# SECTION 1
## HOSPICE OVERVIEW

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Patient and Family Volunteer Training Objectives

Upon completion of the Patient/Family Training Program, volunteers will be able to:

- Describe the goals, services and philosophy of Hospice of the Northwest
- Understand Confidentiality and the protection of the patient’s and family’s rights
- Family dynamics
- Coping mechanisms and psychological issues surrounding terminal illness, death and bereavement
- Understand your duties and responsibilities as a Volunteer for HNW
- Know to whom you should report before being assigned to a patient and family or given administrative duties
- Know whom to contact if you need assistance and instructions regarding the performance of our duties and responsibilities
- Know what procedures to follow in an emergency or urgent patient need or if you are present following the patient’s death
- Understand what the Plan of Care is and what a Visit Frequency Order is and your role as a Volunteer in helping HNW remain compliant with the regulations we operate within
- Define the Interdisciplinary Care Team’s function, roles and responsibilities.
- Identify diagnoses, conditions and symptoms experienced by Hospice patients.
- Be knowledgeable about HNW and Skagit Regional Health policies.
- Utilize effective communication skills
- Describe acceptable and restricted volunteer activities.
- Establish and maintain appropriate boundaries.
- Identify diverse cultural issues and practices related to death and dying.
- Understand and utilize available volunteer support resources.
- Be knowledgeable about volunteer health and documentation requirements.
- Schedule patient visits and document them via CallWyse.
- Describe the unique needs of veterans.
- Be familiar with Infection Control Procedures and Food Safety practices.
- Practice methods of stress management and self-care.
Origin and Evolution of the Hospice Movement

The concept of Hospice is an ancient one, dating from the Middle Ages when hospices were set up as places of rest for pilgrims and other travelers. At the end of the 19th century, hospices were designated specifically to care for the terminally ill, first in Dublin, Ireland (1879) and later in London, England (1905).

Dame Cicely Saunders, MD, is generally credited with establishing the modern hospice movement in Great Britain in the 1960’s. She helped to develop St. Christopher’s Hospice, a facility utilizing a team approach to address the physical, social, emotional and spiritual needs of the dying. St. Christopher’s was the first program to use modern pain management techniques to compassionately care for the terminally ill. The hospice concept was readily received and gratefully embraced by those it sought to serve.

In 1963 Dr. Saunders introduced the idea of hospice to the U.S. in a lecture at Yale University. This set off a chain of events which resulted in hospice care as we know it today. The first hospice in the U.S. was established in New Haven, Connecticut in 1974. The National Hospice Organization was created in 1978, providing a national forum for discussion, education and support of quality standards for hospices.

In 1983, Congress expanded Medicare coverage to include hospice services. Many private insurers, recognizing not only the compassion associated with hospice care but also its cost-effectiveness began offering hospice benefits. Later, some states began offering hospice services under Medicaid as well.

The availability of reimbursement for hospice care has had a dramatic impact. There has been a steady increase in the number of new hospices, and existing hospices have significantly increased the number of patients they care for and the services provided. From 1999 – 2009, the number of Hospice programs in the U.S. increased by 47%; the number of patients increased by 74%. There were 3,400 Hospice programs serving approximately 1.56 million Americans in 2009. Also at this time, 40% of Medicare decedents utilized Hospice at some point in their care.

Today, the basic concept of Hospice remains essentially unchanged from its earliest days. Hospice has earned a place in the mainstream health care and social service system in our country. Hospice’s compassionate and personal character, plus its consummate expertise in the control of pain and symptoms make it a viable choice for those individuals who not only wish to die with dignity, but who also want to live until they die.

Recent Changes in Hospice

- In 1990, 75% of hospice deaths were from cancer.
- In 2004, only 45% of hospice deaths were cancer-related.
- Hospice programs are now characterized by shorter stays, more admissions and reduced payments.
- Hospice programs are also seeing younger patients than ever before.
- In 2016, Medicare changed its payment structure for Hospice services. They now provide a higher reimbursement for the first 60 days of care and for the last seven days of care.
Hospice Philosophy and Goals

Hospice is a philosophy of health care that values life from the moment it begins until the moment it ends. It accepts death as a natural part of the life cycle and focuses on enhancing the quality of life. Hospice affirms life and neither hastens or postpones death.

In the hospice model, the patient is the center of the care team. Their goals are primary as they direct the decision making process. Respecting individual autonomy is a fundamental component of the Hospice - patient relationship, including all members of the interdisciplinary care team and volunteers.

Hospice offers holistic care focused on the physical, emotional, psychosocial and spiritual. Dying peacefully and with dignity is not only possible, but also supported by a caring community. Hospice services support the patient as well as his/her family, caregiver or loved ones as activities and relationships undergo change. Bereavement support is offered to families following the death and for 13 months thereafter.

In summary, Hospice care is:

- **Patient-centered**, rather than disease-focused
- **Offers comfort (palliative)** care rather than curative care
- **Promotes quality of life**
- **Addresses physical, social, spiritual and emotional needs through a holistic approach**
- **Provides interdisciplinary** team care
- **Supports families, caregivers** and the **bereaved**
- **Available 24 hours/day, 7 days/week** wherever the patient resides

Hospice offers palliative care for individuals and their families without regard to age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, and ability to pay.

Hospice team members see patients wherever they reside:

- Homes, condominiums, apartments
- Adult Family Homes (AFH);
- Assisted Living Facilities (AL);
- Skilled Nursing Facilities (SNF);
- Group Homes (Developmental Disabilities, Mental-Health related, etc.); and
- Hotels, motels, homeless centers, cars.
Medicare Eligibility, Payment and Benefits

Eligibility for Services under Medicare Part B
Nearly 90% of patients receiving Hospice services acquire care through the Medicare Hospice benefit. To be eligible for hospice services under Medicare, individuals must:
- Have a terminal prognosis (life expectancy) of six months or less (based on a combination of diagnoses and conditions)
- Agree to forego curative treatment related to their hospice prognosis
- Be eligible for Medicare Part A
- Receive services from a Medicare-certified Hospice

Hospice services may also be paid for by:
- Medicaid
- Commercial Insurance Plans
- Self-pay; some Hospice services may be billed according to ability to pay
- Charitable contributions and grants (Hospice of the Northwest Foundation is supported by community donations).

Hospice of the Northwest reviews the need for funds for uncompensated care on an individual basis.

Medicare pays for the following benefits on a per diem basis:
- Intermittent visits by the Care Team (RN, MSW, Spiritual Counselor, Certified Nursing Assistant, Volunteer, Physician and other ancillary providers) to assess and address issues related to a patient’s terminal prognosis, based on a the patient’s needs;
- All medications related to a patient’s primary hospice diagnosis;
- Most medical equipment and supplies;
- Short-term respite care in an inpatient or nursing facility for the purpose of caregiver relief; and
- Short-term inpatient care for difficult-to-control symptoms.

Medicare will not pay for ambulance services, transportation to and from the hospital or appointments, emergency room care, hospitalization and other inpatient care, medical consultation related to a patient’s terminal illness, respite care or diagnostic tests without pre-approval from Hospice. In addition, certain medications, supplies and equipment and/or quantities of such, may not be covered.

When a patient first begins Hospice service, Medicare certifies them for 90 days of care. Before 90 days ends, the patient’s eligibility is reassessed and care may be extended for an additional 90 days. Before the second 90 days ends, the patient is evaluated again. If needed, care can be extended for one or more additional 60 day periods, as long as the patient continues to meet eligibility requirements. Patients must always show evidence of decline to remain eligible.

What do non-Medicare patients pay?
- Medicaid patients are provided with the same hospice benefit but their out-of-pocket costs may vary.
- Patients with private insurance may have varying coverage.
Discharge or Revocation from Hospice

Hospice services end when a patient:

- dies
- no longer meets Medicare eligibility criteria for recertification and must be discharged,
- moves out of Hospice of the Northwest service area, or
- seeks curative treatment, needs surgery or ends Hospice services, for any reason, and signs a Revocation Statement.

Patients may re-elect hospice services at a later date, if eligible.

Levels of Care

There are four levels of care under the Medicare Hospice Benefit, including:

- **Routine Care** – Routine care is paid for each day the patient is under the care of Hospice. The care plan includes the amount and frequency of services based on the patient and/or family’s needs.

- **Continuous Care** – Continuous care is provided when the patient is experiencing a medical crisis and requires predominantly nursing services to achieve symptom relief and control. A minimum of eight hours of care are provided within a 24-hour period. The goal is to provide necessary acute care interventions at home.

- **Inpatient Respite Care** – Medicare provides for short-term respite care up to five days duration (per episode) for situations in which the caregiver needs relief from caring for their loved one at home. The patient generally goes to a contracted skilled nursing facility.

- **General Inpatient Care** – Short-term inpatient services are available for pain control or acute symptom management which cannot be alleviated in any other setting. These must be provided by a Medicare-certified facility and must be pre-approved by HNW.
Hospice of the Northwest History and Overview

In 1989, community volunteers founded the non-profit organization, Skagit Hospice. Later, Skagit Hospice came under the umbrella of Community Homewell, a home health agency in Mount Vernon.

In 1994, Community Homewell joined Whatcom County’s Visiting Nurse Home Health Care, Visiting Nurse Foundation and Whatcom Hospice as part of Affiliated Health Services.

In 2001, Skagit Hospice Foundation was established to support hospice services delivered by Skagit Hospice employees and volunteers.

By 2011 the non-profit, Skagit Hospice had become Hospice of the Northwest (HNW), an LLC of Skagit Regional Health and United General Hospital.

Hospice of the Northwest now provides services in Skagit, Island, San Juan and Snohomish Counties. Our territory encompasses 1,500 square miles. Our web site is: www.hospicenw.org

Today more than 100 staff members and volunteers provide 24,000+ patient visits annually. In 2017, HNW volunteers provided 3,536 hours across 1,089 patient visits, providing 15.3% of total patient care hours at a total value of $122,021; in addition 262 office shifts were completed by volunteers. There were 201 requests for volunteers in 2017, of which 88% were filled. In 2017 32 Vigil requests were made and filled by volunteers. A total of 16% of all patients receive at least one face-to-face visit from a volunteer. However, when phone visits through our Tuck In program are included, that total goes up to 44%, which is slightly above the industry average of 40%. The Music and Memory Program and Pet Partner Project we provide to our patients are both nationally certified programs.

HNW is an Equal Opportunity Employer providing health care services and all related programs without regard to race, sex, creed, age, religion, color, national origin, disability or any other basis prohibited by law.

Mission
Compassion and Dignity Every Moment of Life

Vision
Nationally recognized hospice and palliative care team providing high quality support and comfort, honoring each individual’s life journey.
November is National Hospice and Palliative Care month, and beginning November 1st our outreach and education team is reaching out to people in the four counties we serve to raise awareness about the quality care available for people coping with life-limiting illness. We have “50 Talks in 50 Days”- presentations designed to share knowledge and provide education about hospice. Our goal is to encourage people to start a conversation with loved ones about end of life wishes.

1. **Start the conversation early.** Our long-term goal is to bring death education to high schools around our country. Studies show that the sooner we can provide education – of any kind – the more effective it is on a whole in the community. Kids are taught how to drive, they learn about sex, drugs and alcohol in school; but not a word is ever taught about death and dying. That needs to change.

2. **Document your end of life goals.** To that end, I am encouraging people who are 18 or older to have an advanced health care directive filled out: at minimum their green POLST and the Five Wishes. These are both available in our office to anyone in the community free of charge. In addition they are available for download on our website at [www.hospicenw.org](http://www.hospicenw.org) under the ‘What is Hospice’ tab.

3. **You can refer yourself – don’t wait for your doctor to bring up the topic.** Studies have shown that nationwide doctors on average overestimate by three times the actual life expectancy of their patients. This means when a doctor says a patient has one to two years left to live with a particular illness, the patient is often already in the hospice window with 6 months or less left to live. Why not have that life supported by a team of professionals who have a primary focus of providing personalized care that is tailored to the patient’s wishes?

4. **Refer early!** We want patients sooner than what we typically see: hospice is for people with a life limiting or terminal illness that have a prognosis of 6 months or less to live. We have this amazing team of people who are dedicated to providing excellent care, but so often we only have days or weeks with someone before their life ends. The sooner they come on service, the more we can help them. Our team consists of Hospice Medical Directors (4 MDs and a Nurse Practitioner), RN case managers, hospice aides, Medical social workers, spiritual counselors, bereavement counselors, massage therapists, music therapists and a robust team of over 60 volunteers that provide companionship, vigil, life story recording and a host of other services to our patients and families.

5. **Your insurance pays for this benefit.** Hospice is an elective benefit paid for by either Medicare, your private insurance, Veteran’s benefits or the generous donors who support our non-profit foundation. ALL of our staff and volunteer education, all of our complementary therapies, and 100 % of costs affiliated with our bereavement department are funded by the donors. We have never refused hospice services to any patient due to their inability to pay. In addition, our bereavement services (private or group grief counseling) are available at no cost to **anyone** in any of the 4 counties that we serve (Skagit, Island, San Juan and Snohomish), regardless if they have used hospice services.

*For more information or if you belong to an organization that would benefit from learning more about our organization, please contact Dana Brothers at 360-814-7647 or dbrothers@hospicenw.org*
Advanced Directives

There are a number of different Advanced Directives that you may hear about while volunteering for Hospice, including Living Wills, Powers of Attorney, Five Wishes and POLST.

A living will is a legal document that indicates preferences about medical treatment in the event of a serious accident or illness that leaves someone unable to give informed consent. Living wills will note life-sustaining measures an individual does and does not want such as assisted breathing, feeding tubes and resuscitation.

The Physician Orders for Life-Sustaining Treatment (POLST) is a form that is more specific than a living will. It describes what an individual wants now based on his or her current condition. Because these are doctor’s orders, if an ambulance is called to a patient’s location and the POLST form is available, the paramedics must follow these orders since they are physician orders. In contrast, physicians aren’t legally obligated to follow a living will. The POLST form is bright green and is usually posted on a patient’s refrigerator or in another easy-to-find place. If paramedics come to your patient’s location, the caregiver or the volunteer should point out the form.

The Five Wishes Document names a Health Care Agent that can make decisions when an individual is no longer competent to do so, and specifies the medical treatment the person would want in the event they cannot speak for themselves. It also lists specifics as to how comfortable a patient would like to be at the end of life, how they would like to be treated and what they would like their loved ones to know. A copy of Five Wishes and more information is in the back pocket of this training binder.
Hospice of the Northwest Foundation

Hospice of the Northwest Foundation provides more than $500,000 a year to HNW in support of uncompensated care, patient assistance, bereavement services, clinical education and training, volunteer services, complementary therapies, equipment and technology, and atypical clinical treatments. These funds help HNW to focus on quality of life and not only the bottom line.

Founded in 2001 with the express purpose of supporting Hospice of the Northwest programs and services, the Foundation is a 501 (c) (3) nonprofit agency governed by a volunteer board of trustees. The HNWF is the official, and only, gift receiving entity for Hospice of the Northwest. Donors support patient needs through memorial gifts, planned and estate gifts, events, and other philanthropic efforts. Volunteers help to support the Foundation by giving, staying aware of HNWF activities, and sharing its mission, vision, and values.

The HNW Foundation was awarded the GuideStar Exchange Platinum Level. This is GuideStar’s highest level. GuideStar assesses non-profit financial health and transparency by reviewing IRS data and other records.

Mission: The Hospice of the Northwest Foundation funds compassion and dignity every moment of life.

Vision: Our vision is to transform the way dying is perceived and experienced so that everyone coping with a life limiting illness has access to hospice care; we envision a future where no one dies alone or in pain.

Values: In the course of fulfilling our mission we will:
   • Be passionate about the need for hospice;
   • Foster a culture of philanthropy;
   • Cherish and respect our donors;
   • Advance community awareness;
   • Ensure that our funding priorities are aligned with Hospice of the Northwest’s needs;
   • Use funds the way our donors expect them to be used;
   • Manage our funds with great care and integrity;
   • Advocate for continued learning and training; and
   • Invest in programs, training and services that enhance quality of life for the patient and their loved ones.

The foundation welcomes volunteers to assist with general office work, events, and other activities.

Contact:

Wendy Rohrbacher, MA, CFRE (Certified Fund Raising Executive)
360-814-5702
Foundation@hospicenw.org
www.hospicenw.org
www.facebook.com/hospicenwfoundation

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Regulatory Bodies, Quality and Compliance

As most of you know, the health care industry is highly regulated. Hospices are no exception. We report to many regulatory bodies and are subject to surprise surveys (audits) to insure compliance. Failure to comply with regulations, even those that may seem minor, is a vital matter with the potential for serious consequences. Many of these regulations specify requirements for our volunteer program.

New regulations arise every year. Last year, there were nine new regulations from Medicare alone that affected us and the way we practice. There were also two new regulations related to volunteers.

Hospice of the Northwest upholds the regulations and guidelines of:

* **Medicare.** We are a Medicare-certified Hospice.
* **Washington State Health Department**
* **Community Health Accreditation Partner.** After a rigorous survey, we achieved certification in 2015. We are one of two hospices in WA State with this accreditation.
* **National Hospice and Palliative Care Organization (NHPCO)**
* **Skagit Regional Health** (one of our LLC co-owners and our managing partner)
* **Hospice of the Northwest Board of Directors**

Because of the possible ramifications, HNW requires its volunteers to uphold all requirements. We audit volunteer visit notes. We also monitor volunteer documents (proof of health tests, background checks, car licenses, car insurance, Conflict of Interest forms, etc.) and all must be current for volunteers to remain active. **Volunteers are responsible for updating documentation before it expires.**

HNW has an active quality assurance program. All complaints and concerns initiated by patients, families, facility staff, physicians, nurses or caregivers are documented and reported to our Quality Compliance Manager who also conducts regular chart audits and insures that issues are addressed and resolved satisfactorily. Quarterly complaint/concern reports (QMM’s) are submitted to the Quality Assurance Committee (QAPI) and reviewed for trends, areas for improvement, etc.

In addition, any incidents, accidents or unusual occurrences are reported and documented by staff, including patient injuries and falls, medication errors, adverse reactions, equipment malfunctions, etc. Reports are submitted to the staff member’s supervisor and followed up on as appropriate.

**Volunteers who have concerns related to quality, accidents, incidents, occurrences, safety, suspected abuse or neglect must report them immediately to the Volunteer Manager. If the Volunteer Manager is not available, ask for the Clinical Manager, Counseling Manager or Executive Director. In addition, if there are concerns about poorly controlled symptoms, increased pain and/or behavioral or psychosocial issues . . . call the Volunteer Manager or the Hospice Care Team.**

A “Community Assessment of Hospice Services” survey is sent to all primary bereaved three months after their loved one’s death. It includes a wide variety of questions related to patient care and family education. The survey is administered by a third party which then compares scores to other hospices throughout the U.S. We use this information to identify performance improvement projects. Results of the CAHPS will be publicly reported by 2017.
Patient Rights

Hospice of the Northwest patients are given information about their rights and responsibilities before treatment begins. The patient’s family or guardian may exercise the patient’s rights and responsibilities if the patient has been judged incapable of doing so. Below is an outline of their rights.

Right to Dignity and Respect for You and Your Property

- To have equal and fair treatment without regard to race, color, national origin, creed, ability to speak English, disability, sex, age, marital status, or who pays for treatment.
- To have fair, respectful and polite treatment in all contacts with Hospice of the NW.
- To have your property treated with respect.
- To have your spiritual and cultural needs considered in your care.
- To make a complaint to HNW without fear of discrimination or reprisal.
- To make a complaint to the state of WA.

Right to be Informed

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

• To know what services HNW does not provide.

• To request a professional interpreter, free of charge, if I am not comfortable communicating in English. HNW will make reasonable efforts to secure a translator as requested by the patient.

Right to Privacy

• To confidentiality of information about your health, social and financial circumstances.

• To expect HNW to release information only as required by law or approved by you.

• To see what is in your records.

• To be advised of the HNW Policy & Procedure regarding disclosure of clinical records.

Right to Financial Information

• To know how much HNW charges and bills for services and how much you need to pay, unless a managed care plan pays for services.

Right to Quality Care

• To have your staff (team members) fully trained in the care they provide.

• To expect that all medically related care is provided under a doctor’s orders.

• To know what to do in a medical emergency.

• To have your pain controlled to the extent possible.

• To choose your attending physician or primary care provider.

• To formulated advance directives for medical treatment, and have the hospice staff comply with these directives.

Patients have the responsibility:

• To notify HNW prior to hospitalization, emergency room use, diagnostic tests or other new treatments. Patients may be responsible for costs associated with unauthorized care.

• To notify HNW of changes in their condition (symptoms, medication problems, etc.).

• To follow the plan of care.
Interdisciplinary Team

The Interdisciplinary Team is integral to the concept and practice of Hospice Care. Through collaboration, the team develops a plan to meet each patient’s physical, social, emotional and spiritual needs. This plan is reviewed at least every two weeks at Interdisciplinary Team Meetings.

Registered Nurses, Medical Social Workers and Spiritual Counselors comprise the “core” of the team. Registered Nurses are the sole staff members that Medicare requires each patient to have. Medicare requires other services be made available to patients, including: medical social work, spiritual counseling, certified nursing assistants (CNA) and volunteers. In addition, HNW offers allied services such as massage therapists, music practitioners and a Pet Partner team.

Medical Directors
Hospice Medical Directors provide consultation to Hospice staff regarding admissions, diagnoses, medications, orders and symptom management. They visit patients as needed and communicate with patients’ primary care physicians to coordinate care. At HNW, the Interdisciplinary Group Team meetings, Quality Assurance Committee and the Ethics Committee are chaired by Medical Directors.

Registered Nurses
An RN serves as the Primary Case Manager for each patient and is responsible for skilled nursing care and coordination with other members of the Interdisciplinary Team. They have extensive experience in caring for patients with life-limiting illnesses and special training in the areas of pain control and symptom management. The Case Manager develops a “plan of care” for each patient that addresses the patient’s individual physical, emotional and spiritual needs.

A Case Manager, and/or nurses under their supervision, is available to patients 24/7. They
  • see each patient at least once every two weeks; visits range from one or more visits per day to twice monthly;
  • consult with patients and their physicians to determine a comprehensive “plan of care” that provides for comfort and independence;
  • implement and monitor the “plan of care;”
  • manage symptoms and pain;
  • help patients obtain needed equipment and services;
  • educate patients/families/caregivers regarding illness, symptoms, comfort measures, medication, etc.;
  • provide specialized nursing procedures as needed;
  • welcome patient and family participation, listen to concerns and offers support;
  • communicate concerns with other care providers ; and
  • serve as the patient’s advocate.

Case Managers, nurses and social workers have full schedules. Volunteers can serve as their eyes and ears. If you have a significant concern regarding your patient, their care team wants to know. Call the Hospice main number (360-814-5550) immediately and tell the receptionist you have an “urgent need” to speak to the on-duty care team member. Staff will then route your call. If it is answered by voicemail, leave your name, patient’s name and your phone number. State if you need a call back and leave the best times for a call. If you request a callback and don’t receive one, let the Volunteer Manager know.
Medical Social Workers
Hospice Social Workers have Master’s Degrees and specialize in helping patients and families work through the many changes that occur as the patient’s health declines and they complete their end of life journey. They assess each new patient within five calendar days of admission; however not all patients choose ongoing social work services. MSW’s focus on changing roles within the family unit, difficulties with coping, major decisions concerning patient care, increased concerns about financial matters and legal issues, advance directives, wills and plans for the future. They may do crisis intervention, family mediation, facility placements, and advocacy.

Hospice social workers can help access needed community resources and gather information to help patients and families make decisions about the present and future. Facilitating discussions regarding final arrangements is often part of this role.

For those experiencing significant anticipatory grief, the social worker may serve as counselor, helping the patient and family to cope. The goal is to make the most of the time left together and help loved ones build a strong foundation for the future. Feelings of loneliness, anxiety or fear may be common, and the social worker is experienced in helping patients and families manage these emotions.

Spiritual Counselors
Hospice Spiritual Counselors assess each patient within five days of admission and then provide ongoing support to those patients and families who request spiritual care. HNW Spiritual Counselors have varied backgrounds, training and degrees, but always meet patients where they are, utilizing the patients’ spiritual language and metaphors rather than imposing their own. In doing so, they honor and respect all individual beliefs.

Spiritual Counselors offer support to ease, resolve or reconcile spiritual pain and suffering by helping patients identify, clarify and use their own skills. Care may also include reconnecting patients with their spiritual heritage, performing requested rites and rituals, being a compassionate listener or offering counseling related to issues of meaning and purpose. This type of spiritual care can reduce anxiety, fear, pain and confusion and can help patients and families experience positive growth during their Hospice experience.

Certified Nursing Assistants (CNA’s)
CNA’s may visit patients once or twice a week if desired, to provide skilled, personal care including: bathing or assisting with bath or shower; grooming/shaving; assisting with toileting; nail, skin and hair care; dressing; changing bed linens; light housekeeping; light cooking or meal preparation; and range-of-motion exercises.

They are skilled at helping with patient lifts and transfers and may perform additional tasks under the supervision of the RN Case Manager. They report their observations to the Hospice RN, the family and/or caregivers as is appropriate.

Volunteers
Medicare requires that at least 5% of all hours of service delivered to patients be provided by volunteers. HNW volunteer consistently provide more than double that amount. Volunteers serve Hospice of the Northwest in a number of ways.
They serve as patient companions, provide respite to families and/or caregivers, serve on the Vigil Team, play iPod music for patients, make “Pet Partner” visits, make “Tuck In” phone calls to patients and/or caregivers prior to week-ends, work in the office, manage the library, assist in training, provide notary services, and assist with fundraising and community relations.

Complementary Therapy
Even as medical technology becomes more advanced, some suffering still eludes the most sophisticated medical care. HNW’s complementary (allied) therapies can be an integral part of patient care that offers an opportunity to relieve suffering and provide comfort. They are a good example of how the multidisciplinary approach to hospice care addresses the total person and their loved ones. HNW currently offers Massage Therapy, Music Practitioner Services and Pet Partner visits.

- Massage therapists are licensed by the state of Washington. They work under contract and are paid with funds provided by the HNW Foundation. They address pain, manage symptoms and offer comfort and relaxation.
- Music practitioners also work under contract and are paid with funds provided by the HNW Foundation. They offer live music (harp, singing and chanting) to address physical, psychological and emotional needs.
- Pet Partner volunteers are not paid for their services. Their pets are specially trained and certified to provide comfort to patients and/or their families. They offer 30-45 minute visits in facilities and private homes.

Bereavement Services
Medicare requires hospices to offer support to the primary bereaved for 13 months following the patient’s death. HNW offers a comprehensive bereavement program, at no charge, to families/caregivers. Bereavement services may include phone support, office or home visits, grief groups, an annual remembrance ceremony and grief-related mailings throughout the year. In addition, materials on grief are available in the office lobby, including more than 1200 books and DVD’s. This is open to the community.

The HNW Bereavement Program has more than 1,000 individual contacts each year and mails more than 4,000 grief support periodicals during that time. Approximately 20% of our patient’s family members choose to participate in some aspect of the Bereavement program.
### SECTION 2  
**MEDICAL ASPECTS OF CARE**

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Palliative vs Curative Care

More than 50 million people die on the planet each year. It is estimated that tens of millions of people die with unrelieved suffering. That many people die with unnecessary or untreated suffering has been well documented in numerous studies and scientific papers. Suffering may be defined as the distress associated with events that threaten the intactness or wholeness of the person. The causes of suffering may include pain, other physical symptoms, psychological, social, cultural or spiritual. The relief of suffering is an ethical imperative.

In 1990 the World Health Organization called for palliative care to be included in every country’s health services.

In the “1993 Standards of a Hospice Program of Care,” the National Hospice organization used the term “palliative care” to refer to “treatment that enhances comfort and improves the quality of the patient’s life.” No specific therapy is excluded from consideration.

Hospice care is a model for delivering Palliative Care. Hospice care, therefore, constitutes a subset of palliative care.

The goals of all Palliative Care are to:

- Provide relief from pain and other physical symptoms
- Maximize the quality of life
- Offer psychosocial and spiritual care
- Provide support to help family/caregivers during the patient’s illness and the bereavement period

Although hospice and palliative care share a similar philosophy, the delivery of care is different. Hospice care is both a type of care and a method of paying for services under Medicare. Palliative care is both a method of providing comfort and is also an administered system of care offered most prevalently by hospitals. Both hospice and palliative care protocols call for patients to receive a combined approach where medications, day-to-day care, equipment and symptom treatment are offered through a single program. Where palliative and hospice programs differ greatly is in the care location, timing, payment and eligibility for services.

In late 2015, Hospice of the Northwest launched a 6 month In-Home Palliative Care Pilot Program, “Palliative Care of the Northwest.” The pilot served patients who had Medicare insurance, were not eligible or ready for Hospice (or had been discharged from Hospice due to non-eligibility), had a PPS of 60% or less, and lived in the Anacortes, Mount Vernon, Burlington or Sedro-Woolley city limits. At the end of the pilot, although it met its goals and was well-received, it was unable to continue due to the unexpectedly high cost of supporting it.

Skagit Valley Hospital has a Palliative Care Program and two of our Medical Directors previously worked on the Palliative Care Team.

The following chart outlines the factors that distinguish Hospice care from other types of Palliative Care.
# Hospice Care as Distinguished from Other Types of Palliative Care

<table>
<thead>
<tr>
<th>Description</th>
<th>Other Types of Palliative Care</th>
<th>Hospice Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Specialized care for people with active, progressive, far-advanced disease. Is not based on life expectancy. May be pursued at same time as curative care.</td>
<td>Specialized care for individuals with a life expectancy of 6 months of less, as determined by a physician. Patients must forego curative efforts.</td>
</tr>
<tr>
<td>Additional Info</td>
<td>Can begin as early as the time of diagnosis; even when aggressive treatment is still being sought. Patients are not yet eligible for hospice services</td>
<td>Patient may have undergone treatment that is no longer working, or may not desire further treatment. Focus is on comfort rather than disease abatement.</td>
</tr>
<tr>
<td>Type of Care</td>
<td>Interdisciplinary model addresses medical, emotional, spiritual and psychosocial needs</td>
<td>Interdisciplinary model addresses medical, emotional, spiritual and psychosocial needs</td>
</tr>
<tr>
<td>Location of Care</td>
<td>Wherever patient lives including: hospitals, outpatient clinics, long-term care services</td>
<td>Wherever patient resides. Limited hospitalization options</td>
</tr>
<tr>
<td>Duration of Care</td>
<td>No limit</td>
<td>Generally 6 months or less (Medicare Guidelines); patient can be re-certified for longer care if they continue to meet Medicare criteria. Bereavement services offered following loved one’s death.</td>
</tr>
<tr>
<td>Treatment/Goals</td>
<td>To achieve highest quality of life while trying to control or eradicate disease process. Pain and symptom management. Better understanding of medical care choices. Detailed practical information and assistance. Emotional support for patient and family. 24 hour telephone support. Prescriptions, medical equipment and</td>
<td>To achieve highest quality of life possible, without some of the negative side-effects that treatments can have. Pain and symptom management. Honor patient’s self-determination and autonomy over his/her care. Family education and support. 24 hour telephone support. Under Medicare Hospice benefit; medications, equipment, oxygen and some supplies are covered.</td>
</tr>
<tr>
<td><strong>Payment for Services</strong></td>
<td>Most insurance plans cover all or part of palliative care treatment, as does Medicare and Medicaid.</td>
<td>Medicare Hospice benefit. Private insurance.</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
<td>Improve quality of life, increase quantity of life, decrease hospitalizations and reduce cost of medical care.</td>
<td>Improve quality of life. Patient dies in the setting of their choice.</td>
</tr>
</tbody>
</table>
Palliative Performance Scale

The Palliative Performance Scale, developed by Victoria Hospice Society (2006), is used to develop a score for each Hospice of the Northwest patient. It is a tool for quickly describing a patient’s current functional level. PPS scores are regularly reevaluated by the Hospice RN; therefore we can see if a patient is declining, improving, or maintaining the same level of function. PPS appears to have prognostic value.

An individual who is perfectly healthy and fully functional is a 100% PPS. 0% denotes death. At HNW we see patients ranging from 10% to about 60%. The average PPS of HNW patients is 35%. Patients at 10% usually have days to live; patients at 20% may have weeks.

<table>
<thead>
<tr>
<th>PPS</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake (oral)</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
</tbody>
</table>
<pre><code>                                  | No evidence of disease          |           |               |                |
</code></pre>
<p>| 90% | Full       | Normal activity &amp; work         | Full      | Normal        | Full           |
| Some evidence of disease        |           |               |                |
| 80% | Full       | Normal activity with effort     | Full      | Normal or reduced | Full       |
| Some evidence of disease        |           |               |                |
| 70% | Reduced    | Unable Normal Job/Work          | Full      | Normal or reduced | Full       |
| Significant disease             |           |               |                |
| 60% | Reduced    | Unable hobby/house work         | Occasional assistance necessary | Normal or reduced | Full or Confusion |
| Significant disease             |           |               |                |
| 50% | Mainly Sit/Lie | Unable to do any work       | Occasional Assistance necessary | Normal or reduced | Full or Confusion |
| Extensive disease               |           |               |                |</p>
<table>
<thead>
<tr>
<th>%</th>
<th>Condition</th>
<th>Activity Level</th>
<th>Assistance Level</th>
<th>Pain Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity</td>
<td>Mainly assistance</td>
<td>Full or Drowsy +/− Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Full or Drowsy +/− Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Full or Drowsy +/− Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Drowsy or Coma +/− Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Trajectory of Decline of Common Hospice Diagnoses

Patients admitted to hospice with a cancer diagnosis may start service with a PPS as high as 60-70%, but because of disease trajectory, they still have a less than 6 month life expectancy.

Patients admitted to hospice with heart, lung or liver disease often have a PPS is the 40-50% range and a clinical course marked by frequent episodes of exacerbation. If they stabilize with hospice care, they are often discharged off hospice.

Patients admitted to hospice with dementia, Parkinson’s disease or other neurodegenerative disease often start care with a PPS of 30% or less due to the slow dwindling nature of these disease trajectories. They may have long lengths of stay on hospice and can stabilize and discharge.

Figure 1.2 Chronic illness in the elderly typically follows one of three trajectories. Copyright 2003, RAND Corp. Reprinted with permission.
Concept of total pain

- Physical Pain
- Emotional Pain
- Spiritual Pain
- Psychosocial Pain
- Bureaucratic Pain

Maintenance and Break-through

BREAK THROUGH:
10% OF TOTAL MEDD Q HR
Primary Hospice Diagnoses: 2017

Below is the breakdown of primary diagnoses of Hospice of the Northwest patients in 2017:

Cancer = 34%
Dementia = 16%
Heart Disease/Failure = 16%
Pulmonary Disease = 6%
Stroke = 10%
Other = 18%

More Disease Information

Cancer
a. Specific Diseases: Of the lung, prostate, breast, ovaries, colon, brain, pancreas, liver, stomach, bones, etc.
b. Description: Cells reproduce rapidly, forming tumors which invade and destroy other tissue. Patients may experience chronic and severe pain, loss of appetite, and depression.
c. Care Tips: Ask about patient’s pain and ask for permission before touching. Some patients may feel guilt that they contributed to disease’s development.

Heart and Circulatory Disorders
a. Specific Diseases: Congestive heart failure, Coronary artery disease, Peripheral vascular disease
b. Description: These diseases impair the flow of blood through the heart and/or the rest of the body. Patients may experience chest pain, shortness of breath, weakness and swelling.
c. Care Tips: Patient should avoid over-exertion. If patient is ambulatory, plan rest stops along the way to where you are going. If patient is anxious, they may benefit from relaxation techniques.

Neurological Disorders
a. Specific Diseases: Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig’s Disease, Alzheimer’s Disease, Dementia, Stroke, Parkinson’s Disease and others
b. Description: ALS is a disease affecting the nerves that work with all voluntary muscles. It results in paralysis, difficulty swallowing and breathing. Mental abilities are not impaired. Alzheimer’s, Lewy Body and other forms of dementia affect the memory and cognitive functions. Patient may experience disorientation, susceptibility to pneumonia and behavioral problems.
c. Care Tips: ALS = Address patients at eye level. Remember that thinking, intelligence, touch, taste, smell, hearing and sight are not affected. Be mindful of the need for rest. Alzheimer’s/Dementia = Approach patient from the front. Always identify yourself. Use soft
tone of voice and gentle body motions. Reduce environmental stimulation. Respond to repeated questions.

Respiratory Disorders
a. Specific Diseases: Chronic Obstructive Pulmonary Disease (COPD), Emphysema, Pulmonary Fibrosis.
b. Description: Respiratory diseases result in an insufficient supply of oxygen to the body. Patients may experience shortness of breath, anxiety and lung infections. They may be on oxygen.
c. Care Tips: Don’t invade the patient’s personal space – they need “room to breathe.” Open a window, use an oscillating fan (many of our respiratory patients have been given hand-held fans by their nurses) and cooler temperatures. Can use relaxation techniques if the patient is anxious.

Diabetes
a. Specific Diseases: Diabetes Type 1 and 2
b. Description: Insulin deficiency, high blood sugars and other metabolic changes lead to multiple-organ disease including heart, kidney, blood vessel and other organ failure.
c. Care Tips: Be aware of the importance of the patient eating the proper foods at scheduled intervals. Patients may be on insulin or medication for their conditions.
Dementia by Anita Meyer, MD
(See Sections 5 & 6 also)

Dementia – Features

• Memory loss and cognitive decline
  ◦ inability to learn new information or recall old
  ◦ loss of reasoning
  ◦ loss of impulse control (frontal dementias)
• Language impairment
• Functional decline
• Behavioral, Emotional and Personality Changes
• Aphasia – word finding difficulties, word substitutions, repetition, stopping mid-sentence
• Apraxia – difficulty with dressing, feeding, combing hair, self-care
• Agnosia – difficulty recognizing familiar faces, objects and places
• Disorientation – unaware of time/place
• Loss of executive functioning – balancing checkbooks, reasoning
• Consciousness intact (unless associated delirium)

Dementia - Statistics

• Projected 16 million people by 2050
• Accounts for over 50% NH (nursing home) patients
• 10-15% over 65 years old, 25% over 80 years old
• Number one reason for NH admission
• Cost – 1.4 billion dollars worldwide

Types of Dementia

• Alzheimer’s Disease – 60% prognosis 8 years
• Lewy Body Dementia – 15% prognosis 7 years
• Vascular Dementia – 5% prognosis 3 years
• Mixed Dementias – 10%

Alzheimer's Dementia

• Problems with language, calculation, abstract thinking, and judgment
• Loss of recent memory
• Personality changes
• Depression and Anxiety occur frequently
• Late in the disease – delusions and hallucinations
• Disoriented
• SLOW PROGRESSIVE COURSE
Vascular Dementia
- Wandering or getting lost
- Loss of bladder or bowel control
- Laughing or crying inappropriately
- Difficulty following instructions
- Problems handling money
- High incidence of depression
- Usually history of vascular disease, DM
- SUDDEN ONSET, STAIRSTEP DECLINE

Lewy Body Dementia
- Often present with visual hallucinations
- Fluctuating course
- Language and recognition usually intact
- PARKINSON-LIKE FEATURES (stiff with tremor)
- Myoclonus is common
- Neuroleptics may worsen symptoms, especially typical antipsychotics (Haldol). Can trigger full blown Parkinsonian crisis
- More rapid decline compared to AD

Behavioral and Psych symptoms of dementia – Psychosis
- Visual or auditory hallucinations
- Impaired connection to reality
- Psychosis is a symptom not a diagnosis
- Differential diagnosis include dementia, delirium, chronic psychotic disorders (schizophrenia, bipolar, etc.), psychotic depression
- Impaired memory from dementia can easily be mistaken for psychosis

Treatment of Behavioral and Psych symptoms of dementia
- BEHAVIORAL APPROACHES
- Identify any contributing stressors
- Review drugs patients are taking
- Choose pharmacotherapy by identifying target symptoms
  - psychosis
  - depression
  - agitation
  - mania/aggression
  - disinhibition
Non-pharmacological Treatments
- Reminiscence therapy
- Validation Therapy
- Distraction Approaches/Redirection
- Music and movement therapy
- Sensory Stimulation Rooms
- Environmental anti-wandering programs
- Physical and Occupational Therapy
- Aromatherapy and Herbal Therapy
- Pet therapy
- ASSESS ENVIRONMENTAL STRESSORS

Environmental Stressors
- Excessive noise or overstimulation (light, noise, temperature, roommate considerations)
- Room location
- Proximity to bathrooms
- Lack of structure
- Assess visual or hearing deficits
- Plan for sleep/rest periods
- Understimulation – need for PT,OT, exercise
- Avoid physical restraints
- Calm staff, redirect/refocus patient

Physical Stressors
- Pain
- Constipation
- Urinary retention
- Urinary tract infection
- Dehydration

Pain Assessment in Dementia
- PAIN – AD scale (range 0 – 10)
  - breathing
  - vocalization
  - facial expressions
  - body language
  - consolability
- Often Undertreated
  - fewer analgesics used in this population
  - patients with hip fractures and dementia received less opioids pre and post o
  - related to decline in cognitive function
  - confirmed by several observational studies
Common Symptoms in the Hospice Patient

Various symptoms may affect quality of life for the terminally ill patient. One of the primary goals of hospice care is to relieve suffering to the greatest extent possible.

Common symptoms may include:

• pain
• fatigue, lethargy
• shortness of breath (dyspnea)
• anorexia, cachexia
• nausea, vomiting, constipation
• incontinence
• restlessness, agitation
• confusion, delirium
• depression
• skin breakdown, pressure ulcers
• edema

For a description of the above symptoms and methods of treatment, see below.

Pain
There are many different types of pain:

• physical (generalized pain, nerve pain, muscle pain, bone pain)
• psychological (depression, anxiety, loneliness, withdrawal, alienation)
• interpersonal
• spiritual or existential

Financial, intellectual and/or bureaucratic pain may also be present.

Sometimes individuals experience multiple types of pain simultaneously. Cicely Saunders, founder of the modern Hospice movement, called this “total pain.” Optimal pain relief is not possible if all dimensions of “total pain” are not addressed.

The HNW team develops a comprehensive pain management plan with interventions based on the patient’s goals of care. Both pharmacologic and non-pharmacologic methods may be used, often in combination with one another.

Medications for Physical and Emotional Pain
Many Hospice patients experience physical pain. Individuals can vary in their pain tolerance and amount of medication necessary for relief. Sometimes, the amount of medication needed to be effective increases over time. Medication may also be prescribed for “breakthrough pain” to take in-between regularly scheduled long-acting pain medications. Our goal is to reduce a patient’s pain to an acceptable level within 48 hours of admittance to Hospice. Pain medications may cause drowsiness. Some patients choose to tolerate a degree of pain so that they can remain alert. Drowsiness and/or may also occur during the first few days on a new pain medication, but will generally disappear.
For patients with psychological or emotional pain, anti-depressants or anti-anxiety medications may be helpful.

**Non-Pharmacologic Treatment for Pain**

**Physical Pain:** Cold/Ice, Heat, Therapeutic Touch, Massage, Reiki, Exercise/Physical Therapy, Acupuncture, Acupressure

**Psychological Pain:** Counseling, Life Review, Relaxation, Guided Imagery/Meditation, Hypnosis, Education, Music, Pet Therapy

**Spiritual Pain:** Meditation, Reflection, Spiritual Readings, Pastoral Counseling, Prayer, Faith Reaffirmation, Rites and Rituals

**Volunteer Role in Management of Physical Pain**

Questions to ask the patient at every visit include:

• Are you experiencing any pain today? If yes, then:
  • On a scale of zero to 10, where zero is no pain at all and 10 is the worst pain imaginable, how would you rate your pain?
  • Where on the pain scale would you like your pain to be?
  • Have you contacted your Hospice Team to let them know of your pain?

The volunteer may also:

• Learn what would help them feel better.
• Let the team know that the patient is experiencing pain.
• Ask the team about what non-pharmacological interventions you can utilize to alleviate pain.

**Fatigue/Lethargy**

Fatigue, lethargy and weakness are common at the end of life. They may arise from both physical and psychological stresses (anxiety, depression). Fatigue may include tiredness, lack of energy not relieved by rest, diminished mental capacity and the subjective weakness associated with difficulty in performing activities of daily living. Fatigue can be extremely debilitating and may have a severe negative impact on quality of life.

**Treatment**

• Rule out other symptom/treatable causes (anxiety, overmedication, infection, etc.)
• Corticosteroids and Psychostimulant medications; antidepressants if patient has fatigue that is non-responsive to other medications
• Decrease pressure on the patient to be energetic
• Educate patient and family that symptom is beyond the patient’s control.
• Give permission to rest

**Shortness of Breath/Dyspnea**

Many Hospice patients experience shortness of breath (dyspnea). Dyspnea can be very frightening to patients and families. It can range from mild or can be so severe that the patient cannot talk, walk or
eat. Patients may feel tightening in the chest, fear they are unable to breathe, may breathe in a fast pattern, and may feel light-headed, confused, or disoriented.

**Treatment**
- Medication
- Oxygen
- Change in position
- Fans (small hand held fans or large room fans)
- Relaxation techniques, decrease in stimulation
- Energy conservation
- Emotional support

**Anorexia, Cachexia**
Cachexia or wasting syndrome is loss of weight, muscle atrophy, fatigue, weakness, and significant loss of appetite in someone who is not trying to lose weight. The formal definition of cachexia is the loss of body mass that cannot be reversed nutritionally: Even if the affected patient eats more calories, lean body mass will be lost, indicating a primary pathology is in place. Cachexia is part of the “normal” end f life process, and caregivers may appreciate reassurance that their care is adequate.

**Treatment**
- Appetite stimulants
- Address nausea
  - Eliminate dietary restrictions; allow patient to choose favorite foods.
  - Reduce portion size and eliminate foods whose odors are unpleasant.
  - Explain that force-feeding is usually ineffective and uncomfortable.
- Treat contributing factors.
  - Explore emotional and spiritual issues related to the patient’s weight loss.

**Nausea and Vomiting**
Nausea and vomiting can be extremely debilitating symptoms. Effective control of these symptoms can be achieved in most patients. Common causes include: chemical (drugs, biochemical, toxins), gastrointestinal (gastric irritation, obstruction, constipation, anatomical/structural), intracranial pressure, psychological (fear, anxiety, pain) or vestibular (motion sickness, cerebellar tumor).

**Treatment**
- Must take into account the cause of nausea and vomiting (see above)
- Add or change medications
- Dietary change
- Environmental modification
- Acupuncture, acupressure
- Visualization, hypnosis
- Distraction
- Counseling for anxiety reduction
Restlessness/Agitation
Families may be surprised when a seriously ill (and usually calm) individual becomes restless or agitated. Some patients do not experience it at all. Still others may just exhibit these symptoms in the last days or hours of life. Signs and symptoms include increase in physical activity that is not purposeful, abnormal or uncharacteristic behavior (irritability, over-sensitivity), and/or delusions or hallucinations.

Treatment
• Rule out other symptoms/treatable cause (pain, infection, constipation, urinary retention, etc.)
• Medication
• Redirection
• Oxygen if appropriate for condition
• Alternative therapies
• Environmental adjustment
• Music therapy

Delirium/Confusion
Delirium is a complex psychiatric syndrome. Signs and symptoms may include change in level of consciousness, decreased short-term memory and attention span, confusion/disorientation to time and place, delusions and/or hallucinations, change in speech, mood swings, sleep disturbances, and/or increased or decreased body movements.

Treatment
• Rule out other symptoms/treatable causes
• Medication
• Alternative treatments
• Environmental adjustment
• Oxygen if appropriate for condition
• Redirection

Nausea, Vomiting, Constipation
Nausea and vomiting are common in many hospice patients. Noxious odors, tastes, or sights can sometimes trigger this response. Certain medications, constipation, or a bowel obstruction may also be causes. Signs may include queasiness, lack of appetite, and/or decreased interest in food or drink.

Treatment
• Rule out other symptoms/treatable cause (pain, infection, constipation, etc.)
• Medication
• Homeopathic remedies
• Cool compresses
• Fresh or cool air
• Avoid odors that trigger nausea
• Offer small meals

Skin Breakdown, Wounds and Pressure Ulcers
People with advanced illness are at increased risk for skin failure, including skin tears, wounds and pressure sores. Skin breakdown almost always occurs due to the progression of the life-limiting
illness, rather than being caused by poor care. The following can compromise skin: pressure, moisture, trauma, weakness, limited mobility, poor nutrition, impaired immune function, and reduced blood flow to tissues. Pressure ulcers are areas of local tissue damage, usually developing where soft tissue is compressed between a bone and an external surface. Skin tears may be caused by falls, repositioning, and/or bumping extremities on hard surfaces.

**Prevention and Treatment**
- Use special support surfaces (e.g. pads) for bed and chairs
- Encourage activity, as tolerated
- Range of motion exercises
- Turn and reposition regularly
- Cleanse skin gently, pat dry, apply moisture barrier
- Compression bandages
- Medications, both oral and topical
- Meticulous skin care, use of barrier creams and frequent dressing changes

**Edema**
Many patients exhibit edema, which is swelling caused by fluid in the body tissues. It usually occurs in the feet, ankles and legs, but can involve the entire body. Causes may include heart failure, kidney disease, liver problems and lymph node issues; some medications; too much salt intake, standing or walking a lot during warm weather.

**Treatment**
- Diuretic medications
- Elevating legs
- Wearing support stockings
- Manual lymphatic drainage massage
- Limiting salt intake

**Incontinence**
There is a high probability that a hospice patient will experience some level of incontinence at the end of life. It may be a result of disease or loss of consciousness, but may also be caused by loose bowel movements or diarrhea. Incontinence can be a great cause of embarrassment for Hospice patients. Communicate patience and understanding, protect individual’s privacy and listen to their concerns, if they choose to share them.

**Treatment**
- A urinary catheter may be placed
- Provide adequate time for bowel functions
- Use urinals, bed pans or bedside commodes so the patient can relieve themselves quickly.
- Use blue pads under the patient or have them wear disposable incontinence pads
- Keep patient clean and dry; immediately change soiled clothing or bedding.
The Dying Process Timeline

**At One to Three Months**
- withdraws from people and activities
- communicates less
- eats and drinks less
- sleeps more

**At One to Two Weeks**
- becomes disoriented and confused
- uses symbolic language (“I want to go home”)
- talks to others not present in the room
- pulse rate increases or decreases
- skin color changes to yellowish or grayish
- breathing patterns become irregular
- body temperatures change, warm or cold
- food or drink intake decreases

**Hours to Days**
- sleeps most of the day
- energy may surge and/or mind clears
- restlessness may increase
- swallowing becomes difficult
- skin may cool and/or appear blotchy
- breathing sounds rattle
- pulse weakens
- fever develops
- blood pressure decreases further
- urine output decreases or stops

**Minutes to Hours**
- breaths become shallower with longer pauses
- unresponsive
- mouth open

**When Death Occurs**
- breathing or heartbeat deceases
- bowel or bladder control may be lost
- no response to voice or gentle shaking
- jaw relaxes and mouth is slightly open

**After Death, families may honor the passing of a loved one in a variety of ways**
- spend time with your loved one after death
- bath and dress the body in special clothes
- tell stories, light candles, play music and/or bring flowers
- say prayers and/or perform rituals from deceased’s spiritual tradition
Changes at the End of Life

There are common changes that occur when someone is dying. Some families want to know about what to expect from the process of death. Families are given a booklet, “What to Expect” which describes the changes below.

Social Withdrawal – A dying person becomes less concerned with the world around them. There may be less need to communicate even with close family. Touch and silence may be more meaningful. Patients who are more “private” and/or “introverted” in life, may prefer solitude during their dying process.

Food – Loss of interest in food is part of the dying process. A dying person is not starving to death but dying from their illness. Small bites or sips may be comforting. Do not “push” food or drink; follow the patient’s lead.

Sleep - A dying person spends more and more time sleeping. Even while awake, keeping their eyes open may become too tiring. Do not insist they keep them open while visiting. They may only be awake for 1-2 hours each day. Focus on making these times special.

Disorientation – Many patients become confused. Processing information and response time may be prolonged. Some patients lose track of time or location. Some see people who are not there, including people who have died. Most often this is not distressing for the patient. If asked, gently answer questions but do not correct the patient’s perceptions.

Restlessness – Many patients become physically restless at the end of life. Create a calm environment by speaking in a calm voice. If restlessness or anxiety is extreme, inform the patient’s care team at hospice. If he patient is getting out of bed and falling or wandering, safety measures have failed.

Decreased Vision – Loss of vision may occur. Soft lights can help patients avoid visual misperceptions.

Hearing - Hearing is the last sense to be lost. Speak in a normal tone of voice. Assume you can be heard at all times.

Incontinence – Loss of bladder and/or bowel control often occurs. A catheter may be used for cleanliness and comfort.

Changes in Breathing Patterns – Changes include periods of rapid breathing, periods of no breathing lasting 30 seconds or more, and/or a rattling sound in the back of the throat caused by pooled saliva. Although distressing to hear, the patient is not suffering. If fear is associated with shortness of breath, Hospice treats it. If not, and the patient is comfortable, treatment is not necessarily needed.
# Hospice, Medicare and Medical Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Advance Directive</strong></td>
<td>Written or verbal instructions for care in the event an individual cannot make decisions for themselves.</td>
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<tr>
<td><strong>Alzheimer’s Disease</strong></td>
<td>The leading cause of Dementia; it may cause memory loss, difficulty with problem solving and decision-making, misplacing items, personality changes, and impaired speaking and writing.</td>
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<tr>
<td><strong>Anorexia</strong></td>
<td>An eating disorder; lack or loss of appetite</td>
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<tr>
<td><strong>Aortic Stenosis</strong></td>
<td>Decreased blood flow to heart when aortic valve does not open fully</td>
</tr>
<tr>
<td><strong>Apnea</strong></td>
<td>To stop breathing for period of time</td>
</tr>
<tr>
<td><strong>Ascites</strong></td>
<td>Fluid accumulation in the abdomen</td>
</tr>
<tr>
<td><strong>Aspiration Pneumonia</strong></td>
<td>Swelling or infection of the lungs or large airways</td>
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<tr>
<td><strong>Atrial Fibrillation</strong></td>
<td>Fast and irregular heart rhythm</td>
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<tr>
<td><strong>Cerebral Edema</strong></td>
<td>Fluid build-up in the brain</td>
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<tr>
<td><strong>Certification</strong></td>
<td>A patient is initially “certified” to receive 90 days of care under Medicare Hospice Benefits. Also see: Recertification.</td>
</tr>
<tr>
<td><strong>Cognitive impairment</strong></td>
<td>Problems with thought processes, including reasoning, memory, learning, concentration, and information-processing</td>
</tr>
<tr>
<td><strong>Comfort Kit</strong></td>
<td>Medications ordered at time of Hospice admission to have available as needed for pain and symptom control.</td>
</tr>
<tr>
<td><strong>Continuous Care</strong></td>
<td>A level of Hospice care initiated when a patient’s symptoms are very difficult to control. A nurse may be placed at the bedside for 8-hour shifts until the symptoms are controlled.</td>
</tr>
<tr>
<td><strong>Dementia</strong></td>
<td>A syndrome or group of symptoms that occur together. It is not a disease. In Dementia, there is a decline of mental abilities such as thinking, reasoning and memory. There are more than 70 types of Dementia, including Alzheimer’s, Vascular Dementia, Lewy Body Dementia and Frontotemporal Dementia (see each of these listings for more information).</td>
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<tr>
<td><strong>Dysphagia</strong></td>
<td>Difficulty swallowing</td>
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<tr>
<td><strong>Dyspnea</strong></td>
<td>Shortness of breath</td>
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<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Edema</td>
<td>Fluid accumulation causing swelling beneath skin or in body cavities</td>
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<tr>
<td>Embolism</td>
<td>Obstruction of an artery; typically by blood clot or air bubble</td>
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<tr>
<td>Face-to-Face Visit</td>
<td>A Hospice physician must have a face-to-face visit with a patient every 60 days to determine continued eligibility once the patient has been on service longer than the two initial 90-day periods.</td>
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<tr>
<td>Fibromyalgia</td>
<td>Long term pain in joints, muscles, tendons and other soft tissues, often accompanied by anxiety and depression.</td>
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<tr>
<td>Frontotemporal Dementia</td>
<td>Accounts for 2-5% of Dementia cases; a degenerative condition of the temporal and frontal brain lobes it can result in impaired social skills and judgment and personality changes.</td>
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<tr>
<td>Gastroreflux</td>
<td>Backward flow of gastric fluid from stomach to esophagus</td>
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<tr>
<td>General Inpatient Care</td>
<td>Hospice patient is hospitalized as symptoms cannot be managed effectively in any other setting.</td>
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<tr>
<td>Healthcare Agent</td>
<td>Person named in an advanced directive to make health-care decisions on behalf of another.</td>
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<tr>
<td>Hydration</td>
<td>Process of providing water or fluid by mouth, tube or intravenously</td>
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<tr>
<td>Intubation</td>
<td>Process of inserting a tube into a patient’s lungs to help with breathing</td>
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<tr>
<td>Kidney Disease</td>
<td>Chronic kidney failure</td>
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<tr>
<td>Lewy Body Dementia</td>
<td>Refers to both Parkinson’s disease Dementia and Dementia with Lewy Bodies. Causes cognitive, physical, sleep and behavioral changes.</td>
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<tr>
<td>Level of Care</td>
<td>Describes a patient’s type of care under Medicare, e.g. routine care, general inpatient care, respite and continuous care.</td>
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<tr>
<td>Lymphadema</td>
<td>Localized fluid retention and tissue swelling caused by compromised lymphatic system</td>
</tr>
<tr>
<td>“Mets”</td>
<td>Cancer cells which have spread to other part of the body; also called metastases.</td>
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<tr>
<td>Mottling</td>
<td>Skin is bluish/purple color</td>
</tr>
<tr>
<td>Myocardial</td>
<td>Pertaining to muscular tissue of the heart</td>
</tr>
<tr>
<td>Neoplasm</td>
<td>Abnormal growth (tumor); either benign or malignant</td>
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<tr>
<td>Neuropathy</td>
<td>Nerve damage causing pain</td>
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</tbody>
</table>
Oriented
Term signifying whether a patient understands person, place and time, e.g. they recognize people, as well as where they are and time of day

Palliate
To relieve the symptoms of a disease or disorder

Palliative Care
Medical specialty focused on relief of pain, symptoms and stress of serious illness

Palliative Sedation
Relieving intolerable pain and suffering by inducing an unconscious state. Patient and/or DPOA must consent. It will not shorten life-span.

Parkinsons Disease
Progressive disease of the nervous system

Pleural Effusion
Excess fluid build-up around the lungs

Pulmonary Edema
Excess fluid in the lungs

Pulmonary Fibrosis
Scarring of the lungs

Recertification
After the initial 90 days on the Medicare Hospice benefit, patients must be recertified to show that they continue to qualify for the benefit. The second “recert” period is 90 days, followed by 60-day periods.

Respite Care
A Medicare term, this benefit allows the patient to be cared for in a facility for up to five days so the family/caregivers may take a break.

Routine Home Care
The level of care most patients receive under Medicare when their symptoms are being controlled.

Sublingual
Medications given under tongue

Terminal Agitation
Restlessness or delirium (usually with confusion, pain or burst of activity) that can occur at the end of life

Thrombosis
Coagulation or clotting of blood in part of the circulatory system

Vascular Dementia
The 2nd most common form of Dementia; caused by brain damage due to impaired blood flow to the brain as a result of a stroke, brain hemorrhage or diabetes. Patients experience difficulty solving problems and completing tasks.

Vascular Disease
Disease of the blood vessels
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living (bathing, dressing, grooming, toileting, ambulating, feeding)</td>
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<tr>
<td>CHF</td>
<td>Congestive Heart Failure</td>
</tr>
<tr>
<td>CNA</td>
<td>Certified Nursing Assistant (also called NAC)</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardiopulmonary Resuscitation</td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebral Vascular Accident (stroke)</td>
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<tr>
<td>DNR</td>
<td>Do Not Resuscitate (A physician’s order not to attempt CPR if a patient’s heart or breathing stops)</td>
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<tr>
<td>DPA</td>
<td>Durable Power of Attorney</td>
</tr>
<tr>
<td>GERD</td>
<td>Gastric Reflux Disease</td>
</tr>
<tr>
<td>IDG/IDT</td>
<td>Interdisciplinary Group (also called Interdisciplinary Team)</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Physician</td>
</tr>
<tr>
<td>PO</td>
<td>Medications taken by mouth</td>
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<tr>
<td>POC</td>
<td>Plan of Care. The Hospice Team develops a plan of care (to include all services, including volunteers, and interventions) which is signed by the physician.</td>
</tr>
<tr>
<td>POLST</td>
<td>Physician’s Order for Life-Sustaining Treatment. A legal document specifying an individual’s preferences for CPR, Medical Interventions and Non-Emergency Medical Treatment. A POLST must be signed by a physician as well as the patient or legal surrogate. HNW patients living in private residences generally post these on their refrigerator.</td>
</tr>
<tr>
<td>PPS</td>
<td>Palliative Performance Scale (Measure of the level of functioning. Ranges from 0 (expired) to 100 (completely functional))</td>
</tr>
<tr>
<td>PRN</td>
<td>As needed</td>
</tr>
<tr>
<td>TIA</td>
<td>Transient Ischemic Attack (stroke)</td>
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Hospice Medical Ethics

Hospice of the Northwest Ethics Committee Mission Statement
To provide a formal mechanism for all involved within our healthcare organization to confront, discuss, and ideally, resolve ethical issues or perceived ethical issues that arise within the context of the delivery of hospice and palliative care services.

Ethics Committee Policies and Procedures
We will achieve our mission through:
- Facilitating communication
- Education
- Policy development and review
- Ethics case consultation

We are available to:
- Hospice of the Northwest staff members
- Hospice patients
- Families and caregivers of hospice patients

Committee composition includes:
- Members of various disciplines from the Hospice of the Northwest staff
- Community members at large from volunteers, foundation and others

Committee terms:
- Three years for each individual representing nurses, chaplains and social workers
- One year for the two members at large positions
- Rotating terms among members so the committee retains experience year to year
- Unlimited term for HMD chairperson

Ethical Principles
- The Ethics Committee will subscribe to and practice the Ethical Principles as outlined by the National Hospice and Palliative Care Organization.

Meetings
- The Ethics Committee meets once monthly and is chaired by a Hospice Physician Medical Director.

The Four Founding Principles
1. Beneficence
   - The obligation to assist those in need
   - Avoid harm (prevention)
2. Non Maleficence
   - Do no harm
   - Informed consent
3. Autonomy
   • Right to choose and follow one’s own plan of life and action
   • Right to choose between medical alternatives
   • Right to say “no”
   • There is no affirmative autonomy
   • Requires a capable, competent patient

4. Justice
   • The fair distribution of social and medical resources
   • Equal cases will be treated equally
   • If limited resources, rationing may be required
   • Triage. Treat the most treatable and severe cases first

Other Principles to Understand
   • Double Effect – a negative effect inextricably linked to the intended effect
   • Futility – When the goals of restoration of health and function seem beyond attainment

Additional Principles to Recognize
Utilitarianism, non-abandonment, truthful disclosure, paternalism, discrimination, refusal of treatment, proportionality, competence, informed consent, confidentiality, advanced directives, clinical judgment, withholding/withdrawal
Facts about Cardiopulmonary Resuscitation (CPR)

What is CPR?
CPR is an attempt to re-start the heart when someone has stopped breathing and the heart starts beating or a type of heartbeat that leads to no pulse and death.

How often does CPR work?
15% of all people who have CPR live through it; 20% of CPR is administered in a hospital.

Who is most likely to live after CPR?
- people who are young and fit
- those with no major health problems
- individuals who have the type of heartbeat that responds to shocks
- those who have CPR started within a few minutes after the heart stops

Who is least likely to live after CPR?
- people with late-stage cancer; only 1% live after CPR
- people who are older, frail and have a chronic illness
  - Older people are less likely to have a heart that can recover and keep beating after CPR.
  - Older people are more likely to:
    - have the type of heartbeat that does not respond to CPR
    - have other diseases of the heart, lungs, brain, liver, kidneys or cancer
    - be harmed by emergency medicines if they have liver or kidney disease and/or
    - be slowly dying from other causes.
  - CPR does not work well for some groups of older adults.
    - Only 5% of people in nursing homes live after CPR, even if administered in a hospital.
    - Only 2% of people with memory loss (dementia) live after CPR.
    - Only 1% of people with late-stage cancer live after CPR.

What medical problems may happen after CPR?
- Half of people will have brain damage that will never improve.
- 97% will have their ribs broken.
- 43% will get breastbone fractures.
- 59% will have bruising to the chest.
- 30% will get burns on their skin from shocks.
- Other problems may include lung damage, bleeding in the chest, and damage to the windpipe or esophagus, damage to lips and/or teeth from the breathing mask and/or tube.
Facts about Feeding Tubes

What is a feeding tube?
There are feeding tubes for short-term and long-term use. A temporary feeding tube can be inserted through the nose into the stomach (N-G tube) for short-term use. A feeding tube for long-term use (Percutaneous Endoscopic Gastrostomy or PEG Tube) is placed directly into the stomach by a surgical incision.

Who is helped most by a feeding tube?
• Patients who function independently but are having chemotherapy or radiation for certain cancers may benefit as well as some stroke survivors in rehabilitation, whose swallowing ability is expected to return.
• Persons with Lou Gehrig’s disease (ALS) may benefit because swallowing problems may occur before they reach the terminal phase of their disease.

When are feeding tubes less helpful?
• Those in the very late stage of dementia who lose their ability to swallow may not benefit; often this is not an isolated event but may represent progression of the disease to the terminal phase.
• Patients in the terminal stages of many diseases, including dementia, may not benefit as the gastrointestinal system shuts down and digestion becomes ineffective.

What are some possible complications from feeding tubes?
• Bleeding occurs in 1% of patients.
• Infection and skin irritation occurs in 1-4% of patients.
• Leakage around the tube occurs in 4% of patients.
• Vomiting or nausea occurs in 9-10% of patients.
• Diarrhea or cramping occurs in 12% of patients.
• Tube feeding during the active phase of dying may cause fluid overload, making breathing more difficult.

Does a feeding tube improve comfort and prevent suffering?
For those with temporary swallowing problems from mouth or throat conditions, a feeding tube may alleviate pain and provide short-term nutritional support.

If my loved one does not have a feeding tube, will s/he starve?
Some people fear that not providing a feeding tube at the end of life means they are letting their loved one “starve to death.” This is not true. Starvation occurs when a hungry person whose body needs and can use the nutrition is deprived of food. When a dying person’s body begins to shut down, the body may be unable to adequately use nutrients and the chance for bloating and discomfort increases.
Overview of the Washington Death with Dignity Act (DWDA)

The Washington State Death with Dignity Act was approved by voters in 2008. It went into effect in March 2009. Washington was the second state in the nation (after Oregon) to adopt the law. Similar legislation was enacted in Vermont in 2013, and in Montana the state Supreme Court ruled in favor of physician-assisted death. In early 2014, a court decision confirmed that New Mexico doctors can help terminal patients die. Death with Dignity legislation is presently under consideration in at least seven other states.

In our state, patients who are interested in learning about Death with Dignity contact End of Life Washington. It is recommended that if an individual is seriously considering this option, that they contact this organization early in their terminal illness as the process for approval takes time.

Individuals must be an adult, a Washington state resident, have a prognosis of six months or less, be capable of making and informed decision (not impaired by mental illness, dementia or depression) and be able to self-administer the medication.

The process includes and oral request of the prescription, consulting two physicians, completing a written request, making a second oral request and then obtaining the medication.

Hospice of the Northwest does not hasten no prolong death. Our detailed policy on Death with Dignity is stated in the following policy document; Death with Dignity (65192).

Statement on Physician-Assisted Dying by the American Academy of Hospice and Palliative Medicine

“Situations in which Physician-Assisted Dying (PAD) is requested are challenging for physicians and other healthcare practitioners because they raise significant clinical, ethical and legal issues. A diversity of positions exists in society, in medicine, and among members of the American Academy of Hospice and Palliative Medicine (AAHPM). AAHPM acknowledges that morally conscientious individuals adhere to a broad range of positions on this issue.

AAHPM takes a position of studied neutrality on the subject of whether PAD should be legally permitted or prohibited. However, as a matter of social policy, the Academy has concerns about a shift to include physician-assisted dying in routine medical practice, including palliative care. Such a change risks unintended long-range consequences that may not yet be discernible, including effects on the relationship between medicine and society, the patient and physician, and the perceived or actual integrity of the medical profession. Any statutes legalizing PAD and related regulations must include safeguards to appropriately address these concerns, such a limiting eligibility to decisionally capable individuals with a limited life expectancy.
Social policy concerns notwithstanding, the Academy recognizes that in particular circumstances some physicians assist patients in ending their lives. Efforts to augment patients’ psychosocial and spiritual resources so that they are better able to manage their suffering may make palliative treatments of physical symptoms more effective and may make these circumstances rarer. Nevertheless, some patients will continue to desire PAD.

Physicians practicing in jurisdictions in which PAD is legally permitted should never be obligated to participate in PAD if they hold moral or professional objections, nor should they be prohibited from participating within parameters defined by relevant statutes and terms of employment. Physicians who affirmatively respond to requests for PAD are obligated to ensure their actions are consistent with best available practices that limit avoidable suffering through end of life.

When a request for PAD is made by a terminally ill patient, medical practitioners should carefully evaluate the patient’s concerns precipitating the inquiry and address the sources. Requests originating from family should not be pursued without direct discussion with the patient. Requests for PAD from surrogates or incapacitated patients should not be considered due to the complexities of the ethics of surrogate decision-making. However, surrogates’ concerns prompting the request should be fully explored.
Policy

Dying is a natural process. Hospice of the Northwest (HNW) does not hasten nor prolong death. The philosophical tenets supporting this policy are:

1. HNW is committed to the value of human life. We optimize the quality of life for all terminally ill people with quality defined by each individual receiving hospice services. This includes the avoidance of prolonged suffering.
2. HNW supports the right of all persons to make their own decisions regarding their care including the legal option of ingesting a lethal dose of medication, as outlined in the Washington State Death with Dignity Act (WSDDA).
3. HNW allows access to hospice care for terminally ill patients regardless of a patient’s stated interest in Death with Dignity (DWD).
4. HNW will address the needs of the terminally ill with compassion, dignity, and respect.
5. HNW embraces the principles within the Hospice and Palliative Care Code of Ethics, which compels us to honor and support patient/family wishes and end of life choices.

Procedure

1. There is no restriction on any professional staff member about discussing DWD or offering information on DWD. We are reminded that our role is to be nonjudgmental and to remain neutral in all patient issues.
2. Staff and volunteers who are ethically opposed to DWD and unable to remain neutral in discussions with, or care of, a patient who expresses an interest in DWD, are required to transfer the care responsibilities of that patient to other hospice members.
3. HNW will not, either directly or through our Foundation, provide, pay for, deliver, administer, or assist with the administration of medications prescribed for DWD use.
4. HNW hospice physicians will not prescribe medications for DWD as part of their hospice duties. Hospice physicians may provide the "consulting physician" role for these patients. As the law stipulates, there is no prohibition of a hospice physician acting outside his/her hospice employment contract with HNW.
5. Patients may request that HNW staff be present during the time the patient plans to ingest the medications. If HNW staff agrees to be present, the staff will not assist the patient with the medications.
6. In the event that a HNW patient exercises his or her right to obtain a legal prescription for DWD, the patient and family will continue to receive ongoing and complete hospice services.
7. HNW staff will encourage patients to consider a safe and protected environment if they choose to use their DWD medication.
8. Any inquiry from a patient about DWD should be routed to the attending physician of record and the Interdisciplinary Group (IDG).
9. All efforts should be made to determine the source of a patient’s suffering.
10. The IDG may request a consultation from the HNW Ethics Committee.
11. Staff and volunteers will document all discussions and interventions in the patient’s health record.
12. HNW will fully discuss the organizational policy on DWD with any patient or family member that inquires about the policy.
13. Post-death, the case review process is available for any staff or volunteer that requests it.
14. When a HNW patient is admitted for care at any hospital or other facility, the policies of that organization take precedence over HNW’s policy concerning DWD.
15. No patient will be discharged who chooses to pursue the legal option of DWD.
Death with Dignity Statistics: Washington State 2013

More than 100 people died in Washington state last year after requesting and taking a lethal prescription through the Death with Dignity law, according to the *Seattle Times* (June 5, 2014).

State Department of Health officials said that 173 people requested and received the medicine in 2013, a 43% increase over 2012. Of those people, 159 are known to have died, including 119 who died after taking the medication. Twenty-six people died without taking the medication, and it’s not known whether the 14 others who died took the medication. These individuals may still be alive or their physicians may be delayed in turning in reports on their deaths.

The prescriptions were written by 89 different physicians and dispensed by 23 different pharmacies.

The Health Department shared other details about patients who died:

- They ranged in age from 29 – 95.
- More than 95% lived west of the Cascade Mountains.
- 77% had cancer, 15% had a neurodegenerative disease, 8% had heart disease or another illness.
- 95% had health insurance.
- 97% were white.
- 52% were married.
- 76% had at least some college education.

Most of the people who asked for a lethal prescription told their physicians they were concerned about losing autonomy, dignity, or the ability to participate in activities that made life enjoyable. Most died at home and were in hospice care at the time of their deaths.

Washington was the second state, after Oregon, to adopt a death-with-dignity law after voters approved the initiative in 2008.
Purpose
To provide guidance to hospice staff in the event that there is a request to no longer provide food or fluid to a patient.

Content
It is well established that a decisional adult has the right to refuse nutrition and hydration, whether provided artificially (TPN and tube feeding) or orally. Because patients have the right to forgo life-sustaining treatment, it is argued that adults with a terminal or incurable illness can choose to voluntarily stop eating and drinking (VSED)1.

There is less clarity regarding withholding nutrition in adults that lack the decision-making capacity but are still able to eat and drink. Even in the case of carefully prepared advanced directives, it can be ethically and legally challenging to withhold food and fluids from a vulnerable adult.

There are medical and ethical mandates to provide food. The American College of Physicians End-of-Life Care Consensus Panel maintains that “food and drink must not be withheld from incompetent persons who are willing to eat”. The right to food is also protected by the Universal Declaration of Human Rights Article 25, adopted by the General Assembly of the United Nations2.

A surrogate can choose to forgo medical procedures on a patient’s behalf, but because hand feeding is not a medical procedure, failure to offer food to a non-decisional patient could be viewed as neglect. Similarly, facility personnel are legally bound to provide adequate nutrition and hydration; if this is not provided, it could be viewed as neglect in a vulnerable adult.

If the act of feeding does not cause any discomfort, oral feeding should continue for this population.

COMFORT FEEDING ONLY:
In an effort to uphold patient directives or surrogate requests that outline known preferences, the concept of “comfort feeding only” can be discussed. This hand feeding is provided with comfort as a goal. Hand-feeding can be continued as long as the patient is not showing any signs of distress or disinterest. Signs of distress or disinterest may include any of the following:

- turning head away,
- unwillingness to open mouth,
- pocketing food,
- choking and coughing despite thickened textures and fluids

If the patient shows repeated signs of distress/disinterest with eating, feeding should be stopped. As illness can often worsen and then improve, reattempts to feed could be resumed periodically to see if the difficulties have resolved. The focus of feeding should be on provision of comfort. When feeding is stopped, there should be ongoing engagement with the patient in lieu of feeding, such as performing oral care, reading or talking to the patient.
patient, therapeutic touch or other forms of interaction. The goals of feeding often change at the end of life, with social and physical contact and engagement becoming more important than nutritional health.

References

2. To Feed or Not to Feed? Report and ethical Analysis, Ethical issues in Palliative Care, Journal of Pain and Symptom Management Vol. 50, No 6, December 2015.

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Summary of Policies and Guidelines for Hospice Volunteers

In order to work with patients, in the Hospice Office, or in other volunteer services, volunteers must:

- Understand and adhere to the Volunteer Services and Employee Immunization Policies
- Understand and abide by state regulation to not toilet, transfer, transport or feed patients in their care
- Understand and abide by immediately contacting the Hospice Office in case of patient emergencies
- Understand and agree to document all volunteer hours on CallWyse
- Understand why and agree to discontinue contact with patients who have been removed or discharged from service immediately following notification by Hospice Office
- Understand why and agree to terminate contact with bereaved family and/or caregivers after one condolence call
- Understand and comply with the Code of Conduct
- Understand and comply with the Dress Code
- Understand and comply with all HIPAA laws and regulations regarding patient confidentiality
- Understand and comply with Safety and Security Policy
- Understand and comply with the Providing Oxygen when Patient Safety is a Concern Policy
- Understand and follow Guidelines for Standard Precautions for Infection Control
- Understand and follow Guidelines for use of PPE
- Understand and follow Guidelines for Safe Food Preparation, Storage, and Handling
- Understand and comply with Hospice Patient Rights and Responsibilities Policy
- Understand and comply with the Abuse, Neglect, Mistreatment and Exploitation policy
- Understand and comply with the Conflict of Interest Policy
- Understand and comply with the HNW Confidentiality and Compliance Statement
Purpose
To ensure that qualified volunteers provide appropriate services in accordance with the interdisciplinary plan of care and hospice program needs.

Services
I. Volunteers are supervised by the Volunteer Supervisor and are used in prescribed roles including, but not limited to:
   i. providing emotional and practical support to patients and families;
   ii. providing respite for the patient's caregiver;
   iii. making “Tuck In” calls to insure patients have what they need for the coming weekend;
   iv. providing 24-hour vigil support for actively dying patients and their caregivers;
   v. assisting agency at health and community events;
   vi. assisting in bereavement education and support services;
   vii. assisting with program administration and development; and/or
   viii. assisting with office duties.

II. Recruitment efforts are sufficient to ensure that the hospice has enough volunteers to meet the needs of patients and families and the requirements of state and federal regulations.

III. Volunteers are selected regardless of race, color, national origin, ancestry, age, sex, religious creed, sexual orientation, or disability.

IV. Applicants for volunteer positions are carefully screened and are required to complete an application form and interview process.

V. Volunteers are required to complete an orientation and training program prior to assignment.

VI. A personnel file is maintained for each volunteer that contains prescribed contents.

VII. Volunteers are assigned to patients and their caregivers based on assessed needs and appropriateness.

VIII. All volunteers report to and are supervised by the Volunteer Supervisor and are provided with ongoing support and continuing education.

IX. Volunteers are required to document all contact with patients and their caregivers, plus meet the documentation requirements of Hospice of the Northwest.

X. The Volunteer Supervisor maintains records of volunteer activity and records levels of volunteer participation and cost savings on a monthly and annual basis.

XI. Ongoing efforts to retain volunteers include, but are not limited to:
   A. regular and consistent contact with the Volunteer Supervisor and other members of hospice's interdisciplinary group;
   B. attendance at interdisciplinary group meetings, when possible; and
   C. attendance at monthly volunteer support groups when possible.

XII. An annual performance evaluation is completed by the Volunteer Supervisor.
Screening and Application

1. When an applicant for a hospice volunteer position inquires regarding the volunteer training program, the Volunteer Supervisor conducts a brief phone interview to determine interest and appropriateness.

2. If appropriate, based on the telephone screening, the applicant is scheduled for an in-person interview. The applicant is either given or mailed a volunteer application.

3. The Volunteer Supervisor follows policies and procedures for conducting a criminal background check and obtaining two references for individuals who apply for volunteer positions at hospice.

4. Once an applicant has been screened and accepted, he or she is invited to attend the next available volunteer training program. If a training program is not scheduled for the near future, the volunteer may, at the discretion of the Volunteer Supervisor, participate in an individualized training program.

Orientation and Training

1. The orientation and training program for volunteers is coordinated and supervised by the Volunteer Supervisor.

2. An initial orientation to Hospice of the Northwest and the hospice philosophy of care is provided to all volunteers. Training is directed toward preparing volunteers to provide services to patients and families and/or administrative support.

3. The length of the training program is variable but must include, at a minimum, the following core modules, taught by qualified individuals:
   a. introduction to the hospice philosophy of care and the patient/family as the unit of care;
   b. the role of the volunteer in hospice and the volunteers duties and responsibilities;
   c. confidentiality and the privacy of protected health information;
   d. patient/family rights;
   e. infection control, safety and emergency preparedness;
   f. safe food handling;
   g. volunteer support, educational opportunities and contact information of the Volunteer Supervisor; and
   h. documentation and record keeping requirements.

4. Volunteers serving patients and families also must complete:
   i. hospice in the nursing home;
   ii. concepts of death and dying;
   iii. grief and loss;
   iv. comfort measures;
   v. communication skills;
   vi. psychosocial and spiritual issues related to death and dying;
   vii. signs and symptoms of approaching death and procedures following the death of a patient; and
   viii. coping with stress.

5. Documentation of the volunteer’s successful completion of orientation and training as well as on-going inservices is retained in the volunteer’s file.

6. Volunteers are expected and must agree to participate in continuing education programs as part of their ongoing training.
Documentation

1. Hospice volunteers use the CallWyse telephone system to document all volunteer services. In addition to recording the type of volunteer service, this system automatically records the number of visits and hours of service.

2. If the patient reports an uncomfortable level of pain or other distressing symptoms, the volunteer should contact Hospice immediately.

3. All volunteer documentation is submitted the same day the volunteer service occurred.

4. Randomly selected CallWyse audits are completed weekly to ensure timely, accurate and appropriate documentation of any patient related contact.

5. The Volunteer Supervisor summarizes the volunteer activity that has occurred and presents it to the QAPI Committee each quarter. The report estimates the total cost savings achieved through the use of donated volunteer hours and demonstrates that the services provided by hospice volunteers equals or exceeds five (5) percent of the total patient care hours of all paid hospice employees and contract staff.

Retention, Support and Education

1. Support is provided to hospice volunteers through:
   i. an annual volunteer recognition event;
   ii. regular and consistent contact with the Volunteer Supervisor and members of hospice’s interdisciplinary group;
   iii. monthly volunteer support meetings, and
   iv. attendance at interdisciplinary group meetings, when possible.

2. Continuing education opportunities for volunteers include specialized in-services on topics relevant to patient care volunteers.

3. Volunteers are encouraged to participate in new volunteer (core) trainings to refresh their skills.

4. Volunteers that have been inactive for over two years will need to retake the core training or a revised portion at the Volunteer Supervisor’s discretion.

Supervision

1. The Volunteer Supervisor provides oversight and supervision of all Hospice volunteers and volunteer activities.

2. The Volunteer Supervisor maintains contact with the hospice Interdisciplinary Group and with patients/caregivers regarding the volunteer’s performance.

3. Volunteers are expected to participate in Volunteer Support meetings.

4. The Volunteer Supervisor monitors volunteer documentation to assure the provision of quality services and to discover any potential areas of difficulty that may require additional support or training.

5. The Volunteer Supervisor provides an annual performance evaluation for each active volunteer that provides a summary of his/her observation and supervision of the volunteer.

Performance Evaluation

1. Each active volunteer is evaluated annually in the following areas:
   i. functioning in accordance with hospice policies and procedures;
   ii. upholding the Volunteer Agreement;
   iii. performance of their duties based on the specific job description;
iv. providing appropriate documentation in a timely fashion;
v. participation in continuing education programs to develop/strengthen skills;
vi. maintaining confidentiality; and
vii. maintaining appropriate duties.

2. The evaluation is presented to the volunteer by the Volunteer Supervisor either in person, by telephone, or via mail. If the volunteer does not return the signed evaluation, and documented attempts to obtain it are unsuccessful, a copy without the volunteer’s signature is placed in their file and the volunteer enters "inactive" status.

Personnel Records

1. Volunteers are considered employees of Hospice of the Northwest and the Volunteer Supervisor maintains a personnel file for each volunteer. Each volunteer personnel file contains:
i. volunteer’s emergency contact information;
ii. completed volunteer application;
iii. Criminal Background Check information;
iv. Confidentiality Agreement;
v. Conflict of Interest and Disclosure Statement;
vi. two (2) references;
vii. volunteer agreement;
viii. signed agreement to follow all policies;
ix. copy of driver’s license;
x. copy of automobile insurance;
xii. current signed job description(s);
xii. documents relating to performance/annual performance evaluation;
xiii. documentation of continuing education;
xiv. miscellaneous (letters from patients/families, etc.); and

2. SVH Employee Health services maintains TB Mantoux.

3. Volunteer personnel files are audited annually to ensure completeness.

References

Regulator Citation: 42 CFR 418.78

NHPCO Standard(s): WE 9.1; WE 9.2; WE 9.3; WE 9.4; WE18.1; WE 18.2
Purpose
To provide clear, consistent information and guidance regarding immunizations for healthcare workers.

Policy
Maintenance of immunity is an essential part of employee health and infection prevention programs for healthcare workers. Vaccination not only protects employees from diseases transmitted by the patients and public they serve, but also protects patients and the public from becoming infected through exposure to health care workers. Skagit Regional Health (SRH) requires its employees to be immunized, provide proof of immunization or a positive titer as provided here. Other immunizations are recommended but not required. Staff who do not wish to be immunized will sign a "Declination of Immunization" form. This form will be filed with Employee Health.

Support Data

1. Healthcare workers have direct contact with patients, public, and material from patients with infections.
2. Healthcare workers are at increased risk for exposure to and possible transmission of vaccine-preventable diseases.
3. Consistent immunization programs can significantly reduce the number of susceptible employees and may reduce employee absenteeism (as during flu season).

Definition
Healthcare workers include all persons, medical or non-medical, paid or volunteer, full- or part-time, student or non-student, with or without patient care responsibilities, who work in facilities that provide healthcare or services to patients.

This includes physicians, nurses, emergency medical personnel, dental professionals, medical and nursing students, laboratory technicians, hospital volunteers, administrative and clerical staff, hospital and clinic housekeeping and maintenance staff, and others.

Procedure

Required Immunizations

1. Required immune-status tests for SRH employees, volunteers and medical staff are available through the laboratory at no charge to the employee or volunteer.
2. These immune-status tests must be coordinated through the Employee Health Department.
3. Employees with a previous history of a complete Hepatitis B vaccination series do not have to be tested unless exposure occurs.

<table>
<thead>
<tr>
<th>Requirements</th>
<th>Vaccine:</th>
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<tbody>
<tr>
<td><strong>Applies to:</strong></td>
<td><strong>Vaccine:</strong></td>
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<tr>
<td>Healthcare workers</td>
<td>• MMR (2 doses or evidence of immunity to measles, mumps, and rubella)</td>
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<td>• Varicella (2 doses 28 days apart, history of varicella or herpes zoster based on physician diagnosis or laboratory evidence of immunity to chickenpox)</td>
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<td>• Influenza (1 dose annually or sign influenza declination form)</td>
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<tr>
<td>Employees performing tasks involving exposure to blood or blood-contaminated body fluids, for example: nurses; physicians; lab and medical technicians,</td>
<td>• Hepatitis B (Documentation of 3 doses or sign declination form)</td>
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<tr>
<td></td>
<td>• Un-immunized new employees must complete a 3-dose series and are offered a post vaccination antibody test to show immunity or sign declination form.</td>
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<td></td>
<td>• If hepatitis b antibody test result is nonreactive, up to 3 additional doses of vaccine may be provided).</td>
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<tr>
<td>Employees involved in food preparation and/or the feeding of patients</td>
<td>• Hepatitis A (2 doses or evidence of immunity) - offered</td>
</tr>
<tr>
<td>Employees performing tasks involving exposure to soil or who routinely work outdoors</td>
<td>• TDaP (complete series with one booster dose every 10 years without history of animal bite or puncture wound. Six years if bite or puncture occurs) - Offered but not required.</td>
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</table>
Skagit Regional Health Policy/Procedure

Code of Conduct: Workplace Environment Compliance 32012 (Rev: 3) Official

Purpose
To articulate clear expectations describing workplace behavior that supports the mission of Skagit Regional Health.

Policy
All individuals within Skagit Regional Health (SRH) will be treated with respect and in a dignified manner. Skagit Regional Health employees, volunteers, independent contractors and vendors are accountable for performing their responsibilities in a manner that meets the Service Standards of Safety, Compassion, Presentation and Efficiency. Employees, volunteers and vendors will conduct themselves in a professional and appropriate manner at all times and will model and act in a manner consistent with these Service Standards. Any employee found to have violated this policy will be subject to disciplinary action, up to and including possible termination of employment.

Support Information
Skagit Regional Health makes every effort to ensure the safety and well-being of every employee, volunteer, vendor, patient and visitor.

Expectation of Personal Accountability
1. As a condition of employment, all employees accept personal accountability and responsibility for acting in a manner consistent with the Service Standards, pursing on-going learning, skill development and maintaining job specific competencies.
2. All employees, volunteers and vendors will work together to maintain a highly professional, safe environment free from harassment, discrimination, hostility and retaliation.

Work Rules/Prohibited Conduct
Grounds for corrective action include, but are not limited to the following list of infractions:
1. Abusive, discourteous or inconsiderate treatment of patients, staff or visitors, or failing to report such observed or suspected behavior.
2. Insubordination, refusing a job assignment, refusing supervisor’s order, or refusing the directive of any authorized management representative.
3. Theft or unauthorized possession or use of SRH, patient, visitor or staff belongings or failure to report observed or suspected theft, unauthorized possession or use of SRH, patient, visitor, or staff belongings.
   a. Theft of Hospital District property must be immediately reported to the Controller and/or CFO.
4. Reporting to work under the influence of alcohol or controlled substance; any unauthorized use and/or possession of alcohol and/or controlled substance or being intoxicated or impaired on the premises.
5. Unauthorized disclosure of confidential employee, patient, family or organizational information.
6. Giving unauthorized medical advice to staff, patients or families.
7. Falsification of statements, patient, or employee records. This includes willful omission of pertinent information from SRH records.
8. Repeated tardiness and/or absenteeism, including failure to notify department manager (or other designated person) when absence is necessary.
9. Soliciting or accepting gratuities, money, gifts, or bribes.
   a. If a monetary gratuity cannot be tactfully declined, the employee should turn the funds into the department manager or director;
   b. The manager or director will send the funds to the Finance Department to be designated to:
      i. The department's Travel and Education budget; or
      ii. The SRH Foundation.
10. Skagit Regional Health's policy is to conduct its business in strict compliance with federal, state and/or local laws and regulations. As such:
    a. Use of SRH funds or other assets for any unlawful purpose is prohibited; no undisclosed or unrecorded hospital funds or assets shall be established for any purpose;
    b. Payments to third parties in connection with the obtaining of business are permitted when such payments are commensurate with the services rendered, are properly entered on SRH records, and do not violate any laws;
    c. No payments from hospital funds or other assets shall be approved for any purpose other than described by the documents supporting the payment.
11. If an employee is aware of a business activity within SRH which could be considered illegal or unethical, he/she is required to immediately bring that activity to the attention of management and/or the Compliance Officer.
12. Exclusion from participation in federal health care programs related to health care fraud.
13. Negligent or willful damage of employee, patient, visitor, or SRH equipment and/or property.
14. Physical violence, verbal abuse, threats, intimidation or possession of a firearm or other weapon while performing duties as an SRH employee.
15. Violation or disregard for SRH policies, procedures, or work rules.
16. Gambling in the workplace is prohibited.
17. Falsification of work, attendance, personnel or other records is prohibited and may be grounds for termination.
18. Any other conduct deemed inappropriate by the Board of Commissioners or the Senior Executive Team.

Prohibited Conduct: Hostile Work Environment

1. Behaviors constituting a hostile work environment include among other things:
   a. Verbal or physical attacks;
   b. Threats of violence;
   c. Attempts to intimidate;
   d. Flagrant insubordination;
   e. To imply another staff member is incompetent.
2. Retaliation against an employee, patient, visitor, vendor or any other individual as a result of a good faith report of a possible "Hostile Work Environment" is strictly prohibited.
3. Conduct which indicates the individual cannot work harmoniously with others in a manner consistent with the Service Standards is not acceptable.

Prohibited Conduct: Harassment

1. Harassment: Workplace harassment is unwelcome behavior that creates an:
   a. Intimidating, hostile or offensive working environment that is;
   b. Directed at or intended to be discriminatory based on the other persons':
      i. His or her race or skin color;
      ii. Religion;
      iii. Sexual orientation or gender;
      iv. National origin or foreign citizenship;
v. Age, disability or marital status; or
vi. Any other legally protected characteristic.

2. Examples of verbal harassment include:
   a. teasing, mimicking or repeatedly commenting on an individual’s disability, dating habits, ethnicity or accent, epithets, slurs or negative stereotyping; or
   b. Email and instant messaging that contains offensive language or racial or ethnic jokes; or
   c. Written or graphic material that denigrates, shows hostility or aversion towards an individual or group.

3. Examples of physical harassment include:
   a. Blocking or otherwise preventing or restricting access to any area within an employee’s workspace; or
   b. Excluding or preventing an employee from hearing or otherwise receiving necessary information, training or tools to perform their work.

Prohibited Conduct: Sexual Harassment

1. Sexual harassment is defined as unwelcome sexual advances, requests for sexual favors and other verbal or physical conduct of a sexual nature when:
   a. Submission to such conduct is made either explicitly or implicitly a term or condition of an individual’s employment;
   b. Submission or rejection of such conduct by an individual is used as the basis for employment decisions affecting such individual; or
   c. Such conduct has the purpose or effect of interfering with an individual’s work performance or creating an intimidating, hostile or offensive working environment.

2. Sexual harassment can take many forms such as:
   a. One highly offensive incident;
   b. A series of less offensive incidents;
   c. A request for sexual favors;
   d. Unwanted touching; or
   e. Repeated inappropriate sexual comments.

3. The perpetrators and victims of sexual harassment can be of either gender, the same or opposite sex.

4. Verbal sexual harassment may include sexual threats, teasing, jokes, comments or personal sexual questions.

5. Nonverbal sexual harassment may include lewd gestures, leering, circulating sexually oriented printed materials.

6. Physical sexual harassment may include unwanted touching of any type ranging from unwanted touching to forcible rape.

7. Unwelcome conduct initiated by contractors, vendors or visitors may be deemed sexual harassment and the victim will be encouraged to make a report to legal authorities.

Prohibited Conduct: Retaliation

No retaliation of any sort is permitted in response to good faith reporting of any concern regarding the practice or services provided by another employee, manager or program director.

Procedure

Duty to Report

1. Any employee or volunteer who has witnessed or believes that he or she has been the subject of harassment has a duty to immediately report the incident or event to his or her supervisor, Human Resources and/or the Compliance Officer and is required to file a complaint;

2. If the supervisor is the alleged perpetrator or may have a role in the incident or event, the employee or volunteer may report to a member of the Administration, Compliance Officer or Assistant Administrator/Human Resources and file a complaint.
Filing a Complaint
1. Complaints of possible hostile work environments, sexual or other harassment or retaliation must be made in writing to the Human Resources Department.
2. The confidentiality of the reporter will be protected to the extent possible and reasonable.

Investigation Procedure
1. When a supervisor is notified of a complaint as described in this policy, he or she must immediately notify the Assistant Administrator/Human Resources.
2. All complaints will be investigated promptly, impartially and in as confidential a manner as is possible by the Human Resources Department.
3. Employees are required to fully and honestly cooperate in any investigation.
4. The investigation may include:
   a. Interviews with the parties directly involved;
   b. Employees who may have observed the event or incident;
   c. Other employees who may be similarly affected; or
   d. Any other persons who may have information pertinent to the investigation.
5. The complainant will be advised of the findings and conclusions of the investigation.
6. Retaliation against any employee for filing a good faith complaint or participating in an investigation is strictly prohibited.

Documentation
Complaints filed with Human Resources and the resulting investigation materials will be kept in a confidential and secure area.

Signed by (02/25/2013) Committee Policy & Procedure
(02/26/2013) Deborah Martin

Effective 02/26/2013

Document Owner Martin, Deborah
Skagit Regional Health Dress Code  
(Modified for Allied Therapists and Volunteers)

Purpose: To provide guidance to Skagit Valley employees (and volunteers) on appropriate attire for the healthcare setting.

Policy  All SVH (HNW) employees and volunteers will wear appropriate clothing and accessories to project a professional image. Extremes in clothing, jewelry, hair color or style, including visible body piercings and tattoos are considered inappropriate for the healthcare setting. Employees will refrain from wearing “perfumed” products. Employees will be counseled regarding appearance or attire that does not meet the intent of this policy, even if not specifically prohibited herein. Employees failing to appear or dress in accordance with this policy will be subject to Corrective Action up to and including termination.

Support Data

- A professional appearance, cleanliness and personal hygiene are important in forming a positive impression of quality patient care.
- Employees and volunteers directly represent SVH and therefore, should use good judgment in selecting clothing, and maintain appropriate standards of hygiene, appearance and dress.
- Many patients and employees have sensitivities and allergies to scented products. Employees will refrain from wearing “perfumed” personal care products.
- This Dress Code is not intended to identify all appropriate and inappropriate dress, rather it is intended to express the intent that SVH employees and volunteers should dress in a manner which reflects positively on the professionalism of the organization.

Definitions

- **Appropriate Clothing:**
  - SVH (HNW) logo shirts may be worn at any time, as long as they are clean and in good repair.
  - Shorter dress pants that convey a professional image may be worn, but must be long enough to cover the knees.
  - SVH (HNW) logo caps may be worn.
  - Scrubs: may be worn when all of the following conditions are met:
    - Scrubs are allowed by the departmental dress code;
    - Employees and volunteers purchase and launder their own scrubs, and
    - The scrubs are not made of denim or look like denim.

- **Inappropriate Clothing:** The following are examples of clothing considered inappropriate:
  - Tank tops, tops that show any portion of the employees midriff;
  - Sleeveless tops are not to be worn by employees providing direct patient care;
  - Shorts, bib overalls, Spandex, stirrup pants and leggings;
  - Exercise and sports attire including baseball or other hats or caps;
  - T-shirts with slogans or pictures on them;
  - Flannel shirts or sweats;
  - Denim including blue jeans and denim skirts/dresses; and
o Scrubs that are made of denim, or look like denim are allowed.

Procedure

- **Body piercing and tattoos:**
  - SVH (HNW) reserves the right to require employees to cover or otherwise remove visible tattoos and/or body piercings that SVH (HNW) administration deems inappropriate for the healthcare setting or unacceptable due to location, size or content.
  - Tongue piercings must be removed when the employee is working.

- **Footwear:**
  - Must be appropriate for the area in which the employee is working.
  - Open-toed shoes shall not be worn in any clinical area or by anyone involved in the transport of patients or equipment.
  - Athletic/tennis shoes are allowed in clinical areas only.
  - Footwear must be clean and in good repair.
  - Professional dress sandals may be worn by non-clinical employees, but does not include any shoe/sandal closely resembling “flip flops” or other beach sandals.

- **False Fingernails:**
  - Personal hand hygiene and infection control efforts prohibit the use or wearing of any type of false or artificial fingernails on employees providing direct patient care.

- **Scents and Perfumes:**
  - Personal care products with a strong scent, such as perfume, cologne or after shave must be avoided. Employees who smell of tobacco or tobacco smoke will be asked to leave and return when the smell has been removed.

- **Professional Events:**
  - SVH leaders and others who may have occasion to meet professionally with outside organization representatives should at all times dress in business attire.
  - The dress exceptions will be articulated when possible in invitations to outside events.

- **Identification Badges:**
  - Employees and volunteers must wear the identification badges at all times.
  - Badges shall not be modified in any way.
  - Never should be attached to the name badge that would damage in any way or otherwise cover the badge (i.e. stickers).

- **Excessive Environmental Conditions:**
  - In situations where the work climate is not controlled to a comfortable level, allied therapists and volunteers may speak to the Community Liaison regarding clothing modifications or measures that may be taken to remain comfortable.
HIPAA: Health Information Portability and Accountability Act

HIPAA is a law that was passed by Congress in 1996. It is designed to protect private health information (PHI). The rules became enforceable as of April 13, 2003.

Who is affected by the law?
- Hospice of the Northwest and almost everyone who handles any kind of health information
- All health insurance plans and health care clearinghouses
- All health care providers, including: physician offices, clinics, hospitals, nursing homes and pharmacies

There are three components to HIPAA:
- **The Privacy Rule**
  - Protects health information from unauthorized uses and disclosures.
  - Provides nationwide minimum standards for the protection of the privacy of health information.
  - Provides health care consumers with more rights and control over the users and disclosures of their health information.

- **The Security Rule**
  - Protects health information in electronic form from alteration, loss or destruction and from unauthorized access
  - Security and privacy go hand in hand; you can’t have one without the other.

- **The Breach Notification Rule**
  - Requires notifying individuals, the media and the government when unsecured protected health information is compromised.
  -

**The Privacy Rule**
What is PHI = protected health information? PHI is any information, in electronic, written or oral form, which relates to an individual’s past, present or future health condition. It includes any information that identifies an individual or for which there is reasonable basis to believe the information could be used to identify an individual. It includes the following:

- Name
- Addresses and zip codes
- Dates (birth, dates of service, death, admissions and discharges)
- Numbers (telephone, FAX, Social Security, Medical Records, Health Plan, account numbers and any other identifying numbers)
- Finger and voice prints, videotapes, photos

The essence of this is that PHI may only be used or disclosed in ways permitted or required by the privacy rule. For all other purposes the patient must sign an authorization form to allow the use or disclosure of his or her health information. PHI can be released without the patient’s permission in the following instances:
• When it is required by law, such as when we are required to report a communicable disease like TB or with a court order.
• When requested by a coroner, medical examiners or funeral director.
• It may be provided to law enforcement officials in some circumstances (see Mandatory Reporters, section 7).

Under HIPAA, patients have the following rights:
• To receive HNW's Notice of Privacy Practices.
• To request access to their PHI
• To request that their medical information be corrected if it is inaccurate or incomplete.
• That information that is released meets the minimum necessary standard.
• To know to whom HNW has released their PHI.
• To request that HNW not disclose their PHI to certain organizations or people.
• To have confidential communications.
• To voice complaints.
• To be notified if a breach occurs.

Protected means that only those who have a “need to know” may have access to private patient information. When information is transferred from person to person, or is requested by another health care organization, only the information necessary for that person or organization to do their job should be shared. This is called the Minimum Necessary Standard.

Employees of HNW are limited in the amount of information they need in order to do their job. Volunteers are even more limited in the information they need in order to care for their patient. Some employees are given access to a patient’s medical record. Volunteers are not given access to a patient’s medical records. The information a volunteer needs to know will be provided by the Community Liaison when a patient is assigned.

The Security Rule
Electronic PHI (ePHI) must not be lost, altered, destroyed or accessed by anyone not authorized. Electronic PHI includes any medium used to store, access, transmit or receive PHI electronically:

• Laptops/desktops
• External hard drives, flash drives, CDs, DVDs
• Magnetic tape or disks
• Smart phones, tablets
• Network servers, email, etc.
• Data warehouses, Cloud providers

Safeguards against security breaches may be administrative, physical or technical in nature. Examples of these may include: security awareness and training, procedures to authorize access and prevent or terminate access, work station use and security, encryption, facility access controls, and disposal and back-up procedures.
The Breach Notification Rule
A breach is defined as the acquisition, access, use or disclosure of PHI in a manner not permitted by the Privacy Rule which compromises the security or privacy of the PHI. Breaches only apply to unsecured protected PHI. Breaches can result in fines of up to $250,000. Examples of breaches include:

• Lost or stolen laptop, desktop or flash drives
• Misdirected fax or email
• Briefcase with patient documentation stolen from care
• Looking at PHI of neighbors/friends out of curiosity

What should you do if you are aware a breach has occurred? Contact the Community Liaison or Executive Director as soon as possible.

VOLUNTEER GUIDELINES

• Do not use a patient’s name or identifying information in personal e-mails.
• Do not discuss a patient (even without identifying information) outside the HNW Office, Support Meetings or at patient’s location.
• Do not leave any information that would identify a patient that can be seen in your car, at your work place, in your home, etc.
• Promptly shred PHI that is no longer needed.
Purpose
Skagit Regional Health (SRH) has in place appropriate administrative, technical and physical safeguards to protect the privacy of protected health information (PHI).

Policy
When handling printed patient documents (e.g. lab slips, care plans, prescriptions), all SRH employees will follow appropriate procedures to ensure the security and confidentiality of all PHI.

Definitions
Protected Health Information (PHI): The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191 protects all individually identifiable health information held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral.

“Individually identifiable health information” is information, including demographic data, that relates to:

- the individual’s past, present or future physical or mental health or condition,
- the provision of health care to the individual, or
- the past, present, or future payment for the provision of health care to the individual,

and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.

Procedure

1. Printed documents containing PHI are to be kept in a secure location
2. Steps that must be followed to ensure documents are given to the correct patient include:
   a. Asking the patient to state his/her name
   b. Looking at each individual document to verify the patient’s name
   c. Highlighting the patient's name with a colored transparent highlighter
   d. Initialing next to the highlighted area, confirming that you gave the correct document(s) to the patient
3. Documents that were printed in error or extra documents containing PHI, except for tamper resistant paper, are never left unattended in an open shred bin and are discarded in approved, locked shred bins
   a. Refer to the Tamper Resistant Paper (TRP) policy for instructions on tracking and disposing.
Documentation

Document any confidentiality breaches according to SRH Breach Notification policy.

Supervisors, Managers, and Directors must document follow-up with any staff member according to the Corrective Action policy.

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Signed/Approved By: (12/15/2016) SRH Policy Procedure Committee

Current Effective Date: 12/15/2016  
Next Review Date: 12/15/2018

Original Effective Date: 12/15/2016  
Document Owner: Burrington-Brown, Jill
Safety and Security

Hospice of the Northwest wants and expects you to stay safe. We do not want to expose you to any dangers. Please follow the precautions below when serving patients and families.

Driving to the Visit
Please be safe on your way to your patient visit. Be sure you have correct directions or a GPS system before taking off for your destination the first time. Have plenty of gas, especially if driving in a rural area. Keep a flashlight and warm blanket handy. If you are uncomfortable driving in a particular neighborhood, or going into a home or facility, please do not. Drive to a safe area and call the Hospice office.

If you are visiting a patient when it is dark, park as close as you can to their location. Take a flashlight to light your way. If you feel uncomfortable, ask someone to escort you to and from your car.

Safety in the Home:
Wear your name tag at all times when serving as a Hospice volunteer.
There are a number of safety factors to be aware of in the home, including:
- Fire Safety
- Firearms
- Electrical Safety
- Emergency Preparedness
- Bathroom Safety
- Infection Control
- Medication Safety
- Communication Barriers
- Medical Equipment and Supplies

You may not be able to mitigate all safety risks in a home; however please minimize yours and your patient’s risks to the extent possible by observing the guidelines below.

Fire, Firearms and Electrical Safety Risks
Fire safety concerns include smoking, space heaters, cooking, cords, electric blankets, candles and Christmas trees. There is a risk of fires with oxygen, as it is highly flammable. Smoking around an oxygen tank is highly dangerous. Ways to minimize fire safety risks include smoke detectors, home fire extinguishers, and having a fire escape plan.

All firearms should be locked up.

Electrical safety risks include extension and electrical cords, overloaded circuits and outlets. Be sure that outlets are not blocked by medical equipment and that all cords are safe. Make sure that electric cords and appliances do not get wet.

Emergency Preparedness
If you are seeing a patient during extremely inclement weather or natural disasters, make sure you are in close communication with the Hospice office and/or the Volunteer/Allied Therapist. Do not drive until you are able to do so safely. Turn on the radio for emergency instructions. If in the unlikely event
you have to evacuate a patient, insure that you get the patient’s medications, supplies and equipment if you have time to do so.

Disaster Call List
In section 2 of this binder is a Disaster Call List. Hospice will activate this call list in the case of an emergency. Please check your phone number to make sure it is correct. Note that you will be expected to call at least one other volunteer on the list. The list will be updated twice yearly.

Bathroom Safety
The bathroom can pose numerous hazards. Safety measures include non-skid mats, grab bars, insuring the water temperature is safe and wiping wet surfaces so that no one slips. As noted above, please make sure that bathroom appliances and cords do not get wet.

Infection Control
See Infection Control Precautions in Section 2 of this binder.

Medication Safety
Patient medications should be properly labeled, handled and stored. Some medications look alike and their names sound alike. Theft of medications can occur when they are not properly secured or stored.

Medical Equipment and Supplies
Use care when raising and lowering beds and operating equipment such as wheelchairs (insure the brake is set if patient should not be moved).

Falling Hazards
Families can minimize falls by picking up clutter from the floor, not letting bedspreads hang to the floor, insuring that rugs have pads or are tacked down; and that cords are taped down.

Extreme home safety risks may indicate that the caregiver is limited in their abilities or cognition due to aging, dementia or other illnesses. Occasionally this can lead to patient abuse, neglect or mistreatment. Be aware of safety issues, assess the risk and respond by contacting Hospice as appropriate.

Falls in the older people can be caused by: environmental hazards, mental health issues (e.g. dementia), weakness and frailty, balance problems, vision defects, musculoskeletal issues, neurological problems, heart problems, and other factors. The effects can be physical (including immobility), mental or social. If a patient falls while you are visiting, and they cannot safely get up on their own, please ask if they are all right and cover them with a warm blanket (if needed). Then call Hospice, 360.814.5550.

DO NOT CALL 911 or the patient may be charged for the ambulance service. DO NOT attempt to lift or move the patient.

Risks to your Personal Safety
Be alert to any red flags that result in you feeling nervous or unsafe in the presence of a patient, caregiver or family member. Some patients who are normally docile may become quite agitated due to their illness. Families and caregivers of Hospice patients are under an extreme amount of stress. They
too, could become upset or even angry. If you feel at any personal risk, please remove yourself from the room or situation and contact Hospice as soon as possible.

Skagit Regional Health
Providing Oxygen to Patients When Safety is a Concern
Hospice of the Northwest 118652 (Rev: 3) Official

Purpose
To provide guidelines for assessment and mitigation of risk of injury from fires related to home oxygen use.

Background
Though oxygen-related fire injury is uncommon, it is potentially devastating. Patients who do not follow recommendations for safe use of oxygen endanger themselves, other people and property. There are known risk factors for fire related oxygen injury and methods to mitigate those risks. Hospice of the Northwest (HNW) recognizes both the obligation to provide oxygen when beneficial and the obligation to protect patients and others from harm when possible.

Our oxygen supplier provides patients and caregivers with verbal and written education regarding safe use of oxygen. HNW team members have the opportunity to observe whether these safety procedures are being followed, and to provide ongoing education about safety.

Data is limited, but the vast majority of oxygen related fires occur with the use of cigarettes rather than other sources of ignition.

Ethics:
Oxygen therapy provides clear benefits of comfort and life-prolongation in many hospice patients. Its improper use also can harm patients and others. Thus we have dual (and potentially conflicting) obligations of providing this beneficial therapy, while preventing risk of injury to patients, caregivers and HNW staff.

Patients have a right to make their own decisions regarding smoking, e-cigarettes or other open flames in the home. They have a right to privacy regarding their personal habits. In some cases, the rights of an individual patient may be outweighed by a real risk to others. We recognize our duty to protect innocents (for example children living in the home or neighbors).

If there is a clear benefit to a patient from oxygen therapy, it should be curtailed only if (1) attempts made to educate and mitigate risks are unsuccessful and (2) there is real and imminent danger rather than theoretical concern.

Definitions:
- The term “smoking” includes smoking cigarettes, cigars, pipes, bongs, vaping, and e-cigarettes.
- “Open flames” can include candles, pilot lights, gas, and pellet or wood fireplaces even when glass screen is in place.
- “Close call” includes new cigarette burns to clothing, bedding, furniture, carpet, and witnessed episodes of smoking with oxygen running.
• “Home” is any patient’s place of residence.
• “Patient” may include patient and/or surrogate decision maker.

Risk factors:
The Joint Commission and Veterans Affairs have identified risk factors for oxygen related fire injury:
• living alone
• problems with smoke detectors
• cognitive impairment
• a history of smoking with oxygen running
• hiding smoking materials or activities
• smoking in patient sleeping room
• any other obvious signs of unsafe smoking (e.g. burns in the carpet or furniture)

Policy
1. To protect themselves, HNW staff and volunteers will not remain in the home of a patient when anyone is smoking while oxygen is running. They will report this to their supervisor.
2. All patients with supplemental oxygen in their place of residence will receive a risk assessment regarding oxygen related fire danger and education regarding safe practices.
3. Improving safety is the responsibility of all hospice staff members and the oxygen vendor. Sharing information and coordinating efforts to maximize safety is expected.
4. If there is a potential or identified conflict between a patient’s right to smoke and the risk of harm to self or others, team members are encouraged to consult the ethics committee.
5. The strategies in this policy pertain primarily to the risk of smoking. Other aspects of safe use of oxygen are addressed in the oxygen vendors information to patients and in the attached safety recommendations.

Procedure
A. General
• All hospice staff members are responsible for providing immediate education if unsafe oxygen use is observed.
• All staff are responsible for documenting their work of i) risk assessment, ii) education, iii) risk reduction strategies, and iv) observed unsafe practices or unsafe home environment.
• IDT will address safety issues for patients who have identified risk factors (listed above).
• Close calls or fire events must be reported to the administrator on call, IDT and the Quality and Compliance Manager (submit a QMM).

B. Prior to admission:
• Referral center will inquire whether anyone in the home smokes. If so, they will notify the oxygen vendor in advance of oxygen delivery if possible.

C. Initial in-home risk assessment and education
5. If patient, household member or caregiver smoke in the home, the following steps will be taken
1. MSW will assess for additional risk factors (listed above)
2. MSW will identify children or vulnerable adults in the home
3. Education regarding the dangers of smoking while using oxygen and instruction on safe practices will be provided to patient, caregivers and household members by a member of the IDT
4. Posting “No Smoking” signage will be strongly encouraged.
5. IDT and oxygen vendor will be notified if not already done
6. Smoking cessation materials and nicotine replacement will be offered to patients
7. Recommend the home have working smoke alarm(s) and fire extinguisher(s)
6. If additional risk factors are present
   1. IDT will work with patient to identify and implement risk reduction strategies. Additional risk reduction strategies may include
      1. Stopping smoking or smoking outside the home only
      2. Avoiding smoking in bed
      3. Additional smoke alarms or fire extinguishers
      4. Additional caregiving
      5. Changes in location of oxygen equipment or furniture
      6. Fire retardant clothing and bedding
      7. Relocation of patient or vulnerable adults or children
      8. For persons who are cognitively impaired and smoke:
         1. Recommend supervision of the person while smoking,
         2. Remove smoking materials, lighters and matches from within sight and reach.
         3. Other cognitive aids
   2. IDT and oxygen vendor will be informed
   3. RN and HMD will evaluate the degree of medical need for oxygen
D. If unsafe behavior or environment persists despite risk mitigating efforts
   7. HMD will be notified and assess the medical need for ongoing oxygen prescription
   8. IDT will coordinate with vendor to assess the degree of risk to people and property
   9. HMD or designee will counsel the patient again regarding the potential risks and the potential consequences of continued unsafe behavior
10. Ethics consultation is preferred prior to any decision to remove oxygen from the home. If ethics consultation is not available or significant/imminent danger exists (especially to children or vulnerable adults in the home) an interdisciplinary team may be assembled to determine the appropriate action. Reporting requirements for Mandatory Reporters will be followed.
Safety Recommendations

- Oxygen tubing, concentrator and tanks should be kept a minimum of 6 feet from any ignition source. The most dangerous ignition sources involve smoking, lighters, matches, cigarettes, pipes, and cigars. Candles and other open flames also present a risk. Less obvious ignition sources include pilot lights, gas stoves behind glass, and anything that can generate a spark, like an e-cigarette, vaping device, toaster, heater, hairdryer or any electric device.
- It is highly recommended that there be no smoking or use of candles in a home where oxygen is in use.
- If there is smoking, it is highly recommended that the oxygen be turned off and the cannula removed from the face several minutes prior to smoking. Oxygen saturates hair and clothing. It is preferred to air out the hair, clothing and nearby bedding prior to smoking. The person smoking should be at least 6 feet from any part of the oxygen tubing even if the oxygen is off.
- Functioning smoke alarms and fire extinguishers are highly recommended. Smoke alarms should be tested monthly and batteries replaced at least yearly.
- Petroleum containing products like Vaseline should not be used on the hands or face of a patient who smokes.

References

I. Department of Veteran Affairs VHA Directive 2006-021, May 1, 2006: Reducing the Fire Hazard of Smoking when Oxygen Treatment is Expected
III. VHA National Center for Ethics in Healthcare Teleconference: Ethical Considerations in the Use of Home Oxygen for Patients and/or Third Parties Who Smoke, July 30, 2008
IV. Discontinuing Oxygen Therapy in the Patient Who Smokes: An Ethical Dilemma, Harry E. Scher
Infection Control Precautions

There are many ways to minimize risk of infection or illness when working with Hospice patients. Please insure you are familiar with the information below and use universal and transmission-based precautions to prevent infection and exposure.

Hand Hygiene

It is estimated that one million deaths a year could be prevented by routine hand washing. Washing your hands is the single most effective action to prevent infection. Cross-contamination can occur from:

- you to patient
- patient to you
- patient to you to another person or patient
- you to patient’s family/caregivers
- you to your family, friends or others

It matters because of:

- risk of infection
- less controlled settings and procedures
- weakened immune systems
- unwarranted suffering and distress
- risk of sepsis

When should you wash your hands?

- before and after contact
- before and after donning gloves when being with a patient
- if you have contact with a patient’s skin
- if you have contact with body fluids, excretions, wound dressings, etc.
- after touching items or surfaces in the immediate patient care environment

Directions:

- Use alcohol-based hand foams or gels, if available, as they effectively kill germs. Apply to palm of hand and rub hands together until all surfaces are dry.
- Or, use soap and running water. Wet hands, apply soap then rub hands together for at least 20 seconds. Pay special attention to nails, between fingers and around rings as they can trap germs. Better yet, remove them before washing. Rinse hands thoroughly under warm, running water. Dry with a paper towel then use towel to turn off faucet and open door to room.

Bloodborne Pathogen Basics

Definitions:

- **Blood**: Human blood, human blood components and products made from human blood
- **Bloodborne Pathogens**: Pathogenic (diseased) microorganisms present in human blood and may cause disease in humans. Includes, but is not limited to, hepatitis B (HBV), human immunodeficiency virus (HIV) and other potentially infectious materials.
- **Contaminated**: Presence or possible presence of blood or other potentially infectious material on items or surfaces
- **Other Potentially Infectious Materials**: Body fluids, any unfixed tissue or organ (other than intact skin), HIV-containing cell or tissue culture
• **Exposure Incident:** A specific eye, mouth, or other mucus membrane, non-intact skin, or needle sticks with blood or other potentially infectious materials that result from doing your job.

• **Personal Protective Equipment (PPE):** Specialized clothing or equipment worn by an employee for protection. Includes, but is not limited to: gloves, eye shield, hair cap, fluid resistant face mask, isolation gown with cuffs, shoe covers, infectious wastes trash liner.

**Basic Universal (“Standard”) Precautions**

• Treat ALL human blood and ALL body fluids, secretions and excretions (except sweat) as if they are infectious.
• Non-intact skin and mucus membranes can also be infectious.
• Observe precautions in all situations where there is a potential for contact with blood or other potentially infectious materials.
• Use appropriate respiratory hygiene and cough etiquette.
• Use appropriate personal protective equipment regardless of patient diagnosis or presumed infection status.
• Report exposure incidents to Hospice.

**Use of Gloves:** You will be given two pairs of gloves. Please ask us for more if needed. In addition, gloves should be available in every patient’s home.

• Use gloves whenever the possibility of contact with body secretions (blood, urine, stool, sputum, saliva and/or draining) presents itself. If you have an open wound, refrain from touching patients until the wound is healed.
• To dispose of gloves without contaminating your hands: 1. Use two fingers and thumb to pinch glove below glove wrist; 2. Twist fingers underneath and peel glove downward without touching skin; 3. Turn completely inside out so contaminants stay inside the glove; 4. Use inside-out glove to protect fingers/hand while removing second glove; 5. Repeat steps 2 and 3; 6. Dispose in appropriate waste container.
• Clean blood and body fluid spills with 1:10 solution of bleach and water.

**Transmission-Based Precautions**

Health care associated infections are one of the top ten leading causes of death in the U.S. They account for an estimated 1.7 million infections and 99,000 associated deaths each year. Transmission-based precautions apply only to patients with confirmed or suspected infection or colonization of certain microorganisms. They are used in addition to standard precautions in the following instances:

• Airborne: tuberculosis, measles, chickenpox
• Droplets: influenza, pertussis, meningococcal disease, smallpox
• Contact: norovirus, rotavirus, MRSA, draining abscesses, shingles, head lice, bed bugs

**DO NOT** visit patients if you have, or know that your patient has, one or more of the above diseases. If you discover, during a patient visit, that your patient has one of the above, call the Volunteer Manager or the Hospice Main Desk to speak with a nurse for further instructions.
Use of Personal Protection Equipment for Hospice Volunteers

Standard Precautions
- Applies to blood, bodily fluids, secretions and excretions (except sweat) regardless of whether or not they contain visible blood; non-intact skin; and mucous membranes.
- Use the precautions below under the following conditions:

Wash Hands
- Before and after each patient visit;
- After touching blood, bodily fluids, secretions, excretions, contaminated items, whether or not gloves are worn;
- Immediately after removing gloves;
- Use plain soap or an antimicrobial agent or waterless antiseptic agent.

Wear Gloves
- When touching blood, body fluids, secretions, excretions, contaminated items, mucus membranes and non-intact skin;
- Remove promptly after use, before touching anything else, and wash hands;

Wear a Mask, Eye Protection, and Face Shield
- To protect mucous membranes of the eyes, nose and mouth during patient activities likely to generate splashes or sprays or blood, body fluids, secretions and excretions.

Wear a Gown
- To protect skin and prevent soiling of clothing during patient activities that may generate splashes or sprays of blood, body fluids, secretions or excretions.
- Remove soiled gown as promptly as possible and wash hands.

Handling Soiled Equipment (Wheelchairs, Walkers, etc.)
- Handle in manner that prevents mucous membrane exposures, clothing contamination and transfer of microorganisms.
- Wear gloves if equipment is visibly contaminated.
- Ensure that reusable equipment is not used until properly cleaned and reprocessed.
- Ensure that single-use items are discarded properly.
- Perform hand hygiene after handling patient equipment.

Handling Soiled Linen
- Handle in manner that prevents transfer of microorganisms.

When Sneezing/Coughing
- Cover mouth/nose with tissue.
- Wash hands if soiled with respiratory secretions.
- Wear surgical mask if tolerated or to maintain spatial separation of at least 3 feet.
Droplet and Contact Precautions

- **Droplet Precautions**
  - Diseases/conditions requiring droplet protection may include but are not limited to influenza, meningitis, pneumonia, epiglotitus, diphtheria, strep throat, adenovirus, mumps, parovirus B19 and rubella. Hospice will notify you if your patient has any of these illnesses/conditions.
  - Droplets may be spread to others who are closer than 3 feet to the patient, if they cough or sneeze.

- **Contact Precautions**
  - Diseases/conditions requiring contact precautions may include but are not limited to Clostridium difficile (C-diff), hepatitis A or rotavirus in incontinent patients; viral or hemorrhagic conjunctivitis or skin infections that are highly contagious or may occur on dry skin (e.g. impetigo, cellulitis, scabies, herpes, etc.).
  - In addition to using standard precautions, volunteers should:
    - Wear gloves for all direct patient contact and for contact with patient’s immediate environment, care items and equipment.
    - Wear gown when there is substantial contact with patient and exposure to urine, feces, wounds, an ileostomy or colostomy, or to surfaces/equipment that may be contaminated with these.
    - Change gloves after patient contact and contact with inanimate objects in patient environment.
    - Remove gloves and gown before leaving patient area and immediately use antiseptic hand rub or wash hands.
    - Do not touch potentially contaminated surfaces (e.g. doorknobs, sinks or commodes) or items in patient’s room after gloves/gown are removed.
Purpose
To ensure Hospice employees and volunteers working in patient homes are aware of food safety when preparing or reheating light meals.

Policy
Employees and volunteers will practice safe food storage, preparation and handling while in patient homes to limit exposure to potential foodborne illnesses.

Procedure
a. Always wash hands with soap and water before you begin to prepare food. Soap and water has been shown to be more effective than alcohol based hand sanitizer when it comes to food preparation.
b. Do any food preparation on a clean surface using clean utensils.
c. Wash all produce.
d. Refrigerate perishable food and leftovers immediately.
Safe Food Storage, Preparation and Handling

Washington State Health Department requires all staff and volunteers working in health care organizations to understand and attain competency regarding food safety practices.

Food safety is the practice of eliminating harmful agents from food, preventing food contamination, and ensuring that food is fit for consumption. The goals of food safety are to: 1) prevent contamination, 2) reduce conditions that favor growth or introduction of microorganisms that cause illness and spoilage, 3) handle, transport, and store food in safe ways, 4) dispose of food that poses a threat to human health.

Foodborne Illness

Foodborne illness is caused by food containing chemicals or germs. Most common foodborne illnesses are caused by infection (germs). Symptoms include diarrhea, nausea, vomiting, fever, headache and stomach aches. Symptoms may be noticed from several hours to several weeks after eating the food. Chemicals, bacteria or certain foods like poisonous mushrooms can cause food poisoning. Symptoms are noticeable within hours after eating and usually include vomiting. Germs that cause foodborne illness are usually bacteria, viruses or parasites.

Certain people are highly susceptible to foodborne illness. They are: a) older than 65 or younger than 6; b) pregnant woman and unborn babies, c) Immuno-compromised individuals.

Food Hazards

Foodborne hazards are physical, chemical or biological objects in food or drink that can cause injury or illness. Most foodborne illnesses are caused by biological hazards (germs). Three types of germs cause most foodborne illness including 1) bacteria, 2) parasites, 3) viruses.

Bacteria: Unlike viruses, bacteria can grow in food. They are found everywhere and can grow when food workers are not careful about time, temperature and cleanliness. Bacteria causing foodborne illness come from sources like soil, animals, raw meat and people. These bacteria only grow in certain foods (potentially hazardous foods). Keep potentially hazardous foods hot or cold to keep bacteria from growing.

To prevent bacteria contamination:

* Keep potentially hazardous foods out of the Danger Zone (between 41 degrees F and 135 degrees F).
* Do not work with food when you are ill
* Wash your hands twice after using the toilet – once in the restroom and again in the kitchen.
* Use gloves or utensils when handling ready-to-eat food.
* Wash, rinse and sanitize all equipment used for food preparation.

Parasites: Parasites in food are usually tiny worms that live in fish, pork or meat. They can be killed if frozen or cooked to the right temperatures. Different kinds of parasites may be found in contaminated water.

To keep your food safe from parasites:
*Cook all pork, beef and fish to the proper temperatures.
* Use fish that has been frozen to kill parasites for raw dishes like sushi.
*Use approved sources of water.

**Viruses:** Although viruses are small, it only takes a few to make you sick. Viruses are not destroyed by freezing. Chicken pox, the common cold, and influenza are all caused by viruses spread from people coughing or sneezing. **Viruses that we get through food usually come from the unclean hands of someone that touched our food.** Viruses spread this way include Hepatitis A and Norovirus. To prevent these illnesses, we must be careful about personal hygiene, especially when working with food.

To keep your food safe from viruses:

*Do not work with food when you have diarrhea, vomiting or fever.
*Wash your hands twice after using the toilet – once in the restroom and then again in the kitchen.
*Use gloves or utensils when handling ready-to-eat food.

**Physical Contamination**

Physical contaminants are those not caused by other living organisms and are not considered chemical. They are objects in food that may cause injury if eaten (e.g. broken glass, bandages, staples, hair). Physical hazards usually happen because of unsafe food handling practices or accidental contamination.

To prevent physical contamination:

*Wash fruits and vegetables carefully – rinse well in running cold water and scrub; tough-skinned produce, such as cantaloupe, should be scrubbed with a brush or cloth during washing.
*Look closely at the foods you prepare.
*Keep food preparation area free of items that can fall into food.

**Chemical Contamination**

Chemical contaminants are poisonous substances that occur naturally or are added during food handling. They include such things as pesticides, cleaning liquids, and personal grooming products, and include soaps, bleach, rat-baits, perfume and hair spray. Chemical contaminants may also include toxic metals from surfaces, natural toxins from seafood, mushrooms and plants and some molds and allergens.

To keep your food safe from chemicals:

*Make sure equipment is working properly.
*Make sure food is protected when you clean the kitchen.

**Potentially Hazardous Foods**

Potentially hazardous foods are foods that need time and temperature control to limit the growth of pathogens for safety. It is important to be able to recognize potentially hazardous foods.
Examples of potentially hazardous foods include:

*Animal Products
  - Raw and most cooked meat, poultry, fish and seafood
  - Most milk and dairy products
  - Eggs and most dishes made with them
*Cooked Starches
  - Rice, beans, pasta, potatoes
*Fruits and Vegetables
  - Cooked vegetables
  - Raw seed sprouts (alfalfa, bean sprouts) and soy products (e.g. tofu)
  - Cut melons, cut tomatoes, cut leafy greens
  - Garlic in oil mixtures that have not been processed

**Food Allergies and Allergens**

Some people are sensitive to certain foods and become ill after eating them. Most people with a food allergy know what to avoid. However, they may need help identifying which ingredients have been used.

Some symptoms of an allergic reaction include:

*Rashes
*Swelling
*Difficulty breathing
*Unconsciousness
*Other symptoms similar to foodborne illness

The top 8 food allergens include:

*Peanuts
*Soybeans
*Milk
*Eggs
*Fish
*Shellfish
*Tree nuts
*Wheat

**Preservation**

Preservation is the control of the safety and quality of food items by delaying spoilage and preventing growth of pathogenic microorganisms. Food is preserved by one or more of the following: 1) killing spoilage and pathogenic microorganisms, 2) removing oxygen, 3) removing moisture.
Types of preservation:

-Cold preservation. Three types: 1) refrigeration (34 – 40F) for short-term storage, 2) chilling (just below refrigeration, but still above freezing) and 3) freezing (below 32 degrees). At around 41F most bacteria stop growing.
-Heat preservation. Raising the temperature of food high enough to kill spoilage and pathogenic bacteria. Three types: 1) pasteurization, 2) ultra-heat treatment, and 3) sterilization and canning.

Temperature Danger Zone

Most bacteria do not grow in hot or cold temperatures. To keep food safe, cold foods must be kept 41F or colder. Hot foods must be kept 135F or hotter. The range of temperatures between 41F – 135F is called the Danger Zone. When potentially hazardous foods are left in the Danger Zone, bacteria can grow fast or make poisons that can make people sick.

Thawing

Frozen foods must be thawed safely to keep bacteria from growing since they enter the danger zone while thawing. There are three safe methods for thawing food: 1) In the refrigerator: Put frozen food in refrigerator until thawed. Be sure that raw meats are on the bottom shelf or in a container so they do not drip onto other foods. 2) Submerge under cold running water: Keep the food covered in cold (70F or colder), running water until thawed. 3) As part of the cooking process or in the microwave. Small items, such as frozen burritos, may be thawed while they cook.

Cooking

All cooked food must be thoroughly heated so that the food is properly cooked. Food must be hot enough for a long enough time to reduce pathogenic microorganisms to safe levels. Thoroughly cooking large pot roasts and poultry requires cutting them into smaller portions when possible. When using a microwave to cook foods, rotate or stir foods halfway or throughout cooking and allow food to stand for two minutes after cooking so the heat can equalize to the required internal temperature in all parts of the food. Raw animal products cooked in a microwave must be cooked to at least 165F. The internal temperature of most foods should be between 130F and 190F before being served safely. Whole meats, fish and shellfish should be cooked to 145F, ground meats to 160F, and 165F for poultry, hot dogs and sausages.

Cooling Hot Food

Cooling is often the riskiest step in food preparation. It is important to cool food through the Danger Zone as fast as possible to keep bacteria from growing. There are three approved cooling methods in WA: 1) Shallow pan method (put food no more than 2” deep in the refrigerator), 2) Size reduction (cutting solid food into smaller pieces and putting in refrigerator), 3) Time and temperature monitored (forcing food to cool in short amount of time). Put pot of hot food in the sink with ice up to level of food pot, and add cold water to ice. Stir often and add more ice as it melts. Ensure food is cooled from 135F to 70F in 2 hours and then from 70F to 41F within the next 4 hours. For all cooling in refrigerator, put items on top shelf where nothing can drip into them and once food is below 41F, it should be covered.
Reheating Foods

Cooked foods that have been cooled and will be reheated need to be heated to at least 165°F for 15 or more seconds. Also, reheat food only once and discard leftovers to avoid foodborne illnesses. Remember that the highest proportion of illness is caused by poor cooling procedures. Bacteria grow rapidly in warm foods that are left to cool for too long; therefore, proper reheating of food items is VERY Important and should not be overlooked.

Top Three Food Safety Defenses

*Food workers with good personal hygiene
*Food cooked to or held at correct temperatures
*Prevention of cross-contamination

Employee Health and Hygiene

Food workers, even if they look and feel healthy, may accidentally spread harmful germs to food if they do not practice good hygiene. Proper food worker hygiene includes: 1) Not working with food when you are sick, 2) Washing your hands the right way and at the right time, 3) Using clean gloves and utensils when handling food, 4) Keeping fingernails trimmed so hands can be easily cleaned.

Hand Washing

Clean hands are the most important food safety practice. Hand washing gets rid of germs on hands that can make people sick. Wash hands throughout the day even if they look clean. Hands should be washed before beginning any food separation, between preparations of different types of food and after handling anything (such as garbage) other than the food being prepared. Washing hands after using the restroom is a courtesy and an obligation. Hands should be washed after touching your body or hair; after sneezing or coughing; after eating, drinking or smoking; after handling a service animal or pet; and before donning gloves. Hand sanitizers work best on hands that are clean. In food service, you may use hand sanitizers after washing your hands if you’d like, but you may not use them instead of washing your hands.

Procedure:

*Wet hands with warm water; apply soap.
*Rub soap in vigorously for 10-15 seconds.
*Be sure to get between fingers and above the wrist.
*Rinse well.
*Dry hands with a clean towel.
*The entire process should take at least 20 seconds.

People who bite their fingernails have a high risk of transferring Staphylococcus Aureus to foods; never bite your nails on the job. Fingernails should be short and clean, free of fingernail polish or fake nails if working with exposed foods.
Gloves

Use tongs, scoops, deli papers, or single-use gloves to keep from touching ready-to-eat foods. Single-use gloves may be used to prepare foods that need to be handled a lot, such as when making sandwiches, slicing vegetables or arranging food on a platter. Gloves must be changed often to keep food safe. Gloves also must be worn if you have sores, bandages or cuts on your hands and you’re working with food.

Rules for use:

* Wash hands before putting on gloves
* Change gloves that get ripped or torn
* Change gloves that might be contaminated
* Never wash or reuse gloves
* Change between working with raw and ready-to-eat foods
* Throw gloves away after use
* Wash hands after taking off gloves.

Food Handling Techniques

Take whatever reasonable measures you can to ensure that your body, body parts, and/or anything you are wearing do not touch food contact surfaces or food. Do not touch ready-to-eat foods with bare hands! Ready-to-eat foods may include: rinsed fruit and vegetables that are eaten raw, bakery or bread items, foods that have already been cooked (pizza, hamburgers, hot dogs, tacos), foods that will not be cooked such as sandwiches, sushi, deli salads.

Prevention of Cross Contamination

Cross contamination can happen when bacteria from raw foods get onto other foods. **Raw meat is the main source of cross contamination.** When blood or juice from raw chicken or other meat gets onto a counter, cutting board, utensils or hands, bacteria can spread to other food. **It is important to keep raw meat away from other food.**

Tips to avoid cross contamination:

* Wash hands after handling raw meat.
* Wash and sanitize all food-contact surfaces that touch raw meat.
* Prepare raw meat in an area away from other foods.
* Use a separate cutting board for raw meat.
* Store raw meat below other foods in the refrigerator and freezer.

Clean and Sanitize

Cleaning and sanitizing are not the same. Cleaning uses soap and water to remove dirt and food from surfaces. Sanitizing uses chemicals or heat to kill germs.
To clean and sanitize items:

* Remove any loose material by wiping and/or scraping.
* Place items in or under heated, soap water to remove the rest of the material.
* Rinse items under clean water to remove soap and dirty water.
* Sanitize by heat or chemicals.
* Allow to dry completely.

**Food Preparation Top 10**

* Only work when you are healthy.
* Wash your hands often and well.
* Don’t touch ready-to-eat food with bare hands.
* Keep food hot or cold.
* Cook food to proper temperatures.
* Cool hot food as quickly as possible.
* Keep raw meat away from other food.
* Wash, rinse, sanitize and air dry – always food the four steps in order.
* Keep food preparation areas and utensils clean and sanitized.
* Ask questions of you have them.
Hospice Patient Rights and Responsibilities

Purpose
To provide Hospice of the Northwest patients, families and caregivers with a clear description of patient rights as well as patient responsibilities.

Policy
Hospice of the Northwest (HNW) seeks to protect the rights, interests and well-being of our patients in conformity with state and federal laws and regulations. HNW 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 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

1. **Access to Care**: Patients have the right to:
   a. Be accorded impartial access to treatment or accommodations that are available and medically indicated, regardless of race, creed, sex, marital status, sexual orientation, national origin, religion, age, physical disability, source of payment for care or ability to pay for care;
   b. Have properly trained staff provide care and services; and
   c. Smooth coordination of services.

2. **Respect for Property and Person**: Patients have the right:
   a. To exercise his or her rights as a patient of the hospice;
   b. To have his or her property and person treated with respect, with recognition of his or her personal dignity, values, cultural norms, and spiritual beliefs;
   c. 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; and
   d. To not be subjected to discrimination or reprisal for exercising his or her rights.
3. **Advance directives:**
   a. 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;
   b. Patients have the right to receive information regarding the HNW advance directive policy and procedure (See Hospice of the Northwest Advance Directives; 42 CFR 489.100, 102, 104).
4. **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.
5. **Privacy and Confidentiality:** Patients have the right, within the law, to personal and informational privacy, as manifested by the right to:
   a. 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;
   b. 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 HNW Notice of Privacy Practices.
   c. Access to, or release of, patient information and clinical records in accordance with 45 CFR parts 160 and 164.
6. **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. Employees of a hospice agency are mandatory reporters under RCW 74.34.020, and as such the hospice will:
   a. 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;
   b. 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 (see 'Abuse, Neglect, Mistreatment and Exploitation' policy 67292); and
   c. Ensure that abuse, abandonment, neglect or financial exploitation of a vulnerable adult is reported to the Washington State Department of Social and Health Services (DSHS), and if sexual assault or physical assault is suspected, it will also be reported to law enforcement.
7. **Pain Management:** patients have the right to:
   i. Be informed and knowledgeable about any medications or treatments that will be administered;
   ii. Receive effective pain management and symptom control from the hospice for conditions related to the terminal prognosis;
iii. Have their comfort assessed on an individual basis; and
iv. Receive timely pain and other symptom management medications.

8. **Identity**: patients have the right to know:
   a. The identity and professional status of individuals providing care to him/her; and
   b. Which Nurse Case Manager is primarily responsible for their care.

9. **Language and Communication**: HNW 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.

10. **Participation in Human Subjects Research**:
    a. Patients shall be informed of their right to consent to, or refuse to participate in any human subjects research or other research/educational projects affecting their care or treatment; and
    b. Patients have the right to refuse to participate in any such activity.

11. **Patient Grievances**: Patients have the right to:
    a. Be provided with information, including a phone number and address, to contact the Washington State Department of Health to directly report a complaint or grievance--the complaint hotline number is 1-800-633-6828;
    b. Information concerning to whom and how to make a complaint or grievance;
    c. Access protective and advocacy services;
    d. Have complaints investigated and responded to in a timely manner;
    e. Express dissatisfaction or complaints in any manner, formal or informal, orally or in writing, by email or the internet; and
    f. Have reasonable expectations that care and services will be timely and provided in a consistent manner.

12. **Refusal of Treatment and Continuity of Care**: 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:
    a. Discontinuing a specific service;
    b. Revoking hospice services; or
    c. Changing the designation of the particular hospice from which the patient elects to receive care and services--the names and phone numbers of any other hospices within the areas HNW serves will be included in the Guidebook provided to all patients on admission.

13. **HNW Charges**: Patients have a right to receive information about the services covered under the hospice benefit. This means:
    a. Patients are informed verbally and in writing 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.
b. 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;

c. Patients have the right to receive an Advance Beneficiary Notice of Non-Coverage and right to appeal discharge;

d. Patients have the right to timely notice prior to termination of eligibility for any third-party payer for the cost of care.

**Patient Responsibilities**

1. **Provision of Information:** Patients are responsible for:
   a. Providing, to the best of their knowledge, accurate and complete information about:
      i. Medications, including prescribed, over-the-counter, natural and alternative remedies;
      ii. Hospitalizations;
      iii. Past illnesses; and
      iv. Present concerns.
   b. Reporting changes in their condition (symptoms, medication problems) to the responsible practitioner;
   c. Requesting authorization from HNW prior to hospitalization, emergency room use, diagnostic tests or other new treatments. Patients may be responsible for costs associated with unauthorized care.
   d. Making it known whether he/she clearly comprehends his or her Plan of Care and what is expected of him/her.
   e. Reporting other matters relating to their health.
   f. Notifying HNW if a scheduled visit needs to be changed.

2. **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.

3. **Respect and Consideration:** Patients are responsible for:
   a. being considerate of the rights of other patients and HNW personnel; and
   b. providing a safe environment for care to be provided.

4. **Patient and Family Participation in Care Decisions:**
   a. Patients have a responsibility to be informed about and participate in decisions regarding their care;
   b. The patients' representative is included whenever possible, at the patient's discretion.

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

6. **Advance Directives:** Patients have the responsibility to tell HNW staff about the existence of, or changes made to, any advance directives

7. **Resolving Conflicts:**
a. 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.

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

References
1. 42 CFR 418.52 Condition of Participation: Patient's Rights
2. 42 CFR 489, Subpart I - Advance Directives
3. 45 CFR parts 160 and 164 - Security and Privacy
4. RCW 74.34 - Abuse of Vulnerable Adults
5. Notice of Privacy Practices
Skagit Regional Health

Abuse, Neglect, Mistreatment and Exploitation

Hospice of the Northwest

(Rev: 1) Official

Purpose
To establish guidelines to follow in the event of suspected abuse, neglect, mistreatment or exploitation of hospice patients.

Policy
HNW follows all Federal and State requirements regarding alleged violations involving mistreatment, neglect, or verbal, mental, sexual and physical abuse, including injuries of unknown source and misappropriation of patient property by anyone providing services on behalf of the hospice.

Definitions

Abuse: The intentional infliction of physical, emotional, or sexual pain or injury that results in physical harm, pain or mental anguish.

Neglect: The failure to provide necessary food, fluids, shelter, clothing, medical care or supervision.

Mistreatment: To treat someone or something roughly, wrongly or badly.

Exploitation: Intimidating or deceiving a victim in a manner that deprives him or her of money, assets or property for the benefit of someone other than the victim.

Procedures

1. During orientation, all new employees receive instruction regarding:
   a. Legal requirements for reporting suspected abuse, neglect, mistreatment and exploitation;
   b. A review of the State's legal definitions of abuse, neglect and exploitation and mandatory reporting requirements and processes; and
   c. The requirement to report all alleged violations of abuse, neglect, mistreatment and exploitation as well as injuries of an unknown source that involve hospice employees or contractors to the hospice Administrator, or designee, immediately upon becoming aware of the alleged violation.

2. During the admission process and throughout the course of care, hospice personnel assess the potential for abuse, neglect, mistreatment or exploitation in the patient's environment.

3. Alleged violations of abuse, neglect, mistreatment and/or exploitation involving a hospice employee or contractor are brought to the attention of the hospice Administrator immediately.

4. The hospice Administrator immediately investigates alleged violations involving persons providing services on behalf of the hospice and immediately takes action to prevent potential further violation during the investigation.
5. The hospice Administrator documents all facts and actions during the investigation related to the alleged violation.

6. If necessary, the hospice Administrator will seek consultation to ensure the alleged violation is thoroughly investigated in order to verify whether or not the violation occurred and constituted abuse, neglect, mistreatment or exploitation.

7. If the violation is verified, the hospice Administrator:
   a. Takes appropriate corrective action in accordance with State laws;
   b. Ensures that verified violations are reported to the Washington State Department of Social and Health Services (DSHS) and, if sexual or physical assault is involved, to law enforcement immediately.

8. All assessments, interventions, discussions and follow up with the State Agency are carefully documented and kept confidential.

9. Failure on the part of hospice personnel to report suspected abuse, neglect, mistreatment or exploitation may result in disciplinary action and the potential for civil damages.

References
Regulatory Citation / Other 42CFR 418.52(b)(4) and 418.52 (c)(6)
Hospice of the Northwest Volunteer Acknowledgement of Policies and Procedures:

1. I have read the above and agree to comply with the SRH Volunteer Services policy.
2. I have read the above and agree to comply with the SRH Code of Conduct: Workplace Environment policy.
3. I have read the above and agree to comply with the SRH/HNW Dress Code policy.
4. I have read the above and agree to comply with HIPAA Policies.

VOLUNTEER GUIDELINES for HIPAA

1. Do not use a patient’s name or identifying information in personal e-mails.
2. Do not discuss a patient (even without identifying information) outside the HNW Office, Support Meetings or at patient’s location.
3. Do not leave any information that would identify a patient that can be seen in your car, at your work place, in your home, etc.
4. Promptly shred PHI that is no longer needed.

5. I have read the above and agree to comply with the Safety and Security Guidelines.
6. I have read the above and agree to comply with the Providing Oxygen to Patients when Safety is a Concern policy.
7. I have read the above and agree to comply with the Infection Control Precautions.
8. I have read the above and agree to comply with the Use of Personal Protection Equipment for Hospice Volunteers policy.
9. I have read the above information and agree to uphold both the Food Storage, Preparation and Handling policy AND the Safe Food Storage, Preparation and Handling practices.
10. I have read the above information and agree to uphold the Hospice Patient Rights and Responsibilities policy.
11. I have read the above information and agree to watch for and report abuse, neglect, mistreatment and exploitation of HNW Patients.

Volunteer Signature __________________________ Date Signed __________________________

Print Name __________________________
Conflict of Interest Policy

Hospice of the Northwest’s success depends on the hard work, dedication and integrity of our employees and volunteers. We all have an obligation to conduct ourselves within guidelines that prohibit actual or potential conflicts of interest.

An actual or potential conflict of interest occurs when we are in a position to influence a decision that may result in our personal gain or that of another individual, a relative or other entity as a result of our service. For the purposes of this policy, a relative is any person who is related by blood, marriage or has a similar relationship to the volunteer.

Examples of potential conflict of interest include, but are not limited to the following:

- We are prohibited from soliciting or securing employment by a family and/or patient of Hospice of the Northwest, while providing service to HNW. “Retiring” from service and then gaining employment as a result of these contacts, is also prohibited.

- Fraternizing with patients, and/or members of their family, is prohibited outside our assigned role. Following a Hospice patient’s death, revocation or discharge, we may make only one follow-up call or visit with their bereaved and then must cease all communication.

- We are prohibited from influencing business transactions involving purchases, contracts or leases that may lead to personal gain for themselves and/or a relative.

- The acceptance of gifts, excessive or unusual entertainment, or other favors patients and/or their families may offer, is prohibited.

- We are prohibited from the transfer of materials, products, designs, plans, ideas and/or data belonging to Hospice of the Northwest, for the purpose of personal gain.

- Sharing confidential Information regarding a Hospice patient, outside the organization, is legally (HIPAA) prohibited.

Volunteers are required to immediately disclose possible conflicts of interest as stated above, as well as any situation not stated that may appear to be a conflict, to the Volunteer Manager.

Disclosure of a conflict of interest, or potential conflict of interest, may be handled by the Volunteer Manager and/or it may be forwarded to the Ethics Committee for review. If sent to the Ethics Committee, that committee will determine if there is a conflict of interest and make recommendations for actions to be taken including coaching, letters of reprimand and/or termination.
CONFLICT OF INTEREST DISCLOSURE

Name ___________________________________________________________ ID# __________________

☐ To the best of my knowledge, none of my current activities create a conflict of interest, or potential conflict, with my role as a Hospice of the Northwest Volunteer.

☐ I believe that my activities as described below may create a conflict of interest, or potential conflict of interest, with my role as a Hospice of the Northwest Volunteer.

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

I hereby agree to not participate in any activities which, as described in the “Conflict of Interest” policy, may create a conflict of interest or a potential conflict of interest. I also agree to disclose to the Volunteer Manager possible conflicts of interest, as well as any situation not stated that may appear to be a conflict.

I have read the above and agree to comply with the HNW Conflict of Interest policy.

_______________________________________________________________     ________________
Volunteer Signature                                      Date

_______________________________________________________________
Print Name
Hospice of the Northwest Confidentiality and Compliance Statement

It is the policy of HNW to respect the right of confidentiality for all of our patients and employees and to insist that all employees and other members of the workforce, or others with access to patient Confidential Information and Protected Health Information at HNW strictly maintain the confidentiality and integrity of this information. “Confidential Information” includes all facts relating to the patient’s medical care (past, present or future), including oral information, written information and any computerized records or data. “Confidential Information” also includes patient financial information, employee records (medical or otherwise) and any other information of a private or sensitive nature at HNW, including financial and operating information of HNW.

HNW is also committed to operating its facilities and services at all times in compliance with all applicable State and Federal laws, rules and regulations, including those related to patient privacy.

1. I understand that I may only access Confidential Information and Protected Health Information as necessary to perform my specific job-related responsibilities at HNW. I agree not to disclose, communicate, or use any Confidential Information in any manner whatsoever other than in the scope of those services and only to others who have a legitimate need to know any Confidential Information.

2. Examples of breaches of my obligations regarding Confidential Information include:
   
   a. Discussing or revealing Confidential Information and Protected Health Information to friends or family members.
   b. Discussing or revealing Confidential Information and Protected Health Information to other employees without a legitimate need to know the information.
   c. Discussing or revealing Confidential Information and Protected Health Information in conversations in public places, including reception areas, hallways, elevators, etc.
   d. Reading all or any portion of a patient’s chart or accessing a patient’s electronic medical record or other clinical data without a legitimate need to do so. **Note: computer access to medical records is tracked by HNW as required by HIPAA.**
   e. Reading all or any portion of an employee’s Confidential Information or accessing electronic or other data without a legitimate need to do so.
   f. Inquiring as to the condition or treatment of a patient without a legitimate need to know, as involved in their care.

3. I also acknowledge that electronic computerized patient records and other electronic data create additional risks as to the privacy and security of Confidential Information. I agree to follow all policies and procedures adopted by HNW regarding access to Confidential Information. I acknowledge that my unique computer access codes cannot be shared or delegated for use to anyone and that HNW will deem data accessed or web sites visited using my access code to have been accessed by me.

4. I am familiar with the policies, procedures and guidelines in place at HNW pertaining to the use and disclosure of patient health information and other Confidential Information and Protected Health Information. I will at all times adhere to these guidelines. Approval should first be obtained from the HNW Privacy Officer, or if unavailable, the Release of Information Specialist in the Health Information
Management Department before any disclosure of patient information or other Confidential Information in a manner not specifically addressed in the guidelines and policies and procedures of HNW.

5. I understand that the unauthorized disclosure of Protected Health Information and other Confidential Information by me can subject HNW and me to civil and, under certain circumstances, criminal liability under State and Federal law.

6. If I observe or have knowledge of (i) any unauthorized release of Protected Health Information and Confidential Information from HNW or (ii) any practice or incident that I believe to be out of compliance with any law or regulation, I must immediately report this to the HNW Privacy Officer. It is HNW’s policy to encourage open communication between employees and the Compliance Officer and to prohibit any retaliation at HNW facilities in connection with requesting assistance from, or reporting to, the Compliance Officer concerning any suspected improper activities.

7. I have read and agree to strictly adhere to this confidentiality and compliance statement. In the case of HNW employees, violation of my obligations related to these matters will subject me to disciplinary action, which may include immediate dismissal from my employment. I understand that this signed statement will be part of my employment record at HNW. If I have access to Confidential Information through arrangements with HNW other than as an employee, violation of my obligations hereunder may result in the immediate termination of my or my employer’s relationship with HNW, and other sanctions under State and Federal law.

8. Termination does not relieve me of my obligation to continue to protect confidential patient health information.

I have read the above and agree to comply with the HNW Confidentiality and Compliance Statement

_______________________________________________________________
Volunteer Signature

_______________________________________________________________
Date Signed

_______________________________________________________________
Print Name
## SECTION 4

Counseling Services

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Needs of the Dying

By David Kessler

• The need to be treated as a living human being.
• The need to maintain a sense of hopefulness, however changing its focus may be.
• The need to be cared for by those who can maintain a sense of hopefulness, however changing this may be.
• The need to express feelings and emotions about death in one’s own way.
• The need to participate in decisions concerning one’s care.
• The need to be cared for by compassionate, sensitive, knowledgeable people.
• The need for continuing medical care, even though the goals may change from “cure” to “comfort” goals.
• The need to have all questions answered honestly and fully.
• The need to seek spirituality.
• The need to be free of physical pain.
• The need to express feelings and emotions about pain in one’s own way.
• The need of children to participate in death.
• The need to understand the process of death.
• The need to die in peace and dignity.
• The need not to die alone.
• The need to know that the sanctity of the body will be respected after death.
Psychosocial Issues in Advanced Illness
by Laurie Rosenblatt, MD and Fremonta L. Meyer, MD

Psychosocial concerns are nearly universal among patients who have advanced life-threatening illness. Patients face challenges to their sense of wholeness. The ways in which people respond to these threats range from highly effective strategies to dysfunctional reactions. Patients undergo adjustment in response to these challenges during which they may deny, withdraw, or become sad and angry at care providers, family members, friends, themselves and/or God. Understanding these issues and the ways in which they interact with physical distress is essential to assessment and management in the end of life care.

Common Issues for Patients with Advanced Illness

- The meaning of the Illness – A patient may blame him/herself for having caused the illness, or they may look at their illness as a sense of abandonment by God. They also may exhibit spiritual or existential distress, disruptions in relationships or depression.

- Loss of dignity – Shifts in identity and role functioning, concerns with legacy and unfinished business, questions about the purpose of life, feeling spiritually disconnected, feeling unsupported or misunderstood by family and/or health care providers.

- Fear of Increasing dependency upon others – the loss of physical and psychological control may trigger shame and fear; feelings of vulnerability and helplessness. S/he may also feel a diminishing sense of control. Feelings of anger, guilt, boredom, loneliness and alienation are common.

- Fear – Worsening illness and impending death can arouse fears of helplessness, abandonment and loss of control. Patients may experience guilt about leaving loved ones behind. They may also fear physical suffering, loss of functioning, their burden upon family or how their death may occur.

- Worries about how much time they have left to live – Patients may ask about their impending mortality. Use of open-ended questions may be most useful in this situation.

- Worries about loved ones – Patients worry about the physical and emotional toll that their illness has on their loved ones and caregivers. Family members often make a major life change in the course of caring for a loved one with a terminal illness. They may experience loss of income and their family savings, may exhibit depression and stress-related symptoms or they may neglect their own health and well-being.

- Grief and loss – Serious illness causes patients to confront current and anticipated physical loss as well as changes in role functioning and relationships. As the disease progresses, patients and their families and caregivers must adjust to these changes. During these transitions, patients struggle to maintain hope. Hope may be preserved when patients and families re-define the goals for care and are able to preserve dignity with the new circumstances.

Values, spiritual beliefs, personality style, characteristic methods of coping and family traditions all influence the way a person comes to terms with a terminal prognosis. Grief may entail reassessment of the scope of personal accomplishments, mourning for the loss of a desired future and relinquishing
many of the roles that have sustained a sense of purpose. Loved ones may experience anticipatory grief and difficulty during the bereavement period.

**Mediators of Coping**

The ways patients cope are mediated by several factors including the patient’s ability to maintain hope, family and social support, and spiritual and religious beliefs. Family members, friends and “significant others” can have a great impact upon a patient’s experience of illness. Even well-functioning families can become destabilized by grief, helplessness and exhaustion. A family’s resilience under stressful conditions seems dependent on their committed attachment to each other, their ability to communicate and disagree without rupturing the bonds of affection and respect, and a capacity to solve problems and make decisions cooperatively.

Denial sometimes occurs. It is a psychological mechanism by which a patient rejects either completely, or in part, the repercussions and effects of an illness, thus avoiding painful feelings. Financial pressures can also be important factors in the ability of the patient and family to cope with terminal illness.

**Psychosocial Complications**

The will to live may fluctuate in patients with advanced disease as a result of grief, the physical toll taken by the illness, and/or spiritual, family and personality issues. Depression, anxiety or other organic mental disorders may contribute to this instability. Patients with a history of psychiatric illness, or trouble coping, have an increased risk for renewed difficulties at the end of life. While depression and grief are normal responses to the losses encountered with life-threatening illness, unremitting low mood, guilt, hopelessness and pervasive loss of interest in activities and relationships often indicate the presence of depression.

Occasionally, patients may want to hasten their death by suicide. They want to live, but not in their current condition. They want the situation to change. Feelings of desperation, due to loss of control over their life, may be unbearable at times. If you sense that your patient is thinking about suicide, it is okay to ask. Listen compassionately. Ask open-ended questions. Use feeling words in your response. Find out if they have shared their feeling with family, friends or HNW staff. Contact the Volunteer Supervisor or the patient’s MSW for guidance as soon as possible.

Anxiety is common. When a person is under stress personality traits, including dysfunctional ones, tend to be amplified. Some patients, under stress, may behave in uncharacteristically demanding, deductive, manipulative or aggressive ways. People with personality disorders display chronic, dysfunctional patterns of behavior in interpersonal relationships and are unable to modulate feelings and behavior.

Substance abuse complicates medical care and mimics and/or magnifies depression and anxiety. Patients may also experience delirium, particularly as they enter the last weeks of life. Delirium is often frightening to patients and distressing for their loved ones. Hospice clinicians should gain an understanding of the patient and his/her loved ones, which can inform how s/he communicates with them. Clinicians should not shy away from end of life discussions.
The Psychological and Social Experience of Dying

For most of us, the inevitability of our own death can be denied, repressed or otherwise not considered. For the dying, awareness of impending death cannot be avoided. The dying person’s life activities, relationships, goals and meanings are reorganized and integrated in light of approaching death. Various physicians, educators, psychologist and others have identified “the tasks of the dying,” “developmental landmarks for the end of life,” and “opportunities for growth at life’s end.” Some of the most common frameworks are outlined below.

Four Types of Death (Sudow, 1967)

Social
• The individual’s social network shrinks as his/her lifestyle changes.
• Others withdraw from the dying person, defensively due to anxiety, some feel anticipatory grief or uncertainty regarding their role with the dying person, others experience discomfort with the awareness of their own mortality.

Psychological
• The patient regresses and becomes dependent as they are no longer able to function as autonomously as before.
• S/he experiences grief with a multitude of losses: activities, roles, abilities, long-term goals and aspirations, relationships, personality and basic senses of identity and self.
• The individual may experience other emotions including fear, depression, anger, guilt and shame.
• It is surprising to some that a person who is dying can be hopeful. However, hope does not have to be directed toward the distant future. Hope can be for accomplishment of short-term goals, relief from pain and suffering, self-efficacy in immediate tasks and activities, satisfaction in relationship and positive self-esteem.
• Biochemical changes in emotions, cognitions and behavior may occur due to progression of illness and medication.
• Withdrawal of others may limit social relationships.
• The patient may withdraw from the world outside the self and develop an increasing awareness of inner life.

Biological
• The patient must come to terms with the fact that their organism as a human entity will no longer exist.
• Life support may be used, but consciousness and awareness in a self-sustaining mind-body organism is not present.

Psychological
• Cessation of all vital organs and systems.
### Landmarks and Developmental Taskwork for the End of Life (Ira Byock, 1996)

<table>
<thead>
<tr>
<th>Landmarks</th>
<th>Taskwork</th>
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<tbody>
<tr>
<td>Sense of completion with worldly affairs</td>
<td>Transfer of fiscal, legal and formal social responsibilities</td>
</tr>
<tr>
<td>Sense of completion in relationships with community</td>
<td>Closure of multiple social relationships</td>
</tr>
<tr>
<td>Sense of meaning about one’s individual life</td>
<td>Life review; telling one’s stories, transmission of knowledge and wisdom</td>
</tr>
<tr>
<td>Experience love of self</td>
<td>Acceptance of worthiness</td>
</tr>
<tr>
<td>Sense of completion in relationship with family and friends</td>
<td>Reconciliation, fullness of communication and closure in one’s important relationships</td>
</tr>
<tr>
<td>Acceptance of the finality of life – of one’s existence as an individual</td>
<td>Acknowledgement of the totality of personal loss represented by one’s dying and experience of personal pain of existential loss</td>
</tr>
<tr>
<td>Sense of a new self (personhood) beyond personal loss</td>
<td>Developing self-awareness in the present</td>
</tr>
<tr>
<td>Sense of meaning about life in general</td>
<td>Achieving a sense of awe, recognition of a transcendent realm, developing/achieving a sense of comfort with chaos</td>
</tr>
<tr>
<td>Surrender to the transcendent, to the unknown – “letting go”</td>
<td>In pursuit of this landmark, the doer and “task work” are one. Little remains of the ego except the volition to surrender.</td>
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Task of the Dying Person (Moos & Tsu, 1977; Rando, 1984)

- **Awareness and Coping with**
  - Physical, social, psychological discomforts and incapacitation
  - Stresses of special treatment and care
  - New relationships with caregiver

- **Preserving and Maintaining**
  - Emotional balance in the face of increasing uncertainty and losses
  - Self-image and sense of competence
  - Importance of interpersonal relationships

- **Preparing for an uncertain future**
  - Arrange to handle a variety of affairs (debts, will, messages to family/friends, funeral arrangements)
  - Provide for the welfare of those left behind
  - Anticipate and plan for future medical care needs
  - Finances and possessions
  - Reunions with significant others
  - Anticipate and prepare for future pain, discomfort and loss of abilities

- **Coping with anxiety**
  - Fear of the unknown
  - Fear of loneliness
  - Fear of loss of family and friends
  - Fear of loss of self-control
  - Fear of loss of body parts and disability
  - Fear of suffering and pain
  - Fear of sorrow
  - Fear of loss of identity
  - Fear of regression
  - Fear of mutilation, decomposition, burial

- **Coping with losses**
  - Activities
  - Roles
  - Responsibilities
  - Social relationships
  - Unfinished and incomplete tasks, goals, plans
  - Values
  - Life meaning
  - Self-identity and the death encounter
  - Ability to take care of one’s self
  - Basic emotions, thoughts and behaviors
• **Decisions**
  - Slow down or speed up the dying process
  - Selection of surrogate decision makers

**How Can a Volunteer Help the Dying Person with Social and Psychological Concerns?**

• Provide time and space for communication. Be available to listen to concerns. Communicate your ability to be present with the dying person verbally and non-verbally. Clarify to make sure you understand their concerns.

• Communicate respect and acceptance of the dying person. Develop an awareness of the values and beliefs of the dying person and their family. Allow the dying person as much control as possible.

• Avoid withdrawing prematurely from the dying person. We may have sadness and grief about seeing someone die. A natural response is to withdraw from these difficult and painful emotions. It is extremely important to be aware of this response and to avoid abandoning the person who is dying.

• Accept that dying may be very difficult for the patient. Avoid minimizing painful emotions when they are expressed. Avoid communicating an overly positive view of dying, especially when it is clear that the patient’s experience is not good.

• Avoid telling the dying person something that is not true. This will erode trust and contribute to their anxiety and fear.
Challenges for Family Caregivers

A 2014 study from the National Alliance for Caregiving and the American Association for Retired Persons (AARP) reveals that the profile of the family caregiver in America is changing as the population ages. While the “typical” family caregiver is a 49-year old woman who takes care of a relative, caregivers on the whole are becoming as diverse as the American population.

In 2015 AARP issued a report on the study based on quantitative, online interviews of 1,248 family caregivers, ages 18 and older. The report concluded . . .

In general:

- Nearly a quarter of caregivers are between 18-35 years.
- 82% care for one person who is likely either living with them or living less than 20 minutes away.
- 60% are female.
- Typically, they are a 49-years old caring for a 69-year old female relative, most likely a mother.
- 40% are male who average 23 hours/week supporting a loved one.
- Caregivers provide care, on average, 24. 4 hours per week for 4 years.
- 38% report high emotional stress from the demands of care giving.
- Nearly half report financial stress as well.
- Difficulty finding affordable care giving services, such as delivered meals, transportation, or in-home health services is an issue for many.
- Those living more than an hour away from their care recipient report the highest levels of financial strain; of these, four of 10 long-distance caregivers use paid help.

Among caregivers who work, 34% have full-time jobs; 25% work part-time. They work an average 34.7 hours/week and receive an annual income of $45,700.

Higher-hour caregivers:

- 32% of caregivers provide unpaid care for at least 21 hours a week; averaging 62.2 hours of weekly care.
- They average 5.5 years of care giving and expect to continue care for another five years.
- Those 75 or older are typically the sole support for their loved one; providing care without paid help or help from relatives or friends.
- They are in particular need of respite care support as well as access to resources and tools to assist them with managing stress and enabling the care recipient to live at home.

According to Gail Gibson Hunt, President and CEO of the National Alliance for Caregiving, “. . . there is not enough being done to support family caregivers in the public or private sector as they age. There’s a double-edged sword when we fail to support caregivers, because we put both the caregiver and the care recipient at risk.”

The above is excerpted from an article found at http://www.caregiving.org/caregiving2015
Self-Care for the Family Caregiver

First, Care for Yourself
On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for you is one of the most important – and one of the most forgotten – things Hospice volunteers and patient caregivers should do.

Caregiving Affects Health and Well Being
Family caregivers of any age are less likely than non-caregivers to practice preventive health care and self-care behavior. Studies show that 46 – 59% of caregivers are clinically depressed. In addition, they may be sleep deprived, have poor eating habits, fail to exercise, fail to stay in bed when ill and postpone or fail to make medical appointments. They are at increased risk for excessive use of alcohol, tobacco and other drugs, and increased risk for depression.

Older caregivers are especially vulnerable to the strain caused by their role. A caregiving spouse between 66 -96 years of age who experiences mental or emotional strain has a risk of dying that is 63% higher than one of the same age who is not a caregiver. Older caregivers are also at increased risk for health issues. Baby boomer caregivers who are caring for parents and raising children face an increased risk for depression, chronic illness and a possible decline in quality of life.

Guidelines for Self-Care
Below are some self-care practices for the caregiver:

- Learn and use stress-reduction techniques.
- Attend to your own health care needs.
- Get proper rest and nutrition.
- Exercise regularly.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities.
- Seek and accept the support of others.
- Seek counseling when you need it, or talk to a trusted counselor or friend.
- Identify and acknowledge your feelings.
- Change the negative ways you view situations.
- Set goals.

How Can Volunteers Help the Caregiver?
- Providing companionship and respite to the Hospice patient is a huge gift to the caregiver. It may be the only opportunity they have all week to nap, run errands, and take care of their own needs.
- Be supportive and complimentary of the caregiver when you are visiting the patient.
- If the caregiver seems to be significantly stressed, suggest they may want to talk with the Hospice social worker, Chaplain, family members or a trusted friend.
- You may wish to remind the caregiver that the Hospice Resource Center has books on caregiving as well as other aspects of death and dying.
- The following organizations offer resources for caregivers:
Resources:

❖ **Family Caregiver Alliance – National Center on Caregiving**
   [www.caregiver.org](http://www.caregiver.org)
   E-mail: [info@caregiver.org](mailto:info@caregiver.org)
   They publish “Because We Care: A Guide for People Who Care,” as well as various fact sheets.

❖ **Caring Connections** – a program of the National Hospice and Palliative Care Organization
   [www.caringinfo.org](http://www.caringinfo.org)
   They offer resources for caregivers, patients, the bereaved and those seeking information on end-of-life planning.

❖ **Area Agency on Aging**
   They can refer caregivers to support groups, respite providers and other caregiving services.
   [www.eldercare.gov](http://www.eldercare.gov)
   800.677.1116

❖ **ARCH National Respite Network and Resource Center**
   They can find local respite providers, if the family needs this.
   [http://chtop.org/ARCH.html](http://chtop.org/ARCH.html)
   800.473.1727
6 SELF-CARE TIPS FOR Caregivers

1. Eat Healthy Meals Regularly
   Caring for someone else can be hard on the mind and body. Keep your body and mind healthy by replenishing your strength with nutritious meals. Be sure to include lots of fruits and vegetables, which will provide antioxidants to protect your health.

2. Stay Hydrated
   It’s important to make a conscious effort to drink water! Adequate water helps keep your mind clear. Although it’s tempting to opt for more caffeinated & sugary beverages to help keep you going – water is by far the best option!

3. Sleep & Rest Regularly
   Making sure you get some sleep – or at the very least a little rest – gives your body a break from stress. Adequate rest is critical for keeping you in good health.

4. Make time for Exercise
   Exercise is an incredible way to help relieve stress – not to mention it’s just plain good for you! Even something as simple as going for a walk outside at a gentle pace will do you a world of good. If you can’t go outside, walk up and down the hall – anything to get your heart pumping.

5. Ask for & Accept Support!
   Let family & friends know how they can help you. People are often very eager to help during difficult times. Accept the support that is offered by your friends & family. If you feel like you need it – don’t be afraid to seek professional support from a counsellor or a spiritual care advisor.

6. Give Yourself A Break
   Give yourself permission to take some YOU time, away from the bedside of your loved one, especially when you’re feeling overwhelmed or exhausted. Although you might be reluctant, a little R&R can dramatically help ease your stress levels and renew your energy.
Checklist for End of Life Planning

Store all of your end of life planning information in one place and make sure one or more friends or family know where this information is stored. You might consider providing these trusted individuals with a copy of your plans. Below is a list of things you may want to include in your end of life planning:

_____ Special bequest of personal items: List specific things you want to leave to designated people or organizations upon your death.

_____ Funeral, burial, memorial service, and related instructions: Having your wishes in writing will provide a sense of security and knowledge that your wishes are being fulfilled by those who love you.

_____ Important personal information: This information includes your social security number, safety deposit box information, location of important papers, the name of your accountant, attorney, any other important information.

_____ List of people and organizations to be notified of your death: list all of the people you want notified of your death as well as any companies or organizations and the contact person (financial, legal, personal, professional contacts).

_____ Password list: upon your death, you will want someone to close your various online accounts such as Ebay, Amazon, social media, banking, other online accounts; as well as messages on your phones and your email accounts.

_____ Loans and mortgages: Make a list of all outstanding financial liabilities that your loved ones will need to settle all of your debts. Include name and address of lender, account number, and contact information as well as a description of the loan collateral.

_____ Credit Card accounts: Your loved ones will need a list of these in order to close these accounts and protect your estate from identity theft as well as to arrange for payments on all outstanding balances.

_____ Financial accounts: Create a list of all financial investment accounts: banks, credit unions, CD’s, money market accounts, retirement accounts, etc. Include the financial institutions name, account numbers, access codes, and dated balances.

_____ Non-Liquid assets: If you have furniture, art work, books, collectibles, or other items that are particularly valuable they should be included in a list with the items assessed value and documentation.

_____ Insurance policies: life insurance, vehicle insurance, home insurance, long term care, burial insurance, etc. Your loved ones will need a written record of your policies so they can be cancelled and any unamortized premiums already paid can be returned to your estate.

_____ Children/Dependents: create a care plan to be put in place after your death, if you have minor children detail out the custody arrangements you and your loved ones agree upon.
_____ **Pets:** create a plan with your loved ones for the re-homing of your pet and designate this in writing.

_____ **Home care:** create a list of individuals and companies you have contracts with to maintain your home and property such as cleaning services, lawn care, or any goods/services that are on auto pay on your credit cards.

_____ **Home utility or service providers:** create a list of utility providers with the companies name and address, your account number, and any applicable contact information.

_____ **Home security:** This information is needed so your loved ones can turn the system on and off as needed to access your home.

_____ **Work/Business contacts:** create a list of those contacts who need to be made aware of your death including associates, customers, vendors, landlords, etc.

_____ **Business financial records:** create a list of business bank accounts, loans, credit cards, other debts, and assets as necessary as well as the plan for the continuation or dissolution of your business.

_____ **Business passwords/access information:** create a list of the passwords and security information necessary to access your business documents.

_____ **Advance directives:** every adult should have written documents appointing a trusted person to make healthcare and end of life decisions on their behalf in the event they are unable to make those decisions themselves.

_____ **Will:** create a will to make your final wishes known to your loved ones.

Any additional information/items you feel necessary to leave documentation for your loved ones about:

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
Advanced Directives

There are a number of different Advanced Directives that you may hear about while volunteering for Hospice, including Living Wills, Powers of Attorney, Five Wishes and POLST.

A living will is a legal document that indicates preferences about medical treatment in the event of a serious accident or illness that leaves someone unable to give informed consent. Living wills will note life-sustaining measures an individual does and does not want such as assisted breathing, feeding tubes and resuscitation.

The Physician Orders for Life-Sustaining Treatment (POLST) is a form that is more specific than a living will. It describes what an individual wants now based on his or her current condition. Because these are doctor’s orders, if an ambulance is called to a patient’s location and the POLST form is available, the paramedics must follow these orders since they are physician orders. In contrast, physicians aren’t legally obligated to follow a living will. The POLST form is bright green and is usually posted on a patient’s refrigerator or in another easy-to-find place. If paramedics come to your patient’s location, the caregiver or the volunteer should point out the form.

The Five Wishes Document names a Health Care Agent that can make decisions when an individual is no longer competent to do so, and specifies the medical treatment the person would want in the event they cannot speak for themselves. It also lists specifics as to how comfortable a patient would like to be at the end of life, how they would like to be treated and what they would like their loved ones to know. A copy of Five Wishes and more information is in the back pocket of this training binder.
Hospice Spiritual Assessment
Listening for the questions
By Jon Prescott, Spiritual Counselor, HNW

Spiritual questions are fundamentally different than body questions. Body questions pertain to facts that can (ideally) be answered through observation. Spiritual questions are open ended and, if answerable at all, are settled through personal reflection, yielding answers pertinent only to this individual at this time. They are not easily captured in chart notes.

Spiritual questions are felt more than thought; they serve as a vehicle to keep the heart open to rather than as a matter of fact to be solved. As such, listening to the emotional flow beneath a person's words may yield more insight into their spiritual issues than direct questioning. A person may not even yet know what their spiritual questions are but do know that something remains unsettled within their hearts. As a volunteer, noticing that this person has unresolved feelings is a sufficient spiritual assessment. The Spiritual Counselor can then further assist the person in exploring, naming or resolving their concern.

It’s important to remember that not everyone uses religion to express or explore spiritual questions. Many turn to nature, family, science, philosophy or culture. The presence or absence of religion is not correlated with the presence or absence of spiritual distress, because while few in our society are religious, nearly everyone wrestles with spiritual questions related to meaning and purpose.

To diagnose the presence of spiritual questions, look for symptoms in both body and mind. Agitation, unsettledness, anxiety or distress along with verbal statements related to meaning and purpose are signs that a referral to Spiritual Care is needed.

Spiritual questions are easy to overlook because they express such every day concerns. They are questions that motivate us and give meaning to our actions, such as:

- Who am I?
- Am I using my gifts well?
- Has my life been meaningful?
- What am I grateful for?
- Do I have things left to do?
- Are my relationships at peace?
- How can I pass on what I've learned?
- How do I make sense of suffering?
- What happens when I die?
- Where do I find strength?
- Is my life meaningful even while I’m weak and dependent?
- Will things be ok when I’m not here?
Companioning

The tenets of companioning the dying are adapted from Dr. Alan Wolfelt’s model of caring for mourners. Companionship is about being present.

- Companioning is about honoring all parts of the spirit; it is not about focusing only on the intellect.
- Companionship is more about curiosity; it is less about our expertise.
- Companioning is about walking along side, it is less about leading or being led.
- Companioning is more about being still; it is not always about urgent movement forward.
- Companioning means discovering the gifts of sacred silence; it is not about filling every moment with talk.
- Companioning is about being present to another person’s emotional and spiritual pain; it is not about taking away or fixing the pain.
- Companioning is about respecting disorder and confusion; it is not imposing order and logic.
- Companioning is about going in the wildness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

Excerpted from Companioning the Dying: A Soulful Guide for Caregivers by Greg Yoder
Internal Process of Dying

The following are processes that those who are in the last stages of life may “walk through.” Those who share this time with them may see and be part of these processes. Patients may experience some or all of these stages. They may experience them in different sequences. The issues may be voiced or may remain private, unseen and unspoken. They may never be consciously experienced. An awareness of these processes may add dimension to your experience of “being there,” just as your caring, non-judgmental presence will enrich the life of the dying and your own.

Redefining Priorities
- If I only have a limited time to live, what do I really want to do?
- What is the most important to me?
- What gives my life meaning?

Facing Fears and Emotions of Death
- What about the people I’m leaving?
- What will happen?
- Will it hurt?
- Anger, sadness and grief

Extraordinary Experiences
- Deathbed visions
- Unexplainable events

Finishing Business
- Completing wills and medical directives
- Making funeral arrangements
- Financial and legal considerations

Life Review
- Review of past experiences and accomplishments
- Dignity vs. despair; what has given my life meaning?
- Passing on knowledge and wisdom to future generations

Seeking Peace
- Resolving inner and outer conflicts, finding forgiveness
- Exploring spirituality

Identifying and Utilizing Support Systems
- Saying goodbye

Hospice of the Valley Volunteer Resource Manual, Phoenix, AZ
The Top 5 Regrets of the Dying
By The Guardian on Facebook, February 2 2012

Bonnie Ware is an Australian nurse who spent several years caring for patients in the last 12 weeks of their lives. She recorded their dying epiphanies in a book called The Top Five Regrets of the Dying. Ware writes of the phenomenal clarity of vision that people gain at the end of their lives, and how we might learn from their wisdom. "When questioned about regrets they had or anything they would do differently," she says, "common themes surfaced again and again." Here are the top five regrets of the dying, as witnessed by Ware:

1. I wish I'd had the courage to live a life true to myself, not the life others expected of me.

"This was the most common regret of all. When people realize that their life is almost over and look back clearly on it, it is easy to see how many dreams have gone unfulfilled. Most people had not honored even a half of their dreams and had to die knowing that it was due to choices they had made, or not made. Health brings a freedom very few realize, until they no longer have it."

2. I wish I hadn't worked so hard.

"This came from every male patient that I nursed. They missed their children's youth and their partner's companionship. Women also spoke of this regret, but as most were from an older generation, many of the female patients had not been breadwinners. All of the men I cared for deeply regretted spending so much of their lives on the treadmill of a work existence."

3. I wish I'd had the courage to express my feelings.

"Many people suppressed their feelings in order to keep peace with others. As a result, they settled for a mediocre existence and never became who they were truly capable of becoming. Many developed illnesses relating to the bitterness and resentment they carried as a result."

4. I wish I had stayed in touch with my friends.

"Often patients would not truly realize the full benefits of old friends until their dying weeks and it was not always possible to track them down. Many had become so caught up in their own lives that they had let golden friendships slip by over the years. There were many deep regrets about not giving friendships the time and effort that they deserved. Everyone misses their friends when they are dying."

5. I wish that I had let myself be happier.

"This is a surprisingly common one. Many did not realize until the end that happiness is a choice. They had stayed stuck in old patterns and habits. The so-called 'comfort' of familiarity overflowed into their emotions, as well as their physical lives. Fear of change had them pretending to others, and to their selves, that they were content, when deep within, they longed to laugh and have silliness in their life again."

What is your greatest regret so far and what will you set out to achieve or change before you die?
Anticipatory Grief

Anticipatory grief includes all that we experience when we are faced with the possibility, the probability, or the inevitability of loss that hasn't yet occurred. We begin to imagine what could happen, how that would feel, how our lives would change and how we might cope. This may begin when someone is first diagnosed with a life threatening illness, when the prognosis changes, or when we see more evidence that the “door is closing.”

When family members and friends know that a loved one is dying, it is normal to feel separation anxiety, to feel overwhelmed in the face of circumstances we didn’t want and can’t control. In addition to being affected by the impending loss, it is likely that we will also grieve losses that have already occurred.

Anticipatory grief does not mean we won’t feel sad after the death occurs. The more aware we are of what is going on for us in the present, the easier our journey may be in the future.

Anticipatory grief may allow for:

- Absorbing the reality of the loss gradually over time.
- Completing unfinished business for the dying person and their caregivers and/or family; resolving differences, making amends for past transgressions, forgiving or asking for forgiveness.
- Remembering and reminiscing about your life together, expressing feelings of love and gratitude, talking about what is important and saying goodbye.
- Giving the gift of good care to a loved one and to you.
- Redefining the family roles in relationship to the dying person.
- Thinking about what life will be like without your loved one.
- Reassigning or learning to handle the responsibilities and roles of the dying person.

Caregivers coping with stress and grief may experience:

- **Loss of energy and vitality:** there is often a high level of physical strain involved in caring for patients with serious, life-limiting illness.
- **Social isolation** may occur as family increasingly focuses on the need of their loved one and has less time, energy and/or interest for other activities.
- **Loss of personal identity** can occur as care givers become increasingly engrossed in their care giving role.
- **Intensified ordinary family dynamics,** affecting both strengths and difficulties in relationships and communication, may manifest.
- **The toll of uncertainty.** Emotional strain, as hope rises and falls, can seem unbearable. Fears may arise, e.g. fear of the actual death, fear of pain, fear about the handling of the situation, fear of suffering and/or fear of the future.
Physically, caregivers may experience:

- tightness in the throat or in muscles; heaviness or pressure in the chest;
- inability to sleep; times of restlessness, anxiety or panic;
- lack of desire to eat or compulsion to overeat;
- headaches or stomach/intestinal discomfort; and/or
- lack of energy; difficulty concentrating.

Mentally and emotionally, caregivers may experience:

- sadness and/or depression;
- being forgetful, distracted, scattered;
- unexpected anger toward others, God or self;
- crying easily and/or unexpectedly;
- mood swings;
- discomfort around others or not wanting to be alone;
- feelings of emptiness;
- thoughts of “if only” things had happened differently; fear of what will happen next;
- desire to run away or becoming over busy; and/or
- feeling like you are “going crazy.”

Caregivers can experience physical and/or emotional relief by:

- Eating a healthy, well-balanced diet. Drink lots of water. Limit caffeine and alcohol.
- Getting some exercise; it helps with relaxation.
- Being gentle with themselves. It is normal for grief to feel overwhelming.
- Reaching out to others, especially to someone who has “been there.”
- Being aware that people are unique in how they handle grief. One should not measure one’s experience against others or expect others to react as you do.
- Tears can be therapeutic. Author Jean Jones says, “Cry when you have to – and laugh when you can.”
- Avoiding being too self-critical; chances are you are doing the best you can.
- Being patient and realistic about your expectations of yourself and others.
- Taking time to give thanks; appreciate yourself and others.
- Doing things that give pleasure, restoring their spirits.

It may be difficult for caregivers to ask for help. Yet, receiving support can help you through a challenging and exhausting time. Family, friends, the hospice Social Worker or Spiritual Counselor can lend support to caregivers and help them access needed resources.
How Grief May Manifest

Grief encompasses a broad range of responses. The following list of feelings, physical reactions, thoughts and behaviors are common, especially in early grief. However, your experiences and reactions will be unique to you. They may be affected by the type and circumstances of the loss, your relationship to the person who died, prior losses you have experienced, as well as many other factors.

**Feelings**
- shock, numbness, sense of unreality
- sadness, depression
- relief
- anxiety, fear, hysteria
- anger, irritability
- guilt, self-reproach
- helplessness, vulnerability
- loneliness
- yearning
- low self-esteem
- mood swings
- feeling of being crazy
- intensity of all feelings

**Behaviors**
- outward expression of emotions; crying, angry outbursts
- searching and calling out
- sighing
- restlessness
- visiting places or carrying objects that are reminders of deceased
- avoiding reminders of the loss
- picking up mannerisms of deceased
- exhibiting symptoms of the deceased’s illness
- accident prone
- changes in sexual activities
- obsessive activity

**Spiritual Reactions**
- searching for meaning in the loss
- changes in religious or spiritual behaviors or beliefs
- questioning “why”

**Physical Reactions**
- tiredness, exhaustion
- appetite changes

- insomnia
- headaches
- muscle aches
- sensitivity to noise
- hollowness in the stomach
- tightness in the chest or throat
- excess of nervous energy
- feeling of being short of breath
- heavy or empty feeling in the body
- heart pounding
- susceptibility to illness

**Mental Reactions**
- difficulty with concentration, memory
- hard to make decisions; scattered
- the death doesn’t seem real
- disorientation, confusion
- continually thinking about the loss
- reviewing the circumstances leading up to the death or recalling the person’s dying
- fantasizing
- apathy
- dreaming about or sensing the deceased’s presence
Practical Challenges
- returning to work
- learning to manage a house
- change in finances
- learning to manage bookkeeping
- transportation issues
- disposing of the deceased's property

Social Changes
- need for support of close friends
- social withdrawal
- concern about acting “normal” around others
- self-focused (no interest in others)
- need for relationships unrelated to loss (e.g. at work)
- marital difficulties
- role changes, role reversal
- change in social patterns (e.g. once a couple, now a single person)

How to be Helpful to Someone Who is Grieving*
Do. . .
- listen more than you talk.
- allow for silence.
- call or contact them when you say you will.
- refer to the deceased person by name.
- be genuine and caring.
- reach out and acknowledge their loss.
- allow the bereaved to express their feelings without interruption or judgment.
- let them tell their story. They may need to tell it again and again in order to come to terms with what happened and how it affects them.
- encourage them to be patient with themselves and to adjust their expectations.
- ask about the funeral or memorial service if there is to be one.
- normalize the grieving process.
- ask about other family members and how they are coping with the loss.
- ask if there is anything you can do (only if you mean it).
- when they are questioning their faith, or asking “why” questions, remember that questioning is normal and only they can find the answers they seek.
- remember them on special occasions or give a call or send a card to let them know you are thinking about them.

Don’t. . .
- dominate the conversation.
- ask one question after another.
- disappear
- use clichés such as: “I know just how you feel.” “At least you can have another child.” “You’re young; you’ll find someone. . .” “This will bring your family closer.” “S/he is in a better place.”
- avoid them because you are uncomfortable with their situation/pain/loss.
- tell them you’ve already heard this or that you’re tired of hearing their story.
- expect them to get over it or to get back to normal in the same time/way you would.
- change the subject when they talk about the person who died.
- tell them they “should” be feeling better now.
- criticize their family’s way of coping.
- give advice, particularly medical or legal unless you are an M.D. or a lawyer.
- try to answer a question you don’t have the answer to.
- try to take away their pain. You can’t
- criticize the care their loved one received; this only increases guilt or doubt.

* These suggestions are primarily for the use of HNW’s Bereavement staff. Volunteers should disengage from ongoing contact with a deceased’s family/caregiver after a condolence call and/or after sending a Sympathy Card. They may, however, be helpful to you in dealing with the personal loss of a loved one.
Hospice of the Northwest Bereavement Program Overview

Medicare requires hospices to offer bereavement services for 13 months following a patient’s death, with only a few stipulations as to what services must be included. Bereavement services are **not** reimbursed by Medicare. As a result, there is a large variation of services provided among bereavement programs. Hospice of the Northwest has a comprehensive bereavement program that offers robust support to the “primary bereaved” identified by the patient.

Services are based on what the “primary bereaved” wants and may include phone support, office or home visits, grief groups, referrals, an annual remembrance service and grief-related mailings throughout the year. A lending library containing more than 1,700 books related to death, dying and bereavement is available to the community at large. There is no charge for any HNW bereavement service, including the library.

Each year, more than 1,000 of the “primary bereaved” are contacted by phone and more than 4,000 grief support periodicals are mailed. Only 20% of the bereaved request bereavement services; reflects national statistics. 80% adjust with support of family members, friends and/or community resources.

**Chronology of Bereavement Services Provided by HNW**

**Patient Admitted**
- A Social Worker completes a pre-bereavement assessment and assists in identifying the primary bereaved. They also determine if early bereavement follow-up is needed (about 25% of those who elect to participate in bereavement services are contacted soon after the death).

**Patient Expires**
- The circumstances of the death and the family’s needs are discussed in an IDG meeting.
- A sympathy card is mailed to the family within three (3) business days; an information packet is sent within two (2) weeks.
- The family is phoned within a few days or weeks, depending on their needs and issues.
- The primary bereaved is contacted in 4-8 weeks after a death to complete a post-death bereavement assessment and plan of care. Follow up is based on the bereaved’s preferences.

**Ongoing Services Provided**
- Follow up may include grief counseling, grief groups and/or referrals and mailings.
- A six-month assessment form is mailed to the primary bereaved.
- On the one-year anniversary, the primary bereaved is called.
- A Family Evaluation of Bereavement Services is mailed at the end of service.

**NOTES:**

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SECTION 5
VOLUNTEER OPPORTUNITIES, RESOURCES and SUPPORT

Volunteer Opportunities
Volunteer Support Meetings, IDG, and Ethics
QAPI Committee

Volunteer Resources

Hospice Resource Center Library
Recommended Books
Volunteer Liaison – Spiritual Counselors
Position Description: Patient/Family Volunteer
“Volunteer Voices” Newsletter
Volunteer Opportunities

A volunteer’s gift of time completes the circle of care that is offered through Hospice of the Northwest. If you are compassionate, are a good listener and have a true desire to help others, becoming a hospice volunteer may be the perfect opportunity for you. Below is a list of current volunteer positions.

All volunteer positions require a one year commitment, a minimum of 30 hours of service per year, and attendance at Volunteer Support Meetings

Positions Serving Patients and Families

Patient/Family Volunteer
Provide support and companionship to dying patients and those who love them. Volunteers serve as friendly visitors and may provide respite for families and caregivers. They care, share, listen, understand, laugh, cry, and share memories and experiences. Activities may include reading aloud, capturing stories, and playing cards, watching movies, listening to music, sharing hobbies, doing safety checks or helping with household tasks. Companionship visits are generally 1-2 hours weekly; respite visits are usually 3-4 hrs/weekly. Volunteers and patients are matched for anywhere from a few weeks to several months.

Due to WA State Health Department regulations, Patient/Family Volunteers MAY NOT provide personal or medical care, dispense medications, transport, lift or transfer patients, assist with walking or toileting, or pick up individuals who have fallen. Volunteers should bring their role as hospice volunteer to an end after the patient has died.

Tuck In Volunteer
Make weekly phone calls to insure that patients living in private residences are comfortable and have sufficient medications, equipment and supplies to last through the upcoming weekend. Calls are made Thursday mornings between 9-11am, which gives Hospice staff time to insure issues are resolved before the weekend. This is a weekly commitment although substitutes are needed periodically.

Vigil Team Volunteer
Sit with patients during the last 24 - 48 hours of life, providing comfort, reassurance and solace. They also offer support to families and caregivers. Sitting at the bedside or being in the home of a dying patient is a very private and intimate time. Vigil volunteers are privileged to be invited to share in this experience. Vigil volunteers complete Patient/Family volunteer training and a short Vigil Training. They complete a 3 - 4 hour shift (as available) one or more times during vigils. Vigil activities may include gentle touch, lighting candles, playing soft music, and reading, sharing comforting words, or sitting in silence.

Patient Engagement Volunteer:
Provide follow-up phone calls to individuals discharged from Hospice services and those not taken for care (due to not meeting eligibility requirements). Will ask questions to determine whether patient now meets admission criteria. Coordinates with Referral Center staff.

Veterans Recognition Volunteer:
Volunteers who are veterans are preferred for this position. Volunteer will spearhead efforts to recognize Hospice patients who are veterans. Will keep current with the National Hospice and Palliative
Care Organization's We Honor Veterans Program. If available, accepts the assignments of patients who are veterans.

**Clinical Communications Volunteer:**  
Attends one Clinical Interdisciplinary Team Meeting each week (Tues, Weds or Thurs, 8:15 – 10:30am), takes notes regarding pertinent information to be passed on to volunteers and follows up.

**Music and Memory Volunteer**  
This innovative program helps dementia patients recover their memories through listening to favorite music from the past. Volunteers create personalized playlists for patients, enabling them to hear favorite songs on devices with headphones or speakers. Programs like this have had resounding success in connecting with those who are non-verbal, withdrawn or socially isolated.

**Pet Partner Volunteer**  
These special Volunteers coordinate with our partner handler/dog teams to provide comforting visits to HNW patients.

**Clerical and Administrative Positions**

**Clerical and Office Support**  
Administrative and office volunteers may assist with typing, data entry, photocopying, scanning, assembling booklets, medical records filing, mailings, and special projects. They serve weekly, monthly, or as needed.

**Administrative Materials Volunteer:**  
Assembles patient admit packets, nursing packets and sends out bereavement mailings.

**Resource Center Library**  
Volunteers maintain the Resource Library in the lobby, containing over 1100 books and DVD's about death, dying, grief and spirituality. These volunteers come in weekly for about 2 hours.

**Sewing Volunteers**  
Hospice volunteers sew “butterfly” pillows, “busy mats” and “marble rolls” for patients. This can be done at home at one’s convenience. Fabric and notions provided.

**Volunteer Resources**

**Volunteer Support Meetings**  
Please note that all volunteers, regardless of role, should attend Volunteer Support Meetings to interact with other HNW Volunteers and receive training updates. If unable to do so due to work schedules, volunteers should make arrangements with the Volunteer Manager for other training opportunities. Also, all volunteers should read the monthly Volunteer Meeting Minutes so that they are aware of what has been discussed and presented.

**Vigil Support Meetings**
Vigil Support Meetings are held immediately following the Volunteer Support Meetings. Volunteers have the opportunity to discuss recent vigils and new information is shared. **Attendance is highly encouraged for support and training opportunities.**

**IDT and Ethics Meetings**
IDT meetings are held Tuesday, Wednesday, and Thursday mornings weekly based on the geographic location of the team, all meetings are held in the HNW Conference Room. Ethics Meetings are held the third Wednesday of each month immediately following IDT. Volunteers are invited to attend IDT and Ethics meetings, however it is recommended to confirm Ethics Meetings with the front desk as they can be cancelled if there is no case to discuss.

**Newsletter: “Volunteer Voices”**
This publication is e-mailed to volunteers. It lists volunteer support meetings and includes news, feature articles, resources, poems, and more. Volunteers are welcome to submit copy for possible inclusion. Volunteers are expected to read all issues.

**HNW Resource Library**
The HNW lobby houses an extensive library of books about death and dying, including topics such as coping with illness, caregiving, end-of-life, grief and children/teens. Books are available for check-out for four weeks. A few videos and DVD’s are also available. The library catalog is on line via the Evergreen System at Burlington Public Library, by going to http://burlington.skagitcat.org.

**Busy Mats, Marble Rolls, Butterfly Pillows, Catheter Bags**
HNW volunteers make these items for patients to use, items are available for pick up at the office.

**Electronic Devices**
IPods, IPads, and Kindles are available for check-out from the Volunteer Manager. You may develop a personalized playlist for a patient after talking with their family about their favorite music. Personalized music has been shown to effectively help those with Dementia recover their memories and become more engaged.

**Moss Basket Video**
Available for check-out is an audiovisual presentation that can be played on the ceiling of bedbound patients. It contains photos of local nature scenes and music. See the Volunteer Manager if you are interested in this resource.

**Dementia DVD**
National Dementia expert Teepa Snow’s DVD, “Filling the Day with Meaning and Joy when Dementia is Part of Life” is available via check out from the Volunteer Manager. This 2.5 hour presentation contains information about engaging Dementia patients with different activities, how to help those with Dementia feel needed, which activities to consider at different stages of illness, and how to successfully navigate challenging behaviors.

**“Alive Inside DVD”**
This DVD is required for all volunteers who wish to participate in our “Replay the Memories” iPod music program. It is a touching, inspiring, award-winning documentary that anyone would enjoy.

**Web-Sites**
- National Hospice & Palliative Care Organization: http://nhpco.org
• Washington State Hospice & Palliative Care Organization: www.wshpco.org
• We Honor Veterans: www.wehonorveterans.org
• Hospice Volunteer Association: www.hospicevolunteerassociation.org
• Hospice Volunteer: www.hospicevolunteer.com
• Hospice Foundation: http://hospicefoundation.org
• Caring Info: www.caringinfo.org
• E-Volunteerism: www.e-volunteerism.com
• Charity Channel: www.charitychannel.com
**Hospice of the Northwest**

**Volunteer Support Meeting Schedule 2019**

**Support Meetings**
Volunteer support meetings are held once/month, they are an opportunity for volunteers to hear presentations, receive agency updates, share experiences, remember patients, and discuss concerns. Volunteers are encouraged to attend every meeting; the more you attend the more you connect with and learn about being a volunteer for Hospice of the Northwest. Volunteers **are required** to attend no less than three Volunteer meetings annually.

**Support Meeting Schedule**
All-Volunteer Meetings are held on the third Monday of the month from 1-3pm. Vigil Volunteer meetings follow at 3:00pm and end at 3:30. Both are held in the HNW Conference Room. Meeting dates and topics are subject to change; changes will be announced in advance.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>All Volunteers</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 23, 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>HNW Volunteer Plan 2019</td>
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<tr>
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<td></td>
<td>Erin Long &amp; Wendy</td>
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<td>Rohrbacher, MA CFRE</td>
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<tr>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>February 27, 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Communication and Sharing Your Presence</td>
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<tr>
<td>Presence</td>
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<td></td>
<td>HNW Spiritual Counselors</td>
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<tr>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<td>Date</td>
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<tr>
<td>March 27, 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Infection Control &amp; Understanding</td>
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<td>Terminal Illness</td>
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<tr>
<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>April 24, 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Grief, Loss, and Bereavement</td>
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<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>May 22, 2018</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Patient Communication &amp; Family</td>
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<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>June 26, 2018</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>HNW Veteran’s Programs / We Honor Veterans</td>
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<td>Date</td>
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<tr>
<td>July 2019</td>
<td>NO MEETING – ENJOY YOUR SUMMER!</td>
<td></td>
<td><strong>VIGIL TEAM MEETING AS NEEDED</strong></td>
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<tr>
<td>August 2019</td>
<td>NO MEETING – VOLUNTEER APPRECIATION GATHERING</td>
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<td><strong>VIGIL TEAM MEETING AS NEEDED</strong></td>
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<tr>
<td>September 25, 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Volunteer Boundaries &amp; Safety</td>
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<td></td>
<td></td>
<td>Christine Nidd</td>
<td>Leanna Anderson &amp;</td>
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<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<td>October 23, 2018</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Recognizing and Reporting Patient</td>
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<td></td>
<td>Leslie Estep</td>
<td>Leanna Anderson &amp; Dr.</td>
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<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>Date</td>
<td>Time</td>
<td>Volunteers</td>
<td>Event Description</td>
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<td>November 27, 2018</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Pet, Music, and Allied Therapy</td>
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<td></td>
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<td>Erin Long &amp; Leanna</td>
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<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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<tr>
<td>December 2019</td>
<td>1:00 – 3:00</td>
<td>All Volunteers</td>
<td>Volunteer Luncheon with HNW Staff</td>
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<td>Bob Laws &amp; Erin Long</td>
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<tr>
<td></td>
<td>3:00 – 3:30</td>
<td>Vigil Volunteers</td>
<td>Vigil Team De-Brief and Training</td>
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Interdisciplinary Group and Ethics Team Meeting Schedules

Interdisciplinary Group (IDG Meetings)

**Purpose:** Meetings held three week day mornings, during which our interdisciplinary teams discuss patients, plans of care, admits, deaths and Medicare re-certifications. Hospice Medical Director and staff facilitators participate.

**Schedule:** Held every Tuesday, Wednesday, and Thursday morning from 8:15am – 10:30am (or until business is finished):

- **Tuesday - South Team** (Mount Vernon, La Conner, Conway, Stanwood/Camano, Arlington, Darrington and Snohomish County)
- **Wednesday - West Team** (Anacortes, Whidbey Island, San Juan Islands)
- **Thursday - North Team** (Alger, Burlington, Bow, Clear Lake, Concrete, Marblemount, Newhalem, Rockport, Samish Island, Sedro Woolley etc.)

**Location:** Hospice of the Northwest Conference Room

**Comments:** You are encouraged to attend these meetings, particularly if your patient is being discussed.

Ethics Team Meeting

**Purpose:** Monthly meetings to help staff, volunteers, patients and families with difficult health care decisions that occur near the end of life. These meetings are chaired by a Hospice Medical Director; the committee includes HNW staff, community members and a volunteer.

**Schedule:** This one (1) hour meeting is held the third Wednesday of each month following IDG meetings. They generally start around 10:30 am and run until about noon.

**Location:** HNW Conference Room
Purpose
The intent of the Quality Assurance and Performance Improvement (QAPI) Charter is to establish a common understanding of the authority and responsibilities of this Quality Committee. Adoption of the Charter indicates agreement with the purpose and content as described herein. By adopting this document, each Quality Assurance Team representative agrees to rely on the Charter as the basis for determining and fulfilling all actions executed on behalf of the Quality Assurance Team.

Membership and Terms of Service
Committee members shall include the following permanent members:

- Manager of Quality and Compliance (Chair & Secretary)
- Either the Hospice Medical Director or Assistant Medical Director
- Executive Director
- Manager of Clinical Services – Nursing
- Manager of Clinical Services – Counseling
- Referral Center Manager
- Volunteer Services Manager
- Bereavement Coordinator
- Care Aide Supervisor
- Outreach and Communications Program Manager

In addition, the following members will have 2-year terms, with the possibility of serving up to 2 consecutive terms:

- A Registered Nurse
- A Social Worker
- A Spiritual Counselor
- A Hospice Aide
- A Community Member

Policy Subcommittee Members
The Interdisciplinary Team responsible for the policies governing the day-to-day provision of hospice care and services is made up of the members representing the 4 core disciplines (physician, RN, social worker, spiritual counselor) on the Quality Committee, or their same discipline designate, as well as any additional members as determined by the subcommittee.

Member Substitution
If one of the core team members (physician, social worker, spiritual counselor, registered nurse) is unable to make a scheduled meeting, a substitute from the same discipline will be arranged to stand in for that meeting.
Meeting Schedule
The Quality Committee meets monthly, as needed, but no less than six times a year. Meeting dates typically occur on the 1st Friday of the month, or at a different time as agreed to by the committee.

Authority
The Quality Committee makes recommendations to the Administrative Team, and to the Operating Council. It is not up to the Quality Committee to implement change.

Responsibilities
The Quality Committee assists the Operating Council in overseeing and ensuring the quality of clinical care, patient safety, and customer service provided throughout the organization.
The Quality Committee will report to the board at least quarterly, including an in-depth annual quality review. Regular reports will include:

- Quality indicators, including roll-up measures of clinical quality, patient safety, and customer service.
- Progress on major performance improvements.
- Root Cause Analysis, if any.
- Patient/family satisfaction/perceptions.
- Employee satisfaction/perceptions.
- Accreditation.
- Compliance Audits.
HOSPICE RESOURCE CENTER LIBRARY

The Hospice Resource Center Library, boasting over 1100 titles, workbooks and DVD’s, is one of the largest collections of its kind in the country. The library is open to the general public, Hospice staff and volunteers.

Before you check out a book, you will need to fill out a library card. These are available on the bookshelf on the right side as you enter the Hospice lobby. Please fill out the card completely and give it to the Receptionist. Books may be checked out for three weeks and returned to the basket on the shelf. Please return books on time so that others may use them.

If you are at home, and want to see what books we have available, you will use the Evergreen Library System which is part of Burlington Library. Go to http://burlington.skagitcat.org. On the opening page you’ll see the search links and can open the drop down box for Libraries. Simply scroll down to Hospice of the Northwest Library, click, and you can search by topic, author, titles, and so on.
Volunteer Liaison Role by the Spiritual Counselor

Purpose:
To bring the perspective of the volunteer into the IDG as well as provide support and coaching (not supervision) for the volunteer. This will encourage integration of the volunteer into the team and help them with role identity and healthy boundaries. All essential to improved patient/circle of support care and increased volunteer involvement/satisfaction.

Process:
1. SC will be provided volunteer assignments on a daily basis by their Manager

2. SC will add themselves to the team if not already involved:
   - Add Care Team Attribute
   - Add Goal – Use Cert Period for timeframe
     - Suggestion – “Promote integration of all members within the IDG Team”
   - Add Intervention Suggestions
     - “Initiate and maintain contact with Volunteer”
     - “Provide support and coaching to volunteer”
     - “Provide volunteer perspective to the IDG”
   - Add VFO – 1 x month for monthly phone calls to volunteer. If a phone call is not needed it can be canceled as not needed.

3. Use SC Phone Visit to document the calls
   - Use Narrative Form – document contact with the volunteer as needed. Contact with a newly assigned volunteer should occur within 2 – 3 weeks after assignment. Further contact is determined by the SC on an as needed basis.

4. IDG Documentation:
   - Document “From the Volunteer” and add any new info the volunteer would like the team to know. This documentation can be repeated as long as it is current.

5. If the SC believes regular contact with the Volunteer is not necessary or the Volunteer would not like this support the SC can d/c the plan of care including VFOs and remove themselves from the team if no SC involvement.
This position reports to the Volunteer Manager.

**Responsibilities:** Volunteers must . . .
- Accept assignments and supervision from the Volunteer Manager for patients/families referred by the Hospice Interdisciplinary Team.
- Provide **1 - 4 hours of service to the patient/family per week** which may include: support and companionship, respite, light household tasks and simple meal preparation.
- Schedule all patient visits with designated HNW staff.
- Document all patient/family contacts on CallWyse.
- Maintain universal health precautions.
- Uphold confidentiality and protection of patients’ and families’ rights.
- Maintain appropriate boundaries.
- Attend at least six (6) volunteer support meetings or educational in-service trainings per year.
- Complete an annual self-assessment, site evaluation and interview with the Volunteer Manager.
- Agree to uphold HNW policies, procedures and philosophy.

**Requirements:** Volunteers must . . .
- Complete an Application.
- Meet with Volunteer Manager for formal, in-person interview.
- Successfully complete a Washington State Background Check.
- Sign a Confidentiality/Compliance form.
- Provide at least 2 recommendations.
- Complete required health screenings with negative results.
- Provide required, current documentation including: immunization records, driver’s license, and proof of automobile liability insurance.
- Successfully complete an **18-hour training class** for Patient/Family volunteers.
- Participate in an annual evaluation and site visit.
- Sign a Volunteer Agreement.

**Qualifications:** Volunteers must . . .
- Be 21 years of age or older.
- Demonstrate emotional maturity.
- Not have had a significant personal loss in the preceding 12 months.
- Demonstrate excellent listening and communication skills.
- Respect a variety of patient and family belief systems.
- Be reliable and punctual.
- Have means of transportation or is able to access public transportation.
- Have access to phone service and the Web.

I have read, and agree, to the above ____________________________ Name ____________________________ Date
SECTION 6
PATIENT/FAMILY BOUNDARIES, SELF-CARE and IN THE END

Boundaries and Self Care
Boundary Issues Questionnaire  Page 3-4
Understanding the Patient and the Volunteer’s Role  Page 5
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In the End
Supporting Patients at the End of Life, Saying Goodbye  Page 43-44
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Hospice of the Northwest volunteers often face situations with patients and families in which they may have difficulty deciding what to do.

1. Accept a gift from a patient or family. Yes No
2. Buy a gift for a patient or family. Yes No
3. Accept money from a patient or family. Yes No
4. Take food or beverages from home to a patient or family. Yes No
5. Lend personal belongings to a patient or family. Yes No
6. Give your home phone number to a patient or family. Yes No
7. Invite a patient or family to an activity or party outside of your volunteer assignment. Yes No
8. Transport a patient or family member in your car. Yes No
9. Email or text a patient or family. Yes No
10. Use a patient’s name, ID number or other identifying information in an unencrypted email. Yes No
11. Provide a standby assist for a patient. Yes No
12. Lift or turn a patient. Yes No
13. Share personal/intimate information about yourself with a patient to the extent that it diverts attention away from them. Yes No
14. Talk about a patient in public. Yes No
15. Talk about a patient with a friend or family member. Yes No
16. Provide opinions or advice to a patient (e.g. on medical care, family issues, funeral options, wills and other issues). Yes No
17. Try to persuade a patient to change their religious or spiritual beliefs. Yes No
18. Perform heavy household tasks for a patient or family (vacuuming, mopping, cleaning bathrooms). Yes No

19. Help a patient with toileting. Yes No

20. Disclose information about other Hospice volunteers or staff. Yes No

21. Speak poorly of Hospice, its staff or volunteers. Yes No

22. Offer your opinion about “Death with Dignity” with patient/family. Yes No

23. Attend the memorial service for a patient. Yes No

24. See a family socially after a patient dies. Yes No
Understanding the Patient and the Volunteer’s Role

Each person has his/her own history and experiences, personality, beliefs, values, culture, spirituality, family and social network.

- Do respect who they are, how they are, why they are as they are.
- Do not try to change them.
- Do not try to fix them.
- Do respect their way of doing things.
- Do not try to impose your ways on to them.
- Do be patient with them.

People who receive care may be losing control of their life, their body, their mobility, their independence, their ability to do things for themselves and their personal space.

- Do be sensitive to their need for control.
- Do ask permission and give choices.
- Do not assume you know what they need or want.
- Do not do what they can do for themselves.

Hospice patients often have multiple needs and it may be overwhelming to them or to you.

- Do the job(s) you are assigned to do.
- Do not take on other tasks if asked.
- Do report to the Volunteer Manager, RN Case Manager, Social Worker, or Spiritual Counselor if you have concerns about your patient’s safety or welfare.

People may have difficulty being dependent or receiving care from others.

- Do be patient and sensitive to how it is for them to be in need.
- Do not take grumpiness, efforts to control, rejection or resentments personally.

It may take time for your patient to trust you.

- Do keep your word and honor your agreements.
- Do not expect instant intimacy; start where s/he is comfortable.
- Do respect confidentiality and privacy.
- Do not preach or try to convert to your ways of belief.
- Do not give unsolicited advice and be cautious about giving advice when asked.
- Do not join in their complaints about family and/or friends.
- Listen but do not join in on their complaints about HNW Staff.
- Do listen with caring and concern while they share their distress, stress or pain.
- Do not give medical advice or nursing care.
- Do report anything uncomfortable or questionable to the Volunteer Manager.
Things You Should Do as a HNW Volunteer

Communication

- Call the Volunteer Manager when you have a question or concern.
- Return phone calls, e-mails and/or texts from the Volunteer Manager as soon as possible.
- Notify the Volunteer Manager if you will miss more than one patient visit due to a vacation. Please give as much notice as possible regarding whether the patient requests a substitute volunteer.
- Notify the Volunteer Manager when you stop seeing a patient, become unavailable or available to take a patient(s).
- Notify the Volunteer Manager if you decide to “retire” from volunteering or become “inactive.”
- Notify the Volunteer Manager of changes to your contact information: name, address, phone numbers and/or e-mail.
- Call patients/families/caregivers before every visit, if visiting a home, to confirm the time and insure that the patient feels “up to” a visit. If there is no answer after two (2) attempts, do not visit that day and note as “Patient Not Home” in CallWyse.
- Call the receptionist if you have concerns about a patient and ask to be connected to their Case Manager. Concerns include pain, falls, accidents, increased symptoms, etc.

Documentation

Volunteers are subject to the same documentation requirements and consequences as Hospice staff, and therefore must cease Hospice volunteering if any documentation is out of date. Volunteers may be made active again once documentation is current.

- Schedule all patient visits by calling, or e-mailing the Volunteer Manager.
- Sign In to CallWyse at the beginning of each patient visit.
- Sign Out of CallWyse at the end of each patient visit.
- If volunteering in another capacity (e.g. in the office), use CallWyse at the end of your shift.
- Report to the Hospice Office suspected abuse, neglect and safety issues as soon as you are aware of them.
- Submit annual Flu Shot documentation.
- Submit current Driver’s License and Auto Liability Insurance coverage documentation as they come due.
- Complete an annual Field Observation and Evaluation.
- Complete and submit a Volunteer Agreement annually.

Safety

- Wear your name tag to all patient visits.
- Wash your hands with soap and water before and after all patient contact.
- Follow all infection control guidelines learned in this manual.
- Do not lift or transfer patients.
- Do not toilet or assist with toileting patients.

Support

- Attend as many Volunteer Support Meetings per year as possible; Vigil Volunteers must
Also attend as many Vigil Volunteer Meetings annually as possible.

- Utilize other support and Education opportunities through Hospice of the Northwest.
- Use the volunteer self-care suggestions and resources in this binder.

**Evaluation**

- Complete and submit *written evaluation* annually.
- Participate in at least one, in-person *Field Observation* annually.

**Privacy and Confidentiality**

- Uphold all HIPAA guidelines.
- Contact the Volunteer Manager if you unsure if HIPAA guidelines apply.
- Immediately notify the Volunteer Manager if you inadvertently fail to uphold the HIPAA guidelines.
Things You Should Not Do as a HNW Volunteer

MOST COMMON VOLUNTEER VIOLATIONS:

1) Giving your personal phone number to patients/families (Use *67 or *69 to block your phone number)
2) Using patient names or ID numbers in emails
3) Spending time with a patient after Hospice discharge or revocation, or spending time with the family members after a Hospice patient has died.
4) Providing standby assists
5) Using your own computer for anything for the patient EXCEPT for playing music or a movie
6) Taking a patient’s photo on your camera or phone

Moving Patients: DO NOT . . .

- Help a patient walk (even gently holding their arm as they ambulate)
- Lift patients. This includes lifting a patient off the floor after he/she has fallen. If a patient has fallen and can’t get up on his/her own, please call Hospice and they may direct you to call 911 for a citizen’s assist.
- Transfer (move) patients from one place to another (bed to chair or wheelchair, etc.)
- Turn a patient in bed or place them in a prone position (lying on stomach).
- Transport patients, caregivers, friends or relatives in a vehicle or by other means.

Toileting Patients: DO NOT . . .

- Provide personal toileting care such as wiping or cleaning up after toileting accidents.
- Help a patient to the commode or bathroom.
- Empty bed pans, urinals, commodes or catheter bags.
- Change a patient’s underwear or incontinent pads.

Confidentiality and Privacy Issues: DO NOT . . .

- Talk about the patient/family to anyone other than a Hospice of the Northwest staff member or volunteer.
- Talk about your patient in public.
- Leave patient names, phone numbers or other identifying information, in plain view, in your vehicle. Lock it in the trunk or take it with you.
- Take a photo or video of a patient/family on any camera or cell phone other than their own.
- Type a patient’s life story or other information on any computer other than their own.
- Store a patient’s photo or any other documentation (autobiography, e.g.) on your computer.

Medications and Medical Assistance: DO NOT . . .

- Put medications directly into a patient’s mouth. If the patient can pick up the pills, or can pick up a cup in which the caregiver or family has measured out the medication, you may assist with sips of water.
- Administer suppositories.
- Give injections.
- Use specialized medical equipment.
- Change bandages.

Personal Care and Activities of Daily Living: DO NOT . . .

- Put food into a patient’s mouth, either by hand or with a spoon or fork.
• Bring food or beverages from home to a patient, family or caregivers.
• Drink alcohol with a patient or family.
• Smoke while visiting a patient or visit while smelling of smoke.
• Assist in giving the patient a bath, bed bath or shower.
• Cut fingernails or toenails.
• Shave a patient.
• Give a massage anywhere other than on the hands and feet. Remember to be very gentle.

Respite Care: DO NOT . . .
• Provide respite care unless you can provide it safely and without violating Hospice policies.
• Provide respite care unless you have answered all the questions on the page “Questions to Ask/Consider before You Are Left with a Patient.”

Financial and Legal Issues: DO NOT . . .
• Witness the signing of legal documents.
• Give out your personal phone number, email or other contact information to patients/families/caregivers, nor text or email patients/families.
• Accept money or gifts from a patient/family member/caregiver.
• Accept money in order to purchase something for the patient. The patient/family must provide you with a prepaid gift card (Fred Meyer, Safeway, Haggen).
• Accept employment or do business with a patient and/or their family/caregivers.

Boundary Issues: DO NOT . . .
• See any patient without an assignment from the Volunteer Manager or his/her designee.
• Provide more than four (4) hours per week of volunteer service without first clearing it with the Volunteer Manager.
• Visit a patient after they have been discharged from Hospice or their Hospice benefit has been revoked.
• Have regular contact with the family/caregiver/loved after the patient’s death.
• Visit a patient’s family, caregiver or loved ones after the patient passes away.
• Overstep your role as a volunteer and perform tasks or ask questions which are within the domain of HNW paid staff.
• Take a friend or family member on a visit.
• Give gifts to patients.
• Provide child care for a patient/family unless it is during a vigil and a responsible adult is also on the premises.
• Take a pet to visit a patient or facility unless you are with an approved Pet Partner Volunteer and have been assigned to provide pet visits to this patient.

Please note that violation of these guidelines may result in consequences up to and including termination of volunteer status. If you inadvertently perform one of the activities above, contact the Volunteer Manager immediately.
Maintaining Boundaries

On the surface, maintaining boundaries between yourself and your patients may seem like something that isn’t important. After all, you are a Hospice volunteer rather than a staff member, and you are there specifically to bring comfort and support to the patient and family. Doesn’t it always help to extend ourselves and go the extra mile to help patients and their loved ones? The answers are actually yes and no.

Patients are vulnerable on many levels. Maintaining professional boundaries protects patients, and their families, from exploitation during their time of vulnerability. Appropriate boundaries also protect volunteers, HNW and its two hospital owners, from liability risks.

Boundary violations result when there is confusion between the needs of the volunteer and those of the patient. These violations can include excessive personal disclosure by the volunteer, secretive behavior, accepting or giving gifts, spending inappropriate amounts of time with a patient, “helping” the patient and/or family in ways outside their job description or continuing the volunteer/family relationship after the patient dies. Boundary violations can cause delayed distress for the patient, which may not be recognized or felt by the patient at the time the violation occurs. There are, of course, serious boundary violations that can lead to criminal prosecution and legal liability, including theft, sexual misconduct, etc.

Hospice staff and volunteers who provide services should inspire confidence in their patients. In turn, patients can expect the caregiver to act in their best interest and respect their dignity. Volunteers should abstain from obtaining personal gain at the client’s expense. Staff and volunteers should refrain from inappropriate involvement in the client’s personal relationships. The volunteer should always promote the client’s independence.

Guidelines for “Staying Within the Lines”

- Understand the importance of boundaries.
- Maintain behavior and presence which supports the patient’s best interest and dignity.
- Be self-aware and understand why you choose to volunteer for Hospice.
- Before you go to each assignment, clear your mind from the day and prepare to give your patient your complete attention.
- Be clear about your role, and its limitations, from your first visit.
- Use appropriate and limited self-disclosure.
- Encourage patient and families to use the 24-hour Hospice phone number.
- Set and stick to time limits in your work.
- Do not give patients and/or families your personal phone number or e-mail; do not send text messages, e-mail them, communicate with them on Facebook or other social media (HIPAA violation).
- Many of the clauses in the Volunteer Agreement, and information in the “Volunteers Do’s and Don’ts” handouts, address boundary issues. A condition of your continued volunteer involvement with HNW is that you follow these guidelines. If you have any questions, or find yourself unable to comply, contact the Volunteer Manager.
- If you do, inadvertently, cross a boundary, please notify the Volunteer Manager within 24 hours.
Just Imagine. . .

- A hospice volunteer brings a homemade dinner and bottle of wine to her patient and family.
- A volunteer speaks at a patient’s funeral, explaining that he was one of her most beloved Hospice patients.
- A hospice volunteer invites a patient’s spouse to attend church with her.
- A hospice volunteer brings his wife on a visit to his patient’s home.
- A hospice volunteer accepts $50 cash from a patient to buy her medication.
- A hospice volunteer drives a patient in her car.
- A hospice volunteer lifts a fallen patient off the floor, cleans them up after an “accident” or assists them in the bathroom.
- A hospice volunteer offers to clean the patient’s house for a fee.
- A patient asks for a back rub from a volunteer, takes off his shirt, and she gives him one.
- A hospice volunteer becomes friends with a bereaved spouse after his patient’s death and sees him on an ongoing basis afterwards.
- A hospice volunteer stays with a patient for 8 hours while her husband goes to Olympia for the day.
- A hospice volunteer suggests to her patient that it would be a good idea to take some aspirin for his headache.

. . . and then remember that these are examples of boundary violations.
FAQ for New Hospice Volunteers: 15 Simple Questions You’re Afraid to Ask
By Lizzy Miles, pallimed.org, November 16 2016

Before I was a hospice social worker, I was a volunteer. I was so nervous to visit my first patient. Over time, I became more comfortable. Through the course of switching careers from volunteer to social worker, I attended volunteer training at several organizations. There is a lot of really good information provided, but sometimes hospice staff forget what it’s like to be NEW. These are the questions I had when I first started. Once I gained experience, and went to school for further training, I decided it might be helpful to write out the answers for others who are just embarking on their hospice journey. It is rewarding.

How do I start the conversation?

If you are meeting a patient for the first time it may be helpful to speak with the volunteer coordinator to get some helpful information about the patient. Introduce yourself and explain who you are and why you are there. If this is not possible, then it may be helpful to start by checking in with the patient, "How are you feeling?" Ask them about their comfort level and possibly "Do you have any pain?" Ask them about their family, interests, and if they would like to share anything. A good conversation starter and question is "tell me about.... cars, when you were young, a time when you were happy?"

Other tips:
• Talk about weather, news, or something that is going on currently. It’s probably best to stay away from politics, but if patient wants to talk about it, you can listen.
• Silence is okay, give them time to think. Avoid rapid fire questions as they will confuse and be hard to understand.
• Look around the room for cues of things to talk about: pictures, decorations, religious artifacts, figurines.
• You can comment on people in pictures, but keep in mind, if patient has dementia, they may be distressed by not being able to identify who it is. So you can remark on their expression. "She looks happy!"
• Make this time about them. Redirect back to them if they ask you too many questions about yourself.
• Be patient. It takes time to build a relationship.
• Listen and observe their body language.

Why do I need to ask permission?

Hospice philosophy emphasizes patient-centered care. Hospice patients and families can feel like they have no control over the situation they are in. By asking permission before you sit or start a visit, you are giving them a sense of control. As a volunteer you want to show respect for patients and make them as comfortable as possible. When you ask permission, they know they have the option to say NO, or refuse your visit. In addition, being courteous and respectful helps to open up the conversation and ensure the patient is willing to meet today.

What do I do if they are sleeping?

If a patient is sleeping you can wake them if you are only there to see this patient and do not want to waste a visit. They can always send you away if they do not want to visit. You will learn by their reaction the first time you try to wake them whether it is a good idea.
Sometimes all you have to do is sit down next to the patient and they hear you and wake up on their own.

The best way to wake a patient is to call their name at a slightly raised voice. If this does not work, then proceed to touch their forearm or hand just above the wrist, and call their name again. If after several attempts to wake the patient they do not wake, whether you stay in the room or leave will depend on the plan of care you’ve been given and the purpose of your visit. Your volunteer coordinator may be able to offer suggestions regarding the best time of day to visit.

Other tips:
Facility patients: If you have other patients in the facility, then go and see them first and then return to this patient.
Home patients: The caregiver can give you guidance as to whether to wake the patient.

What do I say when they ask me about myself?

If you feel comfortable answering the question and sharing about yourself then that is okay. Be aware that some information should not be shared and the visit is for the patient. The patient has enough to worry about with their own life without worrying about us, so we should keep our sharing on a positive note. One should share information if it will help to strengthen the relationship and build rapport with the patient. If you do not feel comfortable with a question simply tell them so. Sometimes patients will ask your opinion on things. You can redirect back to them by saying, “I’m not sure. What do you think?”

What do I say if the patient asks me, “Why am I still here?”

It is not uncommon for patients at the end of life to have existential questions. They do not really expect you to have an answer to this. A simple way to respond to these type of questions would be to provide a reflective statement. “You’re wondering why you’re still here.”

What do I do if family is there? (Facility)

Introduce yourself as a hospice volunteer. Ask if the family member(s) would like you to join them with visiting the patient or if they want time alone. Their visit takes priority, so never let them feel they need to leave so you can visit. However, sometimes family members will use the arrival of a volunteer to allow themselves to leave. You will have to read the situation.

What do I do if they ask me to leave?

Say "Thank you for your time" and leave. It is important to remember that this is their home whether in the community or in a facility. As a volunteer we should respect their wishes and their desire for privacy. If the situation allows, ask if you can return some other time to visit with them.

What if I have to leave and they won’t stop talking?

The best way to handle a talkative patient is to start “leave-taking” behavior before you actually need to leave. Leave-taking behavior is the non-verbal actions that someone does when they are about to leave a room. If you do them slowly, the patient will understand your visit time is coming to an end. Behaviors can include putting on a coat, gathering your things or shifting forward in your chair. When you have the opportunity to say something, you can tell the patient "I have to leave in 5 mins." Another way of saying this is "I'm sorry, I have to get going and I had a wonderful time with you today. I hope we can continue
our conversation next time we visit.”

As you get to know the patient, you will learn how much time in advance that you need to start the leave-taking. If you are scheduled as a regular volunteer with the patient, you can tell them that you will continue the conversation the next time and that you look forward to hearing more about xyz. If they ask when your next visit will be, you may tell them an answer if you know (i.e. next week, in a few days).

**What does it mean to “be present”?**

When we are with a hospice patient or family member, we want to be completely there, both physically and mentally. Turn off your cell phone and put it away. Disregard what has happened on your way to see the patient and do not think about what is happening after the patient. Give 100% to the patient and what their needs are at this moment.

**What do I do if they want to give me something?**

Hospice patients and families are considered to be “vulnerable populations.” It is not uncommon that they may feel indebted for the time that you are spending them. Gracefully decline all gifts, as it is hospice policy. Assure them that knowing them is a gift in itself. If they want to do “something” you can tell them to write a thank you letter to the hospice, or tell their friends and family about their positive hospice experience.

**What if I want to give the patient or family something?**

Remember, that for most patients, they are learning to “let go” of the material world. Patients at the end of life have a greater appreciation for the intangible gifts such as your time and presence. Do not underestimate the value of what you do.

Ask the volunteer coordinator if you have something in mind that you want to give the patient. It may be acceptable to give a small item such as a flower, but beware of the power of reciprocity. By giving gifts you could create a greater feeling of imbalance. Food items can be tricky for multiple reasons. Family members may have a different idea of what the patient should be eating, or the patient could have a medical condition that affects their swallowing or digestive capabilities.

**What do I do or say if the patient or family member starts crying?**

Allow the tears to flow. Don’t be uncomfortable with the tears and do not rush to offer a tissue unless they appear to be looking for one. (Try to read their body language.) You don’t have to say anything, but if they seem like they want to talk about it, you can say something like, “It seems like I may have said something that has stirred up some emotions. Would you like to talk about whatever is going on?”

**What do I do if they say they are in pain?**

Hospice nurses are specialists in pain control and so this is not likely to be a frequent occurrence, but it could happen. If the patient is in a facility, you can press the call button or ask the patient if they want you to find a nurse. Sometimes a patient may describe pain but then tell you they do not want you to call a nurse. If a patient is at home, notify the patient’s caregiver of their pain report. In the meantime, you can ask if there is anything you can do to make them more comfortable (i.e. adjust their pillow or blankets, hold their hand).
What to do if they fall?

Do not move them!! Ask if they are okay. If in a facility go and get a nurse or notify a staff member that the patient needs assistance. If at a home notify a family member and call the hospice nurse or volunteer coordinator. As a volunteer we are not trained to assess a fallen patient or assist in transferring them safely so it is best to leave it to those who are familiar with the process.

What to do if they complain about a facility?

There are some things about our lives that we can change and some things we cannot. Sometimes patients just need to vent. It’s important to remember that we cannot necessarily “fix” every situation. Your primary role is to let the patient feel they are being heard. You may also ask them if they have raised their concerns with the facility. If they haven’t, then encourage them to share their concern with the appropriate department.

Some questions or complaints are resolvable “I don’t know when dinner is.”

Do not get involved in trying to resolve an issue, unless it is an immediate need that you can support by finding someone, “I pressed the call button 20 minutes ago and they still haven’t come.” You may be able to walk to nurse’s station and relay the patient’s need. Talk with your volunteer coordinator if you have questions or concerns related to information the patient tells you.

Depending on the nature of the complaint, you may also be able to reframe or redirect.

When you reframe, you are helping the patient look at the situation in a new light. For example, if they are talking about the food being bad then say something like “you were telling me the other day how much you loved the tapioca pudding.”

To redirect a patient, you might say something like, “it’s not the same as home-cooked meals. What were some of your favorite foods to make?”

Always remember you are not in this alone. The volunteer coordinator is just a phone call away for any questions or concerns that you have.

Lizzy Miles, MA, MSW, LSW is a hospice social worker in Columbus, Ohio and author of a book of happy hospice stories: Somewhere In Between: The Hokey Pokey, Chocolate Cake and the Shared Death Experience. Lizzy is best known for bringing the Death Cafe concept to the United States. You can find her on Twitter @LizzyMiles_MSW
Creating Meaning through Storytelling and Life Review

For someone with a limited prognosis, looking back on life provides an opportunity to create meaning. In the telling of their unique story, patients are able to acknowledge life accomplishments and the value they contributed to the world and to others. This is an important aspect of life closure.

Two Minnesota psychologists, Howard Thorsheim and Bruce Roberts researched the impact on storytelling on more than 10,000 elderly people. They found that reminiscing helps people find common ground with others and engage in a process that brings about mutual support. In the hospice setting, storytelling can help the patient feel empowered by focusing on positive life experiences. Encouraging patients to share their stories can also strengthen familial bonds.

For caregivers, a loved one’s story may provide opportunity for understanding and enlightenment. Learning of history and traditions may bring comfort and meaning following loss. Too often, in the midst of focusing on the tasks of caregiving, families may forget to find time for meaningful conversation and dialogue.

Storytelling may not come naturally to your patient and you may be unsure of what to ask or how to start the conversation. In addition, your patient must trust you, not only to keep his or her confidence, but to receive favorably their efforts to share. It is important not to probe too deeply too soon. You may wish to start by focusing on a picture or object on display, because it provides a safe boundary between what is open to discussion and may be too personal.

Asking basic questions about childhood, education, marriage or career may get the dialogue started. Inquiring about favorite foods, hobbies, movies, books or music may bring some surprises that can be incorporated into caregiving and quality time together.

These conversations may lead to more reflective questions including:

- Has this illness changed you? What have you learned?
- What are the important lessons you’ve learned in life?
- If you could hold on to one memory from your life forever, what would that be?
- How would you like to be remembered?

Below are some questions you may wish to use to start a conversation. You may choose to re-state them in your own words, or devise your own questions. Pick a few to start with, see how it goes and then proceed with a few others.

**Great Questions for Everyone**

- Who has been the most important person in your life? Can you tell me about him or her?
- What was the happiest moment of your life?
- Who has been the biggest influence in your life? What lessons did he or she teach you?
- What are you most proud of?
- What is your favorite place you’ve been?
- What are some of the biggest obstacles you’ve overcome?
- What are the important lessons you’ve learned in life?

**Past Generations**

- Where did your grand- or great-grandparents come from?
• What do you remember about them?
• What stories did your parents tell you about them?
• Where did your parents live when they were growing up?
• How did they meet?
• Where were they married?
• What were they like?
• Are there any customs or family traditions that have been passed down through the generations?

Growing Up
• Where were you born? Where did you grow up?
• What was your childhood like?
• What are your favorite family memories?
• What was the most important thing your parents taught you?
• Did you have brothers or sisters? What were they like growing up?
• How would you describe yourself as a child?
• Do you have a nickname? How did you get it?
• Did you have pets?
• What are your favorite memories of going to school?
• Who were your best friends? What were they like?
• What were your favorite songs or artists in your teens or twenties?

Ethnicity and Religion
• What is your ethnic background?
• Have you ever traced your ancestry? Tell me about it.
• Can you tell me about your religious or spiritual beliefs?
• Are there religious or spiritual books, readings or rituals that have been important to you?
• What brings you peace?

Love, Marriage and Relationships
• When did you first fall in love? Do you believe in love at first sight? If so, why?
• How did you meet your husband/wife/partner?
• What is/was your favorite thing about your wife/husband/partner?
• What were the best times?

Work
• What did you do for a living? How did you choose that profession?
• If you could have had a different career, what would it have been?

Parenting
• Do you have sons or daughters? Where do they live now?
• How did you choose their names?
• How has being a parent changed you?
• Do you have any favorite stories about your children?
Activities for Patients with Dementia

A person with dementia doesn’t have to give up activities that he or she loves. Many activities can be modified to the person’s ability. In addition to enhancing quality of life, activities can reduce behaviors like wandering or agitation.

In the early stages of dementia, the patient may withdraw from activities he or she previously enjoyed. It is important to help the person remain engaged. As dementia progresses, the following guidelines may be helpful:

- **Keep the patient’s skills and abilities in mind**, and focus on enjoyment, not achievement. This will help the individual enjoy their experiences rather than becoming frustrated.

- **Pay special attention to what the individual enjoys**. Take note when the patient seems happy, anxious, distracted or irritable. Some people enjoy watching sports, while others may be frightened by the pace or noise.

- **Encourage involvement in daily life**. Activities that help the individual feel that they are making a contribution can provide a sense of success and accomplishment. These might include folding laundry, setting the table, etc.

- **Relate to past work life**. A former office worker might enjoy activities that involve organizing, like putting coins in a holder or making a to-do list. A farmer may enjoy being in the garden.

- **Look for favorites**. The person who enjoyed drinking coffee and reading the paper may still find these activities enjoyable, even if he/she is not able to completely understand what the newspaper says. He or she may also enjoy watching the news on television.

- **Adjust activities to disease stages**. As the disease progresses, you may want to introduce more repetitive tasks. Be prepared for the patient to eventually take a less active role in activities.

Your Approach

- **Help get the activity started**. People may lack the ability to organize, plan, initiate and successfully complete the task.

- **Offer teaching, support and supervision**. You may need to show the person how to perform the activity and provide simple, easy-to-follow steps. If you notice the patient’s attention span waning or frustration level increasing, it’s time to end or modify the activity.

- **Concentrate on the process, not the outcome**. Does it matter if the towels are folded properly? Not really. What matters is that you were able to spend time together, and that the person feels as if he or she has done something useful.

- **Be flexible**.
When the patient insists that he or she doesn’t want to do something, it may be because he or she can’t do it or fears doing it. Don’t force it. If the person insists on doing it a different way, let it happen, and change it later if necessary.

- **Assist with difficult parts of the task.**

- **Let the individual know he or she is needed.**
  Ask, “Could you please help me?” However, do not place too many demands upon the person.

- **Stress a sense of purpose.**
  If you ask the patient to make a card, he or she may not respond. But if you say that you’re sending a special get-well card to a friend and invite him or her to join you, the person may enjoy working on this task together.

- **Don’t criticize or correct the person.**
  If the person enjoys a harmless activity, even if it seems insignificant or meaningless to you, encourage the person to continue.

- **Encourage self-expression.**
  Include activities such as painting, drawing, coloring, music or conversation.

- **Involve the person through conversation.**
  Even though the patient may be unable to talk, speak to them as you are participating in an activity together. You may wish to explain what you are doing.

- **Substitute an activity for a behavior.**
  If a person with dementia rubs his or her hand on a table, provide a cloth and encourage the person to wipe the table. Or, if the person is moving his or her feet on the floor, play some music so they can tap their feet.

- **Try again later.**
  If something isn’t working, if may just be the wrong time or day or the activity may be too complicated. Try again later, or adapt it.


### Additional Activity Ideas

- **Busy Mats:** These are colorful, fabric mats with objects that will keep fingers busy. They provide visual and tactile stimulation, and can awake memories of activities and routines that have been lost. The mats also help with eye-hand coordination. Mats can provide a few minutes of relief for loved ones and caregivers. Contact the Volunteer Manager to arrange to pick up a mat.

- **Marble Roll:** These are soft fabric squares with a maze sewn into them. Patients can keep their hands busy by pushing the marble through the maze. Contact the Volunteer Manager to arrange to pick up a mat.

- **Fun Kit:** Use items in the Volunteer “Fun Kit,” for example bubbles, clay, and tactile objects.
• **Sorting:** Items such as buttons, coins, poker chips, balls, bottle caps and spoons can be sorted. Playing cards can be sorted by suit, color or number. Be sure to be with and watch the patient at all times during this activity to ensure that items are not ingested.

• **Play Dough/Clay:** This can be good exercise for the hands and patients may enjoy the tactile stimulation.

• **Bubbles:** Blowing bubbles and asking the person to blow them out can be provide enjoyment.

• **Book Making:** Have the patient go through magazines and look for a specific item (e.g. birds, babies, cats, food, cars, etc.). Then cut them out and help residents to make a book.

• **Coloring:** Coloring from coloring books or coloring cut out objects such as hearts, flowers, shamrocks, stars, flags or butterflies can be entertaining.

• **Stringing:** Cheerios or fruit loops can be strung and hung outside for the birds.

• **Counting:** Counting items such as tickets, socks, clothespins, etc. can be enjoyable.

• **Ball Toss:** Throwing and catching balls can be a fun activity, especially when several patients are involved at once.

• **Look at Photos:** Dementia patients may enjoy looking at family photos or photos on your Iphone.

• **Life Skills:** Have patient fold clothes, sweep, dust, etc. can be enjoyable and help individuals feel they are making a contribution.

• **Exercise:** If allowed, take your patient outside to enjoy the fresh air. It is alright to push patients in a wheelchair.

• **Music:** Put on music and sit back and listen. Some people will sing along, some will dance, etc. Consider checking out an IPod, create a personalized song list for a patient, and let them listen to it on headphones.

• **Hand or Foot Rub:** Applying lotion gently to hands or feet can be pleasurable.

• **Finish the sentence:** Ask patients to finish nursery rhymes, songs, or sayings.
We Honor Veterans Program

In order to better serve our patients who are veterans, Hospice of the Northwest has joined a pioneering program of the National Hospice and Palliative Care Organization in collaboration with the Department of Veteran Affairs. By recognizing the unique needs of veterans and their families, Hospice of the Northwest staff will guide them through their life stories toward a more peaceful ending. The “We Honor Veterans” program is being implemented in phases. Its goals are:

- To build professional and organizational capacity for veterans
- To develop and strengthen partnership with VA and other veterans organizations
- To increase access to hospice and palliative care for veterans

We use a “Military History Checklist” as part of our intake process.

If you are a veteran and are interested in serving other veterans, or if you grew up in a military family, please let us know. We are also looking for individuals to help develop the program. Please contact the Volunteer Manager for further information. The national We Honor Veterans web-site is [www.wehonorveterans.org](http://www.wehonorveterans.org).

In addition, there is a separate national movement to collect stories of veterans. Details regarding the Veterans History Project can be found online at [www.loc.gov/ folklife/vets](http://www.loc.gov/ folklife/vets).

Supporting Our Veterans

According to recent estimates, more than 25% of those who die annually are veterans. This amounts to more than 650,000 veteran deaths each year. Moreover, because our veteran population is aging, deaths among them increase by eight percent per annum. Approximately 29,000 of these veterans die in a VA Hospital.

At Hospice of the Northwest, about 33% of our patients are veterans, 33% are spouses of veterans, and 33% have no affiliation, past or present, with the military.

Some veterans fought in World War II, and are now in their late 80’s and nearing the end of their natural life spans. Others are Korean or Vietnam War veterans. Even different wars have different cultures: soldiers coming home from World War I and II were considered heroes; while Vietnam veterans received no support when returning home. Veterans who did not go to war may have experienced innumerable losses of friends or fellow soldiers.

If veterans have seen active combat, they have seen horrific things. Some veterans returned from war able to integrate the trauma into their lives. Others bury their anguish and pain. Still others suffer from Post-Traumatic Stress Syndrome (PTSD), a severe anxiety disorder that can develop after a traumatic event resulting in psychological trauma. Symptoms include flashbacks, nightmares, avoidance of stimuli associated with the trauma, and increased arousal (difficulty falling or staying asleep, anger, and hyper-vigilance). For those veterans who were prisoners of war, confinement can feel overwhelming.

Sometimes memories of combat may remain buried for years, surfacing only during the dying process. Others are conditioned to a kind of stoicism that prevents them from admitting to being in pain or asking for medication to relieve symptoms. Some veterans experience atypical reactions to medications. Anti-anxiety drugs, for example, can make veterans feel more anxious.
At the end stages of life, some veterans experience a magnitude of guilt. Spiritual Counselors may play an important role in healing these feelings.

Volunteers can help by cultivating trust and a listening ear. Common themes are “I left my soul in Vietnam,” or another war, or “I came back a different person.” Some veterans may wish to talk about their experiences, others may not. Let them initiate the subject; do not bring it up. Questions you may wish to ask a veteran if they open the subject of their military service include:

- Tell me about your military experience.
- When and where did you serve?
- What did you do while you were in the service?
- How has military service affected you?

In addition, it is important to thank veterans for their service to our country. Acknowledging their sacrifices is a way for them to heal. Be a witness to their stories, and let yourself feel touched.

### Veteran to Veteran Volunteer Program

Hospice of the Northwest has volunteers who are veterans who are willing to make one-time or ongoing visits to patients who are vets. They have a special understanding of military culture, challenges, re-entry issues, PTSD and the need for healing. If you have a patient who is a veteran, please bring this to the attention of the Volunteer Manager so she can determine, with staff, if a volunteer veteran visit is appropriate.

Our veteran volunteers do outreach to patients who are vets during the week of Memorial Day and Veterans Day and present veterans with a small gift as a thank you for their service.

In addition, HNW veteran volunteers also offer “pinning” ceremonies at the bedside for veterans. These can take place any time of year. These may include a reading, family participation, salute, presentation of a military pin, coin or decal, along with a certificate.

### “Pinning Ceremony” / Veteran Pinning Ceremony:

The purpose of the Pinning Ceremony is to publicly acknowledge there military service and sacrifices made by the Veteran and his/her family. The ceremony gives an opportunity for each veteran to share part of his/her story (If the Veteran chooses to do so). By doing so, a sense of meaning and purpose can be gained by the Veteran.

The National Hospice-Veterans Partnership is a coalition of the Department of Veterans Affairs (VA) facilities, We Honor Veterans partners and other organizations that share the vision of improving end-of-life care for Veterans and their families.

Veteran Pinning Ceremony:

The purpose of the Pinning Ceremony is to publicly acknowledge the military service and sacrifices made by the Veteran and his/her family. The ceremony gives an opportunity for each
veteran to share part of his or her story (If the Veteran chooses to do so). By doing so, a sense of meaning and purpose can be gained by the Veteran. In order to better address the service and sacrifice of the Veteran some questions, prior to the ceremony, would assist in personalizing the Pinning Ceremony.

**Pinning Ceremony check list:**
1. What Service were you in?  
2. When and where did you enter the military?  
3. What was your rank/rate upon discharge?  
4. Where were your duty stations/assignments?  
5. How long did you serve?  
6. Did you serve in combat?  
7. Did you receive any personal medals/ribbons?  
8. Would you or any of your family members be willing to say something during the ceremony?  
9. Would you like to have someone read a personal statement from you or your family?  

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Veteran Issues at the End of Life
By We Honor Veterans Program, NHPCO

Facts about U.S. Veterans
• 26 million are alive today
• 25% of all deaths in U.S. are veterans
• More than 1,800 veterans die each day
• Only 33% of veterans are enrolled in the VA and receive benefits.
• The VA cares for a minority of vets at the end of life: 96% die in the community.

Veterans’ Unique Needs
Veterans and their loved ones may have unique needs that may be influenced by:
• Combat or non-combat experience
• Which war they served in
• If they were POWs
• If they had/have PTSD
• The branch of the service and rank
• Whether they were enlisted or drafted

War Experiences
• World War II
• Korean Conflict
• Vietnam War
• Gulf War
• Other conflicts around the world
• Peacetime

Military Cultural Norms
Influences on end-of-life experience:
• Promotion of stoicism
• Fear and admitting pain seen as a sign of weakness

Possible Outcomes from Combat
Some are able to integrate experience into their lives, especially if they:
• Are naturally resilient
• Have good family and social support
• Had a positive war outcome
• Talked about their war experiences

Traumatic Combat Memories Can Cause
• Alcohol/drug abuse
• Social isolation
• Anxieties
• Anger outbursts
• Difficulty concentrating
• Post-Traumatic Stress Disorder (PTSD)

Post-Traumatic Stress Disorder
• Exposure to a traumatic event
• Persistently re-experienced through recollections, flashbacks, nightmares or sensory distress cues
• Individual consistently avoids associated traumatic stimuli: thoughts, feelings and conversations about trauma and situations that trigger sensory distress cues
• The onset of PTSD can be acute, chronic or delayed
• How it will manifest and who it will affect is unpredictable
• Immediate treatment and ongoing support helps

Post Traumatic Growth Symptoms
• Relating to others
• Open to new possibilities
• Personal strength
• Spiritual changes
• Appreciation of life

Types of Response to War Trauma
Three responses to war trauma:
• Integrated response = Trauma has been processed and healing has occurred
• Incomplete Integration of trauma = PTSD is prolonged
• Apparent integration of trauma = Trauma is kept in the unconscious and everything seems to go on; lingering effects of war trauma; undiagnosed or delayed onset

Incomplete Integrated Response to Trauma
Indications include:
• PTSD
• History of alcohol and/or drug abuse
• Estranged relationships
• Unfulfilled longings
• Suspicion and lack of trust
• Anxiety and agitation or acting out the trauma
• Nightmares or sleeping “on guard”

How to Respond to Incompletely Integrated Trauma
• Remember that their behavior is related to trauma
• Allow the veteran to initiate the topic of their military experience.
• Provide a supportive, listening ear.
• Don’t touch unexpectedly. Call their name first.
• Some medications may help.
• Assess for environmental triggers.
• Realize that certain stimuli can re-stimulate trauma

Apparent Integration of Trauma
“I don’t want to talk about it. What good will it do anyway? Indicators that a veteran may have
Apparent Integration of trauma include:
• Acting out behaviors
• Workaholic or other addictive behaviors
• Veteran appears hollow or aloof
Integrated Response to Trauma
“...I’ve faced death before... I’m not afraid anymore... “I’ve faced death and survived... Every day since then has been a gift.” It’s important to:
- Listen carefully
- Invite them to tell their stories
- Express appreciation for their service to our country and celebrate their accomplishments with them
- Affirm the wisdom they have gained and let it impact your life

As a Veteran
- You may offer camaraderie
- Keep the focus on the veteran patient, not yourself
- Remember the veteran’s experience may be different than yours
- Open the door but never push

Veteran Volunteers who Work with Veterans in Hospice
- Bring their military training and history to their hospice work
- Offer unique opportunities that support life review and healing
- Are able to share a common language
- Share a cultural bond that opens doors of trust
- Share codes of conduct and honor
- May facilitate dissolving the barriers of stoicism and secrecy

Responding to Guilt
- Creating a safe emotional space through active listening
- Avoid trite responses

Recommended Interventions with all Veterans
- Make the environment emotionally safe
- Affirm the feeling aspect of their conversation
- Remember that stoicism may interfere with acknowledging physical, emotional or spiritual pain

Recommended Interventions for Women Veterans
Recognize them:
- Military nurses saw trauma/mutilation
- Thank older women veterans for paving the way
- Look for PTSD in women
- May have been sexually assaulted in the military

Remember
- Non-combat veterans may have served on dangerous assignments
- Combat veterans may have served in “safe” areas
- Avoid making assumptions
- Not all people who have suffered trauma will experience PTSD

Replacing Lost Medals
Volunteers may:
- Contact agencies that replace lost or stolen medals, with the veteran’s permission
• Coordinates the replacement of medals
• Directions on how to obtain medals can be found online at the National Archives website: http://www.archives.gov
• Frame the medals once they arrive.

Veterans Day/Memorial Day
Ideas for Volunteers:
• Visit Veterans on Veterans Day in homes, nursing facilities, assisted living facilities or hospitals
• Could assist facilities in celebrating Veterans Day/Memorial Day
• Volunteers who are veterans might wear their uniform and take part in the service
• Provide hospice education to veteran’s groups
• Some hospices have volunteers do “pinning” ceremonies with their patients, not connected with any holiday
Honoring Cultural Diversity at the End of Life

It has been said that appreciating differences in others helps us better understand ourselves, and that this is what ultimately unites humankind. Nobel Peace Prize winner Kofi Annan said, “We may have different religions, different languages and different colored skin, but we all belong to the same human race.”

Volunteers for Hospice of the Northwest serve a diverse cross section of the community. In our service area (particularly in Skagit County) there are a significant number of individuals with Hispanic and Latino backgrounds. In Snohomish County, those of Asian descent comprise nearly 10% of the population. Nationally, as well as locally, the number of people who identify themselves as bi-ethnic is steadily growing. Recent immigrants from various countries are scattered throughout the communities we serve. In the Skagit Valley in particular, there is an influx of migrant workers during the growing season. Awareness of cultural diversity, customs, beliefs and traditions assist us as we serve patients of all backgrounds, cultures and ethnicities.

By broadening our understanding of different cultures, we can be more skillful and sensitive communicators, not just with our patients, but with anyone we meet. Below are some strategies for developing cultural awareness:

- learn basic concepts, values and preferences of various cultures, racial and ethnic groups
- get to know the individual as well as their unique cultural influences
- refrain from making assumptions
- be sensitive and respectful
- provide a “safe” environment for communicating
- use culturally appropriate approaches

Below is the breakdown of ethnic and racial groups in the four counties we serve. Data is taken from the 2013 U.S. census.

<table>
<thead>
<tr>
<th>Ethnic or Racial Group</th>
<th>Skagit County</th>
<th>Island County</th>
<th>San Juan County</th>
<th>Snohomish County</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>75.8</td>
<td>81.2</td>
<td>89.6</td>
<td>72.8</td>
</tr>
<tr>
<td>Hispanic-Latino</td>
<td>17.6</td>
<td>6.7</td>
<td>5.8</td>
<td>9.5</td>
</tr>
<tr>
<td>Two or more Races</td>
<td>2.9</td>
<td>4.4</td>
<td>2.4</td>
<td>4.3</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>2.7</td>
<td>2.7</td>
<td>.8</td>
<td>1.5</td>
</tr>
<tr>
<td>Asian</td>
<td>2.1</td>
<td>4.8</td>
<td>1.3</td>
<td>9.9</td>
</tr>
<tr>
<td>Black</td>
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<td>3.0</td>
</tr>
<tr>
<td>Hawaiian/Pacific Islander</td>
<td>.3</td>
<td>.05</td>
<td>.1</td>
<td>.5</td>
</tr>
</tbody>
</table>
Due to the growth of ethnic minorities in America, increased attention and study has been devoted to understanding culture as it relates to death and dying. Cultural factors may impact patient perceptions of health and suffering, death and dying, health care, hospice, health care providers, medical practices and remedies. They may also impact accepted religious and spiritual beliefs, practices and rituals, communication patterns and how people express themselves. The role of the family can also differ in different cultures. And finally, culture can influence problem-solving patterns, decision-making and help-seeking behaviors.

Although all of these issues are important, research has identified three major dimensions related to the end-of-life that can vary in different cultures:

• **Communication of “bad news.”** Although disclosure of diagnoses and prognoses is fairly common in the U.S., it is not uncommon for physicians in other countries to conceal serious news from patients, because sharing it may be viewed as disrespectful, harmful and to destroy hope.

• **Health Care Decision-making.** In Western society, individualism and independence are encouraged, thus a high value is placed on patient autonomy in health care. In other cultures, there may be greater emphasis on inter-dependence and collective decision-making. In some cultures families, rather than patients, are the recipients of information about their loved one’s medical status and end up making health care decisions for them. In cultures with a high regard for authority, patients and families may prefer physician-based decision-making.

• **Attitudes towards Advance Directives and End of Life Care.** There is a lower rate of advance directives among non-whites in the U.S. This is thought to be related to mistrust of the healthcare system, healthcare disparities, cultural perspectives and family dynamics. Some studies have revealed cultural differences regarding withholding or withdrawal of life support, use of hospice services, organ donation and autopsy. A 2009 survey by the National Hospice and Palliative Care Organization revealed that the proportion of Hospice patients by ethnicity differed from the percentages in the population overall.

<table>
<thead>
<tr>
<th>Ethnic or Racial Group</th>
<th>% of U.S. Population</th>
<th>% of U.S. Hospice Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>65%</td>
<td>81.9%</td>
</tr>
<tr>
<td>Hispanic-Latino</td>
<td>13%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Two or more Races</td>
<td>2.5%</td>
<td>% not given; est. between 0-4%</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>1.5%</td>
<td>.3%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4.5%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Black</td>
<td>13%</td>
<td>7.2%</td>
</tr>
</tbody>
</table>

Below is some general information highlighting variations between cultures. It is important to understand that there are differences within cultures, families and individuals, so we must avoid the tendency to over generalize. Given that fact, it is still useful to outline some of the general characteristics that reflect a given culture and its beliefs and practices at the end-of-life.
Hispanic/Latino American Culture and the End of Life

• **General information.** The terms Hispanic and Latino are too general; it is important to learn where the patients and families are from. Elders should be addressed as Mr. or Mrs. Hispanic/Latinos are very family oriented (the family is the unit, not the individual). Extended families care for the sick and dying. The patient may be stressed if separated from the family. Hispanic males often do not go to doctors. Families are very private, with the first generation being very traditional.

• **Preparation.** End-of-life planning is not usually done, as the amount of hope one has is a sign of the depth of faith. Planning is “western thinking.” Amount of hope is a sign of the depth of faith. Many times the word “death” is never used. Pregnant women are usually prohibited from caring for a dying person or attending funerals. Family will likely want to be told of patient’s condition first but may decide not to tell the patient. They do not discuss an individual’s decline in their presence as it is seen as a sign of disrespect.

• **Home versus hospital.** Dying in the hospital may not be desirable for some patients who believe their spirit may get “lost” and not be able to find its way home.

• **Beliefs and practices.** Most Hispanic Americans are Catholic. Spiritual amulets, religious medallions or rosary beads may be used. The religious anointing of the sick may be recited and last rites are usually administered. Wailing at death is a sign of respect. There is a belief in miracles.

• **Pain and medication.** Patients may under-report pain, especially males. They may decline pain medication because pain and sickness may be viewed as punishment for past sins. Patient may use folk/herbal treatments, as well as mainstream methods.

• **Care of the body.** Death is a very important spiritual event. A relative or member of extended family may help cleanse the body. Families will request some time to say their good-byes before a body is taken to morgue.

• **Attitudes toward organ donation and autopsy.** The body is highly respected. According to the Catholic faith, organ donation is not permitted since the body must be intact for burial. There is generally a preference for burial over cremation. Autopsy becomes a family matter and must be decided by the entire group.

• **Holiday.** Dia de los Muertos on November 2 celebrates loved ones that have passed away and encourages their souls to revisit the living. Graves are decorated, elaborate altars are made and food is prepared to welcome home the spirits of the departed.

Native American Culture and the End of Life

• **Preparation.** Most American Indian cultures embrace the present. Some tribes avoid contact with the dying. In other tribes, immediate and extended family and close friends may be present up to 24 hours/day; small children included. Sadness and mourning are done in private, away from the patient. Patients may prefer to have an open window or have their body oriented toward a cardinal direction, prior to death.

• **Home versus hospital.** This varies depending upon the tribe. Individuals who are part of tribes that avoid contact with the deceased may prefer to die in the hospital.
• **Beliefs and practices.** There is a belief in a Supreme Creator and a Spirit World. The Spirit World is a place where one is met by ancestors who have passed before. It is a world of love and beauty and not to be feared. The end of life is a time of peace and understanding. Some tribes believe in two souls; one that dies when the body dies and one that may wonder on when the spirit dies.

   **African American Culture and the End of Life**

• **Preparation, beliefs and practices.** African Americans’ are historically distrustful of the health care system and lack of accessibility. Withholding life-prolonging treatment, nutritional support and resuscitation may be seen as an attempt to limit access to health care. Advance care planning is viewed with mistrust. Providers should communicate with the eldest family member.

• **Home versus hospital.** The family frequently cares for loved ones at home until death is imminent; then they are taken to the hospital. Some believe that death in the home brings bad luck.

• **Care of the body.** Families often want the health care team to clean and prepare the body. The deceased are highly respected.

• **Attitudes toward blood and organ donation and autopsy.** It is considered taboo to donate blood or organs, except if needed by immediate family members. Cremation is unacceptable because of the sanctity of body and spirit. When the need for autopsy is explained, most families understand and will allow it.

• **Funeral services.** Funerals are sometimes called “home goings” to indicate that the deceased is going to a better place. Public displays of emotion are common.

   **Asian and Pacific Island Culture and the End of Life**

• **Preparation.** Many Asian cultures are patriarchal and hierarchal; usually the eldest male or an older male makes healthcare decisions for the family. Older Korean adults and caregivers are not knowledgeable about advanced care planning or hospice and therefore the family makes end of life decisions. In the Filipino and Hawaiian communities, the extended family makes decisions for the seriously ill family member.

• **Beliefs and practices.** There is a belief that talking about bad things will create them. Some families believe that speaking about death will hasten it, or that doing so is disrespectful to the soon-to-be ancestor. Even when a loved one is in great distress while dying, there is great restraint in communicating the situation to health care providers. Traditional Filipinos may request that the family member not be told he or she is nearing end of life due to concern for the person’s loss of hope and belief that only a deity can decide one’s fate. In traditional Asian Indian cultures, there is a belief that disease is due to karma; the result of one’s actions in past lives. Illness may also be attributed to body imbalances and toxins.

• **Home versus hospital.** Individuals generally prefer to pass away at home where they may perform religious rituals to facilitate a soul’s reincarnation to another life. Cremations are rare.

   **Chinese Culture and the End of Life**

• **Preparation.** Some believe that a death in the home brings bad luck. Others believe that a patient’s spirit will get lost if death occurs in the hospital.
• **Practices.** Family members make use of special amulets or clothes. Some families may prefer to bathe the patient themselves. They may believe that the body should be kept intact; organ donation and autopsy are uncommon.

**Customs and Services**

End of life events and rituals often include cultural and religious or spiritual elements. Below is a summary of traditional customs and services.

- **African American**
  - Funerals are sometimes called “home goings” to indicate that the deceased is going to a better place.
  - Public displays of emotion are common.

- **Asian**
  - Belief that a loved one who is buried without the proper customs may bring bad luck to the family.
  - Services may be held at the home of the deceased.
  - Wreaths, flowers and a picture of the deceased often sit atop the coffin; white or yellow mums are used.
  - The deceased’s family wears white. Dark-colored clothing is increasingly acceptable at most modern Asian services. The color red is forbidden because it symbolizes happiness.
  - Incense may be lit and monetary offers may be given.
  - Family members may wear a piece of cloth as an outward sign of grief for the next 100 days.

- **Buddhist**
  - Buddhists believe in reincarnation.
  - The family and monks may wash and shroud the deceased’s remains.
  - Monks recite prayers and burn incense.
  - White flowers are the traditional color of mourning. Sending red flowers or gifts of food to the family are not considered appropriate. Instead, donations are given to the family.
  - Candles and incense are burned at the viewing and it is traditional to bow before the body.

- **Hindu**
  - A Hindu priest conducts the final services which are typically held within 24 hours of death.
  - Mourners often dress casually in simple white clothing.
  - Guests do not exchange greetings with the official mourners, but instead nod or offer a brief embrace in sympathy.
  - Flower garlands and sprays may be laid in the open casket.
  - Ten days after death a ceremony is held at the home of the deceased to liberate the soul for its ascent into heaven. Visitors to the home bring an offering of fruit.

- **Hispanic**
  - Hispanic services often follow the Roman Catholic faith and include a Sunday mass or church service. The Wake may include mariachi music and a family feast.
  - Flowers and candles are given as condolence gifts.
  - Grieving loved ones may place personal gifts inside the casket to accompany the deceased to the afterworld.
  - Mexicans and Central Americans believe that a loved one’s spirit lives on once their body has passed away.
➢ **Roman Catholic**
  - Before the final service, Catholics hold a vigil, sometimes called a Wake.
  - Candles and flowers are used at the Wake, funeral service and burial site.
  - It is customary to make a brief visit and spend a few moments in prayer and then pay respects in person to the bereaved family.
  - A priest performs the final mass, also called the Requiem, in a Catholic church.
  - Lighting a candle to honor the deceased comforts the mourners.
  - After the burial, friends and family gather at the home of a family member to share a meal and remembrances.

➢ **Jewish.**
  - Some Jewish services are held exclusively at the graveside while others occur at the synagogue or a funeral home.
  - Services cannot take place on Saturday, the Jewish Sabbath or Shabbat, or on most Jewish holidays.
  - A rabbi performs the service.
  - Burial usually takes place within 24 hours.
  - Mourners were dark colors.
  - Men wear a head covering called a yarmulke.
  - Placing earth in the grave of a loved one is an important part of the service.
  - For seven days after the burial, the immediate family sits in mourning or “Shiva” at home.
  - Family and friends may visit and pay their respects.
  - Desserts, fruit and kosher food baskets are given as are donations.
  - Observant Jews do not believe in altering the appearance or state of the body, other than ritual washing.
  - A simple shroud is used to dress the deceased for burial in a plain coffin.
  - The Caddish, a prayer affirming God, is received by the deceased children and other close relatives in the synagogue for 11 months after the funeral.

➢ **Muslim**
  - According to Islamic law, or Sharia, remains should be buried as soon as possible after death.
  - Customs vary as to whether it is appropriate to send or display flowers at an Islamic service. If appropriate, fragrant flowers and palm branches may be given.
  - Male reaction to grief may include restraints, self-control and worshipping Allah.
  - Female reaction may include traditional wailing calls, loss of self-control, such as ripping their clothes, pulling their hair, or scratching their faces.

➢ **Mormon**
  - Final services are typically held within one week of death; they are conducted by a Bishop.
  - Use of a cross or crucifix is not permitted because Latter-day Saints believe in the bodily resurrection of Christ.
  - There may be an open casket.
  - Modest, respectful attire is worn.
  - Floral tributes are encouraged and appropriate for the service.
  - Guests are expected to attend the burial.

**References:**

- Estrada, Christine M., D.O., MPH, “Cultural Traditions in the End of Life,” Hospice Inspiris
- Hospice of Florida Suncoast Volunteer Training Manual
Communication

Compassionate Communication

*Compassionate Communication is...*
- Listening with your heart instead of your head
- Listening to the emotions and feelings beneath the words
- Making room within yourself for the other person
- Meeting the other’s feelings with understanding and acceptance
- Keeping your focus on the other person
- Hearing the conflict, yet not becoming part of it by taking sides
- Staying clear and not problem-solving

The Nature of Communication

Communication is the building block of any relationship. It involves listening and speaking; both of which are equally important. Problems occur when one becomes more important than the other. We often tend to focus more on what we want to say rather than listening and clarifying what another person has said.

Listening, understanding and remembering take practice. When done well, they create better relationships, promote understanding and make the volunteer a more effective and useful support for patients and families.

The language of the body sends messages whether we are conscious of them or not. Voice volume and tone, posture, eye contact and head nods can convey that we support, honor and value what the speaker has to say. It allows for authentic presence and witnessing of another’s life and experience.

The vast majority of HNW patients are elderly. They grew up in a generation where emphasis was placed on respecting elders. Addressing senior citizens by “Mr. or Mrs.” was seen a sign of respect. Greeting your elderly patient by “Mr. or Mrs.” when you first meet can help break down barriers. If he or she asks you to call them by their first name after this, feel free to do so.

Effective Communication Techniques

Reflective or “Active” Listening

Reflective listening is saying in your own words what another has said he/she thinks or feels. Never underestimate the power of reflective listening. It is one of the most powerful communication skills available to us. In addition, it gives others an opportunity to clarify what has been said (if needed), ensures the other that they have been heard, and encourages her/him to continue talking. After re-stating or paraphrasing the patient’s words, you may want to check to make sure you have understood correctly.

*Example:*

**Patient:** My pain is really bad today. I don’t know if I can handle it much longer.

**Volunteer:** It sounds like you’re uncomfortable and find it hard to cope. Is that correct?
Open-Ended and Indirect Questions
Open-ended questions are those that elicit more than a “yes” or “no” response. They encourage an individual to share more.

Example: Volunteer: How are you feeling today? What would you like to talk about? What is your happiest childhood memory? Who, other than family members, were significant influences on you?

Welcoming Body Language
Although the spoken word is important in communicating, studies have shown that 55% of communication derives from voice tone and inflection, 38% from body posture/gestures, and 7% from the spoken word.

Use relaxed posture. Keep your hands in your lap or at your sides. Maintain eye contact. You may nod your head to show that you are listening, or occasionally use words such as “ummm.”

Use of Touch
It can be helpful to introduce touch at the beginning of your relationship with the patient. Always begin by asking if you can touch them. Shake their hand gently and warmly (please be careful due to frailty) and put your hand on his/her shoulder are examples of non-threatening touch. Consider individual and cultural differences regarding touch.

Touch demonstrates caring and concern and strengthens interactions. It should be spontaneous. Encourage the opportunity for hand and body touch through games, social interaction and even a walk down the hall. Touch can be particularly helpful with individuals who are confused and/or have visual or hearing loss.

Barriers to Effective Communication
When another person is experiencing a problem and shares it with you, this does not mean that they necessarily want help or advice. More often, people want to express how they are feeling. If you are in doubt, ask if they are willing to hear suggestions, or just want a sounding board. The following are examples of behaviors that are generally not helpful when communicating with others:

- Preaching/Moralizing by using Should’s/Ought’s (these statements convey that you are judgmental and will cause the patient to become defensive).
- Advising/Giving Suggestions/Ordering (suggests that the patient cannot solve their own problem; takes the focus away from the patient and onto yourself)
- Judging/Placing Blame (puts individual on defensive; may cause anger)
- Identification (sharing a similar experience that happened to you; rather than truly listening to the patient. You are there to support him/her, not to tell your stories. This is one of the most common communication errors).
- Stacking Questions (asking two questions at once, which is confusing)
- Warning/Admonishing (convey a paternalistic attitude)
- Using Platitudes
Additional Guidelines

There is no foolproof formula to creating effective communications. Establishing a trusting, caring relationship with your patient promotes openness. This enhances the possibility that you will respond appropriately to his/her needs.

• Remember that each patient and family is unique. **Respond sincerely,** rather than with rote answers.
• **Talk about the “here and now.”** Let the patient direct conversations.
• Stay on the patient’s topic. Don’t be eager to ask questions of interest to you; instead let the patient’s statements/stories guide your questions and comments.
• **Don’t share your own problems,** but be willing to expose some of your own insecurity, fear and vulnerability.
• **Appreciate the patient’s need for privacy.** Develop a sense of when silence is appropriate and when a person wants to talk.
• **When a patient is silent, don’t give in to your own need to fill the space with words.** Often when people are silent, they are thinking or processing what has been said.
• **Hear what the person is saying as well as what he or she is not saying.** Use all of your senses to understand what is being said.
• Be attentive, acknowledge what is being said; **be affectionate, kind and accepting.**
• **Bring good cheer;** an outward and visible expression of life, hope and joy.

Conversation Tips

• **Beginning a conversation**
  o “How has your week been?”
  o “What would you like to talk about?”
  o Tell me about your . . . . (career, family, hobbies and interests, pets, travel).
• **Useful phrases during conversation**
  o I’m listening.
  o Can you tell me more about that?
• **Acknowledging feelings**
  o You seem . .
  o You feel . .
• **Helping the patient problem solve** (if they indicate they want to)
  o What have you tried?
  o Have you told . . .?
• **Ending a conversation/topic.**
  o I’m glad you shared that with me.
  o Perhaps we can talk about this again.
Supporting Patients in the End-of-Life Journey

As death nears, hospice patients may experience a desire to deal with unfinished business, focus on their life experiences and say their “goodbyes.” Volunteers are often invited to support their patient in this journey. Below are some suggestions for helping patients in the last phase of life.

**Encourage Life Review**
If the patient wants to talk, you might ask questions about:
- Past experiences
- What has given life meaning
- Knowledge and wisdom gained to pass on to future generations

**Help the Patient and Family Find Peace**
When you listen without judgment and with genuine interest and empathy, it may make it possible for the patient to:
- Resolve inner and outer conflicts and find forgiveness
- Explore spirituality
- Identify and use their support system

**Help the Patient Say Goodbye**
Hospice patients often, when death nears, want an opportunity to say “goodbye” to those who have played a significant role in their lives. Volunteers may help achieve this by:
- Making phone calls on the patient’s behalf
- Writing letters or notes dictated by the patient
- Sitting quietly with the patient as he or she reminisces about family and friends

**Role of the Volunteer when Talking about Death**
When the patient, caregiver or family wants to talk about death, the role of the volunteer is to listen, to avoid expressing opinions or challenging beliefs, and to avoid platitudes such as “He’s going to a better place.” Listening with empathy enables a healthy venting of emotions.

**Role of the Volunteer When a Patient Dies**
When your patient dies, you may have feelings of loss, denial, anger and sadness. Feel free to discuss your emotions with the Volunteer Manager. Volunteer Support Meetings are also a place where you can share your feelings and experiences.

When you are ready, we recommend that you make a condolence call to the primary contact person. See “Condolence Calls” in this section for more information.

Hospice of the Valley Volunteer Resource Manual, Phoenix, AZ
The Value of Saying Goodbye

As a Hospice volunteer, you will learn that some patients and families will want to talk about death and dying, but others will not. Watch for cues that a conversation on this subject is welcome (see below), or simply let the patient initiate the topic if they so choose. Respect their desire to talk about it or not talk about it.

Being mindful of the moment and sharing what your patient has meant to you may give them an opportunity to do the same, without having to say a formal “goodbye.” This way, every visit will feel complete, and if a patient suddenly passes away, you will know that he or she and you have had some closure.

Talking about death: extend an invitation

- It seems like fighting this illness is wearing you down” . . . leave the door open for what they want to talk about.

Ask gentle questions or make comments that encourage discussion about the subject of death.

- “You seem a little sad this morning. How are you feeling about being so sick?”
- “I know this must be hard for you. Do you want to talk about it?”
- “You’ve gotten so sick this last month, and I’m sorry to see you suffering. How are you doing?”

Direct Discussion

- “Is there anything you would like to talk about?”
- “I know this must be a really scary and difficult time, do you feel like you are getting the support you need?”

Saying Goodbye: as much talk about life as death

- Reminiscing, taking stock in what the patient is saying goodbye to.
- The opportunity to heal conflicts and say “I’m sorry.”
- If someone can’t talk about death, this gives the opportunity to talk about life.
- “Seeing you sick makes me stop and think about how much I enjoy your presence.”
- “I’ll never forget when you shared with me. . .”
- “I think sometimes I’ve forgotten to tell you how special you are.”

Fears: fear of being alone is one of the biggest emotional aspects facing the dying and their caregivers.

- Offer presence for the dying
- For caregivers, offer companionship, talk about experiences
Condolence Phone Calls

After the death, the patient’s loved ones transition to becoming the “bereaved.” To assist this transition, members of the interdisciplinary team (RN, Social Worker, Case Manager) make a condolence phone call to the primary bereaved within three working days of the death. **Volunteers may also make condolence phone calls if they so choose, especially if the relationship was long-term.** These calls should be made in a timely manner (within 3-5 days of the patient’s death).

Condolence calls show respect for the patient and family, validate the patient’s life, and validate the caregiver’s journey. Volunteers may choose to share a special memory or story about the patient. The volunteer may wish to remind the family that support is available from HNW for the next 13 months during the bereavement period.

Condolence calls can also be helpful to the volunteer in providing closure, so that they do not “carry” the death with them. They can also bring comfort to loved ones; validating the patient’s life and the caregiver’s journey.

**Ideas to start/continue the conversation:**
“*I heard and I wanted to call and offer my condolences.*”
“*My heart goes out to you.*”
“*I heard and wanted you to know I am thinking about you.*”
“*I am sorry for your loss.*”
“*It was such an honor to help your family during this difficult time.*”

**Suggestions:**
- Mention the patient by name.
- Make sure to listen. Avoid the need to fill a moment of silence.
- Encourage expression of feelings, whatever they may be.
- Validate care that was given to the patient.

Avoid extending yourself beyond the condolence phone call.

**However, if a bereaved invites you to attend a patient’s funeral, you may do so if you wish.** However, because HIPAA confidentiality clauses protect patients even after death, you must refrain from stating that you are a Hospice volunteer, and you may not wear your Hospice pin or name badge. Thank you for insuring that patient privacy is protected.

**NOTE:** Hospice of the Northwest’s policy is that VISITS TO THE PRIMARY BEREAVED ARE NOT TO BE MADE BY STAFF OR VOLUNTEERS AFTER A PATIENT DIES. This can cause a complicated situation for the bereaved. Thank you for upholding this policy.
The Sympathy Card

The Hospice Bereavement team sends a sympathy card to the primary bereaved within three days of the patient’s death. As a Hospice volunteer, if you have had a relationship with the patient a family for a period of time, you may wish to do the same.

Blank sympathy cards are available in the Volunteer Manager’s office. If the patient lived in a private residence, you may address the card to the family at that address. It the family lives elsewhere, you may sign a sympathy card and the Volunteer Manager will address and stamp it for you. Due to confidentiality we are unable to give family addresses to volunteers.

Getting Started

- Write neatly, preferably with black or blue ink.
- Handwrite the address on the envelope.
- Use proper titles on the envelope.
- Address the card to the closest relative.
- Clearly identify yourself, e.g. “As ___________’s Hospice volunteer, I treasure the time we spent together.”

What to Say

- Be simple in your expression, e.g. “I was deeply saddened when I learned of ___________’s passing.”

- Express your condolences. It is appropriate to refer to the person’s death as a “loss.”
  - “My heart goes out to you in your time of sorrow.”
  - “Please accept my sympathy for the loss of your husband.”
  - “My thoughts are with you and your family during this difficult time.”

- Share a short story, conversation or memory regarding the deceased.”
  - “___________’s grace during her illness was an inspiration to me.”
  - “___________ taught me the meaning of true courage.”
  - “___________ devotion to your family was heartening.”

- It is alright to acknowledge the patient’s illness.
  - “I know that ___________ experienced a great deal of suffering during the last phase of his illness. I hope that you will find comfort in knowing he is no longer in pain.”

- Pick an appropriate and sincere phrase to sum up your feelings and send the card.
  - “You are in my thoughts.”
  - “With heartfelt condolences.”
  - “With sincere sympathy.”
## SECTION 7
### Volunteering 101

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# Volunteer Assignment Flow Chart

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<th>1-Volunteer Requested</th>
<th>2-Volunteer Assigned</th>
<th>3-Volunteer Contacts Patient/Family</th>
<th>4-Scheduling</th>
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<tr>
<td>Order submitted by Hospice Nurse, Social Worker or Spiritual Counselor</td>
<td>Volunteer assigned to patient; Volunteer Manager enters in medical chart</td>
<td>Volunteer calls within 24-48 hours and schedules first visit within 4-7 days</td>
<td>Volunteer calls Manager at 360.814.5588 to notify of visit. Call is made at least 1 day in advance.</td>
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<tr>
<th>5-CallWyse</th>
<th>6-Visit</th>
<th>7-CallWyse</th>
<th>8-Scheduling</th>
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<tr>
<td>Volunteer checks into CallWyse upon arrival at patient location</td>
<td>Volunteer visits patient and decides on next visit date</td>
<td>At end of visit, volunteer logs out of CallWyse</td>
<td>Volunteer calls Scheduler to notify her of next patient visit</td>
</tr>
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The Volunteer Request and Assignment Process

How do patients/families learn about the availability of volunteers?

- Every patient/family receives a “Hospice Guidebook” upon admission.
- The Guidebook has information about the volunteer program and other HNW services.
- Hospice field staff (RN, MSW and Spiritual Counselor) may introduce the idea of a volunteer to the patient/family.

How are volunteers requested?

- Requests are made to a patient’s Case Manager, RN, MSW, HCA, or Spiritual Counselor.
- The staff member determines patient/family preferences, what the patient/family would like the volunteer to do, and provides this information as well as details about the patient’s medical status and functional level to the Volunteer Manager.
- Or the family can call and request a volunteer; in which case the Volunteer Manager contacts the patient’s Case Manager to get an okay to proceed with this.
- The request comes to the Volunteer Manager on our Electronic Medical Record software.

When can a volunteer be requested?

- Field staff can request a volunteer during the second week a patient is on service, or any time thereafter.
- Volunteer requests are not accepted immediately following the admission visit unless urgent.

How will I learn about available patients?

- The Volunteer Manager will call or e-mail volunteers individually regarding new patients or will send out a group e-mail to all volunteers.
- If the request is sent out by e-mail, generally the patient is assigned to the first volunteer who responds.

How are volunteers and patients matched?

- Patients can be selected by volunteers (see above section) or
- The Volunteer Manager will assess potential matches based on geographic location, volunteer schedules, mutual interests, volunteer skills, etc.

What information will I receive about the patient?

- According to HIPAA’s Protected Health Information (PHI) clause, volunteers may receive the minimal private information necessary to do their job. Specifically, PHI can relate to the individual’s past, present or future physical or mental health or condition, the provision of health care to the individual and payment for the provision of health care. It also includes names, medical ID numbers, addresses, and birth dates.

- You will generally receive the following information:
  - Name, age, contact information (for patient and Power of Attorney/contact person)
  - Major Diagnoses, Palliative Performance Scale (PPS) score, DNR Status
  - Basic Background Information, including career, interests and hobbies (if available)
  - Marital status, basic family information
  - Functional status and mood (including mental status, communication ability, mobility, toileting, food/drink, equipment, safety precautions)
- Home Environment (smoking, pets, hazards) or Facility Information
- Type of Volunteer Request (Companionship, Respite, Household Tasks, Errands) and details as to what the Patient/Family would like volunteer to do
- Volunteer Preference, if any (male/female, speaks foreign language, etc.)
- Pain Level, Symptoms
- Significant Behavioral or Psychosocial Issues

Do patients/families ever decline volunteers?

- Yes. Although the patient/family initially states they would like a volunteer, despite that, sometimes volunteers are declined once assigned. Volunteers may be declined for several many reasons. Please know that if volunteer services are declined at the time of the initial phone call, or after a visit or two, that in most cases this has nothing to do with the volunteer and should not be taken personally.

- Sometimes a volunteer is assigned to a patient/family, and although the service is never utilized, it may just be comforting to the patient/family to know they have a volunteer assigned to them in case they need help down the road.

How Do I Make the First Contact?

- The first contact is made by phone, generally to the patient or their primary caregiver.

- The call should be made if at all possible within 24 hours of assignment (and no later than 48 hours).

- Please see “Guidelines for the First Phone Call and Visit” for more information.

- The patient should be seen within four days of assignment and no later than seven days post-assignment. If s/he cannot be seen within seven days, please contact the Volunteer Manager. When notifying the Volunteer Manager that you are interested in an assignment, please tell her when you will be available for the first visit.
Guidelines for the First Phone Call and Visit

When you accept a new patient assignment, you will be given the name/number of the primary contact person and in most cases, will receive information about a second contact person. Please make contact within 24 hours and no longer than 48 hours after you accept an assignment. If you cannot make contact that quickly, please let the Volunteer Manager know and she may choose to assign the patient to a different volunteer.

If you call the contact person and must leave a message, please ask them to return your call by dialing the main number for Hospice 360-814-5550 and asking the receptionist to transfer them to your phone number. PLEASE DO NOT LEAVE YOUR PHONE NUMBER. If you cannot reach the patient or their contact after leaving two (2) messages, call the Volunteer Manager.

The First Phone Call: Patients Living in a Private Residence

Before you make the first phone call to arrange the initial visit, review the patient information you received from the Volunteer Manager. Familiarize yourself with the situation. It’s a good idea to have a couple of dates and times in mind for the first visit. It is recommended, when possible, to first schedule an introductory visit so you can get acquainted with the patient and family or caregiver and establish an ongoing schedule. Please try to visit the patient within four days of assignment and no later than seven days after assignment. If you are unable to see the patient within a week, please contact the Volunteer Manager.

- Talking points for the first phone call:
  - **Call and introduce yourself** and share that you are a Hospice volunteer.
  - **Ask if it is convenient for them to talk** at this time (If not, arrange to call back).
  - Tell them you understand that they or a family member would like a volunteer; confirm this.
  - **Confirm the purpose of your visit:** companionship, respite or both. Ask how you can be most helpful. If they’re not sure, make some suggestions.
  - Clarify what you are not able to do and the number of hours/week you are available to visit.
  - Find the best day and time to meet.
  - If you plan a get-acquainted visit, then say “During this first visit, we can get acquainted and I can learn how I might be most helpful.”
  - If not doing a get-acquainted visit and you are going to provide respite, tell them you will come early to get acquainted and so I can meet your family member, learn where things are in the home, etc. ” (At that time we can schedule subsequent visits.)
  - State that you will call the morning of the appointment to confirm. (It’s possible the patient may feel poorly and not want a visit).
  - **Confirm the address and ask for directions** if needed.
  - Remind the family that should they need to cancel the appointment, to call Hospice at 360-814-5550 and ask to have the call transferred to you the volunteer.
  - Tell them that you look forward to meeting them.

The First Phone Call: Patients Living in a Facility

For patients in facilities, if there is a contact person, call and follow the script above. Ask them if they know a good day/time to visit. Otherwise, either call or stop by the facility and ask them about meal times. They likely will not tell you what your patient’s schedule is or release information to you because you are not listed as someone who can receive private patient information.
The First Visit in a Home

It’s natural to feel nervous before the first visit. Just be yourself, trust your training and your instincts, and assume an attitude of openness and receptivity. In turn, patients and families will let you know what they need and you’ll also be able to make observations about what might be helpful. You can let them know what you can offer and the relationship will unfold naturally.

- **Wash your hands** or use hand sanitizer gel before you leave the house.
- You may wish to **pack a bag** with some books that you can read to the patient, playing cards, etc.
- Dress neatly; **insure that your Hospice name tag is visible.**
- **Refrain from wearing scented products** as these can be unpleasant to patients.
- When the family/caregiver opens the door, **introduce yourself and state that you are a Hospice volunteer.**
- If you have not washed your hands; ask if you may do so before visiting the patient.
- **Ask how you can be most helpful** to the family today and in the future.
- **Ask questions about the patient** to get further information. Explain your role.
- Discuss a visit schedule and if possible, **set a regular meeting time.** Tell the family/caregiver that you will call the morning of each visit to confirm.
- **If asked to provide respite, see instructions below.**
- **Inform them of any planned vacations** you have and that there may be a possibility of a substitute.
- When you meet the patient, **ask how they would prefer to be addressed.**
- **If you want to touch them, ask first,** e.g. “May I shake your hand?”
- **Ask how they are feeling today, and if there is anything you can do to help.** If they are unsure, you may wish to make suggestions. A great icebreaker is to ask about things in their room – photos, etc. and if there are any stories behind them.
- At the conclusion of your visit ask “**May I visit you again?”** If they say no, I would still call the contact person the next week to see if the patient feels differently or if the contact person needs your assistance.
- **Wash your hands** before leaving and confirm the next visit.

The First Respite Visit in a Home – additional questions to ask

- Be sure to ask all the questions in the following section “What to do before you are Left with a patient.”

The First Visit in a Facility

- Remember to wear your name tag.
- When you enter the facility, stop and introduce yourself at the reception desk. **Ask if they have sign-in/sign-out procedures.** You may need a door code to get into memory care if your patient is in such a unit.
- **Confirm the patient’s room number and location.**
- **Ask what you should do if you have a concern while there; should you push the patient’s call button?**
- When you go to meet the patient, **follow the steps above.**
- **Sign out** when you leave the facility.
Questions to Ask Before Being Left with a Patient

These questions may be asked during the phone call preceding your visit or when you arrive.

1. What is the caregiver’s destination and cell phone number, or a number where they can be reached?
2. What name/number to call if caregiver can’t be reached?
3. What time will the caregiver return? Ask them to call if running late and remind them that 4 hours is the maximum stay per respite/week.
4. Does the patient ambulate or are they bedbound? If they ambulate, what assistance, if any, is needed? What is the plan if they need assistance? Remind caregiver that you are not allowed to lift, transport or transfer.
5. Is the patient toileting independent? Can the patient control bladder and bowels? What is the plan for toileting accidents? Remind caregiver that you are not allowed to assist in toileting.
6. Does the patient have trouble eating, drinking and/or swallowing? Are there any concerns or special directions? Will the patient need to eat during the respite stay? If so, what food/drink is available? Remind caregiver that you are not allowed to feed patients.
7. Medications.
   a. When should medications be taken, and which medications? Patients must be able to place their medications in their own mouth without assistance. Volunteers may lift water to patient’s mouth.
   b. Ask caregiver to measure out medications the patient may need to take while you are there.
8. Is patient alert and oriented?
9. Has the patient shown evidence of increased pain or other symptoms recently? Have they spoken to their nurse about these issues?
10. Does the caregiver want the phone or front door answered? Are visitors expected?

In an emergency: Call Hospice at 360-814-5550 or 1-800-894-5877. DO NOT CALL 911.
Once You Are Assigned a Patient

Please do the following:

*Once you receive an assignment, please call the contact person within 24 hours (48 hours at most) to introduce yourself and schedule the first visit

*Remember to NOT leave your personal phone number if you must leave a message; instead leave the number for Hospice and ask that the caller return your call during business hours of 8:00 am – 5:00 pm and have our front desk staff transfer the call to you.

*If you leave two messages without a response, contact the Volunteer Manager. Do not continue to leave messages.

*If more than one week elapses between the day of your assignment and the first visit, contact the Volunteer Manager

*If the patient or family decline the first visit, or declines more than two visits in a row, contact the Volunteer Manager

*Call or send a generic (no patient information) email to the Volunteer Manager after your first visit to let her know how it went

*If your visit frequency or activities change, please inform the Volunteer Manager so she can change the plan of care

*Whenever a visit is declined, please log the “Patient Not Home/Refused Visit” option in CallWyse

*If your patient/family states they want a different volunteer or no longer wants a volunteer, notify the Volunteer Manager

*If you stop seeing the patient for any reason, notify the Volunteer Manager

*If you are dissatisfied with your volunteer assignment or have any concerns, contact the Volunteer Manager
**Vacations, Substitutes and Illnesses**

In many cases we are able to find a substitute volunteer to make visits to their patients during their absence. A substitute cannot be guaranteed, however. It is particularly difficult to find one if requested at the last minute, during summers or on holidays.

**Never promise a patient/family/caregiver** that a substitute volunteer will fill in for you unless it has been confirmed by the Volunteer Manager. Please do not suggest that the patient/family/caregiver call Hospice to ask for a substitute while you are absent; substitutes MUST be arranged beforehand.

Please do the following if you are unable to visit your patient(s) due to illnesses, travel, family emergency, etc.

1. **If you will miss one volunteer visit and know less than 24-48 hours in advance . . .**
   - Call your patient (or their contact person), as soon as possible, to let them know you will not be there as expected. **Definitely call before the time you are scheduled to arrive.**
   - Then Call the Volunteer Manager (360.814.5588), as soon as possible, to let her know of the cancellation and to confirm your next visit, if there is to be one.
   - In **RARE** cases, if the need is urgent, (e.g. providing respite care while a caregiver has a doctor appointment), **ask if they would like a substitute, if one can be found.** Let them know that there is no guarantee one will be available due to the short notice.
   - Then call the Volunteer Manager (360-814-5588) as soon as possible. She will then see if a substitute is available. If one is found, she or the substitute volunteer will contact the patient (or their contact person) to let them know.

2. **If you will miss one or more volunteer visits and know 48 hours or more in advance. . .**
   - Let your patient/family/caregiver know **(with as much notice as possible)** when you will be away.
   - If your patient/family/caregiver requests a substitute volunteer while you are away, let them know that one **may be assigned, if available**, but that there are **no guarantees**.
   - Find out if a specific time/day for visits is required or if they are flexible.
   - The Volunteer Manager or the substitute volunteer will call to confirm the availability of a sub.

   **Whenever you are unavailable to visit patients, notify the Volunteer Manager as soon as possible; (360-814-5588) or elong@hospicenw.org.**
The Volunteer Visit Bag

Some volunteers like to have a packed “volunteer visit bag” that they take to every patient visit. Vigil volunteers, in particular, often do this, but other volunteers do as well. The visit bag includes items volunteers may wish to use patients as well as items of use to the volunteer.

Below are some suggestions as to what you may want to include:

● Volunteer Name Badge

● Patient Contact Information

● Cell Phone and Pertinent Numbers (Hospice number, etc.)

● CallWyse Instructions

● Picture book, other books, poems or readings for the patient

● Book and book light or Book Reader (Kindle, etc.)

● Volunteer Training Manual

● Water Bottle

● Hand Sanitizer

● PPE (Personal Protective Equipment) Kit

● Items for use in patient activities (e.g. items from the Volunteer Kits)
Transportation Issues

All volunteers are expected to have access to transportation in order to visit patients. Volunteers must have a copy of their current Driver’s License and current proof of Auto Liability Insurance (with expiration date on it) on file at Hospice at all times in order to remain active.

Hospice does not reimburse for volunteer mileage, however volunteers may keep a personal log of miles driven for Hospice by calendar year and the Volunteer Manager can write a letter to the Internal Revenue Service stating the total miles.

Volunteers choose how far they wish to drive to visit a patient. Driving time is not deducted from a patient’s volunteer visit time. In other words, if a patient wants 4 hours of respite per week and a volunteer is willing to drive 45 minutes each way to see the patient, the 1.5 hour round trip driving time is NOT deducted from the patient’s visit time. They still get 4 hours.

The same goes for taking a ferry. If a volunteer on the mainland chooses to serve a patient in the San Juan’s, for example, the patient they are seeing is entitled to the length of visit they desire. The ferry time is not deducted from this. We make every effort to have volunteers who live on the islands serve our island patients, but this is not always possible.

Should a mainland volunteer be assigned to an island patient, that volunteer’s ferry fare (car and driver) will be paid for by Hospice ONLY IF the volunteer contacts the Volunteer Manager in advance (5 days if possible) and requests a ferry pass from the office. We get these at discount and so we do not reimburse volunteers who choose to pay cash up front for the ferry. Due to ferry schedules, your island stay may end up lasting longer than you expect. Check the schedules in advance. Make a reservation if at all possible, especially in the summer, as there can be long waits.
Visit Orders, Frequencies and Activities

When a Hospice of the Northwest team member requests a volunteer, they write a medical order for the service being requested (e.g. volunteer). The order specifies how frequently the visits are to be provided (e.g. four times monthly). Finally, they write a clinical order listing which activities the volunteer is expected to perform (e.g. companionship, respite, errands). These orders become part of the Plan of Care and are signed by a Hospice Medical Director.

Hospice of the Northwest is audited regularly to insure compliance with all orders, including visit frequencies and activities. If orders are not followed, the patient suffers by not getting the care recommended by the Clinical Team. Another consequence is that this puts HNW out of compliance with Medicare and insurers. This can have serious consequences for HNW. **Therefore, it is very important that volunteers fulfill all orders as written.**

**Visit Orders and Frequencies:** The order will always be for a Volunteer. Volunteer visit frequencies are nearly always 3-5 times per month (an average of once weekly), unless otherwise specified.

**Activities** include one or more of the following:
- Companionship
- Companionship and Support
- Respite
- Errands
- Life Review
- Planning/Organization (includes household tasks)
- Music Reminiscence
- Pet Partners Visits (Animal Assisted Therapy)
- Pet Peace of Mind Visits

When you document volunteer visits on CallWyse, the volunteer activities in the order are read aloud and you will indicate whether you fulfilled them or not. See the section on CallWyse for further details.

**What to Do if a Patient/Family Requests a Change in Orders, Frequencies or Activities:**
Unless we hear differently, we assume that volunteers are following the orders at the correct frequency and are performing the assigned tasks. **Should any of the following occur, please contact the Volunteer Manager as soon as possible and no later than the next scheduled visit:**

- **Visit Frequencies** – The patient/family wants you to visit more or less than is in the order, or you are unable to visit as often as ordered
- **Activities** – the patient/family does not want all activities performed, would like a new activity added, or you are unable to perform the ordered activities
- **Discontinuation of Volunteer Visits** – The family does not want you to visit anymore or you have decided to not continue visiting
- **Difficulty Reaching the Patient/Family** – If you have left two messages for the patient or family and they have not been returned

The Volunteer Manager can then modify the Plan of Care as appropriate or discontinue the volunteer assignment or order. Of critical importance is that volunteer frequencies and activities match what is actually being done. **Compliance with volunteer orders, frequencies and goals will be assessed as part of the Annual Volunteer Evaluation.**
Purpose
To outline the process for establishing a written plan of care.

Policy
Hospice care and services provided to patients and their families are in accordance with an individualized, documented plan of care established by the hospice Interdisciplinary Group (IDG) in collaboration with the patient's attending physician (if any), the patient and/or representative and the primary caregiver, as able.

Definitions
Visit Frequency Orders (VFO) - when indicating a VFO in terms of weekly visits, the week starts on Sunday at midnight and carries through to Saturday at 23:59; when indicating a VFO in terms of monthly visits, the month starts on the effective date of the VFO and ends after 30 days, when the effective day is day 1.

Procedure
14. The plan of care process begins with the orders confirming eligibility.
15. The patient's plan of care specifies the care and services necessary to meet the needs of the patient/caregiver as identified in the initial, comprehensive and updated assessments of the patient.
16. The plan of care includes, but is not limited to:
   a. Interventions to manage pain and symptoms, spiritual and psychosocial needs;
   b. A statement of the scope and frequency of services necessary to meet the specific patient and family needs;
   c. Measurable outcomes anticipated from implementing and coordinating the plan of care;
   d. Drugs and treatment necessary to meet the needs of the patient;
   e. Medical supplies and equipment necessary to meet the needs of the patient; and
   f. Documentation from the IDG of the patient's or representative's level of understanding, involvement and agreement with the plan of care.
17. The services provided are linked explicitly to the assessed needs of the patient/family related to the patient's terminal illness and related conditions.
18. When determining Visit Frequency Orders:
   a. Registered Nurse visits must occur no less than every 14 days;
b. Hospice Aide visits may be reduced or canceled after three consecutive refusals or cancellations, or at the clinician's discretion;

c. Social Work and Spiritual Care may discontinue visit attempts after three consecutive refusals or cancellations;

d. Allied Therapy, Volunteer, Social Work and Spiritual Counselor visits may include a visit frequency range;

e. Any discipline that does not have visit frequency orders may be added as soon as another team member assesses the need and the patient/family accept the service.

19. Each patient and his or her primary caregiver(s) receive education and training from hospice as appropriate to their responsibilities for the care and services provided in the plan of care.

20. Efforts to involve the patient's attending physician (if there is one) in the development and updating of the hospice plan of care and the results of those efforts are documented in the patient's clinical record.

21. When the patient/representative have impediments to participating in care planning and understanding the plan of care, those impediments are documented in the patient's clinical record and the level of understanding or lack of understanding are recorded. When the patient, representative or primary caregivers decline to be involved in actively developing the plan of care, this is documented in the patient's clinical record.

22. The plan of care is reviewed and updated by the IDG every two weeks or more frequently if needed.

23. Revisions to the plan of care are based on the information from the patient's updated comprehensive assessment and the patient's progress toward outcomes specified in the plan.

24. Reviews of and changes to the plan of care are documented and communicated to members of the IDG.

25. The Plan of Care includes infections and diseases, as well as food, drug and other allergies, if any.

References

NHPCO Standard(s): PFC 2.5; PFC 4.2; PFC 4.3; PFC 6; PFC 6.1; PFC 6.2; PFC 7; PFC 7.1; PFC 7.2

Regulatory Citation/Other: 42 CFR 418.56
Sample Patient Scenarios

When new patients request volunteers, I develop short profiles (with no PHI) that are e-mailed to volunteers. Interested volunteers notify me.

Please note that the patients below are/were not “real” patients. The profiles below illustrate the types of patients Hospice serves.

Patient #1: Mt Vernon.

Respite request. 57 year old male living with wife. Brain tumor, epilepsy. Some left-sided paralysis. 30% PPS. Worked for airlines. Wife works part-time; lonely when she is gone. 3 children. Friendly, talkative, pleasant, cooperative. Memory problems, lethargic, confused. Slurred speech. Used to enjoy camping, hiking, skiing. Prefers Tuesday or Thursday morning visits.

Patient #2: Anacortes.

Companionship and respite requests. 84 y.o. male living with daughter and son-in-law. Lung Cancer, Shortness of Breath, Heart Failure, Anxiety. 40% PPS. Retired Boat Builder; was in the Navy. Friendly, cooperative, and calm. Enjoyed carpentry, fishing, rock collecting, and hockey. Fully oriented. Short-term memory problems. Blind in one eye. Can walk short distances with walker but has fallen. On oxygen. Prefers volunteer who is a veteran.

Patient #3: Burlington.


Patient #4: Concrete.


Patient #5: Stanwood.

Companionship request. 82 year old male living in Adult Family Home. Has Prostate Cancer, Dementia, Depression. Widowed 2 years ago and grieving wife. Had lived independently until she passed away. Retired Businessman. Loved all sports and the outdoors. Has son and two grandchildren in area. Confused, forgetful, hard of hearing. Sometimes restless and agitated. Staff take care of his personal needs. Short visits best as he usually can’t tolerate longer ones.
Introduce the Facilities

Below Hospice, understand. Some Facilities (usually hospital) you might see include:

- **Adult Family Home** – A home in which a family is licensed to accept adults for care (similar to a foster home for children). Generally has just a few patients.

- **Assisted Living Centers** – Apartments in which relatively healthy seniors eat in a common dining area, participate in activities together. Some patients may receive help with medications, grooming, etc.

- **Dementia/Memory Care** – May be a locked unit as patients can tend to wander. You may need to get the door code from the front desk. These units have a smaller ratio of staff to patients to insure patient safety and that care needs are met. The inside environment is fairly controlled.

- **Skilled Nursing Facilities** rehabilitate patients following a medical event or surgery, or when they require such extensive medical care that is difficult to provide it in another setting. Most of these patients are bedbound. They generally have meals in their room, which may be shared or private. When the nursing home is the patient’s residence, Hospice can provide care in the same way as if the patient were in his or her private home. HNW must have a contract with the nursing facility in order to provide services there. Hospice care augments regular nursing home care. If a family or caregiver elects the 5-day respite service offered by Medicare, the patient stays in one of HNW’s contracted nursing facilities.

Serving Patients in Facilities

Caring for patients in facilities may pose some challenges. There is a philosophical difference in that facilities are focused on patient maintenance and improvement. When patients are admitted to Hospice, it may be seen as a sign of “giving up.” In addition, facility staff are used to sending patients to the hospital in acute situations. Hospice changes this which may be hard for their employees to understand. Their staff may also be uncomfortable and untrained in working with the dying.

Facilities are over-regulated and often short-staffed. Show kindness and support for their efforts. Introduce yourself to any facility staff that come to see your patient. Staff turnover is high thus you will need to keep introducing yourself to new employees.

Below are some additional items to consider:

- Since patients in facilities, especially skilled nursing facilities, tend to be quite ill, they will have less stamina. They also will have good days and bad days.

- Short visits (30 – 45 minutes) tend to work better than long visits. One or two short visits/week can work well.

- Avoid scheduling visits on the same day as other Hospice staff due to patient fatigue.
• Find out if the patient prefers visits at specific times of day. Some patients like to have visitors during meal times; some do not. Others may attend activities in the facility at certain times and may want you to join in, or may not.

• If the patient has a roommate and you would like some privacy, ask the facility if there is a private room where you can visit.

• If your patient has a need while you are visiting, feel free to press their call button. If the need is urgent and someone does not come quickly, consider walking to the nearest nurse station to find assistance.

• If you have a significant concern about the overall care the patient is receiving, or hear a patient complaint, please bring this to the attention of the Volunteer Manager, rather than the facility staff.

• Understand that facility staff are bound by HIPAA and cannot give you information about the patient. Please do not seek this out.

• Suggested activities with patients in facilities:
  o Read letters and cards they have received. Help them respond if they wish.
  o Listen.
  o Ask about things in their room (photos, etc.)
  o Go for a walk or wheelchair ride outside.
  o Participate in a facility activity with them (when applicable).
  o Read a book or poetry (you can bring your own if desired). You could also bring a large-print book with pictures to show them.
  o Watch television together.
  o Play music.
  o Play cards or other simple games.
  o Bring flowers from your garden

• Some nursing home patients have no family or friends in the area and few visitors. It is highly important that you not let them down. Providing social, emotional and spiritual support can make a huge difference in the lives of these individuals. You can call them occasionally or send cards, also.

• Patients in skilled nursing facilities may fall asleep while you are talking, may be angry and crying “to go home,” and may be confused. It can be helpful to ask them about their home and what they miss about it. The foreign environment of a facility can cause additional confusion.

• If you have a patient in a facility, consider taking a second one; especially if it’s in the same facility. It’s convenient, takes no extra driving time, and since your visits are shorter, it doesn’t always take much extra time.
After the Patient Visit, Ask Yourself . . . .

- Did I create a comfortable environment for talking with the patient and family?
- Did I spend more of my time listening than talking?
- Did I let the patient and family “lead” the visit?
- Did I act in the belief that people have a right to their feelings?
- Did I respect the patient’s and family’s right to privacy? Do I keep all information about the patient confidential?
- Was my bedside manner warm and friendly? Calm and unhurried? Neither overly cheerful and bubbly, nor too sad and gloomy?
- Did I give the patient broad openings and offer general leads so that he/she is encouraged to talk freely?
- Did I demonstrate respect?
- Did I show compassion?
- Was I genuine?
- Was I sensitive to patient/family needs regarding physical contact?
- Did I take initiative to contact the patient and family?
- Did I meet the hospice family where they are?
- Did I practice the art of healthy distancing? True healthy distancing doesn’t prevent closeness; it makes true closeness safe for you and the family you’re serving.
- Do I keep a healthy balance in my own life? Remember to nurture yourself emotionally, physically, socially and spiritually.
Volunteer Self Care

Finding a balance between caring for our patients and caring for ourselves when working with the dying is one of the main challenges in hospice work. Empathy with patients means being open to their pain, but we need to develop the skills to leave the suffering behind us at the end of the day. When we fail to take care of ourselves we may develop what is called compassion fatigue. This can be experienced by family members or caregivers of the dying as well as Hospice staff and volunteers.

The issue of how we use ourselves in the service of our patients and how we care for ourselves as we do so is central to our work. The balance that must be achieved is a complex one. When we are working with the dying there is no “us” and “them.” We are working with issues we experience in our own lives as well. We either have, or know we will, lose people critically important to us. This commonality can serve as some of our best sources of information but at times will also pose significant challenges and stumbling blocks.

Work that is centered on the emotional suffering of others results not only in absorbing information about suffering, but often includes absorbing that suffering as well. Offering support to someone who is dying or coping with the death of a loved one can be taxing. Please remember to first care for yourself before you care for others.

Below are some tips for avoiding compassion fatigue (commonly called “burnout”):

- Establish healthy stress management practices
- Set and maintain boundaries
- Use affirmations to remind yourself of the importance of self-care (see below)
- Recognize the causes, signs and symptoms of burnout
- Know when and where to seek help for burnout
- Allow yourself to say “no” when asked to do more than you are willing or able to give

Alan Wolfelt of Mission Hospice Society has developed affirmations for volunteers to use. Reading them or saying them aloud may help you to avoid compassion fatigue.

1. I deserve to lead a joyful, whole life. No matter how much I love and value my work, my life is Multi-faceted. My family, my friends, my other interests and my spirituality also deserve my time and attention. I deserve my time and attention.

2. My volunteer work does not define me. I am a unique, worthy person outside my volunteer work. While relationships can help me feel good about myself, they are not what is inside me. Sometimes I need to stop “doing” and instead focus on simply “being”.

3. I am not the only one who can help the dying. When I feel indispensable, I tend to ignore my own needs. There are many other caregivers in my community who can also help the dying.

4. I must develop healthy eating, sleeping and exercise patterns. A well-balanced diet, adequate sleep and regular exercise allow me to be the best I can be.

5. I must maintain boundaries in my helping relationships. As a volunteer I must remember that I am responsible to others, but not for them.
6. I am not perfect and I must not expect myself to be. I realize that even when I offer compassionate, “on-target” help, the recipient isn’t always prepared to use it. When I do make mistakes, I should see them as an integral part of learning and growth, not as measurements of my self-worth.

7. I must practice effective time-management skills. I must set practical goals for how I spend my time.

8. I must set limits and alleviate stresses I can do something about. I must work to achieve a clear sense of expectations and set realistic deadlines. I should enjoy what I do accomplish in helping others but shouldn’t berate myself for what is beyond me.

9. I must listen to my inner voice. As a caregiver to the dying, I will at times become overloaded. When my inner voice begins to whisper its fatigue, I must listen carefully and allow myself some grief down time.

10. I should express the personal me in both my work and play. I shouldn’t be afraid to demonstrate my unique talents and abilities. I must also make time each day to remind myself of what is important to me. If I only had three months to live, what would I do?

11. I am a spiritual being. I must spend alone time focusing on self-understanding and self-love. To be present to those I work with and to learn from those I companion, I must appreciate the beauty of life and living. I must renew my spirit.

If you Feel Overwhelmed

If you feel you are overwhelmed with the demands of volunteering or are experiencing burnout:

- Please contact the Volunteer Manager for support
- Share your experiences with other volunteers at the monthly support meetings
- Use practices that have helped you relieve stress in the past (meditation, journaling, reading, yoga, prayer, taking a bubble bath).

Take a Break

Volunteers whose life demands increase or who are experiencing burnout may wish to take a leave of absence from Hospice volunteer work.
Activity Suggestions

Volunteers are the only Hospice of the Northwest team members whose primary purpose is to provide companionship, offer support and socialize with patients. Doing activities can brighten their day, stimulate their minds and enhance your relationship. Keep in mind, when suggesting an activity that some patients may not have the energy, might be in too much pain or are simply not interested; they may only want to talk or rest.

There are an endless number of possible activities. The following are but a few suggestions:

- Listen
- Read aloud (a book, magazine, newspaper, poetry)
- Put together a puzzle
- Have afternoon tea
- Bake cookies or bread
- Look at photos
- Record memories or life experiences
- Assemble favorite music on CD, etc.
- Bring in nature – fall leaves, shells, rocks, beach glass, pine cones
- Hold hands
- Bring a glass of water or other beverage
- Create a scrapbook, memory box or photo album
- Do laundry or ironing
- Make a family tree; research genealogy
- Show pictures on your iPad or cell phone
- Gardening activities (indoors or out): Plant seeds or flowers, water plants, weed, trim, mow, rake, sweep driveway
- Play cards or board games
- Help write letters
- Set up a bird feeder
- Make a legacy project (see “Building Creative Legacy Projects” in this section)
- Create a virtual experience
- Describe the world around the patient, e.g. the sunset, beach, fishing, mountains, lake
- Provide small items for the patient to hold or feel:
  - Women: beads, shells, smooth stones, glittering fabric, lace, silk, jewelry
  - Men: toy cars, polished stones, rocks, fossils
- Ask about things in the room or home
- Sew pillows, busy mats or teddy bears to take to patients
- Give a light foot or hand massage
- Dust, sweep, straighten
- Bring fresh flowers
- Sing – patients are more likely to remember childhood songs rather than the most recent
- Organize patient’s files, paperwork, drawers
- Show the Moss Basket video (see Volunteer Resources)
- Straighten the room
- Listen to music
- Paint or draw
- Make handprints with a grandchild
- Wash dishes
- Watch TV or a movie together
• Share hobbies
• Walk a dog
• Make bookmarks with printed cardstock paper and ribbon or tassels
• Blow bubbles
• Tell a joke
• Teach a patient to use an IPad or computer. They may wish to learn to send email, play computer games or talk to loved ones via Skype.
• Play an instrument
• Bring books from the Hospice or public library, Goodwill etc.
• Make/hang a craft for visual stimulation
• Bring in the newspaper
• Put family recipes in a book

. . . . OR CHECK OUT A VOLUNTEER KIT AND BE INSPIRED!

Notjustbingo.com is a web-site that lists hundreds of activity ideas for patients who are bedbound, in nursing or assisted living facilities or memory care units. It has a monthly calendar with activity suggestions for every day. There are also six monthly activities especially for those with dementia, and four activities specifically for men. Not Just Bingo also has a Facebook page. Membership to the site is $17/month but I was able to access activity calendars without a membership.
Patient Scheduling Instructions
To be done BEFORE using CallWyse

✓ CallWyse will not work unless appointments are scheduled before visiting patients. If you see your patient before the Scheduler enters your scheduled visit, you will be unable to check in and out of CallWyse.

✓ Schedule visits before seeing patients.
Call Erin Long at 360-814-5588 (Monday – Friday; 8:00 am – 5:00 pm). If she is unavailable, leave a voice mail. DO NOT communicate by unencrypted e-mail; this is a HIPAA violation. Visits can only be scheduled during work hours. A voicemail message sent in the evening or on a week-end will not be heard until her next work day. Schedule your visits well in advance.

✓ Provide the following information when scheduling your visit:
  o your name and role;
  o reason for your call;
  o your patient’s name; and
  o date and time of visit
CallWyse and You

What is CallWyse?

CallWyse is a telephone system by which all volunteers document their time.

Why is it important to document Hospice volunteer time?

Because we are required to by our funders and governing bodies. Medicare mandates that we provide proof of direct patient care and administrative volunteer hours, as well as hours for training and education. In addition we must demonstrate that at least 5% of all patient care hours are delivered by volunteers. We also track the number of volunteer visits and shifts, the number of days from volunteer request to assignment, and assignment to first visit. Finally, we calculate the annual value of donated hours.

It is especially important to document patient visits as this becomes part of the permanent medical and legal record. In addition, volunteer visit documentation is available to other Hospice staff seeing the patient so they know when volunteers visited and what they did.

How will using CallWyse benefit me personally?

Your documentation is audited regularly and will be assessed in your annual volunteer evaluation. You will have legal proof of when you were with a patient and when you were not, in case it is ever needed.

What steps do I follow to use CallWyse?

If visiting a patient:

- **Schedule** your visit first (see “Patient Scheduling Instructions”).
- On the day of the visit, **Check In** to your patient visit when you arrive (see “CallWyse for Patient/Family Volunteers”).
- On the day of the visit, **Check Out** of your patient visit when you are done (see “CallWyse for Patient/Family Volunteers”).

If volunteering in a role in which you do not have face-to-face patient contact:

- **Simply Check Out** of your shift when you are finished (see “CallWyse for Office/Admin. Volunteers”).

Why is accuracy important when using CallWyse?

When visits are entered incorrectly, records and reports will be inaccurate. Omissions and inaccuracies can have an adverse effect on our audits. Correcting mistakes is complicated and time consuming. If you believe you had omitted something, please follow the directions below (“What are some common CallWyse mistakes”) to correct it. If you think you documented something that is incorrect, please contact Erin Long.

What do I do if I have trouble using CallWyse?

- See if your problem is listed below; if so, please follow the instructions to fix it.
- If it is not listed below, and you have tried at least two to three times to use CallWyse without success, and it is during the work week, call Erin Long at 360.814.5588 or Jessica Enders,
What are some common CallWyse mistakes and how do I fix them?

a. **Problem:** The CallWyse number is busy.
b. **Solution:** Try the second number; if busy also, wait 10-15 minutes, then try again.

a. **Problem:** Volunteers forget how to set their password or forget what it is once it is set.
b. **Solution:** The first time you use CallWyse, enter 0000 for the password. CallWyse will then prompt you to set your own personal 4-digit password that you will use from now on. Write this down as Hospice staff will not know or have access to your password. If in the future you forget your password or it is not accepted, enter 0000 and follow the above steps.

a. **Problem:** CallWyse tells you that you do not have a scheduled visit.
b. **Solution:** If you did not schedule your visit ahead of time with the Scheduler, do so now if it is during office hours. See “Patient Scheduling Instructions.”

If you did schedule your visit, try continuing with the call and follow the prompts. In most cases, CallWyse will still allow you to document your visit.

a. **Problem:** Volunteers forget or fail to use CallWyse at all.
b. **Solution:**
  - For Volunteers Seeing Patients: If your visit was previously scheduled, try checking into CallWyse to start your visit as soon as you remember this. It will allow you to change the time or date of your visit. Then you will check out of your visit. If this does not work, call Erin Long or Jessica Enders (numbers are listed under the first question at the top of the page). **The visit must be documented the same day it occurred and before midnight.**
  - For all other Volunteers: Log your visit time (by using the instructions following) as soon as you remember to.

a. **Problem:** Volunteers fail to Check in or Check Out of a visit or both.
b. **Solution:** Same solution as above; try logging your visit after the fact and adjust the time or date as needed. If this does not work, call for assistance.

**DO NOT LET MORE THAN ONE UNDOCUMENTED VISIT OR SHIFT PASS WITHOUT CONTACTING THE VOLUNTEER MANAGER.**

Besides via CallWyse, are there any other ways in which volunteer hours are documented?

Yes, there are a couple of categories of volunteer hours that are NOT logged in on CallWyse:

- Training and support meeting time are documented via volunteer sign-in sheets.
- Vigil volunteer hours are documented by the Team Leader and submitted to the Volunteer Manager when the vigil ends.
- Totals of 1) and 2) above are added to the volunteer hours logged on CallWyse to arrive at an annual sum.
CallWyse for Patient/Family Volunteers

Step 1 – Check In

- Dial Call Wyse
  800-903-8666 or 800-366-6612
- Enter Hospice ID Number: 1663
- Enter your VID # ________ followed by #
- Enter your Password _____ followed by #

The first time you use CallWyse, enter 0000 for your Password. It will prompt you to set up your own 4-digit password which you will use thereafter. Write it down__________ as Hospice will not have access to it. If you ever have trouble logging in with your personal password, enter 0000 again to set a new one.

- If told “New Mail,” ignore
- “Check In” - press 1
- Check in time given
  o press 1 - correct
  o press 2 - make changes
- Accept patient as listed – press 1
- Confirm patient - if correct, press 1
  - If name change required
    o press 2 - enter Medical Record # or
    o press 3 - spell last name
  - If new patient name given/spelled out
    o press 4 - to confirm
    o press 2 – re-enter if incorrect
- Scheduled visit duration noted
- Confirm reason for visit or why unable to visit patient.
  o 30 – routine visit–volunteers
  o 13 – patient not home
  o 14 – patient refused visit
- If traveling from home, press 1, if not, press 2
- Confirm finished - Press 4
- Exit - Press 0
**Step 2 – Check Out**

- Dial Call Wyse
  
  **800-903-8666 or 800-366-6612**

- Enter Hospice ID Number: **1663**

- Enter your VID # ________ followed by 

- Enter your Password _______ followed by 

- If told “New Mail,” ignore

- “Check Out” – press 

- Call Wyse gives patient’s medical record number and name

- Press 3 to “Check Out”

- To request “Errand Miles” if applies - press 0 + 

- Press 1 for completion of each activity listed

- Press 2 when complete

- Check Out time noted
  - Press 1 – if correct
  - Press 2 – to change

- *Check out is complete*

- If want to hear your next scheduled visit, Press 0 to return to Main Menu

- CallWyse will state the elapsed time and will say “Check Out Complete”
CallWyse for Office/Admin Volunteers
Submission Instructions Following Volunteer Service
(any volunteer service that does not involve face-to-face patient contact)

- From the office, dial CallWyse 9.1.800.903.8666 or 9.1.800.366.6612
- Enter HNW ID 1663
- Enter volunteer “VID” + # XXXXX #
- Enter volunteer password + # XXXXXX #
- Press 3 check in/confirm “time sheet management”
- Press 2 add “time sheet activity”
- Press 85 confirm “ancillary and office activity”
- Press 1 OK
- Enter miles to/from HNW + # XX #
- Press 1 OK
- Enter minutes to/from HNW + # XX#
- Press 1 OK
- Enter number of minutes of service + # (see below)
- Press 1 OK
- Press 1 agree work is “ancillary and office activity”
- Press 5 “time sheet submitted”

Volunteer Time:
1 x 60 = 60 minutes
2 x 60 = 120 minutes
3 x 60 = 180 minutes
4 x 60 = 240 minutes
5 x 60 = 300 minutes
6 x 60 = 360 minutes
7 x 60 = 420 minutes
8 x 60 = 480 minutes
Hospice Volunteer Annual Requirements

Although volunteering for Hospice of the Northwest (HNW) can be extremely rewarding and meaningful, it comes with several responsibilities. When we accept you as a volunteer, it carries the expectation that you will take personal responsibility for fulfilling all of our requirements on an ongoing basis. To not do so puts Hospice, Skagit Regional Health, our patients and you at risk.

To order remain on active status as a volunteer, you must be up-to-date on all requirements at all times. Please familiarize yourself with these. Thank you for your cooperation.

REMEMBER: All documentation goes to Jessica Enders, jenders@hospicenw.org.

<table>
<thead>
<tr>
<th>DOCUMENTATION</th>
<th>DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copy of Current Driver’s License</td>
<td>New copy must be provided on or before the date the old one expires</td>
</tr>
<tr>
<td>Copy of Current Auto Insurance</td>
<td>New copy must be provided on or before the date the old one expires</td>
</tr>
<tr>
<td>Proof of Current Flu Vaccine or Signed Agreement to Wear a Mask when on Duty with Hospice*</td>
<td>Required every October by the 31st. See Section C for instructions and form to use</td>
</tr>
<tr>
<td>Contact Update</td>
<td>Contact information must be kept current (phone numbers, email address, etc.). Notify the Volunteer Manager if your information changes.</td>
</tr>
<tr>
<td>Hospice Photo Identification (Name Tag)</td>
<td>Replace at Skagit Regional Health if lost; cost is $7.00.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OTHER REQUIREMENTS</th>
<th>DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logging Volunteer Time</td>
<td>All volunteer visits and office shifts must be logged on CallWyse before midnight of the day the service occurred.</td>
</tr>
<tr>
<td>Volunteer Support Meetings &amp; Vigil Support Meetings</td>
<td>Attending all meetings is recommended. All volunteers must attend at least 6 Volunteer Support Meetings annually; Vigil Volunteers must also attend at least 6 Vigil Meetings annually; read meeting minutes and handouts for meetings missed.</td>
</tr>
<tr>
<td>Annual Field Evaluation</td>
<td>Must have a 1:1 observation with the Volunteer Manager each year,</td>
</tr>
<tr>
<td>Availability Update</td>
<td>If your availability changes, due to vacation, illness, or other commitments, please notify the Volunteer Manager as soon as possible</td>
</tr>
<tr>
<td>Call Julie after the first visit</td>
<td>To let me know how the visit went</td>
</tr>
</tbody>
</table>
| Notify Julie if you have a patient issue or concern | *More than 1 week has elapsed between the day you received your assignment and the first visit

*A patient or caregiver declines the first visit, or declines two or more visits in a row.

*You cannot reach the patient or caregiver after 2 attempts.

*Your visit frequency or activities change.

*Your patient/caregiver would like a substitute volunteer when you are unavailable. Please give me 2 weeks’ notice if at all possible. Substitutes are not guaranteed. Families SHOULD NOT be told to call while you are gone to ask for a sub; this should be done in advance.

*Your patient states they would like a different volunteer.

*You stop seeing your patient for any reason.

*You have a concern during or after a patient visit.

*You are dissatisfied with your patient assignment. |

| Notify the Volunteer Manager if | *You would like support, a sounding board, or help problem-solving.

*You are dissatisfied with your volunteer role.

*You have an idea for improving the Volunteer Program.

*You are interested in a new volunteer role or growth/leadership opportunities with Hospice. |
## Volunteer Evaluation Form

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Volunteer's Name:</strong></td>
<td>Date:</td>
</tr>
<tr>
<td>Period of Evaluation: 2017-2018</td>
<td></td>
</tr>
<tr>
<td>Rating Scale</td>
<td></td>
</tr>
<tr>
<td>0 = Not Applicable 1 = Needs Improvement 2 = Fair 3 = Good 4 = Excellent</td>
<td></td>
</tr>
<tr>
<td>1. Ability to interact appropriately with patients and/or families (maintains confidentiality, respects values of others):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>2. Availability</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>3. Dependability/Follow through (completes given assignments or notifies appropriate person when not able to fulfill commitment):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>4. Accountability (accurate/timely documentation; contacts office when appropriate):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>5. Ability to interact with the interdisciplinary team (IDG/IDT):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>6. Flexibility (ability to adapt to change):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>7. Participation in on-going support (team meetings, in-services, support groups, special events):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>8. Self-Care (ability to utilize effective time management skills; verbalizes own limitations):</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>9. Follow through on program policies and procedures:</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>10. Overall impression of performance:</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>11. Patient Scheduling and documentation are complete, appropriate and timely</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td>12. Confidentiality; adherence to HIPAA requirements</td>
<td></td>
</tr>
<tr>
<td>13. Sanitation and infection control</td>
<td></td>
</tr>
<tr>
<td>14. Active listening skills</td>
<td></td>
</tr>
<tr>
<td>15. Compassion, dignity and respect extended to patients, caregivers, Hospice and facility staff</td>
<td></td>
</tr>
<tr>
<td>16. The Plan of Care and visit frequency upheld</td>
<td></td>
</tr>
<tr>
<td>17. Appropriate boundaries maintained at all times</td>
<td></td>
</tr>
<tr>
<td>18. Increased symptoms and concerns communicated to Hospice in a timely manner</td>
<td></td>
</tr>
<tr>
<td>19. Self-Care (volunteer does not over‐extend themselves)</td>
<td></td>
</tr>
</tbody>
</table>

Additional Comments:

I would encourage you to communicate directly with the team regarding any patient concerns and/or needs: RN Case Manager, Medical Social Worker, Spiritual Counselor, and/or Health Care Aides can all be called at 360-814-5550 and ask for the discipline desired on this patient’s team.
Manager Signature
_________________________________________ Date ________________

Volunteer Signature
_________________________________________ Date ________________

Volunteer Comments/Goals
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
SECTION 8

AGENDA, EVALUATIONS, QUIZZES, HOMEWORK

Training Objectives .......................................................... Page 3
Session Evaluations ......................................................... Pages 5-10
Competency Quiz ............................................................. Pages 11-12
Food Safety Quiz .............................................................. Pages 13-14

Homework
Perspectives on Dying ....................................................... Pages 15-18
Getting in Touch with Your Own Death ......................... Page 19
Spiritual Self Awareness Inventory ............................... Page 21
Bucket List ........................................................................ Pages 23-29
Show and Tell ................................................................. Page 30
Hospice of the Northwest

Patient and Family Volunteer Training Objectives

Upon completion of the HNW Patient/Family Training Program, volunteers will be able to:

- Describe the philosophy, mission, goals and services of Hospice of the Northwest.
- Understand the regulatory environment in which Hospice operates.
- Be familiar with patient rights.
- Define the Interdisciplinary Care Team’s function, roles and responsibilities.
- Identify diagnoses, conditions and symptoms experienced by Hospice patients.
- Be knowledgeable about HNW and Skagit Regional Health policies.
- Describe the role of the volunteer in hospice care.
- Utilize effective communication skills and understand how to interact with those who have cognitive, hearing or visual impairments.
- Describe acceptable and restricted volunteer activities.
- Establish and maintain appropriate boundaries.
- Understand social, emotional, psychological and spiritual issues related to terminal illness.
- Delineate concepts of grief and bereavement.
- Identify diverse cultural issues and practices related to death and dying.
- Understand and utilize available volunteer support resources.
- Be knowledgeable about volunteer health and documentation requirements.
- Schedule patient visits and document them via CallWyse.
- Describe the unique needs of veterans.
- Be familiar with Infection Control Procedures and Food Safety practices.
- Practice methods of stress management and self-care.
VOLUNTEER TRAINING EVALUATION

SESSION 1 – Online

1) What did you enjoy the most about the online training?

2) What did you enjoy the least?

3) What did you learn that you anticipate using in your work as a Hospice volunteer?

4) What would you like more information about?

5) Was there anything in today’s curriculum that concerned you? If so, what?

Please add comments, suggestions and/or observations on the back if desired.
Hospice of the Northwest volunteers often face situations with patients and families in which they may have difficulty deciding what to do.

<table>
<thead>
<tr>
<th>Number</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>25.</td>
<td>Accept a gift from a patient or family.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Buy a gift for a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>27.</td>
<td>Accept money from a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>28.</td>
<td>Take food or beverages from home to a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>29.</td>
<td>Lend personal belongings to a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>30.</td>
<td>Give your home phone number to a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>31.</td>
<td>Invite a patient or family to an activity or party outside of your volunteer assignment.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>32.</td>
<td>Transport a patient or family member in your car.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>33.</td>
<td>Email or text a patient or family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>34.</td>
<td>Use a patient’s name, ID number or other identifying information in an unencrypted email.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>35.</td>
<td>Provide a standby assist for a patient.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36.</td>
<td>Lift or turn a patient.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>37.</td>
<td>Share personal/intimate information about yourself with a patient to the extent that it diverts attention away from them.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>38.</td>
<td>Talk about a patient in public.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>39.</td>
<td>Talk about a patient with a friend or family member.</td>
<td>Yes</td>
<td>No</td>
</tr>
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<tr>
<td>40.</td>
<td>Provide opinions or advice to a patient (e.g. on medical care, family issues, funeral options, wills and other issues).</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>41.</td>
<td>Try to persuade a patient to change their religious or spiritual beliefs.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>42.</td>
<td>Perform heavy household tasks for a patient or family (e.g. vacuuming, mopping, cleaning bathrooms).</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>43.</td>
<td>Help a patient with toileting.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>44.</td>
<td>Disclose information about other Hospice volunteers or staff.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>45.</td>
<td>Speak poorly of Hospice, its staff or volunteers.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>46.</td>
<td>Offer your opinion about “Death with Dignity” with patient/family.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>47.</td>
<td>Attend the memorial service for a patient.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>48.</td>
<td>See a family socially after a patient dies.</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Competency Quiz for HNW Patient/Family Volunteers

Name __________________________________ VID # ________________ Date _____________

TRUE OR FALSE: Please mark T or F next to each of the questions below.

1. _____ Hospice care is focused on comfort and symptom management rather than curative treatment.

2. _____ The patient’s plan of care addresses physical, emotional and spiritual needs. It also specifies which services are to be provided and how often.

3. _____ When visiting patients, it is usually more important to talk than to listen.

4. _____ Boundary violations occur when there is confusion between the needs of the volunteer and those of the patient. Appropriate boundaries support patient autonomy.

5. _____ Volunteers must serve at least 30 hours per year and attend a minimum of 3 Support Meetings.

6. _____ If a patient needs me to take their arm for stability while they walk, I may.

7. _____ Things that I may do as a Patient/Family Volunteer include: reading aloud, watching movies, texting patients, and visiting families after their Hospice patient dies.

8. _____ It is important to be familiar with cultural perspectives on death and dying if I have a patient of a different background.

9. _____ I may use my best judgment, rather than follow Hospice policy, if I think the situation warrants it.

10. _____ Patient visit dates must be called to our Scheduler at least 24 hours in advance.

11. _____ If my patient falls and appears to be injured, I should call 911.

12. _____ If my driver’s license or auto liability insurance have expired, I may not continue volunteering until current copies have been provided to Hospice.

13. _____ Typical patient visits are once weekly. I must follow the visit frequency as ordered by Hospice staff.
14. I may give my phone number to patients and families so they can contact me.

15. Patient visits must be documented on CallWyse by midnight on the day the visit occurred.

15. It is all right to take photos of patients on my camera or type their stories on my computer as long they give permission first.

16. If I have a question about a patient, I may mention their name or ID# in an email to the Volunteer Manager.

17. PPS stands for: (Circle correct answer)

   a) Patient Pathology Score
   b) Patient Prognosis Scale
   c) Palliative Performance Scale

18. What procedure do you follow in the event of an emergency or following the patient’s death (if you are present)?

19. Who do you contact if you need assistance and instructions regarding the performance of your duties and responsibilities?

20. When is it acceptable to take cash or purchase something for a patient?
FOOD SAFETY QUIZ FOR VOLUNTEERS

Volunteer Name ___________________________ Date __________________

TRUE of FALSE (Write correct answer in space)

______ 1. The internal temperature for poultry should be at least 165 degrees F.

______ 2. It is safe to thaw food by submerging it under running drinking quality water at or below 70 degrees F.

CIRCLE THE ONE CORRECT ANSWER TO EACH QUESTION BELOW:

3. What steps should you take before preparing food:
   a. wash hands with soap and water
   b. make sure food preparation surfaces and utensils are clean
   c. wash all produce
   d. all of the above

5. Most viruses that we get through food are caused by:
   a. Leaving food out on the counter for too long
   b. Unclean hands of someone that touched our food
   c. Not cooking food long enough
   d. Using contaminated water
6. What are the key components of washing your hands prior to food preparation?

   a. Wet hands with warm water; apply soap
   b. Rub soap in vigorously for 10-15 seconds
   c. Be sure to get between fingers and above wrists
   d. Rinse well and dry with a clean towel
   e. All of the above

7. All of the following are food safety defenses except:

   a. Good personal hygiene
   b. Food cooked or held at correct temperatures
   c. Putting uneaten food that has been reheated into the refrigerator immediately
   d. Prevention of cross contamination

8. If you have sores, bandages or cuts on your hands, you should:

   a. Not work with food
   b. Wear gloves
   c. Report to you supervisor
   d. Proceed with food preparation as normal

9. What type of hazard is represented by using a knife to cut beef and then using the same knife to cut vegetables without washing in between?

   a. Biological contamination
   b. Physical contamination
   c. Cross contamination
   d. Chemical contamination

10. How may symptoms of an allergic reaction to food manifest:

    a. Rashes, Swelling, Difficulty Breathing
    b. Unconsciousness
    c. Diarrhea, nausea, vomiting, fever, headache and stomach ache
    d. All of the above
The first death I experienced was:

- a. grandparent or great-grandparent
- b. parent
- c. brother or sister
- d. other family member
- e. friend or acquaintance
- f. pet

When I was young, the subject of dying was talked about in my family:

- a. openly
- b. with some sense of discomfort
- c. only when necessary and then with the eldest children
- d. as though it were a taboo subject
- e. never recall any discussion

My childhood concept of what happened after death is best described as:

- a. heaven and hell
- b. an after life
- c. asleep
- d. cessation of all physical & mental activity
- e. mysterious and unknown
- f. something other than the above
- g. no concept

Today, my concept of what happens after death is:

- a. heaven and hell
- b. an after life
- c. asleep
- d. cessation of all physical & mental activity
- e. mysterious and unknown
- f. something other than the above
- g. no concept

My present attitudes toward dying have most been influenced by:

- a. death of someone close
- b. specific reading
- c. religious upbringing
- d. introspection and meditation
- e. ritual (e.g. funerals)
- f. TV, radio or film
- g. longevity of my family
- h. my health or physical condition

The role that religion or spirituality has played in the development of my attitudes about dying is:

- a. very important
- b. somewhat important
- c. relatively minor
- d. nothing at all
- e. very rarely or never

I think about dying:

- a. very frequently (at least once/day)
- b. frequently
- c. occasionally
- d. rarely (no more than once a year)
To me, death means:

a. the end, the final process of life  
   e. a kind of endless sleep, rest, peace
b. the beginning of life after death  
   f. termination of life but survival of
c. joining of the spirit with the universe the spirit
d. don't know

I __________ that psychological or emotional factors influence or even cause a person to begin dying:

a. firmly believe that  
   c. am unsure if
b. tend to believe that  
   d. don’t know if

To me, the most disagreeable aspect of my death would be that I’d:

a. no longer have experiences  
   e. cause grief to others
b. not be able to complete plans/projects  
   f. die painfully
c. be uncertain of what happens to me  
   g. have to break promises
d. no longer be able to provide for my family  
   h. be fearful of what might happen to my body

When I think of dying, or when circumstances make me aware of my own mortality, I feel:

a. afraid or anxious  
   d. purposeless
b. discouraged  
   e. resolved, in relation to life
c. sad  
   f. grateful to be alive

With regard to the degree to which effort should be made to keep a terminally ill Person alive, I believe that:

a. all possible effort should be made  
b. efforts that are reasonable for the person’s age, physical condition, mental condition and pain
c. after reasonable care has been given, a person ought to be permitted to die a natural death  
   d. a person should not be kept alive by elaborate artificial means
   e. it should be an individual’s choice

If my physician knew that I had a terminal illness, I _______ want him/her to tell me:

a. would  
   b. would not

If I had a terminal illness, I would _______ to talk to someone about dying:

a. want  
   b. not want

I would most want to talk to _______ about my dying:

a. My spouse  
   d. Friends  
   g. Nurse
b. Immediate family members  
   e. Clergy
   f. Physician
c. Other relatives
I probably would feel ______________ about talking with someone about my dying:
  a. embarrassed                d. at ease
  b. distressed                e. uneasy; worried I’d make someone
  c. willing                   uncomfortable

When I think of dying, I mostly fear:
  a. a long-term illness                f. depending on others to take care of
  b. a painful death                  my personal needs
  c. that I’ll be mentally disoriented g. what happens after death
  d. that I’ll be mentally alert but h. Physical disability
     disabled physically

To me, the sight of a dead body is (or would be)
  a. horrifying                    c. I don’t know
  b. somewhat natural               d. unsettling
  c. meaningful or mysterious        e. holy

When I’m notified of a funeral, I:
  a. usually decline gracefully     d. dread it but usually go
  b. attend if at all possible      e. am willing to attend
  c. hate to go

So far in my life, I feel:
  a. that it has been satisfying     e. I’ve worked too hard
  b. I wish I could start over       f. I’ve wasted too much time
  c. I’ve been very fortunate        g. I’ve been cheated out of lots of good
  d. I made some bad decisions, but  things
     basically had a good life
Is there someone I need to forgive?

Who do I need forgiveness from?

What in my life is my special gift(s) to give?

To whom will I give my gifts?

What gifts have I received from those who have died?

Who feels close to me?

To whom do I feel close?

What do I hold back from saying?

What do I wish others would say to me?

What kind of death do I fear the most?

What kind of death would I most like?

What would I like my legacy to be?
Spiritual Self-Awareness Inventory

1) Identity
   Who are you?
   What do you like about yourself?
   What would you change about yourself?

2) Meaning and Purpose
   What gives meaning and purpose to your life?
   What do you look forward to when you wake up in the morning?
   What are your goals? In the next year? In the next 5 years?
   What do you need to maintain and sustain meaning in your life?

3) Hope
   What conditions in your life can be improved?
   What do you desire?

4) Love and Relatedness
   What are your most meaningful relationships?
   Why is each important to you?
   With whom do you feel the most loved?
   Where do you feel the most appreciated?
5) **Forgiveness**

   How do you feel when you experience the bitterness and resentment of others?

   How do you handle your own feelings of guilt? Anger? Resentment? Bitterness?

   How do you forgive others?

   How do you experience others’ forgiveness of you?

6) **Pain and Suffering**

   What is your usual response to physical pain?

   What is your response to emotional pain?

   How do you deal with pain or loss?

7) **Transcendence**

   Do you see yourself “going on” after your body dies? If so, how?

   How would you like to be remembered after you die?

   If you could leave things – traits, values, etc. – to your children or other loved ones, what would they be?
Show and Tell

Please bring an item to share that reminds you of someone you loved who has passed away.

It can be a photo, an object, or anything else.

Be prepared to share the item and a memory at the next training session.
SECTION 9
VIGIL TRAINING

Contact Numbers and Forms  
Vigil Overview  
Vigil Volunteer Guidelines and Support

Pages 3-8  
Pages 10-20  
Pages 21-36
Peace My Heart...

Peace, my heart
Let the time for the parting be sweet.
Let it not be a death but completeness.
Let love melt into memory and pain into songs.
Let the flight through the sky end in the folding of the wings over the nest.
Let the last touch of your hands be gentle like the flower of the night.
Stand still, O Beautiful end, for a moment, and say your last words in silence.
I bow to you and hold up my lamp to light you on your way.

-Rabindranath Tagore
Vigil Phone Numbers

Vigil Phone Line/Team Leader – 8:00 am to 6:00 pm; 7 days per week
360.630.4485

Hospice of the NW Office and On-Call Nurse (Telepage) – 24/7
360.814.5550

Erin Long, Volunteer Manager
Weekdays, M – F, 8:00 – 5:00  Office:  360.814.5588
Work Cell:  360.899.6393

Eves/Weekends:  Personal Cell:  360.202.3554
## VIGIL VOLUNTEER CONTACT/AVAILABILITY and UPDATE

### Please Print Contact Information

<table>
<thead>
<tr>
<th>Name</th>
<th>VID#</th>
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**Preferred Contact Number**

- [ ] Home
- [ ] Cell
- [ ] Work

**E-mail**

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<tr>
<th>Emergency Contact Number/Relationship</th>
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### How far are you willing to travel? (check all that apply)

- [ ] Anywhere

#### West

- [ ] Anacortes
- [ ] LaConner
- [ ] Bayview
- [ ] Samish Island
- [ ] Oak Harbor
- [ ] Coupeville
- [ ] Langley
- [ ] Guemes Island
- [ ] San Juan Islands

#### East

- [ ] Concrete
- [ ] Rockport
- [ ] Day Creek
- [ ] Hamilton
- [ ] Lyman
- [ ] Clear Lake
- [ ] Big Lake

#### Central

- [ ] Mount Vernon
- [ ] Sedro Woolley
- [ ] Burlington
- [ ] Bow
- [ ] Edison

#### South

- [ ] Camano Is
- [ ] Stanwood
- [ ] Conway
- [ ] Lake McMurray
- [ ] Arlington
- [ ] Darrington
- [ ] Everett

### Which Days/Times are You Most Likely to be Available: (circle all that apply)

- Sunday:
  - morning
  - afternoon
  - evening
  - night
- Monday:
  - morning
  - afternoon
  - evening
  - night
- Tuesday:
  - morning
  - afternoon
  - evening
  - night
- Wednesday:
  - morning
  - afternoon
  - evening
  - night
- Thursday:
  - morning
  - afternoon
  - evening
  - night
- Friday:
  - morning
  - afternoon
  - evening
  - night
- Saturday:
  - morning
  - afternoon
  - evening
  - night

### Do Not Call Before ____________________________ or After ____________________________

**Time Restrictions/Out of Town**

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# VIGIL TEAM LEADER REPORT

Team Leader __________________________________________ VID # ____________________

Vigil Requested by (RN/MSW/SC) ____________________________________________________________

Vigil Requested for dates/times ______________________________________________________________

Patient Name ___________________________________________ PID # ____________________________

Patient Location  [ ] Private home  [ ] Facility (name) __________________________________________

Who was Involved?  **Family:**  [ ] Yes  [ ] No  **Caregiver:**  [ ] Yes  [ ] No  **Other:**  [ ] Yes  [ ] No

Did patient die while vigil volunteer was present?  [ ] Yes  [ ] No

Number of volunteers contacted ____________  Number of minutes calling/organizing ___________

<table>
<thead>
<tr>
<th>Names of volunteers who sat vigil</th>
<th>VID#</th>
<th>Bedside Vigil Time Volunteered (Total Minutes)</th>
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Total Minutes on Vigil by Volunteers ____________

Total Minutes Team Leader Spent Coordinating Vigil ____________

TOTAL Minutes ____________
Comments regarding the Vigil, including special challenges, family reactions, etc.

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

Return report to Volunteer Manager as soon as possible, and in no more than seven days after vigil conclusion.
Vigil Request Procedure

Call Vigil Team Leader at, 360.630.4485 (8am – 6pm)

YOU DO NOT NEED TO ENTER A VISIT ORDER OR FREQUENCY in HealthWyse Mobile; you do need to enter an Attribute. Vigils are staffed as the volunteers are available and generally do not go past 48 hours. Patient should be actively dying.

The Vigil Team Leader information is listed on the daily Who’s Who as well as in When 2 Work. If you cannot reach the Vigil Team Leader by phone, call Erin Long: office 360.814.5588 or work cell 360.899.6393; if Erin is not available reach out to the Admin On Call.

Please note that the volunteer may request an RN visit to reassess the patient, i.e. if the patient is up and chatting with the volunteer or eating lunch and/or doesn’t appear to be actively dying. If you know a day or more ahead of time that you will likely be requesting a vigil, please call the Team Leader or Erin to give a “heads up.”

HNW Staff Procedure:
• Call Vigil Team Leader on Vigil Line at 360-630-4485 between 8:00 am and 6:00 pm; leave a message or text that line if you don’t get a live person, this is an HNW device
• Provide the basic patient information, primary contact information, and anything pertinent that the Vigil Team may need to know about family/facility dynamics and/or access
• Notify primary contact that Vigil Team Leader will be calling to get additional information
• Add the Attribute “Volunteer 4” with staff of “Vigil Volunteer, 360-630-4485”
• Send a HOSPICE wide email that a vigil has been called for the patient

Vigil Team Leader Procedure:
• Vigil Team Leader calls primary contact (family member, facility staff, etc.) to gather all necessary information
• Vigil Team Leader sends out request to Vigil Team volunteers
• Vigil Team Leader notifies HNW Staff member requesting the vigil and the Volunteer Manager of the vigil status (staffed, or if a shift is unstaffed)

Volunteer Manager Procedure:
• Volunteer Manager verifies the Vigil Attribute is listed in the patient’s chart
• Volunteer Manager follows up with the HOSPICE wide email for any updates as needed

NOTE: If patient passes while vigil is being held:

DURING WORKING HOURS:
Vigil Team Leader notifies Volunteer Manager
Volunteer Manager notifies the front desk

AFTER WORKING HOURS:
The Vigil Team notifies the On Call HNW Staff
The Vigil Team Leader notifies the Volunteer Manager next available work day

***If patient passes when Vigil Team members are not present; the HNW Front Desk Staff will contact the Vigil Team leader of passing (only if the Vigil Attribute is marked in the chart).***
Vigil Volunteer’s Role and Responsibilities

Vigil Volunteers:

- provide accurate, up-to-date contact and availability information to the Volunteer Manager, including planned vacations;
- contact the Vigil Team Leader as soon as possible when notified of an impending vigil (whether you can participate or not);
- offer a calm and supportive presence for the patient/family/caregivers, at home or in a facility, during the last 24-48 hours of the patient’s life;
- be available for one or more 3-4 hour shifts during a vigil, if possible. (However, volunteer is not to cover more than one shift in a 24 hour period)*
- educate those present regarding the active phase of dying and model appropriate behaviors;
- be with the patient or family (such as children, so the patient can be attended to by other family members);
- brief the next team member on the state of the patient and any other information s/he may need to know (please do not do this in front of the patient or within earshot);
- contact Hospice Office at 360-814-5550 if the patient appears to be in a pain crisis or if their family/caregiver is in crisis;
- call Hospice to notify of the patient’s death, if you are present; and
- call/text the Team Leader during vigil hours to notify them of a death so they can contact other scheduled volunteers to cancel their shifts.
- Attend Vigil Volunteer Meetings
This position reports to the Volunteer Manager and/or the Vigil Team Leader.

Purpose of the Position:
To support patients who are actively dying as well as the patients’ families, caregivers and loved ones.

Responsibilities:
- Participates in a rotating duty roster.
- Replies to the Vigil Team Leader ASAP regarding the ability to participate in impending vigils.
- Accepts assignments and direction from the Vigil Team Leader.
- Provides 1-2 shifts per vigil, if possible.
- Provides verbal report to vigil volunteer on next shift.
- Confirms vigil service minutes with Team Leader after shift.
- Notifies Hospice of patient’s death, if it occurs while on their shift.
- Maintains universal health precautions.
- Upholds confidentiality and protection of patients’ and families’ rights.
- Maintains appropriate boundaries.
- Upholds HNW policies, procedures and philosophy.

Requirements:
- Successfully completes an 18-hour training class for Patient/Family volunteers.
- Provides current, required documentation including: immunization records, driver’s license, and proof of automobile liability insurance.
- Attends at least six (6) volunteer support meetings or educational in-service trainings per year.
- Attends at least six (6) vigil support meetings annually.
- Participates in an annual evaluation.
- Signs an annual volunteer agreement.

Qualifications: Volunteer must . . .
- Be 21 years of age or older.
- Be emotionally mature.
- Be reliable and punctual.
- Have excellent listening and communication skills.
- Respect a variety of patient and family belief systems.
- Perform duties with a minimum of direction.
- Have means of transportation.
- Have access to phone service and the Internet.
Vigil Team Leader’s Role and Responsibilities

- Be available between 8:00 am and 6:00 pm daily to receive requests, from a HNW patient’s Nurse/MSW/Spiritual Counselor, for a Vigil.

- Vigil Team Leaders are scheduled for one to two-week shifts.

- If unable to perform your duties, arrange with another team leader to take your place; Contact Volunteer Manager Erin Long at elong@hospicenw.org or call 360-814-5588.

- Keep the Vigil Phone and Vigil Volunteer and Team Leader Manual accessible at all times; your secured Vigil Bag is optional if you have one.

- When a call comes in:
  - fill out the Vigil Volunteer Request Form as completely as possible;
  - note the time the Vigil Request was received in order to record and report the total minutes spent by you in setting up the Vigil;

- Call, text, or email Vigil Volunteers about the vigil request in city where patient is located.

- Ask each Vigil volunteer if they are willing/able to fill one or more 3-4 hour shifts over the next 48 hours. Reminder: no Volunteer (or Team Leader) may cover more than one shift in a 24 hour period and no Vigils may go past 48 hours (without permission from the Volunteer Manager).

- Give the Vigil Volunteers information noted on the Vigil Request form.

- Provide volunteers with phone numbers of the volunteers scheduled before and after them. If not available at time of initial call, call them back when you know the names and numbers.

- Give your home or cell number (or both) and the Vigil number 360-630-4485, so they may call if they have questions or concerns.

- E-mail Erin Long, Volunteer Manager that the vigil has been staffed

- Remind the Vigil Volunteer that if the patient dies during their Vigil, that they are to:
  - Call the Hospice Office 24 hour/7 days a week number at 360-814-5550.
  - Note the time of death.

- Call the Hospice office 24/7 number (360-814-5550) to notify that the Vigil has begun. Reception will contact Erin Long, Volunteer Manager during office hours.

- Call the designated family member/caregiver/loved one with the Vigil Volunteer schedule.

- Keep the Vigil Volunteer Schedule updated.

- Update the Vigil Team Leader Manual with any new handouts that are distributed during the period in which you have the phone.

- Be available by phone for calls from volunteers needing consultation or support.

- At the Team Leader’s discretion, s/he may call the Hospice RN 24 hours into the Vigil to request that the patient be re-assessed. This is recommended if the Vigil Volunteer is unsure if the patient is
“actively dying.”

- Vigil Team Leaders may choose to fill Vigil shifts.

- Call Hospice office number (360-814-5550), **during office hours**, to notify Erin Long, Volunteer Manager that a death has occurred. Or, e-mail her 24/7 at elong@hospicenw.org stating that the vigil patient has died (please do not use their name, ID# or other identifying information).

- Once Vigil is over, contact all volunteers who participated to notify of the death and thank them for their service.

- Offer to debrief a volunteer’s experience as needed and/or refer the volunteer to contact the Volunteer Manager.

- Fill out the **Vigil Team Leader Report** including your total minutes, the total number of minutes for Vigil Volunteers and any pertinent comments.

- Send the Vigil Team Leader Report to the Volunteer Manager as soon as possible within 7 days after a Vigil has ended.

- Attend **Volunteer Support meetings**.

- Attend **Vigil Support meetings**.
This position reports to the Volunteer Manager.

Purpose of the Position:
To support and coordinate Vigil Volunteer teams in staffing vigils for patients who are actively dying.

Responsibilities: Vigil Team Leaders . .
- Coordinate all potential and active vigils.
- Follow standard operating procedures related to the vigil program.
- Accept assignments from a Hospice RN/MSW/Spiritual Counselor.
- May provide 1-2 shifts per vigil.
- Report to the relieving Team Leader (if the Vigil is ongoing) when turning over the Vigil Team Leader bag including Manual and Vigil phone.
- Upholds confidentiality and protection of patients’ and families’ rights.
- Agrees to uphold HNW policies, procedures and philosophy.

Requirements: Vigil Team Leaders . .
- Complete an 18-hour training class for Patient/Family volunteers.
- Complete Vigil Volunteer Training or individual Vigil Volunteer Training with Volunteer Manager.
- Provide current, required documentation including: immunization records, driver’s license, and proof of automobile liability insurance.
- Attends at least six (6) volunteer support meetings or educational in-service trainings per year.
- Attends at least six (6) vigil volunteer support meetings annually.
- Participates in an annual evaluation.
- Signs an annual volunteer agreement.

Qualifications: Vigil Team Leaders must. .
- Be 21 years of age or older.
- Demonstrate leadership and administrative abilities.
- Demonstrate exceptional emotional maturity.
- Demonstrate excellent listening and communication skills.
- Respect a variety of patient and family belief systems.
- Be reliable and punctual.
- Be able to perform duties with a minimum of direction.
- Have means of transportation or is able to access public transportation.
- Have access to phone service and the Internet.
VIGIL VOLUNTEER GUIDELINES

Vigil means to “keep watch.” Sitting at the bedside or being in the home of a dying patient is a very private and intimate time. As volunteers and staff, we are privileged to be invited to share in this experience.

While Serving on the Vigil Team
- Check your email regularly to see if there are vigil requests. Three times daily is recommended.
- Volunteers who will be on vacation or out of cell phone range for 4 days or more should notify the Volunteer Manager in advance so it can be noted on the schedule.

When You Receive a Vigil Request Call
- Stop, breathe and check in with yourself to see if you are in the right frame of body/mind/spirit to participate in a vigil.
- **Respond as quickly as possible to calls/emails from the Vigil Team Leader, whether you are able to participate or not. THIS IS IMPERATIVE.**
- Accept or decline the assignment. If you are available, note any and all shifts that you are available during the entire period of the vigil.
- You will be called and given the patient’s name, address, directions to their location and other pertinent information.
- Note **who you will replace**, their contact number and the time you are expected to arrive.
- Note **who will replace you**, their contact information and the time they will arrive to relieve you.
- During the vigil, prior to your assigned shift, **check your email often (every few hours) for updates.**
- **Those who participate in a vigil should update the Team Leader regarding any updates (directions, new information on patient condition, etc.).** The Team Leader will send these out to all scheduled volunteers.

Before You Walk Out the Door for a Vigil . . .
- Make sure you have your Hospice Vigil Bag for your time with the patient and family.
- Remember your name tag.
- If you have accepted this vigil, it is meant to be. You are being called to serve.
- Be yourself. Your peaceful presence will be of service to the patient and their family.
- Breathe.

Suggestions for What to Take in Your Secured Hospice Vigil Bag:
- notes regarding the patient and their family/caregivers/loved ones;
- directions;
- county/city maps or GPS;
- **Vigil Volunteer and Vigil Team Leader Manual** including all relevant phone numbers;
- personal cell phone with charger (on “vibrate” or “off “; check regularly for messages);
- other electronics (I Pads, tablets, etc.) with chargers;
- writing paper and pen;
- antibacterial, waterless skin cleanser;
- plastic gloves (at least 2 pair);
- poetry, inspirational and/or religious readings (only read if requested by a patient and/or their family/caregiver/loved one);
- small, battery-operated candles;
- something for you to read with discretion;
- flashlight or booklight for reading and/or seeing your way in the dark;
- CD player and tapes of calming music;
- crocheting, knitting, etc.;
- drinks and snacks for yourself;
- prescription medications for yourself, as needed;
- miscellaneous self-care items such as lip balm, eye drops, socks or slippers;
- a sweater, jacket, shawl, etc.; and/or

**When You Arrive at the Home or Facility**
- Arrive 10-15 minutes before your scheduled shift so the previous volunteer can “check out” to you.
- Introduce yourself to family/caregivers/loved ones and/or facility staff.
- Explain your role if you are the first Vigil Volunteer on the scene.
- Ask how you can be most helpful during the Vigil.
- Learn a little bit about the patient.
- Orient yourself to the home or facility, the location of restrooms, etc.
- Ask to be introduced to the patient, or introduce yourself, even if s/he is comatose.

**What to Do or Say While Sitting Vigil**
- **Always speak and act in a calm, soothing manner.** The dying process can be disrupted if the patient is over stimulated by loud voices, bright lights and quick movements.

- **Help set the mood** by turning down the lights, lowering the volume on music and encouraging family, friends and caregivers to speak softly, move slowly and be as calm as they are able.

- **Encourage the family/caregiver/loved ones to** touch the patient and share their thoughts and feelings with them. Even if comatose, the patient is likely able to hear and sense the presence of others in the room.

- If the family is unavailable, uncomfortable or unwilling, approach the patient and **offer your support through touch and presence.** Always ask permission first. If patient is non-verbal, look for signs that they are receptive or not.

- You may be with the patient without speaking; **simply holding a hand can be comforting.**

- **Support the family** if they are providing comfort measures (see “Final Phases of Dying” below) by explaining how helpful they are to the patient who is dying.

- **The family may choose to surround the patient’s bed in a circle, hold hands, say a prayer and/or express their thoughts and feelings.** They may wish to perform this ritual in private or include you. The HNW Spiritual Counselor or the patient/family clergy might also be involved. It is your choice whether or not you participate.
• Objects or activities related to the five senses (hearing, sight, smell, touch and taste) may add calmness or meaning to the dying experience, for example:

  ▪ **Sounds** – Keep the space quiet and calm. Speak softly and share encouraging and loving words. Silence can also be a powerful experience.
  ▪ **Reading and Stories** – Focus on the patient’s preference. Poems, religious and spiritual readings are often preferred.
  ▪ **Music** – Play the patient’s favorite music, sing and/or chant.
  ▪ **Nature** – With family permission, you may wish to place a pine cone, leaves, twigs, shells, rocks, stones, nearby. Nature scents may also be welcome.
  ▪ **Sight** – Photos and other images are important for reminding patients of loved ones.
  ▪ **Holy Objects** – The patient and/or family may wish to use rosaries, prayer beads, prayer books, crosses, or other holy icons. Please be sensitive to cultural rituals and practices as noted in the Volunteer Training Manual.
  ▪ **Altars** – The family may wish to make a simple altar with objects that are meaningful to the patient.
  ▪ **Articles of Prayer** – Prayer shawls, prayer books, scripture or other religious readings or items might bring comfort.
  ▪ **Candles** – Only use battery-operated ones as flames may be hazardous.
  ▪ **Smell** – Aromatherapy or incense, flowers or sweet spices can be wonderful, however, some patients are extremely sensitive to smells and can become ill; always check first.

• **Review the following document re: The Final Phase of Dying.**

• Discuss the dying process with the family/loved ones/caregiver, if asked, to normalize what is happening.

• Explain that the patient may need to be given permission to “let go.” If indicated, suggest that everyone leave the room for brief periods, as some patients “hang on” as long as someone is in the room even if they are not being touched and there are no words being spoken.

> If for any reason you become uncomfortable with the behavior of anyone present (e.g. drinking, using illegal drugs or exhibiting inappropriate behavior), you may call the Hospice Office during work hours, or night Nurse after hours, to ask for assistance. You may leave if the inappropriate behavior becomes unacceptable or threatens your safety. Notify the Team Leader and the volunteer scheduled to follow you of your decision and the circumstances.

**At the End of Your Vigil Shift**

When your vigil shift ends, assuming that the patient is still alive, expect your volunteer replacement to show up 10-15 minutes early. Spend some time with introductions, sharing information about the situation, and including what would be most helpful to the patient/ family/loved ones/caregivers if present.
Before you leave, please say goodbye to the patient (even if they are unresponsive). Suggested phrasing is: “It’s been an honor to sit with you during this phase of your journey. _________ (state name of new vigil volunteer) is going to sit with you now.”

Contact the Vigil Team Leader between 8 am and 9 pm following your shift, or no later than the next day, to let them know how many minutes you served. This is important, as Vigils are not documented via CallWyse.

If You Believe the Patient Has Passed Away

- Try to rouse the patient by calling their name and gently shaking their hand or shoulder.

- You will know that death has likely occurred if one or more of the following symptoms are present:
  - there is no pulse and no sound of breath;
  - patient’s skin becomes pale, waxy, and cool to the touch;
  - the jaw falls open as muscles relax; sphincters release urine and stool; and/or
  - the patient’s eyes remain open.

- Ask the family/caregiver if they want a “nurse visit” before calling Hospice. Explain that this is not required (in the state of Washington) and that it may take some time before a nurse is available.

- Call Hospice 24/7 at 360.814.5550 to notify that death has occurred. Give the approximate time of death if known.

- After calling Hospice, call the Vigil Team Leader between 8 am – 6 pm so that they can notify volunteers scheduled to follow you that the Vigil has ended. If death occurs after 6 pm and before 8 am, notify the Vigil Team Leader after 8 am the next morning.

- Between 9 pm and 8 am, call the volunteer scheduled to follow to notify of the death if it occurs. Ask that volunteer to call the volunteer following them, etc. to notify them that the Vigil has ended.

- If you are still at the location of the death when the nurse arrives, you may choose to stay for a while but your presence is not required.

- If asked:
  - You may stay for a while so that the family/caregiver/loved one(s) can talk about the patient, share their feelings or ask what they need to do next. Whether you stay or not, and for how long, it is up to you.
  - The body does not have to be moved until they are ready and can be kept for up to 24 hours.
  - Arrangements for removal can be made by the family calling the funeral home, or the family can request that a nurse make the arrangements.
  - If the family makes the arrangements, Hospice needs to be notified where the body has been taken.
  - If there are questions about a Death Certificate, the family should call the funeral home.
• Before leaving, remind the family that Hospice has a bereavement program and that someone will call soon. Briefly explain that helpful literature will be mailed to them, that we offer grief support groups and individual meetings with our Bereavement Counselors. Tell them that if they want to talk to someone sooner, they may call the Bereavement Department (360-814-5550) at any time.

**If Patient Dies Before You Arrive**

You may find that the patient has passed away just before you arrive and you have yet to receive a call from the Vigil Team Leader or volunteer who preceded you. The volunteer who was present at the time of death will orient you to the situation and will confirm that . . .

• they have notified Hospice and the Team Leader of the death;
• a nurse is on their way or not;
• the family knows they will be contacted by Hospice Bereavement and have the phone number (360-814-5550) should they wish to call;
• they understand the body can be kept for up to 24 hours;
• they are aware that they, or a Hospice nurse, will make arrangements for removal of the body; and
• that they know that if the family makes the arrangements, they need to let Hospice know where the body has been taken.

If asked, you might stay for a while so that the family/caregiver/loved one(s) can talk about the patient, share their feelings or ask what they need to do next. Whether you stay or not, and for how long, it is up to you.

**After Your Vigil Volunteer Experience: Self-Care**

Although it is an honor to be invited to sit vigil with patients and families, it can be physically and emotionally exhausting. Witnessing a death can be a profoundly moving experience. Sharing a family’s pain can sometimes be heart-wrenching. It is important to be gentle and gracious with yourself and allow time to digest the experience. Below are some things you may wish to incorporate into your self-care after your vigil service is over.

• Savor a cup of tea or coffee and reflect on the experience.
• Call your Team Leader, a fellow Vigil Volunteer, or the Volunteer Manager to talk.
• Spend time alone reviewing your experience.
• Take a nap.
• Take a hot bath with scented candles.
• Read something meaningful.
• Exercise.
• Listen to music.
• Give thanks for the life of the person and the gift of their presence in your life.
• Meditate.
• Write.
• Send a card.
• Acknowledge yourself for the gift that you gave.
Final Phase of Dying

Physical Symptoms

Patients and their families often ask Hospice staff to predict when death might occur. Forecasting how long someone will live can be challenging. Statistical averages give a point of reference, but we all have heard stories of people who lived longer than expected or died prematurely.

There are often specific signs of approaching death which may be observed. Each individual patient is different. Not all patients exhibit all of these signs. In Hospice patients who are not elderly, these signs may be less likely to appear. Patients may be actively dying, for example, yet still be cognizant, breathing regularly, and able to converse.

There are two phases which arise prior to the actual time of death: the “pre-active phase of dying” and the “active phase of dying.” The pre-active phase generally lasts about two weeks, while the active phase of dying usually lasts about three days. Some patients may exhibit signs or symptoms for a shorter or longer period of time; some may actually recover and live a week, a month or even longer.

Signs of dying may be disturbing to family members. As a Vigil Volunteer, one of the most important things you can do is to explain that these symptoms are normal and that the patient is not likely in any distress.

Pre-Active Phase of Dying (approximately the last two weeks of life) May Include:

- Increased periods of sleep, lethargy
- Decreased intake of food and liquids
- Increased dehydration. Suggestion: Keep patient’s mouth moist with a sponge, drops of water or ice chips and apply lip balm or petroleum jelly to lips.
- Periods of pausing during breathing (apnea) while awake or asleep
- Increased restlessness, agitation, inability to stay content in one position, insisting on changing positions frequently and/or pulling at bed linens. Suggestion: Be calm and reassuring, create a quiet and peaceful atmosphere, limit the number of people in the room at one time, repeat patient’s name often and keep the patient safe by padding bedrails.
- Increased confusion about time, place or identity of close and familiar people
- Gradual withdrawal from external world
- Increased difficulty with speech and communication. Suggestion: Talk calmly and quietly (don’t try to “orient” the patient) and hold their hand if they are receptive.
- Patient reports seeing others who have died before them or have come for them.
- Comments like “I want to go home” or “I am dying” may be made. Suggestion: They may not be disoriented but rather responding symbolically to another reality – preparing to die.
Deathbed visions are not uncommon. Listen carefully to the messages and respond as if they are true.

- Inability to heal or recover from wounds or infection
- Increased swelling (edema) of either the extremities or the entire body
- Blurred vision. Suggestion: Use soft lights.
- Patient requests family visit to settle unfinished business and tie up loose ends.

**Active Phase of Dying** (approximately the last three days of life):

This is the time when a Vigil may be activated. Volunteers might not always be able to tell if a patient is actively dying. (See paragraph two, under “Physical Symptoms,” on previous page.) Each patient will have a unique experience. Some may exhibit many of the signs below; others might show one or two. After a patient has been under Vigil for 24 hours, the Vigil Team Leader may ask a Hospice RN to reassess a patient if their status is in question.

**Possible Symptoms:**

- Patient cannot be aroused (semi-coma or coma) or is only aroused with great effort, then quickly returns to unresponsive state. Suggestion: Assume the patient can hear you. Hearing is believed to be the last sense to be lost. Speak to the patient even if they don’t respond; it may bring the patient comfort to reminisce or hear that loved ones care about them.
- Much longer periods of pauses during breathing (apnea), very rapid breathing or cyclic changes in the patterns of breathing such as slow progressing to very fast and then slow again, or shallow progressing to very deep breathing while also changing rate of breathing to very fast and then slow and/or other abnormal breathing patterns. Suggestion: It may be helpful if the family or caregiver turns the patient’s head to the side or places pillows beneath. Different sitting positions, a humidifier or oxygen may help.
- A gurgle or rattle sound while breathing (commonly called the “death rattle”) may be heard due to increased respiratory congestion and/or fluid buildup in the lungs. Shortness of breath and rapid chest movements may also occur. Occasionally, after death, there may be a last sigh or noise. Suggestion: Explain to family that this is not uncomfortable or painful for the patient.
- Patient might demonstrate severe agitation and/or hallucinations and not act in their normal manner.
- Patient loses the ability to swallow fluids and no longer takes food by mouth.
- Patient states that he or she is going to die.
- Patient breathes through wide-open mouth continuously and no longer can speak even if awake. This is commonly called “fish mouthing.” Suggestion: Reassure the family that this is a normal part of the dying process.
• Patient may develop urinary or bowel incontinence. **Suggestion:** Advise family/caregiver to use pads or towels to keep the patient dry, clean and comfortable. Reassure patient.

• Urine output is decreased markedly. Urine darkens and/or changes to a very abnormal color such as red or brown.

• Blood pressure drops more than 20-30 points; systolic blood pressure below 70.

• Restlessness may increase due to lack of oxygen in the blood.

• Patient complains that his or her legs or feet are numb and cannot be felt at all.

• Vomiting may occur.

• Circulation slows and there may be changes in body temperature. The chest and abdomen may be warmer than usual, while the arms and legs become cool. The patient may perspire. There may be changes in skin color, including purplish blotchy spots. This is commonly called “mottling.” **Suggestion:** Keep the patient warm with blankets; do not use an electric blanket.

• The patient may experience a brief, final surge of energy. Although this can be confusing to loved ones, it is a normal sign of dying. This is the time to say goodbye.

• Patient’s body is held in rigid unchanging position.

• Patient’s jaw is no longer held straight and may drop to one side. **A Final Thought**

“When we honestly ask which persons in our lives mean the most to us, we often find that it is those who, instead of giving much advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not-knowing, not-curing, not-healing and face with us the reality of our powerlessness . . . makes it clear that whatever happens in the external world, being present to each other is what really matters.”

**Henri J. M. Nouwen**
SECTION 10
MUSIC & MEMORY PROGRAM OVERVIEW

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Benefits of Music
Application to HNW Patients
Program Snapshot
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Patient/Family Interview Sheet
Visit Frequency and Duration
Conducting a Volunteer Visit
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Safety and Cleaning
Communicating with Facility Staff
Music and Memory Program Information Sheet
Music and Memory Staff Information Sheet
Introduction

The attraction towards music begins in infancy, is manifest and central in every culture, and likely goes back to the beginning of our species, observes Oliver Sacks, famed neurologist, researcher and author. It lies so deep in human nature that one is tempted to think of it as innate.

Human beings are exquisitely tuned to the illuminating yet mysterious power of music. It can transform worlds and awaken a sensation of aliveness. Music can calm, animate, comfort, thrill, trigger lost memories, connect us to others and ground us to the present moment. It can be fresh, bursting with raw energy, sweet and powerful and passionate, intellectual yet mystical, full of surprises.

Recent research has demonstrated that music may be especially powerful and have great therapeutic potential for patients with a wide variety of neurological problems. Such people may respond strongly and specifically to music (and sometimes to little else). “Some of these patients have wide-spread cortical problems, whether from strokes or Alzheimer’s or other causes of dementia; others exhibit loss of language or movement functions, amnesias, or frontal-lobe syndromes. Some are developmentally delayed, some autistic; others have Parkinson’s or movement disorders. All of these conditions can potentially respond to music and music therapy,” states William James.

Most of the research has focused on the fact that our brains are hard-wired to connect music with long-term memory. We have all had the experience of listening to a song that takes us back in time, reminding us of a special person or event. These tunes, although long buried, are easily accessible. As we hear them anew, we may find ourselves singing, smiling and transported to another place and a different era.

Musical memory is profoundly linked to emotions. These memories are stored deep in the brain, according to Musicandmemory.org, a program bringing music to dementia patients. The website says, “While Alzheimer’s damages the ability to recall facts and details, it does not destroy these lasting connections between a favorite song and memory of an important life event, no matter how long ago.”

So if music is a gateway to buried memories, are there applications for using it in new or unique ways? Music and Memory is an innovative project that sends trained volunteers to take s into nursing homes and play personalized music for patients with dementia. The results have been nothing short of miraculous. Previously non-verbal patients have begun to speak, sedate patients have started to dance, non-responsive individuals have tapped out tunes with their fingers, sang and lit up with joy. The organization now has volunteers in many nursing homes throughout the country.

HNW staff and volunteers viewed Music and Memory’s award-winning documentary “Alive Inside” in 2015 and were positively impressed with the benefits of music in this patient population. HNW Foundation granted funds to launch a similar program (Replay the Memories) in 2016, in order to better serve our Dementia patients. The first volunteers were trained in July 2016. Nanos were used. In December 2016, the HNW Volunteer Supervisor took a training and our organization became a national Music and Memory Certified Care Program. The title of the program was changed to Music and Memory and we began using iPod Shuffles. Hospice volunteers have embraced this opportunity to be part of an exciting, innovative project that taps into their passion for music and transforms the lives of others.
Application to HNW Patients

Approximately 1 in 5 HNW patients has Dementia as a primary diagnosis (2015 = 22%, 2014 = 19%). Patients with other diagnoses, such as Parkinson’s and other diseases that damage brain chemistry, are also part of the population we serve. A large number of these patients live in facilities; many in memory care units. Some of these individuals have responded positively to music therapists; however their availability is limited. Volunteers who play instruments are also requested by HNW patients and families. Adding music to our repertoire of what is available is yet another way to improve quality of life and well-being.

Benefits of Music

In the patient with neurological disorders, research has demonstrated that music can have the following benefits*:

* positively impact mood
* unlock Parkinson’s patients from their motionlessness
* give words to stroke patients who otherwise cannot speak
* reduce agitation and anxiety
* improve attention, motivation, focus and awareness
* calm and organize people who are volatile
* improve memory and cognitive skills
* improve physical coordination
* reduce pain and other symptoms

Music and Memory’s** research into the effect of personalized music on patients with dementia in the nursing home environment revealed these positive outcomes:

* **Individuals** are happier and more social.
* Music improves patient cooperation and willingness to accept care.
* Relationships among staff, participants and family deepen.
* Everyone benefits from a calmer, more supportive social environment.
* Staff regain valuable time previously lost to behavior management issues.
* Improves staff morale and enables them to be more person-centered.
* It may help reduce reliance on anti-psychotic medications.

** www.Musicandmemory.org

Music gives a soul to the universe,
wings to the mind,
flight to the imagination,
and life to everything.
Program Snapshot

*Music and Memory* is a Hospice of the Northwest program designed to improve quality of life by bringing individualized music to patients. Trained volunteers will share music on s with headphones or via speakers.

**Goals**

- Have a sufficient number of trained Music and Memory Volunteers to serve patients
- Educate staff regarding the program, its benefits and referral process.
- Secure program referrals
- Fill at least 90% of referrals
- Feedback from sources to be largely positive (Staff and Volunteer observations)

**Referrals**

- Requests for this service may be made by HNW nurses, Social Workers or Spiritual Counselors via a Volunteer Order, Call Log, Visit Frequency, Goal and Intervention.
- Bedside Music Practitioners may refer patients by contacting one of the Care Team members listed above or the Volunteer Supervisor (in which case she will notify the Care Team).
- Volunteers may suggest the service if they have a patient they think is appropriate. Requests should be made to members of the Care Team or the Volunteer Supervisor (in which case she will notify the Care Team).

**Visit Frequency and Duration**

- It is recommended that first Music and Memory visits be 15-20 minutes in duration.
- Following the first visit, if the patient is responsive to music, visits will typically be twice monthly for 30-45 minutes.
- However, the duration and frequency can be adapted due to patient schedules and interest in music.

**Play Lists**

- Volunteers may check out s from the Volunteer Supervisor.
- Individualized play lists may be created for each patient and fine-tuned as needed.

**Volunteer Visits**

- “Music and Memory” visits may be stand-alone sessions, with music as its sole purpose.
- Music may also be played as part of a regular volunteer visit (companionship or respite).
• Music and Memory volunteer visits will be documented on CallWyse and via a “Patient Observation Sheet for Music” (see Section 2).

**Families, Caregivers and Facilities**

• Volunteers will contact families and caregivers in order to develop personalized play lists and will update them as appropriate thereafter.

• Families and caregivers are welcome to attend music sessions.

• Facility staff will be informed of this new program and notified that it is available for HNW patients only.

**Program Evaluation**

• Since this is a new program, the Volunteer Supervisor will assess its results and refine the program every six months in 2017 and annually thereafter. Assessment criteria and measurable outcomes can be found in Section 5.
Patient Referrals
Appropriate Patients

Patients with degenerative and cognitive brain impairment may especially benefit from this program. This includes, but is not limited to individuals with one or more of the following diagnoses:

- Alzheimer’s Disease
- Other Dementias
- Parkinson’s Disease
- Other Movement Disorders
- Traumatic Brain Injury
- Stroke
- Paralysis
- Autism
- Amnesia
- Developmental Delays
- Visual Impairment or Blindness
- Multiple Sclerosis (latter stage)
- Muscular Dystrophy (advanced)

Referral Process

Patient referrals may be made by:

- HNW Nurses, Social Workers and Spiritual Counselors via a Volunteer Order, Visit Frequency, Goals and Interventions in MobileWyse. A Call Log accompanying each referral will indicate patient music preferences or musical background, if known.
- See HNW staff instructions “How to Request a Music and Memory Volunteer” via MobileWyse in the Appendix.
- Bedside Music Practitioners may refer patients to the Volunteer Supervisor or Care Team members listed above. The final order must be submitted by the Care Team.
- Volunteers may refer patients to the Volunteer Supervisor or Care Team members listed above. However, the order must be approved and submitted by the Care Team.

Referral Criteria

Below are indicators that a patient may be responsive to music:

- Has shown a positive reaction to music
- Played an instrument
- Enjoyed singing (school, choir, in a band, professionally)
- Liked to attend musical performances (musical theatre, concerts, opera, symphony)
- Is listed as having an interest in music in his/her medical record.
- Had or has a collection of music.
Music may also be beneficial to patients exhibiting the following behaviors:

- Impaired communication or inability to verbalize
- Boredom, withdrawal
- Restlessness, agitation or wandering behavior (includes “sundowning”)
- Anxiety, fear, depression

The above criteria are simply guidelines and are not exclusive.

Patients, of course, must have the ability to hear sufficiently, at least in one ear, to be able to benefit from this program.
Patient/Family Interview Sheet

Patient ___________________________ Date _____________________

Person Spoken to ___________________ Relationship to Patient ________________

How well do you (or does your family member) hear? Does one ear have better hearing than the other? If so, which ear? Do you (your family member) wear hearing aids? If so, in one or both ears? If one ear, which one?

What music did you (or your family member) listen to when you (they) were young (15–30 years of age)?

Who were your favorite singers, performer, groups, bands or orchestras?

Do you still have any records or tapes that were favorites? What are they?

What songs did you sing when you were small (5-15 years old)?

Did you have a favorite classical composer? If so, who?

Did you enjoy going to plays or musicals?

Did you enjoy patriotic songs?

Did you sing at religious services? What were your favorite hymns or religious music?
What songs did you dance to at your wedding? High school dances or proms?

Can you hum any of your favorites?

Are there any types of songs (or particular music) that would NOT be enjoyable for you?

(For family members) Are you interested in feedback about how the visit goes? Would you like to attend a visit?
Visit Frequency and Duration

The First Visit

If the volunteer has not met the patient previously, he/she should spend some time getting to know him or her.

It is recommended that volunteers start with 15-20 minutes of music during the first session. If the patient has a poor reaction to any song, volunteers should immediately stop the music and either wait until the patient is ready to hear different music, or stop playing the altogether.

Subsequent Visits

After the first visit, the patient play list can be modified, depending upon reaction to the first visit. The Volunteer Supervisor can add or delete music to the playlist if you take the device into the office. Please allow two work days’ time for this.

Thirty to forty-five minute sessions are recommended as the duration for visits thereafter.

Visit Frequency

A visit frequency of twice monthly is recommended, but this can vary depending upon patient responsiveness.

Best Time to Visit?

There is no evidence indicating a “best time of day” for patients to listen to music. However, if you are aware that your patient is more alert at certain times of day that might be a good time to visit.

Volunteers may wish to change the time of day and adjust the frequency and length of listening to best engage the patient or to facilitate desired responses (e.g. playing calming music before patients with “sundowning” behavior).
Conducting a Volunteer Visit

Volunteer Procedure Upon Referral

• Volunteers will contact the family or primary caregiver upon receiving the patient music request.

• They will introduce the program and its benefits.

• Volunteers will confirm whether the patient can hear (and if so, determine if it is one ear and which ear it is, or whether it is both ears) and if they have hearing aids (that they wear).

• Tell them that you will bring the device and headphones to each visit and they are owned by Hospice of the Northwest. If a patient strongly insists that you leave the headphones, you may.

• Using the “Patient/Family Interview Sheet,” volunteers will determine patient music preferences, if possible.

• If the patient is verbal and cognitively intact or has no contacts with others who are aware of their musical taste, volunteers will interview the patient directly.

• Volunteers will call the Volunteer Manager at 360.814.5588 to schedule the visit or visits.

• Volunteers will then develop the personalized play list.

The Music Session

• Before starting your visit, make sure you have the device, accessories, Personalized Play List, Patient Observation Sheet and a pen.

• Introduce (or re-introduce) yourself to the patient and any others present. Explain that you have brought music for them to enjoy.

• You make wish to play music on the speaker first, especially if the patient is reticent.

• Otherwise, explain that you will be putting the headphones on the patient and do it gently.

• You’ll want to insure the audio is turned on low to start. You may be able to check the volume by holding the headphones near your ear.

• If a patient has a hearing aid, try putting headphones on the “good ear.” Another option is to consult with the patient’s audiologist to determine if aids should be worn while listening and whether they need to be adjusted for the volume of music. If the patient has aids in both ears or rejects wearing headphones, HNW has an external speaker for your use.

• The speaker has a light that changes colors, which patients may enjoy. You will be able to share the experience of listening to music with your patient if you use speakers. You can recapture a sense of closeness by singing together, holding hands, swaying to the music, dancing, or just quietly listening and enjoying the memories it unlocks.
• As you play the first song, adjust the volume as needed.

• If the patient experiences ringing in the ears or muffled speech, have them stop listening. They will likely need their hearing checked. If this happens, contact the Volunteer Supervisor.

• You may wish to encourage patient participation in the form of clapping, tapping the foot or knee, gesturing, singing along, moving or swaying to the music or dancing.

• Complete the Patient Observation Sheet during the visit. Save this.

• Continue to play music if the patient is enjoying it.

• Before you play the last song, tell the patient that this is the final song for today.

After the Music Session

• Volunteers will document all visits on CallWyse in the same way that other patient visits are documented.

• Call Wyse will read your volunteer activity as “Music Reminiscence.”

• Record your visit on CallWyse by midnight of the day of the visit.

• Clean the device (and speaker if used).

• Using the data on the Patient Observation Sheet, fine tune the Play List for use during your next visit.

• If patient reacts favorably to the music, consider referring him or her to the Bedside Music Practitioner via the Volunteer Supervisor or Care Team.
**Patient Observation Sheet for Music Session**

Patient ___________________________ Date ___________ Visit # _______

Volunteer _______________________ Music Session Length (minutes) ________

<table>
<thead>
<tr>
<th>Observations</th>
<th>Before Music</th>
<th>During Music</th>
<th>After Music</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Check if &quot;yes&quot;)</td>
<td></td>
<td>(Insert song name if it has an effect on the patient)</td>
<td>(Check if &quot;yes&quot;)</td>
</tr>
<tr>
<td>Awake</td>
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<tr>
<td>Confused/Disoriented</td>
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<td></td>
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<tr>
<td>Coherent</td>
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<td></td>
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<tr>
<td>Non-Coherent</td>
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<td></td>
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<tr>
<td>Calm, Relaxed</td>
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<tr>
<td>Restless</td>
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<td>Agitated</td>
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<td>Tense</td>
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<td>Sad</td>
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<td>Moaning</td>
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<td>Tearful</td>
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<td>Smiling</td>
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<td>Singing/</td>
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<td>Humming</td>
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<td>Moving</td>
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<tr>
<td>Dancing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foot Tapping</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Volunteer Observations and Comments (use back side if needed):
Checking Out and Returning Devices

Checking Out

HNW has devices for volunteers to use with their patients. At this time, only Hospice volunteers may use and play the devices (Patient family members, friends, facility staff, caregivers, etc. are unable to use HNW devices) and they are only to be used with Hospice patients.

Devices are expensive to purchase and load with music. For purposes of inventory control, all devices and speakers are numbered.

All volunteers who check out devices should observe the following:

1) You first must have a referral from a HNW staff member who believes the patient will benefit from listening to music.
2) You will then determine the patient’s music preferences.
3) Once you determine what songs should be on a patient’s play list, let the Volunteer Supervisor know and she will download music for you.
4) All devices are to be checked out with the Volunteer Supervisor.
5) Volunteers must come to the HNW office to check out devices, headphones, speakers and cleaning cloths.
6) They will sign for the device when picking it up.
7) You will be given a bag containing one device, a charging cord, headphones, a mini speaker, ear buds, a cleaning cloth, wall block outlet and instructions.
8) Headphones are to be placed in a separate bag and labeled with the patient’s initials or I.D. number. In most cases, you should take the headphones back and forth to patient visits. If the patient insists on keeping them, and you are reasonably sure they won’t be lost, you may leave them.
9) The Volunteer Supervisor can load additional songs for you and delete songs in order to refine the play list.

Returning

1) Fully charge the device by plugging it into the wall before you return it.
2) Devices and speakers may not be left with patient’s in-between visits.
3) Devices must be received back in the office within 7 days of the last time you use it with a patient.
Creating and Fine-tuning Play Lists

Developing Play Lists

There are multiple options for determining the right music for your patient:

1) **You may talk to the patient (if able to converse), family or caregiver about what music the individual likes** (see Patient/Family Interview sheet).

2) **Find out when the patient was born and locate the play lists for music that was popular during the era in which they were young** (teens and twenties. See chart below under “Popular Music Eras.” The song lists in Section 5 allow you to search by time period, song title, artist and type of music). You may wish to try a couple of songs from each genre. This method will, in most cases, require more time due to it being a trial and error process.

3) Experiment with jazz, classical, rhythm and blues, swing music, Big Band tunes, and rock and roll and movie sound tracks.

4) It is suggested that you **start with about 20 songs on a personalized play list** for a patient. New songs can be added and songs can be deleted as you fine-tune the list.

**Popular Music Eras**

<table>
<thead>
<tr>
<th>Patient’s Current Age</th>
<th>May Enjoy Music from the Following Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>85 and up</td>
<td>1940’s – 1950’s</td>
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<td>75 - 85</td>
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<td>55 - 65</td>
<td>1970’s – 1980’s</td>
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<td>55 and under</td>
<td>After 1980</td>
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**Other Tips for Finding the Best Music**

Below are suggestions for selecting music for your patient based on their mood and behavior:

• **Mood Enhancing Music: Personally Meaningful Songs and Familiar Old Favorites**

Listening to old favorites can enhance mood. This could range from a favorite tune to an Elvis Presley song. Ask patients or their families about their loved one’s tastes and favorite songs. Older family members may be able to recall tunes that were special to patients in their youth.

• **Stimulating Music**
Big band, swing and salsa music can be invigorating and inspire dance and movement. Some patients may wish to sing along. Look at the top pop songs from the years when your patient was a young adult.

**Soothing Music for Agitation**

Soft classical music, lullabies and non-rhythmic instrumental music can reduce agitation and anxiety. Agitated patients may benefit from activities such as singing, tapping, drumming or clapping.

**Connecting and Comforting Music**

Classic American folk songs with easy-to-remember lyrics can create a sense of comfort and safety. Sing-alongs such as “Over the Rainbow,” “You are my Sunshine,” “She’ll be Comin’ Around the Mountain,” and “Amazing Grace” may fall into this category.

See the Supplement Section for additional guidelines on selecting music for patients with Dementia, Parkinson’s Disease or Aphasia.

**Fine-Tuning Play Lists**

It’s not enough to simply make up a great playlist for a patient and leave it at that. As you play music for your patient for the first time, observe his/her reactions. Look for clues in facial gestures and body language to gauge the effect of each song. Use the Patient Observation Sheet (section 3) to record their responses. Keep the music stimulating and fresh, and fine-tune the play list by intertwining new songs into old favorites over time.

If at any time a song is agitating the patient, record what song it was and remove it from their individual play list.

You may wish to add to the playlist and include holiday or seasonal songs, or other new tunes.

It’s possible that the patient might enjoy a song one day, but not enjoy it during your next visit. Perhaps it is because of their mood or physical condition. You can still try the song again at a future visit, and if the patient does not respond positively again, you may delete it from their play list.
# Patient Name ______________________________ Date __________________________

# ________  Playlist Title (e.g. Mary’s Music) ________________________________

<table>
<thead>
<tr>
<th>Artist</th>
<th>Song</th>
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</table>

TURN IN THIS FORM TO THE VOLUNTEER SUPERVISOR WHEN YOU STOP SEEING YOUR PATIENT IN CASE WE WISH TO USE THIS PLAYLIST FOR OTHER PATIENTS. Thank you.
Safety and Cleaning

Volunteers are responsible for proper usage, care, cleaning and storage of devices.

Carrying and handling devices

Devices contains sensitive components. Do not drop, disassemble, or insert foreign objects into the Shuffle. Do not use the Shuffle if it has been damaged. The front cover of the Shuffle is made of glass. The glass could break if the Shuffle is dropped on a hard surface or is subjected to a substantial impact. If the glass chips or breaks, do not touch or attempt to remove the broken glass. Stop using the device until the glass is replaced (see Volunteer Supervisor).

Avoid Water and Wet Locations

Do not expose the device to water, rain, or faucets. Take care not to spill food or liquids on it. If the Shuffle gets wet, unplug all cables, turn it off before cleaning, and allow it to dry thoroughly before turning it on again. Do not attempt to dry it with an external heat source.

Keeping the Outside of the Shuffle Clean

Clean the device immediately if it comes into contact with any contaminants that may cause stains, for example inks, dyes, makeup, dirt, food, oils and lotions.

To clean the device, unplug all cables and turn off (press and hold the sleep/wake button). Then use a soft, slightly damp, lint-free cloth. Avoid getting moisture in openings. Don’t use window cleaners, household cleaners, aerosol sprays, solvents, alcohol, ammonia or abrasives.

Charging the device

Remember to charge the device before every patient visit. To charge it, simply plug the pronged power adapter into a wall socket. Put the short charging cord into the device. Make sure it clicks into place. Then plug the cord into the wall socket.

Do not connect or disconnect the power adapter with wet hands. The adapter may become warm during normal use. Always allow adequate ventilation around the adapter. Unplug the adapter if you note any of the following:

- Power cord or plug has become frayed or damaged.
- Adapter is exposed to rain, liquids or excessive moisture.
- The adapter case has become damaged.
- You suspect the adapter needs service or repair.
- You want to clean the adapter.
Communicating with Facility Staff

• During the first visit to a facility, please give a copy of the Program Information Sheet to the front desk. Ask for it to be delivered to the Director.

• If facility staff come into the room while you are conducting your music visit, explain what you are doing. You can share that this type of program has been shown to benefit both patients and staff and to boost morale. At this time, the program is only available to HNW patients.

• If they have questions, answer them as best you can. You can also recommend the “Alive Inside DVD” and the Music and Memory web-site (musicandmemory.org).
“Music and Memory” Program Information Sheet
~ bringing the gift of music to Hospice patients ~

Human beings are exquisitely tuned to the illuminating yet mysterious power of music. Music can transform worlds, awaken feelings of aliveness and take us back to another place and time.

Recent research has shown that music may have great potential to reach those who are withdrawn or have difficulty with memory or communication. In light of these findings, Hospice of the Northwest has launched “Music and Memories,” an innovative project that brings music to patients through trained volunteers. This program is funded by generous community donors.

Volunteers will develop personalized play lists for patients with input from patients, families or other loved ones. Program participants will be able to listen to favorite songs from their childhood or young adult years. Music will be played on with headphones or speakers. Patients will typically engage in two music sessions per month.

Experience has shown that the music may help patients find renewed meaning, connection and joy. Other benefits of individualized music may include:

• improved sociability
• reduced anxiety, agitation or restlessness
• better memory and thinking skills
• improved attention and motivation
• increased verbalization
• improved physical coordination

Families and staff are welcome to attend music sessions.

If you know of a Hospice of the Northwest patient who might be interested in “Music and Memory,” please contact Julie Pryor Barr, Volunteer Supervisor, 360.814.5588 or jbarr@hospicenw.org.
“Music and Memory” **HNW Staff** Information Sheet  
~ bringing the gift of music to Hospice patients ~

Volunteer Services at Hospice of the Northwest is proud to offer “Music and Memory,” an innovative project in which trained volunteers bring personalized music to patients via s. HNW is part of the national program and is fully certified by Music and Memory. The program is funded by generous community donors.

**Appropriate Patients**

Although this program is open to any Hospice patient, those with degenerative and cognitive brain impairment may especially benefit. This includes individuals with dementia, Parkinsons Disease, Other Movement Disorders, Traumatic Brain Injury, Stroke, Paralysis, Amnesia, Developmental Delays as well as those with Visual Impairment or Blindness, Multiple Sclerosis or Muscular Dystrophy.

**Additional Criteria**

Below are indicators that a patient may be responsive to music:

- Has shown a positive reaction to music
- Played an instrument
- Enjoyed singing (school, choir, in a band, professionally)
- Liked to attend musical performances (musical theatre, concerts, opera, symphony)
- Is listed as having an interest in music in his/her medical record.
- Had or has a collection of music.

The above criteria are simply guidelines and are not exclusive.

Patients, of course, must have the ability to hear sufficiently, at least in one ear, to be able to benefit from this program.

**Benefits**

Experience has shown that the music may help patients find renewed meaning, connection and joy. Other benefits of individualized music may include:

- improved sociability
- reduced anxiety, agitation or restlessness
- better memory and thinking skills
- improved attention and motivation
- increased verbalization
- improved physical coordination

**Program Specifics**

Volunteers who wish to participate in *Music and Memories* will view the documentary “Alive Inside” and complete instructional training. They will develop personalized play lists by contacting family members or other loved ones. These will be continually fine-tuned depending upon patient reaction.
Volunteers will complete a Patient Observation Sheet after each visit. Visits will typically be held twice monthly for 30-45 minutes each. However, the duration and frequency can be adapted due to patient schedules and interest in music. Sessions may be scheduled as “stand alone” visits or occur as part of a regular volunteer visit.

Headphones and speakers are the property of Hospice of the Northwest. Our iTunes account and downloaded songs are also the property of HNW, and can only be used on our s. Because our patient population is largely elderly, and preferred music is that which was popular during an individual’s teens and twenties, most of the music is from the 1930’s – 1950’s. Headphones will be labeled. Headphones and speakers will be brought to each session and accessories are for patient use only and may be played only when a HNW volunteer is present.

Families or loved ones may attend and participate in sessions if desired. We have a Family Information Sheet available. Facility staff will be informed of this new program and notified that it is available for HNW patients only.

When referring a patient for Music and Memory, please specify in a Call Log what type of music the patient likes, and/or particular songs and artists. Also please indicate if they have a background in music (singing, playing instruments, etc.). This will assist the volunteer in making the most effective play list.

Please note that the Volunteer Supervisor will add “Music Reminiscence” as the Problem, Intervention and Visit Goal. Please contact the Volunteer Manager (814.5588 or elong@hospicenw.org) if you would like more information.
JOB DESCRIPTION
Music and Memory Volunteer

This position reports to the Volunteer Supervisor

Responsibilities: Volunteers must . . .
• Accept assignments and supervision from the Volunteer Supervisor.
• Develop personalized music play lists for patients.
• Deliver music to patients via s with headphones or speakers.
• Document all patient visits via CallWyse.
• Uphold confidentiality and protection of patients’ and families’ rights.
• Attend at least three (3) volunteer support meetings or educational in-service trainings per year.
• Complete an annual self-assessment and an evaluation interview with Volunteer Supervisor.
• Agree to uphold HNW policies, procedures and philosophy.

Requirements: Volunteers must . . .
• Complete an Application.
• Meet with Volunteer Supervisor for formal, in-person interview.
• Successfully complete a Washington State Background Check.
• Sign a Confidentiality/Compliance form.
• Provide at least 2 recommendations.
• Provide required health screenings with negative results.
• Provide required, current documentation including: immunization records, driver’s license, and proof of automobile liability insurance.
• Successfully complete an 18-hour training class for Patient/Family volunteers.
• View the “Alive Inside” video
• Complete the Music and Memory Volunteer Training.
• Participate in an annual evaluation and site visit.
• Sign a Volunteer Agreement.

Qualifications: Volunteers must . . .
• Be 21 years of age or older.
• Demonstrate emotional maturity.
• Not have had a significant personal loss in the preceding 12 months.
• Demonstrate excellent listening and communication skills.
• Be familiar with operating a Shuffle or Nano.
• Be reliable and punctual.
• Have access to phone service and the Web.

I have read, and agree, to the above __________________________________________________________

Name _____________________________ Date _____________________________
Additional Guidelines: Patients with Diagnoses of Dementia, Parkinson’s Disease and Aphasia

Patients with a diagnosis of Dementia

Patients with Dementia respond to different types of music depending upon what stage of the disease they exhibit (http://www.alzfdn.org/EducationandCare/musictherapy.html), according to the Alzheimer’s Foundation.

• Early Stage

□ Go out dancing or dance in the house.
□ Listen to music from the past.
□ Recognize that perceptual changes can alter the way individuals with Dementia hear music. If they say it sounds bad, turn it off.
□ Experiment with various types of concerts and venues, giving consideration to endurance and temperament.
□ Encourage an individual who played an instrument previously to try again.
□ Compile a musical history of favorite recordings, which can be used in reminiscence and memory recall.

• Early and Middle Stages

□ Use song sheets or a karaoke player so the individual can sing along with old-time favorites.

• Middle Stage

□ To improve balance and gait, play music while the individual is walking.
□ Use background music to enhance mood.
□ Choose relaxing music – a familiar, non-rhythmic song – to reduce behavior problems at night-time.

• Late Stage

□ Memories and responses may become less available as Dementia progresses. However, motor memory and response may still occur via rhythmic activities or dancing.
□ Utilize the music collection of old favorites from the patient’s play list.
□ Do sing-alongs, using tunes sung by rote in the person’s generation. For these patients, discovering that they can still sing is reassuring and can stimulate a sense of identity.
□ Play soothing music to provide a sense of comfort.
Exercise to music.

- Do drumming or other rhythm-based activities.

- Use facial expressions to communicate feelings when involved in these activities.

**Patients with a Diagnosis of Parkinson’s Disease**

Music helpful to these individuals must have a firm rhythmic character, but it does not need to be familiar.

**Patients with a Diagnosis of Aphasia** (inability to speak)

- It is crucial to play songs with lyrics or phases, rather than instrumental music.
Pet Peace of Mind
Hospice Volunteer Training
Partnering with Patients and Pets
Pet Peace of Mind

- **Goal:** To provide our patients with the assurance that *we understand* the role of their pet in contributing to their emotional and spiritual well being

- **Purpose:** To recognize and *actively support* keeping patients and pets together during their time on hospice
Why Do Pets Matter?

- 2012-2013 data: 62% of households now own at least one pet

- Pet spending has risen from $17 billion in 1994 to $60 billion in 2014

- The largest expenditure is for pet food, followed by vet care, supplies and medications. The combined total of these three is $50 billion.
The Human-Animal Bond

- Pets provide a significant source of unconditional love and acceptance for owners
- Pets provide stability, routine and a sense of normalcy during life transitions
- Pets also provide a sense of responsibility and purpose outside of self
The Human-Animal Bond

- Pets are often symbols for owners
  - They may represent relationships, past or present
  - They may represent children of childless couples or empty nest adults
  - They may be the only social outlet or interaction a patient or family member has
How Pet Peace of Mind Helps

- Reduces the impact of the financial burden on family and pet
- Helps manage the loss of control that occurs with hospice
- Provides a non-threatening way to assist patient or caregiver
- Provides a relationship building opportunity for hospice staff and volunteers with patient and family
- Helps with patient’s unfinished business by planning for pet placement; keeps the patient/pet together
- Eliminates the unintentional neglect of pet due to caregiver stress
How Will HNW Help?

- Hospice of the Northwest will support by
  - Pet Care
  - Re-homing Agreement
  - TBD as program grows
Great Volunteers Are Essential

- Pet Experience Inventory will help match you to tasks with your interests and skill level
- Volunteers act as an extension of the patient’s love and concern for their pet
- You can help us identify pet needs as they arise
- Volunteer safety is always a priority
Ways Volunteers Can Help

- Transporting pets to vet or groomer
- Delivering pet food to patients, picking up pet food from donors
- Pet-sitting or visiting to help with pet care and exercise
- Providing temporary or permanent foster homes for displaced pets
- Administrative help for PPOM Coordinator
- Interviewing patients about their pets
Putting Pet Owners at Ease

- Always wear your hospice identification and introduce yourself as a volunteer.
- Review the pets’ names and genders before your first visit.
- Address them by name:
  - I’m here to pick up “pet’s name” for his/her visit to the veterinarian.
  - I’m here to deliver pet food for “pet’s name”.
- Don’t be afraid to interact with pets:
  - May I give “pet’s name” a treat?
- Ask questions about the pet:
  - Is there anything special or unusual about your pet’s behavior I should know? Any likes or dislikes about people or other animals?
Pet Transport

- *All pets* are to be transported in pet carriers or crates—No exceptions!
  - Explain to reluctant owners that this is hospice policy for safety of their pet
  - Pets remain safe and secure inside the crate, even if anxious
  - Reduces driver distraction, keeps vehicle clean
  - Pets have been killed by air bags and injured or lost in automobile accidents
Pet Transport

Pet Carriers (Crates)

- Crates for transport should be of an adequate size for pet to turn around and stand upright in, but no larger.

- Inspect crates prior to use
  - Check doors and side fasteners for security and safety
  - Practice opening and closing door of empty crate
    - Some doors come off in one piece, others are hinged
    - Crates with wire top doors are good for cat transport

- Clean each crate with pet-safe disinfectant between uses!!
Pet Transport

- Volunteer Safety in Pet Transport
  - If at all possible, let the patient or caregiver put the pet in the crate—check for door security afterwards
  - Do not carry smaller crates by their handles—always support them from underneath when pets are inside
  - Do not remove pet from carrier while traveling
  - Always let the veterinary staff remove the pet from the crate and place them back inside for the trip home
Pet Food Volunteering

- Ways to get involved
  - Organizing a pet-food pantry
    - Logging in/out donations, keeping track of expiration dates
  - Obtaining donations of pet food from companies and individuals
  - Shopping for pet food and litter for the hospice
  - Delivering pet food to patients and families
  - Picking up donated pet food from donors
Dog Walking

- Before scheduling a walk
  - Make sure dog has a safe and secure collar and leash
    - Appropriate size and tightness—only two to three fingers’ room between collar and neck
    - Check the fasteners on both collar and leash, along with the condition of each. (No frays or tears)
    - Owner contact information on collar, appropriate vaccination tags/city tags
Dog Walking

- Try walking the pet in a secure area first
  - Keep pet on your left side, not in front of you
  - Keep a firm grasp on the leash with both hands
  - Evaluate pet’s leash handling experience
    - Does pet lunge forward or hang back?
    - Will you have adequate control if pet is distracted or afraid?
Other Precautions

- Always use gloves for litter box cleaning and changing.
- Never attempt to pick up a pet without asking owner’s permission—some bite or scratch when picked up!
- Never abruptly change pet’s diet without consulting with veterinarian—can cause digestive upsets.
- Always ask permission before giving pets a treat---no rawhide or table food!
Challenges

- Boundaries
  - As pet lovers, we all want to provide optimum care for pets
  - The decision making for the pet’s care rests with the owner and caregiver, not hospice staff or volunteers
  - Some owners will be reluctant to pursue veterinary care or agree to additional treatment of pet
    - Fear of euthanasia
    - Loss of control in another area of life
    - Lack of education
Challenges

- What you CAN do:
  - Offer yourself and your presence to the pet, patient and caregiver
  - Be accepting and *non-judgmental* about pet’s care or condition
  - Talk to your PPOM Coordinator about care concerns—they can help you process your concerns and contact the consulting veterinarian for advice, if needed
  - Change volunteer assignments if necessary, but only as a last resort
Pet Bites and Scratches

- Call the Pet Peace of Mind coordinator and/or volunteer coordinator immediately!
  - They will advise you about hospice policy for injuries
- For bite wounds, PPOM coordinator will obtain proof of rabies vaccination immediately
- Wash area liberally with soap and water
- Seek medical attention—even minor injuries can become seriously or severely infected
  - All bite wounds should be examined by a physician
Spread the Word about Pet Peace of Mind

- Tell your veterinarian, your groomer and your local rescue group or shelter about the program
- Give pamphlets to pet-owning friends and relatives
- Volunteer to work an information booth at a local adoption fair or pet-themed event
Conclusion

- Patient care is always the primary goal
- Volunteers helping with care of the family pet may increase the quality of life for patients and their caregivers
- By acknowledging the importance of our patients’ relationships with their pets, we affirm them as individuals
- Keeping pets and patients together is better for both
- Always remember to be safe!
What’s Next?

Now that you’ve completed training, here are some reminders to help you in your volunteer role:

EMAIL

• Check your email daily for Hospice information and available patients.
• DO NOT USE patient and/or family member names in UNENCRYPTED E-mail, this can get confusing, double check which email you are using when you type a name or identifying information.

MEETINGS

• Volunteer Support Meetings are held on the fourth Wednesday of the month from 1-3pm, please attend as many as possible.
• Vigil Volunteer Meetings are held on the fourth Wednesday of the month from 3:15–3:45pm (right after the Volunteer Meeting), please attend as many as possible

PATIENTS

• If you’re interested in a patient you see in an email, please let me know that, and also please tell me how soon you’ll be able to make the first visit.
• Please call the patient/family within 24 hours of being assigned.
• Please visit the patient within 4-7 days of being assigned; the more ill the patient, the sooner you should plan to visit.
• Please notify Erin when you or a patient cancel a visit, 360-814-5588.

SCHEDULING

• Schedule your patient visits at least a day in advance by calling Erin, 360-814-5588

CALLWYSE

• Document all visits on CallWyse before midnight the day of the visit.
• When you log in, if CallWyse says you don’t have a visit scheduled, continue to log in by entering the patient’s last name or ID number. CallWyse will let you “override” the apparently unscheduled visit and continue documenting it.
• If you forget your CallWyse password or if CallWyse tells you to enter a new password, type in 0000. It will either accept that password or ask you to create a new one.
• If you have a problem with CallWyse, review the CallWyse section of your binder before calling Julie.

DOCUMENTATION

• Send your car insurance, driver’s license updates and health records to Jessica Enders, Executive Assistant, Hospice of the Northwest, 227 Freeway Drive, Suite A, Mt Vernon WA 98273 or scan and email to jenders@hospicenw.org, or drop them off in an envelope addressed to Jessica.
• Jessica monitors more than 1200 documents annually, therefore you will receive only one reminder. Please do not send your documentation to me.
• Volunteers with any missing documentation must immediately cease any volunteer activities for Hospice or its patients.
This position reports to the Volunteer Manager.

Responsibilities:

- Accept assignments and supervision from the Volunteer Manager for patients/families referred by the Hospice Interdisciplinary Team.
- Provide 1 - 4 hours of service to the patient/family per week, which may include: support and companionship, respite, light household chores and simple meal preparation.
- Schedule all patient visits with designated HNW staff.
- Document all patient/family contacts on CallWyse.
- Maintain universal health precautions.
- Uphold confidentiality and protection of patients’ and families’ rights.
- Maintain appropriate boundaries.
- Attend at least three (3) volunteer support meetings or educational in-service trainings per year.
- Complete an annual self-assessment and an evaluation interview with Volunteer Manager.
- Agree to uphold HNW policies, procedures and philosophy.

Requirements:

- Complete an Application.
- Meet with Volunteer Manager for formal, in-person interview.
- Successfully complete a Washington State Background Check.
- Sign a Confidentiality/Compliance form.
- Provide at least 2 recommendations.
- Complete required health screenings.
- Provide required, current documentation including: immunization records, driver’s license, and proof of automobile liability insurance.
- Successfully complete the training class for Patient/Family volunteers.
- Participate in an annual evaluation and site visit.
- Sign a Volunteer Agreement.

Qualifications:

- Be 18 years of age or older.
- Demonstrate emotional maturity.
- Not have had a significant personal loss in the preceding 12 months.
- Demonstrate excellent listening and communication skills.
- Respect a variety of patient and family belief systems.
- Be reliable and punctual.
- Have means of transportation or able to access public transportation.
- Have access to phone service and email.

Volunteer Name - Printed  Volunteer Signature  Date
Questions to Ask Before Being Left with a Patient

These questions may be asked during the phone call preceding your visit or when you arrive.

11. What is the caregiver’s destination and cell phone number, or a number where they can be reached?

12. What name/number to call if caregiver can’t be reached?

13. What time will the caregiver return? Ask them to call if running late and remind them that 4 hours is the maximum stay per respite/week.

14. Does the patient ambulate or are they bedbound? If they ambulate, what assistance, if any, is needed? What is the plan if they need assistance? *Remind caregiver that you are not allowed to lift, transport or transfer.*

15. Is the patient toileting independent? Can the patient control bladder and bowels? What is the plan for toileting accidents? *Remind caregiver that you are not allowed to assist in toileting.*

16. Does the patient have trouble eating, drinking and/or swallowing? Are there any concerns or special directions? Will the patient need to eat during the respite stay? If so, what food/drink is available? *Remind caregiver that you are not allowed to feed patients.*

17. Medications.
   c. When should medications be taken, and which medications? Patients must be able to place their medications in their own mouth without assistance. Volunteers may lift water to patient’s mouth.
   d. Ask caregiver to measure out medications the patient may need to take while you are there.

18. Is patient alert and oriented?

19. Has the patient shown evidence of increased pain or other symptoms recently? Have they spoken to their nurse about these issues?

20. Does the caregiver want the phone or front door answered? Are visitors expected?

In an emergency: Call Hospice at 360-814-5550
DO NOT CALL 911
Greetings:

It is my pleasure to introduce you to ____________________, a volunteer for Hospice of the Northwest. This volunteer is available to provide support, companionship and/or respite (caregiver relief) while you or a family member are under the care of Hospice.

Hospice of the Northwest volunteers are chosen for their compassion, maturity and reliability. They complete background, reference and health checks and are closely supervised. Below are some guidelines to clarify the role of the volunteer.

<table>
<thead>
<tr>
<th>Volunteers May</th>
<th>Volunteers May Not</th>
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<tbody>
<tr>
<td>*Visit 1-2x/week at a pre-arranged time</td>
<td>*Help with toileting, personal or medical care</td>
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<tr>
<td>*Serve as companions (usually 1-2 hrs/week):</td>
<td>*Turn, move or lift others, or assist with walking</td>
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<tr>
<td>(visit, read aloud, play cards, do puzzles, share</td>
<td>*Provide transportation</td>
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<tr>
<td>hobbies, do arts and crafts, etc.)</td>
<td>*Mop, vacuum, clean bathrooms, do heavy</td>
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<tr>
<td>*Provide caregiver relief (up to 4 hrs/week)</td>
<td>chores, lifting or home repair</td>
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<tr>
<td>*Make snacks or simple meals</td>
<td>*Handle cash, debit or credit cards</td>
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<tr>
<td>*Do light housekeeping: dishes, laundry, dust,</td>
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<tr>
<td>straighten, bring in mail or paper, take out</td>
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<tr>
<td>garbage</td>
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<tr>
<td>*Run errands if given a pre-paid store card (</td>
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<tr>
<td>Safeway, Fred Meyer, Haggen etc.)</td>
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Volunteers are assigned based on patient and family need, location and schedule. Please discuss your schedule to arrive at a mutually convenient visit time. Volunteers will call to confirm prior to each visit. They will contact you if unable to visit due to illness or vacation. In some cases, if given at least one week’s notice, we can arrange for a substitute volunteer.

If you need to cancel a visit or get a message to a volunteer, please contact me at 360.814.5588 or elong@hospicenw.org and I will contact him or her on your behalf. Volunteers are not able to give out their personal contact information.

If you have questions or concerns regarding your Hospice volunteer, please give me a call or contact one of your Hospice team members.

Sincerely yours,

Erin Long
Volunteer Services Manager
Guidelines for the First Phone Call and Visit

When you accept a new patient assignment, you will be given the name/number of the primary contact person and in most cases, will receive information about a second contact person. **Please make contact within 24 hours and no longer than 48 hours after you accept an assignment.** If you cannot make contact that quickly, please let the Volunteer Supervisor know and she may choose to assign the patient to a different volunteer.

If you call the contact person and must leave a message, do so and try again later. **DO NOT LEAVE YOUR PHONE NUMBER.** If you cannot reach the patient or their contact after leaving two (2) messages, call the Volunteer Supervisor.

**The First Phone Call: Patients Living in a Private Residence**

Before you make the first phone call to arrange the initial visit, review the patient information you received from the Volunteer Supervisor. Familiarize yourself with the situation. It’s a good idea to have a couple of dates and times in mind for the first visit. It is recommended, when possible, to first schedule an introductory visit so you can get acquainted with the patient and family or caregiver and establish an ongoing schedule. Please try to **visit the patient within four days of assignment and no later than seven days after assignment.** If you are unable to see the patient within a week, please contact the Volunteer Supervisor.

- **Talking points for the first phone call:**
  - **Call and introduce yourself** and share that you are a Hospice volunteer.
  - **Ask if it is convenient for them to talk** at this time (if not, arrange to call back).
  - Tell them **you understand that they or a family member would like a volunteer**; confirm this.
  - **Confirm the purpose of your visit:** companionship, respite or both. Ask how you can be most helpful. If they’re not sure, make some suggestions.
  - **Clarify what you are not able to do** and the number of hours/week you are available to visit.
  - Find the best day and time to meet.
  - If you plan a get-acquainted visit, then say **“During this first visit, we can get acquainted and I can learn how I might be most helpful.”**
  - **If not doing a get-acquainted visit and you are going to provide respite**, tell them you will **come early to get acquainted** and so I can meet your family member, learn where things are in the home, etc. **(At that time we can schedule subsequent visits.)**
  - State that **you will call the morning of the appointment to confirm.** (It’s possible the patient may feel poorly and not want a visit).
  - **Confirm the address and ask for directions** if needed.
  - Should you need to **cancel the appointment**, call Hospice at 360-814-5550.
  - Tell them that you look forward to meeting them.

**The First Phone Call: Patients Living in a Facility**

For patients in facilities, if there is a contact person, call and follow the script above. Ask them if they know a good day/time to visit. Otherwise, either call or stop by the facility and ask them about meal times. They likely will not tell you what your patient’s schedule is or release information to you because you are not listed as someone who can receive private patient information.
The First Visit in a Home

It’s natural to feel nervous before the first visit. Just be yourself, trust your training and your instincts, and assume an attitude of openness and receptivity. In turn, patients and families will let you know what they need and you’ll also be able to make observations about what might be helpful. You can let them know what you can offer and the relationship will unfold naturally.

- **Wash your hands** or use hand sanitizer gel before you leave the house.
- You may wish to **pack a bag** with some books that you can read to the patient, playing cards, etc.
- Dress neatly; **insure that your Hospice name tag is visible**.
- **Refrain from wearing scented products** as these can be unpleasant to patients.
- When the family/caregiver opens the door, **introduce yourself and state that you are a Hospice volunteer**.
- If you have not washed your hands; ask if you may do so before visiting the patient.
- **Ask how you can be most helpful** to the family today and in the future.
- **Ask questions about the patient** to get further information. Explain your role.
- Discuss a visit schedule and if possible, **set a regular meeting time**. Tell the family/caregiver that you will call the morning of each visit to confirm.
- **If asked to provide respite, see instructions below**.
- **Inform them of any planned vacations** you have and that there may be a possibility of a substitute.
- When you meet the patient, **ask how they would prefer to be addressed**.
- **If you want to touch them, ask first**, e.g. “May I shake your hand?”
- **Ask how they are feeling today, and if there is anything you can do to help**. If they are unsure, you may wish to make suggestions. A great icebreaker is to ask about things in their room – photos, etc. and if there are any stories behind them.
- At the conclusion of your visit **ask “May I visit you again?”** If they so no, I would still call the contact person the next week to see if the patient feels differently or if the contact person needs your assistance.
- **Wash your hands before leaving and confirm the next visit**.

The First Respite Visit in a Home – additional questions to ask

- Be sure to ask all the questions in the following section “What to do before you are Left with a patient.”

The First Visit in a Facility

- Remember to **wear your name tag**.
- When you enter the facility, stop and introduce yourself at the reception desk. **Ask if they have sign-in/sign-out procedures**. You may need a door code to get into memory care if your patient is in such a unit.
- **Confirm the patient’s room number and location**.
- **Ask what you should do if you have a concern while there**; should you push the patient’s call button?
- When you go to meet the patient, **follow the steps above**.
- **Sign out** when you leave the facility.
# SECTION PREFACE

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How to Handle Emergencies
As one of our amazing nurses says:
“There are no more emergencies, Hospice is here”

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Do Not Call 911
Instead, call Hospice at 360.814.5550 · 7 days/week; 24 hours/day

If you call during regular office hours (Mon – Fri, 8am – 5pm), tell the receptionist what is happening; she will then get you in touch with a Team Member for that day. If you call after hours, you will speak with a Hospice “Telepage” RN or Total Triage/After Hours/Uber Nurse.

It is an emergency if a patient has . . .

- been found on the floor or is unable to move
- fallen and can’t get up
- been injured
- symptoms that have become acute (physical or emotional)
- significantly increased pain levels
- talked about being abused or neglected or you believe you witness signs of this in a patient or caregiver
- talked about suicide
- shown a weapon or talked about using weapons
- begun the active dying phase, or
- died

**REMEMBER - Do Not Call 911**

911 calls are covered by Medicare only if authorized by Hospice NW prior to the call. Calls that are not first authorized by HNW will be charged to the patient and/or their insurance company.

**When is it appropriate to call 911?**

**Police Response:** If you are calling 911 for a police response to a crime

**Citizen’s Assist:** Assistance with lifting a patient; please call HNW First and ask about calling 911 for Citizen Assist.
Administrative Staff Contact List

Main and Emergency Number (24 hours/7 days a week): 360.814.5550

Frequently Called Numbers

Volunteer Manager
Erin Long; elong@hospicenw.org  360.814.5588

Volunteer Scheduling
Erin Long  360.814.5588

Executive Assistant: Volunteer Document Tracking
Jessica Enders; jenders@hospicenw.org  360.814.5577

Other HNW Staff (Use main number above)

Executive Director  Bob Laws, RN

Medical Directors  Anita Meyer, MD
Leslie Estep, MD
Deborah North, MD
Edwin Stickle, MD

Clinical Manager: RN, Aides  Toccare Jule, RN
Clinical Manager: MSW, Spiritual Counseling, Bereavement  Leanna Anderson, MSW
Referral Center Manager  Nadelle Newman, RN
Week Day Receptionist  Esme Loaiza
Patient Registration  Jen Bacci, Linda Baker, and Michaela Murphy

Hospice of the Northwest Foundation Staff

Executive Director  Wendy Rohrbacher, MA  814-8257
Development Coordinator  Maddie MacKenize  814-5702
VOLUNTEER AGREEMENT with HOSPICE

As a Hospice volunteer, I agree to the following: I will

• make a one-year volunteer commitment to Hospice.
• serve 4-10 hours/month for a minimum of 30 hours per year not including meetings or training.
• attend as many Volunteer Support Meetings per year as I’m able.
• fulfill the duties of my Volunteer Job Description.
• perform my role to the best of my ability.
• be on-time for volunteer assignments.
• uphold all Hospice Volunteer Policies.
• provide HNW with updated contact information.
• provide documentation of an annual Flu Shot (or flu shot declination and mask agreement).
• provide current copies of Driver’s License and Automobile Liability Insurance.
• ask for assistance, training or other support as needed.
• participate in an annual evaluation of my activities.
• perform only those activities that are allowed of HNW volunteers.
• observe appropriate boundaries.
• document my hours and activities.
• comply with all HIPAA Laws and regulations concerning patient confidentiality.
• fulfill any new volunteer requirements instituted during my one-year commitment.

For Patient/Family or Vigil Volunteers Only: To

• visit a HNW patient only upon assignment from the Volunteer Manager or his/her designee.
• notify patients or families if I am running late by 10+ minutes or unable to make my shift.
• uphold all Hospice Volunteer Policies, including those related (but not limited to) to toileting, transferring, transporting and feeding.
• document all patient/family visits on CallWyse the day of the visit.
• notify the Volunteer Manager if unable to reach a patient/family, if I no longer am seeing an assigned patient, or if a family no longer desires a volunteer.
• immediately notify Hospice at 360-814-5550 about changes in a patient’s needs or condition, or incidents in which I need guidance as to how to handle a situation.
• notify the Volunteer Manager if I am unable to see my patient for more than a week due to vacations, schedule changes, or other reasons.
• notify the Volunteer Manager if, for any reason, I decide to no longer volunteer for Hospice.
• set expectations throughout our time together that when the patient dies, my relationship with the family as a Hospice volunteer will come to an end as well.
• accept HNW’s right to terminate me.

I have read the Hospice Volunteer Agreement and have had the opportunity to ask questions and discuss its contents with the Volunteer Manager.

_____________________________  ________________________  _________________
Volunteer Name (Print)        Volunteer Signature  Date
HOSPICE AGREEMENT with VOLUNTEERS

Hospice of the Northwest agrees to offer the following to volunteers:

- An accurate job description and pre-service and in-service training.
- Support, coaching and supervision.
- Access to urgent needs assistance from the office 24-hours/day, 7 days/week.
- At least nine monthly Volunteer Support Meetings annually.
- Opportunity to attend Interdisciplinary Team Meetings, Ethics Committee Meetings and appropriate staff trainings.
- Information regarding pertinent outside conferences, educational activities, developments in the Hospice field and other resources.
- Regular updates regarding Hospice of the Northwest, including new policies and procedures.
- Free flu shots.
- Volunteer Voices, the volunteer newsletter.
- An annual recognition event.
- Leadership and growth opportunities.
- For Patient/Family Care volunteers, Hospice will provide regular notifications of available patients and accurate patient information at the time of the assignment.
- Volunteer equipment that may be checked out for use with patients.

_________________________________________  __________________
Volunteer Manager Signature                  Date
Hospice of the Northwest Volunteer Acknowledgement of Policies and Procedures:

12. I have read the above and agree to comply with the SRH Volunteer Services policy.
13. I have read the above and agree to comply with the SRH Code of Conduct: Workplace Environment policy.
14. I have read the above and agree to comply with the SRH/HNW Dress Code policy.
15. I have read the above and agree to comply with HIPAA Policies.

VOLUNTEER GUIDELINES for HIPAA

5. Do not use a patient’s name or identifying information in personal e-mails.
6. Do not discuss a patient (even without identifying information) outside the HNW Office, Support Meetings or at patient’s location.
7. Do not leave any information that would identify a patient that can be seen in your car, at your work place, in your home, etc.
8. Promptly shred PHI that is no longer needed.

16. I have read the above and agree to comply with the Safety and Security Guidelines.
17. I have read the above and agree to comply with the Providing Oxygen to Patients when Safety is a Concern policy.
18. I have read the above and agree to comply with the Infection Control Precautions.
19. I have read the above and agree to comply with the Use of Personal Protection Equipment for Hospice Volunteers policy.
20. I have read the above information and agree to uphold both the Food Storage, Preparation and Handling policy AND the Safe Food Storage, Preparation and Handling practices.
21. I have read the above information and agree to uphold the Hospice Patient Rights and Responsibilities policy.
22. I have read the above information and agree to watch for and report abuse, neglect, mistreatment and exploitation of HNW Patients

Volunteer Signature _______________________________ Date Signed _______________________________

Print Name __________________________________________
Conflict of Interest Policy

Hospice of the Northwest’s success depends on the hard work, dedication and integrity of our employees and volunteers. We all have an obligation to conduct ourselves within guidelines that prohibit actual or potential conflicts of interest.

An actual or potential conflict of interest occurs when we are in a position to influence a decision that may result in our personal gain or that of another individual, a relative or other entity as a result of our service. For the purposes of this policy, a relative is any person who is related by blood, marriage or has a similar relationship to the volunteer.

Examples of potential conflict of interest include, but are not limited to the following:

- We are prohibited from soliciting or securing employment by a family and/or patient of Hospice of the Northwest, while providing service to HNW. “Retiring” from service and then gaining employment as a result of these contacts, is also prohibited.

- Fraternizing with patients, and/or members of their family, is prohibited outside our assigned role. Following a Hospice patient’s death, revocation or discharge, we may make only one follow-up call or visit with their bereaved and then must cease all communication.

- We are prohibited from influencing business transactions involving purchases, contracts or leases that may lead to personal gain for themselves and/or a relative.

- The acceptance of gifts, excessive or unusual entertainment, or other favors patients and/or their families may offer, is prohibited.

- We are prohibited from the transfer of materials, products, designs, plans, ideas and/or data belonging to Hospice of the Northwest, for the purpose of personal gain.

- Sharing confidential Information regarding a Hospice patient, outside the organization, is legally (HIPAA) prohibited.

Volunteers are required to immediately disclose possible conflicts of interest as stated above, as well as any situation not stated that may appear to be a conflict, to the Volunteer Manager.

Disclosure of a conflict of interest, or potential conflict of interest, may be handled by the Volunteer Manager and/or it may be forwarded to the Ethics Committee for review. If sent to the Ethics Committee, that committee will determine if there is a conflict of interest and make recommendations for actions to be taken including coaching, letters of reprimand and/or termination.
CONFLICT OF INTEREST DISCLOSURE

Name ____________________________________________________________ ID# ____________

☐ To the best of my knowledge, none of my current activities create a conflict of interest, or potential
conflict, with my role as a Hospice of the Northwest Volunteer.

☐ I believe that my activities as described below may create a conflict of interest, or potential conflict
of Interest, with my role as a Hospice of the Northwest Volunteer.

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

I hereby agree to not participate in any activities which, as described in the “Conflict of Interest” policy,
may create a conflict of interest or a potential conflict of interest. I also agree to disclose to the
Volunteer Manager possible conflicts of interest, as well as any situation not stated that may appear to
be a conflict.

I have read the above and agree to comply with the HNW Conflict of Interest policy.

______________________________________________________________________________
Volunteer Signature ___________________________ Date ___________________________

______________________________________________________________________________
Print Name ____________________________________________
Hospice of the Northwest Confidentiality and Compliance Statement

It is the policy of HNW to respect the right of confidentiality for all of our patients and employees and to insist that all employees and other members of the workforce, or others with access to patient Confidential Information and Protected Health Information at HNW strictly maintain the confidentiality and integrity of this information. “Confidential Information” includes all facts relating to the patient’s medical care (past, present or future), including oral information, written information and any computerized records or data. “Confidential Information” also includes patient financial information, employee records (medical or otherwise) and any other information of a private or sensitive nature at HNW, including financial and operating information of HNW.

HNW is also committed to operating its facilities and services at all times in compliance with all applicable State and Federal laws, rules and regulations, including those related to patient privacy.

1. I understand that I may only access Confidential Information and Protected Health Information as necessary to perform my specific job-related responsibilities at HNW. I agree not to disclose, communicate, or use any Confidential Information in any manner whatsoever other than in the scope of those services and only to others who have a legitimate need to know any Confidential Information.

2. Examples of breaches of my obligations regarding Confidential Information include:

   g. Discussing or revealing Confidential Information and Protected Health Information to friends or family members.
   h. Discussing or revealing Confidential Information and Protected Health Information to other employees without a legitimate need to know the information.
   i. Discussing or revealing Confidential Information and Protected Health Information in conversations in public places, including reception areas, hallways, elevators, etc.
   j. Reading all or any portion of a patient’s chart or accessing a patient’s electronic medical record or other clinical data without a legitimate need to do so. Note: computer access to medical records is tracked by HNW as required by HIPAA.
   k. Reading all or any portion of an employee’s Confidential Information or accessing electronic or other data without a legitimate need to do so.
   l. Inquiring as to the condition or treatment of a patient without a legitimate need to know, as involved in their care.

3. I also acknowledge that electronic computerized patient records and other electronic data create additional risks as to the privacy and security of Confidential Information. I agree to follow all policies and procedures adopted by HNW regarding access to Confidential Information. I acknowledge that my unique computer access codes cannot be shared or delegated for use to anyone and that HNW will deem data accessed or web sites visited using my access code to have been accessed by me.

4. I am familiar with the policies, procedures and guidelines in place at HNW pertaining to the use and disclosure of patient health information and other Confidential Information and Protected Health Information. I will at all times adhere to these guidelines. Approval should first be obtained from the HNW Privacy Officer, or if unavailable, the Release of Information Specialist in the Health Information Management Department before any disclosure of patient information or other Confidential Information in a manner not specifically addressed in the guidelines and policies and procedures of HNW.
5. I understand that the unauthorized disclosure of Protected Health Information and other Confidential Information by me can subject HNW and me to civil and, under certain circumstances, criminal liability under State and Federal law.

6. If I observe or have knowledge of (i) any unauthorized release of Protected Health Information and Confidential Information from HNW or (ii) any practice or incident that I believe to be out of compliance with any law or regulation, I must immediately report this to the HNW Privacy Officer. It is HNW’s policy to encourage open communication between employees and the Compliance Officer and to prohibit any retaliation at HNW facilities in connection with requesting assistance from, or reporting to, the Compliance Officer concerning any suspected improper activities.

7. I have read and agree to strictly adhere to this confidentiality and compliance statement. In the case of HNW employees, violation of my obligations related to these matters will subject me to disciplinary action, which may include immediate dismissal from my employment. I understand that this signed statement will be part of my employment record at HNW. If I have access to Confidential Information through arrangements with HNW other than as an employee, violation of my obligations hereunder may result in the immediate termination of my or my employer’s relationship with HNW, and other sanctions under State and Federal law.

8. Termination does not relieve me of my obligation to continue to protect confidential patient health information.

I have read the above and agree to comply with the HNW Confidentiality and Compliance Statement

_______________________________________________________________
Volunteer Signature

_______________________________________________________________
Date Signed

_______________________________________________________________
Print Name