



Formerly Skagit Hospice

Table of Contents

1. Introduction to Hospice of the Northwest Services	
Eligibility	1
Philosophy and Goals	2
Levels of Care	3
Traveling & Hospice Services	3
Attending Physician & Hospice of the Northwest Medical Director	4
2. The Hospice of the Northwest Team	
Hospice Nurse Case Manager	5
Hospice Social Workers	5
Hospice Chaplain	6
Hospice Aides	6
Other Support Services	7
Hospice Volunteers	7
Complementary Therapies	8
Hired Caregivers	9
3. Decision Making Resources	
Introduction	11
Helpful Definitions	12
What to do Prior to Death	13
Durable Power of Attorney for Health Care	15
Funeral Homes and Cremation Services	17
What to do After Death Occurs	19
4. Financial and Legal Information	
Financial Issues	21
Comparison of Requirements for Participation in Medicare Benefit	21
Patient Rights	22
Patient Responsibilities	23
Privacy Practices	25

5. Home Safety	
General Guidelines	31
Disaster Preparedness	33
Infection Control.....	33
6. Dealing with Physical Changes	
Pain Management.....	37
Pain Medications.....	38
Destruction of Medications.....	39
Common Physical Symptoms	
Nausea and Vomiting	40
Constipation.....	40
Dry, Sore Mouth	41
Shortness of Breath.....	41
Skin Breakdown.....	42
Nutrition, Hydration, and Eating Difficulties	43
Journey's End: What to Expect – What to Do	45
Recipes.....	50
7. Emotional and Grief Support	
A Message to Family and Caregivers	53
Helping Children & Teens Cope.....	53
Bereavement Services.....	54
8. Forms and Additional Resources	
Statement of Consent and Election (patient copy)	
Home Medication Record	
Symptom Monitor Chart	
Patient and Family Journal	
Instructions for Care	
Visit Log	
Plan of Care/Medication List	
Drug Classification Teaching Sheet	
Medication Destruction Policy	
Advance Directive Policy	
Washington State Death with Dignity Act	



Introduction to Hospice of the Northwest Services

Hospice through the centuries has meant a resting-place for travelers. In modern times hospice is used to describe a special concept of care for people who are facing a life-limiting illness.

In the hospice movement, we continue to be concerned both with the sophisticated science of our treatments and with the art of our caring, bringing competence along with compassion.

- Cicely Saunders, Founder of the Hospice movement.

Hospice of the Northwest Services, LLC (“Hospice of the Northwest”) operates as a joint venture of Skagit Valley Hospital and United General Hospital. We are a community-based, non-profit organization that has provided health-related services to individuals and their families since 1989. Hospice of the Northwest includes physical, emotional and spiritual comfort for both patient and loved ones. Hospice of the Northwest provides comprehensive family-oriented care by a specially-trained team of nurses, social workers, hospice care aides, chaplains and volunteers. We work closely with your physician to help control symptoms, relieve pain, and assist you and your family in achieving the goals you find most important. We are partners in your care and will do our best to help you wherever you live.

WHO IS ELIGIBLE?

Admission requires the patient to have a terminal diagnosis with a life expectancy of approximately 6 months or less, verified by the referring physician and confirmed by the Hospice of the Northwest Medical Director. Hospice care can continue past six months with certification from a physician. If an individual’s health improves or if the patient or family desires, a patient can discontinue hospice care.

Hospice care will provide comfort, rather than cure, for a patient who is no longer responding to or desiring curative treatment.

Some common diseases and conditions experienced by hospice patients include, but are not limited to: ALS, Alzheimer’s cancer, debility, dementia, end-stage heart, lung, kidney or liver disease.

Hospice of the Northwest Services Admission Guide

This guide is a vital tool for communication between you, your family and all the members of your team. It provides information about the services Hospice of the Northwest offers, as well as what you can expect while in the Hospice of the Northwest program. We encourage you to use it to best meet your needs.

This guide also functions as a journal and a place for recording:

- Notes and observations – how you are doing.
- Questions** – to ask a member of the Hospice of the Northwest team on their next visit.
- Medications** – their schedule, effectiveness and side effects.
- Your Hospice of the Northwest team** – schedule and contact information.
- Significant events** that have happened, other pertinent information, anything else you might want to record.

PHILOSOPHY & GOALS

PHILOSOPHY

Hospice of the Northwest accepts death as a natural part of the life cycle.

The purpose of Hospice of the Northwest is to serve persons with life-limiting illnesses and those supporting them. The care available through Hospice of the Northwest includes an interdisciplinary team approach to meeting medical, social, psychological and spiritual needs.

Hospice of the Northwest is concerned with symptom management that promotes patient comfort, enhances feelings of self-worth and well-being, and encourages patient participation in decisions affecting living and dying. The program supports both patient and family as activities and relationships undergo change. Support continues into the period of grief and bereavement.

GOALS

- To promote the quality of life of those with life-limiting illnesses, as well as their families and friends. **Quality of life is defined by the person with the illness.**
- To assist and support the process of grief, dying and bereavement.
- To provide comprehensive hospice services aimed toward comfort during the final phase of life.
- To provide hospice care to all, regardless of the individual's ability to pay.
- To support decisions on disease treatment whether therapeutic or comfort care alone.
-
-

LEVELS OF CARE

Your level of care will be determined by your Hospice of the Northwest team.

1. Routine Care

Routine care is paid for each day the patient is under the care of Hospice of the Northwest. The care plan includes the amount and frequency of services based on the patient and/or family's needs.

2. Continuous Care

Continuous care is provided when the patient is experiencing a medical crisis and requires predominantly nursing services to achieve palliation (symptom relief and control). Hospice of the Northwest must provide a minimum of 8 hours of care within a 24-hour day period, beginning and ending at midnight. The goal of continuous care is to provide necessary medical acute care interventions at home. Although a registered nurse or licensed practical nurse provides more than half of the continuous care, homemaker or home health aide services may supplement the nursing care during the period of crisis.

3. Inpatient Respite Care

Inpatient respite care is arranged by Hospice of the Northwest when the family or caregivers need relief from carrying for their loved one at home. Respite care is provided on a short-term basis for no more than 5 days per episode.

4. General Inpatient Care

General inpatient care is available for pain control or acute or chronic symptom management, which cannot be managed in any other setting. The short-term inpatient services must be provided by a Medicare-certified facility (hospital, skilled nursing, or hospice inpatient) and must be under contract with Hospice of the Northwest.

TRAVELING AND HOSPICE SERVICES

Hospice of the Northwest encourages quality end-of-life care. Many times this includes travel. Hospice of the Northwest can help you and your loved ones with travel arrangements including medication, equipment and support services.

Under Medicare, clients are able to travel while remaining on hospice. This includes out-of-state travel. If you are a Medicaid or private insurance client, travel is still an option. Please consult with your Hospice of the Northwest team to pursue options with these insurance carriers, and to coordinate your travel.

**ATTENDING PHYSICIAN AND
HOSPICE OF THE NORTHWEST MEDICAL DIRECTOR**

As a Hospice of the Northwest patient, you are able to retain your current primary care provider as your attending physician (including a nurse practitioner). Your Hospice of the Northwest team members will work with your primary care provider throughout your Hospice of the Northwest stay, and keep them updated on changes in your care.

The Hospice of the Northwest team includes medical directors, who are physicians who have specialized training in palliative care. They will work with your attending physician to give you the most up-to-date interventions and rapid response. The Hospice of the Northwest medical director may also conduct home visits if needed or requested.

DISCHARGE FROM HOSPICE SERVICES

A patient must meet specific medical criteria to remain eligible for hospice services. Hospice of the Northwest will notify the patient if the attending physician makes a determination that the patient is no longer eligible for hospice care. In addition, a patient may revoke consent for hospice services by signing a Revocation Statement, and be discharged from Hospice of the Northwest. Patients may re-elect hospice services at a later date, if eligible.

NOTES:

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

The Hospice of the Northwest Team

At Hospice of the Northwest, we work together as an interdisciplinary team to manage and control your symptoms while providing care and comfort. Team members will visit your home regularly to provide care and information. Your unique situation will determine which team members participate in your care and how often they visit. The following is a brief description of the roles of the Hospice of the Northwest team members.

HOSPICE NURSE CASE MANAGER

Your nurse is the coordinator of your Hospice of the Northwest care team. The frequency of nursing visits will depend upon your needs. The Hospice of the Northwest nurse has extensive experience in caring for patients with life-limiting illnesses, and special training in the areas of pain control and symptom management. Your nurse will develop a **Plan of Care** with you based upon your specific needs.

YOUR NURSE CASE MANAGER:

- Consults with you and your physician to determine a plan of care which provides for your comfort and independence.
- Teaches you and your caregiver physical comfort measures, medication use and other necessary procedures which may include dressing changes, and care for tubes or catheters.
- Provides any special nursing procedures needed.
- Helps you in obtaining needed equipment and services.
- Explains the effects of illness and treatments, and teaches you what to expect.
- Welcomes your participation, listens to your concerns and offers support in difficult times.

HOSPICE SOCIAL WORKER

Hospice of the Northwest social workers focus on the non-medical needs patients and their families face in the midst of life-limiting illness. They are skilled in individual and family counseling as well as helping patients and families access necessary community services. The social worker sees each patient to determine needs, and then visits on a mutually agreed upon basis.

YOUR SOCIAL WORKER:

- Assist with coordination of care-giving in the home.
- Assist you in finding answers to questions, such as: how to talk with my children, how to help my family adjust, and is it normal to feel this way?

- Help you and your families locate resources through other agencies, government programs and in the community.
- Help you and your families recognize your strengths and identify how they can help you through this time.
- Help you understand feelings you may have when dealing with life-limiting illness.
- Listen to your concerns, either individually or as a family.
- Assist with placement in a care facility if needed.
- Advocate on your behalf to see that your needs are met in the best way possible.

HOSPICE CHAPLAIN

The Hospice of the Northwest team believes what is happening in your mind and spirit is as important as what is happening with your body. The chaplain can visit on a one-time basis or as mutually agreed upon.

YOUR CHAPLAIN:

- Will not impose any particular religious beliefs on you.
- Can provide spiritual counseling, respecting your personal beliefs as you request.
- Will support you in your exploration or struggles with spiritual and emotional issues.
- Is available to meet with you and/or your family to share hopes, fears and concerns, whether spiritual or otherwise.
- Will pray with you if you like.
- Will provide referrals to local clergy for additional spiritual support.
- Will assist with referrals to local funeral homes of your choosing for funeral and memorial service preplanning.

It is our hope that you and your chaplain might create a friendly relationship where you can freely question or search for hope and understanding.

HOSPICE AIDES

Hospice of the Northwest care aides are skilled at providing personal care. Aides visit up to five times a week, depending on the situation. Some of the services they provide include:

- Changing the bed sheets.
- Shampooing, grooming and shaving.
- Nail care.
- Skin care.
- Assisting with toileting when in the home for a scheduled visit.

- Bathing patient or assisting with bath or shower.
- Companionship.
- Light Housekeeping.
- Light cooking or meal preparation.
- Range of Motion (ROM) exercises.
- They may also be delegated to perform additional tasks under the supervision of your nurse.

OTHER SUPPORT SERVICES

Your Hospice of the Northwest team continually evaluates your physical condition and individual/family needs to determine what other support services would be helpful to achieve your goals of care. These services may include physical, occupational and speech therapists as well as dietitian support. If you have related questions, just ask your nurse or other team member.

HOSPICE VOLUNTEERS

Hospice of the Northwest trained volunteers are an essential and important part of your team. They consider it a privilege to be invited into your home to assist you. Their personal contributions and caring can be a great help to the entire family. Volunteers can visit on a one-time-only basis or regularly – usually once or twice a week (up to 4 hours total per week). You can request a volunteer by telling any of your team members or by calling the office. If your nurse or social worker thinks you would benefit from having a volunteer, they may encourage you to accept their help.

Hospice of the Northwest volunteers can help the caregiver with respite by staying with the patient while the caregiver treats him or herself to an outing, or has a meal out with a friend. Some of the tasks volunteers may perform are:

ROUTINE TASKS:

- Respite or companionship; stay with the patient for prearranged periods of time, allowing family members to get away from home, or provide respite while family members nap.
- Transportation of patient or family in volunteer's vehicle with prior approval of Hospice of the Northwest and depending on volunteer availability.
- Meal preparation.
- Perform light household chores or errands.

PERSONAL CARE:

- Washing hands and face, assisting with dressing, or combing hair.
- Feeding, with prior Hospice of the Northwest approval.
- Help with walking or use of walker where minimal assistance required.

- Offering individual doses of medicine to patient, as prepared by family member or nurse.
- Changing linens.

VOLUNTEER ACTIVITIES AND CREATIVE ARTS:

- Emotional support.
- Assist with life review activities.
- Reading, writing letters, playing music and games such as cards.
- Spiritual support.
- Companionship.
- Childcare if needed.
- Some volunteers are also available for a variety of arts and crafts activities such as painting, clay work, knitting, or photo/scrap albums.

TASKS NOT TO BE PERFORMED BY VOLUNTEERS:

- Using specialized medical equipment.
- Positioning patient in prone position (lying on stomach).
- Administering suppositories.
- Massaging legs.
- Giving full bed bath or assisting with shower.
- Giving injections.
- Changing bandages.
- Transferring totally dependent person.
- Caring for contact lenses.
- Shaving with a razor.

Please give us as much notice as possible when requesting a volunteer.

Hospice of the Northwest volunteer assignments are subject to availability. If you have questions about how volunteers can be helpful to you, please call the Hospice of the Northwest Volunteer Coordinator at (360) 814-5550.

COMPLEMENTARY THERAPIES

Professionals trained in various therapies that complement the traditional services provided by your hospice team are available through Hospice of the Northwest. These complementary therapies include massage therapy, Reiki therapy, acupuncture, Jin shin (San Juans only), pet therapy, threshold choir and bedside music. These services are provided based on availability and are not guaranteed. You can request a complementary therapist by telling any of your team members or by calling the Volunteer Coordinator. If your nurse or social worker thinks you

would benefit from complementary therapy, they may encourage you to accept their service.

The Complementary Therapy Program is funded by donations to the Hospice of the Northwest Foundation from individuals in our communities.

HIRED CAREGIVERS

Occasionally, extra help is needed to keep you comfortable at home. If you choose to hire extra help, Hospice of the Northwest can help by:

- Helping identify tasks that can be done by hired caregivers.
- Providing a list of agencies and of self-employed caregivers.
- Helping your family teach hired caregivers about the Hospice of the Northwest plan of care.

Hired care-giving is not covered by Hospice of the Northwest. Generally, the family is responsible for this cost. Your Hospice of the Northwest social worker can provide information about hiring caregivers, or additional funding options. These caregivers can do many things to help, but they cannot give medications or change bandages.

*You can't do anything about
the length of your life,
but you can do something
about its width and depth.*

Even Esar

NOTES

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Decision Making Resources

INTRODUCTION

Our goal at Hospice of the Northwest is to assist our patients to live their final days with peace and dignity, and to assist them and their families in end-of-life decisions. We have provided a number of resources to help you and your family navigate through the process of planning for your care. If you would like assistance, please do not hesitate to share your need with your social worker.

Although your social worker will be able to help you review these concepts and documents, we are unable to provide any legal advice. If you have questions regarding any legal processes, we suggest that you contact your legal representative. If needed, we will be happy to provide you with a list of attorneys in your area.

We realize that it can be confusing trying to understand all of the different terms and phrases you have been hearing, so we have included a glossary of *Helpful Definitions*. As with all of the items in this section, some of these resources will be helpful to you and others will not apply to your situation.

In the section, *What to do Prior to Death*, we have created a list of important issues that you may want to discuss with your family while you are feeling well. It may become more difficult for you to have these conversations once your illness has advanced.

In addition, we have provided a blank copy of a Durable Power of Attorney for Healthcare form, a list of local funeral homes and agencies that provide final arrangements, and a guide of *What to do After Death* for your family members.

You may want to register your wishes for your healthcare decisions with the *Washington State Living Will Registry*. This registry allows you to store your living will documents in a secure, online database. A living will gives you the power to record your medical decisions in the event you are unable to communicate and gives your physician vital information about your treatment wishes. Only authorized health care providers may access and view your documents in the registry. The registry also stores your emergency contact information so that family and next of kin can be contacted.

By using the *Washington State Living Will Registry*, you relieve your family from having to make stressful health care decisions. It may be assuring to know that your attending physician has access to an exact copy of your health care instructions and that your wishes will be honored. You may access the *Washington State Living Will Registry* website at <http://www.doh.wa.gov/livingwill/default.htm>

We hope that these resources will be helpful. We encourage you to let your social worker know if you have questions or need help discussing any of these issues with your loved ones.

HELPFUL DEFINITIONS

Advance Directive – A general term that describes two kinds of legal documents - living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

Artificial nutrition and hydration – Artificial nutrition and hydration supplement or replace ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine, or a vein.

Capacity – In relation to end-of-life decision-making, a patient has medical decision-making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

Cardiopulmonary resuscitation (CPR) – A group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

Do-Not-Resuscitate (DNR) order – A DNR order is a physician's written order instructing healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

Intubation – Refers to "endotracheal intubation" – the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

Life-sustaining treatment – Treatments (medical procedures) that replace or support an essential bodily function. May also be called life support treatments. Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and other treatments.

Living Will – A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate.

It may also be called a "directive to physicians," "healthcare declarations," "Healthcare treatment directive" or "medical directive." **In Washington State, a form called the POLST (Physicians Order for Life Sustaining Treatment) is**

often used. The POLST is a form intended for any individual with a serious health condition.

Medical Power of Attorney – A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a healthcare proxy, Durable Power of Attorney (DPOA) for Healthcare or appointment of a healthcare agent. **In Washington State you do not need to have a notary sign the DPOA for healthcare form.**

Palliative care – A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, and controlling pain and symptoms.

Power of Attorney – A legal document allowing one person to act in a legal matter on another's behalf regarding financial or real estate transactions.

Respiratory arrest – The cessation of breathing – an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating.

Ventilator – A ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own, or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

WHAT TO DO PRIOR TO DEATH

Family and friends who are caregivers are encouraged to discuss these issues with their loved one.

DISCUSS YOUR WISHES REGARDING END OF LIFE CARE INCLUDING:

- Health care decisions regarding end-of-life interventions.
- Who will make healthcare decisions for you when you are no longer capable?
- Desires for long term care (stay at home versus facility care).
- Your financial situation and who will manage your bills when you no longer can.
- Desires and plans for funeral/cremation arrangements.

LOCATE AND OBTAIN IMPORTANT DOCUMENTS: (NOT ALL WILL APPLY TO EVERYONE)

- Health care directive information – including Durable Power of Attorney for Healthcare and Living Will.

- Original Last Will and Testament.
- Insurance policies.
- List of property - a complete list of real estate, stocks, bonds, bank accounts, deeds, and personal property.
- List of creditors.
- Marriage certificate - available from the county clerk where the marriage license was issued.
- Military discharge papers.
- Social Security numbers, for you, your spouse, and dependent children.
- Recent income tax returns.
- Birth certificates - for you, your spouse, and dependent children - available at either the state or county public records offices where the person was born.

NOTES

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Durable Power of Attorney for HealthCare

I, _____ (name), living in the city of _____, in the county of _____, designate _____ (name) as my attorney in fact, to act for me in making healthcare decisions if I become incapacitated. I hereby revoke any and all healthcare powers of attorney previously granted by me.

1. Alternate Attorney in Fact. If for any reason _____ (name) fails to act, or is not able to act, I designate _____ (name), then _____ (name) as alternate attorneys in fact, to serve in the order named. An attorney in fact may resign by delivering written notice to that effect, in recordable form, to an alternate, successor, or co-attorney in fact. In this Durable Power of Attorney for Healthcare, the "attorney in fact" means the then acting attorney in fact.

2. Power to Make Healthcare Decisions. My attorney in fact shall have the right to make decisions, and to give informed consent on my behalf, as to my healthcare, to the extent permitted by law. This authority shall include, but not be limited to, the right to consent to the withholding or withdrawal of life-sustaining treatment which would only prolong artificially the moment of my death and prevent me from dying naturally, in those circumstances in which a physician(s) has/have determined: (a) that I am in a permanent unconscious condition, meaning an incurable and irreversible condition in which I am medically assessed within reasonable medical judgment as having no reasonable probability of recovery from an irreversible coma or a persistent vegetative state, or (b) that I have a terminal condition, meaning an incurable and irreversible condition caused by injury, disease or illness, that would within reasonable medical judgment cause death within a reasonable period of time in accordance with accepted medical standards. I also authorize my attorney in fact to make decisions regarding the artificial administration of food and fluids, consistent with any Healthcare Directive (living will) I have executed.

3. Effectiveness. This Durable Power of Attorney for Healthcare shall become effective upon my incapacity. Incapacity shall include the inability to make healthcare decisions effectively for reasons such as mental illness, mental deficiency, incompetency, physical illness or disability, advanced age, chronic use of drugs, or chronic intoxication. Incapacity may be determined by (a) a court order or (b) a written qualified attending physician.

4. Duration. This Durable Power of Attorney for Healthcare becomes effective as provided in Section 3 above, and shall remain in effect to the fullest extent permitted by Chapter 11.94 of the Revised Code of Washington, or until revoked or terminated as provided in Section 5 or 6 below.

5. Revocation. This Durable Power of Attorney for Healthcare may be revoked, suspended, or terminated by written notice from me to the designated attorney in fact and, if this power has been recorded, by recording this notice in the office where deeds are recorded for real estate located in _____ County, Washington.

6. Termination. If appointed, my guardian may, with court approval, revoke, suspend, or terminate this Durable Power of Attorney for Healthcare.

7. Reliance. Any person dealing with the assigned attorney in fact shall be entitled to rely upon this Durable Power of Attorney for Healthcare to carry out my wishes for healthcare. No one shall deal with this attorney in fact if they know or have written notice of any cancellation, revocation, suspension, or termination of this Durable Power of Attorney for

Healthcare. Any action so taken, unless otherwise invalid or unenforceable, shall be binding on my relatives or inheritors of my estate.

8. Indemnity. My estate shall hold harmless and indemnify the attorney in fact from all liability for acts or omissions done in good faith.

9. Applicable. The laws of the State of Washington shall govern this Durable Power of Attorney for Healthcare.

10. Execution. This Durable Power of Attorney for Healthcare is signed on the _____ day of _____, 20____, to be effective as provided in Section 3 above.

Signature of Declarer _____

NOTE: Washington State law does not require a Durable Power of Attorney for Healthcare be witnessed or notarized. However, it is recommended that there always be two witnesses and that these witnesses be persons qualified to witness the signing of a Healthcare Directive. Such persons are individuals who are not related to the declarer by blood or marriage and who will not be entitled, under any existing will, to any portion of the estate of the declarer. Witnessing and/or notarization is also important as evidence to help confirm the declarer's competence and help assure that the declarer's wishes are carried out should family members or others oppose on the grounds the declarer did not understand what he/she was doing when signing the document.

Date Witness (print name) Witness (signature)

Date Witness (print name) Witness (signature)

Notarization, if needed:

STATE OF WASHINGTON, COUNTY OF _____

I certify that I know or have satisfactory evidence that the GRANTOR, _____ signed this instrument and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in this instrument.

Dated this _____ day of _____, 20_____.

NOTARY PUBLIC in and for the State of Washington

Residing at _____

My commission expires _____

FUNERAL HOMES AND CREMATION SERVICES

We have prepared the following list of providers in our area. For others, please consult your telephone directory yellow pages under "Funeral Directors." Please contact individual businesses for further details. **Hospice of the Northwest does not endorse or recommend one provider over another.**

SKAGIT COUNTY

Affordable Burial and Cremation Services LLC (360) 424-1002
108 S Barker Road, Mount Vernon

Alpha-Omega Burial and Cremation (360) 424-3531
2021 E College Way Suite 114, Mount Vernon

Evans Funeral Home Chapel and Crematory..... (360) 293-3311
1105 32nd Ave., Anacortes www.evanschapel.com

Funeral and Cremation Care.....800-764-0895
www.funeralandcremationcare.com

Hawthorne Funeral Home and Memorial Park (360) 424-1154
1825 E. College Way, Mount Vernon www.hawthornefuneralhm.com

Hulbush Funeral Home (360) 757-6055
281 S. Burlington Blvd., Burlington

Kern Funeral Home (360) 336-2153
1122 S. 3rd Street, Mount Vernon www.kernfuneralhome.com

Lemley Funeral Chapel (360) 855-1288
1008 3rd Street, Sedro-Woolley www.lemleychapel.com

Skagit Cremation Service..... (360) 424-0282
P. O. Box 2411, Mount Vernon

ISLAND COUNTY

Burley's Funeral Chapel (360) 675-3192
30 S. Ely Street, Oak Harbor www.burleyfuneralchapel.com

Visser Funeral Home..... (360) 221-6600
432 3rd Street, Langley www.visserfuneralhome.com

Whidbey Memorial..... (360) 675-5777
746 NE Midway Blvd., Oak Harbor www.whidbeymemorial.com

SNOHOMISH COUNTY

American Cremation & Casket Alliance 1-800-398-7101
3906 – 132nd Place N.E. #701, Marysville www.americancremationandcasket.com

Funeral Alternatives.....(360) 658-1921
1321 State Street, Marysville www.funeralalternativesofsnohomishcounty.com

Gilbertsons Funeral Home..... (360) 629-2101
27001 88th Ave. NW, Stanwood www.gilbertsonfh.com

Linde Funeral Service..... (425)-252-6730
Skagit and Snohomish Counties www.lindefuneralservice.com

Schaefer Shipman Funeral Home (360) 659-3711
804 State, Marysville www.schaefershipmanfuneral.com

Weller Funeral Home (360) 435-2509
327 N. MacLeod Ave., Arlington www.wellerhome.com

SAN JUAN COUNTY

Evans Funeral Home Chapel and Crematory (360) 293-3311
1105 32nd Ave., Anacortes

ANATOMICAL/BODY DONATION

Anatomy Gifts Registry
www.anatomicgift.com..... (800) 300-5433

BioGift Anatomical Inc.
www.biogift.org (866) 670-1799

Life Legacy Foundation
www.lifelegacy.org..... (888) 774-4438

MedCure
www.medcure.org..... (866) 560-2525

University of Washington School of Medicine Willed Body Program
http://wbp.biostr.washington.edu/ (206) 543-1860

OTHERS

Peoples Memorial Funeral Cooperative
www.peoplesmemorial.org (888) 762-2762

Neptune Society
www.neptunesociety.com..... (800) 637-8863

WHAT TO DO AFTER DEATH OCCURS

Finalize funeral and/or cremation arrangements.

Secure an ample number of certified copies of the death certificate. Available from your funeral director or county health department. Most companies will want a certified copy. Use a photocopy when you can to save money.

Notify the insurance companies that insured your spouse of his or her death, in writing. Each company will need a statement of claim and a death certificate before the surviving spouse can receive benefits.

Contact Social Security to find out if you are eligible for new benefits. Social Security benefits are not automatically paid out after a death; you must apply for them. Learn more by calling (800) 772-1213.

Write a formal letter to the deceased's employer, union, and any other group or professional organization with which he or she may have had an association. Many of these organizations have insurance policies of which you may be the beneficiary. Also inquire about any 401(k), pension, or company stock benefits.

If your spouse was a veteran, apply for veterans' benefits at the nearest Veterans Administration office. You will need a copy of the discharge certificate. If you cannot find a copy, contact National Personnel Records Center, 9700 Page Boulevard, St. Louis, MO 63132-5200. Send the request to the attention of the branch in which the deceased served.

Advise all creditors in writing, including issuers of credit cards, that your spouse has died. If you have any loans, find out if they are insured.

Consult a lawyer. Your family may be very well meaning, but they are not necessarily legal experts. Discuss fees before accepting legal help.

Contact the Department of Motor Vehicles. The title of the car owned by your spouse may need to be changed.

WITHIN THE FIRST SIX MONTHS

See a tax accountant or tax lawyer. Federal law requires an estate tax return be filed within nine months of the death in many cases. Since tax laws are constantly being revised, it is important to seek out expert advice to determine your full tax liability.

Probate. These procedures can be complex, depending upon the size of the estate and claims against it. In some states, probate can take a year to complete. Again, an attorney can be helpful.

Financial and Legal Information

Financial Issues

Medicare, Medicaid and private insurance companies usually cover all or part of the costs of hospice services. For details of covered Hospice of the Northwest services, see the *“Snapshot of Hospice of the Northwest Services”* handout.

Hospice of the Northwest cares for patients regardless of their ability to pay. Patients without health insurance or who have insurance plans that do not cover their Hospice of the Northwest services (and who are not eligible for medical insurance) may apply for financial assistance through the Hospice of the Northwest Foundation. Financial assistance is determined by assessing household income, family size, health, medical expenses, and total assets. For more information, please contact Hospice of the Northwest Services, LLC or your Hospice of the Northwest team.

BILLING QUESTIONS

Please call the Billing Specialist at (360) 445-8535 if you have any questions regarding your account.

Comparison of Requirements for Participation in MEDICARE Benefit*

	Regular Medicare	Hospice Benefit
Eligibility	A, A&B, or 3	Part A, or A&B
Treatment Goal	Curative, rehab	Palliation
Prognosis	Unlimited	6 months or less
Duration	Unlimited	2 90-day periods, unlimited 60-day periods
Home Care	Medical necessity must be justified, MSW limited rehab goals required	Extensive benefits for intermittent and extended (continuous) care
Bereavement	Not available	As needed, up to one (1) year after death
Homebound Status	Required	Not required
Requirement of Skilled Nursing	Required	Not required
Room and Board	A	Not covered
Copay/Coinsurance		See “Snapshot” handout

Patient Rights

As a Hospice of the Northwest patient, you have the right to be notified of your rights and responsibilities before treatment begins. The patient's family or guardian may exercise the patient's rights and responsibilities if the patient has been judged incapable of doing so.

RIGHT TO DIGNITY AND RESPECT FOR YOU AND YOUR PROPERTY:

- To have equal and fair treatment without regard to race, color, national origin, creed, ability to speak English, disability, sex, age, marital status, or who pays for services.
- To have fair, respectful and polite treatment in all contacts with Hospice of the Northwest.
- To have your property treated with respect.
- To have your spiritual and cultural needs considered in your care.
- To make a complaint to Hospice of the Northwest without fear of discrimination or reprisal. Call the office at (360) 814-5550 and ask to talk to the supervisor of your caregiver(s). The supervisor will work with you to resolve your complaint.
- To make a complaint to the State of Washington by calling the Investigation Unit at Facilities & Licensing, Department of Health, 1-800-633-6828 (call between 8:00 a.m. – 5:00 p.m., Monday through Friday).

RIGHT TO BE INFORMED:

- To know who owns and runs Hospice of the Northwest.
- To choose whatever agency you prefer to provide your care, subject to limitations set by your insurer.
- To know about services Hospice of the Northwest provides, and about those given to you.
- To know the names of staff that are in your home, what they are doing for you and how often they visit.
- To ask for a different team member.
- To ask for a different type of service.
- To have a say in your plan of care and what the likely results of care may be.
- To ask staff for information about your health and health care.
- To know in advance when the services will stop and why.
- To make advance directives.
- To refuse services or treatments without fear of reprisal or discrimination.
- To know about research done by Hospice of the Northwest that would directly change your care. You have the right to be part of or not be part of that research.
- To participate in the consideration of ethical issues that arise in your care.

- To be able to identify visiting staff members through proper identification.
- To know what services Hospice of the Northwest does not provide.
- To request a professional interpreter, free of charge, if I am not comfortable communicating in English. Hospice of the Northwest will make reasonable efforts to secure a translator as requested by the patient.

RIGHT TO PRIVACY:

- To confidentiality of information about your health, social and financial circumstances.
- To expect Hospice of the Northwest to release information only as required by law or approved by you.
- To see what is in your records.
- To be advised of the Hospice of the Northwest Policy & Procedure regarding disclosure of clinical records.

RIGHT TO FINANCIAL INFORMATION:

- To know how Hospice of the Northwest charges and bills for services and how much you need to pay, unless a managed care plan pays for services (see Financial Information on **page 21**).
- To a detailed monthly statement that shows the date of each service and the charge, upon request, unless a managed care plan pays for services.

RIGHT TO QUALITY OF CARE:

- To have staff (your team members) fully trained in the care they provide.
- To expect that all medically related care is provided under a doctor's orders.
- To know what to do in a medical emergency:
- To have your pain controlled to the extent possible.
- Choose your attending physician or primary care provide.
- To formulate an advance directives for medical treatment, and have the hospice staff comply with these directives.

PATIENT RESPONSIBILITIES

PATIENTS HAVE THE RESPONSIBILITY:

- To notify Hospice of the Northwest prior to hospitalization, emergency room use, diagnostic tests or other new treatments. Patients may be responsible for costs associated with unauthorized care.
- To notify Hospice of the Northwest of changes in their condition (e.g., symptoms, medication problems, etc.).
- To follow the plan of care.

- To notify Hospice of the Northwest if a scheduled visit needs to be changed.
- To tell Hospice of the Northwest staff about the existence of, or changes made to, any advance directives.
- To tell Hospice of the Northwest staff and/or managers of any problems or dissatisfaction with the services provided.
- To provide a safe environment for care to be provided.
- To carry out mutually agreed-upon responsibilities.
- To plan with your Hospice of the Northwest team for day-to-day individual care.
-

NOTES

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

HOSPICE OF THE NORTHWEST SERVICES, LLC PRIVACY PRACTICES

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

USE AND DISCLOSURE OF HEALTH INFORMATION

Hospice of the Northwest Services, LLC ("*Hospice of the Northwest*") may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. Hospice of the Northwest has established policies to guard against unnecessary disclosure of your health information.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH, AND PURPOSES FOR WHICH, YOUR HEALTH INFORMATION MAY BE USED AND DISCLOSED.

To Provide Treatment. Hospice of the Northwest may use your health information to coordinate care within Hospice of the Northwest and with others involved in your care, such as your attending physician, members of the Hospice of the Northwest interdisciplinary team and other health care professionals who have agreed to assist Hospice of the Northwest in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. Hospice of the Northwest also may disclose your health care information to individuals outside of Hospice of the Northwest involved in your care including family members, pharmacists, suppliers of medical equipment or other health care professionals.

To Obtain Payment. Hospice of the Northwest may include your health information in invoices to collect payment from third parties for the care you receive from Hospice of the Northwest. For example, Hospice of the Northwest may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or Hospice of the Northwest. Hospice of the Northwest also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for hospice and the services that will be provided to you.

To Conduct Health Care Operations. Hospice of the Northwest may use and disclose health information for its own operations in order to facilitate the function of Hospice of the Northwest and as necessary to provide quality care to all of Hospice of the Northwest's patients. Health care operations include such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.

- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development including cost management and planning related analyses and formulary development.
- Business management and general administrative activities on Hospice of the Northwest.
- Fundraising for the benefit of Hospice of the Northwest.

For example Hospice of the Northwest may use your health information to evaluate its staff performance, combine your health information with other Hospice of the Northwest patients in evaluating how to more effectively serve all Hospice of the Northwest patients, disclose your health information to Hospice of the Northwest staff and contracted personnel for training purposes, use your health information to contact you as a reminder regarding a visit to you, or contact you as part of general fundraising and community information mailings (unless you tell us you do not want to be contacted).

For Fundraising Activities. Hospice of the Northwest may use information about you including your name, address, phone number and the dates you received care in order to contact you to raise money for the Hospice of the Northwest Foundation. If you do not want the Hospice of the Northwest Foundation to contact you, notify Hospice of the Northwest Foundation at (360) 814-5702 and indicate that you do not wish to be contacted.

For Appointment Reminders. Hospice of the Northwest may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

For Treatment Alternatives. Hospice of the Northwest may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH, AND PURPOSES FOR WHICH, YOUR HEALTH INFORMATION MAY ALSO BE USED AND DISCLOSED.

When Legally Required. Hospice of the Northwest will disclose your health information when it is required to do so by any Federal, State or local law.

When There Are Risks to Public Health. Hospice of the Northwest may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the workforce as legally required.

To Report Abuse, Neglect or Domestic Violence. Hospice of the Northwest is allowed to notify government authorities if Hospice of the Northwest believes a patient is the victim of abuse, neglect or domestic violence. Hospice of the Northwest will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

To Conduct Health Oversight Activities. Hospice of the Northwest may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. However, Hospice of the Northwest may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

In Connection with Judicial and Administrative Proceedings. Hospice of the Northwest may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when Hospice of the Northwest makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

For Law Enforcement Purposes. As permitted or required by State law, Hospice of the Northwest may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.

- To a law enforcement official if Hospice of the Northwest has a suspicion that your death was the result of criminal conduct including criminal conduct at Hospice of the Northwest.
- In an emergency in order to report a crime.

To Coroners and Medical Examiners. Hospice of the Northwest may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

To Funeral Directors. Hospice of the Northwest may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, Hospice of the Northwest may disclose your health information prior to and in reasonable anticipation of your death.

For Organ, Eye or Tissue Donation. Hospice of the Northwest may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

For Research Purposes. Hospice of the Northwest may, under very select circumstances, use your health information for research. Before Hospice of the Northwest discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.

In the Event of a Serious Threat to Health or Safety. Hospice of the Northwest may, consistent with applicable law and ethical standards of conduct, disclose your health information if Hospice of the Northwest, in good faith, believes that such 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.

For Specified Government Functions. In certain circumstances, the Federal regulations authorize Hospice of the Northwest to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations, and inmates and law enforcement custody.

For Worker's Compensation. Hospice of the Northwest may release your health information for worker's compensation or similar programs.

AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

Other than is stated above, Hospice of the Northwest will not disclose your health information other than with your written authorization. If you or your representative authorizes Hospice of the Northwest to use or disclose your health information, you may revoke that authorization in writing at any time.

YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information that Hospice of the Northwest maintains:

Right to Request Restrictions. You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on Hospice of the Northwest's disclosure of your health information to someone who is involved in your care or the payment of your care. However, Hospice of the Northwest is not required to agree to your request. If you wish to make a request for restrictions, please contact the Executive Director of Hospice of the Northwest Services, LLC at (360) 814-5550 or (800) 894-5877.

Right to Receive Confidential Communications. You have the right to request that Hospice of the Northwest communicate with you in a certain way. For example, you may ask that Hospice of the Northwest only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact Director of Hospice of the Northwest Services, LLC at (360) 814-5550 or (800) 894-5877. Hospice of the Northwest will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

Right to Inspect and Copy your Health Information. You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to Director of Hospice of the Northwest Services, LLC at (360) 814-5550 or (800) 894-5877. If you request a copy of your health information, Hospice of the Northwest may charge a reasonable fee for copying and assembling costs associated with your request.

Right to Amend Health Care Information. You or your representative have the right to request that Hospice of the Northwest amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by Hospice of the Northwest. A request for an amendment of records must be made in writing to Director of Hospice of the Northwest Services, LLC at 819 S. 13th Street, Mount Vernon, WA 98274. Hospice of the Northwest may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by Hospice of the Northwest, if the records you are requesting are not part of Hospice of the Northwest's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of Hospice of the Northwest, the records containing your health information are accurate and complete.

Right to an Accounting. You or your representative have the right to request an accounting of disclosures of your health information made by Hospice of the Northwest for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to Director of Hospice of the Northwest Services, LLC at 819 S. 13th

Street, Mount Vernon, WA 98274. The request should specify the time period for the accounting starting on or after January 1, 2004. Accounting requests may not be made for periods of time in excess of six (6) years. Hospice of the Northwest would 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.

Right to a Paper Copy of this Notice. You or your representative have a right to a separate paper copy of this Notice at any time, even if you or your representative have received this notice previously. To obtain a separate paper copy, please contact the Executive Director of Hospice of the Northwest Services, LLC at (360) 814-5550 or toll free at (800) 894-5877.

DUTIES OF HOSPICE OF THE NORTHWEST

Hospice of the Northwest is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. Hospice of the Northwest is required to abide by the terms of this Notice as may be amended from time to time. Hospice of the Northwest reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If Hospice of the Northwest changes its Notice, it will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to Hospice of the Northwest and to the Secretary of DHHS if you or your representative believe that your privacy rights have been violated. Any complaints to Hospice of the Northwest should be made in writing to Executive Director of Hospice of the Northwest Services, LLC at 819 S. 13th Street, Mount Vernon, WA 98274. Hospice of the Northwest encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

CONTACT PERSON

Hospice of the Northwest has designated the Executive Director of Hospice of the Northwest Services, LLC as the contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at 819 S. 13th Street, Mount Vernon, WA 98274, (360) 814-5550 or (800) 894-5877.

EFFECTIVE DATE

This notice is effective January 1, 2004.

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE, PLEASE CONTACT:

Executive Director of Hospice of the Northwest Services, LLC
819 S. 13th Street, Mount Vernon, WA 98274
(360) 814-5550 or (800) 894-5877.

Home Safety

GENERAL GUIDELINES

MOVING AND LIFTING

Patients who are very ill often need help to sit up, change positions, or get from the bed to a chair. Here are some things to remember to prevent injury:

- Assess the situation. Don't try to move anyone if there is any doubt about doing it safely.
- If there is a hospital bed, move it to a comfortable working height.
- Wear comfortable, low-heeled shoes and keep your feet about shoulder-width apart.
- When lifting, flex your knees and use the muscles in your arms and legs, not your back. Don't jerk suddenly; use a smooth fluid motion. Stand as close as possible with your toes pointing to the direction you want to move the patient. Don't twist your body to turn.
- Wherever possible, use a sheet under the patient to lift or turn.

FIRE SAFETY

- Install smoke detectors throughout the home and replace the batteries every year.
- If you have a fireplace, use a fire screen and have the chimney cleaned regularly.
- Turn off appliances (like the oven, television, coffeepot, or iron) when you go out.
- Store flammable chemicals like paints, gasoline, and solvents in a cool, well-ventilated area. Dispose of old rags and empty cans.
- Keep a working fire extinguisher handy and learn how to use it.
- Keep pathways to exits clear.
- Have an easily accessible key near doors that lock from the inside with a key.
- Don't smoke in bed.

ELECTRICAL SAFETY

- Never use a knife or fork to get toast out of a plugged-in toaster. Unplug it.
- Avoid using appliances (like hair dryers, shavers, curling irons, radios and televisions) while bathing.
- Don't overload outlets.
- Don't put electrical cords under furniture or rugs.
- Make sure all cords are in good repair.
- If a patient is using a ventilator or oxygen concentrator, have back-up in case of power failure.

BATHROOM SAFETY

- Put a non-skid mat in the tub or shower.
- Consider having grab bars installed.
- Check water temperature with your hand before stepping into the tub or shower.

KITCHEN SAFETY

- Wipe up spills as soon as they happen.
- Turn pot handles away from the stove's outer edge.
- Wear short or tight sleeves while cooking to prevent burning clothes or tipping pots.
- Use pot holders to remove covers from hot pans.
- Vent steam away from yourself.

BEDROOM SAFETY

- Have a night-light near the bed or keep a flashlight on a night stand.
- Keep closet doors closed.

RUGS AND CARPETS

- Pick up throw rugs that are easy to trip or slip on.
- Tape or tack down loose edges of carpet.
- Do not run electric cords under rugs.

STAIRS AND HALLWAYS

- Keep stairways and halls brightly lit.
- Keep clutter out of stairways and halls.
- Use a night light in a hall if an outlet is available.
- Repair loose railings or banisters immediately.

GENERAL GUIDELINES

- Put emergency numbers and your address in large print on or near all phones.
- People with poor coordination or limited sensation should not handle sharp or hot objects or surfaces.
- When dizziness is a problem, sit for a minute while going from lying to standing.
- If there are guns in the home, they should be kept unloaded and in a secure place that is locked. If guns in the home are not secured, it may mean Hospice of the Northwest will discontinue visits.

These guidelines can help prevent the most common causes of injury in the home.

DISASTER PREPAREDNESS

In the event of a disaster, such as a severe earthquake, Hospice of the Northwest will contact our patients according to their needs. If there is a large-scale disaster, your Hospice of the Northwest team would probably not be able to keep their regular visit schedules. Your case manager or an office supervisor would make every effort to maintain communication with you. Here are some reasonable disaster preparations you can make:

DISASTER SUPPLIES KIT

Ideally, you should keep at least a 3-day supply of water, food, and medical supplies on hand. Each person in the household needs about a gallon of water a day. Food should be non-perishable, whether packaged or canned. Don't forget a non-electric can opener. You should keep an extra pair of glasses, a battery-powered radio, a flashlight, and plenty of batteries in your kit. Some people also put in an extra set of car keys, some cash, and a credit card. You may also want to consider the special needs of infants, the elderly, or disabled family members by including things like a pacemaker serial number or infant diapers and formula.

HOME PREPARATIONS

Fasten shelves securely and bolt bookcases to the wall. Put large, heavy objects on lower shelves and don't hang mirrors or pictures over the bed. Secure the water heater with a thin metal strap screwed to the wall studs. Learn how to shut off water, gas and electricity. You may want to ask a nearby friend or neighbor to check on you in case of a disaster.

IF YOU MUST EVACUATE

Listen to a battery-powered radio for the locations of emergency shelters. Wear sturdy shoes and protective clothing. Take your disaster supplies kit. Lock your house. If there is time, let others know where you are going. You may want to make plans for pets since animals may not be allowed in public shelters. Shut off utilities if instructed to do so, then travel by routes specified by your local officials.

INFECTION CONTROL

Avoiding infections is important to the patient and the caregiver. The following guidelines will help keep both safe and free from the spread of infection.

Hand Washing and Hand Sanitizing

Keeping hands clean is one of the most important steps we can take to avoid getting sick and spreading germs to others. **It is best to wash your hands with soap and clean running water for 20 seconds.** However, if soap and clean water are not available, use an alcohol –based product to clean your hands. Alcohol-based hand rubs significantly reduce the number of germs on skin and are fast acting.

When washing your hands with soap and water:

- Wet your hands with clean running water and apply soap. Use warm water if it is available.
- Rub hands together to make lather and scrub all surfaces, including all around the fingers and around the nail beds.
- Continue rubbing hands for 20 seconds. Need a timer? Imagine singing "Happy Birthday" twice through.
- Rinse hands well under running water.
- Dry your hands using a paper towel or air dryer. If possible, use your paper towel to turn off the faucet.

When should you wash your hands?

- Before preparing or eating food.
- After going to the bathroom.
- After changing diapers or cleaning up after someone who has gone to the bathroom.
- Before and after attending to someone who is sick.
- After blowing your nose, coughing, or sneezing.
- After handling an animal or animal waste.
- After handling garbage.
- Before and after treating a cut or wound.

When using an alcohol-based hand sanitizer: (minimum 60% alcohol)

- Apply product to the palm of one hand.
- Rub hands together and "scrub" all surfaces, including all around the fingers and around the nail beds.
- Rub the product over all surfaces until your hands are dry.

GLOVES

Generally, if it's wet, wear gloves. Saliva, nasal secretions, sweat, and tears are usually not contaminated if they don't contain visible blood. But you should always wear disposable gloves when exposed to blood, urine, feces, wound drainage or pus, stomach contents and vomit. If you need gloves because you are a caregiver handling dressings, urinals, or bedpans, your Hospice of the Northwest nurse or care aide can provide them for you. Be sure to wash your hands before putting the gloves on and after taking them off.

CLOTHING

If you are going to help the patient in some way in which you might get splattered, wear washable clothing or a smock.

MASKS

When a patient has active tuberculosis (TB), the caregiver should wear a mask when providing care.

FLUSH

Flush blood and other body fluids, such as vomit, down the toilet.

SOILED DRESSINGS

Put soiled bandages, disposable pads, and gloves in a big enough plastic bag and seal it securely. If the bag is thin or torn, put it in another plastic bag and tape it securely before putting it in the garbage.

NEEDLES

If a patient uses needles in the course of care, dispose of them in a tough, puncture-resistant plastic container. An empty bleach bottle works well. Be sure to screw the lid on tightly. An alternative is a coffee can with the lid secured tightly with heavy tape. Your Hospice of the Northwest nurse may also give you a special container for disposing of needles.

LAUNDRY

Collect contaminated laundry in a plastic bag. Wash it separately in hot water and detergent. If you hand wash a small-contaminated item, wear gloves.

SPILLS

Wear gloves when cleaning up body fluid spills. Wash spills with hot soapy water, and disinfect with a dilute bleach solution (1 part bleach to 10 parts water) if possible.

***We cannot change the world
by a new plan, project or idea.***

***We cannot even change other
people by our convictions,
stories, advice and proposals,***

***but we can offer a space
where people are encouraged
to disarm themselves,
to lay aside their occupations
and preoccupations***

***and to listen with attention
and care
to the voices speaking their
own center.***

- - - Henri Nouwen

Dealing with Physical Changes

When people have progressive diseases their bodies gradually change and become unable to function as they once did. These changes are normal and expected. These changes may be frightening and upsetting if you are not prepared for them.

Discussing what you observe and feel with your Hospice of the Northwest team is vital for ongoing pain and symptom management.

Following is some information about the kinds of changes often experienced as diseases progress.

PAIN MANAGEMENT

You may experience a variety of sensations that can be described as pain or discomfort. Pain usually begins at the physical level but is affected by your thoughts and emotions. It is important to remember that pain can be controlled in a variety of ways. Your Hospice of the Northwest team will work with you to devise a plan to help relieve your discomfort. Your pain management plan and interventions are based on your goals of care.

It is not a sign of weakness to admit you are having pain. Pain is a common medical problem that requires urgent attention. Don't be afraid to talk about it. It is important for you to tell others about your pain so that treatment can be adapted to your special needs.

It is also important to let your Hospice of the Northwest team know if pain interferes with your sleep or activities of daily living.

You May Notice:

- Your discomfort comes and goes.
- Certain things make it worse and certain things relieve it.
- Your pain varies in intensity (mild, moderate, and severe).
- Your activity level decreases.
- Your ability to sleep is affected so you don't get adequate rest.
- You don't feel like visiting with family and friends.
- You feel irritable or agitated.

Your nurse will either show you a "pain rating scale" or describe it to you. The scale is used to clarify how much your pain hurts. The scale will help you answer several questions your doctor or nurse will ask regarding your pain. For example: Where is it? When does it occur? How often? What makes it worse or better? Does the pain move or stay still? What are the characteristics of your pain? Is it sharp, stabbing, dull, or achy?

Comfort Interventions:

- Take pain medications on a scheduled basis. A constant source of discomfort requires a constant source of relief. If you are unable to take your pain medications regularly or find they are not providing the relief they once did, please contact your Hospice of the Northwest team.
- A warm blanket can soothe cramping pain.
- Find a new position to relieve the discomfort of stiffness.
- Gentle massage of your hands, feet or back may be soothing.
- Activities that may help distract you from your pain:
 - music
 - have someone read to you
 - listen to a relaxation tape
 - practice a visualization exercise

PAIN MEDICATIONS

Many people who take pain medications worry about becoming addicted. Addiction is the use of a drug for non-medical reasons. Ask yourself, "If I didn't have pain, would I be taking this medication?" If your answer is, "Of course not," then addiction is not an issue.

Some people have heard that pain medication will not work if it is used "before I really need it." Pain medication does not stop working. It is a matter of getting the right drug and the right dose at the right time for you.

A common myth about taking medications is that an injection is necessary to achieve the best pain relief. This is not the case. The proper amount of medication taken by mouth is generally more effective and less painful than an injection or intravenous route. Many medications are also effective given rectally.

Sometimes people do not understand why it takes so much medication to have an effect on their bodies. Individual differences can be great. Some people simply need more medication than others. Others may develop a tolerance to medications at a fixed level. Sometimes, the amount of medication needed to be effective increases due to progression of the underlying disease. Your Hospice of the Northwest team will monitor and adjust ("titrate") dosages as needed. Medication may also be prescribed for "break-through pain" to take in-between regularly scheduled medications. It is important to continue your scheduled doses of pain medication, even if a breakthrough dose is given. It is acceptable to take regular and break-through pain medicine at the same time. Generally, you can take pain medications at the same time as your other medications.

Drowsiness that may occur during the first few days taking a new pain medication will disappear as the body adjusts and you recover from sleep deprivation. An increase in the dosage amount may also cause drowsiness. You may experience

nausea for the first few days. This side effect will usually disappear as the body adjusts to the new medication. An anti-nausea medication may be taken to prevent these side effects.

Hospice of the Northwest, in partnership with Hospice Pharmacia, provides medications related to your terminal diagnosis and comfort. Hospice Pharmacia is a hospice-specific pharmacy and has pharmacists specially trained in symptom management and end of life care. If you are a home patient, Hospice Pharmacia sends a two-week supply of medications via Fed Ex directly to your home. If medications are needed more urgently, Hospice of the Northwest works with multiple local pharmacies for immediate pick up. If you reside in a facility, medications related to your hospice diagnosis will be provided by the facility pharmacy and billed to Hospice of the Northwest. It is important to understand that medications for pain require extra steps to obtain. **Please let your Hospice of the Northwest team know immediately when you have less than 5 days of medications left so a refill can be obtained.**

If approved by your primary physician, you will receive a "Comfort Kit" from Hospice Pharmacia. This package will arrive via FedEx. Enclosed in the kits are medications for the most common symptoms observed in hospice. The purpose of the kit is to have medications readily available to provide prompt response to symptoms as they arise. Please do not open the comfort kits unless directed to do so by a Hospice of the Northwest nurse. The kits are sealed and need to be refrigerated. Your Hospice of the Northwest nurse will review the medications with you if a need arises to use the medications. For patients with certain diagnoses there will be two comfort kits provided.

Destruction of Medications

Hospice of the Northwest may assist if requested, in destroying all medications upon death or discontinuation if agreed to by the patient and/or family. They will do so by environmentally safe means. Destroying medications can help prevent medication errors, including taking the wrong medications or too much medication. Hospice of the Northwest is not able to remove medications from the home for use by another patient.

A copy of the Hospice of the Northwest's policy regarding destruction of medications is included under the "forms/additional information" section.

COMMON PHYSICAL SYMPTOMS

Following are common symptoms in a progressive disease. We recommend you discuss the specific causes with your Hospice of the Northwest team.

NAUSEA AND VOMITING

There are several possible causes for nausea and vomiting. These symptoms may arise as a side effect from medications required for pain or may indicate under-treatment of pain.

You May Notice:

- You feel sick and are unable to eat.
- You vomit occasionally or frequently.
- You are unable to keep down oral medications.
- You are comfortable at rest but feel ill or become nauseated with any movement.

Comfort Interventions:

- Adjust your diet according to the severity of your nausea and vomiting. For example, very small amounts of clear fluids are best for severe vomiting. Seek advice regarding your particular situation from your Hospice of the Northwest team.
- Take anti-nausea medications as prescribed. It can often help to take these medications 30 minutes before any other medications.
- While you are feeling nauseated, it may be necessary to take medications in a way other than by mouth. Your Hospice of the Northwest team may suggest suppositories or injections while you are feeling sick. It is important to maintain your medications to ensure your comfort through this temporary situation.
- Freshen your mouth thoroughly with a mild mouthwash or toothpaste after vomiting. Stomach contents can be very irritating to the lining of your mouth.

CONSTIPATION

Constipation is a common problem. It can be caused by progression of the disease, changes in your diet and/or decreased activity. Also, some pain medications slow bowel movement. It is important not to cut back on pain medications if you are constipated. There are medications which can be taken to counteract the constipating effect of these medications.

You May Notice:

- You have bowel movements less regularly and sometimes not for several days at a time.
- Your stool is constipated and you need to strain to have a bowel movement.

Comfort Interventions:

- Take medications as advised by your Hospice of the Northwest team.
- If nausea is not a problem, drink fruit juices, fluids of all kinds, and eat natural laxative foods.
- If you have no bowel movement for 3 days it is important to tell your Hospice of the Northwest team. Your medications may be adjusted or you may need a suppository or enema.

DRY, SORE MOUTH

Your mouth may become dry and sore if you are unable to drink your usual amount of fluids. This may happen if you have nausea, vomiting or lack of appetite. The

reduced amount of body fluid will also dry up saliva. A dry mouth can also be aggravated if you tend to breathe through your mouth.

You May Notice:

- Your mouth feels dry and uncomfortable.
- Your tongue is red and coated, or swollen.
- Your lips are dry and cracked.
- You have a bad taste in your mouth.
- You may have difficulty swallowing.
- Patches of white on the tongue or inside of cheeks.

Comfort Interventions:

- Clean your mouth frequently, especially after eating.
- Check mouthwashes before you use them. Many contain alcohol, which makes the dryness worse. Sometimes rinsing with other solutions may be helpful.
Some suggestions:
 - Combination of 4 cups water, ½ teaspoon salt, 1 teaspoon baking soda
 - Ginger ale
 - Solution of 1 part water, 1 part hydrogen peroxide, and 1 part mouthwash
 - After cleaning your mouth, use a water-soluble lubricant on your lips.
 - If you have dentures, remove and brush them twice a day. With weight loss, dentures may no longer fit correctly.
 - Take small amounts of fluids as often as possible. Sips of water or diluted juices are best if nausea and vomiting are a problem.
 - Suck on ice chips, popsicles or fresh pineapple chunks.
 - Try a commercial product to moisten your mouth. They may come in a swab or spray form and are available over the counter at your pharmacy, or from your Hospice of the Northwest team.
 - Add a small amount of lemon juice to ice water or crushed ice to stimulate saliva.

SHORTNESS OF BREATH

Problems with breathing can be due to physical changes caused by progression of your disease. We recommend you talk with your Hospice of the Northwest team about the specific cause of your shortness of breath.

You May Notice:

- You become breathless when you move around, get dressed or if you try to carry on a conversation.
- You have difficulty breathing even when you are resting.
- Your breathing sounds congested.

- You cough up mucus.
- You feel the need to cough up mucus and are unable to.
- You feel anxious or frightened if you are unable to breathe normally.

Comfort Interventions:

- If your shortness of breath is worse when you move, try to plan frequent rest periods between activities.
- Try to reduce conversation if it makes you feel breathless. You may want to reduce visiting times or ask friends and family to sit quietly with you.
- If your primary physician has prescribed any medication (including oxygen) for shortness of breath, take it as directed.
- You might find a humidifier helpful in loosening mucus so you can cough more easily.
- Get as much fresh air as possible by opening a window or by using a fan blowing directly at your face.
- Remove any clothing or bedding that makes you feel tight or constricted.
- Change your position if possible. Usually a high sitting position is best. This can be done by putting several pillows behind your back.
- You might find a recliner chair useful for sleeping as it keeps you in a semi-upright position.
- Ask a family member or friend to remain with you if you feel anxious.
- Try to keep as relaxed as possible. Tensing of your muscles will add to your feeling of breathlessness.

SKIN BREAKDOWN

Sore areas or breaks in the skin can occur if you have lost weight, are in bed for long periods of time, or have limited mobility.

You May Notice:

- You have red skin or soreness at pressure areas such as your tailbone, elbows, heels, or in skin folds.
- You have itchy skin.
- You have rashes or broken skin areas.

Comfort Interventions:

- Change your position frequently, approximately every 4 hours.
- Lift your body across the sheet rather than sliding.
- Use small pillows or padding such as rolled-up towels to keep skin surfaces from rubbing together and to keep skin from constant contact with the bedding.
- Have extra padding put on your bed. Foam mattresses, sheepskin pads and special mattresses are available.
- A full bath is not required daily as frequent washing can dry the skin.

- Keep skin folds and creases clean and dry.
- Use lotions and oils in the bath to help dry itchy skin.
- Tell you Hospice of the Northwest team if you notice any reddened or open areas. There are protective dressings that can be applied to sensitive skin or pressure areas to reduce irritation and make you more comfortable.

NUTRITION, HYDRATION, AND EATING DIFFICULTIES

A normal component of advanced illness is a decreased interest in eating and drinking. This is a normal body response as metabolism slows down. For many families, this is often distressing and frustrating. Research shows that stopping eating and drinking is not at all uncomfortable for the dying patient, while forced feeding and drinking may actually cause the patient discomfort. Eating and drinking for the hospice patient should never be forced.

For many families, this raises concern about how to assure comfort, and what should be done about dehydration. Your physician and other health care providers are available to provide individualized medical information.

The natural occurrence of dehydration in the last few days of life may include diminished energy, light-headedness, and dry mouth. Studies show that most can be managed to assure comfort. Some benefits may be that dehydration decreases the potential problems of excessive respiratory secretions, vomiting, fluid accumulation in the skin, and frequent urination.

Routine treatment with intravenous (IV) fluids may cause more problems than benefits. Studies and experiences indicate that when dehydration occurs in the last days of life, those treated with IV fluids did not show improvement in alertness, comfort, electrolyte balance, or survival.

Comfort Interventions:

- Eat when and what you want.
- Eat small amounts more frequently.
- Let friends and family help by cooking favorite dishes.
- Try soft foods such as baby food, cottage cheese, applesauce, oatmeal, and yogurt.
- Avoid cooking greasy foods or food with strong odors, as they may cause nausea.
- Some foods are easier to eat from a cup or with a straw.
- Use cold foods if you have a sore mouth or throat.
- Blend instant breakfast with ice cream, milk, or fruit to increase calories.
- Perform mouth care prior to meals to refresh the mouth and stimulate taste buds.
- For heartburn, take an antacid one hour before meals, and remain sitting up for thirty minutes after meals.

*You matter
because of who you are.
You matter
to the last moment of your life,
and we will do all we can
not only to help you die peacefully,
but to live until you die.*

- Dame Cicely Saunders

Journey's End:

WHAT TO EXPECT – WHAT TO DO

Most people are not sure they will know what to do and whether they will be able to manage in the final days of their loved one's life. Here we will tell you about some of the things that may happen, and we will give you some suggestions for ways to provide comfort to him or her. Remember: Hospice of the Northwest is always only a phone call away.

WITHDRAWAL

Sometimes, even weeks before death, a person begins to withdraw from friends and family and the world around. This turning inward may be part of preparing to die. The process may start with the patient sleeping more, eventually becoming difficult to awake. A coma is when you cannot wake the patient.

- Plan activities and visiting for times of day when the patient seems most alert.
- Since hearing seems to remain until the very end, you can continue providing reassurance by talking in a normal tone of voice about what you're doing, how much you care, or things you want your loved one to know.
- Tell the patient what you are going to do before you do it. For example, "Pat, I'm going to clean your mouth now."
- Remember not to say anything in front of the patient that you wouldn't say if they were wide awake.

APPETITE

The need and desire for food and fluids naturally begins to decline. See nutrition section, page 45. All our lives we have associated food with life. We eat to live. Now our loved one doesn't want food or fluids. Hard as it is, we must trust they know what is best for themselves.

- Let the patient be the guide; they will let you know if they wants food or fluids.
- If the patient coughs and sputters when taking fluid and food, it may be time to stop trying to feed them. Talk to your nurse.
- People who can't speak will sometimes bite a straw or spoon, clamp their teeth closed, or spit food out to let you know they don't want to eat.
- Often a person near death may say they are thirsty, but refuse water. They may be trying to tell you their mouth is dry. It is important to provide frequent mouth care to maintain comfort in the final days.

DISORIENTATION

As the body begins to shut down, changes happen that can make a dying person confused. Sometimes it becomes unimportant or difficult for the patient to keep track of time and people.

- If the dying person simply forgets where they are or the date, and is easily reoriented, gently remind them of where they are and the day, date, and time.
- If orienting the patient to the correct date or place agitates or upsets them, let it go.
- Some people seem disoriented to time in another way, sleeping during the day and awake at night. This may be caused by a fear of dying in one's sleep when no one will notice. It may seem safer to sleep when there are people around during the day. Or it may just be caused by too many daytime naps.
- Pets may also help keep a patient oriented.
- If there is a sudden disorientation, call the Hospice of the Northwest nurse.

CONFUSION/HALLUCINATIONS

Sometimes a patient appears to be hallucinating, seeing people and places that aren't visible to anyone else. They may have "imaginary" conversations. At first glance you may think the patient is over- or under-medicated, or that they are "out of it." But if we listen carefully there may be meaningful messages in what sounds like "rambling."

- People nearing the end of life will often talk about travel, as though they plan a journey. A patient might ask about the bus schedule, whether the suitcase is packed, or if there will be a high tide soon. This can actually be reassuring; it lets you know that your loved one is aware of the transition he will soon make.
- Dying people sometimes appear to have one foot in this world and one foot in another. They may talk clearly to people who have already died, often close relatives or friends, and then turn and talk clearly to you.
- Another common theme is seeing a place that those in the room can't see. Or a patient may say he is "ready to go home." At first you may want to answer, "You ARE home." But the patient is probably not talking about his physical home. Instead, you may get more response by asking, "Are you ready to leave?"
- There is no need to argue with the patient, correct him, or belittle him. These are normal experiences. There is no reason to speak louder than usual.
- If the patient is truly having hallucinations (like seeing bugs on the wall) let your Hospice of the Northwest nurse know. Adding or discontinuing medications can often relieve these symptoms.

FEVER

As the body becomes weaker, so does the temperature control mechanism in the brain. Often a patient near death will have a slight fever.

- If it is less than 101°F, the patient may not need any medication. A cool washcloth to the forehead and fewer blankets may be all that is needed.
- If the fever is greater than 101°F, let the nurse know. She may suggest acetaminophen (Tylenol). As their temperature lowers, the patient may

perspire. You may need to change their pajamas and sheets if they become wet.

- If the patient throws the covers off, it is important to remember that they may be warm even when you feel cool.
- Sometimes patients are sweaty and clammy even without a fever.

INCONTINENCE

This is the loss of control of the bowels or bladder that can sometimes occur as the muscles in the lower body begin to relax. The overall goal is simply to keep your loved one clean, dry, and comfortable.

- Adult disposable briefs (these words give the patient more dignity than saying “diapers”) and underpads on the bed may solve the problem. The nurse or hospice care aide can show you how to change these for someone in bed.
- The nurse may suggest placing a catheter (a tube) into the bladder to keep the patient’s skin from being constantly wet. A catheter is uncomfortable only for a few seconds going in. Then the patient generally isn’t aware of it at all.
- Often the patient will provide much less urine in the final few days. Also, the color is usually darker than normal.

RESTLESSNESS

Restlessness sometimes happens as circulation begins to slow. As less oxygen gets to the brain, the patient may become restless and fidgety. They may make repeated motions or pick at the sheets or the air. At this point oxygen is not usually helpful.

- You can reassure your loved one that you are with them. Speak slowly and calmly in a soothing way.
- Try reading to the patient, playing soft music, or massaging the forehead, hands, or feet.
- Don’t try to restrain the patient. But, you may need to use bed rails or have someone sit with them.
- Make sure the patient is still getting their usual pain medications. Just because they no longer tell you they have pain does not mean the pain is gone.

SURGE OF ENERGY

A sudden unexplained surge of energy is a phenomenon you may see in a patient who has been weak, disoriented and withdrawn. They may become unexpectedly alert and clear, or ask to eat when they have not had food for days. Or they may want to get up in a chair to visit when they have not been out of bed for weeks.

- This surge of energy isn't always as obvious as these examples. In hindsight we can often pick it out. It may be the patient marshalling all their physical strength for their last full bodily experience in this life.
- It's easy to see how this could give one false hope that the patient is "getting better." Enjoy this time with your loved one for what it is.

BREATHING CHANGES

When a person's body is fading, breathing patterns often begin to change. Breathing may slow down or there may be rapid shallow breaths followed by periods of no breathing. These periods can last 5 to 30 seconds, or even up to a full minute. These changes usually mean that death will be within a matter of hours or days.

- This kind of breathing is not uncomfortable for the patient. It simply means the end is nearing. There isn't anything you need to do about this.

Sometimes, a person becomes so weak they can't swallow their saliva. It gathers in the back of the throat and makes a "rattling" sound.

- Turning the patient side-to-side and raising or lowering the head of the bed may help to allow these secretions to drain out of the throat.
- This loud breathing isn't hard on the patient. But, it is sometimes hard to listen to.
- Your nurse may suggest medication you can give to reduce excessive secretions.
- At this point the patient is usually breathing with their mouth open. This will make their mouth very dry and they will need mouth care frequently. (See the section on Mouth Care, page 36).

SLOWING CIRCULATION

When death is just hours or a day or so away, a person's circulation slows to the point that their arms and legs begin to feel cooler than usual. Hands and feet may become purplish, and the knees, ankles, and elbows may look blotchy or mottled. Parts of the body the patient is lying on will be darker than the rest. The patient may appear pale and have a bluish cast around the lips and under their fingernails.

- This state doesn't cause any discomfort for the patient, although it is another sign that death is near.
- You may use a warm blanket, gently continue to move them if it is not uncomfortable, and provide very soft massage.
- This is a time to reassuringly tell the patient that you are with them and they won't be left alone. You will see them through.

WHEN DEATH OCCURS

When the patient has died you will see no breathing and feel no heart beat. There will be no response to your voice or touch. The eyes will be partly open and the

pupils will be large and staring. The jaw will relax and the mouth will open. Sometimes there will be loss of bowel and bladder control.

WHAT TO DO

No matter how well prepared you are, death can still feel like a shock. This isn't an emergency; it's what you have been expecting. **Do not call 911.** The police do not need to be notified. At this time you may want to call a friend or relative you've arranged to be with you.

We encourage you to accept our help. Hospice of the Northwest staff are available 24 hours a day to help you through this time. A nurse can remove equipment (like tubes), bathe the patient, and prepare the body. We can call the doctor, dispose of medications, and call the mortuary for you if you wish. Even if you don't want a nurse or social worker to visit, please call Hospice of the Northwest to let us know what has happened. We will call the coroner if it is necessary.

Although the mortuary should be called at the time of death, you can decide when you would like them to come. There is no hurry. It isn't necessary for the body to be removed immediately. It's okay to keep the body in the home for several hours. You may need time to sit and say goodbye, or for other relatives to come. When the mortuary does arrive, most people leave the room while they move the body. You may help if you wish, whichever feels right. The mortuary will let you know about making arrangements for services.

This is all you have to do right now. Let others help you. Don't forget to eat. Don't be surprised if you have feelings of confusion, fear, numbness, anger, sadness, or relief. These are normal responses. Try to rest when you can. Now is the time to take care of yourself.

*Hope is an orientation of the heart, of the spirit.
It is not the belief that
things will turn out well,
But that things will make sense,
however they turn out.
- V. Havel*

HIGH CALORIE DRINK & SNACK RECIPES

DOUBLE STRENGTH MILK

*Calories: 255; Protein: 19 grams per cup;
Yield: 4 servings*

1 quart (4 cups) whole milk
1 cup milk powder

Mix well and chill before using.

PEACHES AND CREAM SMOOTHIE

*Calories: 165; Protein: 5 grams;
Yield: 2 servings, approx. 7 oz. each*

1 cup cold whole milk
½ cup vanilla ice cream
½ cup frozen or drained canned peaches
packed in their own juice.

Combine ingredients in blender until smooth.

SHERBET SHAKE

Calories: 304; Protein: 2 grams

½ cup fruit juice
¾ cup sherbet

Blend and chill.

GREEN HORNET

*Calories: 190; Protein: 1 gram;
Yield: 2 servings, approx. 7 oz. each*

1 cup lime sherbet
2 teaspoons lemon juice (optional)
1 Tablespoon Koolaid powder
(lime or other flavor)
6 ounces 7-up or Sprite
1 cup ice

Combine ingredients in blender until smooth.

BANANA POPS

*Calories: 226; Protein: 8 grams;
Yield: 2 servings*

1 banana cut in half cross-wise
2 Tablespoons peanut butter
2 Tablespoons chopped peanuts

Cut banana in half cross-wise. Spread 1
Tablespoon peanut butter on each half, then
roll in the chopped nuts. Insert a popsicle
stick into one end of each half. Freeze.

FRUIT JULIUS

Calories: 400; Protein: 26 grams

¼ cup egg substitute
1 cup double strength milk
1 cup fruit juice or canned fruit
1 Tablespoon sugar

Blend all ingredients except ice until smooth.
Add ice and blend.

FRESH FRUIT BLENDER DRINK

1 cup sliced fresh or frozen fruit
1 6-8oz. Carton vanilla yogurt
½ cup milk
1 Tablespoon honey or sugar (optional)

In blender container, combine fruit, yogurt,
milk and honey. Cover and blend well.
Garnish with a strawberry, if desired.

FROZEN YOGURT ON A STICK

*Calories: 250; Protein: 8 grams;
Yield: 1 serving*

1 8-oz. Container flavored yogurt.

Cut a small slit in the top. Place a wooden
popsicle stick through the slit into the yogurt.
Freeze yogurt. When fully frozen peel off
wrapping and enjoy.

YOGURT SMOOTHIE

*Calories: 320; Protein: 9 grams;
Yield: 1 serving*

6 ounces yogurt
½ cup ice cream
½ cup prepared flavored gelatin

Combine ingredients in blender until smooth.

BANANOCINO CARBO-SHAKE

Calories: 261; Protein: 16 grams

1 medium-sized banana
½ cup skim milk
3 oz. Low-fat coffee yogurt
1 teaspoon sugar
1 ice cube

Combine and blend for 1 minute.



A Gaelic Blessing

Deep peace of the running wave to you.

Deep peace of the flowing air to you.

Deep peace of the quiet earth to you.

Deep peace of the shining stars to you.

Deep peace of the gentle night to you.

Moon and stars pour their

healing light on you.

Deep peace to you, the light of the

world to you.

Deep peace to you.

Emotional & Grief Support

A MESSAGE TO FAMILY AND CAREGIVERS

You are a key person with a vital role to play in caring for your loved one. It is important for you to develop ways of **self-care to protect your own physical and emotional well-being**. Small things you do for yourself can make a huge difference.

Accept help – this is not easy but really necessary. Friends, family, Hospice of the Northwest volunteers and hired assistants can be a source of great support. Accepting help is not a sign of weakness or failure on your part. Not accepting help can lead to physical and emotional exhaustion. In accepting assistance, tell people specifically what you need. Examples are yard work, errands, bringing in food, and sitting with your loved one while you rest or get out of the house. Remember, most people sincerely want to help. However, they do not always know what to do. They need you to tell them how they can help.

Take time for yourself. Pleasurable events are a time of renewal. They can include a walk, time with a supportive friend, reading a novel or having a leisurely warm bath. This time allows you to focus on other aspects of life. Try to get out of the house at least once a week. A few quiet minutes walking or sitting outside every day can be renewing. **It is appropriate to have good feelings even while your loved one is ill.**

Pay attention to your own physical needs. You may get so busy with being a caregiver that you forget your own health and physical needs. Frozen dinners with good nutritional content are one way to help you get what you need. Food preparation is also a way for others to help you and your family.

Try to get enough sleep. If you feel you are not getting enough restful sleep, you may want to discuss this with your Hospice of the Northwest team. Each situation is different, but there are ways to resolve this problem.

Practice relaxation techniques. Pause for five minutes to breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed and quiet state. A gentle shoulder and neck massage can help. Take a warm bath. Your Hospice of the Northwest team can make other suggestions.

Use your natural stress relievers. For example, laughter and exercise stimulate the production of body chemicals that are natural anesthetics and relaxants.

Recognize & acknowledge your feelings and emotions. This is a very difficult time. You are likely to experience many different emotions. If you are concerned, discuss this with a Hospice of the Northwest team member.

HELPING CHILDREN & TEENS COPE

Children of all ages – infants to teens – are affected when family members are seriously ill. Yet young people often respond differently than adults to the stress and

changes in their families that may result from illness. Depending on their age and developmental level, children may return to earlier ways of behaving, act out their understanding of the situation in play, or ask the same questions repeatedly. Regardless of how old or young they are, all children need to feel included, understood, loved and allowed to grieve in their own ways. Other suggestions for how adults can help support children when a family member is being served by Hospice of the Northwest include the following:

- Provide prompt and accurate information about what is happening. Allow children to ask questions and receive honest answers. What children imagine is often worse than the reality.
- Use language that is clear and understandable to young people. It is better to name the disease, such as cancer, heart failure, diabetes, than to use vague terms, such as “sick.” Provide explanations of changes. For example, “Grandpa has oxygen tanks in his house to help him breathe.”
- Even in the final stages of life, allow children the choice to spend time with their loved ones. They can help in simple ways, share memories and feelings and at some point say goodbye. If the child chooses not to visit, ask what he or she would like to do – perhaps drawing pictures, sending cards or writing a letter, or simply looking at photographs and reminiscing would be more comfortable.
- If children want to participate in family grieving rituals or funeral services, explain in advance what will happen, what they will see and hear and do. Consider asking another adult to help support the children, in case their parent needs to attend to his or her own grief. Be attentive to children’s questions and reactions during and after the service.
- The Hospice of the Northwest Resource Center, a free lending library, has a large collection of storybooks, activity books, videos, and games for children and teens about illness, dying and grief. Also available are books, pamphlets, and videos for adults to aid in understanding and supporting young people during a family member’s illness and after his or her death.

HOSPICE OF THE NORTHWEST BEREAVEMENT SERVICES

The Hospice of the Northwest Bereavement Program is available to help you and your family in your personal journey through loss and grief after your loved one dies. We provide support that matches your needs and preferences.

Bereavement services are offered to you for thirteen months after your loved one's death. Many of our services are also open to anyone in our communities who is grieving a death.

Our bereavement staff consists of a coordinator, counselors, group facilitators, and trained volunteers.

Services we provide include the following:

- **Mailings** with information about grief and coping can be sent to you periodically following the death of your loved one.
- **Bereavement staff contact** is available by phone or in person. We can offer support, address your questions, suggest resources and/or provide short-term counseling for both adults and children.
- **The Hospice Resource Center** is a lending library for adults, teens, and children with informational and inspirational books, pamphlets and videos on care-giving, end of life issues, and grief. You are welcome to drop in during weekdays and browse, or arrange to come after hours by calling the Bereavement Coordinator.
- **Ongoing grief support groups** are held in various locations throughout our service area. Meeting with other bereaved people, and a trained facilitator, allows you to realize that you are not alone. Through discussion and information, sharing what works and where you feel stuck, you can find connection and camaraderie with others who are making similar grief journeys.

Life is forever changed after the death of someone dear to us. The heartache, loneliness and practical adjustments can seem overwhelming at times. There isn't a map to follow in the journey through grief, and it may be hard to tell where you are. Sometimes the road is smooth; sometimes you hit a pothole. You may get stuck somewhere you don't really want to be. Then, hopefully, help comes along, and you are back on the road again. The Hospice of the Northwest Bereavement Team can be part of the helpful hands and hearts that support you through the ups and downs.

UNDERSTANDING GRIEF

Grief is more than sadness – it is all the ways we respond to loss. How you experience your grief will vary according to many factors that are personal to you – including your relationship with the person who died, other losses you have experienced, and the way grief is understood in your family and culture.

Among your family members and friends you will likely see a wide range of responses to the death of your loved one, both immediately and in the months to come. You may not be able to tell from the outside how someone is reacting to the loss on the inside. Some people may tell you how to grieve or how not to grieve. You may need to adjust your expectations of yourself and others.

While every person's grief is unique, these are common responses after a death:

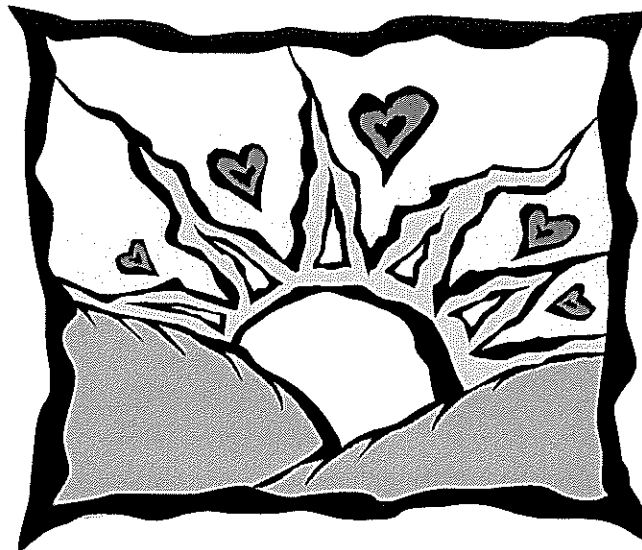
- A sense of relief or acceptance that some suffering is ended.
- Shock and disbelief, a feeling of “unreality.”
- Low energy, tightness in throat or chest, an “empty feeling,” digestive problems.
- Changes in appetite and/or sleep patterns.
- Restlessness, irritability, and/or excessive busyness.
- Lack of interest in usual activities.
- Difficulty concentrating or remembering, difficulty making decisions
- Deep sorrow, missing your loved one's presence.

- Frequent, sometimes unexpected, bouts of tearfulness and/or emotional outbursts.
- Preoccupation with the illness or death, reviewing or reliving what happened.
- Deep regret or guilt, “if only” thinking.
- Anger at yourself, your loved one, the medical community, God, or the situation.
- Need for spiritual comfort and support.

COPING WITH GRIEF

It is natural and normal to experience grief after a death. The following may be helpful as you make your way in the journey through grief:

- Seek out caring people who can understand your loss and will listen.
- Express your feelings through talking, journaling, creative activities.
- Care for your body. Rest, eat well, and get regular checkups.
- Postpone major life changes. Give yourself time to adjust to the loss.
- Be patient. It can take months or more to absorb and adjust to your loss.
- Look to the future. With support, effort, and patience you will make it through the difficult days.
- Allow others to help you, when necessary. It’s a sign of strength, not weakness, to reach out. Contact Hospice of the Northwest Bereavement staff or other professionals for support.



**There is no way out of the desert
except through it.**

- African Proverb