



Ask for us by name...there is a difference. SINCE 1980

Serving Northwest NJ and Northeast PA

Patient/Family Orientation for Hospice Care



STATEMENT OF CONFIDENTIALITY

This booklet may contain protected health information. Persons other than you and your health care providers must have your permission to view this booklet.

Administrative Office
99 Sparta Avenue
Newton, New Jersey 07860
Phone: 1-800-882-1117
Fax: (973) 383-6889
Website: www.karenannquinlanhospice.org

Office Hours and On-Call Guidelines

OFFICE HOURS

Our office hours are from 8:30 a.m. to 4:30 p.m., Monday through Friday, except holidays. You may reach us by calling 1-800-882-1117 during normal office hours.

Examples of issues that are handled during regular office hours:

- Medication refills
- Messages for the primary nurse:
 - You need the nurse to bring or order supplies (i.e., incontinence supplies)
 - Questions about your visit schedule
- Lab or bloodwork results
- Questions about the hospice aide

VISIT CANCELLATIONS: If for any reason you need to cancel your scheduled visit, please call **1-800-882-1117**. The hospice manager will alert your staff and reschedule the visit. Your hospice team will make every effort to advise you of their schedule for visiting. If we need to cancel a planned visit, the hospice manager will call you to reschedule.

ON-CALL GUIDELINES

Call 1-800-882-1117 at any time.

A registered nurse (RN) is available 24 hours a day, seven days a week to assist you with problems after regular office hours, on weekends or holidays. We will talk with you by phone to determine your needs. When appropriate, a nurse will come to your place of residence. We do not carry medications with us and cannot give anything unless ordered by the physician.

Do not call 911 before calling the on-call nurse. If you call 911, you may have to pay for the emergency services.

Examples of situations when you should contact the on-call nurse:

- Pain that does not respond to pain medication on hand
- Difficulty breathing
- New onset of agitation or restlessness
- Falls where possible injury has occurred
- No urine in eight hours associated with discomfort
- Uncontrolled nausea, vomiting or diarrhea
- Uncontrolled bleeding
- Temperature above 101°F that does not respond to fever-reducing drugs
- Unable to awaken patient (new problem)
- Catheter leaking
- Chest pain
- Patient taken to the hospital
- Immediate support issues
- Patient death

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SECTION 1. Mission, Vision and Philosophy

Mission Statement:

Karen Ann Quinlan Hospice is a not-for-profit organization that provides a full continuum of high quality medical, emotional and spiritual services to hospice patients, their family members and the community.

Vision Statement:

We will be the leading provider of home and community-based health services. Our care will be defined by comfort, compassion, individual respect and personal dignity afforded to all. We will continue to foster the advancement of quality of care for our patients and families.

Philosophy:

Karen Ann Quinlan Hospice:

- Provides the highest quality of hospice services that are responsive to the patient's needs, supportive of the family and under the direction of the patient's primary physician.
- Is an active hospice provider member of the community operating in a responsible, efficient and cost-effective manner.
- Provides for sufficient resources to support the mission and ensure the highest quality care.
- Commits to the hospice philosophy of caring that includes comfort, compassion, individual respect and personal dignity for all.
- Provides services regardless of race, color, national origin, sex (including sexual orientation and gender identity), age, religion, disability, diagnosis, ability to pay or source of payment.

LANGUAGE ASSISTANCE SERVICES

Spanish:	ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-882-1117.
Chinese:	注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-800-882-1117。
Korean:	주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-800-882-1117 번으로 전화해 주십시오.
Portuguese (European):	ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-800-882-1117.
Gujarati:	સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-800-882-1117.
Polish:	UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-800-882-1117.
Italian:	ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1-800-882-1117.
Arabic:	ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-800-882-1117.
Tagalog:	PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-800-882-1117.
Russian:	ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-800-882-1117.
French Creole (Haitian):	ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 1-800-882-1117.
Hindi:	ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-800-882-1117 पर कॉल करें।
Vietnamese:	CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-800-882-1117.
French:	ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-800-882-1117.
Urdu:	خبردار: اگر آپ اردو بولتے ہیں، تو آپ کو زبان کی مدد کی خدمات مفت میں دستیاب ہیں۔ کال کریں 1-800-882-1117
Nepali:	ध्यान दिनुहोस्: तपाईंले नेपाली बोल्नुहुन्छ भने तपाईंको निम्ति भाषा सहायता सेवाहरू नि:शुल्क रूपमा उपलब्ध छ । फोन गर्नुहोस् 1-800-882-1117 ।
Burmese:	သတိပြုရန် - အကယ်၍ သင်သည် မြန်မာစကားကို ပြောပါက၊ ဘာသာစကား အကူအညီ၊ အခမဲ့၊ သင့်အတွက် စီစဉ်ဆောင်ရွက်ပေးပါမည်။ ဖုန်းနံပါတ် 1-800-882-1117 သို့ ခေါ်ဆိုပါ။
Portuguese (Brazil):	ATENÇÃO: Caso você fale português do Brasil, você tem serviços assistenciais de idioma gratuitos à sua disposição. Ligue para 1-800-882-1117.
Bengali:	লক্ষ্য করুন: যদি আপনি বাংলা, কথা বলতে পারেন, তাহলে নি:খরচায় ভাষা সহায়তা পরিষেবা উপলব্ধ আছে। ফোন করুন ১-৮০০-৮৮২-১১১৭।
Albanian:	KUJDES: Nëse flitni shqip, për ju ka në dispozicion shërbime të asistencës gjuhësore, pa pagesë. Telefononi në 1-800-882-1117.

TTY SERVICE: English: 1-800-852-7899 (NJ)/1-800-654-5984 (PA)
Spanish: 1-866-658-7714 (NJ)/1-844-308-9291 (PA)

SECTION 2. Hospice Overview

POLICIES

This booklet contains general information regarding your rights and responsibilities as a patient. As state and federal regulations change, there may be additions or changes to this booklet as necessary. Our complete policy and procedure manual regarding your care and treatment is available upon request for your viewing at the agency office at any time during normal office hours.

Policies and procedures for hospice are constantly under review. Changes/additions are made, as appropriate, utilizing New Jersey and Pennsylvania Department of Health Licensure Regulations, Federal Conditions of Participation, Medicare regulations and Community Health Accreditation Partner (CHAP) standards. Any such changes are presented quarterly at the Professional Advisory Committee (PAC) meetings for approval. Additionally, a member of the PAC reviews the policy and procedure manuals annually, and the PAC approves such review.

HOSPICE SERVICES AVAILABLE UNDER THE HOSPICE BENEFIT

If the insurance provider is a public or private insurer the services may differ based on plan coverage. Each patient will have an individualized care plan developed by the Hospice Interdisciplinary Team (IDT).

- Nursing
- Physician* Services
- Social Services
- Volunteer Services
- Spiritual Counseling
- Dietary Counselor
- Hospice Aide Services
- Occupational Therapy, Physical Therapy, Speech/Language Pathology
- Bereavement
- Equipment
 - Hospice can facilitate the ordering of equipment for hospice patients from our contracted provider.
 - Under the hospice benefit, equipment approved by the hospice team is covered 100%.
- Medications
 - Under the hospice benefit, medications related to the terminal diagnosis and that are ordered by the physician are covered 100%.
 - Your hospice nurse will review all your medications and will discuss with our physician those that will no longer be covered and are no longer required at the time.

**The words "physician" or "doctor" will be used throughout this booklet, but also may refer to other allowed practitioners (such as nurse practitioners and physician assistants, who may act as the hospice attending physician, except for certification of terminal illness).*

HOSPICE LEVELS OF CARE

Routine (Home Hospice Care):

- Provided in the patient's home. The Hospice team is available 24 hours a day, seven days a week; and visits are intermittent, as prescribed in the individualized plan of care.
- I understand the obligation to be responsible for the patient's care at all times. I understand that hospice services are intended to support, not replace, my primary caregiver(s).

Continuous Home Care:

- Under the Medicare hospice benefit nursing care may be covered on a continuous basis for as much as 24 hours a day as necessary to maintain an individual at home during periods of crisis. A period of crisis is when the beneficiary requires the higher level of "continuous care" for at least eight hours in a 24-hour period (midnight to midnight) to achieve palliation or management of acute medical symptoms. The care does not have to be "continuous" to qualify but must total eight hours or more of care within the 24-hour period. The care can be provided by an RN, LPN, and Certified Home Health Aide. However, at least 51% of the total care provided must be provided by a nurse. If you are covered under a private or public insurer, benefits are based on your plan coverage. A minimum of eight (8) hours of care per day may be provided during periods of crisis to maintain the patient at home. Criteria for continuous home care are the same as general inpatient care and consist predominantly of nursing care; however, hospice aides or homemakers may also supplement nursing care.

Inpatient Respite:

- This care is provided as relief for the family who has been caring for the patient at home.
- Inpatient respite care is provided in a Medicare or Medicaid approved facility and may not exceed five consecutive days.

Hospice General Inpatient (GIP):

- Short-term care is provided for the relief of pain and symptom management of a terminal disease.
- Treatment is palliative rather than curative.
- General Inpatient care is provided in a Medicare or Medicaid approved facility.

HOSPICE AIDE INFORMATION

What is a Hospice Aide?

Karen Ann Quinlan Hospice employs and utilizes hospice aides who are "certified." This means that they have taken a Medicare-approved training course and have passed a written and practical examination and possess certification through the New Jersey State Board of Nursing. Certified hospice aides practice only under the instruction and supervision of a registered nurse (RN).

How much time will the Aide spend with me?

The primary function of the hospice aide is to perform or assist personal care. Personal care is bathing, dressing, turning and positioning, assisting with transfers from bed to chair, helping to carry out home exercise programs left by a therapist – anything that requires “hands-on” assistance.

The hospice aide will stay in the home for one to two hours. Depending upon patient and family needs, extended circumstances may warrant additional time which will be reviewed by the IDT.

What types of things can a Hospice Aide do for me?

Under the supervision and direction of a registered nurse, the hospice aide may:

- Bathe or assist bathing, shampooing and dressing.
- Assist with use of the bedpan, urinal or commode.
- Assist with transfers (bed to chair, sit to stand, stand to sit, chair to bed; may use mechanical devices to assist with transfers).
- Assist with simple dressings without medication; reinforcement of dressings originally applied by a nurse or family member.
- Make observation of changes in physical or mental condition (and report of same to the nurse).
- Meal planning and preparation.
- Temperature, pulse and respiration testing.
- Assist with oral medications that have been pre-poured by the nurse or a family member (that are ordinarily self-administered, as ordered by the physician). Patient must self-administer.
- Assist with following home exercise programs left by therapists.
- Assist with putting on braces and prostheses as directed by the nurse.
- Assist with following medical recommendations of rest, exercise and physical activity.
- Assist with use of medical and rehabilitation equipment.

Doesn't the Hospice Aide also do housework and shopping?

Medicare dictates that at least 75% of the hospice aide's time in the home is spent doing personal or “hands-on” care. This means that, incidental to the hospice aide's time doing personal care, he or she may clean the patient's immediate living area, usually the bedroom or prepare a meal or do the patient's personal laundry.

Because the time allowed to do these incidental tasks is so limited, it is anticipated that patients and family members will discuss these needs with the nurse on the first visit. For those tasks beyond the ordinary ability of the hospice aide, the nurse will make alternative suggestions.

Home Health Aide Care Plans:

- Aide care plans are developed by the nurse case manager supervising the care.
- Only items on the care plan may be provided.

EXPERIENCE OF CARE/PATIENT SATISFACTION SURVEYS

Our hospice has contracted with Deyta, LLC (HEALTHCAREfirst), a vendor approved by the Centers for Medicare & Medicaid Services (CMS) to perform mandatory Consumer Assessment of HealthCare Providers and Systems (CAHPS®) surveys. The survey considers you and your primary caregiver as a unit of care. Deyta, LLC (HEALTHCAREfirst) may contact your caregiver or family member by mail or telephone after your death to evaluate the experience of care and services you and your loved ones received from our hospice agency.

Our patients are very important to us. Please ask questions if something is unclear regarding our services or the care you receive or fail to receive. Our hospice agency may also contact you, your caregiver or family at intervals to assess your satisfaction with the care and services we are providing. We will not ask the same questions included in the CAHPS® survey. Your answers will help us to improve our services and ensure that we meet your needs and expectations.

NOTICE OF NONDISCRIMINATION/FILING A GRIEVANCE

Karen Ann Quinlan Hospice does not discriminate on the basis of race, color, national origin, sex (including sexual orientation and gender identity), age, religion, disability, diagnosis, ability to pay or source of payment per federal regulations. The Organization has adopted an internal grievance procedure providing for prompt resolution of complaints alleging any action prohibited by Section 1557 of the Affordable Care Act and the Pennsylvania Human Relations Act and its implementing regulations issued by the U.S. Department of Health and Human Services. Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age or disability in certain health programs and activities. The Act may be examined in the office of the Civil Rights Coordinator/Section 1557 Coordinator, 99 Sparta Avenue, Newton, NJ 07860; phone: (973) 383-0115. Any person who believes someone has been subjected to discrimination on the basis of race, color, national origin, sex (including sexual orientation and gender identity), age, religion, disability, diagnosis, ability to pay or source of payment may file a grievance under this procedure. It is against the law for the Organization to retaliate against anyone who opposes discrimination, files a grievance, or participates in the investigation of a grievance.

Karen Ann Quinlan Hospice provides free aids and services to people with disabilities to communicate effectively with us, such as qualified sign language interpreters, written information in other formats (large print, audio, accessible electronic formats, other formats); and free language services to people whose primary language is not English, such as qualified interpreters and information written in other languages. If you need these services, contact the office of the Section 1557/Civil Rights Coordinator.

Grievances must be submitted to Karen Ann Quinlan Hospice within 60 days of the date you become aware of the possible discriminatory action, and must state the problem and the solution sought. We will issue a written decision on the grievance based on a preponderance of evidence no later than 30 days after its filing, including a notice of your right to pursue further administrative or legal action. You may also file an appeal of our decision in writing to the Administrator within 15 days. The Chief Operating Officer will issue a written response within 30 days after its filing.

The availability and use of this grievance procedure does not prevent you from pursuing other legal or administrative remedies.

You may also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights by using any of the following methods:

- Submit electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>.
- Write to Centralized Case Management Operations, U.S. Department of Health and Human Services, 200 Independence Avenue, SW, Room 509F, HHH Building, Washington, D.C. 20201. Complaint forms are available at: <http://www.hhs.gov/ocr/office/file/index.html>.
- Call 1-800-368-1019 (toll free) or 1-800-537-7697 (TDD).

PROBLEM SOLVING PROCEDURE

If you feel that our staff has failed to live up to our policies or has in any way denied you your rights, please follow these steps without fear of discrimination or reprisal:

1. Notify the Chief Operating Officer by phone at **1-800-882-1117**, from 8:30 a.m. to 4:30 p.m., Monday through Friday. You may also submit your complaint in writing to **99 Sparta Avenue, Newton, NJ 07860**. Most problems can be solved at this level.
2. You may also contact the state's toll-free hospice hotline. The hotline receives complaints or questions about local hospice agencies and complaints regarding the implementation of advance directive requirements.
 - ☐ **New Jersey Hotline:** Call **1-800-792-9770**. The hotline operates 24 hours a day, seven days a week. You may also submit your complaint in writing to New Jersey Department of Health, Division of Health Facility Survey and Field Operations, P.O. Box 367, Trenton, NJ 08625-0367; by fax to (609) 943-3013; or online at <http://web.doh.state.nj.us/fc/search.aspx>.
 - ☐ **Pennsylvania Hotline:** Call **1-800-254-5164**. Voicemail is available 24 hours a day, seven days a week. Leave a message with your name, telephone number (including area code), the name of the agency and the nature of your complaint and your call will be returned by the next business day. Normal business hours are from 8:00 a.m. to 4:30 p.m., Monday through Friday (except holidays). You may submit your complaint in writing to Pennsylvania Department of Health, Complaint Unit, Health and Welfare Building, 8th Floor West, 625 Forster Street, Harrisburg, PA 17120.
3. You may also contact the CHAP hotline 24 hours a day at 1-800-656-9656. Customer service hours of operation are 8:30 a.m. to 7:00 p.m., Eastern Time, Monday through Friday (except holidays).

SECTION 3. Hospice Patient's Rights

Each patient shall be entitled to the following rights, none of which shall be abridged or violated by the hospice or any of its staff:

1. To treatment and services without discrimination based on race, age, religion, national origin, sex, sexual preferences, handicap, diagnosis, ability to pay, or source of payment;
2. To be given a verbal and written notice in a language and manner that the patient understands, prior to the initiation of care, of these patient rights and any additional policies and procedures established by the agency involving patient rights and responsibilities. If the patient is unable to respond, the notice shall be given to a family member or an individual who is a legal representative of the patient.
 - i. The hospice shall obtain the patient's or representative's signature confirming that he or she has received a copy of the notice of rights and responsibilities.
 - ii. If the patient has been adjudged incompetent under State law by a court with jurisdiction, the rights of the patient are exercised by the person appointed pursuant to State law to act on the patient's behalf.
 - iii. If a State court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with State law may exercise the patient's rights to the extent allowed by State law;
3. To receive information about the services covered under the hospice benefit and to receive information about the scope of services that the hospice will provide and specific limitations on those services;
4. To be informed in writing of the following:
 - i. The services available from the hospice;
 - ii. The names and professional status of personnel providing and/or responsible for care;
 - iii. The frequency of home visits to be provided;
 - iv. The hospice's daytime and emergency telephone numbers; and
 - v. Notification regarding the filing of complaints with the Department's 24-hour Complaint Hotline at 1-800-792-9770, or in writing to the New Jersey Department of Health, Division of Health Facility Survey and Field Operations, P.O. Box 367, Trenton, NJ 08625-0367.
5. To receive, in terms that the patient understands, an explanation of his or her plan of care, expected results, and reasonable alternatives. If this information would be detrimental to the patient's health, or if the patient is not able to understand the information, the explanation shall be provided to a family member or an individual who is a legal representative of the patient and documented in the patient's medical record;
6. To receive, as soon as possible, the services of a translator or interpreter to facilitate communication between the patient and health care personnel.
 - i. Hospices shall make efforts to secure a professional, objective interpreter for hospice-patient communications, including those involving the notice of patient rights;
7. To receive the care and health services that have been ordered;

8. To receive effective pain management and symptom control from the hospice for conditions related to the terminal illness, in accordance with N.J.A.C. 8:43E-6;
9. To choose his or her attending physician or APN;
10. To be involved in the planning of his or her hospice care and treatment;
11. To refuse services, including medication and treatment, provided by the facility and to be informed of available hospice treatment options, including the option of no treatment, and of the possible benefits and risks of each option;
12. To refuse to participate in experimental research. If he or she chooses to participate, his or her written informed consent shall be obtained;
13. To receive full information about financial arrangements, including, but not limited to:
 - i. Fees and charges, including any fees and charges for services not covered by sources of third-party payment;
 - ii. Copies of written records of financial arrangements;
 - iii. Notification of any additional charges, expenses, or other financial liabilities in excess of the predetermined fee; and
 - iv. Description of agreements with third-party payers and/or other payers and referral systems for patients' financial assistance;
14. To express grievances regarding care and services by anyone who is furnishing services on behalf of the hospice to the hospice's staff and governing authority without fear of reprisal, and to receive an answer to those grievances within a reasonable period of time;
15. To be free from mistreatment, neglect, mental, verbal, sexual and physical abuse and from exploitation, including corporal punishment, injuries of unknown source and misappropriation of patient property;
16. To be free from restraints, unless they are authorized by a physician for a limited period of time to protect the patient or others from injury;
17. To be free from seclusion, of any form, imposed as a means of coercion, discipline, convenience or retaliation by staff;
18. To be assured of confidential treatment of his or her medical health record, and to approve or refuse in writing its release to any individual outside the hospice, except as required by law or third party payment contract;
19. To be treated with courtesy, consideration, respect, and recognition of his or her dignity, individuality, and right to privacy, including, but not limited to, auditory and visual privacy and confidentiality concerning patient treatment and disclosures;
20. To be assured of respect for the patient's personal property;
21. To retain and exercise to the fullest extent possible all the constitutional, civil, and legal rights to which the patient is entitled by law, including religious liberties, the right to independent personal decisions, and the right to provide instructions and directions for health care in the event of future decision making incapacity in accordance with the New Jersey Advance Directives for Health Care Act, N.J.S.A. 26:2H-53 et seq., and any rules which may be promulgated pursuant thereto;
22. To be informed by the hospice of and receive written information concerning the hospice's policies on advance directives, including a description of applicable State law;

23. To be transferred to another hospice provider only for one of the reasons delineated in the Standards for Licensure of Residential Health Care Facilities, N.J.A.C. 8:43-4.16(g); and
24. To discharge himself or herself from treatment by the hospice.

YOU ALSO HAVE THE RIGHT:

1. To exercise your rights as a hospice patient without discrimination or reprisal for doing so. Your court appointed representative or the legal representative you have selected in accordance with state law, may exercise these rights for you in the event that you are not competent or able to exercise them for yourself;
2. To have these rights provided to you or your representative verbally and in writing in a language and manner you can understand, during the initial assessment visit before care is provided and on an ongoing basis, as needed;
3. To have a relationship with our staff that is based on honesty and ethical standards of conduct. To have ethical issues addressed, and inform you of any financial benefit we receive if we refer you to another organization, service, individual or other reciprocal relationship;
4. To be free from mistreatment, neglect, verbal, mental, sexual and physical abuse, injuries of unknown source and misappropriation of your property. All mistreatment, abuse, neglect, injury and exploitation complaints by anyone furnishing service on behalf of hospice are reported immediately by our staff to the hospice administrator. All reports will be promptly investigated and immediate action taken to prevent potential violations during our investigation. Hospice will take appropriate corrective action in accordance with state law. All verified violations will be reported to the appropriate state/local authorities, including to the state survey and certification agency, within five (5) working days of becoming aware of the violation, unless state regulations are more stringent. If our agency staff suspects abuse or mistreatment of any kind, we will report our suspicions in accordance with our policy and state law. To report abuse, please call the appropriate number listed below:
Sussex County: (973) 383-3600; After hours: Call 911
Warren County: (908) 475-6591; After hours: Call 911
Pike County Area Office on Aging ages 60+: (570) 775-5550; Ages 19-59 call 911
Protective Services Hotline: PA: 1-800-490-8505
5. To be free from physical and mental abuse, corporal punishment, restraint or seclusion of any form imposed as a means of coercion, discipline, convenience or retaliation by staff while receiving hospice care;
6. To have cultural, psychosocial, spiritual and personal values, beliefs and preferences respected. You will not be discriminated against based on race, color, national origin, sex (including sexual orientation and gender identity), age, religion, disability, diagnosis, ability to pay or source of payment. If you feel that you have been the victim of discrimination, you have the right to file a grievance without retaliation for doing so;
7. To information in plain language to ensure accurate communication, in a manner that is accessible, timely and free of charge to persons with disabilities. This includes access to websites, auxiliary aids and services in accordance with state and federal law and regulations;

8. To receive information on our complaint resolution process, and know about the results of complaint investigations. We must document both the existence and the resolution of the complaint;
9. To voice grievances/complaints or recommend changes in policy, staff or service/care regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice without fear of coercion, discrimination, restraint, interference, reprisal or an unreasonable interruption of care, treatment or services for doing so. The organization must document both the existence of a complaint and the resolution of the complaint. Our complaint resolution process and the state hotline number are provided in our Problem Solving Procedure;
10. To be informed how to contact CHAP to ask questions, report grievances or voice complaints. Contact information for CHAP is provided in our Problem Solving Procedure;
11. To choose your attending physician and other health care providers and communicate with those providers;
12. To be fully informed in advance about the services/care covered under the hospice benefit, the scope of services hospice will provide, service limitations, the responsibilities of staff members who are providing and responsible for your care, treatment or services; expected and unexpected outcomes, potential risks or problems and barriers to treatment;
13. To be involved in developing your hospice plan of care; and to participate in changing the plan whenever possible and to the extent that you are competent to do so;
14. To be advised of any change in your plan of care before the change is made;
15. To have family involved in decision making as appropriate, concerning your care, treatment and services, when approved by you or your representative, if any, and when allowed by law;
16. To formulate advance directives and be informed if we cannot implement an advance directive on the basis of conscience. You will be informed, before care is provided, of the agency's policies and procedures on advance directives and a description of applicable state law.
17. To have your wishes concerning end-of-life decisions addressed and to have health care providers comply with your advance directives in accordance with state laws and receive care without conditions or discrimination based on the execution of advance directives;
18. To accept, refuse or discontinue care, treatment and services without fear of reprisal or discrimination. You may refuse part or all of care/services to the extent permitted by law; however, should you refuse to comply with the plan of care and your refusal threatens to compromise our commitment to quality care, then we or your physician may be forced to discharge you from our services and refer you to another source of care;
19. To have your person treated with respect and security during home care visits;
20. To restrict visitors or have unlimited contact with visitors and others and to communicate privately with these persons if you are residing in an inpatient hospice facility;

21. To confidentiality of written, verbal and electronic protected health information including your medical records, information about your health, social and financial circumstances or about what takes place in your home;
22. To refuse filming or recording or revoke consent for filming or recording of care, treatment and services for purposes other than identification, diagnosis or treatment;
23. To request us to release information written about you only as required by law or with your written authorization and to be advised of our policies and procedures regarding accessing and/or disclosure of clinical records. Our Notice of Privacy Practices describes your rights in detail;
24. To be advised orally and in writing before care is initiated of our billing policies and payment procedures and the extent to which payment for the HHA services may be expected from Medicare or other sources, and the extent to which payment may be required from the patient. The HHA must advise the patient of these changes orally and in writing as soon as possible, but no later than 30 calendar days from the date that the HHA becomes aware of a change;
25. To receive a Patient Notification of Hospice Non-Covered Items, Services and Drugs if there are conditions, items, services and drugs that the hospice determines to be unrelated to your terminal illness and related conditions and would not be covered by the Medicare hospice benefit;
26. To receive information for your cost-sharing responsibilities for hospice services, if any;
27. To have access, upon request, to all bills for services you have received regardless of whether the bills are paid by you or another party;
28. To receive information about organization ownership and control;
29. To receive high-quality, appropriate care without discrimination, in accordance with physician orders;
30. To receive effective pain management and symptom control from the hospice for conditions related to your terminal illness. You also have the right to receive education about your role and your family's role in managing pain when appropriate, as well as potential limitations and side effects of pain treatments;
31. To be admitted only if we can provide the care you need. A qualified staff member will assess your needs. If you require care or services that we do not have the resources to provide, we will inform you, and refer you to alternative services, if available; or admit you, but only after explaining our limitations and the lack of a suitable alternative;
32. To be told what to do in case of an emergency;
33. To receive pastoral and other spiritual services for you and your family;
34. To receive the name and contact information for the Beneficiary and Family Centered Care-Quality Improvement Organization (BFCC-QIO);
35. To immediate advocacy from the BFCC-QIO if you disagree with any of the hospice's determinations of non-covered items, services or drugs; and
36. To have an environment that preserves dignity and contributes to a positive self-image.

PATIENT RESPONSIBILITIES

Each patient and family has the responsibility:

1. To be under medical supervision as required by hospice, including examinations by a physician, and notify hospice of any change in physician.
2. To inform the physician or nurse of present complaints, unexpected changes in health or reactions to medications and treatments, and make it known if he/she does not understand or cannot follow instructions.
3. To ask questions when he/she does not understand about his/her care, treatment, and services or other instructions about what he/she is expected to do. If he/she has concerns about the care or cannot comply with the plan, let us know.
4. To cooperate with hospice staff without discrimination as to race, religion, age, sex, handicap or national origin.
5. To treat hospice staff with dignity, courtesy and respect.
6. To follow the plan of care designated specifically for him/her in consultation with health professionals providing care.
7. To supply accurate and complete medical history information to his/her nurse and the hospice.
8. To cooperate in giving full and honest information about financial and environmental factors that affect health status.
9. To inform hospice when you will not be able to keep hospice service appointments.
10. To provide information necessary to ensure processing of bills, including proof of health insurance coverage or an alternate plan for payment.
11. To make available, if possible and necessary, a family member or substitute, able and willing to participate in care.
12. To request further information concerning anything you do not understand.
13. To secure animals when a staff member is present to prevent any confrontation that would require mandatory reporting to animal control.
14. To follow the organization's rules and regulations.
15. To make funeral arrangements and inform Karen Ann Quinlan Hospice staff of these arrangements.

SECTION 4. Notice of Privacy Practices

- I. **THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.**

- II. **WE HAVE A LEGAL DUTY TO SAFEGUARD YOUR PROTECTED HEALTH INFORMATION (PHI).**

Pursuant to the Privacy Rules established by the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), we are legally required to protect the privacy of your health information. We call this information "protected health information," or "PHI" for short. It includes information that can be used to identify you and that we've created or received about your past, present, or future health condition, the provision of health care to you, or the payment for this health care. We are required to provide you with this notice about our privacy practices. It explains how, when, and why we use and disclose your PHI. With some exceptions, we may not use or disclose any more of your PHI than is necessary to accomplish the purpose of the use or disclosure. We are legally required to follow the privacy practices that are described in this notice.

We reserve the right to change the terms of this notice and our privacy policies at any time. Any changes will apply to the PHI we already have. Whenever we make an important change to our policies, we will promptly change this notice and post a new notice in public areas of our offices. You can also request a copy of this notice from the contact person listed in Section VI below at any time and can view a copy of this notice on our Web site at <https://www.karenannquinlanhospice.org/>.

- III. **HOW WE MAY USE AND DISCLOSE YOUR PROTECTED HEALTH INFORMATION.**

We use and disclose health information for many different reasons. For some of these uses and disclosures, we need your specific authorization. Below, we describe the different categories of uses and disclosures.

A. Uses and Disclosures That Do Not Require Your Authorization.

We may use and disclose your PHI without your authorization for the following reasons:

1. **For treatment.** We may disclose your PHI to hospitals, physicians, nurses, and other health care personnel in order to provide, coordinate or manage your health care or any related services, except where the PHI is related to HIV/AIDS, genetic testing or services from federally-funded drug or alcohol abuse treatment facilities, or where otherwise prohibited pursuant to State or Federal law. For example, we may disclose PHI to a pharmacy to fill a prescription or to a laboratory to order a blood test.
2. **To obtain payment for treatment.** We may use and disclose your PHI in order to bill and collect payment for the treatment and services provided to you. For example, we may provide portions of your PHI to our billing staff and your health plan to get paid for the health care services we provided to you. We may also disclose patient information to another provider involved in your care for the other provider's payment activities. For example, we may disclose your PHI to a pharmacy in order for the pharmacy to bill for its services to you.
3. **For health care operations.** We may disclose your PHI, as necessary, to operate our business. For example, we may use your PHI in order to evaluate the quality of health care services that you received or to evaluate the performance of the health care professionals who provided health care services to you. We may also provide your PHI to our accountants, attorneys, consultants, and others in order to make sure we're complying with the laws that affect us or for services they provide to our organization.
4. **When a disclosure is required by federal, state or local law, judicial or administrative proceedings or law enforcement.** For example, we may disclose PHI when a law requires that we report information to government agencies and law enforcement personnel about victims of abuse, neglect or domestic violence; when dealing with gunshot or other wounds; for the purpose of identifying or locating a suspect, fugitive, material witness or missing person; or when subpoenaed or ordered in a judicial or administrative proceeding.

5. **For public health activities.** For example, we may disclose PHI to report information about births, deaths, various diseases, adverse events and product defects to government officials in charge of collecting that information; to prevent, control, or report disease, injury or disability as permitted by law; to conduct public health surveillance, investigations and interventions as permitted or required by law; or to notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease as authorized by law.
6. **For health oversight activities.** For example, we may disclose PHI to assist the government or other health oversight agency with activities including audits; civil, administrative or criminal investigations, proceedings or actions; or other activities necessary for appropriate oversight as authorized by law.
7. **To coroners, funeral directors and for organ donation.** We may disclose PHI to organ procurement organizations to assist them in organ, eye or tissue donations and transplants. We may also provide coroners, medical examiners, and funeral directors necessary PHI relating to an individual's death.
8. **For research purposes.** In certain circumstances, we may provide PHI in order to conduct medical research.
9. **To avoid harm.** In order to avoid a serious threat to the health or safety of you, another person, or the public, we may provide PHI to law enforcement personnel or persons able to prevent or lessen such harm.
10. **For specific government functions.** We may disclose PHI of military personnel and veterans in certain situations. We may also disclose PHI for national security and intelligence activities.
11. **For workers' compensation purposes.** We may provide PHI in order to comply with workers' compensation laws.
12. **Appointment reminders and health-related benefits or services.** We may use PHI to provide appointment reminders or give you information about treatment alternatives, or other health care services or benefits we offer. Please let us know if you do not wish to have us contact you for these purposes, or if you would rather we contact you at a different telephone number or address.

B. Uses and Disclosures Where You to Have the Opportunity to Object:

1. **Disclosures to family, friends or others.** We may provide your PHI to a family member, friend or other person that you indicate is involved in your care or the payment for your health care, unless you object in whole or in part.

C. All Other Uses and Disclosures Require Your Prior Written Authorization. Other than as stated herein, we will not disclose your PHI without your written authorization. You can later revoke your authorization in writing except to the extent that we have taken action in reliance upon the authorization.

D. Authorization for Marketing Communications. We will obtain your written authorization prior to using or disclosing your PHI for marketing purposes. However, we are permitted to provide you with marketing materials in a face-to-face encounter, without obtaining a marketing authorization. We are also permitted to give you a promotional gift of nominal value, if we so choose, without obtaining a marketing authorization. In addition, as long as we are not paid to do so, we may communicate with you about products or services relating to your treatment, case management or care coordination, or alternative treatments, therapies, providers or care settings. We may use or disclose PHI to identify health-related services and products that may be beneficial to your health and then contact you about the services and products.

E. Sale of PHI. We will disclose your PHI in a manner that constitutes a sale only upon receiving your prior authorization. Sale of PHI does not include a disclosure of PHI: for public health purposes; for research; for treatment and payment purposes; relating to the sale, transfer, merger or consolidation of all or part of our business and for related due diligence activities; to the individual; required by law; for any other purpose permitted by and in accordance with HIPAA.

F. Fundraising Activities. We may use certain information (name, address, telephone number, dates of service, age and gender) to contact you for the purpose of various fundraising activities. If you do not want to receive future fundraising requests, please write to the Privacy Officer at the below address.

G. Incidental Uses and Disclosures. Incidental uses and disclosures of information may occur. An incidental use or disclosure is a secondary use or disclosure that cannot reasonably be prevented, is limited in nature, and that occurs as a by-product of an otherwise permitted use or disclosure. However, such incidental uses or disclosure are permitted only to the extent that we have applied reasonable safeguards and do not disclose any more of your PHI than is necessary to accomplish the permitted use or disclosure. For example, disclosures about a patient within the patient's home that might be overheard by persons not involved in the patient's care would be permitted.

H. Business Associates. We may engage certain persons to perform certain of our functions on our behalf and we may disclose certain health information to these persons. For example, we may share certain PHI with our billing company or computer consultant to facilitate our health care operations or payment for services provided in connection with your care. We will require our business associates to enter into an agreement to keep your PHI confidential and to abide by certain terms and conditions.

IV. WHAT RIGHTS YOU HAVE REGARDING YOUR PHI.

You have the following rights with respect to your PHI:

- A. The Right to Request Limits on Uses and Disclosures of Your PHI.** You have the right to request in writing that we limit how we use and disclose your PHI. You may not limit the uses and disclosures that we are legally required to make. We will consider your request but are not legally required to accept it. Notwithstanding the foregoing, you have the right to ask us to restrict the disclosure of your PHI to your health plan for a service we provide to you where you have directly paid us (out of pocket, in full) for that service, in which case we are required to honor your request. If we accept your request, we will put any limits in writing and abide by them except in emergency situations. Under certain circumstances, we may terminate our agreement to a restriction.
- B. The Right to Choose How We Send PHI to You.** You have the right to ask that we send information to you at an alternate address (for example, sending information to your work address rather than your home address) or by alternate means (for example, via e-mail instead of regular mail). We must agree to your request so long as we can easily provide it in the manner you requested.
- C. The Right to See and Get Copies of Your PHI.** In most cases, you have the right to look at or get copies of your PHI that we have, but you must make the request in writing. If we don't have your PHI but we know who does, we will tell you how to get it. We will respond to you within 30 days after receiving your written request. In certain situations, we may deny your request. If we do, we will tell you, in writing, our reasons for the denial and explain your right to have the denial reviewed.

If you request a copy of your information, we will charge reasonable fees for the costs of copying, mailing or other costs incurred by us in complying with your request, in accordance with applicable law. Instead of providing the PHI you requested, we may provide you with a summary or explanation of the PHI as long as you agree to that and to the cost in advance. Note also that, you have the right to access your PHI in an electronic format (to the extent we maintain the information in such a format) and to direct us to send the e-record directly to a third party. We may charge for the labor costs to transfer the information; and charge for the costs of electronic media if you request that we provide you with such media.

****Please note, if you are the parent or legal guardian of a minor, certain portions of the minor's records may not be accessible to you. For example, records relating to care and treatment to which the minor is permitted to consent himself/herself (without your consent) may be restricted unless the minor patient provides an authorization for such disclosure. ****

- D. The Right to Get a List of the Disclosures We Have Made.** You have the right to get a list of instances in which we have disclosed your PHI. The list will not include uses or disclosures made for purposes of treatment, payment, or health care operations, those made pursuant to your written authorization, or those made directly to you or your family. The list also won't include uses and disclosures made for national security purposes, to corrections or law enforcement personnel, or prior to April 14, 2003.

We will respond within 60 days of receiving your written request. The list we will give you will include disclosures made in the last six years unless you request a shorter time. The list will include the date of the disclosure, to whom PHI was disclosed (including their address, if known), a description of the information disclosed, and the reason for the disclosure. We will provide one (1) list during any 12-month period without charge, but if you make more than one request in the same year, we will charge you \$10 for each additional request.

To the extent that we maintain your PHI in electronic format, we will account all disclosures including those made for treatment, payment and health care operations. Should you request such an accounting of your electronic PHI, the list will include the disclosures made in the last three years.

- E. The Right to Receive Notice of a Breach of Unsecured PHI.** You have the right to receive notification of a "breach" of your unsecured PHI.

- F. The Right to Correct or Update Your PHI.** If you believe that there is a mistake in your PHI or that a piece of important information is missing, you have the right to request, in writing, that we correct the existing information or add the missing information. You must provide the request and your reason for the request in writing. We will respond within 60 days of receiving your request in writing. We may deny your request if the PHI is (i) correct and complete, (ii) not created by us, (iii) not allowed to be disclosed or (iv) not part of our records. Our written denial will state the reasons for the denial and explain your right to file a written statement of disagreement with the denial. If you don't file one, you have the right to have your request and our denial attached to all future disclosures of your PHI. If we approve your request, we will make the change to your PHI, tell you that we have done it, and tell others that need to know about the change to your PHI.

- G. The Right to Get This Notice by E-Mail.** You have the right to get a copy of this notice by e-mail. Even if you have agreed to receive notice via e-mail, you also have the right to request a paper copy of this notice.

V. HOW TO COMPLAIN ABOUT OUR PRIVACY PRACTICES.

If you think that we may have violated your privacy rights, or you disagree with a decision we made about access to your PHI, you may file a complaint with the person listed in Section VI below. You also may send a written complaint to the Secretary of the U.S. Department of Health and Human Services via email at OCRComplaint@hhs.gov or through the mail at 200 Independence Ave., S.W.; Room 509F; HHH Bldg., Washington, DC 20201. We will take no retaliatory action against you if you file a good-faith complaint about our privacy practices.

VI. PERSON TO CONTACT FOR INFORMATION ABOUT THIS NOTICE OR TO COMPLAIN ABOUT OUR PRIVACY PRACTICES.

If you have any questions about this notice or any complaints about our privacy practices, please contact our Administrator at the following telephone number: (973) 383-0115. Written correspondence should be addressed as follows:

Karen Ann Quinlan Hospice
99 Sparta Avenue
Newton, NJ 07860
Attention: Administrator

VII. EFFECTIVE DATE OF THIS NOTICE

EFFECTIVE: September 10, 2021

SECTION 5. Advance Directives

NEW JERSEY ADVANCE DIRECTIVES

WHAT IS AN ADVANCE DIRECTIVE?

An advance directive is a legal document that you can complete on your own that can help ensure your preferences for various medical treatments are followed if you become unable to make your own health care decisions. Your advance directive only goes into effect if your physician has evaluated you and determined that you are unable to understand your diagnosis, treatment options or the possible benefits and harms of the treatment options.

New Jersey has two kinds of advance directives: a **Proxy Directive** and an **Instruction Directive**. It is your decision whether to have both kinds or to just have one of them.

A **Proxy Directive** is a document (often called a Durable Power of Attorney for Healthcare) you use to appoint a person to make health care decisions for you in the event you become unable to make them yourself. This document goes into effect whether your inability to make health care decisions is temporary because of an accident or permanent because of a disease. The person that you appoint is known as your health care representative and they are responsible for making the same decisions you would have made under the circumstances. If they are unable to determine what you would want in a specific situation, they are to base their decision on what they think is in your best interest.

An **Instruction Directive** is a document (often called a Living Will) you use to tell your physician and family about the kinds of situations you would want or not want to have life-sustaining treatment in the event you are unable to make your own health care decisions. You can also include a description of your beliefs, values and general care and treatment preferences. This will guide your physician and family when they have to make health care decisions for you in situations not specifically covered by your advance directive.

FREQUENTLY ASKED QUESTIONS

Can having an advance directive affect my life insurance, health insurance or the benefits I receive from a governmental benefits program? No.

Can my life insurance company, health insurance company, physician, hospital, nursing home or any other health care facility require me to have an advance directive? No.

Does New Jersey recognize an advance directive that is valid in another state? Yes.

What is the definition of “life-sustaining treatment”? Life-sustaining treatment is any medical device or procedure that increases your life expectancy by restoring or taking over a vital bodily function. The medical device or procedure can be a drug, ventilator (breathing machine), surgery, therapy or artificially provided fluids and nutrition.

What is the definition of “permanently unconscious”? Permanently unconscious means you have permanently lost the ability to interact with your environment and are completely unaware of your surroundings.

What is the definition of “terminal condition”? Terminal condition means the final stage of a fatal illness, disease or condition. To be in a terminal condition you do not have to be diagnosed as having less than a certain amount of time to live (e.g., six months or less).

What happens if I regain the ability to make my own decisions? In that case, your physician must obtain your consent for all treatment. Once you have the ability to make health care decisions your health care representative will no longer have the authority to make decisions for you.

Who should have a copy of my advance directive? You should give a copy to your primary health care representative, alternate health care representative(s), family members and physicians. If you are treated at a hospital or enter a nursing home you should also provide a copy when you are admitted.

Do I need a lawyer to complete an advance directive? No, you can complete an advance directive on your own.

Does my advance directive have to be notarized? No.

Do I need a witness when I sign my advance directive? You can choose to get your advance directive notarized, in which case you don't need additional witnesses. Or you can choose to sign and date your advance directive in front of two adult witnesses who must also sign and date the document.

What does it mean for someone to sign my advance directive as a witness? As a witness the person is stating that you voluntarily signed your advance directive.

Is there anyone who cannot sign my advance directive as a witness? Yes, the person who you appoint as your health care representative cannot be a witness.

Can I change my advance directive? Yes, you can change your advance directive any time you want by completing a new one. You need to sign and date your new advance directive and have two witnesses sign and date it.

Can I cancel my advance directive? Yes, you can cancel your advance directive any time you want. To cancel it you need to tell your physician, family, health care representative, nurse, social worker or a reliable witness that you want to cancel your advance directive. You can tell them verbally or send them a letter.

Can I have an instruction directive without having a proxy directive? Yes.

In what circumstance can I have life-sustaining treatment withheld or withdrawn? Your instruction directive can state you want life-sustaining treatment withheld or withdrawn in any of the following situations: 1) you are permanently unconscious; 2) you are in a terminal condition; 3) the life-sustaining treatment would likely only prolong an imminent death; 4) the life-sustaining treatment would likely be ineffective, or; 5) you have a serious, irreversible condition and the life-sustaining treatment would likely be more harmful than beneficial.

Why is it important to have an instruction directive? You may become unable to make your own health care decisions because of a serious injury, illness or disease. By having an instruction directive your family and physician will know the situations in which you would want or not want to have life-sustaining treatment. And by including a statement about your beliefs, values and general preferences for care and treatment, your physician and family will know what you would want in situations that are not specifically covered by your instruction directive. An instruction directive will also prevent conflicts among your family, physician or other health care providers that can occur when a patient's treatment preferences are unknown.

Can my health care representative make decisions for me if I am still able to make my own decisions? No, your health care representative can only make decisions for you if your physician has evaluated you and determined that you are unable to understand your diagnosis, treatment options or the possible benefits and harms of the treatment options.

Can I have a proxy directive without having an instruction directive? Yes.

What authority does my health care representative have to make decisions for me? Except for any restrictions you have placed on their authority, your health care representative has the right to make all health care decisions for you, including the right to refuse medical treatment. They also have the right to review your medical records and receive from your physician all information about your condition, prognosis and treatment options as is necessary for them to make an informed decision.

Who can I appoint as my health care representative? You can appoint your spouse/domestic partner, parent, adult child, family member, friend, religious/spiritual advisor or any other adult.

Are there any restrictions on who I can appoint as my health care representative? Yes, you cannot appoint the following individuals as your health care representative: 1) your attending physician; or 2) the operator, administrator or employees of a health care institution in which you are a patient or resident, unless they are related to you. A physician who is an operator, administrator or employee of a healthcare institution in which you are a patient or resident can be your healthcare representative only if they are not your attending physician.

Can I appoint more than one person as my primary health care representative? No.

Can I appoint someone as an alternate health care representative in case my primary health care representative is unavailable, unable or unwilling to serve as my health care representative? Yes, you can appoint one or more individuals, listed in order of priority, as an alternate health care representative. In the event the primary health care representative becomes available they would take over for the alternate.

Can I put requirements on how my health care representative makes decisions? Yes, you can require your health care representative to consult with the alternate health care representatives, specific family members, friends or anyone else you want. You can also state specific criteria upon which your health care representative has to base their decisions.

Can I limit the decision-making authority of my health care representative? Yes, for example you can state that your health care representative cannot authorize life-sustaining treatment if it would conflict with the preferences you stated in your instruction directive.

Can my health care representative be required to pay for my medical treatment? No, your health care representative cannot be required by a physician, other health care provider or any health care facility to pay for your treatment, including treatment they have authorized.

Why is it important to have a proxy directive? You may become unable to make your own health care decisions because of a serious injury, illness or disease. If you cannot make your own health care decisions someone will have to make them for you and without a proxy directive your physician will not know who you want that person to be. Having a proxy directive will help ensure your preferences are respected because only the person you have appointed will be able to make health care decisions on your behalf. Also, having a proxy directive will help prevent conflicts among your family members who may disagree on who should have the authority to make these decisions. Even if you have an instruction directive, it is important to have a proxy directive because there are many circumstances in which treatment decisions will have to be made that are not covered by your instruction directive.

Is my physician required to get consent from my health care representative for treatment? Yes, your physician is required to obtain informed consent for your treatment (except in emergencies), and must respect their decisions just as if the decisions were coming directly from you.

Who should I appoint as my health care representative? You should choose someone who knows your values, beliefs and preferences well enough to know what treatment decisions you would want them to make for various medical conditions. The person should be someone with good judgment and who will be a strong advocate on your behalf. They should also be someone you believe will respect your wishes even if they disagree with them, especially when it comes to your preferences about the use of life-sustaining treatment.

Source: <https://www.nj.gov/health/advancedirective/ad/forums-faqs/>

NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

New Jersey law now provides another means for patients who are seriously ill or medically frail with limited life expectancies, to indicate their preferences regarding life-sustaining treatment on a standardized Practitioner Orders for Life-Sustaining Treatment (POLST) form. The POLST form provides instructions for health care personnel to follow for a range of life-prolonging interventions, including your goals, wishes and any medical interventions that you do or do not want at the end of life. The POLST form becomes part of your medical record, following you from one healthcare setting to another, including hospital, home, nursing home or hospice.

Completion of a POLST form is voluntary. If you want to make your desires for end of life care known, you should discuss them with your attending physician or advanced practice nurse and complete the POLST form together. Although an original POLST form is printed on green paper, copies of the executed form are also recognized by health care personnel. If you have a signed copy of a POLST form at home, it should be kept in a location that will be easily located by emergency personnel.

PENNSYLVANIA ADVANCE DIRECTIVES

In Pennsylvania, capacitated adults have the right to decide whether to accept, reject or discontinue medical care and treatment. There may be times, however, when a person cannot make his or her wishes known to a medical provider. For example, a person may be incompetent*, in a terminal condition or in a state of permanent unconsciousness, and unable to tell his or her doctor what kind of care or treatment he or she would like to receive or not to receive. This can be addressed through an advance directive.

An advance directive is a written document that you may use, under certain circumstances, to tell others what care you would like to receive or not receive should you become unable to express your wishes at some time in the future. Advance directives may take many forms, and are commonly referred to as a "living will." In Pennsylvania, a living will is known in the law as an advance directive for health care.

The living will, or advance directive for health care declaration, becomes operative when:

- Your doctor has a copy of it; and
- Your doctor has concluded that you are incompetent and you are in a terminal condition or in a state of permanent unconsciousness.

Pennsylvania's living will law states that you may revoke a living will at any time, and in any manner. All that you must do is tell your doctor or other health care provider that you are revoking it. Someone who saw or heard you revoke your declaration may also tell your doctor or other health care provider.

Your doctor and any other health care provider must inform you if they cannot in good conscience follow your wishes or if the policies of the health care provider prevent them from honoring your wishes. This is one reason why you should give a copy of your living will to your doctor or to those in charge of your medical care and treatment. The doctor or other health care provider who cannot honor your wishes must then help transfer you to another health care provider willing to carry out your directions – if they are the kind of directions which Pennsylvania recognizes as valid.

There is no single correct way to write a living will or declaration. However, your living will is not valid unless you sign your living will. If you are unable to do so, you must have someone else sign it for you; and two people who are at least 18 years old must sign your living will as witnesses. Neither of those witnesses may be the person who signed your living will on your behalf if you were unable to sign it yourself. It is suggested that you also date your living will, even though the law does not require it. In Pennsylvania, you are not required to have your living will notarized; however, if you are contemplating using the document in another state, you should find out if the other state requires notarization.

Eligibility: Any capacitated person may make a living will who is at least 18 years old, or is a high school graduate, or has married. Pennsylvania Law also recognizes a **combination document** that includes both a living will and a health care power of attorney.

*Incompetence is the lack of sufficient capacity for a person to make or communicate decisions concerning himself or herself. The law allows your doctor to decide if you are incompetent, or in a terminal condition or permanently unconscious for purposes of a living will.

HEALTH CARE POWER OF ATTORNEY

What is a health care power of attorney?

A health care power of attorney is an advance directive that names in writing the person that you want to make your medical decisions at any time you can't speak for yourself, without necessarily describing what those decisions should be. This person is also called your health care agent and cannot be your attending physician or other health care provider or owner/operator/employee of a health care provider from which you are receiving care. You should appoint someone you know, trust, and with whom you can talk over your wishes. This legal form may also include your instructions regarding life-sustaining treatment.

The law says that the health care power of attorney can:

1. Authorize your admission to a medical, nursing, residential or other facility;
2. Enter into agreements for your care;
3. Nominate a guardian for you, if needed; and
4. Authorize medical and surgical procedures (arrange for and consent to medical, therapeutic and surgical procedures for you, including the administration of drugs).

What if a person I name as my agent to make decisions for me dies before I do?

It is always a good idea to name a second person to make decisions in case your first choice is not available, for whatever reason.

How is a health care power of attorney terminated?

While of sound mind, you have the right to revoke (cancel), terminate or change the health care power of attorney at any time, either in writing or by personally communicating the revocation to the attending physician, health care provider or health care agent. The document is also revoked when you file for a divorce if you have named your spouse as your agent.

ORGAN AND TISSUE DONATION

What are organ and tissue donations?

Organ/tissue donation is a special way for you to help save someone else's life through transplant surgery after you die. Today, about 25 different organs and tissues may be used, including corneas of the eyes, heart, liver, bone and cartilage, kidneys, bone marrow, and skin.

Who decides about organ and tissue donations?

You, the patient, may indicate your decision by having signed a donor card, by expressing your wishes, or noting them on your advance directive, or driver's license. In most cases, the family decides at the time of the patient's death. Organ and tissue donations are strictly voluntary, but there are limiting factors. If you have any questions or concerns, talk with your doctor or nurse.

By signing a donor card or noting it on your advance directive or driver's license, you can make known your choice about organ and tissue donation.

OUT-OF-HOSPITAL DNR ORDER

What is an out-of-hospital do-not-resuscitate (DNR) order?

An out-of-hospital DNR order is a written order that is issued by a person's attending physician that directs EMS providers to withhold CPR from the person in the event of that person's cardiac or respiratory arrest. Thus, if an ambulance is called to attend to a person for whom an out-of-hospital DNR order has been issued and the ambulance crew observes the out-of-hospital DNR order with original signatures with the person, or observes that the person is wearing an out-of-hospital DNR bracelet or necklace, the ambulance crew will not attempt CPR unless it is appropriately communicated to a member of the crew that the out-of-hospital DNR order has been revoked.

Who is permitted to request an out-of-hospital DNR order for themselves?

A person who has an end-stage medical condition who is competent and 18 years of age or older or, if under 18 years of age, has graduated from high school, has been married or is emancipated, may request an out-of-hospital DNR order for himself or herself.

Are there circumstances in which a person is permitted to request an out-of-hospital DNR order for another person?

Yes. If a person qualifies to request an out-of-hospital DNR order for himself or herself, no other person may request an out-of-hospital DNR order for that person unless that person has conferred that right upon another person. That right may be conferred by a health care power of attorney; however, there are also circumstances under which a person who qualifies to receive an out-of-hospital DNR order is not competent (able to make and communicate health care decisions) to request one.

Also, the person may not yet be 18 years of age or emancipated, or have graduated from high school or been married. In these situations there are circumstances in which another person may request an out-of-hospital DNR order for that person.

If a person has executed a living will providing for no CPR in the event of cardiac or respiratory arrest, does an out-of-hospital DNR order also need to be issued?

No, but if the person has an out-of-hospital DNR order it is easier for an EMS provider to comply with a person's decision to not receive CPR should the person have an end-stage medical condition, be in a terminal condition or become permanently unconscious. The Living Will Act does not permit an EMS provider to withhold CPR when the order to withhold CPR is authorized in a living will unless the provider first contacts and secures approval from a physician who provides the EMS provider with medical direction. While an EMS provider is waiting for the physician's direction, the EMS provider is obligated to initiate CPR even if contrary to the person's wishes stated in a living will; however, if an out-of-hospital DNR order, necklace or bracelet is displayed with the individual, EMS providers do not need to contact a physician prior to withholding CPR. A person should wear an out-of-hospital DNR bracelet or necklace issued for that person to quickly communicate to EMS providers that an out-of-hospital DNR order is in effect. This alleviates the necessity for locating the actual order.

May an out-of-hospital DNR order be revoked by the person for whom it is issued?

Yes. An out-of-hospital DNR order may be revoked by the person for whom it is issued, whether requested by that person, the person's surrogate, or other authorized representative of the person. Revocation may be accomplished by destroying or not displaying the order, bracelet or necklace, or by conveying the decision to revoke the out-of-hospital DNR order to an EMS provider verbally or otherwise prior to the time the person experiences respiratory or cardiac arrest. Neither the person's physical condition nor incompetence preceding cardiac or respiratory arrest will be considered to void the person's decision to revoke the out-of-hospital DNR order.

Any questions you may have about advance directives that are not answered here should be talked over with your doctor, lawyer, family or health care provider.

Below are some additional resources that you may wish to consult:

1. Your local Long Term Care Ombudsman, who can be reached by calling your community's Area Agency on Aging. The telephone number can be found at www.aging.pa.gov/local-resources/Pages/default.aspx.
2. Office of the State Long Term Care Ombudsman PA Department of Aging, 5th Floor
555 Walnut Street, 5th Floor • Harrisburg, PA 17101
Phone: (717) 783-8975
3. Commonwealth of Pennsylvania Department of Aging
555 Walnut Street, 5th Floor • Harrisburg, PA 17101
Phone: (717) 783-1550 • Email: aging@pa.gov
4. American Association of Retired Persons (AARP)
30 N. 3rd Street, Suite 750 • Harrisburg, PA 17101
Toll-free Phone: 1-866-389-5654

The above information was compiled using the following resources: PA Act 169 of 2006; Understanding Advance Directives for Health Care, Living Wills and Powers of Attorney in Pennsylvania, Edward G. Rendell, Governor and Nora Dowd Eisenhower, Secretary of Aging; Out-of-Hospital Do-Not-Resuscitate Orders, Edward G. Rendell, Governor and John B. Johnson, MD, M.P.H., Secretary; and The Hospital & Health System Association of PA Task Force on Advance Directives brochure.

PENNSYLVANIA PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT

The Practitioner Orders for Life-Sustaining Treatment (POLST) form provides another method for stating your wishes concerning medical treatment and interventions at life's end. Even if you have an advance directive, the POLST form is recommended.

The POLST form is voluntary and intended to help you and your physician or nurse practitioner discuss and develop plans to reflect your wishes as clear, specific written medical orders to be used when you can't speak for yourself. A physician or nurse practitioner must sign this form in order for it to be followed by other health care professionals.

A valid POLST form remains with you if you are moved between care settings, regardless of whether you are in the hospital, at home, or in a long-term care facility. The standardized form is printed on bright pink paper and assists physicians, nurses, health care facilities and emergency personnel to honor your wishes for life-sustaining treatment. If you live at home, keep the original POLST form on the refrigerator where emergency responders can find it. Please ask your physician or nurse practitioner if you need further information.

AGENCY POLICY ON ADVANCE DIRECTIVES

Our agency complies with the Patient Self-Determination Act of 1990, which requires us to:

- Provide you with written information describing your rights to make decisions about your medical care;
- Document advance directives prominently in your medical record and inform all staff;
- Comply with requirements of state law and court decisions with respect to advance directives; and
- Provide care to you regardless of whether or not you have executed an advance directive.

An ethics committee is available to serve in an advisory capacity when ethical issues such as the withdrawal or withholding of life-sustaining treatments arise during the care of patients with or without an advance directive. Discussion shall involve the patient and/or designated representatives, the home care staff involved in the patient's care and the patient's physician.

Unless the physician has written a specific **Do Not Resuscitate (DNR)** order, it is our policy that every patient will receive cardiopulmonary resuscitation (CPR). If you do not wish to be resuscitated, you, your family or your Durable Power of Attorney for Healthcare (DPAHC)/Health Care Power of Attorney (HCPOA) must request DNR orders from your physician. These orders are documented in your medical record and routinely reviewed; however, **you may revoke your consent to such an order at any time.**

YOUR WILL IS NOT ENOUGH

Leave one folder filled with the following information to make your loved ones' lives easier when you're gone:

- Banking, credit card and investment account names, numbers and contact information
- Insurance policy information and account numbers
- List of all properties and large assets along with loan information
- Current bills you pay, with account names and numbers
- Computer account user names and passwords
- Safe deposit access information
- Partnership or corporate agreements
- Health care forms, such as Health Power of Attorney, DNR and organ donation
- Burial instructions
- Specific bequests of personal items
- Request/discuss death certificates: how many are needed?

SECTION 6. Emergency Preparedness

AGENCY EMERGENCY PREPAREDNESS PLAN

In the event of a natural or man-made disaster, inclement weather or emergency, we have an emergency preparedness plan to continue necessary patient services. We will make every effort to continue home care visits; however, the safety of our staff must be considered.

When roads are too dangerous to travel, our staff will contact you by phone, if possible, to let you know that they are unable to make your visit that day. Every possible effort will be made to ensure that your medical needs are met. Please notify our office if you evacuate to another location or emergency shelter.

POWER OUTAGE

It is important to be prepared for a lack of electricity.

- Keep flashlights with extra batteries for every household member.
- Keep at least a one-week supply of nonperishable food and water.
- Have an alternate plan (such as a cooler and ice packs) if you rely on refrigerated medicines.
- Check the refrigerator temperature when the power is restored. Throw out food if the temperature is 40°F or higher.
- Determine whether your home phone will work in a power outage.
- Keep mobile phones and other battery-powered equipment charged.
- Keep gas tanks and cans full.

LANDSLIDE

If you live in a low-lying area or near a stream or channel, be alert for any sudden increase or decrease in water flow and notice whether the water changes from clear to muddy. Move away from the path of a landslide or debris flow as quickly as possible. Mudflows can move faster than you can walk or run. Look upstream before crossing a bridge and do not cross the bridge if a mudflow is approaching.

WINTER STORM

Heavy snowfall and extreme cold can immobilize a region, resulting in isolation. Icy and/or blocked roads and downed power lines can happen any time it is cold or snowy. Wear layers of loose, lightweight, warm clothes, rather than one heavy layer. Wear hats and outer layers that are tightly woven and water repellent. Mittens will keep your hands warmer than gloves.

HOT WEATHER

There is a higher risk for heat-related illness in the summer. When it is hot outside:

- Never leave anyone sitting in a closed, parked car.
- Drink lots of water, even if you are not thirsty. Avoid alcohol and caffeine.
- Eat small, frequent meals.

- Stay inside and out of the sun. Stay on the lowest floor, pull shades over the windows and use fans if you do not have air conditioning.
- Mist or sponge yourself frequently with cool water.
- Use sunscreen.
- Wear hats and clothes that are loose and lightweight. Clothes with light colors will deflect the sun's energy.
- Talk to your doctor about how sun and heat exposure will affect you if you take drugs such as diuretics or antihistamines.
- Move to a cool place at the first sign of heat illness (dizziness, nausea, headache, cramps). Rest and slowly drink a cool beverage. Seek medical attention immediately if you do not feel better.

HURRICANE

Preparation is the key to surviving a hurricane. Stay informed of the storm's path and its anticipated arrival. Be prepared for floods, high winds and damage to buildings and landscapes. Move anything that is outside to a waterproof place. Cover windows with wood, shutters or masking tape. Fill your clean bathtub with water. Evacuate to a shelter, if necessary.

EARTHQUAKE

Protect yourself from falls, falling objects and crumbling buildings. It is best to stay where you are. Stay away from the outside of buildings, walls, power lines, trees, street lights and signs.

If you are inside, stay there and:

- Get under a sturdy table and protect your head.
- If you are in a wheelchair, move to a doorway, lock the wheels and cover your head with your arms.
- If you are in bed, stay there. Cover your head with a pillow to protect it from falling objects and debris.

If you are outside, stay there. Stay away from the outside of buildings.

If you are in a car, stop, park away from dangerous items and stay there until the quaking stops.

After the earthquake, wait a few minutes before moving. Make any noise you can if you are trapped or shine a flashlight. Be prepared for aftershocks.

WILDFIRE

Wildfires often begin unnoticed and spread quickly. If a wildfire threatens your area, follow these simple steps to protect yourself. Please evacuate immediately when asked by firefighters and law enforcement officials.

- Wear only cotton or wool clothes.
- Proper attire includes long pants, long sleeved shirt or jacket and boots.
- Carry gloves, a handkerchief to cover your face, water to drink and goggles.
- Keep a flashlight, mobile phone and portable radio with you at all times.

- Take important documents with you (bank, IRS, trust, investment, insurance policy, birth certificates, passports, medical records).
- Make sure to designate a safe meeting place and contact person.
- Close all interior doors of your home.
- Remove lightweight, non-fire-resistant curtains and other combustible materials from around windows.
- Turn off all pilot lights.
- Move overstuffed furniture, such as couches and easy chairs, to the center of the room.
- Place vehicles in the garage, pointing out with keys in the ignition.

CIVIL DISTURBANCE

- Consider installing an electronic security system.
- Unless instructed to evacuate, the safest place to stay is your home.
- Do not go to observe the disturbance or unrest.
- Close all window blinds and curtains.
- Lock all doors and windows and secure your valuables and important records.
- Stay away from doors and windows.
- If confronted, remain calm and try to peacefully remove yourself from the situation.
- Call 911 if there is a threat to life or safety.

BIOLOGICAL THREAT

The first evidence of an attack may be when you notice symptoms of the disease caused by exposure to an agent. It may take time for public health officials to determine exactly what the illness is, how it should be treated and who is in danger. In the event of a biological threat or attack, follow these safety guidelines:

- Check local news websites, TV and radio stations for official news and information, including signs and symptoms of the disease, areas in danger, if medications or vaccinations are being distributed and where you should seek medical attention if you become ill.
- Get away quickly if you become aware of an unusual or suspicious substance.
- Cover your mouth and nose with layers of fabric that can filter the air but still allow breathing (e.g., two to three layers of cotton, such as a T-shirt, handkerchief or towel).
- Depending on the situation, wear a face mask to reduce inhaling or spreading germs.
- If you have been exposed to a biological agent, remove and bag your clothes and personal items. Follow official instructions for disposal of contaminated items.
- Wash yourself with soap and water and put on clean clothes.
- Do not assume that you should go to the emergency department or that any illness is the result of a biological attack. However, contact authorities and immediately seek emergency medical attention if your symptoms match those described and you are in the group considered at risk.
- Expect to receive a medical evaluation and treatment, and follow instructions of doctors and other public health officials.

- You may be advised to stay away from others or even quarantined if the illness caused by the biological agent is believed to be contagious.
- Avoid crowds in the event of a declared biological emergency or developing epidemic.
- Follow the practices listed in the Infection Prevention and Control section of this booklet.
- Follow the instructions provided by emergency response personnel and the Centers for Disease Control and Prevention (CDC). For more information visit www.ready.gov or www.emergency.cdc.gov.

EMERGING INFECTIOUS DISEASES

An emerging infectious disease is a contagious infection whose incidence has increased in recent years and could continue to increase in the future. Some examples are measles, Ebola, Zika, COVID-19, etc.

Preventing an emerging infectious disease:

- Ask your physician if your immunizations are up-to-date and if you need additional vaccinations.
- Wear a face mask to reduce spreading germs if you are sick, or to avoid coming in contact with contagious germs if others around you are sick.
- Follow the practices listed in the Infection Prevention and Control section of this booklet.

Preparing for an emerging infectious disease:

- Check local news websites, TV and radio stations for information, including symptoms of the disease, areas in danger, if medications or vaccinations are being distributed and where to seek medical attention if you become ill. The occurrence of a disease does not necessarily mean there is an epidemic or outbreak.
- Do not assume that any illness is the result of the emerging infectious disease; symptoms of many common illnesses may overlap. However, if you or a family member are in a high-risk group and the symptoms match those described, immediately seek emergency medical attention.
- Follow the instructions provided by emergency response personnel and the Centers for Disease Control and Prevention (CDC). For more information visit www.cdc.gov.

CHEMICAL EXPOSURE

In the event of an exposure to a hazardous chemical, item or poison follow these safety steps:

- Seek medical attention for screening and professional treatment.
- Drink only stored water.
- **If you are outdoors**, get as far away as possible from the contaminant by moving upwind (and uphill if possible) from it.
- **If you are indoors**, close doors and windows tightly, shut off heating and air conditioning and close fireplace dampers. Tape plastic over any windows in the room and use duct tape around the windows and doors to make an unbroken seal. Also, tape over any vents into the room and seal any electrical outlets or other openings. Sink and toilet drain traps should have water in them so you can use them as usual.

Remove possible contamination from your person by:

- Removing any exposed clothing (avoid touching any contaminated areas) as quickly as possible. Cut off clothing rather than pulling it over your head.
- Washing contaminants from your skin with large amounts of soap and water as quickly as possible. If your eyes are burning or your vision is blurred, rinse your eyes with plain water for 10 to 15 minutes. If you wear contacts, remove them and put them with the contaminated clothing. Do not put them back in your eyes. If you wear eyeglasses, decontaminate them with household bleach, then rinse and dry.
- Disposing of contaminated clothing. Avoid touching contaminated areas of the clothing by wearing gloves or using tongs, tool handles, etc., and place it and anything that touched the contaminated clothing inside a plastic bag. Seal the bag, and then seal that bag inside another plastic bag.
- Dressing in clothing that is not contaminated. Since clothing stored in a drawer or closet is unlikely to be contaminated, this will be your safest choice. When you leave your shelter-in-place location, follow instructions from local emergency coordinators to make your home safe again and to avoid any contaminants outside.

EXPLOSION

- Get under a sturdy table or desk if things are falling around you. When they stop falling, leave quickly, watching for falling debris.
- Stay low if there is smoke and check for fire or other hazards such as damaged floors and stairs.
- Do not stop to retrieve personal possessions or make phone calls.
- Do not use elevators.
- Check for fire and other hazards.
- Once you are out, do not stand in front of windows, glass doors or other potentially hazardous areas.
- Move away from sidewalks or streets to be used by emergency officials or others still exiting the building.
- Make any noise you can if you are trapped or shine a flashlight. Shout only as a last resort. Shouting can cause you to inhale dangerous amounts of dust.
- Avoid unnecessary movement so you do not kick up dust.
- Cover your nose and mouth with anything you have on hand.

NUCLEAR EXPLOSION

Remember the three protective factors: distance, shielding and time. Radioactive fallout can be carried by the wind for hundreds of miles. Radiation levels are extremely dangerous after a nuclear detonation but the levels reduce rapidly. During the period with the highest radiation levels, it is safest to stay inside.

If a nuclear attack warning is issued:

- Take cover as quickly as you can, below ground if possible, and stay there until instructed. Go as far below ground as possible or in the center of a tall building.
- Find the nearest building, preferably built of brick or concrete, and go inside to avoid any radioactive material outside. If better shelter, such as a multi-story building or basement can be reached within a few minutes, go there immediately.

- Expect to stay inside for at least 24 hours, unless told otherwise by authorities.
- If you are downwind from the detonation, you may also be asked to take protective measures.

If you are caught outside and unable to get inside immediately:

- Do not look at the flash or fireball – it can blind you.
- Take cover behind anything that might offer protection.
- Lie flat on the ground and cover your head. If the explosion is some distance away, it could take 30 seconds or more for the blast wave to hit.
- Get clean as soon as possible, to remove radioactive material that may have settled on your body.
- Remove your clothing to keep radioactive material from spreading. Removing the outer layer of clothing can remove up to 90% of radioactive material.
- If practical, place your contaminated clothing in a plastic bag and seal or tie the bag. Place the bag as far away as possible from humans and animals so that the radiation it gives off does not affect others.
- When possible, take a shower with lots of soap and water to help remove radioactive contamination. Do not scrub or scratch your skin. If you cannot shower, use a wipe or clean wet cloth to wipe your skin that was not covered by clothing.
- Wash your hair with shampoo or soap and water. Do not use conditioner in your hair because it will bind radioactive material to your hair, keeping it from rinsing out easily.
- Gently blow your nose and wipe your eyelids, eyelashes and ears with a clean wet cloth.

NUCLEAR POWER PLANT EMERGENCY

- Follow Emergency Alert System (EAS) instructions carefully.
- Minimize your exposure by increasing the distance between you and the source of the radiation.
- If you are told to evacuate, keep car windows and vents closed; use re-circulating air.
- If you are advised to remain indoors, turn off the air conditioner, ventilation fans, furnace and other air intakes; shield yourself by placing heavy, dense material between you and the radiation source; and go to a basement or other underground area, if possible.
- Do not use the telephone unless absolutely necessary.
- Stay out of the incident zone. Most radiation loses its strength fairly quickly.

EMERGENCY KIT FOR THE HOME

Bad weather can be dangerous, so be prepared. Keep a kit with these items in case you have a weather emergency:

- | | |
|------------------------------------|--|
| • Battery-powered radio | • Medications |
| • Lamps and flashlights | • Extra blankets |
| • Extra batteries | • Water in clean milk or soda bottles |
| • Food that you don't have to cook | • Rock salt or sand for walkways |
| • Manual can opener | • Extra fuel |
| • Utensils, cups and plates | • Portable battery pack for cell phone |

SHELTER SUPPLIES

The following is a list of what to bring to a shelter during an evacuation:

- Two-week supply of medications
- Medical supplies and oxygen
- Wheelchair, walker, cane, etc.
- Special dietary foods/can opener
- Air mattress/cot and bedding
- Lightweight folding chair
- Extra clothing, hygiene items, glasses
- Important papers
- Valid ID with current name and address
- Hospice folder

Most shelters have electric power from a generator. If you evacuate to a shelter, bring your electrical devices (such as an oxygen concentrator).

EMERGENCY PREPAREDNESS AND PETS

When disaster strikes, if it is not safe for you, it is not safe for your pet. Plan ahead to help your pet survive a disaster.

- **ID your pet.** Make sure your pet is wearing a securely-fastened collar with up-to-date identification including your cell phone number. Consider having your pet micro-chipped. For caged pets, attach identification to the cage.
- **Put together a pet disaster kit.** Food and water for at least five days for each pet; bowls, manual can opener, medications, medical records and vaccination schedules; leashes, harnesses and carriers; waste collection and disposal supplies; current photos of you with your pets to help others identify them in case you and your pets become separated; and written information about feeding schedules and behavior issues.
- **Plan ahead to take your pet with you in an evacuation.** With the exception of service animals, pets usually are not allowed in public shelters. Identify the hotels that will accept you and your pets in an emergency, and prepare a list with phone numbers. Call ahead for reservations if you know you may need to evacuate. Ask if no-pet policies can be waived in an emergency. Identify friends, boarding facilities, animal shelters or veterinarians that can care for your pet in an emergency.

SECTION 7. Home Safety

There are many ways in which an accident or injury can occur in the home. The best precaution is to know how to prevent them. Even when we are careful, accidents can happen. If one does occur, remember to always remain calm and assess your options. If you are unable to move, call out for help. You may want to consider installing LifeLine® if you live alone or are alone for most of the day.

Always keep the telephone numbers to your local police and fire department near all the phones in your house. If you do not have these numbers posted, remember that you can always dial "0" for the operator or "911" if your area has it. Calmly and clearly tell the operator your name, address and what the problem is so you will receive the proper help.

Listed below are some ways to prevent minor accidents or injuries in the home. **Please speak with your nurse/therapist or call hospice at any time if you have any concerns or questions about patient safety.**

PREVENTING FALLS

- Keep clutter out of walkways and off stairs.
- Close cabinet and closet doors.
- Be sure hallways and stairs are brightly lit.
- Keep a lamp near your bed, within easy reach.
- Clean up spills quickly.
- Put away toys and equipment after use.
- Be sure rugs and handrails are secure.
- Use a sturdy stepstool instead of climbing on counters and furniture.
- Install grab bars in the bathroom. Use non-skid mats.
- Improve the lighting in your home.
- Have handrails and lights put in on all staircases.
- Wear shoes both inside and outside the home.
- If you are weak from medication or have a poor appetite, call for help when walking to the bathroom.

AVOIDING ELECTRICAL ACCIDENTS

- Never use a knife or fork to retrieve toast while toaster is plugged in. Keep wooden tongs nearby.
- Keep electrical cords secured from the walkway and out of reach of children.
- Never use electric appliances while bathing.
- Unplug appliances during thunder and lightning storms.
- Do not overload outlets with adaptors and extension cords.
- Cover unused outlets with safety caps.

PREVENTING FIRE AND INJURY

- Make sure the patient has easy access to a telephone, and post the fire department number on every telephone. All family members and caregivers should be familiar with emergency 911 procedures.
- **Do not smoke (including e-cigarettes) in bed or where oxygen is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes in a trash can. Keep ashtrays away from upholstered furniture and curtains.
- Install smoke detectors and check the batteries monthly.
- Keep a working fire extinguisher handy and learn how to use it.
- Be sure gas units are properly vented. Vents and burners should be clean and grease free.
- Do not wear loose, long clothing near fires and stoves.
- Avoid excess clutter of newspapers, magazines, clothing, etc. These piles can become a fuel source for potential fires.
- Use pot holders on hot pots and covers. Vent steam away from you. Turn handles of pots away from the outer edge of stoves.
- Set water heater no higher than 120°F (48.9°C).
- Turn off appliances when leaving home.
- Properly store paints, gasoline and solvents in a cool, well-ventilated area.
- Dispose of old rags and empty cans.

PREVENTING POISONING

- Know how to contact your poison control team: 1-800-222-1222.
- Carefully store hazardous items in their original containers.
- Do not mix products that contain chlorine or bleach with other chemicals.
- Purchase insecticides for immediate need only and store excess properly.
- Keep hazardous items, cleaners and chemicals out of reach of children and confused or impaired adults.
- Dispose of hazardous items and poisons only as directed.

MEDICATION SAFETY

- Do not take medications that are prescribed for someone else.
- Create a complete list of current medications (including prescription and over-the-counter medications, herbal remedies and vitamins), and keep this list with you at all times in the event of emergency situations. Review the list for discrepancies and make changes immediately as they occur. Show the list to your doctor or pharmacist to keep from combining drugs inappropriately.
- Know the name of each of your medicines, why you take it, how to take it, potential side effects and what foods or other things to avoid while taking it.
- Report medication allergies or side effects to your nurse.
- Take medications exactly as instructed. If the medication looks different than you expected, ask your nurse about it.
- Drug names can look alike or sound alike. To avoid errors, check with your nurse if you have questions.
- Do not use alcohol when you are taking medicine.
- Do not stop or change medicines without informing your nurse, even if you are feeling better. If you miss a dose, do not double the next dose later.
- Use a chart or container system (washed egg carton or med-planner) to help you remember what kind, how much and when to take medicine.
- Take your medicine with a light on so you can read the label.
- Read medicine labels (including warnings) carefully and keep medicines in their original containers.
- Store medications safely in a cool, dry place according to instructions on the label of the medication.
- Keep medicines away from children and confused adults.

DISPOSAL OF CONTROLLED SUBSTANCES

As per regulatory process and policy of Karen Ann Quinlan, upon the death of a patient being pronounced by Karen Ann Quinlan, Nursing Staff are prohibited in removal of medications from the home. The family or primary caregiver will be responsible for removal of medications from the home. Once medications enter the home, medications are considered the patient's property.

Procedure:

The Nurse will, upon admission, instruct the primary caregiver/family in proper medication disposal. Under no circumstances will the Nurse handle any of the medications in terms of removal upon demise or discharge of the patient.

Instructions:

- There are drop-off points within your respective county, either at local pharmacy or police station for excess medications.
- Add liquids to either kitty litter, flour or coffee grounds and double bag the residue, and place in the household trash.
- Tablets, capsules, pills, suppositories can be crushed and added to cat litter, flour, coffee grounds and double bagged with disposal in the household trash.
- Trans-dermal patches should be opened and folded face to face so that adhesive edges adhere to themselves while wearing gloves and added to the household trash.

Documentation of instruction as well as primary caregiver's/family's refusal to discard in the above instructed method will be completed by the pronouncing/discharging RN.

Important! The Nurse must not remove any of the medications under any circumstances.

OXYGEN SAFETY

- Use oxygen only as directed.
- Oxygen creates a high risk for fire because it causes an acceleration of flame in the presence of flammable substances and open flames.
- **Do not smoke** around oxygen. Post "**No Smoking**" signs inside and outside the home.
- Store oxygen cylinders away from heat and direct sunlight. Do not allow oxygen to freeze or overheat.
- Keep oil/petroleum products (such as Vaseline®, oily lotions, face creams or hair dressings), grease and flammable material away from your oxygen system. Avoid using aerosols (such as room deodorizers) near oxygen.
- Dust the oxygen cylinder with a cotton cloth and avoid draping or covering the system with any material.
- Keep open flames (such as gas stoves and candles) at least 10 feet away from the oxygen source.
- Keep at least 6 inches of clearance around an oxygen concentrator at all times. Plug it directly into a wall outlet, and limit the use of extension cords.
- Have electrical equipment properly grounded and avoid operating electrical appliances, such as razors and hairdryers, while using oxygen. Keep any electrical equipment (including e-cigarettes) that may spark at least 10 feet from the oxygen system.
- Use 100% cotton bed linens/clothing to prevent sparks and static electricity.
- Place oxygen cylinders in appropriate stand to prevent tipping, or secured to the wall or placed on their side on the floor. Store in a well-ventilated area and not under outside porches or decks or in the trunk of a car.
- Have a backup portable oxygen cylinder in case of a power or oxygen concentrator failure.
- Alert property management of oxygen use when living in a multi-dwelling residence.

SECTION 8. Infection Prevention and Control

To help prevent the spread of a widespread pandemic or isolated infection, follow the guidelines in this section. Stay clean and use good hygiene. Items used in health care, such as bandages or gloves, can spread infection, harm trash handlers, family members and others who touch them, and harm the environment if they are not disposed of properly. Some illnesses and treatments (such as chemotherapy, dialysis, AIDS, diabetes and burns) can make people more at risk for infection. Your nurse will tell you how to use protective clothing (such as gowns or gloves) if you need it.

Please tell your doctor or a hospice staff member if you notice any of the following signs and symptoms of infection: pain, tenderness, redness or swelling; inflamed skin, rash, sores or ulcers; fever or chills; pain when urinating; sore throat or cough; confusion; increased tiredness or weakness; nausea, vomiting or diarrhea; and/or green or yellow pus.

PRACTICE GOOD HEALTH HABITS

Cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, cover your mouth with your upper sleeve, not your hands. Wear a face mask if you are sick, or if others around you are sick.

Avoid close contact with people who are sick. If you are sick, keep your distance from others. Do not share food or utensils.

Avoid touching your eyes, nose or mouth. Germs may spread if you touch something that is contaminated, and then touch your eyes, nose or mouth.

Take proper care of yourself. Get plenty of sleep, remain physically active (within your limits), manage your stress, drink plenty of fluids and eat nutritious food.

WASH YOUR HANDS

Wash your hands frequently and correctly, even if you wear gloves. It is the single most important step in controlling the spread of infection.

Always wash hands before tending to a sick person; touching or eating food; and treating a cut or wound.

Always wash hands after:

- Tending to a sick person
- Treating a cut or wound
- Using the bathroom
- Touching animals or their waste
- Touching soiled linens
- Touching garbage
- Changing diapers
- Coughing, sneezing or blowing your nose

If you have visibly dirty hands, or they are contaminated in any way, wash them using liquid soap and warm running water for at least 20 seconds. Remove jewelry, apply soap, wet your hands and rub them together. Wash all surfaces, including wrists, palms, back of hands, between fingers and under nails. Rinse and dry your hands with a clean towel that has not been shared or a paper towel. Use a towel to turn off the faucet.

If you do not have visibly dirty hands, use a hand sanitizer with 60-90% ethyl or isopropyl alcohol. Apply a dime-size amount (or the amount recommended on the label) in one palm, then rub hands vigorously, covering all surfaces of hands and fingers, until they are dry.

DISPOSABLE ITEMS AND EQUIPMENT

This may include paper cups, tissues, dressings, bandages, plastic equipment, catheters, incontinence supplies, plastic tubing and gloves.

Store these in a clean, dry area. Throw away used items in waterproof (plastic) bags. Fasten the bags securely and throw them in the trash.

NON-DISPOSABLE ITEMS AND EQUIPMENT

This may include dirty laundry, dishes, thermometers, toilets, walkers, wheelchairs, bath seats, suction machines and oxygen equipment.

Wash dirty laundry separately in hot, soapy water. Handle it as little as possible so you don't spread germs. If the patient has a virus, add a mix of 1 part bleach and 10 parts water to the load.

Clean equipment as soon as you use it. Wash small items (not thermometers) in hot, soapy water, then rinse and dry them with clean towels. Wipe thermometers with alcohol before and after each use. Store them in a clean, dry place. Wipe off equipment with a normal disinfectant or bleach mix. Follow the cleaning instructions that came with the item and ask your nurse or therapist if you have questions.

Pour liquids in the toilet. Clean their containers with hot, soapy water, then rinse them with boiling water and let them dry.

SHARP OBJECTS

This may include needles, syringes, lancets, scissors, knives, staples, glass tubes and bottles, IV catheters and razors.

Put used sharps in a clean, hard plastic or metal container with a screw-on or tight lid. Seal it with heavy-duty tape and dispose of it in the trash or according to area regulations. Do not overfill sharps containers or re-cap used needles. **Do not** use glass or clear plastic containers. **Never** put sharps in containers that will be recycled or returned to a store.

DISPOSAL TIPS FOR HOME HEALTH CARE WASTES

Home health care wastes primarily consist of used “sharps,” such as needles, syringes, lancets and other sharp objects, as well as soiled bandages, disposable sheets and medical gloves. You can help prevent injury, illness and pollution by following some simple steps when disposing of these wastes in your household trash.

1. Place all sharps in a puncture-resistant, hard plastic or metal container. An empty detergent bottle with a screw-on cap or an empty coffee can will do.
2. Close the container with its original lid and secure with heavy-duty tape.
3. Place the tightly sealed container in a paper bag and discard it with your household trash. **DO NOT PLACE IT WITH YOUR RECYCLABLES.**
4. Place non-sharp home health care wastes in a doubled, securely fastened, opaque plastic trash bag before putting them in your garbage can with other wastes.

RECOMMENDED TREATMENT – Prior to disposal, disinfect your sharps with a solution of 1 teaspoon of bleach in ½ gallon of water.

DOS and DON'TS

DO:

- Place sharps in an opaque, puncture-resistant container.
- Seal lids on containers of sharps with heavy-duty tape.
- Seal trash bags with tape or wire/plastic ties.
- Label plastic jug or metal can **“DO NOT RECYCLE.”**
- Keep waste containers out of reach of children and animals.

DON'T:

- Place loose sharps in the trash or toilet.
- Label the containers as medical waste.
- Clip needles with a pair of scissors.
- Place sealed containers in with recyclables.

DO NOT RECYCLE ANY SHARPS!

BODY FLUID SPILLS

Put on gloves and wipe the fluid with paper towels. Use a solution of 1 part bleach and 10 parts water to wipe the area again. Double bag used paper towels and throw them in the trash.

PATIENT NAME: _____ **PATIENT ID:** _____

Hospice Philosophy and Coverage of Hospice Care: A representative of Karen Ann Quinlan Hospice has explained the philosophy and methods of hospice care and answered all our questions to our satisfaction. I fully understand that the nature of hospice care, as related to patient's illness, will be palliative, rather than curative in nature. I understand that the services to be provided to the patient include: nursing, medical social services, physician services, counseling (dietary, spiritual, bereavement), therapies (physical, occupational, speech), hospice aide/homemaker services, medical supplies (including drugs and biologicals), short term inpatient care and volunteers. I was provided with the patient rights and responsibilities. Hospice services are available 24 hours/day, seven days/week and I have been informed of the procedure to access care 24 hours/day. I understand the obligation to be responsible for the patient's care at all times. I understand that hospice services are intended to support, not replace my primary caregiver(s). I was provided with information about potential cost-sharing for certain hospice services, if applicable. This information was provided to me by _____ (name of hospice representative).

Medicare will make a payment for unlimited hospice days; however, days are broken into three benefit periods to be used in this order: First period = 90 days, Second period = 90 days, subsequent periods = 60 days. Prior to the beginning of each period, my condition will be evaluated for continued appropriateness by my physician and the hospice medical director. I may be discharged from hospice if care is no longer medically appropriate. I understand that by electing hospice care under the Medicare hospice benefit, I waive (give up) the right to Medicare payments for items, services, and drugs related to my terminal illness and related conditions. This means that while this election is in force, Medicare will make payments for care related to my terminal illness and related conditions only to the designated hospice and attending physician that I have selected. If my services are covered by another, public or private, insurer, those coverage periods and eligibility requirements have been explained to me.

Although it would be rare, there could be some necessary items, drugs, or services that will not be covered by the hospice because the hospice has determined that these items, drugs or services are to treat a condition that is unrelated to the terminal illness and related conditions. The items, services and drugs determined to be unrelated to my terminal illness and related conditions continue to be eligible for coverage by Medicare under separate benefits, however, I understand that Medicare or other insurance doesn't necessarily cover all unrelated items, services and drugs. I understand that I can revoke this benefit at any time and resume regular Medicare coverage and that I will lose any hospice days remaining in the benefit period in which I revoke. I understand that I may transfer my hospice care to another hospice program, once during each benefit period. As a Medicare beneficiary who elects to receive hospice care, I have the right to request at any time, in writing, the "Patient Notification of Hospice Non-Covered Items, Services and Drugs" addendum that lists conditions, items services and drugs that the hospice has determined to be unrelated to my terminal illness and related conditions, and that will not be covered by the hospice. Some items, services or drugs may no longer be medically appropriate for me. Hospice will alert me to these items, if they occur, and discontinue them from the hospice plan of care. If I choose to continue with these items, I will be financially responsible for them. If I request this Notification within five days of the hospice election, Karen Ann Quinlan Hospice must furnish this Notification to me within five days of your request. If I request this Notification at any point after the first five days of the start date of hospice care, Karen Ann Quinlan Hospice must furnish this Notification to me within three days of your request. As a Medicare hospice beneficiary, I have the right to contact the Beneficiary and Family-Centered Care Quality Organization (BFCC-QIO) to request Immediate Advocacy if I disagree with any of the hospice's determinations. The contact info for the BFCC-QIO that services my area has been provided to me.

I choose to elect the Medicare hospice benefit and receive services from Karen Ann Quinlan Hospice effective: _____ (start of care date).

(Note: The start of care date, also known as the effective date of the election, may be the first day of hospice care or a later date, but may be no earlier than the date of the election statement. An individual may not designate an effective date that is retroactive.)

I have been informed of my right to choose my Attending Physician and choose* Dr. _____.

Physicians address: _____

*(if none, the hospice medical director will oversee my care). I understand I may change this selection, by contacting the elected hospice, in writing.

Patient Signature _____ Date _____ Responsible Person Signature and Relationship _____ Date _____

☐ Patient unable to sign due to: _____ Printed Name of Person Above _____

Hospice Representative Signature _____ Date _____

PATIENT NAME: _____ **PATIENT ID:** _____

Hospice Philosophy and Coverage of Hospice Care: A representative of Karen Ann Quinlan Hospice has explained the philosophy and methods of hospice care and answered all our questions to our satisfaction. I fully understand that the nature of hospice care, as related to patient's illness, will be palliative, rather than curative in nature. I understand that the services to be provided to the patient include: nursing, medical social services, physician services, counseling (dietary, spiritual, bereavement), therapies (physical, occupational, speech), hospice aide/homemaker services, medical supplies (including drugs and biologicals), short term inpatient care and volunteers. I was provided with the patient rights and responsibilities. Hospice services are available 24 hours/day, seven days/week and I have been informed of the procedure to access care 24 hours/day. I understand the obligation to be responsible for the patient's care at all times. I understand that hospice services are intended to support, not replace my primary caregiver(s). I was provided with information about potential cost-sharing for certain hospice services, if applicable. This information was provided to me by _____ (name of hospice representative).

Medicare will make a payment for unlimited hospice days; however, days are broken into three benefit periods to be used in this order: First period = 90 days, Second period = 90 days, subsequent periods = 60 days. Prior to the beginning of each period, my condition will be evaluated for continued appropriateness by my physician and the hospice medical director. I may be discharged from hospice if care is no longer medically appropriate. I understand that by electing hospice care under the Medicare hospice benefit, I waive (give up) the right to Medicare payments for items, services, and drugs related to my terminal illness and related conditions. This means that while this election is in force, Medicare will make payments for care related to my terminal illness and related conditions only to the designated hospice and attending physician that I have selected. If my services are covered by another, public or private, insurer, those coverage periods and eligibility requirements have been explained to me.

Although it would be rare, there could be some necessary items, drugs, or services that will not be covered by the hospice because the hospice has determined that these items, drugs or services are to treat a condition that is unrelated to the terminal illness and related conditions. The items, services and drugs determined to be unrelated to my terminal illness and related conditions continue to be eligible for coverage by Medicare under separate benefits, however, I understand that Medicare or other insurance doesn't necessarily cover all unrelated items, services and drugs. I understand that I can revoke this benefit at any time and resume regular Medicare coverage and that I will lose any hospice days remaining in the benefit period in which I revoke. I understand that I may transfer my hospice care to another hospice program, once during each benefit period. As a Medicare beneficiary who elects to receive hospice care, I have the right to request at any time, in writing, the "Patient Notification of Hospice Non-Covered Items, Services and Drugs" addendum that lists conditions, items services and drugs that the hospice has determined to be unrelated to my terminal illness and related conditions, and that will not be covered by the hospice. Some items, services or drugs may no longer be medically appropriate for me. Hospice will alert me to these items, if they occur, and discontinue them from the hospice plan of care. If I choose to continue with these items, I will be financially responsible for them. If I request this Notification within five days of the hospice election, Karen Ann Quinlan Hospice must furnish this Notification to me within five days of your request. If I request this Notification at any point after the first five days of the start date of hospice care, Karen Ann Quinlan Hospice must furnish this Notification to me within three days of your request. As a Medicare hospice beneficiary, I have the right to contact the Beneficiary and Family-Centered Care Quality Organization (BFCC-QIO) to request Immediate Advocacy if I disagree with any of the hospice's determinations. The contact info for the BFCC-QIO that services my area has been provided to me.

I choose to elect the Medicare hospice benefit and receive services from Karen Ann Quinlan Hospice effective:
_____ (start of care date).

(Note: The start of care date, also known as the effective date of the election, may be the first day of hospice care or a later date, but may be no earlier than the date of the election statement. An individual may not designate an effective date that is retroactive.)

I have been informed of my right to choose my Attending Physician and choose* Dr. _____.

Physicians address: _____

*(if none, the hospice medical director will oversee my care). I understand I may change this selection, by contacting the elected hospice, in writing.

Patient Signature _____ Date _____ Responsible Person Signature and Relationship _____ Date _____

☐ Patient unable to sign due to: _____ Printed Name of Person Above _____

Hospice Representative Signature _____ Date _____

PATIENT NAME: _____ **PATIENT ID:** _____

I have received a copy and verbal explanation of the Karen Ann Quinlan Hospice Patient/Family Orientation Booklet, which contains information on Patient Rights and Responsibilities, Advance Directives, HIPAA Notice of Privacy Practices, Disposal of Controlled Substances and the grievance procedure. I agree to provide information and comply with instructions as requested by my practitioners to the best of my ability. I acknowledge, consent and agree to the following:

CONSENT FOR TREATMENT: I give my permission for authorized personnel of Karen Ann Quinlan Hospice to perform all necessary procedures and treatments as prescribed by my physician for the delivery of hospice care and in accordance with the plan of care established by the Interdisciplinary Team in collaboration with my wishes. I understand the following hospice care and services may be provided to me during the course of illness: physician, nursing, social work, therapy services, counseling (bereavement, spiritual, dietary), hospice aide, volunteers, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and continuous care. I understand that hospice care is focused on palliative comfort care and not on cure. I understand that inpatient care may be deemed necessary by my hospice IDT. At that time, they will inform me of my available options for inpatient care. I understand that I may refuse treatment or terminate services at any time and hospice may terminate their services to me as explained in my orientation. I understand that I will be responsible for services and treatments, related to my terminal illness, which are not part of the hospice plan of care or not pre-authorized by hospice. I have been made aware of the medication disposal procedure.

RELEASE OF INFORMATION/RECEIPT OF NOTICE OF PRIVACY PRACTICE:

I further authorize Karen Ann Quinlan hospice to both receive and/or release all medical records and information pertinent to my care (PHI), from hospitals physicians, insurance carriers, Federal, State, insurance and accreditation bodies or other agencies involved in my care. I acknowledge receipt of the Karen Ann Quinlan Memorial Foundation's (d/b/a as Karen Ann Quinlan Hospice) Notice of Privacy Practices. I have read and agree to the release of Protected Health Information as described. I am aware that I can request limits to this policy.

The following persons may be informed of my health care, treatment and condition:

Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____

ADVANCE DIRECTIVES: I understand that my care is not conditional on whether or not I have an Advance Directive.

I have: (If checked, please provide copies to Karen Ann Quinlan Hospice.)

- | | |
|---|---|
| <input type="checkbox"/> Advance Directive | <input type="checkbox"/> Health Care Power of Attorney |
| <input type="checkbox"/> Do Not Resuscitate (DNR) | <input type="checkbox"/> Practitioner Order for Life-Sustaining Treatment (POLST) |
| <input type="checkbox"/> Living Will | |

ASSIGNMENT OF INSURANCE BENEFITS: I certify that the information given by me applying for payment under Title XVIII of the Social Security Act is correct. I request that payment of authorized benefits from Medicare, Medicaid or other responsible payer be made in my behalf to Karen Ann Quinlan Hospice. I understand that I will remain financially responsible to Karen Ann Quinlan Hospice for the charges for all services furnished by them to the extent not covered or paid by my insurance company. I authorize Karen Ann Quinlan Hospice to process claims for payment and appeal claim denials by my insurance on my behalf for covered services rendered by Karen Ann Quinlan Hospice.

My expected payer for hospice services is: ☐ Medicare ☐ Medicaid ☐ Private Insurance ☐ Private Pay

ID: _____

Is the patient/spouse employed with health insurance coverage? ☐ No ☐ Yes If yes, please provide ID: _____

Is the patient/spouse retired with health insurance coverage? ☐ No ☐ Yes If yes, please provide ID: _____

Patient Signature

Date

Responsible Person Signature and Relationship

Date

☐ Patient unable to sign due to: _____

Printed Name of Person Above

Hospice Representative Signature

Date

PATIENT NAME: _____ **PATIENT ID:** _____

I have received a copy and verbal explanation of the Karen Ann Quinlan Hospice Patient/Family Orientation Booklet, which contains information on Patient Rights and Responsibilities, Advance Directives, HIPAA Notice of Privacy Practices, Disposal of Controlled Substances and the grievance procedure. I agree to provide information and comply with instructions as requested by my practitioners to the best of my ability. I acknowledge, consent and agree to the following:

CONSENT FOR TREATMENT: I give my permission for authorized personnel of Karen Ann Quinlan Hospice to perform all necessary procedures and treatments as prescribed by my physician for the delivery of hospice care and in accordance with the plan of care established by the Interdisciplinary Team in collaboration with my wishes. I understand the following hospice care and services may be provided to me during the course of illness: physician, nursing, social work, therapy services, counseling (bereavement, spiritual, dietary), hospice aide, volunteers, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and continuous care. I understand that hospice care is focused on palliative comfort care and not on cure. I understand that inpatient care may be deemed necessary by my hospice IDT. At that time, they will inform me of my available options for inpatient care. I understand that I may refuse treatment or terminate services at any time and hospice may terminate their services to me as explained in my orientation. I understand that I will be responsible for services and treatments, related to my terminal illness, which are not part of the hospice plan of care or not pre-authorized by hospice. I have been made aware of the medication disposal procedure.

RELEASE OF INFORMATION/RECEIPT OF NOTICE OF PRIVACY PRACTICE:

I further authorize Karen Ann Quinlan hospice to both receive and/or release all medical records and information pertinent to my care (PHI), from hospitals physicians, insurance carriers, Federal, State, insurance and accreditation bodies or other agencies involved in my care. I acknowledge receipt of the Karen Ann Quinlan Memorial Foundation's (d/b/a as Karen Ann Quinlan Hospice) Notice of Privacy Practices. I have read and agree to the release of Protected Health Information as described. I am aware that I can request limits to this policy.

The following persons may be informed of my health care, treatment and condition:

Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____
Name: _____	Relationship: _____	Phone: _____

ADVANCE DIRECTIVES: I understand that my care is not conditional on whether or not I have an Advance Directive.

I have: (If checked, please provide copies to Karen Ann Quinlan Hospice.)

- | | |
|---|---|
| <input type="checkbox"/> Advance Directive | <input type="checkbox"/> Health Care Power of Attorney |
| <input type="checkbox"/> Do Not Resuscitate (DNR) | <input type="checkbox"/> Practitioner Order for Life-Sustaining Treatment (POLST) |
| <input type="checkbox"/> Living Will | |

ASSIGNMENT OF INSURANCE BENEFITS: I certify that the information given by me applying for payment under Title XVIII of the Social Security Act is correct. I request that payment of authorized benefits from Medicare, Medicaid or other responsible payer be made in my behalf to Karen Ann Quinlan Hospice. I understand that I will remain financially responsible to Karen Ann Quinlan Hospice for the charges for all services furnished by them to the extent not covered or paid by my insurance company. I authorize Karen Ann Quinlan Hospice to process claims for payment and appeal claim denials by my insurance on my behalf for covered services rendered by Karen Ann Quinlan Hospice.

My expected payer for hospice services is: ☐ Medicare ☐ Medicaid ☐ Private Insurance ☐ Private Pay

ID: _____

Is the patient/spouse employed with health insurance coverage? ☐ No ☐ Yes If yes, please provide ID: _____

Is the patient/spouse retired with health insurance coverage? ☐ No ☐ Yes If yes, please provide ID: _____

Patient Signature _____ Date _____ Responsible Person Signature and Relationship _____ Date _____

☐ Patient unable to sign due to: _____ Printed Name of Person Above _____

Hospice Representative Signature _____ Date _____

SECTION 9. Primary Caregiver Guidelines

We thank you for the privilege of assisting you with the care of your loved one. We recognize all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a sense of peace and love.

Caring for a loved one who has a limited life expectancy and is undergoing many physical, emotional, mental and spiritual changes can be a challenging and fulfilling experience. It can also be confusing and tiring.

Our hospice supports your willingness to take on the role of primary caregiver for your loved one. In this way you help your loved one remain in comfortable and familiar surroundings. We will do everything possible to help you care for your loved one effectively and appropriately. We see ourselves as a team, with each of us having different roles and responsibilities that together achieve maximum benefit for you and your loved one.

Primary care refers to the basic physical and emotional activities involved in meeting the ongoing daily needs of your loved one. This may involve nourishment; use of medications; turning; skin care; oral care; bathing and grooming; and comfort measures such as preventing constipation, nausea or other symptoms. It may include learning skills such as ostomy care and utilizing special equipment. It may include filling prescriptions, communicating with the physician, communicating with community resources, utilizing printed materials and making final arrangements. Generally, it means being available to your loved one to listen, to touch, to share, to be present and to care.

Our hospice team is committed to support you in every possible way as you undertake the primary caregiver role. The team will explain the progression of the illness, the changing needs of your loved one and how to respond as these changes take place. It will seek to help you anticipate these changes and implement procedures so that they do not become big problems or out-of-control situations.

The hospice team will help you arrange for all supportive services that are needed in the home. It will help set up respite care and inpatient care as needed. It will help you clarify your choices, available alternatives and resources. The hospice team also supports you as you deal with your own feelings, values, priorities and beliefs. Our team is committed to helping you to maximize your time, energy and love with your loved one.

TIPS ON TAKING CARE OF YOURSELF

Remember, to be able to take care of another, you must first take care of yourself.

- Love yourself at least as much as you love the one you are caring for.
- Get enough rest, perhaps naps during the day. Conserve your energy.
- Exercise. Even a short walk helps sleep and gives energy.
- Eat well. Choose a variety of foods from the five basic food groups. Drink plenty of water.
- Reduce stress. Think about what has helped in the past.
- Take breaks. Relax and think of other things.
- Pay attention to what your body is telling you. Is it tired, stressed, tense?
- Nurture your spiritual side. Pursue those things that are uplifting to you.
- Pamper yourself, especially on difficult days. Be patient and considerate of yourself.
- Avoid unrealistic expectations of yourself.
- Allow others to help you.
- Set limits. It's OK to say "no" sometimes.
- Recognize your needs and limitations.

TIPS ON HELPING LOVED ONES

- Allow them to talk. Listen without judgment and with only occasional comment.
- Acknowledge and validate their feelings and let them express their feelings in many ways.
- Avoid taking any negative feelings personally.
- Let them have control over their situation as much as possible.
- Include them in decision making and discussions.
- Let them do as much as they want to and have the energy for, no matter how slow, painful or difficult it seems to you.
- Don't underestimate their pains, symptoms and fear. These are real and valid.
- Avoid judging.
- Talk about subjects you use to discuss together, the times you shared. Laugh together.

Experience has shown that often the best patient care is provided by family and friends. Regardless of how capable and efficient a professional's care may be, the presence and touch of a person who has a close relationship with the patient will provide the greatest comfort.

SECTION 10. Understanding the Changes and Symptom Management Issues of Terminal Illness

The Whisper of Wings

Death is simply a shedding of the physical body like the butterfly shedding its cocoon. It is a transition to a higher state of consciousness where you continue to perceive, to understand, to laugh and to be able to grow.

Dr. Elizabeth Kubler Ross, On Death and Dying

This section of the booklet is a collection of resources providing dying patients and their caregivers an understanding of emotional and physical changes and pain and symptom management issues that occur during terminal illness and death.



Most of us have never witnessed someone dying, so it is difficult, both physically and emotionally, to know and accept that someone we are caring for is near death. In general, the human condition portrays definitive physical and emotional symptoms that are a sign of approaching death. As caregivers, if we are alert to these symptoms, we will be prepared to give our loved one the best care in the final days. Knowing these signs will also help caregivers prepare the rest of the family as to what to expect and when.

Let's first try to dispel some myths so we are able to begin with a fresh start on this human process of dying. We must try to keep in mind that death is a personal journey that each individual prepares for in his or her own unique way.

While there are many different paths one can take on this crossing they all lead to the same destination; a journey from the known to the unknown.

As one comes close to death, a mental and physical process begins. As that process is set in motion, a person starts on a path of discovery, trying to comprehend that death will indeed occur, and that the journey will ultimately lead to the physical departure from the body.

We will discuss what has been found on this topic through research, interviews with hospice nurses, other personnel and general current medical information. Again, as we explore the paths most take, keep mind that the journey is unique to the traveler taking it.

MYTHS ABOUT DYING

Cultural misconceptions about dying can get in the way with people receiving the best possible care at the end of life. Revealing these as only folklore will help you understand the realities that can allow you to better support the dying person and loved ones.

"Death is too upsetting to talk about."

We have been isolated from death, which has been hidden away in the back rooms of hospitals or other facilities. Often we are prohibited or are afraid to talk about death, even though death is a normal part of life. Anyone or anything that lives, dies. But we all still fear death.

We can help make death a more positive experience not only for the dying person but also for family and friends by understanding we all fear the unknown, and no one is exempt from the in-depth life review that comes with the dying process. To do this we must be familiar with the needs of dying persons as well as the needs of their caregivers. We must realize that the entire dying process is not frightening but that fear is just a part of the overall progression. The best thing for the dying or their caregivers to do is to make sure that feelings are allowed to be expressed and to seek or give the support needed. If fear is denied, it will only manifest itself in other areas, such as more acute pain, a sense of foreboding or increased anxiety.

“People die as they have lived.”

As some people approach death, they may change if they feel the need. Often with the premise that we “are returning home,” we may get a sense of seizing final opportunities. If people receive loving and good care during their last weeks or months of life, that time can serve as a great opportunity to reminiscence and to seek forgiveness or spiritual growth. This is only possible if there is good communication and openness among patient, caregivers and family.

“Dying is always painful.”

This is one of the most universal misunderstandings about dying. The pain that may accompany illness or disease today can be relieved safely without any danger of causing death or addiction. Hospice caregivers and physicians are familiar with the proper use of analgesic drugs. When given in the correct dose at the right time, drugs can relieve pain without sedating the patient. When pain is relieved, patients can experience a good quality of life until the time that death occurs. Good pain management does not shorten the course of life. On the contrary, patients who receive excellent pain management tend to live longer than expected.

“While dying, people see a light, a tunnel, people who have gone before, etc.”

We have all heard stories of dying people seeing or talking to someone who has passed before or they experience unusual light. Whether it is true or not, or whether it can be explained is irrelevant; it happens and it happens consistently. We should pay attention to it. When dying persons speak about seeing relatives who have previously died, in almost all instances, these last visions are usually pleasant and offer comfort to the dying person, especially regarding the prospect of reuniting with deceased loved ones. These experiences of the dying person should be seen as normal and potentially very wondrous. The dying process, when not interrupted by an unexpected tragedy, is a gradual one with the dying person moving to and from “the other side.”

PRACTICAL GUIDANCE FOR CAREGIVERS ABOUT THE HUMAN BODY AND THE DYING

Bodily Changes of the Dying and What to Do

The following are common occurrences of what one may expect when death is approaching. The signs will vary according to the cause of death, the person's general health, medications and other significant factors.

- **Activity decreases**, with less movement, less communication, less interest in the surroundings. When spending time with the patient, remind the patient who you are and what day and time it is, then begin your conversation.

- **Interest in food and water diminishes**; this is a natural occurrence. We do not die because we stop eating; we stop eating because we are dying.
- **Vital signs and sensory changes may vary.** Vision may become blurry or dim. Hearing may decrease, but always keep in mind most patients are able to hear you even after they can no longer speak. As vision decreases, leave indirect lights on. Continue to speak and touch the patient with reassuring and soothing words and caresses.
- **Bowel and bladder changes.** Urine may become darker in color and decrease in amount. If the patient has a catheter, your nurse will teach you how to care for it.
- **Circulation is diminished**, and as the blood flow begins to decline, the hands and feet are the first to be affected. They may become either darker or more pale than usual and they also may be cold. You may keep patient warm with blankets, but avoid electric blankets and heating pads. They are not necessary for the patient's comfort.
- **Breathing changes** from a normal rate and rhythm into a new pattern, alternating between rapid and slow. Rattling or gurgling with each breath is from secretions in the back of the throat. This may be distressing to listen to but causes no discomfort for the patient. Ten to thirty second periods may occur with periods of no breathing (apnea). Raising the patient's head may give some relief, with the use of pillows to prop the head and chest at an angle. Hospice nurses have medications to help relieve this symptom that is not distressing to the patient.
- **Skin color changes** from normal to a duller, darker grayish hue.
- **The fingernail beds** become bluish rather than the normal pink.
- **Speaking decreases.** The person ceases to respond to questioning and no longer speaks spontaneously. The patient may be confused about time, place and people.
- **Terminal Restlessness.** As patients get closer to death, they may experience a period of restlessness or agitation that usually occurs at night. You might see them trying to climb out of bed, tossing and turning, incessantly speaking, flailing arms, etc. You have to remember that there is no night or day for dying people and sleep patterns are virtually the same as for newborns. They no longer have normal sleep cycles and can sleep 24 hours a day. Or patients may be up for as long as 72 hours. This may be very exhausting for the caregiver, and your hospice nurse will guide you as to what medications might help in alleviating these symptoms. At this time, it is important to set up "shifts," so care does not fall on one person. When periods of sleep increase during the day, it is important to note that the extra sleep and dreams are very important to the dying process, as it is the time for resolution of many life issues. This is an enormous task and requires a great deal of effort. All this aids the patient in getting ready for the next phase of life.
- **Bedsore.** One of the main complications of decreased circulation is the potential to develop bedsores. Bedsores are decubitus ulcers caused by prolonged pressure. Moving or repositioning the patient on a regular basis, every two hours, will help to prevent bedsores. The patient does not have to be moved very far, just enough to change pressure points.
Keeping the skin clean and dry and gently massaging with a good lotion are also preventative measures. Despite best efforts, bedsores still may occur during the dying process. Some patients are so debilitated that even mild pressure for short periods of time can lead to bedsores. If you see a bed sore developing (e.g., a persistent reddened area or blister), be sure to alert or contact your hospice nurse. Also your nurse can help you determine a balance between the patient's comfort and potential risks.
- **Coma ensues** and may last from minutes to days before death occurs.

WHEN DEATH IS APPROACHING

Fluids: The decreased intake of food and fluids is not painful. On the contrary, the administration of food and fluids to dying patients can add to their general discomfort and frustrate their desire to let go and allow nature to take its course. Allow the patient to dictate his or her desire or lack of desire for food and fluids.

In cases where people cannot swallow, it is standard care to apply moisture in some form to the lips and mouth regardless of whether or not the patient is ever able to swallow again. Ice chips, water or juice may be given as requested but should be stopped if there is difficulty in swallowing. Care of the mouth is important and part of basic oral hygiene. Vaseline (or another lubricant applied to the lips will prevent drying. Secretions from the mouth can be removed with the tip of a towel by turning the person to the side. Also, running a vaporizer in the patient's room can ease breathing when lung secretions are dry. Fluids that may accumulate in the lungs (pulmonary congestions) can most often be avoided by not forcing fluids on the patient. This includes IV fluids.

When it is determined that the person is actively dying and it is further determined that hydration would only increase the patient's discomfort, the elimination of fluids is not a painful process. Even patients with total bowel obstruction who had been unable to retain any oral fluids and who voluntarily declined intravenous fluids do not complain of thirst or hunger.

There is a side effect of food and fluid decreasing in which one's metabolism changes and the resulting elevated level of ketones produces a mild sense of euphoria, so that hunger and thirst are not the problem we would imagine.

Respiratory: Airway Rattling – As excess fluid accumulates in the patient's lungs, the mucous in the airway makes a "rattling" sound when the patient breaths. Once referred to as "the death rattle," we now have certain drugs to help the patient clear up the rattling. But these drugs can cause discomfort for the patient, such as very dry skin, mouth and eyes. It is more natural to limit the patient's fluids in the first place. If airway rattling does occur, it can be very loud and often frightening to the caregivers but is seldom taxing to the patient. This is because, by the time the rattling manifests, the patient is often in a coma or semi-coma state and is unaware of any discomfort.

Suctioning should be avoided as it can often irritate and cause more discomfort than the rattling itself. The reason is that in addition to it being traumatic for the patient, no matter how skillfully the suction is performed, the sensitive nature of the windpipe is cause for concern. Even when the suctioning is performed with maximum success, the rattling is still likely to return within ten to twenty minutes. At this stage of the life and death process, the primary goal is the patient's comfort, even though the caregiver may feel the rattling is unpleasant.

Consciousness: Some patients are unconscious for hours or even days before death, while others may be alert until the last moments. You may ask your hospice nurse how to assess for signs and symptoms of pain in a non-verbal patient. Usually there is a gradual development of confusion and semi-consciousness over a few minutes or hours. Pain is one of the first senses to decline in death, but even though patients may not be able to express their pain, it is important to continue medication up to the end of life.

Persons in a coma may still hear what is said even when they no longer seem to respond to verbal or even painful stimuli. Caregivers, family and physicians should always act as if the dying patient is aware of what is going on and is able to hear and understand voices. Your own words of endearment and support may still be understood and appreciated. Touching, caressing and holding are all appropriate.

Temperature: As circulation decreases the dying person's body, starting with the outer extremities, begins to lose color and cool. Although the skin may be cold, dry or damp, the patient is usually not conscious of feeling cold and light bed coverings are usually sufficient. The patient may also have a high temperature as death approaches. This can be treated with Tylenol, suppositories and cool compresses.

Involuntary Movements: Occasionally involuntary or reflex movements may take place. These are rare but may involve muscles, particular an arm, leg or face muscle. In addition, there may be a loss of control of the bladder or the bowels as these muscles relax.

When Death Occurs: When breathing and the heartbeat have stopped, the eyes become fixed in position and the pupils dilate. After death, there is no rush to do anything and you may sit with your loved one as long as you want. Many families find this a significant time to pray or talk together and reconfirm your love for each other as well as for the person who has passed. At home, call us and we will assist you with the final arrangements for your loved one.

THE BASIC NEEDS OF DYING PERSONS

- *Assurance* that they will be cared for, that they will not be abandoned.
- *Assistance* in developing and finalizing documents pertaining to terminal care.
- *Information* that will be accurate, timely and reliable.
- *Excellence* in the delivery of physical care, comfort, privacy, intimacy, sleep and rest.
- *Communication* that is timely, honest and open with family, friends and caregivers: people who will listen. Opportunity to discuss their impending death (if desired) with selected family and caregivers.
- *Management* of pain and other symptoms that is responsive to changing conditions.
- *Permission* to express feelings, both positive and negative; to say "thank you, I love you, I forgive you," as well as to express dissatisfaction, anger, resentment.
- *Opportunity* to explore their finiteness and the spiritual dimensions of life.
- *Opportunity* to discuss preferences about funeral arrangements as well as the impact of dying on survivors.
- *Time* to reflect on the implications of the diagnosis and prognosis, to identify and attend to thoughts, feelings and needs, time to tell their story, to re-affirm their identity and value of their life. Time to reflect on and to grieve prior as well as current losses. Time with selected family and friends. Time to attend to unfinished personal business. Time to plan for distribution of assets and to address their financial responsibilities.

Expanding Goals of Care:

Dying is not primarily a medical condition but a personally experienced, lived condition. – William Bartholomew, M.D. 1997, Kansas City (died of esophagus cancer, 2001)

Once the desires of dying persons are understood and accepted, we are then able to refocus the goals of care. Instead of hoping for a cure, the dying person has a right to hope for a comfortable death, free of pain and discomfort. The dying person can retain the hope of finding or re-finding the value of his or her life; of resolving what was previously not able to be resolved; discovering or re-discovering spirituality.

The dying person may renew a quest for answers to great existential questions. It is not unusual for the person dying to find deep reservoirs of faith that were never suspected before. There is much that a dying person can hope for.

PAIN MANAGEMENT: MYTHS ABOUT PAIN

Again, let's first look at some myths and try to dispel their messages.

"Dying is always painful." Many people die without experiencing pain. If pain does occur, it can be relieved safely and rapidly.

"Once you start taking morphine, the end is always near." Morphine does not initiate the final phase of life or lead directly to death. Morphine provides relief of severe, chronic pain; and it also provides a sense of comfort. It makes breathing easier. It lets the patient relax and sleep. It does not cloud consciousness or lead to death. When used properly, morphine does not kill.

There are also several obstacles that often lead us to misunderstanding effective pain management in advanced disease. Narcotics, while dangerous when used for recreational purposes or as a coping substitute, **are very safe when used to control pain.**

Some obstacles are:

- Inadequate education of health care professionals in the use of analgesics;
- Cultural fears about the use of narcotic analgesics;
- Fear of addiction; and
- Fear of overdose.

CONSEQUENCES OF THE FAILURE TO MANAGE PAIN

When severe and chronic pain is not managed, the consequences are accompanied by anxiety, fears, impaired sleep, reduced appetite, frustration, depression, memories of past pain, anticipation of pain yet to come and, in some instances, thoughts of suicide. Chronic pain has a strong emotional component that fades as soon as the pain is relieved.

Unmanaged pain gets in the way with the person's ability to address one's place on earth in addition to issues of spirituality or unfinished business. Pain control must come first. Once pain is effectively dealt with, dying people can turn to the more vigorous issues of dying, such as religious or spiritual matters.

PATIENTS HAVE A RIGHT TO PAIN RELIEF

Pain, according to health care regulatory agencies, is now a fifth vital sign to be recorded with blood pressure, pulse rate, respiratory rate and temperature. However, the sophisticated techniques of pain control developed by hospice physicians need to be known and shared throughout the medical system. Hospice experience testifies that some patients who were bedridden with severe, chronic pain have been able to return to a higher level of physical activity once their pain is properly managed.

If you are transferred or discharged to another organization, we will provide them with a list of your current medications and information necessary for your continued care, including pain management, using the New Jersey Universal Transfer Form. All transfers or discharges will be documented in your medical record.

Understanding Pain Medications – OPIOIDS (Narcotics) At one time it was believed that patients would become tolerant to opioids, reducing the drug's effectiveness in controlling pain. Clinical experience shows that patients can take opioid drugs for months or even years and still obtain adequate relief.

It is true that while patients can become physically dependent if opioids are taken for a long period of time, that simply means that they may show signs of withdrawal if taken off the drug abruptly. This is not an issue for the dying. Addiction is a term used only to characterize the harmful behaviors of compulsive drug users. Tolerance and physical dependence are often confused with addiction. That confusion is often translated to patients and threatens their right to quality pain management.

There is also the incidence of "pseudo-addiction." Patients in pain may seem to acquire behaviors that are misinterpreted as drug-seeking behaviors.

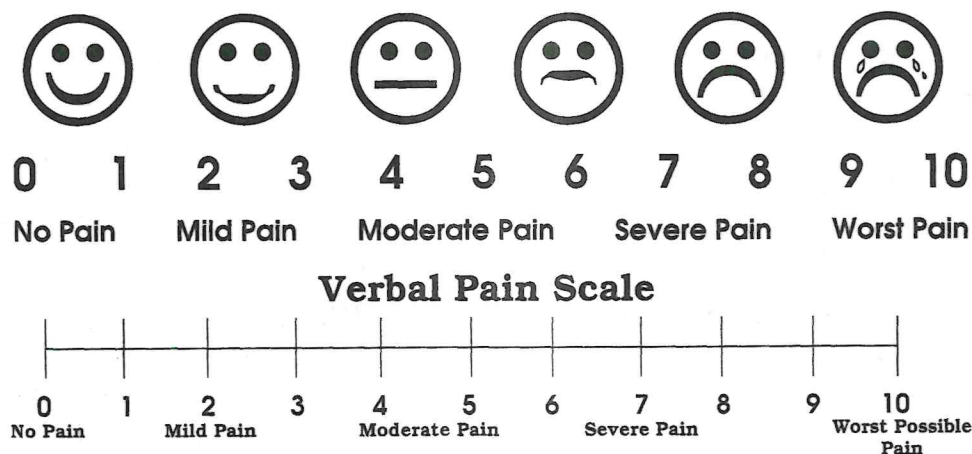
They may request increased doses or take more medicine than prescribed. The reality is that studies of cancer patients have linked these behaviors to inadequate dosages of pain medications. Once pain is properly managed, these behaviors stop.

Side Effects: Opioids and narcotic analgesics have different side effects when administered orally versus through an IV:

- **Sedation.** When properly used, orally administered opioid analgesia brings with it a normal period of sleep. Narcotics exert a calming, relaxing effect through direct sedative action on the brain as well as through relief of pain. Patients often sleep after receiving pain relief because they have been sleep-deprived for days or weeks with recurrent episodes of pain. Such sleeping patients are easily roused by calling their name or touching them. Tolerance develops rapidly to this initial, sedative side effect, and patients on even large doses of narcotic analgesics can be clear-headed, aware of all that is happening and be involved in all decisions affecting their care.
- **Slowed Breathing Rate.** Slowed rate of breathing is rarely a problem as a side effect, as the respiratory rate of patients in pain is usually higher than normal. Patients receiving narcotic analgesics usually breathe less frequently but take deeper breaths. Like the sedative side effect, slowed respiratory rate is a transient side effect and, if present, fades after several days.

- **Constipation.** A major side effect of narcotic analgesics is constipation that must be managed not only with stool softeners but with laxatives, like senna derivatives, that stimulate bowel activity. Laxatives must be provided on a regular basis as long as patients are receiving narcotic analgesics.

PAIN SCALES:



FLACC SCALE (For non-verbal patients)

CATEGORY	SCORING		
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort

The FLACC: A behavioral scale for scoring postoperative pain in young children, by S Merkel and others, 1997, *Pediatric Nurse* 23(3), p. 293-297. Copyright 1997 by Jannetti Co. University of Michigan Medical Center. Reprinted with permission.

Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between zero and ten.

SCORE: _____

In order to be able to accurately assess pain, a variety of pain scales may be used.

In summary, there is always something that can be done to relieve severe, chronic pain in advanced illness. Hospice work has taught us that chronic, severe pain is a complex psycho-physiological process that is best treated by a number of approaches that include narcotic analgesics, psycho-social and spiritual support and the use of a wide variety of therapies ranging from massage to nerve block.

Emotions and Psychological Concerns: We know now about physical symptoms of approaching death and why they are so important. But it is also essential to understand the psychological journey that dying persons go through. With this understanding, we as loved ones and caregivers can help relieve the worries and stresses of the person who is dying. This should make the journey less painful, both physically and emotionally, for all.

Anxiety: Most people have either experienced or observed anxiety at some time in their lives. The awareness that one is dying is dramatic and usually brings forth anxieties related to the fact that one has only a limited time to live. The anxiety of dying persons also relates to practical concerns about what will happen and how dependent survivors will be cared for, as well as spiritual concerns, fear of the unknown and all that is related to what happens with the death experience.

Ways to Help: Identify the causes is the first step to relieving the anxiety. When dying persons know they have trusted people to answer their questions and they know they will be cared for, anxiety diminishes.

- **Establish clear communication.** Patients have a right to know their diagnosis, the prognosis, the treatment alternatives, the side effects of the proposed treatments and the site of care. Most dying persons, given the choice, prefer to spend their last weeks and months at home. If hospice is not already a part of their care, then this is a good time for the matter of hospice to be raised and discussed. The patient should be involved in this decision and should have all necessary information about hospice.
- **Present options.** When options are communicated, anticipatory anxiety can be reduced. The passage from a “non-dying” person to one who now has limits set on his or her life may take several weeks or months to adjust, plus considerable effort for all involved. Knowing the options can help relieve the tension; however, anxiety may reappear as the illness progresses.
- **Consider social, psychological and spiritual needs.**

Anxiety that appears more severe than the “normal” anxiety may not be resolved without prescribed medication. There are anti-anxiety medications available in a variety of forms. Some are more sedating than others. The “sedating” anti-anxiety medications are usually reserved for persons with persistent, disabling anxiety.

DEPRESSION

Depression is a mood disorder lasting at least several weeks in which there is a depressed mood and loss of interest in nearly all activities plus several of the following: change in appetite, weight and psychomotor activity; decreased energy, feelings of guilt or worthlessness, difficulty thinking, concentrating or making decisions; recurrent thoughts of death, or thoughts or plans of suicide.

Depression in dying persons may be either a result of the person's response to stress or a result of the disease itself, e.g., the treatments designed to halt the disease or the medications prescribed to modify the side effects of the treatments.

The sadness in anticipation of one's own death is a normal and expected response and may be compounded by the sustained anxiety and fear of dying. In these cases, it is difficult to separate this normal sadness from true clinical depression.

Truly depressed persons will have a negative outlook and see no good in anything. They have given up and also see no reason to hope. They may experience shame, guilt and self-recrimination and may be overwhelmed by fear and exhausted from anxiety. This prevents them from taking comfort in the support provided them. They may express a desire to die or even talk about suicide.

The classic behavior of depressed persons includes withdrawal, isolation, decreased communication and lack of interest. They may also exhibit a generalized slowing of thinking and acting and weight loss.

Ways to Help:

- Assess pain and make sure it is identified and being controlled. **Unmanaged pain is the most common source of depression in dying persons.**
- Identify the source and extent of depression. What else may be bothering the patient? Is there some unfinished business? Is there some unresolved conflict or dispute with another member of the family or other persons?
- **Review medication.** Make sure all symptoms are being treated.
- **Consider supportive psychotherapy.** Your hospice nurse can help you with seeking support from professionals: physicians, nurses, social workers or clergy. Consider supportive psychotherapy sessions for affected persons in the family. Family members are influenced by depression in the dying person and they may need an opportunity to talk about their response to the depression.
- **Examine the way the person deals with loss.** Dying persons may not just be grieving over their own death, but fear for those they leave behind. Talk to them about all their losses. This may be an opportunity they welcome. They may be equating depression with loss.
- **Consider social, psychological and spiritual needs.** Examine and discuss what is going on in the family, perhaps unfinished business or what is being said, what is not being discussed or what worries have not been addressed.

PAIN AND SUFFERING

This is a catch phrase in that it is used without considering its origin or what it really means. Suffering is a word used to describe something that has to be endured. It characterizes pain as incapable of relief. That is not true today and the two words should not be so casually partnered.

Suffering is the emotional dimension of pain and an indication that something is seriously wrong. If unmanaged pain at first seems to be the culprit, but the suffering persists even after the pain is relieved, then it is necessary to look elsewhere. Severe pain is not an indispensable part of suffering. Sometimes the fear of the unknown contributes to suffering, or the feeling that one deserves pain as a punishment.

In medical circles, the assumption that suffering can make you a better person is generally dismissed. The concept of suffering for the “sake” of good is not a customary conviction.

How to Help:

- Check with your hospice nurse to ensure pain management has been instituted.
- Encourage the patient to talk about his/her worries, fears, regrets and hopes.
- Support the patient in identifying any “unfinished business.”
- Create opportunities for communication between patient and hospice team.
- Have the patient develop a “personal history” or “life review.”
- Ask your clergy or the hospice spiritual counselor to help identify and assist in spiritual and religious concerns.
- Consider all social, psychological and spiritual needs.

ANGER

Anger is a common emotion observed by those who work with dying persons. The anger may be focused on a person or on the disease itself and may also be diffused through many different situations.

Some persons will seek excuses to express anger or it may be a reflection of the unfairness or powerlessness due to the underlying disease. The fear of pain and death may awaken latent feelings of worthlessness and anger, and suicide may be contemplated.

- Try to develop alternative expressions of anger.
- Identify the sources of anger.
- Evaluate the use of anger with respect to the personality.
- The patient may see the disease as punishment and be angry at God or the world in general.
- Anger may just be a part of the underlying personality structure of the patient and the stance they have always used when confronting the world.

In Summary: Caring for a dying person evokes numerous feelings and situations. They will vary depending on the caregiver, the dying person and the relationship that the caregiver has with the dying person. Understanding what to expect during the dying process is the first step to providing comfort and care.

This information draws upon information presented by the Hospice Foundation of America, hospice nurses, health professionals and bereavement counselors.

For more information on the Hospice Foundation of America visit
www.hospicefoundation.org.

For more information on Hospice and Palliative Care visit the National Hospice and Palliative Care Organization visit www.nhpco.org.

For more information on Karen Ann Quinlan Hospice visit
www.karenannquinlanhospice.org.

Other valuable readings include: Crossing the Creek, Key Elements of Transitions, and Dying to Know by Michael Holmes available at
www.crossingthecreek.com.

FINAL STAGES

A quick review of the final stages: "There will come a time when you believe everything is finished. That will be the beginning." – Louis L' Amour

Three Months or Less:

- Your loved one will recognize he or she is dying.
- Withdrawal from the world or people.
- Loss of appetite, an increase in sleep and more introspection.

Two Weeks or Less:

- Your loved one will begin to exhibit the acute stages of the dying process.
- Disorientation, confusion and agitation and talking to unseen persons.
- Blood pressure decreases. Pulse and temperature increases or decreases.
- Skin color changes to a bluish or paling.
- Increase in perspiration.
- Breathing irregularities and congestion.
- Sleeping much more, but still somewhat responsive, body heavy and tired.
- Drinking very little and not eating.

Days or Less:

- Two-week signs are more pronounced. A surge of energy, sitting up and talking.
- Eyes will become glassy or tear up and may only be half open.
- Some may continue to be agitated, while others may cease activity altogether.
- Knees, feet and hands may become purplish and the rest of the skin blotchy.
- Pulse weakens and urine slows. Wetting or stooling the bed is not uncommon.

Minutes:

- Breathing sporadically. Cannot be awakened.
- While you may have prepared for the final process, you may not be prepared for the actual time. If you think your loved one is close to death or has died, call the hospice immediately and the nurse who normally visits you or the on-call nurse will come to assist.

Once death has occurred, you do not need to call 911 and nothing has to be done before the staff arrives.

The hospice nurse will notify the physician (and medical examiner if you are in Pennsylvania). The nurse will call the funeral home once the pronouncement of death has been made.

We are only a phone call away. Call Karen Ann Quinlan Hospice at
1-800-882-1117 or (973) 383-0115.

*(If there is no answer after numerous rings,
please call the answering service directly at (725) 238-5991.)*



Karen Ann Quinlan Memorial Foundation
Serving Northwest NJ and Northeast PA
1-800-882-1117

INFORMATION TO BE GIVEN TO THE FUNERAL DIRECTOR

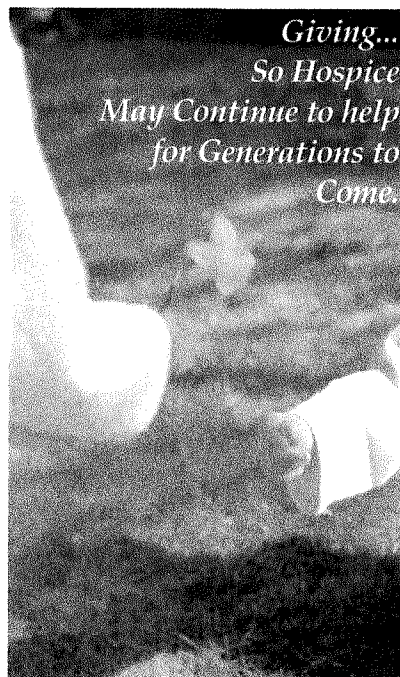
A LEGACY OF LOVE

IT IS THE WISH OF THE FAMILY OF

**THAT THE FOLLOWING BE
INCLUDED IN THE OBITUARY:**

Memorial donations may be made to:
Karen Ann Quinlan Memorial Foundation
99 Sparta Avenue
Newton, NJ 07860

A Legacy of Love



Because Karen Ann Quinlan Hospice provides services regardless of the individual's ability to pay, the need for community support is tremendous.

As we honor each patient in life, we join you in honoring your loved one's memory. Donations in your loved one's name are gratefully accepted and acknowledged and will be dedicated to offering care and support to the patients and families in need of our help.

To designate memorial contributions, please give the signed statement (on the previous page) to your funeral home.

Any questions that you might have regarding memorials can be answered by calling Karen Ann Quinlan Memorial Foundation at 1-800-882-1117.

Thank you.

KAREN ANN QUINLAN HOSPICE MEMORIAL FOUNDATION KEY PERSONNEL

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Clinical Director

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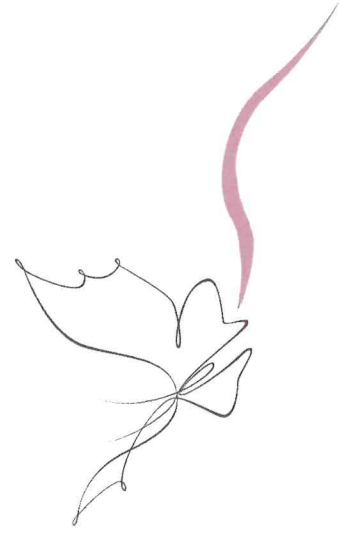
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Michaela R. Csizmar

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Christopher Schroeder



For information about the Karen Ann Quinlan Charitable Foundation,
please call John Quinlan, Director of Foundation, at (973) 383-0115, ext 148.

KAREN ANN QUINLAN HOSPICE - 1-800-882-1117

In the case that there is no answer after multiple rings,
call the answering service directly at (725) 238-5991.

In the case of a community disaster/emergency, please refer to your local media for instructions.

RN: _____ Social Worker: _____

CHHA: _____ Volunteer: _____

Chaplain: _____