TABLE OF CONTENTS

SECTION 1: Introduction

SECTION 2: Managing Comfort

SECTION 3: Care & Safety

SECTION 4: Preparing for Death

Appendixes

Communication Log

Medication Logs

Get to Know Me

Things I use at home
(glasses/contact lenses, hearing aid)

People who are important to me

Things I'm proud of

**My favorite
artists, movies, etc.**

Things I dislike

Things I like to do

My spiritual beliefs

I like to be called:

My work/occupation is (or was):

Institute for
Human Caring
Providence St. Joseph Health

HOW TO CONTACT PROVIDENCE HOSPICE

We are here to serve you! Please call your local Providence Hospice, and you will be connected to a member of your clinical team. When a member of your primary team is not available, your extended team of covering staff will be there to assist you by phone or with a visit as needed. For immediate assistance 24 hours a day, please call the main office number and not an individual team member.

When you call, if you are calling to speak with a nurse right away, please hold the line and nurse will be with you. If you need to speak with anyone else or have a non-urgent need, please press one. All calls are recorded.

Providence Hospice of Seattle 206-320-4000	**Providence Hospice of Snohomish** 425-261-4777	**Snohomish Hospice Care Center** 425-297-6868	**Providence SoundHomeCare and Hospice** 360-493-5900

Communicating with Your Team

Everyone at Providence Hospice is here to listen and learn how we can ease your way. When you first meet your care team, please tell them the best way to share information with you. Persons in need of interpreters or assistive devices will need to notify the agency in advance, and arrangements will be made to have the appropriate assistance in place.

During this time when so much information is being shared, these tips may be helpful:

- Appoint a spokesperson as a primary point of contact.
- Keep a log of non-urgent questions to ask your hospice team at their next visit.
- Let your team know of any cultural or religious needs you may have.

By Phone

- Your care team members have variable schedules; however, you can always reach a nurse to answer your questions, assess your situation and provide instructions for care over the phone.
- The nurse will come up with a plan that may include a home visit.

For your safety, we are unable to send or receive text messages.

Email

- You may choose to communicate with us via email for non-urgent matters. On initial contact you can tell the team member that you would like to receive information via email. Because we want to ensure complete patient confidentiality, the team will email you via a secure system. You will receive instructions on how to establish an account once you receive your first email from us.

In Person

- When visiting your home, we can also write notes in a communication log so you, your family or caregivers can refer to it after our visit.

Afterhours, Weekends, or Holidays

Nurses are on duty 24 hours a day, 7 days a week. You are never waking anyone up or bothering anyone.

We never want you to feel alone or unsure of what to do…
If you have any questions or concerns at all, please call our 24-hour nurse line.

- They have access to your computer chart, and can make suggestions about what to do or what medications to use. If needed, they will offer to send a nurse to visit you.
- There may be a delay due to weather, heavy traffic, or other unavoidable circumstances. In the meantime, the nurse on the phone can help.

WHAT IS HOSPICE CARE?

Many people think “hospice” is a place. Actually, hospice care can be provided anywhere you call home.

Hospice focuses on the whole person at the end of their life. It is provided to those who have decided that comfort, rather than curative care, is desired. You and your family may experience a full range of emotions about the future. The hospice team can help you cope with your experience including physical, cognitive, social, emotional, and spiritual.

We help people spend time living life as fully as they wish in their own familiar, comfortable surroundings, and in the company of family and friends.

We believe there are opportunities for living even when dying. We affirm your right to choose and to be in control of decision-making about your care. We will discuss options and assist you in making informed healthcare decisions to meet your end of life hopes and wishes.

Levels of Care covered by the Medicare hospice benefit:

- **Routine Home Care** – Scheduled visits provided at your home. This is the most common level of care.
- **Inpatient Respite Care** – If an unpaid caregiver needs a break from providing care for a vacation, illness or becoming overwhelmed, you may request a 5-day respite stay at a hospice contracted facility for the patient.

Almost 95 percent of the time, hospice is provided in the home by team members including a physician, registered nurse, hospice aid, social worker, chaplain, and volunteer who come for scheduled visits depending on the needs of the patient and family.

- **Crisis Care** – Continuous hourly care provided in your home on a short-term basis when you are in acute pain or symptom crisis requiring continuous nursing support to be able to remain in your home. Your physician and your care team determine when this is appropriate.
- **General Inpatient Care** – Care provided in a hospice contracted hospital, hospice care center or skilled nursing facility where around the clock care is needed on a short-term basis to manage acute pain or other symptoms which cannot be controlled at home and require a more intensive setting.

YOUR HOSPICE CARE TEAM

Hospice care offers you a team of experienced professionals and volunteers. Each team member brings a specialized skill to work together with you and your family. You and your family, along with the support of our team make care decisions and plan for your care. Your hospice team meets regularly to review your wishes and explore options to help maximize your quality of life and provide comfort.

Providence Hospice provides care for individuals with terminal illness; regardless of race, creed, age, gender, sexual orientation, national origin or ability to pay. We acknowledge and appreciate the rich diversity of those we serve. Our care team members represent this same rich diversity. If you or your loved one requests care from a staff member of a particular gender due to personal concerns, we will make every attempt to honor your request. Beyond such concerns, all staff assignments are made without regard to race, color, religion, age, national origin, gender or sexual orientation.

The team includes:

You and your family are the keys to directing your care. Your needs and wishes will be heard, addressed and followed to the best of our ability.

The Attending Provider of your choice will oversee the medical management of your care throughout your stay on the hospice program. Often this is the physician or nurse practitioner who has been part of your care before receiving hospice services.

The Hospice Provider is either a Physician or Nurse Practitioner who works with your Attending Provider and the hospice team members to maximize your quality of life and provide comfort.

Hospice Aide (Certified Nursing Assistant) provide your personal care and other assistance.

We work as a team. There are times when your assigned team members may be unavailable. At those times, another member of our team will provide your care and coordinate with your assigned team.

What Hospice Aides Can Do

You and your nurse will customize the care the aide will provide. Hospice aides will come to your home and provide intermittent care that may include:

- Training caregivers on positioning, transferring, changing linens.
- Bathing (shower, bed bath, tub bath).
- Wash hair.
- Shaving.
- Hand or foot care.
- Clip fingernails or toenails (see exclusions below).
- Vital signs if you and your nurse believe this is necessary.

- Change bed linens.
- Tidy room and bathroom.
- Start a load of laundry.
- Fix simple meals.

What Hospice Aides Cannot Do

According to policy and State regulations, hospice aides cannot:

- Clip fingernails or toenails for patients with diabetes or severe vascular disease.
- Give an enema or suppository.
- Give or apply any medications.
- Operate a pain pump.
- Change settings on oxygen equipment.
- Insert or irrigate a urinary catheter.
- Change wound dressings.
- Suction oral, nasal or other secretions.
- Provide care to members of the household other than the assigned patient.
- Administer tube feeding.
- Provide 24-hour care.

If you require any of these above tasks, your hospice nurse will train you or your caregiver how to perform them or will help you obtain appropriate skilled assistance.

A **Medical Social Worker** will help you and your family talk about the changes in your life and support you in many ways.
Services Provided:

- Listen, advocate and support you in creating a plan to meet your hopes and wishes as well as address your concerns.
- Offer counseling to assist you and your family to better cope with the end of life.
- Identify community resources and assess eligibility.
- Educate on advance care planning including power of attorney and living will.
- Discuss funeral and memorial planning.

Pharmacists serve as an advisory role on the hospice team and specialize in knowledge of medications used to control pain and symptoms. The pharmacist performs a review of each patient's medications upon admission to Hospice and is available to make recommendations for medication management to your team.

Registered Nurse Case Manager will help coordinate and manage your hospice care.
Services Provided:

- Assess your comfort and symptoms and work with your attending provider to make you comfortable.

- Provide training for the proper use of medication and daily care.
- Educate on what to expect with disease progression at the end of life.

Spiritual Counselor or Chaplain is available to you and your family to support you in your spiritual care needs. Chaplains support people of all faiths or no faith and believe your spiritual, emotional, and existential well-being is as important as your physical comfort.

Services Provided:

- Discuss hopes and share joys.
- Provide comfort through reflection, prayer, or meditation.
- Discuss uncertainty about the meaning and purpose of life.
- Explore feelings of loneliness, fear, and helplessness.
- Assist facing difficult choices and important decisions.
- Offer and provide communion, anointing, blessing, and baptism.
- Nurture reconciliation, forgiveness of self and others.
- Assist those seeking solace through sacred writings or connection with the Divine, Holy or Sacred.
- Contact community clergy or spiritual advisor as requested.
- Assist with planning funeral and memorial services.

Therapists are added to your care based on your specific needs. Additional support services such as occupational therapy, speech therapy, physical therapy or a dietician may be added to your care plan to enhance your comfort and/or safety.

Volunteers are caring adults available to support you and your family in a variety of ways. Our volunteers provide practical and emotional support according to your needs. Your team may suggest volunteer services for you, or you can ask for this support. All volunteers have been thoroughly screened, attended specialized training, and successfully passed a background check.

Volunteers can:

- Provide caregiver respite (for up to four hours) so caregivers can take a break
- Provide emotional support and companionship for you or your family
- Perform light household tasks (laundry, vacuuming, organizing, putting dishes away, etc.)
- Help with light yard work (mowing, weeding, etc.)
- Run errands and/or transport patient or caregiver to store or appointments. The patient cannot be on oxygen and must be able to transfer themselves safely. Volunteer’s vehicle must be used.
- Prepare or heat up simple meals
- Read to, write letters for, or play music for patient

- Record patient’s stories (life review/legacy work)
- Most importantly, volunteers offer a comforting, caring presence—just someone to talk to and be with. Some volunteers are licensed notaries, hairdressers, or have other special skills. Ask your care team about the service you require, and we may be able to locate a volunteer who can provide the service.

Volunteers cannot:

- Give or apply medication
- Feed patients (placing food or liquids into their mouth)
- Adjust, maintain, or handle medical equipment (other than wheelchairs and hospital beds)
- Provide personal care (bathe, wash hair, clip nails, shave)
- Transfer (move) the patient or assist with toileting.

How do I request a volunteer?

Talk with your hospice social worker or nurse, and let them know what you’d like assistance with, if you are flexible or have specific scheduling requests, and whether you’d prefer a male or female volunteer.

Although we attempt to fulfill every request we receive for a volunteer, it’s not always possible to find a volunteer who is a good match for each patient or available for the requested assistance. We will do our best to support you. Note that you can decline or end volunteer service at any time.

Grief Support Counselor supports those who survive the death of a person with a terminal illness through the first thirteen months after the death. Counselors help with grieving through the normal range of feelings and concerns commonly experienced in adjusting to a significant loss.

Services Provided:

- Education and written materials on grief and loss.
- One to one supportive counseling sessions.
- Grief and loss support groups.
- Telephone calls for emotional support.
- Referral to appropriate community resources.
- Yearly memorial service.
- Specialty support for children.

HOSPICE COVERAGE

Most insurances, including Medicare, Medicaid and the Veterans Administration (VA) include a hospice benefit.

Medicare, Medicaid, and VA

- The hospice benefit pays a daily rate for care. This daily rate covers visits, medications, equipment, and supplies including:
- Home visits by the hospice staff
- Medications related to the hospice diagnosis
- Basic medical equipment
- Standard supplies

If you have Medicare insurance, you will receive monthly notices in the mail from Medicare detailing hospice claims made on your behalf. Please understand these are not bills, nor reflective of what Medicare actually reimburses us for your care.

If you have private insurance, your hospice team will work with you to determine the scope of your coverage.

If you have limited or no insurance for hospice care, the medical social worker will work with you to determine your eligibility for financial assistance.

Before seeking medical care outside of Providence Hospice (including emergency room visit), it is necessary to:

- Contact hospice for approval before receiving any treatment, tests or procedures to guarantee payment
- Carry your Hospice Benefit Card with you and show it at the time of care You may be responsible for paying for medical care not pre-approved by hospice

EQUIPMENT AND SUPPLIES

Hospice provides basic supplies and equipment that you and your caregivers need for comfort and safety. Your hospice care team will work with you to determine the equipment and supplies you need.

Supplies:

Supplies are ordered by your care team and delivered by Fed Ex right to your home.
Supplies often arrive the day after ordering but typically no more than 2-3 days after.

Examples of Supplies provided:

- Disposable briefs. Pull up briefs are not paid for by hospice.
- Bed pads
- Body and Hair washing supplies
- Skin protection ointments and lotions
- Catheter supplies
- Wound care supplies with an assessment by the hospice nurse
- Gloves
- Bedpan or urinal
- Mouth swabs and moisturizer

Durable Medical Equipment:

In most cases, equipment can be delivered the day after ordering or in emergent situations, the same day.

When you have equipment from another company, please let us know. The equipment will be replaced with an equivalent item.
Please discuss any other equipment needs or concerns with your hospice team.
Most specialty equipment items are not covered under the hospice benefit.

Examples of Durable Medical Equipment provided:

- Electric home care bed
- Oxygen
- Basic wheelchair
- Over-the-bed table
- Bedside commode
- Walker or cane
- A shower chair or bench

ADVANCE DIRECTIVES: MAKING YOUR WISHES KNOWN

What kind of medical care would you want if you were unable to express your wishes? Advance directives are legal documents that allow you to make decisions about end-of-life care ahead of time. They provide a way to share your wishes with your family and health care providers, avoiding confusion in the future if you are unable to speak for yourself.

Know your Options

The most important thing to remember about planning for your end of life care is, you have the power to determine the kind of treatments you want to receive and the kind of treatments you want to avoid. Whether you're just getting started on this journey of understanding your choices and making a plan, or you've made decisions already, we encourage you to take time to review the options below and discuss your goals of care with your hospice team.

Advance directives may include:

A Living Will

A document which explains which medical treatments you do and do not want if you are dying or permanently unconscious.

Durable Power of Attorney (DPOA)

A document appointing your healthcare representative, called your health care agent or proxy. Your (DPOA) is someone you choose to make health decisions for you if you are unable to do so. This includes not only choices at the end of your life but also in other medical situations. This document is also known as a "healthcare proxy," "appointment of healthcare agent" or "durable power of attorney for healthcare." This document can go into effect either immediately or when your physician declares that you are unable to make your own medical decisions. Durable means the power of attorney document will remain in effect regardless of any future disability.

Some hybrid forms, such as the Providence St. Joseph Health Advance Directive Toolkit, combine both into one advance directive legal document.

Your team social worker can provide you with the Providence St. Joseph Health Advanced Directive Toolkit if you would like.

Selecting a durable power of attorney for healthcare (DPOA-HC)

You should choose someone you trust, such as a close family member or good friend who understands your wishes and feels comfortable making healthcare decisions for you. You should have ongoing conversations with this person to talk about your wishes at the end of life. Make sure your medical power of attorney feels comfortable and confident about the type of medical care you want to receive. You can also select a second agent as an alternate in case your first healthcare agent is unwilling or unable to serve.

Preparing an advance directive(s)

- You can fill out a living will and healthcare power of attorney form without a lawyer. It is important for you to use advance directive forms created explicitly for Washington residents, so they are legal. Read the forms carefully and make sure they met your individual needs. You may need to have a witness signature and get the forms notarized (signed by a notary public.) Your social worker can help you obtain the form to fit your needs best. Your social worker can also help you locate a notary to witness your signing of the document(s).
- Keep your completed advance directive in an easily accessible place and give copies to your primary power of attorney, your secondary, or alternate agent, your provider, and hospice care team. This document stays in effect unless you cancel it, or decide to complete a new advance directive with changes.

Physician Orders for Life-Sustaining Treatment (POLST)

When you or someone you love is seriously ill, you may also want to make decisions in advance about life-sustaining treatment. Once these wishes have been discussed with your provider, they can be transformed into actual physician orders called POLST.

- The POLST form can provide security for you and your loved ones that your wishes will be carried out. The form should remain with you if you are transported between care settings.
- The POLST form must be signed by both the patient and the attending physician, nurse practitioner or physician assistant-certified. The attending physician, ARNP or PA-C that signs the form assumes full responsibility for its accuracy.

What are my options for life-sustaining treatment?

You have the power to determine the kind of treatments you want to receive and the kind of treatments you want to avoid. To help you understand your options have conversations with your family and healthcare professionals.

How is the form used?

In a home setting, the bright green POLST form should be located in a prominent location. It will be recognized by emergency personnel as orders to be followed. In a health care facility, the form should be added to the clinical record.

If I have a POLST form, do I need an advance directive, too?

We encourage everyone to have an advance directive, like a durable power of attorney for health care and/or health care directive (also known as a living will). While advance directives are often very helpful in determining end-of-life decisions, they are not required or necessary for having a POLST form.

Please request more information about advance directives and the POLST form from your hospice team.

PROVIDING FEEDBACK (COMPLIMENTS OR COMPLAINTS)

Providence Hospice is committed to providing excellent care to you and your family. Please feel free to share any feedback about the care you are receiving with us. Also, please feel free to tell us how we can improve our services and share any concerns with us as they arise. You have the right to voice your concerns without fear of it impacting your care. We will make every effort to resolve your concerns immediately.

Please share concerns with your hospice care team. If your team can not address your concerns or you feel uncomfortable speaking about issues with a care team member, please call the local hospice main number and ask to speak with a manager.

Providence Hospice of Seattle	**Providence Hospice of Snohomish County**	**Providence SoundHomeCare and Hospice**
206-320-4000	425-261-4777	360-493-5900

You may also contact: The Washington State Department of Health at 800-833-6828 8am-5pm, Monday through Friday TDD Relay Number is 800-833-6388	Or write to: Department of health Health Systems Quality Assurance (HSQA) Complaint Intake PO Box 47857 Olympia, WA 98504-7857 360-236-4700 Email: HSQAComplaintIntake@doh.wa.gov	To report Abuse and Neglect: Call 1-866-End-Harm DSHS TOLL FREE 1-866-ENDHARM 1-866-363-4276 Voice/TTY Accessible

MANAGING PAIN

Pain

- Pain and discomfort may have many causes and be treated in multiple ways.
- The person having the pain can best describe how it feels and how bad it is.
- Medications are often prescribed on an around the clock schedule to control your pain or to keep the pain from occurring.
- Pain control works best when it is treated before it gets too bad. It is important to follow instructions on taking medications even if you no longer feel pain. When medications are taken only at the time of actual pain, it is harder to keep under control. Waiting too long may require more medication and more time to control the pain.
- Pain can cause other symptoms such as anxiety, irritability, loss of sleep, difficulty moving, and nausea and vomiting. These can also make pain worse.

Rating and Describing Pain

The more accurately you can describe your pain, the better your care team can determine the likely cause and start the most helpful treatment.

The following will help to determine pain cause and best treatment:

- Discussion of what type of pain relief do you want.
- What level of comfort do you want?
- How is pain affecting your family/friends as well as your normal daily activities of life?
- What affects your pain? Time of day? Feelings?
- If there are side effects from pain relief measures, what side effects would be unacceptable to you?
- What type of pain treatments have you tried and how have they worked?
- Is pain present all the time or if it starts suddenly, and if so, how long does it last?
- Is pain is only in one area or does it move to other areas of your body?
- Pain can be rated on a scale of 0 (none)-10 (the worst imaginable). If you are unable to tell us about your pain, there are other signs we can look for, such as moaning, frowning or a creased forehead.
- Pain can be described in many ways. How would you describe your pain? *Aching, burning, cramping, crushing, gnawing, heavy, pounding, pressure, shooting, splitting, stabbing, stinging, or tender.*

Non-Medication Pain management

- Heat or Cold packs applied to the area of pain.
- Distractions, such as a visit from a loved one, a good book, movie or TV show, video games, listening to music or focusing on a task at hand, may take your mind off the pain.
- Changing position may help unless movement makes the pain worse.
- Meditation, soothing music, guided imagery and focus on breathing all relax the body which can reduce the pain level. Utilize your team's chaplain or social worker. They are trained to help you with these techniques.
- Presence, gentle, reassuring touch or massage.

Medication for Pain Management (from mildest to strongest)

Please make sure your hospice nurse is aware of everything you are using. Consult your hospice nurse before starting any medications, even those bought without a prescription.

Acetaminophen (Tylenol) – Tylenol may be helpful taken either routinely or as needed for pain. Even if you are taking stronger pain medications, adding Tylenol may help. Be cautious if you have liver disease as it can be harmful to the liver.

Non-steroidal anti-Inflammatory drugs – NSAIDS (aspirin, ibuprofen or Advil, naproxen or Aleve) – These may be helpful but should be used with caution as they may cause bleeding problems, stomach ulcers and may harm the kidneys.

Narcotics (*tramadol or Ultram, hydrocodone or Vicodin, morphine, oxycodone or Percocet, Dilaudid, Fentanyl*). These are prescribed for moderate to severe pain. Constipation is a normal side effect of these medications. Your nurse will want to talk about additional medications to manage it.

When taking pain medications, notify your nurse if:

- Breathing problems develop.
- Dizziness occurs.
- Rash develops.
- Sudden onset of pain even when taking medications as ordered.
- Sudden change in type or severity of pain.
- Unexpected response to a medication.
- Excessive sleepiness occurs.
- Hallucinations are experienced.
- Constipation occurs.

NARCOTIC MEDICATIONS AT END OF LIFE

As hospice care aims to promote comfort at the end of life, narcotic medications are often used to decrease moderate to severe pain and relieve shortness of breath. The most common narcotic used in hospice care is morphine.
Many people have concerns about using narcotics, including fear of addiction, unwanted side effects, and hastening the dying process.

Fear of addiction: When beginning narcotic medications, understanding the difference between tolerance, dependence, and addiction can be helpful.

Tolerance develops over time as the body physically adapts to the dose of a medicine. A higher dose of medicine may be needed as tolerance develops.

Dependence occurs when the body needs an outside source to maintain comfort. Similar to a diabetic who requires insulin to control blood sugar, a person with pain or shortness of breath may need narcotics for relief.

Addiction occurs when no medical or physical need for a narcotic exists. The narcotic is used for the sole purpose of attaining a 'high.'

Side Effects:

- Nausea, itching, and sleepiness are common when starting a narcotic medication and usually go away in a few days. If any of these side effects do not go away, talk to your hospice nurse about options.
- Dry Mouth and Constipation do not go away but can be managed. Your hospice nurse will help you manage these side effects.
- Hastening the Dying Process: There is no evidence that narcotic medications accelerate the dying process when a person receives the right dose to control their symptoms. Fear of giving 'the last dose' is common among caregivers. Medicine is given to manage symptoms and not to hasten death. Someone will give 'the last dose,' but this does not CAUSE death.

MANAGING OTHER SYMPTOMS

Note: This section is organized in alphabetical order so you can find the symptom you are looking for quickly.

Anxiety & Agitation

- Anyone may get agitated at the end of life or struggle with anxiety.
- Anxiety is a normal response to stress or uncertain situations. You may feel a sense of dread, tension or unease.
- Agitation is an unpleasant state of extreme restlessness. An agitated person may feel stirred up, excited, tense, confused, or irritable.
- Anxiety and agitation may cause highs and lows with unexpected behavior changes.
- Agitation becomes a problem when the person moves around in ways that could injure themselves or others.

Managing anxiety and agitation

- Safety first! Determine possible dangers caused by the agitation and address measures to improve safety.
- Promote a calm environment by reducing noise, playing soothing music, adjusting lighting and the room temperature for comfort.
- Do not use restraints as they create dangers.
- Don't forget basics like glasses, hearing aids and dentures to improve communication and comfort.
- Offer food or drink as tolerated for hunger and thirst.
- Attend to personal care needs. A shower or bed bath can be very calming.
- Make sure toileting needs are met, or briefs are changed if they are soiled or wet.
- Provide presence and gentle, reassuring touch if this is helpful.
- Encourage appropriate social activities and engagement with friends and family members if this is helpful.
- Medications may be helpful. Discuss options with your hospice nurse.

Call hospice if:

- There are safety concerns.
- Anxiety or agitation are increasing.
- The current plan is not working.

Appetite Changes

- A person's desire to eat and drink decreases at the end of life as the body needs less food and fluids.
- When a person does not want to eat or drink, caregivers and family members may feel anxious and fear the person may be starving. Forcing food or drink may cause nausea, vomiting, or increase pain.
- Many people ask about IV fluid for hydration when a person is no longer able to swallow, or they do not want to drink. At the end of life, the body's organs are shutting down, and IV fluid may cause more discomfort such as swelling, trouble breathing or nausea.
- Your hospice team is always willing to listen to your concerns about loss of appetite and to talk about options.

Eating for Pleasure

- Food may be enjoyed in smaller amounts spaced throughout the day.
- Ask about favorite foods and stick to these foods.
- Splurge on 'treats' such as ice cream.
- Thick liquids such as yogurt, pudding, Jell-O™, fruit nectars or smoothies may be easier to swallow.
- Avoid straws to prevent the swallowing of air which can cause discomfort from gas pain.

Constipation

- Constipation is more difficult bowel movements with hard, dry stools. It can also cause abdominal pain or nausea.
- Constipation is common at the end of life. This may be due to reduced activity, less food and fluid, and some medications.
- Your hospice team will ask you about your bowel movements. Keeping your team informed of any pattern that is different for you is important.
- If you are on narcotics, regular bowel medications should be taken. It may take time to find the right balance of bowel medications for your body.

Managing Constipation

- Drink as much fluid as is comfortable.
- Prune or other juices can help.
- Establish regular times for using the toilet.
- Sit upright on the toilet or use a sitting position on a bedpan.
- Coffee or tea may help.
- Take constipation medications if prescribed by doctor and hospice team.

Call hospice if:

- Your bowel pattern changes.
- You have abdominal pain or cramping.
- You experience nausea or vomiting.
- There is blood, diarrhea or oozing of stools.

Confusion

- A person may become confused about time, place and not recognize familiar people at the end of life. This is due to the normal end of life changes in the body.
- Getting days and nights mixed up is common as the amount of time sleeping increases.
- A person at the end of life may see or talk with people who have already died. This does not mean they are having a drug reaction or hallucinating. The person may be beginning to detach from life and preparing to let go. The person may reach out, look up, or talk about needing to go somewhere.

Managing Confusion

- Try not to argue with your family member about what they claim to have seen or heard.
- Affirm their experiences and provide reassurance.
- Identify yourself by name when speaking. Speak softly, slowly, and truthfully and ask one question at a time, giving lots of time for answers. If the person is alarmed or anxious, ask what will help him/her feel safe.

Call hospice if:

- There are safety concerns.
- Confusion is upsetting to the patient.

Dry or Sore Mouth

- Drinking less fluids and some medications, especially narcotics, will cause unusual dryness or soreness in your mouth.

Managing Dry or Sore Mouth

- Drink fluids as you are able.
- Suck on popsicles or hard candy.
- Eat cool, soothing foods such as yogurt, ice cream, smoothie drinks or ice chips.
- Regular mouth care will provide relief. Ask your hospice nurse or aide about using mouth swabs or a mouth moisturizer to keep your mouth moist.
- Make sure dentures are cleaned regularly. If dentures no longer fit, discuss options with the hospice nurse.

- Avoid acidic juices and foods such as citrus and tomato if your mouth is sore.
- Try to limit spicy foods, alcohol, and smoking.

Call hospice if:

- You would like a hospice nurse to examine your mouth for any sign of conditions that might need treatment.
- If you have any new pain, sores or white patches in your mouth.
- Your dry or sore mouth is interfering with enjoyable eating.

Hallucinations

- Hallucinations are seeing or hearing something that is not really there. They may be caused by medications, disease or other distressing factors and are often scary and upsetting.
- Hallucinations should not be confused with visions of dead relatives or pets as this is normal at the end of life and will usually bring comfort to those experiencing them.

Call hospice if:

- Seeing or hearing things causes concern, agitation or fear.

Hiccups

- Hiccups are caused by an irritated nerve in the chest or neck or because the stomach is distended from tumor growth, fluid, food or gas.

Managing Hiccups

- Try holding your breath as comfortable and bearing down like you are having a bowel movement.
- Meditation and deep breathing techniques.
- Medication may help. Your nurse can work with you and your provider to determine the right treatment.

Call hospice if:

- You have painful or irritating hiccups that cannot be controlled.

Nausea & Vomiting

Nausea and vomiting may be caused by disease progression, overeating or medications.

Managing Nausea and Vomiting

Nausea:

- Eat small, frequent meals and drink only in between meals to reduce the volume in the stomach.
- Limit heavy meals, fatty, spicy and strong odor foods.
- Take all medications with a small amount of food, unless instructed otherwise.
- Serve food at cold or room temperature to reduce its smell and taste.
- Rest quietly after eating or taking medication may help.
- A cool, damp washcloth on the back of the neck can sometimes help.
- There are some medications to help prevent or relieve nausea when present.
- Discuss nausea symptoms with your hospice nurse to determine its cause and the best prevention.

Vomiting:

- Stop eating until vomiting passes to allow the gut to rest.
- Rinse mouth thoroughly after vomiting.
- Eat slowly after an episode and start with clear liquids.
- Eat ice chips or flavored ice like popsicles for hydration.
- Sip liquids slowly in small amounts.
- Add bland foods (crackers, dry toast/cereal) as tolerated.

Call hospice if:

- Vomiting recurs after resuming eating and drinking.
- Vomit is bright red, dark brown or smells of stool.
- Interventions, including medications, are not effective.

Seizures

- If you are at risk for seizures or have had seizures in the recent past, discuss this with your hospice nurse.
- If you have anti-seizure medication prescribed, it is important not to miss a dose.

Managing Seizures (Caregiver)

- Lay the person down flat – on the bed or the floor.
- Clear the area around the person.
- Put a soft pillow or towel under the head.
- Loosen any constrictive clothing around the neck.
- Don’t restrain movements, instead, attempt to keep them safe from injury.
- Stay with the person and use reassuring words.
- Don’t put anything into the mouth.

Call hospice if:

- A seizure doesn’t stop in a few minutes.
- After the seizure, call the nurse to report and discuss further seizure prevention and management.

Shortness of Breath

- Breathing changes are normal at the end of life; however, shortness of breath can be uncomfortable.
- Shortness of breath may be caused by many reasons including disease progression, fluid buildup in the lungs, anxiety or natural changes occurring at the end of life.

Managing Shortness of Breath

- Raise the head of the bed 30-45 degrees if in bed or sit up in a chair with good back support if able.
- Use a fan on low directed toward you.
- Ask family or friend to stay with you for reassurance.
- Reduce the temperature of the room or remove heavy clothing or bedding.
- Take slow breathes and try to relax.
- Wear oxygen if ordered and doesn’t cause discomfort.
- Reduce environmental irritants such as strong odors and smoke.
- Use any treatments and medications prescribed by your provider.

Call hospice if:

- Shortness of breath continues to be a problem.
- Oxygen equipment is not working correctly.

Skin Changes

- Skin sores or bed sores result from too much pressure in one area for too long.
- Bed sores may begin as red spots and may progress to open wounds.
- Bony areas of the body such as the tailbone, hips, and heels are most at risk.

Managing Skin Breakdown

- For the person who is bedridden or chair bound, the best prevention is to change body position every 2 hours. Use pillows to prop them up and soften pressure areas.
- Ensure the patient is not sitting or lying on hard objects (remote controls, phones, glasses).
- Keep the skin as clean and dry as possible.

Call hospice if:

- An area of redness or an open sore develops.
- Your sores get worse.
- Your bandages come off.
- Your sore has any oozing or bleeding that does not stop or soaks a bandage.

Social and Emotional Withdrawal

- Emotional withdrawal is normal at the end of life and may look like depression.
- Some causes of withdrawal include a need to conserve energy and a higher need for reflection and life review.
- Social and emotional withdrawal is not uncomfortable for the patient but may cause distress for loved ones. If your family member is withdrawn, it does not mean you are not loved. You can help your family member by allowing them time to be quiet.

Managing Social and Emotional Withdrawal

- Offer touch and physical presence with no words.
- Be aware of your loved one’s body language.
- Explain to other family or friends that this is normal.
- Limit visitors, length of visits or create a schedule for visits as patient wishes.
- Reduce stimulation in the room (i.e. Turn off the TV, be mindful of voice levels, etc.)
- Reflect on a patient’s life by telling stories and sharing photos/videos instead of focusing on the future.
- Ask to speak with hospice social worker or chaplain, if you would like support around these changes or have concerns that your loved one is experiencing depression or emotional distress.

Call hospice if:

- You have concerns about the withdrawal you are seeing.

Swelling

- Swelling occurs when fluid builds up and is retained in various parts of the body such as legs, ankles, feet, and hands.
- Possible causes include less protein, reduced activity or salt/sodium consumption.

Managing Swelling

- Raise affected area above heart if possible.
- Limit salt intake.
- Limit fluids if your doctor or nurse tells you to.
- Take diuretics (water pills) as ordered.
- Move around more if you are able.

Call hospice if:

- Sudden onset of swelling or shortness of breath.

Urination

- The patient may lose control of urine (become incontinent) as the muscles weaken.
- The amount of urine may decrease.
- Urine may be dark-colored and strong smelling.

Managing Urination

- If a person is incontinent, a hospice nurse or aide can help order supplies needed.
- Use hospice aide services to provide baths and personal care.

Call hospice if:

- The patient does not urinate in 12 hours.
- There is pain with urination.
- You see redness, irritation or skin breakdown.

OBTAINING MEDICATIONS WHILE ON HOSPICE

How do I get hospice covered medications?

- Your hospice nurse will discuss which of your medications will be paid for by hospice.
- Your nurse will also discuss which pharmacies may be used for those medications.
- Take your Hospice Benefit card with you if you pick up your hospice medications at a local pharmacy.
- Hospice usually orders a 2 week supply of medications at a time. Your nurse will review your medication supply at every visit and order refills as needed. Inform your nurse if you have less than a 1 week supply.
- Patients in Adult Family Homes, Nursing Homes or Assisted Living facilities will get their medications from the facility pharmacy who will bill hospice.

Are there any co-pays?

- Hospice covered medications are provided to you at no charge.
- If you are picking up medications at a local pharmacy and they have difficulty billing with your Hospice Benefit card, please have the pharmacy call Hospice.
- If you pay for medication out of pocket, we may not be able to refund the cost.

What medications are covered?

- Medications for comfort related to your hospice diagnosis and conditions.

What medications are not covered?

- Medications to treat conditions unrelated to your hospice diagnosis. Thyroid and cholesterol medications are common examples.
- Most over-the-counter vitamins or supplements.
- Chemotherapy drugs.
- Some newer medications are not covered even if they are related to your diagnosis. Hospice will work with you to provide an alternative medication for your needs.

How do I obtain medications that are not covered by hospice?

You will continue to obtain these medications as you always have.

SAFE DISPOSAL OF MEDICATION

The safe management and disposal of all medications is a concern for you, your loved ones, the community and the environment. Unintentional poisoning and drug abuse rates of household medications have risen dramatically in the past 15 years. This rise may be related to improper storage and disposal of medications.

Regulations require we provide you with a copy of our policy on medication disposal.

Policy

- During the admission to hospice, every patient/family or alternate decision-maker will receive education regarding the management and disposal of medications, with specific education on the management and disposal of controlled drugs.
- The patient/family or alternate decision-maker will also receive a copy of this policy and written medication disposal instructions.
- Hospice providers and nurses who have received training may assist in the disposal of medications (including controlled substances) adhering to the following guidelines:

  - Disposal must occur in the patient's home after death or if medication has expired.
  - No hospice personnel may remove medications from a patient's home.
  - Disposal of controlled medications must be documented in the electronic medical record and include the following:

    - Type (name of medication)
    - Dosage
    - Dosage form
    - Route of administration
    - Quantity
    - Time
    - Date
    - Manner of disposal
    - Witness signature

- The patient's family or alternate decision-maker has the right to refuse medication disposal.
- If the patient dies and the Medical Examiner has reason to investigate the case, the family/caregivers will be instructed not to remove or dispose of any medications.

Procedure

Controlled Substances

Controlled drugs may be especially harmful and, in some cases, fatal with just one dose if they are used by someone other than the person for whom the medicine was prescribed. These medications commonly used in hospice should be flushed down the sink or toilet to help prevent danger to **people and pets in the home:**

- Fentanyl patches
- Hydrocodone (Vicodin, Norco)
- Hydromorphone (Dilaudid)
- Meperidine (Demerol)
- Methadone
- Morphine (MS contin)
- Oxycodone (Percocet, Oxycontin)
- Here is a link to the full Food and Drug Administration's (FDA) Flush List: https://www.fda.gov/media/109643/download

Destruction/Disposal

- The hospice nurse will educate patient/family or alternate decision maker on how to manage and dispose of controlled substances.
- The education will be documented in the electronic medical record.
- Some pharmacies will accept controlled drugs for disposal. The following is a link to the DEA search utility: https://apps.deadiversion.usdoj.gov/pubdispsearch/spring/main?execution=e1s1
- Alternatively, the hospice provider or nurse may assist the patient's family or alternate decision-maker to dispose of controlled substances in the following manner:

  1. In the presence of a witness, count the medications to be disposed of and document on the Medication Disposal Form.
  2. Flush the medications down the toilet or sink per Drug Enforcement Agency recommendations.
  3. Obtain witness signature on the Medication Disposal Form.
  4. Take a photo of the Medication Disposal Form and send to Health Information Management to scan into electronic medical record.

Non-controlled substances

- The safest method is to take medications to a medication drop box.
- Information and locations can be found on the following web sites:

  - King County: https://kingcountysecuremedicinereturn.org/
  - Lewis County: https://lewiscountywa.gov/offices/sheriff/safe-option-for-disposal-of-unused-medicines/

    - Thurston/Mason Counties: https://www.co.thurston.wa.us/health/personalhealth/unwantedmedication/index.html
    - Snohomish County: https://med-project.org/locations/snohomish/
    - Washington Poison Center: http://www.takebackyourmeds.org/

- If unable to take medications to a drop box follow the FDA recommended steps below:

1. Remove the drugs from their original containers and mix them with something undesirable, such as used coffee grounds, dirt, or cat litter. This makes the medicine less appealing to children and pets and unrecognizable to someone who might intentionally go through the trash looking for drugs.
2. Put the mixture in something you can close (a re-sealable zipper storage bag, empty can, or other container) to prevent the drug from leaking or spilling out.
3. Throw the container in the garbage.
4. Scratch out all your personal information on the empty medicine packaging to protect your identity and privacy and throw the packaging away.

References

Medicare CoP §418.106(e)(2) Disposing and all subsets
Controlled Substances from DEA Office of Diversion Control
Washington State Drug Take Back Program
Disposal of Controlled Substances of a Hospice Patient by Employees of a Qualified Hospice Program

E-KIT MEDICATION INFORMATION AND INSTRUCTIONS

While on hospice, you may receive an “E-kit.” The “E-kit” includes medications to treat common symptoms quickly. Your hospice nurse will help you determine when to use any of the medications in the E-kit, what dose to give and how often, and the safest way to give. These medications can be given to someone who cannot swallow.

The medications in your E-kit will help to treat symptoms such as:

- Pain
- Shortness of breath
- Nausea/vomiting
- Congestion causing a rattling or gurgling noise
- Constipation
- Hallucinations
- Anxiety, agitation or restlessness

The medicines listed below are the most common. Your emergency kit will be customized to your needs.

Morphine (or related narcotics such as hydromorphone) - Narcotic pain medicines are used to treat moderate to severe pain and shortness of breath safely.

Possible Side Effects – nausea, dizziness, drowsiness, confusion, itching, and constipation.

- Most of these disappear within a few days except constipation. You need to take a laxative while on narcotics. Talk with a hospice nurse about which one is right for you.
- It is best to avoid drinking alcohol when taking this medicine.
- For more details on narcotic use, please refer the page titled “NARCOTIC MEDICATIONS AT END OF LIFE

Lorazepam (Ativan) - Lorazepam is used to relieve anxiety, restlessness or ‘nerves.’

Possible Side Effects –dizziness or drowsiness and can lead to increased falls.
It is best to avoid drinking alcohol when taking this medicine.

Haloperidol (Haldol) - Haloperidol is used for managing nausea, agitation, and hallucinations.

Possible Side Effects –drowsiness

You may view a video on how to draw up medications and how to crush pills by going to the website: www.providence.org/hospicecaregiver

- Click on the heading called **Caring for Someone on Hospice**
- Scroll to the middle of the page and look for all Caregiver Videos under **Caring with confidence**

E-KIT INSTRUCTIONS

Your RN Case Manager will complete this page on their first visit after your E-Kit arrives.

For Pain or Shortness of Breath: _________________________________
(Medicine)

Call Hospice and ask to speak with a nurse before starting any of these medications

Information for the Caregiver: Only the patient can best describe their pain. For patients who cannot communicate verbally, there are non-verbal signs, such as facial expression and vocalizations that your nurse can give you more information to help guide you.

Route: Take orally. Tablets can be crushed and given on the inside of the cheek. Your nurse can show you how to do this.

Medication Information: Opioids can cause stomach upset, dizziness, sleepiness, confusion, itching and constipation. All of these side effects, except constipation, tend to disappear within a few days or are easily controlled with other medications.

For Anxiety: _________________________________
(Medicine)

Information for the Caregiver: Not everyone will be given a medication for anxiety as some diseases may become worse with these types of medicines. Your team will work with you to help reduce anxiety if this is the case for you. The patient can best describe feelings of anxiousness, although other symptoms may cause the patient to be anxious. For patients who cannot communicate verbally, the patient may be restless and unable to be comforted.

Route: Take orally. Tablets can be crushed and given on the inside of the cheek. Your nurse can show you how to do this.

Medication Information: May cause dizziness and drowsiness, especially when taken with certain other medications. Avoid alcohol. Make sure you call the hospice nurse if you experience any abnormal movements, muscle aches or an extremely high fever.

For Constipation: Bisacodyl

Information for the Caregiver: Bisacodyl suppositories usually cause a bowel movement within 15 to 60 minutes of insertion.

Route: Remove wrapper and insert one suppository rectally daily as needed for constipation not relieved by oral laxative medication. May use water soluble lubricant if needed for ease of insertion.

Medication Information: Store in a cool place.

For Congestion: Hyoscyamine ODT

Information for the Caregiver: The patient may have “gurgling” sounds from the chest or it may sound like marbles rolling around inside. The gurgling sounds are a normal change that does not indicate the onset of severe or new pain.

Route: Dissolve tablet in the patient’s mouth.

Medication Information: May cause an excessive dry mouth, blurred vision, drowsiness, constipation or difficulty urinating.

For Nausea and/or Vomiting: Haloperidol

Information for the Caregiver: Patients with Dementia or Parkinson’s disease will not be given haloperidol as it will make symptoms in these diseases worse. Your team will work with you and your provider to obtain the best medication if you experience nausea and/or vomiting.

Route: Take tablets by mouth or insert rectally

Medication Information: May cause drowsiness, blurred vision, or trouble urinating. Make sure you call the hospice nurse if you experience any abnormal movements, jerks, tics, muscle aches or an extremely high fever. Do not take more than prescribed unless instructed by the hospice nurse.

For Mild Pain or Fever: Acetaminophen (Tylenol®) Suppositories

Information for the Caregiver: Acetaminophen suppositories treat or prevent mild pain and fever.

Route: Remove wrapper and insert suppository rectally every 4 hours as needed for pain or fever relief. DO NOT EXCEED 3,000mg of acetaminophen from all sources in a 24 hour period or 2,000mg in a 24 hour period if liver function is compromised.

Medication Information: Keep in a cool place. Let hospice staff know if you have liver problems.

MEDICATION SAFETY

Safe management of all medication is a public health concern affecting all of us and our communities. Accidental poisoning and abuse of household medications have risen in the past 15 years.

Medications should be closely safeguarded. If a medication is missing, please inform your nurse immediately. If your hospice team suspects theft of controlled medications (i.e. narcotics), you may be required to file a police report.

To safely and effectively use medications:

- Store all medications in a safe place, out of reach of children and pets.
- Learn the names of all your medications (including vitamins and supplements), side effects, and the reasons for taking them.
- Inform your nurse of all medications you are taking or any changes (a new or stopped medication, or change in dosage).
- Medications should only be taken by the person for whom they are ordered.
- Stop taking medications only when directed by your physician.
- Do not take expired medications.
- It is not always safe to flush or throw away medications you are no longer taking. See **Safe Disposal of Medication** page or ask your hospice nurse how to dispose of medications safely.

HOW TO CARE FOR SOMEONE

Caring for a loved one on hospice at home can be challenging. As a person's illness progresses, a person will lose the ability to take care of themselves independently. It's normal to have questions about how to care for a person as this happens.

General Tips

Always tell the person you are caring for what you are going to do before you do it even if you don't think they can hear you.
Wash your hands before and after care. Use gloves if needed.
Hospice Aides can provide all the services below and can help train you for when the team is not present.

Mouth Care

A clean and moist mouth helps make the patient more comfortable, avoids irritation and infection, and reduces mouth odor. Mouth care should be provided at least twice a day.
If no longer able to brush teeth, a mouth swab can be used for mouth care.
Moisten mouth swabs with water and gently clean inside the mouth. Repeat as needed.

Preventing dry or cracked lips

If oxygen is not being used, use a lip moisturizer (such as Chapstick® or Vaseline®) on the lips to prevent drying or cracking.
If oxygen is being used, do not use Chapstick® or Vaseline. Instead, use a water-based lubricant such as KY jelly on the patient's lips or in the nose.

Bathing

Bathing increases comfort, allows for inspection of the skin and prevents bedsores. How often one should bathe varies. For most, only 2-3 times a week is needed. You nurse will help you determine what is best.
Bathing may become challenging as the patient becomes weaker. Use of a shower chair or bath bench inside the tub or shower stall will help the patient remain safe and tireless. It is also possible to take a sponge bath sitting next to the sink. Sometimes both of these methods are increasingly difficult, and it may be better to bathe the patient in bed.

Before bathing:

- The patient should never bathe alone using a shower chair or bath bench.
- To reduce the possibility of slipping, make sure the chair or bench is secured in the tub or stall and dry before using.
- Remove all loose throw rugs from the bathroom.

During bathing:

- Try not let patient get chilled. If using a tub or pan, replace water frequently with fresh, warm water. Use extra towels or blanket to cover areas not being washed.
- For bed-bound patients in a home care bed, raise the bed to a comfortable working position to avoid straining your back.
- Clean the skin with soap and water.
- Rinse off all soap.
- Dry skin gently and thoroughly.

Washing Hair for Patient in Bed

Washing a patient’s hair provides cleanliness and comfort.

- If there are scalp lesions, wear gloves.
- Lie patient as flat as possible in bed.
- Place the inflatable hair basin under the head and neck to capture water.
- Pour warm water to wet the hair.
- Add shampoo to wet hair and lather.
- Massage scalp gently while working lather through hair.
- Rinse hair thoroughly by pouring warm water over the hair until all shampoo is rinsed.
- Gently blot hair dry with a towel.

Changing Bed Linens with a patient in bed

Crumbs, creases or moisture in the bed are uncomfortable and may contribute to bedsores. When a patient becomes too weak to get out of bed, your nurse or aide can teach you how to make the bed with the patient in it. Bed linens should usually be changed twice a week after a bed bath, more often if the sheets get damp or soiled.

Think of the bed in two halves. Change one half of the bed while the patient lies on the other half. Then, roll the patient onto the clean half and change the second half.

- Be sure the patient can’t roll off either side of the bed.
- Lower the head bed as much as possible and remove all but one pillow.
- Help the patient roll to one side of the bed.
- Go to the side with patient’s back facing you.
- Loosen all the sheet(s) and blanket(s) on your side.
- Roll the bottom sheet(s) under the patient to the middle of the bed.
- Place the clean sheet(s) on the bed and tuck as needed. Pull the rest of the clean sheet to the middle of the bed.
- If you are using a pull sheet or incontinence pad, place those in the same way.
- Have patient turn toward you over the roll of linens onto the clean side of the bed.

- Move to the other side of the bed and pull out the dirty sheet(s).
- Unroll the clean sheet(s) and tuck as needed.
- Place top covers in a way that is comfortable for the patient. If tucking these covers in at the bottom of the bed, allow extra space for the feet.

You may also view a video on how to change the sheets with a person in the bed by going to the website: www.providence.org/hospicecaregiver
- Click on the heading called **Caring for Someone on Hospice**
- Scroll to the middle of the page and look for all Caregiver Videos under **Caring with confidence**

Transferring Patient from Bed to Chair or Wheelchair

People who are weak will need help moving from bed to chair to prevent a fall and injury. You will do two things to help:

1. Provide extra strength and stability.
2. Guide the direction of the patient's movements to complete the transfer.

How to transfer a patient from Bed to Chair or Wheelchair

Determine whether you can safely transfer patient by yourself. If the patient is much taller or heavier than you, has severe weakness or is confused and unable to participate in the required movements for the transfer, you should get help from another person.

- Tell the patient how you would like them to help by moving during the transfer.
- Place chair or wheelchair at a slight angle to the bed, or the patient's strongest side, facing the foot of the bed.
- Keep the front corner of the chair as close to the bed as possible.
- If using a wheelchair, place the footrests in the "up" position so the patient's feet can easily touch the floor.
- Make sure the patient is not too dizzy or weak to complete the transfer.
- Put shoes or non-skid slippers on patient's feet before you begin the transfer.
- Place one of your legs between patient's legs so your leg can act as a support (brace).
- Place your other leg outside patient's leg furthest from the chair.
- Place your hands under patient's armpits and onto their back. Use a gait belt if your nurse has told you to do this.
- The patient can use their arms to help push up from the mattress to a standing position.
- You can assist the patient in standing by flexing your knees and rocking back while lifting under the arms at the same time.
- Stabilize patient after the patient is in a standing position.
- Instruct the patient to pivot while at the same time reaching for the far arm of the chair with their hand closest to the chair.
- After a successful pivot, the patient should be facing the foot of the bed and their back toward the seat of the chair.

- Assist patient in stepping backward until the back of the patient's knees are touching the edge of the chair seat.
- Lower the patient into the chair by bending your knees to allow your upper body to descend as patient gradually descends into the chair seat.
- If using a wheelchair, lower footrests and place patient's feet on them.

You may view a video on how to transfer a patient from bed to wheelchair by going to the website: www.providence.org/hospicecaregiver

- Click on the heading called **Caring for Someone on Hospice**
- Scroll to the middle of the page and look for all Caregiver Videos under **Caring with confidence**

Using a Bedpan

If the patient cannot easily transfer or comfortably get to or use a toilet, a bedpan may be recommended.

How to use a bedpan:

- Have patient lie down.
- If they are able to lift their hips, have them do so. If unable, roll them to one side, taking care they do not fall off the bed.
- Place bedpan on moisture-proof bed protector under the buttocks.
- Have patient lower hips or roll them back over on top of the bedpan. Your nurse or hospice aide will show you what the correct position is for the bedpan you have.
- If the patient is able, help them to a sitting position by raising the head of the bed.
- When the patient is done, lower the head of bed back down. Have them lift their hips or carefully roll them to the side.
- Remove bedpan and carefully dispose of contents.
- Clean the area thoroughly, wiping from front to back.
- If soap and water are used, make sure to rinse thoroughly.
- Pat dry and use other lotions or creams if needed as instructed by your nurse.
- Help the patient get into a comfortable position.

Using Disposable Briefs

Briefs are used to prevent skin breakdown and keep clothing and bedding clean. Briefs can be used throughout the day and night. They should be checked at least every two hours during the day (4-6 at night) for moisture and changed when wet or soiled.

Briefs work best when they are the right size. Briefs that are too large can cause leaking. Leaking can also occur if using more than one brief at a time. Ask your nurse to make sure the size is correct.

Changing a disposable brief

- Place a moisture-proof pad beneath the patient's buttocks before removing the soiled incontinent brief, if one is not already protecting the bed linens.
- Loosen tabs that attach back of brief to the front.
- Roll brief from abdomen toward buttocks.
- Turn patient on their side and continue rolling brief across and under buttocks.
- Dispose of the soiled brief in a covered waste container.
- Clean the area thoroughly, wiping from front to back.
- If soap and water are used, make sure to rinse thoroughly.
- Pat dry and use other lotions or creams if needed as instructed by your nurse.
- Place the side of the brief with the adhesive tabs on the bed. The soft side will be touching the patient.
- Roll patient onto the brief to position it under their buttocks.
- Pull front panel of brief up between patient's legs. It should fit snugly around the crotch with no gaps around the legs.
- Open adhesive tabs on the back of brief and stick to the front.

Repositioning in bed

As a person becomes weaker, they spend more time lying in bed. Changing positions every 2-4 hours can help prevent bed sores and reduce pain and discomfort. Changing positions can be as simple as moving a pillow for pressure relief. Your nurse and hospice aide will show you how to do this.

Here are some helpful tips when repositioning a patient in bed:

- Give pain medication before if moving is uncomfortable.
- Have someone help you if possible.
- Be careful of tubing, so it does not become tangled or get pulled.
- Raise the bed to a comfortable height, so you aren't bending over so much. Remember to return it to the lowest position when you are done.
- Protect your body by moving carefully:
- Use your legs and feet to turn your whole body, rather than twisting your back.
- Bend or flex your knees – use leg and stomach muscles
- If the person isn't able to communicate, imagine yourself in their position. Would you feel comfortable? For example, make sure they are not laying on their arm.
- Pillows can be placed for support under the patient's head, between the knees, under the knees or under hands or arms.

Draw sheet

A folded sheet placed under the body (neck to buttocks) that can be used to move the patient around in the bed. Blankets or large towels may also be used.

Placing a draw sheet

- Stand next to the patient at the side of the bed, roll them onto their side, taking care they do not fall.
- Lay the sheet open on the empty part of the bed. Tuck half the sheet up against the patient's back.
- Go to the other side of the bed, roll the patient back onto the sheet. Pull out and straighten the tucked half of the sheet.

Moving a patient with a draw sheet

- Lower the head of the bed if it is not too uncomfortable for the patient.
- Two people can move a patient up in the bed by rolling both sides of the sheet up close to the patient's hips and together sliding the patient up in the bed.
- One person can use a draw sheet to move a patient up in bed by going to the head of the bed, grabbing the top end of the draw sheet, and pulling it and the patient up toward the head of the bed.
- The patient may be able to help by flexing at the knees and pushing up with feet and knees
- Put the head of the bed back up.
- One person can also use a draw sheet to move a patient from one side of the bed to the other. Roll draw sheet up next to the patient, lift and pull toward yourself.

You may view a video on how to reposition a bed bound patient by going to the website: www.providence.org/hospicecaregiver
- Click on the heading called **Caring for Someone on Hospice**
- Scroll to the middle of the page and look for all Caregiver Videos under **Caring with confidence**

SUPPORT FOR CAREGIVERS, FAMILY, AND FRIENDS: CARING FOR YOURSELF

When you are a caregiver, it is common to focus all of your energy and time on the person receiving hospice care, neglecting your own needs. This can lead to stress, exhaustion, burnout, and unmanageable grief. It is essential for you to take care of yourself so you can continue to be a caregiver and maintain your health.

Keep to your routine

- If you're used to a morning walk or having a cup of tea in the afternoon, stick to your routine even if it is only 15 minutes a day.
- Be aware of your exercise, eating, and sleeping habits
- It is easy to lose track of time and fall into habits that do not provide you with the energy you need. Exercise can be as simple as stretching or taking a walk around the block; anything to get your body moving. Be aware of what and when you are eating. Sleep can be difficult. Is there someone who can give you a break at night on a regular basis? Ask your hospice team for resources that may be able to help you.
- Make a list of tasks you need help with
- When someone says "let me know if there is anything I can do" point to the list! For example; grocery shopping, laundry, errands, lawn care, housecleaning, or spending time with the patient. This can give you time to take a break or do something else.
- Embrace joy in the midst of sadness
- Providing care at the end of life may be a sad time. Sometimes it can be helpful to remember more joyful times and to share these with your loved ones. Laughter does not mean you are a bad person; it means you are still engaged with life.

Ask for support

- Feeling anxious, scared, guilty, sad, frustrated are all normal parts of the grief process. Allow yourself to feel these feelings and reach out to people who can support you through these. Being in the moment while thinking about letting go of your loved one is not an easy task.
- You don't need to do this alone. Reach out to family and friends who provide you comfort during hard times. The hospice social worker and chaplain are there to provide emotional and spiritual support for the patient and family. Also, there are in-person or online support groups available. Ask your hospice social worker or chaplain for more information if needed.

Take time to reflect

How have you gotten through difficult times in the past? What has supported you? Are you addressing your physical, mental, social and spiritual well-being? Have you experienced loss before, and how is this impacting how you are feeling now? Reach out to your Hospice Team for assistance in processing some of these questions as needed.

I know I am feeling stress or grief when:

____
____
____
____
____

When I am feeling this way, I can call:

Name	Phone Number

Five simple activities I can do every day are:

Activity	When	Time Required

Caregiver Resources

American Cancer Society 800 227 2345 https://www.cancer.org	Alzheimer's Association 800 272 3900 https://www.alz.org
National Hospice and Palliative Care Organization: CaringInfo https://www.caringinfo.org	

FALL PREVENTION

Your hospice team will work to ensure your safety no matter where you live. Here are some safety recommendations. Your hospice team may make additional suggestions for your living environment.

Falls at home

Each year thousands of people fall at home. Hospice patients are at an increased risk of falling because, as their health declines, they become more debilitated and frail. Falls are often caused by hazards that are easy to overlook but may also be easy to fix.

This checklist below provides some simple suggestions to prevent falls.

Floors: Look at the floor in each room.

☐ When you walk through a room, do you have to walk around furniture?
☐ Ask someone to move the furniture, so your path is clear.
☐ Do you have throw rugs on the floor?
☐ Remove the rugs, or use double-sided tape or a non-slip backing so the rugs won’t slip.
☐ Are there papers, books, towels, shoes, magazines, boxes, blankets or other objects on the floor?
☐ Pick up things that are on the floor. Always keep objects off the floor.
☐ Do you have to walk over or around wires/cords, such as a lamp, telephone or extension cords?
☐ Wind up the cords/wires or tape them next to the wall so you can’t trip over them. If needed, have an electrician install an extra outlet.

Stairs and steps: Look at the stairs inside and outside your home.

☐ Are there papers, shoes, books or other objects on the stairs?
☐ Pick up things that are on the stairs. Always keep the stairs clear.
☐ Are any steps broken or uneven?
☐ Fix loose or uneven steps.
☐ Is there a light over the stairway?
☐ Have an electrician install an overhead light at the top and bottom of the stairs.
☐ Do you have a light switch only at the top or bottom of the stairs (just one switch for the stairs)?
☐ Have an electrician install a light switch at both the top and bottom of the stairs. (Get light switches that glow so you can see them in the dark.)
☐ Has the stairway light bulb burned out?
☐ Ask a friend or family member to change the light bulb for you.
☐ Is carpeting on the steps loose or torn?
☐ Make sure the carpet is firmly attached to every step. Or, replace the carpet with non-slip rubber treads on the stairs.
☐ Are the handrails loose or broken? Is there a handrail on only one side of the stairs?

☐ Fix loose handrails or install new ones. Make sure handrails are on both sides of the stairs and are as long as the stairs.

Bathroom: Assess for safety, many falls happen here.

☐ Is your bathroom as safe as it can be?
☐ Use a rubber mat or skid-proof strips in tub or shower.
☐ Install grab bars in the tub or shower at the appropriate height.
☐ Use raised toilet seat and grab bars to assist with getting up.
☐ Talk to your nurse about other options when getting to the bathroom starts to be a safety concern.

Other things you can do to prevent falls:

☐ Ask your hospice nurse to look at all the medications you take, including over-the-counter medications. Some medications can make you sleepy or dizzy.
☐ Have your vision checked, if possible, because poor vision can increase your risk of falling.
☐ Get up slowly after you sit or lie down.
☐ Wear shoes both inside and outside the house. Avoid going barefoot or wearing slippers, especially on shiny floors.
☐ Improve the lighting in your home.
☐ Put in brighter light bulbs. Fluorescent bulbs are bright and cost less to use.
☐ It’s safest to have uniform lighting throughout a room. Add lights in dark areas. Hang lightweight curtains or shades to reduce sun glare.
☐ Paint a contrasting color on the top edge of all steps so you can see the stairs better. For example, use a light-color paint on dark wood.
☐ Keep emergency numbers in large print near each phone.
☐ Keep a cell phone nearby in case you fall and can’t get up.
☐ Think about wearing an alarm device that will bring help if you fall and can’t get up.

BED RAILS – RISKS AND BENEFITS

Caregivers in the home setting sometimes request bed rails to keep their loved one safe from falls. Many studies, however; have shown bed rails are a safety hazard.

Risks of danger from side rails may include:

- Severe injuries from falls when patients climb over rails.
- Strangling, suffocating, bodily injury or even death when persons or part of their body are caught between rails or between the bed rails and mattress.
- Skin bruising, cuts, and scrapes.
- Inducing agitated behavior when bed rails are used as a restraint.
- Feeling isolated or unnecessarily restricted.
- Preventing those who are able to get out of bed, from performing routine activities such as going to the bathroom.

Consider these alternatives to bed rails:

- Anticipate the reasons they may want to get out of bed such as hunger, thirst, going to the bathroom, restlessness, and pain.
- Meet these needs by offering food and fluids, allowing for ample toileting, providing a calming environment, and ensuring pain relief.

Other ways to calm restlessness:

- Sit calmly at the bedside.
- Play their favorite music.
- Read to them from a book.
- Gently massage their hands or feet.
- Always be sure pain is well managed.
- Use a room monitoring device or a call system for patient use (such as a baby monitor or wireless doorbell).
- When are bedrails helpful?
- Bed rails can be helpful for patients who are alert and oriented.
- Provides a hand-hold and support for getting into or out of bed.
- Enables patients to assist with turning and repositioning within the bed.
- Provides easy access to bed controls and personal care items.

If you feel bed rails would be helpful, please speak with your hospice nurse. If bed rails are provided, your nurse will assess for ongoing need and safety. When a person’s condition changes and rails become a hazard, they will be removed for safety.

EMERGENCY PREPAREDNESS

Natural and man-made emergencies can make communication and transportation difficult and may impact our ability to provide care.

In the event of a local emergency, you will be contacted by hospice as soon as possible. You will receive specific instructions at the time regarding how your care will be provided.

At the conclusion of a local emergency, hospice will contact you with further instructions.

You can find these below instructions and much more by going to the Washington State Department of Health https://www.doh.wa.gov/Emergencies/BePreparedBeSafe/GetReady

Get Ready for an Emergency

Emergency events in our state range from earthquakes, tsunamis and volcanic eruptions to more common events such as flooding, windstorms or disease outbreaks. Now is a good time to get ready for whatever might happen.

Have an Emergency Kit

You should be prepared to take care of yourself and your family for at least three days. Store a kit at home, at work and in your car. Some items to keep in your kit include:

- Dry or canned food and drinking water for each person
- Can Opener
- First aid supplies and first aid book
- Copies of important documents such as birth certificates, licenses, and insurance policies
- “Special needs” items for family members such as infant formula, eyeglasses and medications
- A change of clothing
- Sleeping bag or blanket
- Battery powered radio or television
- Flashlight and extra batteries
- Whistle
- Waterproof matches
- Toys, books, puzzles, games
- Extra house keys and car keys
- List of contact names and phone numbers
- Food, water and supplies for pets

Home Emergency Preparedness

Before disaster strikes

- Choose a place for your family to meet after a disaster.

- Choose a person outside the immediate area for family members to contact in case you get separated. This person should live far enough away so he or she won't be involved in the same emergency.
- Know how to contact your children at their school or daycare, and how to pick them up after a disaster. Let the school know if someone else is authorized to pick them up. Keep your child's emergency release card up to date.
- Put together an emergency supply kit for your home and workplace. If your child's school or daycare stores personal emergency kits, make one for your child to keep there.
- Know where the nearest fire and police stations are located.
- Learn your community's warning signals, what they sound like and what you should do when you hear them.
- Learn first aid and CPR. Have a first aid kit, a first aid manual and extra medicine for family members.
- Learn how to shut off your water, gas and electricity. Know where to find shut-off valves and switches.
- Keep a small amount of cash available. If the power is out, ATM machines won't work.
- If you have family members who don't speak English, prepare emergency cards in English with their names, addresses and information about medications or allergies. Make sure they can find their cards at all times.
- Conduct earthquake and fire drills every six months.
- Make copies of your vital records and store them in a safe deposit box in another city or state. Store the originals safely. Keep photos and videotapes of your home and valuables in your safe deposit box.
- Make sure family members know all the possible ways to get out of your home. Keep all exits clear.
- Make sure all family members agree on an emergency plan. Give emergency information to babysitters or other caregivers.

During an emergency or disaster

- Keep calm and take time to think. Give assistance where needed.
- Listen to your radio or television for official information and instructions.
- Use the telephone for emergency calls only.
- If you are ordered to evacuate, take your emergency kit and follow official directions to a safe place or temporary shelter.

After the emergency or disaster is over

- Use caution in entering damaged buildings and homes.
- Stay away from damaged electrical wires and wet appliances.
- Check food and water supplies for contamination.

- Notify your relatives that you are safe. But don't tie up phone lines, they may be needed for emergency calls.
- If government disaster assistance is available, the news media will announce where to go to apply.

Out-of-Area Contacts

If you are separated from your loved ones when disaster strikes, you will need a way to find out where they are. The stress of the event may make it difficult to remember even routine information, like phone numbers. Every household member should have an out-of-area contact card in a wallet, purse or backpack at all times.

Things to do before disaster strikes

- Ask an out-of-area family member or friend to be your contact person. This person should live at least 100 miles away from you. It may be difficult to make local calls because large numbers of people may be using the phone lines at the same time. However, you should be able to make long distance calls.
- Make small cards with the contact person’s name and phone number for all family members to carry in their wallets, purses or backpacks.
- Keep a phone that does not require electricity. Cordless phones use electricity—if the power is out, they will not work!

Contacting loved ones after disasters

- All household members should call the out-of-area contact. The contact person will collect information about each family member, where they are and how to contact them.
- You may be able to send text messages to your loved ones on your cell phone. Keep messages short.
- Make sure the handsets to your phones are hung up—during events such as earthquakes handsets can get knocked off their bases. When large numbers of phones are off-the-hook, local phone service may stop working correctly.

You should be able to use a pay phone if your home phone does not work. Pay phones are part of the emergency services network, and are a priority to be restored to service. Tape the coins needed to use a pay phone to your out-of-area contact card.

PREVENTING INFECTIONS

Infections are caused by germs that spread from one person or location to another. Some germs spread when you come in contact with a contaminated surface, some are found in blood, and other body fluids and others are carried on tiny particles in the air. Helping prevent the spread of infection is one of the responsibilities of being a caregiver.

Here are some of the most important things you can do to fight the spread of infection:

Clean Your Hands Often

Washing your hands the right way and at the right times is the best way to prevent infection.

- Use soap and warm water, rubbing your hands for at least 20 seconds.
- Get in the habit of washing your hands both before and after: providing care; eating, drinking, or handling food; smoking; using the toilet; covering a cough, or blowing your nose.
- If washing with soap and water isn't possible, use an alcohol-based sanitizer hand gel, then wash your hands as soon as you are able to. The reason for always washing with soap and water is that some potential sources of infection are not killed by sanitizers and must be removed through hand-washing.

Maintain a Clean Caregiving Space

- Clean and disinfect bathroom and kitchen surfaces. Use paper towels that can be thrown away, cloth towels that can be washed in hot water or disposable sanitizing wipes.
- Laundry soiled with blood and/or body fluids should be washed separately from other laundry in hot water with one cup detergent. A cup of bleach can be added with an extra rinse.
- Disposable items soiled with blood and body fluids should be double bagged, sealed and disposed of in the regular, household garbage.
- Flush urine, stool, and vomit down the toilet.
- If bedpan or commode bucket is soiled, clean with toilet brush. Rinse with a dilute bleach solution. Mix 1/4 cup bleach with 2 1/4 cups water. Mix solution daily.
- Disposable syringes, needles, and lancets should be placed in a sharps container that your hospice nurse will provide to you. Close securely when 3/4 full and have your nurse pick it up for disposal.
- Do not recap needles, or purposefully bend, break or remove them from syringes.

Include Others in the Work of Preventing Infections

Your Hospice team can provide you with color posters for your door if you would like.

- Make it clear to others involved in care, and to guests who visit, what is expected, especially hand washing.
- Don't be afraid to ask healthcare providers if they've cleaned their hands!

If you are Sick, Avoid Close Contact with Others

- If you are sick, avoid close contact with others or stay home.
- When you sneeze or cough, cover your mouth and nose to prevent the spread of infection to others. Use a tissue and clean your hands after coughing or sneezing. If you don't have a tissue, cover your mouth and nose with the bend of your elbow or hands.

Prevent Unprotected Contact with Blood and Other Body Fluids

- If there is a spill of blood, avoid direct contact with blood during clean-up. Use extra caution around blood, body fluids, and any sharp objects (like used syringes).
- If personal protective items, such as gloves or masks, are recommended or specified by the hospice team, be sure you learn how to put them on and take them off correctly, and then use them as directed.

OXYGEN AND FIRE RISK

Oxygen may be provided for patient comfort. However, having open flames near oxygen may fuel a fire that could result in injury and/or the loss of property and life.

Instructions and Safety Tips for Oxygen Use

- DO place “Oxygen in use” signs in your front window and/or front door.
- DO keep oxygen and equipment at least 6 feet away from any source of heat or flame.
- DO ensure there is a fire safety device on your oxygen if there is a smoker in your home.
- DO store and secure oxygen properly:
- Small cylinders need to lay flat on the floor for storage or be kept in a storage rack
- Concentrators should be placed well-ventilated areas, at least 12 inches from the wall
- DO NOT smoke or vape any substance, or let anyone else do so where oxygen is in use.
- DO NOT use any petroleum-based products such as Vaseline on nose or face.
- DO NOT use an extension cord to plug in the concentrator.

Because of the risk of generating a spark, it is recommended that oxygen is kept at least 6 feet away from electric blankets, hairdryers, electric razors, and electric toothbrushes.

If traveling by car or RV

- Remind passengers not to smoke
- Securely fasten cylinders
- Keep one window partially open
- Do not store oxygen in the trunk

SUPPORTING STAFF AND VOLUNTEER SAFETY

In order to provide the best possible care for you and your family, please help to ensure our staff safety by following these guidelines:

- Secure all weapons such as guns.
- Do not smoke cigarettes or any other substance in the presence of our staff.
- Keep pets contained upon arriving to and during staff visits.
- Understand that our team members are unable to make or receive phone calls while driving their vehicle.
- Verbal or physical abuse toward any hospice team member is not acceptable.

Team members are encouraged to immediately leave any situation where they feel unsafe and report concerns to their supervisor.

FINAL DAYS…

Although death is a part of life, most of us have little to no experience with the dying process. The following information will help support you, family and friends, through your end of life. Many changes occur as death approaches, and we want you to feel confident in knowing what to expect. Not everyone who is dying will experience all of the changes described here. If you have questions, your hospice team will be glad to answer them.

While the processes listed in this section are normal, please be sure to alert your team if you see these changes. Your team wants to actively support you during this time.

Easing the mind

Communication

We're often concerned about how to express our feelings when a loved one is dying, and we worry about saying the right things. It is normal in these circumstances to feel sad, helpless or awkward. Honestly talking to the person who is dying lessens the likelihood they will feel alone.

Here are some helpful guidelines if you find yourself struggling with what to say or how to say it:

- Speak directly to the person who is dying instead of about them to others in the room.
- If they want to talk about death, listen actively. Resist the urge to change the subject or to "cheer them up."
- Allow deeper conversations. People who are dying want to know their lives have meaning. Ask them to share their favorite memories and share yours.
- If they are reluctant to share feelings, ask if they would like to speak with the hospice team social worker or chaplain.
- Even if eyes are closed, and they are unresponsive, they likely can hear your words. Speak to them.
- When words fail, your presence alone can be meaningful and reassuring. Sit quietly with them.

Surroundings

- You can create a comforting and familiar environment during the person's last few days of life.
- If they prefer solitude, create a quiet room with warm lighting, soft music, and photographs of family and friends.
- If they enjoy the bustle of family, allow relatives to gather and children to visit.
- Household pets have been known to stay close to the person who is dying. If they do not cause discomfort, pets may provide calm support.
- Touch can be supportive. Hold hands, gently stroke the forehead, rub lotion gently on skin or massage hands and feet.

- If they are in a hospital or facility, ask what changes can be made to the room to make it more peaceful and comfortable.

Withdrawal

- As the person’s strength decreases, they will likely show less interest in activities, surroundings or people. They may limit interactions to just a few family members or friends. If possible, ask the person who they would like to see.
- Withdrawal is common in the dying process. It’s natural for you to feel sad or even rejected if this happens. They may stop speaking in the final days. If you are a close family member or friend, your presence will continue to communicate your love and care.
- We believe hearing remains until the end. Speak in a calm, normal tone and know you will be heard.
- If they are sleeping, do not try to awaken them.
- Consider shorter visits by friends and extended family to avoid exhausting them.
- Touch may become important now.

Comforting the body

Changes in appetite

- The person will gradually stop eating or drinking. We often offer food as an expression of love and concern; however, it is normal in the dying process for your loved one to stop experiencing hunger or thirst. In fact, eating and drinking can cause discomfort during the last days.
- Respect their decision not to eat; do not try to force food or drink.
- If they are still eating, this is a good time to prepare favorite foods.
- Offer smaller portions of food throughout the day.
- Ask the nurse for ideas about what foods and fluids may be given.

Difficulty or inability to swallow

- It may become more difficult to swallow as the throat muscles become weaker.
- Offer small sips of water to test their ability to swallow.
- If they are choking or coughing, this may be a sign their ability to swallow is changing. Call the hospice nurse for options.
- Thicker liquids may be easier to swallow.
- If their mouth is dry and they can no longer swallow, offer ice chips or swab the mouth.

Temperature and skin changes

- The person may feel hot or cold. The hands, legs, and feet, may become cool to touch. Lips, hands, and feet may become darker, blotchy or bluish in color.
- Add or remove blankets as needed. Do not use an electric blanket.

- If they feel too warm, gently place a cool washcloth against the forehead.

Confusion, disorientation

- It's possible the dying person will become confused or disoriented.
- Identify yourself by name when speaking.
- Speak slowly, ask one question at a time, and allow more time for them to respond.
- Explain what you are planning to do when providing physical care.
- Avoid over-stimulation and limit the number of visitors in the room.
- If they appear uncomfortable, call the hospice nurse.
- Ask the chaplain or social worker to visit for emotional or spiritual support.

Restlessness and agitation

- It's possible the dying person may appear agitated and restless. You may notice repetitive motions such as tugging at bedding or clothing. This may be caused by increased fear, discomfort or the effects of medication. It may also mean they are having emotional or spiritual distress.
- Create a calm environment.
- Talk calmly, read to them, or play their favorite music.
- Sit quietly with them.
- You might try a light, soothing massage on the forehead, hands or feet.
- Allow the patient to move freely. Do not restrain them. Restraint may actually increase restlessness.
- If they appear uncomfortable, call the hospice nurse.
- Ask the chaplain or social worker to visit for emotional or spiritual support.

Decrease in urine, loss of control

- As the person drinks less, urine will become more concentrated and darker and may have a stronger odor. As the body weakens, it's common for the person to lose bowel and bladder control. This change can be upsetting to both you and the dying person; however, this is a normal result of the changes in the body.
- Keep them warm and dry, using disposable pads if necessary.
- Change soiled bed linens. Pads between the body and the bed will help keep the mattress clean.
- Ask the nurse about incontinence supplies or urinary catheter.
- Inform the hospice nurse if they have not urinated in twelve hours.

Congestion and breathing changes

- Fluid may begin to collect in the lungs and throat, resulting in gurgling and rattling sounds. Although these sounds can be disturbing to hear, they cause little or no distress to the dying person. Breathing may become fast and shallow, followed by deeper, irregular breaths. They may stop breathing entirely for up to a minute. They may moan when exhaling. This does not mean there is pain or suffering; it is merely air moving over relaxed vocal cords.
- Raise the head of the bed slightly and turn them on their side.
- Share any concerns with your nurse.

Honoring the spirit

Spiritual and dream experiences

- As the person moves closer to death, it is not unusual for the person to speak symbolically about their death, asking for help to "pack my bags" or wanting to "go home."
- They may see or talk to people whom we cannot see. Often this is a family member, friend or pet who has died. These experiences prepare a person for death and are a normal, natural part of the dying process. For the caregiver, this is an indication the person is in the final days of life.
- Encourage your loved one to talk about what they are experiencing.
- Do not try to talk them out of their experience.
- If they are frightened, offer comfort and call the hospice nurse.

Letting Go and Saying Good-Bye

- Sometimes at the end of life, the body appears ready to stop working at any moment yet the person seems to be lingering. A dying person sometimes lingers, even at the risk of discomfort, if there are issues still needing to be resolved such as:
- Saying goodbyes
- Letting go of regrets
- Receiving or giving forgiveness
- Knowing those left will be ok
- As a family member or friend, you may talk with the person who is dying about any unresolved issues and help as you can. Not all issues, though, can be resolved.

You may want to

- Give them permission to go when they are ready.
- Say goodbye in your own way. This may include offering words of love, forgiveness or gratitude; quietly holding their hand and sending love, or talking about important memories.

- It may be helpful to call friends and family who can’t be there and hold the telephone to their ear to say goodbyes.
- Rituals can be meaningful. If you are seeking support for a ritual for the dying process, the hospice chaplain can be an excellent resource.
- Let them know you will miss them and you will be okay.
- Tears are a natural part of saying goodbye. You don’t need to hide them or apologize for them. They are a normal part of grief and love.
- The hospice team social worker and chaplain are also here to assist.

WHEN DEATH OCCURS

How will you know when death occurs?

The following signs are an indication that a person has passed away.

- No breath.
- No heartbeat.
- No response to touch or noise.
- Eyes may be open with a fixed gaze.
- The body will stay warm for a short while and will become cooler as time passes.

At the time of death

- You do not need to call 911 because death is not a medical emergency.
- Notify hospice that your loved one has passed away. The hospice staff will ask the approximate time of death.
- The hospice team will provide support and answer questions by phone or with a visit.
- Hospice will confirm the funeral home or body donation program and will call for you upon your request.
- It often takes the funeral home an hour or more to arrive. If you would like more time with your loved one, just let hospice know, and we will inform the funeral home.
- You may want to honor your loved one before their body leaves the home either alone or with family or friends.
- The removal of your loved one's body may be hard to watch. Consider if you want to be present and if you want family or friends to be with you.
- Hospice will contact the attending provider, the medical equipment provider, and the coroner/other authorities where indicated.

Caring for a body after death

You may want to

- Spend time with the person who died and continue saying good-bye.
- Sit quietly, pray or share sacred readings.
- Honor them by gently washing the body, combing hair, or applying lotion or oils.
- Call your hospice team to help with preparing the body and for support.

Information you want to have readily available at time of death

Family or friend you would like to be with you at time of death:

Name: ________________________________
Phone Number: ________________________

Others you may wish to call:

Name: ________________________________
Phone Number: ________________________

Name: ________________________________
Phone Number: ________________________

Name: ________________________________
Phone Number: ________________________

Spiritual Provider from your faith community:

Name: ________________________________
Phone Number: ________________________

Funeral Home:

Name: ________________________________
Phone Number: ________________________

Notes: ____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____

UNDERSTANDING HOW DEATH CERTIFICATES WORK

Washington State replaced the paper process for filing death records with the Electronic Death Registration System (EDRS). The system is used by those with the legal authority to complete a death certificate, including funeral directors, physicians, medical examiners, coroners, and deputy registrars.

The funeral home will start the process after the patient has been transferred into their care. They will use the EDRS to send a request to the patient's attending provider to fill out the information needed to complete the Death Certificate. The Attending will do everything they can to complete this in a timely manner. Once the information is entered into the EDRS, the Death Certificate will be filed with the Washington State Center for Health Statistics or you can order them online by going to https://www.doh.wa.gov/LicensesPermitsandCertificates/BirthDeathMarriageandDivorce.

If you require the Death Certificate Process to be completed within 24 hours, please let your team know ahead of time so they can work with the attending and funeral home to move this process quickly during the day.

You can order certified copies of the death certificate from the funeral director. Often you can get them from the local Department of Health off in the county where the death occurred. Generally, you will need one certified copy of the death certificate for each major asset (cars, land, bank accounts, life insurance policies, etc.) for which you will need to transfer ownership.

GRIEF SUPPORT AFTER LOSS

Our Grief Support Services team is available to your and your family throughout the coming year. Within a few weeks, a member of that team will be in contact with your family.

If at any time you would like to speak to a member of the Grief Support team, please don't hesitate to call.

Providence Hospice of Seattle	**Providence Hospice of Snohomish County**	**Providence SoundHomeCare and Hospice**
206-749-7702	425-261-4807	360-493-4684

For urgent counseling assistance please call the Crisis Line

King County	**Snohomish County**	**Lewis County**
206-461-3222	800-584-3578 425-258-4357	800-559-6696 **Thurston and Mason County** 360-754-1338

FINAL ARRANGEMENT PLANNING

Hospice patients and their loved ones have various decisions to make regarding their final arrangements. Some patients are able and willing to be involved in the planning and decision making before or during their hospice care. Others will need their loved ones and/or legal decision maker to decide. Your hospice social worker can be a resource to talk with you about options, community resources, funeral homes and practical things to consider regarding final arrangements.

Some patients are interested in preplanning and may even choose to prepay for their final arrangements and/or join a cremation society or cooperative funeral association. Whether you are reading this at the time or need or want to plan in advance, the following information introduces what to consider regarding final arrangements.

Decisions to be made include:

- Burial vs. cremation.
- Funeral home or mortuary choice.
- Final resting place.
- Considering the costs for final arrangements and resources.
- If you will have a memorial or celebration and how to plan for it.
- Designate a legacy contact, someone who will handle online and social media accounts after death.

Tips for working with Funeral Home or Cremation Society

- Hospice will ask at time of death when you will be ready for the funeral home to transport.
- The funeral home or mortuary selected will transport the body from the place of death into their care facility.
- The funeral home completes the necessary paperwork for the death certificate with medical information provided by hospice and vital statistics from the family. Death certificates are provided for a fee (set by the government) per certified copy from the funeral home. It is helpful to consider how many certified copies are needed to settle the estate.
- The funeral home makes the initial notification to social security administration that a beneficiary is deceased.
- The funeral home can assist with preparing an obituary and funeral notice for a newspaper(s) and/or online.
- Meeting with the funeral director can be stressful. If possible have someone go with you for support and help with decisions.
- Make sure you understand what is included in the service fees and what will be charged as an additional service.
- It is ok to take time to make decisions about what you want. If you are uncertain, go home and think about it, then call the funeral home back.

- Ask about costs and consider what you can afford. Funeral homes are required to provide information on price for services upon request including by phone.
- Only purchase what seems reasonable and appropriate for your situation.

Planning a Funeral or Memorial Service

Services, both formal and informal, can be a source of comfort and strength as loved ones gather together to remember and grieve. Various rituals of remembrance can be helpful to celebrate a life. Your hospice social worker or chaplain can help with service planning and discuss ways to honor your loved one.

Things to consider in planning a service:

- Are there any specific instructions about the kind of services wanted? Do these instructions include any requests for readings, music, or location?
- When will it be convenient for the service to take place? Do religious beliefs determine the timing? Are there family or friends that need to make travel arrangements?
- Where will the service take place? If a religious community is involved, when can it schedule a service?
- Who will officiate (lead the service)? Will it be a religious leader, clergy, family member or friend? Funeral directors and hospice chaplains can be helpful to find a formal officiate.
- Do you want an organist, soloist, or another provider of music?
- Do you want to choose someone to deliver a formal eulogy? Do you or other family members and/or friends wish to share some words of remembrance at the service?
- Do you wish to have visiting hours (a time when people can view the body and say a private goodbye)?
- Are there pictures, music, readings or any other elements that would add to the ceremony’s meaning for you and other loved ones?
- Will there be any kind of reception or informal gathering of family and friends after the service?

Practical Issues after a Loved One Dies

- How will you notify others after your loved one has died? Some people list contacts to be called when a death occurs and ask those contacts to inform others within that social circle. Some calls you will want to make yourself. You may prefer to assign a trusted person to make other calls for you.
- Taking care of all of the business that needs to be sorted out after a death can take weeks to months. It is tiring and often emotionally draining for survivors who are grieving. Whenever possible, share the responsibilities with another person and focus on priorities. For many families handling their loved one’s personal possessions is difficult, and often easier when multiple people can share the load.

- Checklists are available to help you understand and organize the things to do after a death has occurred. Please ask your hospice social worker if you would like a checklist to manage the various practical matters to consider.

HOW YOU CAN HELP HOSPICE

Many times a family will look for ways to say thank you to the staff who have cared for their loved one. A donation to Providence Hospice is a special way to express your gratitude. Your gift makes it possible for us to care for all regardless of their ability to pay.

Honoring Your Loved One

- You may make a gift to the hospice who served your loved one by donating via phone, online or by completing and mailing the donation envelope included in this binder.
- Suggest donations to Providence Hospice instead of flowers through a funeral home or newspaper announcement. We always inform families of gifts made in memory of their loved one. We don’t disclose the amount of the contribution.
- You can make a gift through your will.

We are a nonprofit organization. Your donations are tax deductible.

Providence Hospice of Seattle
Providence Hospice of Seattle Foundation
2811 S. 102nd Street, Suite 220
Tukwila, WA 98168
www.providence.org/hosdonate.
206-320-7188.

Providence Hospice and Homecare of Snohomish County
Providence Hospice and Home Care Foundation
2731 Wetmore Ave, Suite 500
Everett, WA 98201
https://washington.providence.org/donate/hospice-home-care-of-snohomish-county-foundation
425-261-4822.

Providence SoundHomeCare and Hospice
Providence St. Peter Foundation
413 Lilly Road NE
Olympia, WA 98506
https://washington.providence.org/donate/st-peter-foundation
360-493-7981

APPENDIX A: RIGHTS AND RESPONSIBILITIES

Rights and Responsibilities are a valuable part of our teamwork with you. It is important to us that we have a mutual understanding of these shared rights and responsibilities. Patients have a right to be notified verbally and in writing of their rights and responsibilities and to exercise those rights as a hospice patient.

You have the right:

- To be treated with courtesy, respect and privacy;
- To have your property treated with respect;
- To be free from mistreatment, neglect or verbal, mental, sexual, and physical abuse; exploitation, and discrimination including injuries of unknown source and misappropriation of patient property;
- To be cared for by properly trained personnel, contractors, and volunteers with coordination of services;
- To know the name of the individual supervising your care and the manner in which that individual may be contacted;
- To be involved in developing your plan of care and to have ongoing participation in the development of that plan of care;
- To refuse care or treatment or services;
- To receive information about the services covered under the hospice benefits;
- To receive information about the scope of services that the hospice will provide and specific limitations on those services;
- To receive quality services from hospice for services identified in the plan of care;
- To be informed of the agency's policies and procedures regarding the circumstances that may cause the agency to discharge a client;
- To receive effective pain management and symptom control from the hospice for conditions related to your terminal illness.
- To be informed of the agency's policies and procedures for providing backup care when services cannot be provided as scheduled;
- To choose your attending physician;
- To privacy and confidentiality of personal and a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164;
- To be informed of what the hospice agency charges for services, to what extent payment may be expected from care insurance, public programs, or other sources, and what charges the client may be responsible for paying;
- To a fully itemized billing statement upon request, including the date of each service and the charge. Agencies providing service through a managed care plan are not required to provide itemized billing statements;

- To be informed about and have the power to execute advance directives and POLST , and the agency's scope of responsibility;
- To information regarding access to the department's listing of providers and to select any licensee to provide care, subject to the individual's reimbursement mechanism or other relevant contractual obligations;
- To know the process for submitting complaints to the hospice about the services and care you are receiving and to have those complaints addressed without retaliation;
- To be informed of the state complaint hotline number, the purpose of which is to receive complaints or questions about the local hospice, and hours of operation.

  Washington State Health Care Hotline:
  1-800-633-6828, 8:00 AM to 5:00 PM, Monday – Friday
  OR
  Write to:
  Department of Health, Facilities Licensing,
  P.O. Box 47852
  Olympia, WA 98504-7852
  TDD Relay number for the hearing impaired: 1-800-833-6388, OR

  Community Health accreditation Program
  1-800-656-9656, 8:00 AM to 5:00 PM, Monday – Friday, Eastern Standard Time.
- To be informed of the DSHS end harm hotline number to report suspected abuse of children or vulnerable adults.

  Call 1-866-ENDHARM (1-866-363-4276)
  Call 9-1-1 if a child or adult is in an emergency situation.

You have the responsibility to:

- Participate in decisions involving your care.
- Provide a complete and accurate medical history to the best of your knowledge, and provide information about current medications or treatments, including experimental or herbal treatments.
- Ask questions and seek clarification about your diagnosis, course of treatment or care plan.
- Provide information about complications or health symptoms.
- Follow the proposed course of treatment or care, recommendations and advice, upon which you, your provider and the hospice have agreed.
- Provide accurate and timely information about sources of payment and your ability to meet financial obligations.
- Make it known whether you understand what is expected of you, and whether you are able and willing to comply.
- Be available for scheduled visits, notify Providence Hospice if unable to make appointments.

- Refrain from smoking cigarettes or any other substance in the presence of our staff and at all times if oxygen is in use.
- Ensure our staff safety by securing all weapons; guns etc.
- Ensure our staff safety by keeping pets contained during staff visits.
- Notify Providence Hospice before, or immediately after, any calls to 911 or intent to seek emergency medical treatment.
- Parents and guardians may represent or assist a patient in fulfilling these rights and responsibilities.

PLEASE LET ANY MEMBER OF YOUR TEAM KNOW IF YOU HAVE ANY QUESTIONS REGARDING THESE RIGHTS AND RESPONSIBLITIES.

APPENDIX B: JOINT NOTICE OF PRIVACY PRACTICES

Joint Notice of Privacy Practices

This Joint Notice of Privacy Practices (Notice) describes how health information about you may be used and disclosed and how you can get access to this information. Please review it carefully. The Notice is being provided to you on behalf of Providence Health & Services (Providence), its medical staff and other providers (collectively referred to herein as "we" or "our").

Providence is committed to protecting the confidentiality of your health information.

We are required by law to maintain the privacy of your protected health information (commonly called PHI or health information), including PHI in electronic format. We are also required to notify you of our legal duties and privacy practices regarding your health information and abide by the practices of this Notice, unless more stringent laws or regulations apply. This Notice applies to all Providence facilities, services and programs that provide health care to you.

Application of this Notice

The information privacy practices described in this Notice will be followed by:

Any health care professional who treats you at any of our locations
All facilities, departments and units, including hospitals, surgical centers, home care, clinics and other affiliates
All workforce members such as employees, medical staff, trainees, students, volunteers and other persons under our direct control whether or not they are paid by us
Other health care providers that have agreed to abide by this Notice of Privacy Practices

This Notice provides detailed information about how we may use and disclose your health information with or without authorization as well as more information about your specific rights with respect to your health information.

Uses and disclosures of your health information that we may make without your authorization

To contact you: Your information may be used to contact you to remind you about appointments, provide test results, inform you about treatment options or advise you about other health-related benefits and services.

Treatment: Your information may be shared with any health care provider who is providing you with health care services. This includes coordinating your care with other health care providers and providing referrals to other health care providers. Examples of health care providers who may need your information to treat you include your doctor, pharmacist, nurse and other providers such as physical therapists, home health providers, and X-ray technicians. We may share your information electronically with your health care providers in order to make sure they have your information as quickly as possible to treat you.

We may share your health information with any family member or friend who is involved in assisting with your health care. We will only do this if you agree or do not object, and will only share with them the information they need in order to help you. If you are unable to either agree or object to such a disclosure, we may disclose your health care information as necessary if we determine that it is in your best interest based on our professional judgment.

We may disclose health information to a family member, relative or another person who was involved in your health care or payment for health care when you are deceased if not inconsistent with your prior expressed preferences.

Payment: In order to obtain payment for your health care services, we may have to provide your health information to the party responsible for paying. This may include Medicare, Medicaid (state health plan) or your insurance company. Your insurance company or health plan may need your information for activities such as determining your eligibility for coverage, reviewing the medical necessity of the health care services provided to you or providing approval for hospital services or stays.

Health care operations: Your health information may be used in order to support our business activities and to assure that quality health care services are being provided. Some of these activities include quality assessments, peer or employee review, training of medical personnel, licensure and accreditation, data aggregation and audits by regulatory agencies.

We may share your PHI with third parties who perform services such as transcription or billing. In those cases, we have written agreements with the third parties that they will not use or disclose your health information except if permitted by law.

We may also use your information (name, address, date of birth, department of service, treating physician, dates of treatment, outcome) for our fundraising activities.

You have the right to opt out of receiving such communications. If you do not want to receive these materials, please contact our foundation office and request that these materials not be sent to you.

Unless you object, your name and location may be included in our patient directory. If it is included, we will only share very limited information about you, such as your location in a hospital and general status, with anyone who asks about you by name. If you choose to provide your religious affiliation and do not object, we may provide your name and room number to clergy from your faith or religious community.

This Notice also describes the privacy practices of an Organized Health Care Arrangement (“OHCA”) between us and certain eligible health care providers and organizations. An OHCA allows legally separate covered entities to use and disclose PHI for the joint operation of the arrangement.

We participate in such an arrangement of health care organizations who have agreed to work with each other to facilitate access to health information relevant to your care. For example, if you present to a hospital for emergency care and cannot provide important information about your health, the OHCA will allow us to use your PHI from our OHCA participants to treat you. When it is needed, ready access to your PHI means better care for you. We store health information about our patients in a joint electronic health record with other health care providers who participate in this OHCA. Providence and members of the OHCA must be able to share your health information freely for treatment, payment and health care operations purposes. For this reason, we have created the OHCA and this Joint Notice. OHCA members may choose to have their own Notice(s). For information about organizations participating in our OHCA, please contact the Privacy Office listed in this Notice.

Other uses and disclosures that we may make without your authorization

There are a number of ways that your health information may be used or disclosed without your authorization. Generally, these uses and disclosures are either required by law or for public health and safety purposes.

When required by law: We may use or disclose your health information when required by law. If this happens, we will comply with the law and will only disclose the information necessary.

Public health: We may disclose your health information to a public health authority for public health activities. Public health activities include preventing or controlling disease, injury, disability, and responding to reports of abuse, neglect or domestic violence. We may disclose your health information to a person or agency required to report adverse events, product defects or problems, biologic product deviations, or for product recalls, repairs or replacements. Any disclosures of this nature will be made consistent with state and federal law.

Health oversight: We may disclose your health information to health oversight agencies for oversight activities authorized by law, such as audits, investigations, and inspections. Health oversight agencies include government agencies that oversee the Health care system, government benefit programs, government regulatory programs and civil rights.

Legal proceedings: We may use or disclose your health information in response to a court or administrative order in an administrative or judicial proceeding, or in response to a subpoena, discovery request or other legal process.

Law enforcement: We may use or disclose your health information for law enforcement purposes. Examples include (1) responding to legal processes; (2) providing limited information to identify or locate a suspect; (3) providing information about crime victims; (4) reporting suspicion that death has occurred as a result of criminal conduct; (5) reporting a crime which occurred on our premises; and (6) for medical emergencies, reporting where it appears likely a crime occurred.

Preventing a serious threat: We may use or disclose your health information if we believe in good faith that the use or disclosure is necessary to prevent or lessen a serious and imminent threat to the health and safety of a person or of the public. Disclosure may only be made to a person reasonably able to prevent or lessen the threat.

Coroners, funeral directors, and organ donation: We may disclose your health information to a coroner or medical examiner for identification purposes, determining cause of death or other legally required duties. We may disclose your health information to a funeral director in order to permit him/her to perform his/her duties. We may disclose your information to facilitate an organ, eye or tissue donation.

Research: We may disclose your health information to researchers, provided that the research has been approved by an Institutional Review Board and/or a Privacy Board, and the research protocols have been approved to ensure your privacy. We may disclose health care information about you to people preparing to conduct a research project.

Military activity and national security: We may disclose the health information of Armed Forces personnel: (1) for activities deemed necessary by appropriate military command authorities; (2) for the purpose of a determination by the Department of Veterans Affairs of your eligibility for benefits; or (3) to a foreign military authority if you are a member of that foreign military service. We may also disclose your health information to authorized federal officials to conduct national security and intelligence activities, including the provision of protective services to the President or others legally authorized to receive information.

Inmates/arrestees: We may use or disclose your health information to a correctional institution or law enforcement official if you are an inmate of a correctional facility or are in custody and the information is necessary to treat you or protect the health and safety of you, other inmates, employees at the correctional facility or others.

Workers’ compensation: We may use or disclose your health information as necessary to comply with workers’ compensation laws and other similar legally established programs.

Disaster relief: We may disclose health care information about you to an entity assisting in a disaster relief effort so that your family and friends can be notified about your condition, status, and location.

Uses and disclosures of your health information that we may make with your authorization

Certain uses and disclosures of your health information, including marketing, sale of health information or release of psychotherapy notes, will be made only with your written authorization. You may revoke an authorization in writing at any time, except to the extent that we have already taken action in reliance on the authorization.

Uses and disclosures not otherwise described in this Notice will be made only with your written authorization. Federal and state laws may place additional limitations on the disclosure of your health information for drug or alcohol abuse treatment programs, sexually transmitted diseases, or mental health treatment programs. When required by law, we will obtain your authorization before releasing this type of information.

Your Rights

Right to request restrictions: You have the right to ask us to place restrictions on the way we use or disclose your health information for treatment, payment or health care operations. We will consider your request but are not required to agree to the restriction (except as described below). If we agree to a restriction, we will not use or disclose your health information in violation of that restriction unless it is needed for an emergency. If a restriction is no longer feasible, we will notify you.

Right to restrict disclosure to health plans: You may request in writing, at the time of service, that we not disclose information to health plans where you have paid for items or services out of pocket in full. We must agree not to disclose this information to your health plan if certain conditions are met.

Confidential communications: We will accommodate reasonable requests to communicate with you about your health information by different methods or alternative locations. For example, if you are covered on a health plan but are not the subscriber, and would like your health information sent to a different address than the subscriber, we can usually do that for you.

Breach notification: You have the right to receive notification of breaches of your health information as required by law.

Access to your health information: You have the right to receive a copy of your health information that we maintain, with some limited exceptions. You may request access to your information in writing, and you may request a copy of your information in electronic format. We reserve the right to charge a reasonable fee for the cost of producing and providing your health information. You have the right to request that your health information be sent to any person or entity, such as another doctor, caregiver or online personal health record.

Amendment of your health information: You have the right to ask us to amend any of your health information. You need to request this amendment in writing and submit it to the facility’s medical records department. We may deny your request in certain situations, such as when the health information in your records was created by another provider or if we determine your information is accurate and complete. Any denials will be in writing. You have the right to appeal our denial by filing a written statement of disagreement.

Accounting of certain disclosures: You have a right to a listing of the disclosures we make of your health information, except for those disclosures made for treatment, payment, or health care operations, or those disclosures made pursuant to your authorization. The type of disclosures typically contained in a listing would be disclosures made for mandatory public health purposes, law enforcement, legal proceedings, or for other required reporting such as birth and death certificates.

Exercising your rights: To exercise any of the above rights or if you need to share your health information with someone for purposes other than those listed here, contact the appropriate medical records department.

Questions and complaints

If you have questions or are concerned that any of your privacy rights have been violated, please contact our Privacy Officer:

Alaska, 1-800-510-3375
California, 1-800-628-7768
Oregon, 1-855-360-3464
Washington and Montana, 1-855-768-7145

You also have the right to complain to the Secretary of Health and Human Services at:

Office for Civil Rights – AK, WA, OR, MT
U.S. Department of Health and Human Services
2201 Sixth Avenue - M/S: RX-11
Seattle, WA 98121-1831

Office for Civil Rights – CA
U.S. Department of Health and Human Services
90 7th Street, Suite 4-100
San Francisco, CA 94103

You will not be retaliated against for filing a complaint.

Changes to Joint Notice of Privacy Practices

We reserve the right to change the terms of our Notice at any time. New Notice provisions will be effective for all protected health information that we maintain. You may view a copy of our most current Notice on our website at www.providence.org, or request a current copy from the medical records department, privacy officer, or registration staff at any time.

COMMUNICATION LOG

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

Communication Log		
Date	Time	Name and Comments/ Observations/ Questions/ Instructions

MEDICATION LOG

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

<table>
<tr><td colspan="4">Medication Name:</td><td colspan="4">Medication Name:</td></tr>
<tr><td>Date</td><td>Time</td><td>Dose</td><td>Comments</td><td>Date</td><td>Time</td><td>Dose</td><td>Comments</td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

<table>
<tr><td colspan="4">Medication Name:</td><td colspan="4">Medication Name:</td></tr>
<tr><td>Date</td><td>Time</td><td>Dose</td><td>Comments</td><td>Date</td><td>Time</td><td>Dose</td><td>Comments</td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

Medication Name:				Medication Name:			
Date	Time	Dose	Comments	Date	Time	Dose	Comments

OPIOID DISPOSAL FORM

Patient Name:

MRN:

Family/Caregiver agrees to allow hospice staff to dispose of controlled drug(s) ☐ Yes ☐ No

Name of person declining disposal of controlled drug(s):

Signature of person declining disposal of controlled drug(s):

Name	**Dosage**	**Dosage Form**	**Route of Administration**	**Quantity**

Time:

Date:

Method of Disposal:

Name of Staff Disposing of Drug(s):

Signature of Staff Disposing of Drug(s):

Name of Witness to Drug Disposal:

Signature of Witness to Drug Disposal: