# Willamette Vital Health

# Patient Handbook



**HOSPICE CARE** 

503.588.3600 or 1.800.555.2431



Willamette Vital Health is a community owned, not-for-profit organization providing innovative, personalized, and compassionate care to patients and families facing serious illness. It is our privilege, duty and commitment to serve our patients and their families with respect and dignity. Founded in 1978, Willamette Vital Health has provided hospice services in the community for over 45 years.

Hospice care is specialized care for a person with a life-limiting prognosis. It is a concept of humane and compassionate care that can be provided in a variety of settings, such as patients' homes, hospitals, long-term care and assisted living facilities. Hospice care seeks to empower patients to carry on an alert, pain-free life and to manage other symptoms so that their last days and months are spent with dignity and quality, wherever they call home.

On behalf of the Willamette Vital Health Team, thank you for allowing us to provide care and be present during this challenging time.

Sincerely,

Iria T. Nishimura, RN, MSN Executive Director

Nurse	
Social Worker	
Spiritual Counselor	
Hospice Aide	
Additional Team Members	

# **Table of Contents**

Deciding On Hospice	1
Your Hospice Team	3
Your Hospice Benefit	5
Safety	9
Caregiving	13
Nearing End of Life	17
When Death Occurs	23
Your Rights	29
Consents and Forms	37



## Willamette Vital Health Contact Information

Office hours are 8:00 am to 5:00 pm Monday through Friday. After office hours, and on weekends or holidays, if you have an urgent need, please call us. *If you do not receive a call back within twenty minutes, please call again.* 

### **CALL Willamette Vital Health FIRST**

503.588.3600

**TOLL FREE 800.555.2431** 

Please note that calls from hospice staff will have numbers that show up as a blocked call.

#### WHEN TO CALL HOSPICE DAY OR NIGHT:

- Before you call 911 or go to the emergency room
- You have a fall
- You have pain, trouble breathing, upset stomach or anxiety that does not improve with medicine
- You see changes and you do not know what to do

#### WHEN TO CALL HOSPICE DURING OFFICE HOURS

- Your medicine needs to be refilled
- You need to change the time of your visit
- You have questions about lab results
- You are in need of supplies
- You need to notify your nurse before you visit your doctor or you are planning any tests or treatments for your hospice diagnosis

#### **DECIDING ON HOSPICE**

Hospice care may be offered to a person when life is measured in weeks or months rather than in years. Hospice provides comfort care. Hospice does not seek to prolong life or to hasten death. Rather, hospice offers services from a team of people with skills that can help a person who is living with a life-limiting illness.

You may decide to choose hospice when your doctor has told you that you have an illness that is life limiting (six months or less), and you have been told that more treatment will not prolong your life, or you have chosen not to have any more treatment to try to cure your illness.

When you choose hospice care, you agree to treatment that improves comfort and quality of life rather than a course of treatment to prolong life. When your doctor and our hospice doctor agree that you have a life-limiting illness, and you choose to receive hospice service, you will help your hospice team create a plan of care based on the goals that you have for your comfort and quality of life.

To receive care from Willamette Vital Health, you must live within the area served by our hospice, and in a place that is safe for you, your caregivers and your hospice team to receive and provide care.

Hospice is always a voluntary service, and you always have the right to end hospice service if you choose to do so. If you decide that you want to seek life-prolonging treatment, or you no longer agree with the hospice plan of care, or want treatment in a facility that does not have a contract with Willamette Vital Health, you have the choice to end hospice services.



#### YOUR HOSPICE TEAM

#### You

You are the most important member of the Willamette Vital Health team. As you begin service with Willamette Vital Health, you and your hospice team will create a plan of care based on your goals for your care and comfort.

#### Your Family and Caregivers

Family members may have many roles as you create your goals of care. Willamette Vital Health wants to make sure that those who are most important to you have the support that they need while you receive hospice care.

Your caregiver might be a family member, close friend, significant other, or paid caregiver. These are the people who provide or manage care when you are unable to care for yourself independently. Caregiving might include helping you with personal care such as bathing and dressing, giving you medicines and/or keeping a log of medicines taken, providing more help in the home if needed, and working with you and Willamette Vital Health staff to plan your care.

#### **Your Attending Doctor**

Your doctor is still part of your care through your Willamette Vital Health nurse and by office visits if needed. Your doctor still manages your care through regular contact with the hospice team. Talk with your hospice nurse about any referrals or planned appointments with your doctor or other health care providers.

## Your Medical Director and Hospice Doctors

The hospice Medical Director and medical staff are in charge of the medical care given to all the patients who are receiving hospice services. They make sure you have the right drugs and treatment to allow you to stay comfortable and fulfill your

goals for care. They decide if you continue to meet the Medicare requirements to stay on hospice, and for this reason may visit you during your time on hospice. They consult with your own doctor about your care, and may also serve as your "attending physician" if you do not have a local doctor.

#### **Your Nurse**

Your nurse will visit you regularly and help to provide care for your physical symptoms. At their visit, you will be asked about your medicines, any problems you are having, and what you may need before your next planned visit. Your nurse acts as your doctor's "eyes and ears" and will keep them informed of changes in your condition. Your nurse will also provide information about your care to your caregivers and to other members of your hospice team. Always tell your hospice nurse of new concerns and the things that are important to you. If your usual nurse is not available, another nurse (sometimes called a "float" nurse) will visit you.

#### Your Social Worker

Your social worker will visit to offer emotional support to you and your family. They will listen to your concerns and help you arrange for resources in the community that might be helpful. Your social worker may help your caregivers arrange for additional help. They are available to help you with funeral arrangements, and other planning needs.

#### Your Spiritual Counselor

Your spiritual counselor will support you and your family by providing emotional and spiritual care that is respectful of your beliefs and values. They do not replace your own pastor, priest, rabbi or other spiritual support person, but can visit to offer whatever is helpful to you and your loved ones. This might include listening, reading, contacting your spiritual care providers, offering prayer, helping with funeral planning or other services.

#### **Your Hospice Aide**

Your hospice aide is able to help with your personal care, such as bathing, dressing, shaving, mouth care, toileting, nail care, changing the bed, and giving back rubs and applying lotion. They may also prepare some light meals, tidy your room or do a load of laundry. You and your nurse will decide the care that will meet your needs.

# Your hospice team may also include:

#### Afterhours and Weekend Team

From 5 pm until 8 am and during the weekends, the afterhours team provides support and will make visits as needed to help with keeping you comfortable. They will also visit at the time of death.

#### Volunteer

You may have a trained volunteer who will visit you up to once a week and do many different things, such as just listening and keeping you company, writing letters, running errands, preparing a snack or playing cards. Though they are not personal caregivers, they can provide a break for your caregiver. When a volunteer is needed, our Volunteer Coordinator will work with you and your family to provide a volunteer to meet these needs.

### Pet therapy/Pet Peace of Mind

Willamette Vital Health recognizes that pets are often an important part of a person's life. Volunteers may provide comforting visits with specially trained cats or dogs. In addition, our Pet Peace of Mind program may help with some care for the pets of persons on hospice service, helping persons and their pets stay together.

#### Massage Therapy

Massage therapy can often help with symptom relief. Your hospice nurse may talk to you about having a licensed massage therapist provide massage to ease symptoms and help with relaxation.

#### **Music Therapy**

Music therapy may be used in some instances to help you with relaxation to reduce pain, ease symptoms of anxiety or trouble breathing, and provide a sense of peace and well-being. Your hospice team may discuss with you the benefit of having a licensed music therapist provide music therapy.

#### **Bereavement Services**

Willamette Vital Health offers grief support services for family and friends both while on service with us, and through the first year following death of a loved one. Your hospice team will talk to you and your loved ones about the many ways that Willamette Vital Health can support you and those who are most important to you.

#### **Additional Support**

Other members of the team might include a pharmacist, speech therapist, a dietitian, or a physical or occupational therapist. They help meet the unique needs of every person on hospice.

# HOSPICE MEDICARE AND PER DIEM INSURANCE PROGRAMS

#### How Medicare Pays for Hospice

Medicare pays hospice a fixed daily amount for each day someone is enrolled in hospice (a "per diem" rate). The payment is intended to cover all costs a hospice incurs in providing services to Medicare patients. These costs include medical equipment, medical supplies, medications and treatments related to the terminal illness. all visits and phone calls made by hospice staff, time spent by the team discussing the patient, and other expenses necessary to run the hospice. Medicare provides the same daily payment for each patient, no matter what their diagnosis or medical needs are. As a result, some patients' care cost the hospice much more than they are paid, while other patients' care cost the hospice less than they are paid.

#### **Medicare Summary Notice**

Medicare sends you a notice that summarizes all your Medicare claims. This is not a bill. No money should be sent to Medicare. No money should be sent to hospice or any other providers based on this summary. Hospice accepts Medicare payment as full payment, so you will not receive a bill from hospice.

Hospice is required to report to Medicare the number and types of visits that hospice staff make to a person receiving hospice service. Hospice must also report the cost of providing these visits. Medicare, in turn, chooses to report this information on the Medicare Summary Notice in a way that may be confusing. This has led some patients and families to think that they will be charged for these visits or that hospice is overbilling Medicare.

On the Medicare Summary Notice, under the "amount charged," you will see the daily payment charge made by Medicare. You will also see the cost of the visits (even though we are not actually charging Medicare for these). The cost of the visits also appears under the "non-covered charges."

The "non-covered charges" are subtracted from the "amount charged", leaving only the daily payment charge. That is the amount that Medicare actually pays hospice. We do not expect any payment beyond that. You will not be billed for any hospice services.

We are glad to answer any questions you may have. Feel free to talk to your social worker or call our accounting department at 503-588-3600.

#### What is Covered

Under the Medicare Benefit and other per diem insurance coverage for hospice care, medications, medical supplies, and equipment may be included in your hospice benefit if they are related to your hospice diagnosis. Examples of supplies and equipment include catheters, wound care materials, hospital bed, commode, oxygen, etc.

Always talk with your hospice nurse or social worker before you have any tests or treatments done. Willamette Vital Health must pre-approve all services related to your hospice diagnosis as well as reviewing these with your insurance company. Please call us before going to any physician/nurse practitioner, hospital, emergency room, or other medical facility.

#### Medications

Willamette Vital Health will develop an initial list of all prescription and over the counter medications that you are taking. The nurse will identify who is responsible for paying for each medication. You may request a copy of the medication list if that would be helpful.

Medications related to your hospice diagnosis that have a goal of comfort will be paid for by Willamette Vital Health from their contracted pharmacy. Approved medications will normally be delivered to your place of residence within two days of ordering. You will have to pick up urgently needed medications at designated local pharmacies. You may want to identify family or friends ahead of time who can help you.

Medications not related to your hospice diagnosis or medications that do not have a comfort care (palliative) goal are not part of your hospice benefit. You may continue to purchase them at your own pharmacy. WVH does not pay for these medications.

An attempt to determine coverage for medications will be made by the nurse at the initial admission visit. However, sometimes a review of medical records and discussion with the attending physician/nurse practitioner and/or Hospice Medical Director is necessary before the determination can be made. In either case, you will be informed of the final decision.

If you and your physician decide on a new medication or an adjustment to a current medication, tell the hospice nurse. Until the nurse reviews the medication order and authorizes it as palliative and related to the hospice diagnosis, Willamette Vital Health will not accept financial responsibility for the cost of any medication.

Willamette Vital Health is unable to reimburse you for medications or supplies purchased by the patient or family.

### **Medical Equipment**

Equipment may be used to improve your comfort and mobility and must be approved and ordered by the hospice nurse from our contracted vendor. If you prefer equipment from another vendor or have equipment not approved by Willamette Vital Health, payment will be your

responsibility. If you are currently using equipment from another vendor, Willamette Vital Health will help arrange to have that equipment replaced.

#### **Treatments**

Your doctor/nurse practitioner and Willamette Vital Health are working together to care for you. If your attending or consulting doctor/ nurse practitioner recommends new tests or treatments, please discuss them with the hospice nurse before you have the test or treatment. In order for Willamette Vital Health to pay for a test or treatments, they must be part of the hospice plan of care and agreed upon by the Willamette Vital Health team. If you have treatments or tests that have not been authorized, Willamette Vital Health will not pay for any expenses incurred. It is important to realize that Medicare or your insurance also may not pay for these expenses if they are not related to your hospice diagnosis, and that you may be responsible for these costs.

Your attending doctor/nurse practitioner continues to be reimbursed by Medicare or your insurance company for care he/she provides to you. Any other doctors/nurse practitioners who are part of your care as it relates to your hospice diagnosis must also be part of the hospice plan of care and agreed upon by Willamette Valley Hospice.

### Hospitalization

Our hope is that you may remain at your place of residence with your symptoms well managed. If this is not possible, Willamette Vital Health will work with your doctor/nurse practitioner to set up and provide hospital care. The hospice nurse must pre-authorize hospitalization including emergency room visits and outpatient procedures in order for Willamette Vital Health to pay for it. Willamette Vital Health uses contracted facilities; please ask your nurse whether your usual hospital is a contracted hospital.

## Your Medicare Hospice Benefit includes several levels of care.

#### Routine Home Care

Your hospice care is provided in your place of residence, wherever that may be. Your hospice team will visit at regular times.

#### **General Inpatient**

Your Willamette Vital Health team works hard to manage symptoms where a person resides. However, there may be times when a person has symptoms that cannot be managed at home and may require a more intense level of care. Willamette Vital Health has arranged with certain facilities to provide this increased care until symptoms are managed so that they may return home.

#### **Continuous Care**

Continuous care is a service available when patients are having periods of crisis. Nurses and those who help them can come into the home for an extended period of time to provide nursing care that would otherwise be provided in a hospital.

#### Respite

From time to time, caregivers may need to rest for a few days. Willamette Vital Health will help in arranging a respite stay (this is a brief stay in a contracted nursing facility to provide care for you). This will be paid for by Willamette Vital Health or your health insurance. Check with your social worker if you have any questions regarding respites or are interested in using this benefit.

#### **Transportation**

In most instances, you or your caregiver will be expected to provide transportation if you can ride in a car.

Transportation to and from the hospital and/ or respite may be paid for by your Medicare or Per Diem hospice benefit if you cannot ride in a car, depending upon the carrier. If so, your nurse or social worker can make these arrangements with a contracted vendor.

#### **Limits**

Willamette Vital Health neither provides nor pays for ongoing private duty care in the home or in nursing homes, assisted living facilities or adult foster care homes. The hospice social worker can help you make arrangements for more care giving when needed.

#### If You Plan to Travel

Because Willamette Vital Health cannot provide services outside our service area, we need to know if you plan to travel outside the service area. We will talk with you about your hospice benefit limitations. You may have other choices available to you, including discharge from Willamette Vital Health or transfer to another hospice in your travel area.

#### When Patients Live in a Care Facility

Sometimes our patients live in nursing homes or other types of care facilities. Your hospice plan of care will be coordinated with the facility care plan so we are all working toward the same goals. The facility staff is welcome to attend our care conferences and one or more members of the hospice team will attend the facility care conferences whenever possible to ensure continuity of care.

Team members will visit regularly to care for you. The hospice nurse will meet with the facility nurse, review your chart and obtain needed prescriptions. Throughout your stay at the facility, the hospice stays responsible for the professional management of the terminal illness, including pain management, symptom management and supportive care to you, your family and facility staff.

The hospice-covered medications will be obtained through the facility pharmacy. If you use an alternate pharmacy, we will notify all pharmacies that you are on hospice services and explain which medications are covered by hospice and should be obtained through the facility pharmacy.

We may provide medical equipment and supplies for you in a facility as well. Many care facilities have hospital beds in place, but Willamette Vital Health can order beds and equipment if there is a need. Typical supplies would include incontinent briefs, gloves and wound care products.

### Types of Care Facilities Available

Nursing Facilities are centers that provide professional level nursing services 24 hours a day for people who have acute and/or chronic medical problems. Intermediate Care Facilities (ICF) provide care for residents needing health services, and they may also have hospice care at the same time. Skilled Nursing Facilities (SNF) have medical supervision and rehabilitation services available, but residents cannot receive both skilled care and hospice care at the same time.

Residential Care Facilities (RCF) are group living centers (congregate living facility). Generally, residents do not require professional nursing-related services. There is not a licensed nurse on the premises 24 hours a day. Routine medical care is supervised and provided.

Assisted Living Facilities (ALF) are group living centers with apartment style living areas. Residents usually do not need professional nursing-related services. Nursing services may be included, but there is not a licensed nurse on the premises 24 hours a day. Most personal and health care must be requested by the resident.

Adult Foster Home (AFH) care is offered in a home-like setting. These homes are located in residential neighborhoods and usually have between one to five residents.

Facilities with Memory Care Units provide care in a safe, secure environment for individuals that have Alzheimer's or a dementia related diagnosis. These units may be part of a nursing facility or residential care facility setting.

When a person lives in a facility, hospice supplements these services, but does not

replace the services already provided by the facility. If you do not currently live in a facility, but are considering placement, our social workers can help you decide on the right level of care to meet your needs.

#### **Discontinuing Hospice Services**

It is possible that Willamette Vital Health could discontinue our services if your condition improves and you no longer meet Medicare requirements for hospice service, you seek treatment that is not in your hospice plan of care or pre-approved by Willamette Vital Health, or you move out of our service area. Hospice service may also be ended if your safety, as well as that of our hospice staff, is at risk, even after Willamette Vital Health has made every effort to ensure safety.

If you choose to transfer to another hospice, Willamette Vital Health will provide the information needed for your continued care, including pain management. Medicare allows a onetime transfer per benefit period when transferring to another hospice.

If a discharge is planned, Willamette Vital Health will give you advance notice and coordinate the discharge so you will have continued needed care.

An assessment will be done and a written plan of care provided to the receiving organization or doctors/nurse practitioners to assure your ongoing care. You will receive a current medication list. If you are being discharged because you are no longer thought to be terminally ill, you have the right to ask for a medical review (appeal) of this decision. You will receive a written notice with this information. You may be referred back to Willamette Vital Health whenever your condition changes.

You may choose to end services from Willamette Vital Health and resume your normal Medicare or insurance benefit. If you wish to end hospice service from Willamette Vital Health, you must sign a revocation form to restart your former insurance benefits.

#### **SAFETY**

We want you to be as safe as possible in your home. The hospice team will teach you about some of the common safety concerns, such as fall risks, equipment, oxygen use and medication. Ask us about anything you are unsure of and tell us about your safety needs. To report any concerns call:

#### Willamette Vital Health 503.588.3600 TOLL FREE 800.555.2431

#### **Falls**

A risk of falls increases as people age, use certain medicines, are confused, sleepy or have increased weakness. The nurse will talk with you about your fall risk, and things that can help to prevent falls at home. Call Willamette Vital Health if you have a fall.

Keep stairs and paths free of clutter. Avoid throw rugs. If you must use throw rugs, use slip-proof ones.

Use only step stools in good repair with a handrail if you must reach high shelves.

Stairways should be well lit and have secure handrails.

Avoid stretching telephone, electrical, or oxygen cords across walk areas.

Be aware of your pet's location.

Use slip-proof mats or strips in bath or shower, and use secure grab bars (not towel racks) in the bathroom as needed for support. Use a bath bench or shower chair to help with safe bathing. Use slip-proof bath rugs to absorb water.

If you have shortness of breath, muscle weakness, or loss of balance, you should only bathe in the tub or shower with someone present in the home. If you are unsteady or dizzy, do not attempt to walk without help. Talk with the nurse about the use of medical equipment that may help. A physical therapy or occupational therapy consultation is available when needed.

#### Oxygen Safety

Your hospice team will talk with you about safe oxygen use, and will have you sign a contract for using oxygen safely in the home. You may refer to the contract, which is found in the back of this handbook.

We encourage you to register as a "high priority customer" with your utility companies if you use your oxygen all the time. Make sure your back-up tank is full at all times, especially if you use it as a portable system. In case of an electrical storm, turn off and unplug your concentrator, and use your portable tanks during the storm. When not in use, be sure to store portable oxygen tanks upright in a cylinder rack or lying flat in a well-aired area at all times.

It is important to be aware of possible fire hazards when using oxygen. Petroleum-based products and spray cans should not be used around oxygen equipment. The concentrator should be plugged directly into a wall outlet without any other appliances in the same outlet. Small appliances like electric razors, blankets or heaters should not be used near your oxygen.

To keep your oxygen equipment clean, wash the filter on your concentrator with warm, soapy water, rinse it well and blot dry with a towel. Be sure the filter is dry before placing it back in your concentrator. If you have a humidifier bottle, fill to the maximum fill line with distilled water and clean daily with warm, soapy water, 10% vinegar solution (or follow manufacturer's directions). The nasal cannula tubing should be changed every four weeks, or more often if needed. Your hospice nurse can help you with this. You may wipe down the outside of the concentrator with a damp cloth to remove dust, but be sure to unplug the concentrator first. Do not change the flow rate of the oxygen from what your doctor or nurse practitioner has prescribed. Call hospice for any problems with the oxygen equipment or if you are having trouble breathing.

#### **Medication Safety**

Several steps can be taken to ensure that medications are stored and used safely. When medications are delivered, check the container(s) to be sure that the right medicine is being delivered to the right person. Leave medicines in their original container. If helpful, the nurse can give you a medicine box and fill it weekly to ensure the right medicine is in the right slot each day.

If children are in the home, store medicines and poisons out of reach and in childproof containers. The hospice team may suggest using a lock box for medicine if there are safety concerns.

Always measure doses carefully. Check the container and dose amount at least twice, and use a well-lit area to prepare your medicines. Call hospice if you make a mistake taking or giving medicines (missed dose, take an extra dose, or use the wrong medicine).

Never give or take any medicines without a current prescription. **Do not take or give medicines prescribed for other people**.

The Comfort Kit is a package of medicines ordered by Willamette Vital Health that may be used at the end of life to manage symptoms. When the comfort kit is delivered, store it in the refrigerator until it is needed. The nurse will tell you if and when to use the medicine in the comfort kit. The comfort kit medicines may include:

Morphine or Hydromorphone liquid, given in small does to relieve pain or breathing difficulty;

**Lorazepam tablets**, given to reduce anxiety and also help with breathing difficulty;

Haloperidol tablets, given for delirium, hallucinations and also used to relieve nausea and vomiting;

**Tylenol suppositories**, given for mild pain or fever

Bisacodyl suppositories, used for constipation. If you have been asked to do so, dispose of unused medicines as advised by the nurse. Some medicines may be placed in kitty litter or used coffee grounds, within a sealed plastic bag and placed in the trash; some medicines can be taken to a "take back" center. (See the medication disposal policy in the back of the handbook.)

## Safety tips for handling and disposal of Sharps and Contaminated Wastes

Never try to recap needles, and always dispose of used needles, syringes, glass vials and any other sharp objects in puncture-proof containers made for this purpose. Tape the container lid before throwing them away.

Wear gloves when coming in contact with body fluids. Use heavy-duty plastic bags to discard used supplies.

#### **Preventing Infections**

Wash your hands before and after giving personal care. Ask your team members to wash their hands if you do not see them do this before giving you care (using either a hand cleanser or soap and water). Use gloves when helping with toileting or contact with any body fluids. Handle soiled linens and dressings carefully and do not place them on the floor or furniture.

Store medicines, tube feedings and intravenous fluids as directed by the nurse.

Cover your cough or sneeze with a tissue or your sleeve and then wash your hands. Ask friends or family to stay away if possible when they are sick with colds or flu.

#### Bed Safety

A hospital bed is designed to help you move in bed comfortably and to assist in your care. If you choose to use bed rails, you should know both the risks and benefits. Risks include strangling or suffocating, injuries from falls when patients climb over the rails, bruising, cuts, scrapes, and increased agitation when used as a restraint. We will ask you to sign a release form if you choose to use side rails.

To ensure your safety, keep the wheels of the bed locked so that it does not move when getting in and out of bed, and keep the bed in the lowest position to make getting in and out of bed easier. Ask your nurse or therapist about assist devices and ways to help with moving in bed and to get out of it safely. If you use a heating pad, do not use the high setting, and do not use the heating pad while sleeping. Bed rails may be used to help you change positions, but are not to be used as a means of restraining someone from getting out of bed.

If rails are used, make sure the mattress on the bed fits snug next to any rails without gaps. If bed rails are used for repositioning, do not use full length rails, so that a person may get up from bed safely, and do not leave a person alone in the home when bed rails are being used. Make sure that the person can call for help if needed. You may consider a bell, baby monitor or intercom.

Anticipate the reasons for getting out of bed (such as hunger, thirst, need to use the bathroom) and meet these needs ahead of time. Do not wait to use the toilet or commode until the need is urgent.

### Being Prepared for an Emergency

If there is a local or area wide disasters or emergencies, such as an earthquake or wildfire, it may affect you at your home and/or prevent emergency personnel or us from being able to communicate with you or travel to your home.

In a major disaster that interrupts phone service or ability to travel, tune to the emergency broadcasting network on television or radio for emergency updates. Our agency will try to have general messages sent to you regarding our services.

Some questions to consider as you develop an emergency plan are:

- Do you have an evacuation route from your home? Practice it. Think about how you would remove a bed bound person. Ask hospice staff how to do this.
- Do you have a place to meet if you or your loved ones are separated?
- Do you have emergency telephone numbers near your phone?
- Do you have a friend or relative in another town to be your contact for extended family?
- Do you know where the main utility switches and water valves are in your home and do you know how to turn them off if they burst?
   NOTE: Once some utility switches/valves are turned off (such as natural gas), they can only be turned on again by utility service personnel and sometimes takes several days.
- Do you depend on medical equipment that requires electrical power, and do you have a generator or battery back-up? Have you registered with your local utility company as a priority customer?
- Do you have fire extinguishers available and do you know how to use them? Are they up to date?
- Do you have enough food, water, and tools to last three days?

More details about disaster preparedness can be found at the Oregon Office of Emergency management website (www.oregon.gov/OEM) under "Individual Preparedness."



#### **CAREGIVING**

#### A Word to the Caregiver

Care giving is helping to care for the physical and emotional needs of a family member or friend who is terminally ill. One of your greatest gifts is the loving support you give to your loved one.

We are here to support you so that you are very confident knowing what to do and feel prepared as your loved one declines.

It is easy to feel overwhelmed, alone, even resentful with all the demands of the role.

To care for another, it is important to first take care of yourself.

## Some things you can do to take care of yourself:

- Get enough rest, take naps, and save your energy where able.
- Take breaks and relax when you can.
- Get regular exercise.
- Eat balanced meals and drink plenty of water.
- Reduce stress when able, think of what things have helped in the past.
- Find things that are uplifting to you. Even if your loved one has not asked for a spiritual counselor, you can request visits for you.
- Be patient and gentle toward yourself.
- Don't expect too much of yourself.
- Allow others to help you.
- Set limits. It's O.K. to say "no" sometimes.
- Recognize your needs and limitations.
- Ask for help.

#### Tips on Helping Loved Ones

- Let your loved one talk... Just listen.
- Acknowledge your loved one's feelings, and let those feelings be expressed.
- Try not to take any negative feelings personally.
- Let your loved one have as much control over the situation as possible.
- Include them in decision making and discussions.
- Let them do what they have energy for and want to do for themselves.
- Their pains, symptoms, and fears are real and valid.
- Try not to judge.
- Talk about things you have enjoyed talking about, and times you shared. Laugh!
- As the body weakens and physical symptoms like pain and nausea are controlled, emotional and spiritual things may become more important, even if your loved one had little interest in spiritual matters in the past. Listen for clues now.
- At some point, your loved one cannot be left alone. The hospice staff can help find resources to assist you when this time comes.

### **Providing Care for Symptoms**

#### Pain

The best way to control pain is to prevent pain. The hospice team will work closely with you to help keep your pain at the level that you want.

A person may take their medicine at regular times, "around the clock", or only as needed for "breakthrough pain". Always follow the directions that are given for using pain medicine. Some persons find it helpful to keep track of the pain medicine that is used every day. Show this to the nurse when she visits. Tell the hospice nurse early if the medicine does not seem to be working.

Let the nurse know as soon as possible if medicines need refilled. WVH nurses do not carry pain medicine. They must get prescriptions from the doctors. The hospice nurse will order refills during daytime hours, Monday through Friday. Allow two days for delivery.

Some persons worry about being dependent on pain medicine. Dependence on taking regular doses of pain medicine is not the same as addiction. Morphine and other medicines can be used at any stage of an illness (not just at end of life); it is easy to use and adjust the amount given, and may be used for both pain and/or trouble breathing.

Pain medicines are usually given by mouth. If a person has trouble swallowing, the nurse will suggest other ways to give the medicine, which may include under the tongue, patches on the skin, and rectally. Your hospice nurse will review this when discussing all your medicines, and explain any side effects to watch for.

There may be ways other than medicine that could also help relieve pain, like massage, relaxation, music, and applying heat and/or cold. Ask your nurse about other therapies.

The nurse will ask you questions about your pain at each visit, such as where a person's pain is, what it feels like, how bad it is, (rate from O-10), what level of pain is okay with a person, what makes it better or worse, how well medicines are working, and if a person is having any side effects.

### Signs Someone May Have Pain

When a person cannot answer questions about their pain, the nurse will ask the caregiver to look for and report signs that pain may be a problem, such as frowning or grimacing, moaning or crying out, flinching, guarding or holding a part of the body and shallow and rapid breathing.

#### Common Side Effects of Pain Medicine

You may feel drowsy when a new pain medicine is started or the dose is increased; this may last a day or two.

If you feel sick to your stomach, anti-nausea medicine may help, taking a bit of food with the pain medicine may also help.

If you have constipation, the nurse will instruct you on taking daily laxatives or a stool softener. Dry mouth may be relieved with ice chips, hard candy, gum, drinking plenty of fluids, and good mouth care.

#### Difficulty with Breathing

Adjust the position of a person in a bed or chair, and raise the person's head with pillows or raise the head of the bed. Using a fan if you have one, or open a window to help with air moving.

Use oxygen if ordered and in the home, but do not adjust rates without talking to the nurse first. Give pain medicine or sedative medicine as ordered by the nurse.

Stay with the person, speak calmly and give reassurance. Sometimes calm music may help a person relax and breathe easier.

Call the nurse if breathing does not get better

#### Difficulty Having a Bowel Movement

People have their own individual pattern for bowel movements. Use a logbook or calendar to keep track of a person's last bowel movement. The nurse will want to know about bowel problems at each visit.

Give bowel medicine on a regular basis, as directed. Remember that pain medicine causes constipation and most people will need to use laxatives to help have regular bowel movements. A person may be experiencing constipation if they have had no bowel movement for two or more days, are feeling sick to their stomach and/or vomiting, have a bloated or firm belly, stomach pain, and/or a lot of runny stools.

Some dietary things may help: a person may try to eat foods high in fiber, fruits and vegetables, use prune juice and drink more water, and get some exercise each day if they are able. Do not expect a bowel movement every day if a person is eating very little.

Always talk with your nurse about any worries you have.

## Nausea and Trouble Eating or Drinking

Families worry when their loved ones begin eating less. This is a natural response to the body's metabolism slowing down. The most common reasons for lack of appetite include disease progressing, dry or sore mouth, nausea and vomiting, pain, constipation and depression. A lack of interest and ability to drink fluids can cause families to worry. Talk with your hospice team about your concerns.

Offer food and drink, but please do not force food. Your loved one will have days when they do not want to eat; this is okay and is in fact normal. Serve small meals more often and try favorite dishes. Sometimes foods with strong odors, or greasy foods, may bother a person. Soft foods are easier to eat (cottage cheese, applesauce, yogurt, mashed potatoes, and pureed foods). Cold foods are best for a sore mouth or throat. Use Boost, other nutrition drinks added to ice cream, yogurt, or fruit and blended for high calorie shakes.

If the person is taking medicine for nausea, give nausea medicine about a half hour before offering food. Ask the nurse if medicine can be crushed and put in applesauce, pudding, or ice cream. Encourage the person to take sips of fluids, popsicles, Jell-O, dry crackers or toast to help with nausea.

Spoon liquids or gently squirt small amounts into the mouth. Do mouth care before meals to stimulate appetite. Do mouth care often, use moist oral sponges and lip moistener. Never try to give food or fluids to a person who is not responsive.

Call Willamette Vital Health if your loved one can no longer swallow, has uncontrolled diarrhea, nausea or vomiting, or any time you are worried about something that cannot wait until the next regular visit.

### Using Briefs and Care of a Catheter

If a person becomes unable to make it to the bathroom as their illness progresses, talk with your nurse about commodes, urinals, or bedpan use. Keep toilet items such as wipes and hand cleanser within reach.

You may also talk with your nurse about using adult briefs, bed padding, or having a catheter (to drain the bladder) placed. If a catheter is placed, be sure the tubing is not kinked and the bag is kept below the level of the patient. The collection bag should be emptied daily, and any time it is more than half-full. Your nurse and hospice aide will show you how to best care for the catheter. Call the nurse if there is no urine in eight hours or the person has pain around the catheter and feels the need to urinate but is unable to do so.

#### Taking Care of Someone in Bed

As people become weaker, they stay in bed and/or chairs longer and cannot move easily on their own. Helping to move and change positions with even small changes of position can relieve pressure. Your nurse or aide will help show you how to safely turn or move someone in bed and how to care for your loved one as they become less able to care for themselves. If there is something you do not know or understand, just ask.

When you are caring for someone in bed, remember to explain ahead of time what you are going to do. Check the area and make sure that tubing will not be kinked, blocked or stretched as you move a person. If moving in bed causes a person pain, provide pain medicine 30-45 minutes before moving them. The more someone knows what you are doing and is prepared for it, the more they can help and let you know what they would like.

Keep yourself safe as you move a person. Enlist help to make it easier on you and the person being moved. Avoid twisting your back or trunk. Bend or flex your knees and use your legs and stomach muscles, not your back.

A folded sheet ("draw/lift sheet") placed under the body (neck to buttocks) can be used to move a person around in the bed. Ask your nurse or aide to show you how to use this.

Always support the head if the person is unable to do so.

Use two people to move a person up in the bed by rolling the sides of the sheet up close to the person's hips, gripping the rolled sheet firmly and together moving the person up in the bed.

One person can use the sheet to move a person over to one side of the bed and/or to roll her/ him onto a side. Once moved, rearrange pillows and place pillows for support under the person's head, between the knees, or under hands or arms as needed for the person to be comfortable.

## When moving someone from bed to chair:

- Always assist the person to his/her strong side.
- Always lock and secure the bed, wheelchair, or chair. Place the chair close to the bed, at equal height.
- Stand in front of the person being transferred.
- Stand with your feet apart.
- Help the person to a sitting position.
- Once the person is sitting up, give them time to adjust so that they do not feel dizzy.
- Use your knees and legs, not your back.
   Keep your back straight and hips flexed.

- Stand in front of the person and put your arms around his/her body, placing your hands on the ribs in back.
- Tell the person to place his/her hands on your waist, not around your neck.
- Make sure the person who is being moved has his or her feet on the ground.
- Using your weight to balance, and keeping your knees slightly bent, gently rock the person into a standing position.
- To turn, keep feet apart and pivot on your feet, slowly turning your whole body, not twisting your truck.
- Gently lower the person into the chair by bending your knees.

#### Skin Care

Good skin care becomes even more important when a person is in bed or sitting for long periods. You can help prevent pressure sores and increase comfort by helping a person turn in bed every two to three hours. Encourage small shifts in position while sitting and sit for no more than an hour at a time.

When a person is in bed, keep the head of bed no higher than 30 degrees except during and after meals. Use a lift or draw sheet when pulling someone up in bed, and be careful when moving not to damage skin. Use pillows or soft rolled towels between knees and ankles, and to keep heels and elbows off the mattress.

Do not sit on plastic or rubber ring cushions. Keep linens clean, dry and wrinkle free.

Clean and inspect skin daily, and report any areas of skin redness to the nurse. Ask the nurse about skin creams that you might use, and about other ways to help a person move in bed to avoid sores or discomfort.

#### **NEARING END OF LIFE**

Call hospice if you think your loved one is dying today or if death has occurred.

Loved ones and caregivers often want to know, "How long do I have?" Your doctor or nurse can only give you a best guess. You may be told weeks to months, days to weeks, hours to days, minutes to hours, soon, or an honest, "I don't know".

Our goal is to help you know what changes or cues you might see, so you can be as prepared as possible. A person may experience some or none of these changes, over a short time or over many days or even weeks.

Call Willamette Vital Health when you see changes, or if you do not understand, or are worried about what is happening. You should always ask for a visit if you feel this would help or reassure you.

Ask your loved one about:

- What is most important to them?
- Where do they want to be? (Some may prefer quiet while others want to be in the center of the house)

- What do they want to surround them (things like sights and sounds, kind of music)?
- Whom would they like at their bedside?

You may find that you have feelings of grief or sadness when you know that someone you care about is dying. These feelings, sometimes referred to as "anticipatory grief", are not uncommon. These feelings are an important part of the grieving process. You may want to use this time to say goodbye to your loved one, take care of affairs, and plan for the funeral and other rituals around dying.

While thinking of losses ahead may be hard to do, planning ahead will help you get through these hard times. We suggest that patients and families take care of important paperwork such as wills, funeral plans, and learn about options to take care of all financial concerns. Having family and friends gather to ask questions and talk about worries gives time for everyone to express feelings about the realities of death.

It is a labor of love to create a safe and peaceful place for your loved one's transition from life to death. Your hospice team is here to help with this.



## **Sleeping**



#### What you may see

A person may be more tired, sleeping a lot of the day. You might not be able to wake them.

#### This is what is happening

This may be caused by physical or chemical changes in the body. Sometimes, this may be caused by medicines.

## What you can do to help

- Let them know you are near.
- Talk to them and expect them to hear you, even if they seem unable to respond.
- Tell them what you are going to do before you do it, such as, "Mom, I'm going to turn you now."

## Confusion/Disorientation



#### What you may see

A person may become confused, not know the time of day or recognize familiar people, places, or objects. Speech may be slurred or make no sense. They may pull at linens or reach out and pick at the air.

### This is what is happening

This may be due to physical or chemical changes in the body. Medicines needed to control other symptoms may also contribute. Sometimes unfinished emotional issues may be disturbing or prevent them from letting go.

## What you can do to help

- Gently remind them what time of day it is, where they are and who is with them.
- Sit and speak where they can see you.
- Create a calm setting. Speak slowly and calmly. Soft music may help.
- Talk to them about people or experiences that were pleasant or important to them.

- Use gentle touch if it seems to help.
- Do not try to stop them from picking at things, as this may make things worse.
- The spiritual counselor or other team member may be able to help.

## Restlessness/ Agitation/Delirium



#### What you may see

A person may toss and turn, be unable to stay in their bed or chair, moan, pace, have upsetting hallucinations\*, have muscle spasms or jerking, or otherwise not seem to be able to rest.

This may go on for many hours, and sometimes days.

\*visions of things or hearing voices that are not real.

#### This is what is happening

This may be caused by physical problems such as full bladder, severe constipation, or pain, which can be treated. It may also be caused by chemical changes in the body, or sometimes by medicines being given and from their by-products.

### What you can do to help

- If they become restless, call the nurse who will visit to check on them.
- Sometimes oxygen tubing can add to a person's restlessness (if they keep pulling the tubing out, you may want to leave it off).
- Do not try to restrain them as this may make the problem worse.
- Because this may go on for many hours, the main caregiver can become exhausted. Ask and plan for help from friends, family, or other caregivers to allow you to rest.
- Give medicines as ordered.

# Changes in Urine or Bowel Movement



### What you may see

A person may lose control of urine and/or bowels. The amount of urine may be much less or stop completely. The color may appear very dark. Bowel movements may become less frequent or stop completely.

#### This is what is happening

Muscles may relax causing incontinence\*. As less fluid is taken in, urine and stool amounts will decrease. Kidney and bowel function may be reduced due to less blood flow to these organs.

\*loss of control of the bladder or bowel.

#### What you can do to help

- The nurse may put a catheter into the bladder to drain urine. This can be uncomfortable when the catheter is first put in.
- The catheter may decrease the discomfort of diapering and linen changes.
- The nurse or hospice aide will show you how to clean them and use diapers and how to care for the catheter.

If urine or bowel movements stop suddenly and the person becomes painful or very restless, call the hospice nurse who will visit to check for full bladder or severe constipation.

## **Less Eating/Drinking**



### What you may see

A person may have less of a desire, or stop eating or drinking all together. Usually they stop eating first, and later stop drinking.

#### This is what is happening

Chemical changes in the body as disease progresses may cause slowed appetite and decreased thirst. The body loses its ability to process food for nourishment. As a person gets weaker, eating may become more of a chore instead of something to enjoy. Increasing weakness may lead to loss of ability to swallow and cause choking.

### What you can do to help

- Let them decide about taking in food and fluid. They may want to try to eat, but take only a few bites.
- Do not worry about special diets; let them eat whatever they want and tolerate.
- Use mouth swabs or cool washcloths to offer comfort, and apply lip balm to dry lips.
- When a person begins to have trouble swallowing, call the nurse to talk about what to do for their medicines.
- Small chips of ice, popsicles, frozen juice, or sports drink may help with a dry mouth.
- Do not give food or fluid by mouth to a person who is not responding.

## Skin Changes (mottling)



### What you may see

A person's face, arms and legs may become cool to touch, with dark color or blotches on the back side of the body and legs.

#### This is what is happening

As blood flow slows down, blood begins to pool in the body's tissues.



#### What you can do to help

Keep turning the person every 2-4 hours and use pillows to keep them in a comfortable position.

## Fever/Sweating



#### What you may see

The person may have a fever, or they may sweat heavily, with or without a fever.

#### This is what is happening

Chemical changes in the body may cause the part of the brain that keeps the body's temperature regular to stop working. Fever does not always mean there is an infection.



### What you can do to help

- Tylenol or other medicines may be given, though they may not always help.
- Place cool cloths to forehead or neck if this seems comforting to them.
- Change linens and pajamas more often if there is a lot of sweating.

## **Breathing Changes/** Congestion



#### What you may see

A person's breathing may sound like snoring, grunting, rattling or wet. The breathing pattern may change; it may be irregular with periods of no breaths, it may become rapid and deep, or it may be very shallow. You may see several changes in breathing that happen.

#### This is what is happening

Throat muscles begin to relax and a person may not be able to clear saliva from their throat. Fluid buildup may occur from changes in organ systems. Changes in body chemistry may cause changes in breathing patterns from deep in the brain.



### What you can do to help

 These changes may be more upsetting to caregivers than to the dying person. Call the hospice nurse who will talk with you or visit to offer help.

- Turning the patient on their side, and using pillows for the head, back, arms and legs, may help reduce rattling/ wet breathing.
- If you have questions about use of suctioning, talk with the nurse.
- Medicines may be used to reduce build-up of saliva that cause noisy breathing (these may not stop the sounds completely).
- Oxygen may help if a person has trouble breathing (it does not help with noisy breathing).
- Give mouth care as the nurse or hospice aide have shown you.
- Apply lip balm to dry lips as needed.

## Jaw Breathing



#### What you may see

When a person is very close to dying and taking their last few breaths, sometimes their lower jaw moves up and down as if trying to swallow or talk.

#### This is what is happening

The breathing is so shallow that there is no air exchange; only their mouth is moving. This usually means that death will occur in minutes up to a few hours.



### What you can do to help

- Not every person will do this and if you are not at the patient's bedside when death nears, you may not see it.
- You may hold them or talk to them, but expect death to occur very soon.

## **Dry Eyes**



A person's eyes may become dry and crusted. Blinking may be absent and eyes may stay partly or completely open.

#### This is what is happening

The blinking reflex may be lost as blood flow to the brain lessens. It is normal for eyes to be at least partly open after death.

- What you can do to help
  - Artificial tear medicine may be used to keep the eyes moist and reduce crusting.
  - The eyelids may be gently washed with a warm, moist cloth.

## **Muscle Twitching**

What you may see

Sudden muscle movements like twitching or jerking.

#### This is what is happening

Chemical changes in the body can cause random firing of nerves. Sometimes this happens from a buildup of medicine by-products.

- What you can do to help
  - If mild, these do not usually cause discomfort.
  - If they get worse or become severe, call the nurse as a change in medicine or other treatment may help.

# Not Wanting To See Others

What you may see

A person may withdraw, or want to be with only a few, or even just one person.

This is what is happening

A person may have less or very little energy

for contact with others. Change in body chemistry may slow thinking and make it harder to deal with changes around them.

- What you can do to help
  - If you are not part of the "inner circle" of those the person wants close, it does not mean you are not loved or important. Help support those who are doing the hands-on care.
  - Provide a quiet setting without too much stimulus to meet the person's needs. Limit visitors in the home, turn off or turn down TV or radio.
  - If they let only one person provide caregiving, talk with the nurse, social worker, or spiritual counselor about support so that person will not burn out.

# Hearing and Seeing Strange Things

What you may see

A person may speak to or see people who have died or cannot be seen by others. They may find it comforting to describe or talk about what they see or hear.

#### This is what is happening

This is a common thing for many dying people, and is usually not frightening. It may mean they have reached a level of acceptance coming closer to dying.

- What you can do to help
  - Do not disagree with their experience if it is a comforting one to them.
  - If they are frightened by what happened, explain that the experience is common. Call the nurse. A visit from a spiritual counselor may help.
  - Do not try to explain away, argue or belittle what a person says they have seen or heard.

## **Surge of Energy**



#### What you may see

A person may have a sudden increase of energy as they get closer to dying. They may want to get out of bed and talk to loved ones. They may ask for food when they have not eaten in days. This surge of energy does not last long, sometimes a day or too.

#### This is what is happening

This may be one of the final physical expressions that a person may show. It can often be misunderstood to mean that the patient has made a miraculous recovery.



#### What you can do to help?

- Not every person will experience this.
- Honor their requests if you can.
- This may be a final chance to say anything that needs to be said-things like, Good-bye. I love you. I'm sorry.
- Enjoy this time, but remember that it usually does not last long.

## Holding on



#### What you see

A person may seem to be holding on to life beyond what is expected, even though this may make discomfort last longer.

#### What is happening

No one can know all that is going on in the body, mind, and spirit of someone who

A younger person or one without many medical problems may seem to hold on longer than expected.



#### What you can do to help

- If it seems right for you, in your own words you may "give permission" to them to "let go" when they are ready. Saying something like, "It's okay for you to go, when you are ready."
- This may be the time to say again, "I love you. Forgive me. I forgive you. Thank you. Good-bye."
- It may comfort you and/or your loved one to lie in bed with them and say what you need to with touch and words. It may be as simple as, "I love you."
- Tears are normal and natural. You do not need to apologize or hide your tears from your loved one unless they are upsetting them.

#### WHEN DEATH OCCURS

## How will you know death has occurred?

- No breathing chest and abdomen do not move and no air flow can be felt at the nose or mouth.
- No heart beat a pulse cannot be felt or seen at the throat.
- A person is motionless no speech or response to touch or voice.
- Eyelids may be open.
- Jaw may be relaxed and mouth open.
- Some people empty their bladder or bowels at or after death due to muscle relaxation.

If none of the team members are present when the person dies, please call the Willamette Vital Health office as soon as you are able to do so. A support visit will be made. We advise you to accept this visit, especially if you are alone. Hospice team members will help with verification of death, provide emotional support, help with phone calls as you wish, and help destroy unused medicines.

**Mortuary:** Willamette Vital Health staff will notify the mortuary of your choice. There is no rush for the mortuary to come. Family and friends may wish to visit at home before the mortuary arrives, we will let the mortuary know what time you would like them to arrive.

Notification to doctor: Willamette Vital Health staff will notify the attending physician/nurse practitioner and the county Medical Examiner's office according to law. The mortuary will arrange to have the death certificate signed.

Medical equipment: Equipment is normally picked up the next business day. If the death occurs on the weekend, the equipment will be picked up Monday, unless that is a holiday. If this is a problem for you, please let the nurse know or call the office and tell the office when you are ready to have equipment picked up.

Medication destruction: You will be asked to destroy medicines, especially narcotics, in the home as a safety measure and to follow drug enforcement laws. Refer to medication safety, and ask the nurse if you have any other questions. Remove and destroy identifying personal information from all pill containers before throwing them in the trash.

**Deliveries after death:** If any deliveries of medicines or supplies arrive in the next few days, please refuse the delivery and they will be returned to the supplier.

Caring for a dying loved one can be very meaningful, but it is also physically, emotionally, and spiritually tiring. It can be natural to feel a sense of relief after the death. You may feel guilty or feel like you have betrayed your loved one by having a sense of relief. Please know that it is not uncommon to have these feelings. The hospice social worker or spiritual counselor can talk with you about this, and you will also receive support from Bereavement Services.

## **Making Funeral Arrangements**

For many people, thinking about and planning a funeral is hard to talk about. Give yourself time to contemplate and discuss the decisions that must be made. Talking about funeral plans openly before death has occurred does not hasten death, but it does make it possible to plan and feel at peace about the funeral service you and your family want.

There are many things to consider. You may want to talk with the Social Worker or Spiritual Counselor. Willamette Vital Health Spiritual Counselors are often called upon to plan and lead services. There is no cost to you for planning or leading services. With their knowledge and experience, spiritual counselors can talk with you about options, and lend general guidance through the process. They can also help talk with family and friends. Please remember whatever your needs and choices, the WVH team will support you and provide any help we can.

#### **Bereavement Services**

Bereavement services continue for 12 months after the death of a loved one and are free to anyone in the community who has suffered loss of someone whether or not they were on hospice. Call 503.588.3600 for more information about support groups and other services.

#### Services offered include:

- Adult and family grief support groups.
- A number of memorial services throughout the year for family, friends and the community.
- A children's day camp Camp Mighty Oaks
   for children and families.
- Access to trained Bereavement Counselors, who can meet with you as needed.
- Specialized workshops which address topics common for bereaved loved ones.
- Referral services as requested.

#### **Grief**

Grief is a strong, sometimes overwhelming emotion for people. It is the natural response to loss. A sense of loss may begin even before the death of a loved one, sometimes called anticipatory grief. After being told about a life-limiting illness, it is natural to consider the losses related to the end of life: loss of independence and control, loss of future plans and dreams, and the loss of a future with loved ones. Grief is both a universal and a uniquely personal experience.

Hospice is here to help with both uncertainty and being prepared for what is ahead.

## **Common Responses to Grief**

- Weight loss or gain.
- Problems with sleeping, or feeling tired all of the time, and changes in energy levels.
- Having a hard time concentrating.
- Mood swings, crying, feelings of sorrow or sadness, anger, guilt, relief, shock, denial, loneliness.
- Social withdrawal, avoiding situations where you would see people you know.
- Dreaming of the deceased and feeling their presence, and feeling a need to reach out for more support during your grieving.
- Loss may cause a person to question their faith or view of the world, or it may strengthen a person's faith by giving a new understanding of the meaning of life.

Grief in children looks different depending on the child, his/her age, the circumstances of the death, and the relationship with the person who died. Our social workers and bereavement counselors can help you with helping children during the dying and grieving period.

## **Taking Care of Yourself**

After the death of a loved one, try not to make any major decisions right away.
Give yourself time to recover, heal, and acknowledge your loved one. We suggest that you:

- Avoid the use of alcohol or drugs, thinking they will stop or delay the grief process.
- Talk with your doctor if you have any concerns about the medicines you are taking, including over the counter drugs, and physical symptoms that are worrying you.
- Think carefully before making major decisions about moving, your finances, or what to do with the belongings of the person who has died.
- Try and let others you trust know what you need and how they can help you.

Our team of nurses, social workers, spiritual counselors and bereavement counselors can help you and your family with the grieving process.

#### ADDITIONAL RESOURCES FOR FAMILIES AND CAREGIVERS

- Serious Illness Website (www.seriousillness. org/salem) A resource sponsored by Willamette Vital Health with information to help those with serious illness and their families learn to live more comfortably and independently. Includes helpful listings for local, state, and national programs that offer services and support.
- Alzheimer's Network of Oregon (www.alznet.org) 866-425-9638 A nonprofit network of volunteers offering support to persons with memory loss, their families and caregivers. In Salem you may call 503-364-8100.
- Caregiver Media Group (www.caregiver.com) 800-829-2734 Provider of information, support and guidance for family and caregivers.
- Caring.com (www.caring.com)
   Information for caregivers of aging persons. On-line forums for support.
- Caring Bridge (www.caringbridge. org) Free, personalized websites that support and connect loved ones during illness, treatment, and recovery.
- Compassion & Choices (www. compassionandchoices.org)
   800-247-7421 A nonprofit organization working to expand choices at the end of life. Focuses on offering support, education and advocacy.
- Family Caregiver Alliance (www.caregiver. org) Addresses the needs of families and friends providing long-term care at home.
- Growth House, Inc. (www.growthhouse.org)
   Provides information and referral services for agencies working with death and dying issues.

- Lots of Helping Hands (www. lotsahelpinghands.com) Create a free of charge, private, web-based community to organize family, friends, neighbors-a family's 'circles of community'-during times of need.
- National Alliance for Caregiving (www. caregiving.org) Coalition of national organizations providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.
- National Family Caregivers Association (www. nfcacares.org) 800-896-3650 A grass roots organization created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged or disabled loved ones. Offers services to connect caregivers, including a pen pal program and caregiver message boards.
- Northwest Senior and Disability Services (www.nwsds.org) 866-206-4799 Working to assist older persons and people with disabilities in making and implementing choices that maximize their independence and quality of life. Offer services such as Meals on Wheels and caregiver support programs.
   \*List of available pre-screened caregivers
- The Caregiver Space (www. thecaregiverspace.org) A resource for connecting caregivers with one another. Includes helpful articles, discussion forums on many topics for caregivers.
- NHPCO (https://www.nhpco.org/ resources/end-life-care-resources)
   National association with list of on-line resources for additional information.
- For information on anatomical gifts, such as eye, organ, or tissue donation, contact these websites for additional information: Lions VisionGift, (www.VisionGift.org) or Community Tissue Services (www.communitytissue.org).

#### **POLICY**

It is the policy of Willamette Vital Health to dispose of controlled substances in accordance with applicable state and federal regulations. WVH will educate patients and families on policies and procedures in the management and disposal of controlled substances in the home.

#### **PURPOSE**

Define appropriate disposal of controlled medications

#### **REFERENCE**

CHAP Standards: HCDT 34.D, HCDT 35.I Medicare CFR/CoP: 418.106(e)(2)(i)(A-C)

#### **PROCEDURE**

- When a new controlled substance is ordered, the patient/family/caregiver will be instructed in the use of and proper disposal. A copy of the WVH Disposal of Controlled Substances policy will be provided to the patient or patient representative and family in a language and manner that they understand to ensure the safe use and disposal of controlled substances. Documentation in the patient's clinical record will reflect that the written policies and procedures for managing controlled drugs was provided and discussed.
- 2. A member of the household may dispose of controlled substances on the patient's behalf. Such prescriptions cannot be transferred to the possession of any other persons, including heirs of the deceased. In addition, per the amended Section 302(g) of the Controlled Substances Act as of January 2019 certain trained Hospice employees may also dispose of the opioid and other mediations in the home, if the drugs are not taken to an Oregon drug take back site.

# SEC. 2. DISPOSAL OF CONTROLLED SUBSTANCES OF A DECEASED HOSPICE PATIENT BY EMPLOYEES OF A HOSPICE PROGRAM.

(a) IN GENERAL.-Section 302(g) of the Controlled Substances Act (21 U.S.C. 822(g)) is amended by adding at the end the following:

"(5) (A) An employee of a qualified hospice program acting within the scope of employment may handle, in the place of residence of a hospice patient, any controlled substance that was lawfully dispensed to the hospice patient, for the purpose of assisting in the disposal of the controlled substance after the hospice patient's death.

"(B) In this paragraph:

- "(i) The term 'employee of a qualified hospice program' means a person (including a physician, nurse, or physician assistant) who—
- "(I) is employed by, or pursuant to arrangements made by, a qualified hospice program; and
- "(II) is licensed or certified to perform such employment in accordance with applicable State law.
- 3. When medications are no longer needed, are outdated, or when the patient has died, WVH staff will instruct the patient or patient representative to dispose of pharmaceutical controlled substances using the safe disposal options set forth by the FDA and State of Oregon Health Authority. A trained Hospice staff that meets the above requirements may also assist or dispose of the medications using the safe disposal options set forth by the FDA and the State Health Authority as stated in #5 below. A WVH staff member will not remove ANY medications from the patient home. If the patient representative refuses, the WVH staff person is required to advise them that responsibility for disposal of controlled substances then lies with family/caregivers. All discussions and instructions will be documented in the patient's clinical record.
- 4. Take back programs are available for unwanted/ unused medications by several law enforcement collection sites throughout Oregon. (See Disposal Site list on Disposal of a Controlled Substance Addendum VII-16A).

## To find permanent collection boxes in Oregon, visit:

https://public.health.oregon.gov/ HealthyEnvironments/DrinkingWater/ SourceWater/Pages/takeback.aspx

5. Some medications should be mixed with water to make a slurry and then mixed with undesirable substances such as kitty litter or used coffee grounds and put in impermeable, non-descript containers such as empty cans or sealable bags and placed in the garbage. This method can be used for any prescription medications and for overthe-counter medications as well.

The State of Oregon Department of Environmental Quality continues to caution any that medications should *not* be flushed into sewer or septic systems and strongly recommends the use of Oregon drug take back sites and or other acceptable disposable mechanisms as the primary disposal method. The established mail-in program can be utilized. Patients should also refer to printed material accompanying their medication for specific instructions. Manufactured medication disposal systems can be used for proper disposal of medications.

- 6. CADD Solis pump cassettes or infusions will be disassembled and drained using the appropriate disposal method outlined above. A needleless syringe may be used to withdraw the medication from a cassette that cannot be cut. The pump reservoir volume remaining should be documented in the patient's clinical record along with any witnesses.
- 7. If the patient resides in a setting other than home, WVH staff should inquire as to their procedure for disposing of controlled substances, and advise facility staff to follow their organization's policy for disposal of medications. (Long term care facility staff should dispose of medications per their own policies.) This should be documented in the patient's clinical record.

8. If abandoned drugs or (meds by exception) are to be disposed, the disposal of controlled substances is to be done with a witness and in the setting where the medications are found.

WVH staff shall not remove medication from the home unless specifically authorized by WVH Leadership for patient and community safety. In such instances the staff member may dispose of the medications at an official drop site and written confirmation from the drop site or return medication to office, or return to office and medication disposed of by two clinical staff members, documented on the medication destruction form, and the form placed in the patient's clinical record.

- If medications are returned by accident to the
  office by family or others, medications will be
  considered abandoned and disposed of by two
  clinical staff members, documented on the
  medication destruction form, and the form placed
  in the patient's clinical record.
- At time of death, the nurse will give instructions regarding disposal of medications, and document that instructions were given in the patient's clinical record.
- 11. If patient representative calls the office regarding destruction of medications, office staff will suggest dropping them off at one of the law enforcement collection sites. If the patient representative cannot or will not use one of the sites, office staff will refer calls to the nurse or clinical manager, so appropriate instructions may be given.

For unusual circumstances conflicting with policy, consult management for direction.

**Origin:** 5/97

Reviewed: 5/98; 5/99; 2/21

**Revised:** 11/00; 7/03; 12/05; 6/06; 5/07; 4/09;

05/12: 10/12: 9/15: 8/17: 1/18: 5/20:

03/21; 7/2022

## COLLECTION LOCATIONS FOR UNWANTED AND UNUSED DRUGS OREGON LAW ENFORCEMENT COLLECTION SITES

for Willamette Vital Health Service Areas

Under federal law, only law enforcement agencies can collect all types of unwanted and unused drugs. Law enforcement agencies providing collection drop off sites in Oregon include:

LOCATION	DROP OFF SITE	HOURS OF OPERATION
Albany	Albany Police Department 2600 Pacific Blvd SW Albany, OR 97322	Monday – Friday 7:30 – 5:30
	541/917-7680	No sharps or needles
Canby	Canby Police Department 1175 NW 3 <sup>rd</sup> Avenue Canby, OR 97013	Monday – Friday 8:00 am – 5:00 pm Except holidays
	503/266-1104	Dropbox is 24/7
Dallas	Dallas Police Department 187 SE Court Street Dallas, OR 97338	Monday – Friday 8:00 am – 5:00 pm Closed from 12-1pm for lunch.
	503/831-3516	Only takes drugs for those inside city limits
Keizer	Keizer Police Department 930 Chemawa Rd. NE Keizer, OR 97307	Monday – Friday 8:00 am – 5:00 pm
	503/390-3713	
McMinnville	McMinnville Police Dept. 121 SE Adams Street McMinnville OR 97128 503/434-7307	Monday - Friday 8:30 am - 5:00 pm Dropbox is small and mainly used for "house-hold" size drugs. Large quantities must be called in ahead of time. Lobby doors are locked, contact number on door to open.
	OR	
	Yamhill County Sheriff Office County Courthouse 535 NE 5 <sup>th</sup> St. McMinnville, OR 97128 503/434-7506	Monday – Friday 8:00 am – 5:00 pm Dropoff location is in front of Court Entrance/ Court Security
Newberg – Dundee	Newberg-Dundee Police Dept. 401 E. Third Street Newberg, OR 97132	Lobby Drop Box Monday – Friday 8:00am - 4:30pm
	503/538-8321	
Salem	Salem Police Department 555 Liberty Street, SE Salem, OR 97301	Drop box 24/7 Personal use amount only. No liquids, syringes, needles, or inhalers.

Information courtesy of Oregon ACWA – 11/2012 Reviewed/phone numbers verified Feb. 2018, Oct 2020, Mar 2021; 7/22

#### PATIENT BILL OF RIGHTS

- The patient has the right to exercise his or her rights as a patient of Willamette Vital Health which includes the right to:
- Have his or her property and person treated with respect.
- b. Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice and to not be subjected to discrimination or reprisal for exercising his or her rights.
- Receive effective pain management and symptom control from the hospice for conditions related to the terminal illness.
- d. Be involved in developing his or her hospice plan of care.
- e. Refuse care or treatment.
- f. Choose his or her attending physician.
- g. Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with HIPAA Privacy Rules (please see the Notice of Privacy Practices in this handbook).
- Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.
- Receive information about the services covered under the hospice benefit.
- Receive information about the scope of services that Willamette Vital Health will provide and specific limitations on those services.
- Be advised that Willamette Vital Health complies with all regulations regarding advance directives, and to receive a copy of our organization's written policies and

- procedures regarding advance directives, including a description of an individual's right under applicable state law and how such rights are implemented by our organization.
- Receive written information describing Willamette Vital Health's grievance procedure, which includes the contact information, contact phone number, hours of operation, and mechanism(s) for communicating problems (see the Willamette Vital Health Corporate Compliance statement in this handbook).
- m. Receive an investigation by the organization of complaints made by the patient or the patient's family or guardian regarding treatment or care and that the organization will document the existence of the complaint and the resolution of the complaint.
- Receive information addressing any beneficial relationship between Willamette Vital Health and referring entities.
- 2. The patient has the right to expect that Willamette Vital Health will:
- Protect and promote the patient's right to exercise the rights.
- b. Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees and contracted staff to the hospice administrator.
- c. Immediately investigate all alleged violations involving anyone furnishing services on behalf of the hospice and immediately take action to prevent further potential violations while the alleged violation is being verified.

(Adapted from Community Health Accreditation Partner [CHAP]
Standards of Excellence for Hospice)

# WILLAMETTE VITAL HEALTH ETHICS AND CORPORATE COMPLIANCE

Willamette Vital Health does not tolerate fraud, waste, abuse, or unethical behavior in conducting its business and delivering services to patients and families. We comply with all federal and state laws and regulations. Our employees are expected to act in a manner that upholds the law and they are accountable for ethical behavior in their job performance. Employees are also expected to report any known activity that violates law, regulation, or policy.

Anyone who has concerns or questions related to compliance issues, ethical practice, or HIPAA privacy violations can report these by calling 971.707.4091. This may be done anonymously if desired (direct feedback is only possible if you leave your name and phone number). All inquiries and concerns will be held in confidence by the Compliance Officer. Your concern will be thoroughly investigated and action taken as appropriate. If you would like to speak directly with the

Compliance Officer, call 503.763.2324. You may also contact the Oregon Health Authority Hotline at 800.542.5186 (Monday through Friday, 8:00 am to 5:00 pm, or voice mail message may be left). The purpose of the hotline is to receive complaints and questions about local home health agencies, and to make complaints regarding implementation of advance directive requirements.

#### **Accreditation**

Willamette Vital Health is an accredited agency. The public may contact our accrediting agency to report any concerns or to register complaints using the information below.

Community Health Accreditation Partner 1275 K Street NW, Suite 800 Washington, DC 20005 Phone 202.862.3413



#### PRIVACY PRACTICES NOTICE

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY

Willamette Vital Health reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains.

Willamette Vital Health, its employees, contract employees and volunteers are bound by the terms of this notice and will use and disclose our patient's individually identifiable health information in the manner described below. This notice is provided to inform patients of their rights and obligations.

#### This notice is effective March 2022.

If you have concerns or questions regarding our privacy practices and your rights under the Federal Privacy Standard please contact our Compliance Officer at 1015 3rd St NW, Salem, OR 97304, 503.588.3600.

## We have the right to use and disclose health information without your permission.

Willamette Vital Health may use your health information for purposes of providing your treatment, obtaining payment for your care and conducting health care operations. Willamette Vital Health has a policy to guard against unnecessary disclosure of your health information.

The following is a summary of the circumstances under which, and purposes for which, your health information may be used and disclosed.

1. To Provide Treatment: Willamette Vital Health may use your health information to coordinate care within Willamette Vital Health and with others involved in your care, such as your attending physician, members of the interdisciplinary team and other health care professionals.

For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. Willamette Vital Health may also disclose your health care information to individuals outside of Willamette Vital Health involved in your care including family members, clergy whom you have designated, pharmacists, suppliers of medical equipment or other health care professionals that Willamette Vital Health uses in order to coordinate your care.

- 2. To Obtain Payment: Willamette Vital Health may use your health information to determine your eligibility for and to collect payment from third parties. For example, Willamette Vital Health may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or Willamette Vital Health. Willamette Vital Health may also need to obtain prior approval from your insurer and may need to explain to the insurer your need for Willamette Vital Health care and the services that will be provided to you.
- To Conduct Health Care Operations:
   Willamette Vital Health may use and disclose
   health care information for its own operations
   in order to facilitate the function of Willamette
   Vital Health and as necessary to provide
   quality care to all of our patients. Health care
   operations include such activities as Quality
   review and improvement activities, business
   management and general administrative
   activities.

For example, we may use your health information to evaluate staff performance, combine your health information with other Willamette Vital Health patients in evaluating how to more effectively serve all Willamette Vital Health patients. Willamette Vital Health may disclose protected health information to other covered entities for certain of their health care operations if the other covered entity has a relationship with the individual whose PHI is disclosed, as well as for fraud and abuse detection or compliance.

- 4. Incidental Use and Disclosure: Willamette Vital Health may make incidental use and disclosures of your health information in the course of other use and disclosures permitted by this notice. For example, if you live in a facility in a semi private room, conversation regarding your care and treatment may be overheard.
- 5. To Business Associates: Willamette Vital Health may disclose health information to third parties pursuant to a written agreement that obligates the third party to protect the individual's information and use it only for the purposes specified in the agreement. Some disclosures to business associates may require the patient's authorization. For example, we would communicate protected health information to our contract pharmacy to provide your medications without your authorization. However, if our business associate wished to disclose your health information to a marketing agent they would be required to obtain your written authorization.
- 6. For Research, Public Health, and Health Care Operations: Willamette Vital Health may disclose limited health information to third parties for purposes of research, public health and health care operations. Such information must be limited to admission, discharge, and service dates, date of birth and death, age, and 5-digit zip code or other geographic information less specific than street address. If this limited information is released to a third party, a written agreement that obligates the third party to protect the individual's information and to use it only for the purposes specified in the agreement is required.
- 7. Uses and disclosures that we may make unless you object: Willamette Vital Health may use or disclose health information for some purposes unless you object and make your objection known. If you object to any of the following uses or disclosures of health information, you must inform the Privacy Officer in writing.

- A. For Fundraising Activities: Willamette Vital Health may use information about you including your name, address, phone number and the dates you received care in order to contact you to raise money for Willamette Vital Health. However, your personal information will not be sold.
- B. Family and Friends Involved in Your Care: Health professionals, using their best judgment, will disclose to a family member, caregiver or close friend, or anyone else you identify, health information relevant to that person's involvement in your care. We may also give information to someone who helps pay for your care.
- C. Disaster: We may disclose health information about you to other health care providers and to an entity assisting in a disaster relief effort to coordinate care and so that your family can be notified about your condition and location.
- D. Appointment Reminders: We may use and disclose health information to contact you as a reminder that you have an appointment for treatment or medical care.
- E. Health-related Services or Benefits: We may use and disclose health information to tell you about health-related benefits or services that may be of interest to you.
- 8. Federal privacy rules allow Willamette Vital Health to use or disclose your health information without your authorization for a number of reasons:
- A. When Legally Required: Willamette Vital Health will disclose your health information when required by Federal, State, or local law.
- B. When there are Risks to Public Health: Willamette Vital Health may disclose your health information for public activities and purposes to:
- Prevent or control disease, injury, or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.

- To report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirement of the Food and Drug Administration.
- To notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- C. To Report Abuse, Neglect, or Domestic Violence: Willamette Vital Health is allowed to notify government authorities if we believe a patient is the victim of abuse, neglect or domestic violence. Willamette Vital Health will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.
- D. To Conduct Health Oversight Activities: Willamette Vital Health may disclose your health information to a health oversight agency for activities including audits; civil, Administrative, or criminal investigations; inspections; licensure or disciplinary action.
- E. In Connection With Judicial and Administrative Proceedings: Willamette Vital Health may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process. Willamette Vital Health will obtain satisfactory assurances from the party requesting PHI that a reasonable effort has been made to notify the individual, that the individual has not made a timely objection or that the matter has been resolved by a court.
- F. For Law Enforcement Purposes: Willamette Vital Health may disclose your health information to law enforcement officials as required by law or as directed by court order, warrant, or other lawful process and in other limited circumstances for purposes of identifying or locating suspects, fugitives, material witness, missing person or crime victims.

- G. To Coroners and Medical Examiners:
  Willamette Vital Health may disclose your
  health information to coroners and medical
  examiners for purposes of determining
  your cause of death or for other duties, as
  authorized by law.
- H. To Funeral Directors: Willamette Vital Health may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, Willamette Vital Health may disclose your health information prior to and in reasonable anticipation of your death.
- I. For Organ, Eye or Tissue Donation: Willamette Vital Health may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.
- J. For Research Purposes: Willamette Vital Health may, under very select circumstances, use your health information for research. The project will be subject to review and approval by an Institutional Review Board or Privacy Board before Willamette Vital Health discloses any of your health information for such research purposes.
- K. In the Event of a Serious Threat to Health or Safety: Willamette Vital Health may, consistent with applicable law and ethical standards of conduct, disclose your health information if, in good faith, we believe that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.
- L. For Specified Government Functions: In certain circumstances, Federal regulations authorize Willamette Vital Health to use or disclose your health information to facilitate specified government functions relating to the military, veterans, national security, intelligence activities, protective service for the President and others, medical suitability determinations, inmates and law nforcement custody.

M. For Worker's Compensation: Willamette Vital Health may release your health information for worker's compensation or similar programs.

## Uses and Disclosures requiring your authorization

- Other than what is stated above, Willamette Vital Health will not disclose your health information without your written authorization. If you or your representative authorizes Willamette Vital Health to use or disclose your health information, you may revoke that authorization in writing at any time. Revocation of authorization is effective only for future uses and disclosures; uses or disclosures already made in reliance on your authorization are not affected by your revocation.
- 2. If we have HIV or substance abuse treatment information about you, then we cannot release that information without a special written authorization from you, even for treatment, payment, or healthcare operation purposes.

## Your Rights concerning your health information

You have the following rights regarding your health information that Willamette Valley Hospice maintains:

- I. Right to request restrictions: You may request restrictions on certain uses and disclosure of your health information. You have the right to request a limit on the disclosure of your health information to someone who is involved in your care or the payment of your care. However, Willamette Vital Health is not required to agree to your request. If you wish to make a request for restrictions, please contact our Privacy Officer.
- 2. Right to receive confidential communications: You have the right to request that Willamette Vital Health

- communicate by alternative means or at alternative locations. For example, you may ask that Willamette Vital Health only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact our Privacy Officer. Willamette Vital Health will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.
- 3. Right to inspect and copy your health information: You have the right to inspect and receive a copy of your medical records, billing records, and other records maintained by Willamette Vital Health to make decisions about your care. In some limited circumstances, Willamette Vital Health may deny your request for access. You have the right to request that a denial be reviewed. A request to inspect and receive a copy of records containing your health information may be made to our Privacy Officer. If you request a copy of your health information, we may charge a reasonable fee for copying and assembling costs associated with your request. You may request a copy to be either paper or electronic format.
- Right to amend health care information: You have a right to make a written request that medical records, billing records, or other records maintained by Willamette Vital Health, to make decisions about your care, be changed if you believe those records are inaccurate or incomplete. Willamette Vital Health may deny your request to amend if it is not in writing, if it does not provide a reason for amendment, if Willamette Vital Health believes that the records are complete and accurate, if the records were not created by Willamette Vital Health and the records' author is unavailable. or if the records are otherwise not subject to patient access. Willamette Vital Health will put denials in writing and explain its reasons for denial. You have the right to respond in writing to Willamette Vital Health's explanation of denial and to require that your request, Willamette Vital Health denial, and your statement of disagreement, if any, be included in future disclosures of the disputed record.

- 5. Right to an accounting: You or your representative has the right to request an accounting of disclosures of your health information made by Willamette Vital Health for any reason other than for treatment, payment, health care operations, disclosures to the individual, disclosures authorized by the individual, disclosures to family or other persons involved in the individuals care, or disclosures for national security or law enforcement purposes. The request for an accounting must be made in writing to the Privacy Officer. The request should specify the time period for the accounting starting on April 14, 2003. Accounting requests may not be made for a period of time in excess of six years. Willamette Vital Health will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.
- 6. Right to a paper copy of this notice: You or your representative has a right to a separate copy of this Notice at any time, even if you or your representative has received this Notice previously. To obtain a separate paper copy, please contact our Privacy Officer. You may also view a copy online by visiting our web site located at wvh.org.
- 7. Right to opt out of receiving any fundraising communication: You or your representative has the right to decline to receive any fundraising solicitation.
- 8. Right to restrict information if paying out of pocket in full: You or your representative has the right to request restriction on disclosure of health information to your health plan if you are paying out of pocket in full.

## **Duties of Willamette Vital Health**

- Willamette Vital Health is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices.
- If a breech in your protected health information occurs, Willamette Vital Health will notify affected individuals of this occurrence.
- Willamette Vital Health is required to abide by the terms of this Notice, as may be amended from time to time.
- If Willamette Vital Health changes its Notice, we will provide a copy of the revised Notice to you or your appointed representative on request. A revised Notice will also be available online by visiting our website located at wvh.org.
- You or your personal representative has the right to express complaints to Willamette Vital Health or the Secretary of Health and Human Services if you or your representative believes that your privacy rights have been violated.
- Any complaints to Willamette Vital Health should be made in writing to our Compliance Officer.
- Willamette Vital Health encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

IF YOU HAVE ANY QUESTION REGARDING THIS NOTICE, PLEASE CONTACT Willamette Vital Health'S COMPLIANCE OFFICE

1015 3rd St NW Salem OR 97304 503.588.3600 • 800.555.2431

## **CONSENTS, CONTRACTS AND FORMS**

The following pages are written consents, contracts and forms. Consents and contracts will be signed on the laptop computer so these are for your reference. If for some reason they are not signed on the computer, these forms may be used instead. They can be signed, removed from the book, and given to Willamette Vital Health staff.

- Consent for Evaluation
- Admission Authorization and Privacy Practices Acknowledgment
- Election of Benefits
- Genetic Privacy Opt Out Statement
- Informed Consent for Use of Bed Rails
- Oxygen Safety Contract
- Hospice Benefit Revocation





## Planning ahead will help you have the best possible response to disaster.

**Talk.** Discuss with your family the disasters that can happen where you live. Establish responsibilities for each member of your household and plan to work together as a team. Designate alternates in case someone is absent. If a family member is in the military, also plan for how you would respond if they are deployed. Include the local military base resources that may be available.

**Plan.** Choose two places to meet after a disaster:

- Right outside your home, in case of a sudden emergency, such as a fire.
- Outside your neighborhood, in case you cannot return home or are asked to evacuate your neighborhood.

Choose an out-of-area contact for all members of the family to call in case of disaster. The selected contact person should live far enough away that they would be unaffected by the same event, and they should know they are the chosen contact. Remember that during a disaster, it may be easier to make a long distance phone call than to call across town.

Having predetermined meeting places will save time and minimize confusion should your home be affected or if the area is evacuated.

**Learn.** Each adult in your household should learn how and when to turn off utilities such as electricity, water and gas. Ask your local fire department to show you how to use a fire extinguisher.

**Tell** everyone in the household where emergency information and supplies are kept. Make copies of the information for everyone to carry with them. Keep the information updated.

**Practice** evacuating your home twice a year. Drive your planned evacuation route and plot alternate routes on a map in case main roads are impassable.

Examples of emergencies might be severe storms; natural disasters (like an earthquake), major power outages, severe, widespread medical illnesses.

If you require life-sustaining support systems, the hospice will inform the electrical company. You and/or your caregiver will be instructed to be taken to the nearest hospital in case of a power outage. Back-up equipment (such as portable oxygen) can also be delivered to your home. If a widespread emergency or evacuation is necessary, rescue agencies will be notified of our patients requiring assistance to evacuate.

Emergency Contact Information - DIAL 911 IN AN EMERGENCY				
LOCAL POLICE ASSISTANCE		HOSPITALS		
City	Phone	Hospital	Phone	
Albany	541-967-4333	Salem Hospital - Main	503-561-5200	
McMinnville/Dayton/Yamhill	503-434-6500	Salem Hospital - Emergency Dept	503-814-1572	
Salem	503-585-8910			
Salem/Dallas	503-588-6123	Santiam Memorial	503-769-2175	
Stayton/Turner	503-769-3886	Silverton Hospital	503-873-1500	
Woodburn	503-982-2345	West Valley Hospital	503-623-8301	
	Additional Res	sources		
American Red Cross	877-272-7337	Salvation Army	503-585-6688	
Providence Nutrition	503-215-4201	Sublimity Pharmacy	503-769-4344	
Elite Transport	503-569-7070	Northwest Senior & Disability Services	503-304-3400	
Rural Metro Transport	503-588-6538	Norco Medical Equipment	503-378-1756	
TripLink-Medical Transportation	503-315-5544	KBZY Radio Station	503-362-1490	
Yellow Cab Medical Transport	503-362-2411			
State and Co	unty Emergency M	lanagement Informatio	n	
Oregon Emergency Response System	800-452-0311 or 50	03-588-1378		
Marion County Emergency Management	503-588-5108			
Clackamas County Emergency Management	503-655-8378			
Benton County Emergency Management	541-766-6864			
Polk County Emergency Management (Sheriff's Office)	503-623-9251	Primary Evacuation Center: 850 Main Street, Dallas, OR 97338 Alternate Site: 884 SE Jefferson Street, Dallas, 97338		
Yamhill County Emergency Management	503-434-7340	414 NE Evans Street, McMinnville, 97128		
Linn County Emergency Management	541-967-3950	Primary Evacuation Cente 1115 SE Jackson, Albany 97 Alternate Site: Albany City 333 SW Broadalbin, Albar	7322 / Hall,	

Your closest Emergency Shelter is:\_\_\_\_\_\_

In an emergency, additional shelters will be identified and announced by the County Emergency Management or by the Red Cross in your area.

# Willamette Vital Health Election of Benefits & Informed Consent

Patient Name:	Account #:
I have been informed that Willamette Vital He	alth (MMH) offers bospice care under:

Medicare / Medicaid (OHP) / VA / Champus / Tri-Care / Private and employer-based group health insurances.

I choose to elect the Medicare, Medicaid, or my other insurances Hospice Benefit and receive Hospice Services from Willamette Vital Health.

## **Hospice Philosophy**

I acknowledge that I have been given a full explanation and have an understanding of the purpose of hospice care. Hospice care is to relieve pain and other symptoms related to my terminal illness and related conditions and such care will not be directed toward cure. The focus of hospice care is to provide comfort and support to both me and my family/caregivers.

### Effects of a Hospice Election on my Medicare, Medicaid, or other insurance

- I understand that WVH offers hospice care benefits through Medicare, Medicaid, and other insurers. I
  understand that by electing hospice care under the Medicare or Medicaid Hospice Benefit, I waive my rights
  to payments for curative services related to my terminal illness and related conditions. I understand that
  while this election is in force, my insurance pay for care related to my terminal illness and related conditions
  only to the designated hospice and attending physician that I have selected. I understand that services not
  related to my terminal illness or related conditions will continue to be eligible for coverage by Medicare,
  Medicaid or my other insurance benefits.
- I understand that by electing the Hospice Benefit, I am entitled to hospice care for two (2) election periods of 90-days each, and unlimited 60-day periods, thereafter, based on Medicare criteria for eligibility.
- I may change hospices once during each benefit period, without losing my hospice benefit days. To change hospice programs, I must confirm that I wish to change to another hospice and sign a Transfer Form informing WVH of the date and the agency I wish to transfer.
- Management of care is in my home by a team of healthcare professionals and my attending physician. Services
  may include nursing, physician care, social work, spiritual counseling, bereavement services, music therapy,
  massage therapy, personal care hospice aides, and other therapies as needed. Hospice nursing services are
  available 24 hours per day for urgent and emergent medical needs. The hospice team is not intended to take the
  place of the family, rather to support and assist the family in caring for me.
- Medical supplies, equipment, medications, and other items related to my terminal illness, as well as shortterm inpatient care will be provided, or arranged, for by WVH, under our preferred drug list and contracted vendors.
- I understand that items, services, and drugs unrelated to my terminal illness and related conditions are exceptional and unusual. In general, the hospice will be providing virtually all of my care while I am under a hospice election. The items, services, and drugs determined to be unrelated to my terminal illness and related conditions continue to be eligible for coverage by Medicare under separate benefits.

Patient Name:	Account#:
may revoke this Election and wit Statement, which will be given to any remaining days in the election	ligible for hospice care if I choose to pursue curative care. I understand that I chdraw from the hospice program at any time by signing a Revocation or me upon my request. If I revoke this election, I understand that I will forfeit on period but will be eligible for Medicare benefits previously waived by my by opt to re-elect my Hospice benefit at a later date, if eligible.
	or other organization from whom I am entitled to receive payment for ent for such services directly to WVH. I understand and agree to pay for urance plan.
	overage will be considered private pay. You will be responsible for any ided by, or under contract with Willamette Vital Health.
Individual cost-sharing based on your in	surer or your private-pay responsibility will be billed to you at the rates up to:
<pre>\$ /day for Routine \$ /day for Inpatient</pre>	
	or payment of all deductibles, co-payments and share of cost by benefits to pay for Willamette Vital Health Services.
have had an opportunity to review	a copy of the Genetic Testing Opt-Out Form included in the Patient Handbook. and ask questions about my options. I understand that I can request to Opt- by signing the Opt-Out form and submitting to any WVH employee.
Patient Rights & Responsibilities	
	a copy of the Patient Handbook, including Patient Rights and Responsibilities view and ask questions about them. I understand and agree to the Patient
individually identifiable health inform	ees, contract employees, and volunteers will only use and disclose my mation in the manner described in the Patient Handbook. I acknowledge that Practices Notice and have had an opportunity to review and ask questions. I y Practices.
Right to choose an attending physi	cian
•	oose my attending physician to oversee my care. My attending physician will ce agency to provide care related to my terminal illness and related conditions.
$\Box$ I do not wish to choose a attending.	an attending physician. Willamette Vital Health will serve as my
$\Box$ I acknowledge that my c	hoice for an attending physician is:
I acknowledge and understand the a by WillametteVitalHealth to begin o	above, and authorize Medicare hospice coverage to be provided n (Effective Date of Election)
-1	

Right to Request "Patient Notification of Hospice Non-	-Covered Items, Services, and E	<b>Drugs</b>				
As a Medicare beneficiary who elects to receive hospice care, you have the right to request at any time, in writing, the "Patient Notification of Hospice Non-Covered Items, Services, and Drugs" addendum that lists conditions, items, services, and drugs that the hospice has determined to be unrelated to your terminal illness and related conditions, and that will not be covered by the hospice.						
	The hospice must furnish this notification within 5 days, if you request this form on the start of care date, and within 72 hours (or 3 days) if you request this form during the course of hospice care.					
Beneficiary and Family-Centered Care Quality Organiz	zation (BFCC-QIO)					
As a Medicare hospice beneficiary, you have the right t	o contact the Beneficiary and F	amily-Centered Care				
Quality Improvement Organization (BFCC-QIO) to rec	quest Immediate Advocacy if yo	ou disagree with any of the				
hospice's determinations. The BFCC-QIO that services	s your area is: KEPRO. They can	be contacted by calling:				
1-888-305-6759.						
Note: The effective date of the election may be the first earlier than the date of the election statement. An indicent retroactive.						
Signature of Patient / Authorized Representative	Relationship to Patient	Date				
Reason for Someone Signing Other than the Patient	t					
Signature of WVH Witness	Date	_				

Patient Name: \_\_\_\_\_

Account #: \_\_\_\_\_

#### Willamette Vital Health

# NOTICE OF YOUR RIGHT TO DECLINE PARTICIPATION IN FUTURE ANONYMOUS OR CODED GENETIC RESEARCH

The state of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to decline to have your health information or biological samples used for research. A biological sample may include a blood sample, urine sample, or other materials collected from your body. You can decide whether to allow your health information or biological samples to be available for genetic research. Your decision will not affect the care you receive from your health care provider or your health insurance coverage.

Research is important because it gives us valuable information on how to improve health, such as ways to prevent or improve treatment from heart disease, diabetes and cancer. Under Oregon law, a special team reviews all genetic research before it begins. This team makes sure that the benefits of the research are greater than the risks to the participants.

In anonymous research, personal information that could be used to identify you is kept separate from your health information or biological sample so it could be very difficult for someone to link your personal information to your health information or biological sample. Your identity is protected in both types of research.

If you want to allow your health information and biological sample to be available for anonymous coded research, you do not have to do anything. If you make this choice, your health information or biological sample may be used for anonymous or coded genetic research without further notice to you.

If you want to decline to have your health information and biological samples available for anonymous or coded genetic research, you must inform us of your decision by completing the Genetic Privacy Opt Out Statement located in the Consents section at the very back of this handbook. Once you have completed this form, please give it to your health care provider.

Your decision is effective on the date your health care provider receives this form.

If you have any questions or concerns about this notice, please contact the Privacy office at Willamette Vital Health at 503.588.3600.

No matter what you decide now, you can always change your mind later. If you do change your mind, please inform your health care provider in writing by sending a letter with your mailing address included. Please note: your new decision will apply only to health information or biological samples collected after your health care provider receives written notice of your new decision.

# Willamette Vital Health GENETIC PRIVACY OPT OUT STATEMENT

(Effective 1/1/2007)

I do not want to have my health information and biological samples available for anonymous or coded genetic research.					
No deseo que mi information de salud y muestras investigacion genetica codificada o anonima.	s biologicas esten disponibles para la				
Patient Name (Print)	Patient Date of Birth				
Patient/ Personal Representative (Signature)	Date				

If signed by Personal Representative, Describe Authority / Relationship to Patient

## Willamette Vital Health

Patient Name: \_\_\_\_\_ Medical Record Number: \_\_\_\_\_

INFORMED CONSENT FOR USE OF BED RAILS (RESTRAINT UTILIZATION)
There are many reasons that people feel that bed rails are a good solution and for many they have been helpful. People have used them to increase their bed mobility, improve their positioning, or for a sense of security.
There are also risks associated with the use of bed rails. These risks are higher with frail, elderly or confused patients. The type of bed rail (half or full) does not seem to reduce the risk. Risks include the possibility of fractures, bruises, skin tears, strangulation, suffocation, entrapment, or even death.
Some research has indicated that there is an increased risk of falls with injury for patients with bed rails compared to those without rails, as patients may attempt to climb over the rails or off the ends of the bed.
In addition, the inability to get out of bed to use the bathroom may result in incontinence.
Some regulatory agencies consider the use of bed rails as a form of physical restraint. As such, they may cause loss of personal dignity, feeling isolated or unnecessarily restricted, increased agitation, and reduced freedom of movement for the patient.
The alternatives such as lowering the bed, use of mats, increased monitoring of patient, use of transfer or mobility aides, and anticipating and scheduling patient needs have been explained to me.
I understand and accept the risks of bed rail usage. Despite these risks, I request bed rails to accomplish the following purpose:
Signature of patient: Date:
Signature of family member if patient unable to sign:
Relationship to patient: Date:
WVH Staff: Date:

# Willamette Vital Health OXYGEN SAFETY CONTRACT

Oxygen must always be handled with caution and awareness of potential hazards. Oxygen is not flammable, but it can cause other materials that burn to ignite more easily and to burn more rapidly. To reduce the potential of fire hazard, oxygen safety precautions **must** be observed.

Willamette Vital Health requires patients to follow the oxygen safety precautions below when oxygen is used.

### I agree to the following Oxygen Safety Precautions:

- 1. I will not **smoke** or allow others to smoke within 5 feet of oxygen equipment or tubing.
- 2. I will place an "Oxygen in Use No Smoking" sign in a prominent place near the front door.
- 3. I will keep oxygen and tubing at least five feet from gas stoves, candles, lighted fireplaces and other heat sources.
- 4. I will store oxygen cylinders upright in a cylinder rack (if one is provided) or lying flat, in a well-ventilated area (not in closets or confined space).

I have read and agree to follow the above oxygen safety precautions.

I understand that the first time Willamette Vital Health staff observes unsafe oxygen use I will be provided additional education in safe oxygen use.

I understand for my safety and the safety of others, that if unsafe oxygen use is observed a second time, the oxygen may be discontinued and removed from my place of residence OR Willamette Vital Health services may be discontinued.

Name of Patient - MRN#	
Patient Signature	Date
Caregiver Signature	Date
WVH Staff	

# Willamette Vital Health HOSPICE BENEFIT REVOCATION

Patient Name:	<del></del>		
Hospice #	<del> </del>		
Hospice Benefit Revocation			
Medicare			
DMAP (Oregon Health Plan)			
Foundation Health Federal Services,	Inc. (Champus/Tri	-Care)	
I choose to revoke the Hospice Benefit, effective _			_
·	Date	Time	
<ol> <li>I understand that I am revoking hospice benefits doing, I forfeit the remaining days of the benefit  </li> </ol>		of the current benefi	t period and that in so
2. Revocation during the first benefit period (90 day (90 days) should I elect to resume hospice service		omatically commence	e the second benefit period
<ol><li>Revocation during the second benefit period (90 period should I elect to resume hospice services.</li></ol>	days) will mean I a	automatically comme	ence the 1st 60 day benefit
<ol><li>Revocation during subsequent 60 day benefit pe begin on day one of the next 60 day period.</li></ol>	riods mean that sh	nould I elect to resum	e hospice services I would
Again, the benefit periods are as follows:			
First Benefit Period - 90 days Second Benefit Period - 90 days Series of 60 day Election Periods			
I understand that the regular health care benefits I velfective date of this revocation.	waived to receive h	nospice coverage will	be resumed after the
Patient Signature or Legal Representative	Date		Time
Witness			

