring. To continue as a caregiver you will periodically need to take a break.

Medications

The Hospice should be notified if medications are changed by the primary physician. For the patient's safety, all medications are to be given as instructed by the Hospice nurse and any questions or changes should be reported to the hospice. Store all medications as instructed.

Plan Ahead: Prescriptions should be refilled before medicines run out. Certain pain medications have specific refill requirements. Remember to think ahead for weekends and holidays. The Hospice's pharmacy will provide a special Comfort Pack containing emergency medication. This pack should be stored unopened in the refrigerator until your Hospice nurse advises you as to how and when these emergency medications should be used.

Additional Help

Family, friends, and neighbors may offer to help. Keep a list of errands, nutritional needs, chores and appointments that must be done so that when people offer, you will be able to suggest specific things that will be of help. People who offer to help genuinely want to make your life a little bit easier. Help them and yourself by giving them something to do that eases your burden.

Communication

Please keep the Hospice informed about the patient. Someone is always available to answer any questions that may arise, so do not hesitate to call. Outside normal business hours, messages can be left with the on-call service. If possible, give a relative or trusted neighbor a spare house key. Tell Hospice the name and phone number of that person in case of an emergency.

Patient and Family Safety

The Hospice nurse and/or social worker will discuss suggestions for ensuring the safety of the patient's physical environment. Some changes in the home may be necessary to facilitate better patient care. The last two pages of this booklet contain a plan for emergencies and important phone numbers. Please keep this in a place that is accessible to all caregivers and visiting Hospice staff. As caregivers, please understand that Hospice of New York welcomes all questions. When it comes to the comfort and safety of the patient, please call with all comments, questions and concerns.



PLANNING A FUNERAL

When you are called upon to make funeral arrangements for a family member or close friend, you will find there are many details to be handled and decisions to be made; therefore, it is advisable to begin the planning before the death has occurred. The funeral you arrange will honor the life of the person you have lost and allow you to express and share your grief with others according to an individual's beliefs, religious practices and family traditions.

The following information will give you an idea of what to expect as you begin making the funeral arrangements. It outlines the information required by the funeral director regarding those arrangements.

Choosing a Funeral Director

Your first decision will be the selection of a funeral director. In some families, a funeral director is known to the family or there is a relationship with a funeral home through church, synagogue or other community organization. If you have not had personal experience with any funeral home, there are four important points to consider as you make your selection:

■ Convenience

Since family members will have several occasions to visit the funeral home before and after the service, convenience of location will be an important consideration.

■ Reputation

If more than one funeral home is convenient, you may want to ask a friend to recommend one with which he or she is familiar. Your clergy person, social worker or nurse may also be able to make some suggestions.

■ Integrity and Stability

If you cannot or do not wish to consult someone, you can often judge the integrity and stability of a funeral home by the length of time it has been in business. You can usually assume that a funeral home which has been in business for many years has been performing to the satisfaction of the families it serves.

■ Responsiveness

The most important step in selecting a funeral home is to call or visit the funeral home. This is an opportunity to discuss any aspects of the arrangements that are of particular concern to you. You can then compare the responses and choose the funeral home that best suits your needs.

What to Expect When You Call the Funeral Director

Once you have chosen a funeral director, you can begin to make the arrangements. While it is very helpful to make most of the funeral arrangements before death occurs, some families instead prefer to select the funeral director early on but wait until after the patient has passed away to plan the funeral. Whenever the decision is made, rely on the funeral director to assist you with every aspect of funeral planning. Some of the details you may wish to discuss include:

- What type of service you desire.
- Who will officiate at the service.
- Who will serve as pallbearers.
- Whether there will be flowers and music.
- Which type of casket is preferred.
- Whether the deceased will be interred or cremated.



When pre-planning funerals there is no obligation to pay for these services in advance, and funeral directors must provide itemized information regarding cost.

What About Cost?

When all the particulars of the funeral have been discussed and decided upon, the funeral director will furnish you with a completed contract indicating all the services and costs. This is to prevent any misunderstandings and to assure that all essential items have been considered. Feel free to discuss with your funeral director any questions you have about cost or arrangements. Medicaid recipients may be entitled to limited funds that can be applied to funeral costs. For further information on these and other burial assistance benefits, ask your hospice social worker.

At Time of Death

After the death occurs, contact Hospice of New York at 718.472.1999 or 516.222.1211. A nurse or social worker will help arrange for the removal of the deceased from the home or Hospice unit and obtain the death certificate from the physician. In order to complete the death certificate the funeral director will need specific information from you about the deceased, including:

- Full name
- Social Security number
- Marital status
- Occupation
- Level of education
- Mother's first and maiden name
- History of military service

You will need separate copies of the death certificate to close bank accounts or trusts and to collect Social Security, insurance premiums, or any other death benefits to which you may be entitled. The copies must be official imprinted with the seal from the Department of Health. Your funeral director will help you obtain these initial copies; be aware there is a charge for each copy of the death certificate. If subsequent copies are needed at a later date, they must be obtained directly from the Bureau of Vital Statistics for a charge.



BEREAVEMENT

The Hospice Bereavement Program works with patients and families to understand their needs related to grief. The hospice team has tremendous capacity to assess and understand the dynamics of family history and to facilitate appropriate good-byes. Bereavement therapy can help provide the tools needed for better coping and coming to a sense of resolution.

Some Key Factors That Impact Upon Resolution of Grief Include:

- The bereaved person's relationship with the deceased.
- The length of the illness.
- The ability of the bereaved to have participated in the care of the deceased.
- The ability to express emotions.
- The ability to accept support.
- The strength and nature of the family system.
- General health and lifestyle.
- The availability of support systems.
- The reactions to previous loss.

The Hospice Bereavement Program incorporates many resources that have proven effective over time. The most fundamental resource is the commitment of people who listen. Each bereaved person is invited to participate in our bereavement groups, follow-up telephone contact, informational mailings and memorial services.

*We are not human beings on a spiritual journey.
We are spiritual beings on a human journey.*

— Pierre Teilhard de Chardin

EMERGENCY TELEPHONE NUMBERS

Below are contact numbers of family and friends and other emergency numbers, along with items that should be on hand for the patient, household residents and pets.

During weather-related emergencies, the Hospice will contact you to ensure that plans are in place for safety and emergency needs. In case of an emergency, the following contact numbers should be utilized and evacuation plans should be followed. Patients who reside in a nursing home will follow that facility's written emergency plan.

IN A LIFE-THREATENING EMERGENCY, DIAL 911.

Other emergency numbers are located on the first few pages of your phone book.

**FOR PATIENT-RELATED EMERGENCIES, ALWAYS CALL HOSPICE FIRST.
718.472.1999 OR 516.222.1211**

POLICE: 911

LOCAL PRECINCT: _____ - _____ - _____

FIRE: 911

LOCAL FIRE DEPT: _____ - _____ - _____

GAS AND ELECTRIC

CON EDISON

<http://www.coned.com/>

800.752.6633

LONG ISLAND POWER AUTHORITY

<http://www.lipower.org/>

800.490.0075

Español: 800.490.0085

OTHER: _____ - _____ - _____

MY ATTENDING PHYSICIAN:

NAME _____

_____ - _____ - _____

NEAREST EMERGENCY CONTACTS

NAME _____

HOME _____ - _____ - _____

WORK _____ - _____ - _____

CELL _____ - _____ - _____

NAME _____

HOME _____ - _____ - _____

WORK _____ - _____ - _____

CELL _____ - _____ - _____

NAME _____

HOME _____ - _____ - _____

WORK _____ - _____ - _____

CELL _____ - _____ - _____

NAME _____

HOME _____ - _____ - _____

WORK _____ - _____ - _____

CELL _____ - _____ - _____

CALL HOSPICE FIRST:

New York City 718.472.1999

Nassau County 516.222.1211

FAMILY EMERGENCY PLANNING

HAZARDS

Is the home especially vulnerable to any particular hazard, such as flooding or power outage?

Hazards: _____

DOES THE HOME HAVE:

- A hard-wired phone?
- A hand-operated can opener?
- A garage door opener that operates without electricity?
- Extra cash in case ATMs are out?
- Extra gasoline for the car, or a generator?
- Batteries, flashlight, emergency radio, etc.?
- First aid kit?
- Bottled water?
- Non-perishable food?

TO GO OR TO STAY?

- Are there plans for evacuation or a shelter in place?
Area Shelter: _____
- Do you have a minimum of 3 days' supplies?
- How long can the family go without power?
- Do you have a "Go" bag?
- Do you have plans for pets or service animals?
- Do you have a JEEP (Joint Emergency Evacuation Point) planned?

MEDICAL RECORDS

Are there copies of vital medical information (prescriptions, insurance and Medicare cards, Advance Directives including DNR orders) in case of evacuation or alternate care providers?

Where are they? _____

MEDICATIONS

Call Hospice of New York for medications supplied by Hospice.

LOCAL PHARMACY: _____ - _____ - _____

OTHER RESOURCES

Red Cross

www.redcross.org

American Red Cross Greater New York

520 West 49th Street, New York, NY 10019

Phone: 877.733.2767

Fax: 212.875.2309

American Red Cross on Long Island

195 Willis Avenue, Mineola, NY 11501

Phone: 516.747.3500

Fax: 516.384.1304

New York City Office of Emergency Management

http://www.nyc.gov/html/oem/html/ready/seniors_guide.shtml

By mail:

165 Cadman Plaza East, Brooklyn, NY 11201

By phone:

Public inquiries in NYC: 311

Public inquiries outside NYC: 212.639.9675

New York State Department of Health

<http://www.health.ny.gov/publications/7064.pdf>

Metropolitan Region (NYC) 212.417.5550

Central Islip Field Office (L.I.) 631.851.3087

U.S. Department of Homeland Security

<http://ready.gov>

Disaster survivors, please call:

Phone: 800.621.FEMA (3362)

TTY: 800.462.7585

Centers for Disease Control and Prevention

<http://www.bt.cdc.gov/>

1600 Clifton Rd., Atlanta, GA 30333, USA

800.CDC.INFO (800.232.4636) TTY: 888.232.6348

Hospice & Palliative Care Association of New York State

http://www.hpcanys.org/provider_resources.asp

2 Computer Drive West, Suite 105

Albany, NY 12205

Phone: 518.446.1483

Fax: 518.446.1484

Toll Free: 800.860.9808

MISSION STATEMENT

Hospice of New York, LLC has been providing compassionate care to patients, families and caregivers since 1997. Our interdisciplinary team of physicians, nurses, social workers, home health aides, spiritual counselors, therapists and volunteers work together to provide for the needs of patients and families as they are facing the challenges of living with a life threatening illness. Hospice of New York is a Medicare, Medicaid CHAP accredited Hospice licensed by the State of New York to serve Manhattan, Queens, Brooklyn, the Bronx and Nassau Counties. Our hospice maintains the standards of excellence in all we do and Hospice is the ONLY thing we do. Our promise is to *comfort always*.

QUALITY CARE FOR ALL

Hospice of New York provides care, employs staff, and offers volunteer opportunities regardless of race, religion, creed, color, gender, national origin, disability, age, diagnosis, or sexual orientation.

LICENSES AND CERTIFICATION

Hospice of New York is licensed by the State of New York and certified by the Medicare and Medicaid Program. Hospice of New York is an independent limited liability corporation.

ACCREDITATION

Hospice of New York is accredited by the Community Health Accreditation Program.



Hospice of New York

Metro New York: 718-472-1999 • Nassau County: 516-222-1211
Fax: 718-472-5222 • E-Mail: info@hospice.nyc • www.hospice.nyc