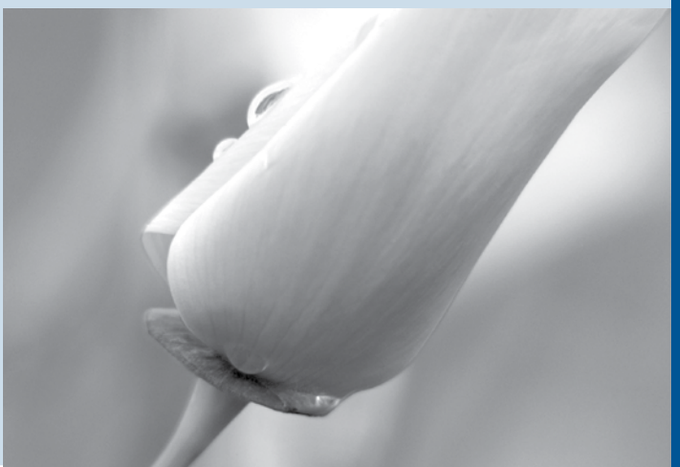
Franciscan Hospice and Palliative Care

Hospice Patient and Family Information



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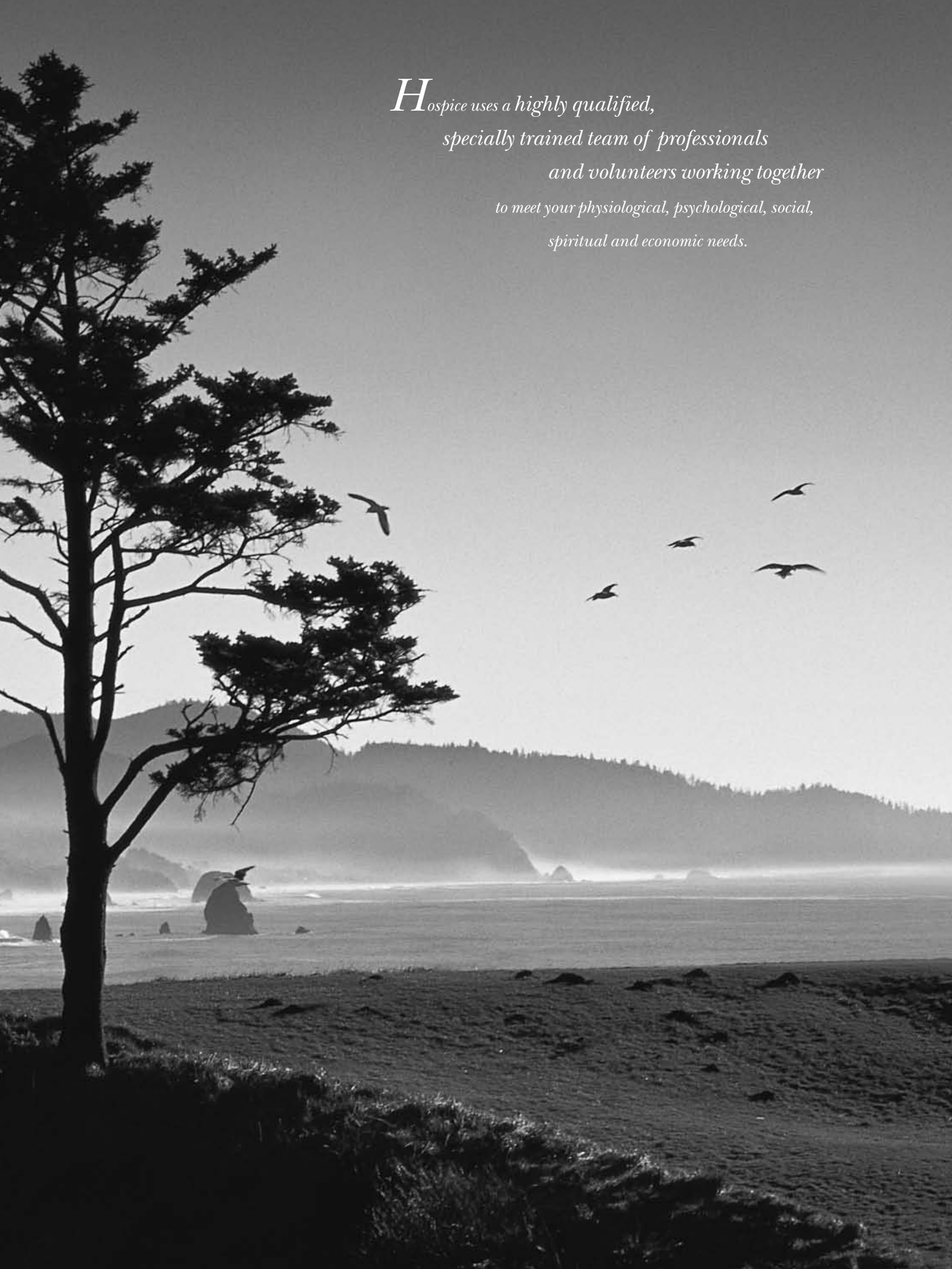
Franciscan Hospice
Team Members

NAME	TELEPHONE
Primary Nurse(s)	
Social Worker	
Home Health Aide(s)	
Homemaker	
Chaplain	
Volunteer Coordinator	
Volunteer(s)	
Comfort Therapist(s)	
Bereavement Coordinator	
Registered Dietitian	
Pharmacist	
Occupational Therapist	
Physical Therapist	
Speech Therapist	
Other Team Members	



Hospice uses a highly qualified, specially trained team of professionals and volunteers working together to meet your physiological, psychological, social, spiritual and economic needs.

About Hospice

The word “hospice” dates back to medieval times, when a hospice was a place where weary travelers could find shelter and temporary respite from their journeys. The modern concept of hospice is a comprehensive model of care with services specially tailored to meet the needs of people and families who are facing life-limiting illness.

While the meaning of hospice has evolved through the years, these basic values have not changed:

- People who face the end stages of their life due to illness deserve to live their final days to their fullest, surrounded by the persons and things which they hold dear.
- Family members and friends deserve to receive the support they need to cope with the many changes and challenges they will face.

To support and uphold these values, hospice has adopted the following philosophy and basic principles:

Concentration of Care

The focus of hospice care is on the quality of remaining life rather than only extending life. Therefore, hospice works to provide effective pain management and symptom control.

Hospice offers a coordinated program of care from the time of admission through bereavement. Hospice trains and facilitates family and other caregivers to meet their loved one’s needs.

Patient and Family as the "Unit of Care"

Hospice recognizes that patients, families and caregivers will be affected by a life-limiting illness, needing the support of the hospice team.

Hospice Interdisciplinary Group

Hospice uses a highly qualified, specially trained team of professionals and volunteers working together to meet the physiological, psychological, social, spiritual and economic needs of persons facing the end of life and bereavement.

Interdisciplinary Group Plan of Care

The hospice interdisciplinary team collaborates on an on-going basis with a patient's physician to develop and maintain an individualized plan of care based on the needs of the patient and family.

Access to Care

Hospice offers services and support to all people and their families regardless of age, gender, nationality, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver or ability to pay.

Coordination and Continuity of Care

Hospice personnel are available 24 hours a day, seven days a week for phone consultations or home visits. Hospice services will usually be able to follow the patient if their care setting changes.

You and your family are unique, and the way in which you deal with this stage of life will also be unique. Franciscan Hospice understands and supports your individuality. We are committed to helping you identify your specific needs and find ways to meet those needs.

We are born with the will to live. This strong drive helps you and your loved ones make each day the best it can be—filled with qualities of love, care, concern and support. We at Franciscan Hospice will do all we can to help you find peace of mind in your own way and in your own time frame.

This manual is designed to provide practical information to help you and your family in the days and months ahead. We hope this information will be helpful to you, and we urge you to call our office or ask our patient care staff about any questions you might have.

It is the Mission of Franciscan Hospice

To provide dignified, comfortable care to the terminally ill of our community

To assure the long-term mental and physical health and well-being of survivors

To enhance the care of all dying in the community by education and example

To serve as a symbolic reminder to the community that death is a part of life for all

Hospice
A Special Kind of Care

A Group Approach to Care

Physician Services

- Serves as a key member of your Hospice team.
- Provides medical direction to the Hospice team in the development, provision and revision of your plan of care.
- Provides physical and emotional support to you and your family during the terminal phase of this illness.
- Participates with your Hospice care team in the management of pain and other symptoms with a goal of comfort care.
- Coordinates with your primary physician with regard to your care plan.

May I keep my regular doctor?

Your regular doctor usually will continue as your primary care physician. Your physician will continue to provide medical direction to the Hospice team with regard to your medications, treatments, changes in your care plan and any other questions or concerns you, your family or the Hospice team may have that affects your care. The Hospice nurse is primarily responsible for keeping your doctor informed and up-to-date on how you are doing. Occasionally, the Hospice medical director for Franciscan Hospice assumes care for you if you do not have a physician or your regular doctor can no longer follow your care needs. Occasionally, a Franciscan Hospice physician assists your regular physician by consultation with regard to your plan of care.

Hospice Nurse

- Assesses your medical needs and coordinates with your physician and other team members to achieve physical and emotional comfort.
- Provides education to you and your caregivers concerning the needs of seriously ill individuals.
- Assesses current needs for medication and equipment, and anticipates future needs.
- Provides 24 hour consultation and/or home visits, for problems, questions, concerns or needs.
- Recognizes this new experience by listening to you, teaching you, helping you to clarify your choices, and by providing a sense of normalcy to this experience.

Does the nurse talk about this life limiting illness?

The nurse provides the opportunity to talk about the impact of this illness on you and those who love and care for you. It's up to you to decide if or when you are ready to share those thoughts. Hospice values the experience of preparing for one's own death in ways that are important to you and your family.

When does the nurse visit?

Nurse visits depend on your needs. The frequency and length of those visits change with your needs. Your primary nurse works Monday through Friday. On-call staff are available 24 hours a day for your evening and week-end needs. When you call the office after hours, you will be connected to an answering service. The answering service will have a hospice nurse call you back within 10 minutes. Your hospice nurse will explain this in more detail at the time you begin to receive hospice care.

Hospice Social Worker

People often mistakenly identify the social worker as an agent of a government or state agency. In actuality, the social worker is a trained counselor who will help you prioritize what is important to you. The social worker supports you and your family emotionally and can facilitate individual or family conferences to provide support to all who are affected by your illness. The Social worker:

- Educates and makes referrals to resources to meet needs such as caregiving, homemaking, respite, food and shelter, legal assistance, and funeral arrangements.
- Works on such things as life reviews (recalling memories of your life) or leaving a legacy of audio or video tapes, written messages or photos. These activities help to accentuate the joys and landmarks of your life.
- Helps you examine relationships you may want to strengthen.
- Supports you and your family through the anticipatory grief process and helps to prepare your survivors for the grief they will experience later.

When does a social worker visit?

Visits vary patient to patient. The social worker will visit on a schedule that will attempt to meet your and your family's needs.

Hospice Chaplain

The chaplain is an integral member of your hospice care team and is available to support you emotionally and spiritually during this part of your life.

You may ask the chaplain to help with life changes, decision making, relationships, life values and matters of faith, troubling feelings or whatever is most important to you. The chaplain can be a partner in prayer or simply a good listener during difficult times.

While all chaplains have an advanced ministerial education, they also receive specialized training in hospice care and the unique spiritual issues that can arise with serious illness, loss and grief.

What about my family and friends?

The chaplain is there to support your life, that means supporting the people you care about and those who care about you. This is a new experience for all of you.

What if I'm not religious?

The chaplain's first concern is that this time of your life be as satisfying and as rich as possible. Religion may or may not be a part of that. Belief in a higher power may not even be a part of that. Only you can say what makes your life good. The chaplain follows your lead and is there to support whatever gives your life meaning.

What if I have my own church?

The chaplain will be happy to assist your religious or spiritual community or faith leader, if you wish, or just provide a little extra support. Sometimes a person will be far away from their home church when they come on hospice service. In such cases the chaplain can sometimes arrange to bring the sacraments, rituals or prayer services of your tradition directly to your home.

The hospice interdisciplinary group collaborates on an on-going basis with a patient's physician to develop and maintain an individualized plan of care based on the needs of the patient and family.

Who decides if I need a chaplain?
You do. If you feel unsure, you may want to schedule a get-to-know-you visit to see if you and the chaplain are a good fit. You may discontinue chaplain visits at any time.

Request for chaplain support may be made at the time of admission to hospice service or any time afterwards through your nurse, social worker or certified nurses's aide.

When does the chaplain visit?
After the first visit the chaplain will ask if you would like more visits. The frequency of visits will depend on your preference and the chaplain's existing schedule.

Will the chaplain help with funeral or memorial services?
The chaplain will be glad to help you or your family make plans for these important events. However, chaplains are not available to officiate at these services.

Certified Nurses Aide

Providing assistance with personal care is the primary responsibility of the aide. The aide visits depending on your needs. The aide may help with shampooing, shaving and other general grooming as well as changing bed linens to make you feel clean and refreshed. The aide can also train other family members who care for you.

How long will the aide stay in my home?
The aide's visit usually lasts an hour. If you need more care in the home, ask to speak with your social worker. Your social worker can assist you in obtaining extra caregiving in the home.

What supplies will the aide need?
A clean washcloth and several towels, soap for bathing and any other toiletries you normally use would be helpful to have ready. These items might include shampoo, cornstarch, toothbrush, toothpaste, lotion, and a comb or brush.

How are aide services initiated?
Your hospice nurse will arrange for aide services to begin. A staff member will call you to set up a visiting schedule. The nursing assistant will provide your hospice nurse with any changes related to your comfort that he or she observes. The nursing assistant may provide personal care and assist with activities of daily living.

Bereavement Counselor

The Bereavement counselor provides support and education to help families understand their grief journey after the death of a loved one. The bereavement program provides follow-up for 16 months which includes the following:

- Periodic mailings to provide information, support and inspiration
- Growing Through Grief - Eight-week support groups offered quarterly
- Annual Special Events
  Spouse Loss Brunch (February)
  Living with Parental Loss (May)
  Living with Grief and the Holidays Seminar (November)
  Celebration of Life (December)
  Newly Bereaved Drop-in Group (monthly)
- Contact with a Bereavement Counselor for those seeking additional support

How do I receive the periodic mailings and contact from bereavement staff?
When a patient is admitted to Hospice, the Social Worker will provide you a packet of information. Included in this packet is a violet colored form, "Franciscan Hospice Support Mailings". Please complete this form and return it to a hospice staff member to ensure you receive our mailings.

How much does it cost to receive bereavement support?
The Franciscan Hospice Bereavement Program is included as a covered benefit under most insurance plans and is also made possible through donations to the Franciscan Foundation.

Hospice Volunteer

A volunteer provides emotional, physical, and spiritual support to the patient and their family depending on the need. Volunteers go through extensive training to understand the needs and experiences of terminally ill individuals and their families. Volunteers may:

- Stay with the patient so that caregivers may leave the home for short periods, rest, or to accomplish other tasks
- Provide transportation for doctor appointments and other outings
- Help with shopping and assisting with household tasks such as preparing light meals
- Assist with child care, writing letters, reading to the patient or running errands
- Provide companionship to both the patient and caregivers in homes and nursing homes

How many hours can a volunteer help?
A volunteer will usually help from one to four hours a week. When a volunteer is assigned, the time and schedule will be mutually worked out between the patient, family and volunteer.

How do I get a volunteer?
Make a request for a volunteer to your hospice nurse or social worker.

Other Members

Other specialists provide services to you on a consulting basis. As needed, your hospice nurse will refer you to the following services:

- **Pharmacist.** Can assist you and your nurse with medication education and symptom management
- **Dietitian.** Can assist you and your family to meet your nutritional needs
- **Physical Therapist.** Can help you and your family maintain your mobility and strength
- **Occupational Therapist**. Can assist you and your family to adapt your home to provide you as much independence as possible
- **Speech-Language Pathologist.** Can assist you with swallowing problems and find ways to help you communicate.

You and your family are unique, and the way in which you deal with this stage of life will also be unique.

Comfort Therapies

We are proud to be the first Hospice in the community to expand our service to include massage, music, art, relaxation and aroma therapies. The program is funded through the generosity of the community and the patients and families we serve. These comfort therapies help to decrease pain and increase quality of life.

You may select one or more therapies for a maximum of eight sessions. Massage therapy is the only one which requires an order from your doctor.

These therapies are available to all patients without charge. If you would like to participate in meeting the cost of the comfort therapies, a donation to the Hospice program would be greatly appreciated.

Therapeutic Music

Music touches the soul in ways words cannot. Music can stimulate memories of past years and events that can help summarize life in a meaningful way. Music can help decrease depression and uplift spirits to bring peace. By helping the patient relac, music assists medications to work more directly. Franciscan's Music Practitioners provide live music to meet the taste and individual needs of each patient.

Art Therapy

Art therapy is a refuge from stress. It can be a diversion from pain and anxiety. Art expresses emotions and increases quality of life. It stimulates memory and provides relief from isolation and boredom as it increases self-esteem and dignity. The artwork is a legacy for family members and friends. The art therapist provides art material and teaches activities that are tailored to the patient and his or her physical abilities.

What kind of art activities may be used? Collages, cut snowflakes, clay work, painting, water color and acrylic, weaving, paper mache, use of chalk, crayons, markers and bead and jewelry making.

Massage Therapy

A massage therapist gently strokes skin and muscles providing great comfort to the body, particularly for those who are often isolated from touch. Massage can promote relaxation by decreasing anxiety and relieving stress. Massage can also decrease pain, improve sleep and reduce feelings of loneliness. The massage can be as light as necessary for comfort. Massage may also decrease swelling and improve circulation. Lotions, oils, scents and music are often used to enhance the massage experience.

Are male and female massage therapists available?
Yes. At your preference, a male or female massage therapist will be provided.

May massage be given to clothed patients?
Absolutely. The patient's comfort is of prime importance. Massage may be given to those who are fully clother.

Is massage helpful in the last few days of life?
Yes, touch is almost always comforting.

Relaxation Therapy

The hypnotherapist is a specialist in relaxation therapy. A hypnotherapist listens to your concerns and symptoms and helps you to create images which help your mind and body to relax. Relaxation therapy can help control pain, nausea, and other medical symptoms. It can help decrease anxiety, worries and fears. The experience is similar to daydreaming, relaxing or imagining.

Do I have to be hypnotized during a relaxation session?
No, only if you desire. You will remain aware and in control at all times.

Will relaxation honor my religious beliefs?
The therapist will tailor your session to fit in with your belief system. The therapist will attempt to use words which honor your religious faith. Feel free to give them any directions which make you feel comfortable.

Aromatherapy

What is aromatherapy?
Aromatherapy is the use of essential oils, which are natural, high quality, pure oils derived from the distillation of plants.

What does Aromatherapy do for me?
Aromatherapy has three main functions: to reduce stress, to balance and increase one's sense of well being, and to treat physical and mental ailments.

How are the oils used?
The oils can be inhaled with steaming water, breathed through a diffuser or breathed through personalized spray bottles.

Hospice and Insurance

Hospice services are now covered under nearly all insurance plans. However, the coverage and payment rates vary greatly from plan to plan. If you have any questions about your coverage, please call the Hospice office and ask to speak with a reimbursement representative. Franciscan Hospice will always provide care for those who are unable to pay for services.

Medicare, Tricare and Medicaid hospice benefits

The following chart details the specific services available to persons covered by Medicare (Part A), Tricare, and Medicaid who elect to use their specialized hospice benefits. In addition to having one of these forms of insurance coverage, a patient's physician and the Hospice medical director must certify that a patient is terminally ill with a prognosis of six months or less. Patients with a terminal prognosis of greater than six months may still be eligible for some hospice services (this is subject to care needs, insurance coverage and place of residence).

Coverage and payment rates for hospice services vary greatly from plan to plan. If you have any questions about your coverage, please call the Franciscan Hospice office and ask to speak with a reimbursement representative.

Medications

Medications for pain relief and symptom management are usually provided through Franciscan Hospice's own pharmacy. Having our own pharmacy allows us to deliver medications directly to you and to provide the highest quality of pharmacy service. Your hospice nurse will review with you the procedure for refilling medications.

The hospice nurse will be asking your physician to order a small supply of medicines called "comfort kit" for use in the home and will review these medicines with you. The medicines in this comfort kit are used for specific symptoms that may arise. Do not use these medications unless instructed by the hospice nurse.

Medical Equipment

Often medical equipment will be needed at home or in the nursing home. These items are usually provided as a covered benefit through your insurance coverage. The hospice nurse will help arrange for delivery of these items. Franciscan Hospice operates its own medical equipment service. This allows us to provide the highest quality of medical equipment and service directly to you.

MEDICARE, TRICARE, MEDICAID INSURANCE PLAN	HOSPICE BENEFIT COVERAGE
Intermittent visits by hospice interdisciplinary team	100%
Drugs for pain relief and symptom management	100%
Medical supplies	100%
Medical equipment	100%
Inpatient respite care (short-term nursing home stay)	100%
Continuous nursing care in the home during a crisis period	100%
Bereavement services	100%
Authorized inpatient care for acute pain and/or symptom management	100%
All other insurance plans	

Franciscan Hospice House

Franciscan Hospice is the largest, most comprehensive provider of hospice care in the South Puget Sound. We have offered care here for 15 years, and have completed the continuum of hospice care by adding an inpatient hospice facility, known as Franciscan Hospice House.

A Unique Approach

As our region's only inpatient hospice facility, Hospice House:

- Assists hospice patients who require a higher level of care in avoiding rehospitalization.
- Allows family and patient to transition between care venues, for example, between hospital and home.

Franciscan Hospice House has provisions for family to stay with loved ones (by providing hide-a-beds and separate bedrooms) and to participate in patient care (through flexibility in preparing meals, providing spiritual care).

Special Features of Franciscan Hospice House

- Comfortable furnishings, lighting, plants and artwork that create a homelike environment.
- Kitchen/family room devoted to family needs
- Garden areas with walkways and a meditative setting inviting to family and patients
- Meditation chapel for prayer and meditation
- Highly qualified and trained staff to provide compassionate and comprehensive end-of-life care
- Trained community volunteers
- Comfort therapies (massage therapy, music therapy, art therapy, aromatherapy) to enhance patients' quality of life.

Type of Care

Short-term hospice care is provided in 20 single patient rooms to patients facing imminent death whose symptoms are no longer manageable in the home. Short-term care may also be provided to patients in transition between the hospital and home.

Hospice in Nursing Homes

Why would a person living at home with a life threatening illness want to move to a nursing home?

Many times as the illness progresses, the responsibilities of caregiving grow beyond the capacity of family and friends. When that happens, the work aspect of caregiving can become overwhelming. When the loved one's care is transferred to the professional staff of a nursing home, family and friends may once again able to be the loving supporters they desire to be.

Hospice serves the patient and family in either the private home or the nursing home. The role of the hospice team is to provide the professional coordination for all caregivers,

The need to enter a nursing home always presents difficult choices for a family. Even though the decision is made in order that your family member will receive the quality of care you desire, family members often feel guilty or burdened by the decision. The Hospice team understands these feelings and will be able to support you in this caregiving decision.

Hospice serves the patient and family in either the private home or the nursing home. The role of the hospice team is to provide professional coordination for all caregivers. And, of course, whatever services hospice paid for when the patient was at home (medications, equipment, visits by hospice staff) are also paid for in the nursing home.

How to choose a nursing home.

You will find a list in this booklet of nursing homes currently working with Franciscan Hospice to provide hospice services for their residents with terminal illness. This list does not include all the facilities available in Pierce County and is not intended to restrict your choice.

Many families say that the most important reason they had for choosing a nursing home was its location. So we have listed the facilities according to their location. The booklet *When Someone You Love Needs Nursing Home Care* is available from your hospice nurse or social worker, who will also give you personal assistance in choosing a facility.

How can I find out more about insurance benefits for hospice in the nursing home?

If your loved one is already admitted to hospice as a home patient, ask your hospice nurse or social worker for information.

A Message to Caregivers

(Adapted from the book *Taking Care of Your Aging Family Member* by Nancy Hooyman and Wendy Lustbader)

It is important to realize that although disease and its symptoms happen to the patient, illness affects the entire family. Caring for the terminally ill loved one can be rewarding, but it is physically and emotionally draining for both the caregivers and the rest of the family.

You are an important person with an extremely important role to play in caring for your loved one. It's important for you to develop ways of self-care to protect your own physical and emotional well being. Small things you do for yourself can make a big difference. Some suggestions for staying strong are:

Accept help

Friends, family and hired assistants can be a source of great support. Accepting help isn't a sign of weakness or failure on your part. Not accepting help can lead to burn-out. In accepting assistance, you need to tell people specifically what you need help with. Examples are yard work, errands, bringing in food, sitting with the patient while you rest or get out. Remember, most people sincerely want to help. They may need you to tell them what to help with and how they may best support you.

Take time for yourself

Pleasurable events are a time of renewal. They can include a long walk, time with a supportive friend, reading a novel or having a leisurely bath. Taking time for yourself allows you to focus on other aspects of life. Set a goal of at least one outing per week and designate a time and date. Be sure to pay attention to the enjoyable feelings derived from your leisurely activities so you can recall them when needed.

It is imperative that you pay attention to your own physical needs

You may get so busy with being a caregiver that you forget your own diet and fitness. Frozen dinners with good nutritional content are one way to assure that you are getting what you need. Food preparation by others gives them a way to help and gives you good nourishment.

Excercise regularly

Get some exercise—even a little helps. Exercising produces benefits of better sleep, increased energy, maintenance of the cardiovascular system, improved joint flexibility, and stimulation of the production of chemicals which alleviate stress. If you can't get out of the house, you can benefit from a stationary bike, aerobic tapes or records, and tension-releasing exercises which can be done while watching television or talking on the phone. If you have never exercised regularly, it may be hard to start now. However, even stretching exercises and very short walks can help.

Get uninterrupted sleep

Finding someone to provide occasional night duty can assure you a few restful nights. If you are having trouble sleeping, exercising late in the afternoon, avoiding naps, and drinking warm milk before bedtime can help you sleep. If you can't get a night of uninterrupted sleep at home, tell a Hospice team member. Local hotels are sometimes able to donate a night's lodging to families under hospice care.

Practice relaxation

Pause for five minutes to breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed and quiet state. A gentle shoulder and neck massage can help.

Keep your sense of humor

Laughter stimulates the production of body chemicals, which are natural anesthetics and relaxants. Acknowledge the funny aspects of the care situation and laugh at mistakes rather than feeling remorse—it can make the situation more manageable. Remember: You are important too.

Helping Children to Cope with Death and Grief

Children and grandchildren are an important part of families and are affected by the illness of a family member.

Until recently, it was thought that children, especially the very young, were unable to comprehend separation and loss, and therefore did not grieve. Based on more recent information, however, child development experts now agree that children do in fact grieve and that the effects of unresolved grief can be severe, even lasting into adulthood. Ways of helping children cope include:

- Giving prompt and accurate information about what is happening, allowing them to ask questions and receive honest answers
- Allowing them to participate in the family grieving process, including the funeral
- Reassuring them that the other family relationships are secure and that they will be taken care of and supported

Children and teens need clear, concise information about what is happening. It is far better for adults to name the disease—tumor, cancer, diabetes, for example—than to use vague terms such as "sick."

Children adjust and learn from the adults in their lives. When changes occur regarding a loved one, children can easily be prepared by stating the facts in simple language that they can understand. For example, "Grandpa has oxygen tanks in the house to help him breath," or "Mom is going to lose her hair because of the treatments she is getting to help her fight cancer."

If a close friend or family member is in the final stage of life, children should be given the choice to visit, touch and talk with them. This will provide an opportunity for the child to recall good memories, share feelings and say a loving farewell to the loved one. In addition, sharing family togetherness is important to the ill person. It can also help the child understand that death is a natural part of the life process.

A list of suggested books for children is available from Hospice. The local libraries can help you locate these books.

The hospice social workers and nurses are available to speak with you and the children in your family in order to help you cope as a family.

Activities of Daily Care (Basic Tips)

Hygiene

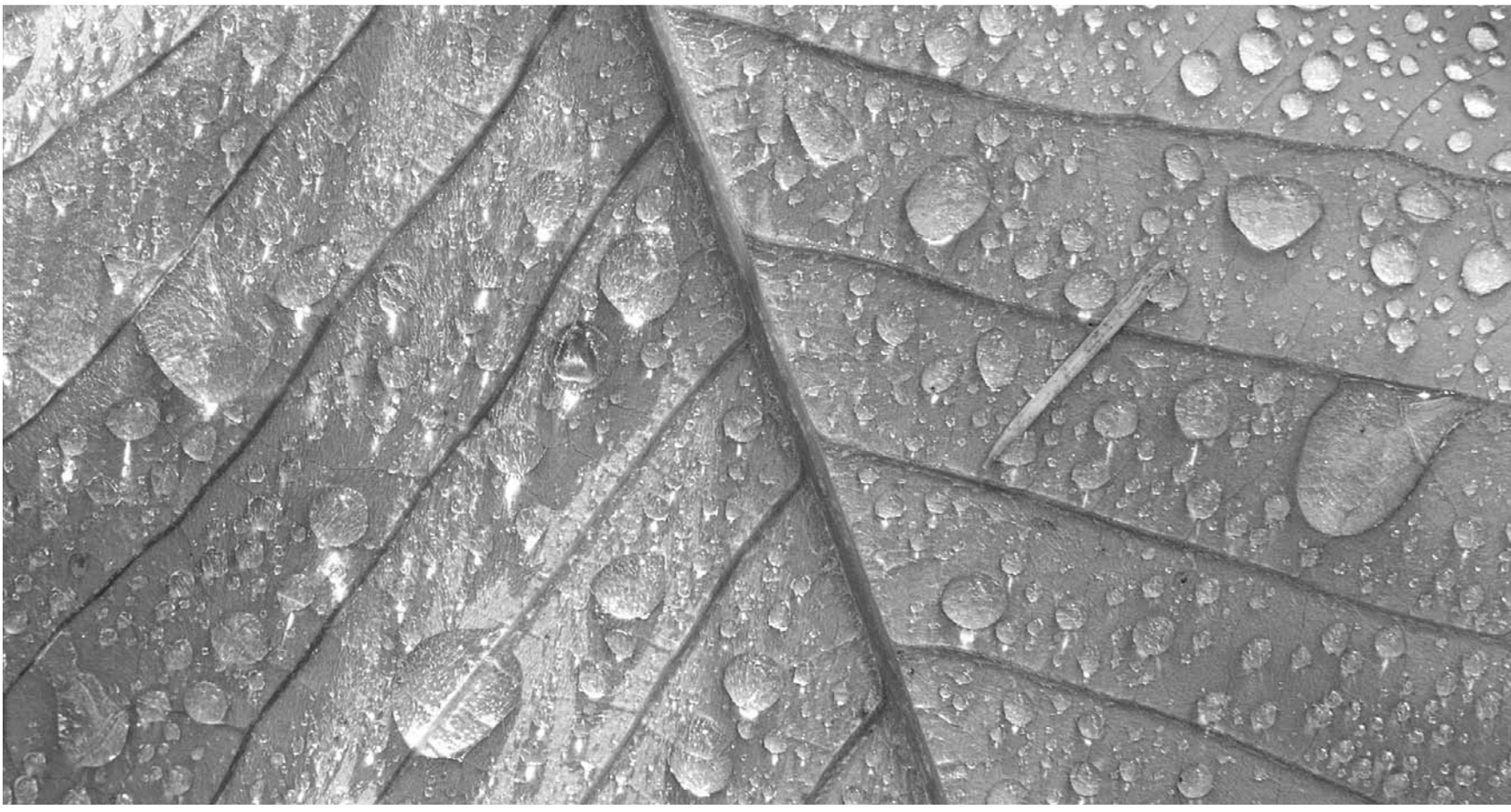
Bathing often feels good for the loved one who is bedbound. This activity provides cleanliness and helps to refresh the body and spirit. A bath is usually given in the morning when the individual has more energy but may be given at any time during the day.

Equipment

- Large bowl with warm water
- Soap and towels
- Light bed cover to prevent chills
- Lotion containing lanolin

How to provide hygiene

- Bathe only a small area at a time to avoid chills.
- Gently soap the skin, rinse and pat dry. Some soaps are rinseless—ask the hospice nurse.
- Begin washing the face and work down toward the feet.



- Don't forget to wash the back and apply lotion.
- After washing the feet, change the water.
- Gently wash and dry the buttocks and genitalia. Daily attention to this area is especially important since bacteria tends to collect there. A skin-protecting lotion or ointment should be applied if control of stool or urine is a problem.
- Sheets should be changed at least weekly. This task usually requires two people.

Remember

- Give pain medication one hour before bathing if movement is painful.
- Use a light blanket or sheet during the bath to avoid chills. Provide plenty of privacy.
- If the individual is unable to t tolerate a full bath, offer to wash the face, hands, back and genital areas only.

- Avoid powders. Cornstarch is a good substitute and can be lightly sprinkled on the linen.
- Personal grooming often helps improve your loved one's attitude and increases a sense of dignity and respect.
- If moving does not cause pain, exercising the arms and legs can be done during or after the bath. Passive exercises can help maintain muscle tone. Please check with your hospice nurse before exercising your loved one's arms or legs.

Mouth Care

Cleaning the mouth provides several benefits for your loved one. Regular mouth care helps prevent sores and may improve the appetite.

Equipment

- Soft toothbrush or Toothette
- Toothpaste
- Mouthwash (alcohol-free) or a homemade solution of a tsp. baking soda to 2 cups warm water.
- Cool water
- Small basin
- Dry towel
- Water-soluble jelly

How to provide mouth care

- To promote independence, allow your loved one to clean their own mouth.
- Raise the head to a half-sitting position to prevent choking.
- Put a dry towel under the chin.
- Moisten the toothbrush or Toothette and apply toothpaste or mouthwash.
- Gently move the brush or Toothette over the teeth and gums.
- Rinse the mouth with either cool water or diluted mouthwash.
- Apply a small amount of water-soluble jelly to the lips to prevent drying.
- Individuals with dentures should continue their usual denture cleaning routine and schedule.
- As the individual loses weight, dentures may not fit properly and cause additional mouth sores. You may want to consult your dentist about lining dentures for a better fit.
- Try to provide mouth care twice daily.

Remember

- Do not attempt to wash the mouth with a toothbrush or oral swabs if the mouth is very sore. Offer to rinse the mouth with mouthwash or cool water.
- Always raise the head to avoid choking.
- If the mouth is very sore, your Hospice nurse can give you special instructions.
- Report any discoloration or white patchy areas in the mouth or on the tongue to the nurse.
- If dry mouth is a problem, sugar-free hard candy or ice chips can be helpful.

Skin Care

The skin is the body's natural barrier against infection. Unfortunately, as the body becomes weaker, pressure ulcers are difficult to prevent. Pressure ulcers often increase as the person becomes immobile. Skin over a bony area becoming reddened or purple is the first indication of the development of a pressure sore. The following recommendations can help prevent skin breakdown.

How to provide good skin care:

- Keep the skin clean and dry.
- Keep the bed linen dry and wrinkle free.
- Provide pain medication as needed when turning the individual.
- Position the individual off the pressure-sensitive area.
- Use pillows or other supportive devices to maintain good body alignment.
- Explain to your loved one the importance of changing position every two hours or so.

Always check the skin during the daily bath. If you see reddened areas, tell the Hospice nurse. Other devices such as air mattresses or special pillows can help in maintaining the skin.

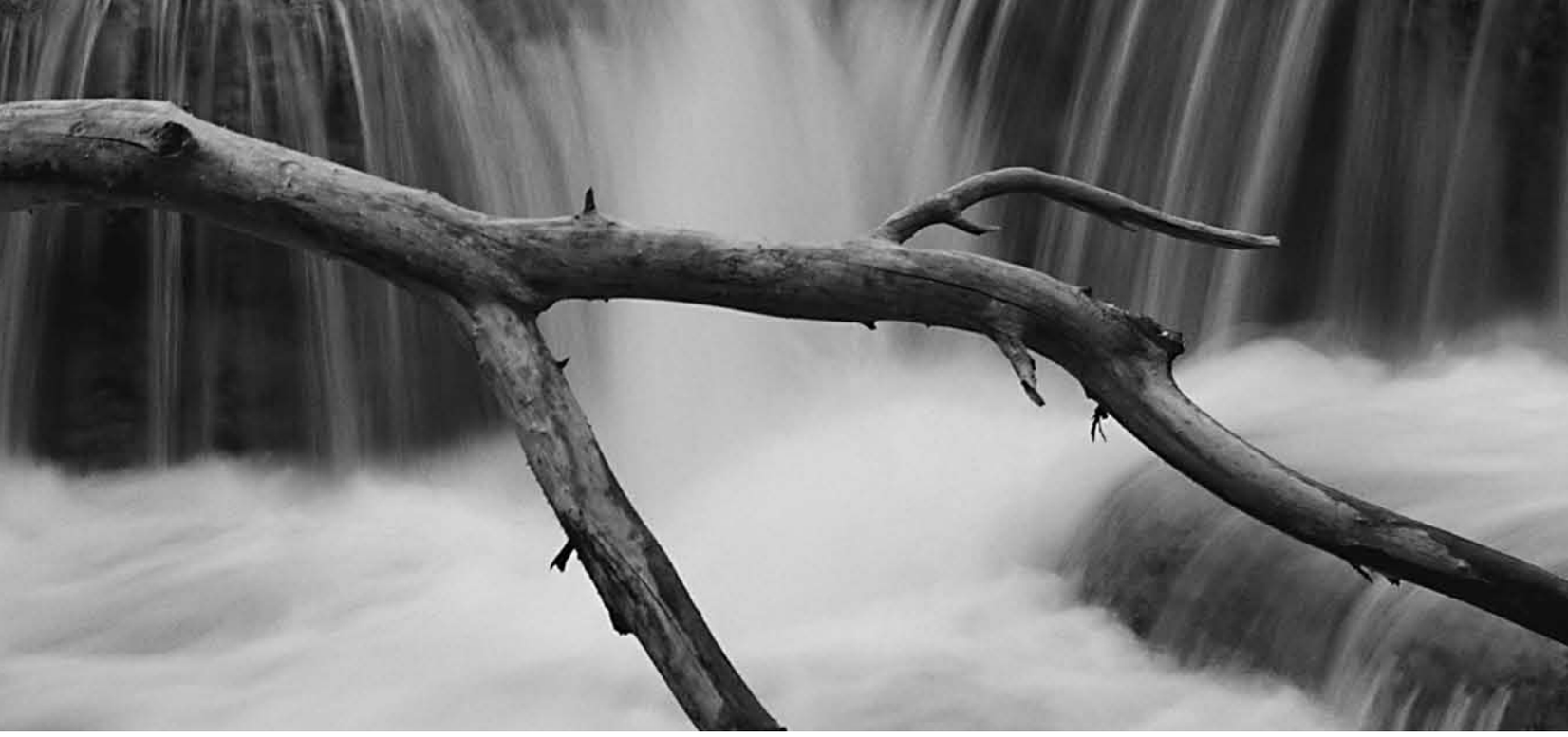
Nutrition

Anytime someone is ill, their appetite decreases, whether the illness is the flu, an injured ankle, or a cancer-related process. The body's need for calories and protein-rich foods is altered because of decreases in activity, exercise, and general metabolic rate. If we "listen" to our body, it will tell us exactly what it needs in order to sustain life. As the body's systems begin to shut down, the body is no longer able to digest or use food and fluids. A decrease in food or fluid intake is normal.

How to provide nutrition:

- Do not force the patient to eat or constantly remind them of the need to eat in order to get better. Offer food and drink but do not force. Eating is the choice of the individual.
- Serve the meal in small portions and in a relaxed and comfortable atmosphere. Suggest the family eat together. Foods attractively served in a social atmosphere often increase the appetite.
- Remove unpleasant odors and avoid unpleasant procedures before meal time.
- Mouth care before meal time often stimulates the appetite.
- Appetite tends to decrease later in the day. Breakfast may be the best meal of the day.
- Allow the individual to rest after meals.
- Small, frequent meals are more likely to be tolerated as the appetite lessens.

Personal grooming often helps improve your loved one's attitude and increases a sense of dignity and respect.



Fluids and Drink

Fluids are important for the body. They are necessary to keep the skin healthy and the mouth moist. Fluids also help the body remove waste products through the stool and urine. Fluid needs typically decrease as the disease progresses.

How to provide fluids:

- Do not force the individual to drink. Offer drink at times when the individual is most likely to want a drink.
- High-calorie, high-protein drinks are very nutritional and can help the body maintain strength. The Hospice nurse or dietitian can suggest what drinks may be most appropriate.
- Keep the head of the individual in a half sitting position when offering liquids.
- Avoid the use of straws. Frequently, individuals will swallow air and become more nauseated. Ice chips, Jello and popsicles are other ways to give liquids to individuals who are very weak and have difficulty swallowing.

Elimination

The elimination of urine and stool is the body's way of removing waste products. Problems with elimination may cause discomfort, anxiety and embarrassment.

Urine

Urine is composed primarily of the body's waste products dissolved in water. For the person confined to bed, a bedpan or urinal is needed to collect the urine. When the person is not able to control urinary flow, protective underwear may be used. Other options should be discussed with your Hospice nurse.

For many patients, a soft catheter (tube) can be used in order to control the natural flow of urine and to drain the patient's bladder. With the consent of the doctor, the nurse may place this catheter. The nurse will teach you how the catheter works and how to care for it.

Remember:

- Always wash your hands before and after working with the catheter or drainage bag, even when wearing protective gloves.
- Check the drainage tubing for any kinks and make sure the drainage bag is below the level of the patient to allow drainage by gravity.

Care of the patient with a catheter

It is important to clean the area around where the catheter enters the patient's body. This should be done during the patient's bath. Gently wash the area with warm water and a mild soap; rinse and then pat dry. Your hospice nurse will teach you how to clean the catheter.

Sometimes, the catheter may become blocked because of sediment in the urine. Catheter blockage should be suspected if urine flow has stopped. Check to see that there are no kinks or loops in the catheter tubing and that the drainage bag is below the level of the patient. Your hospice nurse will teach you how to irrigate the catheter and will provide you with the necessary supplies.

Remember:

- Keep the bedpan close to the patient to avoid accidents.
- Place waterproof bedding under the patient. If leakage should occur, the pad may help to prevent additional changes of the entire bed linen.
- After each stool, the rectal area should be washed with a mild soap and water, and dried thoroughly and gently. A skin protection lotion should be applied.
- Encourage the patient to drink fluids as tolerated.
- Give the patient privacy.
- Wear gloves and wash your hands after helping the patient with toileting. Wash the patient's hands as well.
- Check for any leaking around where the catheter enters the body. If you see leakage, tell your Hospice nurse.
- Empty the drainage bag twice a day, or as instructed by your Hospice nurse.

Stool

Bowel habits differ from person to person. Some people move their bowels once a day, while others may only move theirs two to three times a week. With the hospice patient, bowel movements are less frequent and constipation often occurs. Inactivity, pain medication and decreased food intake can frequently cause constipation. The best treatment for constipation is prevention. The following suggestions are offered to help prevent constipation.

Remember:

- Try to eat fruits and vegetables.
- Drink plenty of water and juices.
- Exercise as tolerated.
- Set aside a quiet time each day with plenty of privacy to sit on the toilet or commode.
- **Notify your hospice nurse if the person has not had a bowel movement for three days.**

Your hospice nurse will suggest non-prescription laxatives to assist the patient in maintaining regular bowel function.

Yakima Fruit Paste Recipe

DOSE: 1–2 tablespoons per day

1 pound prunes	4 oz senna tea
1 pound raisins, pitted	1 cup brown sugar
1 pound figs	1 cup lemon juice

1. Prepare tea. Use about 2 1/2 cups boiled water added to tea and steep 5 minutes.
2. Strain tea to remove tea leaves and add only 1 pint tea to a large pot; then add fruit.
3. Boil fruit and tea for 5 minutes.
4. Remove from heat and add sugar and lemon juice. Allow to cool.
5. Use hand mixer or food processor to stir fruit mixture into smooth paste.
6. Place in plastic container and place in freezer. (Paste will not harden.)
7. Spoon out what you require each day.

Enjoy eating fruit paste straight off the spoon. Spread it on toast or add hot water and make a drink.

- If the fruit paste is not working (no bowel movements), then increase the amount of fruit paste each day.
- If the fruit paste induces very loose stools, cut down on the amount of fruit paste intake. Consider taking it every other day in some cases.

For questions or problems with the fruit paste, contact your home care or hospice nurse.

Diarrhea

Frequent watery stools accompanied by stomach cramping may become a discomfort for the patient. Notify your Hospice nurse should diarrhea occur. Non-prescriptive medication can be effective to control diarrhea, although stronger medication might be necessary to eliminate this problem.

Remember:

- Keep the bedpan close to the patient to avoid accidents.
- Place waterproof bedding under the patient. If leakage should occur, the pad may help to prevent additional changes of the entire bed linen.
- After each stool, the rectal area should be washed with a mild soap and water, and dried thoroughly and gently. A skin protection lotion should be applied.
- Encourage the patient to drink fluids as tolerated.
- Give the patient privacy.
- Wear gloves and wash your hands after helping the patient with toileting. Wash the patient's hands as well.
- Talk to your hospice nurse about non-irritating foods and beverages.

Body Mechanics

When a patient is confined to bed, frequent changes in the patient's position are very important. This can help the patient feel more comfortable. Changing the patient's position prevents bed sores and stiffness of joints. The patient's position should be changed every two to four hours.

Remember

- Explain to the patient what you are about to do. This will minimize fear and encourage cooperation.
- Encourage patient independence.
- Use a "pull pad" whenever possible.
- Loosen the bed linen and remove extra pillows.
- Support the arms and legs with pillows or rolled towels.
- Check all tubing to ensure it will move freely.

When turning the patient from back to side:

- Move the patient to the near side of the bed beginning with the head and shoulders, the trunk, and then legs and feet.
- Make sure all tubing is free with enough slack to allow the patient to turn without pulling.
- Flex the patient's nearest knee as tolerated to the point where the foot is nearly flat on the mattress. The flexed knee acts as a fulcrum when turning the patient.
- If the patient is already on a pull pad, use the sheet to maintain body alignment.
- Adjust the patient's hips and shoulders so that they are at a right angle to the mattress. This will help maintain the patient's position on their side.
- Support the patient's joints with pillows to maintain good alignment.
- Check the patient's shoulder and arm to make sure they are not lying directly on it.
- Place one or two pillows under the patient's knee and back, supporting the patient's hands and feet with pillows or rolled towels.

Good body mechanics are essential to avoid injury from lifting patients. It also helps the patient to feel confident and safe.

Remember:

- Two people are better than one when lifting or moving a patient.
- Tell the patient what you are going to do before moving them.
- Stand firmly on the floor and as close to the patient as possible.
- Always flex your knees when lifting.
- Avoid twisting or turning your back.
- Stand directly in front of the patient when transferring the patient in and out of bed.

When the patient needs to be moved up in bed:

- Assist the patient to flex his or her knees.
- Move to the head of the bed (hospital bed only).
- Place both hands under the patient's shoulders.
- On signal, help the patient to move upward as they plant their heels into the mattress.

Repositioning the patient requiring two persons:

- Turn the patient from side to side, positioning a pull pad under the patient's hips and lower back.
- Roll both ends of the lift sheet towards the patient until they are snug against the patient's hips.
- On signal, lift the patient together.

Transferring the patient in and out of bed:

- Place the bed in a low position.
- Determine if the transfer will be from the right or left. Always have the patient assist using their strongest side. This determines the direction of the wheel chair, recliner or bedside commode.
- Remove arm rests or detatchable leg rests. from the wheel chair that are not necessary.
- Always lock the wheel chair.
- Assist the patient to sit safely on the edge of the bed.
- Stand in front of the patient.
- Wrap your arms around the waist in "bear hug" fashion and bring the patient to a standing position.
- Pivot and assist the patient to sit while bending your knees.
- Position patient's arms and legs. Support them with pillows if necessary.

Symptom Control

Managing Physical Symptoms

There are many potential physical symptoms related to life-threatening illness and the side effects of treatment. The following are effective ways of managing some of the more common problems. You will probably not experience all of these, but you should be aware of helpful ways to manage them if they occur. Please be sure to notify your nurse about physical symptoms you are experiencing.

Pain

Pain is both a physical sensation and an emotional experience. We want to help you with pain management so together we can work toward maximizing your comfort as much as possible. Having a life-limiting illness does not necessarily mean you will experience pain. If you do experience pain, you can be confident that medications and other interventions are available to ease the pain. The overwhelming majority of hospice patients can be kept comfortable.

How to help us help you

Your nurse may ask you to describe your pain. If you use the same system each time, you can tell us how your pain changes over time. This helps us to determine how much relief you are getting from your pain medicine. One way to do this is by using the 0–10 scale. In this method, 0 equals no pain and 10 equals the worst pain imaginable. The scale below demonstrates this idea

If the score goes down, the plan for your pain is working. If it goes up, perhaps you need more medication or a different schedule.

Anxiety, tension and pain

Anxiety, tension and depression can add to your pain. They do not necessarily cause pain, but they can compound your pain experience. One of the major benefits of achieving pain relief is that anxiety is also reduced.

Basic principles of pain management

When you experience pain, it is important to understand the preventive approach. An important part of that approach involves taking pain medication on a regular basis instead of simply as needed. If you wait too long to take your pain medication, the pain can become so severe that the medication is no longer effective. Taking medication as scheduled will help prevent pain from returning. Once you become pain free, it is important to continue the medication schedule set up by your nurse as a preventative measure. Maintaining a regular medication schedule is the best means of managing pain.

Concerns About Medications

Many people who take pain medications express concern about the possibility of addiction. It is important to understand the definition of addiction and other terms related to the use of drugs.

Drug abuse is the use of a drug in a manner that is not medically necessary. Addiction is a pattern of overwhelming desire in obtaining and using a drug for its effects on the mind. If you are concerned about these things, just ask yourself the following question: "If I didn't have pain, would I be taking this medication?" Your answer is probably, "Of course not!"

Types of Pain Medications

There are many different pain medications, both opioids and non-opioids. The amount and type of pain that you have will determine how much and what type of medication your doctor prescribes.

Non-Opioids

Non-opioids are pain medications which are used to treat mild or moderate pain. Two well known non-opioids are aspirin and acetaminophen. Both of these drugs can be very effective for many types of pain. They may be all you need to find relief, or you may need to take them along with another medication. Even though you can buy these drugs without a prescription, they need to be used with care. Always let your hospice nurse know if you are taking them because there may be times when you should avoid them. It is also important to know that aspirin is found in a wide variety of medications purchased without a prescription—be sure to read the labels.

There are other non-opioid drugs which are helpful in the relief of pain. These include medications to treat depression, muscle tension, anxiety, inflammation and others. Whenever you receive a prescription for such a medication, your Hospice nurse will discuss its purpose, side effects and actions with you.

Your hospice nurse will continually assess the patient's needs and discuss any recommended changes in treatment with you.

Opioids

Opioids are used for the relief of more severe pain. They are available only by prescription. Many people are concerned about the possibility of addiction with opioids. Again, it is important to remember that the only reason you are taking these medications is the relief of pain. This is an appropriate use of opioids.

Opioids come in many different forms—pills, oral liquids, topical gels, rectal suppositories and injections. A common myth about these medications is that an injection is necessary to achieve the best pain relief. That is not the case. The proper amount of medication taken by mouth will be equally as effective as injections.

In most cases, the appropriate use of opioids will relieve your pain. If your pain is not adequately controlled, your doctor may want to increase the dosage or increase the number of times you take medication each day.

Remember:

- Pain medication for chronic pain needs to be taken at regular intervals. The hospice nurse will help you establish the best times to use the medication.
- Pain medication can be taken before the patient experiences pain.
- Record the time you take your pain medication.
- All opioids need a written prescription signed by the doctor to be refilled.
- Opioids are likely to have a constipating effect on the bowels.
- Opioids often cause the patient to become sleepy, but as the body adjusts to the narcotic the sleepiness should diminish.
- Non-opioids such as ibuprofen should be taken with food if possible.
- Do not crush long-acting narcotic pills. If the patient is unable to swallow, tell the hospice nurse. A different route or medication may be indicated.

Call the hospice nurse immediately if

- Your loved one is unable to take the medication as prescribed
- Pain is experienced in new areas
- There is an increase in the intensity of pain
- There are concerns among family members about over-sedation
- The patient experiences symptoms of confusion, restlessness, "bad dreams" or hallucinations
- Equipment used to assist with pain relief is not functioning properly
- The loved one experiences nausea and/or vomiting

Nausea

Nausea means being sick to the stomach and vomiting means throwing up. Nausea and vomiting can happen even when a person is not near food or thinking about food. Some common reasons for nausea and vomiting are radiation or chemotherapy treatments, disease process or cooking smells. Sometimes diseases themselves may cause nausea and vomiting.

How to Help

- If the nausea occurs only between meals, give frequent small meals, snacks at bedtime, and leave food within easy reach.
- Seek out taste preferences; many patients develop a distaste for red meat and broths. Substitute other protein sources. Avoid fried and spicy foods.
- Avoid fatty and hard to digest foods.
- Serve food cold or at room temperature to decrease its smell and taste.
- Offer clear liquids (ginger ale, Jello, tea, popsicles).
- Have the patient rest comfortably in a quiet environment.
- Provide distraction such as soft music or favorite television show; stay and keep the person company.
- Provide good mouth care.
- Give appropriate medication to prevent nau sea, if ordered.

Call your hospice nurse immediately if:

- You are concerned that some of the vomited material has been inhaled.
- Vomiting episodes occur more than 3 times an hour for 3 or more hours.
- The person is unable to take their medications.
- Any blood or material that looks like coffee grounds appears in the vomit.
- The person loses consciousness.

Be sure to tell your hospice nurse about nausea or vomiting because there are several medications that can be given to help control this problem.

Breathing

Breathing difficulty occurs when not enough oxygen is delivered to the body. Either the lungs cannot breathe in enough air, or they cannot deliver enough oxygen to the bloodstream. A number of different problems can cause this difficulty including chronic lung disorders, airway obstruction, pain, stress or anxiety, or fluid in the lungs. You may see breathing changes as your loved one's disease progresses.

Remember:

- Be calm and reassuring.
- Have the person sit up. Occasionally leaning forward helps with difficulty in breathing. This position will help the lungs operate most efficiently.
- Raise the head of the bed or place more pillows behind the back.
- Avoid having the person lie flat.
- Fresh air or a fan on low setting may be comforting.

Call the hospice nurse if:

- The patient complains of difficulty breathing or chest pain.
- The patient coughs up thick yellow, green or bloody sputum.
- The patient's skin is pale or blue or it feels cold and clammy.

Your hospice nurse will continually assess the patient's breathing. If breathing problems exist, the nurse will discuss the possible need for additional medication or oxygen. If oxygen is needed, the nurse will order the needed equipment.

As the patient becomes weaker, clearing the throat may become more difficult and secretions may collect in the airway. If secretions can't be removed by coughing, the nurse will discuss various means of dealing with excessive secretions.

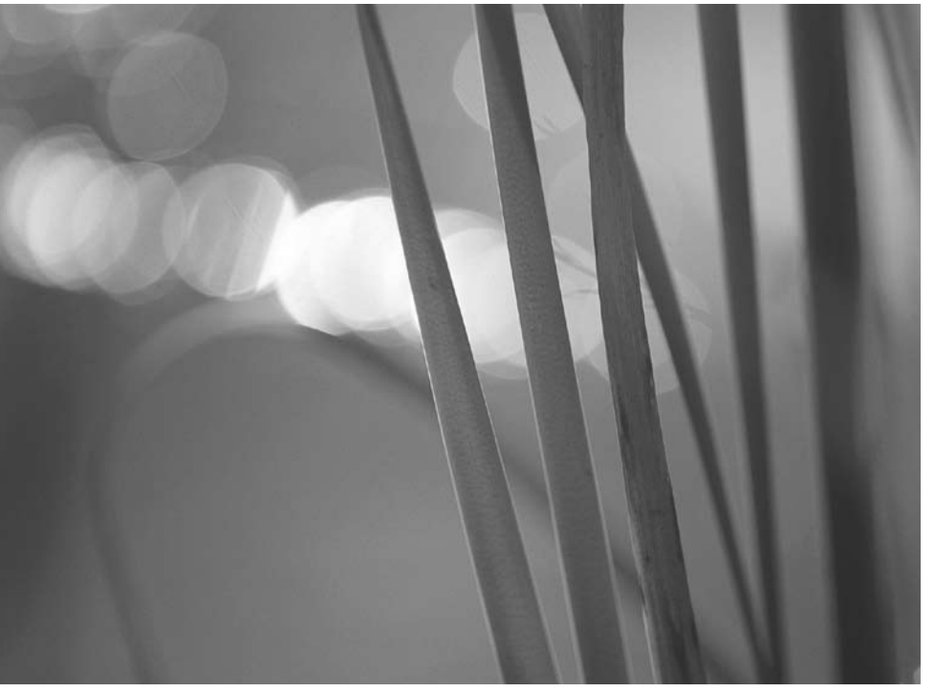
Anxiety, Fear and Depression

Some degree of anxiety, fear and depression can occur for persons coping with a serious illness. These feelings are normal.

For the patient, feelings of anxiety, fear and depression can be due to loss of family role, loss of control over events of everyday life, changes in body image, fear of uncontrollable suffering and pain, fear of the unknown, and fear of death.

Family members may experience these feelings because of the loss of their loved one, anger at why this person has to die, fear of the patient's death, frustration at not being able to "do enough," or stress due to increased responsibility at home.

If you or someone in your family needs support in dealing with anxiety, fear and depression, you may want to tell a hospice worker. The hospice care team knows many ways of helping people develop their own coping abilities.



Approaching Death

Adapted from Hospice of North Central Florida, Gainesville, Florida

When a person enters the final stage of the dying process, two different dynamics that are closely inter-related and inter-dependent are at work. 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 that are not medical emergencies requiring invasive interventions. These physical changes are normal, natural ways 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 is at work 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, its immediate environment, and all attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature and reception of permission to "let go" from family members. These "events" are the normal, natural way in which the spirit prepares to move from this existence into the next dimension of life. The most appropriate kinds of responses to the emotional-spiritual-mental changes are those which support and encourage this release and transition.

When a person's body is ready and wanting to stop, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, they may tend to linger even though uncomfortable or debilitated in order to finish whatever needs finishing. On the other hand, when a person is emotionally-spiritually-mentally resolved and ready for this release but their body has not completed its final physical stages, the person will continue to live until the physical shut-down is completed.

The experience we call death occurs when the body 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 life-style of the dying person.

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 of love you have to offer your loved one as this moment approaches.

The physical and emotional-spiritual-mental signs and symptoms of impending death that follow are offered to you to help you understand the natural kinds of things that 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.

Signs and Symptoms

1. **Coolness.** The person's hands and arms, and feet and then legs may be increasingly cool to the touch, and at the same time the color of the skin may change. The underside of the body may become darker and the skin become mottled. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric one.
2. **Sleeping.** The person may spend an increasing amount of time sleeping, appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to the changes in the metabolism of the body. Sit with your loved one, hold their hand; do not shake or speak loudly, but speak softly and naturally. Plan to spend time with them during those times when they seem most alert/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.
3. **Disorientation.** The person may seem to be confused about the time, place, and identity of people, including close and familiar people. This is also due in part to the metabolism changes. 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.
4. **Incontinence.** The person may lose control of urine and/or bowel matter 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.
5. **Congestion.** The person may have gurgling sounds coming from their chest as though marbles were rolling around inside. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp 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.
6. **Restlessness.** The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. 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.

7. **Urine Decrease.** The person'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.

8. **Fluid and Food Decrease.** The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy that is expended on these tasks. Do not try to force food or drink into the person or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person much more uncomfortable. Small chips of ice, frozen Gatorade, or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidance). A cool, moist washcloth on the forehead may also increase physical comfort.

9. **Breathing Pattern Change.** The person's regular breathing pattern may change with the onset of a different breathing pace. One particular pattern consists of breathing irregularly, i.e., shallow breaths with periods of no breathing of 5 to 30 seconds and up to a full minute. This is called "Cheyne-Stokes" breathing. The person may also experience periods of rapid, shallow, breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head, and/or turning the person on their side may bring comfort. Hold their hand. Speak gently.

Dealing with Grief

Grief is a natural response to loss. It is not a disease but a healthy process that mourners can pass through to adapt to change. Individuals grieve differently and there is no uniform way people cope with their feelings of loss. You may find it helpful to talk with friends. Naming our feelings aloud often helps us to adjust to our profound pain of loss. Family and friends are often a source of support during this time. Although no one will ever replace your loved one nor will any words lessen your pain, trusted family and friends are ready to listen and be there for you. If there are children in the home, you need not hide your sadness. Children understand when a person is sad and will learn that grief is part of life and is a natural experience when someone you love is dying. Dealing with grief takes time. It may last more than a year. Feelings of grief may be experienced at different times and in varying degrees of intensity. This work requires patience and the belief that you will survive. Hospice is ready to help you through this process.

Emotional-Spiritual-Mental Signs and Symptoms with Appropriate Responses

1. **Withdrawal.** The person may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of "letting go." 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."

2. **Vision-like Experiences.** The person may speak to persons who have already died or see places not presently visible to you. This does not usually indicate a hallucination or a drug reaction. The person is beginning to detach from this life and is being prepared for the transition so it will not be frightening. 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's not real to your loved one. Affirm their experiences. They are normal and common. If they frighten your loved one, explain that these are normal experiences.

3. **Restlessness.** The person may perform repetitive and restless tasks. This may in part indicate that something is still unresolved or unfinished that is disturbing them and preventing them from letting go. Your hospice team members will assist you in identifying what may be happening and help you find ways to help the person find release from the tension or fear. Other things that may be helpful in calming the person are to recall a favorite place or experience the person enjoyed, read something comforting, play music, and give assurance that it is okay to let go.

4. **Fluid and Food Decrease.** When the person may want little or no fluid or food, this may indicate that the person is ready for the final shutdown. Do not try to force food or fluid. You may help your loved one by giving them permission to let go whenever they are ready. At the same time affirm the person's ongoing value to you and the good that you received from them that you will carry forward into your life.

5. **Decreased Socialization.** The person may only want to be with a very few or even just one person. This is a sign of preparation for release and an affirming of who the support is most needed from in order to make the appropriate transition. If you are not part of this "inner circle" at the end, it does not mean you are unimportant or are not loved. It means you have already fulfilled your task with them, and it is the time for you to say "good-bye." If you are part of the final "inner circle" of support, the person needs your affirmation, support, and permission to let go.

6. **Unusual Communication.** The person may make a seemingly "out-of-character" or nonsequitur statement, gesture, or request. This indicates that they are ready to say " good-bye" and are "testing" to see if you are ready to let them go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry, and say whatever you most need to say.

7. **Giving Permission.** Giving permission to your loved one to let go without making them feel guilty for leaving or trying to keep them with you to meet your own needs can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure that 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's 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.
8. **Saying Good-bye.** When the person 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 achieves closure and makes the final release possible. It may be helpful to lay in bed with the person and hold them, or 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 tensions 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 let go.

How do you know death has occurred?

Although you may be prepared for the death process, you may not be prepared for the actual death moment. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the death moment. The death of a hospice patient is not an emergency. Nothing must be done immediately. The signs of death include such things as: no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed, and mouth slightly open. Do not call 911. If you would like to sit with the person for some time before calling Hospice, please do. Call the Hospice nurse. The nurse or social worker will vist at your request.

The body does not have to be moved until you are ready. If the family wants to assist in preparing the body by bathing or dressing, that may be done. The police do not need to be called. The hospice nurse will notify the physician and funeral home and will assist in getting equipment removed from the home.

Franciscan Hospice makes spiritual and emotional support available to both patient and family members. Chaplains and counselors are available to meet you to discuss funeral planning and issues relating to grief and loss, and to support you through this time of transition and transformation.

Personal Record Profile

Everyone, and particularly people experiencing a terminal illness, will need certain documents and records assembled in one place or file. A manila envelope, marked to show its contents, and kept in a place known to your survivors, is sufficient. This will save your loved ones considerable difficulty. In this envelope you should have (if applicable) copies or originals of the following.

- Will, with name and address of attorney
- Life, property, and auto insurance policies with name and addresses of life insurance advisors
- Real estate deeds, title policies, closing statements, mortgages, record of mortgage payments, tax receipts for home improvements over the years, etc.
- Leases
- Name and address of broker, or the stock certificates and bonds you own (plus the purchase slips or other records of cost and date of purchases)
- Name of banks, account numbers (including savings bank books and the names of bank officers with whom you deal)
- List of other assets and locations (including loans and accounts receivable)
- Safe deposit key, name of bank, and box number
- Income tax returns for the last three years, plus the name and address of person preparing these returns
- Birth certificates for yourself, your spouse, and your dependents
- Marriage certificates or proof of divorce, if appropriate
- Automobile ownership certificates and registration receipts
- Social security card and record of numbers
- Veteran's discharge paper or certificate
- Contracts to which you are a party (including installment purchaser agreements)
- Business records
- Charge account numbers and cards
- Receipts, appraisals, or valuations for items of substantial value such as jewelry, furs, furniture, silver, art objects, antiques, etc.
- List of close relatives, addresses and phone numbers
- Burial instructions (including location of plot and name of funeral director)
- General directions to surviving spouse and children

FUNERAL/MEMORIAL PLANNING

Data and Preferences for Consideration Following Death

Full and legal name: _____

Name, address and phone of funeral director you desire: _____

_____

If any prearrangements have been made, please indicate whether all or some of these prearrangements have been prepaid: _____

_____

Location of will: _____

_____

Executor: _____

_____

Power of Attorney: _____

Location of safety deposit box and key: _____

Name, address and phone of your attorney/bank trust department: _____

The lot number and location of cemetery, if applicable: _____

_____

If you do not have a cemetery plot, where do you wish to be buried? _____

_____

Kind of grave monument or marker you wish: _____

_____

If you own a mausoleum space, where is it: _____

_____

Do you wish to be cremated and, if so, what do you wish to have done with your remains? _____

_____

_____

Instructions concerning selection of casket and vault: _____

_____

Do you suggest your survivors have “calling hours” or a visitation? _____

a. If yes, where? _____

b. If yes, should casket be opened or closed? _____

List anything special you wish to wear or have buried with you: _____

_____

Is the service to be public or private? _____

Name, address and phone of clergyperson or other officiant: _____

_____

Special requests for service (hymns, other music, readings, etc.): _____

_____

In addition to or instead of flowers, do you wish donations made in your memory and where? _____

_____

_____

Name, address and phone numbers of persons you would like to have as casket bearers: _____

_____

_____

Anything special you wish to have placed in your obituary? _____

_____

Newspapers in which your obituary and/or paid death notice is to be placed: _____

_____

Are you donating your body or any part thereof to medical science? _____

If so, where is the permission card, what part of your body is donated, and who should be notified? _____

_____

_____

Any additional information or personal desires not covered in this checklist? _____

_____

_____

Funeral Memorial Planning

Many individuals and families have a difficult time making plans for after death. The reality of one's life coming to an end or saying a final good-bye to one we love can be painful to face, let alone to make plans for. Yet, many of us feel a need to gather with other relatives and friends and participate in the ancient ritual of the funeral or memorial service. We seem to know that this tradition has a purpose and somehow helps us cope with loss and embrace the mystery of death.

There is no "right" way to do the service, no perfect funeral plan. The choices you make for the service may not be as important as your very personal reasons for making them. A chaplain, religious leader or funeral director can help you think through what will bring comfort to family and friends and will honor the memory of your loved one. A service that celebrates the fullness of life—and the lasting memories, qualities and accomplishments—can help family and friends through their grief and assist them in finding the strength to face the future.

You might consider taking the time with your loved ones to share what you would like to have in your funeral/memorial service. Planning one's own memorial can be an opportunity to say those things to loved ones and friends through personal writings, specially selected music, poetry or readings from literature. If it is planned as a project with other family members and friends, the process itself may help everyone to celebrate your life. If you are not involved in planning your own service, family and friends can create, select, read and share those things they would like to include, or they may be read by the presider. Photographs, favorite objects and symbols collected on a "memory table" may help friends and relatives share their recollections. Telling stories can mix laughter with tears and help preserve precious memories.

The following is a general outline for a memorial service. This is only an example, an encouragement for you to use your own faith, tradition, beliefs and needs to direct you in creating a gathering that will help you say good-bye.

Ingredients for a Funeral or Memorial Service

- Music for gathering (prelude)
- Welcome by presider
- Opening prayer
- Special song or musical selection
- Readings from scripture or literature
- Homily or short talk by presider
- Sharing by family or friends
- Special song or musical selection
- Walking by casket for final good-bye if casket is present and family desires it
- Burial
- Reception at home, church or funeral home

Ten Freedoms for Creating Meaningful Funeral Ceremonies

Alan D. Wolfelt, Ph.D., Director, Center for Loss and Life Transition Fort Collins, Colorado

Meaningful funerals do not just happen. They are well thought out rituals that, at least for a day or two, demand your focus and your time. But the planning may feel less burdensome if you keep in mind that the energy you expend now to create a personalized, inclusive ceremony will help you, your family, and other mourners embark on healthy, healing grief journeys.

The following list is intended to empower you to create a funeral that will be meaningful to you and your family and friends.

1. **You have the right to make use of ritual.** The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. It is a way for you and others who loved the person who died to say, "We mourn this death and we need each other during this painful time." If others tell you that rituals such as these are silly or unnecessary, don't listen.
2. **You have the freedom to plan a funeral that will meet the unique needs of your family.** While you may find comfort and meaning in traditional funeral ceremonies, you also have the right to create a ceremony that reflects the unique personality of your family and the person who died. Do not be afraid to add personal touches to even traditional funerals.
3. **You have the freedom to ask friends and family members to be involved in the funeral.** For many, funerals are most meaningful when they involve a variety of people who loved the person who died. You might ask others to give a reading, deliver the eulogy, play music, or even help plan the funeral.
4. **You have the freedom to view the body before and during the funeral.** While viewing the body is not appropriate for all cultures and faiths, many people find it helps them acknowledge the reality of the death. It also provides a way to say goodbye to the person who died. There are many benefits to viewings and open-casket ceremonies; don't let others tell you this practice is morbid or wrong.
5. **You have the freedom to embrace your pain during the funeral.** The funeral may be one of the most painful but also the most cathartic moments of your life. Allow yourself to embrace your pain and to express it openly. Do not be ashamed to cry. Find listeners who will accept your feelings no matter what they are.

6. **You have the freedom to plan a funeral that will reflect your spirituality.** If faith is a part of your life, the funeral is an ideal time for you to uphold and find comfort in that faith. Those with more secular spiritual orientations also have the freedom to plan a ceremony that meets their needs.
7. **You have the freedom to search for meaning before, during, and after the funeral.** When someone loved dies, you may find yourself questioning your faith and the very meaning of life and death. This is natural and in no way wrong. Don't let others dismiss your search for meaning with cliched responses such as "It was God's will" or "Think of what you still have to be thankful for."
8. **You have the freedom to make use of memory during the funeral.** Memories are one of the best legacies that exist after the death of someone loved. You will always remember. Ask your funeral officiant to include memories from many different people in the eulogy. Create a "memory board" or a "memory table." Ask those attending the funeral to share with you their most special memory of the person who died.
9. **You have the freedom to be tolerant of your physical and emotional limits.** Especially in the days immediately following the death, your feelings of loss and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals.
10. **You have the freedom to move toward your grief and heal.** While the funeral is an event, your grief is not. Reconciling your grief will not happen quickly. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you, before, during, and after the funeral. Neither you nor those around you must forget that the death of someone loved changes your life forever.

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** Ten Freedoms for Creating Meaningful Funeral Ceremonies (Wallet Cards—available for purchase) * Companion Press (970) 226-6050*

How to Support Franciscan Hospice

Franciscan Hospice depends on your donations to help us enhance the quality of life for the patients and families we serve. Some of our services, including comfort therapies, are funded exclusively by donations. All gifts to Franciscan Hospice are received and administered by the Franciscan Foundation, whose staff is available to answer questions and help you decide how to best express your appreciation for the services of Franciscan Hospice.

Memorial Gifts

Memorial gifts can be made using the donation envelope in this information booklet or by sending contributions to the address below. Some families may wish to designate memorial gifts to Franciscan Hospice in lieu of flowers. Each donation will be acknowledged in writing, and a notice of the gift will be sent to the family of the deceased. For more information about making a memorial gift, contact our Director of Annual Giving (see below).

Bequest Gifts

You might want to join our many friends who have helped by making a bequest—a gift made through your will or living trust. Bequest gifts may be made for a specific item or amount, as a percentage of your estate, and/or as a contingent gift (a gift made only after you have provided for all of your loved ones). You may add a bequest to Franciscan Hospice using a codicil to your existing will or by creating a new will. For more information and suggested bequest language that will ensure your bequest is directed to Franciscan Hospice, contact our Director of Major and Planned Giving (see below).

Planned Gifts

There are other ways to make a planned gift to Franciscan Hospice, including naming Hospice as a beneficiary of your individual retirement account or life insurance policy, creating a charitable reminder trust or charitable gift annuity, or donating appreciated stock or real estate. In many instances, the tax savings are excellent. To determine the best way to give, contact our Director of Major and Planned Giving (see below).

Gifts of Time

In addition to supporting Franciscan Hospice financially, many people enjoy investing their time, talent and expertise as Hospice volunteers. Hospice offers a wide variety of volunteer opportunities, from patient/family care to office work, sporting events, and gardening. To help you find a volunteer role that's right for you, contact our Volunteer Manager at 253.534.7070.

Everyone is or will be affected by death or grief in their lifetime. Your gift, big or small, will make a difference in someone's life and in the quality of care available to those facing terminal illness.

Director of Annual Giving
253.428.8483

Director of Major and Planned Giving
253.428.8415

Franciscan Foundation
P.O. Box 1502
Tacoma, WA 98401-1502
Phone: 253.428.8411
Fax: 253.428.8466
Toll free: 888.814.3740
Web: www.foundation.FHShealth.org
Email: foundation@fhshealth.org

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Franciscan Hospice and Palliative Care
2901 Bridgeport Way West
University Place, WA 98466

For more information call: 1-800-338-8305
To make a referral call: 1-866-969-7028
Referral fax: 253-534-7098

www.hospice.FHShealth.org

CATHOLIC HEALTH INITIATIVES

Franciscan Hospice and Palliative Care

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