

Welcome

Reaching EvergreenHealth Hospice

Most hospice visits are pre-scheduled. However, there may be situations that require hospice interventions at night or weekends. To take your calls, answer your questions, and visit if needed, EvergreenHealth Hospice has nurses available 24 hours a day, seven days a week. Please call one of the following two numbers for assistance:

425.899.1070 or 1.800.442.4546

The following are examples of when to call EvergreenHealth Hospice:

- Your doctor recommends or orders tests, such as lab work or x-rays.
- Your doctor orders a new medication.
- You feel stressed and need to talk to someone.
- You have questions about medications.
- You have questions about symptoms or have developed new symptoms.
- There is an unexpected change in condition such as difficulty swallowing, restlessness, less responsive, or difficulty breathing.
- An emergency situation arises (**call EvergreenHealth Hospice first**); a nurse can guide you and reach a physician if necessary.
- Your care situation changes.

Your Hospice team members include:

Nurse: _____

Social Worker: _____

Chaplain: _____

Hospice Aide: _____

Volunteer: _____

Pharmacy: _____

Medical Equipment Company: _____

Infusion Company: _____

Other: _____

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Supporting You & Your Family through Hospice Care

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Thank You for Choosing EvergreenHealth Hospice Services

What is Hospice?

Hospice is a comprehensive model of care designed to meet the needs of people and their families whose goals of care are focused on quality of life rather than cure while facing a life-limiting illness. Hospice focuses on comfort care and emotional support to help enhance coping with the transition at end of life, using your wishes as a primary guide. Hospice care helps to ease disease symptoms such as pain, nausea, and breathing problems, while helping to address the emotional, mental and spiritual needs of you and your family and friends.

A Brief History of Hospice

- The term “hospice” can be traced back to medieval times, referring to a place of shelter and rest for weary or ill travelers.
- The name was first applied to specialized care for dying patients by physician Dame Cicely Saunders, who began her work with the terminally ill in 1948 and eventually went on to create the first modern hospice—St. Christopher’s Hospice—in a residential suburb of London.
- Saunders introduced hospice to the U.S. during a 1963 visit to Yale University; her lecture during this visit launched the development of hospice care as we know it today.
- In the late 1960s Dr. Elizabeth Kubler-Ross taught about the concept of terminally ill patients participating in the decisions that affect how they will live during their final days .
- In 1982, Congress included a provision to create a Medicare Hospice Benefit.
- Today the hospice philosophy of care is central to models for palliative and end-of-life care and is covered by most insurance plans.

EvergreenHealth Hospice Services began in 1991 to serve those living in King and Snohomish counties. Our visits to you, your family members and caregivers take place intermittently throughout the week depending on your specific needs. Providing information and education about what to expect through the disease process is fundamental to successful hospice care. Although most people remain at home while receiving hospice care, EvergreenHealth Hospice Services also has the Gene and Irene Wockner Hospice Center (as well as local contracted hospitals) for short-term inpatient care when a change in symptoms requires skilled nursing interventions (such as complicated medication changes) that cannot be managed in the home care setting. Once you are more comfortable, you will be discharged home and/or to a care environment that meets your needs.

Services provided by EvergreenHealth Hospice

- Intermittent visits by your hospice team: nurse, social worker, hospice aide, chaplain, volunteer and/or others as authorized.
- Coordination of care between physician, Hospice team, family members, and caregivers.
- 24-hour per day phone availability for nursing consults to answer questions and/or address disease-related symptoms; after-hours nursing visits as determined by the Hospice nurse.
- Medications for symptom management related to the hospice diagnoses and authorized by an EvergreenHealth Hospice physician.
- Medical equipment and supplies related to your hospice diagnosis and authorized by EvergreenHealth Hospice.
- Short-term (up to five days) respite care in a skilled nursing facility (SNF).
- Short-term (usually three to five days) inpatient care for complicated symptom management as determined by your Hospice nurse, attending physician, and Hospice physician.
- Office visits with your attending physician.
- Ambulance or cabulance transport to and from respite or short-term inpatient care (as determined by your Hospice nurse or social worker).

Myths about Hospice

Myth: Hospice is about dying.

Truth: Hospice is about living. With the help of hospice, you can live the last days, weeks and even months of your life more fully – utilizing the expertise of the Hospice team and focusing on the things that matter most to you.

Myth: Hospice is a place.

Truth: Hospice is a concept of care for you and your family. Hospice can take place anywhere you call home – your house, adult family home, nursing home, assisted living facility, etc.

Myth: Hospice is only for cancer patients.

Truth: Anyone with a disease causing a limited life expectancy of six months or less (as determined by two physicians) is eligible for hospice care. In addition to cancer, some common hospice diagnoses are Alzheimer’s disease and other types of dementia, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), stroke (CVA) and Lou Gehrig’s disease (ALS).

Myth: Hospice is only for the patient.

Truth: Hospice focuses on the family as well as your individual care. While the hospice team works with you to achieve your goals of care, the team also focuses on family, friends, and caregivers to offer emotional support and education about the disease process and caring for their loved one.

Myth: Hospice is for the last days of life.

Truth: A person is eligible for hospice when his/her life expectancy is six months or less. One of the most common comments we hear is, “I wish we had started hospice services sooner.”

Myth: Hospice will provide daily care.

Truth: While hospice provides many services, including intermittent visits from nurses, social workers, chaplains, hospice aides and volunteers, it does not provide services for daily personal care (dressing, toileting, meals, feeding, keeping the patient clean, etc.), daily medication administration nor heavy transfers. Around the clock care needs are provided by family, friends, paid caregivers, and/or facility staff.

Criteria for Hospice Eligibility

An individual may be self-referred to EvergreenHealth Hospice Services or referred by a family member or medical provider. Medical eligibility for hospice care is determined by your medical provider and a hospice medical director. Typically hospice care is appropriate if you:

- Have a life expectancy of six months or less (if the disease runs its normal course) as determined by your physician and the hospice medical director.
- Desire palliative treatment instead of curative care.
- Prefer not to return to the hospital or emergency room.
- Are experiencing pain and/or other discomfort.
- Want to stay home as long as possible.
- Would like assistance with emotional, social and/or spiritual needs.

Insurance Coverage for Hospice Services

Medicare/Medicaid

Hospice care is a covered benefit under Medicare Part A and certain categories of Medicaid. Medical care and medications for diagnoses related to the terminal prognosis must be preauthorized by the Hospice Physician.

Private Insurance

Hospice services are covered by most private insurance plans. Your hospice team will advise you of your specific hospice coverage and its scope. If you have two or more insurance policies, please inform your hospice team so they may coordinate your available coverage.

Limited or No Insurance

Your hospice social worker will assist you in determining your potential eligibility for Medicaid and/or uncompensated care. You may also pay out-of-pocket for your hospice care; information regarding the cost of hospice services is available from your hospice social worker or nurse.

Roles of the Hospice Team Members

Nurse

You will be assigned a nurse case manager who will visit with you as needed (in-person or by phone). In addition, on-call nurses are available 24 hours a day, seven days a week via a paging system to answer your questions and concerns over the phone. The nurse's main role is assisting with symptom management to improve your comfort. This is facilitated in the following ways:

- Collaborating with you, your physician and other team members to meet your goals of care.
- Assessing your medical needs and symptoms.
- Assessing current and future needs for medications, medical equipment and supplies.
- Teaching you and your caregiver about strategies for maintaining your comfort, medication use, wound care and other necessary procedures.
- Providing special nursing procedures as necessary.
- Educating about the effects of the illness and what to expect as it progresses.

Social Worker

A social work case manager is also a member of your Hospice team. He/She is available to visit in-person or by phone to assist you in the following ways:

- Identifying community resources (and facilitating referrals) to meet your needs related to caregiving, respite, legal assistance, etc.
- Providing information about advance directives (such as a Living Will and/or Durable Power of Attorney for Health Care).
- Providing assistance in completing and submitting applications for Medicaid and/or other programs to address financial needs.
- Supporting you and your family through the process of anticipatory grief.
- Providing information and education related to the disease process and end-of-life stages, helping with awareness of feelings and identifying end-of-life goals.
- Listening to your concerns, either individually or as a family.

Chaplain

A hospice chaplain will visit at your request to provide spiritual, mental and/or emotional support that includes:

- Meeting with you and/or your family to listen to your hopes, fears and concerns.
- Exploring with you and/or your family any struggles with spiritual or emotional issues.
- Using a non-denominational approach (not promoting specific religious beliefs and not replacing your minister, rabbi, or priest).

- Following your lead and, if desired, supporting you through prayer and/or other rituals.
- Assisting you in planning funeral/ memorial services and/or other spiritual observances.
- At your request, helping obtain clergy services from the denomination of your choice.

Hospice Aide

The hospice aide typically visits one to two times per week depending on the patient's needs. The length of an average visit is 30 to 60 minutes. The role of the hospice aide is to assist with personal care, and help train family members and caregivers on how to provide your personal care. Personal care is best provided in pairs ("the power of two"), to maintain your safety and those providing care.

Under the direction of the hospice nurse, the hospice aide may offer assistance with the following:

- Bathing, shampooing and shaving.
- Dressing and undressing.
- Mouth care.
- Cleaning and filing nails.
- Lotion rubs (hands, arms, legs, feet and forehead).
- Transfers (e.g., from bed to wheelchair).
- Standby assistance for walking.
- Gentle range of motion exercises.
- Specific exercises as directed by a physical therapist or nurse.
- Special procedures as directed by the hospice nurse such as catheter care, care of drain tubes, colostomies, and simple dressing changes.
- Changing bed linen.
- Cleaning your immediate living environment.
- Preparing a simple meal for you.

Volunteer

Volunteers are an important part of your EvergreenHealth Hospice team. They are screened and specially trained to support the needs of terminally ill individuals and their families. A volunteer may perform duties which supplement (but do not substitute for) professional services. Generally, a volunteer, once assigned, will visit once a week for up to four hours. Volunteer assignments are based on availability. Please let your social work case manager know if you would like the assistance of a volunteer. Typically, a volunteer may be asked to:

- Stay with you so the caregiver may leave the home for short periods, rest or do other tasks.
- Run errands including grocery shopping.
- Write letters and/or read to you.
- Provide companionship.
- "Comfort Therapy" volunteers can provide comforts such as massage or Reiki.
- Volunteers are unable to provide personal care or help with transfers.

Medical Director

The hospice medical director has many responsibilities including:

- Overseeing clinical aspects of our program.
- Providing consultation to Hospice staff and community physicians.
- In-service training for hospice staff.
- Active participation in admission, eligibility and recertification decisions.
- Participating in interdisciplinary team meetings.
- The hospice medical director does not take the place of your personal physician who oversees your care.

Levels of Hospice Care

Routine Care

The “routine” level of hospice care is provided where you reside, whether it be a private home, adult family home (AFH), assisted living facility (ALF) or skilled nursing facility (SNF). This level of care includes the visits and phone calls you receive from your Hospice team members providing support, information, and education. It is often the case that you may only need this level of hospice care.

Respite Care

Your hospice benefit may include short-term respite care at a Hospice-contracted SNF. Under Medicare, this benefit may last up to five days. Some private insurance plans cover in-home respite instead of SNF-based respite. Your hospice social worker can help you determine your respite coverage and assist you in planning for and setting up the respite care. The purpose of this benefit is to provide a period of rest for your primary caregiver and, when necessary, develop an alternative plan for your care.

Short-Term Inpatient Care

Generally hospice care can be provided in the home setting under the “routine” level of care. Occasionally, however, your hospice team may recommend an admission to an “acute care” setting for help with symptoms that have not been successfully managed at home. This is called “short-term inpatient care” (STIP) and can be provided at a Hospice-contracted hospital or the EvergreenHealth Gene and Irene Wockner Hospice Center. “STIP” level of care is used for brief periods of time (usually no more than three to five days) when one or more symptoms causing discomfort requires daily visits by a physician or nurse practitioner as well as 24-hour nursing to manage medication changes and monitor symptoms. Family and friends are encouraged to visit frequently and stay involved with your care when STIP is required. The goal is for you to return to your place of residence once improved comfort is achieved.

Crisis Care

Crisis Care is a level of hospice care used when difficult-to-manage symptoms are occurring that otherwise would require “STIP” level of care but the individual receiving care prefers to stay at home (rather than go to a Hospice-contracted hospital or the Hospice Care Center). Crisis Care is provided on a short-term basis in your home when nursing care is required to achieve palliation of acute disease-related symptoms (such as pain, shortness of breath or restlessness). This level of care typically includes intermittent nursing visits over the course of several hours to adjust your medications (under the direction of your physician) until comfort is achieved. A Crisis Care episode typically lasts one day or less.

Scheduling Visits

Your EvergreenHealth Hospice team is committed to giving you the best care possible. You will receive visits from various disciplines during hospice care including nurses, social workers, chaplains, hospice aides and volunteers. These visits are based on the specific needs of each patient and family.

Our staff will provide an approximate time of day for each visit (usually within a two hour window). We follow appointment times as closely as possible. However, we appreciate your understanding when visit times may need to be adjusted due to unanticipated events. Visits may last 30 to 60 minutes, sometimes longer; our goal is to stay with you and your family until your questions and concerns are addressed.

Thank you for choosing to receive your hospice care from EvergreenHealth Hospice Services. Our care team is privileged to serve you and your family.

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Planning for Care and Communicating Choices

Family Members Working Together

Coping can be difficult for family members when a loved one is dying. It's not uncommon for patterns of interaction to emerge that are similar to when other stressful family events have occurred. This may be a time of deeper bonding and/or a time for reconciliation related to painful past experiences. Your Hospice team is here to help you navigate together the challenges that come when you or a loved one faces a life-limiting illness.

Here are a few guidelines you may find helpful:

- Try to keep an open mind about how this experience is affecting each family member.
- Be patient and respect differences inasmuch as possible.
- As with all highly stressful situations, ask yourself what is most important to focus on now and what is in your best interest?
- Share with each other the meaningful and happy times as well as the experiences that may be burdensome.
- Ask each other for help as emotional and physical exhaustion can come upon you quickly.
- Ask for help to find resources in the community to help you and your family cope.
- Keep the lines of communication flowing between family members to prevent misunderstandings and to help everyone feel included.
- Ask for help if you run into difficulties with communication and/or decision-making; avoiding conflict is natural but it can lead to more conflict down the road.
- Family meetings are helpful in giving everyone the opportunity to be heard. Your hospice social worker, chaplain or nurse welcomes the opportunity to join you in these meetings to listen, offer support, and help determine next steps so you can move forward together.

Planning for Care

Over time you may become weaker and require help with activities of daily living (dressing, feeding, bathing, taking medications, going to the bathroom, etc.). These care needs can be met in your home with the help of family and friends and/or hired caregivers. The care provided within residential care facilities may also meet these daily care needs.

Providing Care in the Home

If friends and family are providing care, this requires coordination related to who is responsible for what tasks and when. Financial compensation may need to be a part of this planning to provide the means for family member(s) or friend(s) to take time off from regular employment in order to care for the patient. The Hospice nurse and Hospice aide can help teach those who are caregiving how to provide the care that is required. Your Hospice social worker can help you review options for in-home care and coordinate a comprehensive care plan.

Respite for the Caregiver

Caregiving takes a special set of skills. Not all family members are emotionally and/or physically capable of caring for other family members. One key to successful caregiving is to ensure the caregiver(s) is also taking care of him/herself. Providing respite to the primary caregiver is an important aspect to the overall care plan. For those with less time or caregiving experience, providing respite to the primary caregiver for a few hours at a time may be exceptionally helpful.

Private Caregiving Agencies

If family members or friends are not providing the in-home care, you may choose to hire in-home caregiver(s). Paid for by yourself, a long-term care policy (if you have one), or Medicaid for those who are financially eligible, privately hired caregivers are typically paid by the hour, by the day, or receive a live-in rate. For a finder's fee, there are employment agencies which will find a caregiver that you or your family pays directly. There are also private caregiving agencies that place their own caregiver(s) in the home in which you pay the agency (not the caregiver). Contact your Hospice social worker with your questions or for additional information. See Appendix A for a list of caregiving agencies.

Residential Care Facilities

If you are unable to be cared for at home, there are three types of residential care facilities available to help:

1. **Adult Family Home (AFH):** A licensed private home that provides a high level of personal care for up to six patients.
2. **Assisted Living Facility (ALF):** A licensed facility that provides a private or semi-private room, meals, housekeeping, and planned social activities. Typically additional charges apply for personal care services such as assistance with toileting, showers and checking on the resident up to every two hours. Family members may need to supplement ALF care as your care needs increase.
3. **Skilled Nursing Facility (SNF):** A licensed facility that includes 24-hour nursing and is intended for people who need assistance with most or all care needs.

Placement Services

Placement Services are community agencies that assist with locating a residential care facility if you need caregiving. Most agencies are free to the patient. Please see Appendix B for a list of Placement Services.

Guiding Your Care & Choices

We encourage you to discuss the goals of your care with family members, caregivers, and health care providers. Consider your answers to the following questions **as they relate to your care and health condition** and communicate this information to those who are here to help: 1. What is your understanding? 2. What are your fears? 3. What are your hopes? 4. How can we help? Your answers to these questions will help define your goals of care. Goals of care may change over time as your health changes, opinions change or understanding of the situation changes.

Legal documents specific to health care choices can help guide the care you receive should you be unable to make your choices and decisions known. These documents (also known as Advance Directives) include a Health Care Directive (also known as a Living Will), Durable Power of Attorney for Health Care (DPOA for Health Care) and Physician Orders for Life-Sustaining Treatment (POLST). If you have not completed these documents and would like to, copies are in the pocket of this handbook or can be found at WSMA.org (WA State Medical Association). Your physician, hospice nurse or social worker can help to answer your questions. It is important that your physician, EvergreenHealth Hospice team and family members receive copies of these documents so your choices are communicated to those who are helping guide your care.

If you have not completed Advance Directives and become unable to complete them, the state of Washington authorizes the following individuals, in order of priority, to act as a surrogate decision-maker on your behalf: 1. Guardian (if any); 2. DPOA for Health Care (if any); 3. Spouse (if any); 4. Children who are at least 18 years of age (all); 5. Parent(s); 6. Adult siblings (all).

Health Care Directive (Living Will)

This legal document is used only if you have a terminal condition as certified by your physician where life sustaining treatment would artificially prolong the process of dying, or you are certified by two physicians to be in an irreversible coma or other permanent unconscious condition and there is no reasonable hope of recovery. In either situation, the Health Care Directive directs treatment to be withheld or withdrawn to allow a natural death. You may also direct whether you would want artificially provided nutrition and/or hydration stopped under these circumstances. Also in the directive you can give further instructions regarding your care. The Health Care Directive must be signed by you and two witnesses who are not related to you and will not inherit anything from you. You can change or revoke this directive at any time.

Durable Power of Attorney (DPOA) for Health Care

A DPOA for Health Care is a legal document in which you name someone to make medical decisions on your behalf if or when you are unable to make your wishes known. A DPOA for Health Care is different than a DPOA for Finance (which needs to be notarized) although clauses for making health care decisions may be embedded within a DPOA for Finance. The person you appoint as your DPOA for Health Care can consent to stop or refuse most medical treatment for you. The person you choose should be a trusted family member or friend with whom you have discussed your values and medical treatment choices.

Physician Orders for Life Sustaining Treatment (POLST)

The POLST form is intended for any individual with serious health condition(s) to indicate choices in advance related to the following life-sustaining treatments:

- Cardiopulmonary resuscitation (CPR)
- Medical Interventions
- Antibiotics
- Medically Assisted Nutrition

The POLST form is to assist health care facilities and emergency medical personnel in honoring your health care wishes. Whereas a Health Care Directive (Living Will) communicates your wishes, it is not a physician's order. The POLST form helps to translate your wishes into specific medical orders for health care providers to follow.

It's important to know that choosing not to receive CPR when the heart stops as a natural consequence of an irreversible illness does not mean care is not provided to prevent suffering as the body is shutting down. In fact, Hospice helps to ensure that those caring for you know how to keep you as comfortable as possible throughout the end of life process.

Whether or not to use antibiotics is a choice as well; there may be infections for which you choose medication other than an antibiotic to help maintain your comfort. Speaking with your physician and hospice team about your goals of care will help you identify specific medical interventions that are in line with your wishes.

The POLST may be changed at any time by completing a new POLST form with the appropriate signatures from the patient (or patient's legal representative) and physician.

Choices in Funeral Home Planning

Funeral home planning also involves many choices. Planning in advance gives you the opportunity to learn about options and communicate your wishes. Please call your Hospice social worker, chaplain and/or any local funeral home with questions. For your protection when choosing a funeral home, the following information is provided by the Federal Trade Commission (consumer.ftc.gov):

Many funeral home providers offer various "packages" of goods and services for different kinds of funerals. When you arrange for a funeral, you have the right to buy goods and services separately. That is, you do not have to accept a package that may include items you do not want. When making decisions about funeral services:

- Research various funeral/cremation services in advance. Compare prices from at least two funeral homes. Taking this step in advance allows you to comparison shop without time constraints, creates an opportunity for family discussion, and lifts some of the burden from your family. It may also be helpful to know that you can supply your own casket or urn.
- Ask for a price list. The law requires funeral homes to give you written price lists for products and services.
- Resist pressure to buy goods and services you don't really want or need.
- Avoid emotional overspending. It's not necessary to have the most high end casket or the most elaborate funeral to properly honor a loved one.
- Recognize your rights. Laws regarding funerals and burials vary from state to state. It can be very useful and help guide your decisions if you know which goods or services the law requires you to purchase and which are optional.
- Apply the same smart shopping techniques you use for other major purchases. You can decrease costs by limiting the viewing to one day or one hour before the funeral, and by dressing your loved one in a favorite outfit instead of costly burial clothing.

Funeral Home and Cremation Services

To help research funeral homes, EvergreenHealth Hospice Services offers the following list as a resource but does not endorse or suggest you use any of the organizations included. Please call the funeral home directly to confirm the location and their services. A comprehensive list of funeral homes, including a price survey, is available online at peoplesmemorial.org.

If you would like additional assistance with funeral home planning, your Hospice social worker is available to help.

- **A Sacred Moment**, specializing in at-home and green funerals; serving King and Snohomish counties: 425.316.8290
- **American Cremation and Casket Alliance**, 1.800.398.7101
- **Barton's Family Funeral Service**, Seattle: 206.420.1875; Kirkland: 425.823.1900; Renton: 206.329.7800
- **Beck's Funeral Home**, serving south Snohomish and north King counties: 425.771.1234
- **Bonney-Watson**, Capitol Hill: 206.322.0013; Ballard: 206.782.4700; SeaTac: 206.242.1787; Federal Way: 253.839.7317
- **Butterworth Funeral Home** (Arthur A. Wright Chapel) also affiliated with Cremation Society Northwest and Queen Anne Columbarium, Seattle: 206.282.5500
- **Cascade Memorial**, serving King, Pierce and Snohomish counties: 425.641.6100
- **Chapel of the Resurrection Mausoleum & Funeral Home**, Bothell: 425.939.1332
- **Columbia Funeral Home**, Rainier Valley and greater Seattle area: 206.722.1100
- **Currow Funeral Home & Cremation Service**, Sumner and Bellevue: 253.863.2800
- **Dignity Memorial**, Washington State: 1.800.34.DIGNITY
- **Elemental Cremation & Burial**, serving King, Pierce and Snohomish counties: 206.357.1141
- **Evergreen Washelli**, Seattle: 206.362.5200; Brier: 425.483.0555; Bothell: 425.486.1281; Toll free: 1.800.755.1350
- **Flintoffs Funeral Home and Crematory**, Issaquah: 425.392.6444
- **Funeral and Cremation Care of Washington**, serving all areas of Washington: 1.800.764.0895
- **Gilbertson Funeral Home**, serving the Stanwood and Camano Island areas: 360.629.2101
- **Harvey Funeral Home** (a.k.a., Hoffner, Fisher and Harvey), serving King County and surrounding counties: 206.632.0100
- **The Jewish Chapel and Cemetery**, greater Seattle area: 206.725.3067
- **Muslim Community Resource Center**, 1-888-404-6272; mapsmcrc@mapsredmond.org
- **Neptune Society**, Seattle/Lynnwood, Tacoma and Spokane: 425.672.8587 or 1.877.529.4679
- **People's Memorial Association**, Washington state: 206.325.0489
- **Purdy and Kerr Funeral Home**, Monroe: 360.794.7049
- **Purdy and Walters at Floral Hills**, serving King and Snohomish counties: 425.672.1800
- **Rosebud Funeral Service**, serving the Seattle area: 206.525.7800
- **Seattle Sephardic Brotherhood**, providing burial assistance to members of the Sephardic Bikur Holim and Congregation Ezra Bessaroth Synagogues and current members of the Seattle Sephardic Brotherhood: 206.344.5238
- **Solace Cremation**, serving King and Snohomish counties: 1.844.385.9589; support@solacecares.com
- **Solie Funeral Home and Crematory**, serving Everett, Snohomish and surrounding areas: 425.252.5159
- **Yahn & Son Funeral Home and Crematory**: 253.833.8877
- **Weeks' Funeral Home**, serving Enumclaw, Buckley, Tacoma, and surrounding areas: 360.829.1171

Anatomical Donation*

Anatomical donation is the gift of organs and tissues for medical research and education at the time of death. You can make arrangements for donation with any of the following organizations:

- Lake Washington Technical College, Funeral Services Education Program: 425.739.8155 or 313.717.8524.
- LifeLegacy Foundation: 1.888.774.4438
- MedCure: 866.560.2525
- University of Washington, Department of Biostructures: 206.543.1860
- SightLife: 800.214.6356
- LifeNet Health: 1.800.847.7831

*In the event you are ineligible to donate, it is also necessary to have a funeral home selected.

Online Resources

- **Caring Connections** (www.caringinfo.org): A national consumer and community engagement initiative to improve care at the end of life. Caring Connections is a program of the National Hospice and Palliative Care Organization (NHPCO).
- **Five Wishes** (www.agingwithdignity.org/five-wishes.php): Five Wishes is changing the way America talks about and plans for care at the end of life.
- **WashingtonLawHelp.org** (www.washingtonlawhelp.org): A guide to free civil legal services for low-income persons and seniors in Washington. Includes printable pamphlets on Medicaid programs, Dealing with Death, After Death Occurs: a Checklist, Washington Probate Instructions and Forms, and How to Claim the Personal Property of Someone Who has Died: Affidavit Procedure for Small Estates.
- **Washington State Attorney General** (www.atg.wa.gov): Includes consumer information on funeral homes, organ donation, legal information, and ordering additional death certificates.
- **Washington State Bar Association** (www.wsba.org): Offers legal information including pamphlets on Wills, Trusts, and Probate.
- **End of Life Washington** (www.endoflifewa.org): Assists people with all aspects of end-of-life decision making as they face incurable and terminal illness.
- **Washington State Funeral Directors Association** (www.wsfda.org): Provides information about what to do when a death occurs and funeral planning.

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Maintaining Comfort

Symptom Management

To help manage a variety of symptoms you may experience, a Comfort Kit is ordered in collaboration with your attending physician at admission into our Hospice program. The “Comfort Kit” includes a small supply of a few key medications that are effective for treating many symptoms. Additionally, the medications can be given even if you cannot swallow (e.g., under the tongue or rectally). Typically these medications are easily absorbed and provide swift relief. Although they are not the only medications used for comfort, they are the most commonly needed.

The following provides an overview of symptom management, including pharmacologic and non-pharmacologic methods for relieving your symptoms.

Pain

While pain can be both a physical sensation and an emotional experience, it is important for your Hospice team to understand and trust your report of pain. Only you can best describe the pain, its intensity and the effectiveness of various pain relief measures. If you cannot express your pain verbally or reliably, your hospice team will rely on nonverbal indicators of pain such as facial and body expressions, heart rate and respiratory rate.

Using the same system for evaluating pain each time will indicate how your pain is changing. This helps to determine how much relief you are getting from your current dosage of pain medicine. One commonly-used method of evaluating pain is the numeric scale. In this method, 0 equals no pain and 10 equals the worst pain imaginable.

No	Slight		Moderate			Severe		Worst Pain		
0	1	2	3	4	5	6	7	8	9	10

If your pain score is consistently low, your pain management plan is working. If your pain score is consistently high, perhaps you need more medication, a different schedule, or a different medication.

Important Facts about Pain Management

- Evidence suggests that the preventive approach works best in managing chronic pain. Often this means taking pain medication on a regular basis instead of simply as needed. If you wait too long to take your pain medication, the pain can potentially become so severe that the medication is no longer effective. Therefore, maintaining a regular medication schedule is the best means of managing pain. Remember, too, that once you become pain free it’s important to continue the medication schedule as directed by your physician.
- Anxiety, tension, and depression can amplify one’s experience of pain. You may need medication in addition to that used for pain to help in the management of your overall comfort.
- Medication for chronic pain should be taken at regular intervals. Your Hospice nurse and attending physician will help you establish the best times to use the medications.
- Accurate record-keeping regarding the time of day you take your pain medications allows your hospice team to better manage your pain control needs. The Appendix includes useful tools to help monitor your pain (see Appendix F) and track medications and symptoms (see Appendix G).
- Opioid analgesics are likely to have a constipating effect. Talk with your hospice nurse about medications to prevent this.
- Some non-opioid analgesics such as ibuprofen should be taken with food if possible.
- Do not crush long-acting pain medications. If you are unable to swallow, consult your hospice nurse. A different route or medication may be suggested.
- There are different types of pain medication for specific kinds of pain. Your hospice nurse, in partnership with your attending physician, will determine the most effective medications for treating your discomfort.

Non-Pharmacological Methods for Relieving Pain

- Meditation
- Music
- Guided imagery
- Use of cool or warm packs
- Changing position
- Massage or Reiki Therapy
- Distraction

Pharmacological Methods for Relieving Pain

Liquid morphine concentrate is contained in your Comfort Kit. Depending on the type and severity of your pain, your hospice nurse in collaboration with your attending physician may recommend this medication. Only use this medication as instructed by your hospice nurse.

Notify EvergreenHealth Hospice immediately if:

- The medication cannot be taken as prescribed.
- Pain is experienced in new areas.
- There is an increase in the intensity of pain.
- There are concerns about over-sedation.
- You experience symptoms of confusion, restlessness, “bad dreams” or hallucinations.

Misconceptions about Pain Medications

“I’m afraid I might get addicted to these medications.”

Addiction is a pattern of psychological desire in obtaining and using a drug for its effects on the mind (to get “high”). If you are concerned about addiction, just ask yourself the following question: “If I didn’t have pain, would I be taking this medication?” Most likely your answer is, “No.”

“I’m afraid taking morphine will hasten my death.”

You may have seen a dying person with symptoms of severe pain or shortness of breath for whom morphine was prescribed and within hours or days the person died. This can mistakenly be interpreted as morphine hastening the person’s death. The reality is that symptoms of pain and distress can cause people to hang-on (inhibiting the ability to “let go” from the body). When severe symptoms of discomfort are treated (and morphine is generally very effective for these symptoms) the person is able to experience a peaceful state, allowing him/her to let go of the physical body as a natural consequence of the disease process. Additionally, it’s important to know that the doses of morphine and type of morphine (usually oral liquid concentrate) commonly used in hospice care ensure minimal potential for harm. In fact, studies show that the use of morphine in hospice care neither hastens nor prolongs life. Please discuss any concerns you have about this with your hospice team.

“Pain is an inherent part of illness.”

Some people report less pain than they are actually experiencing due to the belief that pain and illness go hand-in-hand and must be tolerated. In fact, pain can affect your mood and the ability to think. Pain can also make other symptoms worse. Hospice philosophy promotes managing your pain because this is fundamental to improving quality of life.

“If I take the strong pain medicine now, it will prevent good relief in the future when I really need it.”

Pain medication administered correctly does not stop working with time. The key is using the right medication at the right dose throughout the course of the illness. Your physician and Hospice nurse work with you to ensure this occurs. As the disease progresses, more pain medication may be required. This does not indicate addiction but rather a natural progression of the disease.

“If they don’t say they’re in pain, then they’re not having pain.”

Patients who have long-term, chronic pain may not exhibit the same signs of pain that we are used to seeing.

They may not speak about the pain or even moan, but this does not mean they are not experiencing pain. Nonverbal signs of pain are key indicators when assessing the level of comfort. These include, but are not limited to, facial grimacing, restlessness, inability to sleep and irritability.

Anxiety

Anxiety tends to be a feeling involving worry or nervousness; it is a natural human response to real or perceived uncertainties or fears. Within the framework of hospice, a certain level of anxiety is not uncommon. However, when anxiety is prolonged and ongoing, it has the potential to impact an individual's quality of life and, at times, even their safety. Anxiety can often intensify the perception of an existing symptom, especially pain and shortness of breath. Potential causes of anxiety include:

- Breathing trouble.
- Anticipation of increased pain.
- Facing the unknown aspects of a life-limiting condition.
- Unresolved emotional issues regarding one's life.
- Directly caused by a disease process (such as advanced dementia).
- Diagnosed or undiagnosed mental illness.

Signs of anxiety may include feeling tense, fearful of being alone, frequently asking for help from your family or caregivers, shortness of breath for no apparent reason, difficulty sleeping and inability to concentrate.

Non-Pharmacological Methods for Relieving Anxiety

- Discussing your concerns with others can help. If you are experiencing anxiety, consider:
 - Calling the Hospice 24-hour number to discuss your concerns.
 - Talking to your Hospice social worker or chaplain.
 - Calling your county's 24-hour Crisis Line number (this is a free service). Sometimes having a caring professional present on the phone listening to you can have a therapeutic impact. King County Crisis Line: 1.866.427.4747 or 206.461.3222; Snohomish County Crisis line: 425.258.4357.
- Practicing deep breathing exercises.
- Listening to soothing music.

Pharmacological Methods for Relieving Anxiety

Lorazepam (Ativan) is included in your Comfort Kit and may be used as instructed by your physician and/or hospice nurse. In low doses this anti-anxiety medication is generally effective and well-tolerated.

Restlessness/Agitation

Anxiety and agitation are not the same. Anxiety is usually a "feeling" whereas agitation is an action typically involving constant movement such as pacing, frequently shifting positions, repeatedly trying to get out of bed, or fidgeting with bedding or clothing. Sometimes agitation is a non-verbal sign of pain.

When restlessness or agitation is observed, answers to the following questions will be helpful to your hospice team for determining how to proceed:

- Is this a new and/or sudden behavior?
- Is it increasing in severity and duration?
- Is the behavior disturbing to you and/or your loved-ones/caregivers?
- Will the behavior potentially lead to a safety risk?

Restlessness/agitation may be in response to physical discomfort. Your hospice nurse will help to assess potential issues contributing to restlessness/agitation, including:

- Constipation.
- Urinary retention (your hospice nurse can determine this by inserting a special catheter to

determine the volume of urine in the bladder; sometimes it's necessary to have a urinary catheter placed in the bladder to allow free flow of urine and prevent retention).

- Urinary tract infection (or other infection).
- Generalized pain.
- Dehydration.
- End of life restlessness.

Non-Pharmacological Methods for Relieving Restlessness/Agitation

- Distraction.
- A calm environment and decreasing stimulation (such as loud noises or TV).
- Providing soothing music.
- Providing emotional support and comforting words to reassure the person.
- Gentle touch by a loved one may have a calming effect.

Pharmacological Methods for Relieving Restlessness/Agitation

Your Comfort Kit contains Haloperidol (Haldol) to help manage symptoms of restlessness. Take only as instructed by your hospice nurse.

Nausea/Vomiting

Nausea and/or vomiting may occur for a variety of reasons. Your hospice nurse will help you manage these symptoms in the context of the underlying medical cause which may include:

- Side-effect of certain medications. For example, some people report experiencing nausea upon taking the first few doses of morphine. This initial side effect usually subsides and often completely goes away with subsequent doses.
- The disease process. For example, diseases involving the liver or kidneys may cause nausea.
- Severe constipation. When the movement of food in the intestines is slowed or blocked, the “back up” can generate the feeling of nausea.

Non-Pharmacological Methods for Relieving Nausea

- Carbonated drinks such as ginger ale.
- Ginger-flavored teas, hard candies and lollipops.

Pharmacological Methods for Relieving Nausea

Your Comfort Kit contains Haloperidol (Haldol) to help manage symptoms of nausea. This medication has a dropper with markings for ease of measurement. Your hospice nurse can help determine if other anti-nausea medications may be appropriate for your situation.

Constipation

Constipation is taken very seriously because although in most people it only causes intermittent discomfort, it can lead to severe pain and discomfort if not managed proactively. Therefore, it's important to track the frequency of your bowel movements. See Appendix C for a chart to help you track bowel movements.

Common causes of constipation include:

- Decreased mobility.
- Decreased fluid intake.
- Decreased intake of fiber in the diet.
- Use of opioid pain medication such as morphine, oxycodone, or hydrocodone. Although opioid analgesics are generally considered the most effective medications for severe pain, they have a constipating side-effect. For this reason, taking a laxative concurrently with opioid pain medication is generally recommended.
- The disease process itself (e.g., colon cancer or ALS impact the motility of the gastrointestinal tract).

Your hospice team has extensive experience in managing constipation and will collaborate with your physician to find the right medication(s) for your specific needs (including various types of bowel medications). Timely updates from you will impact the success of your bowel regimen. Please notify Hospice anytime you have not had a bowel movement in three days.

Non-Pharmacological Methods for Relieving Constipation

- Warm prune juice.
- Increase fiber from natural sources in your diet such as vegetables and fruits.
- Fruit paste. See Appendix D for a fruit paste recipe.
- Attempt a bowel movement at a consistent time every day.
- Decrease high calcium-content foods because calcium is constipating.
- Gentle abdominal massage (consult your hospice nurse first).

Pharmacological Methods for Relieving Constipation

Your hospice nurse will be proactive in implementing bowel medication(s) in order to prevent severe constipation. These medications may include pills, oral liquids, suppositories and/or enemas. Your Comfort Kit includes Bisacodyl suppositories; a Bisacodyl suppository is indicated when a patient has not had a bowel movement in three days and should only be used if directed by a Hospice nurse.

Shortness of Breath

When someone is having trouble breathing, the term “shortness of breath” is often used to describe this symptom. Other terms used to describe breathing trouble include “air hunger” or “labored breathing.” Shortness of breath may have a variety of underlying causes including, but not limited to:

- Progression of the disease process. For example, diseases that affect the lungs or cardiac system may cause shortness of breath.
- Fluid buildup in cavities near the lungs which pushes against the lungs.
- Anxiety.
- Natural changes in the brain chemistry at end of life, leading to various breathing pattern changes.

Regardless of the underlying cause, shortness of breath often causes anxiety. Anxiety, in turn, increases the oxygen demands of the body which then worsens the shortness of breath. Treating both the shortness of breath and its associated anxiety helps to break this cycle.

Non-Pharmacological Methods for Relieving Shortness of Breath

- Use a fan or open a window to allow better air circulation.
- Perform pursed-lip breathing (the hospice nurse can instruct you on this exercise).
- Decrease the room temperature.
- Elevate the head of the bed or sit upright in a chair.
- In some situations, limiting the number of people in the room may lessen the feeling of claustrophobia.
- Eliminate environmental irritants, such as smoke and strong odors.
- Distraction and relaxation.
- Turn patient on their side to drain excess secretions.

Pharmacological Methods for Relieving Shortness of Breath

Morphine is known for its pain-relieving benefits but it is also very effective in relieving shortness of breath. Lorazepam is used to treat the anxiety associated with shortness of breath. In some medical situations, oxygen may be helpful and can be ordered. Consult your hospice nurse before using these medications.

Hallucinations and Delusions

Hallucinations occur when a person is seeing or hearing things that are not really there. A delusion is a persistent false or mistaken belief.

Potential causes of these altered states of mind include:

- Metabolic changes during the dying process which can alter the normal functioning of the brain.
- The underlying disease process. Diseases that directly impact the brain (such as dementia or certain cancers) may cause confusion; also diseases that affect the liver may lead to an accumulation of toxins in the brain, causing confusion.
- Some infections (e.g., urinary tract infections) can sometimes cause hallucinations.

Pharmacological Methods for Relieving Hallucinations and/or Delusions

Hallucinations and/or delusions may or may not cause distress to you or your family/caregivers. Intervention(s) may only be necessary if you are disturbed or a safety risk develops. If the underlying cause is treatable (such as a urinary tract infection) your Hospice team will help you evaluate the benefits of a treatment such as antibiotics. In situations where the cause is not treatable, medication may be recommended. Haloperidol is an effective medication for hallucinations. This medication should only be initiated if you are instructed by a hospice nurse or your attending physician.

Contents of the Standard Comfort Kit

For safety, keep these medications secure and only use as directed by your Hospice nurse. Consult your hospice nurse before starting any new medication and before making any changes in dosage or frequency. Please note that the medications within the “standard” Comfort Kit are slightly different than the medications within the Parkinson’s Comfort Kit.

Symptom	Comfort Kit Contents	Quantity	Directions
Agitation & Restlessness	Haloperidol 2 mg/mL oral concentrate	15 mL	Take 0.5 mL (1 mg) by mouth or under the tongue every six hours as needed for agitation.
Nausea & Vomiting	Haloperidol 2 mg/mL oral concentrate	See above.	Take 0.25 mL (0.5 mg) by mouth or under the tongue every four hours as needed for nausea or vomiting.
Secretions	Hyoscyamine ODT 0.125mg	8 tabs	Dissolve one tab on the tongue and swallow every 6 hours as needed for excessive secretions.
Anxiety	Lorazepam 0.5 mg tablet	20 tabs	Take one tablet by mouth every six hours as needed for anxiety.
Pain & Breathlessness	Morphine sulfate 100mg/5mL (20 mg/mL) oral concentrate	15 mL	Take 0.25 mL (5 mg) by mouth or under the tongue every four hours as needed for moderate to severe pain or shortness of breath.
Constipation	Bisacodyl 10 mg suppository	Three suppositories	Insert one suppository rectally once daily as needed for constipation.

Record the time and dosing any time Comfort Kit medications are used (see Appendix E for the Comfort Kit tracking sheet).

Helpful Tips for Administering Comfort Kit Medications

How to Give a Suppository

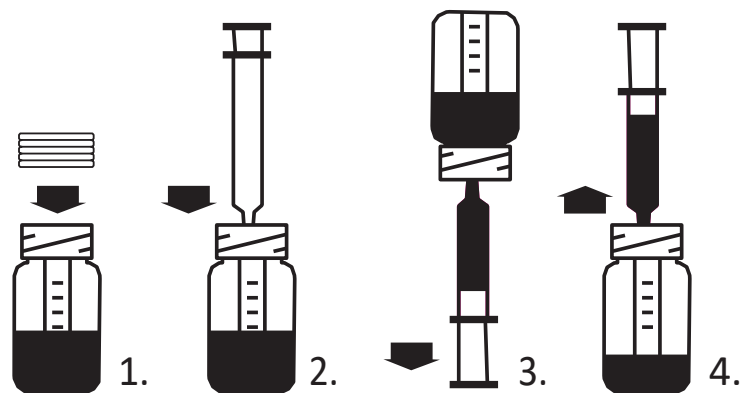
- 1) It's easiest to administer a suppository when the person is in a side-lying position.
- 2) Remove the suppository from the foil packet and with a gloved hand, coat the suppository with a little lubricant from the small package in the Comfort Kit (other lubricants can be used such as KY Jelly).
- 3) With your opposite hand, gently part the buttocks to view the rectal opening.
- 4) Place the pointed end of the suppository into the rectal opening and push straight in with your index finger.
- 5) If stool is present in the rectum, the suppository should be inserted against the rectum wall (not into the stool) because the medication is absorbed through the rectal tissue.

How to Administer Lorazepam under the Tongue

- 1) Crush the tablet into a powder by pressing it between two teaspoons
- 2) Mix with 0.5 to 0.75mL of warm tap water
- 3) Draw the dissolved Lorazepam and water mixture into your small syringe stirring the water and powder together as you draw
- 4) Gently expel the medication from the syringe under the tongue or into the cheek pocket.

How to Set-up and Administer Liquid Morphine

- 1) Uncap the bottle and cut out the thick silver seal (this may require a sharp knife or scissors).
- 2) Insert the bottle plug into neck of bottle, ribbed end first, with or without the syringe attached (see figure 1).
- 3) If not already attached, insert the syringe tip into hole on the top of the plug until secure (see figure 2).
- 4) Turn the bottle upside down and pull down white syringe plunger so the blue liquid lines up with the line on the syringe corresponding to prescribed dose (see figure 3).
- 5) Turn bottle right side up and remove the syringe (see figure 4).
- 6) Administer the medication by slowly pushing the plunger until the oral syringe is empty. If the person is unable to swallow, administer the medication into the cheek pocket. This medication will work whether swallowed or left in the mouth.
- 7) Leaving the plug in the bottle, recap the bottle tightly.



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For the Caregiver: Providing Care & Support

How to Provide Personal Care

Over time there may be some activities of daily living (ADLs) your loved one is no longer able to perform independently. Below is information for caregivers about how to provide mouth care, bathing, changing an occupied bed, toileting and incontinence care, skin care and feeding.

Mouth Care

It is important to keep the mouth clean and moistened. Cleaning the mouth is refreshing and helps the patient feel more comfortable. Regular mouth care helps prevent sores and may improve the appetite.

If the person you are caring for can cough and spit, it is generally safe to brush their teeth, but ask your Hospice nurse if you are unsure. To help prevent choking, make sure his/her head and torso are upright (in a sitting or standing position) even if they are unable to get out of bed. It can be difficult to be as thorough with another person as you would with yourself, but try to brush their teeth twice a day and as needed in between. Know that there are other methods for cleaning the mouth if brushing seems too difficult (e.g., the mouth is clenched shut or the patient is coughing while brushing is taking place). Toothettes are small sponges on a stick that can be moistened with mouth wash and/or water and used to clean a person's mouth when brushing is difficult.

Things You'll Need

- Soft toothbrush or Toothette
- Toothpaste
- Mouthwash
- For Dentures: Denture brush and cleanser
- Cool water
- Small basin or bowl
- Dry towel
- Lip balm or Vaseline

Steps for Providing Mouth Care

- Put a dry towel under the chin.
- Moisten the toothbrush and apply toothpaste, or dip a Toothette in mouthwash.
- Gently move the brush or Toothette over the teeth, gums and tongue.
- Rinse the mouth with either cool water or diluted mouthwash.
- Apply a small amount of lip balm or Vaseline to the lips to prevent drying.
- Individuals with dentures should continue their usual denture cleaning routine. After eating, remove and clean the dentures and clean the person's mouth.
- As an individual loses weight, dentures may not fit properly and can cause mouth sores. Some people may choose not to wear their dentures and eat softer food.

Oral Care after Meals

It is common for people to need their mouth cleaned after meals, especially if they are having a hard time swallowing and tend to hold food in their mouth (aka, "pocketing"). Pocketed food can create a choking hazard so it is important to check all areas of the mouth after meals and remove any uneaten food. Do not use your finger to remove the food! Instead, Toothettes or a toothbrush can work well to get the food out.

Keeping the Mouth Moist

As a person's illness progresses, losing one's appetite is common; some may stop eating or drinking entirely. The ability to swallow will diminish as well, so giving a drink of water is not always an option, yet keeping the mouth moist is an important comfort measure. In this situation, dip a Toothette in water (or preferred

beverage) and run it along the inside of the patient's mouth or cheeks. When a patient is unable to swallow, too much water introduced into the mouth at once may create an aspiration risk. For this reason, squeeze the Toothette against the inside of the cup and get some of the excess water out before attempting this task.

Bathing and Washing Face/Hands

Bathing is important to maintain cleanliness and provide a sense of well-being. How often someone needs to be bathed varies from person to person. Many people only need to be bathed a couple of times per week. If the individual you are caring for can no longer bathe themselves, giving them a bed bath is a safe and effective way to keep them clean.

Things You'll Need

- Large bowl or basin for warm water
- Soap
- Washcloths
- Towels
- Light blanket to prevent chills
- Lotion
- Clean clothes
- Gloves

How to Give a Bed Bath

- If required for comfort, give pain or anti-anxiety medication at least 30 minutes prior to the bath.
- Bathe only a small area at a time, and dry as you go to avoid chills.
- Only uncover the area actively being cleaned to maintain modesty and warmth.
- Begin by washing the face and work down to the feet. Gently soap the skin, rinse and pat dry.
- The face should be cleaned daily (especially around the eyes, nose, and mouth) even if the person is getting a bath that day. Start by cleaning the eyes. Use a warm, moist washcloth. Don't use soap around the eyes. Start by cleaning the inner corner of the eye, then move toward the outer corner.
- Roll the person to their side and wash/dry their backside.
- Wash the legs and feet before washing the buttocks area.
- After washing the feet, change the water.
- Gently wash and dry the genitalia. Daily attention to this area is especially important since bacteria tend to collect there. Wash from front to back to prevent the spread of bacteria.
- Apply a skin-protecting lotion or ointment if the person you are caring for is incontinent.
- Keep hands and nails clean along with the rest of the body. Trim and file nails as needed.

Key points to Remember

- Change the water frequently, especially if dirty or cool.
- If the person is too tired or unable to have a full bath, wash the face, hands and genitalia (groin area).
- Avoid powders (unless recommended by your Hospice team or physician) because they can promote the growth of bacteria and yeast.

How to Change an Occupied Bed

Crumbs, creases, or moisture in the bed are uncomfortable, and may contribute to bed sores. If or when the person you care for is too weak to get out of bed, it is possible to change the linen while he/she remains in bed.

Things You'll Need

- Sheets
- Pillowcases
- Incontinence pads (if necessary)
- Gloves

Things to Consider

Changing an occupied bed may require two people. Good body mechanics are essential to avoid injury while providing this care. It may be helpful to think of the bed as two halves. Change one half of the bed while the person you care for lies on the other half. Then roll him/her onto the clean half and make the other half. Be sure he/she cannot roll off the bed. Consider using bedrails to provide something he/she can hang onto to self-assist with positioning. Consult your Hospice nurse with questions.

Tips for Replacing the Bed Linens

- Have everything you need within reach.
- Raise the bed to a working height, usually no lower than your waist if possible.
- When rolling the person on his/her side, stand on the right side of the bed if you are going to roll to the left and vice versa.
- For this example, the person is on his/her back to start and will be rolled to the left.
- Extend the person's left arm above their head or pull it across their chest to ensure they do not roll on top of it.
- Straighten the left leg. Bend the right knee so that the foot is flat on the bed and the knee is pointed toward the ceiling. If he/she cannot hold their leg in that position, let their bent leg lean into the direction that they are going to be turned.
- If possible, use the draw sheet or incontinence pad that is placed under the person to help roll them. If you lift the edge of the sheet nearest you, that should roll them onto their side. Otherwise you can put your hands and forearms under their shoulder and back (bending at the knees); you may also need to put one of your knees up onto the bed to stabilize yourself. Roll them onto their left side, using the weight of their bent leg to help pull their body over, as well as to keep their body in that position.
- You may also use a pillow tucked under their back to help keep him/her in position.
- Un-tuck the sheets on the occupied side of the bed.
- Then un-tuck the sheets on the unoccupied side and roll the sheets like a log along the back of the person.
- Place new sheets including anything you would like directly under the person (such as fitted sheets, draw sheet, and incontinence pads) on the unoccupied side of the bed.
- Roll the clean bedding (intended for the other side) like a log along your loved one's back. Tuck it under the old, dirty sheets.
- Roll the person you care for to their other side (over the clean and dirty "logs" of bedding) the same way you rolled them onto their left side.
- Remove the dirty linen from the bed and unroll the clean linen; tuck in the clean linen as you normally would to make the bed.
- Reposition him/her in a comfortable position and cover with the top sheet.

Toileting, Incontinence and Catheter Care

To help ensure the person you are caring for can get to the bathroom safely, ensure the pathway is well lit with nothing in the way. Obstructions such as furniture, rugs, pets, or toys are a tripping hazard.

If he/she cannot tell you when they need to urinate and/or defecate, consider taking them to the bathroom on a regular schedule. If accidents are occurring, track when these occur as information for a toileting schedule. For example, if he/she has an accident about every two hours, take them to the bathroom every two hours to help prevent accidents from happening.

If the person you are caring for is too weak to get to the toilet, other options may include using a bedside commode, bedpan or urinal. The bedside commode can be placed right next to the bed so the patient doesn't have to walk to the bathroom. If they cannot get out of bed, a bedpan may be used (he/she rolls onto one side and the bedpan is placed on the bed next to the lower back and buttocks; he/she then rolls onto the bedpan).

Consider the following information if the person you care for cannot control when he/she needs to go to the bathroom (also known as "incontinence"):

- Clean them promptly if he/she has urinated or defecated; this will help protect the skin from sores, prevent infection, and promote comfort and dignity. If he/she has the strength and you think it can be done safely, help them take a shower or a bath. Consult your Hospice nurse if you are unsure. If he/she is bedbound, take off their dirty undergarments and wipe their skin clean. For females it is very important to wipe from front to back to prevent urinary tract infections. Be sure to dry the skin thoroughly and apply a protective lotion if appropriate before placing a new brief on them.
- Use absorbent undergarments (such as adult briefs) and waterproof pads to protect the bed and furniture.
- Reassure him/her when accidents occur. Help them to know it is not their fault.

Catheter Care

A urinary catheter is a soft tube placed into the bladder to release urine; the urine drains through the tube into a bag. For those who are incontinent of urine, a catheter can be used to help keep the skin dry and protect it from rashes. A catheter can also help to empty the bladder if urinary retention is an issue, improving overall comfort. Here are some tips to care for the catheter:

- Because the urine drains out of the bladder and into the catheter bag by gravity, be sure the urine bag is always below the hips.
- Hang the bag on the bed frame or place it in a clean waste basket on the floor next to the bed. This will prevent the urine from flowing back into the bladder. If possible, never raise the bag above the bladder.
- Clean around the insertion site once a day and after bowel movements, using soap and water or hospice-provided hygiene spray, and making sure to rinse and dry the area afterward.
- Be careful not to tug on the catheter tubing; this can cause injury and/or pain.
- To clean the catheter tubing, gently start at the insertion site and move away from the body. Clean with soap and water or hygiene spray, and rinse. Try not to use creams and powders near the insertion site as this can increase the risk of infection.

How to Empty a Catheter Bag

The supplies you need include gloves, a container to drain the urine into, and a towel or absorbent pad to place on the floor under that container. There are different types of catheter bags that come with different kinds of clamps. Your Hospice nurse can teach you how to use the clamp for the bag in use. To drain the catheter bag, unclamp the clamp, empty the bag into the container you have placed underneath it, swab the outside of the clamp with an alcohol swab and re-clamp the bag when empty. This should be done at least twice per day and whenever the bag is more than halfway full.

Troubleshooting Problems with the Catheter

- If no urine is draining into the catheter bag, check the catheter tubing for kinks. If the tubing is twisted, bent or kinked, urine flow may be blocked.
- If you notice leaking around the insertion site, contact Hospice.
- If there is no urine output for greater than 12 hours (unrelated to a kink) contact Hospice.
- Sometimes the urine will become darker or have in it what looks like white clots. The change in color is normal and generally not a concern. The white clots are usually mucus and this is normal in small amounts. If you notice blood in the catheter bag or large amounts of mucus, contact EvergreenHealth Hospice to consult.

Skin Care

- If the person you are caring for is incontinent, check them (and clean as needed) at least every two hours to ensure he/she is kept clean and dry.
- If they are bedbound, reposition him/her every two to four hours because when left in the same position for too long, circulation becomes impaired causing pain and the potential for bedsores.
- When repositioning, roll him/her onto a different side or onto the back to maintain circulation.
- Pillows may be placed behind the back and bottom to help maintain the new position.
- Place pillows between the knees, arms, and ankles to prevent rubbing.
- When the patient is on his/her back, place pillows under the lower part of the legs to relieve pressure on the heels of the foot; this is called “floating” the heels and will help to prevent sores from developing.
- Certain areas are more susceptible to developing sores, such as the tailbone and the heels.
- There are also areas susceptible to skin ailments, such as a yeast rash or raw skin. These areas include the groin and between skin folds, including under the breasts and between abdominal folds. Monitor these areas closely and keep them clean and dry.
- Notify EvergreenHealth Hospice if you notice any redness, open areas, bruising, rashes or abnormal spots on the skin.

Nutrition, Eating and Swallowing

Nutrition/Eating

It is common for nutritional needs to change as disease progresses. The intestinal tract slows down and nutrients move more slowly through the intestinal wall. The body’s metabolism also slows. As these processes change, the appetite diminishes and the kinds of foods that appeal to the patient may change. It will also become more difficult to digest certain kinds of foods (for example, beef will become more difficult to digest than yogurt or applesauce).

Offer food but do not insist that they eat. Serve smaller portions; this may be more appetizing and less taxing. They may request a certain food but then not eat it, or eat only one or two bites. He/she may eat well one day but not eat at all another. This is normal.

Swallowing

Weakness increases with disease progression and this includes weakness of the throat muscles (which affect speech and swallowing). If a person has difficulty swallowing, he/she is at greater risk for aspirating—to inhale food or fluid into the lungs. Signs of a swallowing deficit may include:

- Weak voice.
- Hoarseness.
- Choking.
- Moist cough, even hours after eating or drinking.

If swallowing becomes a problem, the following can help prevent aspirating:

- Only offer food and/or fluids if he/she is awake, alert and agrees to it.
- Sit him/her fully upright during, and for 30 minutes after eating or drinking.
- Tilt the chin slightly forward to assist swallowing.
- Encourage eating and drinking slowly. Give small bites and sips (if they need to be fed) to prevent choking.
- Cue the person to not talk when eating.
- If his/her voice gurgles, cue them to clear their throat.
- Supervise the person during a meal for signs of choking.
- Adjust the consistency of food as needed (e.g., from a regular texture to soft, then to a puree).
- Adjust fluids to a thicker consistency as needed. For example, milk or nutritional supplements are thicker than water, clear juice, soda, coffee or tea. Likewise, nectar such as apricot or tomato juice is thicker than milk or a thin liquid.
- Speak with your Hospice nurse if you suspect your loved one is having difficulty swallowing.

Maintaining a Safe Environment

Infection Control and Prevention

There are many types of bacteria which can cause infection; many people carry bacteria on their skin or bodies without ever feeling ill. Infection is when an organism gets past your normal defenses and causes disease.

MRSA (Methicillin-Resistant Staphylococcus Aureus) is one type of infection that can result from bacteria commonly carried on the skin. The particular strain of this bacterium, however, makes it resistant to certain antibiotics. In the hospital setting, persons with MRSA may be placed in isolation rooms. In the home setting, however, MRSA does not usually pose a health risk to members of their households.

For families whose loved one has been diagnosed with MRSA the following precautions are adequate in the home setting:

Hand Washing

Washing your hands is one of the most important things you can do to stop the spread of germs that can make people sick. In certain situations hand sanitizer may be used in place of hand washing. Consult with your Hospice nurse to see if hand sanitizing is an option for your household.

It is best to wash your hands:

- Before close contact with anyone who is sick.
- After contact with body fluids or items with body fluids on them (towels and sheets).
- Before and after providing care such as giving IV medications, emptying the Foley catheter bag, doing colostomy care, suctioning fluids or emptying the bed pan.
- After using the toilet, covering a cough or sneeze or blowing your nose.
- After removing gloves you wore while giving care.
- Before fixing meals.
- Whenever hands are dirty.

To wash your hands correctly:

- Use warm running water if possible.
- Wet hands and use soap (liquid soap is best).
- Scrub hands for at least 10 – 15 seconds (long enough to sing the Happy Birthday song).
- Be sure to include fingernails and between fingers and thumb.
- Rinse hands well.

- Dry hands gently with paper towels or a clean cloth towel.
- Turn the water off with the towel.

Additional Measures for Infection Control and Prevention

- Wear gloves if you handle body substances (blood, urine, wound drainage) and wash your hands after removing the gloves.
- Heavily soiled or wet linen should be washed separately from other household laundry using the regular wash and dry cycles. Linen that is not soiled can be washed with other household laundry.
- Dishes and silverware may be washed with normal household dishwashing liquid. Gloves are not needed when handling food, dishes or eating utensils.
- Periodically clean the person’s room and bathroom with a commercial disinfectant or a solution of one tablespoon of bleach in one quart of water.
- Wear a mask around other people if you have a cold.
- Avoid your hands when you cough or sneeze – cover your mouth and nose with a tissue or cough or sneeze into your upper sleeve.

Disposing of Medical Waste

To prevent the spread of bacteria or infection to others, it is important to dispose appropriately of all medical waste as follows:

Soiled dressings, disposable pads and gloves

- Put in plastic garbage bag, tie securely and place in regular trash can.

Used needles and syringes

- Put into a special “sharps” container supplied by your Hospice nurse.
- Securely close container when $\frac{3}{4}$ full and replace with a new one.
- Keep container close to where the needles and syringes are used.
- Keep container out of reach of children/pets.
- Consult your Hospice nurse regarding proper disposal; sharps containers are considered hazardous waste and cannot be placed in the regular garbage.

Proper Body Mechanics

Proper body mechanics are essential to prevent injury from lifting the person you care for. It also helps the person being lifted to feel confident and safe. Tips for proper body mechanics include:

- Two people are better than one when lifting or moving a person.
- Stand as close to the person as possible. Keep your feet spread apart for a firm balance.
- When lifting, keep your back straight, bend your knees and lift with your legs.
- Always turn with your entire body rather than twisting or turning your back.

Preparing Your Home

Creating a safe home is important to help prevent falls and other kinds of accidents; it also helps day to day caregiving activities go smoothly. The following suggestions will help make your living environment safe and comfortable:

- The phone should be in working order and within reach. Keep your list of key people and their phone numbers close to the phone.
- Have an up-to-date medication list in the home at all times.
- Cluttered areas create a risk for falls or injuries. Remove clutter to prevent tripping—especially if the person you care for is using a cane, walker or wheelchair.
- Rearrange furniture to provide more space for maneuvering.
- Remove and/or reroute cords stretched across pathways such as electrical or telephone cords and oxygen tubing.
- Throw rugs should be removed.

- Keep articles of necessity within reach, such as near the person’s wheelchair, on a bedside table and on their best side to avoid falls when reaching or dropping items.
- Wipe up spills immediately.
- The risk of falling out of bed may be reduced with bedrails, pillows and/or positioning.
- Maintain adequate lighting day and night, especially in pathways and stairways. Stairs should have railings on both sides and be well-lit.
- Always lock the wheelchair before transferring from bed to wheelchair or vice versa.
- Place a cushion in the seat of low chairs to raise the seat for ease of getting up and down. Elevate the commode seat.
- A seat in the shower or tub may be helpful if the person has balance or endurance difficulties.
- To avoid hurried trips to the bathroom which increases risk of falling, schedule regular bathroom trips (every two to three hours), consider a bedside commode for nighttime use and use incontinence pads as needed.
- Outlets and extension cords should be in good repair. Extension cords should be inspected regularly for frayed wires. Do not overload outlets or extension cords. Do not use electrical equipment or extension cords around the sink, bathtub, or cooking area.
- Keep medications and harmful household products out of reach if they may be used inappropriately or if children are in the home.
- Ensure firearms are in a locked cabinet or remove them from the home.
- Restrain pets when guests are coming.

Oxygen Safety

If your physician prescribes oxygen as part of your care plan, it is important to follow the oxygen order as prescribed and to consult your physician before making any changes to the flow rate.

Because oxygen is combustible, a spark or flame near oxygen can cause a fire in seconds. Follow all safety precautions for your safety and those around you. Oxygen is stored under high pressure, so proper care of the cylinders or concentrator is very important. Tanks stored upright should always be secured (in an oxygen stand or chained against a wall). Tanks not in use may be stored on the floor out of the way where they cannot roll around (under the bed, for example). Take care to avoid accidental tipping or dropping. Oxygen tanks can become extremely dangerous objects if damage occurs to the tank or valve. Refer to your vendor’s complete instruction booklet for more detailed instruction.

Additionally, ensure the following for the safety of yourself and others:

- Have a functional smoke alarm and fire extinguisher and know how to use them.
- Maintain a smoke-free environment when oxygen is in the home. Post the warning sign, “Oxygen in Use, No Smoking” on your front door to alert visitors.
- Don’t use certain products and appliances near oxygen, including:
 - Oil, lubricants or anything greasy (such as Vaseline) on your mouth, nose or lower part of your face.
 - Anything flammable such as aerosols, alcohol containing sprays, hair spray or cleaning sprays.
 - Small electric appliances such as electric blankets, electric razors, heating pads or space heaters.
 - Open flames such as gas ranges, candles or fireplaces.
- Store your oxygen tank in a safe place, avoiding the trunk of a car or any enclosed, small space.
- Turn oxygen off when not in use.
- Turn oxygen off and leave the home if a fire starts.
- Post vendor phone numbers in an accessible location and call the vendor in the event of a power outage or other disaster.

Emotional Care

Family members and caregivers can provide emotional care and comfort to their loved one in the following ways:

- Be gentle. Be patient.
- Acknowledge and allow them to talk about their situation and feelings. Give them permission to express their feelings in many ways.
- If they prefer, include them in discussions and decisions.
- Try not to take their impatience and anger personally.
- Allow them as much control over their situation as possible.
- Allow and encourage them one to do as much as they can for themselves, while also being aware when your assistance is needed.
- Don't underestimate their symptoms, pains and fears. They are real.
- Learn what you can about the disability/disease to help you understand and provide care to the best of your ability.
- Give them some space – physical and emotional.
- Avoid nurturing false hopes or unrealistic goals.
- Talk with them about your good memories.
- Maintain an environment that is as peaceful as possible.
- Avoid disrespectful or disruptive behavior near your loved one.

How to Comfort People with Severe Memory Loss

(by Wendy Lustbader, MSW; Adapted from: Lustbader and Hooyman, Taking Care of Aging Family Members, Revised Edition, Free Press, 1994)

Speaking to Feelings

The nonverbal sensing ability in people with severe memory loss is frequently as keen as that possessed by young children. Instead of listening to loved ones' words, people with dementia react to the anxiety in someone's tone of voice, body posture and facial expression. Learning to speak to feelings takes practice but it can be much more effective than relying on words alone. Caregivers may need to separate themselves from the agitated person for a few minutes to compose themselves and master their own feelings before trying to calm their relative through a soothing voice, relaxed posture, and serene facial expression.

Past as Present

It is usually not fruitful to try to force currently accurate information on someone whose thoughts are focused in another time and who is consequently uninterested in "reality" as known by family members. For example, if the person speaks happily about deceased relatives as if they are still alive, there is no point in making the person experience fresh grief. However, if the person asks directly whether a deceased loved one is still alive, then it is important to give accurate information. Families must listen closely to distinguish reality testing from speech which moves back and forth in time without concern for current information.

Sundowning: Agitation during the Transition from Day to Night

When the sun begins to go down, people with severe memory loss often become more confused and agitated. This problem is so common that it has been termed "sundowning." Solutions tend to vary from person to person, and sometimes from night to night for the same person. One response is to turn up the lights and play music, thereby increasing the amount of stimulation in the environment. Some people need to be taken for a brisk walk outside in order to release their anxiety through exercise. Others become calmer after a hot bath, a back rub, and a glass of warm milk.

Endlessly Repeated Questions

Respond to the emotional tone behind the question, rather than to its content. Reassure the person with a touch on her shoulder and affirm that everything has been taken care of. Then, distract the person by

switching the conversation to another topic. Reassurances on an emotional level combined with touch may be more effective than facts for soothing feelings of fear or loneliness.

Confabulation: Filling in Gaps in Memory with Invented Information

People with dementia are not lying when they say things that are not true. They are trying to make sense of circumstance altered by memory loss.

Anticipatory Grief

Grief has limits, whereas apprehension has none. For we grieve only for what we know has happened, but we fear all that possibly may happen. ~ Pliny the Elder, 79 AD

It is normal to begin grieving the many losses that occur as an illness progresses such as the loss of independence, functioning, roles and lost opportunities. Grief can also be present from anticipating life without your loved one. This is known as anticipatory grief and can be experienced by both you and the person you are caring for. Anticipatory grief may appear in various ways, including:

- Emotionally: heightened anxiety, sadness, anger, fear, guilt, irritability
- Physically: added fatigue, tightness in chest, dizziness
- Behaviorally: changes in sleep, diet, clumsiness
- Cognitively: preoccupation, confusion, inability to concentrate
- Socially: role changes, desiring support, wanting to do it all
- Spiritually: loss of meaning, lost sense of purpose, questioning one's values

It is important to remember that from your perspective, you are losing your loved one but from your loved one's perspective, he/she is anticipating the loss of everyone and everything dear to them. It is understandable that experiencing and anticipating these losses can feel overwhelming at times. A person may withdraw (for instance, turn their face toward the wall) in order to process the impact of these anticipated losses. It is important to not pathologize the symptoms of anticipatory grief as being something wrong, but rather know it to be the normal reaction to so many losses. For the person you are caring for, it is part of their end of life work; for the family member it is the necessary path of adaptation.

Unfortunately anticipatory grief lacks social support and understanding. It is therefore important to be able to identify and name it when the symptoms occur. The social worker and chaplain assigned to your care team can be an important source of support, understanding and comfort.

Anticipating a death can present an opportunity for both the hospice patient and family members to take care of relationships. In Ira Byock's book, *Dying Well: The Prospect for Growth at the End of Life*, he notes "five things of relationship completion:"

- Forgive me.
- I forgive you.
- Thank you.
- I love you.
- Goodbye.

Individuals often need encouragement and permission to do this end of life work. The social worker and chaplain assigned to your care team are trained in facilitating these conversations and would be honored to assist.

End of Life Stages, Death and Grief

What to Expect as End of Life Approaches

Although dying is a natural part of life, most people are not familiar with the stages that often occur as end of life approaches. Many have never experienced the death of a loved one or helped to care for someone who is at end of life. Questions and concerns are common no matter what your experiences have been. We hope this information will help you navigate through uncertainty by increasing your awareness and understanding about what to expect during this potentially difficult yet richly meaningful time of life.

The dying process is unique for every individual, yet there are common stages that tend to occur when one is within months, weeks, hours and minutes from death. These stages will vary in order and duration and involve not only physical symptoms but also emotional, spiritual and/or mental signs and symptoms. Having knowledge about these changes lends to understanding that they are not medical emergencies requiring emergent or invasive interventions but are a natural way in which the body shuts down.

For some within the final stages, the body appears ready to stop at any moment yet death does not come. Experience tells us that there may be issues yet to resolve, such as letting go of regrets, receiving and/or giving forgiveness, knowing that family and friends will be okay, and/or receiving assurances that worries and concerns are no longer warranted and why. Individuals may linger, too, until seeing or hearing from specific family members or friends to say and/or hear “goodbye.” Goodbyes can be experienced in person, by phone, via computer such as Skype or in writing. Likewise, for some who appear emotionally, spiritually, mentally at peace, death may not come as expected because the physical processes necessary for the body to shut down are not yet complete. This is a time for patience and to honor the body’s resilience.

The physical, emotional, spiritual and mental signs and symptoms which follow are offered to help you understand the natural kinds of events which may happen as end of life approaches, and how you can respond. Not all of these signs and symptoms will occur with every person, nor will they occur in this particular sequence. Each person is unique and will be your guide as you carefully and lovingly observe and care for them during their final stages of life.

One to Three Months

Behavior	What to Expect	What You Can Do
Sleeping More	The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive. At times he/she may be difficult to arouse. This normal change is due, in part, to changes in the metabolism of the body.	Sit with your loved one. Gently hold his/her hand. Identify yourself by name and speak in your normal voice. Do not shake the person in an effort to wake them. Speak to him/her directly as you normally would even though there may be no response. Never assume the person cannot hear (hearing appears to be retained until death). Plan to spend time together when he/she seems most alert.
Withdrawing	A normal part of the end-of-life process may include withdrawing from friends, family and the surrounding world. The person may lose interest in visiting with people and need time to be quiet and/or alone. Withdrawing may be necessary as one prepares for detaching from surroundings and relationships.	Provide opportunities for your loved one to be alone even if for short periods of time (while maintaining their safety). Even if your loved one seems unable to hear you, tell them specifically when you are leaving and when you plan to return. Do not take personally your loved one’s need to be alone; your understanding is a gift.

Appetite	Your loved one may have a decrease in appetite and thirst, wanting little or no food or fluids. This can be difficult to witness because food nourishes the body and prolongs life. For those with a normal appetite, it is difficult to understand the lack of appetite (not feeling hungry) for someone who is dying. Eventually, your loved one may have difficulty swallowing and favor small chips of ice, frozen popsicles or juice which may be refreshing in the mouth.	Prepare food based on the person's preferences (which may vary from day to day). He/she may want foods that are soft and/or have more flavors. There may be times when the taste or smell of familiar foods in small amounts is comforting. Do not try to force food or drink. Do not use "guilt" or persuasion to coax eating or drinking. Consult your hospice nurse, but generally this is not a time to worry about special diets.
Fatigue/ Weakness	For someone approaching end of life, fatigue and/or weakness may be their greatest source of discomfort. Often energy is limited and there is inability to endure lengthy social events or visits. Weakness can create the potential for falling. The person may also become unable to move to a comfortable position in their chair or bed.	Check to see when assistance is needed. Talk to the person about being safe from falls so that he/she does not suffer an injury. Understand that weakness and/or fatigue caused by a life-limiting illness tends not to diminish with exercise. Do not "push" the person to exercise to gain strength. If your loved one wants to exercise, help him/her with limited movements/range of motion. Ask what kind of activities the person wants to do and for how long.

One to Three Weeks

Behavior	What to Expect	What You Can Do
Vision-like Experiences	Your loved one may speak to, or claim to have spoken to, person(s) who have already died. They may also see, or claim to have seen, places you cannot see. This is not necessarily indicative of hallucinations or drug reactions because "visioning" is a common experience even for those who do not require medication.	Do not contradict, explain away, or argue about what the person claims to have seen or heard. The experience is real to them even though you can't see or hear it. Affirm his/her experiences by asking about what they see. Affirm for your loved one that visions are normal and common.
Fever/Chills	As the body becomes weaker, so does the temperature control mechanism in the brain; this can cause the person to have a fever or cause the body to become cool. Also, as the body becomes weaker, circulation decreases so he/she may feel cool to the touch.	If a fever develops let your hospice nurse know. Often placing a cool wash cloth on the forehead and removing blankets may be all that is needed. The hospice nurse can assess for any needed medications. Consider using a fan or opening a window. If the person is cool, keep him/her warm with a blanket. Electric blankets should not be used. If the person is cool and becomes restless, removing blankets may decrease the restlessness.
Disorientation	Your loved one may seem confused about the time, place and/or identity of people surrounding him/her (including those with whom he/she is most familiar). This is due in part to metabolic changes.	Identify yourself by name rather than asking the person to guess your name. Speak softly, clearly and truthfully when you need to communicate something important related to comfort such as, "It's time to take your medicine." In addition, explain the reasons for the medication, such as, "So you don't begin to hurt."

Incontinence	The person may lose control of bladder and/or bowel function as their muscles begin to relax and they become less aware of their surroundings.	Discuss with your hospice team what you can do to keep your loved one clean and comfortable including using disposable briefs and/or underpads on the bed. Often the care required is too much to manage alone; consider how to incorporate the help of friends and family and/or hire professional caregiving help.
Physical Restlessness	Restless and repetitive motions, such as pulling at bed linen or clothing, is common at end of life. This is due, in part, to the decrease in oxygen circulation to the brain and to the body's metabolic changes.	Do not try to restrain such motions. Remain calm. Speak in a quiet, natural way. Lightly massage the forehead, read to the person, and/or play soothing music. When in doubt, consult your hospice nurse.
Breathing Pattern Changes	Your loved one's regular breathing pattern may vary. One common pattern consists of irregular breaths—shallow breaths then periods of no breathing for five to 30 seconds or more; this is called "Cheyne-Stokes" breathing. A person may also experience periods of rapid, shallow, pant-like breathing. These patterns are very common and can be indicative of decreasing circulation in the internal organs.	Elevating the head of the bed and/or turning the person on his/her side may bring comfort. Gently hold his/her hand. Speak gently.

Days to Hours

Behavior	What to Expect	What You Can Do
Surge of Energy	Your loved one may experience a surge of energy which is short in duration. This may happen for a variety of reasons such as the need to attend an important family gathering or because he/she is no longer taking certain medications. Sometimes this energy surge gives caregivers/loved ones a false impression that the person is getting better.	Enjoy this time for what it is. Reminisce and create new memories as you spend this meaningful time together.
Mental/Spiritual Restlessness	The person may perform repetitive and restless tasks. This may indicate physical discomfort or that something emotional is unresolved or unfinished.	Consult your hospice team members for help in identifying for your loved one what is physical versus emotional/spiritual/mental discomfort; discuss strategies for resolution. Recall for your loved one a favorite place or experience they enjoyed or you enjoyed together. Thank them for their presence in your life. Give them examples of how they have made a difference in the world. Read something comforting. Play music he/she has enjoyed. Offer words of forgiveness related to situations that involved strife. Give assurance that it is okay to "let go" and provide specific examples as to how you will be okay without them.

<p>Giving Permission/ Saying Good-bye</p>	<p>One of the most difficult tasks at end of life may be giving permission to “let go.” It can be emotionally painful to picture life without your loved one. It’s normal not to want them to die. Experience tells us, however, that a dying person will try to hold on (even if it means prolonged discomfort) if there is uncertainty for the well-being of those they are leaving.</p>	<p>Saying “good-bye” is a gift that can help achieve closure for the living and the dying. It is important to say everything you need to say such as, “I love you” and “Thank you for...” Saying goodbye may include recounting favorite memories, places and activities you shared. It may include saying, “I’m sorry for whatever I contributed to tensions or difficulties in our relationship.” Give examples of specific ways in which you will be okay when they are gone. It is important to offer reassurance that it is alright to “let go whenever you are ready.” It may be helpful to lie in bed and hold your loved one. Tears are a normal and natural part of saying “good-bye;” they do not need to be hidden from your loved one or apologized for.</p>
<p>Urine Decrease</p>	<p>Urine output normally decreases and may become “tea” colored or have an unusual odor. This is referred to as concentrated urine. This is due to the decrease in fluid intake as well as the decrease in circulation through the kidneys.</p>	<p>Consult your hospice nurse to determine whether there may be a need to insert (or irrigate) a catheter.</p>
<p>Congestion</p>	<p>It is common to hear gurgling sounds coming from the chest or throat. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and can cause discomfort. The sound of the congestion does not indicate discomfort.</p>	<p>Gently turn the person’s head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth.</p>
<p>Mottling/ Weak Pulse</p>	<p>Hands, arms, feet and sometimes legs may become increasingly cool to the touch and at the same time the color of the skin may change. The underside of the body may become darker. The skin may become mottled (uneven skin tone). These are normal indications that the circulation of blood to the body’s extremities is decreasing and is focused on the vital organs.</p>	<p>Do not be alarmed and understand that these signs do not indicate discomfort and are not unusual for someone who is within the stages of “actively dying.”</p>

The following excerpt provides vignettes illustrating some of the various cues your loved may give as they approach the final stages of life.

From “Understanding the Final Messages of the Dying” by Maggie Callanan Pflaum, RN, Home Care Nurse and Patricia Kelley, RN, Nursing Education Coordinator, Hospice of Northern Virginia, Arlington, Virginia

Frequently, people who are dying will say things that seem hallucinatory. But listen to these words well. Jumbled and rambling as they may be, these final communications often hold important meaning for those who are leaving this world and those whom they’re leaving behind.

Family members, thinking that their loved one's "mind is wandering," that "he/she doesn't know what's going on any more," are often more distressed by this behavior than by physical symptoms. Frightened, anguished, they may try to humor or reorient him/her. Medical staff may give medication to try to "calm" him/her. But these measures can compound the dying person's sense of isolation and bewilderment.

Instead, if we listen carefully and gently, we may be able to understand what the dying are struggling to tell. Sometimes they're telling us what's happening to them in those last hours or weeks. Sometimes they're asking for something that will help them die peacefully. By helping to interpret these hidden messages, we can ease the anxiety of patients and family members, and help them find a special closeness.

In working with hundreds of dying patients, we've found that they're generally mentally at ease or "busy" in a purposeful way, trying to work out one last thing. And, most important, we've identified several recurring themes.

Being in the Presence of the Dead

The dying commonly talk to or "see" someone who has died. Here is how a hospice nurse drew out such a patient:

Laura, 81, was cared for at home by her husband, Joe. She was particularly concerned about leaving him because he relied heavily on her. A year before, her daughter Susan had died of cancer. During a visit 2 weeks before Laura died, the nurse noticed that she seemed distant, withdrawn. Joe and a nursing assistant reported that she rarely talked anymore, always seemed to be "looking through" them. Wanting Laura to know she would like to share whatever she was feeling and experiencing, the nurse said, "Laura, what's happening to you? Where 'are' you, dear?" "It's time," Laura said, "to get in line." "Tell me about the line," the nurse said, never questioning its existence. "Is there anyone you know?" Smiling, Laura replied, "Susan." The nurse said, "How nice for you." And, exploring further, "Would you like to get in line? Is it okay? Tell me more." Laura's smile vanished and she said, "But Joe—he can't go with me." The nurse said, "That must be a hard choice for you." (Indeed, it was the heart of her dilemma.) "Can we help Joe get ready for the time when you have to get in line?" "Yes" Laura said.

The nurse repeated the exact conversation with Joe. He wept but took comfort in the realization that Laura was looking forward to being with Susan again. And he added another bit of insight. He and Laura had traveled extensively in their lives, and now for this solo voyage, perhaps she was remembering the many times they'd stood in line during their travels together.

It is obvious from the conversation that Laura, like so many dying patients, was caught up in the struggle of whether to stay or go. She needed "permission" to die in peace. And Joe was able to give it, to talk to her about the plans he'd made for his future, to assure her he would be all right. She grew peaceful and remained so until she died.

Preparing to Travel, Change

As we saw with Laura, the theme of travel is a familiar one with the dying. John, 20, suddenly began asking, "Where am I? How do I get home? If I could find a map, I could get home."

His parents attributed his confusion to the fact that they'd moved him from his bedroom on the second floor to a room on the first floor next to theirs. In an attempt to reorient him, they moved in all of his things from his own room and even hung a map of the town on his wall. But his confusion and agitation increased.

We suggested to his parents that he might be trying to find his way to his new home. They felt we were right and, fighting their grief, reassured him that he would find his way soon, that they were ready for him to leave them. His anxiety and frustration drained away; he died the next day.

Seeing a Place

Many dying people have glimpses of "another world." Others speak of having a "dream" or a "feeling of being in another place." And it doesn't happen only when death is imminent; it can occur weeks before.

For instance, Bob, 42, spoke coherently only once in the last 24 hours of his life. “I can see the light down the road,” he said, “and it’s beautiful.” Peter, 51, told us 2 weeks before his death, “I can see through the doors to the beautiful scene.” It was 3 weeks before she died that Elizabeth, 60, said, “When I woke up this morning, I thought I had died and an angel was in the light coming through the window; I was so disappointed that it was my daughter and that I was still alive.”

This phenomenon can comfort some patients but puzzle others. Thus, one of our roles is to help them explore what it was like (if they want to) and to offer reassurance if necessary. It’s important to remember, too, that families often need to be reassured that this isn’t caused by drugs or mental dysfunction, that it’s indeed common.

Choosing When to Die

Most of us are aware that the dying often seem to cling to life until a loved one arrives. But we also see patients wait until a loved one leaves.

Jean, 59, lived with her friend Barbara. Piecing together some things Jean had said, her hospice nurse realized that Jean didn’t want Barbara to be alone with her when she died. The hospice nurse assured Jean that she would help to coordinate additional support to be with her. Jean, who had developed a close relationship with the nurse, said, “I’d prefer if you were with Barbara.”

Several days later the hospice nurse visited Jean as she lay dying, apparently comatose. A [caregiver] was with her, and Barbara was in the next room. Leaning over Jean, the hospice nurse told her she didn’t think it would be much longer, that it would be easy from now on, and that Jean should go whenever she wanted to.

Kissing Jean’s cheek, she said, “I’ll be back in a little while. I’m just going to spend some time with Barbara in the other room.” Within minutes Jean died, the [caregiver] at her side, the hospice nurse with Barbara as Jean had wished and planned for.

Knowing the Image of Death

Many times the message the dying give is that they’re about to die. Eileen, 19, told her father – without really saying it.

She called him from the hospital to say, “I love you, Dad. I want to thank you for being such a good father.” When he told her he was coming to see her after work, she said, “I need to tell you now. I won’t be able to then.” Since Eileen was in a stable period and her friends would be visiting that evening, he thought she meant that the two of them wouldn’t have private time together. Eileen was in a coma when he arrived, and she died that night. But she’d said, in her own way, her good-bye.

Confusion of the Dying

Not only is it essential to listen to the dying with complete attention but also to let them know you’re listening. Here are some techniques we’ve found helpful:

- Respond in ways that tell them you accept whatever they say or “see.”
- Follow up what they say in a gentle way. Ask questions and offer sensitively probing insights that might encourage that they say a little more.
- Support them. For instance, if they’re having difficulty “letting go,” don’t deny the problem. Acknowledge it and offer to help.
- Equally important, however, don’t keep pushing. If they don’t want to talk, drop it – they have to be ready. But at the same time, reinforce that you’re still greatly interested, that they should let you know whenever they want to talk.

The Family

It is often easier for family members to grasp what the patient says, to understand the possible symbolism and references, because of their knowledge of his/her life-style, experiences, values, and usual way of talking. Listen carefully and consider the meanings from what the patient is saying. Family members go through so much together in their lives. They share so much with each other. And this too, the time of dying, can often be a wonderful time of sharing.

What to Do When Death Occurs

When your loved one reaches the end of life at home, there is no need to call 911. Take your time and when you are ready, **call EvergreenHealth Hospice at 425.899.1070 to report the death of your loved one.** If he/she resides in a residential facility, please check with a facility representative to ensure EvergreenHealth Hospice is notified.

The Hospice Triage nurse will ask for the approximate time of death. He/she will facilitate a visit by a Hospice representative to provide support (such as help with answering your questions and, if you wish, help with bathing and dressing your loved one in the way you would find meaningful before they leave your/their home for the last time).

The Hospice Triage nurse will make several calls related to your loved one's death including the funeral home, attending physician, medical examiner and medical equipment provider.

Honor this day and your feelings. Your family and friends will want to come to be with you. Reach out and allow their support. Solace may also be found in the following ways:

- A special quilt, pictures or flowers can help with creating a sacred space. Some people light a special lamp or open a window.
- Allowing yourself to express your feelings in your own way. Take the time you need as a family and individually.
- Knowing that each person's experience is unique. Some family members may want to come in person and others may not.

It may take at least one to two hours for the funeral home to arrive, but you can arrange with the funeral home for more time if you like. When the funeral home representative arrives, he/she will talk with you about the process for transporting the body and answer any questions. You may choose to be present or not when the representative transfers the body to a stretcher and places it in the legally-required bag which encloses the body. This may be difficult for some to witness. The funeral home representative is there to provide respectful care of the body and assist with your concerns.

It can be very difficult to transition from the intensity of caregiving to the numbness and sometimes disbelief you may feel as a consequence of the death. Take time to rest, drink water, eat, walk outside and breathe deeply.

Begin the process of contacting those who will want to know of the death.

Make an appointment to meet with the funeral home director to discuss and confirm all arrangements. You may find that planning and experiencing a memorial service or celebration of life is one of the most meaningful steps you can take within your grieving process. Funeral directors are experienced professionals in helping you create a meaningful memorial service to honor and remember your loved one. Include your spiritual community. Consider involving the whole family which may help the healing process for all.

Funeral arrangements can take time, whether for cremation or burial. Death certificates are created and processed by the funeral home with the information you provide. The funeral home director obtains the signature of the attending doctor to complete and register the death certificate at the appropriate county courthouse. The funeral home director will need to know how many certified copies of the death certificate you need; one rule of thumb is to order one certified copy for each financial institution where your loved one has an account. Some institutions may accept a copy of the certified copy, but most require an original certified copy. Your funeral director can help to answer your questions.

Writing an obituary may be helpful for you in remembering your loved one. Many funeral homes offer free online posting of obituaries and guest books. Funeral homes can also help with posting an obituary in a local newspaper; costs vary per newspaper.

Considerations and Tasks Following the Death

Many tasks can wait and take place within a reasonable timeframe following your loved one's death. Consider delegating tasks to trusted friends and/or family members to help, knowing that:

- Calls to financial institutions do not have to be made immediately nor all at once.
- Social Security is contacted by the funeral home. However, you should also contact Social Security within a reasonable timeframe to see if you qualify for the small death benefit they offer.
- If the Department of Social and Health Services (DSHS) has been involved, contact your DSHS caseworker or financial worker.
- If your loved one was a veteran, the Veterans Administration should be contacted. A death benefit may be available. Veterans are eligible for burial with full honors within a national cemetery. Your funeral director can provide additional information and coordinate this upon request.
- Begin to gather paperwork. The deceased may have left a letter of instructions and/or a Last Will and Testament. An executor will be named within the Will who is responsible for coordinating how the estate is settled. Settling the estate of a loved one can be a time-consuming, complicated process. You may wish to hire an attorney to manage the process for you. The cost can be fairly minimal compared to the stress involved trying to navigate the legal steps on your own. Contact your local bar association if you need a referral for an attorney. Call more than one attorney and compare services and cost.
- The deceased may have a safe deposit box. There may be financial arrangements already made for paying for the funeral and/or burial such as a life insurance policy.
- Gather information on existing financial accounts that are in the name of the deceased.
- Gather information on outstanding bills and debts, passwords and/or security codes as well as other issues that may need to be addressed.
- In Washington state, if the deceased has no funds to pay for after-death expenses, the law allows the funeral home and/or the medical examiner to turn to surviving family members for payment.
- Unused medications, medical supplies and equipment can be disposed of or donated when appropriate. Appendix J provides guidelines for how you can do this safely after death.

Grief & Bereavement Services

What is Grief?

Grief has been described as a piece of the lifelong journey. It is the thoughts, feelings and meaning given to a person's experience when someone they love dies. Each person's experience will be influenced by a variety of factors, including:

- Relationship with the deceased.
- Circumstances surrounding the death.
- Grieving person's support system.
- Cultural and spiritual background.

Grief instructs us in the healing art of profound acceptance. - Molly Fumia

How You Might Be Feeling

In times of loss, it is helpful to know that the reactions you are experiencing are natural and healthy. While each person experiences grief differently, you may find comfort knowing that others share similar loss responses. You may experience grief in some of the following ways:

- Physically.
- Emotionally.
- Mentally.
- Spiritually.
- Behaviorally.
- Socially.

Path to Healing

Each person has an individual style of coping with painful experiences. There is no right way to grieve and no specific time table. Grieving is a process. The list below may help you generate ideas for managing your feelings of grief:

- Be kind and patient with yourself.
- Accept your feelings.
- Seek information about grief.
- Care for your physical self with good nutrition, exercise and rest.
- Be flexible in your routine.
- Tell your story; write about your feelings.
- Seek good listeners.
- Honor and remember your loved one.
- Involve yourself in work or meaningful activity.
- Identify important dates that may be difficult, and plan ahead.
- Begin to create goals and meaning in your life.
- Embrace your spirituality.

Normal Manifestations of Grief

- Loss of appetite, nausea, diarrhea.
- Feeling of emptiness in the stomach.
- Lump in the throat.
- Tightness in the chest.
- Inability to sleep, early morning awakening and/or fatigue.
- Grinding the teeth during sleep.
- Dryness of the mouth.

- Inability to concentrate, forgetfulness regarding what is being done in the middle of a task, forgetting what is being said in the middle of a sentence.
- Loss of time perception.
- Difficulty with remembering or maintaining a schedule.
- Sense of loneliness and feeling of social isolation.
- Overwhelming sense of sadness.
- Longing for life to return to the way it was.
- Crying at unanticipated times.
- Oversensitivity to noise.
- Breathlessness, frequent sighing.
- Experience occasions of resentment that “life goes on” for others.
- Hear, smell, see loved one, particularly in familiar settings.
- Need to often retell the details of the loss.
- Temporarily attempt to preserve life “as it was” for the loved one.
- Have recurrent feelings of guilt or remorse.
- Assume characteristics, mannerisms of the loved one.
- Irritability, feeling “on edge.”

Grief in Children

- Ask the child what they understand of their loved one’s condition/situation.
- Explain their loved one’s condition in simple, realistic terms.
- Ask the child how he/she is feeling.
- Let the child know who they can talk to.
- Let the child know who is caring for them.
- Have them involved with their loved one to the extent they want to be involved.
- Discuss death as a natural and inevitable process.
- Don’t link death to sin or punishment or half-truths.
- Provide books and stories that help them learn about death.

Moving Through Grief

For a while, your grief may feel intensely personal and confusing. Move at your own pace. It is important to know that the intensity of your grief will lessen over time. You do not stop loving someone because the person has died. While each person’s experience is unique, the following may help manage your grief.

- Acknowledge the reality of the death. Begin to accept that your loss is real.
- Experience the emotional pain of the loss. Lean into the pain of your grief, feel it, listen to it and learn from it.
- Adjust to a new environment without your loved one. Interact with the world individually and with others day by day.
- Find an enduring connection with your loved one in your current life. Remembering, honoring and continuing to love them.

The experience of grief is powerful. So too, is your ability to help yourself heal. In doing the work of grief, you are moving toward a renewed sense of meaning and purpose in life. - Alan Wolfelt

Bereavement Support

After the loss of your loved one, professional bereavement staff at EvergreenHealth Hospice is available for individuals and families seeking support. Realizing that each person's grief experience is different, a variety of services are offered:

- Supportive mailings.
- Individual support sessions.
- Support groups.
- Informational workshops.
- Special focus programs.
- Seasonal events.
- Annual memorials.
- Community referrals.

Contact Us

EvergreenHealth Hospice is here to offer compassionate support and information to help guide you through your time of loss.

For more information about our grief and bereavement services, please speak with a member of your Hospice care team or call EvergreenHealth Hospice Bereavement Services at 425.899.1077. Our professional bereavement staff would be happy to speak with you.

Visit our website at evergreenhealth.com/grief.

Grief is a journey that does not have to be taken alone. - Author Unknown

EvergreenHealth Foundation

Donations to EvergreenHealth Hospice Services

Often families and organizations choose to honor or remember their loved one or colleague with a commemorative gift to support EvergreenHealth Hospice Services. Here are a few helpful tips in making a gift:

- Please be sure to identify the person you wish to honor or memorialize.
- Please provide a name, address and phone number of the person you wish to be notified of your gift. We will share with them that a gift has been made; however, we will never divulge the amount given.
- If you wish to include the EvergreenHealth Foundation as the charity of your choice in a newspaper obituary, we recommend the following language:
 - **Memorial Gifts may be made to EvergreenHealth Foundation, 12040 NE 128th Street, MS#5, Kirkland, WA 98034-3098 or visit www.evergreenhealthfoundation.com to support the “ ” program** (i.e., Hospice, Home Care, Cancer Center, Parkinson’s, etc.).
- Donor envelopes or memorial business cards are available for any funeral or memorial service by calling 425.899.1900 or email your request to foundation@evergreenhealth.com.

Grateful patients and their family may wish to acknowledge the quality care they received, but please remember that staff members cannot accept gifts. Instead, you may acknowledge your professional team members by a commemorative gift in their honor.

Ways to Give

We appreciate your interest in supporting the essential goals of the EvergreenHealth Foundation. Gifts can be made in the form of cash, gift of securities, real estate, or personal property. The Evergreen Legacy Society exists to honor those individuals who have chosen to leave a lasting legacy for future generations through a bequest in your will, living trust, a gift of life insurance; or through a gift plan that provides you or a loved one with life income.

We can accept monetary gifts in one of four ways. Please choose whichever is most convenient for you:

Mail	Checks payable to: EvergreenHealth Foundation Mail to: 12040 NE 128th Street, MS#5, Kirkland, WA 98034-3098
Phone	425.899.1900. You can make a contribution over the phone and charge your gift to your credit card.
Online	You can donate online, using your credit card on our secure server at www.evergreenhealthfoundation.com . You may also print the Donation Form (pdf) and mail the form along with your check or credit card information to the above address.
Fax	Please print the online Donation Form (pdf) and fax the form with your credit card information to 425.899.1904.

EvergreenHealth Foundation is registered with the Internal Revenue Service as a non-profit 501(c)(3) organization. Federal Tax ID# 91-1519430. The Foundation is registered with King County and the State of Washington to solicit funds.

APPENDIX A

Private Caregiving Agencies

EvergreenHealth Community Healthcare Access Team (CHAT) offers this list as a resource to you, but does not endorse or suggest you use any of the agencies listed. Most agencies are licensed and bonded with the state of Washington; however, for your protection, ask for verification. Unless otherwise noted, agencies serve both King and Snohomish Counties. (Updated June 2015).

Agency Name	Phone Number	
Advanced Health Care (King County)	800.690.3330	
All About Care	425.678.8400	425.315.4662
Andelcare	206.838.1844	425.283.0408
Bellevue-Synergy Home Care	425.462.5300	
BrightStar	206.777.1190	425.679.0310
Capability Home Care	425.679.5770	
CareForce	425.712.1999	206.439.1303
Catholic Community Services	253.850.2528	800.722.3479
CHC Services	425.275.5858	877.907.6013
Companion Care	425.488.7575	
Concierge Care	425.802.6613	855.444.7364
Family Best Care	425.647.8510	206.779.6424
Family Resource Home Care: East King County	206.545.1092	425.455.2004
Fedelta Home Care	Bellevue: 425.454.4548	Seattle: 206.362.2366
Griswold Home Care	425.922.1617	
Health People	425.454.1947	
A Helping Hand Home Care	206.686.7440	877.281.7111
Home Care Associates (Jewish Family Services)	206.861.3193	
Home Instead (East King & Snohomish County)	425.454.9744	425.670.2292
Homewatch Caregivers	206.363.4599	425-889-2627
HomeWell Senior Care	206.440.5500	
Maxim Health Care Services	206.985.4625	
Rescare Home Care	206.368.7667	
Right at Home	425.818.7744	206.774.1100
Sound Options	800.628.7649	
Visiting Angels (Seattle, Eastside, Everett)	425.828.4500	206.361.7066
With A Little Help	206.352.7399	

APPENDIX B

Placement Services

EvergreenHealth Community Healthcare Access Team (CHAT) available at 425.899.3200 offers this list as a resource for you, but does not endorse or suggest that you use any of the agencies listed. Information provided is subject to change.

AGENCY	SERVICES
Adult Care Solutions 425.941.5163 adultcaresolutions.net	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Assisted Living Facilities and Retirement Centers. • Medicaid placement assistance.
Assisted Living Options 1.877.705.1359	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Retirement Communities, Assisted Living Facilities and Nursing Homes. • Limited Medicaid placement assistance.
Care Management Partners 206.533.8761	<ul style="list-style-type: none"> • RN consultation for care options. • Assist with placement in Adult Family Homes and Assisted Living Facilities.
Choice Advisory Services, Inc 1.800.361.0138 choiceadvisory.com	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Retirement Centers, Assisted Living facilities, and Nursing Homes and in home care.
CayCare 866.337.1176 caycare.com	<ul style="list-style-type: none"> • Assist with placement in Adult Family Homes, Retirement Centers, Assisted Living, Nursing Homes and Medicaid placement. • Assist with current assessment for facility type.
Concierge Care 425.802.661	<ul style="list-style-type: none"> • Personalized assistance for all types of pre-qualified senior living home/communities. • Independent RN consultation/care services.
Dedicated Care Solutions 425.737.3865	<ul style="list-style-type: none"> • Family Consultations to assist with placement for Independent Living, Assisted Living, Memory Care and Adult Family Homes, as well as in home care.
Eastside Senior Care 425.998.6883	<ul style="list-style-type: none"> • Assist with placement in Assisted Living facilities, Retirement & Adult Family Homes. • Eastside focus.
Elder Placements, Inc 206.719.5566 rneldercare.com	<ul style="list-style-type: none"> • RN consultation for care options. • Assist with placement in Adult Family Homes and Assisted Living facilities.
Fedelta Care Solutions 425.454.4548 fedeltacaresolutions.com	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Independent Living, Assisted Living and Nursing Homes.
My Parent Matters 425.652.2000 myparentmatters.com	<ul style="list-style-type: none"> • Consultation for care options/free RN assessment. • Assist with placement in Adult Family Homes and Assisted Living Facilities.
Options for Seniors 425.827.0894 optionsforseniors.com	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Retirement Communities, Assisted Living Facilities, Nursing Homes, Condos & Apartments, and in home care.
Professional Placement Services, Inc. 206.608.0188	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Adult Family Homes, Assisted Living Facilities and Retirement Communities.

<p>Seattle Senior Care Consultants 206.395.2288 Seattleseniorcareconsultants.com</p>	<ul style="list-style-type: none"> • RN consultation for care options. • Transitional counseling. • Assist with placement in Adult Family Homes and Assisted Living Facilities. • Limited Medicaid assistance.
<p>Senior Care Solutions 425.644.8050</p>	<ul style="list-style-type: none"> • RN consultation for care options. • Assist with placement in Adult Family Homes and Assisted Living Facilities.
<p>Senior Placement Solutions, Inc 206.612.7689</p>	<ul style="list-style-type: none"> • RN consultation for care options. • Assist with placement in Adult Family Homes and Assisted Living Facilities.
<p>Serving Our Seniors 425.968.8322 servingourseniorsllc.com</p>	<ul style="list-style-type: none"> • Consultation for care options. • Assist with placement in Retirement Homes, Assisted Living Facilities or in home care.
<p>Sound Transitions 206.355.5653 soundtransitions.net</p>	<ul style="list-style-type: none"> • RN consultation for care options. • Assist with placement in Adult Family Homes. • Limited Medicaid assistance.

APPENDIX C

Bowel Tracking Program

Month: _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

APPENDIX D

Fruit Paste Recipe

Take 1 - 2 Tablespoons per day

- 1 pound prunes, pitted
- 1 pound raisins
- 1 pound figs
- 4 ounces senna tea leaves (available at most health food stores)
- 1 cup brown sugar
- 1 cup lemon juice

Directions:

1. Prepare senna tea. Use about 2 ½ cups boiled water added to tea leaves and steep for 5 minutes.
2. Strain tea to remove tea leaves and add only 1 pint tea to a large pot; then add fruit.
3. Boil fruit and tea for 5 minutes.
4. Remove from heat and add sugar and lemon juice. Allow to cool.
5. Use hand mixer or food processor to stir fruit mixture into smooth paste.
6. Place in plastic container and place in freezer. (Paste will not freeze but will keep forever in freezer.)
7. Spoon out what you require each day. Enjoy eating this straight off the spoon or spread it on toast. You can even add hot water and make a drink of it.

If the fruit paste is not working (no bowel movements), then increase the amount of fruit paste each day.

If the fruit paste induces very loose stools, cut down on the amount of fruit paste intake; consider taking it every other day.

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APPENDIX G

Symptoms Tracking Tool

Hospice care helps to treat symptoms of discomfort that affect your quality of life. This tool for tracking symptoms can help explain what symptoms you are experiencing, how often and how severe they are. List your symptoms and rank them between 1 (affecting you the least) and 10 (affecting you the most). Show this list to your Hospice nurse each visit. Symptoms may include bone ache, constipation, depression, diarrhea, dizziness, fatigue, fever, headache, incontinence, swelling of the arms or legs, memory loss, mouth sores, muscle ache, nausea, no appetite, numbness or tingling, generalized pain, urinary pain, urinary urgency, weight gain, weight loss, etc. List the symptoms you are experiencing, enter the date in the Date column, and rank the symptom from 1 to 10.

Symptom (across)	<i>nausea</i>									
Date (down)										
3/26	4									

APPENDIX H

Emergency Phone Numbers

In the event of an emergency or natural disaster, ensure that important telephone numbers are reachable in several places and by the telephone. Complete, copy and post this page as needed.

- Fire: 911
- Police: 911
- EvergreenHealth Hospice Services: **425.899.1070** or **1.800.442.4546**
- Medical Equipment Company:
 - o Bellevue Healthcare: 1.866.451.2842
 - o Other: _____
- Oxygen Supplier:
 - o Bellevue Healthcare: 1.866.451.2842
 - o Other: _____
- Infusion Services:
 - o _____
- Hospital:
 - o EvergreenHealth: 425.899.1000
 - o EvergreenHealth Monroe: 360.794.7497
 - o Overlake: 425.688.5000
 - o Virginia Mason: 1.888.862.2737
 - o University of Washington: 206.598.3300
 - o Northwest (Seattle): 206.364.0500
 - o Swedish Edmonds: 425.640.4000
 - o Swedish Issaquah: 425.313.4000
 - o Snoqualmie Valley (Snoqualmie): 425.831.2300
 - o Valley Medical Center (Renton): 425.228-3450
 - o Cascade Valley (Arlington): 360.435.2133
 - o Other: _____
- Utility Company: _____
- Other: _____

Emergency Preparedness

Contents for an Emergency Preparedness Kit

- Drinking water, one gallon per person per day, for at least 3 days
- Food, at least a 3-day supply per person, non-perishable
- Battery-operated or hand crank radio w/ extra batteries
- NOAA Weather Radio w/ extra batteries
- Flashlight and extra batteries
- First aid kit
- Whistle
- Dust masks
- Plastic sheeting
- Duct tape
- Moist towelettes
- Garbage bags (small) w/ plastic ties for personal sanitation
- Wrench and/or pliers, pocket knife
- Can opener for food
- Local maps
- Prescription medications and glasses
- Infant formula and diapers if needed
- Pet food and extra water for pets
- Important family documents
- Cash and change
- First Aid book
- Sleeping bag or warm blanket for each person
- Complete change of clothing for each person; include long sleeved shirt, long pants and sturdy shoes
- Household chlorine bleach (not scented) and medicine dropper to be used as disinfectant (9 parts water to 1 part bleach) or as water purifier (16 drops bleach in 1 gallon of water)
- Fire extinguisher
- Matches in waterproof container
- Personal hygiene supplies
- Feminine hygiene supplies
- Paper and pencil
- Activities for children



Fire Safety

- Install and maintain smoke detectors on each level of your home and outside of each sleeping area. Test regularly and replace dead batteries immediately. Smoke detectors warn you of a fire in time to let you escape.
- **Plan and practice escape routes.** If fire breaks out in your home, you must get out fast. Do not use elevators. Choose a meeting place outside where everyone will gather.
- Keep portable and space heaters at least 36 inches from paper, curtains, furniture, clothing, bedding or anything else that can burn. Never leave heaters on when you leave the house or go to bed, and keep children well away from them.
- Check all your electrical cords and replace any that are cracked or frayed. If you use extension cords, don't overload them or run them under rugs.
- If your clothes catch fire, don't run. Stop where you are, drop to the ground, and roll over and over to smother the flames. Cover your face with your hands to protect your face and lungs.
- Crawl low under smoke. If you get caught in smoke, the cleanest air will be several inches off the floor. Get down on your hands and knees and crawl to the nearest safe exit.

What to Do During an Earthquake

- If you are inside when the shaking starts, stay inside and take cover under a desk or table and hold on or sit against an inside wall and cover your head and neck.
- If you are outside when the shaking starts, sit down in an open area away from power lines and buildings.
- If you are in a vehicle, stop in an open area away from bridges and buildings. Stay in the vehicle.
- If you are in bed, stay in bed and cover your head with pillows or bedding.
- In all situations, stay clear of anything that could break or fall such as mirrors, windows, chimneys, and tall furniture.

What to Do Following an Earthquake

- Turn on a battery-powered radio for damage reports and information.
- Do not use the telephone unless there is a severe injury.
- Do not use electrical switches or appliances if gas leaks are suspected.
- Switch off electrical power if there is damage to your home's electrical wiring.
- Do not touch downed lines or broken appliances.
- Know how to turn off electricity, gas and water at main switch and valves.
- Do not use your vehicle, unless there is an emergency.
- Be prepared for aftershocks; they may cause additional damage.

If You Have to Evacuate Following an Earthquake

- Post a message in clear view stating where you can be found (such as at neighbors, friends, relatives, school or community center).
 - o See Evacuation checklist

Prepare for a Power Outage

- Prepare an Emergency Preparedness kit.
- Keep emergency telephone numbers handy.
- Know whom to call if you use medical equipment such as an oxygen or infusion.
- If you have a generator, keep it outside the home and do not connect it to your home's wiring system.

What to do if a Power Outage Occurs

- Use your radio to tune into emergency Alert Systems or stations such as <1100 AM KIRO> or <1000 AM KOMO>.
- Keep refrigerator and freezer doors closed.
- Put on layers of clothing if it is cold outside.
- NEVER BURN CHARCOAL OR PROPANE for heating or cooking indoors.
- Do not use your gas oven as a source of heat.
- Turn off or disconnect appliances that may be damaged by a power surge when the power returns.
- Do not consume food that may have become spoiled.

Prepare for a Flood

- Flooding can happen anywhere and at any time of the year. Prepare for flooding if you live in low-lying areas near any body of water.
- Keep an Emergency Preparedness Kit. Be on watch if the conditions are right for flooding in your area. Listen to weather updates and emergency instructions.
- Make a flood plan. Have a place to go where there is higher ground and you can get there quickly.

What to do if Flooding Occurs

- Disconnect electrical appliances and do not touch electrical equipment if you are wet or standing in water.
- If instructed by emergency announcements, turn off your gas or electricity at the main switch, to prevent fires and explosions.
- Evacuate immediately if directed by emergency management announcements.
- Move immediately to higher ground.
- Avoid walking or driving through floodwaters. Turn around! Your vehicle can be swept away by only 12 inches of moving water.

Plan for Family Communication

- Make sure everyone carries a copy of this information in his/her backpack, purse, or wallet.
- Post a copy in a central location in your home, such as your refrigerator or family bulletin board.
- If you are using a mobile phone, a text message may get through when a phone call will not. Text messages may also save and then send automatically when capacity becomes available.
- Text is best when using a mobile phone, but if you make a phone call, keep it brief and convey only vital information to emergency personnel and/or family or household members. This will minimize network congestion.
- Write down phone numbers and email addresses for everyone in your household.
- Identify someone outside of your community or state who can act as a central point of contact to help your household reconnect. In a disaster, it may be easier to make a long-distance phone call than to call across town because local phone lines can be jammed.
- Conserve your mobile phone battery by reducing the brightness of your screen, placing your phone in airplane mode, and closing apps you do not need.
- Keep charged batteries, a car phone charger, and a solar charger available for backup power for your mobile phone.
- Because a disaster can strike during school or work hours, know their emergency response plans and how to stay informed. Discuss these plans with children, and let them know who could pick them up in an emergency. Make sure your household members with phones are signed up for alerts and warnings from their school, workplace, and/or local government.

Family Contact Information

Name: _____
Mobile #: _____
Other #: _____
Social Media: _____
Email: _____
Important medical or other information: _____

Name: _____
Mobile #: _____
Other #: _____
Social Media: _____
Email: _____
Important medical or other information: _____

Name: _____
Mobile #: _____
Other #: _____
Social Media: _____
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Other #: _____
Social Media: _____
Email: _____
Important medical or other information: _____

Name: _____
Mobile #: _____
Other #: _____
Social Media: _____
Email: _____
Important medical or other information: _____

Prepare for Evacuation

Make a plan today. Your family may not be together if a disaster strikes, so it is important to know which types of disasters could affect your area. Know how you will contact one another and reconnect if separated. Establish a family meeting place that's familiar and easy to find.

Consider These Questions in Your Plan

- How will we leave? (by car, on foot, etc.)
- Where will we go? Have locations in different directions from your home. If you have pets, make sure they are allowed at your planned destinations.
- Have a list of shelters in your area.
- Keep a go-bag (backpack or easily carried) for emergency evacuation on foot or by public transportation.
- Keep your gas tank half-full at all times, and full if evacuation seems likely.
- Have a family communication plan.

Evacuation Checklist

- Unplug electrical equipment except for freezers and refrigerators. Unplug **all** equipment in case of possible flooding.
- Shut off water, gas and electricity as directed by emergency management announcements.
- Leave a note at your home telling others when you left and where you are going.
- Wear sturdy shoes and clothing.
- Check with neighbors who may need a ride.
- Secure your home before leaving it by closing and locking doors and windows.
- Take your emergency kit in the car, or have a separate emergency kit you keep in the car.
- Take one car per family as the road will be crowded and traveling will be slow.
- Follow recommended routes. Shortcuts may be blocked or dangerous.

Additional Emergency Phone Numbers in the Event of a Natural Disaster

- Red Cross King County: 206-323-2345
- Red Cross Snohomish County: 425-252-4103
- FEMA: 1-800-624-3362
- Also reference Chapter Three: **“Emergency Preparedness and Personal/Home Safety”**

APPENDIX J

Disposal of Unused Medication and Donation of Medical Supplies/Equipment

Due to Health Department regulations, EvergreenHealth Hospice Services cannot accept returned medications, medical supplies or equipment. The following are options for disposal or donation:

Medication

Dispose of any prescribed medication that you are not using. EvergreenHealth Hospice Services employees are not permitted to remove medications from your home to dispose of them for you.

To dispose of medications in the household trash:

- Mix medications (do not crush tablets/capsules) with an undesirable substance such as wet coffee grounds or wet kitty litter so the drugs are unusable.
- Place this mixture in a sealable plastic bag, then into a non-transparent container or bag, and then into the trash.
- Scratch out personal information on your empty pill bottle labels or medicine packaging before placing in the trash.
- The Federal Drug Administration (FDA) recommends that drugs not be flushed down the sink or toilet unless the label or information sheet specifically gives this instruction.
- See the State of Washington's webpage www.takebackyourmeds.org for alternatives to home drug disposal including a list of pharmacies in Washington State participating in medication take-back programs.
- Ask your own pharmacy if they will accept your medications for disposal.

Medical Supplies/Equipment

- **Bridge Disability Ministries** accepts supplies and medical equipment in good condition. Lift chairs & hospital beds by appointment only. Call 425.885.1008 for more information or to leave a message. Their office, located at 12340 Northrup Way, Bellevue, WA 98005, is open for donation drop-off from 11 a.m. – 5 p.m., Tuesday through Thursday.
- **Local healthcare teams** that travel to third world countries often accept donated medical supplies. Two examples include Medical Teams International (425.454.8326) and World Concern (1.800.755.5022).
- **Local senior centers, food banks or charity organizations** may accept donations of unopened packages of incontinence and hygiene supplies. Call individual groups or agencies to verify.