Hospice
of the northwest

Patient Guidebook

360-814-5550 | www.HospiceNW.org

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-360-814-5550.

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-360-814-5550。

Hospice of the northwest

Compassion and dignity every moment of life

Contact Hospice Day or Night

Call Hospice before calling 911

Hospice of the Northwest
Phone: 360-814-5550
www.HospiceNW.org
Backup Phone: 877-590-6317

Scan this QR code with the camera on your phone to store our information as a contact in your phone or mobile device.

We honor the dignity and worth of each individual, as well as the diverse and unique perspectives of our patients, our workforce, and the communities we serve.

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A letter from Bob Laws

Executive Director, Hospice of the Northwest

Dear Patient, Family, and Caregivers;

I want to thank you for trusting us as a partner during this important time. The journey to hospice has likely been difficult. I want to assure you that our team is highly trained and ready to support you, your loved ones, and those who care for you.

Hospice of the Northwest is committed to providing high-quality services and exceptional communication. Our goal is to provide excellent patient care. I invite you to call me directly, or speak with our Quality Manager, Christine Nidd, if we are not meeting these standards. You can reach me at 360-814-5579 and Christine Nidd at 360-814-5554.

This guidebook will be a resource while you are receiving hospice services. The first part of the guidebook is written with the patient in mind. Later sections of the guidebook will provide information and resources for loved ones and caregivers. We want to support you and all those who care for you.

This experience can be overwhelming at times. Questions may come up between visits with your Hospice Team. I encourage you to write these questions down in the note pages of this book, so we can make sure they are answered during your next visit.

Please call our office, day or night, if you have questions about hospice services or patient care: 360-814-5550.

This may be a difficult time. Please know that we are here to help and support you, your loved ones, and everyone on your care team.

Sincerely,

Notes

Section 1: About Hospice

The Concept of Hospice Care

Hospice is a special kind of medical care focused on quality of life. We usually think of medical care as a method for curing illness. However, the philosophy of hospice is to accept death as a natural part of life. We treat the symptoms and the person rather than the disease itself. Our team is focused on providing comfort and creating a caring environment.

Your Hospice of the Northwest care team will be made up of dedicated experts in end-of-life care. We provide holistic care, treating the mind, body and spirit of each individual, while recognizing the interconnected nature of a person's environment and their unique social and cultural identities. We provide specialists to support you in a number of ways. For example:

- **Physical Comfort** – Addressing pain, inability to "get a breath", sick stomach or nausea
- **Emotional Wellness** – Reducing anxiety, worry about becoming a burden, leaving loved ones, seeking closure, sadness
- **Spiritual Support** – Looking for meaning, seeking forgiveness
- **Process Assistance** – Medication management, assistance finding caregiving, medical equipment coordination
- **Decision Support** – Understanding what care makes the most sense for you

We encourage you to be *in charge of your care*. We ask you to guide us in exploring who you want help from and what kind of help you desire. Your hospice care team is here to help you meet your goals.

About Hospice of the Northwest

Hospice of the Northwest is a **Medicare certified, Washington State approved**, hospice. We are fully accredited by an objective third party, the Community Health Accreditation Partner (CHAP). This accreditation demonstrates our commitment to providing excellent hospice care. If we are unable to fully address a concern, you may contact our accrediting organization at 1-800-656-9656. This hotline receives consumer concerns and questions about CHAP accredited organizations 24 hours a day, seven days a week. You may also contact the Washington Department of Health's Complaint Hotline at 1-800-633-6828.

Hospice of the Northwest has been providing hospice services since the early 1980’s. We are co-owned by two Public Hospital Districts: Public Hospital District #1, commonly known as Skagit Regional Health, and Public Hospital District #304.

Your Hospice Care Team

Each patient is supported by a team of highly-trained professionals. Each member of your team has a specialty practice that focuses on you. The team works together to help you plan and achieve the care you want.

The Core Team includes:

Board Certified Hospice Physician – Your hospice physician reviews your medical history and makes recommendations for comfort and symptom reduction. They will keep your primary doctor informed through direct contact and reports. Your primary doctor may ask the hospice physician to manage your care. If that happens, your hospice team will let you know.

Registered Nurse (RN) – Your registered nurse is also your case manager. Registered nurses serve as team leaders, coordinating your care with the rest of the team. Your nurse will assess your needs and symptoms on every visit. They will discuss changes to your plan of care with you, your caregivers, loved ones, and the physician(s).

Social Worker (SW) – Your social worker is an expert in many areas that support your end-of-life journey. The social worker will provide counseling, as well as information about financial issues, final arrangements, care environment options, hiring additional caregivers, and other community resources as needed.

Spiritual Counselor – Your spiritual counselor will give you the opportunity to share and explore your feelings and your spirituality, if you choose to do so. There are end-of-life struggles common to most people, no matter their spiritual or religious background. Spiritual Counselors do not come with a specific religious affiliation or agenda. We use the title of Spiritual Counselor to assure you that whatever your spiritual views are, we will support you.

As your team begins to understand your goals and needs, additional team members may be added.

Additional team members could be:

Hospice Care Aide (HCA) – Every hospice care aide is a Certified Nursing Assistant (CNA). They will assist you with personal care, such as bathing, hair care, and mouth/teeth care. In addition, the aide can assist with light housekeeping and with tasks which increase your safety and your ease, as directed by your registered nurse.

Integrative Therapists – Integrative therapies and services may include massage, aromatherapy, energy work, clinical music, pet therapy, and other services. Foundation donors provide 100% of the funds to support and pay for integrative therapies and services. There is never a cost to you for these services.

Volunteer - Volunteers are trained to provide companionship, listening, and support. Volunteers can provide short term (up to four hours, once per week), in-home respite for your caregiver, allowing them to take a break. They can also offer pet care. It is important to note that Washington State Department of Health regulations limit the volunteers' scope of work. Volunteers cannot feed, transfer, medicate, bathe, assist in the bathroom, or transport patients.

Other specialists may occasionally be added when your team determines medical necessity. All of the services provided by Hospice of the Northwest are assessed by your team and are discussed with you prior to beginning.

It is important to note that Hospice of the Northwest cannot provide hourly or shift-type caregiving. *The services provided by your hospice team are intended to support you, your family, and your caregiving team. If hourly/shift-type caregiving is necessary, your social worker will provide the information for you to arrange this type of care.*

Your hospice team meets regularly to review the care you are receiving, including your goals and cultural, religious, and/or spiritual preferences. Often, in conversation with a team member in your home, you will hear "I'll bring this up in team." This meeting assures that your plan is comprehensive and individualized.

Your team is assigned to you. The continuity and consistency of your assigned team benefits your care. However, when a member of your team is not on duty, you may receive visits from other team members. And, at times, a permanent change of assignment may occur which will result in a change of a team member. Hospice of the Northwest strives to limit these changes as we know you develop trust with your team. When a change to the team is made, key information is shared with the new team member regarding your plan of care and goals.

Levels of Care That Hospice Provides

Our commitment is to ensure you, your loved ones, and caregivers are fully supported while receiving hospice services. We work to assure your comfort, dignity, and quality of life as defined by you. Levels of care are determined through consultation with your hospice team, the hospice physician, and your primary doctor.

Routine Care – Routine care is provided “where you live.” This could be a private residence, a retirement apartment, an Adult Family Home, or a skilled nursing facility. Routine care is the typical type of care hospice patients receive.

Respite Care - Respite care is available on an occasional basis for your loved ones and caregivers. When they can’t be with you for some reason (perhaps they need to briefly be out of town or they need to rest) your hospice team will arrange for respite care. Respite care moves you to a contracted skilled nursing facility for up to 5 days. Hospice of the Northwest makes all the arrangements for you, including paying for transportation, if needed.

Continuous Care - Continuous care is provided in the home if your symptoms increase and a nurse needs to stay with you to get symptoms controlled. The nurse may stay longer than a routine visit and you may have a hospice care aide assist once symptoms are more controlled.

General Inpatient Care (GIP) – General inpatient care is provided in a contracted hospital for symptoms that we cannot manage in the home setting. Although this level of care is provided in a hospital, the focus remains on comfort and symptom reduction. General inpatient care is directed by your hospice physician and hospice team.

As stated previously, hospice services are not designed as an hourly, private duty service. We provide care on a per-visit basis. If more care is needed in the home, we may suggest you arrange for additional services. Sometimes your desire to stay in your home is complicated by safety concerns. Your team will work with you and your loved ones to address safety, while respecting your values and goals.

Call Hospice, Day or Night

Hospice provides support around the clock, including holidays. **Call 360-814-5550 day or night** to talk with a staff member. Please note that your calls may be recorded for quality assurance.

In the unlikely event that the main phone line is not working, the back-up number to dial is 1-877-590-6317.

During the day - Our phone system answers your call with a recorded message and lines up your call to be answered by our staff. Please do not hang up. You will be asked to briefly describe the reason you are calling. By asking for this information, we can assure that you get the help you need quickly.

For after-hours and weekends - Hospice has an on-call registered nurse on duty for phone consultations and visits. In addition to the on-call nurse, a hospice physician and a counselor are also available. Even “after hours,” the hospice team is ready to help.

Urgent Problems or Concerns

Stressful situations or urgent concerns may arise. In these situations, it is important that you **call Hospice before calling 911**. We strongly recommend you inform hospice prior to seeking *any* health care services. We have expertise in end-of-life problems that other providers may not have.

NOTE: If you do not inform Hospice of the Northwest before seeking medical care, you may be responsible for health care expenses. Calling 911 or going to the emergency department must have prior authorization from hospice. Without this authorization you may be responsible for all costs related to 911, including transport, emergency department care, and hospitalization if this is the result of the emergency department visit.

Learn more about the costs of hospice care and outside medical care in Appendix A.

San Juan County

We are able to provide telephone consultation 24 hours a day, every day of the year for San Juan County. However, due to the public ferry system, we may be unable to provide an urgent nursing assessment in-person every day. **Please call hospice anytime for support.** We will work with island-based providers to arrange and authorize necessary care.

HIPPA, Billing, and Payments

Our policy for Protected Health Information (PHI) and our Notice of Privacy Practice is contained in Appendix H**.**

Hospice is a Medicare benefit that covers most of your needs including equipment, medication, and home visits. Learn more about the Medicare benefit in Appendix A.

Hospice of the Northwest bills your insurance directly. If you have private insurance, you may have to meet deductibles or other “out of pocket” expenses. If Hospice isn’t able to pay for a certain medicine or piece of equipment, you will be informed of this before the expense is incurred.

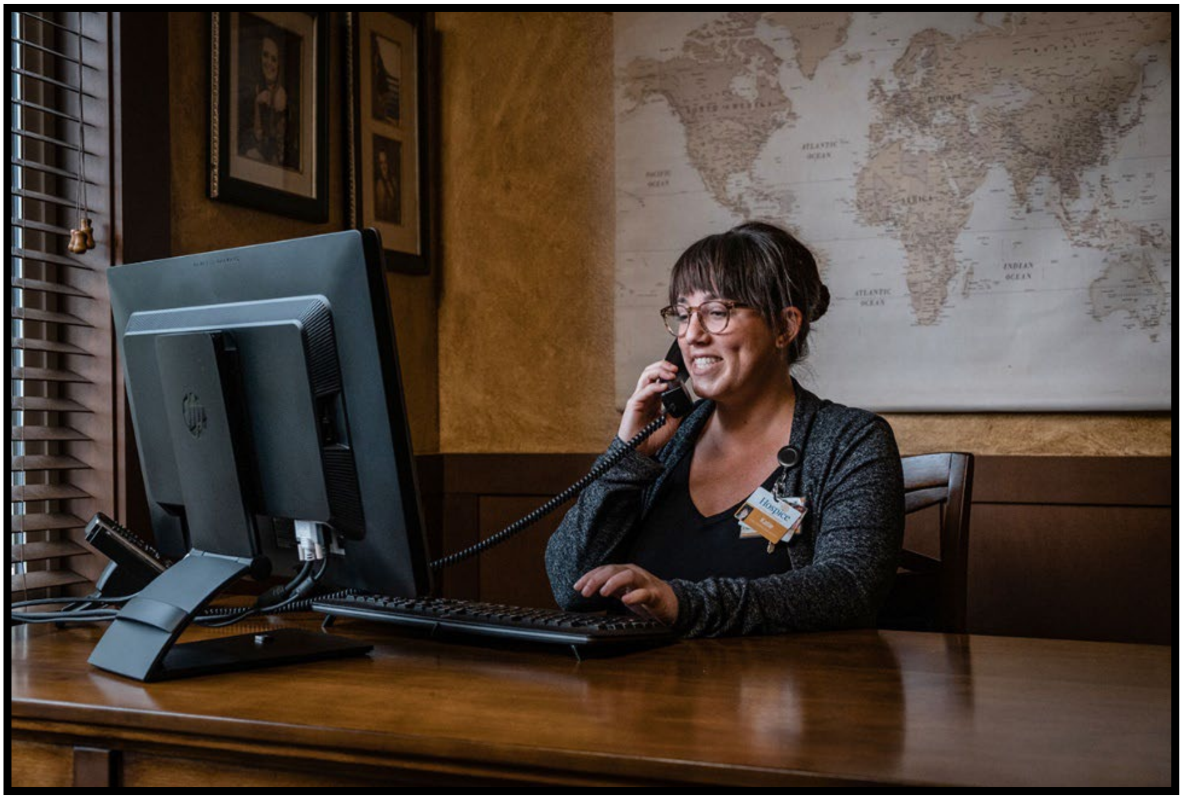
Billing Questions – Please call 360-814-5550 and ask to speak with the Billing Specialist if you have any questions regarding your account.

Traveling or Transferring Service

Travel - If you travel while receiving hospice services, we will locate a hospice provider where you are traveling and contract with them to be your support team while you are there. Give your team prior notice if you plan to travel, so we can continue to serve you. If you want to travel outside of the United States or you want to be away from home for more than 14 days, your social worker can explain other options for your care.

Transfer - If you would like to receive hospice services from a hospice other than Hospice of the Northwest, you may request a transfer. Transfers can be requested once in every benefit period. Please note that Snohomish County and Whidbey Island are the only areas within our service area offering additional Washington State approved, Medicare-certified hospice services. Notify a team member to request a transfer.

Remember - Do not seek any healthcare without prior approval from hospice. If you reside in a care facility, make sure the facility staff **call hospice first** before they call 911.



Notes

Section 2: For Patients

What to Expect When Service Begins

During the first five days of your care, your nurse, social worker, and spiritual counselor will contact you to set up initial visits. It can feel overwhelming to have so many visits, but you may choose to postpone a visit when a team member reaches out to schedule it. We encourage you to meet each team member as early as possible to make sure we get you the best care from the beginning.

The focus of the initial visit will be to get to know you, your goals, and help orient you and caregivers. The frequency of home visits differ for each person. Hospice staff will pre-schedule visits and make every effort to make visits convenient for you. If you live in a care facility, hospice staff will work with your caregivers and the care facility staff to schedule visits.

Hospice care is about caring with compassion and dignity. We will provide you with all the information you need to be comfortable, safe, and confident. Sometimes it may feel like you are getting too much information and perhaps, at other times, not enough information. Please ask questions and communicate with your hospice team. We need to know if there is anything unclear or concerning. This includes questions or worries about what lies ahead during this journey.

What is Included with Hospice Service

In addition to visits from your team, hospice care provides prescription medications, medical equipment, and medical supplies that are necessary to treat your terminal conditions as decided on by a physician.

- **Prescribed Medications** - As is the case in all health benefit plans, hospice's plan of coverage includes a preferred drug list. For covered medications, you will need to arrange to pick up prescriptions at your preferred pharmacy.
- **Medical Equipment** - Equipment is delivered to you at a pre-scheduled time, usually within a few days of joining hospice. If furniture must be moved to

accommodate equipment, please have it moved before the delivery. The medical equipment staff cannot move furniture. If you had rented medical equipment before you were admitted to hospice, you will need to contact the rental company to remove the equipment and stop the rental fees to you.

- **Medical supplies** - These medical supplies (items like catheter supplies, skin creams, etc.) will be sent to you by a hospice staff member during your first week of service. A replenishment of these supplies can be ordered every two weeks. Supplies provided by Hospice of the Northwest are supplemental, and the patient or caregivers should be prepared to provide main supplies needed for care.

If something is needed for your care that is not within our standard resource list, your team will decide if it is medically necessary and essential for your comfort and goals. You may be able to obtain these supplies without cost to you. However, if hospice is not able to provide a certain medication or piece of equipment, you will have the option to either pay for it directly or try other options. Your team will keep you informed of all decisions and restrictions.

You may appeal any decisions regarding medications, equipment, and/or supplies. The appeal process is available to every Medicare patient. The Medicare appeal form is available from any member of your team.

Medications

All medications prescribed by Hospice of the Northwest are part of your hospice benefit. Medications covered under your hospice benefit will be available for pick-up or delivery depending on your preferred pharmacy. Hospice staff and volunteers may not pick-up or deliver medications, except under certain approved scenarios. If picking up your medications is a hardship, your hospice team can help you make arrangements. If you reside in a care facility or senior living community, the care facility or community will manage the ordering and refilling of hospice medications.

Comfort Medications

When you enter hospice, the focus is on making you comfortable. This means there is usually a change in the medications, so that we can work to ensure your comfort. We will order comfort medications soon after admission to hospice, and Hospice of the Northwest will provide you with a red “comfort kit” box to store these. Once you have acquired these medications from your local pharmacy, place them in your refrigerator. Begin the comfort medications when you are instructed to do so by the hospice nurse. Keeping medications in the refrigerator assures us that we know where they are at all times, in every patient's home.

Medication Refills

Your hospice nurse will assess your medication supply on every visit and will remind you to reorder based on your use and the quantity in the home.

Not Covered Medications

Medications that are not related to your hospice condition will not be covered or paid for by hospice. If you have a Part D plan under Medicare (or a prescription plan through your private or state insurance) you will still be able to have those medications paid for by the Medicare Part D plan. Please notify our main office at 360 814-5550 if you experience any confusion or delay at your local pharmacy.

Medication Changes Over Time

Medications that were essential in the past may become less essential as your condition changes. For example, a "statin", used for high cholesterol, will likely offer no benefit during hospice care. Your nurse will consult with the physician about your medications. They will then discuss the best course of action with you and your loved ones. The goal will be to reduce the costs, risks, and side effects of unnecessary medications.

If you agree with the medical recommendations, some of your medications will be discontinued. If you don't agree, we will continue to explore options about discontinuing certain medications towards the end-of-life. If you desire to continue medications that we recommend you stop taking, you may need to pay for them. This doesn't happen often, but it is important to know that it is possible.

Medication Destruction

Never flush medications down the down the toilet or the sink. Medication destruction kits are available through hospice.

Appendix B also outlines safe ways to dispose of medications.

It is important to destroy medications you aren’t using anymore. Having unnecessary medications in your home increases the risk of making a mistake when taking your medication. In addition, medications could be taken by someone else and may do them harm.

Any member of your Hospice of the Northwest team can supply you with a pre-made medication destruction kit at no cost. Your hospice nurse may also help destroy any medications that are no longer needed, if you are not comfortable doing so.

Patient Rights and Responsibilities

We care about who you are and we are committed to caring for you with compassion and dignity. You have a right to be treated with respect and receive quality end-of-life care. You have the right to voice concerns without discrimination.

We honor the dignity and worth of each individual, as well as the diverse and unique perspectives of our patients, our workforce, and the communities we serve.

You have a responsibility to treat your hospice care team with dignity and respect, just as they are expected to treat you with dignity and respect. You have a responsibility to *keep the team informed* regarding your comfort, pain level, symptoms, and any changes. It is important that your team is fully informed in order to adjust your plan of care. For example, most people don’t want to speak about our bowel movements. However, this is important information for your hospice care team.

You have the right to have your private health information protected. Let us know who should be informed about your care.

All of your Rights and Responsibilities are stated in Appendix G.

Decision Making Resources

At this time of your life, there are many decisions to be made. These decisions may include financial, legal, and final arrangements. The team member best suited to assist with these decisions is your hospice social worker. The social worker cannot provide legal advice or pricing information. They can support discussions about these decisions and, if desired, can provide contact information for additional services.

Hospice of the Northwest also continually offers an educational class, called Advance Care Planning, to help you prepare your wishes for end-of-life. Please check our website (www.hospicenw.org) for upcoming classes or scan this QR code with the camera on your phone.

We encourage you to have conversations with your loved ones, your legal representative, and others while you feel well enough to consider some of these decisions. Sharing your plan can make all the difference.

Advance Directive

"Advance Directive" is a general term that describes many kinds of legal documents. Living wills and durable power of attorney are the most common documents. Advance directive documents put your wishes in writing, so everyone knows your plans.

Hospice of the Northwest has handouts regarding advance directives. Ask for:

- Advanced Care Directive and Health Care Durable Power of Attorney Booklet *provided by Honoring Choice PNW, in partnership with the WSHA and WSMA Foundation*
- Washington Advance Directive/Planning for Important Health Care Decisions *copyright 2005 NHPCO*
- Questions and Answers on Power of Attorney *copyright 2013 Columbia Legal Services (includes form)*

Our policy on Advance Directives is included in Appendix E.

Capacity

When you have the ability to understand the risks, benefits, and burdens of available treatment options for your medical conditions, you are considered to have “capacity” to make your own decisions. Capacity is not the same as competency and hospice does not determine competency. Only the judicial system can rule on competency.

It is best to make decisions while you have capacity. In the event that you do not have capacity, your Surrogate Decision Maker can make decisions on your behalf. Information on Surrogate Decision Maker is included in the Appendix F.

If language access or translation services are needed, the hospice care team can help you coordinate or connect you with those services to ensure all information provided is clearly understood by you, your family, and/or your Surrogate Decision Maker.

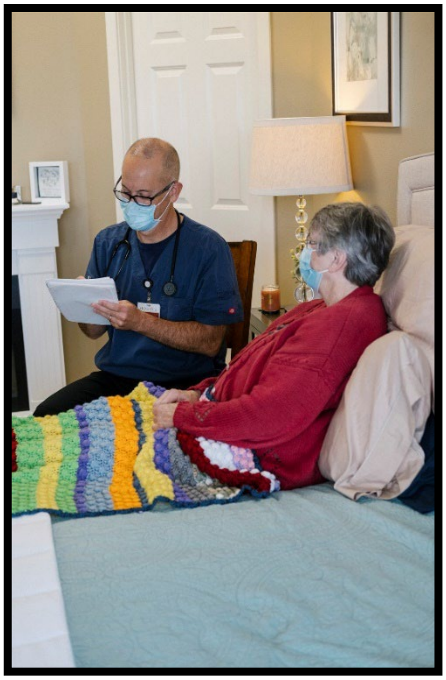
Washington State Death with Dignity Act

- Dying is a natural process. Hospice of the Northwest is committed to the value of human life and we work to optimize the quality of life for all terminally ill people as defined by each individual. This includes the avoidance of prolonged suffering.
- Hospice of the Northwest supports the right of all people to make their own decisions regarding their care. This includes the legal option of ingesting a lethal dose of medication as outlined in the Washington State Death with Dignity Act.
- Hospice does not restrict any professional staff member from discussing Medical Aid in Dying (MAID) or offering information about it. If a patient chooses, Hospice of the Northwest staff may be present during the time the patient plans to ingest the MAID medication. Please discuss with your hospice team prior to making your plans.
- It is important to note the patient needs to follow the state mandated process to receive the medication. **This process can take three or more weeks** and there are no insurance plans, including Medicare and Medicaid, which will pay for the MAID medication.
- Hospice of the Northwest staff cannot administer medications used for MAID. Hospice of the Northwest providers may act in the Consulting Provider or Attending Provider roles.

Hospice of the Northwest encourages patients seeking more information about Medical Aid in Dying to:

- Discuss the issue with their attending physician
- Speak with their hospice social worker
- Contact End Of Life Washington – Toll Free 1-877-222-2816 or www.endoflifewa.org
- Review the Department of Health website: http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct.aspx or scan the QR code above with the camera on your mobile device.

Portable Orders for Life Sustaining Treatment (POLST)



All hospice patients will be asked to complete a POLST form. The POLST provides specific direction about your healthcare wishes and informs all healthcare decisions moving forward. Your social worker and your nurse will spend time talking about your goals and ensure your wishes are clearly defined.

Five issues are covered by the POLST:

- **CPR or DNR** - Cardiopulmonary Resuscitation (CPR) is an intervention used when a person’s heart and/or breathing stops. CPR is used as an attempt to restart the beating of the heart and/or the lungs to breathe.

  Do Not Resuscitate (DNR) is an order written/signed by a physician instructing healthcare providers not to begin CPR if a person stops breathing or their heart stops. CPR is not often successful when the body is already weakened.

  See Appendix D for more information on CPR and hospice care.

- **Artificial Nutrition** - As the body slows, it desires less and less nutrition (food). As bodily systems slow down, metabolism slows, energy is reduced, and food can become a burden. Artificial nutrition by means of a stomach tube or food through the veins may prolong life, but could also extend suffering. Every individual's situation is different. Your hospice nurse and hospice physician can discuss this with you and your loved ones.

- **Artificial Hydration** - Water can be more of a burden than most of us understand. As the body systems slow, there is less need or desire for fluids. Sometimes, fluids over-burden the body when the body can't manage them. Your hospice nurse, team, and physician will talk to you and your loved ones about the burden versus benefit of artificial hydration.

- **Intubation** - If you can no longer breathe on your own, a tube can be placed in your throat. This tube is connected to a machine that will assist your breathing. It is also known as a ventilator. If you do not want assistance breathing, it is important that the POLST include your wishes on that topic.

- **Antibiotics** - At the end-of-life, antibiotics are often unnecessary and less effective. However, your comfort is our highest priority, and the use of antibiotics may be considered on a case by case basis.

Home Safety

Your Hospice Team will assess home safety and provide suggestions for you to improve your safety. We want you to avoid risks and injury. However, applying our suggestions is always your choice.

Falls

Falls can happen to anyone at any time. There are a number of ways you and your caregivers can reduce your risk of falling. Many falls can be prevented, especially ones caused by the home environment. Your nurse and others on the team may suggest one or more of the following safety items:

- **Lighting** – Have bright lights, night lights, tap lights, flashlights throughout the house, especially next to where you sleep.

- **Floors** - Remove throw rugs, clutter, cords, and vacuum hoses. Wipe up spills.

- **Hallways and Stairways** - Remove clutter, use handrails, and put nonskid tape on stairs.

- **Bathroom** - Use properly installed grab bars, a raised toilet seat, nonskid tape in tub, or a bedside commode. **Do not** lock the bathroom door.
- **Oxygen** - If you are on oxygen, be mindful of long oxygen tubing as you navigate through your home. Also, make sure the tubing is not being crushed/squished in any way to ensure you are receiving the proper amount of oxygen you need.

Medications and Falls

There are some medications that may increase your risk for falls. Your nurse may check your sitting, then standing, blood pressure if you are receiving medications that can cause dizziness. Pain medications, and medications for sleep, can make you drowsy. If you are concerned about side effects, talk with your nurse. Sometimes medications are continued for your overall comfort. Other times, we may adjust the dose or ask you to stop taking it.

Other Safety Thoughts:

- Put emergency contact numbers in large print next to every phone.
- Make sure your house numbers are clearly visible from the road for EMS.
- Limit access to sharp or hot items if your sense of sight or coordination is weak.
- If you are dizzy when you first change position, sit for a minute until the dizziness passes before standing up.

OTHER TIPS TO PREVENT FALLS

- **Do** tape or nail down loose carpet corners, and avoid placing carpet over carpet.
- **Do** wear nonskid shoes/slippers, not socks.
- **Do** carry a portable phone or consider a wearable medical alert system.
- **Do** wear your glasses and clean them often.
- **Do** sit up and stand up slowly and give yourself a moment or two to steady yourself before you begin to walk.
- **Do** keep an eye on smaller animals to make sure they are not underfoot.
- **Do not** wear pants or other clothing that is too long and that could cause you to trip.
- **Do not** put electrical cords under rugs.

- If you have guns in your home, unload them and lock them away; or may also want to consider having someone else hold on to them for safe keeping.
- **Please do not smoke when hospice staff or volunteers are in your home**.

If you use an Emergency Call system or Medical Alert system, please ask the company to notify your emergency contacts in this order:

1. Contact a nearby family member or friend first.
2. Call Hospice of the Northwest next: 360-814-5550.
3. 911 should be a last resort, or not at all.

Extreme Heat

High temperatures can create serious health issues, especially for populations who are heat sensitive. Most hospice patients fit into the highest risk category.

During any period of excessive heat, we encourage patients and their circle of support to be extra diligent about staying cool and hydrated.

Some additional strategies:

- Use fans carefully - do not pull warm air in from outside with a window fan, or circulate warm air. Consider putting a tray of ice water in front of a fan to move cooler air.
- Be aware of windows and sunshine coming into your home. Close windows and drapes during peak sunshine hours to reduce incoming sun as much as possible.
- Open drapes and windows for fresh air when temperatures are cooler, early in the morning or in the evening. If you don’t have blinds or curtains, hanging a bed sheet over the window will also work.

IDEAS FROM THE CDC TO STAY COOL

- Drink lots of water, avoid sugary or alcoholic drinks
- If there are challenges taking in enough fluids, try popsicles or ice chips
- Put a cold, wet cloth on the back of your neck
- Stay inside with air conditioning when possible
- Wear loose-fitting, light-colored clothing
- Avoid hot and heavy meals

Older adults may not exhibit obvious signs of dehydration and may have trouble taking in enough fluids. We recommend caregivers pay extra attention to fluid intake and be proactive about offering cold drinks and popsicles.

If there are any concerns or an urgent situation arises, please call us day or night.

Infection Prevention

Wash your hands with soap and water for 20 seconds. This is the simplest, and most effective way to protect yourself from getting an infection. If you cannot wash your hands under clean running water with soap, consider using an alcohol-based hand sanitizer, rubbing it in until dry, this should take about 15-20 seconds.

Wash your hands before and after preparing and eating food; after going to the bathroom; before and after caring for someone with a cold, a wound, or a catheter; after blowing your nose, coughing, or sneezing; after handling animal waste or garbage; after providing personal care to a loved one.

- **Masks** – Wear a mask if someone has an active cold, flu, COVID-19 (or any variant), tuberculosis (TB), or you are using crushed medications.
- **Soiled dressings** – Put in a plastic bag, seal it, and place in trash.
- **Needles** – Put into a red “sharps” container which can be provided by your nurse.
- **Flush** – All blood, vomit, and other body fluids down the toilet.
- **Laundry** – Wash laundry with blood, vomit, etc. separately from other laundry in hot water and detergent.
- **Spills** – While wearing gloves, swipe up, and clean the area with a diluted bleach solution of 1 part bleach to 10 parts water.

For Caregivers

Wear exam gloves when providing personal or wound care for a loved one. Wash your hands immediate after remove the gloves. Gloves are single-use only; throw them in the trash after one use.

Emergency/Disaster Preparedness

To be prepared, think about what you will do and where you will go if a disaster occurs. If you have pets, consider placement for them if you have to go to a public shelter.

Ideally, every home should have a 3-day supply of water, food, and medical supplies on hand. Each person typically needs about a gallon of water a day for drinking purposes. Other things to consider would be extra eyeglasses, medications to take with you, a battery-powered radio and batteries, flashlights, cash, clothing for rain/cold/heat. If you are on oxygen, consider having a generator to keep your concentrator running. If you need to evacuate, take your medications, medical supplies, clothes, and water and food.

In the event of a disaster, Hospice of the Northwest will contact you based on your needs, relative to other patients' needs and availability of staff. Hospice staff will make every effort to maintain communication with you. However, based on the severity of the disaster, it could take several hours to days for a team member to reach you. If you evacuate to an emergency shelter, let someone there know that you are a hospice patient and a team member will attempt to locate you there.

End-of-Life Decisions

There are many discussions to have and decisions to be made at this time. We encourage you and your loved ones to have some or all of these conversations, as you are able.

Some conversations and questions that might be helpful during this time:

- Do you need to continue to talk with loved ones about issues concerning Portable Orders for Life Sustaining Treatment. What kinds of interventions do you want or not want?
- Have you made a decision about who will make healthcare decisions for you if/when you are no longer able to make them yourself?
- If all goes according to plan, where do you want to be when you die? At home? With loving family/friends present?
- Do you feel your obligations (bills, statements, bank, other) are taken care of? Does this distress you in any way?
- Are there any cultural, religious, or spiritual practices or preferences you would like to be observed or followed?
- Have you discussed your desires for final arrangements with your loved ones and your hospice team?

Please tell us what your wishes are, and your hospice team will support them as much as we are able. What you want at end-of-life is very important to us.

Other Suggestions

The following is a list of ideas for your consideration:

CHECKLIST

- ☐ Durable Power of Attorney for Health Care
- ☐ Durable Power of Attorney for Finances
- ☐ Living Will/Advance Directives
- ☐ Original Last Will and Testament
- ☐ Insurance Policies – life, health, disability
- ☐ Real Estate Titles and Deeds
- ☐ Financial Records – stocks, bonds, bank accounts, or access to safety deposit
- ☐ Income Tax returns for last few years
- ☐ List of Creditors, if any
- ☐ Military Discharge documents (DD-214) and Veteran Benefits
- ☐ Social Security numbers for you, your spouse, and any dependent children
- ☐ Birth Certificates for you, your spouse, and any dependent children – contact State where these relatives were born

Notes

Section 3: Symptom Management

Managing Pain

Your hospice team will regularly ask if you are in pain and the amount of pain. We encourage you to be honest and vocal about your pain level so we can help make you as comfortable as possible. We understand that you may get tired of answering questions about pain, but we need your help to best help you.

Physical Pain

Almost every hospice patient reports having some level of pain. It is not a sign of weakness. Some common causes of physical pain include: lack of oxygen to the heart (angina); tumor pressure (cancer related); and neuropathic (a result of nerve damage).

Medications for physical pain are often in the drug category called narcotics or opiates. Sometimes people worry about becoming addicted or staying sober if they use these medicines, especially if they have past trauma associated with drug use. However, using an appropriate amount of medicine for an appropriate reason does not mean you are a drug-seeking person nor is it likely to lead to addiction. If you have concerns about this, please speak with your nurse so we can work together to find a solution that will make you feel comfortable while taking prescribed pain medications.

Hospice will often use a long-acting opiate combined with a short-acting one to get good pain coverage. Do not hesitate to take the short-acting one as prescribed when your pain is “breaking through” or increasing. We recommend you “stay ahead of the pain.”

Please try to write down, or have a caregiver write down, what time you experienced the break-through pain and the dose of medication you took to address it. This written record allows the nurse and physician to adjust medications safely and effectively. We acknowledge that keeping records at a time like this can feel burdensome, however, it is essential in order to make the best decisions possible. It is important for your care team to know what, when, and how much of any medication you are taking to avoid any negative interactions between medications and to make sure you are getting the best results. We also use this information to make sure enough medication is ready when you need it.

Non-Physical Discomfort

Your hospice team knows that other sources can contribute to your discomfort. For example, non-physical discomfort or frustration can come from needing to rely on others to get around, getting fatigued doing things that took no effort before, or needing to have a difficult conversation with a loved one.

Your team is skilled in listening and helping you identify other, non-physical issues that may be adding to your discomfort or pain levels. If you are able and willing, please consider sharing any non-physical issues you are experiencing, and/or any cultural, religious, or spiritual practices or beliefs that would support your discomfort, so we can help.

Managing Common Symptoms

Nausea and Vomiting

Sometimes nausea and vomiting are a result of medications you are taking. They can also be related to disease progression. Options include, but are not limited to, medication changes, dietary changes, and the way you take the medication.

- If prescribed medications for nausea/vomiting are not effective, tell your nurse.
- Consider decreasing the type, amount, or frequency of your food/fluids if these seem to be increasing your nausea.
- If you vomit, clean your mouth well afterwards (as you are able).

Constipation

Pain medications cause constipation, which is a slowing of bowel movements. Your nurse will ask often about your bowel movements and will teach you how to avoid constipation. Questions about your bowels may feel intrusive, but due to the side effects of pain medications, these questions become vital for us to help you remain comfortable.

Normal bowel movements require fiber (roughage), water, motion, and lubrication. When patients are ill, they spend more time resting, often drink less water, and eat less. In addition, many medications can cause constipation.

Constipation is much easier to prevent than to treat. Here are some tips to help prevent constipation and treat any symptoms of constipation you may be experiencing.

- Try to drink **fruit juice** daily. Choose any juice you like, but prune juice, apricot nectar, and apple juices seem to work best. Drinking more water can help, too.
- Giving the body some **daily activity** is helpful. Try walking, even slowly, a few times a day. If you are becoming weaker, try using a rocking chair or rolling your legs side to side in bed.
- **Massage** can be helpful in moving things along, too.

NOTE: Fiber can help prevent constipation in healthy patients, but may make constipation worse for hospice patients because, often, they are not getting enough water or physical activity.

- **Laxatives** that help the bowel muscles contract are usually the best treatment in hospice patients**. If you need an opiate for pain or breathlessness, we suggest you start a laxative at the same time.**
    - **Senna** is a natural product that can be swallowed as a liquid or pill. Senna can be increased incrementally up to 4 tablets, twice a day to help with bowel movement.
    - **Lactulose** is an oral laxative that pulls more water into the stool, which can be helpful. It comes as a liquid and can be increased to 20 grams (30

milliliters) twice a day to achieve soft stools daily. Check with your nurse to increase further.

- If you have hard stools that are painful to pass, **Vaseline balls** (pea sized white petroleum balls, frozen in the freezer and rolled in powder sugar) can be taken orally and work very well. Patients can start with 2 balls, twice and day and increase to 4 balls, four times a day to help with stool lubrication. This is usually a temporary treatment until stools are softened with another approach.
- **Suppositories and enemas** are sometimes needed if you have been constipated for several days.

Most importantly, let your hospice nurse know if you are starting to experience any symptoms of constipation. Symptoms may start with harder or less frequent stools and progress to stomach cramping, nausea, or painful bowel movements.

Constipation Action Plan

Your action plan will change as illness progresses or medications change, but this is a good starting point. *If your pain medication doses increase, you will need to increase your constipation prevention medication.*

To prevent constipation:
Fluids, motion, and fiber as tolerated

To treat mild symptoms of abdominal fullness or less frequent bowel movements:

To treat more severe symptoms (hard stool that is difficult to pass, cramping or no bowel movement for several days), ***Call your hospice nurse.***

Please call your hospice nurse if you have questions about your symptoms or medication plan.

Diarrhea

Diarrhea often occurs for hospice patients, often as a result of your diagnosis. If it something you are dealing with, let your nurse know. The nurse will offer suggestions regarding diet and/or suggest medications to relieve diarrhea.

Skin Issues

Your hospice nurse and care aide will help prevent skin breakdown by telling you what to be aware of and monitoring your skin's condition. Skin issues are related to decreased physical movement, pressure, and diet changes that can result in "bedsores" or pressure wounds. These appear as reddened or blanched areas, open sores, or ulcerations. Things to be aware of and/or to do for skin care:

- Change your position in bed every couple of hours
- Watch your skin where your bones are close to the skin. If these areas appear blanched or red, lotion and massage these areas with every position change
- Keep skin clean and moisturized with lotion
- If bladder/bowel control is weakened, work with your care giver to make sure you are cleaned promptly and thoroughly after incontinence (involuntary urination/bowel movement)

Mouth Issues and Providing Mouth Care

You may develop issues involving your mouth, like: dry mouth, soreness, bleeding, white spots, or dentures that don't fit as well. This could be a sign of declining health or may be related to treatments that you are receiving.

Mouth care suggestions:

- Clean teeth and tongue frequently with gentle brushing
- Avoid alcohol-based mouthwashes. Here are two alternatives:
    - 4 cups water, ½ teaspoon salt, and 1 teaspoon baking soda **OR**
    - 1 cup water, 1 cup hydrogen peroxide, and 1 cup mouthwash
- Keep lips moist with a water-soluble lubricant or petroleum-based lip balm
- Sip water or non-acidic juices, or suck on ice cubes or popsicles
- A bit of fresh lemon juice in your water may stimulate saliva
- If you have dentures, clean twice a day. If they are loose, speak to your nurse; a dental consultation may be possible
- Ask your nurse about mouth swabs

Nutrition and Hydration

As we approach the end of life, food and fluid may become less desirable. If possible, talk to others about what you want and don't want in regards to food and fluid. Below are some ideas on how to get nutrition from food and stay better hydrated when eating and drinking becomes difficult:

- Eat or drink only when you want to, listen to what your body needs and wants
- Eat or drink smaller amounts, perhaps more frequently
- Ask family and friends for what you really want to eat, not what you 'should' eat
- Try soft foods if chewing is tiring you. Some good options might be foods such as cottage cheese, applesauce, yogurt, mashed potatoes, and, yes, even ice cream
- Cold foods may ease a sore mouth and feel more comfortable to eat
- Freshen your mouth before and after you eat. Gently brush your teeth and tongue
- If you suffer from regurgitation (involuntary food/fluid coming up from your stomach), reduce the amounts of food/fluids and try to sit upright for 30 minutes after eating/drinking

Shortness of Breath

Sudden breathlessness can be frightening, but it usually passes after a few minutes. Knowing what steps to take can reduce the panic that breathlessness causes. It can even reduce the breathlessness itself. Breathlessness can happen as part of many health problems, but is especially common in lung and heart conditions.

Here are some **tips to help you overcome breathlessness**:

- Weigh yourself regularly if you have heart disease and let your nurse know if your weight has increased by 5 pounds or more
- Let your nurse know if you develop an increased cough or dark phlegm
- If you have difficulty swallowing, eat slowly, and tuck your chin when you swallow
- Pace yourself during exertion instead of trying to rush through it
- Keep your shower shorter and with cooler water
- Pre-medicate with an inhaler medication or opioid before an activity you know will make you breathless
- Practice self-calming skills. The body and mind are very closely connected when it comes to feeling like you aren't getting enough air. The mind is a powerful tool in recovering from breathlessness. Your hospice team can teach you these techniques
- Avoid exposure to irritants such as wood smoke, dust, or strong odors. If your religious, cultural or spiritual practices include the burning of herbs, incense, or other substances as part of the healing process, please make your hospice team aware of this.

Signs of severe breathlessness include:

- Inability to speak in full sentences or to talk at all
- Blue color in the lips or hands
- Seeing muscles working hard to inflate/deflate the chest; labored breathing
- Anxiousness or panic
- Rapid or noisy breathing

It may be helpful to develop a hand signal for when breathlessness is severe, as it may not be possible to talk when breathless. Always notify your hospice nurse if breathlessness is increasing.

Breathlessness Action Plan

Consider this ideas and options as you create your Breathlessness Action Plan.

- **FAN** - Turn your body to face a fan or open a window.
- **REPOSITION** - Usually sitting upright, even leaning forward supporting weight on elbows or arms helps. Patients with pulmonary fibrosis, or other forms of stiff lung, may breathe better lying flat.
- **OXYGEN -** Place oxygen mask on your face or turn up the flow. Turn the flow back down after recovery. Be sure to check that oxygen is turned on, tubing is connected, and tubing is not kinked.
- **BREATHING** - Breathe into your body through your nose and breathe out through pursed lips.

For Caregivers:

STAY CALM: Quiet the room. Speak slowly and in a calm voice.

REASSURE: Let the person know you are there to help and stay with them.

- **RELAXATION** - Use techniques that help quiet the mind and reduce fear: music, prayer, focused breath, hand or back massage, meditation, guided imagery, focusing on a view or beautiful object, saying a mantra.
- **MEDICATIONS** - Have the medications for breathlessness nearby. These may include oxygen, a rescue inhaler or nebulizer, an opioid, and/or a sedative. Have your nurse write the medication plan here and adjust it as needed.
- **ASK -** Is the breathlessness is getting better? Is time to call the hospice nurse?

Other ideas:

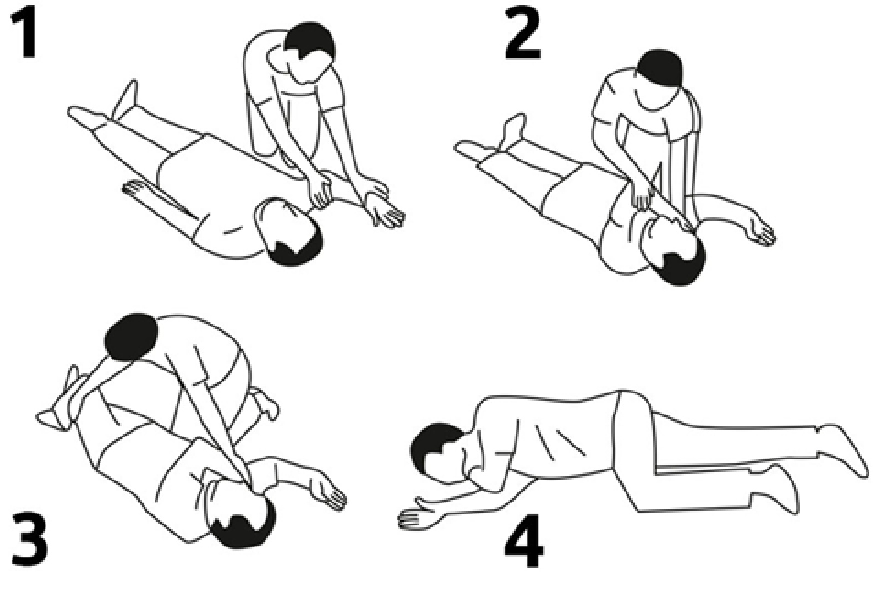
Noisy Breathing & Respiratory Secretions

What you need to know: When we are awake and alert, we continuously clear our throats and swallow to keep our throat clear. As people decline at the very end of life, they are too sleepy or week to swallow, cough, or clear the throat, causing secretions to build up. Air moves past the secretions, creating noisy breathing or gurgling sounds. These can be natural noises of very deep sleep. Sometimes there is a rattling sound. We don't believe these sounds cause distress for patients if they are otherwise resting peacefully, but they can be hard to hear.

Is my loved one okay or struggling to breath? Look at the face. Is it grimacing or relaxed? Look at the hands. Are they clenched or open naturally? Is the body restless or quiet? If you see a relaxed face, open hands, and quiet body, then be assured that they are not uncomfortable. It is still okay to use the recommendations to move the secretions. If there is facial grimacing, clenched fists, and/or restlessness AND it has been more than 30 minutes since last medicated, then it would be beneficial to use the medication that your nurse has recommended for trouble breathing.

What you can do: Below are some tips to help manage noisy breathing.

- If your loved one has a hospital bed, try to raise the head of the bed to 45 degrees.
- Reposition the head with pillows to allow secretions to pool in the cheek or lower mouth and drain out of the mouth. These can be removed with a soft cloth.
- Place your loved one in the "rescue position" shown below to help secretions drain.



- Oral swabs (small sponges on a stick) can help remove secretions. Only remove secretions in the front of the mouth as deeper probing can be uncomfortable.
- Provide gentle suction with a bulb suction to remove pooled secretions from the cheek. See diagram and instructions.
- Sometimes medications can be helpful. As your nurse if this would be recommended:
    - **Atropine drops:** 2 drops under the tongue or in the cheek pocket every 2 hours as needed.
    - **Hyoscyamine tablets:** 0.125 mg oral dose under the tongue every 4 hours.

Use a bulb suction to remove secretions:

- Prepare a bowl of clean, warm water.
- Position your loved one's head to the side. The rescue position works well
- Hold bulb away from the face and squeeze the air out.
- While still squeezing, gently place the tip just inside the cheek or beside the tongue. Try not to place the tip too far inside the throat as it can cause discomfort.
- Slowly release the bulb. As air is sucked into the bulb, so is the mucus.
- Empty the bulb by squeezing it into the bowl of clean water.
- Repeat as often as needed, as long as it is not causing distress.
- Clean the bulb by squeezing and releasing several times in hot water.

If these suggestions are not working or if you have any doubts about your loved one's comfort, give us a call. We have nurses available to answer your questions 24 hours a day.

Anxiety

The end-of-life brings change and uncertainty that can cause anxiety. Anxiety is a normal response to perceived danger. Our minds become hyper-alert and our bodies prepare us for “fight or flight” by making stress hormones. Anxiety can help us in some situations. However, too much anxiety can interfere with our ability to think clearly, communicate effectively, or connect with others. Anxiety can also cause new physical symptoms or make existing symptoms worse.

Recognizing Anxiety

Sometimes we aren’t aware of our own anxiety and we rely on family or caregivers to see it instead. When anxiety is mild, we might be overly alert or overly focused. We may have trouble sleeping, or feel driven to work. As anxiety gets worse, we may have trouble concentrating, may go over the same ideas again and again. We become irritable, tearful, or physically restless. There may also be physical symptoms like palpitations, fast breathing, loose bowels, or shakiness.

At its worst, anxiety can cause a disconnected state where we are unable to focus or follow directions, and may feel physically overwhelmed. This is called a panic attack. Symptoms of a panic attack can include feelings of despair, feeling smothered or unable to breathe or swallow, chest pain, out-of-body experience, dry mouth, sweating, lightheadedness, and/or uncontrollable crying or agitation.

Managing Anxiety

There are many ways to manage anxiety. You can talk through your worries, engage in relaxing activities, pray, meditate, and/or make a plan. Some people with longstanding or severe anxiety use medication to treat it. It is very common for hospice patients to need extra help with anxiety, including medication.

Anything that improves the wellbeing of the mind, spirit, or body will improve anxiety. What helps most varies from person to person and your hospice team can help you make a personalized plan to control your anxiety.

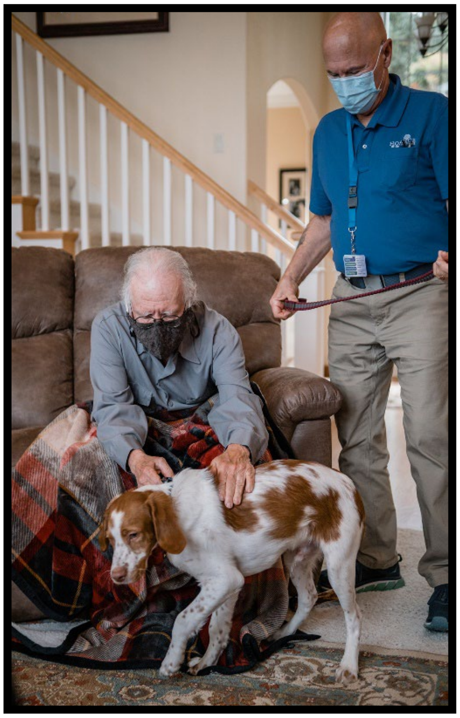
Here are several general strategies that both patients and caregivers can use.

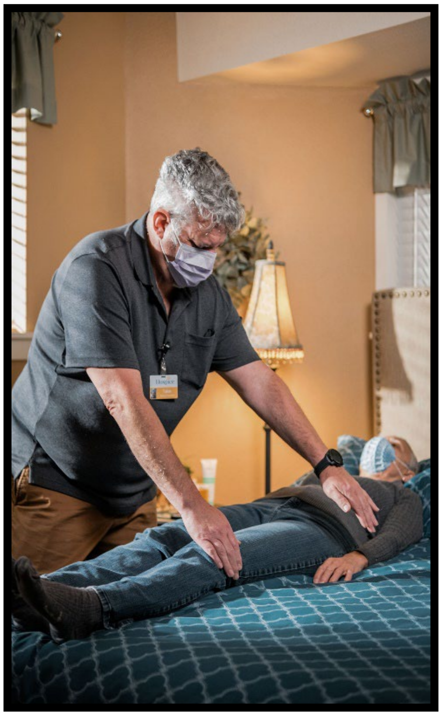
- Use deep breathing techniques when you feel anxious. Take a few slow, deep breaths in through the nose and out through the mouth to reset the nervous system.
- Use your senses. Focus on a beautiful view, a candle flame, or a mental image. Listen to a favorite piece of music. Use aromatherapy with scents that ease your anxiety. Focusing your attention on something like this can soothe the senses and calm the mind.
- Gently massage the hands, scalp, or feet.
- Talk about your worries with someone you trust. Being heard and understood is healing.
- Distract yourself with a pleasant activity.
- Consider cultural, religious, or spiritual practices that have helped you in the past.
- Ask questions. Your hospice team can work with you to find solutions to your unspoken worries.
- Allow yourself enough time for tasks. Time pressure almost always makes anxiety worse.

- Make a plan in advance to manage anxiety for events that you expect will make you anxious.
- Take the medications already prescribed for your anxiety, or consider starting medication if needed.

- Create a calm environment.
- Talk to your team about a personalized plan to manage your anxiety.

Caregivers and family can help by remaining calm, by staying nearby, and being willing to talk through worries compassionately. They can remind of the tools your loved one already uses to help with anxiety like breathing, music, or medication.





Anxiety Action Plan

Sadness and Depression

People facing a terminal illness are very likely to experience feelings of sadness. It is completely normal to feel sadness and grief during this time.

Sadness and depression are normal responses when we meet difficult and painful challenges. Some hospice patients struggle with losing independence. Others feel isolated and alone. For many, it is the fear of the future and what comes next. Sorting these feelings out with the right person can be very helpful. Talking with those who are close to us can help, but you may prefer to talk to someone else.

Your hospice team can help you work through feelings of sadness in several different ways:

Education - Coping with sadness and grief involves educating the person who is terminally ill, and their circle of support, about what can be expected at the end-of-life. A lot of strong emotions come from feeling helpless and not understanding what is happening now, and what will happen next. Your nurse, social worker, and spiritual counselor can offer strategies and resources to help.

Counseling - Talking to a professional, or someone who has experience with what you are going through, can help reduce sadness and grief. Sometimes hospice patients are reluctant to talk with loved ones about what is happening because of how it may affect their loved ones. Your hospice team can help you discuss your feelings and concerns about the end-of-life. They can also help your family talk more knowledgeably and more calmly about the process.

Treatment - Sometimes depression goes beyond the usual sadness and grief that can occur to anyone facing terminal illness. This depression can be treated with medication and other interventions. Signs of depression may include:

- You don't feel like doing the things you usually enjoy, even when you are still able to do them
- You find that you get little pleasure out of these activities when you do participate
- Your sleeping and/or eating habits change significantly. You eat/sleep much more or less. (These symptoms may also be side effects of your illness, medications, or treatments, so be sure to talk with your nurse.)
- You isolate yourself or withdraw from your loved ones and friends
- You have thoughts of suicide

If you experience any of these signs, talk with your nurse or others on your hospice team. Get help right away if you are having thoughts of suicide. Hospice counseling staff is available day or night at 360-814-5550.

Another excellent resource is the National Suicide Prevention Hotline which is also available day or night at 1-800-273-TALK (1-800-273-8255).

Restlessness and Agitation

Restlessness and agitation are common at as a person approaches the end of life. They can be distressing to both you and your caregivers. Evidence shows that restlessness and agitation are often a result of discomfort (physical, emotional, or psychological).

Some signs of restlessness or agitation may include:

- Fidgeting, including repeatedly picking at clothes or bed sheets, unable to concentrate or relax.
- Trying to get out of bed, impulsivity, and/or wandering with difficulty redirecting.
- Distressed behavior, sometimes including anger and possible aggression.
- Night/day reversals with feeling sleepier during the day but active at night. Restlessness can increase as the day progresses often peaking in afternoon or evening (referred to as “sun downing”).
- Muscle twitching, physical tension in the body or extremities.

FOR CAREGIVERS:
SIGNS TO BE AWARE OF

- Calling out, shouting, or screaming
- Requests not to be left alone
- Anxious or fearful facial expressions, especially if they are unable to express why they are afraid
- New or increased confusion and difficulty soothing
- Hallucination or paranoia (fear of someone harming them)

For caregivers: When speaking to someone who is agitated, i
dismiss their distress. Validate their experience with gentle lang
that you are having distressing thoughts.” Or, “You seem worri
to express what they’re thinking and feeling.

Some strategies to help manage these symptoms:

- Use a distraction. Try looking at something familiar like a photo album or a well-known task such as folding laundry. Talk about known experiences or people which have brought them peace and comfort.
- Keep the environment calm (consider fewer visitors or visits that are shorter, lower lighting, reduced noise, opening a window).
- Play soothing music or calmly read a favorite story, poem, or letter.
- Ask your hospice team for additional support. We can tailor care to your specific needs, addressing not just physical, but also emotional and spiritual concerns.
- Take medications as recommended by the hospice staff and request reassessment if current medication plan is no longer effective

You may hear the term "Terminal Agitation," which is used to describe some of the symptoms of extreme restlessness, anxiety, and agitation that may occasionally occur in the days leading to death. This can be challenging to manage without the use of medications that result in sedation. Your hospice team is knowledgeable in this type of symptom management and is available day or night to help. We encourage you to call so both you and your loved one can be supported in a timely manner.

Additional Symptoms

The team will ask about other symptoms such as fatigue and nausea. If you are worrying, can't sleep, are just "not you" right now, this is also important information. Please share all changes, concerns and symptoms with your Hospice Team.

Let us know how we can help you. Tell us if the symptom management is not enough. **We need to hear from you**.

STRATEGIES FOR CAREGIVERS

- Provide reassurance in a calm voice
- Offer soft touch, hand holding, or gentle massage
- Avoid arguing with or correcting if they are confused. Instead, "go along" with their experience and reassure them to reduce their fear.
- Provide medications as recommended; if it is not working, speak with a nurse.

Non-Pharmaceutical Symptom Management Suggestions

Some patients want to avoid opiates or other strong pain medication when treating the discomfort that may occur toward the end of life. They find complementary therapies and alternative pain medication fit better with their values and goals. The following therapies are some of the alternatives we use to treat pain at Hospice of the Northwest. Please talk with your hospice team about which of these ideas appeal to you.

Alternative Medications:

- **Anti-inflammatory and non-opiate pain relievers** such as Ibuprofen and Acetaminophen can help mild to moderate pain. When strong anti-inflammation medication is needed, dexamethasone (a steroid medication) may be helpful.
- **Medications to improve sleep** and allow rest often improve pain management. If you are not able to rest, ask your hospice nurse to help you outline a trial of medication to help you sleep.
- **Medicines for depression** are often used to treat pain because they work on areas of the brain that process pain.
- **Seizure medications** have been found to be helpful for some painful nerve-related symptoms, but may cause some sleepiness. These medications help with overactive nerves.
- **Topical medications** are medications applied to the skin and can help with some painful symptoms. Capsaicin cream made from hot peppers, topical numbing medicines, and topical anti-inflammatory medications can provide mild to moderate improvement in localized pain areas.
- **Medical Marijuana** has been shown to benefit some patients, and is now available legally at retail and medical stores in our community. If this is an acceptable alternative to you, we can use your physician-signed document at these locations to obtain marijuana. *Hospice of the Northwest does not provide dose or frequency recommendations.*

    - View a list of medical marijuana dispensaries on the Department of Health website, also available through this short link www.hospicenw.org/GB1001 or by scanning this QR code with your phone.

- **Traditional Tobacco** has been used by American Indian nations for centuries as a medicine with cultural and spiritual importance, and can be used in a prescribed way to promote physical, spiritual, emotional, and community well-being. Traditional tobacco is sometimes used directly for healing in traditional medicine. It may be burned in a fire or smoked in a pipe, yet the smoke is generally not inhaled.

Non-Medication Options:

- **Heat** on a painful area can help reduce pain from muscle tightness or cramping.
- **Cold** can help reduce pain from injury or inflammation.
- **Elevation** (or raising) of a painful area can help relieve the discomfort of throbbing, particularly after an injury. It can help with the discomfort of tightness from swelling, as well.
- **Compressive dressings** such as ACE wraps can help relieve the discomfort of muscle and tissues.
- **TENS (**or transcutaneous electrical stimulation units) use electrical currents applied to the skin by patches and may modulate the nerves creating pain. It is a safe and non-invasive technique that can be self-applied. It can be particularly helpful with nerve and muscle related pain.
- **Relaxation Techniques** can help relax your body, such as deep breathing exercises. Relaxing the mind can help with how the body feels pain. People can learn to quiet their pain or make it less bothersome through relaxation.
- **Gentle stretching,** yoga, and/or muscle relaxation training may help pain.
- **Mind-body techniques** include practices such as hypnosis, guided imagery, meditation, biofeedback, and prayer. These techniques may be useful to control anxiety, pain, or nausea and vomiting before or during painful/stressful situations.
- **Talking** with your hospice social worker or spiritual counselor often improves the emotional and psychological aspects of pain.

- **Acupuncture** involves inserting thin metal needles into the skin at specific points on the body associated with specific discomforts. It causes little or no pain and can relieve symptoms.

- **Hypnosis** is a state of altered consciousness that allows you to focus away from your pain, anxiety, or nausea. You are not sleeping while hypnotized, but are in a state of heightened imagination, similar to daydreaming. You can learn self-hypnosis techniques.

- **Visual or guided imagery** is a technique that encourages the patient to relax by focusing on calming thoughts or experiences.

- **Massage therapy** involves stroking and kneading the skin, muscles, and connective tissues. *Classic* massage is aimed primarily at muscles. It reduces tension and increases blood flow. *Reflexology* is massage of the hands and feet based on the idea that certain points on the body correlate to problem areas elsewhere in the body. *Chair massage* is done while the patient sits forward. *Deep tissue massage* is a form of intense tissue manipulation.

- **Energy therapies** involve using energy fields to heal and maintain wellness. Disruptions in energy fields can cause illness; balancing that energy may aid in healing. *Reiki* is a form of energy medicine that has been evaluated in several clinical trials for treatment of anxiety and improved well-being of cancer patients.

- **Homeopathy** involves using remedies that are dilutions of substances derived from plants, minerals, and animals.

- **Creative arts therapies** can reduce physical and emotional distress through music, dance/movement, and art. Creative arts therapy can improve anxiety, depression, pain symptoms, and quality of life among patients

- **Therapeutic Pet Visits** are a complementary approach to helping people with a wide range of medical conditions. Animals can be stress-relieving, but studies also show they boost the body's production of pain-fighters and immune-system healers.

- **Aromatherapy** uses various aromatic oils, often in conjunction with massage or diffuser, to treat symptoms of anxiety and depression.
- **Distraction therapy** involves patients changing their focus by watching movies or playing computer games. Distraction can help coping better with pain.

We work with our patients to find the best matched therapies to treat pain and respect patient beliefs and values. Hospice of the Northwest may not provide each of these options, but can help you find them.

Please let us know if you would like additional information on any of these treatment options.

Medications: Doses, Administration, Observation

For Pain/Breathlessness	
Medication and Strength	**Dose and Administration**
Morphine 20mg/mL	5mg (0.25mL) orally
Hydromorphone 1mg/mL	1mg (1mL) orally
Oxycodone 5mg tabs	5mg (1 tab) orally*
Call hospice nurse if symptoms not improving after 30 minutes	May repeat dosing of ANY of above **every one hour** as needed **if unable to swallow, crush and dissolve in warm water*

SYMPTOMS TO WATCH FOR

- Facial grimacing
- Moaning, restlessness, shielding/guarding body area
- Increased irritability or agitation due to pain or breathlessness
- Rapid and/or labored breathing
- Complaints of pain/breathlessness

Try this First:

- Repositioning
- Check briefs, bed linens, catheters
- Redirect (if anxious): music, TV, other activity
- Check oxygen tubing (if in use)
- Elevate head of bed 30 degrees
- Open a window or have a fan lightly blowing on face

For Saliva	
Medication and Strength	**Dose and Administration**
Atropine Sulfate 1% drops	2 drops under the tongue
Hyoscyamine 0.125mg tabs	0.25mg (2 tabs) orally*
Call hospice nurse if symptoms not improving after 2-4 hours	May repeat dosing of ANY of above every **2-4 hours** as needed **If unable to swallow, crush and dissolve in warm H2O*

SYMPTOMS TO WATCH FOR

- Persistent drooling
- Gurgling, wet breathing

Try this first

- Reposition to one side or the other, avoiding flat on the back
- Elevate head of bed to 30 degrees
- Provide oral care with swab/toothette

For Constipation

Medication and Strength	Dose and Administration
Senna 8.6mg tabs	8.6mg (1 tab) orally
Lactulose 10gm/15mL syrup	10gm (15mL=1 TBSP) orally
Call hospice nurse if symptoms not improving after 1-2 days	May repeat dosing of ANY of above up to **twice a day** as needed

SYMPTOMS TO WATCH FOR

- Decrease in normal stool pattern
- Increased straining and/or hard stools
- Complaints of lower abdominal pressure/fullness/ discomfort

Try This First:

- Increase fluid intake
- Add prunes/prune juice to daily diet
- Increase physical activity (i.e. walking)

For Anxiety/Breathlessness

Medication and Strength	Dose and Administration
Lorazepam 2mg/mL	0.5mg (0.25mL) orally
Lorazepam 0.5mg tabs	0.5mg (1 tab) orally*
Call hospice nurse if symptoms not improving after 30 minutes	**If unable to swallow, crush and dissolve in warm water* May repeat dosing of ANY above medication **every 2 hours**, as needed

SYMPTOMS TO WATCH FOR

- Unable to sit/lay quietly
- Increased irritability
- Abnormal or increased fidgeting
- Complaints of breathlessness,
- Rapid and/or labored breathing
- Inability to sleep

Try this First:

- Redirect (if anxious): music, TV or other activity
- Repositioning
- Decrease environmental stimuli
- Open a window or have a fan lightly blowing on face (for breathlessness)

For Agitation/Nausea

Medication and Strength	Dose and Administration
Haloperidol 2mg/mL	0.5mg (0.25mL) orally
Call hospice nurse if symptoms not improving after 30 minutes	May repeat dosing of above every **2 hours** as needed

SYMPTOMS TO WATCH FOR

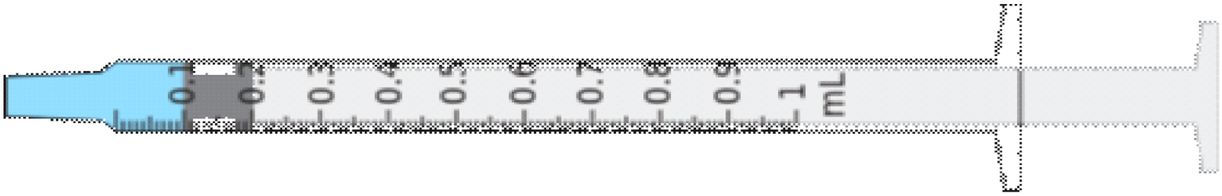
- Nausea, even without vomiting
- Active vomiting
- Persistent hiccups
- Restlessness/anger statements Resistance/ combativeness with care
- Distressing hallucinations

Try this First:

- Nausea: Cool cloth on forehead/neck
- Nausea: Fan blowing lightly on face
- Agitation: Change caregiver/distract
- Provide calm, soothing atmosphere

Medication Measurement Help

Non-invasive, Needleless Oral Syringes



*Oral syringe currently drawn up to 0.1mL

Please Note:

***Milliliter (mL)** is a measurement of liquid volume in the oral syringe ***Milligram (mg)** is a measurement of the strength of a medication	**A milliliter is not equal to a milligram**. The measurements on an oral syringe are in milliliters, NOT milligrams. The amount of medication in milligrams is NOT reflected on this oral syringe.	Draw up and administer medications based on how many **milliliters** are needed to give the correct milligram dosage of a medication. Call Hospice if you have concerns about giving the correct amount of medication.

Oral syringe from: By Timothy W Ford (Own work) [CC BY-SA 3.0 (http://creativecommons.org/licenses/by-sa/3.0)], via Wikimedia Commons

Notes

Section 4: For Caregivers

Online Caregiver Toolbox

We partner with several excellent groups and organizations to provide tools and resources for families and caregivers. Your Hospice Team can connect you with materials from our volunteer-managed Resource Library, and our website offers a variety of helpful videos and online tools that are accessible anytime. Visit www.hospicenw.org/caregiver-toolbox to access the online caregiver toolbox, or scan the QR code with the camera on your mobile device.

Caring for the Caregiver

Recognize and acknowledge your feelings and emotions. The journey towards death affects your loved one and you. Consider relaxation techniques you've used throughout your life; perhaps laughing with friends, breathing deeply, or exercising. Maybe talking about your loved one or a quiet walk. Whatever has worked in the past, it may help now.

Your Hospice team can help you with relaxation techniques if you are still struggling. Ask them to help you access someone from hospice, or elsewhere, who can help you with practicing relaxation, if you are interested. Our Resource Library has an extended catalogue of material. Ask a member of your Hospice team for recommendations.

Accept Help

Ask for and accept help before you are exhausted. You may want some help with yard work, with grocery shopping, or with errands. Most people want to help - they just don't know what is best for you. Tell your circle of support what would be most meaningful for you.

Take Time for Yourself

By taking time for yourself, you can focus on other aspects of life which can be renewing and rejuvenating. It is okay to have peaceful, energizing moments even as your loved one is dying.

Take Care of You

Take care of your physical self. Remember to eat. Take a walk. Spend an extra 5 minutes relaxing in the shower. You will find it hard to balance all of the tasks and emotions during this time. That is perfectly normal. But, as a caregiver, you also need to remember to do what's necessary for your own physical, mental, and emotional wellness.

Try to Get Enough Sleep

If this is a challenge, speak with your Hospice team and see if they can offer suggestions. While we cannot prescribe medication to family members, we have many resources available and may be able to make suggestions.

Moving and Lifting

You will not be able to care for your loved one if you injure yourself while moving and lifting them. Your Hospice team will teach you how to safely move and lift someone and we have videos available on our website to show you the best ways to move and lift someone you are caring for. Visit www.hospicenw.org/caregiver-toolbox to view the caregiver videos or scan the QR code with the camera on your mobile device.

Here are some tips:

- When lifting, always flex your knees. Use the muscles in your legs and arms, not your back, to lift.
- Don't jerk and don't twist. The goal is to lift smoothly.
- Stand as close as possible to the person you are lifting with your toes pointed in the direction you want to move the person.

How to Advocate for a Loved One in a Care Facility

Build Relationships with Facility Staff

Care facility staff are part of the team caring for your loved one, alongside the hospice team. It helps to keep a good attitude and understand realistic expectations for the facility staff. Talk with any member of your hospice team if you are having trouble communicating with facility staff.

- When visiting with your loved one, please communicate to facility staff if you see any distressing symptoms. Treating discomfort is a priority and staff will want to hear from you.
- Sometimes, you may need to act as your loved one's eyes and ears, especially if your loved one cannot fully participate in their own care. Share with care facility staff your loved one's likes, dislikes, goals, and what's most important to them — including any spiritual, religious, or cultural preferences or practices. Care facilities have specific policies and procedures to follow, but when they understand your loved one's wishes for care and quality of life, staff can try better to accommodate them.
- You know your loved one best. Your knowledge and experience with them are valuable to your care team. It is helpful for caregivers to be familiar with past emotional trauma and challenging experiences so that we can help prevent additional or unnecessary distress.

If You Have Concerns

If you feel concerned about the care of your loved one, notify your hospice team and/or facility staff to discuss the benefits of a Care Conference. Care Conferences provide a forum for all of the people involved in the care for your loved one (facility staff, hospice staff, family members, etc.) to discuss the patient's goals and how to best meet them.

- Ask your hospice counseling team to help communicate with staff, if needed. We are here for patients AND their families or circle of support.

- Speak with the facility social worker and/or the hospice social worker to discuss finances and long-term care options as needed. Long term care can be expensive for many and your loved one may be eligible for assistance with this burden.

- If you are unable to visit your loved one, you are welcome to check in regularly both with the hospice team and facility staff. We can help provide regular updates on your loved one's condition, as well as any changes to the care and recommendations for comfort. We also want to know how we can support you as you care from a distance.

  If you have concerns about abuse, neglect, or exploitation, call 1-866-END-HARM (363-4276). You are encouraged to contact your local Adult Protective Services office and/or the Washington State Long-Term Care Ombudsman at 1-800-562-6028.

  These services are free of charge and confidential. Your hospice team can help you connect to these services.

If you believe a crime has been committed, contact your local law enforcement agency immediately. Your Hospice team will help you if needed.

What Should We Expect During the End-of-Life Process?

As your loved one approaches the end of life, it can be difficult emotionally and physically for you to care for them. Hospice of the Northwest wants to help prepare for some things you may encounter during this time. Some things are written in this guidebook but you can also view videos on our website specifically for caregivers.

Visit www.hospicenw.org/caregiver-toolbox to view the caregiver videos or scan the QR code with the camera on your mobile device.

Withdrawal

Sometimes, even weeks before death, a person begins to withdraw from family and friends. This “turning inward” may be part of preparing to move on. You might see more sleeping and difficulty waking. Suggestions:

- Plan activities and visiting for times of the day when your loved one is most likely to be alert.

- Let your loved one know what you are going to do before you do it. For example, if they are drowsy, tell them, “I’m going to turn you over now.”

- Hearing seems to remain until the very end. Continue to provide reassurance by talking in a normal tone about how much you care and what you want your loved one to know.

- Remember not to say anything in your loved one’s presence that you wouldn’t say if they were wide awake.

Appetite

The need and desire for food and fluids naturally begins to decrease. It is important to respect their wishes when they decline food or fluids. Suggestions:

- If coughing and sputtering occur with food or fluids, it may be time to adjust or stop.

- If your loved one can’t speak and they spit food or bite down on a spoon or straw, they are likely telling you they don’t want any more.

- Even if they ask for water, they may not drink. Provide mouth care to alleviate dryness. (Information about mouth issues and providing mouth care is available in Section 3.)

Incontinence

Weakness in the lower body can cause some people to lose control of their bladder and/or bowels. The goal is to keep your loved one clean, dry, and comfortable.

Suggestions:

- Disposable briefs and under pads on the bed may be adequate. These are not "diapers." The nurse and aide can help teach you how to change the briefs for someone in bed or with limited mobility.
- A catheter (small tube) inserted into the bladder may be offered to help with incontinence.
- As fluid intake reduces and decline continues, the amount of urine will decrease and may become darker and more concentrated. The smell may be stronger. This is typical.

Disorientation or Confusion

As changes occur in the body, the mind is also affected. Forgetfulness, disorientation, and confusion may result. If your loved one is easily reoriented, gentle reminders of where they are, etc., may work fine. If this gentle reminder upsets them, don't try to reorient them. If there is a sudden disorientation, call the nurse.

Hallucinations

Sometimes people appear to be hallucinating, meaning they see or hear things no one else can see or hear. This could be caused by medications and you will want to ask the nurse about this. However, if we listen carefully, there may be meaningful messages to be heard, such as:

- People nearing the end of life will often talk about travel, as though they plan for a journey. This can be reassuring for caregivers and family because it lets them know their loved one is aware, at some level, of the transition that will soon take place.
- Loved ones approaching end of life may talk clearly to people who have already died, often close relatives or friends, and then turn to talk clearly to you. This is normal.

- Sometimes, loved ones will call out about wanting to “go home.” They are probably not talking about their physical home but instead some other, anticipated home. Consider asking them if they “are ready to leave.” This may give them permission to “go” or to “move on.”

When a loved one who is approaching the end is confused, disoriented, or hallucinating, there is no need to correct them or argue with them. Continue to speak in a normal voice with them. If, however, they report alarming or concerning hallucinations (for example, bugs on the walls or snakes on the ceiling), please call the nurse.

Restlessness

If your loved one is starting to fidget, pick at things such as their sheets or be in constant motion, it could possibly be caused by a full bladder or an infection. Try to recall the last time they emptied their bladder, then talk to the nurse. Restlessness can also be due to decreasing oxygen levels or other physical changes. While providing your loved one with additional oxygen will likely not help at this time, you can:

- Speak slowly and softly; reassure them you are there with them.

- Play soft music, read to them, or massage their hands/feet/back gently.

- Don’t try to restrain their movements. However, if their movements are frequent and may cause them harm, contact the nurse.

- Continue to administer pain and other comfort medications as you have been doing. Even if they can’t tell you their symptoms, they likely still have them.

Additional tips for managing restlessness and agitation can be found in the Symptom Management section, on page 50.

Fever

The brain starts losing its ability to control the body’s temperature near the end of life, so you may discover your loved one has a slight fever. A cool washcloth to the forehead or a fan on low in the room may help them feel more comfortable.

Saliva

Weakness can result in loved ones not being able to swallow, even their own saliva (mouth fluid). This fluid can gather in the back of the mouth and create a ‘rattling’ sound. Suggestions:

- Turn your loved one from side-to-side and position their head to the side. This may clear some of the fluid from the mouth.

- Provide mouth care while they are on their side as other parts of their mouth may become dry. (Information about mouth issues and providing mouth care is available in Section 3.)

- Call the nurse. There are medications that may reduce the amount of fluid produced.

- The excess fluids are probably not causing your loved one any discomfort. The ‘rattling’ sound can be disturbing to family and caregivers. If you have any concerns about what you are hearing or what may be happening with your loved one, call the nurse.

Circulation

Everything is slowing down, including the blood flow in the body. The body wants to protect the heart and brain. You may see or feel your loved one’s hands or feet become cold to the touch, and perhaps a bit bluish. Joints such as the knees or elbows may also appear blotchy. The nail and lips may become bluish as well. All of these changes are normal as a person nears the end of their life. Keep reassuring your loved one you are present with them and you care for them.

Moaning

Many of our patients make noises, such as moans, at the end. This does not necessarily mean they are in pain, suffering, or in any kind of distress. If you have any questions about what you are hearing or what may be happening with your loved one, please call the nurse.

How Will I Know When My Loved One Has Passed?

No matter how well prepared you are, or thought you were, your loved one's passing can feel like a shock. What you have been expecting, and what we have been helping you with, has occurred.

When your loved one has passed, they will be "quiet." You will see no breathing and feel no heartbeat. Watch their chest; there won't be rising and falling. No air will be coming in and out of their nose or mouth. If you feel for a pulse, you will not feel or hear a heartbeat/pulse.

Their eyes may be open or shut. Their jaw will likely relax and their mouth will open. Sometimes, their bladder or bowel will relax too.

Sit quietly with them.

This is not an emergency. **Do not call 911.** Hospice is available day or night. We want you to call us, when you are ready, after your loved one has passed.

When someone dies while receiving hospice care, the death is expected and no "pronouncement of death" must be made. When you call us, we will:

- Offer a visit to support you; you may choose to have us visit or not.
- Offer to contact the funeral home that you have chosen in order to save you that phone call. Please note that although we may have the funeral home of choice on file, the nurse that speaks with you may not have ready access to this information. They may need to ask again for this information.
- Notify the coroner and the attending physician of record.

When the Funeral Home Arrives to Take Your Loved One's Remains

There is no hurry on this – the choice is yours. However, if your loved one died during the summer season, you will want to keep the body as cool as possible prior to the funeral home's arrival. If you have questions about this, please speak with the nurse.

For deaths in a care facility, the facility will sometimes ask a nurse to confirm the death, due to their unique regulations. Hospice with coordinate with the care facility staff to do this.

Disposing of Medications After Your Loved One’s Passing

When you are ready, you will need to safely dispose of, or drop off, the medications left in your home (see Drop off Locations in Appendix B).

Final Arrangements

See a list of local options in Appendix C.

Some things to consider as you make final/funeral arrangements for your loved one:

- The option you choose should depend on such factors as your religious affiliation, culture, budget, and the requests your loved one may have made before they passed.

- There is a movement toward greater personal choice with funerals and burials giving families more options in regards to the economy, concern for the environment, and personal expression. “Alternative funerals” are rising in popularity. We encourage you to do what feels right for your family and the loved one you are honoring.

- You may want to discuss your ideas with a funeral director. They can advise you regarding cost and local regulations regarding what may or may not be possible to do with your loved one’s remains.

Consumer Protection

The Funeral Rule, enforced by the Federal Trade Commission, requires funeral directors to give you itemized prices in person and, if you ask, over the phone. The Rule also requires funeral directors to give you other information about their goods and services.

For example, if you ask about funeral arrangements in person, the funeral home must give you a written price list (to keep) that shows the goods and services the home offers. If you want to buy a casket or outer burial container, the funeral provider must show you descriptions of the available selections and the prices before actually showing you the caskets.

Many funeral providers offer various "packages" of commonly selected goods and services that make up a funeral. When you arrange for a funeral, you also have the right to buy individual goods and services. You do not have to accept a package that may include items you do not want.

According to the Funeral Rule:

- You have the right to choose the funeral goods and services you want (with some exceptions).
- The funeral provider must state this in writing on the general price list.
- If state or local law requires you to buy any particular item, the funeral provider must disclose it on the price list, with a reference to the specific law.
- The funeral provider may not refuse or charge a fee to handle a casket you bought elsewhere.
- A funeral provider that offers cremations must make urns available.

Hospice social workers and other staff will answer any questions about cremation, whole body donation, and burial. They will not recommend specific funeral homes. We encourage you to call or look at reviews of specific funeral homes online to explore the options available to you.

Suggestions for Tasks to Complete After Your Loved One Has Passed

The things to do after a loved one's passing can feel overwhelming and you may feel like you don't know where to start. Here are some suggestions.

Soon After Loved One Has Passed

- Finalize funeral and/or cremation arrangements.
- Get many certified copies of the death certificate. Your chosen funeral home or the county health department can assist with this. It will save you money and time if you obtain these soon after your loved one passes.
- Consult an attorney and discuss fees before accepting legal help or advice from family or friends. We encourage you to seek legal advice, if needed.

Who to Notify that Loved One Has Passed

- Notify your loved one's insurance companies in writing of their passing. Each company will need a death certificate before the survivors can receive any benefits.
- Contact Social Security to find out if survivors are eligible for benefits. If there are any benefits available, they are not automatically paid out. You must apply for them. Learn more by calling 800-772-1213 or look online.

NOTE: The coroner/funeral home notifies Social Security and Medicare of the death.

- Send a formal letter to your loved one's employer, union, and any other group or professional organization. Check with them about any benefits such as insurance policies or retirement funds.

- If your loved one was a veteran, apply for Veteran’s Benefits. You will need a copy of their discharge certificate. Send copies of their discharge certificate and death certificate with a letter to the nearest Veteran’s Administration Office, addressed:

  Attention: [branch they served in.]

- Contact all creditors in writing informing them of your loved one’s passing. This may include loans, banks, credit cards, etc. If any debt remains, inquire regarding death insurance on the accounts.
- Notify the Department of Motor Vehicles if your loved one had a vehicle titled in their name. You may need to request a title change.

Within the First Six Months Following Loved One’s Passing

- See an accountant or attorney regarding **taxes**. Federal law requires an estate tax return be filed within nine months of the death in many cases. Tax laws are revised frequently, thus it is imperative that you seek advice on the current laws and your tax liability.
- **Probate** procedures can be complex, depending on the size of the estate and claims against it. Seek an attorney’s advice, if necessary.

Bereavement

Your Hospice Bereavement Counselor will be able to help you understand and integrate your grief in a healthy way. They understand how devastating loss can be. The Bereavement team provides education, one-on-one counseling, support groups, and will send you inspiration messages throughout the following year.

A Bereavement team member will be calling to support you. You can also contact them directly by calling 360-814-5570.

The Foundation

Giving can be healing

Our Medicare funding is supplemented by donors through the Hospice of the Northwest Foundation. The funds received by the Foundation help provide medical, emotional, spiritual, and financial support for patients and their loved ones.

A 501(c)3 nonprofit corporation, the Hospice of the Northwest Foundation raises funds in a variety of ways including, memorial gifts, bequest gifts, planned gifts, events, and direct mail. The primary caregiver's name and contact information is provided to the Foundation for fundraising purposes.

Creating a memorial or acknowledging the care a loved one received can be done in several ways:

- Family and friends may make direct gifts to the Foundation by donating via phone, online, or by emailing foundation@hospicenw.org.
- Suggesting donations to the Foundation in lieu of flowers through a funeral home or newspaper announcement.
- Including the Foundation in estate planning conversations.

Gifts to the Hospice of the Northwest Foundation will:

- Help those without adequate financial resources to die comfortably and with dignity. No one is denied care because of an inability to pay.

- Fund integrative therapies, like massage and music, which are proven to help reduce pain and discomfort at the end of life.

- Bring comprehensive bereavement services to families coping with grief and loss.

- Provide staff training and education to ensure that our community continues to receive the highest quality care at the end of life.

- Purchase up-to-date technology and equipment to provide the most effective and responsive patient care possible.

- Fund volunteer services that bring companionship and comfort to patients' homes.

There are many ways to give in support of the care Hospice of the Northwest provides. If you would like more information about our Foundation, how to make a gift, or the work the foundation does, please call Hospice of the Northwest Foundation at 360-814-5702 or email at foundation@hospicenw.org.

Please note: Hospice of the Northwest staff and volunteers are not permitted to accept personal gifts or gratuities. If you insist on sharing a token of your appreciation, our team members are required to bring it to the hospice office to be shared with everyone. Cash or gift cards cannot be accepted under any circumstances unless donated directly to Hospice of the Northwest Foundation. Thank you for your understanding and support!

Notes

Section 5: Appendix and Policies

Appendix A: Paying for Hospice Services

The following is a summary of the ways hospice services can be paid for. Not every option listed here is possible for every person, but it describes general ways in which many patients may have the option to pay for hospice services.

Medicare Coverage

When a person has Medicare and they want to use their hospice benefit, they "elect" to switch from regular Medicare to Hospice Medicare. When you elect the hospice benefit, your regular Medicare will stay in place for health care that is not related to your life-limiting conditions. For care related to your life-limiting condition, the Hospice portion of Medicare will cover this, provided it is part of your plan of care.

Medicare provides benefit periods of 90 days, another 90 days, and then every 60 days. At the end of each benefit period, your team will assess your continued eligibility. If you remain eligible, your eligibility will be recertified. After the first two benefit periods (180 days of care), the hospice physician or a nurse practitioner will perform a face-to-face visit to assess your comfort and continued eligibility.

The Medicare Hospice benefit is somewhat similar to a managed health plan. This means you need prior authorization before you receive other health care.

NOTE: We strongly recommend you inform hospice prior to seeking any health care services, related or not related, to your life-limiting condition. If you do not inform hospice, you may be responsible for health care expenses. Calling 911 or going to the emergency department must have prior authorization from hospice. If not, you may be responsible for all costs related to 911, transport, emergency department and hospitalization.

You may continue to see your primary doctor for office visits. When you sign the consent/election of benefit, you identify your primary doctor. You can change the name of your primary doctor by completing the appropriate form, available from your team.

We ask you to remind your primary doctor that you are receiving hospice services when you see them. **Unless you have prior authorization from hospice, any tests or procedures your primary doctor orders may be your financial responsibility.**

Atypical Interventions, Revocation, and Discharges

Atypical Interventions – Your team may use this term to describe procedures and treatments that are generally not included in the hospice benefit. Some examples include blood transfusions, palliative radiation, breathing machines for apnea, etc. The Atypical Intervention will be discussed with you in terms of benefit vs burden, who and/or where it is provided, costs, etc. Not all hospices can offer these interventions, but we can sometimes provide these through the Hospice of the Northwest Foundation.

Revocation - You may "revoke" your Medicare hospice election any time you wish. When you revoke, this means you resume regular Medicare the same day as the revocation. Some reasons to revoke:

- You want to seek treatment or therapies to cure or delay disease progression.
- You want to go to the Emergency Room for a reason hospice doesn't cover.
- You are unhappy with the managed care aspect of the hospice benefit.

If you revoke, you lose the remaining days in the benefit period. To revoke, Medicare states you or your Durable Power of Attorney (DPOA) must sign a revocation document before seeking other health care. Verbal revocations are not accepted by Medicare.

Note: After you revoke, you may be eligible to request hospice benefits again in the future.

Discharge - Hospice may discharge you from hospice services if your condition stabilizes and you no longer meet the eligibility criteria set by Medicare. You will be given notice if discharge is pending and your team will work with you to coordinate your discharge plans.

You may appeal any decisions regarding pharmaceuticals, equipment, supplies and/or discharge. The appeal process is available to every Medicare patient. The Medicare appeal form is available from any member of your team.

What if I Don’t Have Medicare?

Medicaid Coverage

Medicaid follows Medicare’s rules very closely. The care and decisions for Medicaid are almost equal to Medicare. There are two items to highlight for you if you have Medicaid:

- You must continue to pay your participation as determined by the Department of Social and Health Services (DSHS) to keep your Medicaid in place.
- Medicaid does not cover appointments with your primary doctor. **If you want to see your Primary Doctor, you will need prior authorization from hospice.** In most cases, hospice will approve one closure visit with your Primary Doctor.

Commercial or Private Insurance

Each insurance is different. Most tend to follow Medicare’s rules closely. However, there are some plans that will cover a little more or less than Medicare. Usually, co-pays and/or deductibles will remain your responsibility while in hospice care. Your hospice team can try to answer your questions or can help you access this information for yourself. It’s important to note that we are not insurance experts. We can only assist you. Please contact your insurer directly for coverage or claim questions and information.

Self-Pay/Uncompensated Care

When it is confirmed that there is no payer/coverage, the Financial Assistance Verification process will begin. If you are able to pay privately, a payment plan will be arranged. If you have inadequate financial resources, you may be partially or wholly eligible for Uncompensated Care through the Hospice of the Northwest Foundation. A social worker will help you with the process to determine eligibility for financial assistance.

See Appendix J for financial assistance information or ask your social worker.

Appendix B: Medication Destruction

The following is a summary of how you can safely destroy patient medications after they are no longer needed.

How to Destroy Medications in your Home

- **NEVER FLUSH DOWN THE TOILET and NEVER DRAIN INTO THE SINK**
- Take a plastic bag, an empty coffee can, or an old jar with lid – some type of container
- Put dry kitty litter, flour, coffee grounds, or dry pancake mix into the container
- Pour all pills, tablets, liquids into the container
- Unwrap patches and suppositories and put the medicine into the container
- Pour some water or vinegar into the container, enough to dissolve the medications
- Close the container and put it in your trash
- Put emptied medicine bottles in the trash, preferably marking off the patient's name and prescription number from the bottle before you do so

Hospice of the Northwest can also supply you with medication destruction kits. If you would like a kit, please ask your nurse.

Medication and Supply Drop-off Sites

The US Drug Enforcement Agency [DEA] suggests a drug take-back program for disposal of medication. Washington has an active drug take-back program in most areas of the State. If you decide to destroy the drugs yourself, please follow the instructions in this section.

Drug Take Back Programs

- A few sites take liquid medications, all take pills and capsules
- Generally no labeled containers or needles (syringes) are accepted
- All drugs must be in plain plastic bags, zip-lock style work best

See also resources at TakeBackYourMeds.org .

Accepts medication in both liquid & pill form:

Arlington Police Department
Address: 110 E. 3rd Street
Arlington
Phone: 360-403-3400
Hours: 8am to 5pm, M-F
Liquids and pills in plastic bags

Skagit County Sheriff
Address: 600 South 3rd Street
Mount Vernon
Phone: 360-336-9450
Hours: 8:30am to 4:30pm, M-F
Liquids and pills in plastic bags

Accepts ONLY medication in pill form:

Anacortes Police Department
Address: 1218 24th Street
Phone: 360-293-4684
Hours: 8am to 5pm, M-F
Pills in plastic bags

Oak Harbor Police Department
Address: 865 SE Barrington Drive
Phone: 360-279-4500
Hours: Lock box in lobby, open 24/7
Pills in plastic bags

Mount Vernon Police Department
Address: 1805 Continental Place
Ph: 360-336-6271
Hours: 8am to 5pm, M – F
Pills in plastic bags

Sedro-Woolley Police Department
Address: 325 Metcalf Street
Ph: 360-855-0111
Hours: 10am to 5pm, M-F
Pills in plastic bags

San Juan County Sheriff

Friday Harbor
Address: 96 2nd Street
Phone: 360-378-4151
Hours: Lockbox in lobby, open 24/7
Pills in plastic bags

Orcas
Address: 1323 Mt Baker Road
Phone: 360-378-4151
Hours: Drop box outside of station, 24/7
Pills in plastic bags

Lopez
Address: 2228 Fisherman Bay Road
Phone: 360-378-4151
Hours: Drop box outside of station, 24/7
Pills in plastic bags

Disposal of Medication Policy

Hospice of the Northwest nursing staff may assist in the disposal of medications in a manner consistent with state and federal regulations. Nursing staff may physically assist in the disposal of medications when the drug is expired or the patient has passed away. Verbal or written directions for disposal will be provided for medications no longer in use for other reasons.

Caregivers are instructed not to bring medications to the hospice office. Hospice staff will not remove medications from the home for any reason. Hospice staff will educate patients and families about the importance of safe disposal of unwanted medications, especially controlled substances.

Donating Medical Supplies

Local organizations such as senior centers, homeless shelters, or food banks may accept unopened and unexpired supplies. Animal shelters and rescues may be able to use incontinence products. Please call ahead to confirm what they will accept and their donation drop-off hours.

Appendix C: Final Arrangements

The following is a summary of options for loved ones to make final arrangements. This is not an all-inclusive, comprehensive, or hospice recommended list, but common options other hospice families have used and may good a place to start.

Skagit County Funeral Homes	
Evans Funeral Home Chapel and Crematory (360) 293-3311 1105 32nd Avenue Anacortes www.evanschapel.com/	Kern Funeral Home (360) 336-2153 1122 S. 3rd Street Mount Vernon www.kernfuneralhome.com/
Hawthorne Funeral Home and Memorial Park (360) 424-1154 1825 E. College Way Mount Vernon www.hawthornefuneralhm.com/	Lemley Funeral Chapel (360) 855-1288 1008 3rd Street Sedro-Woolley www.lemleychapel.com/
Hulbush Funeral Home (360) 757-6055 281 S. Burlington Blvd. Burlington www.hulbushfuneralhome.com/	
Whidbey Island Funeral Homes	
Wallin-Stucky Funeral Home & Cremation (360) 675-3447 1811 NE 16th Avenue Oak Harbor www.wallinfuneralhome.com/	Whidbey Memorial (contracted with Peoples Memorial) (360) 675-5777 746 NE Midway Blvd. Oak Harbor www.whidbeymemorial.com/
Wallin-Stucky Funeral Home (360) 221-6600 5533 East Harbor Road Freeland, WA 98249 www.wallinfuneralhome.com/	

Snohomish County Funeral Homes	
Gilbertson’s Funeral Home (360) 629-2101 27001 88th Avenue NW Stanwood www.gilbertsonfh.com/	Evergreen Funeral Home (425) 504-8518 4504 Broadway Everett https://www.dignitymemorial.com/
Schaefer Shipman Funeral Home (360) 659-3711 804 State Street Marysville www.schaefershipmanfuneral.com	Solie Funeral Home & Crematory (425) 252-5159 3301 Colby Avenue Everett www.soliefunerals.com/
Weller Funeral Home (360) 435-2509 327 North Macleod Avenue Arlington www.wellerfh.com	
San Juan County Funeral Homes	
Evans Funeral Home Chapel and Crematory (360) 293-3311 1105 32nd Avenue Anacortes www.evanschapel.com	

Funeral Home Alternatives and Direct Cremation

Alpha-Omega Burial and Cremation (360) 424-3531 1825 E College Way, PO Box 398 Mount Vernon www.alphaomegaburialandcremation.com	American Cremation & Casket Alliance 1-800-398-7101 3906 132nd Place N.E. #701 Marysville www.americancremation.com
Choice Cremations of the Cascades (425) 231-0809 3305 Colby Ave Everett www.choicecremations.com/	Funeral Alternatives of Snohomish County (Includes Mt Vernon area) (360) 658-1921 1914 Fourth Street Marysville www.funeralsandcremationswa.com

Mount Baker Cremation (360) 392-8881 325 Pine Street Suite F Mount Vernon www.mtbakercremationsociety.com/	Skagit Cremation Services (360) 424-0282 PO Box 2411 Mount Vernon
Recompose (body composting) 206-800-TREE 4th S. Idaho Street Seattle info@recompose.life www.recompose.life	Whatcom Cremation & Funeral (360) 734-7073 4202 Guide Meridian #106 Bellingham www.wcremation.com
Peoples Memorial Funeral Cooperative (Locally Contracted Funeral Services: **Discuss with MSW)* www.peoplesmemorial.org (206) 325-0489 or (888) 762-2762	

Anatomical/Whole Body Donation

Aeternitas Life (844) 330-7040 www.aeternitas.com	LifeNet Health **Tissue Donation Only* (800) 888-9597 www.lifenethealth.org
MedCure (866) 560-2525 www.medcure.org	Science Care (800) 417-3747 www.sciencecare.com
University of Washington School of Medicine Willed Body Program (206) 543-1860 www.uwmedicine.org/willedbody	

Funeral Home Alternatives and Direct Cremation

Earth Funeral (877) 327-4109 www.earthfuneral.com	Return Home (206) 502-4042 www.returnhome.com

Appendix D: CPR and Hospice Care

The following is a summary of what Cardiopulmonary Resuscitation (CPR) is and why or when it may not be appropriate to use on patients in hospice care. It is not definitive or comprehensive as each case is individual.

Cardiopulmonary Resuscitation is a medical treatment that tries to restart blood flow and breathing in a person whose heart has stopped. The goal of CPR is to keep vital organs (brain, kidneys, and heart) working while trying to restart breathing and heartbeat. It does not fix the reason that breathing or the heartbeat stopped in the first place.

Is CPR helpful for hospice patients?

Cardiopulmonary Resuscitation works best for people who are in overall good health. It does not work very often for people who are seriously sick or who in advanced age. Even in the hospital, when CPR can be started right away, only one in eight people who have CPR live to leave the hospital.

For people who have kidney failure, are older than 70 years old, or who have a severe infection, only 4 in 100 people live after CPR. In people with a new stroke, or in people with metastatic cancer, almost no one (less than 1 in 100 people) live to leave the hospital after CPR.

For people in hospice care, near the end of life, CPR almost never works. This means almost all people either die during CPR or do not live to leave the hospital.

Is CPR harmful?

Cardiopulmonary Resuscitation causes broken ribs in almost all patients (97 out of 100) and a broken breastbone in almost half of patients. Not only is this painful, but this makes it very hard to breathe. The skin of the chest is burned from the shock in many patients (30 out of 100). People who have CPR are almost always moved to a hospital and started on a breathing machine. This can be harmful if the hope was for a peaceful death at home with family by their side.

For Caregivers

Cardiopulmonary Resuscitation (CPR) can change death from peaceful and family centered to one focused on medical procedures and staff.

Choosing CPR and Hospice

If you choose to try CPR, the staff of Hospice of the Northwest will do their best to support your decision. All hospice nurses and aides are certified to provide CPR. Most likely, a hospice staff member would not be in your home, or close enough for rapid response. If after a few cycles of CPR, breathing and heartbeat do not restart, families may wish to call 911. Before going to the hospital, the person with Durable Power of Attorney (decision-maker) may wish to revoke the hospice benefit and resume regular Medicare. Resuscitation care is not part of the plan of care for hospice patients so unless hospice care is revoked, families or the estate could be responsible for the hospital bills.

Your hospice team will talk to you about CPR when you come on to hospice care. They may talk about it again if you are becoming more ill. The goal is to give you the information you need to match your medical treatment to what is most important to you and your family.

Appendix E: Advance Directives

The following is a summary of Hospice of the Northwest's policy regarding the patient's care and end-of-life goals. These wishes, as expressed by the hospice patient, are known as Advance Directives.

Purpose

To facilitate a patient's fundamental right to control the decisions relating to the rendering of their own health care, including the decision to have life-sustaining treatment withheld or withdrawn.

Policy

Hospice of the Northwest will follow the patient's Advance Directives, including rights provided under the Washington State "Natural Death Act." Hospice of the Northwest informs and distributes written information to the patient on their right to formulate advance directives and encourages the patient to discuss the issue with their surrogate decision makers/Durable Power of Attorney. In the event that the patient is without the capacity to make treatment decisions for themselves, this decision shall be made by an appropriate surrogate. The provision of hospice care is not dependent upon whether or not the individual has completed an advance directive.

Procedure

Prior to receiving care, the hospice representative provides written information and instruction on advance directives to the patient. If the patient is unable to understand this information it is given to the patient's legal health care representative or proxy. The written information given to the patient or legal representative includes:

- The hospice's policies on the implementation of the patient's advance directives;
- A description of the patient's rights under State law, including the patient's right to:
    - Make decisions concerning the patient's medical care;
    - Execute an advance directive;

  - Revoke an advance directive at any time; and
  - Accept or refuse medical treatment, including Do Not Resuscitate (DNR) orders.

- At the admission assessment, the hospice nurse documents whether or not the patient has executed an advance directive, and whether or not the patient or legal health care representative wishes to engage in the discussion. Hospice of the Northwest recognizes and respects that some cultures prefer not to discuss issues related to sickness or death, or choose to defer these discussions to a proxy/family representative.

- If available, a copy of any advance directive is placed in the patient's clinical record and the patient's wishes, including his or her Do Not Resuscitate status, are communicated to hospice staff to be included in care planning for the patient.

- If the opportunity to formulate an advance directive is declined at the time of admission, the patient may execute one at a later date by notifying a staff member who then notifies the social worker. The social worker provides the patient with appropriate forms and ensures that they are properly completed.

- Portable Orders for Life-Sustaining Treatment (POLST) orders are signed by a physician with a copy placed in the patient's clinical record and the original retained by the patient who is encouraged to post the form on the refrigerator if at home, or in a prominent location of the patient chart if in a facility.

- A patient or their surrogate decision maker has the right to change or update an advance directive or POLST as goals or status changes.

- If a hospice employee is present during a medical emergency, the patient’s signed Portable Orders for Life-Sustaining Treatment form (if any) will be provided to emergency medical personnel.

Appendix F: Surrogate Decision Maker

Surrogate Decision Makers play an important role in patient care. Designated surrogate decision makers make healthcare decisions on behalf of a hospice patients who is no longer legally competent to make those health care decisions. This section summarizes the policies, procedures, rights, and responsibilities of a surrogate decision maker.

Washington State Decision-Making Hierarchy

Health care decisions for a patient who is not competent may be obtained from a person authorized to consent on behalf of such patient. This surrogate decision maker is:

- Someone authorized to provide informed consent to health care on behalf of a patient who is not competent to consent, based upon a reason other than incapacity, shall be a member of one of the following classes of persons in the following order of priority:
    - The appointed guardian of the patient, if any
    - The individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions
    - The patient's spouse or state registered domestic partner
    - Children of the patient who are at least eighteen years of age
    - Parents of the patient
    - Adult brothers and sisters of the patient.

When the Primary Surrogate Decision Maker Cannot be Located

If the health care provider seeking informed consent for proposed health care of the patient who is not competent to consent, other than a person determined to be incapacitated because he or she is under the age of majority and who is not otherwise authorized to provide informed consent, makes reasonable efforts to locate and secure authorization from a competent person in the first or succeeding class and finds no such person available, authorization may be given by any person in the next class in the order of descending priority. However, no person under this section may provide informed consent to health care:

- If a person of higher priority under this section has refused to give such authorization; or

- If there are two or more individuals in the same class and the decision is not unanimous among all available members of that class.

Before a Decision Can Be Made by Someone who is Not the Official Surrogate Decision Maker

Before any person provides an informed consent decision **who is not otherwise authorized to provide informed consent** on behalf of the patient, the healthcare provider must first determine in good faith that the patient, if competent, would consent to the proposed health care. If such a determination cannot be made, the decision to consent to the proposed health care may be made only after determining that the proposed health care is in the patient's best interests.

Informed Consent

Informed consent for health care, including mental health care, for a patient who is not competent because they are not an adult, or who is not otherwise authorized to provide informed consent, may be obtained from a person authorized to consent on behalf of such a patient. This may include:

- Persons authorized to provide informed consent to health care, including mental health care, on behalf of a patient who is incapacitated because they are not legally an adult or is not otherwise authorized to provide informed consent, shall be a member of one of the following classes of persons in the following order of priority:
    - The appointed guardian, or legal custodian authorized of the minor patient
    - A person authorized by the court to consent to medical care for a child in out-of-home placement
    - Parents of the minor patient
    - The individual, if any, to whom the minor's parent has given a signed authorization to make health care decisions for the minor patient
    - A competent adult representing himself or herself to be a relative responsible for the health care of such minor patient or a competent adult

who has signed and dated a declaration stating that the adult person is a relative responsible for the health care of the minor patient. Such declaration shall be effective for up to six months from the date of the declaration.

- A **health care provider** may, but is not required to, rely on the representations or declaration of a person claiming to be a relative responsible for the care of the minor patient, if the health care provider does not have actual notice of the falsity of any of the statements made by the person claiming to be a relative responsible for the health care of the minor patient.

    a. A health care facility or a health care provider may, in its discretion, require documentation of a person's claimed status as being a relative responsible for the health care of the minor patient. However, there is no obligation to require such documentation.

    b. The health care provider or health care facility where services are rendered shall be immune from suit in any action, civil or criminal, or from professional or other disciplinary action when such reliance is based on a declaration signed stating that the adult person is a relative responsible for the health care of the minor patient.

Appendix G: Patient Rights & Responsibilities

As a patient of Hospice of the Northwest, individuals are guaranteed specific rights concerning their treatment and care. In order to best serve patients, the patients and their loved ones have specific responsibilities. Those rights and responsibilities are summarized below.

Policy

Hospice of the Northwest seeks to protect the rights, interests and well-being of our patients in conformity with state and federal laws and regulations. Hospice of the Northwest ensures that all patients know and understand their protected rights as well as their responsibilities as patients. Patients are provided with a written statement of Patient Rights and Responsibilities at the eligibility assessment and/or admission visit in advance of furnishing care. This information is reviewed orally in a language and manner that the patient and/or their healthcare representative understands. Participation by patients in clinical training programs or in the gathering of data for research purposes is voluntary. Patients have a right to make decisions concerning medical care, including the right to formulate advance directives.

If a patient has been adjudged incompetent under Washington state law, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf. If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient's rights to the extent allowed by state law.

This policy and procedure expresses the fundamental rights of patients but is not all-inclusive. Hospice staff also have the right to expect responsible, respectful behavior on the part of patients, their relatives, caregivers, and friends.

Patient Rights

Patients of Hospice of the Northwest and their loved ones have rights in regards to their care, property, pain management, advanced directives, privacy, identity, and more.

Access to Care - Patients have a right to:

- Be accorded impartial access to treatment or accommodations that are available and medically indicated, regardless of race, color, national origin, age, disability, sex, sexual orientation, gender identity or expression, ancestry, citizenship status, marital or parental status, pregnancy, military or veteran status, religion, socioeconomic status, source of payment for care, ability to pay for care, or any other category protected by law.

- Be informed of the circumstances that may cause the agency to discharge a patient
- Choose an attending physician
- Have properly trained or credentialed staff provide care and services
- Have smooth coordination of services.

Respect for Property and Person - Patients have the right:

- To exercise their rights as a patient of the hospice
- To have their property and person treated with respect, with recognition of their personal dignity, values, cultural norms, and spiritual beliefs
- To voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice
- To not be subjected to discrimination or retaliation for exercising their rights

Advance Directives – Patients have the right to:

- Formulate and trust that their wishes, as expressed orally or in writing, such as in an advance directive, living will, or Health Care Durable Power of Attorney, are fully respected and honored within the limits of the law
- Patients have the right to include significant others or legal representatives in decision making and care planning according to their preferences; and
- Receive information regarding the Hospital of the Northwest advance directive policy and procedure.

Participate in the Plan of Care - Patients have the right to participate in the development and implementation of his or her hospice plan of care. This includes the right to a listing of the total services offered by the hospice and those being provided to the patient.

Privacy and Confidentiality - Patients have the right, within the law, to personal and informational privacy, as manifested by the right to:

- Expect that any discussion or consultation involving their care will be conducted discreetly, and that individuals not directly involved in their care will not be present without their permission;
- Expect all communications and other records pertaining to their care, including the source of payment for treatment, be treated as confidential as outlined in the Hospice of the Northwest Notice of Privacy Practices.
- Access to, or release of, patient information and clinical records in accordance with 45 CFR parts 160 and 164.

Personal Safety - Patients have the right to expect that their personal privacy and safety will be protected, and that he/she will be free from abuse or harassment. Washington State Department of Social and Health Services has a hotline (1-866-END-HARM or 1-866-363-4276) to report suspected abuse of children or vulnerable adults. Employees of a hospice agency are mandatory reporters and as such the hospice will:

- Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees and contracted staff to the hospice administrator
- Immediately investigate all alleged violations involving anyone furnishing services on behalf of the hospice and immediately take action to prevent further potential violations while the alleged violation is being verified. Investigations and/or documentation of all alleged violations must be conducted in accordance with established procedures
- Ensure that abuse, abandonment, neglect or financial exploitation of a vulnerable adult is reported to Department of Social and Health Services, and if sexual assault or physical assault is suspected, it will also be reported to law enforcement.

Pain Management - Patients have the right to:

- Be informed and knowledgeable about any medications or treatments that will be administered
- Receive effective pain management and symptom control from the hospice for conditions related to the terminal prognosis
- Have their comfort assessed on an individual basis
- Receive timely pain and other symptom management medications.

Identity - Patients have the right to know:

- The name and role of individuals providing care to them
- Which Nurse Case Manager is primarily responsible for their care and how to contact that person
- How care is arranged when services cannot be provided as scheduled.

Language and Communication - Hospice of the Northwest will inform the patient and/or legal representative of their rights in a language or format that they understand. This may include the use of large print materials, communication devices, or a competent interpreter when the patient does not speak, hear, or understand English.

Participation in Human Subjects Research – Patients have the right to

- Be informed and consent or refuse to participate in any human subject research or other research/educational projects affecting their care or treatment
- Refuse to participate in any such activity.

Patient Grievances - Patients have the right to:

- Information concerning to whom and how to make a complaint or grievance:
    - Executive Director or Quality Manager at Hospice of the Northwest: 360-814-5550.
    - Community Health Accreditation Partner (CHAP): 1-800-656-9656
    - Washington State Department of Health: 1-800-633-6828

- Access protective and advocacy services
- Have complaints investigated and responded to in a timely manner
- Express dissatisfaction or complaints in any manner, formal or informal, orally or in writing, by email or the internet
- Have reasonable expectations that care and services will be timely, reasonable and provided in a consistent manner.

Refusal of Treatment - Patients can rescind or refuse to give consent for treatment or care at any time without fear of reprisal either orally, in writing, or by any reasonable means of communication.

This may include:

- Discontinuing a specific service
- Revoking hospice services
- Changing the designation of the particular hospice from which the patient elects to receive care and services.

Hospice of the Northwest Charges - Patients have a right to receive information about the services covered under the hospice benefit. This means:

- Patients are informed of billing and reimbursement methodologies prior to start of care and as changes occur, including fees for services/products provided, direct pay responsibilities, and notification of insurance coverage.
- Regardless of the source of payment for their care, patients have the right to request and receive an itemized and detailed explanation of their total bill for services rendered
- Patients have the right to receive an Advance Beneficiary Notice of Non-Coverage and right to appeal discharge
- Patients have the right to timely notice prior to termination of eligibility for any third-party payer for the cost of care.

Patient Responsibilities

At Hospice of the Northwest we work with our patients and their loved ones to try for a comfortable and peaceful end-of-life experience. This means we need cooperation from the patient and their loved ones and are responsible for the following things.

Provision of Information - Patients are responsible for:

- Providing, to the best of their knowledge, accurate and complete information about:
    - Medications, including prescribed, over-the-counter, natural and alternative remedies
    - Hospitalizations
    - Past illnesses
    - Present concerns
    - Reporting changes in their condition (symptoms, medication problems) to the responsible practitioner
    - Requesting authorization from Hospice of the Northwest prior to hospitalization, emergency room use, diagnostic tests or other new treatments. Patients may be responsible for costs associated with unauthorized care
    - Making it known whether they clearly comprehends his or her Plan of Care and what is expected of them
    - Reporting other matters relating to their health
    - Notifying Hospice of the Northwest if a scheduled visit needs to be changed.

Refusal of Treatment - Patients are responsible for following the plan of care, for the consequences resulting if he/she refuses treatment or does not follow the clinician's instructions.

Respect and Consideration: - Patients are responsible for:

- Being considerate of the rights of other patients and HNW personnel
- Providing a safe environment for care to be provided.
- Treating all hospice staff with respect and dignity, regardless of gender, ethnicity, age, religion, or culture.

Patient and Family Participation in Care Decisions – Patients are responsible for:

- Being informed about and participating in decisions regarding their care
- Including the patient’s representative whenever possible, at the patient's discretion.

Financial Responsibility - The patient is responsible for assuring that the financial obligations of their health care are fulfilled as promptly as possible.

Advance Directives - Patients have the responsibility to tell Hospice of the Northwest staff about the existence of, or changes made to, any advance directives

Resolving Conflicts - Patients have a right to participate in ethical questions that arise in their care. This may include issues of conflict resolution, including talking directly with the care providers regarding withholding resuscitation and foregoing/withdrawing life sustaining measures.

Patients have the responsibility to express any dissatisfaction with care or services rendered so that improvements or explanations can be made.

Hospice of the Northwest has the right to discontinue services if harassment or abuse of staff is occurring.

Appendix H: Notice of Privacy Practices

The following is a summary of the purposes for which Hospice of the Northwest may use and disclose health information about you. Not every type of use or disclosure is listed, but the general ways in which we use and disclose information will fall under these purposes.

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

Uses and Disclosure for Treatment, Payment, and Health Care Operation

To Treat You - Hospice may use and disclose health information about you to provide care to you and to coordinate care within hospice. This includes disclosure with others involved in your care, such as your attending physician, members of hospice interdisciplinary team, and other health care professionals. For example, physicians involved in your care will need information about your symptoms to prescribe appropriate medications.

To Bill for Your Services - Hospice may use and disclose health information about you related to hospice services to be paid by third parties, or by you for the care you receive. For example, your health insurer may require hospice to provide information regarding your health care status so that the insurer will reimburse you or hospice. Hospice also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for hospice services.

To Run Hospice of the Northwest - Hospice may use and disclose health information for its own operations to run hospice and as necessary to provide quality care to all our patients. For example, hospice may use health information about you to evaluate its staff performance, may combine health information about you with other hospice patients to see how to more effectively serve all hospice patients, may disclose health information about you to hospice staff for training purposes, and may use health information about you to contact you as a reminder regarding a visit to you, or send you informational mailings.

Uses and Disclosures of Health Information if You Do Not Object

As long as you do not object, Hospice of the Northwest may use and disclose health information about you in the following situations.

Individuals Involved in Your Care - Hospice may disclose health information about you to a friend, family member, or other person you designate who is involved in your care or the payment for your care.

Notification Purposes - Hospice may use and disclose health information about you directly or to an entity assisting in a disaster relief effort so that your family can be notified about your condition and location.

Directory Information - Hospice may include certain limited information about you in the facility directory.

For Emergency Services - Hospice may disclose health information to emergency responders to help them respond to 911 calls for assistance.

Other Uses and Disclosures of Health Information Without Your Authorization

Hospice of the Northwest may use and disclose health information about you without an authorization as may be required or permitted by law. Hospice of the Northwest has to meet many conditions in the law before it can use or disclose health information for these purposes, including:

For Philanthropic Purposes - Hospice may provide limited information about you, such as your name, address, phone number, age, treating physician, and the dates you received care to Hospice of the Northwest Foundation. You have the right to opt out of receiving fundraising-related communication.

When Legally Required - Hospice will disclose health information about you when it is required to do so by federal, state, or local law.

To Business Associates - Hospice may disclose health information about you with its contractors who create, receive, maintain, or transmit health information for certain activities on behalf of the Hospice. All these business associates must agree to safeguard your information.

For Public Health - Hospice may use and disclose health information about you for public activities, such as to: prevent disease and injury; report disease, injury, and vital events (such birth or death); assist with the public health surveillance, investigations, and interventions; report adverse events, and product defects; help with product recalls; and notify a person who may be at risk of getting or spreading a disease.

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

To Conduct Health Oversight Activities - Hospice may disclose health information about you to a health oversight agency for activities authorized by law, such as for audits, investigations, inspections, licensure, or disciplinary actions.

For Legal Actions - Hospice may disclose health information about you for lawsuits and legal actions, such as court orders, subpoenas, discovery requests, and other lawful process.

For Law Enforcement - Hospice may disclose health information about you to a law enforcement official for certain law enforcement purposes including: as required by law; for reporting of certain types of injuries; as required by a court order, warrant, subpoena, summons, or similar process; and, in limited situations, about a person who is a victim of a crime.

To Coroners and Medical Examiners - Hospice may disclose health information about you to coroners and medical examiners for purposes of determining cause of death or for their other duties.

To Funeral Directors - Hospice may disclose health information about you to funeral directors, as permitted by law, as necessary for them to carry out their duties with respect to funeral arrangements. If necessary to carry out their duties, Hospice may disclose health information about you prior to and in reasonable anticipation of your death.

For Organ, Eye, or Tissue Donation - Hospice may use, or disclose health information about you to organ procurement organizations, for organ, eye, and tissue donation and transplant purposes.

For Research Purposes - Hospice, under very limited circumstances, may use and disclose health information about you for research.

Where there is a Serious Threat to Health or Safety - Hospice may use and disclose health information about you if we believe that the disclosure is necessary to prevent or lessen a serious and imminent threat to someone's health and safety.

For Special Government Functions - Hospice may use or disclose health information about you for special government functions, such as military and veterans, national security, protective services for the president, and law enforcement custody.

For Worker's Compensation - Hospice may disclose health information about you for worker's compensation and similar programs.

Incidental Disclosures - Incidental disclosures of health information about you may occur as a by-product of permitted uses and disclosures.

De-identified Information and Limited Data Sets - Hospice may use and disclose health information that has been "de-identified" by removing certain identifiers (such as name and address) making it unlikely that you could be identified. We also may disclose limited health information, contained in a "limited data set," as allowed by law.

Personal Representatives - Minors and incapacitated adults may have "personal representatives." These personal representatives may be able to act on the individual's behalf and exercise the individual's privacy rights.

Authorization to Use or Disclose Health Information

Other than is stated above, Hospice of the Northwest will not disclose health information about you without your written authorization. Hospice of the Northwest will not sell health information about you, use or disclose health information about you for marketing, or use or disclose health information about you in psychotherapy notes without your authorization. Generally, you may revoke an authorization in writing at any time. If you revoke your authorization, then hospice no longer will use or disclose health information about you for the reasons covered by your authorization, except to the extent that hospice already relied on your authorization. Hospice cannot take back any disclosures already made based on your authorization. Hospice is required to retain our records of the care that hospice provided to you. Certain information, such as information related to mental health, AIDS/HIV, substance abuse, and genetic testing, may have additional protections under federal and state law.

Your Rights

When it comes to health information about you, you have certain rights. This section explains these rights.

Right to Request Limits to Uses and Disclosures - You may request restrictions on certain uses and disclosures of health information about you. Except as required by law, hospice does not have to agree to your request. If hospice does agree, then hospice will comply with your request unless the information is needed to provide you with emergency treatment. Hospice will agree not to disclose to a health plan information about services for which you pay out-of-pocket in full, subject to certain exceptions.

Right to Receive Confidential Communications - You have the right to request that hospice contact you in a certain way. Hospice will try to honor your reasonable requests.

Right to Get a Copy of Health Information About You - You have the right to see and get a paper or electronic copy of certain health information that hospice uses to make decisions about you. Hospice may charge a reasonable cost-based fee.

Hospice may deny your request in certain limited circumstances. If you are denied access to health information, then, generally, you may request that the denial be reviewed.

Right to Correct Health Care Information - If you believe that health information about you is incorrect or incomplete, you have the right to request that hospice correct or amend information that hospice uses to make decisions about you. You must give us a reason for your request. We may deny your request in certain situations. If your request is denied, then you may write a statement of disagreement, and hospice may include a rebuttal statement.

Right to an Accounting of Disclosure - You have the right to request a list (called an accounting) of disclosures of health information about you made by hospice for certain reasons. The request should specify the time period for the accounting, which may not be longer than six years. Hospice will provide the first accounting at no charge, but may charge a reasonable cost-based fee for other ones during a 12-month period.

Right to a Paper Copy of This Notice - You have a right to get a paper copy of this notice even if you agreed to receive this notice electronically.

Right to File a Complaint - If you believe your privacy rights have been violated, then you may contact or submit your complaint to the privacy contact. Hospice encourages you to tell the privacy contact about any concerns you may have about the privacy of your information. You also have the right to file a written complaint with the Office for Civil Rights. The quality of your care will not be jeopardized, and you will not be penalized (or retaliated against) for filing a complaint.

Duties of Hospice

Hospice is required by law to: maintain the privacy of health information; to provide to you this notice of its duties and privacy practices; follow this notice as may be amended from time to time; and notify affected individuals following a breach of unsecured health information.

Changes to this Notice

Hospice of the Northwest reserves the right to change this notice. Changes to this notice will apply to health information hospice already has, as well as any information hospice creates or receives in the future. The revised notice will be available upon request, in the hospice's facilities, and on the Hospice of the Northwest's website.

Contact Person

Hospice has designated the Executive Director of Hospice of the Northwest as the contact person for all issues and complaints regarding patient privacy and your rights.

If you have any questions or concerns about this notice, please contact Bob Laws at 227 Freeway Drive, Suite A, Mount Vernon, WA 98273, (360) 814-5550 or (800) 894-5877.

Appendix I: Notice of Non-Discrimination

This is a summary of the non-discrimination principles and practices followed by Hospice of the Northwest that comply with Federal and State laws.

Hospice of the Northwest complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, sex, or sexual orientation.

Hospice of the Northwest:

- Provides free aids and services to people with disabilities to communicate effectively with us, such as: qualified sign language interpreters; written information in other formats (large print, audio, accessible electronic formats, other formats)

- Provides free language services to people whose primary language is not English, such as: qualified interpreters; information written in other languages

If you need these services, contact your case manager.

If you believe that Hospice of the Northwest has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Christine Nidd, Manager of Quality and Compliance
227 Freeway Drive, Suite A • Mount Vernon, WA • 98273
Phone (360) 814-5550 • Fax (360) 814-5591 • CNidd@hospicenw.org

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

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

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html.

Appendix J: Financial Assistance

This is summary of some of the financial assistance options, policies, and procedures for patients of Hospice of the Northwest. This is not a comprehensive list and not all options are available to all patients, but we will work with every patient to try to get them what they need.

Purpose

To define policies and procedures regarding financial assistance for hospice patients who have financial hardship, are underinsured, or who have no insurance for hospice services.

Policy

Hospice of the Northwest will provide hospice services to anyone who meets hospice eligibility criteria, regardless of ability to pay for said services.

When a viable payment source is not available, hospice will attempt to validate financial resources in a timely manner so that no one is declined admission to hospice services due to inability to pay. If it is determined that a patient has the financial means to pay for all or a portion of hospice services, the Skagit Regional Health Business Office will manage the payment plan per Skagit Regional Health policies. Hospice of the Northwest will comply with federal and state regulations regarding financial management of patient accounts while following ethical principles in regards to justice in healthcare.

Billing practices are conducted in an ethical manner and are in compliance with all Federal and State laws and regulations. Patients are informed of billing and reimbursement methodologies prior to start of care and as changes occur. When appropriate, hospice services are supported by the Hospice of the Northwest Foundation through donor gifts.

Procedures

The Referral Center verifies insurance coverage at the time of referral.

- **Medicare (HETS) -** Beneficiary is fully covered for standard hospice services.
- **Medicaid** - Beneficiary is fully covered for standard hospice services.
- **Commercial Payer** - When the payer is a commercial insurance carrier, a designated hospice staff member will contact the payer to determine hospice coverage and benefits.
    - If there is a co-pay or deductible to be met, the clinical manager/counseling and the executive director will be informed.
    - A social worker will be assigned to communicate the outcome of the commercial insurance coverage to the patient/Financial Power of Attorney and to institute the Financial Assistance Verification process.

Veteran - The referral comes pre-approved, or a call is placed to United Healthcare via Tricare.

- **No Payer/Self Pay -** When there is no insurance coverage, the clinical manager/counseling and the executive director will be informed, a social worker will be assigned to institute the Financial Assistance Verification process.
- A patient may also be changed to private pay if they have a liability once insurance has paid. The patient and/or their family will be advised of financial responsibility prior to the start of care. This would include annual deductibles, co-insurance, and any co-pays as applied by their insurance carrier. Specific amounts cannot be determined by Hospice of the Northwest and the patient is encouraged to contact their insurance carrier for questions regarding their contract provisions.
- Once Hospice of the Northwest has been advised by the billing agency that a patient liability exists, they are converted to private pay, and an invoice is generated with a letter which is sent to the patient explaining their liability.
- A copy of the insurance Explanation of Benefits will be included if available. Invoices will be sent every 30 days until paid. Hospice of the Northwest will follow up until either the amount owed is received or until further action is determined. This could be a write off or collection action.

- Additional action is at the sole discretion of hospice. Hospice of the Northwest may agree to offer a payment plan to the debtor. In those cases, Hospice of the Northwest will be responsible for the initial and any future billings to the debtor until the debt is satisfied.

Financial Assistance Verification

The patient/Financial Power of Attorney must participate in the exploration of financial resources and liabilities in order to be eligible for partial or full financial assistance. The social worker will encourage this participation in an effort to reduce unnecessary financial hardship in the future for the patient and their estate.

NOTE: If there is no Financial Power of Attorney and/or the patient/family indicate a need for estate planning, the social worker:

- Does not give legal advice
- Provides resources from Northwest Regional Council for area attorneys
- Directs the patient/Financial Power of Attorney to view the Northwest Justice website for additional legal assistance.

The Financial Assistance Verification form will be used to document the patient's financial resources and debts.

Financial Resources

In order to determine the appropriate amount of financial assistance, Hospice of the Northwest will need information on patient financial resources.

- Income is derived from both earned and unearned sources and includes the gross amount, i.e., before taxes; less payments made for support of dependents, if any.
    - Spousal income is included in the Financial Assistance Verification process.

- Exempt resources (assets) include the residence, other real property, vehicles and personal property.

- The following documents are required for income verification:

    - Current and prior months' pay stubs from all employment

    - Anticipated employment income for the next month

  - Income tax return from the most recent calendar year

- Information regarding Non-Exempt resources is required. Non-Exempt (countable) resources include assets such as
  - Savings
  - Checking account balance
  - Certificate of Deposit
  - Retirement accounts
  - Stocks, bonds, and annuities.

Financial Liabilities

Liabilities are defined as any accrued debts and financial obligations. To verify liabilities, documentation must be provided. Providing such documentation may enhance the patient’s eligibility for financial assistance.

Government Assistance

Following the determination of Financial Resources and Liabilities, government assistance programs will be considered and take the following actions:

- The social worker will inform the patient and Financial Power of Attorney if they will likely qualify for state Medicaid programs.
- The social worker will assist the patient/Financial Power of Attorney with the application process for Medicaid.
- Confirmation of eligibility from Medicaid often requires many weeks. A patient who is deemed eligible for Medicaid through the hospice Financial Assistance Verification process, but whose eligibility status is not yet confirmed by Medicaid for the period during which hospice services were rendered, may be granted financial assistance for hospice services.
- Hospice may make the granting of financial assistance contingent upon application for Medicaid assistance.

Financial Assistance Eligibility Guidelines

A patient will be eligible for *full* financial assistance if their household income is less than four times (400%) the most recent Federal Poverty Income Guidelines and their non-exempt resources are below $100,000 (patient) and $200,000 (patient and spouse).

If a patient is eligible for *partial* financial assistance, the assistance is based on a sliding scale.

Decision Process

- The social worker will return the Financial Assistance Verification form to the clinical manager/counseling, or designee.
- The clinical manager/counseling will review the information and will make a recommendation, within the sliding scale parameters, to the executive director.
- The executive director will review then forward the decision to the Hospice of the Northwest billing department.
- **NOTE**: If the Hospice of the Northwest Foundation will be providing funds for uncompensated care, the Business Office will submit an invoice to the finance department who then invoices the Foundation. The Foundation submits payment to Finance and Finance informs the Business Office that payment has occurred.
- The executive director will inform the Hospice of the Northwest Foundation, as a courtesy, when appropriate.
- **NOTE:** Communication regarding financial assistance will be entered in the electronic medical record under “financial aid”.
- The Hospice of the Northwest billing department will formalize the payment plan, if any, and will provide the patient/Financial Power of Attorney the plan in writing, via United States Postal Service (USPS).
- Hospice of the Northwest will follow their internal procedures regarding invoicing and collections unless the Hospice of the Northwest Foundation is involved.
- The Hospice of the Northwest billing department will notify the executive director of outstanding balances, when all of their internal procedures have been completed. The executive director, along with appropriate managers at hospice,

will make a final determination to either write off the debt or request the account be sent to Collections or submit to Hospice of the Northwest Foundation for uncompensated care.

- If the request for assistance is denied, hospice will notify the patient/Financial Power of Attorney, in writing, that the request for financial assistance has been denied and the reasons for the denial.
- The patient/Financial Power of Attorney has the right to appeal the decision by providing additional information to hospice that verifies income, family size and/or other liabilities within fifteen (15) days of receipt of the notice.

Other Considerations

- This policy is publicly available in this Patient Guidebook and upon request.
- The availability of Hospice of the Northwest Foundation funding is directly related to the generosity of community donors. Thus the availability of financial funds is not guaranteed.
- This policy supersedes the Skagit Regional Health Financial Assistance/Sliding Fee Scale policy except where this policy does not address a specific issue.
- When the patient/Financial Power of Attorney has limited ability to provide needed information, the financial assistance verification process may be adjusted by Hospice of the Northwest. Patients residing in a nursing home, long term care facility, or custodial care facility with disposable income of less than $150.00 per month may qualify for financial assistance even if their income exceeds the guideline limit but is used for their principal care.
- Prima Facia Write Offs: Hospice of the Northwest may choose to grant financial assistance based solely on the initial information. In such cases, Hospice of the Northwest will not complete full verification or documentation of any request.

Exceptions to this policy may be considered on a case by case basis.

Additional Financial Support

When goods and services not typically provided by hospice are determined to be helpful, the patient and/or caregiver will be asked whether or not they are able to contribute towards the associated cost, referencing the foundation and donor funds being available for those most in need.

Appendix K: Equity, Diversity, and Inclusion Statement

We create a community where every person can succeed. We envision a diverse, equitable and inclusive environment in which every person can grow and contribute because we have made it emotionally, intellectually, psychologically and spiritually safe and nourishing. We strive to have our staff and volunteer groups reflect the diversity of our greater community in order to better serve the community's end-of-life needs. We recognize there are innumerable experiences -- internal, external, systemic, familial, and cultural – that create each one of us, and that trauma is part of those experiences. With this in mind, we strive to bring compassion and skill to our speech and actions.

We commit to:

- Serve all people in our communities, all ages, ethnicities, races, cultures, religions, sexual orientations, gender identities, and those from all socioeconomic backgrounds.
- Communicate with our patients in a language they prefer.
- Respectfully challenge biases and stereotypes, especially our own.
- Continually listen, learn, and understand differences by engaging with, and learning from, our diverse community groups.
- Seek out cutting-edge trainings and developments within our communities' diverse populations and integrate best practices as they develop.
- Recruit, develop, promote, retain and empower a diverse and inclusive workforce.

We boldly embrace feedback, and continuously learn from our mistakes. We strive to recognize our blind spots, accept them with humility, and view them as an opportunity for growth in our organization. In diversifying our workforce, we seek diverse perspectives and opinions and listen with open hearts, providing a safe environment to express opposing points of view. We hold ourselves accountable by tracking indicators of diversity on a dashboard that is reported to our Quality Committee. **We are unequivocal in supporting dignity, respect and compassion for our patients, our workforce and the communities we serve.**

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Hospice
of the northwest

Phone: 360-814-5550 www.HospiceNW.org Backup Phone: 877-590-6317