

Patient and Family Guide



THE
DENVER
HOSPICE
More from life

PATIENT SUPPORT: 303-228-5600

BACKUP NUMBER: 303-281-8383

Dear Friends,

Welcome to The Denver Hospice. On behalf of our staff members and volunteers, I sincerely thank you for the opportunity to be a part of your life and to care for you and your loved ones. To us, hospice is not a place, but a program of personalized care that supports the mind, body and spirit. We always seek to give our patients and their families control over their lives with dignity, joy, compassion and unparalleled expertise and support.

At The Denver Hospice, we are driven by the belief that hospice and palliative care is not about losing life, but adding to it.

- We believe no matter where you are in life's journey, you deserve to get the most out of every day.
- We believe you should have more opportunities to create memories and moments of joy.
- We believe in less pain and more quality of life.
- We believe your wishes should be heard and respected.

We are here to give you more. It's not just our job, it's our calling. And we wouldn't have it any other way.

Thank you for allowing us to serve you.

Sincerely,



Melinda Egging, CHC
President



**Office Hours: 8 a.m. to 5 p.m.
Monday – Friday**

ADMINISTRATIVE OFFICES

501 S. Cherry Street, Suite 700
Denver, Colorado 80246
303-321-2828

INPATIENT CARE CENTER AT LOWRY

8299 E. Lowry Boulevard
Denver, Colorado 80230
303-418-3000

PATIENT SUPPORT

303-228-5600

Office Hours and On-Call Guidelines

OFFICE HOURS

Our office hours are Monday through Friday from 8:00 a.m. to 5:00 p.m., except during holidays. You may reach us by calling the number on the front or back cover of this booklet during normal office hours.

Issues that are handled during regular office hours:

- Medication refills
- Messages for the primary nurse:
 - You need the nurse to bring supplies (i.e., incontinence supplies)
 - Questions about your visit schedule
- Calls for social worker, spiritual counselor or other hospice staff
- Lab or bloodwork results
- Questions about the hospice aide/homemaker

ON-CALL GUIDELINES

Call the number on the front or back cover of this booklet at any time.

A registered nurse (RN) is available 24 hours a day, 7 days a week to assist you with problems after regular office hours, on weekends or holidays. We will talk with you by phone to determine your needs. When appropriate, a nurse will come to your place of residence. We are available after regular office hours for urgent conditions.

Do not call 911 before calling the on-call nurse. Should you call 911, this may not be a covered hospice expense. The following is a list of some reasons for which you may need to contact us after regular hours. We do not carry medications with us and cannot give anything unless ordered by the physician.

Examples of after-hours situations:

- Pain that does not respond to pain medication on hand
- Trouble breathing
- New onset of agitation or restlessness
- Falls where possible injury has occurred
- No urine in 8 hours associated with discomfort
- Uncontrolled nausea, vomiting or diarrhea
- Uncontrolled bleeding
- Temperature above 101°F that does not respond to Tylenol®. **Note:** Patients on chemotherapy may be instructed to call before taking Tylenol®.
- Unable to awaken patient (new problem)
- Catheter leaking
- Chest pain
- Patient taken to the hospital
- Patient death

Hospice Admission Booklet

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SECTION I. Understanding Hospice and Palliative Care

The mission of hospice is to provide physical, emotional, social and spiritual support to terminally ill patients, as well as their families and loved ones. Hospice care is coordinated and provided by an interdisciplinary care team – one that includes the patient's physician to assist patients and families to live with dignity and comfort as they cope with end of life issues.

We believe:

- Hospice affirms life.
- Hospice recognizes dying as a process and so our care provides comfort rather than cure.
- Hospice neither hastens nor postpones death.
- Hospice provides physical, emotional and spiritual care to terminally ill persons and their families.
- Hospice helps the terminally ill person maintain quality of life and helps family members through an extremely stressful time in their lives.

Hospice is primarily a home care program; however, we serve our patients in many settings – in their home, in an independent living residence, assisted living facility or skilled nursing facility. Specialized acute care is also available when appropriate. The hospice team helps the patient and family make informed decisions about caregiving, provides training and necessary skills for "hands-on" care. Hospice also offers help through the bereavement period.

As a not for profit organization, we are owned by the community. We are licensed in the state of Colorado. We are committed to ensuring your rights and privileges as a hospice patient. We have written this booklet to help you better understand hospice care. If you have additional questions, please do not hesitate to ask us.

Thank you for selecting us as your hospice provider.

CONSUMER ASSESSMENT OF HEALTHCARE PROVIDER AND SYSTEMS SURVEY (CAHPS)/SATISFACTION SURVEY

YOUR FEEDBACK IS IMPORTANT.

SATISFACTION SURVEY

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

What is the CAHPS survey?

- The CAHPS survey is an experience of care survey that hospices are required to send to patient's primary caregiver.

Are we meeting your needs?

- As the primary caregiver, you oversee the care of your loved one and can let us know if we've met your needs by completing the CAHPS survey that will be mailed to your home.
- Our Hospice supports the CAHPS survey process because it enables us to align our care in ways that best serve our patients and families and helps future patients and their families make informed decisions when choosing a hospice.

Please return the survey within 30 days.

- As a primary caregiver, you will receive the survey about two months after your loved one is no longer in our care.
- Please complete the survey and return it within 30 days.
- Our goal is to have 100 percent of the surveys returned.

OUR COMMITMENT TO PATIENTS AND FAMILIES:

- You will ALWAYS receive the help you need – days, evenings, weekends and holidays.
- We will ALWAYS keep you informed of your loved one's condition.
- We will ALWAYS treat your loved one with dignity and respect.
- We will ALWAYS ask about pain, at every visit.
- We will ALWAYS provide the training needed to manage the side effects of pain medication.
- We will ALWAYS provide the training needed to manage your loved one's symptoms which may include constipation, trouble breathing, sleepiness, restlessness and agitation.
- We will ALWAYS offer emotional support and help with symptoms of anxiety and sadness.
- We will ALWAYS listen carefully to your concerns.

If you have any questions or concerns, we want to hear from you. Call us anytime at the number listed on the front or back cover of this booklet.

LANGUAGE ASSISTANCE SERVICES

ID Code: _____

Spanish: ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-523-1786.

Vietnamese: CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-800-523-1786.

Chinese: 注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-800-523-1786。

Korean: 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-800-523-1786 번으로 전화해 주십시오.

Russian: ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-800-523-1786.

Amharic: ማሳሰቢያ: የሚናገሩት ቋንቋ አማርኛ ከሆነ የትርጉም እርዳታ ድርጅቶች በነጻ ሊያግዝዎት ተዘጋጅተዋል፡ ወደ ሚከተለው ቁጥር ይደውሉ 1-800-523-1786.

Arabic: ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-800-523-1786.

German: ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-800-523-1786.

French: ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-800-523-1786.

Nepali: ध्यान दिनुहोस्: तपाईंले नेपाली बोल्नुहुन्छ भने तपाईंको निम्ति भाषा सहायता सेवाहरू निःशुल्क रूपमा उपलब्ध छ । फोन गर्नुहोस् 1-800-523-1786 ।

Tagalog: PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-800-523-1786.

Japanese: 注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。1-800-523-1786 まで、お電話にてご連絡ください。

Cushite (Oromo): XIYYEEFFANNAA: Afaan dubbattu Oroomiffa, tajaajila gargaarsa afaanii, kanfaltiidhaan ala, ni argama. Bilbilaa 1-800-523-1786.

Persian (Farsi): توجه: اگر به زبان فارسی گفتگو می‌کنید، تسهیلات زبانی بصورت رایگان برای شما فراهم می‌باشد. با 1-800-523-1786 تماس بگیرید.

Bassa (Kru): Dè dɛ nià ke dyédé gbo: ɔ̃ jũ ké m̃ [Bàsòò-wùdù-po-nyò] jũ ní, níí, à wuɖu kà kò dò po-poò béín m̃ gbo kpáa. Dá 1-800-523-1786

Ibo: Ntị: Ọ bụrụ na asụ Ibo, asụsụ aka ọasụ n'efu, defu, aka. Call 1-800-523-1786.

Yoruba: AKIYESI: Bi o ba nsọ èdè Yorùbú ọfẹ ni iranlọwọ lori èdè wa fun yin o. Ẹ pe ẹrọ-ibanisọrọ yi 1-800-523-1786.

Sign Language: 24-hour services at 1-888-811-2424.

SECTION II. Hospice Overview

POLICIES

This booklet contains general information regarding your rights and responsibilities as a patient. As state and federal regulations change, there may be additions or changes to this booklet as necessary.

CRITERIA FOR ADMISSION

Admission to our hospice program is made upon the recommendation of your physician/medical provider and is based upon your needs. Normally, appropriate candidates for hospice are patients:

- With a life expectancy of 6 months or less if the illness runs its normal course;
- Who desire comfort care;
- Who want to stay at home as long as possible; and
- Who have a primary caregiver.

On admission, our nurse will visit you or your family to discuss hospice services, assess your immediate needs and recommend a plan of care.

If we cannot meet your needs, either directly by our hospice or indirectly through service agreements with other providers, we will not admit you or will not continue to provide services to you.

HOSPICE CONCEPT

What is Hospice?

- Hospice care provides comfort and kindness to those persons nearing the end of life's journey.
- Hospice will help you make decisions about how and where you want to spend the rest of your life.
- Hospice is a special kind of caring.

Why Hospice?

- Hospice treats you, not the disease. The focus is on care, not cure. You and your family's medical, social, emotional and spiritual needs are addressed by a team of hospice professionals and volunteers.
- Hospice considers your entire family, not just you, as the "unit of care." You and your family are included in the decision making process. Hospice will help you and your family make choices about end-of-life issues and enable you to have greater control over these choices. Bereavement counseling is provided to your family for up to 13 months after your death and is available 7 days a week.
- Hospice offers palliative, rather than curative treatment. Hospice will provide care and comfort when cure is no longer an option. Through ever advancing technology, pain and symptom control will enable you to live as fully and comfortably as possible.
- Hospice emphasizes quality, rather than length of life. Hospice neither hastens nor postpones your death. It affirms life and regards dying as a normal process.

SERVICES

Hospice services include **Nursing (Case Manager), Physician/Provider Services, Medical Social Services, Hospice Aide/Homemaker Services, Physical, Occupational and Speech Therapy, Volunteer Services and Spiritual, Dietary and Bereavement Counseling**. All services are provided under the direction of a physician and/or the Hospice Medical Director.

Arrangements will be made for hospice approved medications, medical supplies and equipment, as appropriate.

THE ROLES OF THE HOSPICE STAFF

Nursing: You will be assigned a case manager who will coordinate your care with other members of the interdisciplinary group and handle any nursing needs. The role of the case manager is to help prevent and relieve pain and other symptoms, and to teach caregivers ways to provide for your care. The case manager will also make certain that necessary medical supplies and equipment are ordered, and will assist in monitoring medications. Regular communication with your physician will make certain that he/she is aware of your status and that orders are being followed. Your hospice case manager will try to anticipate your needs and assist you to better understand the natural progression of your illness. With this information you will be encouraged to make decisions regarding your care.

Physician/Provider Services: The hospice medical director, physician/provider employees and contracted physician(s) of the hospice, along with your attending physician are responsible for the palliation and management of your terminal illness and any conditions related to the terminal illness. If your attending physician/provider is not available, the hospice medical director, contracted physician and/or the hospice physician/provider employee is responsible for meeting your medical needs.

Social Worker: Facing a serious illness can be a time of tremendous pain and confusion for you and your family. Because you must deal with emotions and challenges throughout the time in which the illness is occurring, a social worker may be assigned to help you and your family. Services that may be provided by the social worker include:

- Providing emotional support, counseling and guidance to the patient and family in coping with stress related to the illness (available 7 days a week);
- Identifying community resources which are available to help you;
- Assisting the patient and family with planning for funeral arrangements, nursing home placement, etc.; and
- Offering information about Advance Directives.

Hospice Aide/Homemaker: Our hospice aide/homemaker services are provided under the supervision of a registered nurse to patients who have a need for personal care on a part-time basis. Our hospice aides have experience in caring for people in need and have been carefully chosen to provide care for the patients of the hospice. The hospice aide assists with the patient's personal care which may include bathing, hair care, shaving, skin care, linen changes, catheter care and straightening the patient's immediate surroundings. Hospice aides are not allowed to dispense medication. They will report any changes in the condition of the patient to the appropriate team member. The nurse schedules their visits and days may vary to meet the patient's needs.

Physical, Occupational and Speech Therapists: Services are provided by a licensed therapist or licensed therapy assistant under the direction of the therapist. Therapy services may be provided only as reasonable and necessary for symptom control or to enable you to maintain activities of daily living and basic functional skills in accordance with the hospice philosophy. These services must be approved by the Hospice Interdisciplinary Group (IDG), and may not be appropriate for all hospice patients.

Volunteers: A vital part of hospice is the carefully selected and well-trained volunteers working alongside the professional staff. These special people provide many different types of support for the hospice program and those coping with terminal illness, grief and loss. They are good listeners, nonjudgmental, adaptable and have a strong desire to reach out with love and concern to others. Volunteers may be used on a regular schedule or scheduled when needed.

Spiritual Counselor: Hospice spiritual care is based on a high respect for the patients' and caregivers' personal faith and belief. The hospice spiritual counselor is available to assist patients and families cope with the significant spiritual issues that often arise during terminal illness. The services offered include regular pastoral care visits, being on-call and available for crises, conducting funerals and memorial services as requested, and contacting a patient's own clergy, pastoral counselor or other individuals for additional support, if desired. The hospice spiritual counselor does not impose his/her personal belief systems or seek to change the beliefs of others.

Dietary Counselor: Dietary counseling may be provided by a dietitian, nurse or other qualified staff member to address and ensure that your dietary needs are met.

Bereavement: Bereavement services are an integral part of the hospice program. Following a terminal diagnosis, patients and families often struggle with anticipatory grief issues. The medical social worker and spiritual counselor are available to assist families during this emotionally difficult time, as well as provide information on common aspects of anticipatory grief. Following a hospice patient's death, hospice continues to provide bereavement support to grieving families. While one individual is identified as the primary contact with the family, generally the spouse or primary caregiver, all members of the family are eligible to receive bereavement services.

These services are available 7 days a week for a period of not less than 13 months following the patient's death. They include regular mailings to provide support and education regarding grief issues, a grief support group, phone contacts and individual visits (as desired by the bereaved family) by the medical social worker or spiritual counselor to assess bereavement coping skills and provide emotional support. For needs that exceed the scope of hospice bereavement services, referrals to other organizations and professionals within the community are available. These services are also made available to anyone in the community in which hospice services are provided.

LEVELS OF HOSPICE CARE

Routine Home Care: Care is provided intermittently by hospice team members in the patient's or family's home or in a nursing care facility.

General Inpatient Care: Care is provided at a contractual hospital, skilled nursing facility or inpatient hospice facility for patients who need pain control or acute/chronic symptom management which cannot be managed in other settings. The necessity for inpatient care will be determined by the hospice interdisciplinary group. If a hospice patient needs hospitalization for any reason unrelated to the terminal diagnosis, traditional Medicare Part A will be utilized, or the insurance payer will be contacted.

Inpatient Respite Care: Up to five (5) days of respite care at a contractual hospital, nursing care facility or inpatient hospice facility will be paid by hospice, if approved by the hospice interdisciplinary group. This benefit may be used to give the family/caregiver a period of rest.

Continuous Home Care: A minimum of eight (8) hours of care per day may be provided during periods of crisis to maintain the patient at home. Criteria for continuous home care are the same as general inpatient care and consist predominantly of nursing care; however, hospice aides or homemakers may also supplement nursing care.

MEDICARE HOSPICE BENEFIT

Medicare will reimburse the cost of hospice care under your Medicare Hospital Insurance (Part A). When all requirements are met Medicare will cover the following:

Services Covered Under the Medicare Hospice Benefit (if included in the plan of care)	Services Not Covered Under the Medicare Hospice Benefit
<ul style="list-style-type: none"> • Physician services • Nursing care • Medical appliances and supplies • Medications for symptom management and pain relief of the terminal illness and related conditions (must be pre-approved by hospice) • Short-term inpatient care for pain and symptom control • Hospice aide/homemaker • Spiritual counseling • Bereavement counseling • Physical therapy, occupational therapy, speech therapy • Medical social services • Dietary counseling • Volunteer services • Short-term respite care 	<ul style="list-style-type: none"> • Treatment for the terminal illness which is not for palliative symptom management and <u>is not within</u> the hospice plan of care • Care provided by another hospice that was not arranged by the patient's hospice • Ambulance transportation not included in the plan of care • Medications that are not related to the terminal illness • Visits to the emergency department without the prior approval or arrangements by hospice • Inpatient care at non-contracted facilities • Sitter services/hired caregivers • Admission to the hospital without the prior approval or arrangements by hospice • Lab studies, medical testing and/or any treatments not indicated

If you are receiving care under the Medicare Hospice Benefit, Medicare requires that no more than 30 days prior to the beginning of the third benefit period (180 days) and prior to each subsequent benefit period, a hospice physician or nurse practitioner must conduct a face-to-face visit with you to determine continued eligibility for hospice care. If you refuse to allow the face-to-face visit, you will no longer be eligible to receive hospice care under the Medicare Hospice Benefit.

If you have Medicare Part D coverage, we will work with your physician and pharmacy to determine which medications we will cover under the Medicare Hospice Benefit, which medications will be covered under your Part D plan and which medications are determined to be no longer medically necessary and if continued, would become your financial responsibility. If you disagree with any drug coverage determination, you may appeal the decision through the Medicare fee-for-service appeals process, Part D appeals process or submit a complaint with a Medicare-contracted Quality Improvement Organization (QIO). Please ask your hospice representative if you need assistance with any of these steps.

CHARGES

In most cases, your insurance company will pay hospice directly; however, not all insurance plans provide full coverage for hospice care and some hospice services may not be covered under your plan. We receive our reimbursement from Medicare, Medicaid and private health insurance for services. All third party payers are billed for hospice services as appropriate.

All patients, who meet the requirements, are accepted regardless of ability to pay. Medicare or Medicaid patients will not be refused care or have their hospice care discontinued or reduced due to their inability to pay for that care. Our social worker will meet with the patient/family to determine concerns and needs.

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.

Should any change be made in this policy regarding services or charges, you or your responsible party will be advised. Please call our office if you have questions about charges or insurance billing.

PLAN OF CARE

Our hospice involves key professionals and other staff members in developing your individual plan of care, which is based upon identified problems, needs and goals, physician orders for medications, treatments and care, your environment and your personal wishes whenever possible. Effective pain management is an important part of your treatment plan.

The plan includes five basic areas:

- Physical Care
- Spiritual Needs
- Bereavement Care
- Personal Care and Comfort
- Psychosocial Needs

The plan is reviewed and updated as needed, based on your changing needs. We encourage your participation and will provide necessary medical information to assist you. You have the right to refuse any medication or treatment procedure; however, such refusal may require us to obtain a written statement releasing the agency from all responsibility resulting from such action. Should this happen, we would encourage you to discuss the matter with your physician for advice and guidance.

On admission, you and an agency clinician will create a list of your current medications (including any over-the-counter medications, herbal remedies and vitamins). We will compare this list to the medications ordered by your physician. Our staff will continue to compare the list to the medications that are ordered, administered or dispensed to you while under our care. This will be done to resolve any discrepancies (such as omissions, duplications, contraindications, unclear information, potential interactions and changes).

We fully recognize your right to dignity and individuality, including privacy in treatment and in the care of your personal needs. We will always notify you if an additional individual needs to be present for your visit for reasons of safety, education or supervision. Prior to anyone visiting your home, we will ask your permission. You have the right to refuse any visitors and this will not compromise your care in any way.

We do not participate in any experimental research connected with patient care except under the direction of your physician and with your written consent.

COLORADO MEDICAL RECORDS

Your medical record is maintained by our staff to document physician orders, assessments, progress notes and treatments. Your records are kept strictly confidential by our staff and are protected against loss, destruction, tampering or unauthorized use. Our Notice of Privacy Practices describes how your protected health information may be used by us or disclosed to others, as well as how you may have access to this information.

DISCHARGE, TRANSFER AND REFERRAL POLICY

Discharge, transfer or referral from hospice may result from several types of situations including the following:

- The hospice determines that the patient is no longer terminally ill;
- The patient moves out of the hospice's service area;
- The patient is receiving treatment for a medical condition unrelated to the terminal illness or related conditions in a facility with which the hospice does not have a contract and is unable to access the patient to provide hospice services;
- The patient transfers to another hospice;
- The patient's behavior (or situation) is disruptive, abusive or uncooperative to the extent that delivery of care to the patient or the ability of the hospice to operate effectively is seriously impaired;
- Issues of patient or staff safety cannot be resolved; and/or
- Patient/family requests to end (revoke) the services of the hospice.

You will be given a timely advance notice of a transfer to another agency or discharge, except in case of emergency. If you are referred, transferred or discharged to another organization, we will provide them with a list of your current medications and information necessary for your continued care, including pain management.

If you are discharged because you are no longer considered to be terminally ill, we will provide any necessary family counseling, patient training or other services as indicated.

All transfers or discharges will be documented in the medical record on a discharge summary. When a discharge occurs, an assessment will be completed and instructions will be provided for any needed ongoing care or treatment. We will coordinate your referral to available community resources as needed.

If you are a Medicare beneficiary, you or your authorized representative will receive and be asked to sign and date a **Notice of Medicare Non-Coverage (NOMNC)** at least two days before your services will end. If you or your authorized representative are not available, we will make contact by phone, and then mail the notice. If you do not agree that your covered services should end, you must contact the Quality Improvement Organization (QIO) at the phone number listed on the form no later than noon of the day before your services are to end and ask for an immediate appeal.

NOTICE OF NONDISCRIMINATION/FILING A GRIEVANCE

Our hospice 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 physical/mental disabilities with regard to admission, access to treatment or employment.

Our hospice provides 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 any member of your clinical team.

If you believe that our hospice has failed to provide these services or discriminated in any other way, you may file a grievance in person or by mail or phone by using the following contact information. If you need help filing a grievance, contact our Clinical Leadership.

It is the law for our hospice not to retaliate against anyone who opposes discrimination, files a grievance or participates in the investigation of a grievance.

Grievances must be submitted to Care Synergy, Attention Corporate Compliance Officer; Address: 501 S. Cherry Street, Suite 700, Denver, CO 80246; Phone: (303) 780-4600 within 60 days of the date you become aware of the possible discriminatory action, and must state the problem and the solution sought. We will issue a written decision on the grievance based on a preponderance of evidence no later than 30 days after its filing, including a notice of your right to pursue further administrative or legal action. You may also file an appeal of our decision in writing to the President within 15 days. The President will issue a written response within 30 days after its filing.

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

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

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

PROBLEM SOLVING PROCEDURE

We are committed to ensuring that your rights are protected. If you feel that our staff has failed to follow our policies or has in any way denied you your rights, please follow these steps without fear of discrimination or reprisal:

1. Notify the Clinical Manager by phone **at the number on the front or back cover of this booklet**. You may also submit your complaint in writing to **the address on the outside or inside front cover**. Most problems can be solved at this level.
2. You may also contact the state's toll-free home care/hospice hotline at 1-800-842-8826 which operates 24 hours per day, 7 days per week. If voicemail answers, please leave a message and your call will be returned. The purpose of the hotline is to receive complaints or questions about local home care/hospice agencies and to lodge complaints concerning the implementation of advance directive requirements.

You may also write to the Health Facilities and Emergency Medical Services Division of the Colorado Department of Public Health and Environment, 4300 Cherry Creek Drive S., Denver, CO 80246.

3. The agency will provide contact information for applicable accrediting bodies.

SECTION III. Patient Rights and Responsibilities

As a hospice provider, we have an obligation to protect your rights and to provide these rights to you or your representative verbally and in writing in a language and manner you can understand, during the initial assessment visit before care is provided and on an ongoing basis, as needed.

YOUR RIGHTS

RESPECT AND CONSIDERATION - YOU HAVE THE RIGHT TO:

- Exercise your rights as a hospice patient without discrimination or reprisal for doing so. Your court-appointed representative or the legal representative you have selected in accordance with state law may exercise these rights for you in the event that you are not competent or able to exercise them for yourself. If you are a minor, both you and your parent, legal guardian or other responsible person are fully informed of these rights. If you are a minor, both you and your parent, legal guardian or other responsible person are fully informed of these rights.
- Have a relationship with our staff that is based on honesty and ethical standards of conduct and to have ethical issues addressed. You have the right to be informed of any financial benefit we receive if we refer you to another organization, service, individual or other reciprocal relationship.
- Be free from mistreatment, neglect, verbal, mental, sexual and physical abuse, injuries of unknown source and misappropriation of your property. All mistreatment, abuse, neglect, injury and exploitation complaints by anyone furnishing service on behalf of hospice are reported immediately by our staff to the hospice administrator. All reports will be promptly investigated and immediate action taken to prevent potential violations during our investigation. Hospice will take appropriate corrective action in accordance with state law. All verified violations will be reported to the appropriate state/local authorities, including to the state survey and certification agency, and ACHC within five (5) working days of becoming aware of the violation, unless state regulations are more stringent.

- Be free from physical and mental abuse, corporal punishment, restraint or seclusion of any form imposed as a means of coercion, discipline, convenience or retaliation by staff while receiving hospice care.
- Be treated with respect and consideration; recognition of your individuality and dignity; and to have cultural, psychosocial, spiritual and personal values, beliefs and preferences respected. You will not be discriminated against based on social status, political belief, sexual preference, race, color, religion, national origin, age, sex or physical/mental disabilities. If you feel that you have been the victim of discrimination, you have the right to file a grievance without retaliation for doing so. Our staff is prohibited from accepting gifts or borrowing from you.
- Have an environment that preserves dignity and contributes to a positive self-image.
- Receive information in plain language to ensure accurate communication, in a manner that is accessible, timely and free of charge to:
 - Persons with disabilities. This includes access to websites, auxiliary aids and services in accordance with state and federal law and regulations.
 - Persons with limited English proficiency. This includes access to interpreters and written translation.

FILING A GRIEVANCE - YOU HAVE THE RIGHT TO:

- Receive information on our complaint resolution process, and know about the results of complaint investigations. We must document both the existence and the resolution of the complaint.
- Voice grievances/complaints or recommend changes in policy, staff or service/care regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice without fear of coercion, discrimination, restraint, interference, reprisal or an unreasonable interruption in care, treatment or services for doing so.
- Be advised when you are accepted for treatment or care, of the availability of the state's toll-free home care/hospice hotline number, its purpose and hours of operation. The hotline receives complaints or questions about local home care/hospice agencies and is also used to lodge complaints concerning the implementation of the advance directives requirements.
- Be informed how to contact the applicable accrediting body to ask questions, report grievances or voice complaints.

Our complaint resolution process, contact information for the state hotline number are provided in our Problem Solving Procedure.

DECISION MAKING - YOU HAVE THE RIGHT TO:

- Choose your attending physician and other health care providers and communicate with those providers.
- Be fully informed in advance about the hospice concept, admission criteria, services/care covered under the Medicare or other hospice benefit, the scope of services hospice will provide, treatment options available, service limitations, name(s), disciplines and responsibilities of staff members who are providing and responsible for your care, treatment or services, the planned frequency of visits proposed to be furnished, expected and unexpected outcomes, potential risks or problems and barriers to treatment.
- Be fully informed of your responsibilities.

- Be involved in developing your hospice plan of care; and to participate in changing the plan whenever possible and to the extent that you are competent to do so.
- Be advised of any change in services or your plan of care before the change is made.
- Have family involved in decision making as appropriate concerning your care, treatment and services, when approved by you or your representative, if any, and when allowed by law.
- Participate or refuse to participate in research, investigational or experimental studies or clinical trials. Your access to care, treatment and services will not be affected if you refuse or discontinue participation in research.
- Formulate advance directives and receive written information about the agency's policies and procedures on advance directives, including a description of applicable state law. You will be informed if we cannot implement an advance directive on the basis of conscience.
- Have your wishes concerning end of life decisions addressed and to have health with your advance directives in accordance with state laws. You have the right to receive care without conditions or discrimination based on the execution of advance directives.
- Accept, refuse or discontinue care, treatment and services at any time without fear of reprisal or discrimination after being informed of the consequences for doing so. You may refuse part or all of care/services to the extent permitted by law; however, should you refuse to comply with the plan of care and your refusal threatens to compromise our commitment to quality care, then we or your physician may be forced to discharge you from our services and refer you to another source of care.

PRIVACY AND SECURITY - YOU HAVE THE RIGHT TO:

- Personal privacy and security during home care visits and to have your property and person treated with respect. Infants, small children and adolescents will be provided special attention in regards to their right to privacy, choice and dignity.
- Identify agency personnel through agency-generated photo identification.
- Restrict visitors or have unlimited contact with visitors and others and to communicate privately with these persons if you are residing in an inpatient hospice facility.
- Confidentiality of written, verbal and electronic protected health information including your medical records, information about your health, social and financial circumstances or about what takes place in your home.
- Refuse filming or recording or revoke consent for filming or recording of care, treatment and services for purposes other than identification, diagnosis or treatment.
- Access, request changes to and receive an accounting of disclosures regarding your own protected health information as permitted by law.
- Request us to release information written about you only as required by law or with your written authorization. Our Notice of Privacy Practices describes your rights in detail.

FINANCIAL INFORMATION - YOU HAVE THE RIGHT TO:

- Be advised orally and in writing before care is initiated of the extent to which payment may be expected from Medicare, Medicaid, any other federally funded or aided program or other third party sources known to us; charges for services that will not be covered by Medicare; and the charges that you may have to pay.
- Be advised orally and in writing of any changes in payment, charges and patient payment liability as soon as possible when they occur but no later than 30 calendar days from the date that we become aware of a change.
- Have access to all bills, upon request, for the services you have received regardless of whether the bills are paid by you or another party.

QUALITY OF CARE - YOU HAVE THE RIGHT TO:

- Receive high quality, appropriate care without discrimination regardless of race, religion, sex, age, and/or physical or mental disabilities or ability to pay, in accordance with physician orders.
- Receive care from professional staff and volunteers who have been adequately trained for the level of service they provide.
- Receive effective pain management and symptom control from the hospice for conditions related to your terminal illness(es). You also have the right to receive education about your role and your family's role in managing pain when appropriate, as well as potential limitations and side effects of pain treatments.
- Receive pastoral and other spiritual services for you and your family.
- Be admitted only if we can provide the care you need. A qualified staff member will assess your needs. If you require care or services that we do not have the resources to provide, we will inform you, and refer you to alternative services, if available; or admit you, but only after explaining our care/service limitations and the lack of a suitable alternative.
- Receive emergency instructions and be told what to do in case of an emergency.

YOUR RESPONSIBILITIES

YOU HAVE THE RESPONSIBILITY TO:

- Provide complete and accurate information to the best of your knowledge about your present complaints and past illness(es), hospitalizations, medications, allergies and other matters relating to your health.
- Remain under a doctor's care while receiving hospice services.
- Notify us of perceived risks or unexpected changes in your condition (e.g., hospitalization, changes in the plan of care, symptoms to be reported, pain, homebound status or change of physician).
- Follow the plan of care and instructions and accept responsibility for the outcomes if you do not follow the care, treatment or service plan.
- Ask questions when you do not understand about your care, treatment and service or other instruction about what you are expected to do. If you have concerns about your care or cannot comply with the plan, let us know.
- Report and discuss pain, pain relief options and your questions, worries and concerns about pain medication with staff or appropriate medical personnel.
- Tell us if your visit schedule needs to be changed due to medical appointment, family emergencies, etc.
- Tell us if your Medicare or other insurance coverage changes or if you decide to enroll in a Medicare or private HMO (Health Maintenance Organization).
- Promptly meet your financial obligations and responsibilities agreed upon with the agency.
- Follow the organization's rules and regulations.
- Tell us if you have an advance directive or if you change your advance directive.
- Tell us of any problems or dissatisfaction with the services provided.
- Provide a safe and cooperative environment for care to be provided (such as keeping pets confined, putting away weapons or not smoking during your care).
- Show respect and consideration for agency staff and equipment.
- Carry out mutually agreed responsibilities.

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 agency 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.

The agency maintains 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 agency 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.

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;
14. **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
15. **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 (includes 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.

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 by law; 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. If 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.
- **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 in writing, 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: **Compliance Officer, Care Synergy, 501 S. Cherry Street, Suite 700, Denver, CO 80246; Phone: (303) 708-4600.**

EFFECTIVE DATE - This notice is effective February 13, 2019. 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: Compliance Officer, Care Synergy, 501 S. Cherry Street, Suite 700, Denver, CO 80246; Phone: (303) 708-4600.

SECTION IV. Advance Directives

It is your right to decide about the medical care you will receive. You have the right to be informed of treatment options available before giving consent for medical treatment. You also have the right to accept, refuse or discontinue any treatment at any time.

All of us who provide you with health care services are responsible for following your wishes. However, there may be times when you may not be able to decide, or make your wishes known.

Many people want to decide ahead of time what kinds of treatment they want to keep them alive. **Advance Directives let you make your wishes for treatment known in advance.** It is a document written before a disabling illness. The Advance Directive states your choice about treatment and may name someone to make treatment choices if you cannot. In Colorado, the following kinds of Advance Directives are recognized:

- **Living Will** - allows you to make your medical wishes known in the event you become terminally ill or are in a persistent vegetative state and lack decision making capacity.
- **Medical Durable Power of Attorney** - allows you to name an agent who can make health care decisions for you.
- **CPR Directive** - a directive instructing emergency and other health care personnel not to perform cardiopulmonary resuscitation (CPR) on you.
- **Medical Orders for Scope of Treatment (MOST form)** - summarizes your preferences for medical treatment, CPR, artificial nutrition/hydration and antibiotics when you have a chronic, serious, advanced or terminal illness.

A **Living Will** is a legal document you sign instructing your doctor not to use artificial life support measures should you become terminally ill, which means an incurable, irreversible condition or persistent vegetative state for which the administration of life-sustaining procedures will only serve to postpone the moment of death. In Colorado, your living will does not go into effect until two doctors agree in writing that you have a terminal condition or are in a persistent vegetative state and lack decision making capacity.

In Colorado, living wills may be used to stop tube feedings and other forms of artificial nourishment, but only if your living will clearly says so. If you are able to take food by mouth, your living will won't prevent you from being fed. In any case, artificial nourishment may be used if necessary to provide comfort or relieve pain.

Two witnesses must sign your living will. The following cannot witness or sign a living will: patients in the facility in which you are receiving care, any doctor or employee of your doctor, any employee of the facility or agency providing your care, your creditors, or people who may inherit your money or property. Legal assistance is not required to complete a living will; however, if you have legal questions, you may want to talk with a lawyer.

You can cancel or change your living will at any time. You can do this by destroying it. You may also sign a statement that you no longer want it or you may prepare a new one. If you cancel or change your living will, you should tell your family, your doctor and anyone who has a copy of it that it has been canceled or changed.

A **Medical Durable Power of Attorney for Health Care Decisions** is a legal document you sign naming someone to make your health care decisions. The person you name is called your agent. Your agent stands in for you when it is time to make any and all medical or other health care decisions with your doctor. Your agent can get copies of your medical records and other information to make medical decisions for you.

There are other types of durable powers of attorney which allow an agent to make different kinds of decisions for you, including financial status.

A Medical Durable Power of Attorney can cover more health care decisions than a living will does and is not limited to terminal illness. You may put instructions or guidelines into your medical durable power of attorney telling your agent what you really want. You can cancel (revoke) your medical durable power of attorney at any time.

Your Medical Durable Power of Attorney can become effective immediately, or you can make it become effective when you are unable to make your own medical decisions. You will probably need to talk to a lawyer if you want it to become effective immediately.

You can appoint anyone to be your health care agent as long as the person is at least 18 years old, mentally competent and willing to be your agent (someone you trust). Your agent does not have to live in Colorado, although you may want to choose someone nearby. If you appoint your spouse as your agent, and then later you are divorced, legally separated, or your marriage is annulled, your former spouse is automatically removed as your agent unless expressly stated otherwise in your Medical Durable Power of Attorney.

It is important to talk with your doctor, your family and your agent about your medical care choices and your advance directives.

If you executed a Living Will or Medical Durable Power of Attorney for Health Care before July 1, 1991, you may want to review it, since a new law has gone into effect which gives you more options and information. Even if you decide not to update it, the old documents are still legal.

Under Colorado law, family members and close friends can select a substitute decision maker (proxy) if you do not have an advance directive or a guardian, and if a doctor or a judge determines that you are unable to make medical decisions. Your spouse or parent or adult child, grandchild, brother/sister, or a close friend may be chosen as the proxy by mutual agreement. The person chosen as your proxy should be the one who knows your medical wishes the best. If the patient is re-examined later and has regained decision-making capacity, the proxy is relieved of duty.

A Guardian can be appointed by the court to assist with the personal affairs of an individual who is unable to make his or her own decisions. The law regards a person as being unable to make personal decisions if he or she lacks sufficient understanding or capacity to make or communicate responsible decisions concerning himself or herself. This may result from mental illness, mental retardation, physical illness or disability, chronic use of drugs and/or alcohol, or other causes. A person who is subject to a guardianship is called a "ward." It is important to recognize that, other than in emergency situations, it may take several months for the appointment of a guardian.

Any person aged 21 or over, or an appropriate agency who is willing to serve, may be appointed as a guardian. A guardian is not required to provide for a ward out of his or her own funds, nor is he/she required to live with the ward. In addition, a guardian is not responsible for a ward's behavior. Guardianship can be shared by more than one individual. The duties of a guardian include where a ward shall live, to arrange for necessary care, treatment or other services for the ward, and to see that the basic daily personal needs of the ward are met, including food, clothing and shelter. A court may allow a guardian to make medical care and treatment decisions and manage the financial matters for the benefit of the ward. The court may appoint a limited guardian to provide particular services for a specific length of time.

You should give a copy of your Living Will and/or Medical Durable Power of Attorney for Health Care to your doctor, family or friends, and health care providers. Keep the originals with other important papers in a safe place that is easy to find. **Please inform us if you execute or change either of these documents during the course of your care.**

A **Cardiopulmonary Resuscitation (CPR) Directive** allows you, your agent, guardian or proxy to refuse resuscitation. CPR is an attempt to revive someone whose heart and/or breathing has stopped by using special drugs and /or machines or very firm pressing on the chest.

If you have a CPR Directive, and your heart and/or lungs stop or malfunction, then paramedics and doctors, emergency personnel or others will not try to press on your chest or use breathing tubes, electric shock, or other procedures to get your heart and/or lungs working again.

Most health care facilities have a policy which requires that resuscitation be done unless there are written physician orders (DNR or Do Not Resuscitate Orders) or patient CPR Directives to the contrary. DNR orders are written by a physician when in the physician's judgment, and often after consultation with the patient, resuscitation would not be appropriate.

Anyone over the age of 18 can sign a CPR Directive, which becomes effective upon a physician's signature. CPR Directives are usually signed by patients with terminal illnesses. They are sometimes signed by very frail elderly patients who are not ill at the time but may in the future have small strokes, a weak heart, hardening of the arteries, failing liver or kidney or other conditions. If resuscitation is performed, it may result in the patient being paralyzed, forever unconscious, or unable to speak or understand.

After a physician issues a "Do Not Resuscitate" order for a minor child, and only then, the parents of the minor, if married and living together, or the custodial parent or the legal guardian may execute a CPR Directive for the child.

If you do not have a CPR Directive or a DNR order, your consent to CPR will be assumed. In most situations, hospitals and nursing homes respond as if all patients want resuscitation unless they have refused it. Patients, families and/or agents, guardians or proxies are encouraged to check with the facility in question as to their CPR Directive and DNR order policies.

Even if you have other types of advance directives, the use of a CPR Directive is strongly recommended if you do not want to be resuscitated. Colorado law does not require that a specific CPR Directive form be used. There is a state approved CPR form, but other CPR Directive forms may be used. Regardless of the form you use, you should inform family members of your wishes and about the locations of the CPR Directive form. If this directive is not found or you are not wearing a CPR necklace or bracelet, CPR will probably be initiated.

Signing a CPR Directive will not prevent you from receiving other kinds of needed medical care such as treatment for pain, bleeding, broken bones or other comfort care. A CPR Directive may be canceled at any time by the person who has signed it. All original forms must be canceled.

CPR Directive forms may be obtained from your physician or from licensed health care facilities. This directive must be signed by you, or your agent or proxy and your doctor. The original copy must be made available to appropriate personnel, and you are urged to order and wear a necklace or bracelet (these are chargeable items) that will quickly identify you as someone who does not want to be resuscitated.

A **Medical Orders for Scope of Treatment (MOST Form)** is intended for use by individuals who are in frequent contact with health care providers due to a chronic, serious, advanced or terminal illness. The MOST form is voluntary and allows you to address medical treatment options which might be relevant to an emergency or end-of-life situation. When signed by a physician, advanced practice nurse or physician's assistant, the summary of your medical treatment preferences become "portable" medical orders that travel with you and are honored by providers across all health care settings.

AGENCY POLICY ON ADVANCE DIRECTIVES

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

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

Our agency must document in your medical record whether or not you have executed a Living Will and/or Medical Durable Power of Attorney for Health Care. We will abide by your advance directives. Care will be provided to you regardless of whether or not you have executed a Living Will or Medical Durable Power of Attorney for Health Care.

An ethics committee is available to serve in an advisory capacity when ethical issues, such as the withdrawal or withholding of life-sustaining treatments arise during the care of patients with or without an advance directive.

COLORADO END-OF-LIFE OPTIONS ACT

ABOUT THE COLORADO END-OF-LIFE ACT:

The Colorado End-of-Life Options Act which went into effect on December 16, 2016, also known as Proposition 106, allows a terminally ill adult resident of Colorado with a prognosis of six months or less with mental capacity to request and obtain a prescription for medical aid in dying medication to end his or her life.

Our hospice response:

- We believe that hospice care provides the best option for care at the end of life and will continue to support our patients through the process by providing care, comfort and compassion.
- We will not abandon nor discharge patients and families considering or who choose to pursue medical aid in dying.
- The medical aid in dying medication will not be paid for or dispensed by the hospice and is not covered as part of the hospice benefit.
- Staff and volunteers will not assist in administration of medical aid in dying medication.

If you have additional questions, please ask your hospice nurse or social worker.

For specific guidance, to find a physician, receive a free consultation or learn more about medical aid in dying, please call Compassion & Choices at 1-800-247-7421 or visit compassionandchoices.org.

SECTION V. Emergency Preparedness

EMERGENCY MANAGEMENT PLAN

In the event of a natural or man-made disaster, inclement weather or emergency, we have an emergency operations/management plan to continue necessary patient services. We will make every effort to continue home care visits; however, the safety of our staff must be considered. When roads are too dangerous to travel, our staff will contact you by phone, if possible, to let you know that they are unable to make your visit that day. Every possible effort will be made to ensure that your medical needs are met.

In case of bad weather or other situations that might prevent our staff from reaching you, turn to your local radio or TV station(s) or check local news websites. Listen/watch for official information and follow the instructions provided by emergency response personnel. Based on what is known about the threat, you may be asked to take shelter, go to a specific location or evacuate the area. Please notify our office if you evacuate to another location or emergency shelter.

POWER OUTAGE

If you need help in a power outage and our phone lines are down:

- Call 911 or go to the emergency room if you have an emergency.
- Call your closest relative or neighbor if it is not an emergency.

LIGHTNING

If you are inside:

- Avoid tubs, faucets and sinks because metal pipes conduct electricity.
- Stay away from windows.
- Avoid using phones with cords except for emergencies.

If you are outside:

- Avoid natural lightning rods such as tall trees in open areas.
- Get away from anything metal.

FLOOD

Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam. Flooding can take days to happen, but flash floods produce raging waters in minutes. Six inches of moving water can knock you off your feet. Avoid moving water if you must walk in a flooded area. Use a stick to test if the ground is firm enough to walk on.

Be ready to evacuate if a flood watch is issued. Move important items upstairs. Fill a clean bathtub with water in case water becomes contaminated or is shut off. Turn off your utilities at the main valves if you are instructed to do so. Do not touch electrical equipment if you are wet or standing in water.

LANDSLIDE

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

TORNADO

As soon as a tornado is sighted, go to the lowest floor and find an interior room. Good shelters are basements, rooms and halls with no outside walls, bathtubs and spaces under the stairs. Many public buildings have designated shelter areas. Stay away from windows, doors and outside walls. Get under a sturdy item, such as a table, and protect your head. Stay until the danger passes.

If the patient is bedbound, move the bed as far from windows as you can. Use heavy blankets or pillows to protect the head and face.

If you are in a vehicle, trailer or mobile home, get out immediately and go to a sturdy structure. If there is not one close by, lie flat in the nearest ditch and cover your head. Do not try to out-drive a tornado. They are erratic and move swiftly.

HOT WEATHER

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

- Never leave anyone sitting in a closed, parked car.
- Drink lots of water even if you are not thirsty. Avoid alcohol and caffeine.
- Eat small, frequent meals.
- Stay inside and out of the sun. Stay on the lowest floor, pull shades over the windows and use fans if you do not have air conditioning.
- Mist or sponge yourself frequently with cool water.
- Use sunscreen.
- Wear hats and clothes that are loose and lightweight. Clothes with light colors will deflect the sun's energy.
- Talk to your doctor about how sun and heat exposure will affect you if you take drugs such as diuretics or antihistamines.
- Move to a cool place at the first sign of heat illness (dizziness, nausea, headache, cramps). Rest and slowly drink a cool beverage. Seek medical attention immediately if you do not feel better.

WINTER STORM

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

EARTHQUAKE

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

If you are inside, stay there and:

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

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

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

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

WILDFIRE

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

- Wear only cotton or wool clothes.
- Proper attire includes long pants, long sleeved shirt or jacket and boots.
- Carry gloves, a handkerchief to cover your face, water to drink and goggles.
- Keep a flashlight, mobile phone and portable radio with you at all times.
- Take important documents with you (bank, IRS, trust, investment, insurance policy, birth certificates, passports, medical records).
- Make sure to designate a safe meeting place and contact person.
- Close all interior doors of your home.
- Remove lightweight, non-fire-resistant curtains and other combustible materials from around windows.
- Turn off all pilot lights.
- Move overstuffed furniture, such as couches and easy chairs, to the center of the room.
- Place vehicles in the garage, pointing out with keys in the ignition.

BIOLOGICAL THREAT

The first evidence of an attack may be when you notice symptoms of the disease caused by exposure to an agent. It may take time for public health officials to determine exactly what the illness is, how it should be treated and who is in danger. Watch TV, listen to the radio or check local news websites for official news and information including signs and symptoms of the disease, areas in danger, if medications or vaccinations are being distributed and where you should seek medical attention if you become ill. In the event of a biological threat or attack, follow these safety guidelines:

- If you become aware of an unusual and suspicious substance, quickly get away.
- Protect yourself. Cover your mouth and nose with layers of fabric that can filter the air but still allow breathing. Examples include two to three layers of cotton such as a t-shirt, handkerchief or towel.

- There may be times when you would want to consider wearing a face mask: to reduce spreading germs if you are sick, or to avoid coming in contact with contagious germs if others around you are sick.
- If you have been exposed to a biological agent, remove and bag your clothes and personal items. Follow official instructions for disposal of contaminated items.
- Wash yourself with soap and water and put on clean clothes.
- If a family member becomes sick, it is important to be suspicious; however, do not assume that you should go to the emergency department or that any illness is the result of the biological attack. Symptoms of many common illnesses may overlap; however, if your or your family member's symptoms match those described, and are in the group considered at risk, immediately seek emergency medical attention.
- Be prepared for public health officials and medical professionals to issue mandatory quarantine if the illness caused by the biological agent is believed to be contagious.
- Otherwise, expect to receive a medical evaluation, and follow instructions of doctors and other public health officials.
- Implement the health and hygiene practices listed in the Infection Prevention and Control section of this booklet.

CHEMICAL EXPOSURE

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

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

Remove possible contamination from your person by:

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

EXPLOSION

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

EMERGENCY KIT FOR THE HOME

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

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

SHELTER SUPPLIES

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

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

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

SECTION VI. Home Safety

It is the responsibility of our hospice to provide care, treatment and services in an environment that poses no risk of an immediate threat to your health or safety; however, all patients need to take special precautions to ensure a safe living environment. Most accidents in the home can be prevented by eliminating hazards. This list will help you find potential hazards in your home. Take note of each statement that you need to work on to make your home a safer place. **Please speak with your nurse or call the hospice at any time if you have any concerns or questions about patient safety.**

PREVENTING FALLS

At least half of all falls happen at home. Each year, thousands of older Americans experience falls that result in serious injuries, disability and even death. Falls are often due to hazards that are easily overlooked but easy to fix. Use the following **SELF ASSESSMENT**. Check all of the risk factors below that apply to you and your home. The more factors checked, the higher your risk for falling.

- ☐ **History of Falling** - 2 or more falls in last 6 months.
- ☐ **Vision Loss** - changes in ability to detect and discriminate objects; decline in depth perception; decreased ability to recover from a sudden exposure to bright light or glare.
- ☐ **Hearing Loss** - may not be as quickly aware of a potentially hazardous situation.
- ☐ **Foot Pain/Shoe Problems** - foot pain; decreased sensation/feeling; skin breakdown; ill-fitting or badly worn footwear.
- ☐ **Medications** - taking four or more medications; single or multiple medications that may cause drowsiness, dizziness or low blood pressure.
- ☐ **Balance and Gait Problems** - decline in balance; decline in speed of walking; weakness of lower extremities.
- ☐ **High or Low Blood Pressure** that causes unsteadiness.
- ☐ **Hazards Inside Your Home** - tripping and slipping hazards; poor lighting; bathroom safety; spills; stairs; reaching; pets that get under foot.
- ☐ **Hazards Outside Your Home** - uneven walkways; poor lighting; gravel or debris on sidewalks; no handrails; pets that get under foot; hazardous materials (snow, ice, water, oil) that need periodic removal and clean up.

Review each of the following safety tips and note the ones you need to work on:

- Keep emergency numbers in large print near each phone.
- Put a phone near the floor in case you fall and can't get up.
- Wear shoes that give good support and have thin, non-slip soles. Avoid wearing slippers and athletic shoes with deep treads.
- Remove things you can trip over (such as papers, books, clothes and shoes) from stairs and places where you walk.
- Keep outside walks and steps clear of snow and ice in the winter.
- Remove small throw rugs or use double-sided tape to keep them from slipping.
- Ask someone to move any furniture so your path around the house is clear.
- Clean up spills immediately.
- Be aware of where your pets are at all times.

- Do not walk over or around cords or wires, i.e., cords from lamps, extension cords or telephone cords. Coil or tape cords and wires next to the wall so you can't trip over them. Have an electrician add more outlets if needed.
- Keep items used often within easy reach (about waist high) in cabinets.
- Use a steady step stool with a hand bar. Never use a chair as a step stool.
- Improve the lighting in your home. Replace bulbs as needed. Lamp shades or frosted bulbs can reduce glare.
- Make sure stairways, halls, entrances and outside steps are well lit. Have a light switch at the top and bottom of the stairs.
- Place a lamp, flashlight and extra batteries within easy reach of your bed.
- Place night lights in bathrooms, halls and passageways so you can see where you're walking at night.
- Make sure the carpet is firmly attached to every step. If not, remove the carpet and attach non-slip rubber treads on the stairs. Paint a contrasting color on the top front edge of all steps so you can see the stairs better.
- Fix loose handrails or put in new ones. Make sure handrails are on both sides of the stairs and are as long as the stairs. Fix loose or uneven steps.
- Install grab bars next to your toilet and in the tub or shower.
- Use non-slip mats in the bathtub and on shower floors.
- Use an elevated toilet seat and/or shower stool, if needed.
- Exercise regularly. Exercise makes you stronger and improves your balance and coordination. Talk to your doctor about what exercise is right for you.
- Have your nurse, doctor or pharmacist look at all the medicines you take, even over-the-counter medicines. Some medicines can make you sleepy or dizzy.
- Have your vision checked at least once a year by an eye doctor. Poor vision can increase your risk of falling.
- Get up slowly after you sit or lie down.
- Use a cane or assistive device for extra stability, if needed.
- Consider wearing an alarm device that will bring help in case you fall and can't get up.

FIRE SAFETY/BURN PRECAUTIONS

- Make sure the patient has easy access to a telephone, and post the fire department number on every telephone. All family members and caregivers should be familiar with emergency 911 procedures.
- Notify the fire department if a disabled person is in the home.
- **Do not smoke (including e-cigarettes) in bed or where oxygen is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes in a trash can. Keep ashtrays away from upholstered furniture and curtains.
- Install smoke detectors on every floor of your home, including the basement. Place smoke detectors near rooms where people sleep. Test smoke detectors every month to make sure they are working properly.
- Install new smoke detector batteries twice a year or when you change your clocks in the spring and fall.
- Fire extinguishers should be checked frequently for stability.

- Make a family fire escape plan and practice it every six months. Plan at least two different escape routes from each room for each family member. If your exit is through a ground floor window, make sure it opens easily.
- If you live in an apartment building, know where the exit stairs are located. Do not use an elevator during a fire emergency.
- Designate a safe place in front of the house or apartment building for family members to meet after escaping a fire.
- If your fire escape is cut off, remain calm, close the door and seal cracks to hold back smoke. Signal for help at the window.
- Evacuate a bedbound patient to a safe area by placing him or her on a sturdy blanket and pulling or dragging the patient out of the home.
- Avoid excess clutter of newspapers, magazines, clothing, etc. These piles can become a fuel source for potential fires.
- Remember, life safety is first, but if the fire is contained and small, you may be able to use your fire extinguisher until the fire department arrives.
- Have your heating system checked and cleaned regularly by someone qualified to do maintenance.
- Wood-burning stoves should be properly installed. The chimney should be inspected and cleaned by a professional chimney sweep and trash should not be burned in the stove because it could overheat. Gasoline or other flammable liquids should never be used to start wood stove fires.
- Keep portable electric or kerosene heaters out of high-traffic areas. Operate them on the floor at least three feet from upholstered furniture, drapes, bedding and other combustible materials, and turn them off when family members leave the house or go to sleep. Use kerosene heaters only in well-ventilated rooms. Store kerosene outside in a tightly sealed, labeled container.
- Make sure electrical appliances and cords are clean, in good condition and not exposed to liquids.
- Electrical outlets should be grounded and outlets with several plugs should not be used.
- Keep cooking areas free of flammable objects (potholders, towels, etc.).
- Keep storage area above the stove free of flammable/combustible items.
- Wear short or tight sleeves while cooking; don't reach over stove burner.
- Do not leave the stove unattended when cooking, especially when the burner is turned to a high setting.
- Turn pan handles away from burners and the edge of the stove.
- Avoid cooking on high heat with oils and fat.
- Puncture plastic wrap before heating foods in the microwave.
- Never place hot liquids/solids at edge of counter.
- Place layered protection between skin and heating pad.
- Keep electrical appliances away from the bathtub or shower area.
- Never leave patient alone in the shower/tub.
- Set water heater thermostat below 120°F to prevent accidental scalding.
- Store flammable liquids in properly labeled, tightly closed, non-glass containers. Store away from heaters, furnaces, water heaters, ranges and other gas appliances. Make sure the garage is adequately ventilated.

MEDICATION SAFETY

- Do not take medications that are prescribed for someone else.
- Create a complete list of current medications (including prescription and over-the-counter medications, herbal remedies and vitamins), and keep this list with you at all times in the event of emergency situations. Review the list for discrepancies and make changes immediately as they occur. Show the list to your doctor or pharmacist to keep from combining drugs inappropriately.
- Know the name of each of your medicines, why you take it, how to take it, potential side effects and what foods or other things to avoid while taking it.
- Report medication allergies or side effects to your health care provider.
- Take medications exactly as instructed. If the medication looks different than you expected, ask your health care provider or pharmacist about it.
- Drug names can look alike or sound alike. To avoid errors, check with your health care provider if you have questions.
- Do not use alcohol when you are taking medicine.
- Do not stop or change medicines without your doctor's approval, even if you are feeling better. If you miss a dose, do not double the next dose later.
- Use a chart or container system (washed egg carton or med-planner) to help you remember what kind, how much and when to take medicine.
- Take your medicine with a light on so you can read the label.
- Read medicine labels (including warnings) carefully and keep medicines in their original containers.
- Store medications safely in a cool, dry place according to instructions on the label of the medication.
- Keep medicines away from children and confused adults.
- **Federal disposal guidelines for medications:** Follow any specific disposal instructions on the prescription drug labeling or patient information insert. Do not flush medications down the sink or toilet unless this information specifically instructs you to do so. If your community has a pharmaceutical take-back program, take your unused drugs to them for proper disposal. If no such program is available, remove drugs from their original containers and mark out any identifying information on the original containers. Mix the drugs with an undesirable substance like coffee grounds or kitty litter. Place the mixture in a sealable bag, empty can or other container and place it and the empty, original containers in the trash.

MANAGEMENT AND DISPOSAL OF MEDICATIONS IN THE HOME

Once a common practice, the disposal of unused medication down sinks and toilets is no longer recommended. Current studies reveal the presence of unaltered pharmaceuticals has a negative impact on our environment, in our lakes, rivers and drinking water resources given that sewage treatment plants are not designed to remove these chemicals. Medications also misused or ingested accidentally can be tragic. As a result, hospices are offering alternative methods of disposal which help prevent unused medications from contaminating the water or to avoid misuse. Disposing what is often a large amount of unused medications can be daunting.

Management of medications for home patients:

1. Upon admission and in this admission booklet, hospice provides information to the patient/family about how to manage and dispose medications in the home.
2. In the presence of the patient, family, significant other or caregiver, the nurse will complete a count of medications periodically; verify the medication count is correct; and verify that if a Care Kit is utilized, it is sealed and/or not expired.
3. The nurse will attempt to account for any discrepancy of controlled medications, document any discrepancy, and report to supervisor.
4. If the patient dies or is no longer using the medication(s), disposal of the medication will be encouraged by the nurse; however, drugs obtained by prescription belong to the patient or estate.

Disposal of medications in the home:

1. When a patient dies, or is no longer using the medication(s), a count of the drug(s) should occur by the nurse in the presence of the family, significant other or caregiver and documented as part of the patient note.
 - a. If the family wishes to retain any drugs, the nurse will discuss the risk of keeping the dangerous drugs in the home or using the medications prescribed for someone else.
 - b. The nurse will document the desire for the family to retain the drugs.
 - c. The family should cross out any personal information on the medication containers to safeguard the private health information of the patient.
2. Medications to be disposed may be kept in their original containers or combined in a larger container with a screw-top lid.
3. To render the drugs unusable and to prevent the unintended ingestion of discarded medications a non-edible dry substance (i.e., dry kitty litter, sand or dirt) can be added in the following ways:
 - a. Liquids and IV medications - Add a non-edible dry substance to the container or pour the liquid medications into a plastic baggy and add the non-edible substance.
 - b. Tablets and capsules - Add rubbing alcohol or warm water to the container, shake to dissolve, then add the non-edible substance and recap.
 - c. Suppositories - Add a non-edible dry substance to the container and recap.
 - d. Transdermal patches - Using disposable gloves when available, remove the medication patch(es) from the packaging, cut the patch in half carefully, handling it by the edges, and place in a container. Add a non-edible dry substance to the container or bag and recap.
 - e. Medicated ointments and creams - Mix a non-edible dry substance into the original container and recap. If not feasible, then squeeze or scoop the medication into a plastic container or bag and mix in the non-edible dry substance and cap.
4. Place all contaminated containers in a plain paper bag to discourage identification and tampering, and dispose of the bag in the trash or at a medication disposal site.
5. **DisposeRX.com** is a simple product that is inexpensive and available to buy for medication disposal and available at Walmart and online.
6. Walgreens offers a medication disposal service that a person can drop off unused medications into a store kiosk at certain local stores for easy disposal. Check **Walgreens.com** and enter Safe Medication Disposal into the search for a location near you.

HAZARDOUS ITEMS AND POISONS

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

MEDICAL EQUIPMENT SAFETY

- Keep manufacturer's instructions with or near specialized medical equipment. Perform routine and preventive maintenance according to the instructions.
- Keep phone numbers available in the home to obtain service in case of equipment problems or equipment failure.
- Have backup equipment available, if indicated.
- Provide adequate electrical power for medical equipment such as ventilators, oxygen concentrators and other equipment.
- Test equipment alarms periodically to make sure that you can hear them.
- Have equipment batteries checked regularly by a qualified service person.
- Have bedside rails properly installed and use only when necessary. Do not use bed rails as a substitute for a physical protective restraint.
- If bed rails are split, remove or leave the foot-end down so the patient is not trapped between the rails.
- The mattress must fit the bed. Add stuffers in gaps between the rail and mattress or between the head and foot board and mattress to reduce gaps.
- Register with your local utility company if you have electrically powered equipment such as oxygen or ventilator.

OXYGEN SAFETY

- Use oxygen only as directed.
- Oxygen creates a high risk for fire because it causes an acceleration of flame in the presence of flammable substances and open flames.
- **Do not smoke around oxygen.** Post “No Smoking” signs inside and outside the home.
- Store oxygen cylinders away from heat and direct sunlight. Do not allow oxygen to freeze or overheat.
- Keep oil/petroleum products (such as Vaseline®, oily lotions, face creams or hair dressings), grease and flammable material away from your oxygen system. Avoid using aerosols (such as room deodorizers) near oxygen.
- Dust the oxygen cylinder with a cotton cloth and avoid draping or covering the system with any material.
- Keep open flames (such as gas stoves and candles) at least 10 feet away from the oxygen source.
- Keep at least 6 inches of clearance around an oxygen concentrator at all times. Plug it directly into a wall outlet, and limit the use of extension cords.

- Have electrical equipment properly grounded and avoid operating electrical appliances such as razors and hairdryers while using oxygen. Keep any electrical equipment (including e-cigarettes) that may spark at least 10 feet from the oxygen system.
- Use 100% cotton bed linens and clothing to prevent sparks and static electricity.
- Place oxygen cylinders in appropriate stand to prevent tipping, or secured to the wall or placed on their side on the floor. Store in a well-ventilated area and not under outside porches or decks or in the trunk of a car.
- Have a backup portable oxygen cylinder in case of a power or oxygen concentrator failure.
- Alert property management of oxygen use when living in a multi-dwelling residence.

SECTION VII. Infection Prevention and Control

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

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

PRACTICE GOOD HEALTH HABITS

Cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, cover your mouth with your upper sleeve, not your hands.

Avoid close contact with people who are sick. If you are sick, keep your distance from others.

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

Get plenty of sleep, be physically active, manage your stress, drink plenty of fluids and eat nutritious food.

WASH YOUR HANDS

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

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

Always wash hands after:

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

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

If you do not have visibly dirty hands, use an alcohol-based hand rub to clean them. Use a rub with 60-90% ethyl or isopropyl alcohol. Open the cap or spout and apply a dime-size amount (or the amount recommended on the label) in one palm, then rub hands vigorously, covering all surfaces of hands and fingers, until they are dry.

DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not sharp: *paper cups, tissues, dressings, bandages, plastic equipment, catheters, incontinence supplies, plastic tubing, gloves, etc.*

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

NON-DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not thrown away: *dirty laundry, dishes, thermometers, toilets, walkers, wheelchairs, bath seats, suction machines, oxygen equipment, mattresses, etc.*

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

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

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

SHARP OBJECTS

Some items that are sharp: *needles, syringes, lancets, scissors, knives, staples, glass tubes and bottles, IV catheters, razors, etc.*

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

BODY FLUID SPILLS

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

SECTION VIII. Symptom Management

PAIN

Pain in hospice patients:

- People in the end stages of life often may not be able to communicate due to their disease process, stroke, dementia or other illnesses.
- Just because a person cannot speak does not mean they are not experiencing pain.
- Family members and other caregivers are often the first to notice little changes in a patient's mood or behavior that may mean the person is having pain.
- Patients who are unable to speak or have dementia may still have the ability to answer questions about their pain by nodding or with eye movements.
- Poorly managed pain can lead to depression, impaired ambulation, increased falls, agitation and restlessness and decreased quality of life.

Signs and symptoms of pain:

- Saying things about general hurting, aching or unspecific sensations, like "I hurt all over," or "It feels funny or bad."
- Changes in usual activity levels, becoming more aggressive or more withdrawn.
- Facial expressions such as grimacing, frowning, looking sad and wrinkling of the brow.
- Movements such as rocking back and forth, restlessness, fidgeting, pacing, wringing and clenching.
- Holding or protecting a body part.
- Increasing confusion and agitation.
- Difficulty concentrating or communicating.
- Looking scared, troubled or worried.
- Trouble breathing, noisy, labored breathing; sucking in or holding breath.
- Moaning or groaning.
- Any change in the patient's usual behavior such as talkative persons becoming quiet or a quiet person suddenly talking more; changes in usual sleeping or eating patterns.

What YOU can do:

- Always ask the patient if they are in pain and if they are hurting anywhere. Patients who are nonverbal or have dementia may still be able to answer by nodding or shaking their heads.
- Ask family members and other caregivers if they have noticed any changes in behavior that might indicate the patient is having pain.
- Communicate with your hospice care team for any help you need to manage your loved one's pain.
- Actively listen to and participate in the training your hospice nurse will provide so you can:
 - Detect nonverbal signs and symptoms of pain.
 - Use nonverbal pain scales to help determine when your loved one is having pain.
 - Understand the pain medication regimen.
- Always give medications as instructed by your hospice team. The goal is to keep the patient comfortable with as little pain as possible. Medications are ordered at certain times to assist in the management of pain and it often takes less medication to manage pain if it is given regularly, as scheduled. Your hospice care team will provide the training you need on how to give pain medications.

- Break-through pain is pain that happens in spite of regularly scheduled doses of medication. If advised by your hospice care team to give extra doses of medication for break-through pain, always give it. Otherwise, the pain could continue to increase out of control.
- Integrative therapies are non-drug methods of relieving symptoms, often used to complement traditional medications. These can be requested through your hospice care team.
 - **Touch Therapy** - Involves rubbing of hands and feet with aromatherapy oils by trained volunteers. Very relaxing and helpful for breakthrough pain.
 - **Aromatherapy** - Uses essential oils from plants to stimulate senses and promote relief and peace.
 - **Soothing Sounds** - Involves a person participating with music by beating a rhythm or singing a song, or listening intently to the music of their choice.
 - **Animal Companions** - Interaction with certified therapy dogs can relieve stress and help relieve pain by lowering blood pressure.
 - **Energy Work** - Reiki (pronounced Ray-key) Healing Touch, Craniosacral Therapy - uses "laying on hands" providing a gentle touch for "energy flow."

PAIN MEDICATION AND SIDE EFFECTS

Pain medication and hospice patients:

- Opioids, sometimes called narcotics, are a class of medications usually used to treat pain.
- Opioids come in many forms, including short-acting and long-acting tablets, patches, oral liquid and liquid for injection or infusion.
- Examples of opioids include morphine, oxycodone, hydrocodone, hydromorphone and fentanyl. Brand names include Vicodin, Percocet and Dilaudid, among many others.
- The hospice uses opioids, including morphine, to control symptoms such as pain or difficulty breathing.
- Some patients don't have these problems or they find relief with other medications, making opioids unnecessary.
- Some forms of opioids are long-acting and slowly release medicine into the body over an 8-12 hour period. Other forms of opioids are short-acting so patients may get pain relief sooner, but it doesn't last as long.
- To better control symptoms throughout the day, many patients with chronic pain or breathing problems do best with a combination of short-acting and long-acting opioid treatment.
- There is no maximum dose of morphine or similar pain medications.
- Morphine is an opioid and is the most common drug used for pain relief in terminally ill patients. It allows patients to rest better, eat more and interact with family and friends when their pain is controlled.
- Some patients develop 'tolerance' to morphine. This is when the body changes its response to morphine over time, requiring a slightly larger dose. It is easily taken care of by increasing the morphine dose to the level that controls the pain or by switching to one of the other equally effective pain medications now available.
- No patient should ever be in pain because of the fear of 'starting on strong pain medication too soon.'

Side effects of pain medication:

- **Constipation** - This universal side effect does not improve or get better over time; your nurse will help you find a bowel program that is right for you.
- **Sleepiness/Sedation** - Sleepiness is common when starting opioids or increasing dosage, but usually fades or subsides after a few days. Let your nurse know if this continues.
- **Nausea/Vomiting** - Nausea may be present when first starting an opioid, but usually fades after a few days. Let your nurse know if you have these symptoms. There are ways to manage or minimize these side effects.
- **Itching** - Itching may be present when first starting the opioid, but usually fades after a few days. Let your nurse know if this continues.
- **Confusion/Delirium** - Let your nurse know if the patient becomes confused so it can be treated quickly.
- **Muscle Twitching/Jerking** - Let your nurse know if this occurs so it can be treated quickly.
- **Slow Breathing** - When first starting opioids the patient's breathing may slow, but usually fades or subsides after a few days. Let your nurse know if this continues.

What YOU can do:

- Talk to your care team about:
 - Persistent pain in spite of the patient's medication regimen.
 - The patient's pain goals, i.e. no pain with drowsiness or some pain with alertness.
 - Side effects of pain medication: sleepiness, constipation, nausea/vomiting, itching and increased confusion.
 - Integrative therapies that may supplement current treatment.
- Always give medications as ordered. The goal is to keep the patient comfortable with as little pain as possible. Medications are ordered at certain times to assist in the management of pain and it often takes less medication to manage pain if it is given regularly, as scheduled.
- Give medication as needed for "break-through" pain. "Break-through" pain is pain that happens in spite of regularly scheduled doses of medication. If advised by the hospice care team to give extra doses of medication for break-through pain, always give it. Otherwise, the pain could continue to increase out of control and cause the patient more suffering.
- Keep track or record the medication you give - how often and how much will help the hospice care team determine changes that should be made to your plan of care.

SLEEPINESS

Sleepiness in hospice patients:

- Fatigue is a feeling of excessive tiredness or lethargy with a constant desire to rest or even sleep. Both mental and physical fatigue are common symptoms for hospice patients and can make every day normal tasks difficult.
- Sleepiness can also be a side effect of adjusting to pain medications. Your hospice care team will provide the training you need to understand the side effects of pain medications.

Signs and symptoms of sleepiness:

- Excessive tiredness or lethargy.
- Constant desire to rest or even sleep.
- Difficulty completing everyday normal tasks.

What YOU can do:

- Schedule regular times for rest and uninterrupted sleep. Take short rests or naps during the day.
- Limit alcohol and tobacco use.
- Avoid caffeine and other stimulants in the evening hours if you have trouble sleeping at night.
- Use caffeine and other stimulants if you have trouble staying awake. Get exposure to sunlight daily.
- Follow a nutritious diet. Good nutrition can help maintain energy.
- Eat six small meals instead of three large meals. It takes less energy to eat small meals.
- Eat high protein snacks, if possible.
- Maintain good mouth care in order to make eating meals easier. Eat a light bedtime snack.
- Drink supplements, such as Ensure, if you can tolerate them.
- Ask the hospice care team any questions you have about diet and nutrition.
- Here are ways your loved one can deal with mental fatigue:
 - Plan time outdoors either sitting or taking a short walk. Listen to music.
 - Meditate or use relaxation techniques. The hospice social worker or chaplain can suggest some simple techniques.
 - Work on a hobby.
 - Plan visits with friends and family or other social activities.
- Here are ways your loved one can conserve energy during activity:
 - Use a walker, cane or wheelchair.
 - Use a bedside commode.
 - Place chairs in different areas so you can sit and rest while walking around your house or yard.
 - Use a tray for meals rather than eating at the table.
 - Try to bundle care interventions together to allow for more rest and less interruptions.

CONSTIPATION

Constipation in hospice patients:

- Constipation is when bowel movements occur less than normal, when hard stools occur and/or when there is difficulty moving the bowels.
- Constipation can be caused by:
 - Medications, especially narcotic pain medications.
 - Diet changes, such as drinking less water and eating less fiber.
 - Lack of physical activity.
 - Obstruction in the stomach or bowel, although this is rarely the cause.
- Constipation can be, and frequently is, very uncomfortable and if left unresolved for too long, can involve uncomfortable remedies.
- Complications of constipation include:
 - Impaction (total inability to pass stool with hard stool becoming trapped in the intestines).
 - Bowel incontinence (the leakage of liquid stool around the impacted hard, trapped stool).
 - Hemorrhoids.

Signs and symptoms of constipation:

- Reduced and/or difficulty passing stools (straining).
- Lumpy or hard stools.
- Feeling as though the rectum is blocked, preventing bowel movement.
- Feeling as though the rectal vault is not empty after passing stool.
Needing help to pass stool; pressing on the belly or using a finger to remove stool.

What YOU can do:

- If your loved one is experiencing signs of constipation, you should always tell the hospice care team and note the following:
 - No bowel movement in two or more days.
 - Change in bowel routine, such as more or less frequent bowel movements.
 - Pain, cramping, tenderness.
 - A feeling of fullness or bloating.
 - Nausea and/or vomiting.
 - Diarrhea or oozing of stools.
 - Blood in their bowel movement, either bright red blood or black stools.
- Keep track of when the patient has a bowel movement and note whether it was large, medium, small, soft or hard.
- Suggest your loved one try the following, as appropriate and as discussed with your nurse:
 - Drink liquids whenever possible, especially water. Warm drinks, such as coffee or tea can help stimulate bowel movements.
 - Eat more fruits and drink more fruit juices.
 - Walk or sit upright after meals to assist with digestion.
 - Be physically active, if possible.
 - Sit upright on the toilet, commode or bedpan when going to the bathroom, if possible.
 - Try resting your feet on a low stool while sitting on the toilet - knees should be higher than hips.
 - Establish routine times for using the toilet when you can relax and spend the necessary time emptying your bowels. Mornings are often the best time.
 - Take medications for constipation as discussed with the hospice nurse and doctor, such as laxatives, stool softeners, suppositories and/or enemas.
 - If taking narcotic pain medicine, it is important to also take laxatives. Avoid bulk laxatives, such as Metamucil®.
 - If unable to drink enough fluids increase daily fiber (18-30g/day); add wheat bran to diet; fiber supplements should be discussed with the hospice care team prior to taking them.
 - Avoid alcohol and caffeine containing fluids.
- Keep a record of bowel movements, including:
 - Date/time.
 - Consistency.
 - Any uncomfortable symptoms (nausea, cramping, bloating).
 - Any mechanical difficulties passing stool (straining, feeling of incomplete emptying, diarrhea, hemorrhoid pain, bleeding).

TROUBLE BREATHING

Trouble breathing in hospice patients:

- Trouble with breathing, shortness of breath, breathing problems or dyspnea is the uncomfortable feeling of having difficulty breathing. It feels a little different for each individual, but is often described as:
 - Not being able to catch my breath.
 - Not getting enough air.
 - Feeling like suffocating or the room is closing in.
 - Congestion.
- Breathing problems can be caused by illnesses such as lung cancer, lung disease or heart disease.
- Depending on the patient's illness, these problems may be recent, long-standing, mild or severe.
- Patients may also experience terminal respiratory secretions which are commonly referred to as the "death rattle" or "noisy breathing." Terminal respiratory secretions occur when saliva and mucous build up in a patient's throat. As a terminally ill person becomes weaker or loses consciousness, they may lose the ability to swallow or clear their throat. The result is a wet, cracking sound as the secretions move with the patient's breathing.

Signs and symptoms of trouble breathing:

- Poor appetite.
- Restrictions and limitations on activities.
- Anxiety (for both patient and caregivers).
- A slight bluish discoloration around lips, nose, fingers or toes.
- Wet, crackling sound as the secretions move with the patient's breathing.

What YOU can do:

- If your loved one is experiencing trouble breathing, you should always tell your hospice care team members and note:
 - If trouble breathing stops the patient from doing what they want to do.
 - If trouble breathing causes the patient or their family fear, anxiety, nervousness or restlessness.
 - When the patient's skin looks bluish, especially on the face, nose, fingers, toes.
 - What makes their breathing better and what makes it worse.
 - How often they need their medications and treatments and how hard they are working.
- Take breathing treatments to help open airways and cough up secretions.
- Use medications as instructed by your hospice care team. These medications may include:
 - Narcotic medication to slow breathing.
 - Decongestant to help loosen secretions.
 - Medication to help lessen anxiety.
 - Medication to dry up excess secretions.
 - Use oxygen therapy.
 - If oxygen is needed, your hospice nurse will talk to your doctor to determine how much oxygen you need. Your nurse will have a medical supply company deliver the oxygen equipment and the medical supply company will teach you how to use the equipment. Do not smoke or use matches or any type of open flame in a room where oxygen is being used. **THIS IS A FIRE HAZARD!**

- Use suctioning techniques.
 - On rare occasions, a patient may need suctioning to help clear their mouth or throat secretions. Sometimes, suctioning may make the patient feel more anxious and shorter of breath. Your hospice nurse will help you decide if suctioning would be helpful. If necessary, your hospice nurse will arrange for the appropriate equipment to be delivered by a medical supply company and your hospice nurse will teach you the proper way to suction.
- When the patient is having trouble breathing, help them focus on their breathing by taking slow, deep breaths or using breathing exercises:
 - **Exercise One:** Breathe in through the nose for two counts, then pucker lips and exhale slowly through the mouth.
 - **Exercise Two:** Sit in a comfortable position with your hands resting on your stomach. Inhale slowly through the nose so you can feel the stomach muscle relax. Then, tighten the stomach muscle and exhale slowly through pursed lips.
- Elevate the patient's head or have them sit in a chair or recliner. Sometimes leaning forward resting elbows on a table can help.
- Keep the room quiet or play quiet soothing music.
- Raise the head of the bed or prop the patient up to a sitting position with pillows.
- Assist the patient with sitting and leaning forward to help the lungs fill more easily
- Increase air movement in the patient's environment by using open windows or fans.
- If they are experiencing terminal respiratory secretions:
 - Reposition the patient on their side and elevate the head of the bed.
 - If ordered, medication including Hyoscyamine (Levsin) or Atropine may be administered to decrease saliva production.
- Keep the patient and their environment cool by applying cool cloths to the face, using air conditioning, or putting a bowl of ice in front of a fan.
- Talk with your hospice care team about possible integrative therapies and emotional or spiritual support that can help.
- Ask the patient to record what makes them feel short of breath and what decreases it.

ANXIETY

Anxiety in hospice patients:

- Anxiety, sometimes described as fear or worry, is a feeling that things are not right or out of control.
- Anxiety can be caused by a number of things, including illness, family situations and certain medications. It can be a normal feeling for patients and families facing the end-of-life.
- The ability to tolerate anxiety can differ from one person to the next and may depend on a person's cultural background, history or other circumstances.
- Sometimes anxiety can become all-consuming or distressing and interfere with the ability to experience life and the comfort that is possible all the way through death. In that situation, it may be appropriate to seek help for anxiety.

Signs and symptoms of anxiety:

- Fear.
- Persistent or obsessive thoughts or worries, a deep sense that something is not right.
- Rapid breathing.
- Tension.
- Shaking and/or sweating.
- Inability to relax or get comfortable.
- Sleeplessness.
- Confusion or difficulty paying attention or concentrating.

What YOU can do:

- If your loved one is experiencing anxiety, you should always tell your hospice care team and note:
 - Feelings that may be causing the anxiety (for example, fear of dying, worrying about money, family or relationships or spiritual concerns).
 - A known history of anxiety and/or being on medication for anxiety, or in counseling for anxiety.
 - Signs and symptoms that the anxiety is getting worse.
 - What the anxiety feels like.
 - What physical symptoms the anxiety is causing.
- Try interventions that have helped the patient's anxiety in the past.
- Keep track of when anxiety may be worse than other times.
- Have the patient write down their feelings and thoughts.
- Treat physical problems such as pain that can cause anxiety.
- Help the patient to participate in relaxing activities.
- Keep things calm.
- Limit visitors, if possible.
- Play soothing music.
- Try a gentle massage on patient's back, arms, hands or feet.
- Give ordered medications - as discussed with the hospice nurse and physician.

SADNESS

Sadness in hospice patients:

- Sadness and grief are natural feelings for patients and families facing the end of life.
- Sadness is a normal response to difficult life experiences and often is accompanied by tears, anger and/or disappointment.
- Grief occurs for people who have experienced or are experiencing a loss. Grief often occurs before a loved one dies as friends and family begin to experience changes in activities, relationships and routines due to the person's health issues.
- Feelings of sadness and grief may come and go and can be interspersed with joy and laughter.
- Sadness and grief often look different from one person to the next depending on each person's background and culture. However, these feelings can become all-consuming and can interfere with the ability to experience joy and happiness during meaningful times.
- When sadness becomes overwhelming, it is important to reach out and talk to someone.

- Sadness vs. Depression - Identifying the difference between grief or sadness and depression can be difficult. Your hospice care team, particularly your counselor, can help you sort it out. Depression differs from sadness and is a serious illness that should be taken seriously. While sadness can be intermittent, depression usually lingers and can be profoundly difficult to deal with. Depression can include:
 - Feelings of persistent helplessness or hopelessness.
 - Feelings of worthlessness, guilt or shame.
 - Long lasting, unending sadness, gloom, numbness.
 - Physical symptoms like fatigue, weight changes and changes in sleep patterns.
 - Difficulty focusing and thinking.
 - Sometimes persistent thoughts of death and suicide.
 - If you or your loved one is suffering from these symptoms or has a known history of depression, please tell your hospice care team so that they can help you identify treatment options to help reduce the suffering of depression.

Signs and symptoms of sadness:

- Crying, disappointment.
- Anger.
- Fatigue.
- Withdrawal from family and friends.
- Loss of appetite with weight loss.
- Sleep disturbances, trouble sleeping or sleeping all the time.
- Difficulty paying attention or thinking clearly.

What YOU can do:

- If your loved one is experiencing sadness, you should always tell your hospice care team.
- Your care team is always here to help you cope with the emotions related to a loved one's dying process so talk to your hospice care team about symptoms of sadness or depression.
- The counselor on the team can help sort out the differences between sadness and depression.
- Some people prefer to talk about their emotions with a close and trusted friend or family member and others prefer a trained, neutral expert like those on your hospice care team.
- Whatever you prefer, remember that you do not have to be alone as you experience these emotions.

AGITATION AND RESTLESSNESS

Agitation and restlessness in hospice patients:

- Restlessness is an inability to rest, relax or concentrate. Extreme restlessness is sometimes called agitation. Some hospice patients become restless or agitated, especially in the hours or days before the patient dies.

Signs and symptoms of agitation and restlessness:

- Inability to get comfortable; moving around or trying to get out of bed with no known reason.
- Sleeplessness and fidgeting.
- Grimacing or muscle twitching.
- Pulling at sheets, blankets or clothing.
- Reaching out or grabbing for things in the air.

What YOU can do:

- If your loved one is experiencing signs of restlessness or agitation, you should always tell your hospice care team and note the following:
 - If they are unable to swallow medications.
 - If there are specific things that seem to make the restlessness worse or better, like loud music or the sounds of familiar voices.
 - Situations that could be unsafe, such as the potential for falling out of bed.
 - The need for emotional or spiritual support for you or the patient.
- Manage the patient's care environment:
 - Keep the patient safe; make sure the environment is arranged to prevent falls and injuries.
 - Create a peaceful, soothing care setting, without loud noise.
 - Play familiar, soothing music.
 - Maintain a comfortable room temperature, neither too warm nor too cold.
 - Keep a nightlight on at night and keep familiar objects nearby.
- For restlessness:
 - ALWAYS ask permission before touching the patient; tell them what you're doing as you do it.
 - Reassure the patient frequently; stay calm and do not distress the patient with your own anxiety about their restlessness.
 - Monitor the restless person; do not leave them alone if they are potentially unsafe.
 - Offer relaxation activities if the patient is alert and oriented.
 - Read favorite stories or poems.
 - Provide gentle massage, comforting touches or other things to calm the patient.
 - Restlessness may be a sign that the patient is close to death; ask your hospice care team for training and support as needed; let friends and family know the end may be near.
- For sudden onset agitation:
 - Notify your care team.
 - Remind the patient about time, place, and who they are, when appropriate; don't argue with them.
 - Provide glasses and/or hearing aids if the patient uses them safely.
 - Remind the patient who you are when you assist them; tell them everything you are going to do before you do it, for example, "I am going to help you sit up in bed now".
 - Avoid asking a lot of questions or offering complex choices.
 - Offer spoken reassurances such as "I am right here with you".
 - Try to maintain the normal routine including comfortable eating and drinking habits.
 - Encourage the patient to stay awake during the day in order to sleep better at night.
 - Explain to visitors that the unusual behavior is likely due to the patient's medical condition.
- For dementia:
 - Treat the patient with respect and compassion; do not embarrass or shame them by treating them like a child. Don't talk about them as if they aren't there.
 - Don't use words like 'honey' or 'sweetie' unless this is how the patient has always wanted to be addressed.
 - Be patient with unusual or strange behavior; stay calm and reassuring.
 - Provide physical affection; try touching, gestures and eye contact.

- Show your own feelings appropriately; the patient may better understand your emotions and presence than your words.
- Even if the patient doesn't make sense, try to understand their emotions and feelings; patients with dementia often react to situations on an emotional level; keep in mind that you may not understand everything; you can only do your best.
- Offer explanation before helping the patient; tell them what you are going to do before you do it; "I'm going to help you take a bath now".
- Resist the impulse to overly control the patient's behavior; you can help the patient maintain their self-esteem by allowing them to do as much of their own care as possible.
- Set limits kindly; behaviors may have meaning to the patient even if they don't make sense to you; try to move to a new activity when the patient becomes stressed.
- Keep tasks simple; have the patient do only one thing at a time.
- Create a daily routine with small rituals; these can include prayers, washing hands or preparing food. Try not to do too little or too much.
- Include former habits and memories; provide the patient with things to hold that represent a part of his/her life; these can include pictures, clothing, or anything of meaning to the patient.
- Watch for situations that could result in aggression; patients with dementia can become violent and may throw things or try to hit; be aware of your own personal safety.
- Take care of yourself; caring for someone with dementia is very demanding; the sooner you accept help, the longer you can continue to help the patient.

PATIENT POSITIONING/MOVING YOUR FAMILY MEMBER

Why is proper positioning important?

- To safely move the patient in bed or in a wheelchair.
- To achieve proper body positioning and alignment.
- To relieve pressure points and prevent bed sores.
- To prevent problems of contractures and deformities.
- To prevent skin breakdown.

What YOU can do:

- Safely reposition the patient in bed to provide comfort.
- Use pillows to provide support.
- Raise the bed to a comfortable working level.
- Support the patient's head with a pillow.
- Position the head in line with the spine.
- Make sure that the patient's spine is straight, and not twisted.
- Flex the arms at the shoulders and the elbow and support the upper arm with a pillow under it.
- Slightly flex the legs at the hips and slightly raise the upper leg by supporting it with a pillow.
- Ensure the hip, knee and ankle of the patient are at approximately the same height.
- Help maintain or support the position, by placing a pillow behind the patient's back.

SECTION IX. For the Caregiver

We thank you for the privilege of assisting you with the care of your loved one. We salute you for all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a sense of peace and love. You have given your loved one the most wonderful, beautiful and sensitive gifts we humans are capable of, and, in giving that gift, have given yourself a wonderful gift as well.

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

Our hospice supports your willingness to undertake the role of primary caregiver for your loved one. In this way you permit him or her to be maintained in comfortable and familiar surroundings at this vulnerable time in his or her life's journey. We will do everything possible to help you do this effectively and appropriately. We see ourselves as a team with each of us having differing roles and responsibilities which, taken together, achieve maximum benefit for your loved one and for you.

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

Your individual hospice team is pledged to support you in every possible way as you undertake this role. It will help you deal with your limitations and frustrations. It will help you arrange for all supportive services that are needed in the home. It will help facilitate utilization of respite care and inpatient care as needed. It will help you deal with your own feelings and how this situation is affecting your life, your needs and your hopes. It will help you clarify your choices, your available alternatives and resources, and your values, priorities and beliefs, and implement them in the most helpful manner.

The team will explain the progression of the illness, how the needs of your loved one will change and how to respond as these changes take place. It will seek to help you anticipate these changes and implement procedures so that they do not become big problems or out-of-control situations.

In all that the team says, does and offers you, it is the team's deepest commitment to enable you to maximize your involvement of time, energy and love with your loved one.

**TO BE ABLE TO TAKE CARE OF ANOTHER,
YOU MUST FIRST TAKE CARE OF YOURSELF.**

Tips on taking care of yourself:

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

Tips on helping loved ones:

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

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

SECTION X. Preparing for the Dying Process

When a person enters the final stage of the dying process, two different but interrelated dynamics are at work. On the physical plane, the body begins the final process that ends when all physical activities cease to function. Usually, this is an orderly and progressive series of physical changes that, rather than invasive medical intervention, are best responded to through comfort enhancing measures.

The second dynamic of the dying process occurs on the emotional, spiritual and mental plane. This dynamic may appear as a withdrawal from one's present surroundings and relationships or a letting go of all that keeps one attached to this life. This process also tends to follow its own path and schedule but it often includes activity or conversations to resolve whatever is unfinished in one's life. Examples of this work may be attempts to resolve misunderstandings or broken relationships, or to make preparations for the well-being of a loved one following one's own death. There is sometimes the need to receive family permission to die or to let go. For patient and for family, it is helpful to offer words of forgiveness, if needed, as well as words of appreciation and love. Acceptance and compassionate support assist both patient and family through this time of transition.

When a person's body is ready to stop but he/she still has important matters that are not resolved or a significant individual with whom he/she has not made peace, the patient may linger even though very debilitated. On the other hand, when a person is emotionally, spiritually and mentally ready to let go, but his or her body has not completed its final physical process, he/she will continue to live. The person dying appears to have some control over the process, and sometimes staff, reading the signs, can offer estimates of when death is approaching. Ultimately, one's death is not under human control or prediction.

The goal of hospice care at this point is to help you and your family prepare for dying, death and for their continued living. Working with hospice staff to control symptoms that cause pain and discomfort, taking responsibility to complete unfinished business and understanding what the dying process looks like will give you active ways to interact with loved ones as caregivers.

The physical, emotional, spiritual and mental changes which indicate impending death are offered to you below to help you understand the natural circumstances which may happen and how you can respond appropriately. Not all of these changes will occur with every person, nor will they occur in this particular sequence. Each person is unique, and what has been most characteristic of the way your loved one has lived consistently, may affect the way this final death phase and release occurs. This is not the time to try to change your loved one, but the time to give full acceptance, support and comfort.

PHYSICAL CHANGES WITH SUGGESTED RESPONSES

Coolness: The person's hands and then arms, and feet and then legs become increasingly cool to the touch and at the same time the color of the skin may change. This is a normal indication the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the person warm with a blanket. Do not use an electric blanket.

Sleeping: The person may spend an increasing amount of time sleeping and appear to be noncommunicative and unresponsive. This normal change is partly due to changes in body chemistry. Sit with your loved one, hold hands and speak softly and naturally. Do not talk about the person in the person's presence as the sense of hearing remains intact during the dying process. Speak to him or her directly as you normally would, even though there may be no response.

Disorientation: The person may seem confused about the time, place and identity of family and friends. This is also due in part to the body chemistry changes. Sometimes a paper or white board reminder of the day and time is helpful. Identify yourself by name before you speak rather than asking the person to guess who you are. For the patient's comfort, speak softly, clearly and truthfully when you have to communicate, such as, "It is time to take your medication..." and explain the reason for the communication, such as, "... so you won't begin to hurt."

Incontinence: The person may lose control of urine and/or bowel matter as the muscles in those areas begin to relax. Discuss with the hospice nurse what can be done to keep your loved one clean and comfortable as well as how to protect the bed.

Congestion: The person may have sounds of congestion coming from his or her throat or chest, as small amounts of fluids accumulate and cause a vibration noise. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes much discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain and is normal for the physical decline.

Intake Decrease: The person may begin to want little or no food or liquid. This means the body is conserving energy for other functions and getting ready for the end phase. Do not try to force food or drink or use guilt to manipulate them into eating or drinking. To do this only makes the person uncomfortable. Small chips of ice, frozen juice or sports drink may be refreshing in the mouth. Glycerin swabs may help keep the mouth and lips moist. A cool, moist washcloth on the forehead may increase physical comfort.

Urine Decrease: The person's urine output normally decreases due to the decreased fluid intake as well as decrease in circulation through the kidneys. Consult with your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

Breathing Pattern Change: The person's regular characteristic breathing pattern may change with the onset of a different breathing pace which alternates with periods of no breathing. This pattern is called the "Cheyne-Stokes" syndrome. It is very common and indicates a decrease in circulation in the internal organs. Elevating the head, holding hands and speaking gently may help bring comfort.

EMOTIONAL, SPIRITUAL AND MENTAL CHANGES WITH SUGGESTED RESPONSES

Decreased Socialization: The person may only want to be with a very few or even just one person. This is a sign of preparation for release and affirms from whom the support is most needed in order to make the approaching transition. If you are not a part of this inner circle at the end, it does not mean you are not cared about or are unimportant. It means you have already fulfilled your task with him or her, and it is the time for you to say goodbye. If you are part of the final inner circle of support, the person needs your affirmation, support and permission.

Withdrawal: The person may seem unresponsive, withdrawn or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships and a beginning of letting go. Hearing is believed to remain until the end, so speak to your loved one in your normal tone of voice, identify yourself by name when you speak, hold his or her hand and say whatever you need to say that will help the person let go.

Sensory Experiences: The person may speak or claim to have spoken to those who have already died, or to see or have seen places not presently accessible or visible to you. This does not indicate a drug reaction or hallucination. The person is beginning to detach from this life and is being prepared for the transition so it will not be frightening. Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean it's not real to your loved one. Affirm the experiences. They are normal and common. If they frighten your loved one, explain to him or her that they are normal.

Restlessness: The person may perform repetitive and restless tasks. This may be caused by decreased oxygen circulation to the brain and body chemistry changes. The restlessness may in part indicate that something is unresolved or unfinished that is disturbing and prevents him or her from letting go. Do not interfere or try to restrain such motions. Your hospice team member will assist you in identifying what may be happening and help you find ways to help the person find release from the tension or fear. Other things which may be helpful in calming the person are to speak in a quiet natural way, recall a favorite place, lightly massage the forehead, read to the person or play music. Give assurance that it is OK to let go.

Unusual Communication: The person may make statements, gestures or requests that are seemingly out of character. This may indicate the time is ready for the person to say goodbye and is testing to see if you are ready to let him/her go. Accept this moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you need to.

Giving Permission: Giving your loved one permission to let go without making him or her feel guilty for leaving or trying to keep him or her with you to meet your own needs can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. Therefore, your ability to release the dying person from this concern and give him or her assurance that it's all right to let go whenever he or she is ready is one of the greatest gifts you have to give your loved one at this time.

Saying Goodbye: When the person is ready to die and you are able to let go, then is the time to say goodbye. Saying goodbye is your final gift of love to the loved one, for it achieves closure and makes the final release possible. It may be helpful to lie in bed with the person and hold him or her. It may also be helpful to take your loved one's hand and say everything that you need to, so that afterward you do not have regrets for not saying certain things. It may be as simple as saying, "I love you." It may include recounting favorite memories, places and activities you shared. It may include saying, "I'm sorry for whatever I contributed to add tensions or difficulties in our relationship." It may also include saying, "Thank you for..."

Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden from your loved one and you do not need to apologize for them. Tears express your love and help you to let go.

HOW TO KNOW WHEN DEATH HAS OCCURRED

The death of a hospice patient is not a medical emergency. Nothing must be done immediately. The signs of death include such things as:

- No breathing
- Loss of control of bowel and bladder
- Eyelids slightly open
- No blinking
- No heartbeat
- No response
- Eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

FAMILY GUIDELINES WHEN DEATH OCCURS

We have a hospice nurse on call 24 hours a day, seven days a week.

1. Call the hospice nurse at the number on the front cover of this booklet.
2. The hospice nurse will call the funeral home when he/she arrives.

PATIENT DEATH IN THE CARE CENTER, HOSPITAL OR ALTERNATIVE SETTING

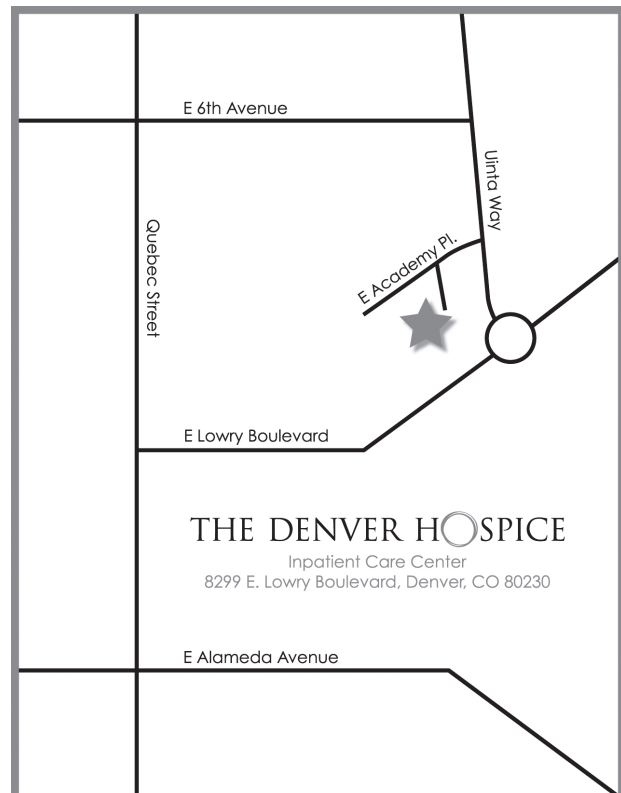
Frequently asked questions:

1. **Can he/she still hear me?**
We believe a person is able to hear sounds (voices) until time of death. We encourage friends and family to talk with their loved one even if they cannot respond.
2. **How much longer until he/she dies?**
Although we are able to identify signs and symptoms of approaching death, we cannot be exact with this information. However, we can give an educated guess in terms of 'hours to days', 'days to weeks', 'weeks to months.' Please remember that anything can change at any time.
3. **Should we go or stay?**
We encourage folks to do what is most comfortable for them. Let your loved one know that you are leaving, when you are returning, and be sure that you have said all that you want to say to that person before you leave. Most importantly, do not feel guilty if your loved one dies while you are away. Often times a person waits until he/she is alone to die.
4. **Will you call me if there is any change in my loved one's condition?**
Any time we assess a change in a person's condition, we notify the primary caregiver or medical durable power of attorney. That doesn't mean that you need to come in, it is just our policy to let you know if we see any changes. We want to communicate with you what we see any changes in your loved one's condition as we care for them.
5. **What will happen if my loved one dies and I am not present?**
After we have noted that your loved one has died, we will call the primary caregiver or medical durable power of attorney. At that time, you can choose whether or not to come in. If you choose to come in, we will ensure your loved one remains in their room until you arrive and let us know when to call the mortuary. If you choose not to come in, we will call the mortuary to have your loved one transported to the mortuary you have selected.

6. **If I am present, how can I know if my loved one has died?**
The first thing that you may notice will be a stopping of breathing. Prior to that you may have noticed a change in the breathing pattern. You may also have noted a lessening in the breathing rate (4-6 breaths/minute). If you have any concerns about this, call your nurse and he/she will check for a heartbeat.
7. **How long can I stay at the hospice care center after my loved one has died?**
We do not want you to feel rushed in any way at the care center. Please take as much time as you need to be with your loved one after he/she has died. If someone is coming from out of town, we can keep your loved one here for up to eight hours.
8. **What happens to any personal belongings?**
If you are present when your loved one dies or you let us know that you are coming in, you have the choice to collect the personal belongings yourself or have the staff do that for you. The staff will not gather up personal belongings unless directed by you to do so. At your direction, we will dispose of personal hygiene items. If you would like to leave any items to be donated, we will gladly keep them here, if needed, or donate them to another nonprofit organization. If you are not going to come into the care center, the staff will gather all personal items and we will hold them for 10 days after the death of your loved one.
9. **How do I select a mortuary?**
We suggest that you select a mortuary prior to the death of your loved one. It may be more difficult for you to do so at the time of death. If you are unsure of a mortuary, the hospice chaplain will assist you in making that selection either before or after the death of your loved one. You do not need to contact the mortuary prior to your loved one's death, but it is ok to do so to begin discussing arrangements.
10. **What else happens at time of death?**
At the hospice care center and in most alternative settings, our staff will bathe your loved one and dispose of any equipment that is being used. Our hope is to create a quiet and comfortable environment for you to spend with your loved one. We will notify the physician of the death. When you are ready, we will notify the mortuary that it is time to transport your loved one. You may stay until the mortuary arrives or you may decide to leave.
11. **How do I obtain the death certificate?**
You will receive the death certificate from the mortuary. We suggest that you ask for several (8-10) since you will need them to transact business after the death of your loved one.

Inpatient Care Center

The Denver Hospice Inpatient Care Center at Lowry offers hands-on, compassionate, state-of-the-art care to patients requiring short-term management of uncontrolled pain and other symptoms. The centrally-located building has 24 private suites with patios. The homelike setting includes such amenities as a family dining room and day rooms, a multi-faith chapel, library and hydro-therapy spa. Original artworks by distinguished area artists decorate common areas and patient rooms. Gardens, walkways and high-tech innovations add to the light-filled ambiance and comforts of our Inpatient Care Center.



We believe in more.

We believe no matter where you are in life's journey, you deserve to get the most out of every day. The most comfort, kindness, respect and love. We believe you should have more opportunities to create moments of joy and memories. We believe in more smiles, more hugs, more sweet moments of gratitude. We believe in less pain and more quality of life. We believe in less stress and more peace of mind. We believe in less "No" and more "Yes, we can make that happen."

We believe that you, and you alone, know how you want to navigate these moments and that your wishes should be heard and respected. We believe in being there for you whenever and wherever you need us with the compassion and expertise to help you find your unique "more from life" and make it a reality.

We are here to give you more. It's not just our job, it's our calling. And we wouldn't have it any other way.

Our care is made possible by your giving

The Denver Hospice is a not-for-profit organization. We count on community generosity to ensure we are able to meet the needs of nearly 5,000 patients and families who need our help each year.

Gifts of any size or type to The Denver Hospice and our Grateful Hearts program make a big difference. Please considering joining your friends and neighbors to help sustain a vital community treasure.

Learn more about ways to support The Denver Hospice.

TheDenverHospice.org

The Denver Hospice Grief Center

Our Grief Center offers a full range of grief support services to help you process and explore your loss, including grief support groups, individual counseling, children and teen support and memorial services.

303-321-2828

GroupBereavement@care4denver.org