



PATIENT AND FAMILY GUIDE TO HOSPICE CARE

ACARA HOSPICE GUIDE TO YOUR HOSPICE JOURNEY

ACARA HOSPICE
601 GRAHAM RD
College Station, TX 77845
979-661-7272



Dear Patient and Family,

Our team is honored to walk with you during your hospice journey. We strive to put you at the center of every decision we make. As the owners, we want you to have our direct cell phone numbers and know you can call us if you feel our care could be improved in any way.

Our phone number is 979-661-7274.

In the future you may also receive a survey. Please complete this survey and return it. Your feedback, based on your experience with our team, helps us to shape the care we provide.

Through this introductory booklet, you will see the services available to you. Please spend time with the hospice team and ask questions. Thank you for allowing us to help care for you and your loved ones. It is our privilege to assist you.

Sincerely,

The image shows two handwritten signatures in cursive. The top signature is "Dana Rowse" and the bottom signature is "Stacey Rowse".

Dana and Stacey Rowse

Acara Hospice Owners

Introduction

Our purpose is to provide caring, compassionate, supportive healthcare services for people with a life-limiting illness. At Acara Hospice, we strive to make you smile when you think about us. As the highest quality provider of outpatient palliative care and hospice services, we ensure your needs are seamlessly met. We lend our hearts to everyone...patient, family, and community.

Our philosophy is keeping you at the center of every detail of care. We recognize dying as a normal part of living and believe the end of life should be as special as the beginning of life.

Office Hours

Our office hours are 8:30am – 5:00pm Monday through Friday.

Please call our office during these hours for medication refills, to leave a message for your nurse, supplies, questions about your plan of care, lab results, or to get in touch with anyone on your hospice team.

Available 24 Hours

At Acara Hospice you are never alone, we know your condition may change at any time and/or you may have important caregiving questions. For this reason, we have Registered Nurses on call 24 hours a day, seven days a week. They are prepared to answer any urgent needs after normal business hours, on weekends, and on holidays. When appropriate, a nurse will come to your place of residence. You can reach us after hours by calling the office.

College Station Office

601 Graham Rd
College Station, TX 77845
979-661-7272

Right to Immediate Advocacy

As a Medicare hospice beneficiary, you have the right to contact the Beneficiary and Family-Centered Care Quality Improvement Organization (BFCC-QIO) to request Immediate Advocacy if you disagree with any of the hospice's determinations. The BFCC-QIO that services your area is:

KEPRO 888-315-0636

www.KEPROQIO.com

Notice of Nondiscrimination/Grievance Policy

Acara Hospice complies with applicable federal civil rights laws and does not discriminate, exclude, or treat people differently based on social status, political belief, sexual preference, race, color, religion, national origin, age, sex, or disability regarding admission, access, to treatment, or employment.

Acara Hospice provides free aid and services to people with disabilities to assist in communicating 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. This includes interpreters and information written in other languages. If you need these services, please contact our office. 979-661-7272

If you believe that Acara Hospice has failed to provide these services or discriminated against you in any other way, you may file a grievance by phone or email by using the following contact information. If you need help filing a grievance, our Civil Rights/Section 1557 Coordinator is available to help. Monday-Friday, 8:30am-5:00pm. 979-308-3848, Office@acarahospice.com .

It is the law for Acara Hospice not to retaliate against anyone who files a grievance or participates in the investigation of a grievance.

Grievances must be submitted to Acara Hospice within 60 days of the date you become aware of the possible discriminatory action and must state the problem and the solution sought. We will issue a written decision on the grievance based on a preponderance of evidence no later than 30 days after 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 Governing Body within 15 days. The Governing Body 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 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).

You have the right to contact the State Health Department at Department of Aging and Disability Service's Consumer Rights and Services 1-800-458-9858 (toll free). The hotline is answered 24 hours a day, 7 days a week. After regular business hours, leave a message on the telephone answering service and a representative will return your call on the next business day.

You may also contact the hotline of our accrediting organization the Accreditation Commission for Health Care (CHAP) 1-202-862-3413 or 800-656-9656



Do Not Call 9-1-1 Before Calling the On-Call Nurse

Calling 9-1-1 before calling the on-call nurse could result in services being provided that are not covered by hospice. We would like you to call if you experience anything of concern to you.

Examples of reasons to call the on-call nurse include:

- | | | |
|-------------------------|------------------------|-------------------|
| *Pain | *No urine for 8 hours | *Catheter leaking |
| *Difficulty breathing | *Uncontrolled nausea, | *Chest pain |
| *New onset of agitation | *vomiting, or diarrhea | *Death |
| *Falls | *Unable to awaken | |

Language Services Available 1-888-808-9008

Available languages include Albanian, Arabic, Bulgarian, Cantonese, Haitian Creole, Croatian, Czech, Farsi, French, German, Georgian, Greek, Gujarati, Hindi, Hmong, Italian, Japanese, Kirundi, Korean, Mandarin, Polish, Portuguese, Romanian, Russian, Serbian, Serbo-Croatian, Slovak, Somali, Spanish, Swahili, Tagalog, Thai, Turkish, Ukrainian, Urdu, and Vietnamese.

Policies

This packet 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 packet as necessary. You may view our complete policy and procedure manual regarding your care and treatment at our office during normal office hours.

Charges

In most cases, your insurance company will pay the hospice directly; however, not all insurance plans provide full coverage for hospice care. You will have the opportunity to receive a Notification of Non-Coverage for any medications, equipment, or services that might not be covered at the beginning of your services, or anytime thereafter. In certain instances, you will be asked to sign an Advanced Beneficiary Notice of Non-Coverage if a service/item will not be covered by Medicare/your insurance.

I understand that by electing hospice care under the Medicare hospice benefit, I waive (give up) the right to Medicare payments for items, services, and drugs related to my terminal illness and related conditions. This means that while this election is in force, Medicare will make payments for care related to my terminal illness and related conditions only to the designated hospice and attending physician that I have selected. Although it would be rare, there could be some necessary items, drugs, or services that will not be covered by the hospice because the hospice has determined that these items, drugs, or services are to treat a condition that is unrelated to the terminal illness and related conditions.

I understand that items, services, and drugs unrelated to my terminal illness and related conditions are exceptional and unusual and, in general, the hospice will be providing virtually all of my care while I am under a hospice election. The items, services, and drugs determined to be unrelated to my terminal illness and related conditions continue to be eligible, for coverage by Medicare or other insurance under separate benefits. Medicare or other insurance doesn't necessarily cover all unrelated items, services, and drugs. Some items, services or drugs may no longer be medically appropriate for you. Hospice will alert you to these items, if they occur, and discontinue them from the hospice plan of care. If you choose to continue with these items, you will be financially responsible for them.

I understand that Medicare will make payment for unlimited hospice days; however, the days are broken into three benefit periods to be used in this order. These periods are as follows: First Benefit Period – 90 days, Second Benefit Period – 90 days, Subsequent 60 day Periods – Unlimited as long as beneficiary meets requirement for benefit. Prior to the beginning of each benefit period my medical condition will be evaluated for continued hospice appropriateness by my physician and the hospice interdisciplinary group.

I understand that I can revoke this benefit at any time and resume regular Medicare coverage. I know I will lose any hospice days remaining in the benefit period in which I revoke. I understand that I may transfer my hospice care to another Hospice Program once during each election period.

Should any change be made regarding our financial policy, you will be advised. Every patient who meets the requirements is accepted regardless of ability to pay.

Daily Rates

Service	Fee	Service	Fee
Routine Hospice	\$275.00	Continuous Care	\$1,950.00
Respite Care	\$650.00	General Inpatient	\$1,455.00

Non-Discrimination

Pursuant to Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, and the Age Discrimination Act of 1975, our agency does not discriminate in the provision of services or in employment on the basis of age, race, color, marital status, religion, creed, sex, veteran or military status, national origin, physical or mental handicap, or any other legally protected category.

What is Hospice?

Hospice is about living well until the end of life. Hospice neither hastens nor postpones death. It is a life-enhancing support system that promotes the best quality of life for the patient and his or her family. Hospice enables the patient to remain at home and caregivers to receive instruction and support in caring for their loved one.

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 will provide comfort care when cure is no longer an option. Through advancing technology, pain and symptom control will enable you to live as fully and comfortably as possible.

Hospice Services



Levels of Care

Per Medicare guidelines, we can provide four levels of hospice care:

1. Routine Home Care (provided intermittently in the patient's home or place of residence)
2. General Inpatient Care (provided in a contracted hospital or inpatient facility for acute/chronic symptom management which cannot be managed in other settings)
3. Inpatient Respite Care (provided in a contracted facility for up to five days)
4. Continuous Home Care (provided as a minimum of eight hours of care per day during periods of crisis to maintain the patient at home)

Plan of Care

We utilize a plan of care to coordinate your treatments and professionals to meet your identified needs, goals, and wishes. The plan includes five basic areas: physical care, personal care and comfort, spiritual needs, psychosocial needs, and bereavement care. 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. Such refusal may require us to obtain a written statement from you releasing us 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 the 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.

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 experimental research connected with patient care except under the direction of your physician and with your written consent.

There must be a willing, able, and available caregiver to be responsible for your care between hospice visits. This may be you, a family member, or a paid caregiver.

Medical Records

Your medical record is created and maintained by our staff to document physician orders, assessments, progress notes and treatments. During each visit your caregiver will make an entry in your record. Please understand, it is important to keep your record accurate to provide the best care, and staff may be charting at times during the visit. 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 staff 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 the hospice provider is unable to access the patient to provide service.
- 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.
- Patient/family request to end (revoke) the services of hospice.

You will be given 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 education, or other services/resources as indicated.

All transfers or discharges will be documented in your medical chart 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 a Notice of Medicare Non-Coverage (NOMNC) at least two days before your covered Medicare 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 at KEPRO 888-315-0636, no later than noon of the day before your services are to end and ask for an immediate appeal.

Experience of Care

Our hospice has contracted with Fazzi, 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. Fazzi Research may contact your caregiver or family member by mail or telephone after your death to evaluate the experience of care and services you and your loved ones received from our hospice agency.

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

Patient Bill of 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.

1. Be involved in the development of his or her plan of care
2. Be informed about the scope of services the hospice provides and any specific limitation on those services
3. Refuse care or treatment
4. Choose his or her attending physician
5. Receive effective pain management and symptom control for conditions related to the terminal illness
6. Be free from mistreatment, neglect, or verbal, mental sexual, or physical abuse, including injuries of unknown source, and the misappropriation of patient property
7. Have person and property treated with respect by anyone providing services on behalf of the hospice
8. Voice grievances to the hospice, CHAP, or a state entity without fear of discrimination or reprisal
9. Voice grievances regarding treatment or care that is - or fails to be - provided

10. Be informed and receive written information concerning the hospice's policy on advance directives, including state law and regulation
11. Have a confidential record per state and federal law and regulation
12. Receive information about the services covered under the hospice benefit

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 if 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 will be 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 during our investigation. Hospice will take appropriate corrective action in accordance with State law. All verified violations will be reported to the appropriate state/local authorities, including to the State survey and certification agency, within five (5) working days of becoming aware of the violation. If our agency staff suspects abuse or mistreatment of any kind, we will report our suspicions in accordance with our policy and State law.
- 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 disability. If you feel you have been the victim of discrimination, you have the right to file a grievance without retaliation for doing so.
- 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 an interpreter and a written translation.

Filing a Grievance

- 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 provider without fear or coercion, discrimination, restraint, interference, reprisal or an unreasonable interruption in care, treatment, or service 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 directive's requirements.
- Be informed about how to contact CHAP to ask questions, report grievances or voice complaints. Contact information for CHAP is provided in our Problem-Solving Procedure.
- Our complaint resolution process and the State hotline number are provided in our Notice of Nondiscrimination/Grievance Policy.

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 services/care covered under the Medicare or other hospice benefit, the scope of services hospice will provide, 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 your services or 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 before care is provided. You will be informed if we cannot implement an advance directive based on conscience.

- Have your wishes concerning end of life decisions addressed and to have health care providers comply with your advance directives in accordance with State laws. 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 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. Our visiting staff will wear proper identification so you can identify them.
- 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 and to be advised of our policies and procedures regarding accessing and/or disclosure of clinical records. Our Notice of Privacy Practices Policy describes your rights in detail.

Financial Information – You Have the Right To:

- Be advised orally and in writing, before care is initiated, of our billing policies and payment procedures and 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 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 information about organization ownership and control.
- Receive high quality, appropriate care without discrimination, in accordance with physician orders.
- Receive effective pain management and symptom control from the hospice provider 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.

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

“THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THE 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 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 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; evaluation 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 home 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; 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.
11. Other health care providers 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 practical 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 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.
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.
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 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.
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 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 of a copy of the written request for disclosure. We will provide the accountings with 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 have 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 § 160.36] For further information regarding filing a

complaint, contact: Administrator, Acara Hospice 601 Graham Rd, College Station, TX 77845; Phone 979-661-7274.

Effective Date – This notice is effective September 30th, 2022. We are required to abide by the terms of the notice currently in effect, but we reserve the right to change these terms as necessary for all protected health information that we maintain. If we change the terms of this notice (while you are receiving service), we will promptly revise and distribute a revised notice to you as soon as practicable by mail, email (if you have agreed to electronic notice), hand delivery or by posting on our website.

If you require further information about matters covered by this notice, please contact Administrator, Acara Hospice 601 Graham Rd, College Station, TX 77845; Phone 979-661-7274.

Advance Directives

Making Decisions About Your Healthcare

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

As an Adult, You Have These Rights:

- You have the right to choose what medical treatment you do or do not want now or in the future.
- You have the right to appoint someone to make your medical care decisions for you if, in the future, you cannot make those decisions yourself.
- You can make your decisions about our care known by telling your doctor or by putting your directions in writing.
- You can change your mind at any time.

The following information tells you how you can make decisions about your medical care.

Why should I be involved in decisions about my medical care?

Your medical care affects *you* most of all, so *you* should be involved in any decisions about your medical care.

How can I be involved in decisions about my medical care?

Talk with your doctor or nurse about the choices you want to make. Ask questions and let those involved in your care know what your preferences are. Talk to them about what you would want now, but also talk to them about what you would want in the future, if you ever became incapable of making your own health care decisions. You can protect your rights by

writing down your wishes and having two witnesses sign the statement. Such a statement is called an Advance Directive. We have Advance Directive forms for you to use.

What is an Advance Directive?

An advance directive is a document in which you state what you want done if, in the future, you cannot make your own medical decisions. In Texas, a document that appoints another adult to make health care decisions for you is called a Medical Power of Attorney. A document that gives specific directions to your doctor and others involved is called a Living Will, which you may attach to your Medical Power of Attorney. You can have a document that both appoints someone and leaves specific instructions.

Who decides I am incapable of making health care decisions?

By law, you are assumed to be capable of making health care decisions unless your doctor, sometimes with assistance of other doctors, decides that you are not capable of understanding the health care decisions you need to make or the risks and benefits of alternative decisions.

Who will make health care decisions for me?

If you do not appoint someone to make health care decisions for you, anyone involved in your care, or a court could end up making decisions for you.

Who must follow what I say in my Advance Directive?

If your wishes are legal, anyone involved in your care must follow your wishes or try to find someone who will.

What if I disagree with my doctor or visiting nurse?

Your doctor or nurse will treat you according to what he or she believes is best for you. If you and your doctor or nurse cannot agree about your medical care, you may want to find another doctor or visiting nurse.

What should I say in my Advance Directive?

You can say anything you want, but it is best to appoint someone and discuss the following situations with that person. You can also put your feelings regarding these questions in your Advance Directive:

- Do you want to be brought back to life (resuscitated) if your breathing or heart stops?
- Do you want to be put on a breathing machine (ventilator or respirator) if you can't breathe on your own?
- Do you want to be fed by tubes (receive artificial nutrition and hydration) if you cannot be fed otherwise?
- Do you want medications, such as painkillers, even if they might make you die more quickly?

- Do you want medications, such as painkillers, even if they might make you die more slowly?

Must I have an Advance Directive?

No, but it is good to have one so those involved in your medical care know what you want if you ever become incapable of making health care decisions for yourself.

How do I write an Advance Directive?

A copy of the state of Texas Advanced Directive form is attached and your Social Worker will be happy to assist you in completing this document.

What should I do with my Advance Directive? You should give a copy to the person you appoint to make health care decisions for you, your doctor, your family, and anyone else that might be involved in making decisions about your medical care.

What if I want to change my Advance Directive?

You can change or cancel your advance directive at any time. You can write a new advance directive, destroy the old one or tell those involved in your care that you have changed your mind. You should let anyone you talked to about your earlier wishes know that they have changed. It is particularly important to let your doctor or nurse know of any changes in your wishes.

How can I make sure my Advance Directive is legal?

The form we give you meets the requirements of Texas State law. If you follow the directions on the form, your advance directive should be legal in the State of Texas. You can also have a lawyer help you draft your advance directive or review the one you have drafted. At this point, there is no advance directive form that is valid in all 50 states.

What if I need more information about Advance Directives?

Ask us and we will try to answer your questions or refer you to someone who can help.

Do Not Resuscitate/Do Not Intubate Orders

What is a Do-Not-Resuscitate or Do-Not-Intubate order?

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

If the patient is in a nursing home or home care setting, a DNR or DNI order instruct the staff not to perform emergency resuscitation and not to transfer the patient to a hospital for such procedures.

Can I request a DNR or DNI order?

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

What are the advantages and disadvantages of CPR?

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

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

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

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

Are DNR and DNI orders ethically acceptable?

It is widely recognized by health care professionals, clergy, lawyers, and others that DNR and DNI orders are medically and ethically appropriate under certain circumstances. For some patients, CPR offers more burdens than benefits, and may be contrary to the patient's wishes.

Is my consent required for a DNR or DNI order?

Yes, your physician must obtain your consent before entering a DNR or DNI order in your record if you are mentally capable of deciding, unless a discussion about CPR and your condition would cause you severe harm. In an emergency, it is assumed that all patients would consent to CPR unless a DNR order is in the record.

How can I make my wishes about DNR and DNI known?

An adult patient in a hospital or nursing home can consent to a DNR or DNI order orally, if two witnesses are present. One witness must be a physician.

You can also make your wishes known before or during hospitalization in writing, before any two adults who must sign your statement as witnesses. A Living Will may be used to convey these wishes if it is properly witnessed.

Before deciding about CPR, you should speak with your physician about your overall health and the benefits and burdens CPR would provide you with. A full and early discussion between you and your doctor can avoid later misunderstandings.

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

If you do not want to be resuscitated and you request a DNR or DNI order, your physician must either:

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

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

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

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

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

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

- A person you have selected to decide about resuscitation
- A court appointed guardian (if there is one)
- Your closest relative
- A close friend

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

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

- A person you have selected to decide about resuscitation
- A court appointed guardian (if there is one)

- Your closest relative
- A close friend.

How can I select someone to decide for me?

If you are a patient in a hospital or nursing home, you can appoint a person orally, with two witnesses present.

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

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

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

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

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

What if members of the family disagree?

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

What happens when I change my mind after I consent to a DNR or DNI order?

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

Emergency Preparedness Plan

In the event of natural or man-made disaster, inclement weather, or emergency, we have an emergency operation 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 they are unable to make your visit that day. Every possible effort will be made to ensure your medical needs are met.

All patients are assigned a priority level code that is updated as needed. The code assignment determines agency response priority in case of a disaster or emergency. These codes are maintained in the agency office, along with information which may be helpful to Emergency Management Services in case of an area disaster or emergency. You will be contacted for medical attention:

- Level I – Within 24 hours
- Level II – Within 24-48 hours
- Level III – Within 48-72 hours

In case of bad weather or other situations that might prevent our staff from reaching you, turn to your local radio and/or TV station(s). Please notify our office if you evacuate to another location or emergency shelter.

Power Outage

If you need help during 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.
- Fill your bathtub (so you have supply of water for drinking, washing, and flushing the toilet).
- Switch to oxygen e-tanks.

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.

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 if you must be outside.
- 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.

Hurricane

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

Civil Disturbance

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

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

Shelter Supplies

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

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

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

Home Safety

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 you need to work on to make your home a safer place. **Please speak with a team member or call the agency 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 injury, disability, and even death. Falls are often due to hazards that are frequently overlooked but easy to fix.

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 or keep a cell phone in your pocket.
- 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 walkways.
- Remove small throw rugs or use double-sided tape to keep them from slipping.
- Clean up spills immediately.
- 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.
- 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 stair 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 and uneven steps.
- Install grab bars next to the toilet and in the shower.
- Use non-slip mats in the bathtub and on shower floors.
- Use an elevated toilet seat and/or shower stool, if needed.
- 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.
- 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. All family members and caregivers should be familiar with emergency 911 procedures.
- Notify the fire department that a disabled person is in the home.

- **Do not smoke (including e-cigarettes) in a 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 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.
- 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 that could become a fuel source for a potential fire.
- Have your heating system checked and cleaned regularly by someone qualified to do maintenance.
- 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.
- Keep electrical appliances away from the bathtub or shower area.
- Never leave patient alone in the shower/tub.
- Set water heater thermostat below 120° to prevent accidental scalding.

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.

- 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.
- 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.

Hazardous Items and Poisons

- Know how to contact your poisons control team.
- Carefully store hazardous items in their original containers.
- Do not mix products that contain chlorine or bleach with other chemicals.
- 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 preventative 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 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 a 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 in 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 products), 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 covering the system with any material.
- Keep open flames (such as gas stoves and candles) at least 10 feet away from the oxygen source.
- Always keep at least 6 inches of clearance around an oxygen concentrator. 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, secure to the wall, or place them on their side on the floor. Store in a well-ventilated area and not under outside porches or in the trunk of a car.
- Have a backup portable oxygen cylinder in case of a power outage or oxygen concentrator failure.
- Alert property management of oxygen use when living in a multi-dwelling residence.

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

Wash Your Hands

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

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

Always wash hands after:

- | | | |
|-------------------------------------|--------------------------|-------------------------|
| *Tending to a sick person | *Treating a cut or wound | *Touching soiled linens |
| *Touching garbage | *Using the bathroom | *Changing diapers |
| *Touching animals
or their waste | *Coughing/Sneezing | *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 15 seconds. Wash all surfaces, including wrists, palms, back of hands, between fingers and under nails. Rinse off the soap and dry your hands, between fingers and under nails. Rinse off the soap and dry your hands with a clean towel to turn off the faucet. If you used paper towels, throw them in the trash. To avoid dry or chapped hands, pat them dry and use lotion after washing.

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 finger, until they are dry.

Proper Handling and Disposal of Items

Some items that are not sharp: such as paper cups, tissues, dressings, bandages, plastic equipment, catheters, incontinence supplies, plastic tubing, gloves, etc. should be stored in a clean dry area. Throw away used items in waterproof bags. Fasten the bags securely and throw them in the trash.

Non-Disposable Items and Equipment

Some items that are not thrown away may include: 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. Store them in a clean, dry place. Wipe off equipment with a normal disinfectant or bleach mix. Follow the cleaning instructions that came with the item and ask your nurse or therapist if you have any questions. Pour liquids down the toilet. Clean their containers with hot, soapy water. Rinse with hot water and let them dry.

Sharp Objects

Some examples of sharp items you might encounter include: needles, syringes, lancets, scissors, blades, staples, glass tubes and bottles, IV catheters, razors, etc. Put used sharp items 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 sharp containers or re-cap used needles. Do not use glass or clear plastic containers. Never put sharp items 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.

Symptom Management

Pain Management

Discuss with your physician or your hospice nurse any concerns or questions you have about your pain management. Following are a few of the common concerns or questions of hospice patients.

If I have a lot of pain, does that mean I'm in bad shape? Pain is not a measurement of disease advancement. Some people have severe pain early in the disease process, others have no pain. Pain depends solely on the location and involvement of the disease not on how far along it is.

How will my pain be controlled? Your physician and nurse will work with you so you are as pain free and alert as possible. The nurse will ask you at each visit how your pain and comfort have been and will need honest answers from you about your pain.

Should I only take my pain medicine if it gets really bad? It is proven that the best way to control pain is to prevent pain. Your physician and nurse will encourage you to take your pain medicine at regular intervals rather than only when needed. For example: every 4,6,8, or 12 hours. You'll sleep better and generally feel better if you keep your pain under control.

What is the correct dose I should be taking? The correct dose of pain medicine is the dose that relieves your pain and is within the orders prescribed by your doctor.

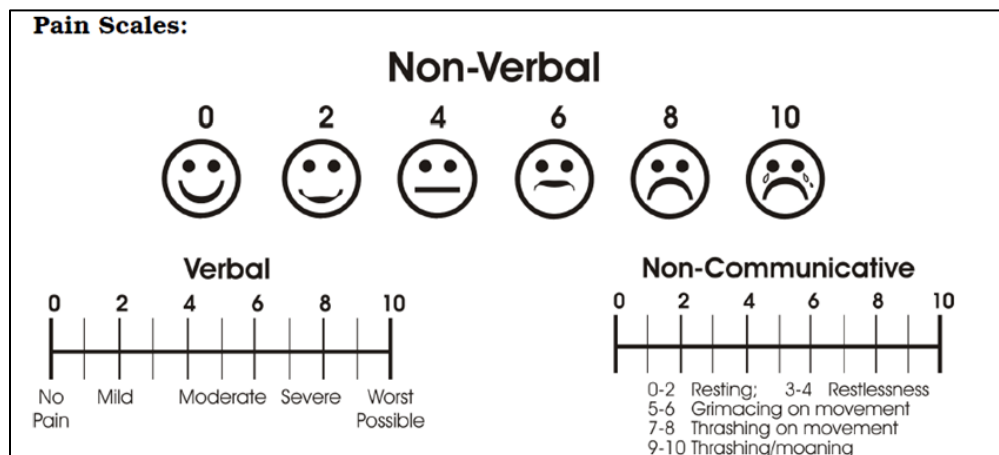
If I take pain medications, such as narcotics, will I sleep all the time? It is normal to experience mild drowsiness the first two to three days when narcotics are prescribed. This is due to your body getting much needed rest. Fighting pain is exhausting. After the first few days, you will feel and sleep better as your pain will be under control. Narcotic medication is often in a long-acting form, so you can have longer pain relief.

If I take pain medicine too often, will I get addicted? You will not become addicted because there is a real need for the medication – pain relief. If you take medication to relieve pain, you are not an addict, nor will you become tolerant to pain medications.

What if I can't swallow? There are many ways to deliver pain medication. If you have difficulty swallowing, other ways will be suggested. Other options are equally as effective as oral. Some examples include rectal, under the tongue, under the skin, through a patch, or IV.

What if I don't want to take morphine because it's so strong and is used as the last resort? Morphine is no longer viewed as a last resort for pain control. It is easy to use, easy to change, offers the best relief for people who have pain and has a very wide window of safety. Studies have shown many ideas about morphine are not correct.

I've heard there are side effects from taking narcotics. Is there anything that can prevent these side effects? To prevent the common side effects from narcotics, your physician and nurse will suggest such medications as laxatives, anti-nausea medications, and anti-histamines. If you experience side effects, please report them to a team member.



Nutrition

Nutrition is an important part of our lives from the time we take our first breath as an infant. Our culture places much importance on meal planning and social interactions centered on food. Often feeding and preparing meals for a loved one is a non-verbal way of communicating love, concern, and caring.

Whenever anyone is ill, it is common for his or her appetite to decrease, whether the illness is the flu or a cancer-related process. The body's need for calories and other nutrients is altered because of the change in activity and the change in metabolic rate, due to the disease process.

Many hospice patients experience one or more of the following problems that interfere with nutrient intake: decrease or loss in appetite, nausea, vomiting, chronic pain, diarrhea and constipation. This makes it difficult to find the right kind of foods that are well tolerated and accepted by the patient. Sometimes this means looking to foods that have more calories per bite.

Too often food becomes a challenge between the patient and the caregiver. Please allow the patient to eat what and when he/she desires. Disease processes may cause aversions to foods they used to like. Below are some common concerns and suggestions. For increased nutritional needs such as calorie dense foods, protein, fluids, vitamins and or minerals, please speak with your hospice nurse.

When it is difficult to swallow liquids or solids:

- Thin liquids are usually the most difficult to swallow, softer blended foods are sometimes easier to swallow. There is also commercial thickener available.
- If mucus is a problem, then cranberry, pineapple or citrus juice may be helpful in cutting or thinning the mucus. If milk products increase mucus production, a dairy-free nutritional supplement can be used.
- For further information on swallowing difficulties or for special products, contact the hospice nurse.

When you are just not hungry:

- Keep snacks handy and in sight for nibbling.
- Drinks made with ice cream or smoothies may be helpful.
- High calorie snacks that are a few bites to eat.
- Breakfast foods are often well tolerated. Do not feel that a particular food should be eaten at a particular time.
- **Eat whatever you like, whenever you like.**
- Try eating small meals with snacks in between. Small meals may even be just one item.
- Imagine a flower at the end of its season. Additional water and nutrients in the pot will only cause the plant to be flooded. The body at the end of life is much the same. Extra food and water can end up sitting in the patient's stomach or going into the tissues instead of being utilized. If the patient is reporting a lack of appetite or refusing to eat, it is often a natural response to the body not being able to digest and use the food. **Do not force a patient to eat or drink.**

When you are nauseated:

- Eat frequent small meals.
- Choose bland foods that are not greasy or too sweet, such as chicken noodle soup with saltine crackers, gelatin with fruit and apple juice.
- Drink liquids between meals rather than at mealtimes. Clear, cool beverages are usually better tolerated. Popsicles and flavored ice cubes are also good choices.
- Dry foods such as toast and crackers are usually well tolerated.
- Do not lie down for at least two hours after eating. Sit up or recline with your head at least four inches above your feet.

When your mouth or throat is sore or dry:

- Take small bites of food and take a swallow of beverage with each bite.
- Try cold foods such as Popsicles, sherbet ice cream, fruit ices, milk shakes, and ice chips. Sometimes eating ice-cold foods first may make eating other foods more tolerable.
- Sometimes using a straw can make swallowing more comfortable.
- Smooth foods such as whipped cream, pudding cream pies, canned fruits or gelatins are usually less irritating to the mouth or throat.
- Creamed soups and other creamed foods are often well tolerated. Keep temperatures warm rather than piping hot.
- Drink soothing beverages such as apple juice, peach or pear nectar and milk (if tolerated). Carbonated beverages, salty liquids (such as broth or vegetable juices), citrus juices (containing acid) and spicy foods may irritate a sore mouth or throat.

Bowel Management

Most hospice patients have some difficulty with their bowel movements. There are several reasons why you may be constipated. Changes in your diet, decreased fluid intake or decreased activity may contribute to constipation: however, the use of pain medications (narcotic analgesics) is usually the major cause of constipation.

Untreated constipation can lead to a more serious condition (impaction or bowel obstruction) and a daily bowel program can help to prevent such problems. The overall goal is to have a bowel movement approximately every three (3) days. The following guidelines should help you maintain normal bowel function.

- Drink plenty of liquids, especially in combination with high-fiber foods. Tea, hot lemon water and juices, such as prune juice, may be effective.
- Try to have a bowel movement at the same time of the day. Be sure to allow adequate time on the toilet or bedpan.
- Keep a record of your bowel movements and note whether they are hard or soft.
- Take your stool softener/laxative pill as prescribed. The dose can range from two to eight (2-8) pills per day or more if needed. Examples of such preparations are Peri-Colace®, Senokot S®, or Doxidan®.

- Other laxative preparations can be added if the stool softener/laxative pill alone does not work. Examples are Dulcolax®, milk of magnesia, or lactulose.
- Call the nurse if you do not have a bowel movement in three (3) days. It might be necessary for you to have a rectal suppository, and enema, or be checked for a stool impaction.
- Call the nurse if you have any of the follow symptoms:
 - Abdominal distention or bloating
 - Rectal pain with your bowel movement
 - The urge but inability to pass stool
 - Oozing of liquid stool
 - No bowel movement for several days
 - Rectal fullness and pressure

Primary Caregiver Guidelines

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 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 a 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, and utilizing special equipment. It may include filling prescriptions, communicating with the hospice team, and making final arrangements. Generally, it means being available to your loved one to listen, to touch, to share, and to be present.

Your individual hospice team is pledged to support you in every possible way as you undertake this role. We will help you deal with your limitations and frustrations. We will help you arrange

for supportive services that are needed in the home. We will help facilitate utilization of respite care and inpatient care as needed. We will help you deal with your own feelings and how this situation is affecting your life, your needs, and your hopes. We will help you clarify your choices, your available alternatives, and resources. We will help you make decisions based on your values, priorities, and beliefs, and implement them in the most helpful manner. We 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. Additionally, we will seek to help you anticipate these changes and implement procedures, so they do not become big problems or out-of-control situations. It is our 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.

- Love yourself at least as much as you love the one you are caring for.
- Get enough rest, perhaps a nap during the day.
- Conserve your energy.
- Exercise. Even a short walk gives energy and helps you sleep better.
- Eat well and drink plenty of water.
- Think about what has helped you cope with stressful situations in the past. Talk to your hospice team about what helps you cope with stress and have a plan for when things seem overwhelming.
- Take breaks to think about other things.
- Pay attention to what your body is telling you.
- Nurture your spiritual needs. Pursue things that are uplifting to you. When you are at peace it will help your loved one be at peace too.
- Pamper yourself a bit, especially on difficult days. Be patient with yourself.
- Avoid unrealistic expectations of yourself.
- Make a list of how others can help you so, when they offer, you can be prepared to accept.
- Set limits. It is OK to say “no” sometimes.
- Recognize your needs and limitations.

Tips for Helping Loved Ones

- Allow them to talk. Listen without judgement and with only occasional comment.
- Acknowledge and validate their feelings.
- Avoid taking any negative feeling 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.

- 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.**

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, 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 prepare 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 let go. For patients 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 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 would like to see, the patient may linger even though very debilitated. Ultimately, it is impossible to predict when a person will die. We will try our best to help you identify changes that indicate the time is drawing near.

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 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 that 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 whiteboard 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 must 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 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 physical decline.

Stops Eating and Drinking: 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 Decreases: 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. Breathing may be noisy but does not indicate pain or distress. Elevating the head may help.

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 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 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 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, 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 indicate something is unresolved or unfinished and is disturbing and prevent 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. 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 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.;" or "thank you."

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

Please call the office.

We will call the funeral home for you.

Heart Of Acara Foundation

Many families choose to designate memorial gifts to the Acara Foundation as a meaningful remembrance of a loved one. Gifts can also be made in honor of an individual as a unique way of expressing appreciation or recognizing a birthday, anniversary, or other special event.

You may designate the Acara Foundation as beneficiary of memorial contributions so that family and friends can make donations in memory of your loved one. Please note that donations are also tax deductible.

Contributions may be made to:

Acara Foundation

Enclosed is my/our gift of \$ _____

Name of Donor: _____

Phone: _____

Address: _____

City: _____

State: _____ Zip: _____

Name of Person Being Memorialized Honored:

Your contributions will be used to assist patients with terminal illness with financial burdens like rent, utilities, or food or in aiding with meeting their end-of-life wishes. This may include helping to make a visit with a family member possible or supporting an activity like a fishing outing or trip to a beauty salon. The donations are also used to support activities like Honoring our Heroes which provides a small "thank you" ceremony for Veterans at the end of life. We thank you for considering a donation to this foundation.