

Guide to Supporting A Hospice Patient From Afar

“All I know of tomorrow is that
Providence will **rise before the sun.**”

— Lacordaire

Welcome to Providence Hospice

Dear Family Member or Close Friend,

On behalf of the entire staff at Providence Hospice and Palliative Care, we would like to take this opportunity to express our gratitude for allowing us to serve your loved one, you and your family at this very important time in your lives. We know there are many important reasons why you may be unable to be physically present with your loved one on a daily basis. Even if you live far away or have other challenges that limit your ability to visit when the care team sees your loved one, we want you to feel confident in what to expect through the end of their life.

The hospice care team typically includes a Registered Nurse (RN), a Master of Social Work (MSW), a Chaplain, a Hospice Aide and a Hospice Physician. You will find more information on each of these disciplines in this packet. The RN is the case manager who is in charge of the overall care provided by the Providence Hospice care team. Our goal is to provide excellent care to your loved one and support you in anything you may need.

As part of our commitment to excellence, Providence Hospice has elected to participate in the Family Evaluation of Hospice Care Survey. You have been identified as the survey recipient. If your loved one passes while on services with Providence Hospice, you will receive a survey approximately 4-6 weeks later asking you to evaluate the care your loved one received. If you feel it would be more appropriate for another family member to receive the survey, please inform the care team.

We encourage you to let the hospice team know the best way to communicate changes with you. Please contact us at any time to ask questions or share your concerns as they come up so we can best support you and your loved one. Please review the written resources we have included in this packet; we hope you will find these materials beneficial.

Thank you for allowing us to provide hospice services to your loved one, you and your family.

Sincerely,

Providence Hospice Staff

This guide provides **helpful information** for families whose loved one is on hospice.

Your Care Team at Providence Hospice

Hospice nurse – who will visit your loved one to determine his/her individualized needs and identify what services they are interested in receiving. The nurse's primary goal is to provide symptom management and comfort. Responsibilities include:

- Assessing comfort level and any symptoms which may need attention, such as pain, nausea, etc.
- Working with the physician to manage symptoms.
- Performing medical/nursing procedures.
- Caregiver education.
- Helping coordinate needed equipment, supplies and services.
- Explaining the effects of illness and treatment, answering your questions and offering support.

Social worker – who will explain the hospice philosophy, goals and services. This individual works closely with the patient and family to create and maintain a supportive care setting that provides for the patient's safety, comfort and dignity through end of life. The social worker is also available to help the patient and family deal with personal, financial, emotional and care planning issues that arise. A hospice social worker may also help by:

- Identifying available resources in the community.
- Determining eligibility for state and local assistance programs.
- Providing information on advance directives (living will, health care directive, health care proxy, etc.).
- Listening to concerns, answering questions and providing emotional support.

Chaplain or spiritual counselor – who is available to visit, listen and provide support to both the patient and family. Chaplains (or spiritual or pastoral care counselors, as they are often called) take a non-denominational approach, and can also connect you or your loved one with someone representing a preferred religious faith or tradition. The hospice chaplain can:

- Meet with you or your loved one to share hopes, fears, dreams and concerns.
- Support you in exploration or struggles with spiritual and/or emotional issues.
- Provide spiritual counseling, while respecting personal beliefs.

- Pray with your loved one, if requested.
- Assist in planning a funeral, memorial service or other similar gathering.

Therapists – including physical, occupational or speech therapists who may play a role during hospice care in promoting the independence, quality of life and safety of the patient and family. The hospice nurse can help determine if a referral to one of these therapists might be helpful. Therapists may:

- Assist in identifying and filling medical equipment needs, such as a hand-held shower, bath seat, walker, etc. Help identify any safety hazards in the home.
- Help the patient improve strength and mobility through the use of equipment and exercise programs.
- Evaluate leisure interests and teach skills and activities that improve quality of life.
- Demonstrate safe patient transfer techniques.

Other types of specialized therapy may also be available to help promote relaxation, improve sleep, reduce pain and enhance comfort and quality of life in other ways.

Hospice aides – who help with personal care needs. Hospice aides help with:

- Bathing, shampooing, grooming, shaving and changing bed linens.
- Assistance with toileting.
- Light homemaker tasks.
- Teaching caregivers good personal care techniques.

Hospice volunteers – who are often an important part of the hospice care team. Hospice volunteers receive in-depth training before they are assigned to a patient and family.

Depending on your loved one’s needs and wishes, a hospice volunteer may be able to help by:

- Staying with the patient so the caregiver can rest.
- Providing companionship – spending time with the patient in conversation, playing a few hands of cards or sharing things of interest to the patient.
- Running small errands, doing light housework, running a load of laundry or preparing a meal.

Bereavement or grief counselor – who provides education, counseling and support for dealing with grief and loss. This member of the hospice team helps by:

- Providing counseling and support both before and after the patient’s death.

- Identifying other resources available in the community, such as a grief workshop or support group.
- Following up, typically for at least 12 months after the patient's death, to see how the family is coping with their loss.

Clinical Hospice Pharmacist – a pharmacist dedicated solely to the needs of hospice patients, with expertise in pain management. The Clinical Hospice Pharmacist works with the entire team to develop the best and safest medication plan to address pain, symptom management and comfort. Responsibilities of the Clinical Pharmacist include:

- Regular review of the patient's medication profile for drug interactions.
- Routine medication management interventions.
- Consultation for the team on pain and symptom management.
- Education to patients and family members.

Physician/Medical Director – who provides medical expertise in end of life care to the hospice team and oversees the patient's hospice plan of care. This physician is the hospice medical director and does not replace the patient's personal health care provider, rather he or she works with this provider so that the most effective symptom management and comfort care can be delivered. The physician may make a visit to the home in circumstances where this level of expertise is needed. Responsibilities of the medical director include:

- Serving as part of the team that develops and updates the patient's plan of care.
- Certifying that hospice services, both new and ongoing, are appropriate for the patient based on their illness, life expectancy and plan of care.

How to Communicate With us

How to contact us:

Someone from the team call you shortly after your loved one is admitted to our services. We encourage you to contact the care team if you have any questions prior to this. The receptionist will direct your call to the care team or the clinical manager. Our regular office hours are Monday through Friday from 8 a.m. to 4:30 p.m. PT. Our after-hours support team is available 24/7 and they will assist you with any urgent needs, or take a message if you would like your call returned.

If you need to speak in another language, tell the receptionist what language you prefer and they will place you on hold for a few moments until a phone interpreter can join the call.

In Everett/Snohomish County: (425) 261-4777

In Seattle/King County: (206) 320-4000

In Olympia/ Thurston, Lewis and Mason Counties: (877) 620-3286

Email:

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

Frequently Asked Questions About Supporting a Hospice Patient from Afar

Q: How much longer does my loved one have to live?

A: The criteria for a hospice admission is a life expectancy of 6 months or less, however everyone is different and your loved one's disease progression may be faster or slower. No one can predict precisely when death will occur, however there are changes we typically see in the final days to week of life. We encourage loved ones to ask the care team about changes and what to expect and also to become familiar with the materials we provide such as "Preparing for Approaching Death" and "Gone from My Sight."

Q: Should I travel a long distance to visit my loved one now or wait?

A: This question is best answered by determining what is most important to you when you visit. The MSW can help you understand the Family Medical Leave Act (FMLA) if needed. Common things to consider include:

- Do you have any unfinished business that needs attention?
- If your loved one dies in the near future without you seeing her/him, how are you going to feel afterwards (guilty, at peace, etc.)?
- How alert do you want your loved one to be when you next see her/him?
- Is it important for you to be present at time of death?
- Do other family members need a break and could your visit help provide care to your loved one?

Q: What happens when our loved one can no longer care for him/herself in the home?

A: The care team MSW can educate you on care options which range from hiring help in the home to placement at a facility. They will help explore the costs, resources and services your loved one may be eligible for. Many patients and families enjoy planning in advance with the MSW so everyone feels educated before the changes need to occur. Contact the MSW to discuss.

Q: Will hospice call if my loved one starts showing rapid decline or changes for the worse?

A: The care team will notify the designated decision maker as we notice major changes in your loved one's condition. If you would like routine calls from the hospice care team please notify the team to determine what intervals and what communication method is most practical.

Q: What kind of services does hospice provide?

A: Hospice provides routine homecare services for the majority of patients in their place of residence and access to support 24 hours daily for urgent needs and symptom management. We provide medication and equipment for comfort care related to the terminal diagnosis. We

offer emotional support to patients and for loved ones. We offer anticipatory grief support for adults and children. When symptoms cannot be managed for patient comfort in the home, an inpatient admission may be ordered by the physician until symptoms can be managed for comfort in the home. Please reference the care team and general hospice FAQs in this packet or call us for more information.

Questions We Encourage You to Ask Us or the Caregivers Responsible for Daily Care

(These questions can be asked of the team members or re-phrased to be asked of the daily caregivers themselves)

- 1. Is my loved one in pain or uncomfortable?**
- 2. How is the pain or discomfort being managed?**
- 3. Is my loved one anxious or sad?**
- 4. How is the anxiety or sadness being managed?**
- 5. Are the daily caregivers confident in the use of pain medications or interventions?**
- 6. Are the daily caregivers confident in the use of medications or interventions to manage the anxiety or sadness?**
- 7. Are the daily caregivers confident about doing what they need to do to take care of my loved one?**
- 8. Have the daily caregivers received information about what to expect while my loved one is dying?**
- 9. Are the daily caregivers confident of what to do when my loved one is dying?**
- 10. Are the daily caregivers confident of what to do at the time of death?**

Frequently Asked Questions You or Your Loved One May Have Regarding Hospice Care

Q: Are medications covered under hospice?

A: Medications for pain and to help control symptoms related to the hospice diagnosis are covered. The hospice staff will supply these medications. Medications the patient continues to take for other conditions will be their financial responsibility and they will obtain them through their current pharmacy.

Q: Can they still see their regular doctor?

A: Yes! The hospice staff works closely with the patient and their doctor to make sure they get the care they need and establish the Hospice Plan of Care. If the doctor says the patient needs to see a specialist, they will need to discuss this with their Care Team.

Q: What does the Medicare/Medicaid Benefit cover?

A: The Medicare/Medicaid Plan has two parts, Hospital Insurance (or Part A) and Medical Insurance or (Part B). Part A covers hospice services and pays nearly all the costs of the hospice care, which can include:

- Intermittent home visits by the Hospice staff.
- Approved medications for symptom control and pain relief.
- Medical equipment (like wheelchairs or walkers) and supplies (like bandages and catheters).
- Short-term respite care in a nursing home.
- Authorized outpatient procedures to alleviate symptoms.
- Approved hospitalizations for symptom management.
- Grief and loss counseling.

The Medicare/Medicaid Hospice Benefit **does not** cover the following:

- Treatment intended to cure the terminal illness.
- Care from another hospice other than the current hospice provider (Providence Hospice).
- Room and board.

Private insurance coverage is often similar. Patients or families should contact their insurance company's customer service department for specific information regarding their hospice benefit.

Q: How long can they get hospice care?

A: Patients can continue to receive hospice care as long as their doctor certifies that they are terminally ill and probably have six months or less to live. Even if they live longer than six

months, they can continue to receive hospice care as long as their doctor recertifies that they are terminally ill.

Hospice care is covered in certification periods. As a hospice patient, they can get hospice care for two 90-day periods followed by an unlimited number of 60-day periods. Their doctor will need to recertify at the beginning of each certification period that they are still appropriate for hospice services. A certification period starts the day they begin receiving hospice care. A certification period ends when their 90-day or 60-day period ends.

Q: What is respite care?

A: Respite care is part of the hospice benefit. It entitles a patient up to 5 days of respite care (usually in a skilled nursing facility) so the patient’s family member or caregiver can rest.

Q: What if they want care that hospice doesn’t cover?

A: If the patient and family prefer to receive care that is outside of the Hospice Plan of Care (i.e. curative or aggressive treatment), they will need to revoke the hospice benefit and discontinue hospice services. Revocations are effective the date they sign our revocation form. The form must be signed prior to beginning treatment. Please contact the Care Team or our after hours on-call staff if they are considering this option.

Q: What if they don’t want hospice services anymore?

A: We hope the patient and family want to continue with our services, but if they would prefer to stop hospice care, they will need to revoke the hospice benefit. Revocations are effective the date they sign our revocation form. Please contact the Care Team or our after hours on-call staff if they are considering this option.

Medicare Hospice Benefit information provided by: Department of Health & Human Services. Medicare Hospice Benefits. CMS02154 (2003): 1, 4, 5, 7.

Complaint Resolution

We make every effort to immediately resolve any concerns or issues that may arise.

Persons in need of interpreters or assistive devices will need to notify the agency in advance, and arrangements will be made to have the appropriate assistance in place as we address your concerns.

If you have concerns or questions about the care your loved one is receiving, please contact our office and speak with the Clinical Manager for the Care Team to whom the patient is assigned.

If you are not satisfied after speaking with the Clinical Manager, please call the Director.

Or, you may contact:

Washington State Home Care Hotline

(800) 633-6828,

8:00 a.m. to 5:00 p.m., Monday through Friday.

The **TDD Relay number** for the hearing impaired is **(800) 833-6388**.

Or write to:

Department of Health

Facilities and Services Licensing

PO Box 47852

Olympia, WA 98504-7852

Preparing for Approaching Death and Plan for Time of Death

The following information is provided to the patient and caregivers to educate them on what to expect as death approaches and to plan for the time of death.

We think these are good tools for you to review as well as for you to manage the care of your loved one from afar. You may find them useful in your discussions with the patient, other family members and/or the caregivers.

Please contact your loved one's Care Team if you have any questions regarding this information.

Preparing for Approaching Death

When a person enters the last stage of the dying process, the body begins the final process of shutting down. These are normal changes, not medical emergencies. There are many things you can do to make your loved one more comfortable.

The following physical signs of dying are offered to help you understand the natural way dying occurs. Not all of these signs and symptoms will occur with every person. It may be helpful for

you and your family to think and talk about what you will do when death occurs. The death of a hospice patient is not an emergency. There is no rush. Nothing must be done immediately.

At Providence Hospice, we respect that each person or family has its own culture, traditions and needs. Your hospice team is available to answer your questions. We can provide support and information on what to expect and what you can do to make your loved one comfortable. There is a hospice nurse available to answer questions 24 hours a day.

Physical Signs of Approaching Death and Appropriate Responses	
What May Happen	What You Can Do
<p>Fluid and Food Decrease:</p> <p>The patient has less need for food and drink. This is common. The response to taste and smell may change. The body is beginning to shut down.</p> <p>When a loved one won't eat, caregivers may feel anxious and fear they may be starving. The body is unable to process food. Forcing food or fluid can cause discomfort, nausea, vomiting or increased pain.</p>	<p>Fluid and Food Decrease:</p> <p>Your loved one should not be forced to eat or drink. If they can swallow, offer ice chips, frozen juice, popsicles, ice cream, broth, yogurt, pudding, applesauce, jello, shakes, instant breakfast drinks or a dietary supplement drink. A small spoon or syringe can be used. Offer small portions or bites of food frequently throughout the day. Thicker liquids can be easier to swallow. Good mouth care using toothettes (supplied by hospice) will maximize comfort.</p> <p>Your hospice team can offer ideas for food and drink and ways to increase comfort. Hospice also provides mouth care products and supplies including a thickener, which can be added to any liquid to aid in easier swallowing.</p>
<p>Sleeping:</p> <p>The patient will gradually spend more time dozing or sleeping during the day and at times will be more difficult to arouse.</p>	<p>Sleeping:</p> <p>Plan your time with your loved one for those times when they seem more alert. Identify yourself by name; hold their hand. Be sure to talk directly in a normal tone of voice to your loved one, even when they cannot respond to you. Hearing is one of the last senses to be lost. Consider shorter visits by friends and extended family to avoid exhausting your loved one.</p> <p>Your care team social worker can help you identify ways to honor your loved one's preferences and needs. The social worker can also suggest ways to take care of yourself while caring for your loved one and improving communication in the family setting.</p>

What May Happen	What You Can Do
<p>Decreased Socialization/Withdrawal:</p> <p>Depending on cultural and family norms, the patient may want to be with very few people or just one person. The patient may need quiet time to think, or deal with a wide range of feelings. Sometimes people just need to be quiet.</p>	<p>Decreased Socialization/Withdrawal:</p> <p>If your loved one is withdrawn, it does not mean you are not loved. You can help your loved one by allowing them time to be quiet. This might be a time for you to rest, reflect or take some time to relax.</p>
<p>Vision-like Experiences:</p> <p>The patient may see or talk with people who have already died. This does not mean they are having a drug reaction or hallucinating. The patient may be beginning to detach from life and preparing to let go. The person may reach out, look up or talk about needing to go somewhere.</p>	<p>Vision-like Experiences:</p> <p>Try not to argue with your loved one about what they claim to have seen or heard. Affirm experiences and provide reassurance. Explain this is normal and commonly occurs. If the person is alarmed or anxious, ask what will help him/her feel safe.</p> <p>Inform the hospice care team.</p>
<p>Disorientation:</p> <p>The patient may become confused about time, place and not recognize you or other familiar people. This is due to normal end of life changes in the body.</p>	<p>Disorientation:</p> <p>Identify yourself by name when speaking. Speak softly, clearly and truthfully. It is best to avoid arguments. Speak slowly, ask one question at a time and give more time for answers. Explain what you are doing if you plan to provide physical care.</p>
<p>Incontinence and Urine Decrease:</p> <p>The patient may lose control of urine and/or bowel matter as the muscles in that area begin to relax. The amount of urine may decrease. Urine may be “tea-colored.”</p>	<p>Incontinence and Urine Decrease:</p> <p>If your loved one does not urinate in 12 hours, inform the hospice nurse. Pads between the body and the bed will help to keep the bed clean. Discuss other options for keeping your loved one clean and comfortable with the care team. Your nurse may suggest a catheter (tube in the bladder).</p> <p>Hospice provides incontinence supplies. A Home Health Aide can visit routinely to provide bed baths and personal care.</p>

What May Happen	What You Can Do
<p>Difficulty or Inability to Swallow:</p> <p>It may become difficult for the patient to swallow. The muscles in the throat are getting weaker.</p>	<p>Difficulty or Inability to Swallow:</p> <p>If choking or coughing occurs, take a break to allow your loved one to recover. Offer small spoonfuls of water to test their ability to swallow. Frequent mouth care with toothettes (supplied by hospice) to keep the mouth and lips clean and moist will improve comfort. Discuss different ways to give food, fluid and medication with the hospice nurse.</p>
<p>Restlessness:</p> <p>The patient may appear agitated and restless, making repetitive motions such as pulling at bed linens. This can be due to normal end of life changes in the body. Sometimes, it may mean they are having emotional or spiritual distress or increased pain.</p>	<p>Restlessness:</p> <p>It is best not to stop or control your loved one's movements. Talk calmly. Read passages from a favorite book. Play your loved one's favorite music. Talk about pleasant memories. Try a gentle massage or use lotion to relax tense muscles. Change your loved one's position. If the forehead is hot, apply a cool cloth. Reduce the activity level in the area. Changing the lighting may be calming. This may be the time to give reassurance that you will be okay, and your loved one can "let go." The care team social worker and chaplain can provide support and help with addressing emotional or spiritual distress. If extreme restlessness or agitation occurs, call the hospice nurse.</p>
<p>Breathing Changes:</p> <p>Breathing may change and become irregular. Breaths may be rapid and shallow with periods of five to 60 seconds with no breath.</p>	<p>Breathing Changes:</p> <p>Elevate the head and/or turn your loved one on his or her side. Hold their hand. Speak to him or her gently. If they seem to be struggling to breathe, notify the hospice nurse of this change.</p>
<p>Increased Secretions/Congestion:</p> <p>Saliva may increase and collect in the back of the throat or chest, producing a rattling noise. The patient is too weak to cough up saliva. This does not mean they are experiencing distress with breathing or having pain.</p> <p>Suctioning is not recommended because it increases the secretions and</p>	<p>Increased Secretions/Congestion:</p> <p>Elevate the head of the bed. Gently turn your loved one's head to the side and allow gravity to drain the saliva. Provide mouth care frequently with toothettes (supplied by hospice). Discuss with the hospice nurse. Medication may be provided to decrease secretions.</p>

causes discomfort.	
<p>Coolness:</p> <p>The patient’s hands, arms, feet and legs may be increasingly cool to the touch and the color of the skin may change. The underside of the body may become darker and the skin mottled. This is a normal sign that the circulation of blood is decreasing.</p>	<p>Coolness:</p> <p>Keep warm blankets on your loved one’s body. Do not use an electric blanket.</p>

Plan for Time of Death

Call Providence Hospice when death occurs.

Death is not a medical emergency. There is no need to call 911.

- The hospice nurse will call the Medical Examiner, physician and medical equipment staff.
- The Hospice nurse will confirm the funeral home or body donation program and may call the funeral home for the family/caregivers upon request.
- Consider when family/caregivers would like the body transported to the funeral home.
- Know that the removal of the body from the home may be difficult to watch. Consider if family/caregivers want to be present or have someone with them.
- Family/caregivers can request to have a Hospice team member make a visit at the time of death.

Providence Hospice is here to support you. Call us anytime.

In Everett/Snohomish County: (425) 261-4777

In Seattle/King County: (206) 320-4000

In Olympia/ Thurston, Lewis and Mason Counties: (877) 620-3286

Plan for Time of Death

Designate a family member or friend if you would like someone to be with you at the time of death.

Name: _____ Phone Number: _____

Other friends and family members you may wish to call:

Name: _____ Phone Number: _____

Name: _____ Phone Number: _____

Name: _____ Phone Number: _____

Name: _____ Phone Number: _____

Identify if you would like spiritual support from your faith community:

Name: _____ Phone Number: _____

Funeral Home Name: _____ Phone Number: _____

Notes: _____

Other Resources

The “Patient and Family Guide to Hospice Care” booklet is one of the items we include in the Providence Hospice folder at time of admission. This guide explains hospice care, the role of the hospice team and information on rights and responsibilities. It contains information and skills for caregivers such as information on preparing for approaching death and general information on planning a funeral or memorial service. The folder also includes a booklet titled “Gone From My Sight: The Dying Experience” by Barbara Karnes, RN. Some loved ones like to use this as a guideline for what one can expect at end of life. If you would like a copy of either of these booklets or if you have any questions about the material provided by Providence, please contact the care team.

