The Hospice Resource Guide

Your essential hospice resource
has been produced by:

With you.

Table of Contents

The Basics of Hospice

Emergency Calls

Your Family's Care Team

Rights & Ethics

Table of Contents (Cont.)

Patient Care

Safety in the Home

For the Caregiver

Financial Information

The Basics of Hospice

The Hospice Philosophy

Making the decision to ask for hospice care for a family member or a loved one is especially emotional and one that is often filled with fear and uncertainty. That's because few of us understand the many benefits that hospice can bring to individuals suffering from a terminal illness, and to their families as well. But choosing hospice care is one of the best decisions that can be made at end of life.

Hospice is specialized, end-of-life care that provides treatment and support for patients in the final phase of illness. The goal of hospice is to enable patients to live life free of pain and with symptoms well-managed, so that their remaining time may be focused on quality of life and time with those they love — at home or in a home-like setting.

Hospice is comfort-focused care that is concerned with the physical, mental, emotional, and spiritual state of patients and their loved ones. Hospice clinicians strive to bring balance to each of these areas of life through pain and symptom management, education, counseling, and grief support.

We are committed to providing the best quality of life possible for our patients and their families. Our primary focus is to make our care available to anyone who needs it, regardless of diagnosis, complexity of care, or ability to pay.

How Hospice Works

Hospice services are available to patients who no longer benefit from, or choose to forgo, curative treatment. The typical hospice patient has a life expectancy of six months or less, if the illness takes its expected course. Most patients receive care at home or in a long-term care setting such as a nursing home or assisted living community. Services are provided by a team of trained professionals who provide medical care and support services, not only to the patient, but to the patient's family and caregivers as well.

An important component of hospice is palliative care-pain and symptom management designed to provide maximum relief to the patient. Palliative medicine may include chemotherapy or radiation, but when accessed as part of hospice care, these treatments are comfort-oriented rather than curative. Hospice clinical team members are experts in symptom management and know how to alleviate pain caused by advanced illness.

Together with the patient's attending physician, the hospice care team establishes and monitors a Plan of Care that incorporates reasonable and necessary medical and support services for the management of the terminal illness. Part of this plan is to avoid unnecessary hospital stays and emergency room visits.

Studies regarding hospice care have demonstrated significant benefits to both the patient and his/her family when an early referral to hospice is made. Pain and accompanying symptoms are better managed which leads to significant improvement of life, and often, longer length of life.

Patients Who Benefit From Hospice Care

Patients who may benefit from hospice care are those in the final stages of chronic lung disease, congestive heart failure, AIDS, cancer, cardiovascular disease, Parkinson's disease, Alzheimer's and dementia, and other life-limiting, terminal illness.

How Hospice Differs From Other Types of Healthcare

Hospice emphasizes quality of life, rather than length of life. The hospice movement regards dying as a normal process in the life cycle and seeks to help both patient and family become comfortable with this concept.

Hospice offers help and support to the patient and his/her loved ones, twenty-four hours a day, seven days a week. For hospice patients, help is just a phone call away. Patients routinely receive periodic in-home services of a nurse, hospice aide, social worker, chaplain, volunteer, and other members of the hospice care team.

Care received from hospice is collaborative — patients and their loved ones are included in each step of the decision-making process. And after the death of a patient, care does not end. Grief support is provided for up to thirteen months to any loved one who needs it.

How Hospice Is Funded

Commercial insurance as well as Medicare and Medicaid are accepted, with coverage varying by payor source. Payment for services not covered by insurance is based on the patient's or family's ability to pay. It is our intent that ability to pay not be a barrier to receiving care. If needed, a financial assessment may be requested to assess eligibility for financial assistance. Our hospice services will never be denied to eligible patients because of inability to pay.

Contributions from individuals, foundations, corporations, communities of faith, and civic organizations help us to care for everyone who needs our services, and to provide valued programs beyond those covered by insurance, such as grief care and community education. Memorials, honorariums, bequests, and other contributions are also important sources of support for our programs.

Hospice Is Cost Effective

During the last months of life, cost savings of over 30% have been realized using hospice services for the care of cancer patients. (An Analysis of the Cost Savings of the Medicare Hospice Benefit conducted by Lewin-VHI.) Costs are kept low because hospice patients have fewer hospital visits and because they have chosen not to participate in expensive treatments that neither extend nor enhance their quality of life.

Hospice Levels Of Care

Hospice patients may require differing intensities of care during the course of their disease. The Hospice Benefit affords patients four levels of care to meet their clinical needs: routine home care, general inpatient care, continuous home care, and inpatient respite care. Payment for each covers all aspects of the patient's care related to the terminal illness, including all services delivered by the interdisciplinary team, medication, medical equipment, and supplies.

Routine Home Care

This level of care is provided in the patient's place of residence — in your private home, an assisted living community, a skilled nursing or long-term care facility, or another residential setting. Under routine care, you receive regular visits from members of your care team, based upon your specific needs. As your needs change, team members adjust their visits to accommodate these changes and ensure optimal care.

General Inpatient Care

If you experience acute symptoms that cannot be safely managed in your home or other residential setting, you may require a higher level of care called general inpatient (or GIP) care. GIP care may be provided in a hospice house, in a skilled nursing facility, or a hospital. Once symptoms are under control, you may return to your home under the routine level of care.

Respite Care

Many patients have their own caregivers. If your caregiver needs a rest from their caregiving responsibilities, respite care may be available. Under respite care, you may stay in a Medicare-certified facility or other inpatient center for up to five days.

Continuous Care

Sometimes a medical crisis occurs that needs close attention. When this happens, skilled care may be brought into your home for up to 24 hours per day to possibly avert the need for a hospital visit. When the crisis is over, you can return to routine care.

Emergency Calls

In Case of Emergency

Call your hospice first!

A nurse is available 24 hours a day to assist with unexpected emergencies such as:

» Pain or any symptom not relieved with current medication

» Unexpected change in condition

» Death

If you are considering hospitalization, please call your hospice office first!

Your hospice will want to discuss all available options and coordinate your needs with your physician. If you choose to have services, tests, or procedures related to your terminal illness without prior approval from your hospice, you may be responsible for payment of any costs incurred.

Have vital information ready.

Provide the following information when you call:

- Patient's name
- Your name
- Your phone number
- Reason for the call

Remain by the phone.

A nurse will respond to your emergency as soon as possible — usually within 10 minutes. Please remain by the phone until the nurse has returned your call. (If you have call-block, please remove it while your loved one is under hospice care.)

Be ready to answer questions.

The nurse will ask questions to assess the patient's needs and determine the most appropriate response to address those needs. If an after-hours visit is necessary, the nurse will send an after-hours team member to the patient's home as quickly as possible.

The patient's primary nurse will work with you to anticipate needed supplies, medication refills, etc., during regular working hours in order to free after-hours nurses' time for emergencies, such as those noted above.

Turn on the lights.

If an evening or night visit is required, turn on the outside light in preparation for clinician's arrival.

Your Family's Care Team

All members of our care team work together, utilizing their special training in hospice and palliative care, to meet the needs of the patient, his/her caregivers, and loved ones.

Patient's Attending Physician

Typically, the patient's attending physician informs the patient and his/her family of the life-limiting illness, makes a recommendation for hospice services, and orders the plan of care. Medications, treatments, therapies, and hospice services are ordered by this physician. There is on-going communication between the attending physician and the hospice team members, even when the patient is physically unable to visit his/her physician in the office.

Hospice Physician & Nurse Practitioners

Our physicians and nurse practitioners are responsible for coordinating activities between our organization and the local medical community, and for monitoring policies and standards for the medical aspect of our patient care program. In addition, these clinicians:

- Provide medical direction and support to the patient on a routine and 24-hour emergency basis;
- Participate in the development of the patient's individualized plan of care;
- Certify or recertify the patient's Medicare Hospice Benefit eligibility (physicians only);
- Act as consultants to the patient's attending physician;
- May serve as the patient's attending physician, if requested and allowed in the state you reside;
- Are available for home visits to assist in management of the patient's symptoms.

Nursing Team

A registered nurse visits the patient to conduct an evaluation for admission to hospice and to assess his/her physical status and comfort level. All services are explained, initial questions are answered, and any teaching needs are met. Consent forms are signed and symptom management is provided as needed. Initial needs for equipment, supplies, and medications are evaluated and orders are placed.

A designated registered nurse or licensed practical nurse visits the patient on a regular and emergency basis, to evaluate the comfort level, provide symptom management, and other care as needed. Ongoing needs for equipment and supplies are also evaluated and addressed. Symptom management and changes in the condition of the patient are discussed with a team physician, and changes in medications and the Plan of Care are made accordingly. Ongoing caregiver education is also provided.

Hospice Aide & Homemaker

A hospice aide helps the patient with bathing and personal care on a regular basis, as needed. Homemakers perform light housekeeping support as recommended by the patient's care team.

Medical Social Worker

A social worker counsels the patient and his/her caregiver and other loved ones in the home, hospital, or other facility. He/she provides emotional support, referrals to helpful community resources, and assists with communications with healthcare providers and caregivers. The patient's rights to receive and refuse treatments are clarified with the social worker's help.

Chaplain

A chaplain is available for non-denominational spiritual support and guidance that honors the patient's beliefs and values. In addition, volunteer chaplains and community clergy are available.

Grief & Loss Counselor

Our Counselors provide support throughout the grief experience, maintaining contact with the patient's caregivers and loved ones for up to one year after the death. They are also available at other times in the grief process, and to anyone in the community experiencing grief from loss.

Hospice Volunteer

Our volunteers play an integral role in the support we provide to the patient and their caregivers. They provide support and companionship, allow caregivers to have a break, read aloud, run errands and more. Those with special skills such as haircutting, landscaping, carpentry, cooking, music, and photography bring comfort to family members and add joy to the patient's life. Some even bring certified therapy pets for visits.

Each volunteer is carefully screened, receives thorough orientation about our programs and areas of care, and completes an intensive 12- hour training program that provides him/her with the education and resources needed to work confidently with our patients and their families. Volunteers support patients in their homes, long-term care communities, and our hospice houses.

An assessment of need for volunteer support is made by the patient's social worker. Volunteers are then assigned on both a "case-by-case" and "as-needed" basis. Our volunteers typically commit to a maximum of 2-4 hours per week. Generally, only one volunteer is assigned to a patient, and although we try to meet all volunteer support requests, there may be times when request cannot be accommodated.

After-Hours Team

A nurse is always available to handle after-hours emergencies. Once the nurse has assessed the problem, he or she may advise the patient or caregiver over the phone, or make a visit, to further evaluate and address the patient's needs. One of our medical practitioners, on-call for the attending physician, may also be consulted.

Our Commitment to Your Satisfaction

We are committed to providing high-quality care to patients and their families, and we appreciate feedback from the patients we serve as we continually strive to improve our performance. As a patient, you have the right to voice grievances regarding the care and services we provide, as well as the manner in which we provide it. You also have the right to not be subjected to discrimination or reprisal for exercising your right to voice concerns. If at any time during our service you would like to express a concern, complaint, or compliment, we encourage you to do so.

The process to voice any concerns, complaints or compliments is as follows:

- Contact your local branch;
- If you feel your concern or complaint is not resolved satisfactorily, contact customer service at **800-932-2738**;
- If you feel your concern or complaint is not resolved satisfactorily, contact the appropriate regulatory oversight agency. Please see Please see Section 3 of the supplement in this packet for state-specific contact information.

Upon receipt of all concerns or complaints, a thorough investigation is initiated, and the person registering the concern or complaint is contacted to ensure his or her issues have been satisfactorily addressed. All concerns, complaints, and ideas for improvement are reviewed by our Quality Assurance Department.

We also seek to improve our services by conducting periodic satisfaction surveys with our patients and their loved ones. When responding to our surveys, we hope you will offer honest feedback concerning ways we can improve our service. Your comments help us provide care that is sensitive to and addresses the needs and wishes of our patients and their families.

SHP
STRATEGIC HEALTHCARE PROGRAMS

Strategic Healthcare Programs (SHP) Survey

Primary caregivers may receive a survey regarding the care and services provided by our team. However, this survey does not come from us. It was developed by the Centers for Medicare & Medicaid Services (CMS) to measure and assess the hospice experiences of patients and their informal primary caregivers. It is mailed, collected, and submitted to CMS by an organization named Strategic Healthcare Programs (SHP). Hospices use this valuable feedback to continually improve processes and systems in order to consistently meet and exceed patient and family expectations. All primary caregivers who receive this survey are encouraged to participate.

Additional Resources

We Honor Veterans

To help provide care and support that reflect the important contributions made by these men and women, we have become a national partner of We Honor Veterans, a pioneering campaign developed by the National Hospice and Palliative Care Organization in collaboration with the Department of Veterans Affairs. The nation is seeing many of the veterans who served in World War II and the Korean War pass away—and the number of deaths of Vietnam veterans is beginning to rise.

As a We Honor Veterans Partner, we have obtained a Level Four Status with the VA-NHPCO Partnership. Partner Level One: We were recognized for intentionally providing veteran-centric education for staff and volunteers, and identifying patients with military experience. Partner Level Two: We were affirmed for building an organizational capacity to provide quality care for veterans. Partner Level Three: We continue to develop and strengthen relationships with VA medical centers and other veteran organizations. Partner Level Four: We have demonstrated a high level of commitment to veteran-centric care in the community.

The We Honor Veterans campaign provides tiered recognition to organizations that demonstrate a systematic commitment to improving care for Veterans. "Partners" can access their ability to serve Veterans, and using resources provided as part of the campaign, integrate best practices for providing end-of-life care to Veterans into their organization. By recognizing the unique needs of our nation's veterans who are facing a life-limiting illness, we are better able to accompany and guide veterans and their families toward a more peaceful ending. In cases where there might be some specific needs related to the veteran's military service, combat experience or other traumatic events, our teams will find tools to help support those they are caring for.

WE HONOR VETERANS

Inpatient Hospice Care

When a patient's symptom management requires greater medical care than can be provided at home, short-term, high-quality hospice care can be provided at inpatient hospice care locations. Typically, patients will only stay for skilled hospice care that enables them to return to their home setting or to die comfortably in place. While there, an experienced team of hospice professionals provides 24-hour comfort-oriented care. While not intended to replace home care, in some cases patients may stay at our inpatient hospice care locations after symptoms are managed, while discharge plans to home or another residential setting are finalized.

Contracted Services

We contract with licensed pharmacies, as well as physical, occupational, and speech therapists to participate on a patient's care team if such services are necessary.

Support Staff

The activities of the clinical staff are supported by other departments within the organization, such as Human Resources, Volunteer Services, Finance & Operations, Health Information Management, Information Systems, Development, Marketing & Community Awareness, and Quality Improvement.

The 11th Hour Team

Our 11th Hour Team provides an immediate response to the newly admitted patient who may be in the 11th hour of life, actively dying, or expected to soon pass away.

We have recognized the need to meet physicians on their own terms, and that some doctors may wait later, rather than sooner to refer a patient to hospice. This team will be assembled when appropriate and will consist of the following:

An RN case manager who is comfortable with medication titration and dealing with 11th hour patients.

A social worker who will quickly identify the family dynamics and any issues that may need to be resolved. The social worker will also assist with the final arrangements for the patient.

A bereavement coordinator and/or chaplain who will arrive to assist with anticipatory grieving and dealing with emotions related to the patient's decision to no longer seek aggressive treatment. A chaplain will provide spiritual care on the day of or the day after admission.

After admission, the patient will continue to be seen by each of the team members on a regular set schedule, along with CNAs, and visits from our 11th Hour volunteer services to help around the house and give the family some off time.

A comfort kit along with any durable medical equipment needed will be provided. The team will assist the family with information on local funeral homes and flower shops and any other services that will make the planning of the patient's funeral easier for the family. Our team will continue to offer grief support to the family, along with specialized grief support to children and teens.

Our team is here to support your patients and their families. **Please do not let your patients and families face the 11th hour of life alone. For more information, contact your local office. Contact information can be found in Section 3 of the supplement in this packet.**

Rights & Ethics

Standards of Conduct

All personnel are bound to comply, in all official duties and acts, with all applicable laws, rules, and standards of conduct; including, but not limited to, laws, rules, regulations, and directives of the federal government and the state.

All personnel are educated regarding the organization's code of conduct and are expected to uphold the provisions of the code. Any potential conflict of interest involving a team member will be examined and he/she will be excused from any decision-making process regarding the patient and/or the conflict.

Managers and supervisors are required to adequately instruct their team regarding the corporate compliance program, applicable policies, and legal requirements.

All personnel have an obligation to act within their professional discipline's scope and standards of practice.

All personnel, including volunteers, will receive education regarding confidentiality, and they will be expected to adhere to the organization's confidentiality policy.

Our Standards of Conduct include:

- Excellence in quality of care
- Compliance with laws and regulations
- Compliance with policy regarding billing and reimbursement
- Adherence to the highest ethical standards
- Maintenance and preservation of accurate records
- Compliance with marketing materials and practices
- Respect for the rights and dignity of others

Ethics Committee

Our Ethics Committee is a multidisciplinary group formed to enhance the quality of care for patients. It does so by providing a forum for identifying and addressing the complex medical, clinical, social, legal, and bioethical issues affecting the hospice community.

Corporate Compliance Oversight
The Board of Directors is committed to ensuring that individuals and entities associated with our company comply with all ethical, legal, and regulatory obligations, and that all services provided are consistent with accepted standards of practice.

As evidence of this commitment, the Board of Directors authorizes a comprehensive Corporate Compliance Program in order to detect, prevent, and correct any potential violations of law or regulation. In particular, the Corporate Compliance Program will respond to the areas of concern outlined in the Office of the Inspector General's Compliance Program Guidance for Hospices.

The Board of Directors commits sufficient financial and personnel resources to ensure the effectiveness of our Corporate Compliance Program. If you are interested in more information, or to contact the Ethics or Compliance Committee, please contact 844-962-1277.

Patient & Caregiver Nondiscrimination Statement

Our company does not discriminate against any patient or caregiver, as stated in the following:

Our company complies with applicable federal civil rights laws and does not discriminate, exclude or treat people differently on the basis of social status, political belief, sexual preference, race, color, religion, national origin, age, sex or disability with regard to admission, access to treatment, or employment.

Our company 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 our Vice President of Quality Assurances, who acts as our Civil Rights Coordinator.

If you believe we have failed to provide these services or discriminated in any other way, you may contact us in person or by mail or phone. If you need help filing a complaint, our Civil Rights/Section 1557 Coordinator is available to help: Vice President of Quality Assurance, 187 N. Church St. Suite 201 Spartanburg, SC 29306; phone: 844-962-1277.

It is the law for our company not to retaliate against anyone who opposes discrimination, files a discrimination-related complaint or who participates in the investigation of such complaint.

Discrimination-related complaints must be submitted to our company 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 the preponderance of evidence no later than 20 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 Chief Compliance Officer within 15 days. The Chief Compliance Officer will issue a written response within 30 days after its filing.

The availability and use of this grievance procedure do 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 Ave, SW Room 509F, HHH Building, Washington, D.C. 20201. Complaint forms are available at: https://www.hhs.gov/ocr/office/file/index.html
- Call 800-368-1019 (toll-free) or 800-537-7697 (TDD).

If you have any questions concerning this policy, or desire to file a complaint alleging violations of the above, please contact us at 844-962-1277.

Language Services

English: ATTENTION: If you speak English, language assistance services, free of charge, are available to you. Please call 844-962-1277.

Spanish: ATENCIÓN: Si habla español, hay servicios de asistencia de idiomas, sin cargo, a su disposición. Llame al 844-962-1277.

Chinese: 請注意：如果您說中文，我們免費為您提供語言協助服務。請致電：844-962-1277。

Vietnamese: XIN LƯU Ý: Nếu quý vị nói tiếng Việt, quý vị sẽ được cung cấp dịch vụ trợ giúp về ngôn ngữ miễn phí. Vui lòng gọi 844-962-1277.

Korean: 알림: 한국어를 사용하시는 경우 언어 지원 서비스를 무료로 이용하실 수 있습니다. 844-962-1277 번으로 전화하십시오.

Tagalong: PAUNAWA: Kung nagsasalita ka ng Tagalog, may makukuha kang mga libreng serbisyo ng tulong sa wika. Mangyaring tumawag sa 844-962-1277.

Russian: ВНИМАНИЕ: бесплатные услуги перевода доступны для людей, чей родной язык является русском. Позвоните по номеру 844-962-1277.

Arabic: تنبيه: إذا كنت تتحدث العربية، فإن خدمات المساعدة اللغوية المجانية متاحة لك. الرجاء الأتصال بـ 844-962-1277.

Haitian Creole: ATANSYON: Si w pale Kreyòl ayisyen, ou kapab benefisye sèvis ki gratis pou ede w nan lang pa w. Tanpri rele nan 844-962-1277.

French: ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Veuillez appeler le 844-962-1277.

Polish: UWAGA: Jeżeli mówisz po polsku, udostępniliśmy darmowe usługi tłumacza. Prosimy zadzwonić pod numer 844-962-1277.

Portuguese: ATENCÃO: Se você fala português, contate o serviço de assistência de idiomas gratuito. Ligue para 844-962-1277.

Italian: ATTENZIONE: in caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Si prega di chiamare il numero 844-962-1277.

German: ACHTUNG: Falls Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie 844-962-1277 an.

Japanese: 注意事項：日本語を話される場合、無料の言語支援サービスをご利用いただけます。844-962-1277 にお電話ください。

Farsi: توجه: اگر زبان شما فارسی است، خدمات امداد زبانی به طور رایگان در اختیار شما می باشد. 844-962-1277 تماس بگیرید.

Hindi: ध्यान दें: यदि आप हिंदी बोलते है, आपको भाषा सहायता सेबाएं, नि:शुल्क उपलब्ध हैं। कृपया 844-962-1277 पर कॉल करें।

Hmong: CEEB TOOM: Yog koj hais Lus Hmoob, muaj kev pab txhais lus pub dawb rau koj. Thov hu rau 844-962-1277.

Khmer: ចំណាប់អារម្មណ៍: បើសិនអ្នកនិយាយភាសាខ្មែរសេវាជំនួយភាសាដោយឥតគិតថ្លៃ គឺមានសំរាប់អ្នក។ សូមទូរស័ព្ទទៅលេខ 844-962-1277។

Ilocano: PAKDAAR: Nu saritaem ti Ilocano, ti serbisyo para ti baddang ti lengguahe nga awanan bayadna, ket sidadaan para kenyam. Maidawat nga awagan iti 844-962-1277.

Navajo: DÍÍ BAA’ÁKONÍNÍZIN: Diné bizaad bee yáníłti’go, saad bee áka’anída’awo’ígíí, t’áá jíík’eh, bee ná’ahóót’i’. T’áá shoodí kohjį’ 844-962-1277 hodíilnih.

Somali: OGOW: Haddii aad ku hadasho Soomaali, adeegyada taageerada luqadda, oo bilaash ah, ayaad heli kartaa. Fadlan wac 844-962-1277.

Notice of Privacy Practices For Protected Health Information

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

Our company is required by law to maintain the privacy of protected health information, to provide you adequate notice of your rights and our legal duties and privacy practices with respect to protected health information and to notify affected individuals following a breach of unsecured protected health information. [45 CFR § 164.520] We will use or disclose protected health information in a manner that is consistent with this notice.

We maintain a record (paper/electronic file) of the information we receive and collect about you and of the care we provide to you. This record includes physicians' orders, assessments, medication lists, clinical progress notes and billing information.

As required by law, the company maintains policies and procedures about our work practices, including how we coordinate care and services provided to our patients. These policies and procedures include how we create, receive, access, transmit, maintain and protect the confidentiality of all health information in our workforce and with contracted business associates and/or subcontractors; security of the agency building and electronic files; and how we educate staff on privacy of patient information.

As our patient, information about you must be used and disclosed to other parties for purposes of **treatment, payment and health care operations**. Examples of information that must be disclosed:

Treatment: Providing, coordinating or managing health care and related services, consultation between health care providers relating to a patient or referral of a patient for health care from one provider to another. For example, we meet on a regular basis to discuss how to coordinate care for patients and to schedule visits.

Payment: Billing and collecting for services provided, determining plan eligibility and coverage, utilization review (UR), precertification, medical necessity review. For example, occasionally the insurance company requests a copy of the medical record be sent to them for a coverage review prior to paying the bill.

Health Care Operations: General agency administrative and business functions, quality assurance/improvement activities; medical review; auditing functions; developing clinical guidelines; determining the competence or qualifications of health care professionals; evaluating agency performance; conducting training programs with students or new employees; licensing, survey, certification, accreditation and credentialing activities; internal auditing; and certain fundraising activities and with your authorization, marketing activities. For example, our agency periodically holds clinical record review meetings where the consulting professional of our record review committee will audit clinical records for meeting professional standards and utilization review.

Privacy Practices, (Cont.)

The following uses and disclosures do not require your consent, and include, but are not limited to, a release of information contained in financial records and/or medical records, including information concerning communicable diseases such as Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome {AIDS), drug/alcohol abuse, psychiatric diagnosis and treatment records and/or laboratory test results, medical history, treatment progress and/or any other related information as permitted by state law to:

1. Your insurance company, self-funded or third-party health plan, Medicare, Medicaid or any other person or entity that may be responsible for paying or processing for payment any portion of your bill for services;
2. Any person or entity affiliated with or representing us for purposes of administration, billing and quality and risk management;
3. Any hospital, nursing home or other health care facility to which you may be admitted;
4. Any assisted living or personal care facility of which you are a resident;
5. Any physician providing you care;
6. Licensing and accrediting bodies;
7. Contact you to raise funds for the Agency; you will be given the right to opt out of receiving such communications;
8. Any business associate or institutionally related foundation for the purpose of raising funds for the agency (information may include: demographics - name, address, contact information, age, gender, date of birth; dates of health care provided; department of services; treating physician; outcome information; and health insurance status). You will be given the right to opt out;
9. Refill reminders for drugs, biologicals and/or drug delivery systems that have already been prescribed to you;
10. Marketing communications promoting health products, services and information if the communication is made face to face with you or the only financial gain consists of a promotional gift of nominal value provided by the agency; and
11. Other health care providers to initiate treatment.

We are permitted to use or disclose information about you without consent or authorization in the following circumstances:

1. **In emergency treatment situations**, if we attempt to obtain consent as soon as practicable after treatment;
2. Where **substantial barriers to communicating with you** exist and we determine that the consent is clearly inferred from the circumstances;
3. Where we are **required by law** to provide treatment and we are unable to obtain consent;
4. Where the use or disclosure of medical information about you is **required by federal, state or local law**;
5. To provide information **to state or federal public health authorities**, as required by law to: prevent or control disease, injury or disability; report births and deaths; report child abuse or neglect; report reactions to medications or problems with products; notify persons of recalls of products they may be using; notify a person who may have been exposed to a disease or may be at risk for contracting or spreading a disease or condition; and notify the appropriate government authority if we believe a patient has been the victim of abuse, neglect or domestic violence (if you agree or when required or authorized by law);
6. **Health care oversight activities** such as audits, investigations, inspections and licensure by a government health oversight agency as authorized by law to monitor the health care system, government programs and compliance with civil rights laws;
7. **To business associates** regulated under HIPAA that work on our behalf under a contract that requires appropriate safeguards of protected health information;
8. **Certain judicial administrative proceedings** in response to a court or administrative order, a subpoena, discovery request or other lawful process by someone else involved in the dispute, but only if efforts have been made to tell you about the request or to obtain an order from the Court protecting the information requested;
9. **Certain law enforcement purposes** such as helping to determine whether a crime has occurred, to alert law

enforcement to a crime on our premises or of your death if we suspect it resulted from criminal conduct, identify or locate a suspect, fugitive, material witness or missing person, or to comply with a court order or subpoena and other law enforcement purposes;

10. **To coroners, medical examiners and funeral directors,** in certain circumstances, for example, to identify a deceased person, determine the cause of death or to assist in carrying out their duties;
11. **For cadaveric organ, eye or tissue donation purposes** to communicate to organizations involved in procuring, banking or transplanting organs and tissues (e.g., if you are an organ donor);
12. **For certain research purposes** under very select circumstances. We may use your health information for research. Before we disclose any of your health information for such research purposes, the project will be subject to an extensive approval process. We will usually request your written authorization before granting access to your individually identifiable health information;
13. **To avert a serious threat to health and safety:** To prevent or lessen a serious and imminent threat to the health or safety of a particular person or the general public, such as when a person admits to participation in a violent crime or serious harm to a victim or is an escaped convict. Any disclosure, however, would only be to someone able to help prevent the threat; For specialized government functions, including military and veterans' activities, national security and intelligence activities, protective services for the President, foreign heads of state and others, medical suitability determinations, correctional institution and custodial situations; and
14. **For Workers' Compensation purposes:** Workers' compensation or similar programs provide benefits for work-related injuries or illness.

We are permitted to use or disclose protected health information about you provided you are informed in advance and given the opportunity to individually agree to, prohibit, opt out or restrict the disclosure in the following circumstances.

1. Use of a directory (name, location, condition described in general terms) of individuals served by our Agency;
2. Share information to a public or private entity authorized by law or by its charter to assist in disaster relief efforts for purposes of notifying your family, personal representatives or certain others of your location or general condition;
3. Provide proof of immunization to a school that is required by state or other law to have such proof with agreement to disclosure by parent, guardian or other person acting in loco parentis if record is of an unemancipated minor; and
4. Provide a family member, relative, friend or other identified person, prior to, or after your death, the information relevant to such person's involvement in your care or payment for care; to notify a family member, relative, friend or other identified person of your location, general condition or death.

Other uses and disclosures not covered in this notice will be made only with your authorization. Authorization may be revoked, in writing, at any time, except in limited situations for the following disclosures:

1. Marketing of products or services or treatment alternatives that may be of benefit to you when we receive direct payment from a third party for making such communications;
2. Psychotherapy notes under most circumstances, if applicable; and
3. Any sale of protected health information resulting in financial gain by the agency unless an exception is met.

Privacy Practices, (Cont.)

YOUR RIGHTS - You have the right, subject to certain conditions, to:

- **Request restrictions on uses and disclosures of your protected health information** for treatment, payment or health care operations. However, we are not required to agree to any requested restriction. Restrictions to which we agree will be documented. Agreements for further restrictions may, however be terminated under applicable circumstances (e.g., emergency treatment).

  We must agree to your request to restrict disclosure of protected health information about you to a health plan if: 1) the disclosure is for the purpose of carrying out payment or health care operations and is not otherwise required bylaw; and 2) the protected health information pertains solely to a health care item or service for which you or someone on your behalf paid the covered entity in full. (164.522 Rights to request privacy protection for protected health information).
- **Confidential communication of protected health information**. We will arrange for you to receive protected health information by reasonable alternative means or at alternative locations. Your request must be in writing. We do not require an explanation for the request as a condition of providing communications on a confidential basis and will attempt to honor reasonable requests for confidential communications. If you request your protected health information to be transmitted directly to another person designated by you, your written request must be signed and clearly identify the designated person and where the copy of protected health information is to be sent.
- **Inspect and obtain copies of protected health information** that is maintained in a designated record set, except for psychotherapy notes, information compiled in reasonable anticipation of, or for use in, a civil, criminal or administrative action or proceeding, or protected health information that may not be disclosed under the Clinical Laboratory Improvements Amendments of 1988 [42 USC§ 263a and 45 CFR § 493 (a)(2)]. If you request a copy of your health information, we will charge a reasonable, cost-based fee that includes only the cost of labor for copying, supplies and postage, if applicable, in accordance with applicable state and federal regulations. If the requested protected health information is maintained electronically and you request an electronic copy, we will provide access in an electronic format you request, if readily producible, or if not, in a readable electronic form and format mutually agreed upon. If we deny access to protected health information, you will receive a timely, written denial in plain language that explains the basis for the denial, your review rights and an explanation of how to exercise those rights. I/we do not maintain the medical record, we will tell you where to request the protected health information.
- **Request to amend protected health information** for as long as the protected health information is maintained in the designated record set. A request to amend your record must be in writing and must include a reason to support the requested amendment. We will act on your request within sixty (60) days of receipt of the request. We may extend the time for such action by up to 30 days, if we provide you with a written explanation of the reasons for the delay and the date by which we will complete action on the request. We may deny the request for amendment if the information contained in the record was not created by us, unless you provide a reasonable basis for believing the originator of the information is no longer available to act on the requested amendment; is not part of the designated medical record set; would not be available for inspection under applicable laws and regulations; or the record is accurate and complete. If we deny your request for amendment, you will receive a timely, written denial in plain language that explains the basis for the denial, your rights to submit a statement disagreeing with the denial and an explanation of how to submit that statement.•	Receive an accounting of disclosures of protected health information made by our Agency for up to six (6) years prior to the date on which the accounting is requested for any reason other than for treatment, payment or health operations and other applicable exceptions. The written accounting includes the date of each disclosure, the name/address (if known) of the entity or person who received the protected health information, a brief description of the information disclosed and a brief statement of the purpose of the disclosure or a copy of the written request for disclosure. We will provide the accountings within 60 days of receipt of a written request. However, we may extend the time period for providing the accounting by 30 days if we provide you with a written statement of the reasons for the delay and the date by which you will receive the information. We will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

Privacy Practices, (Cont.)

- **Receive notification of any breach in the acquisition, access, use or disclosure** of unsecured protected health information by the agency, its business associates and/or subcontractors.
- **Obtain a paper copy of this notice**, even if you had agreed to receive this notice electronically, from us upon request

COMPLAINTS - If you believe that your privacy rights have been violated, you may complain to the Agency or to the Secretary of the U.S. Department of Health and Human Services. There will be no retaliation against you for filing a complaint. The complaint should be filed inwriting and should state the specific incident(s) in terms of subject, date and other relevant matters. A complaint to the Secretary must be filed in writing within 180 days of when the act or omission complained of occurred and must describe the acts or omissions believed to be in violation of applicable requirements. [45 CFR §160.306] For further information regarding filing a complaint, contact: **Chief Compliance Officer, 187 N. Church Street, Suite 201, Spartanburg, SC 29306; Phone: 800-932-2738.**

EFFECTIVE DATE – This notice is effective December 6, 2022. We are required to abide by the terms of the notice currently in effect, but we reserve the right to change these terms as necessary for all protected health information that we maintain. If we change the terms of this notice (while you are receiving service), we will promptly revise and distribute a revised notice to you as soon as practicable by mail, email (if you have agreed to electronic notice), hand delivery or by posting on our website.

If you require further information about matters covered by this notice, please contact: Chief Compliance Officer, 187 N. Church Street, Suite 201, Spartanburg, SC 29306; Phone: 800-932-2738.

Patient Care

Pain

Pain is a manageable symptom, and we support the philosophy that all patients have the right to pain relief. Every person experiences pain differently, and pain tolerance levels vary from individual to individual. Our goal is to provide adequate pain control to the patient to ensure maximum comfort and quality of life.

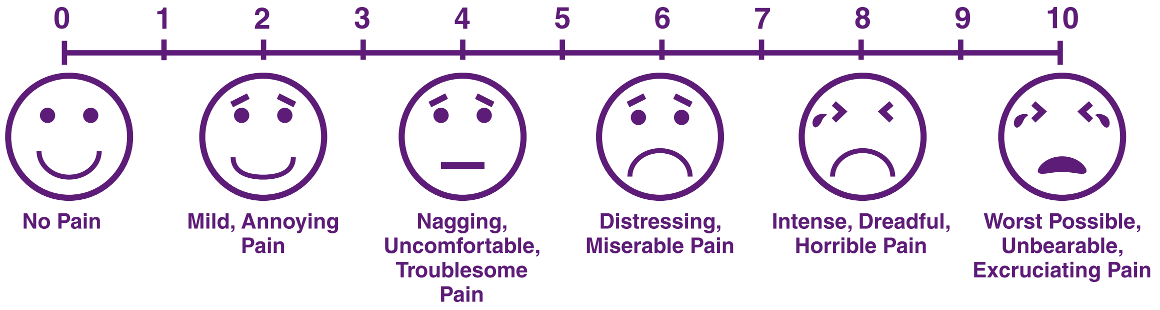
Fear of pain and suffering is a common symptom experienced by patients at the end of life. The care team nurse will discuss individual goals of care for pain management and will assist with identifying strategies to help meet those goals. He/she will regularly evaluate pain, provide the appropriate medications to control the pain, and instruct patients and caregivers on the proper use of pain medications.

When taking adequate doses of pain medication, there may be times when the patient is not fully alert, and some patients may choose to endure a certain amount of pain in order to remain alert. Some patients and caregivers also express concerns regarding the use of pain medications and the possibility of addiction. Addiction is not a concern in the treatment of pain in patients with life-limiting, progressive, or terminal illness. In fact, the patient in pain who seems to be craving medication is probably experiencing inadequate pain relief.

The patient’s care team nurse will work with you to answer questions regarding pain medication management and any other concerns that you may have and will review medications weekly to ensure an adequate supply of pain medication is available.

Tips on pain management for the caregiver:

- Give the pain medicine at the first sign or complaint of pain. Do not wait for pain to go away.
- Use breakthrough pain medication for pain that occurs in between doses of long-lasting medications or when using a pain patch. If pain is still occurring 30 minutes after taking the breakthrough medication, call and ask to speak to your care team nurse.
- If movement causes pain, give pain medicine approximately 30 minutes before any planned activity, like a bath or physician appointment.
- Believe the patient when he/she says there is pain and acknowledge it to the patient.
- The patient cannot always tell you there is pain. Look for signs of pain like frowning, moaning, restlessness, agitation, or withdrawal.
- Have the patient use the Pain Scale below when evaluating pain:
- When the patient is in pain he/she may not always want someone nearby. Limit visitors, dim the lights, keep room temperature comfortable, and let the patient rest or sleep.



- Encourage slow, deep breaths. Remind the patient that relaxing can help while the medicine begins to work. Listening to soft music with closed eyes may also help.
- If the patient likes touch, offer to hold his/her hand or gently massage the hands or feet. Reassure the patient that improvement in the pain is coming.
- Read the directions carefully on all pain medicine. If directions say to give 1-2 pills and you have only given one, yet the patient still has pain after 20-30 minutes, give the second pill. If pain continues after the second pill, call your care team nurse.
- Keep record of when you give the pain medicine. This information is helpful when the nurse visits, to determine if a different or stronger medicine might be needed.
- Pain medicines might cause: constipation, dry mouth, confusion, nausea, or a sleepy feeling. Call the nurse if any of these symptoms become a problem. (See specific sections for guidelines to follow.)
- Call the nurse immediately if the patient begins to have difficulty swallowing pain medicine so other options for pain relief can be used.
- Remember, it is important for caregivers to stay as relaxed as possible. Patients can pick up on a caregiver's nervousness.
- Take needed doses of pain medication for the patient with you whenever you leave home.
- Make sure the patient takes pain medication on a regular schedule, as ordered by your physician and instructed by your nurse.
- Notify your care team nurse if medication supply is getting low.
- Always report pain, unrelieved by medication, to your care team nurse.

Nutrition & Eating

One of the most common problems with life-limiting conditions is loss of appetite. Taste changes, nausea and vomiting, depression, and the dying process can contribute to a lack of interest in food. This is very distressing for caregivers and is painful to watch.

The body uses food for life energy. As the body prepares for death, food and drink are the first things it gives up. This is a natural process and should be expected. It is not uncommon for patients to give up all food and drink for days, or even weeks, before death occurs.

As the caregiver, continue to gently offer food and fluids frequently, but never force food. Trying to force food or constantly talking about how little the patient is eating will only add to the patient's and your own stress. Your care team nurse may ask a dietitian for help with special nutritional problems.

Helpful hints to stimulate eating:

- Avoid extremes in temperature of foods.
- Prepare foods in the morning. Strong cooking odors may increase nausea.
- Ensure good ventilation when preparing foods with strong odors.
- Use small plates and glasses.
- Use plastic eating utensils if metallic taste is an issue for the patient.
- Keep a variety of high calorie, nutritional food on a small plate for patient snacks.
- Offer a variety of favorite juices, ice cream, or drinks that contain calories and nutrition.
- Offer small portions frequently. Keep foods simple and easy to chew and swallow. If taste is decreased, sweet or tart foods and the addition of herbs or agreeable spices may help.
- Make food as attractive as possible.
- Offer liquid breakfast drinks or canned supplements if appropriate.
- Ask the patient to rinse his/her mouth frequently.
- Encourage and/or assist with oral care.
- Keep the patient's favorite foods frozen and in portions easy to prepare. Be understanding and tolerant if favorite foods are refused. (The patient may ask for a special food item, and then eat only one or two bites.)

Nausea & Vomiting

Nausea with or without vomiting is unpleasant, but can be controlled by the following steps:

Look for the cause:

- The disease itself
- Constipation
- Pain medication
- Medicine taken on an empty stomach

Correct the cause if possible:

- Give the medication on a regular schedule to relieve symptoms, 45 minutes before eating or drinking, beginning early in the day.
- Avoid foods that seem to trigger nausea.
- Eliminate unpleasant odors.
- Avoid cooking strong-smelling foods without good ventilation.
- Avoid constipation. (See Constipation.)

Tips:

- Provide good mouth care; brush the patient’s teeth and tongue frequently during the day.
- Offer popsicles, gelatin, or frozen juices.
- Avoid offering excessive sweets or fatty foods.
- Have the patient sip cool, clear fluids.
- Have the patient eat toast or crackers, and then progress to small meals.
- Give nausea medication 45 minutes prior to giving a laxative.
- Have the patient drink additional fluids after nausea medication has taken effect.
- Have the patient avoid excessive movement.
- Provide small, frequent meals.
- If nausea and vomiting occur only in the morning, offer crackers or toast 20-30 minutes before regular medication is given. If the patient takes a large number of daily medications in the morning, the nurse may suggest giving some later in the day.
- During times of nausea, offer attractive, light foods such as fruits or salads, and avoid heavy foods that contain gravy or cheese.

Report nausea and vomiting, unrelieved by medication, to the care team nurse.

Skin Care

Changes in the skin are often concerning to the patient and the caregiver. Early recognition and prevention of problems are key factors.

Look for the cause:

- Decreased appetite
- Decreased fluid intake
- Decreased mobility

Correct the cause if possible:

- Offer more fluids. Juices and vegetable drinks provide vitamins and minerals.
- Offer foods high in calories and nutrition.
- Examine the patient’s body daily for blisters, red areas, cracks, or tears.
- Report the first signs of breakdown to your care team nurse.
- Reduce pressure on bony areas as often as possible.

Pressure areas or bedsores can develop rapidly. Use the following example to understand how this breakdown of the skin occurs. Place a clear glass or plate on your fingertip. The weight of the object blanches or forces the blood out of the fingertips, just as the weight of the body presses against the bed. The oxygen carrying blood is not available to the skin tissues and it begins to break down. Frequent areas of skin breakdown include ears, spine, elbows, hips, ankles, and heels.

Daily Care:

- Keep the patient’s skin clean and dry.
- Avoid over-padding the foam mattress.
- Use a flat sheet folded in half or quartered (draw sheet) under the trunk of the body to turn and position.
- Smooth wrinkles from sheets.
- To provide comfort and reduce skin irritation, turn the patient every two hours or remind the patient to turn during waking hours.
- Use pillows to support the patient’s arms, legs, and back.
- Use lotions containing lanolin to replace moisture loss due to reduced fluid intake.
- Report all changes in the skin to the nurse.

Excessive perspiration may or may not follow a fever. Change pajamas and sheets as needed. Wipe the patient’s skin with a dry, cool cloth. Comb damp hair away from the patient’s face and turn damp pillows to help provide comfort.

Mouth Care

Frequent mouth care may improve the taste of foods and liquids. Use a soft toothbrush or a soft cloth wrapped around a finger to provide the best cleaning results. While disposable foam-covered sticks may also be used, a toothbrush dipped in warm water will do a better job of a cleaning the teeth, gums, and tongue.

Daily Care:

- Remove the patient's dentures regularly for cleaning, or if gums and mouth are sore.
- Weight loss may require relining of dentures to avoid rubs and abrasions.
- Frequent antibiotic use can result in thrush, a condition that causes soreness and white patches. Eating yogurt daily replaces the "good" bacteria lost when taking antibiotics.
- Keep the patient's lips moist with use of lip balm.

Dry Mouth:

- Have the patient sip on fruit juices.
- Offer foods high in water content (well-cooked vegetables, canned fruits, gravies, or sauces).
- Have the patient suck on hard candy or popsicles.
- If dry mouth is severe, a saliva substitute may be needed. Ask your care team nurse.

Sore Mouth:

- Report any soreness to your care team nurse for treatment.
- Avoid offering salty or tart foods, crackers, or hard foods that may cut or rub sore areas. Also avoid offering extremely hot or cold food or liquids.
- Offer regular yogurt daily to replace good bacteria if thrush is present.
- Avoid acidic food and beverages such as orange juice, tomato juice, and citrus fruits.
- Have the patient use a straw to prevent liquids from coming in contact with sores.

Report to the Nurse:

- Sore mouth
- White patches in the mouth

Elimination

Changes in urination and bowel movements can be embarrassing and frustrating for the patient and the caregiver. It often is viewed by the patient as a loss of control, not only of their body functions but of their life. A caring and supportive attitude by the caregiver lessens the feeling of helplessness.

Use of bedside commode, bedpan, or urinal may be needed as weakness increases. A catheter may be inserted for urinary incontinence or the inability to urinate. Incontinence pads or briefs are available to protect the patient and the bed from getting soiled.

Tips:

- Wear gloves when handling the bedpan, urinal, or emptying a bedside commode.
- Offer as much privacy as possible while maintaining patient safety.
- Use talcum powder on the edges of the bedpan.
- Raise the head of the bed while the patient is on the bedpan.
- Keep 1/2” to 1” of water in the bedside commode (a few drops of dish detergent in the water lessons soiling and makes rinsing easier).
- Rinse the urinal twice between use and keep it within the patient’s reach.
- Notify the care team nurse if the patient is unable to urinate for 12 or more hours, or if the lower abdomen is swollen or painful.
- Dark, small amounts of urine are a sign that the patient is drinking less.
- Record bowel movements and report if they seem hard or painful to the patient.

Constipation

Changes in bowel elimination may occur with illness. This may cause discomfort, embarrassment, and frustration. Early intervention is the key to avoiding this common problem.

Look for the cause:

- Medications (especially pain medication)
- Changes in diet
- Decreased physical activity
- Decreased fluid intake
- Disease process

Correct the cause if possible:

- Offer more fruit and fiber. (Note. High fiber foods will not decrease constipation without adequate fluid intake.)
- Increase the patient’s fluid intake, especially apple juice and water.
- Avoid offering foods that may be constipating, such as cheese, peanut butter, and bananas. (These may vary with individuals.)
- Keep a record for two days to get a clear idea of how much the patient drinks.
- Do not decrease pain medications to avoid constipation. A natural stool softener and laxative can be ordered and the dosage increased as pain medication is increased.

For unrelieved constipation:

- Give the patient 2-4 tablets, morning and night, of Senokot-S or generic brand (if ordered by your physician). **Remember, fluids are needed to aid the effectiveness of all laxatives.**
- If there is no bowel movement in 72 hours, notify your care team nurse. The nurse will advise you of any additional measures to take

Diarrhea

Frequent, watery stool, often with abdominal cramping, is distressing to the patient. Your care team nurse will help identify the cause. Review all facts with your nurse before offering medication for diarrhea. Forceful liquid stools may signal a bowel impaction if the patient has been constipated or has had small, hard stools. Occasionally the patient may be sensitive to a daily laxative/stool softener. A change in the dosage is more effective than stopping medication or giving another medication.

Tips:

- Offer more fluids frequently. Avoid caffeine (found in coffee, tea, and soft drinks).
- Review the patient's food intake and avoid foods known to stimulate the bowels (excessive intake of fruits or fruit juices, greens, milk or milkshakes, nuts, corn).
- If diarrhea continues for more than two hours, give fluids only, and in small amounts.
- Clean the rectal area and wash your hands, and the patient's hands, after each movement.
- Report blood (red or black) or blood odor to your care team nurse.

Urinary (Foley) Catheter

If needed, a urinary catheter will be inserted to continuously empty the bladder. It is held in place by a small balloon inflated at the end of the tubing, inside the bladder. Your care team nurse will insert the catheter.

Daily Care:

- Wear gloves when providing any kind of catheter care.
- Avoid tugging or pulling on the tubing.
- Wash around the tubing one or two times a day with warm, soapy water; rinse and dry.
- Keep the drainage bag below the level of the bladder at all times.
- Avoid touching the tip of the drainage bag when emptying it.
- Empty the drainage bag in the morning and evening.
- Avoid resting the drainage bag on the floor.

Report to the Nurse:

- Any strong urine odor (offer more fluids as appropriate)
- If the urine is not draining into the bag
- Urine that is leaking around catheter tubing
- Blood in the urine
- Pain and fullness in the patient's lower abdomen
- If the catheter accidentally comes out, and look for bleeding if the balloon is still inflated

A decrease in the amount of urine or a change in the color of urine is a normal part of the disease process.

Dizziness

Dizziness may result from many causes. Suggestions to help manage dizziness include:

- Have the patient rise out of bed slowly, allowing his/her feet to dangle at the side of the bed first for a few minutes.
- Change the patient's position slowly.
- Have the patient use a cane or walker if needed.
- Have the patient avoid activities like driving, cooking, handling machinery, etc., if he/she is dizzy, drowsy, or very tired.
- Encourage fluid intake if the patient is able.
- Encourage frequent rest periods to conserve energy.

Breathing

Shortness of breath may occur. This is often related to increased weakness. With less activity and longer periods in bed, a patient's breathing may become shallower, and congestion may cause a rattling sound in the throat and lungs. As time passes, you may see the rate and rhythm of breathing change. You may notice pauses between breaths and the rate of breaths may vary between six and forty breaths a minute.

Tips:

- Remain calm; this will help keep the patient from becoming more anxious and possibly more short of breath.
- Encourage slow, deep breathing.
- Plan activities that will decrease exertion.
- Changes in position will promote comfort and may reduce congestion.
- Raise head off the bed.
- Using a small fan may help the patient feel the sensation of moving air.
- A cooler room often helps.
- Place a cool, moist cloth to the patient's forehead and cheeks.
- Good pain control helps a person to breathe easier. Your care team nurse can assist you with this.
- Medications to manage anxiety can also help breathing. Your care team nurse can assist you with this.
- Play music that the patient enjoys, or find other relaxing activities to do with the patient.
- Turn off bright lights and limit additional noise.
- Sit with the patient and provide calm, quiet reassurance through your presence.
- For thick phlegm, hot tea with lemon may be helpful.
- Report fever or green phlegm to the nurse.

Safety in the Home

Safety In the Home

An unsafe home can result in unnecessary injury or harm such as broken bones, burns, or loss of property. By following simple safety measures, these risks may be reduced.

Preparing for Emergencies

- Post emergency numbers by each phone.
- Let neighbors know you may need help during an emergency.
- Have a battery-powered radio and extra batteries, or a neighbor to keep you informed.
- Keep a working flashlight and extra batteries handy.
- Keep a bell or whistle and a flashlight near the patient's bed.
- Register with your utility company as a priority user during power outages, when oxygen is in use.
- Post medical instructions (such as Do Not Resuscitate) on your refrigerator in an easy-to-see spot.
- Prepare an emergency exit plan. (See below.)

Emergency Exit Plan

- Have an emergency exit plan and practice it periodically. Your social worker can help you develop this escape plan.
- Make sure to indicate at least two escape routes from each room.
- If someone in your home uses a wheelchair, make more than one exit from your home wheelchair-accessible in case the primary exit is blocked in a disaster.
- Keep doors free from obstructions.

Fire Safety Tips

- Keep a fire extinguisher in working order and in a convenient location.
- Never allow anyone to smoke in bed.
- Keep all flames away from oxygen. Never smoke around oxygen.
- Notify the fire department that there is a patient in the home.
- Call your local fire department if you have questions.

Smoke Detectors

- Install smoke detectors and replace batteries according to manufacturer's recommendations. All homes should have smoke detectors in working order.
- Check your smoke detector twice a year. Test it according to manufacturer directions.
- Place smoke detectors near your bedroom, on the ceiling, or on the wall, six to twelve inches below the ceiling.
- Place smoke detectors away from air vents.

Heat Sources

- Never leave cooking stoves, kerosene heaters, wood stoves, or fireplaces unattended while in use.
- Do not keep flammable materials (curtains, towels, loose clothing) within three feet of space heaters and stoves.
- Use caution if you wear long, loose-sleeved clothing when cooking. Robes or sweaters can catch fire.
- Keep space heaters away from furniture, curtains, rugs, and line of traffic.
- When using a wood stove, use correct fuel and vent it properly.

Storage Areas

- Store items such as gasoline and paint in their proper containers, away from heat sources and out of the reach of children.
- Do not stockpile old papers or clothes.
- Place most frequently used items on lower shelves.

Electrical

- Do not overload extension cords or outlets.
- Replace or repair damaged cords and plugs.
- Never rest anything on top of electrical cords.
- All unused wall outlets should be plugged with covers.
- Do not operate electrical appliances near water.
- Turn off all electrical equipment when not in use.
- Keep electrical cords in good condition. Discard if frayed or cracked.
- Use extension cords that can carry sufficient amperage or wattage for appliances (most cords are for 1250 watts).
- Keep lamps, extension cords, and telephone cords out of the flow of traffic.
- Keep cords out from beneath furniture and rugs or carpeting.

Oxygen Safety

Here are some tips to use your oxygen equipment safely and effectively:

- Oxygen does not burn, but it does support combustion, so anything that can burn will burn much faster in an oxygen-rich environment.
- Oxygen should never be used near an open flame or anything that can produce intense heat, flames or sparks, such as a burning cigarette, a lighted match, heaters, heating pads, hairdryers, a stove or pilot light. Anything that can produce hot flames or sparks during operation should be kept at least 15 feet away from your oxygen equipment. The highest safe temperature for an oxygen tank is 125 degrees Fahrenheit.
- Do not use oil, grease, Vaseline or any other flammable substance on your oxygen equipment or

on your skin near the equipment. Use water-based products only.

- Store cylinders in an upright position and secured in an approved cart or other storage device.
- If you are using a humidifier, use only the recommended type and amount of water. Due to increase in back pressure and resistance to flow, disposable humidifier bottles should not be used for oxygen flows greater than 6 liters per minute. There are humidifier bottles available for higher oxygen flows.

Durable Medical Equipment

We will provide durable medical equipment (DME) related to the palliation and management of the terminal illness and related conditions, as identified in the hospice plan of care. There are many different types of DME available to ensure independence for individuals with life-long support requirements or short-term recovery needs. They range from complex medical equipment like oxygen concentrators and low air loss mattresses to simple assistive devices like walkers or wheelchairs.

- Closely follow instructions that accompany any medical equipment placed in your home.
- Your care team can answer any questions you may have regarding medical equipment.

Emergency Preparedness

Be alert and prepared for threatening storm conditions, hurricanes, tornadoes, thunderstorms, winter storms, or other civil disasters.

Be Prepared

- Plan ahead for possible storm conditions by knowing where you will be safest.
- Assemble and keep your own “Portable Disaster Kit” (identification papers/valuable paper documents, medicine, personal hygiene products, portable radio, flashlight, batteries, bedding, clothing, plastic bags, rope or twine, candles, kerosene lamp, lighter).
- Listen to your local radio and television stations for National Weather Advisories.
- Follow direction from National Weather Service and local authorities regarding preparing for storms and/or evacuation instructions.
- Local government will open shelters as they are needed. Please note that shelters do not allow pets, so plan to protect them in another way.
- Listen to your radio for announcements regarding openings and closings of local businesses, shelters, etc.
- Remain inside unless otherwise directed.
- Fill containers, bathtub, and indoor washing machine with clean water.
- Secure awnings and outdoor furniture.
- Fill the gas tank of your car, and park it in a garage or away from trees and utility poles.
- Have identification.

Emergency Disaster Information Guidelines for Emergency Management

DURING ANY OF THE BELOW LISTED EMERGENCIES, IMMEDIATELY CONTACT US FOR INFORMATION AND DIRECTIONS CONCERNING YOUR NEEDS AND CARE.

Severe Weather/Earthquakes

- Have emergency equipment and medical supplies readily available.
- Close all drapes.
- Move away from windows.
- CLOSE exit doors.
- Go to inside room of building with no windows, if available.
- Do not enter damaged portions of the building until instructed.
- Monitor weather bulletins/radio announcements.
- Do not exit building until instructed.

Hurricanes/Tornadoes

Have emergency equipment and medical supplies readily available.

- Close all drapes.
- Move away from windows.
- CLOSE exit doors.
- Go to inside room of building with no windows, if available.
- In the event of severe winds caused from the Hurricane/Tornado, go to an interior bathroom, get in the bathtub, and cover with a mattress for safety from debris.
- Do not enter damaged portions of the building until instructed.
- Monitor weather bulletins/radio announcements.
- Do not exit building until instructed.

After the Event

- Do not enter the building until an all-clear has been given.
- Do not use any open flame devices until the building has been inspected for possible gas leaks.
- Do not turn on any electrical equipment that may have gotten wet or may be broken/disconnected.

Floods

- (Flood Warnings, Alerts, or Actual Flood)
- Precautions Before the Flood:
- Make sure emergency supplies and equipment are readily available.
- Do not touch any electrical equipment unless it is dry.

Precautions If Evacuation of Building is Ordered

- Travel only routes designated.
- Do not try to cross a stream or other water areas unless you are sure it is safe.
- Monitor local radio broadcast.
- Watch for fallen trees, live wires, etc.
- Watch for washed-out roads, earth slides, broken water lines, etc.
- Watch for areas where rivers, lakes, or streams may flood suddenly.

After the Flood

- Do not enter the building until an all-clear has been given.
- Do not use any open flame devices until the building has been inspected for possible gas leaks.
- Do not turn on any electrical equipment that may have gotten wet.
- Shovel out mud while it is still moist.

Flash Floods

- Remember, flash floods can happen without warning.
- When a flash flood warning is issued, take immediate action.

Emergency Disaster Information Guidelines for Emergency Management (Cont.)

FOLLOW ALL INSTRUCTIONS ISSUED WITHOUT DELAY

Snow Emergency

(Snow Emergency or Winter Storm)

- Keep a one (1) to two (2) week supply of heating fuel, food, and water on hand in case of isolation at home.
- Keep your car properly serviced, with snow tires and filled with gas.
- Keep emergency supplies in the car: container of sand, shovel, windshield scraper, tow chain or rope, flares, blanket and flashlight.
- Dress appropriately — wear several layers of loose, lightweight, warm clothing, mittens, and winter headgear to cover head and face.
- Carry a cellular phone (if available).
- If it is necessary to leave the home, drive with all possible caution. If caught in a blizzard, seek refuge immediately. Keep car radio on for weather information.
- If your car breaks down—turn flashers on or hang a cloth from the radio aerial; stay in your car.
- If your car is stuck in snow or traffic jam and car is running, crack windows to prevent carbon monoxide poisoning and keep exhaust pipe free of snow. If engine is not running, you do not need to crack windows.

- Keep a one (1) to two (2) week supply of heating fuel, canned food, and water on hand in case of electrical service interruption and inability to use refrigerator.
- Keep your car properly serviced and filled with gas.
- Dress appropriately – wear several layers of loose, lightweight, warm clothing in the event of gas or electrical interruption causing the furnace not to work in extreme cold weather or have lightweight clothes available if air conditioner/fans are not working in extreme hot weather.
- Carry a cellular phone (if available) in case of electrical outage causing home phones not to work.
- Turn off all pilot lights, i.e. hot water heater, stove, furnace in the event of a gas outage and confer with proper authorities prior to relighting after gas service is restored.
- Any patient admitted to our services on oxygen or a new order received will receive a letter that may be forwarded to their local electric power source to advise them of the patient’s medical need for oxygen in order that they can be noted as priority for having their power restored in the event of a power outage.

Fall Prevention

Falls are a leading cause of unintentional injury for individuals over the age of 65, and especially for those with chronic and/or life-limiting illnesses. No single risk factor causes all falls, but the probability of a fall increases when an individual is exposed to numerous risk factors. Please follow these important tips below to reduce the risk of falls.

Patient

- Make sure the patient's footwear fits well and has non-slip soles.
- The patient should avoid wearing clothing that trails the floor, such as long gowns or robes.
- Have the patient use a cane or walker if recommended by his/her healthcare provider.
- Make sure wheelchair wheels are locked and footrests are up when moving the patient from a sitting to standing position.

Lighting

- Keep all areas where the patient walks in the house well lit, especially stairs.
- Position lights so the patient can turn on a light before entering a dark area.
- Keep night lights on at night.
- Use the correct light bulb size and type for lamps or fixtures. If you do not know the wattage for a lamp, do not exceed 60 watts.

Living Area

- Keep stairs, hallways, passageways, and exits free of clutter.
- Stairs and handrails should be sturdy and well secured.
- Carpet, rugs, and mats should be slip resistant, secured to the floor, or removed.
- Keep passageways free of telephone and/or electrical cords.
- Clean up spills promptly and dry the area thoroughly.

Bedroom

- Keep a light within easy reach of the bed.
- Keep items such as eyeglasses, telephone, tissue, water, etc., within easy reach of the bed or chair.
- Keep a bell and/or monitor within reach of the patient, in case he/she needs to summon assistance.
- Have a bedside commode available.
- If using a step stool, make sure it has a handrail for support in case you or the patient loses balance.
- When using an electric blanket, remember not to lay anything on top of it and do not tuck ends under the bed.

Bathroom

- Place non-skid mats or abrasive strips in the bathtub or shower to keep the patient from slipping.
- Have a grip bar for helping the patient get into the tub, shower, or toilet areas.
- If the patient cannot stand in the shower, have a bathtub seat with a hand-held shower head.
- Keep the water heater thermostat on 120 degrees, or lower.
- Consider toilet extenders or raised seat to help the patient if he/she has trouble getting up or down from the seat.
- Use rugs with non-skid backing.
- Keep floors dry.

Stairs

- Provide lighting at the top and bottom of the stairs that the patient can turn on.
- Install a colored strip along the edge of the step to help the patient see the end of the step.
- Check to make sure the carpet on the stairs is firmly attached.
- Have a handrail along all stairs.
- Keep objects off the stairs.
- Do not allow the patient to climb the stairs with bare feet or with socks only.
- Make sure the patient wears well-fitted, rubber-soled shoes on stairs.

Infection Prevention

Infections are caused by germs that spread from one person or location to another. Some germs, like a cold or flu, spread when you come in contact with a contaminated surface. Washing your hands the right way and at the right times is the main way to prevent these kinds of infections.

Other infections, like HIV (the virus that can cause AIDS) and Hepatitis B, are found in blood and other body fluids. The key to stopping these types of infections is to prevent unprotected contact with blood and other body fluids. Still, other infections, like Tuberculosis, are carried on tiny particles in the air. Helping prevent the spread of infection is one of the major responsibilities of being a caregiver.

Infections can cause diseases and serious complications for the patient, the caregiver, and others visiting or living in the home. So, what are your "must-do" steps for stopping the spread of infection? Here are five of the most important rules to know and follow:

1. **Get in the habit of washing your hands both before and after** providing care; eating, drinking, or handling food; using the toilet; covering a cough; or blowing your nose. If washing with soap and water isn't possible in a particular situation, use an alcohol-based sanitizer hand gel, and then wash your hands as soon as you are able to. (The reason for always washing with soap and water is that some potential sources of infection are not killed by sanitizers and must be removed through handwashing.) When you wash your hands, take the time to do it correctly. Follow these steps:
   - Push up your sleeves and rinse with warm water.
   - Work your hands together with soap for at least 20 full seconds (about the time it takes to sing the "Happy Birthday" song twice).
   - Get under your nails and cuticles.
   - Rinse well.
   - Dry your hands using a clean paper towel then use a dry paper towel to turn off the faucet; it is good practice to not share a cloth hand towel.
2. **Use extra caution around blood, body fluids, and any sharp objects** (like used syringes). Ask the hospice team what special safety precautions they recommend.
3. **Learn how to use protective items.** If personal protective items, such as gloves or masks, are recommended or specified by the hospice team, be sure you learn how to put them on and take them off correctly, and then use them as directed.
4. **Maintain a clean caregiving environment.** If there is a spill of blood, avoid direct contact with blood during clean-up. Ask the hospice team about correct disposal of used syringes, bandages, and other contaminated items. Follow the directions they give you.
5. **Finally, include others in the work of preventing the spread of infection.** Make it clear to others involved in care, and to guests who visit, what is expected, especially the how and when of hand washing.

Medication Safety

- Create a complete list of current medications (including prescription, over-the-counter, vitamins, and herbals) that the patient is taking. Review the list for discrepancies and make changes immediately as they occur. Show the list to all the patient's healthcare providers to keep from combining drugs inappropriately.
- Report medication allergies or side effects to the patient's healthcare provider.
- Make sure the patient takes medications exactly as instructed. If the medication looks different than expected, check with the patient's healthcare provider or pharmacist.
- Do not stop or change medications without a physician's approval, even if the patient is feeling better. If the patient misses a dose. Do not double the next dose.
- Keep medicines away from children and confused adults.

How to Dispose of Unused Medication

Do you have unused medications that you no longer need? Before you throw them out, here are three suggested methods of disposing unused medications from the Food and Drug Administration (FDA):

1. Take advantage of community drug take-back programs that allow the public to bring unused medications to a central location for proper disposal. The public may call the Drug Enforcement Agency's (DEA) Registration Call Center at 800-882-9539 to find a collection receptacle location near them.
2. If no take-back program is available in your area, you can throw the medications out in your household trash, but first: Take them out of their original containers and mix them with an undesirable substance, such as used coffee grounds or kitty litter. The medication will be less appealing to children and pets and unrecognizable to people who may intentionally go through your trash. Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.
3. If no take-back program is available in your area, you can also flush the medications down the toilet, but first: Take them out of their original containers.

The FDA's Deputy Director of the Office of Compliance offers some additional disposal tips:

- Before throwing out a prescription medicine container, scratch out all identifying information on the prescription label to make it unreadable. This will help protect your identity and the privacy of your personal health information.
- Do not give medications to family or friends. Doctors prescribe medications based on patient's specific symptoms and medical history. A drug that works for you could be dangerous for someone else.
- When in doubt about proper disposal, talk to your pharmacist.

Medication Management Process for Patients with Medicare Part D

As hospice providers, we are required to meet the rules and regulations that the Centers for Medicare and Medicaid (CMS) set for us. As of May 1, 2014, if you have Medicare Part D drug coverage, your pharmacy must bill all your medications to us, your hospice provider, to determine whether they are covered under the hospice benefit or by your Part D plan. We will work with your physician and pharmacy to determine which medications we will cover under the Medicare Hospice Benefit, which ones will be covered under your Part D plan, and which medications are determined to be no longer medically necessary. Any medications determined to not be medically necessary, if continued, would become your financial responsibility. Your Part D plan will be contacted regarding those coverage determinations so that they will continue to provide coverage of your medications that are medically necessary but are not covered under the Hospice Benefit.

Upon electing the Medicare Hospice Benefit, all medications will be reviewed with the patient, representative and family by a hospice nurse. Medications will be designated as related and covered by hospice, unrelated to the terminal illness and covered by Part D, or medically unnecessary and not covered by hospice or Part D.

Medically Unnecessary Medications

When a medication is determined to be related to the terminal illness but not medically necessary for the palliation of pain and/or symptom management by the hospice physician, hospice will not pay for the medication. This medication also will not be covered by your Part D plan. If you choose to continue taking the medication, you will need to pay for it out of pocket unless you have coverage from another insurer.

Medication Not On the Hospice Formulary

If you request a drug for your terminal illness or related condition that is not on the hospice formulary and you refuse to try a drug that the hospice believes will be as effective and is on the hospice formulary, you may opt to pay for the drug out of pocket. If you choose that option, no payment for that medication will be available by the hospice or under Part D.

Comfort Kits

What Are Comfort Kits?

During your hospice care, there will be physical changes and needs may arise. Symptoms may have a rapid onset and changes can occur quickly. It is our goal to be prepared for any sudden changes and be able to respond as soon as possible to control and manage these potential bothersome symptoms.

We have developed comfort kits so that you will have the necessary medications to treat these symptoms when they occur. This kit includes a variety of medications that will only be used when necessary for common symptoms such as pain, nausea, vomiting, restlessness, fever, and/or shortness of breath.

When Is the Comfort Kit Used?

The comfort kit is used in urgent situations when symptoms develop rapidly or worsen suddenly.

The kit should not be opened except under instruction from a hospice nurse. If you are experiencing symptoms, please call our hospice office at the number provided on your emergency plan. The nurse will talk with you and provide step by step instructions.

The comfort kit has a very minimal supply of each medication. The nurse will obtain a prescription from your physician for any ongoing treatment.

Where Should the Comfort Kits Be Stored?

The comfort kit should be stored in the refrigerator. As with all medications, this kit should be kept secure and out of the reach of children. Hospice must assess home safety on an ongoing basis to determine if comfort kit medications are safe in the home.

Phone Access

- Make sure the patient can reach a phone if he/she falls and is alone.
- Post emergency numbers on or near the telephone (hospice office, pharmacy, medical equipment, etc.).
- Have an enlarged or lighted dial or a lamp close by to help see the numbers on the phone.

Consider using a medical alert system or service for a patient who is frequently alone in the home.

If an emergency occurs, this service will transmit information about the patient, including his/her address, to emergency personnel.

For The Caregiver

Your Role

You have taken on the role of caregiver for a person with a terminal illness. You may not realize it, but you are giving a gift to this person. Remember, this does not mean you have to give up your own life or that you have to do this alone. Friends, relatives, and your care team want to help. Without this help, the tasks may become overwhelming — draining you physically and emotionally.

Each person's experience is different as they face the death of a loved one. There is no right or wrong way to express your feelings. No other event in life will bring as many emotions to the surface as watching someone you love slowly journey from your world to one you are not ready for them to enter. During this time, it is important that you also take care of yourself. Your social worker is an important resource in helping you meet your needs.

Recommendations

- Take time for yourself. Ask friends to sit with the patient and get out of the house on a regular basis.
- Exercise by walking or stretching your arms and legs for 20-30 minutes several times each week. Stress will be released and your energy level will increase.
- Eat a balanced diet.
- Limit your intake of caffeine and alcohol. They may further drain your energy.
- Rest and sleep are important. Some household tasks may need to be left undone when a nap is needed. Ask friends and family not to call during certain times of rest. Ask your care team for help limiting visitors. Try to rest/sleep when the patient is resting/sleeping.
- Report any problems the patient is having with sleeplessness to the care team nurse.

Asking for Help

Others will ask you how they can help; you might suggest the following:

- Allow friends to help with regular household duties, including dusting, changing beds, preparing a meal, trips to the grocery store for small items, doing laundry, etc. Often, people want to help, but they do not know what they can or should do.
- Suggest small gifts for the patient, such as lotion, baby wipes, note cards, flowers, etc.
- Suggest ways to help with the patient, including foot or back massages, sitting and talking or reading to him/her, sharing old photographs, etc.

Tasks for Families of Dying Patients

When someone close is diagnosed with a terminal illness, everyone begins to grieve. This anticipatory grief process can be confusing and difficult. On one hand, you are attending to the needs of the ill family member and maintaining involvement with that person. On the other hand, you find that you begin to invest emotional energy toward how life will continue after the person dies. It is hard to find time or energy to attend to these opposing needs.

The steps that you take to cope are called tasks. You will find yourself engaged in all these tasks to varying degrees at the same time. Looking at each of these separately will help you to understand the demands of the situation and will allow you to make the best use of family time, energy, and coping ability.

Fluctuating from Denial to Acceptance of the Illness & Death

Some denial of reality is healthy and necessary. It allows you to take in information at a more tolerable pace and gives you a break from the emotional stress of the situation. Acceptance of what is happening may come in stages.

Establishing a Relationship with Health Care Professionals

You may need to learn how to be constructively assertive with others, as well as find a way to deal with your frustrations. Family and caregiver conferences with your care team social worker can help reduce your anxiety by opening communication lines and giving you direct information. It may help to write your concerns down before meeting with healthcare professionals.

Meeting the Needs of the Dying Person

As the illness progresses, the patient's physical and emotional needs will change. Your task will be to help in the best way you can without taking away the patient's control or independence. Remember to ask the patient what his/her needs are.

Maintaining a Functional Family Unit

When a loved one has a terminal illness, it means that everyone has to take on new roles and responsibilities. At the same time, it is important to maintain some of the normal family routines. This gives you some security in the midst of chaos.

Living with the Emotions of the Anticipatory Grief

During this time, both the patient and the family members may experience intense swings of emotion. Having information about these feelings and being aware of your own reactions helps you begin to cope. It is important to let other family members know how you are feeling and what you need. There may also be concerns that you prefer to discuss with someone outside the family, such as your care team social worker.

Dealing with People Outside the Family

You may have little energy at this time for outside relationships, and others' reactions and coping skills will be unpredictable. You may find that friends avoid you and your loved one because they are uncomfortable with death. You may resent others' stability and good fortune. And people will not always understand what you are going through.

Anticipating the Family's New Reality After Death

It is impossible to imagine the future without your loved one. However, you can help prepare yourself by thinking about estate planning, taking care of unfinished business, and building in emotional supports.

Finding Appropriate Hope

Your goals for yourself, the patient, and your family will change throughout this time. Long-term plans need to be replaced by short-term goals; you may find yourself giving up curative treatment and opting instead for treatment that relives symptoms. As you accept the goal of comfort, you are taking a step toward acceptance of the inevitability of death.

Allowing the Dying Person to Make Decisions

The patient's refusal to take medications or accept personal help may be very difficult for you to deal with, but it important to recognize the patient's right to choose activities that may put him/her at risk.

Making Decisions for the Dying Person

There may come a time when your loved one is unable to make decisions for himself/herself. Prior discussions, the use of a Living Will, and/or your knowledge of his/her wishes will help you represent his/her best interests.

Children's Needs

Helping Children Adjust to Illness & Death

Children, grandchildren, and siblings are an important part of families and are affected by the illness of a family member. Until recently, it was thought that children, especially the very young, were unable to comprehend separation and loss. Therefore, they did not grieve. Child development experts now agree that children do grieve, and that the effects of unresolved grief can be severe, often lasting into adulthood. Ways to help children cope include the following:

- Give children prompt and accurate information about what is happening. Allow them to ask questions and give honest answers in return. Children and teens need clear and concise information. It is far better for adults to name the disease, i.e., cancer, diabetes, than to use vague terms such as "sick."
- When changes occur regarding a loved one, prepare children by stating the facts in simple language which they can understand. For example, "Grandpa has oxygen tanks in his house to help him breathe." Children adjust and learn to respond to situations from the adults in their lives.
- Children should be given the choice to visit, touch, and talk with the patient. This will provide an opportunity for the child to recall good memories, share feelings, and say goodbye. In addition, sharing family togetherness is important to the patient. It can also help the child understand that death is a natural part of the life process.
- Allow children to participate in the family grieving process, including the funeral, if the child chooses to do so. It is important that the child observe the adult handling the grief well, as adults are role models for children. Adults can help the younger children by reading books about the cycle of life, which includes death.
- Reassure children that they will be taken care of and supported and that their other family relationships are secure.
- Our social workers, grief counselors, chaplains, and nurses are available to speak with you and the children in your family.

No one can take away the pain of loss. But we can help children by saying, "Lots of people think about death in different ways. No one has the final answer. Tell me what you think." Children may not remember what we say, but they will remember our attitude. They will remember whether or not we were willing to listen to them and be present with them.

Spiritual Care

Spiritual care relates to the values, beliefs, attitudes, and feelings that individuals bring to situations in order to give meaning and purpose to life. Many people find meaning and comfort in religious faith while others look elsewhere to meet their spiritual needs. Acknowledging each person's unique religious and/or spiritual practices is an important part of caregiving.

Spiritual Caregivers

Spiritual caregivers may be religious leaders- clergy, ministers, pastors, priests, and rabbis, or professional and trained laypersons of both traditional and non-traditional beliefs. Our team of chaplains coordinate spiritual care services, working to ensure that the needs of patients and families are met. These chaplains have been clinically trained and have vast experience understanding the unique spiritual needs of patients and families.

Spiritual caregivers work with patients and families to help them find the spiritual comfort, strength, and hope that is consistent with their own values, beliefs, and practices. Spiritual caregivers can also offer the support needed to sort, clarify, or often resolve spiritual issues of concern. Other services may include but are not limited to:

- Prayer and meditation
- Religious rites and sacraments
- Scripture and other religious literature
- Educational and community resources
- Counseling and communicating with family
- Funeral planning
- Grief and loss counseling
- Support from communities of faith (churches, synagogues, temples)

To learn more about these services, contact your care team, social worker or chaplain.

Grief & Loss

Grieving usually begins soon after receiving the diagnosis of a life-limiting illness. As part of the preparatory grief process, patients grieve for the changes that are taking place within their own body, for the loss of the ability to do things they can no longer do, and for the shortened time they have with those they love. Pain and loss are a normal part of life- and grieving is a healthy way of taking care of ourselves.

As part of anticipatory grief, loved ones grieve not only for what they see happening to the patient, but also for the emptiness they are already beginning to feel. Grief is natural. It is our human response to change or loss and it can be painful. How the pain of grief moves through the body, mind, and soul is unique to each person. Sometimes you don't know why you feel empty, hurt, or sad, but it helps just to say the feeling out loud and to allow yourself to feel it.

Grieving persons have the right and responsibility to do their grief work in their own way, to interpret their loss, to make choices that are right for them, and to determine the quality and direction of their lives.

Talk to someone. Call your care team social worker, chaplain, or grief counselor and say, "Help me understand these feelings. Where are they coming from?" These emotions are powerful and they often bring tears. Tears, however, are normal. Tears are precious. Crying sometimes helps move the feelings through the body.

Grief has a direct and sometimes adverse effect on job performance, interpersonal relationships, and personal well-being. It is a process that is not completed in a finite period of time. Because of this, our grief care is extended to family members and other significant persons both before and after the death of a hospice patient.

The goal of grief counseling is to facilitate a safe and healing environment for people who are adjusting to a significant loss in their lives. For grief counseling initiated after the death of a loved one, the goal is to enable survivors to discover, and perhaps rediscover, their own support networks and inner resources to continue integrating their loss into a meaningful future.

Common Responses to Grief

- "Why me? Why now?"
- "I can't believe this is happening."
- "Where is God?"
- "It can't be true."
- "I'm so empty, so numb."
- "I don't want to talk to anyone."
- "Is God punishing me?"
- "Why can't things just be the way they were?"
- "Where did I go wrong?"
- "My heart hurts. I can't think."
- "I don't know what to do."
- "How can she leave me now?"
- "Someone should be able to fix this."
- "If the physicians and nurses had just done their job!"
- "When will the pain go away?"
- "I can't cry."
- "I can't stop crying."
- "I hate what this is doing to me."
- "Why can't I say what I feel?"
- "What do I feel?"
- "I'm so tired."
- "I hate this."
- "What's the use?"
- "It hurts! It hurts! It hurts!"

Our Grief Care Services include:

- Programs for all age groups: children, teens, adults, and senior adults
- Regular correspondence and conversations with a grief counselor
- Short-term individual counseling, including referrals for more intensive therapy when appropriate
- Support groups (both on-going and time-limited). Our support groups are educational and supportive in nature. They are not intended to be therapy sessions; rather, they are to be times of opportunity for sharing and growth.
- Educational forums for those who want to learn more about coping with their grief in a one-on-one session workshop environment
- An annual Life Blooms Eternally memorial service
- A resource library

To learn more about these services, please call your care team.

Financial Information

Paying for Hospice

Hospice services can be covered in many ways, but typically they are covered under Medicare, Medicaid, and private insurance plans. However, there are some plans that do not cover hospice services, as well as patients who have no insurance. We believe that your (the patient's) financial situation should not be a barrier to receiving quality healthcare, so we provide need-based financial assistance that is funded through community support.

In order for us to receive third-party reimbursement and meet federal guidelines, a fee must be charged for services based on their frequency and the type provided. We bill per diem (a charge per each day a patient is under care).

As a Medicare-certified hospice agency we are reimbursed, on a per diem basis, by Medicare and Medicaid at a predetermined rate which is based on a patient's geographical region. The Centers for Medicare & Medicaid Service (CMS) determine this rate, not the hospice. Most private insurance companies also reimburse us on a per diem basis through negotiated contracts. Uninsured patients are billed on a per diem basis as well.

The Medicare Hospice Benefit

The Medicare Hospice Benefit pays the hospice provider for your hospice care; however, it does not cover room and board in facilities such as nursing homes or assisted living communities. In certain cases, if the hospice staff determines that you need general inpatient care in a hospice facility, or your caregiver needs a short period of respite, then that level of care would be covered under the Medicare Hospice Benefit.

Most Medicaid plans provide a benefit, similar to the Medicare Hospice Benefit, to cover your hospice services. Your assigned social worker can assist you regarding your Medicaid eligibility or you can contact your Medicaid caseworker.

Private Insurance

Some private insurance plans have hospice benefits. If you have an employer-based plan through your work or spouse, or if you have been laid off but are covered under COBRA, contact your benefits coordinator at the employer's office. If your plan is purchased through a broker or insurance company, contact the customer service number on your card. Our financial counselor will also review your eligibility upon admission to determine your benefits. You will be mailed a Patient Liability Information Form within 30 days from the start of care that will provide details regarding the policy limitations, deductible, out-of-pocket expenses, and specific benefit limitations applicable to your plan, as verified with your insurance company. If you have any further questions regarding your private insurance benefits, contact our financial counselor.

If You Do Not Have Insurance

We believe that your financial situation should not be a barrier to receiving quality healthcare. Through generous community support, we are able to offer assistance to patients in need. If you do not have insurance, upon admission you will be evaluated for consideration for financial assistance. If you qualify for financial assistance, our per diem charge will be adjusted using a sliding fee scale. You will be mailed a letter detailing the amount of financial assistance available to you, including a contact name and number to answer your questions.

Frequency of Bills

We will bill your insurance provider at the end of each month during which you receive hospice services. If, after receiving payment from your insurance company, there is a remaining balance that is your responsibility (i.e. co-payments, co-insurance, and deductibles not paid by your insurance company) you will be mailed a monthly account statement. The statement will show charges for billable services, payments received, amount not paid by insurance, sliding fee scale discount (if applicable), and the amount due from you. Should you have any questions regarding your bill, please contact our financial counselor.

If Insurance Changes While Under Care

It is either your or your designated financial representative's responsibility to immediately contact our financial counselor when there has been a change in your insurance benefit or insurance provider. If we receive delayed notification of changes, you may be responsible for charges, as some providers require pre-authorization for our services.

Financial Disclosure

Medicare and most Medicaid plans will cover all levels of care at 100%. Hospice coverage through commercial insurance will vary depending on the policy. The following rates are the maximum out-of-pocket charges. Actual daily rates can vary based on the county where you live. If you experience a financial hardship now, or at any time in the future, the patient or representative may contact a financial counselor to arrange a payment schedule.

• Routine Home Care	$225/day
• General Inpatient	$1,425/day
• Respite Care	$475/day
• Continuous Care	$1,050/day
• Inpatient Room & Board	$300/day

(A hospice house rep will discuss this rate with the pt/rep should the patient need long term placement inside one of our hospice houses.)

Medicare Benefits

Hospice care is available as a benefit under Medicare Part A (Medicare's Hospice Insurance). Medicare beneficiaries who choose hospice care receive non-curative medical and support services for their terminal illness. For all other healthcare needs not related to your terminal illness, Medicare Part A and B may still be used. If you are an Original Medicare (fee for service) beneficiary and we believe Medicare may not pay for an item or service that Medicare usually covers, you or your authorized representative will be issued and asked to sign and date an Advance Beneficiary Notice (ABN) prior to receiving the service.

Hospice Eligibility Under Medicare

You can access your Medicare Hospice Benefits when you meet all of the following conditions:

- You are eligible for Medicare Part A (Hospice Insurance).
- Your physician and the hospice medical director certify that you are terminally ill and have six months or less to live, if your illness runs its expected course.
- You sign a statement electing hospice care instead of other Medicare-covered benefits to treat your illness.*
- You can get care from a Medicare-approved hospice provider. (We are a Medicare-approved hospice provider.)
- Your routine Medicare A and B will still pay for covered benefits for any other healthcare needs that are not related to your hospice diagnosis.

Services Covered Under the Medicare Hospice Benefit

Your physician and care team will work with you and your family to set up a Plan of Care that meets your needs, including:

- Physician and nursing services
- Social worker services
- Hospice aide services
- Grief and loss counseling
- Prescription medications for pain control and symptom relief related to terminal illness
- Medical equipment (wheelchairs, walkers, etc.)
- Medical supplies (bandages, catheters, etc.)
- Short-term inpatient care (for pain and symptom management), if needed
- Dietary counseling
- Physical, occupational and speech therapies
- Short-term inpatient respite care when needed to relieve family members or primary caregivers

The Medicare Summary Notice

If you receive a Medicare-covered service, such as hospice, you will receive a Medicare Summary Notice (MSN) in the mail. The MSN shows all the services or supplies that were billed to Medicare during each three-month period, what Medicare paid, and what you may still owe the provider. **The MSN is not a bill.**

Medicare requires hospices to list certain information on the bills (claims) sent to them to pay for your hospice care. Specifically, Medicare requires that we include the number of days you have received hospice care and the number of visits made to you during the month by our physicians, nurses, hospice aides, and social workers. Medicare has also requested that we list as "visits" any time our physicians, nurses, hospice aides, and social workers provide direct care to you. In addition, Medicare has asked that we assign a charge to each visit.

When you receive your Medicare Summary Notice from Medicare, you will see the charges associated with the visits made by our staff. These charges do not increase or decrease the amount Medicare pays us for the care that we provided to you; we will still receive the same daily rates. More importantly, these charges will not result in any additional payments expected from patients and families.

If you have any questions regarding the MSN, please contact our Executive Director. You can also find additional information regarding the Medicare Summary Notice (MSN) on Medicare.gov.

How Long Can You Receive the Medicare Hospice Benefit?

You can receive hospice care as long as your physician and the hospice medical director (or other hospice physicians) continue to certify that you are terminally ill, with a life expectancy of six months or less if the disease runs its expected course. If you live longer than six months, you can still receive hospice care as long as our medical director or other physician re-certifies that you are terminally ill. Hospice care is provided in benefit periods. You can be under the care of a hospice for two 90-day periods followed by an unlimited number of 60-day benefit periods.

At the start of each benefit period, the hospice medical director or other hospice physician must re-certify that you are terminally ill, so that you can continue to receive hospice care. A benefit period starts the day you come under hospice care. It ends when your 90-day or 60-day benefit period ends.

Stopping the Medicare Hospice Benefit

The decision to revoke an election of the Medicare Hospice Benefit, and to return to traditional coverage, is up to the patient and his/her family. The benefit may be revoked at any time by signing a revocation form provided by our team. A revocation must be in writing and include the effective date of revocation. The effective date of the revocation cannot be earlier than the date the revocation was signed. You will forfeit the remaining benefit days in your current benefit period with the revocation. You can resume care under your Medicare Hospice Benefit at any time, as long as you are eligible. The following are reasons you may wish to revoke if:

- Your health improves or your illness goes into remission
- You are moving outside of our service area*
- You have decided to resume curative treatment for your illness

For More Information

For more information on the Medicare Hospice Benefit, please contact your care team social worker or the Finance & Operations Department.

You can also call Medicare at 800-MEDICARE (800-633-4227; TTY users should call 877-486-2048); or visit medicare.gov.

Estate Finances

Uncashed Checks

Checks that are made out to the deceased which have not been cashed prior to death are a very common problem. Usually the bank will not cash these checks after the death. Law requires that the checks be processed though the Clerk of Courts office in the county in which the deceased lived. The clerk will give you proper authorization to cash them.

Social Security Benefit

When a person is qualified, Social Security may pay a lump sum death benefit. The request may be filed by the family. The Social Security check a person receives on the third day of the month while they are living is payment for the month before. According to Social Security, if the deceased individual did not live the entire month before, the check arriving the next month must be returned to the Social Security Administration office and may not be cashed. Write "Deceased" on the envelope and return it. In some cases, a surviving spouse will receive an increase in the amount of his or her monthly check. This survivor's benefit must be requested by the family. The request may be telephoned to the Social Security Regional Office.

Life Insurance Benefits

Life insurance benefits should be filed promptly. In order to file a claim, you will need the policy, a certified copy of the death certificate, and a claimant's statement or proof of death form signed by the beneficiary. Many times, if a local agent is available, he/she will assist you in filing the claim.

Veterans Benefits

The Department of Veterans Affairs has several benefits for honorably discharged veterans. These benefits, like many others, are filed for by the funeral director. Honorably discharged veterans who serve in active duty during wartime are entitled to a flag to drape the casket, a marker for the grave, and the right to be buried in a national cemetery. If the family of the veteran chooses to have him or her buried elsewhere, the VA may pay toward the funeral expense. The family may choose a monetary settlement in lieu of the government's grave marker. The VA also has benefits for surviving spouses and surviving minor children that apply in some cases.

With you.