HOSPICE GUIDEBOOK

For Patients and Families

KLINE GALLAND

BENAROYA SERVICES

KLINE GALLAND
BENAROYA SERVICES

6100 4th Ave S Suite 403, Seattle, WA 98108
(206) 805-1930, F: (206) 805-1931

Office Hours: 8:30 a.m. – 5:00 p.m Monday through Friday

ALERT!

THIS IS A KLINE GALLAND HOSPICE PATIENT

Please call the number below immediately if there are any changes in the patient's condition:

PRE-AUTHORIZATION IS REQUIRED* FOR ALL:

- **HOSPITALIZATION**
- **MEDICATION ORDERS**
- **IV THERAPY**
- **LAB WORK**
- **MEDICAL EQUIPMENT**
- **OXYGEN**
- **X-RAY**
- **PT, OT, & SPEECH THERAPY**
- **MENTAL HEALTH SERVICES**
- **PROVIDER SPECIALTY CARE**
- **TRANSPORTATION/AMBULANCE**
- **BLOOD PRODUCTS**

CONSULT YOUR HOSPICE TEAM PRIOR TO SEEKING ANY OF THE ABOVE SERVICES

CALL 24 HOURS A DAY FOR AUTHORIZATION (206) 805-1930

***Your Insurance Coverage may not pay without prior consultation with your Hospice Provider.**

YOUR HOSPICE CARE TEAM

RN Case Manager: _____

Social Worker: _____

Spiritual Counselor: _____

Hospice Aide: _____

Hospice M.D.: _____

Volunteer: _____

Other Team Members: _____

_____

CALL US FIRST *because we care!*
(206) 805-1930

Please notify Kline Galland Hospice at any time for the following changes in patient condition:

- Change in the condition or comfort level, such as increased pain, difficulty breathing, nausea, anxiety, bleeding, or fever
- Patient falls
- New orders for medications from M.D.
- Plans to transfer patient to the emergency room or hospital
- Plans for lab work or treatment
- Plans to visit a specialist
- Time of death
- Any other concern of question

A nurse is available 24 hours a day, every day.

Call (206) 805-1930.

Emergency After-Hours Backup Line: (206) 741-3022
Between the hours of 5:00pm and 8:30am, Monday – Friday
and available 24 hours on Saturday and Sunday

PATIENT AND FAMILY INTRODUCTION TO HOSPICE

TABLE OF CONTENTS

Your Hospice Team 4

Hospice Philosophy 5

What is Hospice Care? 7
- Levels of Care 8
- Hospice Team Members 8
- Frequently Asked Questions 9
- Hospice Eligibility 10
- Minimum Home Safety Requirements 11

Discharge Policy 13

Advanced Directives 15
- Health Care Directives 15
- Durable Power of Attorney for Healthcare 15
- POLST 16

Death with Dignity Act and Medical Aid in Dying 17

Training Guidance – Patient and Family Care 19
- What to Report to the Hospice Team 19
- Pain Management 20
- Misconceptions about Pain Medications 22
- Nutrition, Eating and Swallowing 24
- Managing Constipation 28
- Anxiety, Restlessness and Agitation 29
- Shortness of Breath 30
- Bathing 30
- Skin Care 31
- Mouth Care 32
- Planning for Care and Communicating Choices 33
- Funeral Planning 34
- Caregiver Needs 35
- Preparing for Death 36
- Physical Signs and Symptoms of Approaching Death 37
- Emotional, Spiritual and Mental Signs and Symptoms of Approaching Death 38
- What to Do When Death Occurs 40
- A Guide to Bereavement, Mourning and Grief 42
- Children and Grief 44

General Home Safety 45
- Falls and Medications 47
- Home Use and Disposal of Controlled Substances Policy 49
- Infection Control/Disposal of Contaminated Material and Medical Sharps 50
- Disposal of Unused Medication and Donation of Medical Equipment and Supplies/Equipment 51

Rights and Responsibilities 53

Notice of Privacy Practices 55

Non-Discrimination Acknowledgement 59

Language Assistance 61

Giving Back 63

We Value Your Feedback 65

Additional Resources 67
- Adult Protective Services 67
- Influenza Vaccine Information 71
- Prepare: Home Emergency Guide 73

Forms Used During Hospice Care 93
- Admission Agreement and Informed Consent 93
- Authorization of Payment/Notice of Coverage 97
- Hospice Election Statement 99
- Primary Caregiver Agreement 101
- Patient Contact List 103
- Request for Patient Notification of Hospice Non-Covered Items, Services and Drugs 105
- Patient Notification of Hospice Non-Covered Items, Services and Drugs 107
- Hospice Benefit Revocation Form 109
- Hospice Transfer Summary 111

COMMUNICATING EFFECTIVELY WITH YOUR HOSPICE TEAM

To reach a hospice care team member, call (206) 805-1930. 24-hours per day.

Calls answered during regular business hours will be directed to our triage nurse or one of your care team members.

Calls made after hours (evenings between 5:00 pm and 8:30 am and on weekends) will be received by our answering service.

Calls to the answering service will be most effective if you follow their prompts and provide short answers. This helps get the help you need as quickly as possible. Below is an example of the script the answering service will use:

- "Are you calling about hospice, private duty home care, or home health?" Respond: **HOSPICE**
- *What is the patient's name?*
- *What is your name?*
- *Telephone number?*
- *"Is this an urgent or pressing issue?"* Respond YES, if you want to be connected to the on-call nurse, even if you don't think it is urgent.

  Respond NO if the issue is a not urgent that and can responded to the next business day.
- *What is your message?*

  Respond with a **very brief** reason for your call, for example, my loved one is having pain, or, the patient has had a change in condition.

Important note regarding communication with your team members

In order to protect your personal health information (PHI) and fully comply with the federal laws surrounding the Health Insurance Portability and Accountability Act (HIPAA), methods and types of communication used between patients/family/DPOA and their care team must be limited.

The most effective way to reach your care team is to call the main number: (206) 805-1930.

Communication via texting and email are not secure and therefore cannot be used to relay any personal health information.

If you would like access to information that is part of your medical record, a request must be provided in writing on the Kline Galland Request for Information form. As your team member for a copy or call (206) 805-1930 and as for the medical records department. If you are a power of attorney (POA), please be prepared to submit a copy of the POA documentation.

Thank you.

HOSPICE PHILOSOPHY

Hospice reflects a spirit and philosophy of caring that emphasizes comfort and dignity for the individual's final phase of life. Hospice provides an interdisciplinary, individualized and ethical care to meet the physical, emotional, social, spiritual and practical needs of people with life-limiting illness. Patients in the last phase of their lives choose hospice care for support and comfort when efforts towards recovery are no longer probable. Hospice emphasizes supportive services, such as pain control and home care, rather than cure-oriented treatments and focuses on maintaining the highest quality of remaining life. Hospice neither hastens nor postpones death.

Hospice care is centered on the patient, family and caregiver. Services are provided by a medically directed team of volunteers and professionals who respect and respond to the unique differences of each individual's life style, values and wishes. After the patient's death, hospice care continues as bereavement support for the surviving family to normalize their grief so that they may return to leading full and productive lives.

Hospice affirms life even as it is accepting of its finiteness. Kline Galland Hospice helps families embrace the end of days, maintaining hope throughout.

Our goal is to facilitate the highest quality of life for the individualby providing care from committed, dedicated professionals, freeing families to attain a degree of mental and emotional preparation for a death that is satisfying to them.

WHAT IS HOSPICE CARE?

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice involves an interdisciplinary team- oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.

Support is provided to the patient's loved ones as well. At the center of care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Hospice focuses on caring, not curing and, in most cases; care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.

Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

How is it different from Palliative Care?

Palliative care programs generally address the physical, psychosocial, and spiritual needs and expectations of a patient with a life-threatening illness, at any time during that illness, even if life expectancy extends to years. Palliative care does not replace aggressive treatment of an illness, and provides comfort to patients and their loved ones.

How does hospice care work?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services.

Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The team usually consists of:

- The patient's Attending Physician
- Hospice Medical Director
- Nurses
- Nursing Assistants
- Social Workers
- Spiritual Counselors/Chaplains
- Trained Volunteers
- Speech, physical, occupational therapists, and dieticians, if needed.

*See page 8 for provider descriptions.

What services are provided?

Among its major responsibilities, the interdisciplinary hospice team

- Manages the patient's pain and symptoms
- Assists the patient and family with the emotional and psychosocial and spiritual aspects of dying
- Provides needed drugs, medical supplies, and equipment
- Coaches the family on how to care for the patient
- Delivers special services like speech, physical, massage and music therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Provides bereavement care and counseling to surviving family and friends

LEVELS OF CARE

Routine Care

Care provided in the comfort and security of your home wherever you are - home, assisted living facility or skilled nursing facility. A hospice nurse will work with a patient's primary physician to bring the appropriate hospice services to your home. Members of a hospice team will work with caregivers to help them feel comfortable performing routine care activities.

Respite Care

Care provided when caregivers would benefit from short-term relief from the day-to-day care they provide at the home. This type of short-term care is usually provided at a skilled nursing facility for up to five days in a row.

Continuous Care

Care provided for short periods in your home when skilled nursing care is required to help manage symptoms. This type of care is provided for a set number of hours per day for a few days.

General Inpatient (GIP)

Care provided for a short-term stay in a hospice care center, skilled nursing facility, or hospital when 24-hour skilled nursing care is necessary to help manage acute symptoms.

HOSPICE TEAM MEMBERS

- The **Attending Physician** for the person receiving care is responsiblefor continued medical management. You have the right to choose your own Attending Physician. This may be your Primary Care Provider or a specialist already involved in your care
- The **Hospice Physician** acts as a resource for hospice medical care, and reviews the plan of care on a regular basis
- A **Hospice Nurse** visits on a regular basis to xperform physical assessments, provides education on medications, physical care needs, and updates the doctor. Your nurse is valuable source of knowledge
- Your **Social Worker** helps explore care options, understand legal and financial issues, and provide emotional support. Social workers are dedicated to helping the patient and family with the many areas of life impacted by an illness
- **Hospice Aides** care for patients not only in the traditional duties of bathing, dressing and personal care, but in being present for emotional support
- Your **Occupational Therapist** addresses issues of safe mobility and makes recommendations for appropriate medical equipment to promote quality of life
- **Spiritual Counselors/Chaplains** explore ways to find joy, meaning and purpose in life. For those who have a religious faith, this may include working closely with your clergyperson and faith community. Every one can benefit from their listening ear, guidance and willingness to explore questions, forgiveness and hope
- **Comfort Therapists** offering massage and music integrate specialty therapies in the plan of care as needed
- **Overnight** and **Weekend Team Members** assure access to care 24hours a day, 7 days a week
- A **Bereavement Coordinator**, trained in supporting those who are grieving, offers supportive services to family members and significant others during the 13months following a death
- **Volunteers** receive extensive education and are dedicated to maintaining the privacy and dignity of the person receiving care. They share their unique skills and talents in many ways

FREQUENTLY ASKED QUESTIONS

May I keep my own doctor?
Yes. In fact, your Attending Physician will play an important role on the hospice team. Your doctor will work closely with hospice to develop a plan of care that best meets your individual needs and those of your family and caregivers. In addition, the hospice nurse will keep your doctor regularly informed as to your condition and any changes which may be taking place.

What if my doctor hasn't spoken with me about hospice?
Your doctor may feel that your condition is not yet appropriate for hospice. However, it is wise to request information about hospice before you need it, so that you can understand your options and access appropriate services when you want and need them. Feel free to raise the issue with your physician, and if you would like additional information, speak with a hospice staff member.

May I continue with my treatments and therapies?
Hospice specializes in palliative, or "comfort" care. Therefore, treatments and therapies focus on controlling symptoms and managing pain, rather than attempting to cure. Some treatments, such as chemotherapy, can be either curative or palliative, depending on the circumstance. You should discuss with your physician which palliative treatments will be provided in your plan of care.

Patients who wish to continue to aggressively seek a cure should seriously consider whether hospice is right for them at this point in time.

May I continue to see my to see my medical specialist while I am on hospice?
Your insurance will continue to pay for visits with your Attending Physician. If you are interested in seeing other providers, please consult with your hospice team, as these visits to specialists may not be covered

Will I be in pain?
Pain is not an inevitable side-effect of terminal illness. Hospice doctors and nurses dedicate themselves to providing the very best pain control and symptom management. With proper medication and management of an individual's changing condition, the vast majority of hospice patients can live pain-free throughout the course of an illness.

Do you care for patients with any kind of terminal illness?
Hospice care is available to individuals with any life-limiting diagnosis, including: cancer, cardiac and respiratory diseases, neurological diseases, AIDS, liver disease, Parkinson's disease, Alzheimer's disease, dementia and others.

What if I get better?
It is possible that your condition may improve to the point where you no longer need hospice, or where it again becomes appropriate to seek curative treatment. In such cases, your hospice team can discharge you from the hospice program and help you to carefully transition to a different level of care. It is also possible that your life expectancy may exceed the six months anticipated when you became eligible for hospice. Patients discharged from hospice care can always be readmitted should your doctor find that your condition once again is appropriate for hospice care.

Will I become a burden on my family?
Many patients worry about this. You should know that hospice provides considerable support to your family, helping them to manage your care in an environment of trust and respect. Almost all families describe their hospice experience as one of the most meaningful in their lives - a time when they strengthened relationships and captured valuable memories

What if my family is unable to care for me?
Hospice understands that some people do not have the option to stay with a family member who can serve as their primary caregiver. In such cases, you may choose to live in an extended care facility. Several hospices offer services in their own residences. Hospice will work with you to address your unique situation to ensure your safety and well-being.

How often will I see my hospice team?
The plan of care developed by your physician and hospice will determine the frequency of scheduled visits from the various members of the hospice team. This plan will evolve to meet your changing needs. In addition, you can reach a hospice nurse by telephone around-the-clock, and emergency visits will be provided whenever necessary.

Will my personal beliefs be respected?
One of the founding philosophies of hospice involves an abiding respect for each individual's unique values. All hospice team members appreciate diversity in cultural heritage, faith, spirituality and lifestyle. If requested, hospice chaplains and social workers can provide an extra measure of support, offering spiritual comfort with an attitude of openness and acceptance.

How can I let my family know my informed health care decisions?
You can help your family to understand your wishes by preparing them in advance. You may wish to discuss your choices with your family, friends, doctor, clergy or others close to you, so that you can gain a clear sense of the options and decisions which lie ahead.

HOSPICE ELIGIBILITY

In order to qualify for hospice benefit, you must present medical justification that you or your loved one has a life-limiting illness with less than six months prognosis.

Although there are no absolute rules, there are guidelines, followed by hospice and providers to determine whether someone is expected to only live for six months.

Guidelines
The following guidelines help hospice staff and physicians determine who is eligible for hospice benefits. Generally, they are looking for a pattern of functional and physiologic decline. The following characteristics should be present before the patient enters into a hospice program.

Medicare Guidelines
- Patient must be eligible for Medicare Part A (the hospitalization benefit)
- Patient must have life limitingcondition with prognosis being 6months or less
- The prognosis and terminal illness must be certified by 2 doctors, usually the patient's primary care or attending physician and the medical director of the hospice agency
- There are also Disease-Specific Guidelines (AIDS, cancer, heart, pulmonary, dementia, liver, and kidney diseases) used by hospice in determining terminal status and eligibility
- Patient/decision maker must desire palliative or comfort approach rather than curative focus
- Patient or family (if the patient is unable to do so) must give informed consent
- Hospice care must be provided by a Medicare-certified hospice
- To remain eligible, progression of disease must be documented. Progression can be documented by:
  -Disease specific markers
  -Decline in functional status

Benefit Period
The benefit runs for two (2) periods of 90- days followed by an unlimited number of 60-day periods. At the end of each period, the patient must be recertified. To be "recertified," a patient must still have the terminal illness certified by a physician, and must manifest a functional decline.

Hospice benefits can also be obtained through private and for-profit insurance policies, as well as the VA.

MINIMUM SAFETY AND RELATED REQUIREMENTS FOR KLINE GALLAND HOSPICE TO PROVIDE CARE

For our team to provide care to you in your home, we have identified a minimum set of safety requirements that must be met, as described below. ***Failure to comply with any of the following standards may: prevent Kline Galland from initiating care and admission of the patient; or require Kline Galland to discontinue services and discharge the patient for cause from hospice.***

- All guns and other weapons must be in a locked cabinet/safe/drawer during visits
- All pets should be in either a cage or another room, away from care, during visits
- Bed bugs or other pest infestations must be disclosed to the team in advance of the visit
- Exposure/potential exposure to someone with COVID-19, or other infectious disease must be communicated to the team prior to visits
- No active illicit drug use, sale, or exchange of illicit drugs is permitted during visits. Paraphernalia related to illicit drug use should not be visible during visits
- No smoking or vaping of any kind should occur in the home during visits
- Neither patient nor others present shall be under the influence of alcohol or other non-prescribed substances during visits
- Patient's home environment shall be free of hostile, aggressive, or threatening language
- Patients must be appropriately clothed during visits (except when participating in planned toileting, bathing, and/or dressing activities as part of home hospice services)
- Patients shall not audio-record Kline Galland staff. Patients shall not use any video recording device in areas where care may be provided
- Patient's home should meet a minimum standard of safety which includes:
  - Free of excrement and hazardous debris on floor and surfaces
  - Appropriate disposal of any needles or other sharps
  - Clear pathway free from obstruction from the entryway to the area in which care is provided. Unobstructed ability to enter/exit the house/room where care is provided
- If there is danger or perceived danger surrounding the perimeter of the patient's home, clinician will request a joint visit with the supervisor (or peer as designated by supervisor) to assess the safety concerns. If imminent danger is perceived, the clinician will leave the visit immediately and care may be discontinued entirely, following management consultation
- As determined by Kline Galland Hospice, minimum safety and related requirements may apply to any other behavior, circumstance, or condition that significantly interferes with the ability of Kline Galland Hospice to deliver safe, appropriate, and effective care

DISCHARGE OR TRANSFER FROM HOSPICE PROGRAM
Policy No. H:2-085

Review Cycle:

☐ Annual
☐ Every two years
☐ Every three years

Initial Approval & Subsequent Review

Dates: 09.27.2010; 4.01.26; 8.1.26

Policy Owner: Kline Galland Hospice Services, Director

PURPOSE

To establish standards and a process by which patients are discharged from the hospice program.

POLICY

Kline Galland Hospice Services will provide service to a patient and family/caregiver as long as the patient remains terminally ill and lives in the designated service area. The organization will not discontinue or reduce care provided to a Medicare or Medicaid beneficiary because of the inability to pay.

REASONS FOR DISCHARGE OR TRANSFER

The Hospice may discharge the patient if:

1. It determines that the patient is no longer terminal according to standard clinical criteria for determining disease prognosis of six (6) months or less.
2. The patient leaves the service area of Kline Galland Hospice Services or transfers to another hospice.
3. The patient requests discharge.
4. The Hospice determines that discharge for cause is required, with such discharge process conducted consistently with procedures outlined in this Policy and applicable state and federal regulations.

PROCEDURE

1. **Discharge Planning - General.**
   - A. The hospice interdisciplinary group will develop a discharge plan, which includes timeframes and recommendations for resources
   - B. The Case Manager will ensure that necessary paperwork is completed at the time of discharge, as required by applicable law and this policy

2. **Clinical Record – Discharge.** When a patient is discharged, transferred, or referred to another organization, relevant information in the clinical record will include:
   - A. Reason for transfer or discharge
   - B. Physical and psychosocial status at time of transfer or discharge, including specific medical, psychosocial, or other problems requiring interventions or follow-up
   - C. Summary of the care provided and progress toward achieving goals, including both positive and adverse patient responses to treatment or services
   - D. A copy of the current plan of care
   - E. A copy of the medication profile, including discontinued medications
   - F. The latest physician orders
   - G. Continuing symptom management needs, e.g., pain, nausea, dyspnea
   - H. Follow-up to be provided by an interdisciplinary team member from the service transferring the patient
   - I. All pertinent laboratory data
   - J. Summary of patient education provided to the patient and his/her comprehension of that information.
   - K. Instruction and referrals provided to the patient
   - L. Existence of any Advance Directives, if applicable
   - M. The date of discharge, which is the date of the last visit made

Documentation will be filed in the clinical record. Information will be documented on a discharge/transfer form, embedded in the electronic health record.

3. **Discharge for Cause Procedure.** If the hospice determines the patient should be discharged for cause (e.g., failure to meet minimum safety requirements, refusal of required face-to-face encounter), the following steps, aligned with 42 CFR 418.26 (a)(3) must be followed:
   A. Advise the patient and/or caregiver that a discharge for cause is being considered. Provide recommendations to patients and family/caregiver and physician to resolve an unsafe situation and consider referrals to other agencies
   B. Make a serious effort to resolve the problem and document efforts in the clinical record. As appropriate, refer to social worker for assistance with placement planning. As appropriate file incident report with the Washington State Department of Health and DSHS Adult Protective Services
   C. Ascertain that the discharge is not due to patient's utilization of necessary hospice services
   D. Document in the medical record the problematic behavior, resolution, and communication to patient regarding the foregoing.
   E. Prior to discharge, notify the Medicare contractor and Washington State DOH, of the circumstances surrounding the impending discharge.
4. **Discharge Order.** Prior to discharging a patient for any reason other than patient revocation, transfer or death: obtain a written discharge order from the hospice medical director (or physician designee), or a member of the physician interdisciplinary group; and consult the attending physician (if applicable) and include their review and decision in the discharge note.
5. **NOMNC; ABN.** The Notice of Medicare Non-Coverage (NOMNC) shall be issued as required by law including when hospice services are ending for coverage related reasons such as the patient is no longer eligible for the Medicare Hospice benefit. The Advance Beneficiary Notice of Noncoverage (ABN) shall be issued when Medicare is expected to deny payment for specific hospice items and services, although it is not directly tied to discharge.
6. **48 Hour Notice.** Patients must receive at least 48 hours written or verbal notice before discharge, unless immediate discharge is necessary for safety, noncompliance, or nonpayment; notice must be documented in the record, in compliance with WAC 246 335 620(1)(a). Notwithstanding the foregoing, hospice may not discontinue or reduce care provided to a Medicare or Medicaid beneficiary because of the beneficiary's inability to pay for the care.
7. **Discharge Summary.** A copy of the discharge summary will be sent to the attending physician. If requested, the patient's clinical record will be provided. If a hospice patient is transferred to a Medicare/Medicaid certified facility, a copy of the discharge summary shall be forwarded to the facility and the patient's record, if requested. The discharge summary shall include a summary of the patient's hospice stay, the patient's current plan of care, the patient's latest physician order, and any other documentation that will assist in the post discharge continuity of care or that is requested by the receiving facility or the attending physician.
8. **Medicaid Discharges.** Discharges of a Medicaid client shall be subject to WAC 182-551-1350. Upon patient discharge and within five (5) business days, the Medicaid Hospice Notification form shall be forwarded to the Medicaid Hospice Program Manager and the appropriate DSHS home and community services office.

Regulatory Citations: 42 CFR 418.26; 42 CFR 418.100 (d); 42 CFR 418.104; WAC 246-335; Medicare Benefit Policy Manual Chapter 9, Section 20.2.3; CHAP HCDT 37.1.

ADVANCE DIRECTIVES

Advance directive is a general term for oral or written instructions about future medical care if a person becomes incapable of stating their wishes. In these documents, both wanted and unwanted treatment may be specified. In Washington, there are three types of advance directives: the Health Care Directive, the Durable Power of Attorney for Health Care, and the Physician Orders for Life-Sustaining Treatment.

Remember, advance directives are only part of the process. Protecting your health care choices is a three-step process: deciding what you want; communicating your intentions so that others understand them; and committing your providers, family, and health care agent(s) to the acceptance (and sometimes defense) of your choices.

A **Health Care Directive** (also known as a living will, directive to physician, or physician directive) is a legal statement to all your health care providers that describes your general wishes or desires for end-of-life care. In particular, Health Care Directives speak to the question of whether and how you want to be kept alive by medical treatment if you are unable to make decisions. Your Health Care Directive should specifically state the life-sustaining treatments you do or do not want. These should include resuscitation, use of an artificial ventilator, and artificial nutrition and hydration. It should be in all your medical records.

When you present your Health Care Directive to your physician, ask if they will honor it. If not, find a physician who will. Most states do not require a specific form or format. In Washington, the basic form available covers only terminal illness, and End of Life Washington considers it too limited. In order to make a Health Care Directive legally binding, you must sign the document in the presence of two qualified, adult witnesses. A Health Care Directive can prevent immense family conflict about your wishes for treatment if you become unconscious or unable to make medical decisions.

A **Durable Power of Attorney for Health Care** (DPAHC) is the legal means by which you designate someone (referred to as your health care agent, surrogate decision maker, health care proxy, or attorney in fact) to make health care decisions if for any reason you should lose the capacity to do so. In the event that your primary agent is unable to make decisions on your behalf, you may also name an alternate agent. Anyone over the age of 18 may make a DPAHC, provided they are competent. Additionally, any individual over 18 can act as an agent or alternate agent, provided they are of sound mind and meets certain qualifications.

A DPAHC is limited to health care decisions and does not affect a power of attorney you may have for financial or other matters. Washington State law does not specifically require witnessing or notarizing your DPAHC. A DPAHC stands up legally, particularly when the agent's decisions are consistent with directives contained in the patient's Health Care Directive.

Once the DPAHC is in place, you continue to make your own care decisions for as long as you are able. It is only when you cannot make your wishes known that your health care agent can act. When you are again able to make your own decisions, your agent loses power to make decisions for you. It is very important to pick someone you trust and who knows your wishes. It is also important to choose an individual you feel can be assertive in the event that caregivers or family members challenge your wishes.

Communicate: Let your agent know exactly what kind of care you wish to have, and what types of treatment you do and do not wish to have. Make clear to other family members that your health care agent(s) will have final authority to act on your behalf. If you feel that certain family members will not honor your wishes, you may include a statement directing physicians and the courts to disregard their demands and to follow only the directives of your agent(s). For the sake of all concerned, be sure to discuss your intentions face-to-face.

A **Physician Orders for Life-Sustaining Treatment** (POLST) form (formerly called the EMS - No CPR form) is intended for any adult, 18 years of age or older, with serious health conditions. You (or your health care agent) and your physician may use POLST to write clear and specific medical orders that indicate what types of life-sustaining treatment you want or do not want at the end of life. Both the maker and a physician must sign the bright green form in order for it to be honored by other health care professionals. No witnessing or notarizing is required. Emergency Medical Services (EMS) personnel are required to honor POLST, and it remains with you if you are transported between care settings. If your physician does not have POLST forms available, ask her or him to contact the Washington State Medical Association (see contact information below), or contact our office and request one. *Properly completed, the POLST form is probably the most effective advance directive because your wishes are expressed as medical orders.*

OTHER CONSIDERATIONS

- After you complete your advance directives, send or give copies to your physician(s), lawyer, agent(s), family members, and other loved ones who should know about your wishes
- Health Care Directives have limitations. They are part of the health care planning process and should be best thought of as "living wishes." In the real world of medical decision-making, fear of liability can keep providers from acting on patients' intentions
- One of the best uses for a Health Care Directive is as a guide to the DPAHC agent. When the health care agent(s) acts within the general scope of the Health Care Directive, he or she is on solid legal ground. If there is no Health Care Directive, or the agent's actions are not consistent with the Health Care Directive, the health care agent may be challenged. For these reasons, you should have both a DPAHC and a Health Care Directive
- Review your Health Care Directive and DPAHC occasionally to be sure they reflect your current preferences and values. To affirm that they reflect your current wishes, initial and date the documents whenever you review them
- End of Life Washington recommends that advance directives be signed and witnessed in the presence of a notary because it eliminates any doubt about the validity of your documents. Additionally, if you travel out of state, some states do require notarization

These Forms Are Available From:

- Your attorney or physician
- End of Life Washington – (206) 256-1636 or 877.222.2816 (toll free), info@EndofLifeWA.org or www.EndofLifeWA.org
- National Hospice and Palliative Care Organization, www.nhpco.org, provides basic advance directives online for each state
- Washington State Medical Association – (206) 441-9762 or 800.552.0612 provides basic advance directives. They provide POLST forms only to physicians and other medical providers

SUMMARY OF KLINE GALLAND'S POLICY SURROUNDING ADVANCED DIRECTIVES

Kline Galland Home Health and Hospice Services recognizes that all adult persons have a fundamental right to make decisions relating to their own medical treatment, including the right to accept or refuse medical care. It is the policy of Kline Galland Hospice Services to encourage individuals and their family/caregivers to participate in decisions regarding care, treatment, and services. Valid Advance Directives, such as living wills, Durable Powers of Attorney, and DNR (Do Not Resuscitate) or DNI (Do Not Intubate) orders will be followed to the extent permitted and required by law. In the absence of Advance Directives, Kline Galland Hospice Services will provide appropriate care according to the plan of care/service or as authorized by the attending physician. Kline Galland Hospice Services will not determine the provision of care/service or otherwise discriminate against an individual based on whether or not the individual has executed an Advance Directive.

If there is no POA in place, and the patient cannot sign their own consent, then the Washington Next of Kin (NOK) laws apply: In Washington State, NOK goes in this order: Patient's: Spouse, Children over 18 years of age (all must sign), Parents (both must sign), adult siblings (all must sign).

DEATH WITH DIGNITY ACT PATIENT EXPLANATION

Kline Galland Hospice, which acknowledges that Washington State law recognizes certain patients rights under the Death with Dignity Act ("Death with Dignity Act" or the "Act"). All providers and staff at Kline Galland Hospice are expected to respond to any patient's query about life ending medication with openness and compassion. Providers and staff provide support to patients who access end of life services through the Death with Dignity Act.

Kline Galland provides consulting provider review and confirmation services under the Act, as well as other services and support to patients accessing care under the Death with Dignity Act. However, Kline Galland providers, including its hospice agency partners, while acting within their scope of employment or under contract with Kline Galland, do not act as prescribing (attending) providers for medication to hasten death under the Act.

Kline Galland's hospice providers will work to help any dying patient to be as comfortable as possible by controlling pain and other physical, emotional and spiritual symptoms associated with they dying process. Hospice care is provided by members of the interdisciplinary team which includes nurses, social workers, chaplains, nursing assistants, physicians, massage therapists for comfort therapy, music therapists and volunteers.

The Washington Death With Dignity Act an Overview for Patients and Families

Eligibility:

- Must be an adult Washington State resident
- Diagnosed by a physician as terminally ill, with disease or condition that will cause death within six months
- Capable of making an informed decision, not impaired by mental illness, dementia, or depression
- Able to self-administer the prescribed dose of life-ending medication

PROCEDURES FOR REQUESTING LIFE-ENDING MEDICATION

1. Ask your primary care physician or specialist if they will support your decision to obtain life-ending medication and write the prescription. The provider who writes your prescription is called the"Attending Qualified Medical Provider." If they decline, ask if they would be your Consulting Physician. Qualified Medical Providers include licensed Washington physicians; licensed Washington Physician Assistants; and Washington Advanced Registered Nurse Practitioners.
2. Make a first oral request for the Death with Dignity Act (DWDA) prescription. Ask your provider, even if they have declined to participate in DWDA, to document your first oral request in your medical record.
3. You must have two providers: an Attending (prescribing) Qualified Medical Provider and a Consulting Qualified Medical Provider to confirm your diagnosis, prognosis, and mental capacity.
4. After you have seen both the Attending and Consulting Qualified Medical Providers, complete a Written Request for Medication form. This form must be signed by two qualified witnesses. At least one witness must be impartial as to the patient, not a relative by blood or marriage, not an heir, and not an owner, operator or employee of the healthcare facility where the patient is resident or receiving treatment. The Attending Qualified Medical Provider cannot be a witness.. When the form is completed, give it to your Attending Qualified Medical Provider.
5. Make a second oral request to the Attending Qualified Medical Provider, no sooner than 7 days after the first oral request, and ask your Attending Qualified Medical Provider to document your request in the medical record.
6. At least 7 days must elapse between the initial oral request and the writing of the prescription. You or someone you designate may pick up the prescription. You can leave the prescription on file with the pharmacy for up to six months, until you are ready to fill it (check with the pharmacist).

Recommendations to Clients

- When you have a life expectancy of six months or less, request a referral to hospice from your physician
- Complete your Will, Health Care Directive, Durable Power of Attorney for Health Care, and Physician Orders for Life-Sustaining Treatment (POLST) form
- Talk to your loved ones about your decision
- Keep your decision private and only share it with your inner circle of family and friends. If you do talk about it, please do not reveal the identities o fparticipating physicians and pharmacists

For more information regarding Washington State's Death with Dignity Act, please contact End of Life Washington at (206) 256-1636 or 877.222.2816 (toll free), info@EndofLifeWA.org or www.EndofLifeWA.org.

WHAT YOU SHOULD REPORT TO YOUR HOSPICE STAFF

As a family/caregiver, you are the person who often learns things first about the patient or your loved one and your family. Some things need to be told to the nurse so that appropriate interventions by other team members can be made. The nurse assigned to your loved one must be notified of any changes noted. Below are some suggestions of the things to report that are in the categories of Mind, Body and Spirit.

Mind

- Increase in sleeping
- Inability to sleep
- Sudden confusion
- Changes in attitude: suddenly angry or withdrawn or sad, increased irritability
- Suddenly unaware of surroundings
- Inability to recognize familiar people
- Agitation
- Inability to be comforted

Body

- Complaints of pain
- Signs of pain: frowning, moaning, groaning during movement or when still, refusing to move, refusing a bath, crying
- Skin problems including any sores anywhere, tears in the skin, skin looking a different color (yellow, pale, red), bruises, rashes, itching
- Changes in bladder or bowel function
- Refusal to eat or drink
- Dressings that have come off
- Sudden loss of sight or hearing
- Changes in breathing
- Weakness or changes in mobility
- Falling

Spirit

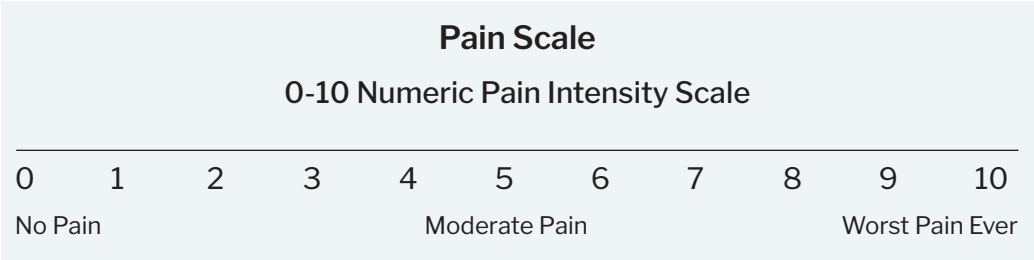
- Angry and/or belligerent
- Talking about “ending it all”
- Expressions of anger toward God, caregivers or those around them
- Disgust with self
- Sudden refusal to talk with anyone
- Sudden refusal to have visitors
- A sense that the patient is depressed

Other issues

- Pills found in places where they do not belong. Is the patient hiding pills?
- Any of the family members refusing to give medications?
- Have you seen signs of caregiver/family stress like crying, anger, not caring for themselves?
- Has the patient voiced concerns about loss of finances?

PAIN MANAGEMENT

Hospice's goal in pain management is to achieve pain control while allowing the patient to remain as alert as possible. The physician and nurse will work with the patient to control the pain. The best way to get help for pain is by being able to accurately describe it. The patient needs to be honest and open in describing symptoms in order for the nurse to provide the best care. One way to do this is by using the 0-to-10 scale to describe severity of the pain.



Other important facts to share with us about your pain include:

- Location- where is the pain?
- When did the pain begin?
- Was it triggered by anything?
- What does the pain feel like? Burning, stabbing?
- What makes the pain worse?
- Does anything make the pain better?
- Does it affect your appetite / your sleep?
- Does the pain make you feel nauseated, tired, weak or dizzy?

There are many different types of medications as well as different forms and ways to take the medications. Your nurse will help in assessing the pain and communicating with the physician. The amount and type of pain will determine how much and what type of medication is prescribed. Taking medications as directed by the physician and nurse is very important in achieving proper pain control.

Many effective pain-relieving medicines are available. Some are non-narcotic, and some are mild or strong narcotics. Depending on the cause of the pain, the physician may also use medication not commonly thought of as useful for pain control. These medications work together to give greater patient comfort.

Treating Pain

Pain can affect you in many ways. It can keep you from being active, from sleeping well, from enjoying family and friends, and from eating. Pain can also make you feel afraid or depressed.

If you are feeling pain, you need to tell your doctor or nurse right away. Getting help for your pain early on can make pain treatment more effective.

Non-Pharmacological Methods for Relieving Pain

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

When to Take Pain Medication

- Take your medicine on a regular schedule (by the clock). Taking medicine regularly and as your doctor tells you will help to keep pain under control. Do not skip a dose of medicine or wait for the pain to get worse before taking your medicine
- Ask your doctor or nurse how and when to take extra medicine. If some activities make your pain worse (for example, riding in a car, having a dressing changed or changing positions), you may need to take extra doses of pain medicines before these activities. The goal is to prevent pain. Once the pain begins to increase, it is harder to get it under control

Treating pain is important, and there are many medicines and treatments that can be used. If one medicine or treatment does not work, there is another one that can be tried. Also, if a schedule or way that you are taking the medicine does not work for you, changes can be made. Talk to your doctor or nurse because they can work with you to find the pain medicine that will help you the most.

It may be helpful for you to keep a record of how the medicine is working. Keeping a pain control record and sharing it with your doctor or nurse will help to make your treatment more effective.

Side Effects

All medicines can have some side effects, but not all people get them. Some people have different side effects than others. Most side effects happen in the first few hours or days of treatments and gradually go away. Some of the most common side effects of pain medicines are:

- Constipation (Inability to have a bowel movement). The best way to prevent constipation is to drink lots of water, juice, and other liquids, and to eat more fruits and vegetables. Exercise also helps to prevent constipation. Your doctor or nurse may also be able to give you a stool softener or laxative
- Nausea and Vomiting. When this happens, it usually only lasts for the first day or two after starting a medicine. Tell your doctor or nurse about any nausea or vomiting. They can give you medicine to stop these side effects
- Sleepiness. Some people who take opioids feel drowsy or sleepy when they first take the medicine. This usually does not last too long. Talk to your doctor or nurse if this is a problem for you.

MISCONCEPTIONS ABOUT PAIN MEDICATIONS

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

"I'm afraid taking morphine will hasten my death."
You may have seen a dying person with symptoms of severe pain or shortness of breath for whom morphine was prescribed and within hours or days the person died. This can mistakenly be interpreted as morphine hastening the person's death. The reality is that symptoms of pain and distress can cause people to hang- on (inhibiting the ability to "let go" from the body).

When severe symptoms of discomfort are treated (and morphine is generally very effective for these symptoms) the person is able to experience a peaceful state, allowing them to let go of the physical body as a natural consequence of the disease process. Additionally, it's important to know that the doses of morphine and type of morphine (usually oral liquid concentrate) commonly used in hospice care ensure minimal potential for harm. In fact, studies show that the use of morphine in hospice care neither hastens nor prolongs life. Please discuss any concerns you have about this with your hospice team.

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

"If I take the strong pain medicine now, it will prevent good relief in the future when I really need it."
Pain medication administered correctly does not stop working with time. The key is using the right medication at the right dose throughout the course of the illness. Your physician and Hospice nurse work with you to ensure this occurs. As the disease progresses, more pain medication may be required. This does not indicate addiction but rather a natural progression of the disease.

"If they don't say they're in pain, then they're not having pain."
Patients who have long-term, chronic pain may not exhibit the same signs of pain that we are used to seeing. They may not speak about the pain or even moan, but this does not mean they are not experiencing pain. Nonverbal signs of pain are key indicators when assessing the level of comfort. These include, but are not limited to, facial grimacing, restlessness, inability to sleep and irritability.

RECOGNIZING PAIN IN PATIENTS WITH AN INABILITY TO COMMUNICATE VERBALLY

Patients may not be able to speak or describe their pain in the late stages of dementia, if they have had a stroke, or if they are in the late stages of other diseases such as amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease). However, just because they cannot speak does not mean that they are not experiencing pain.

Family members may be the first to notice little changes in the patient's mood or behavior that may mean the patient has pain.

- Always ask the patient if there is pain or if the patient is hurting anywhere. Patients who are non-verbal or have dementia may still have the ability to answer questions by nodding or with eye movements.
- Ask family members or other caregivers if they have noticed any changes in behavior that might indicate the patient is having pain.

Patients may display any of the following behaviors:

- Facial expressions such as grimacing, frowning, looking sad, and wrinkling the brow
- Movements such as restlessness, fidgeting, moving slowly, protecting a body part, pacing, rocking back and forth
- Noisy, labored breathing
- Looking scared, worried or troubled
- Acting tense
- Wringing of hands or clenching fists
- Pulling at or touching a body part or area
- Increased confusion, restlessness, or agitation
- Any change in the patient's usual behavior, for example: a very talkative patient may become quiet or a very quiet patient may become very talkative
- Moaning or groaning

NUTRITION, EATING AND SWALLOWING

Nutrition/Eating

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

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

Swallowing Problems (Dysphagia)

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

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

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

- Only offer food and/or fluids if they are awake, alert and agrees to it
- Sit him/her fully upright during eating/drinking, and for 30 minutes after eating or drinking
- Tilt the chin slightly forward to assist swallowing
- Encourage eating and drinking slowly. Give small bites and sips (if they need to be fed) to prevent choking
- Supervise the person during a meal for signs of choking
- Adjust the consistency of food as needed (e.g., from a regular texture to soft, then to a puree)
- Adjust fluids to a thicker consistency as needed. For example, milk or nutritional supplements are thicker than water, clear juice, soda, coffee or tea. Likewise, nectar such as apricot or tomato juice is thicker than milk or a thin liquid

Speak with your Hospice nurse if you suspect your loved one is having difficulty swallowing.

FEEDING THE HOSPICE PATIENT

Suggestions for the Family/Caregiver

Encourage, Do Not Force
There is a fine line between encouraging increased intake and attempting to force-feed. It is often difficult for healthy people to put themselves in the place of someone who is ill, in terms of desire to eat.

Do not feel guilty about the patient's inability to eat. It is part of the natural course of terminal illness. Do not take it personally if your loved one refuses to eat.

Portion Size
Psychologically, the illusion of portion size may play a role in the amount the patient will eat. Smaller plate sizes give the illusion of smaller portions. This may enable the patient to eat more.

Patience and Understanding
Sometimes the patient may crave and ask for a certain food only to find it impossible to eat once it arrives. Avoid anger in these situations. The intent to eat was there. Displays of anger or disappointment may only serve to discourage the patient from asking for a desired food again. Remember that it is important to allow the patient to continue to have control.

Nutrition/Feeding Tips
- It's important to provide mouth care to avoid sore gums and a sore mouth that can affect eating
- Allow the patient to eat as often and whatever they want
- Offer smaller, more frequent meals high in protein and calories
- Serve smaller portions on a small plate
- Find and use the patient's food temperature preference – cold, hot or room temperature

FOOD AND FLUID ISSUES AT THE END OF LIFE

The desire to eat or drink at the end of life usually decreases. This is a natural response of the body as the organs are slowing down and it becomes difficult to manage the intake of food and/or fluids.

What to report to the hospice team?

Tell them if the person:

- Is unable to eat or drink
- Has trouble swallowing
- Has a dry mouth, tongue, or skin
- Loses more than five pounds in a week. You may notice the weight loss by loose fitting clothes or dentures
- Makes less urine
- Becomes confused or drowsy

What can be done?

If there is a problem that can be managed, your health care team will discuss possible treatment options. It is normal for the person to lose interest in food and drink as the illness progresses. Treatment choices will depend on the person's wishes and illness.

Things you can do:

- Encourage favorite foods and drinks, never force a person to eat or drink
- Help family members and friends understand why eating and drinking may make the person uncomfortable as the body loses the ability to use nutrition and hydration
- Offer drinks or sips often – at least every two hours
- Clean the mouth often – a pleasant tasting mouth may make food taste better
- Support the person's decision if they refuse food and/or fluids
- Encourage the person to rest before and after a meal
- Make mealtime a quiet and pleasant time
- Offer small meals and use smaller dishes
- If nausea is a problem, serve small portions of salty (not sweet), dry foods and clear liquids
- Find other ways besides food and drink to show care and support. For example, offer the person a massage, apply lotion to their hands or feet, look through a picture album together

CHANGES IN HYDRATION

Caregiver Concerns

Families often ask about giving fluids within the final days when their loved one stops drinking.

Because providing fluids may hold important spiritual and emotional meaning that may go beyond the physical benefits, the entire family may be affected by the patient‘s inability to take fluids. Dehydration in the final days is expected as part of the normal physiological process.

Although dehydration is beneficial for the patient, it can be distressing to the family.

Respecting the patient and family’s wishes and providing treatment that is beneficial is important when deciding whether to offer fluids in the final days. Depending on the situation, giving fluids in the final days may cause more harm than good.

Before offering fluids, it is important to consider:

- What are the goals in giving fluids? Are they consistent with the patient and/or family goals?
- Will giving fluids cause harm or discomfort?
- Will it improve quality of life?

Myths regarding fluids in the final days

- **Myth:** Not drinking enough fluids causes thirst and discomfort.
- **Myth:** Not giving fluids is not giving care.
- **Myth:** Artificial hydration will prolong life.

Facts

- The focus of hospice and palliative care is individualized care based on defined patient goals including the choice to refuse fluids
- There is a physiological benefit to dehydration as death nears. Endorphins are released in the body that may cause a feeling of calmness and comfort
- Lack of interest in drinking is a normal part of the dying process. The patient will not likely feel thirsty and it is best not to force fluids as it may make them uncomfortable
- As body systems begin to shut down with approaching death, fluids may build up and cause congestion in the lungs. This may make breathing uncomfortable and difficult for the patient
- Fluids may cause swelling (edema), which can cause generalized discomfort in the body
- Thirst is caused by dry mouth, not dehydration. Providing a small amount of fluid and gentle oral care is usually sufficient to provide comfort: use a mouth sponge moistened with cool water to gently swab the inside the mouth, the front of the tongue, and the lips

NATURAL EFFECTS OF DEHYDRATION AT END OF LIFE

Artificial hydration has long been thought to ease the discomfort of terminal illness. Recent studies suggest that it does the opposite. Physicians once ordered IV fluids for terminally ill patients to prevent what they believed to be the agonizing effects of dehydration and electrolyte imbalance. *Now it is believed that dehydration is not painful. In fact, it may even be beneficial.*

Natural Anesthesia

As death approaches, dehydration occurs naturally from inadequate oral intake, gastrointestinal and renal losses, and the loss of secretions. Transitory thirst, dry mouth and changes in mental status have been found to develop.

However, the headache, nausea, vomiting, or cramps frequently associated with water deprivation rarely occur. The mental changes—while upsetting to loved ones—brings relief to patients by lessening their awareness of suffering.

This effect stems from the production of ketones, which caloric deprivation stimulates. The brain converts this derivative of metabolic fat to a substance with anesthetic properties that is believed to dull consciousness.

Artificial hydration vs. Dehydration

The administration of IV fluids may produce a feeling of well-being, but it's usually temporary. In time, artificial hydration is likely to heighten the discomfort of a terminally ill patient, and often aggravates underlying symptoms such as kidney function, lung secretions, and gastrointestinal fluid. Artificial hydration also contributes to peritumor and peripheral edema (swelling), which causes painful pressure sores. Natural dehydration makes such painful symptoms unlikely.

MANAGING CONSTIPATION

What is constipation?

- Bowel movements occurring less often than what is the normal pattern
- Hard stool
- Increased difficulty moving bowels

Constipation can be caused by:

- Diet changes, such a drinking less water and eating less fiber
- Medications, especially narcotic pain medications
- Lack of physical activity

What to report to the hospice/palliative care team?

- No bowel movement in 3 days or a change in the frequency of bowel `movements
- Pain, cramping, tenderness
- A feeling of fullness or bloating
- Blood in stools
- Diarrhea or oozing stools

What can be done?

The team will try to discover the underlying cause and discuss treatments best for you.

- Record when the bowel movements have occurred.
- Follow a regular bowel regimen, even if you are not constipated (many medications can cause constipation)
- Drink as much fluid (liquids) as is comfortable. Drinking warm liquids may promote bowel movement
- Eat more fruits and fruit juices, including prunes and prune juice
- Increase physical activity if possible. Walking can be beneficial
- Take laxatives/stool softeners as ordered by healthcare provider
- Sit upright on toilet, commode or bedpan
- Establish routine times for toileting
- Avoid bulk laxatives if not taking enough fluids
- Notify hospice/palliative care team if constipation continues

ANXIETY, RESTLESSNESS AND AGITATION

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

Potential causes of anxiety include:

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

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

Non-Pharmacological Methods for Relieving Anxiety

Discussing your concerns with others can help. If you are experiencing anxiety, consider:

- Talking to your Hospice social worker or chaplain
- Practicing deep breathing exercises
- Listening to soothing music
- Keep the environment calm and decrease external stimulation
- Calling the Hospice 24-hour number to discuss your concerns

Pharmacological Methods for Relieving Anxiety

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

Restlessness/Agitation

Anxiety and agitation are not the same. Anxiety is usually a "feeling" whereas agitation is an action typically involving constant movement such as pacing, frequently shifting positions, repeatedly trying to get out of bed, or fidgeting with bedding or clothing. Sometimes agitation is a non-verbal sign of pain. Some hospice patients may become restless or agitated especially in the hours or days before the patient dies.

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

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

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

Here are ways that you can manage your loved one's restlessness and agitation:

- Give medication as instructed by the nurse
- Do not leave them alone when they are restless
- Offer frequent reassurance to them
- Keep their surroundings calm
- Quietly read to them or play soothing music
- Provide gentle massage and physical closeness, as appropriate

MANAGING SHORTNESS OF BREATH

What is shortness of breath (dyspnea)?

- A personal experience for each individual
- An uncomfortable feeling of having difficulty breathing
- Can be described as not getting enough air (a feeling that you cannot catch your breath, like the room is closing in or that there is not enough air in the room)

When should I seek advice about my shortness of breath?

- When it stops you from doing what you want to do
- When it causes you or your family fear, anxiety, nervousness or restlessness
- When it causes bluish discoloration of your face, ears, nose, fingers or toes

What can be done?

The good news is that there is much you, your caregiver and the hospice and palliative care team can do for shortness of breath. The team will always try to find out the cause and discuss treatment options with you and your family.

Things that may be helpful:

- Sit in a chair or recliner
- Elevate your head on pillows when lying in bed
- Practice pursed lip-breathing technique. Take slow, deep breaths breathing in (inhale) through nose and then breathe out (exhale) slowly and gently through pursed lips (lips that are "puckered" as if you were going to whistle)
- Increase air movement by opening a window, using a fan or air conditioner.
- Apply a cool cloth to your head or neck
- Use oxygen as directed by your healthcare provider
- Take medication as directed by your doctor
- Keep your environment quiet to decrease feelings of anxiety
- Use relaxing activities such as prayer, meditation, calming music, and massage
- Notify the team if your shortness of breath is not relieved or gets worse

BATHING

Bathing is an activity that provides cleanliness and comfort, and can be refreshing to body and spirit. A complete bath can be tiring and is not necessary every day. Between baths, give the patient a sponge bath. Supplies needed may include: bowl or basin with warm water, soap, washcloth towels, lotion and a light blanket or sheet to prevent chill.

To bathe the patient:

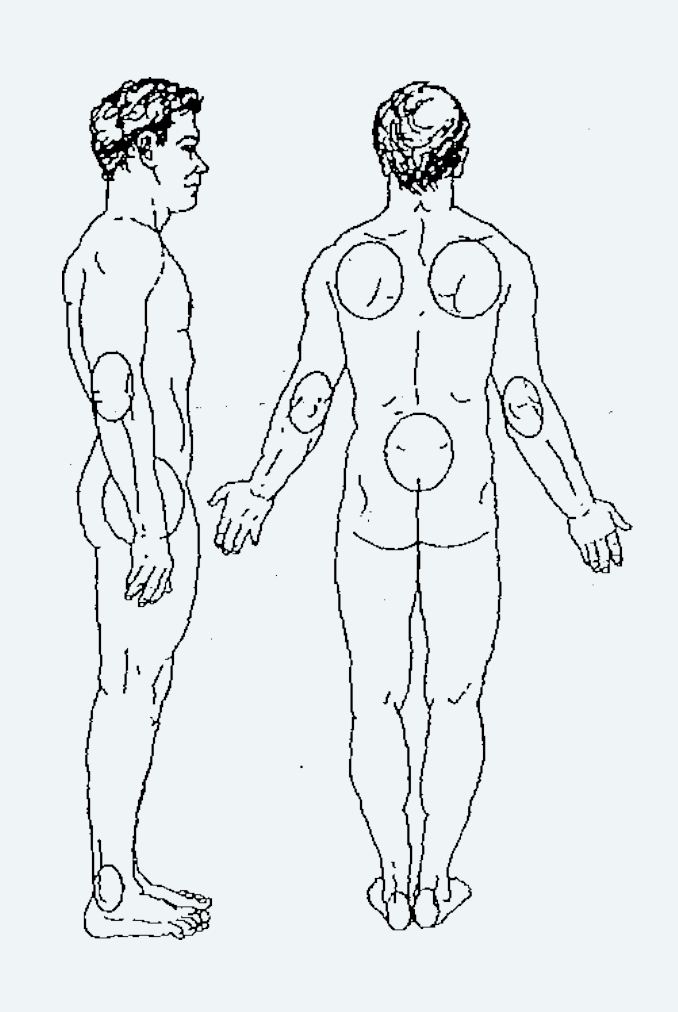
- Cover patient with a blanket or sheet and wash a small area at a time to prevent chilling Make sure room is warm and that there are no drafts
- Beginning at the face and working down, gently soap the skin, then rinse and pat dry. Make sure all creases and folds in the skin are completely dry
- After washing and drying the back, apply lotion. A back rub or massage may be soothing to the patient at this time
- Daily washing of the genital and rectal area is especially important since bacteria tend to collect there. Wash between the patient's legs, from the front towards the back. Rinse well and dry. Change the water before and after washing the genitals and the buttocks. This area should be washed after a bowel movement

Bathing Hints:

- If movement causes pain, give the patient pain medication ½ - 1 hour before the bath
- Ask if you are rubbing too hard or too lightly; everyone has a different sense of touch
- If the patient is in a hospital bed, raise the level of the bed to lessen the strain on your back. Or, place a table next to the patient's bed that is a comfortable working height for you
- If the patient is unable to tolerate a complete bath, try to wash the face, hands, back, underarms and genitals daily
- Brushing and styling the hair, as well as shaving, can also be done around bath time. For some people this brightens their spirits

SKIN CARE

Keeping the skin in good condition is most important. Pressure ulcers (bedsores) can occur on persons confined to bed who do not change their positions often enough, and for patients whose nutrition is compromised. Bedsores occur over bony areas of the body (see graphic).



- Keep the skin clean and dry
- If patient can't move independently, reposition every 2-3 hours
- Provide pain medication as needed to make movement easier
- Use pillows to support the patient when lying on their side, especially between the knees, arms and ankle.
- Apply lotion and gently massage reddened skin once or twice a day
- Use a pressure-relief device (like a four-inch foam pad) for the bed or chair. Your nurse can help you decide what is best in your situation
- Check the skin daily and report to the hospice nurse any reddened areas or breakdowns in the skin
- Wash the skin with warm water. Soap and alcohol can dry out the skin. Soap also leaves a film unless it's carefully rinsed off. Use a brand like Dove that are non- alkaline and non-drying
- For patients that cannot control their bladder or bowels, wash genital area (front to back) after each urination or passage of stool using neutral skin cleaners
- After the skin is cleaned and dried, use a protective ointment or spray

MOUTH CARE

To help prevent dry mouth it is important to have good mouth care. The mouth should be cleansed at least twice a day. If your loved one needs help with mouth care, raise them to a sitting or half-sitting position to prevent choking. Place a dry cloth under the chin. Give a sip of water to moisten the mouth, and gently brush teeth and gums. Use the preferred toothpaste. The person can rinse and spit into a bowl.

If rinsing and spitting out is difficult, you can clean the mouth using a disposable foam sponge (toothette) moistened with water, or a moistened gauze pad or cloth wrapped around your finger. Your nurse can provide toothettes. Ask your nurse to show you how to provide proper mouth care.

Remove and clean dentures after a meal or snack, and gently clean the mouth with a soft toothbrush or cloth. When a person loses weight, dentures may no longer fit properly.

Loose dentures can cause mouth sores. If this happens and a dentist cannot refit the dentures, you may choose to leave the dentures out.

Dry mouth is often a problem. To reduce the discomfort of dry mouth:

- Sip water in small amounts throughout the day
- Try sugarless gum or hard candy
- Moisten dry foods and avoid spicy foods
- Avoid mouthwash with alcohol
- Don't breathe through your mouth
- Use lip balm to keep lips moist (do not use petroleum based products such as Vaseline if the patient is on oxygen)
- Try a vaporizer or humidifier
- Use toothettes to freshen mouth
- Use a saliva substitute (discuss with nurse)
- Avoid alcohol and caffeine

PLANNING FOR CARE AND COMMUNICATING CHOICES

Family Members Working Together

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

Here are a few guidelines you may find helpful:

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

Planning for Care

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

Providing Care in the Home

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

Respite for the Caregiver

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

Private Caregiving Agencies

If family members or friends are not able to provide the in-home care, you may choose to hire in-home caregiver(s). Paid for by private funds, a long-term care policy (if you have one), or Medicaid for those who are financially eligible, privately hired caregivers are typically paid by the hour, by the day, or receive a live-in rate. There are employment agencies that will find a caregiver that you or your family pays directly. There are also private caregiving agencies that place their own caregiver(s) in the home in which you pay the agency (not the caregiver).

Hospice Services in Long-Term Care Settings

People living in long-term care settings, including nursing homes, assisted living facilities or adult family homes, may receive hospice care. A team of specialized hospice workers, who are familiar with the staff at these facilities, provide the same support and care for a resident as they would for a person living in a private home. Kline Galland Hospice works collaboratively with many long-term care settings in King County, enhancing the care provided by nursing facility staff. The charge for room and board at long-term care settings is not covered under the Medicare Hospice Benefit. If the patient is living at home, but expects to enter a long-term care facility, the hospice social worker will assist the patient/family in locating a facility that works in collaboration with Kline Galland Hospice.

There are many different types of homes or facilities where a person can live and get care services in a residential setting. One important consideration is whether the person will be using State funds (Medicaid) to pay for care, long-term care insurance or their Veterans benefits. If State funds will be used, the home or facility must be licensed by Washington State and accept Medicaid payment for residents.

Skilled Nursing Facilities

Skilled Nursing Facilities (nursing homes) provide 24-hour supervised nursing care, personal care, therapy, nutrition management, organized activities, social services, room, board and laundry.

Adult Family Homes

Adult Family Homes are regular neighborhood homes where staff assumes responsibility for the safety and well-being of the adult. A room, meals, laundry, supervision and varying levels of assistance with care are provided. Some provide occasional nursing care. Some offer specialized care for people with mental health issues, developmental disabilities or dementia. The home can have up to six residents and is licensed by the State.

Assisted Living Facilities

Assisted Living Facilities are facilities in a community setting where staff assumes responsibility for the safety and well-being of the adult. These facilities offer a housing alternative for older adults who may need help with dressing, bathing, eating, and toileting, but do not require the intensive medical and nursing care provided in nursing homes.

Your Hospice social worker can help you review options for in-home care and/or long-term residential care, and coordinate a comprehensive care plan.

FUNERAL PLANNING

Planning a funeral or memorial is a complicated process, which is made even more difficult by the emotional stress that accompanies the death of a loved one. Fortunately, many of the arrangements can be made ahead of time, which will decrease the burden on those left behind. And while the main goal of a funeral service is to honor your loved one's life, it's also an opportunity for you and those who know your loved one to say goodbye.

It is important for the hospice team to be notified about the family's preferred funeral home early in the hospice care process, because the hospice team notifies the funeral home of the patient's death. No other pre-arrangements are necessary.

If you would like additional assistance with funeral home planning including price lists and information about possible financial assistance, your hospice social worker is available to help.

CAREGIVER NEEDS

We Are Here For You Too

Although you may not consider yourself a caregiver, you are. A caregiver is anyone who cares for a seriously ill person. A caregiver is most often a family member or close friend. Caring for someone can be both rewarding and stressful. It is not unusual to experience a variety of feelings at this time. These feelings are neither good nor bad. They are your feelings and they may affect your life and wellbeing during the time you are providing care. Over the years, we have learned from caregivers that caring for someone with a serious illness is a life-changing process. They have taught us that even in the midst of hurt and sadness, there are chances to learn and grow and heal.

Being a caregiver can be a valuable time to create lasting and positive memories together. Other rewards of caregiving include:

- Sense of inner peace
- Times of laughter and joy
- Feelings of intimacy
- Completing unfinished business
- Stronger sense of self-worth

We understand that it is easy to become tired and overwhelmed as your caregiving responsibilities are many. Please be aware of:

- Excessive fatigue
- Fear of the unknown
- A loss of control
- A loss of “normal” activities
- Financial worries
- Social isolation
- Emotional challenges
- Feelings of obligation, guilt or resentment
- Difficulty making plans

In order to effectively care for another person, you need to care for yourself. Here are some valuable suggestions:

- Establish visiting hours so that you can have both support and privacy from others
- Select a family member or friend to be in charge of relating updates by phone or email to others who are concerned
- Educate yourself about the condition of the person receiving care. Talk to your physician. Information is empowering
- Realize that no one can be all things to all people. You may not be able to live up to everyone’s expectations. Try not to dwell on negative comments
- Maintaining good health is a priority: Get enough rest, eat properly, and exercise

PREPARING FOR DEATH

When a person enters the final stage of the dying process, two different dynamics are at work which are closely interrelated and interdependent. On the physical plane, the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly and undramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort enhancing measures.

The other dynamic of the dying process at work is on the emotional-spiritual-mental plane, and is a different kind of process. The spirit of the dying person begins the final process of release from the body. This release tends to follow its own priorities, which may include receiving permission to "let go". These events are the normal, natural way in which the spirit prepares to move on. The most appropriate kinds of responses to the emotional-spiritual-mental changes are those which support and encourage this release and transition.

The experience we call death occurs when the body completes its natural process of shutting down, and when the spirit completes its natural process of reconciling and finishing. These two processes need to happen in a way appropriate and unique to the values, beliefs, and lifestyle of the dying person.

Therefore, as you seek to prepare yourself as this event approaches, the members of your Hospice care team want you to know what to expect and how to respond in ways that will help your loved one accomplish this transition with support, understanding, and ease. This is the great gift you have to offer your loved one as this moment approaches.

The emotional-spiritual-mental and physical signs and symptoms of impending death are offered to help you understand the natural kinds of things which may happen and how you can respond appropriately. Not all these signs and symptoms will occur with every person, nor will they occur in this particular sequence. Each person is unique and needs to do things in their own way. This is not the time to try to change your loved one, but the time to give full acceptance, support, and comfort.

PHYSICAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

The following signs and symptoms described are indicative of how the body prepares itself for the final stage of life. These changes can often begin 1-2 weeks prior to death and become more pronounced as death approaches.

Coolness

Your loved one's extremities (hands and arms, feet and then legs), may be increasingly cool to the touch, and at the same time the color of the skin may change. This a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep them warm with a blanket, but do not use one that is electric.

Increased Sleep

Your loved one may spend an increasing amount of time sleeping, and appear to be uncommunicative or unresponsive and at times be difficult to arouse. Sit with your loved one, hold their hand, but do not shake it or speak loudly. Speak softly and naturally. Plan to spend time with your loved one during those times when they seem most alert or awake. Do not talk about the person in the person's presence. Speak to them directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

Disorientation

Your loved one may seem to be confused about the time, place, and identity of people surrounding them including close and familiar people. Identify yourself by name before you speak rather than to ask the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important for the patient's comfort, such as, "It is time to take your medication", and explain the reason for the communication, such as, "So you won't begin to hurt". Do not use this method to try to manipulate the patient to meet your needs.

Incontinence

Your loved one may lose control of urine and/or bowels as the muscles in that area begin to relax. Discuss with your Hospice nurse what can be done to protect the bed and keep your loved one clean and comfortable.

Congestion

Your loved one may have gurgling sounds coming from their throat or chest. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to clear normal secretions. Suctioning usually only increases the secretions and can cause discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain.

Restlessness

Your loved one may make restless and repetitive motions such as pulling at bed linen or clothing. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage the forehead, read to the person, or play some soothing music.

Decreased Urine Output

Your loved one's urine output normally decreases and may become tea colored, referred to as concentrated urine. This is due to the decreased fluid intake as well as decrease in circulation through the kidneys. Consult with your Hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

Decreased Need for Food and Drink

Your loved one may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy which is expended on these tasks. Do not try to force food or drink, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person more uncomfortable. Sports drinks, juice, or small chips of ice, may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by

teaspoon. Glycerin swabs or toothette sponges may help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

Change in Breathing Pattern

Your loved one's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, i.e. shallow breaths with periods of no breathing of five to thirty seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common. Elevating the head, and/or turning the person onto their side may bring comfort. Hold your loved one's hand and speak gently.

EMOTIONAL, SPIRITUAL, AND MENTAL SIGNS AND SYMPTOMS OF APPROACHING DEATH

Withdrawal

Your loved one may seem less responsive, withdrawn, or in a comatose-like state. This is a time of withdrawing from everything outside one's self, and focusing more and more on the inside. This is an important time for them to sort out, evaluate and review their life. It is something that the person can only do alone. This mental processing of one's life is usually done with the eyes closed, so sleep increases. A morning nap is added to the usual afternoon nap. Staying in bed all day and spending more time asleep than awake becomes the norm.

Since hearing remains all the way to the end, speak to your loved one in your normal tone of voice, identifying yourself by name when you speak, hold their hand, and say whatever you need to say that will help the person let go.

Decreased Socialization

With withdraw comes less of a need to communicate with others. As the physical life is slowly being left behind, words lose their importance. Your loved one may only want to be with a very few or even just one person. Touch and nonverbal communication takes on more meaning. Learn to "be with" the person without talking. Offer support through your touch and presence.

Vision-like Experiences

Your loved one may speak or claim to have spoken to persons who have already died, or to see or have seen places not presently accessible or visible to you. This does not indicate a hallucination or a drug reaction. This is common and natural, and is usually comforting to your loved one. Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm their experiences and encourage your loved one to tell you about them. If for some reason they frighten your loved one, explain that they are normal occurrences, also inform your hospice team about this as they may be able to help.

Restlessness

Your loved one may perform repetitive and restless tasks. Your Hospice team members will assist you in identifying ways to help the person find release from the restlessness. Things which may be helpful in calming the person may include recalling a favorite place the person enjoyed, a favorite experience, reading something comforting, playing music, and giving assurance that it is OK to let go.

Refusal of Food and Fluids

When your loved one wants little or no fluid or food, this may indicate readiness for the body to shut down. This is a natural and common part of their decline. Do not try to force food or fluid, this may actually make them more uncomfortable. You may help your loved one by giving permission to let go whenever they are ready. At the same time affirm the person's ongoing value to you and the good you will carry forward into your life that you received from them.

Giving Permission

Giving permission to your loved one to let go, without guilt for leaving or trying to keep them with you to meet your own needs, can be difficult. A dying person might try to hold on, even though it brings prolonged discomfort, in order to be sure those who are going to be left behind will be all right. Therefore, your ability to release the dying person from this concern and give them assurance that it is all right to let go whenever they are ready is one of the greatest gifts you have to give your loved one at this time.

Saying Good-bye

When your loved one is ready to die and you are able to let go, then is the time to say good-bye. Saying good-bye is your final gift of love to your loved one, for it brings closure and makes the final release possible. It may be helpful to lay in bed and hold the person, or to take their hand and then say everything you need to say.

It may be as simple as saying, I love you. It may include recounting favorite memories, places, and activities you shared. It may include saying, "I'm sorry for whatever I contributed to any tension or difficulties in our relationship". It may also include saying, "Thank you for…"

Tears are a normal and natural part of saying good-bye. Tears do not need to be hidden from your loved one or apologized for. Tears express your love and help you to let go.

Your loved one becomes nonresponsive (unable to respond to their surroundings) sometime just prior to death. The separation becomes complete when breathing stops. What appears to be the last breath is often followed by one or two long spaced breaths and then the physical body is empty.

WHAT TO DO WHEN DEATH OCCURS

How to Know That Death Has Occurred:

- No breathing
- No heartbeat
- Loss of control of bowel or bladder
- No response to verbal commands or shaking
- Eyelids slightly open
- Eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

If you think that death is close at hand or has occurred, please call Kline Galland Hospice at (206) 805-1930. DO NOT call 9-1-1, the police, paramedics or the fire department.

Your hospice nurse will help you confirm that death has occurred and handle calls to the funeral home of your choice and your physician.

Although this information may sound frightening, the hospice team's goal is to prepare you for what to expect. Your physical and emotional well-being is as important to us as your loved ones. A member of the hospice staff is always available to help you.

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

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

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

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

It may take at least one to two hours for the funeral home to arrive, but you can arrange with the funeral home for more time if you like. When the funeral home representative arrives, they will talk with you about the process for transporting the body and answer any questions. The funeral home representative is there to provide respectful care of the body and assist with your concerns.

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

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

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

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

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

Considerations and Tasks Following the Death

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

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

A GUIDE TO BEREAVEMENT, MOURNING, AND GRIEF

People cope with the loss of a loved one in many ways. For some, the experience may lead to personal growth, even though it is a difficult and trying time. There is no right way of coping with death. The way a person grieves depends on the personality of that person and the relationship with the person who has died. How a person copes with grief is affected by their experience with illness, the way the disease progressed, the person's cultural and religious background, coping skills, mental health history, support systems, and the person's social and financial status.

The terms grief, bereavement, and mourning are often used in place of each other, but they have different meanings:

Grief is the normal process of reacting to the loss. Grief reactions may be felt in response to physical losses (for example, a death) or in response to symbolic or social losses (for example, divorce or loss of a job). Each type of loss means the person has had something taken away. As a family goes through an illness, many losses are experienced, and each triggers its own grief reaction.

Grief may be experienced as a mental, physical, social, or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness, and despair. Physical reactions can include sleeping problems, changes in appetite, physical problems, or illness. Social reactions can include feelings about taking care of others in the family, seeing family or friends, or returning to work.

People who are grieving often feel extremely tired because the process of grieving usually requires physical and emotional energy. The grief they are feeling is not just for the person who died, but also for the unfulfilled wishes and plans for the relationship with the person.

Bereavement is the period after a loss during which grief is experienced and mourning occurs.

Mourning is the process by which people adapt to a loss. Mourning is also influenced by cultural customs, rituals, and society's rules for coping with loss.

Grief work includes the processes that a mourner needs to complete before resuming daily life. These processes include separating from the person who died, readjusting to a world without them, and forming new relationships.

To separate from the person who died, a person might find another way to redirect the emotional energy that was given to the loved one. This does not mean the person was not loved or should be forgotten, but that the mourner needs to turn to others for emotional satisfaction.

The mourner's roles, identity, and skills may need to change to readjust to living in a world without the person who died. The mourner might also give other people or activities the emotional energy that was once given to the person who died in order to redirect emotional energy.

The Four Tasks

One theory suggests that there are specific tasks of mourning that need to be accomplished in order for mourning to be completed. The concept of tasks implies that effort on the part of the individual is required. These tasks are:

1. **Accept the Reality of the Loss** – Coming full face with the reality that the person is dead and will not return is the first task that needs to be completed. Without accomplishing this, the grieving person will not be able to continue through the mourning process
2. **Work Through the Pain** – Grief is painful, physically and emotionally. It is important to acknowledge the pain and not suppress it
3. **Adjust to the New Environment in Which the Deceased is Missing** – This may require adjusting to the roles that the deceased once carried out. If it is a spouse that has died, it required the bereaved to accept their new identity as a widow
4. **Emotionally Relocate the Deceased and Move Forward** – While the bereaved will never be compelled to totally give up on the relationship, the goal is to find an appropriate place in their emotional lives for the deceased. This requires a letting go of attachments so new relationships can begin to form

Completing these tasks will help the bereaved come to terms with their loss and return to a new state of normalcy. Involvement in bereavement support groups or seeking grief counseling can help individuals move through the tasks. Hospice integrates bereavement care into our comprehensive approach to care.

CHILDREN AND GRIEF

Every child, just as every adult, will grieve in their own way. Children respond to grief as adults do—physically, emotionally, behaviorally, even spiritually. It may seem daunting to have to explain death to a child, especially when there are no simple answers. The following guidelines may make this process easier.

What should I say?

Consider a child's age and ability to understand complex ideas. Many experts believe children do not have a mature understanding of death until about age 8 or 9. Younger children may think that being dead is temporary and that the dead person will return in the future.

It is okay to say you don't know the answer to a child's question. You can even say, "No one knows for sure, but this is what I think." If the child asks whether you will die, respond that everybody dies someday, but that you hope to live to do things with the family for a long time.

Use precise terms when talking about death. People typically refer to "losing" a loved one. Children may interpret this literally and assume that the person can be found. You should also explain that being dead means that the body has stopped working and that it cannot be fixed. It no longer feels cold or gets hungry, and it does not feel any more hurt or pain.

Giving children information and choices when facing death and grief can be very helpful. Preparing children ahead of time for what they might encounter at the hospital or during the funeral can be very important. Once they have that information, let them make a choice. Perhaps they would like to go to the funeral, but would choose not to attend the service at the cemetery.

Remember that children cannot tolerate long periods of sadness; they may want to play and participate in their usual activities. This does not mean that they didn't love the person who died, nor does it mean that they are being disrespectful. It is okay to permit or encourage children to have fun like they did before the death. Changes in the child's behavior or patterns might be signs that the child is experiencing problems associated with the death. In these instances, it's appropriate to obtain advice from a specialist in child bereavement counseling.

Ways to help grieving children

Many school-age children benefit by participating in **bereavement groups** with other children who have suffered losses. Children hate to be different from their peers; in a group, they discover they are not alone.

Art and other expressive approaches can be great ways to help children identify their feelings of grief. Activities might include painting a picture of the feeling; writing and drawing in a journal; reading books or watching movies that open up discussions of death and loss; making a list of what makes you angry, sad, afraid, frustrated, etc.

GENERAL HOME SAFETY

We have prepared this guide to assist you and your family to remain safe at home. Patient safety is a major concern for clients and families and for us, your hospice providers. Use this checklist to determine the safety level of your home. Check each statement that applies to you and your home then, review the unchecked boxes to decide how you can make your home safer.

General Safety

- Emergency phone numbers are posted by each telephone
- Electrical appliances and cords are clean and in good condition
- Electrical equipment bears the Underwriters (UL) label
- An adequate number of outlets are located in each room where needed. There are no "octopus" outlets with several plugs being used
- Electrical outlets are grounded
- Burned out lights are replaced
- The heating system is checked and cleaned regularly by someone qualified to do maintenance. Space heaters, if used, are maintained and used according to the manufacturer's specifications
- Set water heater thermostat below 120 degrees F to avoid burns
- Carpeting and rugs are not worn out
- Throw rugs have a nonskid backing and are not placed in traffic areas
- There are exits from all areas of the house
- Medications are safely and securely stored in a cool/dry place according to instructions on the label
- When you are home alone, do not let door-to-door salesmen into your house
- Remember, if telephone/television solicitations sound "too good to be true," they probably are
- Schedule household maintenance (painting, roofing, etc.) with a reputable company or have a friend or family member assist you
- Keep valuables that may be easily stolen, out of sight

Bathroom Safety

- Bathtub or shower has a nonskid mat or strips in the standing area
- Bathtub or shower doors are glazed with safety glass or plastic
- Grab bars are installed on the walls by the bathtub and toilet
- Towel bars and soap dish in the shower are made of durable materials and firmly installed; however, they are not strong enough to be used as grab bars
- Make sure faucets and towel bars are easy to reach
- Install a hand-held showerhead
- Old medications are safely disposed of
- Electrical appliances (radio, TV, heater) are kept away from bathtub or shower area

Bedroom

- Have a phone and working flashlight within easy reach of your bed
- Night-lights are used to brighten the way to the bathroom at night

Living Room

- Electric cords are placed along walls--not under rugs--and away from traffic areas
- Chairs and couches are sturdy and secure

Kitchen Safety

- Stove and sink are well lighted
- Curtains are kept away from the stove and other open flame areas
- An exhaust hood with filters is provided
- Kitchen exhaust system discharges directly outside
- Hazardous cleaners and chemicals are out of reach of children and confused adults
- Adequate counter space is available to keep from lifting or carrying packages
- Multipurpose fire extinguisher kept nearby

Stairways & Halls

- Steps are in good condition and are free of objects and clutter
- Smoke detectors are in place in hallways and near sleeping areas
- Hallways are equipped with night-lights
- Handrails are sturdy and securely fastened
- Light switches are located at the top and bottom of stairways and at both ends of long halls
- Doors do not swing out over stair steps
- Clearance in the stairway provides adequate headroom

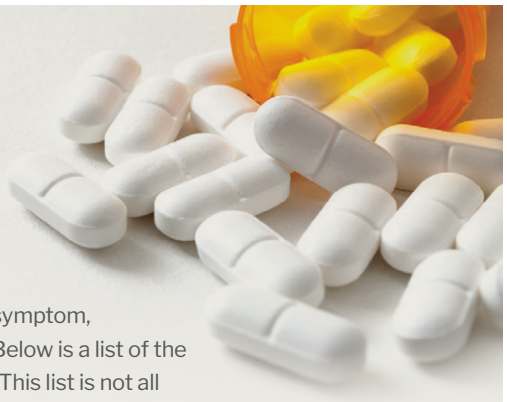
Outside Areas

- Steps and walkways are in good condition and free of objects and clutter
- Handrails are securely fastened
- Doorways are well lighted
- Porches, balconies, terraces and other elevations or depressions are protected by railings or other protective measures
- The garage is adequately ventilated

Medical Equipment

- Manufacturer's instructions for specialized medical equipment should be kept with or near the equipment
- Routine and preventative maintenance is performed according to the manufacturer's instructions
- Emergency phone numbers are available in the home so that you can notify the company and obtain necessary assistance in case of equipment problems or equipment failure
- Equipment batteries and/or supplies are checked regularly by a qualified service person

Falls & Medication



WHAT IS THE CONNECTION?

Medications are prescribed for certain ailments. Along with treating the disease or symptom, medications can affect other systems and lead to an increase in your risk of falling. Below is a list of the most common medications by category and how they can affect your risk of falling. This list is not all inclusive and any medication can create a reaction at any time. Be sure you know what you are taking and how they can affect you. The more medications you take, the more your risks increased due to medication interactions. Medications should be reviewed anytime a medication is added or dosing changed. Are there some meds that can be stopped? Decrease dosing? Are you taking an over the counter medication that is creating duplicate therapy or interacting with your prescriptions?

MEDICATION TYPE	EXAMPLES OF MEDICATIONS	EFFECT ON RISK OF FALLING
Pain Medications (Narcotic & Non-Narcotic)	Tylenol, Ibuprofen, Aleve, Oxycodone, Percocet, Morphine, Dilaudid, Vicodin, Norco, Fentanyl, Hydrocodone	Pain medications can affect your balance, slow reaction time, or make you sleepy making falls more likely. You may feel more stable than you really are when pain is decreased.
Psychotropic medications (antidepressants, anti-anxiety, anticonvulsants, sedatives)	Alprazolam, Lorazepam, Valium, Zoloft, Ambien, Neurontin, Lyrica, Depakote, Dilantin, Melatonin, Paxil, Effexor, Celexa, Lunesta, Sonata	This category affects the brain which controls all of your movements. Side effects can be increased sleepiness, decreased reaction time, poor balance, impaired spatial perception, confusion, nausea, blurred vision.
Medications affecting cardiac status including hypertension medications, arrhythmia medications, diuretics	Lasix, Bumex, Hydrochlorothiazide, Amiodarone, Diltiazem, Metoprolol, Norvasc, Lisinopril, Nitro, Vasotec, Captopril, Metolazone, Zaroxolyn	These affect your heart rate, rhythm, and blood pressure, which can create dizziness, syncope, vision changes, rapid changes to your vital signs leading to dizziness, loss of balance, fatigue, confusion.
Urinary medications	Flomax, Vesicare, Detrol, Ditropan	These can cause changes in vision, changes in blood pressure, which can increase risk of falling.
Diabetic medications	Insulins, Glyburide, Metformin, Avandia, Glipizide, Amaryl	Anything affecting your glucose levels can also affect your brain function, level of alertness, create confusion, dizziness, unstable gait, tremors, nausea.
Antihistamines	Benadryl, Allegra, Claritin, Zyrtec, Pseudoephedrine (Sudafed)	Nearly all of these can increase sleepiness- even the “non-drowsy” versions. Some can cause changes in blood pressure and pulse.

HOME USE AND DISPOSAL OF CONTROLLED SUBSTANCES POLICY

PURPOSE

To ensure the appropriate use and disposal of controlled substances in accordance with applicable state and federal regulations.

POLICY

Kline Galland Hospice Services voluntarily adheres to a controlled drug reporting process in accordance with the Controlled Substances Act and Medicare Conditions of Participation 418.106.(e)(2). Per the Support for Patients and Communities Act, Kline Galland Hospice's policy disallows staff to dispose of medications.

PROCEDURE

1. Controlled substances will be distributed directly to the patient or their representative. Examples of controlled substances that may be issued to a patient during hospice services include fentanyl, morphine, oxycodone and lorazepam. The dispensing pharmacist will be responsible for monitoring the amount of drug issued and the length of time between renewals.
2. The Case Manager or other member of the IDG as designated will provide a copy of the written policies and procedures on the management and disposal of controlled drugs to the patient/representative and family. The Case Manager will verbally discuss the policy in a language and manner that they understand to ensure the safe use and disposal of controlled drugs. Written instructions regarding Safe Disposal of Medications will be provided. (See Addendum H2.059A)
3. The Case Manager or other member of the IDG as designated will outline an informal documentation procedure for the patient and family/caregiver when hospice personnel are not present in the home.
4. In cases where hospice personnel are in the home 24 hours a day, a drug count will be made by the licensed personnel at the time of shift change.
5. Controlled drugs will be accounted for on a narcotic count record, which will be maintained as a part of the clinical record.
6. When a hospice patient no longer has a need for a controlled substance, the Case Manager will instruct the patient and family/caregiver to dispose of them.
7. The Case Manager or another member of the IDG as designated will document in the clinical record that the patient and family/caregiver were given the written policies and procedures for managing controlled drugs and disposal of medications and took responsibility to do so.
8. The hospice nurse, social worker, or chaplain attending the death of a hospice patient will inform the family/caregiver of their responsibility to dispose of all the patient's prescribed medications and will document this instruction in a clinical note.
9. Hospice personnel will not dispose of any patient medications.
10. For patients who reside in a facility, the facility is responsible for disposal of controlled substances, and may do so according to their facility policy, or in accordance with information provided by KG Hospice.

INFECTION CONTROL/DISPOSAL OF CONTAMINATED MATERIAL AND MEDICAL SHARPS

You can help prevent injury, illness and pollution by following these steps when you dispose of sharp objects and contaminated materials used in administering health care in your home.

You should place Needles, Syringes, Lancets and Other Sharp Objects in a puncture-resistant, closeable, leak-proof containers.

Kline Galland Hospice will provide you with containers specifically designed for the disposal of medical waste sharps and your nurse or your aide will be responsible for discarding them. Be sure to reinforce the lid with heavy-duty tape prior to discarding. Do not put sharps in any container you plan to recycle or return to a store and do not use glass or clear plastic containers. Finally, make sure that you keep all containers with sharp objects out of the reach of children and pets.

We also recommend that you place Soiled Bandages, Disposable Sheets and Medical Gloves in a garbage bag and then securely fasten the top of the bag.

Once this is accomplished, the bag can be disposed of in the garbage. For specific information regarding environmental requirements and or suggestions for disposing of your medical waste, please contact your local environmental authorities.

Remember to wash your hands frequently-especially before preparing food, before eating, after using the restroom and after handling any type of equipment, sharp objects, soiled laundry or contaminated materials. Soiled laundry should be washed apart from other household laundry in hot soapy water. Handle these items as little as possible to avoid spreading germs. Household liquid bleach should be added if viral contamination is present.

Blood and other bodily fluids

Bloody/body substance spills are cleaned by putting on gloves and wiping fluid with paper towels. Use a cleaning solution of household bleach and water (1 cup of bleach to 10 cups of water) to wipe the area again. Double bag used paper towels and dispose of in the trash.

Equipment used by the patient should be cleaned every day.

Small items (except thermometers) should be washed in hot soapy water, rinsed and dried with clean towels. Household cleaners such as Lysol or diluted bleach water may be used to wipe off equipment. Follow equipment cleaning instructions and ask your nurse or therapist for clarification. Thermometers should be wiped with alcohol before and after each use. Store in a clean, dry place. Liquids may be discarded in the toilet and the container cleaned with hot, soapy water, rinsed with boiling water and allowed to dry.

DISPOSAL OF UNUSED MEDICATION AND DONATION OF MEDICAL SUPPLIES/EQUIPMENT

Safe Medication Disposal

Any prescribed medications that are not being used should be destroyed. Health department regulations prohibit hospice organizations from accepting returned medications, medical supplies or equipment. We have listed some alternatives below to help you choose the best way for disposing of or recycling these items.

*Please note that Kline Galland Hospice employees are not permitted to remove medications from your home to destroy or dispose of them for you.

In Washington State, some businesses and law enforcement offices are participating in a program to take back unwanted/expired/un-needed medications in an effort to protect children, families and the environment. To find a list of participating locations, visit the "Take Back Your Meds" website.
http://www.takebackyourmeds.org/what-you-can-do/locations

If you are not able to take medications to a drug disposal location, the following steps should be followed:

1. Keep the medication in its original container.
2. Modify the medications to discourage consumption by mixing them with kitty litter, coffee grounds, flour or sawdust.
3. Tape the container closed and place in a sealable bag then in a non-transparent container.
4. Discard the container in the garbage (not the recycling bin) and secure your trash to prevent access by children and pets.
5. DO NOT flush medications down the toilet or down a sink drain.

Need more information about specific medications? Below are resources for accessing medication information sheets:

Medline Plus
http://www.nlm.nih.gov/medlineplus/druginformation.html

U.S. Food and Drug Administration
http://www.fda.gov/Drugs/default.htm

Medical Equipment/Supplies

Durable Medical Equipment (DME) provided by Kline Galland Hospice, must be returned upon patient discharge, and will be coordinated by the nurse case manager. Privately purchased equipment or supplies may be donated. Below are several local resources:

1. Bridge Disability Ministries - http://bridgemin.org/medical-equipment/give-equipment/
2. Washington Access Fund - http://washingtonaccessfund.org/other-resources/
3. ALS Association Evergreen Chapter - http://webwa.alsa.org

PATIENT & FAMILY RIGHTS AND RESPONSIBILITIES

Both Washington State law and the federal Medicare Conditions of Participation set forth patient rights and responsibilities. Hospices must follow these regulations:

Your Responsibilities

As a patient receiving care from Kline Galland Hospice, we also ask a few things of you (or as applicable, your representative). You are responsible to:

- Remain under a physician's care while receiving hospice services and inform us of any changes in health status condition, or treatment
- Provide your Kline Galland Hospice Team with a complete and accurate health history and a safe home environment in which your care can be provided
- Participate in creating your plan of care, asking your Hospice Team what to expect and discuss symptom management options with your team
- Provide your Hospice Team with all requested insurance and financial information records
- Sign (or have your representative sign) required consents/releases for insurance billing
- Allow your Hospice Team to act on your behalf in filing appeals regarding denied payment of service
- Treat your Hospice Team with respect and dignity without discrimination as to color, religion, sexual orientation, sex or national/ethnic origin
- Accept the consequences for any refusal of care or choice of noncompliance

Patient Rights...We Care

You should be informed, both verbally and in writing, of your rights related to your Hospice care in a way that you can understand. These include rights:

- To be treated with courtesy, respect, and dignity, and to have your person and property treated with respect by anyone providing services on behalf of Hospice. You have the right to privacy and to the confidentiality of your personal information and health care records. Your clinical record will be kept confidential, and any access to or release of your information will comply with HIPAA and applicable law.
- To receive effective pain management and symptom control for conditions related to your illness
- To be involved in designing a plan of care that addresses your specific needs and preferences, updating it as your condition changes, and to be informed of the nature, purpose and outcome(s) of care and services that are provided to you
- To be informed of the Hospice's policies and procedures for providing back-up care when services cannot be provided as scheduled and regarding the circumstances that may cause the Hospice to discharge a patient.
- To refuse care, treatment or services. Notwithstanding the foregoing, you are subject to applicable state and federal law as well as the Kline Galland discharge policy, including requirements relating to discharge for cause.
- To choose your attending physician
- To be cared for by properly trained personnel, contractors and volunteers with coordination of services; and to be informed by knowledgeable staff about your medical condition
- To receive information about the scope of services provided by Hospice and those provided to patient, and specific limitations on those services.
- To be informed of what the Hospice charges for services; Hospice billing and payment methodologies; to what extent payment may be expected from health insurance, public payers (e.g., Medicare, Medicaid), or other sources; and what charges the patient may be responsible for paying.
- To access Hospice's listing of providers and select any licenses to provide care, subject to your reimbursement mechanism or other contractual obligation(s)
- To know the name of the individual within the Hospice responsible for supervising the patient's care and the manner in which that individual may be contacted.
- To be informed in advance of the disciplines that will furnish care, the care to be furnished, any changes in the care to be furnished and frequency of visits proposed

Patient's Rights...We Comply

Patients and their families also have the right:

- To report any grievances about care given (or not given) or lack of respect for property, by anyone furnishing services on behalf of Hospice, without fear of interference, coercion, discrimination or reprisal for exercising your rights. To receive an investigation by Kline Galland of your grievances
- To receive a copy of Kline Galland's written policies and procedures describing the process for submitting and addressing complaints about the services and care they are receiving and to have those complaints addressed without retaliation. Kline Galland will document the existence and resolution of your complaints or concerns
- To receive information from Kline Galland addressing any beneficial relationships between Kline Galland and referring entities
- To be informed about Advanced Directives and POLST and Hospice's scope of responsibility to implement them
- To have your legal representative exercise your rights on your behalf, to the extent allowed by State laws
- To obtain a billing statement upon request, if available, including the date of each service and the charges
- To be informed, within a reasonable amount of time, about the anticipated termination of your hospice services or benefits
- To be free from exploitation, discrimination, unlawful use of restraint or seclusion, mistreatment, neglect or verbal, mental, sexual and /or physical abuse, including injuries of unknown source, and/or misappropriation of your property

What Patient Rights Mean to Providers of Hospice Care

- Hospice staff must provide you a written notice of your right in advance of furnishing care to you (or during your initial evaluation visit) and make every effort to ensure that you understand your rights and responsibilities
- Hospice staff must protect and promote your right to exercise your rights as a patient, at any time, and implement or update your rights, as appropriate
- Hospice staff must ensure that all alleged violations of your rights involving mistreatment, neglect or abuse, are reported immediately, are investigated immediately and acted upon immediately to prevent further potential violation from occurring. Hospice administration must document the existence and resolution of the complaint, take appropriate corrective action and ensure that verified violations are reported to State and local authoritative bodies. Below, Hospice also provides patient with the Washington Department of Health complaint hotline number and the Washington Department of Social and Health Services end harm hotline number to report suspected abuse of children or vulnerable adults

Questions or Concerns?

If you have questions about your rights, please ask your Kline Galland Hospice Team, at (206) 805-1930 (including 24 hour answering service), Erin Sheridan, our Chief Compliance Officer, at (206) 805-2364, ext. 204, or call the National Hospice and Palliative Care Organization's Toll-Free Helpline at (800) 658-8898.

File a complaint: Washington State Department of Health

- WA DOH Complaint Hotline Number: (360) 236-4700

Report Abuse and Neglect: DSHS

- WA DSHS End Harm Hotline Number: 1(866) END-HARM (1866-363-4276)

Additional Resources:

- Community Health and Accredidation Program (CHAP) (800) 656-9656

KLINE GALLAND BENAROYA SERVICES NOTICE OF PRIVACY PRACTICES

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

UNDERSTAND YOUR HEALTH RECORD/ INFORMATION

Kline Galland Benaroya Services (including Home Health, Home Care, Hospice and Palliative Care ("Kline Galland") originates, records, and maintains health information about patients describing their health history, symptoms, examination and test results, diagnoses, treatment and any plans for future care or treatment. This information, often referred to as the health or medical record, serves as:

- a basis for planning your care and treatment
- a means of communication among the many health professionals who contribute to your care
- a source of information for applying the diagnosis information to your bill
- a means by which a third-party payer (insurance companies, governmental or private entities responsible for paying a patient's bill) can verify that services billed were actually provided
- a tool for routine health care operations, such as assessing quality and reviewing the competence of health care professionals
- a tool with which we can assess and continually work to improve the care we render and the outcomes we achieve
- a source of data for medical research
- a source of data for facility planning, fundraising and marketing
- a source of information for public health officials charged with improving the health of the nation

Understanding what is in your medical record and how your health information is used helps you to:

- ensure its accuracy
- better understand who, what, when, where, and why others may access your health information
- make more informed decisions when authorizing disclosure to others

YOUR HEALTH INFORMATION RIGHTS:

Although your health record is the physical property of Kline Galland, the information belongs to you. You have the right to:

- request a restriction on certain uses and disclosures of your information as provided by 45 CFR 164.522, a**lthough we are not required to agree to a requested restriction, subject to applicable legal requirements**
- obtain a paper copy of the Notice of Privacy Practices upon request
- inspect and obtain a copy of your health record as provided for in 45 CFR 164.524 and RC W 70.02.030
- amend your health record as provided in 45 CFR 164.526
- obtain an accounting of disclosures of your health in formation as provided in 45 CFR 164.528 and RCW 70.02.020
- request confidential communications of your health information by alternative means or at alternative locations
- revoke your authorization to use or disclose health information except to the extent that action has already been taken.
- Opt out of fundraising uses of your health information

OUR RESPONSIBILITIES:

Kline Galland is required to:

- maintain the privacy of your health information
- provide you with a notice as to our legal duties and privacy practices with respect to information we collect and maintain about you
- abide by the terms of this notice
- notify affected individuals following a breach of unsecured protected health information
- notify you if we are unable to agree to a requested restriction

- accommodate reasonable requests you may have to confidentially communicate health information by alternative means or alternative locations

We reserve the right to change our practices and to make the new provisions effective for all protected health information we maintain. Should our information practices change, we will mail a revised notice to the address you have supplied us.

We will not use or disclose your health information without your authorization, except as described in this notice.

In the following cases we will never share your information unless you give us written permission for: sharing information for marketing purposes; sale or your information and disclosure of most psychotherapy notes.

To the extent we receive your substance use disorder patient records, subject to 42 CFR part 2, we will not share that information for investigations or legal proceedings against you without (1) your written consent or (2) a court order and a subpoena. These records have stronger privacy protections than other health information.

For More Information or to Report a Problem

If you have questions and would like additional information, you may contact the Chief Privacy Officer at (206) 725-8800.

If you believe your privacy rights have been violated, you can file a complaint with the Chief Privacy Officer or with The Department of Health and Human Services. There will be no retaliation for filing a complaint.

Please bring any privacy complaints you may have to the attention of the Chief Privacy Officer. The person most appropriate to address your complaint will provide you with a response in a timely manner.

A complaint may be filed with the Office of Civil Rights/Department of Health and Human Services either on paper or electronically (http://www.hhs.gov/ocr/privacy/).

Below, this notice contains a number of examples of the ways in which we are permitted to and may use health information for treatment, payment and health operations, without obtaining your specific authorization.

Examples of Disclosure for Treatment, Payment and Health Operations Which Do Not Require Specific Authorization:

We will use your health information for treatment.
For example: Information obtained by a nurse, physician, or other member of your Care Team will be recorded in your record as well as posted in your room, as appropriate, and used to determine the course of treatment that should work best for you. Your Physician will document in your record his or her expectations of the members of your Care Team. Members of your Care Team will then record the actions they took and their observations. In that way, your Physician will know how you are responding to treatment.

We will also provide your Physician or a subsequent healthcare provider with copies of various reports that should assist him or her in treating you once you're discharged.

We will use your health information for payment.
For example: A bill may be sent to you or a third-party payer (insurance companies. governmental or private entity responsible for paying your bill). The information on or accompanying the bill may include information that identifies you, as well as your diagnosis, procedures, and supplies used.

We will use your health information for regular health operations.
For example: Members of the medical staff, the risk or quality improvement manager, or members of the quality improvement team may use information in your health record to assess the care and outcomes in your case and others like it. This information will then be used in an effort to continually improve the quality and effectiveness of the healthcare and service we provide.

We are allowed or required to share your information in other ways---usually in ways that contribute to the public good. We have to meet many conditions in the law before we can share information for these purposes. Below are other ways we use or share your health information:

Business associates: There are some services provided in our organization through contracts with business associates. Examples include physician services in the emergency department, and radiology or laboratory tests. When these services are contracted, we may disclose your health information to our business associate so that they can perform the job we've asked them to do (in performing a function or activity on behalf of Kline Galland) that involves the creation, use or disclosure of protected health information, and then you or your third-party payer for services rendered. To protect your health information, however, we require the business associate to appropriately safeguard your information.

Directory: Unless you notify us that you object we will use your name, location in the facility, general condition, and religious affiliation for directory purposes. This information may be provided to members of the clergy and, except for religious affiliation, to other people who ask for you by name.

Notification: We may use or disclose information to notify or assist in notifying a family member, personal representative or another person responsible for your care, of your location, and general condition.

Communication with family: Health professionals, using their best judgment, may disclose to a family member, other relative, close personal friend or any other person you identify, health information relevant to that person's involvement in your care or payment related to your care.

Research: We may disclose information to researchers when their research has been approved by an institutional review board that has reviewed the research proposal and established protocols to ensure the privacy of your health information.

Deceased individuals: We may disclose health information to funeral directors, coroners or medical examiners consistent with applicable law to carry out their duties.

Organ procurement organizations: Consistent with applicable law, we may disclose health information to organ procurement organizations or other entities engaged in the procurement, banking, or transplantation of organs for the purpose of tissue donation and transplant.

Specific communications we may provide:

- Communications for treatment of an individual by us, including case management or care coordination for the individual, or to direct or recommend alternative treatments, therapies, healthcare providers, or settings of care to the individual
- Communications to describe a health-related product or service (or payment for such product or service) that is provided by, or included in a plan of benefits of, Kline Galland, including communications about: Kline Galland's participation in a healthcare provider network or health plan network; replacement of, or enhancements to, a health plan; and health-related products or services available only to a health plan enrollee that add value to, but are not part of, a plan of benefits
- Communications for case management or care coordination, contacting of individualswith information about treatment alternatives, and related functions to the extent theseactivities do not fall within the definition of treatment

Fundraising: We may contact you as a part of our fundraising efforts, and may use certain protected health information in doing so, as permitted under 45 CFR 164.514(f), including through sharing with a HIPAA Institutionally Related Foundation.

However, you have a right to opt-out of receiving such fundraising communications. You may exercise your right to opt out of receiving fundraising communications by notifying us at any time. Please indicate whether you wish to opt out of participating in a particular fundraising campaign, or from all Kline Galland fundraising.

Should you later determine you wish to opt back in, you may also contact us by one of the following means:

in writing at:

Privacy Officer
The Caroline Kline Galland Home
7500 Seward Park Avenue S.
Seattle, WA 98118

by email at:

compliance@klinegalland.org;

or by telefax addressed to:

Privacy Officer at
(206) 722-5210

If we have your substance use disorder patient records, subject to 42 CFR part 2, we will give you clear and obvious notice in advance and a choice about whether to receive fundraising communications that use your Part 2 information.

Food and Drug Administration (FDA): We may disclose to the FDA health information related to adverse events with respect to food, supplements, product and product defects, or post-marketing surveillance information to enable product recalls, repairs, or replacement.

Workers compensation: We may disclose health information to the extent authorized by and to the extent necessary to comply with laws relating to workers compensation or other similar programs established by law.

Public health: As required by law, we may disclose your health information to public health or legal authorities charged with preventing or controlling disease, injury, or disability.

Government authority: We may disclose your health information to a government authority, including a social service or protective services agency, authorized by law, if we reasonably believe you are a victim of abuse, neglect or domestic violence.

Correctional institution: Should you be an inmate of a correctional institution we may disclose to the institution or agents thereof health information necessary for your health and the health and safety of other individuals.

Law enforcement: We may disclose health information for law enforcement purposes as required by law or in response to a valid subpoena.

Health oversight agency, public health authority or attorney: Federal law makes provision for your health information to be released to an appropriate health oversight agency, public health authority or attorney, provided that a work force member or business associate believes in good faith that we have engaged in unlawful conduct or have otherwise violated professional or clinical standards and are potentially endangering one or more patients, workers or the public.

Redisclosure: Information disclosed by us may be subject to redisclosure by the recipient and may no longer be protected by HIPAA.

NON-DISCRIMINATION ACKNOWLEDGMENT

Our commitment is to provide care and services that are accessible to all and free from discrimination. We invite you to review our Non-Discrimination Statement, below. We also provide information on Language Assistance for individuals not proficient in English. If at any time you feel our actions have not lived up to our Non-Discrimination Statement, we invite you to take advantage of our Grievance Procedure.

NON-DISCRIMINATION STATEMENT

Kline Galland complies with applicable Federal civil rights laws and does not discriminate, exclude people or treat them differently on the basis of race, ethnic group, color, creed, sex, gender identity, gender expression, religion, national origin, familial status, age, disability, diagnosis, sexual orientation, same-sex marriage, language or any other legally protected characteristic.

As part of this commitment:

- We provide free aids and services to people with disabilities to communicate effectively with us. For example, this includes:
  - Qualified sign language interpreters, and
  - Written information in other formats, such as large print, audio, and online.
- We provide access to free language services to people whose primary language is not English, such as:
  - Qualified interpreters, and
  - Information written in other languages.

If you need any of these services, please contact Erin Sheridan, our Chief Compliance Officer at:

Kline Galland
Attn: Chief Compliance Officer
7500 Seward Park Ave S.
Seattle, WA 98118
(206) 725-8800

If you believe that we have not provided these services or that we have discriminated in any other way on the basis of race, color, national origin, age, disability or sex, you may file a grievance with our Non-Discrimination Coordinator. Please see our Grievance Procedure and Form. You may file a grievance in person, by mail, fax, or email. If you need help filing a grievance, our Non-Discrimination Coordinator will be glad to help you.

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

U.S. Department of Health and Human Services, 200 Independence Avenue SW., Room 509F, HHH Building, Washington, DC 20201, 1-800-868-1019, 800-537-7697 (TDD).

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

LANGUAGE ASSISTANCE

The following are published here pursuant to Section 1557 or the Affordable Care Act and implementing regulations, 45 CFR 92.8(d)(1)

Spanish

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-844-826-1042.

Vietnamese

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-844-826-1042.

Serbo-Croatian

OBAVJEŠTENJE: Ako govorite srpsko-hrvatski, usluge jezičke pomoći dostupne su vam besplatno. Nazovite 1-844-826-1042.

Lao

ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັງຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທຣ 1-844-826-1042.

Chinese

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-844-826-1042.

German

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-844-826-1042.

Hmong

LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-844-826-1042.

Korean

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-844-826-1042.

Arabic

ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-844-826-1042.رقم

Tagalog – Filipino

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-844-826-1042.

Russian

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-844-826-1042.

Indonesian

PERHATIAN: Jika Anda berbicara dalam Bahasa Indonesia, layanan bantuan bahasa akan tersedia secara gratis. Hubungi 1-844-826-1042.

Samoan

MO LOU SILAFIA: Afai e te tautala Gagana fa'a Sāmoa, o loo iai auaunaga fesoasoan, e fai fua e leai se totogi, mo oe, Telefoni mai: 1-844-826-1042.

Ukrainian

УВАГА! Якщо ви розмовляєте українською мовою, ви можете звернутися до безкоштовної служби мовної підтримки. Телефонуйте за номером 1-844-826-1042.

Diné Bizaad (Navajo)

D77 baa ak0 n7n7zin: D77 saad bee y1nt7[t7 go Din4 Bizaad, saad bee 1k1'1nida'1wo'd66′, t'11 jiik'eh, 47 n1 h0l=, koj8′ h0d77lnih 1-844-826-1042.

GIVING BACK

Giving Back

Families often ask what they can do to thank us for the excellent care they and their loved ones have received. There are many ways to give back in support of our community-based, non-profit end-of-life care, including supporting us with your donations, volunteering, and being an advocate for Kline Galland Hospice in the community. We are grateful for the support of our community which makes our work possible.

Kline Galland Hospice team members provide excellent care for patients and their families. However, please understand that it is a conflict of interest for our employees to accept tips, gifts, or to provide any services outside of what they provide through hospice.

Obituary Gifts

When announcing the passing of a family member in the obituary pages of the local paper or online, you may request that a memorial donation be made to Kline Galland Hospice instead of flowers. (Example: "In lieu of flowers, please send a contribution in tribute of _____ to Kline Galland Hospice, 6100 4th Ave S Suite 403, Seattle, WA 98108") A member of the Fund Development Team will be happy to assist you with any questions. For more information or questions, please call (206) 456-9718.

Tributes & Memorials

If you wish to recognize a particular employee, a great way is to make a donation to Kline Galland in their honor. Your donation allows us to offer additional services and programs (not covered by insurance), such as massage and music therapy. You or your loved one may experience some of these programs during your hospice journey.

Hospice Focused Garden Memorials

Located on the grounds surrounding Kline Galland Home, the Hospice Focused Garden offers a wonderful space for remembrance and celebration of life. There are a wide range of memorial offerings to serve as a lasting memorial to the people whose lives have been affected by our Hospice services. For more information or if you have any questions, please contact (206) 456-9710.

Bequests & Planned Gifts

If you would like to learn more about Kline Galland's Planned Giving program, please contact Nate Nusbaum, Chief Philanthropy Officer at (206) 456-9702 or by email at NateN@klinegalland.org.

Become a Volunteer

Our wonderful team of hospice volunteers provide companionship and support to patients and their families through the end-of-life journey. Family members of hospice patients must wait for one year after the death of a loved one to begin training to be a Patient Care Volunteer, but we have many other volunteer opportunities. Please visit our website at www.klinegalland.org/volunteer to learn more.

Be an Advocate for Hospice

Perhaps the most important way you can support community-based, non-profit end-of-life care is to tell friends and family about your positive hospice experience and remind them to ask for Kline Galland Hospice by name.

For more information, you can visit our website at: www.klinegalland.org/donate

WE VALUE YOUR FEEDBACK

YOUR EXPERIENCE WITH THE CARE WE PROVIDE IS IMPORTANT TO US.

There are several ways you can share your feedback:

- Give us a call at **(206) 805-1930**
- Send your comments to:

  Kline Galland Benaroya Services

  6100 4th Ave S Suite 403
  Seattle, WA 98108

- Send an email to: feedback@klinegalland.org
- Complete the Survey. Family members may receive a survey in the mail. We would love to hear any feedback about the care we have provided

We are deeply grateful for the opportunity to serve you.

Please give us feedback about your family member's hospice experience.

You may be asked to complete a survey about your family member's hospice care. The survey asks about the hospice services that patients and their families receive. We hope that you will help us learn about the quality of care that you and your family member received.

If you receive a survey in the mail, by email, or receieve a phone call from **Strategic Healthcare Programs (SHP)**, please take a few minutes to share your and your family member's experience with our hospice care.

Your voice matters!

- Visit medicare.gov/care-compare/ to find and compare the quality of hospice care agencies across the country.

Your answers will help us improve the quality of our care and help others choose a hospice agency! Your participation in the survey is voluntary.

Thank you in advance for your feedback!

KLINE GALLAND
BENAROYA SERVICES

SHP
STRATEGIC HEALTHCARE PROGRAMS

Adult Protective Services

Reporting Suspected Abuse, Neglect, Self-Neglect or Financial Exploitation of Vulnerable Adults

Washington State Department of Social and Health Services
Aging and Long-Term Support Administration

What does Adult Protective Services do?

Adult Protective Services' (APS) primary responsibility is to receive and investigate allegations of abuse (physical, mental, sexual, and personal exploitation), abandonment, neglect, financial exploitation, and self-neglect of vulnerable adults living in their own homes and in facilities.

Receiving help from DSHS is an individual's choice. Vulnerable adults must consent to services and be informed of the right to accept or refuse services. DSHS cannot remove adults from their residence or place them in a different residence against their wishes.

What is abuse?

Abuse may include intentional or neglectful acts that cause or lead to injury. Abuse can occur anywhere and can happen to anyone. Men and women from all ethnic, social, and economic backgrounds can be victimized. ***Perpetrators can be strangers, caregivers, family members, friends, or others.***

What are some types of abuse?

- Abandonment
- Financial Exploitation
- Improper use of Chemical/Physical/ Mechanical Restraints
- Neglect
- Physical
- Self-Neglect
- Sexual
- Verbal/Psychological/Emotional

Who is considered a Vulnerable Adult?

An adult 60 years or older who has the functional, mental, or physical inability to care for him or herself is considered a vulnerable adult. Other adults considered vulnerable are 18 years or older and:

- Have a legal guardian.
- Have a developmental disability.
- Admitted to any facility.
- Receive in-home services through a licensed home health, hospice, or home care agency.
- Receive services from an individual provider.
- Have a personal aide who performs care under his/her direction for compensation.

What are some warning signs of adult abuse?

Warning signs may include a variety of behaviors and physical indicators that can be obvious or subtle. ***If you suspect abuse report it.***

OBVIOUS WARNING SIGNS OF ADULT ABUSE	SUBTLE WARNING SIGNS OF ADULT ABUSE
INJURIES Suspicious or unexplainable bruises, sores, or weight loss.	**ISOLATING** Individuals are kept from or are absent from normal activities with family, friends, or social events.
BEHAVIORS OR EMOTIONS Change in normal personality.	**MISSED OR CANCELLED APPOINTMENTS** Regular appointments, such as medical or professional, are stopped without communication.
DAILY LIVING NEEDS Neglect or inattention to hygiene, clothing, medication, food, or home.	**SUDDEN APPEARANCE OF UNKNOWN INDIVIDUALS OR PREVIOUSLY UNINVOLVED RELATIVES** New individual(s) become involved and take over personal and financial matters.
PROPERTY AND FINANCES Unexplainable financial changes or missing money and personal belongings.	**IRRATIONAL EXCUSES OR EXPLANATIONS** Individual or caretaker explanation of behaviors or physical indicators don't make sense.
VERBAL AGGRESSION Comments or statements that are intimidating, threatening, or degrading.	

What can Washington citizens do to protect Vulnerable Adults from abuse?

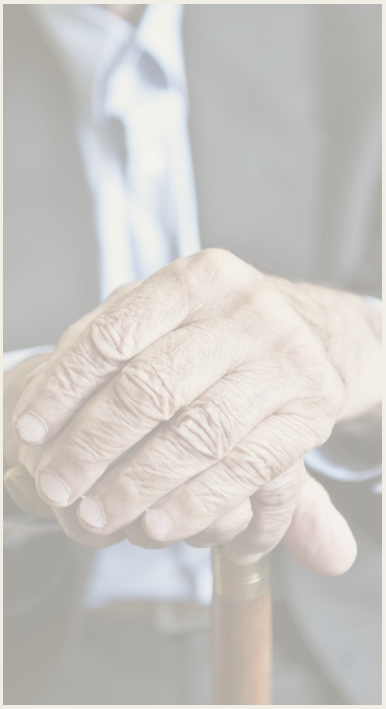
Health and safety is everyone's responsibility. Everybody has a role to prevent and report abuse of vulnerable adults. Reporting is a partnership. APS relies on family, friends, neighbors, and community members to report abuse.

VISIT	• Maintain contact with vulnerable adults in your family and community. • Share DSHS contact information and reassure individuals help is available.
RAISE AWARENESS	• Talk with your family and community about APS and how to report abuse. • Invite APS to share information in your community.
SUPPORT CAREGIVERS	• Encourage caregivers of vulnerable adults to practice self-care and take necessary breaks or respite from caregiving.
REPORT	• Never assume someone else has already made a report. • Recognize adult abuse warning signs and report to APS.

Who is a Mandated Reporter and what is required of them?

Mandated Reporters are individuals who, as a result of their profession or employment, are more likely to become aware of vulnerable adult abuse. Mandated Reporters are required to report abuse; it is Washington State Law RCW 74.34.020. Some Mandated Reporters include DSHS Employees, Individual Providers, Law Enforcement, Medical Professionals, and Social Workers.

- In Washington state, Mandated Reporters can be penalized for failure to report suspected abuse [RCW 74.34.053].
- Report immediately if you have reasonable cause to believe that a vulnerable adult is being harmed, you do not need proof of harm [RCW 74.34.035].
- Report suspected **physical** or **sexual assault** to both law enforcement and DSHS [RCW 74.34.035].
- Report immediately to the coroner or medical examiner, law enforcement, and DSHS if you suspect a death was caused by abuse, neglect or abandonment [RCW 74.34.035] [RCW 68.50.020].



What happens when an Adult Protective Service report is made?

When you report, you will be asked:

- For your name and contact information
- The names and contact information of the vulnerable adult and the person you think is causing the harm.
- To share what you know about the situation, a description of the concern or what is occurring or what happened.
- For names and the contact information of other individuals who can provide information about the situation.
- If you know of any safety concerns.

What happens after I report:

- An unannounced visit will be attempted with the individual.
- DSHS (APS) will report suspected crimes to law enforcement.

What else is important to know?

- If you report in good faith, you have immunity from liability.
- Your name and information about the vulnerable adult is confidential (public disclosure and other state and federal regulations apply).
- Reports can be suspicions or observations. You do not need to prove abuse is occurring when making a report.
- APS is unable to share contents of an investigation.

Where can I get more information?

https://www.dshs.wa.gov/altsa/home-and-community-services/adult-abuse-and-prevention

Contact APS for reports on allegations of abuse, abandonment, neglect, self-neglect and financial exploitation of vulnerable adults living in the community and in facilities.

If you think someone may be in imminent danger or needs urgent help, call 911 immediately!

Online reporting is accessible and available 24 hours a day and APS intake phone lines are available Monday – Friday 8:00 a.m. – 5:00 p.m. with the ability to leave a message before and after hours. Please contact the area in which the victim resides.

For online reporting:
https://www.dshs.wa.gov/altsa/reportadultabuse

Regional Intake Phone Lines

COUNTY	APS CONTACT
Adams, Asotin, Benton, Chelan, Columbia, Douglas, Ferry, Franklin, Garfield, Grant, Kittitas, Klickitat, Lincoln, Okanogan, Pend Oreille, Spokane, Stevens, Walla Walla, Whitman, Yakima	1-800-459-0421 (TTY) 509-568-3086
Island, King, San Juan, Skagit, Snohomish, Whatcom	1-866-221-4909 (TTY) 1-800-833-6384
Clallam, Clark, Cowlitz, Grays Harbor, Jefferson, Kitsap, Lewis, Mason, Pacific, Pierce, Skamania, Thurston, Wahkiakum	1-877-734-6277 (TTY) 360-664-9469

Washington State Department of Social & Health Services

Transforming lives

DSHS 22-810 (Rev. 9/15)

Influenza (Flu) Vaccine (Inactivated or Recombinant): *What you need to know*

Many vaccine information statements are available in Spanish and other languages. See www.immunize.org/vis

Hojas de información sobre vacunas están disponibles en español y en muchos otros idiomas. Visite www.immunize.org/vis

1. Why get vaccinated?

Influenza vaccine can prevent **influenza (flu)**.

Flu is a contagious disease that spreads around the United States every year, usually between October and May. Anyone can get the flu, but it is more dangerous for some people. Infants and young children, people 65 years and older, pregnant people, and people with certain health conditions or a weakened immune system are at greatest risk of flu complications.

Pneumonia, bronchitis, sinus infections, and ear infections are examples of flu-related complications. If you have a medical condition, such as heart disease, cancer, or diabetes, flu can make it worse.

Flu can cause fever and chills, sore throat, muscle aches, fatigue, cough, headache, and runny or stuffy nose. Some people may have vomiting and diarrhea, though this is more common in children than adults.

In an average year, **thousands of people in the United States die from flu**, and many more are hospitalized. Flu vaccine prevents millions of illnesses and flu-related visits to the doctor each year.

2. Influenza vaccines

CDC recommends everyone 6 months and older get vaccinated every flu season. **Children 6 months through 8 years of age** may need 2 doses during a single flu season. **Everyone else** needs only 1 dose each flu season.

It takes about 2 weeks for protection to develop after vaccination.

There are many flu viruses, and they are always changing. Each year a new flu vaccine is made to protect against the influenza viruses believed to be likely to cause disease in the upcoming flu season.

Even when the vaccine doesn't exactly match these viruses, it may still provide some protection.

Influenza vaccine **does not cause flu**.

Influenza vaccine may be given at the same time as other vaccines.

3. Talk with your health care provider

Tell your vaccination provider if the person getting the vaccine:

- Has had an **allergic reaction after a previous dose of influenza vaccine**, or has any **severe, life-threatening allergies**
- Has ever had **Guillain-Barré Syndrome** (also called "GBS")

In some cases, your health care provider may decide to postpone influenza vaccination until a future visit.

Influenza vaccine can be administered at any time during pregnancy. People who are or will be pregnant during influenza season should receive inactivated influenza vaccine.

People with minor illnesses, such as a cold, may be vaccinated. People who are moderately or severely ill should usually wait until they recover before getting influenza vaccine.

Your health care provider can give you more information.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

4. Risks of a vaccine reaction

- Soreness, redness, and swelling where the shot is given, fever, muscle aches, and headache can happen after influenza vaccination.
- There may be a very small increased risk of Guillain-Barré Syndrome (GBS) after inactivated influenza vaccine (the flu shot).

Young children who get the flu shot along with pneumococcal vaccine (PCV13) and/or DTaP vaccine at the same time might be slightly more likely to have a seizure caused by fever. Tell your health care provider if a child who is getting flu vaccine has ever had a seizure.

People sometimes faint after medical procedures, including vaccination. Tell your provider if you feel dizzy or have vision changes or ringing in the ears.

As with any medicine, there is a very remote chance of a vaccine causing a severe allergic reaction, other serious injury, or death.

5. What if there is a serious problem?

An allergic reaction could occur after the vaccinated person leaves the clinic. If you see signs of a severe allergic reaction (hives, swelling of the face and throat, difficulty breathing, a fast heartbeat, dizziness, or weakness), call **9-1-1** and get the person to the nearest hospital.

For other signs that concern you, call your health care provider.

Adverse reactions should be reported to the Vaccine Adverse Event Reporting System (VAERS). Your health care provider will usually file this report, or you can do it yourself. Visit the VAERS website at **www.vaers.hhs.gov** or call **1-800-822-7967**. *VAERS is only for reporting reactions, and VAERS staff members do not give medical advice.*

6. The National Vaccine Injury Compensation Program

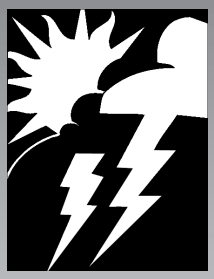
The National Vaccine Injury Compensation Program (VICP) is a federal program that was created to compensate people who may have been injured by certain vaccines. Claims regarding alleged injury or death due to vaccination have a time limit for filing, which may be as short as two years. Visit the VICP website at **www.hrsa.gov/vaccinecompensation** or call **1-800-338-2382** to learn about the program and about filing a claim.

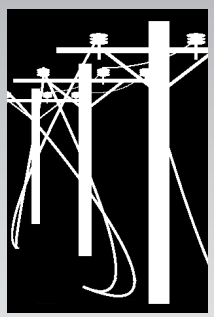
7. How can I learn more?

- Ask your health care provider.
- Call your local or state health department.
- Visit the website of the Food and Drug Administration (FDA) for vaccine package inserts and additional information at **www.fda.gov/vaccines-blood-biologics/vaccines**.
- Contact the Centers for Disease Control and Prevention (CDC):
  - Call **1-800-232-4636** (**1-800-CDC-INFO**) or
  - Visit CDC's website at **www.cdc.gov/flu**.

Prepare

Home emergency guide





Make a plan

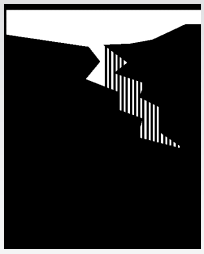
Store emergency supplies

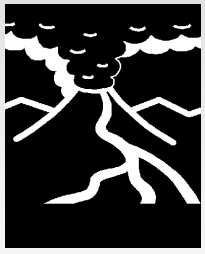
Know what to do when the power is out

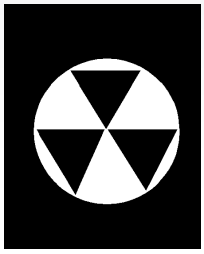
Be sure your water is safe to drink

Prevent the spread of germs

Learn about earthquakes, floods and more







Washington State Department of Health
www.doh.wa.gov

WASHINGTON MILITARY DEPARTMENT
Emergency Management Division
www.emd.wa.gov

Protect Your Health During an Emergency

Disasters such as earthquakes, floods or volcanic eruptions can cause a great deal of destruction and personal injury. These events can also damage power and water systems, leaving us without electricity or running water for many hours or days.

Without power, things we take for granted like heating our homes or cooking become much more difficult, and sometimes even dangerous. Many people die each year from carbon monoxide poisoning when they try to heat or cook in their homes with charcoal grills or gas powered devices.

Other emergencies, such as pandemic flu or disease outbreaks, also put people at risk and strain resources.

Planning ahead can help you get through any emergency, from natural disasters to disease outbreaks. The tips in this guide will help you and your family prepare.

Washington State Department of Health

DOH 821-076 June 2013

For persons with disabilities this document is available on request in other formats. To submit a request, please call 1-800-525-0127 (TTY/TDD 711).

This guide was developed by the Washington State Department of Health and made possible through funding from the National Centers for Disease Control and Prevention. Portions of this guide were developed jointly with the Washington Military Department – Emergency Management Division.

Make a Plan

Make sure all family members agree on an emergency plan, including where to meet and who to contact during an emergency. Give emergency information to caregivers.

Things you can do now

- Choose a place for your family to meet after a disaster.
- Put together an emergency supply kit for your home and workplace. If your child's school or day care stores personal emergency kits, make one for your child to keep there.
- Know how to contact and pick up your children at their school or day care after a disaster. Let the school know if someone else is authorized to pick them up. Keep your children's emergency release cards up to date.
- Know where the nearest fire and police stations are located.
- Learn your community's warning signals, what they sound like and what you should do when you hear them.
- Learn first aid and CPR. Have a first aid kit, a first aid manual and extra medicine for family members.
- Learn how to shut off your water, gas and electricity. Know where to find shut-off valves and switches.
- Keep some cash available. If the power is out, ATMs won't work.
- If you have family members who don't speak English, prepare emergency cards in English with their names, addresses and information about medications or allergies. Make sure they can find their cards.
- Conduct earthquake and fire drills every six months.
- Make copies of your vital records and store them in a safe deposit box in another city or state. Store the originals safely. Keep photos or videotapes of your home and valuables in your safe deposit box.
- Make sure those in your home know all the possible ways to get out. Keep all exits clear.

During an emergency or disaster

- Listen to your radio or television for official information and instructions.
- If ordered to evacuate, follow official directions to a safe place or temporary shelter. Take your emergency kit.
- Use the telephone for emergency calls only.

Choose Out-of-Area Contacts

Choose a person outside the immediate area for family members to contact if you get separated. The person should live far enough away so they won't be involved in the emergency.

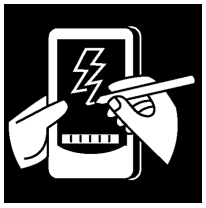
Before disaster strikes

- Make cards with the contact person's name and phone number for all family members to carry in their wallets, purses or backpacks.
- Keep a phone that does not require electricity. Cordless phones use electricity—if the power is out, they will not work!
- Many communities have systems that will send instant text alerts or e-mails to let you know about bad weather, road closings or local emergencies. Sign up by visiting your local Office of Emergency Management website.

Contact loved ones after disasters

- All household members should call the out-of-area contact. The contact person will collect information about each family member, where they are, and how to contact them.
- It may be difficult to make local calls because large numbers of people may be using the phone lines at the same time. However, you should be able to make long distance calls.
- You may be able to send text messages to your loved ones. Keep messages short.
- You should be able to use a pay phone if your home phone does not work. Pay phones are a priority to be restored to service. Tape coins for pay phone use to your out-of-area contact card.

Store Emergency Food, Water and Supplies



Be prepared to take care of yourself and those in your home for at least three days. For events such as a flu pandemic, you may need to prepare for a week or more.

Keep the following supplies at home

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

More items that are useful during an emergency

Cooking supplies

- Barbecue and camp stove (never use these indoors!)
- Fuel for cooking, such as charcoal or camp stove fuel
- Plastic knives, forks, spoons
- Paper plates and cups
- Paper towels
- Heavy-duty aluminum foil

continued

Sanitation supplies

- Large plastic trash bags for trash and water protection
- Large trash cans
- Bar soap and liquid detergent
- Shampoo
- Toothpaste and toothbrushes
- Feminine and infant supplies
- Toilet paper
- Household bleach with no additives, and eyedropper (for purifying drinking water)
- Newspaper—to wrap garbage and waste

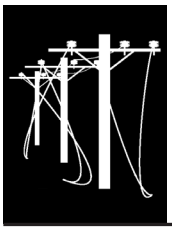
Comfort

- Sturdy shoes
- Gloves for clearing debris
- Tent

Tools

- Ax, shovel and broom
- Crescent wrench for turning off gas
- Screwdriver, pliers and hammer
- Coil of one-half inch rope
- Plastic tape and sheeting
- Knife or razor blades
- Garden hose for siphoning and fire fighting

Power Outages



Many disasters can include power outages that make it difficult to heat homes, store or cook food safely, and communicate. Here are some important things to know when the power goes off.

Before a power outage

- Register life-sustaining and medical equipment with your utility company.
- Stock your disaster preparedness kit with light sticks, flashlights and a battery-powered radio with extra batteries.
- Have a corded telephone available—cordless phones will not work when the power is out.
- If you own an electric garage door opener, know how to open the door without power.

During a power outage

- Turn off lights and electrical appliances except for the refrigerator and freezer. Even if it is dark, turn light switches and buttons on lamps or appliances to the "off" position.
- Unplug computers and other sensitive equipment to protect them from possible surges when the power is restored.
- Leave a lamp on so you will know when power is restored. Wait at least 15 minutes after power is restored before turning on other appliances.
- Conserve water, especially if you use a well.
- Candles can cause a fire. Use battery-operated flashlights or glow sticks for lighting.
- Stay away from downed power lines and sagging trees with broken limbs.
- ONLY use a generator outdoors and far from open windows and vents.
- NEVER cook or heat inside on a charcoal or gas grill.

Beware of Carbon Monoxide Poisoning When Cooking and Heating

Hundreds of people die accidentally every year from carbon monoxide poisoning caused by appliances that are not used properly or that are malfunctioning. Learn how to protect yourself and your family.

NEVER use a generator indoors, in garages or carports.
NEVER cook or heat inside on a charcoal or gas grill.

What is carbon monoxide?

- Carbon monoxide is a poisonous gas that cannot be seen or smelled and can kill a person in minutes.
- Carbon monoxide is produced whenever any fuel such as gas, oil, kerosene, wood or charcoal is burned.
- Carbon monoxide can build up so quickly that victims are overcome before they can get help.

If inhaled, carbon monoxide can cause chest pain, heart attacks in people with heart disease, or permanent brain damage.

Symptoms of carbon monoxide poisoning

Headache	Weakness	Dizziness
Confusion	Fatigue	Nausea

Prevent carbon monoxide poisoning

- Never burn charcoal inside homes, tents, campers, vans, trucks, garages or mobile homes.
- Do not burn charcoal in your fireplace.
- Never use gasoline-powered equipment indoors.
- Never use a gas oven to heat your home, even for a short time.
- Never idle a car in a garage, even when the garage door is open.
- Never sleep in a room while using an unvented gas or kerosene heater.
- Make sure that chimneys and flues are in good condition and are not blocked.
- Carbon monoxide warning devices may help protect you, but should not replace other prevention steps.

If you suspect someone has been poisoned by carbon monoxide

- Move the person to fresh air immediately.
- Take the person to an emergency room and tell emergency room staff that you've brought a potential victim of carbon monoxide poisoning.

Use your generator safely

- Never use a generator in your home, garage, carport or any enclosed or partially enclosed area. Opening doors and windows or using fans will not prevent carbon monoxide buildup in the home.
- Keep your generator away from your home's windows, doors and vents.
- Follow the directions supplied with the generator.
- If you start to feel sick, dizzy or weak while using a generator, get to fresh air right away!
- Install battery-operated carbon monoxide alarms in your home.
- Never plug the generator into a wall outlet—it's dangerous. Plug appliances into the generator using an outdoor extension cord.

Keep Food Safe When Power Is Out

When the power is out, your refrigerator, stove or microwave won't work. When food is not kept cold or is not fully cooked, bacteria can grow and make you sick. Be very careful with food such as meat, milk, eggs or seafood. Keep these foods cold and cook them to help prevent foodborne illness.

Use foods first that can spoil fast

Use meat, milk, eggs, fish or shellfish before you use foods that do not require refrigeration or cooking.

Keep food cold

If the power outage is expected to last more than a day, it is most important to keep meat, seafood and dairy products cold.

- Keep refrigerator and freezer doors closed. Freezers that are part of a refrigerator-freezer combination will keep food frozen for up to a day. A free-standing freezer will keep food frozen solid for two days if it is fully loaded. A half-full freezer will keep food frozen for a day, especially if the food is grouped together.
- Buy an ice chest.
- Find out where you can buy ice blocks or dry ice to keep your freezer or refrigerator cold.
  - Never touch dry ice with bare hands. Never taste it or put it in your mouth.
  - Ventilate well before placing dry ice in freezer and don't inhale the gas vapors.
  - Don't place dry ice directly on food or glass shelves and don't use in an operating freezer.

If you can't fit everything into the ice chest

In cold weather, items such as the following can be stored in a cardboard box in a garage or shed:

- Jams and jellies
- Ketchup, mustard, pickles, other condiments
- Butter and margarine
- Fresh uncut fruit and vegetables

Don’t store food outside during winter

Storing food outside during winter isn’t recommended because outdoor temperatures change throughout the day. The sun may thaw frozen foods or warm cold foods so that they grow bacteria.

Know what food to keep and what to throw out

If food is cold to the touch and you know it has not been above 45 degrees Fahrenheit for more than an hour or two, it is probably safe to keep, use or refreeze. Throw away all meat, seafood, dairy products or cooked foods that don’t feel cold to the touch. Even when refrigerated, many raw foods should be kept only three or four days before they are cooked, frozen or thrown away.

If in doubt, throw it out. Never taste suspicious food. It may look and smell fine, but the bacteria that cause foodborne illness may have grown on the food and will make you sick.

Be Sure Your Water is Safe to Drink

The treatments described below work only to remove bacteria or viruses from water. If you suspect the water is unsafe because of chemicals, oils, poisonous substances, sewage or other contaminants, do not drink the water. Don't drink water that is dark colored, has an odor or contains solid materials.

Storing water safely

The best source of drinking water during an emergency is water you have stored with your emergency supplies.

- Store one gallon of water per person per day—enough for at least three days.
- Store-bought, factory-sealed bottled water is best. Check for an expiration date and replace the supply as needed.
- If you choose to fill your own water containers:
  - Collect the water from a safe supply.
  - Store water in thoroughly washed plastic containers such as soft drink bottles. You can also purchase food-grade plastic buckets or drums.
  - Add two drops of household bleach per gallon to maintain water quality while in storage.
  - Seal water containers tightly, label with date and store in a cool, dark place.
  - Replace water every six months.
  - Never reuse a container that held toxic substances such as pesticides, chemicals or oil.

Purifying by boiling

If your tap water is unsafe, boiling is the best method to kill disease-causing organisms. If tap water is unavailable, the following may be considered as potential water sources. Water taken from these sources should be boiled before drinking:

- Rainwater
- Lakes
- Rivers and streams
- Natural springs
- Ponds

CAUTION: Many chemical pollutants will not be removed by boiling.

Cloudy water should be filtered before boiling. Filter cloudy water using coffee filters, paper towels, cheesecloth or a cotton plug in a funnel.

- Bring the water to a rolling boil for at least one full minute.
- Let the water cool before drinking.
- Add two drops of household bleach per gallon to maintain water quality while in storage.

Purifying by adding liquid chlorine bleach

Boiling is the preferred method of treating water taken from lakes, rivers, ponds, rainwater and other surface water sources. If surface water or unsafe tap water is the only source of water available in an emergency and boiling is not possible, the next best alternative is to treat the water with chlorine bleach.

- Treat water by adding liquid household bleach such as Clorox® or Purex®.
- Household bleach is typically between 5.25 percent and 8.25 percent chlorine. Read the label.
- Avoid using bleach that contains perfumes, dyes or other additives. Be sure to read the label.
- Cloudy water should be filtered before adding bleach.
- Place the water in a clean container. Add the amount of bleach according to the table below.
- Mix thoroughly and let stand for at least 60 minutes before drinking.

Treating water with household bleach containing 5.25 – 8.25 percent chlorine

Volume of Water to be Treated	Bleach Solution to Add
1 quart/1 liter	5 drops
1/2 gallon/2 quarts/2 liters	10 drops
1 gallon	1/4 teaspoon
5 gallons	1 teaspoon
10 gallons	2 teaspoons

CAUTION: Bleach will not kill some disease-causing organisms commonly found in surface water. Bleach will not remove chemical pollutants.

Places to Find Water in an Emergency

In an emergency, when tap water and bottled water are unavailable, you can find water in some unexpected places. Some of these places are listed below.

What are some alternative sources of water *inside* your home?

- Water can be drained from the drain spout of a water heater. Be sure the electricity and/or gas are off before opening the drain. Drain the water into a clean container.
- Water can be drained from the pipes inside your home. Open a faucet on the top floor of your home. Next, go to the faucet at the lowest point in your home. Open the faucet and drain out the water you need into a clean container.
- Water from your toilet storage or reserve tank can be used if no chemicals have been used in this tank. Do not use this water if you have added chemicals to your toilet.
- Water that has been placed in ice cube trays in the freezer can be used.

What are some alternative sources of water *outside* your home?

- Rainwater
- Lakes
- Rivers and streams
- Natural springs
- Ponds

Water taken from these outside sources should be boiled before drinking. If boiling is not possible, the next best alternative is to treat the water with chlorine bleach. See the previous page "Be sure Your Water is Safe to Drink" for information about boiling or adding bleach to your water.

Prevent the Spread of Germs

Conditions during emergencies often make it easier for germs and disease to spread. Here are some simple tips to help keep respiratory infections and many other contagious diseases from spreading at any time.

Respiratory infections affect the nose, throat and lungs; they include influenza (the "flu"), colds and pertussis (whooping cough). The germs (viruses and bacteria) that cause these infections are spread from person to person in droplets from the nose, throat and lungs of someone who is sick.

You can help stop the spread of these germs by practicing good health manners:

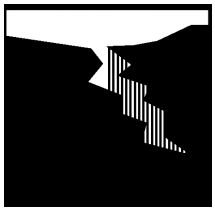
Keep your germs to yourself

- Cover your nose and mouth with a tissue when sneezing, coughing or blowing your nose.
- Discard used tissues in the trash as soon as you can.
- Always wash your hands after sneezing, blowing your nose or coughing, or after touching used tissues or handkerchiefs.
- Use warm water and soap to wash your hands. If you don't have soap and water, use alcohol-based hand gel or disposable wipes.
- Try to stay home if you have a cough and fever.
- See your doctor as soon as you can if you have a cough and fever, and follow their instructions. Take medicine as prescribed and get lots of rest.
- If asked, use face masks provided in your doctor's office or clinic's waiting room. Follow office or clinic staff instructions to help stop the spread of germs.

Keep the germs away

- Wash your hands before eating, or touching your eyes, nose or mouth.
- Wash your hands after touching anyone who is sneezing, coughing or blowing their nose.
- Don't share things like towels, lipstick, toys or anything else that might be contaminated with respiratory germs.
- Don't share food, utensils or beverage containers with others.

What to Do During a Disaster

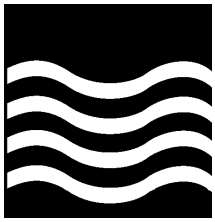


Earthquake

- **If you are indoors,** Drop, Cover and Hold when you feel the earth shake. Get under a desk or table away from windows and objects like bookcases that could fall. Hold on to the desk or table. Stay until the shaking stops.
- **If you are outdoors,** move to a clear area away from trees, signs, buildings or downed electrical wires and poles.
- **If you are in a downtown area** outside of a tall building, get into a building's doorway or lobby to protect yourself from falling bricks, glass or debris.

Tsunami

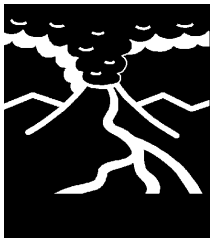
- If you are near the shore, move to higher ground or inland as far as you can go immediately if:
  - You hear a siren.
  - You feel the earth shake.
  - The ocean recedes dramatically from the shoreline.
  - A tsunami warning is issued for your area.
- Follow established tsunami evacuation routes. If no higher ground is near, go to upper levels of reinforced buildings.
- A tsunami can cause a series of waves that arrive over several hours.



Flood

- **Do not** try to walk or drive through flooded areas. Water can be deeper than it appears and water levels rise quickly. Moving water six inches deep can sweep you off your feet. Cars can be swept away in just two feet of water.
- Stay away from downed power lines.
- If your home is flooded, turn the utilities off until emergency officials tell you it is safe to turn them on. Do not pump the basement out until floodwater recedes. Avoid weakened floors, walls and rooftops.
- Wash your hands frequently with soap and clean water if you come in contact with floodwaters.

What to Do During a Disaster continued

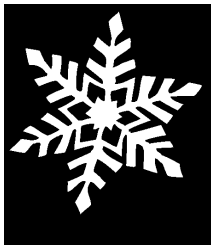


Volcano

- Be prepared to stay indoors and avoid downwind areas if ashfall is predicted.
- Be prepared to evacuate when instructed by officials if ashfall is very heavy or mud and debris flows could reach your area.
- Avoid rivers and streams that could carry mud or debris.

Disease outbreak or pandemic

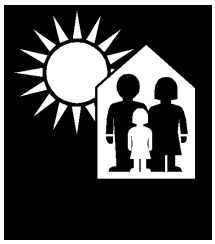
- **To protect yourself and others, cover your mouth and nose when you sneeze, wash your hands often and don't touch your eyes, nose or mouth.**
- Stay home from work when you are sick. Know work policies about sick leave, absences, time off and telecommuting. Make a plan for taking care of your children if schools are closed.
- Be prepared to get by for a week or more with the food and supplies you have at home. Stores may not be open or may have limited supplies.



Extreme cold weather

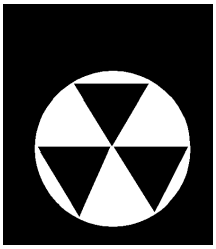
- Do not drive unnecessarily.
- Wear layers of loose-fitting, lightweight clothing rather than one layer of heavy clothing. Wear mittens rather than gloves. Wear a warm hat.
- Reduce the temperature in your home to conserve fuel. Heat only the areas of your home you are using. Close doors or curtains, or cover doors and windows with blankets.

What to Do During a Disaster continued



Extreme hot weather

- Stay indoors and in an air-conditioned area as much as possible.
- Drink plenty of fluids but avoid beverages that contain alcohol, caffeine or a lot of sugar.
- Cover windows that receive direct sunlight.
- If it is too hot to remain in your home, your local government may provide emergency cooling shelters. Listen to radio and television or read the newspaper to find out where they are located.



Radiation release

- Stay inside your home or office unless otherwise instructed by authorities. Close the windows, turn off the heating or air conditioning and stay near the center of the building. By staying inside, you will reduce any potential exposure to airborne radioactive material. Go to the basement if one is available.
- If told to evacuate, do so promptly. Take items you will need for an extended absence. Take prescription medicines, clothing, food, water and money. Experts will recommend the best ways to safely leave the area.
- Avoid drinking fresh milk or eating fruits and vegetables grown in the affected area. Wait until the Department of Health declares food and water safe to consume. Food stored in cans or bags is safe to eat. Fresh food harvested before the radiation release and stored inside is safe. Thoroughly rinse off containers before opening.
- If you suspect you are contaminated, carefully remove your outer layer of clothing and put it in a plastic bag. Take a warm shower. Use soap and shampoo to wash off any radioactive materials. Place the sealed plastic bag in a room away from people.

Resources on the Web

Washington State Department of Health

Over 50 fact sheets and other resources devoted to emergency preparedness: **www.doh.wa.gov**

Washington State Emergency Management Division

Emergency preparedness information for schools, businesses and individuals, including how-to videos: **www.emd.wa.gov**

Ready.gov

Personal, community and business preparedness information featuring an online tool you can use to create a preparedness plan: **www.ready.gov**

Admission Agreement and Informed Consent

Patient Name: _____ **DOB:** _____

HOSPICE OVERVIEW

I am requesting admission to Kline Galland Hospice Services (KGHS). I have been advised of my diagnosis, prognosis and terminal illness and am ready to take a palliative approach to care.
The focus of hospice care is to provide comfort and support to both me and my family/caregivers.

Hospice care will be coordinated and managed by the KGHS Interdisciplinary Team. Hospice services provided to me will be in accordance with my Plan of Care and I will be included in the review and implementation of this Plan of Care. The Hospice Team will not be present in my home 24-hours a day and does not replace my primary caregiver. **Hospice services provided to me in my home include:**

1. Management of my life-limiting related physical symptoms including education and individualized support.
2. Nursing, social work, spiritual counselor, and Hospice Aide Visits on an intermittent basis.
3. Physical therapy, occupational therapy, speech therapy and diet counseling on an intermittent basis.
4. Volunteers who have completed training in hospice to supplement professional care.
5. Comfort therapies such as massage and music therapy.
6. Levels of care available based on condition and need:
    - **Routine** – Hospice care at home (wherever home is) to support comfort and quality of life. This entails intermittent visits to the home; frequency adjusted per patient need.
    - **Continuous Care** - To manage acute symptoms at home and avoid hospitalization (Minimum of 8 hours of care per day.)
    - **Respite** – Temporary inpatient stay to support primary caregiver.
    - **GIP (General Inpatient) – Short-term** Inpatient care if patient's acute symptoms cannot be managed at home.
7. Durable medical equipment and supplies, which have been approved for my care, and are related to my hospice prognosis.
8. Palliative pharmaceuticals and biologicals as needed for pain and symptom control related to my hospice prognosis.
9. Availability of Hospice nurse for telephone consultation, problem-solving and acute care needs **including visits** 24-hours a day/7-days a week **by calling (206) 805-1930.**

In keeping with these palliative care goals, hospice will usually not authorize aggressive treatments such as blood transfusions, IV antibiotics, IV nutrition, diagnostic imagery, surgery or other therapies including curative radiation or chemotherapy, cardiopulmonary resuscitation (CPR) or ventilator care.

I have been advised that I must obtain prior authorization by KGHS for any medical care, treatment or services outside of the scope of Kline Galland Hospice Services. Failure to do so may result in a Medicare, Medicaid or private insurance denial leaving me or my estate financially responsible. I understand that KGHS is financially responsible only for those services included in its Plan of Care and/or approved by its Medical Director, my attending physician and the Hospice Team.

REVOCATION, DISCHARGE, & TRANSFER

I may revoke my election of hospice care any time during a benefit period, and therefore resume the Medicare/Medicaid/Private Insurance coverage and benefits that I have waived. In order to revoke this election I must sign a revocation statement with KGHS. If my attending physician, in collaboration with the KGHS Medical Director and Interdisciplinary Team, deems that my prognosis no longer meets hospice criteria, I will be discharged from the Hospice Program with appropriate notification. If my status changes at any time, and my prognosis meets hospice eligibility requirements, I can elect the Medicare/ Medicaid hospice benefit again in the next benefit period. I can change hospice providers (limit of once per Medicaid/Medicare benefit period) by signing a transfer form.

CONSENT FOR TREATMENT

I hereby authorize KGHS to render all necessary palliative procedures and palliative treatments to me as ordered by my attending physician and/or hospice physician. I understand that I may refuse treatment or terminate services at any time and that hospice may terminate their services to me as explained in my orientation to hospice services.

PATIENT RIGHTS & RESPONSIBILITIES

I acknowledge that I have been provided with a written copy of my rights and responsibilities as a patient. A hospice representative has discussed them with me and I understand them. I acknowledge that I have chosen Kline Galland Hospice Services to provide my hospice care. No employee of KGHS has solicited or coerced my decision in selecting hospice.

RELEASE OF INFORMATION

I acknowledge receipt of the Notice of Privacy Practices and have been given an opportunity to ask questions and voice concerns. I understand that KGHS may use or disclose protected health information about me to carry out treatment, payment, or health care operations, all as described in greater detail in the Notice of Privacy Practices. For example, KGHS may release information to or receive information from insurance companies, health plans, Medicare, Medicaid or any other person or entity that may be responsible for paying or processing for payment or any portion of my bill for services; any person or entity for purposes of health care operations, billing and quality and risk management; any hospital, nursing home or other health care facility to which I may be/have been admitted; any assisted living or personal care facility of which I am a resident; any physician providing my care or other health care providers in order to initiate treatment; family members and other caregivers who are part of my Plan of Care; and as may be required or permitted under applicable law to licensing agencies and accrediting bodies.

CONSENT TO SHARE INFORMATION

Unless I notify Kline Galland otherwise in writing, I consent to have my name and contact information, and that of my emergency contacts, shared internally with the Kline Galland departments and their business associates to facilitate my healthcare and other services provided to me, and to enable Kline Galland to communicate effectively with us regarding present and future programs and services.

CONSENT TO PHOTOGRAPH OR RECORD

I hereby consent for KGHS to photograph or record me and allow them to use the photographs/recordings for their internal use, for documenting my medical condition or for insurance providers to document my condition for payment purposes.

TELEHEALTH CONSENT

Telehealth refers to health care visits which are conducted using interactive video, audio and telecommunications technology through remote connections using computers, tablets or smart phones, rather than in-person ("Telehealth Technology"). Telehealth services for hospice typically involve ongoing assessments ("Telehealth Services"), but such visits are entirely voluntary and may be discontinued at any time. While Kline Galland shall endeavor to maintain the privacy and security of Telehealth Technology communications, I understand that no technology is entirely secure and that such technology has inherent risks (e.g. hacking). Kline Galland telehealth care professionals may include MDs, RNs, and ARNPs, all of whom are licensed in the State of Washington. I have been given the opportunity to ask questions regarding Telehealth, and hereby consent to receive Telehealth Services.

OTHER INFECTIOUS DISEASE TESTING

KGHS is committed to limiting transmission of SARS-CoV-2 and other infectious diseases among our patients and staff. We may request that you be tested for SARS-CoV-2 or other infectious diseases if you are exposed to a confirmed case, or show symptoms, have recently discharged from a facility (hospital, skilled nursing facility, or other congregate care setting), or if there is clinical concern that you could be carrying SARS-CoV-2 or other infectious disease asymptomatically I agree that KGHS can obtain testing specimens for SARS-CoV-2 or other infectious diseases by collecting samples from me via a nasal swab or other verified specimen per clinical recommendations. I also agree to allow KGHS representative(s) to receive and review my test results once they are available.

ADVANCE DIRECTIVES

I understand that the Federal Patient Self-Determination Act of 1990 requires I be made aware of my right to make health care decisions for myself. I understand I may express my wishes in a document called an Advance Directive so that my wishes may be known when I am unable to speak for myself. I have the following type(s) of Advanced Directives:

☐Living Will ☐Uniform Donor Pledge

☐Durable Power of Attorney for Health Care ☐POLST

☐I have been asked to provide a copy of my Advance Directive(s) for my medical record.

☐I do not have Advance Directive, but I have received information regarding Advance Directives with my admission materials.

Authorization for Payment/Notice of Coverage

Patient Name: _____ **DOB:** _____

I certify that the information given by me in applying for payment is correct. I authorize release of all records required to act on this request. I request that payment of authorized benefits from Medicare, Medicaid, or other responsible payor be made on my behalf to Kline Galland Hospice Services. I understand that I am responsible for all amounts not paid by my commercial insurance. If I am a private pay patient, I agree to pay for all services rendered by KGHS. I have been provided a full understanding of hospice care and understand that certain benefits are waived by election of the Medicare hospice benefit if applicable. I hereby elect to participate in hospice care under the following program checked:

- ☐ Medicare (100% coverage of Hospice Visits)
- ☐ Medicaid
- ☐ Other (Variable Coverage)
- ☐ Veterans Affairs (TriWest)
- ☐ Private Pay

If I have Medicare Part A benefits, I understand that Medicare payments will be accepted as payment in full and I have no financial liability, unless I have been notified in writing that service(s) will not *be covered by Medicare and wish to receive the care or service. If I have other insurance, I may be responsible for the co-payment, deductible and any charges that my insurance will not cover.*

INSURANCE INFORMATION

Insurance Provider _____ **Co-Pay Responsibility** _____

ID Number _____ Deductible _____

Group Number _____ Amount Met _____

Health Plan _____ Max. Out of Pocket _____

Coverage (e.g.80/20) _____ Amount Met _____

AUTHORIZATION INFORMATION

Visit Authorization ☐Yes ☐No Auth. No. _____

Type (Visit/Certification) _____

Authorization Date Range _____ Start Date _____ End Date _____

The information provided is based on information received from your insurance provider at the Start of Services. Please be advised that deductibles, and out of pocket expenses may reset at the beginning of the year and/or according to our individual insurance provider.

RECEIPT OF NOTIFICATIONS:

I have received and had the opportunity to discuss the following sections of the Kline Galland Hospice Guidebook that includes but is not limited to:

- Patient Rights & Responsibilities
- Notice of Privacy Practices
- Nondiscrimination Policy
- Patient or Family Concern Process (Grievances)
- Emergency Preparedness
- Policy on Use and Disposal of Controlled Substances
- Minimum Home Safety Requirements

PRINT NAME (PATIENT OR AUTHORIZED LEGAL REPRESENTATIVE)	SIGNATURE	DATE

RELATIONSHIP TO PATIENT (e.g.: self, DPOA)	HOSPICE REPRESENTATIVE	DATE

Note: Legal Representative means an individual who has the authority under State law (whether by statute or pursuant to an appointment by the courts of the State) to authorize or terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill patient who is mentally or physically incapacitated. This may include a legal guardian.

NON-DISCRIMINATION & LANGUAGE ASSISTANCE

Kline Galland complies with applicable Federal civil rights laws and does not discriminate, exclude people or treat them differently on the basis of race, color, national origin, age, disability or sex.

LANGUAGE ASSISTANCE: The following are published here pursuant to Section 1557 of the Affordable Care Act and implementing regulations, 45 CFR 92.8(d)(1).

Spanish: ATENCIÓN – si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1- 855-797-9952.

Vietnamese: CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-855-797-9952.

Hospice Election Statement

Patient Name: _____ **DOB:** _____

Hospice Agency Name: Kline Galland Hospice

Hospice Election

I, _____ **(Patient Name)** choose to elect the Medicare hospice benefit and receive Hospice Services from Kline Galland Hospice to begin on _____ (Start of Care Date).

(Note: The start of care date, also known as the effective date of the election, may be the first day of hospice care or a later date, but may not be earlier than the date of the election statement. An individual may not designate an effective date that is retroactive.)

Right to Choose an Attending Physician

- I understand that I have a right to choose my attending physician to oversee my care.
- My attending physician will work in collaboration with the hospice agency to provide care related to my terminal illness and related conditions. The KGHS Medical Director or KGHS Hospice Physician will manage my medical care should my chosen physician be unavailable.

☐I do not choose an attending physician.
☐I acknowledge that my choice for an attending physician is:

Physician full name: _____ NPI (if known) _____

Office Address: _____

Hospice Philosophy and Coverage of Hospice Care

By electing hospice care under the Medicare hospice benefit, I acknowledge that:

- I was given an explanation and have a full understanding of the purpose of hospice care including that the nature of hospice care is to relieve pain and other symptoms related to my terminal illness and related conditions and such care will not be directed toward cure. The focus of hospice care is to provide comfort and support to both me and my family/caregivers.
- I was provided information on which items, services, and drugs the hospice will cover and furnish upon my election to receive hospice care.
- I was provided with information about potential cost-sharing for certain hospice services, if applicable.
- I understand that by electing hospice care under the Medicare hospice benefit, I waive (give up) the right to Medicare payments for items, services, and drugs related to my terminal illness and related conditions. This means that while this election is in force, Medicare will make payments for care related to my terminal illness and related conditions only to the designated hospice and attending physician that I have selected.
- I understand that items, services, and drugs unrelated to my terminal illness and related conditions are exceptional, and unusual and, in general, the hospice will be providing virtually all of my care while I am under a hospice election. The items, services, and drugs determined to be unrelated to my terminal illness and related conditions continue to be eligible for coverage by Medicare under separate benefits.

Right to Request "Patient Notification of Hospice Non-Covered Items, Services, and Drugs"

- As a Medicare beneficiary who elects to receive hospice care, you have the right to request at any time, in writing, the "Patient Notification of Hospice Non-Covered Items, Services, and Drugs" addendum that lists conditions, items, services, and drugs that the hospice has determined to be unrelated to your terminal illness and related conditions, and that will not be covered by KG hospice.
- If I request this form within the first 5 days of the election start date, the hospice must furnish the written addendum within 5 days of the request date. If I request this form during the course of hospice care (that is, after the first 5 days of the hospice election start date), the hospice must furnish this written addendum within 3 days of the request date.

☐I elect to receive the "Patient Notification of Hospice Non-Covered Items, Services, and Drugs" addendum

Initials _____ Date _____ Email Address: _____

☐ I decline to receive the "Patient Notification of Hospice Non-Covered Items, Services, and Drugs"

Initials _____ Date _____

Beneficiary and Family-Centered Care Quality Organization (BFCC-QIO)

As a Medicare hospice beneficiary, you have the right to contact the Beneficiary and Family-Centered Care Quality Organization (BFCC-QIO) to request Immediate Advocacy if you disagree with any of the hospice's determinations. The BFCC-QIO that services your area is:

BFCC-QIO Name: Acentra Health
BFCC-QIO Phone Number or Website: 888-305-6759 (toll free); TTY: *711;
https://www.keproqio.com/bene/statepages/washington/

Signature of Beneficiary: _____

☐ Beneficiary is unable to sign

Signature of Beneficiary Legal Representative (if beneficiary is unable to sign): _____

Printed name of Legal Representative: _____

Date signed: _____

Primary Caregiver Agreement

Patient Name: _____ **DOB:** _____

Kline Galland Hospice encourages the active involvement of a Primary Caregiver – someone to assist with personal care and activities of daily living when hospice staff members are not available.

_____ (Patient Name) has identified that _____
(Name of Primary Caregiver) will be my Primary Caregiver and agrees to do the following:

- Participate with the KGHS Interdisciplinary Team and the patient in the development of the patient's Plan of Care (POC).
- Communicate the patient's needs and preferences.
- IMMEDIATELY report any changes in the patient's condition to the hospice staff, who may be contacted 24 hours a day, 7 days a week at (206) 805-1930.
- Make other arrangements for safe home care if I am unavailable.
- Use Kline Galland's attached policy and procedure for safe disposal of patient's medication.

I have been verbally informed of Kline Galland's policy on *Home Use and Disposal of Controlled Substances* and have been provided with a written copy of the information discussed.

PRIMARY CAREGIVER SIGNATURE **DATE**

PRIMARY CAREGIVER MAILING ADDRESS

LANGUAGE TO RECEIVE PATIENT SATISFACTION SURVEY

PRIMARY CAREGIVER EMAIL ADDRESS **PRIMARY CAREGIVER PHONE NUMBER**

HOSPICE REPRESENTATIVE SIGNATURE **DATE**

Patient Contact List

Patient Demographics

Patient Name: _____ DOB/MRN: _____

Race: _____ Ethnicity: _____

Primary Language: _____ Pronouns: _____

Does the patient have DPOA or Legal Guardian? ☐ Yes ☐ No

If yes, have you provided documents to Kline Galland? ☐ Yes ☐ No

Please identify which contact is the DPOA if applicable.

Contacts

Name: _____ Relationship (spouse, child, etc): _____

Are we allowed to discuss your care with this person? ☐Yes ☐No

DPOA: ☐Yes ☐No **Emergency Contact**: ☐Yes ☐No

Phone: _____ May we leave a detailed voicemail? ☐Yes ☐No

Email: _____ Address: _____

Name: _____ Relationship (spouse, child, etc): _____

Are we allowed to discuss your care with this person? ☐Yes ☐No

DPOA: ☐Yes ☐No **Emergency Contact**: ☐Yes ☐No

Phone: _____ May we leave a detailed voicemail? ☐Yes ☐No

Email: _____ Address: _____

Name: _____ Relationship (spouse, child, etc): _____

Are we allowed to discuss your care with this person? ☐Yes ☐No

DPOA: ☐Yes ☐No **Emergency Contact**: ☐Yes ☐No

Phone: _____ May we leave a detailed voicemail? ☐Yes ☐No

Email: _____ Address: _____

Request for Patient Notification of Hospice Non-Covered Items, Services and Drugs

Date Requested: _____

Patient Name: _____

Patient DOB: _____

Please provide the following:

"Patient Notification of Hospice Non-Covered Items, Services, and Drugs" addendum that lists conditions, items, services, and drugs that the hospice has determined to be unrelated to your terminal illness and related conditions, and that will not be covered by the hospice.

Signature of Patient or Representative:

X: _____

Relation to patient: _____

FOR OFFICE USE

Date Request Received: _____ **Received by:** _____

Date Request Completed: _____ **Completed By:** _____

Patient Notification of Hospice Non-Covered Items, Services, and Drugs

Patient Name: _____

Patient MRN: _____

Hospice Agency Name: _____ **Date Furnished:** _____

Purpose of Issuing this Notification

The purpose of this addendum is to notify the requesting Medicare beneficiary (or representative), in writing, of those conditions, items, services, and drugs not covered by the hospice because the hospice has determined they are unrelated to your terminal illness and related conditions. If you request this notification within 5 days of a hospice election, the hospice must provide this form within 5 days of your request. If you request this form at any point after the first 5 days of the start date of hospice care, the hospice must provide this form within 3 days of your request.

Diagnoses Related to Terminal Illness and Related Conditions

1.	**5.**
2.	**6.**
3.	**7.**
4.	**8.**

Diagnoses Unrelated to Terminal Illness and Related Conditions:

1.	**5.**
2.	**6.**
3.	**7.**
4.	**8.**

Non-covered Items, Services, and Drugs Determined by Hospice to be Unrelated to Your Terminal Illness and Related Conditions:

Items/Services/Drugs	Reason for Non-coverage

Note: The hospice makes the decision as to whether or not conditions, items, services, and drugs are related for each patient. As the patient or representative, you should share this list and clinical explanation with other healthcare providers from which you seek items, services, or drugs, unrelated to your terminal illness and related conditions to assist in making treatment decisions. The hospice should provide its reasons for non-coverage in language that you (or your representative) understand.

Right to Immediate Advocacy

As a Medicare beneficiary, you have the right to contact the Medicare Beneficiary and Family Centered Care-Quality Improvement Organization (BFCC-QIO) to request for Immediate Advocacy if you (or your representative) disagree with the decision of the hospice agency on items not covered because the hospice has determined they are unrelated to your terminal illness and related conditions.

Patient Notification of Hospice Non-Covered Items, Services, and Drugs

Please visit this website to find the BFCC-QIO for your area: https://qioprogram.org/locate-your-qio or call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

Acentra Health BFCC-QIO Toll Free at 1-888-305-6759 or TTY 1-855-843-4776 to appeal, or if you have questions.

Signing this notification (or its' updates) is only acknowledgement of receipt of this notification (or its updates) and does not constitute your agreement with the hospice's determinations.

☐ Beneficiary is unable to sign

Signature of *Beneficiary*: _____

Date Signed: _____

Signature of *Representative*:

Date Signed: _____

If the beneficiary and/or representative refuses to sign, the hospice must document on the addendum the reason the addendum is not signed and it becomes part of the beneficiary's medical record.

Notes:

HOSPICE BENEFIT REVOCATION FORM

Patient Name _____ DOB _____

Start of Care Date: _____ Revocation Date: _____ Benefit Period: _____

Hospice Payer Source: ☐ Medicare/Medicaid ☐ VA ☐ Private Pay ☐ Commercial Insurance

PCP: _____ Hospice Dx:_____

Reason for Revocation:

- ☐ I am choosing aggressive/curative treatment of my terminal illness within a hospital setting.
- ☐ I am moving outside of Kline Galland Hospice's geographical service area and do not chose care from another hospice at this time.
- ☐ I am choosing to be treated at a facility that does not contract with this Hospice.
- ☐ Other (specify) _____

For Medicare/Medicaid Patients:

I understand that by signing this revocation form:

- ☐ I am no longer accessing my Medicare Hospice Benefit, effective on this date _____, at _____ ☐ a.m. ☐ p.m.
- ☐ I may elect my Medicare Hospice Benefit again at any time, as long as I am medically eligible.
- ☐ I am eligible to resume my non-hospice Medicare benefits immediately upon the effective date _____, at _____ ☐ a.m. ☐ p.m.

Additional Information and Comments:

_____

_____

_____

_____ _____ _____

Patient or Authorized Representative (Print) Signature Date

HOSPICE TRANSFER SUMMARY

Patient Name _____ DOB _____ Today's Date_____

Start of Care Date: _____ Transfer Date: _____ Benefit Period: _____

Hospice Payer Source: ☐ Medicare/Medicaid ☐ VA ☐ Private Pay ☐ Commercial Insurance

PCP: _____ Hospice Dx:_____

Receiving Hospice:_____

Additional Information and Comments:

_____

_____

_____

_____

_____

_____

_____

_____ _____ _____

Patient or Authorized Representative (Print) Signature Date

_____ _____ _____

Transferring Hospice Representative (Print) Signature Date

KLINE GALLAND

BENAROYA SERVICES

Compassion · Respect · Excellence · Dignity · Integrity · Tradition

6100 4th Ave S Suite 403, Seattle, WA 98108

(206) 805-1930 • KlineGalland.org