

Be Loved



HOSPICE

Patient
Resource
Handbook



Notes

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Important Names & Phone Numbers

BeLoved Hospice, Inc.

main: .971.236.1199

fax: 971.414.6111

670 Hawthorne Ave SE, Suite 160
Salem, OR 97301

25195 SW Parkway Ave, Suite 200
Wilsonville, OR 97070

Your Hospice Team

Case Manager

Attending Physician

Hospice Physician

Social Worker

Doula

CNA / Aide

Massage Therapist

Music Therapist

Call BeLoved Hospice at **971.236.1199** 24 hours a day, 7 days a week with any questions or concerns!



Welcome Message

Dear Friend,

Welcome to BeLoved Hospice and thank you for allowing us to provide hospice care for you and your family. We understand that coping with a life-limiting illness can be extremely challenging for both the patient and their loved ones. We strive to offer you the best care possible to provide ease and comfort for both physical and emotional symptoms. At BeLoved Hospice, we have tailor-made your hospice plan to suit your individual needs. Should you feel the need to change anything about the care that you receive from us, please feel free to contact us directly at 971.236.1199.

The contents of this Patient Resource Manual are designed to be a wealth of information about hospice care. We hope to introduce you to the history and philosophy of the hospice movement and describe the programs and services that we offer today. Keep this manual close by to use as a resource throughout your hospice journey. If you have any questions, we are just a phone call away.

Again, we thank you for the opportunity that you have given us and sincerely hope that we can meet and exceed your expectations.

Sincerely,

A handwritten signature in black ink, reading "Amber Perelgut". The signature is fluid and cursive, with a long horizontal line extending from the end of the name.

Amber Perelgut
Administrator



BeLoved Hospice

MISSION

BeLoved Hospice is committed to providing comfort, support and dignity to patients and their loved ones on their journey through end-of-life care. BeLoved Hospice believes that valuing each patient as an individual is the most important aspect of care that we can give.

BeLoved Hospice strives to be an advocate and educator in the community about the benefits of hospice and palliative care both for the patient and those who love and care for them.

SERVICES

- Nursing
- CNA
- Physician
- Hospice Massage
- Acupuncture
- Naturopathic Doctor
- Psychosocial Services
- Spiritual Support
- Music Therapy
- Hospice Doula
- Bereavement and Grief Support

Hospice Overview

OFFICE HOURS

Our office hours are Monday through Friday from 8:00 a.m. to 5:00 p.m., except during certain holidays. You may reach the office and clinical staff by calling 971.236.1199.

ON-CALL

BeLoved Hospice is available 24 hours a day 7 days a week at 971.236.1199.

A Nurse is available 24 hours a day, 7 days a week to assist you with problems or concerns after regular office hours, on weekends, and on holidays. We will speak with you or your representative by phone to determine your needs. When appropriate, a nurse will come to your place of residence. We are available after regular office hours for emergencies and urgent issues.

DO NOT CALL 9-1-1 BEFORE CALLING THE ON-CALL NURSE.

SHOULD YOU CALL 9-1-1, THIS MAY NOT BE A COVERED HOSPICE EXPENSE.

EXAMPLES OF AFTER-HOURS SITUATIONS

Pain that does not respond to medication on hand.

- Difficulty breathing.
- New onset agitation or restlessness.
- Falls where a possible injury has occurred.
- No urine output within the last 8 hours associated with pain or discomfort.
- Uncontrolled nausea, vomiting, or diarrhea.
- Uncontrolled bleeding.
- Temperature above 101°F that does not respond to Tylenol.
- Catheter leaking.
- Chest pain.
- Patient/family/caregiver considering admitting the patient to the hospital.
- Patient death.

THE HOSPICE CONCEPT

Hospice differs from other types of health care. Hospice focuses on caring, rather than curing. Under the direction of a physician, hospice uses specialized methods of pain and symptom control that enable the patient to live as fully and comfortably as possible.

Hospice treats the person, not the disease. The interdisciplinary hospice team is composed of professionals who can address the medical, emotional, psychological, and spiritual needs of the patient and those who love them.

Hospice emphasizes quality rather than length of life. Hospice neither hastens nor postpones death; it affirms life and

regards dying as a normal process. Just as doctors and midwives lend support and expertise during the time of child-birth, hospice provides its presence and specialized knowledge during the dying process. The hospice movement stresses human values that go beyond the physical needs of the patient.

Hospice considers the entire family, not just the patient, as the “unit of care”. Patients and their families are included in the decision-making process and bereavement counseling is provided after the death of their loved one.

Hospice offers help and support to the patient and family on a 24-hours-a-day, seven-days-a-week basis. For hospice patients and their loved ones, help is just a phone call away. Patients routinely receive periodic in-home services from a nurse, hospice aide, social worker, spiritual care counselor, volunteer, and other members of the hospice interdisciplinary group.

HOW DID HOSPICE BEGIN?

The concept of providing specialized care for dying patients, linking pain and symptom control with compassionate care, began in England in the 1950s when a physician named Dame Cicely Saunders created the first modern hospice in 1967.

Hospice care found widespread use in the U.S. since then. The ideas popular in the U.K. began taking root here when a physician, Dr. Elisabeth Kubler-Ross interviewed 500 dying patients for a book she published in 1969 called, "On Death and Dying", which went on to become an international bestseller. In the book, she made a plea for home care as opposed to treatment in an institutional setting and argued that patients should have the ability to participate in that decision-making.

Years later, an oncologist named Dr. James Hampton from the US was inspired to initiate the first U.S. hospice program, Hospice of Central Oklahoma, in 1980.

Hospice Levels of Care

There are four levels of care in hospice. Your level of care is determined by your hospice needs and is managed by the interdisciplinary team assigned to you.

Routine Home Care: Routine Home Care is care that is provided intermittently by hospice team members in the patient's place of residence, whether that be a private home, a skilled nursing facility, an assisted living facility, or a foster/group home.

General Inpatient Care: Care is provided at a contracted hospital, skilled nursing facility, or inpatient hospice facility for patients who need pain control or acute symptom management which cannot be managed in the home setting. The necessity for inpatient care and paid length of stay will be determined by the hospice interdisciplinary group. If a hospice patient needs hospitalization for any reason unrelated to their terminal prognosis, traditional Medicare Part A benefits will be utilized.

Inpatient Respite Care: Up to five (5) days of respite care at a contracted hospital, nursing facility, or inpatient hospice facility will be paid by the hospice, if approved by the hospice interdisciplinary team. This benefit may be used to give the family/caregiver a rest if the patient does not meet acute care standards.

Continuous Home Care: Criteria for continuous home care is the same as general inpatient care and consists predominantly of nursing care; however, hospice aides may also supplement nursing care.

The Hospice Team

CHIEF MEDICAL OFFICER / HOSPICE PHYSICIAN / NURSE PRACTITIONER

The Chief Medical Officer / Hospice Physician / Nurse Practitioner works in concert with your own Attending Physician to determine the best care possible. The Chief Medical Officer / Hospice Physician / Nurse Practitioner as your Attending Physician in case you don't have one or would like to have all of your care combined with the hospice team. The Chief Medical Officer or Hospice Physician is charged with the general oversight of the medical care for hospice patients. This practitioner group routinely reviews the care provided to patients and makes changes or recommendations about pain and symptom control as needed.

SOCIAL WORKER

Hospice Social Workers work closely with you and your family to create and maintain a supportive in-home care system to ensure the patient's safety and comfort and to address the special needs of caregivers. Hospice Social Workers are available to help you and your family address the many personal, financial, emotional, and care-planning issues that arise during the course of your hospice journey.

The Hospice Social Worker is able to:

- Identify community resources and help with referrals to them.
- Determine eligibility for state and local assistance programs and make referrals when necessary.
- Clarify insurance coverage and answer questions regarding financial concerns.
- Help you and your family arrange for added caregiving support at home or in an alternative care setting.
- Listen to your concerns and provide emotional support.

RN CASE MANAGER

The RN Case Manager's primary goal is to provide symptom management and comfort.

The RN Case Manager will:

- Assess your comfort and any symptoms which may need attention.
- Work in coordination with your Attending Physician and Hospice Physician to manage symptoms.
- Perform procedures such as placing and maintaining catheters, wound care, etc.
- Teach you and your caregivers the proper use of medications and/or medical treatments.
- Suggest and help in obtaining needed equipment and services.
- Listen to your concerns and offer support.



CHAPLAIN / SPIRITUAL CARE COUNSELOR

The Chaplain/Spiritual Care Counselor is available to help with spiritual concerns which may arise. Sometimes a listening ear or a thoughtful reading can help you find meaning in the midst of a difficult time. The Chaplain/Spiritual Care Counselor uses a non-denominational approach and can also help connect you with various religious organizations if that is your desire. The Chaplain/Spiritual Care Counselor is often times a member of the clergy but is not intended to replace your pastor, minister, rabbi, or priest.

The Chaplain/Spiritual Care Counselor is able to:

- Meet with you and/or your family to share hopes, fears, dreams, and concerns, whether spiritual or otherwise.
- Support you in your exploration or struggles with spiritual or emotional issues.
- Provide spiritual counseling, respecting your personal beliefs.
- Not impose any particular religious orientation or affiliation.
- Pray with you and your loved ones, if requested.
- Be available to assist you in planning a funeral, memorial service, or other observance you wish to have conducted if requested.
- Help obtain clergy services from the church or denomination of your choice.

Note: Our agency is not affiliated with any religious organization. Our hospice serves a broad community and does not require patients to adhere to any particular set of beliefs.

HOSPICE AIDE

Hospice Aides or Certified Nursing Assistants (CNAs) provide personal care needs. The Hospice Aides work closely with the nurses and other hospice team members to provide assistance with personal care needs.

The Hospice Aide may:

- Bathe or shower the patient.
- Provide skincare and grooming.
- Change the bed linens and provide light housekeeping.
- Assist with transferring and toileting.
- Provide additional companionship.

THERAPY SERVICES

Physical, Occupational, Speech, and Massage Therapists are available to assist in promoting the quality of life and safety of you and your family with a focus on comfort care. Your RN Case Manager can help determine if a referral to one of these therapists may be appropriate.

The Therapist may:

- Evaluate medical equipment needs.
- Provide or assist in arranging for equipment as needed, such as hand-held showers, bath seats, walkers, canes, and other assistive devices.
- Identify safety hazards and teach transfer skills and energy-saving techniques to maintain safety for you and your caregivers.
- Practice relaxation and breathing treatments to promote comfort and a clear mind.
- Evaluate communication or swallowing difficulties and recommend ways of handling these.

DIETARY COUNSELOR

Dietary counseling may be provided by a dietician, nurse, or another qualified staff member to address and ensure that the patient's dietary needs are met. This may include evaluation and suggestions for an alternative diet.



HOSPICE VOLUNTEER

The Hospice Volunteer Coordinator works closely with all of the interdisciplinary team members to determine how a volunteer and the various services they offer may benefit both the patient and the caregivers. With patient/family approval, the Volunteer Coordinator will assign a volunteer as appropriate and available and will supervise the volunteers.

The Hospice Volunteer is an important member of the hospice care team and performs duties to supplement, but does not substitute for professional services. The Volunteer can provide an empathetic, non-judgmental, listening, and caring presence for both patients and their caregivers. Volunteers, like employees, receive training before they are assigned to a patient or family.

Volunteers can:

- Provide companionship.
- Read to patients.
- Provide limited respite for the family as determined in the plan of care.

BEREAVEMENT COORDINATOR

Hospice is committed to serving and providing support for family and friends both before and after the death of a patient. A bereavement program is an important aspect of this commitment. The program provides a variety of services to the family to help them cope with grief and loss after the death of a loved one.

The Bereavement Coordinator is able to:

- Provide short-term counseling for individuals, couples, or families.
- Provide supportive grief seminars or support groups.
- Complete referrals to other community resources available in your area.
- Follow up after the death of your loved one.
- Provide information on coping with grief and loss.



Who Qualifies for Hospice Care?



Hospice Provides Services for Patients Diagnosed With End-Stage (But Not Limited To):

- Amyotrophic Lateral Sclerosis
- Cancer
- Dementia
- Heart Disease
- HIV/AIDS
- Huntington's Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Myasthenia Gravis
- Parkinson's Disease
- Pulmonary Disease
- Renal Failure
- Stroke
- Pulmonary Disease
- Renal Failure
- Stroke

Hospice care is available to anyone. You will be given appropriate and professional hospice care without discrimination regardless of race, age, gender, creed, religion, disability, sexual orientation, financial status or place of residence.

What is Covered Under Hospice?

Care is delivered through a coordinated team of hospice professionals consisting of:

- Attending & Hospice Physician
- Registered Nurses & Licensed Practical Nurses Social Workers
- Chaplains/Spiritual Care Coordinators Certified Nursing Assistants
- Volunteer Services
- Medications related to the terminal prognosis and symptoms
- Usual and customary medical supplies and equipment such as hospital beds, commodes, oxygen, walkers, and wheelchairs
- Short-term continuous care for crisis management
- Counseling services to patients and family or loved ones
- Short-term respite care
- In-patient care for uncontrolled symptom management
- Bereavement services
- Nurse available for emergencies 24 hours a day 7 days a week

Hospice care is covered at 100% under Medicare and Medicaid. Most major insurance companies also have a hospice benefit.

Your Rights and Responsibilities as a Hospice Patient

As hospice providers, 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 and before care is provided on an ongoing basis.

AS A HOSPICE PATIENT, YOU HAVE THE RIGHT TO:

- Exercise your rights as a hospice patient without discrimination or reprisal for doing so. Your court-appointed representative or the legal representative you have selected in accordance with state law may exercise these rights for you in the event that you are not competent or able to exercise them for yourself.
- Upon request, receive access to a listing of licensed hospice agencies in your area, and select any licensee to provide care, subject to your insurance reimbursement or other relevant contractual obligations.
- Choose your attending physician and other health care providers and communicate with those providers. To have a friend, family member, or advocate present during appointments and at other times as needed within clinical guidelines.
- Be able to identify visiting personnel members through proper agency-generated photo identification.
- Receive care from a team of professionals who will provide high-quality, comprehensive hospice services, as needed and as appropriate for you and your family. To be assured the personnel who provide care are qualified through education and experience to carry out the services for which they are responsible.
- Receive care and services that are respectful of your cultural, spiritual, and social values and provided without regard to your race, color, religion, creed, age, gender, sexual orientation, disability (mental or physical), communicable disease, or place of national origin and will not be subjected to discrimination or reprisal for exercising his/her/their rights. For more information, please see our Notice of Non-Discrimination within this manual.
- Have your property and person treated with respect.
- Receive respectful and compassionate care and support that promotes your dignity, privacy, safety, comfort, individuality, and independence, and that manages your pain and symptoms as well as possible.
- Be free from mistreatment, neglect, verbal, mental, sexual, and physical abuse, injuries of unknown source, misappropriation of your property, and to be free from unlawful restraint or seclusion. All mistreatment, abuse, neglect, injury, and exploitation complaints by anyone furnishing service on behalf of BeLoved Hospice are reported immediately by our staff to the Hospice Administrator. All reports will be promptly investigated and immediate action is taken to prevent potential violations during our investigation. The hospice will take appropriate corrective action in accordance with state law. All verified violations will be reported to the appropriate state and local authorities within five (5) working days of becoming aware of the violation.
- Understand the availability of and access to hospice services and the hospice team 24 hours a day, 7 days a week.
- Be informed of your health status in order to participate in planning for your care, unless medically contraindicated and documented in the clinical record, and to be afforded the opportunity to participate in the planning of hospice services, including referral to health care institutions or other agencies and to participate in experimental research.
- Be informed of the potential benefits and risks of all medical treatments and/or services suggested, and accept, discontinue, or refuse those treatments and/or services as appropriate to your personal wishes.
- 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; and expect that your advance directives will be followed, when applicable. For more information, please see our section about Advance Directives in this manual.
- Have your family and/or caregivers trained to care for you if you cannot care for yourself. Have an environment within an inpatient facility that preserves dignity and contributes to a positive self-image.

- Restrict visitors or have unlimited contact with visitors and others and communicate privately with these persons when residing in an inpatient facility.
- Be informed, in advance, about the services covered and non-covered under the hospice benefit, the scope of services hospice will provide, service limitations, name(s) and treatment of services, the planned frequency of visits proposed to be furnished, expected and unexpected outcomes, potential risks or problems and barriers to treatment. To be notified in a timely manner of appointment cancellations and a plan for meeting patient needs if backup care is needed.
- Be involved in developing your hospice plan of care and 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 plan of care before the change is made, including the agency discharge policies.
- Receive effective pain management and symptom control from the hospice for conditions related to your terminal prognosis.
- Confidentiality of written, verbal, and electronic information including your medical and personal records, and to have access to your medical record.
- Request us to release information written about you only as required by law or with your written authorization.
- Voice grievances 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 or concerning suspected abuse/neglect, without being subject to discrimination or reprisal; to have hospice investigate any such complaints; and to be informed of the procedures to file a complaint with the hospice and any local or state authorities.
- Raise ethical issues concerning your care with your hospice team and participate in their resolution.
- Know, in advance, of any fees or charges for which you may be liable. You have a right to access any insurance or entitlement program for which you may be eligible.
- Request and receive explanations regarding your bill, including payments, insurance status, and charges, and to have help determining financial needs and assistance.
- Withdraw from the program at any time and be assisted in obtaining alternative services.
- Recommend changes in Agency policies and Procedures, personnel, or care/service.
- Disclosure of any financial information, including potential financial benefit, when coordinating referrals to other agencies for services.



YOUR RESPONSIBILITIES AS A HOSPICE PATIENT ARE TO:

- Provide hospice with accurate and complete health information.
- Participate as able in decisions about your medical treatment and the plan of care agreed upon by you and your hospice interdisciplinary group.
- Understand and accept the consequences for the outcome if you do not follow the plan of care agreed upon by you and your hospice team.
- Remain under a physician's care while receiving hospice services.
- Inform your physician or other members of the hospice team if you do not understand your diagnosis or treatment, or if you desire a transfer of care to another physician or another hospice program.
- Ask your physician or hospice team when you do not understand any information or instructions.
- Accept your financial obligations associated with your care and provide appropriate financial information when requesting financial assistance, if needed.
- Follow hospice policies and procedures concerning patient care, safety, and conduct.
- Show respect and consideration for hospice personnel and property.
- To accommodate hospice clinicians' reasonable requests during visits that will allow for a safe environment for both the clinician and patient to perform necessary care delivery functions (including, but not limited to the storing/putting away of firearms or weapons, the extinguishing of smoking materials during the visit, and securing of any animals/pets that may cause a distraction during the visit).



Notice of Privacy Practices

BeLoved Hospice and its professional staff of physicians, nurses, support staff, volunteers, and affiliated entities follow the privacy practices described in this manual. BeLoved Hospice maintains your medical information and records in a confidential manner, as required by law. However, BeLoved Hospice may use and disclose your medical information to the extent necessary to provide you with quality healthcare. To do this, BeLoved Hospice must share your medical information, as necessary for treatment, payment, and health operations. A detailed explanation of our HIPAA practices is enclosed within this manual.

HIPAA PRIVACY POLICY:

BeLoved Hospice understands that your health information is highly personal and we are committed to safeguarding your privacy. Please read this Notice of Privacy Practices thoroughly. It describes how BeLoved Hospice may use and disclose your Protected Health Information (PHI).

BELOVED HOSPICE (“PROVIDER”) PRIVACY NOTICE:

Our Pledge To You – Your health information, which means any written or oral information that we create or receive that describes your health condition, treatment, or payments, is personal. Therefore, the Practice pledges to protect your health information as required by law. We give you this Privacy Notice to tell you (1) how we will use and disclose your “protected” health information or PHI and (2) how you can exercise certain individual rights related to your PHI as a patient of our practice. Please note that if any of your PHI qualifies as mental health records, alcohol or drug treatment records, communicable disease records, or genetic test records, we will safeguard these records as “Special PHI” which will be disclosed only with your prior express written authorization, pursuant to a valid court order or as otherwise required by law.

How We Will Use And Disclose Your PHI – To Provide Treatment. We may use and disclose your PHI to provide, coordinate or manage your health care and any related services. This includes the management or coordination of your health status and cares with another healthcare provider. For example, we may disclose your PHI to a pharmacy to fill a prescription or to a laboratory to order a blood test. We may also disclose your PHI to another physician who may be treating you or consulting with us regarding your care.

To Obtain Payment. We may also use and disclose your PHI, as needed to obtain payment for services that we provide to you. This may include certain communications to your health insurer or health plan to confirm (1) your eligibility for health benefits, (2) the medical necessity of a particular service or procedure, or (3) any prior authorization or utilization review requirements. We may also disclose your PHI to another provider involved in your care for the other provider’s payment activities. For example, this may include disclosure of demographic information to another physician practice that is involved in your care, or to a hospital where you were recently hospitalized, for payment purposes.

To Perform Healthcare Operations. We may also use or disclose your PHI, as necessary, to carry on our day-to-day healthcare operations and to provide quality care to all of our Patients, but only on a “need to know” basis. These healthcare operations may include such activities as quality improvement, physician and employee reviews, health professional training programs, including those in which students, trainees, or practitioners in healthcare learn, under supervision, accreditation, certification, licensing or credentialing activities, compliance reviews and audits, defending a legal or administrative claims, business management development, and other administrative duties. In certain situations, we may also disclose your PHI to another healthcare provider or health plan to conduct their own particular healthcare operation requirements.

To Contact You. To support our treatment, payment, and health care operations, we may also contact you at home, either by telephone or mail, from time to time to remind you of an upcoming appointment date or (2) to ask you to return a call to the Practice unless you ask us, in writing, to use alternative means to communicate with you regarding these matters. We

may also contact you by telephone to inform you of specific test results or treatment plans, but only with your prior written authorization.

To Be In Contact With Your Family or Friends. Additionally, we may also disclose certain items of your PHI to your family members or other relatives, a close personal friend, or any other person specified by you from time to time, but only if the PHI is directly related to (1) the person's involvement in your treatment or related payments or (2) to notify the person of your physical location or a sudden change in your condition while receiving treatment from our staff. Although you have a right to request reasonable restrictions on these disclosures, we will only be able to grant those restrictions that are reasonable and not too difficult to administer, none of which would apply in case of an emergency.

To Conduct Research. Under certain circumstances, we may use and disclose certain items of your PHI for research purposes, but only if the research is subject to special approval procedures and the necessary rules governing uses and disclosures are agreed to by the researchers. For example, a research project may compare two different medications used to treat a particular condition in two different groups of patients by comparing the patients' health and recovery in one group with the second group. Any other research will require your written authorization.

According to Laws That Require or Permit Disclosure. We may disclose your PHI when we are required or permitted to do so by any Federal, State, or Local law, as follows:

- **When There Are Risks to Public Health.** We may disclose your PHI to (1) report disease, injury, or disability, (2) report vital events such as births and deaths, (3) conduct public health activities, (4) collect and track FDA-related events and defects, (5) notify appropriate persons regarding communicable disease concerns or (6) inform employers about particular workforce issues.
- **To Report Suspected Abuse, Neglect, or Domestic Violence.** We may notify government authorities if we believe that a Patient is the victim of abuse, neglect, or domestic violence, but only when specifically required or authorized by law or when the Patient agrees to the disclosure.
- **To Conduct Health Oversight Activities.** We may disclose your PHI to a health oversight agency for activities including audits; civil, administrative, or criminal investigations, proceedings or actions, inspections, licensure, or disciplinary actions, or other activities necessary for appropriate oversight, but we will not disclose your PHI if you are the subject of an investigation and your PHI is not directly related to your receipt of health care or public benefits.
- **In Connection With Judicial and Administrative Proceedings.** We may disclose your PHI in the course of any judicial or administrative proceedings and in response to an order of a court or administrative tribunal. In certain circumstances, we may disclose your PHI in response to a subpoena if we receive satisfactory assurances that you have been notified of the request or that an effort was made to secure a protective order.
- **For Law Enforcement Purposes.** We may disclose your PHI to a law enforcement official to, among other things, (1) report certain types of wounds or physical injuries, (2) identify or locate certain individuals, (3) report limited information if you are the victim of a crime or if your health care was the result of criminal activity, but only to the extent required or permitted by law.
- **To Coroners, Funeral Directors, and for Organ Donations.** We may disclose PHI to a coroner or medical examiner for identification purposes, to determine the cause of death, or for the coroner or medical examiner to perform other duties. We may also disclose PHI to a funeral director in order to permit the funeral director to carry out their duties. PHI may also be disclosed for organ, eye, or tissue donation purposes.
- **In the event of a Serious Threat to Health or Safety, or for Specific Government Functions.** We may, consistent with applicable law and ethical standards of conduct, use or disclose your PHI if we believe, in good faith, that such use or disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public, or for certain other specified government functions permitted by law.
- **For Worker's Compensation.** We may disclose your PHI to comply with Worker's Compensation laws or similar programs.
- **With Your Prior Express Written Authorization.** Other than stated above, we will not disclose your PHI or more importantly, your Special PHI, without first obtaining your express written authorization. Please note that you may revoke your

authorization in writing at any time, except to the extent that we have taken action in reliance upon the authorization.

Your Individual Rights Concerning Your PHI.

- **A Right to Inspect and Copy Your PHI.** You may inspect and obtain a copy of your PHI that we have created or received as we provide your treatment or obtain payment for your treatment. A copy may be made available to you, either in paper or electronic format. Under Federal law, however, you may not inspect or copy the following records: psychotherapy notes, information compiled in reasonable anticipation of, or for use in a civil, criminal, or administrative action or proceeding, and PHI that is subject to a law prohibiting access.
- **The Right to Request Restrictions on How We Use and Disclose Your PHI.** You may ask us not to use or disclose certain parts of your PHI but only if the request is reasonable. You may also ask us not to disclose your PHI to certain family members or friends who may be involved in your care or for other notification purposes described in this Privacy Notice, or how you would like us to communicate with you regarding upcoming appointments, treatment alternatives, and the like by contacting you at a telephone number or address other than at home. Please note that we are only required to agree to those restrictions that are reasonable and which are not too difficult to administer. We will notify you if we deny any part of your request, but if we are able to agree to a particular restriction, we will communicate and comply with your request, except in case of an emergency. Under certain circumstances, we may choose to terminate our agreement to a restriction if it becomes too burdensome to carry out. Finally, please note that it is your obligation to notify us if you wish to change or update these restrictions after your visit by contacting our office directly.
- **The Right to Request Amendments to your PHI.** You may request that your PHI be amended so long as it is a part of our Official Patient Records. All such requests must be in writing and directed to our office directly. In certain cases, we may deny your request for an amendment. If we deny your request for an amendment, you have the right to file a statement of disagreement with us and we may respond to your statement in writing and provide you with a copy.
- **The Rights to Receive an Accounting.** You have the right to request an accounting of those disclosures of your PHI that we have made for reasons other than those for treatment, payment, and healthcare operations, which are specified above. The accounting is not required to report PHI disclosures (1) to those family, friends, and other persons involved in your treatment or payment, (2) that you otherwise requested in writing, (3) that you agreed to by signing an authorization form or (4) that we are otherwise required to be permitted to make by law. As before, your request must be in writing to our office. Accounting requests may not be made for periods of time in excess of six years. 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.
- **The Right to Receive Notice of a Breach.** You have the right to receive written notice in the event we learn of any unauthorized acquisition, use, or disclosure of your PHI that was not otherwise properly secured as required by HIPAA. We will notify you of the breach as soon as possible, no later than sixty days after the breach has been discovered.
- **The Right to File A Complaint.** You have the right to contact our Administrator at any time if you have questions, comments, or complaints about our privacy practices or if you believe we have violated your privacy rights. You also have the right to contact our Privacy Officer or the Department of Health and Human Services Office for Civil Rights in Baltimore, Maryland regarding these privacy matters, particularly if you do not believe that we have been responsive to your concerns. We urge you to contact our office directly if you have any questions, comments, or complaints, either in writing or by telephone as follows:

BeLoved Hospice, Inc.
25195 SW Parkway Ave, Suite 200
Wilsonville, OR 97070
971.236.1199
www.belovedhospices.com

You may also contact the Oregon Health Authority at:

Health License Office
1430 Tandem Avenue NE, Suite 180
Salem, Oregon 97301
Fax: (503) 370-9216
Email: hlo.info@dhsosha.state.or.us

You may also contact the U.S. Department of Health and Human Services at:

Office for Civil Rights
United States Department of Health and Human Services 90 7th Street, Suite 4-100
San Francisco, CA 94103
(415) 437-8310
Fax (415) 437-8329
Online: ocrportal.hhs.gov

Please note that we will not take any action or otherwise retaliate against you in any way as a result of your communications to the Practice or to the Department of Health and Human Services Office for Civil Rights. As always, please feel free to contact us. We look forward to serving you as a patient.



Notice of Non-Discrimination

DISCRIMINATION IS AGAINST THE LAW

BeLoved Hospice complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, religion, sex, sexual orientation, gender identity, national origin, age, disability, or genetic information. BeLoved Hospice does not exclude people or treat them differently because of race, color, religion, sex, sexual orientation, gender identity, national origin, age, disability, or genetic information.

BeLoved Hospice:

Provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats, other formats).
- Provides free language services to people whose primary language is not English, such as:
 - Qualified interpreters; and
 - Information written in other languages

If you need these services, contact your RN Case Manager.

If you believe that BeLoved Hospice has failed to provide these services or discriminated in another way on the basis of race, color, religion, sex, sexual orientation, gender identity, national origin, age, disability, or genetic information, you can file a grievance with:

Amber Perelgut Administrator
c/o BeLoved Hospice
25195 SW Parkway Ave, Suite 200
Wilsonville, OR 97070
Phone: 971.236.1199
Fax: 971.414.6111
amberp@belovedhospices.com

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Amber Perelgut, Administrator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Service, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at:
<https://ocrportal.hhs.gov/ocr/portal/lobby.jsf> or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)
Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>

Advance Directive for Healthcare

An advance directive allows you to state your choices for health or to name someone to make those choices for you if you become unable to make decisions about your medical treatment. In short, an advance directive can enable you to make decisions about your future medical treatment. You can say, “yes” to treatment or “no” to treatment you don’t want.

If you are able to communicate with your doctors, you can tell them your views on the treatment they offer. Advance directives allow people to make their wishes known when they become unable to make health care decisions.

Living Wills

A Living Will is a written declaration stating your wishes regarding the use of life-prolonging medical treatment. If you’re well enough and competent, you tell your doctors what you want and don’t want. The Living Will is only used if you are not able to make your own decisions. In Oregon, the statutes say a Living Will may be used only if you are not able to make your own decisions, you have an incurable and irreversible condition and death is imminent.

Durable Power of Attorney for Health Care

What happens if you’re incapacitated and your living will doesn’t apply? With a Durable Power of Attorney for Health Care, you name the person you want to make medical decisions for you if you become incapacitated and are unable to make your own decisions. Unlike a Living Will, a Durable Power of Attorney for Health Care can be used in any capacity.

Oregon POLST: Portable Orders for Life-Sustaining Treatment®

A POLST is a medical form that you may use to turn your wishes for treatment near the end of life into medical orders.

Who should have a POLST? It is for a person with a serious progressive illness, such as advanced heart disease, advanced lung disease, or cancer that has spread. It is also for someone who is older and frail and might not want all available medical treatments.

Is a POLST the same as the Advance Directive? No. These forms have different purposes and do different things.

A POLST can never be required by a health care professional, care facility, or health system.

COMMON QUESTIONS ABOUT ADVANCE DIRECTIVES

Do I have to write an advance directive?

No. It is entirely up to you. Under the Federal Patient Self-Determination Act, a facility must provide the same care regardless of whether a person has an advance directive.

Where can I get these documents?

Oregon law specifies by statute the suggested forms of a living will and a durable power of attorney for health care. These statutory forms are usually available through your physician, other health care provider, attorney, or The Oregon Health Authority website.

Do I have to use the statutory forms?

You may use or add the language of your own choosing, so long as the documents are in substantially the same form as provided in the statute. The durable power of attorney for health care has several sections where the statute allows you to write in your own specific wishes.

Can I change my mind?

Yes. You may change or cancel these documents, at any time, in accordance with State law. Any change or cancellation should be written, signed, and dated in accordance with State law.

Will I be treated for pain?

Physicians and health care providers are required to provide treatment that is necessary for comfort or to alleviate pain.

My Advance Directive documents were drafted in another state, are they still valid in Oregon?

In many cases, no. It is best to check with your legal counsel, primary care physician, or hospice social worker about your documents being honored per Oregon law.

COMMON QUESTIONS ABOUT POLST

How can I get a POLST?

By having a talk with your doctor or hospice provider about what type of medical care you want near the end of your life. If you are diagnosed with a serious illness or frailty, you can ask about POLST or your doctor or hospice provider may tell you about it. The talk should also include:

- What your medical diagnosis is (what you have).
- What is likely to happen to you in the future (how the illness or disease will affect you).
- What your treatment options are (including the risks and benefits of each option).
- What your wishes are for treatments – What do you want? What do you not want?
- This is a good time to talk about hard topics that you would like to better understand. This includes any questions you or your family have about care near the end of life.

How do I talk about POLST with my doctor?

Remember the ABCs of talking with your doctor.

- **Ask Questions.** If you do not understand something, ask. It is important that you understand what is happening to you and what each treatment option means for you.
- **Be Honest.** Your doctor wants to know what treatments you do or do not want.
- **Communicate with your Loved Ones.** Share your decisions with your loved ones and friends so that they can help advocate for you when you cannot speak for yourself.

Must I have a POLST?

No. Filling out a POLST form is completely up to you. It is your choice. It is always voluntary and can be changed anytime at your request. You do not have to complete a POLST for hospice admission.

Who completes and signs the POLST?

If you are able to speak for yourself, you can complete the POLST form with your doctor or one of the hospice healthcare providers. If you are not able to speak for yourself, your surrogate/health decision-maker can complete a POLST form on your behalf. Because the POLST form contains medical orders, it must be signed by a physician (MD or DO), nurse practitioner (NP), physician assistant (PA), or naturopathic doctor (ND).

Emergency Preparedness

Emergencies can be especially difficult for people who are ill or have difficulty getting around. In the event of an emergency situation, BeLoved Hospice will make every attempt to assure your safety. Clinical staff will contact you and make arrangements for medical care, supplies, and medication and help arrange for transfer to a safe environment if needed.

In the unlikely event of a natural disaster (earthquake, blizzard or flood), every possible effort will be made to ensure that your medical needs are met. Please notify our office if you evacuate to another location or emergency shelter.

Power Outage

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

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

Winter Storm

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

Earthquake

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

If you are inside, stay there and:

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

IF YOU ARE OUTSIDE, stay there. Stay away from the outside of buildings.

IF YOU ARE IN A CAR, stop, park away from dangerous items, and stay there until the quaking stops.

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

Wildfire

Wildfires are unplanned fires that burn in natural areas like forests, grasslands, or prairies. These dangerous fires spread quickly and can devastate not only wildfire and natural areas but also communities.

Prepare for Wildfires:

- Recognizing warnings and alerts: Have several ways to receive alerts (FEMA, National Weather Service, email alerts, etc.). Pay attention to air quality alerts. Make sure everyone in your household knows what to do if needing to evacuate quickly.
- Review important documents: Make sure insurance policies, personal documents, and IDs are up-to-date and copies are kept in a secure, password-protected digital space.

- Strengthen your home.
- Know your evacuation zone and follow instructions from local authorities in case there are changes. Gather supplies and be prepared to take them with you if needing to evacuate.

Stay Safe During:

- Evacuate immediately if authorities tell you to do so! Pay attention to emergency alerts and notifications for instructions.
- Do not return home until authorities tell you it is safe to do so.

Emergency Supplies

- FIRE EXTINGUISHER should be suitable for all types of fires and should be easily accessible. FIRST AID KIT should be in a central location and should include emergency instructions.
- WRENCH – a crescent or pipe wrench should be available to turn off gas and water valves if necessary.
- FLASHLIGHT AND EXTRA BATTERIES are available and flashlights should be kept in several locations in case of power failure. Store extra batteries safely.
- WATER AND DISINFECTANT – several gallons of fresh water should be stored for each person. Also, keep a disinfectant such as iodine tablets or chlorine bleach to purify water if necessary (8 drops per gallon of water). Empty and refill water and disinfectant once a year. Rock salt to melt ice on walkways and sand to improve traction.
- RADIO AND EXTRA BATTERIES – transistor radios will be useful for receiving emergency broadcasts and current disaster information.
- DRY OR CANNED FOOD – store a one-week supply of food for each person. It is preferable to store food that does not require cooking.
- ALTERNATE COOKING SOURCE – store barbeque, charcoal, starter, and matches for cooking in case utilities are out of service.
- BLANKETS, CLOTHING, AND SHOES – extra blankets and clothing may be required to keep warm. Have shoes suitable for walking through glass.

Know how to contact help

- Post important phone numbers in an easy-to-reach spot.
- Contact the electric company and ask if you can be considered a priority during power outages, especially if you use continuous oxygen.
- Consider an emergency response system, particularly if you live alone or are by yourself for a good part of the day.
- Make arrangements with family, friends, or neighbors to check on you in the event of an emergency.

Your BeLoved Hospice Team will help you and your loved ones develop a personalized emergency preparedness plan.

Home Safety

Accidents happen! Illness, medication, and fatigue will increase your risk for falls and other accidents. Helping you maintain a safe home environment is an important goal for hospice. Your hospice team will be discussing home safety with you and your caregivers. We also hope the following suggestions will be of value to you.

- Keep a fire extinguisher available.
- Have utensils and commonly used equipment stored at a convenient height.
- Maintain good lighting.

BATHROOM SAFETY

- Install non-skid strips in the bathtub or shower.
- Consider the addition of grab bars and a hand-held shower.
- If you are weak or prone to dizziness, don't attempt showering or bathing unsupervised. A shower bench may be especially helpful.
- Have a phone next to your bed. Post your important numbers nearby.
- Install a night light.

FALL PREVENTION

- Remove area rugs.
- Check to assure that the floor is clear of electrical cords and oxygen tubing.
- Never attempt to get up unassisted if feeling weak or dizzy.
- Consider building an outside ramp to avoid climbing stairs.
- Nursery monitors allow you to call for assistance from someone in another room.

FIRE SAFETY

- Never smoke in bed.
- Keep space heaters at least three feet away from anything that would burn.
- Have a smoke detector on each floor. Remember to change the batteries when needed.
- Have an escape plan. There should be two ways to get out of every room.
- If you are caught in a fire: stay close to the floor, stuff clothes around the doors to keep the smoke out, and call for help.
- If you suspect a fire, turn off your oxygen equipment immediately.
- Inspect appliances for frayed or damaged cords.
- Don't overload the outlet.
- Unplug small appliances when they are not in use.

HOMES WITH SMALL CHILDREN

- Keep all medication in childproof containers and out of children's reach.
- Post poison control numbers by phone.
- Lock up all potentially dangerous materials.
- Use safety latches.
- Have Ipecac® syrup available.
- Install plastic outlet plugs in all unused electric outlets.

MEDICATION AND MEDICAL SUPPLY SAFETY

- Keep medication in their original containers.
- Store all medicines away from children and pets. This includes used supplies. Check expiration dates.
- Contact your healthcare provider before stopping your medication.
- Never take someone else's medication.
- Discuss with your Nurse different systems to organize your medication.
- Keep all medical supplies in a clean area away from heat or cold sources.

Equipment Safety

Durable medical equipment is intended to improve your level of independence and ability to get around. Improperly used equipment can become a safety hazard. The following information is important to remember if you are using medical equipment:

Wheelchairs: Always lock the wheels and have the footrests in the down position when getting in and out of the chair. If you are feeling weak or dizzy, do not attempt to get in or out of the wheelchair unassisted.

Hospital Bed: Wheels must be locked to prevent rolling. Keep the bed in the lowest position when getting in and out of the bed. Side rails should be up if the patient is alone or confused. A hospital bed can help prevent caregiver back injuries.

Walker: Do not place articles of clothing across the bar while walking. Be sure walking surfaces are free of clutter or electrical cords. Do not use a walker to assist you to stand up from a sitting position.

Commode: If you are feeling weak or dizzy, do not attempt to use the commode alone.

Oxygen: Oxygen is sometimes ordered by your doctor to ease feelings of breathlessness. It is important to follow instructions regarding safety and general use. Oxygen is not explosive, but it does feed a fire.

- Don't smoke while using oxygen or near the oxygen system.
- Keep the oxygen system at least 5 feet away from an open flame, such as a gas or wood stove.
- Do not cook on a gas stove while wearing oxygen. An electric stove is no problem.
- If you plan to leave the house, ask your Nurse about a portable oxygen system.
- Do not change the flow rate of your oxygen without first speaking to your Nurse.
- If your nose feels dry, use only water-soluble lubricant like K-Y Jelly®. Do not use Vaseline® or other Oil-based lubricants.
- Wash the filter in the concentrator weekly. Use warm, soapy water. Rinse, shake, dry, and replace.
- Refer to the manufacturer's instructions for proper care of your oxygen equipment.

HERE IS A LIST OF SAFETY TIPS TO REMEMBER

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

- Do not walk over or around cords or wires. Coil or tape cords and wires next to the wall so that you cannot get hung up in them.
- Keep frequently used items within easy reach
- Improve lighting in your home. Replace light bulbs as needed. Lamp shades or frosted bulbs can reduce glare.
- Make sure stairways, halls, entrances, and outside steps are well-lit. Use night lights to light your pathway to the restroom at night.
- Place a lamp, flashlight, and extra batteries within easy reach of your bed.
- Make sure carpets are firmly attached, especially at the top of stairs and on landings.
- Install grab bars next to your toilet and shower. Many hardware stores sell grab bars.
- Use non-slip, non-skid mats in the bathtub and on the shower floor.
- Use an elevated shower seat and/or shower stool, if needed.
- Have your doctor, nurse, or pharmacist look at the medications you take, including over-the-counter medications. Some medications contribute to drowsiness or dizziness.
- Have your vision checked at least once a year.
- Use a cane or walker for assistance with walking.
- Consider wearing a device to alert help in case you fall and are not able to get up.

FIRE SAFETY/BURN PRECAUTIONS

- Make sure the patient has easy access to a telephone, and post the fire department number near every phone. All family members and caregivers should be familiar with emergency 9-1-1 procedures.
- Notify the fire department if there is a disabled person in your home.
- **Do not smoke (including e-cigarettes) in bed or near where oxygen is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes into a trash can. Keep ashtrays away from upholstered furniture and curtains.
- If possible, keep a fire extinguisher rated for home use in key places in your home. Know how to use it in case of emergency.



Infection Control

A patient with advanced illness is more prone to develop infections because of a weakened immune system. The following information is to help prevent the spread of infection to the patient and the caregivers.

WASH HANDS

- After using the toilet.
- Before handling food and eating.
- Before and after cleaning a wound.
- After cleaning soiled linens, towels, and clothing.
- Try to scrub for at least 20 seconds.
- Use lots of warm running water and liquid soap.
- Dry hands with a paper towel.

DISPOSABLE ITEMS AND EQUIPMENT

Examples: soiled paper cups, tissues, dressings, bandages, plastic equipment, catheters, diapers, Chux, plastic tubing, gloves, etc.

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

NON-DISPOSABLE ITEMS AND EQUIPMENT

Examples: dirty laundry linens, thermometers, commodes, walkers, wheelchairs, bath seats, suction machines, oxygen concentrators or tanks, etc.

Wash laundry soiled with body fluids separately in hot water. Wear gloves and handle it as little as possible so you do not 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, except thermometers, in hot, soapy water, then rinse and dry 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 your equipment or ask your nurse or CNA if you have additional questions.



Pour liquids into the toilet. Clean the containers used to transfer liquids with hot, soapy water, then rinse them with boiling water, and let them air dry.

If an item is too soiled to safely disinfect and reuse, ask your nurse or CNA for proper disposal and replacement instructions.

SHARP OBJECTS

Examples: needles, syringes, lancets, scissors, knives, staples, glass tubes and bottles, IV catheters, razors, etc.

Sharps can harm people, pets, and wildlife when discarded improperly. Placing needles and other sharps in the trash, for example, exposes garbage haulers and other disposal workers to potential injury, or, if contaminated, can transmit disease.

You **CANNOT** dispose of syringes and other medical sharps in the garbage because it is illegal in Oregon. The law also required that medical sharps be disposed of in approved sharps containers. Metro has a contained exchange program for households in Clackamas, Multnomah, and Washington counties. You may take your filled sharps containers to one of Metro's two hazardous waste facilities at no cost. If you enroll at the facility for a container, they will swap your full one for a new one each time you bring back a container at no cost.

Metro Central

6161 NW 61st Ave Portland OR

Open Monday - Saturday from 9:00 a.m. to 4:00 p.m.

Closed on Sunday

Metro South

2001 Washington Street Oregon City, OR

Open daily from 9:00 a.m. to 4:00 p.m.

Closed Holidays

BODY FLUID SPILLS

Put on gloves and wipe the fluid with disposable towels. Use a solution of 1 part bleach and 10 parts water to wipe the area again. Double bag disposable towels, seal them tightly, and throw them in the garbage.

When to Wear Gloves

- When there is a possibility of coming in contact with blood or other body fluids.
- Changing dressings, washing the genitalia, or changing diapers.
- When handling linen that has been soiled with stool, urine, or blood.



Proper Disposal of Household Medication

Over-the-counter and prescription medications should not be disposed of down the drain because wastewater treatment facilities are not designed to remove pharmaceutical compounds and they may end up in your local waterways and may eventually be found in drinking water. Properly disposing of unwanted and expired prescriptions and over-the-counter medications in the trash promotes a healthy aquatic environment and prevents accidental poisoning and intentional abuse.

DO NOT keep excess or expired medication around the home. Improper disposal in your trash allows others to divert the substance and consume medication that was not prescribed to them and can be a potential hazard to children and animals.

THE STATE OF OREGON HAS A SAFE DRUG DISPOSAL PROGRAM!

Call **1-844-482-5322** for more information or to order mail-back supplies

Accepted Items Include:

- Medications in any dosage form, except those identified as *Not Accepted* in their original container or a sealed bag

Not Accepted Items Include:

- Herbal remedies
- Vitamins and Supplements
- Personal Care Products
- Medical Devices
- Batteries
- Mercury-Containing Thermometers
- Sharps
- Illicit Drugs
- Pet Pesticide Products
- Animal Medicines
- Biologics

Pain & Symptom Management

Fear of pain is common for patients and their families. It is important to listen to patients when they say they are experiencing pain. For many patients, pain may be both a physical and an emotional experience. Only the patient can best describe the pain and its intensity.

Eliminating or improving your level of pain and discomfort is an important goal of BeLoved Hospice. Our clinical team will work closely with you, your family, and your physician to find effective pain-relieving medication while minimizing side effects. We will need your participation in developing a pain management system that will work best for you.

Describing the pain is a very important part of the process. Some people report less pain than they are actually feeling. This happens for many reasons. Some patients assume that pain is something they have to learn to live with because of the nature of their illness. Others are fearful of becoming addicted or worry about using strong medications too soon. Pain can be treated safely and effectively. It is very important to keep a record of how often you take pain medication in order to best treat your pain.

Your Nurse will be asking you to describe your pain in several ways. They will be looking for patterns or times when the pain occurs. They may ask for a description, such as sharp, dull, or crampy. The Nurse will also ask you to rate the severity of your pain using a scale from 1 – 10. They will also ask you what a comfortable level within that scale is for you, as it varies from patient to patient. The pain scale rating helps us understand your experience with pain.

How much pain do you have? You can use a scale of 0 to 10 to describe how much pain you have. "0" means no pain at all; "10" means the worst pain you have ever experienced. You may be asked to use this scale to rate your pain, when you are resting, and when you are active.

How do you describe the type of pain that you have? Here are examples of some words people use to describe the pain they are experiencing. You may choose to use other words. Use the words that best fit your experience.

- | | | |
|------------|-----------|-------------|
| • Aching | • Itching | • Shooting |
| • Burning | • Jabbing | • Stabbing |
| • Cramping | • Nagging | • Throbbing |
| • Crushing | • Numbing | • Tingling |
| • Cutting | • Pulsing | |
| • Dull | • Sharp | |

TYPES OF PAIN MEDICATION

Non-Narcotic pain medications are medications used initially for the management of mild to moderate pain. Most people have some of these medications in their medicine cabinet: aspirin, acetaminophen, or ibuprofen. These medications are usually considered very safe.

Narcotic or opioid pain medications may be prescribed when your pain is moderate to severe in intensity. Our goal is to find the right type of medication, which has the least amount of side effects. Opioid medication can make a big difference in your level of comfort and your overall quality of life.

ALTERNATIVE PAIN MANAGEMENT TECHNIQUES

Some patients express an interest in alternatives to medication. Non-medication pain management techniques can also be used in addition to medication. There are many things you can do to help you relax and increase your feeling of well-being. This can add to your level of comfort. A calm environment, soothing music, and pleasant companionship can all be pleasant distractions. Our staff can work with you in learning relaxation exercises or can teach your family to perform simple massages.

RESTLESSNESS AND AGITATION

At times, the person you are caring for may seem restless or unable to stay still or may become agitated or irritable. This is not uncommon and may be caused by a variety of factors. It may be caused by physical discomfort or pain or by emotional or spiritual concerns.

- Let your nurse know about the patient's restlessness or agitation. They can assess for any underlying pain or discomfort.
- Medications may be prescribed to help with these symptoms.
- Utilize the hospice social worker and/or chaplain to assist with any emotional or spiritual concerns.
- Keep the environment calm: play soothing music, decrease visitors, read a favorite book, dim lights, brush hair, etc. Do whatever is usually relaxing.
- Offer reassurance
- Distract the patient with something familiar, such as photos or a task (art, singing, watching a familiar movie)
- Provide a calm presence by speaking slowly and calmly to the patient.

NAUSEA AND VOMITING

Sometimes patients experience nausea and vomiting. The following suggestions may help.

- Eat small, frequent meals.
- Avoid liquids at mealtime - drink them an hour after meals.
- Eat dry food such as toast and crackers.
- Avoid spicy, fried, and fatty foods, red meat, and any food with a strong odor.
- Pay close attention to mouth care.
- Take anti-nausea medication when prescribed.
- Unless instructed not to, take medications with small amounts of food or milk.
- Serve food cold or at room temperature to decrease smell and taste.

Nausea caused by pain medication can feel like motion sickness. If this happens, try resting quietly. If you suspect your pain medicines are making you sick, make sure to inform your hospice Nurse immediately.

CONSTIPATION

When people are very ill many things can affect how their bowels function. Changes in diet, activity, and the use of some medications can produce constipation. This is because the narcotic in pain medicine slows down the bowel, allowing too much water to be absorbed from the waste matter. The result is a sluggish bowel with a hard, dry stool.

Treatment is aimed at speeding up or stimulating the bowel and/or putting water into the stool. You may be prescribed medication to prevent or alleviate constipation. It is important to take these medications as directed by your Nurse or physician. You can also help ease constipation by increasing fluid intake, as tolerated.

BOWEL PROBLEMS TO REPORT TO THE NURSE:

- Very hard, difficult to pass stool.
- More than three days without a bowel movement.
- Constipation followed by diarrhea.
- Constantly passing only smears of stool or liquid stool.
- Blood with stool.
- Abdominal pain.

FOOD AND EATING

It is common for people to lose their appetite when ill. This may be from the disease itself, treatments, medications, pain, or simply changes in the way food tastes. The body's need for calories and protein-rich foods is altered because of decreases in activity, exercise, and general metabolism.

Suggestions for eating when appetite is diminished:

- Eat frequent, small meals.
- Drink liquid breakfast drinks, canned supplements, or homemade, high-calorie shakes.
- Add dried milk or dried protein powder to liquid or soft foods to add calories.
- Drink fruit juices, such as prune or apricot nectars to provide additional calories.
- Eat and drink your favorite foods.
- Give liquids in other forms, such as Jell-O, pudding popsicles, or ice cream.
- Avoid using straws. They increase the swallowing of air, leading to burping or nausea.
- Refer to instructions on dietary supplements for storage, use, and expiration date.

When our bodies are able to heal, we need proper nutrition to regain strength; however, when our bodies are not able to heal (often in the last weeks of life), food can become an unnecessary burden and a source of discomfort.

SKIN PROBLEMS

Superficial skin sores, pressure sores, or bed sores affect some people. They are caused by a decrease in skin health and extended time in bed or a chair. Prevention is the best cure for skin problems. Please let your nurse know if you notice any redness, sores, or bruises on the patient. Here are a few tips to avoid bed sores:

- Change positions in bed by turning from side to side every 2 to 4 hours. If able, get out of bed and sit in a chair.
- Gently rub the skin with lotion to increase circulation.
- Keep skin clean and dry.
- Change soiled or wet linens and clothing as needed to keep the patient dry. Clean the skin regularly of any drainage, blood, or urine.
- Use pillows to support the leg and back when the patient is lying on their side.
- Apply protective pads to bony areas like heels, elbows, and tailbone as recommended by your nurse

Primary Caregiver Guidelines

Caregivers also need to receive care. Your emotional and physical well-being is very important and often difficult to maintain. Small things you do for yourself can make a big difference. It is important that those in the role of caregiver care for themselves. This will allow the best care to be provided to your loved one. Some suggestions are:

- **ACCEPT HELP.** Friends, family, hospice team members, and hired assistants can be great sources of support. Accepting this help is a good way to involve those people, as well as a way for you to take a necessary break. In accepting help, it is best if you can be specific about your needs. Ask someone to run errands, do yard work, bring food, and sit with the patient while you go for a walk or take a nap.
- **TAKE TIME FOR YOURSELF.** A few quiet moments can be renewing. A walk with a friend can help you re-establish your perspective. A bath, while someone else cares for the patient, can ease the aches of the body and soul. It is important to make time for yourself and identify pleasurable activities as part of the caregiving routine. Try to set a goal of at least one outing per week. This kind of personal time allows you to focus on other aspects of life.
- **PAY ATTENTION TO YOUR OWN PHYSICAL NEEDS.** You may become so busy being a caregiver that you forget about your own needs. eating, sleeping, and exercising can make a big difference in your outlook. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and/or a short walk around the block can really help.
- **PRACTICE RELAXATION TECHNIQUES.** Pause for five minutes and breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the patient's care (like when a hospice team member stops by). Do not forget that laughter and keeping your sense of humor are important too.

BEING A FRIEND TO ONE WHO IS DYING

- Let the person decide what you will talk about and when. Let them know you are open to any conversation he, she, or they would like to have.
- If your friend wants to engage you in a discussion about spiritual beliefs concerning life and death, be honest about expressing your feelings and beliefs; however, do not challenge or discourage the expressed feelings or beliefs of the dying person. We all have the right to chart our own spiritual journey!
- If you cannot be present in person, call or write letters. Those at the end of life need to know you are thinking of them.
- Do not be afraid to laugh or cry. Real emotion can bring healing and peace.
- Sometimes when a person is too tired to talk, he, she, or they will still appreciate having someone sit quietly in the room. Often touching (e.g. holding hands) becomes an important means of communicating what you are feeling.
- Cards, flowers, or small gifts help your loved one to remember your visit after you are gone. Before you visit, check to see what length of the visit will be appropriate.
- Often, doing something fun together is as helpful as a serious question. Play games or reminisce.
- Be willing to change your plans or your topic of conversation based on how your friend is feeling at the moment. Be flexible.
- Let those you love know what you treasure about them, why they are important to you, and what memories you especially cherish.

Tips for Supporting Someone with an Illness

When someone we know faces a serious illness, most of us find it hard to know what to do. Here is a collection of truly useful ideas you can use to show your concern and support for people who are close to you.

PRACTICAL TIPS YOU CAN USE TO HELP THOSE FACING SERIOUS ILLNESS

- Do not avoid me. Be the friend...the loved one you have always been.
- Touch me. A simple squeeze of the hand tells me you still care.
- Call and tell me you are bringing over my favorite dish. Bring food in disposable containers so I won't worry about returning them.
- Watch my children while I take a little time to be alone with my loved one. My children may also need a little vacation away from my illness.
- Cry with me when I cry and laugh with me when I laugh. Do not be afraid to share these emotions with me.
- Pain isolates. Help me reconnect with others.
- Take me out for a pleasure trip but know my limitations.
- Call for my shopping list and make a special delivery to my home.
- Before you visit, call to let me know, but do not be afraid to visit. I need you. I can get lonely.
- Help me celebrate holidays (and life) by decorating my room or home, or by bringing me flowers or other natural treasures.
- Help my family. Invite them out. Take them places. I am sick, but they may be suffering also. Offer to come and stay with me to give my loved ones a break.
- Be creative. Bring me a book of thoughts, taped music, a poster for my wall, and cookies to share with my family and friends.
- Let's talk about it. Maybe I need to talk about my illness. Find out by asking me, "Do you feel like talking about it?"
- Do not always feel we have to talk. Sitting quietly together is fine. Help me feel good about my looks.
- Please include me in the decision-making. I've been robbed of so many things. Please do not deny me a chance to make decisions in my family or in my life.
- Talk to me about the future...tomorrow, next week, next year. Hope is important to me. Bring me a positive attitude. It's catching. Help me respect reality.
- What's in the news? Magazines, photos, newspapers, and verbal reports keep me from feeling the world is passing me by.
- Water my flowers.
- Tell me about support groups so I can share with others.

WITH LOVE AND GRATITUDE

With Love and Gratitude is a program of BeLoved Hospice helping hospice patients write and send meaningful messages to their loved ones. If desired, a member of our hospice team will work with the patient to help hand-write or type letters to be sent to their loved ones after their passing. Our hospice team member will keep the sealed letters in a safe location until the date that they are to be sent. Many patients choose to have the letters sent on the one-year anniversary of their passing while others choose to send letters recognizing special birthdays or anniversaries. If you would like more information on participating in this program, please call **(971) 236-1199**.

Preparing for Approaching Death

PHYSICAL SIGNS OF APPROACHING DEATH

Coolness: The person's hands and then arms, feet, and then legs may be increasingly cool to the touch and at the same time the color of the skin may change. The underside of the body may become darker and the skin becomes mottled. 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, but do not use an electric blanket.

Sleeping: The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is partly due to changes in body chemistry. Sit with your loved ones, hold their hand, and do not speak loudly but speak softly and naturally. Plan to spend time with your loved one during those times when they seem most alert and awake. Speak to the person directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last sense to be lost.

Disorientation: The person may seem to be confused about the time, place, and identity of people surrounding them, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name when you arrive, rather than having the person guess who you are.

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

Congestion: The person may have gurgling sounds coming from their chest as though marbles were rolling around inside; these sounds may become very loud. This normal change is due to the decrease in fluid intake and the inability to cough up normal secretions. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of congestion does not indicate the onset of severe or new pain.

Restlessness: The person may make restless and repetitive motions, such as pulling at bed linens or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, in a quiet, natural way, lightly massage the forehead, read to the person, or play some soothing music.

Fluid and Food Decrease: The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy that is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate the person into eating or drinking something. To do this only makes the person more uncomfortable.

Urine Decrease: The person's urine output normally decreases and may become tea colored - referred to as concentrated urine. This is due to decreased fluid intake as well as a decrease in circulation in the kidneys.

Breathing Changes: The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern of breathing irregularly, i.e. shallow breath with a period of not breathing of 5 to 30 seconds and up to a minute. This is called Cheyne-Stokes breathing or apnea. The person may also experience periods of rapid shallow pant-like breathing.

When a Patient Dies

WHEN DEATH OCCURS

People wish to handle the time of death and the events that follow in different ways. A goal of the hospice team is to help prepare you, so you will know what to expect. Your physical and emotional well-being is as important as the patients.

The physical signs of impending death which we have provided here are offered to help you understand the natural way this event occurs and what you can do to help. Not all of these signs and symptoms will occur with every person. Although you may be prepared for the death process, you may not be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you will do when this moment occurs.

The death of a hospice patient is not an emergency as usually defined. There is no rush. Nothing must be done immediately. If you believe that the patient has expired, please call our office at (971) 236-1199. A hospice nurse or other team member will speak with you and may come to your home if you wish.

It may be helpful to have a friend or family member be with you during this time.

If you wish, BeLoved Hospice will call the funeral home for you after your death. You may choose if you wish to spend time with your loved one's body or want to wait for other family members or friends to arrive.

NOTIFYING OTHERS THAT YOUR LOVED ONE HAS DIED

When a loved one dies, some names will come to you immediately as persons who should be contacted. Close family, good friends, the patient's minister, priest, or rabbi, and lawyer. Some calls you will want to make yourself and other calls have to be made but you do not need to make them. When a death occurs, your friends and your loved ones, as well as other family members, will want to be of assistance. It makes sense to let others help in passing the word. With friends, for example, or a church or community group, often you can make only one call and ask that person to organize informing others from that circle of acquaintances. Social media is another way to let people know that your loved one has passed. If there are many calls to be made, keep a list of who has been contacted. That way, there is less chance that someone important will be forgotten.

WORKING WITH THE FUNERAL HOME

Normally, within 24 hours of your loved one's death, you should be in contact with the funeral home to set up an appointment with the funeral director. Funeral homes offer a wide range of services at the time of death. **These usually include:**

- Transporting the body from the place of death to the funeral home.
- Preparing the body for burial, arranging for a casket and other necessary items for burial, or arranging for cremation.
- Working with family and, if desired, a priest, rabbi, or minister for a funeral or memorial service. Providing time and space for visitation and a funeral or memorial service.
- Assisting in the preparation of an obituary and funeral notice.
- Completing the necessary paperwork for the death certificate, and obtaining certified copies of the death certificate for the family.
- Be sure to ask for an adequate number of certified death certificates.
- You will need one for each life insurance policy or pension the person had, and several more for processing the person's

Last Will and Testament and other financial business.

- Transporting the body and family members to the funeral or memorial service and/or to the cemetery.

PLANNING A FUNERAL OR MEMORIAL SERVICE

After someone they love has died, most people find it helpful to participate in some structured ritual of celebration, remembrance, and letting go of the person who has died.

A list of questions that may help in planning a funeral or memorial service:

- Did your loved one leave any specific instructions about the kind of service that they would want? Did those instructions include specific requests for readings, music, a person to preside with, or a place where the service was to be held?
- When will it be convenient for the service to take place? Do close family and friends have schedules that will need to be worked around in planning the time and place of the service?
- Where will the service take place? If the person was a member of a church, synagogue, or other religious community, when can it schedule a service?
- Who will officiate at the service? Will it be a minister, priest, rabbi, family member, or friend? Do you want an organist, soloist, or another provider of music, and how will those arrangements be made?
- Are there readings, music, pictures, or any other elements which you think would be especially meaningful to you and others as part of the ceremony?
- Do you want to choose someone to deliver a formal eulogy? Do you or other friends or family members wish to offer some personal words of remembrance at the service?
- Do you wish to have visiting hours before the service? This custom varies from community to community.
- Will there be any kind of reception or other informal gatherings of friends and family after the service? If so, where will it be held?

OTHER PRACTICAL ISSUES

Along with the major issues of dealing with death when it occurs - talking with the funeral director and planning for a funeral or memorial service - there are other practical tasks large and small that should be attended to in the days and weeks following your loved one's death.

- You will want to contact the person's lawyer regarding the content of his or her will (if one exists) and any other legal business which needs to be attended to.
- You (or whoever has been appointed under the person's will as personal representative of the estate) should contact the person's bank, financial planner, pension administrator, life insurance company, and any others with whom the person had significant financial dealing to inform them of the death. Many of these persons will want certified copies of the death certificate, especially if they are paying out benefits or transferring the, to a surviving spouse or joint tenant.
- You should remember to cancel club memberships and magazine subscriptions and have mail delivery stopped or transferred.
- Outstanding bills need to be collected and paid, but this should always be coordinated with other aspects of handling the estate.
- For many, one of the difficult things to do is to go through your loved one's personal possessions - clothing, papers, mementos, furniture - in order to sort it, sell, or give away what the family does not want to keep and make arrangements for the rest. Like visiting the funeral home, this is a task that is easier if shared among two or more family members.

Taking care of all the business that needs to be sorted out after a death can take weeks or even months, depending on how the person's affairs were organized. It is tiring and emotionally draining work. If you can, share the responsibilities with

other family members, do hard tasks with another person, and do not take on too much at one time. It is normal to feel overwhelmed at times with the finishing of things.

Experiencing Grief & Loss

Watching someone you love decline in health is a painful process. When death is anticipated, both the patient and their loved ones may experience a normal form of grief. It is called anticipatory grief and is similar to the process of grief following a loss.

Some of the aspects of anticipatory grief that you may notice include:

- Heightened fear, anxiety, and depression.
- Increased concern for the well-being of the terminally ill person.
- Imagining the actual event of the death.
- Attempts to adjust the changes that may occur after death.

Although anticipatory grief is a painful process, having some warning prior to the death can allow for several things:

- Absorbing the reality of the loss over a period of time.
- Saying goodbye and completing other unfinished business with the dying person.
- Reassigning the familial roles of the dying person.
- Gradual withdrawal of emotional energy invested in the dying person.

Because you are losing an important person in your life, many difficult changes can occur including:

- Loss of energy and vitality.
- Family members may feel a sense of isolation, as the family focuses their energies on caring for their dying loved one.
- The best and worst family characteristics may come out at this time.
- Communication can break down and misunderstanding can increase tension. Limited finances can increase stress as medical expenses increase.
- Uncertainty about the dying process and feelings of lack of control can be overwhelming.

Not everyone will respond to loss in the same way. It is helpful to know that the following characteristics can be a normal part of the grief experience.

Grief-related thought patterns include:

- Disbelief, sense of unreality
- Preoccupation
- Confusion
- Lack of ability to concentrate

Feelings that are part of the grieving process include:

- Shock, numbness
- Sense of unreality
- Anger
- Irritability
- Guilt, self-reproach
- Sadness, depression
- Anxiety
- Fear, hysteria, helplessness
- Vulnerability
- Low self-esteem
- Mood swings

Physical sensations experienced during grief include:

- Tightness in the chest and throat
- Dry mouth
- Oversensitivity to noise
- Dizziness
- Headaches
- Shortness of breath
- Weakness in the muscles
- Lack of energy/fatigue
- Excessive nervous energy
- Heart pounding
- Heavy or empty feeling in body and limbs
- Hot or cold flashes
- Skin sensitivity
- Stomach and intestinal upsets
- Increase in physical fitness

Behaviors while experiencing grief:

- Appetite and sleep disturbances
- Absent-minded behavior
- Social withdrawal
- Avoiding reminders of the loss
- Dreams of the loss
- Searching and calling out for the deceased
- Restlessness, sighing, crying
- Visiting places that are reminders of the loss
- Treasuring or carrying objects that belonged to them
- Change in sexual activities
- Need for touch, hugs, contact with others
- Increased sensitivity to positive or negative attention

Social Changes brought on by the grieving process include:

- Either an increased desire for the support of close friends or a withdrawal from friends and family
- Increased dependency on others
- A need for acting normal around others
- A need for relationships apart from those related to grief
- Being self-absorbed (no energy or interest in others)
- Marital difficulties - especially with the death of a child
- Role changes, role reversals
- Change in social patterns and status
- Hypersensitivity to topics of loss
- Need for rituals

Suggestions for Coping with Grief:

- Allow yourself to feel your feelings. Someone close to you has died. Many emotions arise. It's okay to feel angry, depressed, or even feel a sense of relief at the time of death.
- Access your support system. Reach out to people who are supportive of you. Family, friends, support groups, clergy, or a therapist may be helpful.
- Share your feelings of grief. Talking about your feelings can be a relief. Do not hide your emotions from those who care about you.
- Educate yourself about grief issues. Reading literature about grief can help you in understanding what you are experiencing.
- Take care of your physical self. Remember that your emotional state can be affected by your physical state. Attempt to eat balanced meals, get adequate sleep,

and do some form of exercise or activity each day.

- Avoid alcohol and other substances not prescribed by your physician. Although drugs and alcohol may numb the emotional pain initially, drugs and alcohol may prolong, delay, and complicate your grief.
- Give yourself permission to say "no". Try not to rush or take on new responsibilities.
- Be patient with yourself. Healing from grief takes time. Your grief may not look like the grief of others around you. Respect your own individual grief style.



"What is grief,
if not love persevering?"

- Jac Schaeffer



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