

Patient & Family Guide to Hospice Care

Halcyon
H O S P I C E

& Palliative Care

Serving Colorado's Front Range

*The Kingfisher, calm and at peace, nested
upon water, quieter of restlessness.*

To All,

I just want you to know what an honor it is for Halcyon to be invited into your lives in such an intimate way. We are very much committed to living up to your expectations, wishes and desires.

Halcyon is a clinician owned hospice. It's vision is to provide patient centered care to people who reside in both rural and urban settings.

This is a strong vision. It means that we will go to where you are; anywhere along the front range of Colorado. It also means that we will listen to you. We have experience, we are compassionate and we are innovative. Our goal is to use these qualities to the extent of our ability, on your behalf, to help make your intentions possible.

Halcyon is a name that has meaning. It stands for the Kingfisher; a legendary bird that nested upon disrupted waters and brought calm and peacefulness. Halcyon wants to bring calm and peacefulness to you as well. We want to live up to our namesake.

Relationships form the foundation of the best hospice care. We will never lose sight of that. Our relationships to you, to one another and to our mutual community are integral to what makes our vision unique. We want everyone we touch to feel they have touched us.

Thank you very much for allowing us to be part of your lives.

Rod Graber, Halcyon Hospice

Halcyon pledges that it will:

- Encourage and support care and services that are safe, patient-centered, effective, efficient, timely, and equitable.
- Uphold high standards of ethical conduct in advocating for the rights of patients and their family caregivers.
- At no time consider a patient's financial disposition for how care will be provided; at admission, in stay, or at discharge.
- Preserve and promote the inherent potential for growth within individuals and families during the last phase of life.

Guide to Hospice and Palliative Care

About This Guide	5
Information for Getting Started	6
Understanding Hospice and Palliative Care	
The Role of Family and Caregiver	
The Hospice Team	
Paying for Hospice and Palliative Care	
Information on Rights and Responsibilities	13
Patients' Rights	
Patient and Family Responsibilities	
HIPAA Compliance – Privacy and Confidentiality	
Healthcare Decisions and Advance Directives	
Information and Skills for Caregivers	15
Keeping a Care Log and Communicating Effectively	
Controlling Pain and Other Symptoms	
Practical Caregiver Skills	
Confused/Anxious/Agitated Patients	
Preventing the Spread of Infection	
Using Oxygen Safely	
Other Home Safety Recommendations	
Conversations Near the End of Life	
Preparing for Approaching Death	
Practical Considerations When a Loved One Dies	
Experiencing Grief and Loss	
When Your Caregiver Role Ends	49
Care Log Form	50
Funeral or Memorial Service Planner	51-53
Levels of Care	54
Advanced Directives	55
Notice of Privacy Practices	56-65
Appendix :	
Guidelines for Medication Disposal.....	A-1



The Kingfisher

A bird of iridescent light;
of visionary blue; as painterly
as a sunflower; swift
as an arrow.

It longs for the milk of rivers,
kindling the rainbowed air
with feather-bright flame;
subtle-winged, the kingfisher
melting to water.

Unearthly jewelled that builds
its nest in the crux of worlds,
tunnelling the arcane earth;

like its wounded namesake,
sovereign of wastelands, whose chalice
pours its solvent of dreams.

Precision-tooled and cuts
like a blade cleaving the wind;
the sharp percussion of its dive,
plunged in its liquid essence.

—*Michael Whan*

About This Guide

You should know three things about the *Guide* you're holding:

First, this is a new, expanded edition of a booklet that has served families and hospice organizations for many years, the *Patient and Family Guide to Hospice Care*.

Second, its goals are the same as those of its parent publication, the healthy aging guide, *Aging in Stride – Plan Ahead, Stay Connected, Keep Moving*. Those goals, simply put, are to inform and empower – to help you understand what's involved in hospice and palliative care and be in a position to take full advantage of the services and support they offer.

Third, like *Aging in Stride*, this *Guide* starts as a printed publication – something you can pick up when you have a question, jot notes in, and share with others. But it doesn't stop there. It also includes an extensive online supplement, with factsheets you can read or listen to, forms and checklists, and video demonstrations. For example, the online supplement contains:

Factsheets and Podcasts:

Spirituality and Pastoral Care Near the End of Life

Handwashing – the Key to Preventing Infection

Keeping a Care Log

Advance Directives – Your Right to Decide

Forms and Checklists:

Care Log Form

Personal Information Organizer Form

Home Safety Checklist

Emergency Readiness Checklist

Form for Planning a Funeral or Memorial Service

Video:

Handwashing Demonstration

Just in Case (Emergency Readiness for Older Adults)

For information on how to access the online supplement, please visit www.halcyonhospice.org

Information for Getting Started

Understanding Hospice and Palliative Care

Centuries ago, the word “hospice” described a place where weary pilgrims could stop, rest, and refresh themselves before continuing on their journey. In 1967, a British physician, Dr. Cicely Saunders, began using the term to mean a new kind of care for patients who were dying. She founded St. Christopher’s Hospice in a London suburb.

Patients did not come to St. Christopher’s with the idea of finding a cure. They came for support in managing pain. Their goal was to maintain their quality of life as much as possible, even in the face of a terminal illness. Since Dr. Saunders founded that first hospice, the hospice movement has spread around the world. Today, patients and their families turn to community-based hospice programs for supportive, quality care near the end of life. Hospice care is provided wherever a patient lives – their private residence, adult family home, assisted living facility, or nursing facility.

What We Mean By Hospice Care and Palliative Care

Hospice care refers to end-of-life care in which the goal is comfort, symptom management, and quality of life, as opposed to finding a cure. It is coordinated and provided by an interdisciplinary care team – one that includes the patient’s physician, plus professionals in nursing, social work, pastoral care, and so on. Hospice care generally isn’t considered an option until a person is terminally ill, with a probable life expectancy of six months or less. Hospice care is intentional in serving not just the patient, but the patient’s family as well.

Palliative care, like hospice care, has as its goal the patient’s comfort, pain and symptom management, and quality of life. Unlike hospice, it is not related to prognosis, and a patient may be seeking curative or life-prolonging treatment and still benefit from palliative care. Palliative care may be appropriate at an earlier point in a prolonged illness; whereas hospice care is the care provided nearer the end of the patient’s life.

Think of it this way:

Palliative Care = Comfort Care

Hospice Care = Comfort Care at the End of Life

What Services and Support Does Hospice Care Include?

Hospice programs come in all sizes – large, small, and in between. But they all share a commitment to a basic range of services that includes:

- Care that focuses not just on the patient’s medical condition, but also on the emotional, social, and spiritual needs of both the patient and the patient’s family
- Care that is directed, as much as possible, by the patient, working together with the family and the hospice staff
- Care provided by an interdisciplinary team that includes physician, nurse, social worker, therapists, chaplain, and trained volunteers
- Nursing support available for patients and primary caregivers on an on-call basis, 24 hours-a-day, seven days a week
- Care directed at effective pain and symptom management
- Care at home, wherever that may be for the patient
- Bereavement support.

“The care (that Halcyon) provided was amazing! I am very thankful for this team. Without them I am not sure we would have been able to fulfill my Mother’s dying wishes. I can only hope other’s experience (will) be as amazing as our family’s was.”

—anonymous family member

When Should Hospice Care Begin?

It is important for someone entering hospice care to have four things:

First, an understanding of their disease prognosis – that they have been diagnosed with a terminal illness;

Second, an understanding of the services hospice does and does not provide, and that the goal of hospice care is comfort and quality of life, rather than seeking a cure;

Third, the cooperation of the person’s personal physician who is willing to work with the hospice team to provide care; and

Fourth, someone to serve as primary caregiver, if hospice care is to be provided at home.

To get the most out of hospice care, it should not be put off until a point at which much of the opportunity to benefit from a focus on comfort care and quality of life has passed. However, even when death is imminent, there is still benefit in hospice support.

The Role of Family and Caregiver

Not so long ago, it was commonplace for people to die at home, surrounded by loved ones and familiar possessions. Now, many people die in hospitals, surrounded by tubes and monitors and other high-tech equipment. One goal of hospice care is to give patients who are terminally ill an alternative to this institutional setting that is more home- and family-focused.

Families who have been supported by a hospice program in caring for a dying loved one most often consider it a positive, empowering experience. Hospice team members are trained to be sensitive to the needs of patient and family. If your mother wants to die at home and you're able to support her in this, but are worried about the skills and support you'll need, hospice will give both you and your mother the training and help you.

Hospice programs also offer options for respite care. Respite care is having someone else care for the patient for a few hours or a few days so that the caregiver can have a break. It provides much-needed time for rest and renewal.

If you are considering taking on the role of family caregiver for a loved one in hospice care, talk with hospice staff. Find out what the expectations would be and what kinds of help and support are available. If you can, talk with others who have made this commitment. What were the challenges they faced? What suggestions would they have? Would they do it again?

Becoming a caregiver is a big, personal commitment. It is not for everyone. But for those who choose it, it can be an incredible gift, as well as a personal experience unlike most any other. Take time to make a good decision for yourself and for your loved one.

If your loved one is not living with you or needs to move to an alternate living arrangement, remember that your love and care remain important. Let the hospice team know how they can best communicate with you and provide support.

The Hospice Team

Hospice care is patient centered, which means that the patient makes care decisions and participates in care planning as much as possible. The patient's primary home caregiver is also an important part of the hospice team. So is the patient's physician, who continues to direct medical aspects of the patient's care. In addition, a hospice team typically includes:

Hospice nurse – who will visit with you and your family to determine your individualized needs and work out what services you 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 procedures, such as placing and maintaining catheters, wound care, blood draws, etc.
- teaching the caregiver proper procedures for catheters, dressing changes, medications, etc.
- helping coordinate needed equipment, supplies, and services
- explaining the effects of illness and treatment, answering your questions, and offering support.

Social worker – who is often the first person you will meet from the hospice team. The social worker will explain the hospice philosophy, goals, and services. A hospice social worker works closely with the patient and family to create and maintain a supportive, in-home care setting that will work in terms of the patient's safety and comfort. The social worker is also available to help patient and family deal with personal, financial, emotional and care planning issues that come up. 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 patient and family. Chaplains (or spiritual or pastoral care counselors, as they are often called too) 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 your exploration or struggles with spiritual and/or emotional issues
- provide spiritual counseling, while respecting your personal beliefs
- pray with you, if requested
- assist you in planning a funeral, memorial service, or other similar gathering.

Therapists – including physical, occupational, and speech therapists. They often 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
- teach exercises for a bed-bound person that can relieve pain and discomfort caused by lack of mobility
- evaluate communication or swallowing difficulties and recommend ways of handling these.

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 and may visit as needed.

Hospice aides help with:

- bathing
- shampooing
- grooming and shaving
- changing bed linens
- wound and skin care
- assistance with toileting
- light homemaker tasks
- support for physical activity and relaxation
- 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 being assigned to a patient and family. Depending on your 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
- spending time with children in the home, so the caregiver can have some private time.

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.

Paying for Hospice Care

If you are eligible for the Medicare Hospice Benefit: Under the Medicare Hospice Benefit (or Medicaid Hospice Benefit, if available), the following are covered:

- intermittent home visits by the hospice staff
- medications related to the hospice diagnosis
- certain supplies
- medical equipment that is normally covered by Medicare
- short-term respite care
- some lab tests
- procedures to manage symptoms.

However, to be covered, these services must be:

- Related to the patient's terminal illness;
- Authorized by hospice as comfort care and part of the patient's plan of care; and
- Obtained through a provider approved under the program.

Office visits to see the primary physician will be covered in the same way as before election of the Medicare Hospice Benefit.

Here are two points to remember if you are receiving care under the Medicare Hospice Benefit:

First, if you access care independently without consulting the hospice team, neither the hospice program nor Medicare (or Medicaid, if applicable) will pay for those services; and

Second, if you decide to change from comfort care to active treatment that seeks a cure, you will need to revoke your Medicare (or Medicaid) Hospice Benefit and revert to your regular Medicare or Medicaid benefits, since your goals would then be different from the goals of hospice care.

If you have private insurance: Hospice staff will work with you to determine the scope of your coverage and arrange for payment by your insurance plan.

If you have limited or no insurance coverage for hospice care: Hospice staff will work with you to determine your eligibility for financial aid and/or set up a reasonable payment schedule.

Information on Rights and Responsibilities

Patients' Rights

Hospice patients have certain rights that are described in a separate document and discussed with the patient when hospice care first begins. Be sure to read carefully the detailed description of patients' rights you receive and ask questions if there is anything you do not understand.

As an overview, each hospice patient has the right to:

- Pain management and symptom control
- Be involved in developing the plan of care
- Refuse care or treatment
- Choose their attending physician
- Have their clinical record kept confidential
- Be free of abuse
- Receive information about what is covered under the hospice benefit.
- Receive information about the scope and limitations of hospice services.

Maintaining quality hospice care depends on good patient and family feedback. If you have questions, please ask them. If you are aware of something you don't like or you think is inconsistent with quality, respectful care, let your hospice know right away. If you are comfortable doing so, discuss your concerns directly with the person or persons involved. If that feels awkward or does not resolve your concerns, contact the hospice manager, director, or administrator.

Patient and Family Responsibilities

Along with patients' rights, your hospice program will let you know what it expects of the patients and families it serves. Patient and family responsibilities include such things as providing accurate information, keeping the hospice team informed of changes, keeping the home where care is being provided clean and safe, and learning and following basic steps for preventing the spread of infection, especially handwashing.

HIPAA Compliance – Privacy and Confidentiality

Hospice patients are covered by the Health Insurance Portability and Accountability Act of 1996, or “HIPAA.” Information on HIPAA policies and procedures will be provided to you. If you have questions or concerns about privacy or confidentiality, ask a member of the hospice team.

Healthcare Decisions and Advance Directives

Hospice patients are entitled to make their own healthcare decisions as much as possible and for as long as possible. When a patient is no longer able to understand the medical options and make decisions, the patient’s representative steps in and makes them on the patient’s behalf.



Advance directives play an important role in this by letting a person say ahead of time how and by whom care decisions should be made, if the patient later loses the ability to make them. Advance directives are legal documents that vary from state to state, but typically there are two kinds. One is a health care directive or living will, a document in which you state your wishes for treatment near the end of your life. The other is a durable power of attorney for health care, sometimes called a healthcare proxy (or “DPOA”), in which you name a close relative or friend to make decisions for you, if you later lose the

ability to make them yourself. If you name someone as your health care back-up decision maker, it’s a good idea to discuss with that person how you would like decisions made if that becomes necessary.

Another healthcare planning document you may hear about is called a physician order on life-sustaining treatment (a “POLST” form) or a do-not-resuscitate (or “DNR”) order. These are orders a physician enters in a patient’s medical record after discussion with the patient or patient’s representative. They notify emergency response personnel and other health care providers that cardiopulmonary resuscitation, or “CPR,” should or should not be started if this person’s heart or breathing were to stop.

The hospice social worker can answer questions about advance directives, and a member of the hospice team will discuss these issues with you when hospice begins.

Information and Skills for Caregivers

Keeping a Care Log and Communicating Effectively

One of the first things a caregiver needs to get in the habit of doing is keeping a care log. It doesn't have to be fancy. We've included a form on pages 50. You may download the form or print extra sheets online.

Keeping a care log is your way of tracking changes in the patient's condition and needs. This information will be important for keeping the rest of the care team informed, and for making adjustments to the care plan. In the care log, record the following information at least once a day, and more frequently if symptoms change:

- The date and time of your observations
- Frequency of bowel movements
- The name and dose of medications the patient has taken.

The hospice nurse will go over the care log and what you should include. Depending on the patient's medical situation, you may be asked to record under "Notes" such things as the patient's temperature, skin color, fluid intake, pain level, or frequency of urination and urine color.

As part of your notes, write down any questions you may want to ask the hospice team during their next visit. There is no such thing as a dumb question when it comes to taking good care of your loved one. So, make a note when you don't understand something, and ask for clarification.

Managing Pain and Other Symptoms

Pain

Fear of pain is common for patients and their families. It is important to listen to patients when they say they are experiencing pain. For patients, pain may be both a physical and an emotional experience. Only the patient can best describe the pain and its intensity. There are many ways to manage pain effectively, and the hospice team will work with you to provide the best treatment.

The nurse and doctor need a clear understanding of the patient's pain level, the type of pain he or she is experiencing, and how well medications are or are not controlling it. They will often ask the patient to rate pain on a scale of

0 through 10, with “0” meaning no pain, and “10” meaning the worst possible pain. The hospice nurse will ask what level is acceptable.

How does the patient describe the pain he or she is experiencing? Here are some words often used to describe different levels of pain? Ask the patient to use the words that best fit.

*sharp shooting aching stabbing pulsing crushing
tingling dull cramping itching burning cutting throbbing*

The type of pain is as important as its intensity in determining the best medications for the patient. Other medications may be prescribed, in addition to the regular pain medication, to better control a particular type of pain. These additional medications may be more familiar to you as treatment for other problems, such as depression, muscle tension, anxiety, or inflammation. However, they may also be used to manage pain.

A hospice patient may have concerns about pain medications. Here are some examples, along with points to keep in mind:

“The pain medication makes me too sleepy.” Some pain medications can make you feel drowsy. This sleepiness usually goes away after a few days. If you have lost sleep because of pain, you may sleep more the first few days after beginning your new medication, because your body is finally relaxing. The medications can be adjusted to decrease sleepiness but maintain comfort.

“The pain medicine makes me constipated.” Constipation is a common side effect of many pain medications and may not go away even after a patient becomes used to a medication. Other factors may also be contributing to constipation, such as decreased activity, decreased appetite, or a disease process. Constipation may be treated or prevented by balancing the effects of medications and decreased appetite and activity with stool softeners and laxatives.

“If I take pain medicine now, what will I do if the pain gets really bad?” Medication dosages may be increased or the medication can be changed to keep pain managed effectively. Keep your nurse informed about your level of pain and your goal.

“Will I become addicted?” Taking medications to treat pain is entirely different from abusing drugs. In a hospice situation, the goal is an important one: alleviating pain and maximizing quality of life.

If “addiction” is a concern for you or your loved one, discuss pain management with the hospice team so that pain is dealt with in a timely, medically appropriate way.

You or your loved one may have other questions about the pain medication schedule. If you do, be sure to ask your hospice nurse.

Taking prescribed pain medication regularly as directed can help manage pain effectively and minimize the need for additional medication. Pain may contribute to other problems, such as nausea and vomiting, irritability, confusion, loss of sleep, and immobility. Most people have a better quality of life when they are pain-free or experiencing low levels of discomfort.

Pain and discomfort can also be managed by other methods. For example, meditation, music, or guided imagery can reduce pain by helping a person to relax. Using cool or warm packs, or changing position may also help in soothing aches. Massage may help decrease discomfort by increasing circulation and relaxing muscles. Your hospice team may be able to assist you with these techniques or direct you to other resources.

Dizziness

Dizziness is a symptom that may have several different causes. Patient safety – in particular, avoiding falls – is a primary concern. Here are some steps to reduce problems with dizziness:

When getting out of bed or a chair, go slowly. For example, let your feet dangle at the side of the bed first, before standing. Often, dizziness will go away after a minute or two.

Change positions slowly, and use a cane or walker if available.

Keep the environment, especially traffic areas, clean and free of clutter.

If you or your loved one feels unsteady, ask for assistance. If they are tolerated, increase fluids – drinks such as Gatorade or Pedialyte can be especially helpful.

Nausea and Vomiting

Many patients experience nausea and vomiting. Here are suggestions that can help:

- Eat small, frequent meals.
- Avoid liquids at mealtime — drink them an hour after meals.
- Eat dry foods such as toast and crackers.
- Avoid spicy, fried, and fatty food, red meat and food with a strong odor.
- Pay close attention to mouth care.
- Take anti nausea medication when prescribed (regularly or prior to meals)
- Unless instructed not to, take medications with small amounts of food or milk.
- Serve food cold or at room temperature to decrease its smell and taste.

Nausea caused by pain medication can feel like motion sickness. If this happens, try resting quietly. If you suspect your pain medicines are making you nauseated, tell your nurse.

Constipation

When people are very ill, many things can affect how their bowels function. Change in diet, activity, and the use of some medications can produce constipation. This is because the narcotic in the pain medicine slows down the bowel, allowing too much water to be absorbed from the waste matter. The result is a sluggish bowel with hard, dry stool.

Treatment is aimed at speeding up (stimulating) the bowel and/or putting more water into the stool. Medications to prevent constipation should be taken routinely, as directed by your doctor or nurse. You can also increase fluid intake and activity, as tolerated, to help decrease constipation. The goal is to have a bowel movement at least every three days.

Bowel problems to report to the nurse include:

- Very hard, difficult to pass stool
- More than three days without a bowel movement
- Constipation followed by diarrhea
- Constantly passing only smears of stool or liquid stool
- Blood with the stool
- Abdominal pain.

Your nurse may advise you to use a fruit paste recipe, such as the following:

Anti-Constipation Fruit Paste (Dose: 1-2 tablespoons per day)

1/4 pound prunes	1/4 cup brown sugar
1 ounce senna tea	1/4 pound figs
1/4 pound raisins or pitted dates	1/4 cup lemon juice

Prepare the tea using 3/4 cup boiling water. Steep for 5 minutes. Strain the tea and pour 1/2 cup into a large pot. Add fruit and boil for 5 minutes. Remove from heat, add sugar and lemon juice. Allow mixture to cool. Using a hand mixer, food processor, or blender, turn fruit mixture into a smooth paste. Spoon into jar or airtight container and place in freezer. Note: the fruit paste does not freeze solid but keeps indefinitely in the freezer.

Serving ideas: on toast, on hot cereal, in ice cream, yogurt, etc. Senna tea can be found in health food stores, grocery stores, and pharmacies.

Dry or Sore Mouth

Good mouth care is very important. Decreased fluid intake, some medications, or physical conditions can leave a hospice patient's mouth dry and/or sore. Here are some ways to help relieve mouth discomfort:

For dry mouth:

- Avoid smoking, drinking alcohol, and eating spicy foods. Try popsicles, shakes, yogurt, pineapple chunks, gum, sugar-free citrus drops, or hard candy such as lemon drops.
- Drink plenty of fluids or use ice chips.
- Rinse your mouth frequently.
- Take good care of teeth and gums by flossing and brushing regularly. A soft toothbrush may be helpful if the mouth is sore.
- The nurse may also have "toothettes," which are sponges on a stick. They can be used with water to moisten the mouth and for general mouth care. Avoid the use of lemon glycerin swabs because they can dry the mouth.

For sore mouth:

- Avoid acidic foods like orange juice, tomato juice, and citrus fruit.
- Use a straw to prevent liquids from coming in contact with sores.
- If dentures are too loose, have them adjusted and remove while sores on the gums are healing.
- Some people get white patches of yeast in their mouths. If this happens, ask the nurse about using medication to ease the discomfort.

Food and Eating

It is common for people to lose their appetite when ill. This may be caused by disease, treatments, medications, pain, or simply changes in the way food tastes. The body's need for calories and protein rich foods is altered because of decreases in activity, exercise, and general metabolism. Here are suggestions for encouraging eating when appetite is diminished:

- Eat frequent, small meals.
- Drink liquid breakfast drinks, canned supplements such as Ensure, or homemade high-calorie shakes.
- Add dried milk or dried protein powder to liquid or soft foods to add calories.
- Use fruit juices, such as prune or apricot nectars, to add calories.
- Eat and drink favorite foods.
- Give liquids in other forms, (Jell-O, pudding, popsicles and ice cream).
- Avoid using straws, which may cause swallowing of air, leading to burping or nausea.
- Follow instructions on dietary supplements for storage, use, and expiration date.

When our bodies are able to heal, we need proper nutrition to regain strength. However, when our bodies are not able to heal (for example, during the last stages of a terminal illness), food can become an unnecessary burden and a source of discomfort.

When this happens, decreased appetite can create anxiety and tension for both the patient and caregiver. Attempting to force oneself to eat may drain precious energy and lead to nausea and vomiting at a time when the body is saying "no" to food or fluids. As a caregiver, you may feel guilty or inadequate or frustrated if your loved one is no longer taking much food or fluids.

If so, talk about your concerns with the hospice nurse.

Dehydration

A person who is very ill may become dehydrated, especially if a fever develops or the person can no longer swallow. Ice chips, lip balm, artificial saliva, mouth swabs and frequent mouth care can be used to promote comfort. To help prevent dehydration when the patient can still swallow, give sips or spoonfuls of fluids frequently over a 4-hour period. Check with your hospice nurse regarding fluid requirements in your situation.

Skin Problems

Skin sores (also called pressure ulcers or bed sores) develop when a person lies too long in bed in one position. These sores can be uncomfortable and can be a medical problem if they become infected. It's much better to prevent them in the first place. Here's how:

- The patient should change positions in bed by turning from side to side every two to four hours.
- If the person is able, help them move occasionally; for example, from bed to chair.
- Gently rub the skin with lotion to increase circulation and moisturize.
- Keep skin clean and dry.
- Change soiled or wet linens and clothing as needed to keep patient dry.
- Clean the skin regularly of any drainage, blood or urine.
- Use pillows to support the leg and back when the person lies on his or her side.
- Use a special mattress on the bed, such as an egg-crate foam pad or air mattress.
- If recommended by the nurse, apply protective pads around affected areas to reduce contact and relieve pressure.

The hospice team may have other suggestions depending on the situation. If you notice any redness, sores or bruises on the patient, let the hospice nurse know.

Emotional Withdrawal

It is common for someone who is terminally ill to begin withdrawing from familiar activities, such as work, hobbies, relationships, and so on. Active communication with others may seem less important. This may mean that touch and just being physically present will play a larger role than normal conversation in supporting your loved one.

Withdrawal is often used by patients to conserve energy and for self reflection. Life review may become an important task. Hospice staff, especially the social worker and chaplain, can help.

Disorientation; Using Symbolic Language

One or two weeks prior to death, the patient may begin to sleep most of the time. It becomes difficult for the patient to keep his or her eyes open. Patients may become disoriented to time and place. They often become confused, talking or gesturing to people who are not present or who have already died.

In the last stages of their illness, they may speak in what is often referred to as “symbolic language.” An example might be, “I’ve got to cross the bridge now.” This is normal and can be reassuring, calming, and meaningful to the person. What a loved one can do is be affirming, understanding that disorientation and use of symbolic language are common and normal among persons nearing death.

Practical Caregiver Skills

Rule Number One: Take Good Care of Yourself

During hospice care, the patient isn’t the only one who needs care. If you are a primary caregiver, your emotional and physical well-being are also important, and often difficult to maintain. Only by taking good care of yourself will you be able to care for your loved one.

Small things you do for yourself can make a big difference. Here are some suggestions:

Focus on your strengths. Think about what others are going through – and know that you, too, will have the inner resources to cope. You’ve been through tough times before and survived. You will cope with this, as well.

Keep to your routine as much as you can. If you’re used to stretching and walking in place for half an hour each morning, stick to that routine every morning you can. Do you have a cup of tea in the middle of the afternoon?

You’ll find you enjoy it even more now, even if you have to juggle your responsibilities to squeeze it in.



Be willing to accept help. Friends, family, hospice volunteers, and hired helpers can provide much-needed backup. Being open to accepting their help is a gift – to yourself, but also to them. In accepting help, be honest and specific about your needs. Ask someone to run an errand, mow the lawn, bring food, or sit with the patient while you go for a walk or take a nap.

Take time for yourself. A few quiet moments can be renewing. A walk with an old friend can help you keep your perspective. A bath, while someone else cares for the patient, can ease the aches of body and soul. It is important to make time for yourself and identify pleasurable activities as a part of your caregiving routine. Try to set a goal of at least one outing per week.

Pay attention to your own physical needs. You may become so busy being a caregiver that you forget about yourself. Eating properly, getting enough sleep and rest, exercising regularly – these are the basic building blocks. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and a short walk around the block to clear your mind can all play a role in keeping you grounded and giving you the emotional and physical reserves you need.

Practice simple relaxation techniques. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the patient’s care – for example, when a member of the hospice team visits. Don’t forget, too, that laughter and keeping your sense of humor are as important as ever.

Renew or grow in your faith and spirituality. If you are part of a faith community or religious tradition, reserve some time each day for living and growing in your faith. If you are not, you may still find renewal and inspiration in spiritual reflection or readings.

Caring for Someone in Bed

As a person becomes weaker, he or she spends more time lying in bed or sitting in a chair. Moving becomes more difficult. Yet changing positions becomes more important than ever – to prevent bed sores and reduce pain and discomfort.

Repositioning a patient in bed – before you begin:

- Start by explaining to the patient what you are doing before you actually do it; if they can help, let them know how.
- Providing pain medication beforehand may help if repositioning has been causing pain.
- If someone is available to help you with repositioning, it will be easier on your back.
- Keep any tubing free, so it does not become tangled or get pulled.

Repositioning a patient in bed – protect your back by using good body mechanics:

- Never twist your back or trunk; instead use your legs and feet to turn your whole body.

- Lift with your legs, not your back.
- Bend or flex your knees; use legs and stomach muscles.

Repositioning a patient in bed – how to use a “draw sheet”

- A folded sheet (“draw” sheet) placed under the body (neck to buttocks) can be used to move the patient around in the bed. It assists in maintaining the patient’s body alignment during movement.
- To place a draw sheet under a patient, stand next to the patient at the side of the bed, roll him onto his side so that half of the bed is exposed. Lay the sheet open on the exposed half of the bed, tuck half the sheet up against the person’s back. Then go to the other side, roll the person the other way onto the sheet, and pull out and straighten out the tucked half of the sheet.
- Always support the head if the patient is unable to.
- Two people can move a patient up in the bed by rolling both sides of the sheet up close to the patient’s hips and together sliding the patient up in the bed. The patient may be able to help by flexing at the knees and pushing up with feet and knees.
- One person can use a draw sheet to move a patient up in bed by going to the head of the bed, grabbing the top end of the draw sheet, and pulling it and the patient up toward the head of the bed. One person can also use a draw sheet to move a patient from one side of the bed to the other.
- To remove the draw sheet, just reverse the side-to-side steps.

Repositioning a patient in bed – other suggestions:

- Raise the bed to a comfortable height level so you aren’t bending over so much.
- When moving the patient to the near side of the bed, begin with the head then the shoulders, trunk, legs, and feet.
- When moving from side to side, it can be helpful to bend or flex the knees. This helps the rotation of the hip; the body will follow.
- When the person is in the new position, support the arms and legs with pillows or rolled up towels, especially when the person is lying on his side.
- If the person isn’t able to communicate, imagine yourself in that position. Check that the person is not lying on a shoulder or arm.
- Rearrange pillows. Pillows can be placed for support under the person’s head, between the knees, or under hands or arms.
- Keep skin clean and dry. Keep linen and clothing dry and wrinkle-free.

- Reddened areas or opened areas of skin need to be checked by the nurse. Apply lotion and massage the skin to promote circulation and general comfort.

Safely Moving a Patient from One Place to Another

There are time-tested techniques for safely moving a frail patient from wheelchair to bed, or from bed to chair. A member of the hospice team can demonstrate the basics, help you practice them, and answer your questions.

Here is one scenario: transferring a patient from bed to chair:

- First, take a moment to plan what you are going to do and the safest way to do it.
- Let the patient know what you'll be doing and how he can help.
- Always assist the patient to his strong side if he has one.
- Always lock/secure the bed, the wheelchair, and/or chair to prevent movement.
- Place the chair close to the bed, equalizing heights as much as possible; normally you will want the bed in a low position, with the head raised to a sitting position, if possible.
- Help the person to a sitting position; raising the head of the bed makes this easier.
- Give the person time in a sitting position to be sure that any dizziness subsides before helping him stand up.
- Stand in front of the person being transferred, with your feet apart – this broadens your base, improving your balance and control.
- Absorb any strain with your knees and legs, not your back – keep your back straight.
- Flex your hips slightly.
- Stand in front of the person and put your arms around their body, placing your hands on their ribs in back.
- Ask the person to place their hands on your shoulders, not around your neck.
- Make sure the person places his feet on the ground.
- Using your weight to balance, and keeping your knees slightly bent, gently rock the person into a standing position. Coaching the patient may help: "1, 2, 3, Up."

- To turn, continue to counterbalance with your weight and maintain a wide-based stance; pivot on your feet, slowly turning your whole body, not twisting your trunk.
- Gently lower the person into the chair by bending your knees.

Giving a Patient a Bath in Bed

When using the bath or shower is no longer possible, the option is to give the patient a bed bath. A bed bath is about more than just being clean – it involves movement and exercise, stimulates circulation, helps prevent pressure sores, promotes relaxation, and gives the caregiver an opportunity to check the patient’s skin for breaks, redness, or areas becoming irritated.

Have these supplies ready:

- Towels and washcloth
- Clean clothes
- Soap (oatmeal soap can help with itching)
- Basin
- Lotion (containing lanolin)

General “how to” principles:

- Give pain medications one hour before bathing, if movement is painful.
- Suggest toileting before beginning.
- When giving a bath, encourage independence when possible.
- Provide privacy and prevent drafts.
- Adjust the bed to a comfortable position.
- Bathe only a small area at a time, keeping the person covered with a towel or blanket to avoid chills.
 - Change the water frequently when it is dirty, soapy, or cool.
 - If the person is unable to tolerate a full bath, offer to wash the face, hands, back and perianal (crotch and groin) area only.
 - Avoid powders. Cornstarch is a good substitute for powder and can be lightly sprinkled on linen.



The steps to follow:

- Fill the basin two-thirds full with warm water.
- Wash one area at a time, starting with the face—drying the person as you move from one area to another.
- Wash the eyes from the inner to the outer corners, using water only, rinsing the cloth after each eye.
- Wash and rinse the face, neck, and ears.
- Work from the head down with long, circular motions, washing, rinsing, and drying thoroughly.
- Roll the person onto her side.
- Wash, rinse and dry the back.
- Wash the feet; sometimes it's comforting to place feet in a basin of warm water.
- Apply deodorant and lotion, and put on clean clothes, gown, or pajamas.

Cleaning the Perianal (Groin) Area

The patient may wish to wash this area by him- or herself. But if this is not possible, proceed this way:

For females, separate the labia with one hand and cleanse the area with downward strokes.

For males, clean the penis with circular motions. Pull back the foreskin of the uncircumcised male to clean this area. Wipe from front to back, changing location with each wipe. Daily washing of this area and after toileting is important to prevent infection and skin breakdown. There are skin protecting lotions which can be applied.

Mouth Care



Good mouth care can be easy to overlook, but it helps prevent sores, improve appetite, and promote general comfort.

Have these supplies ready:

- Soft toothbrush or Toothette
- Towel
- Toothpaste
- Small bowl

General “how to” principles:

- When giving mouth care, have the person sit up in an upright position, if possible.
- Place the towel under the chin.
- Brush teeth and gums gently with toothpaste.
- Try to remove all food particles and crusted materials.
- To prevent gagging, avoid putting the toothbrush too far back in the person’s throat.
- Rinse the mouth out with cool water.
- If the person has dentures, remove and clean them. (Cleaning dentures after meals may also help. When people lose weight, dentures may no longer fit properly. This may be caused by a change in the shape of the jaw. Poorly fitting dentures may result in mouth sores. Some people choose to leave dentures out and eat softer foods.)
- If you notice mouth sores, tell the nurse – there are medications that may help.
- After finishing mouth care, apply a moisturizer to the lips and the corners of the mouth to prevent cracking.

Changing Bed Linens

For most people, clean sheets are one of life’s under-rated pleasures. When we’re sick, we appreciate them even more. Change sheets when they become soiled, wet or sweaty. They may need to be changed as often as several times a day, or as infrequently as once a week.

Changing bed linens is obviously easier if the person can get out of bed. But if that is too difficult, follow these easy steps:

- Have the clean linens available and near before you begin.
- Untuck the top sheet.
- Roll the person to one side of the bed; be careful the person doesn't slip off the side.
- Position yourself at the side of the bed farthest from the patient.
- Loosen the bottom sheet along the near side of the bed and roll it up along the person's back.
- Position the clean bottom sheet on the open side of the bed and tuck it in.
- Roll the rest of the clean sheet up close to the patient.
- Help the person roll back over both sheets and onto the clean sheet.
- Pull away the dirty sheet carefully and tuck the clean one into the bed.
- Help the person back into the middle of the bed in a comfortable position.
- Replace and tuck in the top sheet and cover.
- Change the pillow cases.

Confused / Anxious / Agitated Patients

Sometimes patients become forgetful and confused. They may move about in ways that could injure themselves or others. If this is a risk you feel you are dealing with, talk it over with the patient's physician or the hospice nurse. The hospice team will help you plan for patient safety.

In many cases, there are steps you can take to deal safely with a situation. For example:

Make the person more comfortable with:

- Repositioning frequently
- Food or drink
- A back rub
- Toileting
- Appropriate clothing
- Glasses, hearing aid, dentures

Increase activity level:

- Walking
- Recreation/social activity
- Exercise

Make environmental changes:

- Reduce noise
- Adjust lighting
- Aid mobility (cane, wheelchair)
- Change of location
- Use electronic bells/signals
- Use baby monitors
- Make the home safe (clear pathways, remove loose rugs, etc.)
- Play soft, familiar music
- Personalize space (with familiar objects)
- Have patient in supervised area (not left alone)
- Confine patient to a safety-proofed area

Provide psychosocial stimulation:

- One-to-one attention
- Reality orientation (for example: stating what day it is, the time, location, and who is present)
- Something to hold (gives sense of security)
- Relaxation techniques (massage, warm bath, touch).

Preventing the Spread of Infection

Infections are caused by germs that spread from one person or location to another. Some germs, like colds and flu, spread when you come in contact with a contaminated surface. Washing your hands the right way and at the right times is the main way to preventing these kinds of infections.

Other infections, like HIV (the virus that can cause AIDS) and Hepatitis B, are found in blood and other body fluids. The key to stopping these types of infection is to prevent unprotected contact with blood and other body fluids. Still other infections, like Tuberculosis, are carried on tiny particles in the air.

Helping prevent the spread of infection is one of the major responsibilities of being a caregiver. Infections can cause disease and serious complications for the patient, the caregiver, and others visiting or living in the home.

So, what are your “must do” steps for stopping the spread of infection? Here are five of the most important rules to know and follow:

1. Get in the habit of washing your hands both before and after: providing care; eating, drinking, or handling food; using the toilet; covering a cough; or blowing your nose. If washing with soap and water isn’t possible in a particular situation, use an alcohol-based sanitizer hand gel, then wash your hands as soon as you are able to. (The reason for always washing with soap and water is that some potential sources of infection are not killed by sanitizers and must be removed through hand-washing.)

When you wash your hands, take the time to do it correctly. Follow these steps:

- Push up your sleeves and rinse with warm water.
 - Work your hands together with soap for at least 20 full seconds (about the time it takes to sing the “Happy Birthday” song twice).
 - Get under your nails and cuticles.
 - Rinse well.
 - Dry your hands using a clean paper towel, then use a dry paper towel to turn off the faucet; it is good practice to not share a cloth hand towel.
2. Use **extra caution around blood, body fluids, and any sharp objects** (like used syringes). Ask the hospice team what special safety precautions they recommend.
 3. If **personal protective items**, such as gloves or masks, are recommended or specified by the hospice team, be sure you learn how to put them on and take them off correctly, and then use them as directed.
 4. Maintain a **clean caregiving environment**. If there is a spill of blood, avoid direct contact with blood during clean-up. Ask the hospice team about correct disposal of used syringes, bandages, and other contaminated items. Follow the directions they give you.
 5. Finally, **include others in the work** of preventing the spread of infection. Make it clear to others involved in care, and to guests who visit, what is expected, especially the how and when of hand washing.

Using Oxygen Safely

Safe use of oxygen is important. Basic points for using oxygen safely include:

- The prongs of the nasal cannula must be in the patient's nose.
- If using a face mask, it must fit snugly on the person's face.
- Small pieces of cotton or pads between tubing and skin can lessen irritation if it occurs.
- Understand how to use the equipment and any backup system.
- Oxygen is a drug and must be used only as prescribed by your physician. Treat it just like any other medication your loved one takes. Don't change the amount unless instructed to do so. Oxygen needs vary with activity.
- Never use petroleum products (e.g., oil or grease) if oxygen equipment is being used, because of the risk of combustion. Vaseline is a petroleum-based product and should never be used for nasal irritation. Instead, use a water-based moisturizer such, as K-Y Jelly.
- Make certain that the delivery device (cannula, mask, etc.) is clean, to reduce potential infection and to assure adequate oxygen delivery.
- Oxygen tubing should be no longer than 50 feet, to avoid decreasing the amount of oxygen received.
- Check with your oxygen provider or hospice team regarding safety restrictions on smoking and the presence of any open flame (such as a candle, wood stove, or fireplace) in the home. It is essential that everyone visiting or living in a home where oxygen is in use knows and follows these restrictions to the letter.

Types of Oxygen Delivery Systems—Precautions, Instructions

There are different ways that oxygen can be provided:

Concentrators—These machines take the air and concentrate it into oxygen.

- Place concentrators away from curtains, heating units, or open flame.
- Remove any frayed electrical wiring. Do not use extension cords. Concentrators draw as much as 5-6 amps; be careful not to overload circuits.
- Do not use aerosol sprays in the vicinity of the concentrator, as they may clog the filter.

Liquid Systems

- Store in a cool, well-ventilated place at least ten feet from outlets, open flames or other heat sources.
- Do not touch the fill adapter (the area that frosts over) after filling the portable.
- Special precautions are required when traveling with liquid oxygen, especially during hot weather when car temperatures may exceed 200° F. Windows must be left open for ventilation and the car's electrical system must be in good working order to prevent sparks from igniting in a highly combustible atmosphere.

Tank Oxygen

- Store away from heat sources. The pressure inside the tank increases as cylinder temperature increases.
- Secure tanks to the wall, stand, or other stabilizing device to prevent them from falling over. Because of high pressures inside the tank, damage to the tank or regulator can be dangerous. Do not store in hot, unventilated areas, such as trunks of cars, closets, storage units, etc.
- Tanks that are not secured need to be laid on their side.

Remember: both liquid and cylinder oxygen must be secured with a seatbelt when traveling by car.

Other Home Safety Recommendations

Perform a home safety check up to be certain your home is a safe place in which to provide hospice care. Check to make sure there are no conditions that are "accidents waiting to happen." Here are some practical tips on home safety:

General:

- Be sure the phone works and is within reach.
- Keep a list of key people and their phone numbers next to the phone.

Fire Safety:

- Install working smoke/heat alarms.
- Have fire extinguisher available.
- Avoid smoking in bed.
- Practice and discuss what to do in case of fire or if you smell gas or something burning.

Electrical:

- Do not overload the circuits.
- Do not use frayed cords or faulty switches.
- Do not stretch cords across pathways.

Accident Prevention

- Remove throw rugs or secure them to the floor.
- Keep exits/entrances free of clutter.
- Make sure traffic areas have adequate lighting.
- Wear shoes that will not slip.
- Use non-skid mats.
- Set hot water heater below 120°.
- Consider adding grab bars to the bathroom.
- As walking becomes more difficult, using a bedside commode, walker, and wheelchair may become necessary.

Don't Overlook Emergency Readiness

In the unlikely event of an emergency or disaster, your hospice team will do everything it can to continue providing care and support. But natural or other disaster could prevent that from happening and mean that for a time you will be on your own.

So, spending some time on emergency readiness is always a good idea.

Loss of power is often the first concern. If your loved one's health status depends on electrical equipment, planning ahead is critical and essential. Register any life-sustaining equipment with your power company and ask if there is a center designated to provide emergency power access in your community.

Here are some additional recommendations:

- Know the locations of shut-off valves for your household utilities (gas, electricity, water) and how to use them; if they require a special tool, have it nearby and ready to use.
- Disasters may come as fire, flood, hurricane, tornado, earthquake, winter storms, extremes of hot or cold weather, or prolonged power outages; some of these depend on where you live, so learn what the major risks in your area are, and prepare accordingly.

- Have readily available a list of emergency phone numbers, or in the case of phone outages, a plan with family/neighbors to obtain assistance.
- Designate an out-of-area emergency contact, in case local phone service is disrupted. Make sure others know your emergency communication plan. It is helpful for them to know that you are with a hospice program.
- Use an emergency supplies checklist to pull together both the supplies you would need to be on your own for several days while you “shelter in place” and a “grab and go” bag containing supplies for evacuating safely. You’ll find one as part of the Guide’s online supplement.

Conversations Near the End of Life

The greatest gift we can offer one another is our undivided attention. This is especially true when a person is seriously ill with a life-threatening disease. The person you’re taking care of – loved one, friend or neighbor – may express anxiety, sadness or fear about the future or regret about the past. The person may express a wish to “make right” broken relationships.

Try to listen without judgment or an agenda of your own. You don’t have to be a licensed health care professional to listen respectfully and to share feelings openly and honestly. Expressing these emotions is part of the “work” of dying; listening is part of the work of a loving caregiver. The process also has a strong spiritual element for many people. Your loved one may talk about what life means, or feelings about people or events that have been part of his or her life.

Questions About Living

When there is only a short time left in life, there are often choices to make in order to use one’s remaining time well.

- What do you still want to accomplish?
- What do you need to do to get your affairs in order?
- Who are the people with whom you want to spend time?
- Are there letters you want to write, conversations you’d like to have, matters you need to resolve?
- What will bring pleasure to this part of your life?



It is healthy and natural to think about these questions, and to talk about them with family and friends. Those who know they are going to die soon often experience high quality of life, resulting from the freedom to focus energy on what is really important.

Questions About Dying

Death is a mysterious journey for all of us. It is natural to have questions about the process and what it means. Such questions may include:

- What do I believe about what happens to a person during and after death?
- Are there ways to prepare spiritually for dying?
- What will make me less sad or afraid?
- How do I sum up my life, make peace with who I have been and who I am?
- What kind of funeral, memorial service, or other remembrance do I want after my death?
- Who do I want with me when I die?

These questions and others like them can be painful, but they can also bring great joy and a sense of inner peace. Each of us is different, of course. But many who are experiencing a terminal illness need and welcome persons who do not close off such conversations, but instead encourage them, listen supportively, and offer to share their own ideas and life experience, when that is helpful.

Who Can Help?

Over the past few decades, our culture has become more open in acknowledging dying as a normal stage of life. We now have professionals with special training to help those at the end of life ask the questions and find the answers that will make a difference to them.

Priests, ministers, rabbis, other leaders of spiritual communities: These people can be a significant resource for persons nearing the end of life, and for their loved ones. Every religious and philosophical community has its own beliefs around death and dying. To talk with someone who can both sensitively listen and also articulate a particular faith position can be a real gift. Many religious leaders are happy to extend themselves, even to those who are not officially a part of their church, synagogue, or other faith community. Don't be afraid to ask.

Chaplains, pastoral care counselors and grief counselors: A chaplain, pastoral care professional or volunteer, or grief counselor may be available. They are trained to be helpful to people across a wide spectrum of spiritual beliefs and are available to both patients and their families.

Private therapists: Especially when a person or family faces thorny issues—such as unresolved family conflicts—a private counselor or therapist can help. In finding a therapist, you can ask people you know for referrals. It's usually a good idea to have a "get acquainted" phone conversation with the therapist you are considering to make sure he or she is someone with whom you would be comfortable.

Support groups: Sometimes, it helps to talk with others who are in the same position as you. You can share insights, find humor where others may not, and support one another. Ask your hospice team about support groups available in your community. Online support groups are also becoming popular.

Friends and family: Family and friends probably do not have special training. They may not even have previous experience being with one who is dying. But if they are emotionally able to get past any discomfort they have talking openly about death and dying, they can be the very best resource available.

Suggestions for Being with Someone who is Dying

- Let the person decide what you will talk about and when. Make it clear you are open to any conversation he or she would like to have, even if this is difficult for you. He may want to talk about his funeral or memorial service, for example. This may be an uncomfortable topic for you, but something that is important for the person to discuss.
- If the person wants to talk about spiritual beliefs, be honest in expressing your own – but honor and respect his.
- While you may not be able to tell the person the outcome of the disease process, you can be truthful and respect his right to be informed.
- Don't be afraid to laugh or to cry. Real emotion can bring healing and peace.

Suggestions for Being with Someone who is Dying

- When a person is too tired to talk, your quiet presence is still appreciated. Often, touching or just holding hands becomes an important way of showing your love and presence.
- Often, doing something fun together is as helpful as a serious conversation.
- Be willing to change your plans or your topic of conversation based on how the person is feeling at the moment. Be flexible.
- Let the person know what you treasure about him, why he or she are important to you, and what memories you especially cherish.

Preparing for Approaching Death

When a person enters the final stage of the dying process, two different dynamics are at work which are closely related and interdependent.

One is the physical process, in which the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually, this is an orderly and undramatic, progressive series of physical changes which are not medical emergencies requiring anything other than comfort measures. These physical changes are the natural way the body prepares itself for death. You can aid in this process by keeping the person as comfortable as possible.

The other dynamic at work is the spiritual and emotional process patients go through at the end of their lives. They begin to release themselves from a lifetime of attachments and often feel moved to resolve unfinished business. This may include tying up loose ends in their relationships or looking for permission to die from their family members.

Patients sometimes linger on in their dying process when important issues remain unresolved. Dying cannot be rushed. The person will continue to live until the body has physically shut down. Working through these emotional and spiritual events which simultaneously occur with the deterioration of the body is the normal and natural way a person prepares to die.

Family members can help this spiritual and emotional process along by following the patient's lead. If he wants to communicate with you, be ready to do so. Maintain an open, affectionate heart for whatever way the patient wants to work. For instance, it may be more beneficial to surround the patient with pictures of whatever religious figures he requests, rather than of family photos. This can aid the patient in the sense of transition out of this world into the next. This is not the time to attempt to change your loved one. Instead, it's a time to offer unconditional acceptance, support and comfort.

A natural process

The physical signs of impending death which follow are offered to help you understand the natural way this event occurs and what you can do to help. Not all these signs and symptoms will occur with every person. Although you may be prepared for the death process, you may not yet be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you will do when this moment occurs. The death of a hospice patient is not an emergency as we usually define it. There is no rush. Nothing must be done immediately.

Physical Signs of Approaching Death and Appropriate Responses

Coolness: The person's hands, arms, feet and 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 may 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 blanket. Fluctuations in body temperature are a sign of approaching death. This is normal. A cool washcloth on the forehead or under the arms can feel good to a patient who has a high temperature.

Sleeping: The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one. Hold the person's hand. Do not shake the hand or speak loudly, but speak softly and naturally. Plan to spend time with the person when he or she is most alert and awake. Do not talk about the person in his presence as though he is not there. Speak to your loved one directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

Disorientation: The person may seem to be confused about the time, place and identity of people nearby, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak, rather than have the person guess who you are. Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, "It's time to take your medication." Explain why you are asking something – for example, "So you won't begin to hurt."

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.

Congestion: The person may have gurgling sounds coming from the 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. Raise the head up with pillows to ease breathing. Medications are available that may help dry up secretions. The sound of the congestion does not indicate the onset of severe or new pain, and is usually more disturbing to the caregiver than to the patient.

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, in a quiet, natural way lightly massage the forehead, read to the person, or play some soothing music.

Fluid and food decrease: The person will likely experience decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy which is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person 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 guidelines). A cool, moist washcloth on the forehead may also increase physical comfort.

Urine decrease and change in color: The person's urine output normally decreases and may become tea colored — referred to as concentrated urine. This is due to decreased fluid intake, as well as a 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.

Change in breathing: The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, i.e., shallow breath with a period of not breathing of five to thirty seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head and/or turning the person on the side may bring comfort. Hold the person's hand. Speak gently. Cheyne-Stokes breathing is a normal part of the process. It is not uncomfortable for the patient and is an indication that the patient is close to dying.

When Death Occurs

People wish to handle the time of death and the events that follow in different ways. The hospice team's first goal is to help you prepare, so you will know what to expect. Here are the typical steps when death occurs:

- Call the hospice office. A hospice nurse or other team member will speak with you and may come to your home. Check with them concerning appropriate notices to your doctor, medical examiner or coroner, etc.
- It may be helpful to have a friend or family member come to be with you.
- If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait several hours or longer before the funeral home comes if you wish to spend time with your loved one's body or want to wait for other family members or friends to arrive.
- If you have any concerns or fears, call the hospice nurse.

Signs That a Person Has Died:

- No breathing
- No heartbeat
- No response to communication
- Eyes fixed on a certain spot
- Eyelids slightly open
- Jaw relaxed and mouth slightly open

Practical Issues When Your Loved One Dies

Notifying Others That Your Loved One Has Died

When a loved one dies, some names will come to you immediately as persons who should be contacted. Close family; good friends; the person's minister, priest, or rabbi; their lawyer and physician. Some calls you will want to make yourself. Other calls have to be made, but you do not need to make them yourself.

When a death occurs, both your friends and your loved one's friends, as well as other family members, will want to help. It makes sense to let others help in passing the word. With friends, for example, or a church or community group, often you can make only one call and ask that person to organize informing others from that circle of acquaintances.

If there are many calls to be made, keep a list of who has been contacted. That way, there is less chance of overlooking someone important.

Working With the Funeral Home

Normally, within 24 hours of your loved one's death, you should be in contact with the funeral home to set up an appointment with a funeral director. Funeral homes offer a wide range of services at the time of death.

These usually include:

- Transporting the body from the place of death to the funeral home
- Preparing the body for burial, arranging for a casket and other necessary items for burial, or arranging for cremation
- Working with the family and, if desired, a priest, rabbi, or minister for a funeral or memorial service
- Providing time and space for visitation and a funeral or memorial service
- Assisting in the preparation of an obituary and funeral notice for the local newspapers
- Completing the necessary paperwork for the death certificate, and obtaining certified copies of the death certificate for the family. (Be sure to ask for an adequate number of certified death certificates. You will need one for each life insurance policy or pension the person had, and several more for processing the person's Last Will and Testament and other financial business. A good rule of thumb is to request at least ten copies.)

- Transporting the body and family members (if desired) to the funeral or memorial service and/or to the cemetery.

Some funeral homes also offer support groups and bereavement counseling for family members of the person who has died.

Most funeral directors are professionally trained persons who provide their service with compassion and integrity. The role they play in a community is a necessary one, and most do their work sensitively. However, it is important to realize that funeral directors deal with people who are in an especially vulnerable state. When someone you love has just died, if pre-arrangements have not been made, you need to make quick decisions on painful issues.

These issues include whether the person will be buried or cremated, what kind of casket to buy, where to buy a burial plot, what kind of service to have. Some of these decisions may involve the outlay of significant amounts of money and may also be emotionally charged, so they become more complicated.

The following suggestions will minimize the risk of making decisions you later regret:

- Never send one family member alone to see the funeral director. If possible, have two or three family representatives go, one of whom should be more detached from the pain of the loss than a spouse, or sometimes even a child.
- Most funeral homes offer a basic minimum service package. Additional services beyond that are charged individually. Make sure you understand what is included in the basic service, and what will be charged as additional services. Have the funeral director spell out the charges in writing. If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.
- Remember, money does not equal love. Many people think they must buy an expensive casket or provide a lavish funeral to show their love. This is not true. Buy only what seems reasonable and appropriate in your situation.

The appointment with the funeral director is usually a part of the business of death that people dread. Arranging for caskets and funeral notices is no one's favorite chore. Try to schedule your visit far enough after your loved one's death that you and significant others have had a night's sleep and have had some time to talk among yourselves about the kinds of arrangements that seem best to you.

If your loved one has joined a memorial society or entered into some other form of prepaid funeral plan, you and other family members will have fewer decisions to make. However, you will also have less control. If you are uncomfortable with the arrangements that have been made, you may have little choice but to accept them and understand that they represent your loved one's wishes.

Planning a Funeral or Memorial Service

After one they love has died, most people find it helpful to participate in some structured ritual of celebration, remembrance, and letting go. Depending on the religious tradition and individual tastes of the deceased person and his or her family, this might range from a formal religious service followed by an elaborate wake, to setting a time for family members and friends to gather informally to talk about the one who has died. Such services, both formal and informal, can be a source of comfort and strength, gathering together the community of grief to laugh and cry and remember together.

Below is a list of questions which will help you in planning a funeral or memorial service for a close friend or relative who has died.

- Did your loved one leave any specific instructions about the kind of service that he would want? Did those instructions include specific requests for readings, music, a person to preside, or a place where the service should be held?
- When will it be convenient for the service to take place? Do close family and friends have schedules which have to be worked around in planning the time and place of the service? Do religious beliefs determine the timing?
- Where will the service take place? If the person belonged to a church, synagogue, or other religious community, when can it schedule a service?
- Who will officiate at the service? Will it be a minister or other religious leader, a family member, or friend? Do you want an organist, soloist, or other provider of music, and how will those arrangements be made?
- Are there readings, music, pictures, or any other elements which you think would be especially meaningful to you and others as part of the ceremony?
- Do you want to choose someone to deliver a formal eulogy? Do you or other friends or family members wish to offer some personal words of remembrance at the service?

- Do you wish to have visiting hours (a time when people can see the body, say a private goodbye, and speak with the family) before the service? This custom varies from community to community.
- Will there be any kind of reception or other informal gathering of friends and family after the service? Where will it be held?

If you work through a church or other religious community, your contact in that community will undoubtedly have other questions to ask you about the service. However, it is best to think about the questions outlined above before you meet with the person who will be in charge so that you have some idea about what you want.

Other Practical Issues

Along with the major issues of dealing with the death when it occurs—talking with the funeral director, and planning for a funeral or memorial service—there are other practical tasks large and small which should be attended to in the days and weeks following your loved one’s death.

- You will want to contact the person’s lawyer regarding the content of his or her will, if one exists, and any other legal business which needs to be attended to.
- Whoever has been appointed personal representative or executor under your loved one’s last will and testament will need to contact the person’s bank, financial planner, pension administrator, life insurance company, and any others with whom the person had significant financial dealing to inform them of the death.
- You should remember to cancel club memberships and magazine subscriptions and have mail delivery stopped or transferred.
- Outstanding bills need to be collected and paid, but this should always be coordinated with other aspects of handling the estate.
- For many families, one of the difficult things to do is to go through their loved one’s personal possessions—clothing, papers, mementos, furniture. If there is a personal representative or executor, he or she will coordinate this task. Like visiting the funeral home, sorting through belongings is something that’s usually much easier when two or more family members share the load.

Taking care of all the business that needs to be sorted out after a death can take weeks or even months, depending on how the person’s affairs were organized. It is tiring and emotionally draining work. If you can,

share the responsibilities with other family members, do hard tasks with another person, and don't take on too much at one time. It is normal to feel overwhelmed at times with the finishing up of things.

Experiencing Grief and Loss

Anticipatory Grief

Watching someone you love decline in health is a painful process. When death is anticipated, both the patient and loved ones may experience a normal form of grief. It is called anticipatory grief and is similar to the process of grief following a loss.

Some of the aspects of anticipatory grief that you may notice include:

- Heightened fear, anxiety and depression
- Increased concern for the well-being of the terminally ill person
- Imagining the actual event of the death
- Attempts to adjust to the changes that may occur after the death.

Although anticipatory grief is a painful process, having some warning prior to the death can allow for several things:

- Absorbing the reality of the loss over a period of time
- Saying goodbye and completing other unfinished business with the dying person
- Reassigning the family roles of the dying person
- Gradual withdrawal of emotional energy invested in the dying person.

There are many ways that you can care for yourself during your loved one's illness that can lessen the negative aspect of anticipatory grieving. Plan to have some time for yourself every day. Seek out ways to nurture yourself, including eating well, sleeping enough, exercising, and spending time with a friend for hugs and laughs.

The Grieving Process

A wide variety of feelings and behaviors can be experienced in the grief process. Not everyone will respond to loss in the same way. It is helpful to know that the following characteristics can be a normal part of the grief experience:

Feelings. Feelings that are part of the grieving process can include shock, numbness, a sense of unreality, anger, irritability, guilt, self-reproach,

sadness, depression, anxiety, fear, hysteria, helplessness, vulnerability, low self-esteem, loneliness, relief, feelings of being crazy, mood swings and increased intensity of all feelings.

Physical sensations. Physical sensations experienced during grief can include hollowness in the stomach, tightness in the chest and throat, dry mouth, over-sensitivity to noise, dizziness, headaches, shortness of breath, weakness in the muscles, lack of energy, fatigue, excess of nervous energy, heart pounding, heavy or empty feeling in body and limbs, hot or cold flashes, skin sensitivity, stomach and intestinal upsets and an increase in physical illness.

Thought patterns. Grief-related thought patterns can include disbelief; a sense of unreality; preoccupation; confusion; lack of ability to concentrate; seeing, hearing or feeling the presence of the deceased; thoughts of self-destruction; problems with decision making.

Behaviors. Behaviors while experiencing grief include appetite and sleep disturbances, absent-minded behavior, social withdrawal, avoiding reminders of the loss, dreams of the loss, searching and calling out for the deceased, restlessness, sighing, crying, visiting places that are reminders of the loss, treasuring or carrying objects that belonged to the deceased, change in sexual activities, need for touch, hugs, contacts with others, increased sensitivity to positive and negative attention, assuming the mannerisms of the deceased, and exhibiting symptoms of the deceased's illness.

Social changes. Social changes brought on by a grieving process can include: either an increased desire for support of close friends or a withdrawal from friends and family; increased dependency on others; a need for acting normal around others; a need for relationships apart from those related to grief; being self absorbed (no energy for or interest in others); marital difficulties — especially with the death of a child; role changes; role reversals; change in social patterns and status; hypersensitivity to topics of loss; and the need for rituals.

Suggestions for Coping With Grief

- **Allow yourself to feel your feelings.** Someone close to you has died. Many emotions may arise. It's okay to feel angry, depressed, or even feel a sense of relief at the time of death.

- **Access your support system.** Reach out to people who are supportive to you. Family, friends, support groups, clergy or a therapist may be helpful.
- **Share your feelings of grief.** Talking about your feelings can be a relief. Don't hide your emotions from those who care about you.
- **Educate yourself about grief issues.** Reading literature about grief can help you understand what you are experiencing.
- **Take care of your physical self.** Remember that your emotional state can be affected by your physical state. Attempt to eat balanced meals, get adequate sleep, and do some form of exercise each day.
- **Avoid alcohol and other substances not prescribed by your physician.** Although they may numb the emotional pain initially, drugs and alcohol may prolong, delay and complicate your grief.
- **Give yourself permission to say "no."** Try not to rush or take on new responsibilities.
- **Be patient and gentle with yourself.** Healing from grief takes time. Your grief may not look like the grief of others around you. Respect your own individual grief style.

Helping Children Deal with Their Grief

Children process grief and loss differently than adults do. For example, they may be repetitive in dealing with their loss. As they reach each new level in their own growth, they use their newly acquired skills and maturity to gain further understanding of their grief. The child's history of loss and coping strategies, as well as the child's age and developmental stage, will affect how they experience their loss and the grieving that goes with it.

It's also true that children grieve not only in their own right, but also as part of a family. When a loved one is diagnosed with a terminal illness, it affects the way in which the family functions. Family roles and responsibilities may adjust to accommodate the new needs in the family structure.

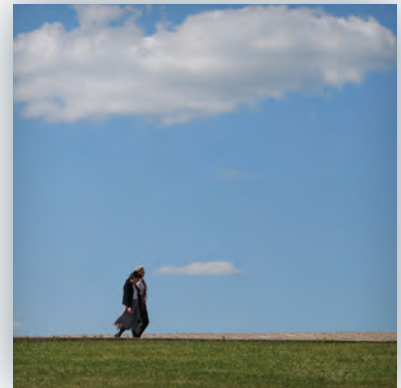
Children may grieve not only for the dying loved one, but also for the secondary losses which result – for example, changes in routine, decreased attention from parents, increased individual responsibilities, etc.

If there are children involved in your hospice situation, feel free to discuss their needs with the hospice social worker.

When Your Caregiver Role Ends

Whether your role as hospice caregiver lasted for days, weeks or months, you will no doubt end your journey with questions. Should we have accessed hospice earlier? What could I have done better? How do I move from an all-consuming focus on being a caregiver to dealing with my own grieving process? What have I learned from this that may one day apply to my own end-of-life care?

As you look back and reflect on the experience you've just been through, remember that you cared for your loved one—spouse, parent, grand-parent, sibling, or other relative or friend—with compassion and skill. You served in an intimate and timeless role, at the moment your loved one needed you. Your being there didn't change the fact that the person died. Nothing could have. But it did fundamentally change the way the person died. You contributed by helping manage pain and other symptoms, by making the person as comfortable as possible, by helping maintain the person's dignity, and, most of all, by just being with the person when he or she needed you.



Many who serve as a caregiver to a loved one who is dying feel a sense of let-down and emptiness when their responsibilities draw to a close. This is a normal reaction after a time of extreme demands and unusual stress. You may have a range of emotions about the experience you have been through—from relief that it's over, to sorrow that you were powerless to alter the outcome, to anger that your loved one has died.

More than anything, remember that you have done your best. And, really, that is all that can reasonably be asked of any of us. So, be gentle with yourself. Treat yourself with the same care and compassion you have shown others. Just as there were resources available to help you as a family caregiver, there are resources available now to help you make sense of your experience and move on to the next chapter in your life.

Funeral or Memorial Service Planner

Name: _____

Date: _____

Type of Service Preferred

Funeral—open casket

Religious

Funeral—closed casket

Non-religious

Memorial service

Family only

Other

Open

Arrangements

Location of service: _____

Time of service: _____

Do you wish to hold visiting hours before the service? _____

When? _____ Where? _____

Do you wish to have a reception after the service? _____

When? _____ Where? _____

Content of Service

Organ or other instrumental music

Soloist

Hymns or songs for congregational singing

Musical selections: _____

Scripture readings/other readings: _____

Eulogies/personal statements or recollections: _____

Other important elements: _____

Participants

Person(s) of ciating: _____

Musicians: _____

Speaker(s): _____

Pallbearers/honorary pallbearers: _____

Ushers: _____

Other notes: _____

Levels of Care

Routine Care

When symptoms are well managed, patients require less intensive care. This level of care is generally provided in your home or in a setting of your choice. However, Medicare and other insurance plans do not cover room and board costs.

General Inpatient: (Acute Care)

Admission or transfer into General Inpatient Care Unit may be required to control a patient's pain or other acute symptom management. The team's efforts are directed toward resolution of the symptoms that prompted the admission. This level of care must be in an inpatient setting where more physician and nursing care is available.

General Inpatient Unit is for patients whose condition necessitates an inpatient setting. These stays are most often viewed as transitional, to control symptoms until the patient can return home or can be cared for in a less acute setting.

Services provided are consistent with the philosophy of the Hospice and are coordinated by a team of professionals. The team consists of a physician, skilled nurses, certified nursing assistants, medical social workers and spiritual counselors.

Transfer Planning

The inpatient interdisciplinary team assesses the level of care of patients daily. Once a patient's symptoms are managed, the social worker discusses care and options for transfer out of the acute care. Hospice services will follow patients to the setting of their choice. Continuity of care is assured through a plan of care involving the patient, family, physician, unit staff and home care staff to facilitate a transfer to one of the following:

- Back Home
- Routine bed available in a Care Center
 - Long Term Care Facilities
 - Assisted Livings
 - Group Homes

Continuous Care

To maintain a patient at home this level of care may be needed to achieve acute symptom management during a medical crisis. This period is generally limited to a short period of time. This level of care requires a minimum number of skilled care during a 24 hour period.

Respite Care

Respite care in an inpatient unit is to provide a rest for family or those persons caring for the patient at home. The Hospice Medicare respite benefit allows up to a five-day stay for this level of care.

Advanced Directives

“Advanced Directives’ are written instructions concerning your wishes about your medical treatment. These instructions are used in the event that you are unable to make health care decisions yourself. You are not required to have advanced directives in order to receive care and treatment.

There are four kinds of advanced directives recognized in Colorado and the following are brief descriptions of each.

Living Will – Document you sign to tell your doctor not to use artificial life support if you become terminally ill. Your living will may also instruct a doctor to stop artificial nourishment and tube feeding when you are terminally ill and if you become unconscious, comatose, or otherwise incompetent.

Medical Power of Attorney - A document that names someone to make your health care decisions. It can cover more health care decisions than a living will and is not limited to terminal illness. This document can be made effective immediately or only if you become unable to make your own decisions.

Five Wishes – Document that expresses your wishes about how you want to be treated if you become seriously ill and cannot tell your doctor, family, or friends. It covers:

- Who you want to make decisions on your behalf.
- The kind of medical treatment you want or don’t want.
- What it means to you to “be comfortable.”
- How you want people to treat you.
- What you want your loved ones to know.

Cardiopulmonary Resuscitation Directive(CPR) –Commonly referred to as a “DNR,” – Do Not Resuscitate. A document that allows you to refuse resuscitation if you stop breathing or your heart stops breathing.

If you have questions about ‘advanced directives’ or want to assistance in preparing advanced directives, please speak with your social service counselor or Interdisciplinary Team member.

Notice of Privacy Practices

A notice of Privacy Practice is a federal law privacy regulation, which governs the use and disclosures on individually identifiable health information.

Halcyon Hospice and Palliative is notifying you of the ways your health information may be used and shared with other agencies, your rights to access your information and how you may limit us from sharing it with others.

Halcyon Hospice and Palliative Care under Health Insurance and Portability Act (HIPPA) may use your health information for the following purposes:

- Treatment: For coordinating care with other agencies such as your physician, care center, staff members, pharmacists and suppliers of medical equipment or community resources for you, your caregivers and family.
- Payment: This disclosure of information is necessary to obtain payment for your care.
- Operations: For health care operations we may disclose information to another covered entity for limited operational use:
 - Certification, licensing or credentialing activities.
 - Reviewing and auditing medical records, including compliance, medical or legal reviews.
 - To local or state agencies required by law regarding risks to public, injuries, incidents of neglect, abuse or violence and certain diseases.
 - Performance evaluations of staff, volunteers, students, interns and contracted personnel.
- Other examples of when health information may be shared
 - In cooperation with law enforcement agencies and health oversight agencies required by law if your health information is directly related to an investigation, including investigations of abuse and neglect.
 - Providing information about your general health status to family members or people you have designated. A patient identifier (determined by agency) must be supplied before information will be released. All other inquires will be referred to the family.

Written authorization must be obtained for information shared that is not related to treatment, payment or operations and that is not required by law.

You have the right with respect to use and disclosure of your protected health information.

- To inspect and/or to request to amend copies of your health information.
- To request an accounting of agencies and individuals with whom information has been shared with in the past, outside of routine disclosures for treatment, payment and operations.
- To receive confidential information in a certain way and request how information is used and shared.

The hospice will apply reasonable safeguards against incidental uses and disclosures of Protected Health Information and implement minimum necessary standards.

Dear Patient:

Hospice has always protected the confidentiality of health information by sealing medical records away in file cabinets and refusing to reveal your information. Today, state and federal laws also attempt to ensure the confidentiality of this sensitive information.

The federal government recently published regulations designed to protect the privacy of your health information. This "privacy rule" protects health information that is maintained by physicians, hospitals, hospices, and health plans. The "privacy rule" protects the confidentiality of your health information.

This new regulation protects virtually all patients regardless of where they live or where they receive their health care. Every time you see a physician, are admitted to the hospital/hospice, fill a prescription, or send a claim to health plan, your physician, the hospital or hospice care provider will need to consider the privacy rule. All health information including paper records, oral communications, and electronic formats (such as e-mail) are protected by the privacy rule.

This privacy rule also provides you certain rights, such as the right to have access to your medical records. However, there are exceptions; these are not absolute. We also take precautions in our office to safeguard your health information such as training our employees and employing computer security measures. Please feel free to ask our privacy officer about exercising your rights or how your health information is protected in our office.

The Notice of Private Practices, [following this letter](#), explain our privacy practices and the privacy practices SeniorMed Pharmacy. These documents contain very important information about how your confidential health information is handled. They also describe how you can exercise your rights with regard to you protected health information, (PHI).

Please let us know if you have any questions about any of the following Notice of Privacy Practices. You may contact the designees below or you may discuss any questions you may have with you assigned social worker.

Adminsitrator
Halcyon Hospice and Palliative Care
237 Main St
Mead CO 80542
888-736-6331

Administrator
SeniorMed Pharmacy
480 S. Chambers
Aurora, CO 80017

For information on submitting a privacy issue complaint go to www.hhs.gov/oct/hippa or www.healthprivacy.org.

If you wish, you may also file a complaint with the Secretary of the U.S. Department of Health and Human Services. You may mail your complaint to U.S. Department of Health and Human Services, 200 Independence Avenue, S.W., Washington, DC 20201.



Notice of Privacy Practices

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

I. Our Duty to Safeguard Your Protected Health Information

SeniorMed is required by certain state and federal regulations to implement policies and procedures to safeguard your health information. Copies of our privacy policies and procedures are maintained in our business office. We are required by state and federal regulations to abide by the privacy practices described in this notice, including any future revisions that we may make to the notice as may become necessary or as authorized by law.

Individually identifiable information about your past, present, or future health or condition, the provision of health care to you, or payment for the health care treatment or services you receive is considered protected health information (PHI). Accordingly, we are required to provide you with this that contains information regarding our privacy practices to explain how, when and why we may use or disclose your PHI and your rights and our obligations regarding any such uses or disclosures. Except in specified circumstances, we must use or disclose only the minimum amount of PHI necessary to accomplish the intended purpose of the use or disclosure of such information.

We reserve the right to change this notice at any time and to make the revised or changed notice effective for PHI that we already have about you as well as any information we receive in the future about you. Should we revise/change this Privacy Notice, we will make this notice available to you upon request. You may request and obtain a copy of any new/revised Privacy Notice from the contact person identified on the last page of this notice.

Should you have questions concerning our Privacy Notice, our contact information is listed on the last page of this document.

II. Examples of How We Use and Disclose Protected Health Information about You

The following categories describe different ways that we use and disclose your protected health information. We have provided you with examples in certain categories; however, not every use or disclosure in a category will be listed.

Treatment. We may use your health information to provide and coordinate the treatment, medications and services you receive. For example, we may contact you regarding compliance programs such as drug recommendations, therapeutic substitution, refill reminders, other product recommendations, counseling and drug utilization review (DUR), product recalls or disease state management.

Payment. We may use your health information for various payment-related functions. Example: We may contact your insurer, pharmacy benefit manager or other health care payor to

determine whether it will pay for your medication and the amount of your co-payment. We will bill you or a third-party payor for the cost of medications dispensed to you. The information on or accompanying the bill may include information that identifies you, as well as the medications you are taking.

Health Care Operations. We may use your health information for certain operational, administrative and quality assurance activities. Example: We may use information in your health record to monitor the performance of the pharmacists providing treatment to you. This information will be used in an effort to continually improve the quality and effectiveness of the health care and service we provide. We may disclose health information to business associates if they need to receive this information to provide a service to us and will agree to abide by specific HIPAA rules relating to the protection of health information. We may also use your health information to provide you with information about benefits available to you, and, in limited situations, about health-related products or services that may be of interest to you.

We are permitted to use or disclose your PHI for the following purposes. However, SeniorMed may never have reason to make some of these disclosures.

To Communicate with Individuals Involved in Your Care or Payment for Your Care. We may disclose to a family member, other relative, close personal friend or any other person you identify, PHI directly relevant to that person's involvement in your care or payment related to your care.

Food and Drug Administration (FDA). We may disclose to the FDA, or persons under the jurisdiction of the FDA, PHI relative to adverse events with respect to drugs, foods, supplements, products and product defects, or post-marketing surveillance information to enable product recalls, repairs, or replacement.

Worker's Compensation. We may disclose your PHI to the extent authorized by and to the extent necessary to comply with laws relating to worker's compensation or other similar programs established by law.

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

Law Enforcement. We may disclose your PHI for law enforcement purposes as required by law or in response to a subpoena or court order.

As Required by Law. We will disclose your PHI when required to do so by federal, state, or local law.

Health Oversight Activities. We may disclose your PHI to an oversight agency for activities authorized by law. These oversight activities include audits, investigations, inspections, and credentialing, as necessary for licensure and for the government to monitor the health care system, government programs, and compliance with civil rights laws.

Judicial and Administrative Proceedings. If you are involved in a lawsuit or a dispute, we may disclose your PHI in response to a court or administrative order. We may also disclose health information about you in response to a subpoena, discovery request, or other lawful process instituted by someone else involved in the dispute, but only if efforts have been made, either by the requesting party or us, to tell you about the request or to obtain an order protecting the information requested.

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

Coroners, Medical Examiners, and Funeral Directors. We may release your PHI to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or determine the cause of death. We may also disclose PHI to funeral directors consistent with applicable law to enable them to carry out their duties.

Organ or Tissue Procurement Organizations. Consistent with applicable law, we may disclose your PHI to organ procurement organizations or other entities engaged in the procurement, banking, or transplantation of organs for the purpose of tissue donation and transplant.

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

Fundraising. We may contact you as part of a fundraising effort.

Correctional Institution. If you are or become an inmate of a correctional institution, we may disclose to the institution or its agents PHI necessary for your health and the health and safety of other individuals.

To Avert a Serious Threat to Health or Safety. We may use and disclose your PHI when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person.

Military and Veterans. If you are a member of the armed forces, we may release PHI about you as required by military command authorities. We may also release PHI about foreign military personnel to the appropriate foreign military authority.

National Security, Intelligence Activities, and Protective Services for the President and Others. We may release PHI about you to federal officials for intelligence, counterintelligence, protection to the President, and other national security activities authorized by law.

Victims of Abuse or Neglect. We may disclose PHI about you to a government authority if we reasonably believe you are a victim of abuse or neglect. We will only disclose this type of information to the extent required by law, if you agree to the disclosure, or if the disclosure is allowed by law and we believe it is necessary to prevent serious harm to you or someone else.

Other Uses and Disclosures of PHI

We will obtain your written authorization before using or disclosing your PHI for purposes other than those provided for above (or as otherwise permitted or required by law). You may revoke an authorization in writing at any time. Upon receipt of the written revocation, we will stop using or disclosing your PHI, except to the extent that we have already taken action in reliance on the authorization.

III. Your Rights Regarding Your Protected Health Information

Obtain a paper copy of the Notice upon request. You may request a copy of our current Notice at any time. You may obtain a paper copy from our business office.

Request a restriction on certain uses and disclosures of PHI. You have the right to request additional restrictions on our use or disclosure of your PHI by sending a written request to our business office. We are not required to agree to those restrictions. We cannot agree to restrictions on uses or disclosures that are legally required, or which are necessary to administer our business.

Inspect and obtain a copy of PHI. In most cases, you have the right to access and copy the PHI that we maintain about you. To inspect or copy your PHI, you must send a written request to our business office. We may charge you a fee for the costs of copying, mailing and supplies that are necessary to fulfill your request. We may deny your request to inspect and copy in certain limited circumstances.

Request an amendment of PHI. If you feel that PHI we maintain about you is incomplete or incorrect, you may request that we amend it. To request an amendment, you must send a written request to our business office. You must include a reason that supports your request. In certain cases, we may deny your request for amendment.

Receive an accounting of disclosures of PHI. You have the right to receive an accounting of the disclosures we have made of your PHI after April 14, 2003 for most purposes other than treatment, payment, or health care operations. The right to receive an accounting is subject to certain exceptions, restrictions, and limitations. To request an accounting, you must submit a request in writing to the business office. Your request must specify the time period. The time period may not be longer than six years and may not include dates before April 14, 2003.

Request communications of PHI by alternative means or at alternative locations. For instance, you may request that we contact you at a different residence or post office box. To request confidential communication of your PHI, you must submit a request in writing to our business office. Your request must tell us how or where you would like to be contacted. We will accommodate all reasonable requests.

Where to obtain forms for submitting written requests. You may obtain forms for submitting written requests by contacting the business office at SeniorMed, 480 S. Chambers Rd. Aurora, CO 80017 or toll-free by telephone at 888. 736.6331

Minors. If you are a minor who has lawfully provided consent for treatment and you wish for SeniorMed to treat you as an adult for purposes of access to and disclosure of records related to such treatment, please notify a pharmacist or the Privacy Office.

IV. How to File a Complaint about Our Privacy Practices

If you have reason to believe that we have violated your privacy rights or our privacy policies and procedures, or if you disagree with a decision we made concerning access to your protected health information, you have the right to file a complaint with us or the Secretary of the U.S. Department of Health and Human Services. You will not be retaliated against for filing a complaint.

You may submit your complaint directly to SeniorMed. Our contact information is listed on the last page of this document.



Notice of Privacy Practices

Record of Acknowledgment / Documentation of Good Faith Effort to Obtain Acknowledgment

Name of [Resident/Patient]: _____ Date: _____

Effective Date of This Privacy Notice

The effective date of this Privacy Notice is April 14, 2003

Contact Information for Questions, Complaints or Requests Regarding Your Health Information

Should you have any questions concerning our privacy practices, obtaining a copy of our privacy notice, requesting restrictions on the release of your information, revoking an authorization, amending or correcting your protected health information, obtaining an accounting of our disclosures of your protected health information, requesting inspection or copying of your medical information, requesting that we communicate information about your health matters in a certain way, filing complaints, or any other concerns you may have relative to our privacy practices, please contact:

Sylvia Brothers
480 S. Chambers
Aurora, CO 80017
888. 736.6331

If you wish, you may also file a complaint with the Secretary of the U.S. Department of Health and Human Services. You may mail your complaint to U.S. Department of Health and Human Services, 200 Independence Avenue, S.W., Washington, DC 20201.

Acknowledgment / Good Faith Effort to Obtain Acknowledgment (check one of the following)

I certify that I received a copy of the above-named entity's Privacy Notice and that I have had an opportunity to review this document and ask questions to assist me in understanding my rights relative to the protection of my health information. I am satisfied with the explanations provided to me and I am confident that the above-named entity is committed to protecting my health information.

Date _____ Signature: _____

Printed Name: _____

I certify that I am the authorized representative of above-identified patient, and that I have received the Privacy Notice on behalf of this individual and that the above-named entity provided me with an opportunity to review this document and ask questions to assist me in understanding the patient's privacy rights. I am satisfied with the explanations provided to me and I am confident that the above-named entity is committed to protecting health information.

Date: _____ Signature of Representative: _____

Printed Name: _____

Relationship to Individual: _____

I, _____, certify that I made a good faith effort to obtain the acknowledgment of the above-identified [resident/patient] or his/her personal representative that he/she had received a copy of the Privacy Notice of the above-identified entity, but was unable to obtain such acknowledgment for the following reason(s):

[Resident/Patient] or personal representative refused to sign.

[Resident/patient] or personal representative was unavailable to sign.

Other: _____

Date: _____ Signature/Title: _____

A copy of this document must be provided to the person to whom the Privacy Notice was provided and a copy must be filed in the patient's record.



This notice describes how medical information about you may be used and disclosed and how you can get access to this information. PLEASE REVIEW IT CAREFULLY.

Under applicable law, we are required to maintain the privacy of your Protected Health Information (PHI) and to provide you with notice of our legal duties and privacy practices with respect to PHI. We are required to abide by the terms of this notice as it may be updated from time to time.

1. Good Day Pharmacy may use or disclose your PHI without your authorization in certain circumstances: We are permitted to make certain types of uses and disclosures of your PHI under applicable law. We may obtain information to dispense prescriptions and for the documentation of information in your records that may assist us in managing your medication therapy or your overall health.

For treatment purposes: We will use PHI to dispense prescriptions to you. PHI will also be used to communicate with your health care providers and to coordinate and manage your health care, for example, when we consult with your physician or specialist regarding your medications, treatment or condition.

For payment purposes: Use and disclosure of PHI will take place to obtain payment or reimbursement for pharmaceutical services, for example, when your case is reviewed to insure appropriate care was delivered. For reimbursement, your PHI may be disclosed to intermediaries employed by your plan sponsor, such as insurers, pharmacy benefit managers, claims administrators and computer switching companies. We may also disclose PHI about you to Good Day Pharmacy's business associates for services that they may provide to or for Good Day Pharmacy.

For health care operations: Use and disclosure of PHI will take place in a number of ways including quality assessment and improvement, provider review and training, underwriting activities, reviews and compliance activities, planning, development management and administration. For example, we may disclose your PHI when we must communicate with a physician or a physician's staff or to another pharmacy which states that they have your request and consent to transfer pharmacy records to them. Your PHI may be used to insure to ensure proper pharmacy operations, including communicating refill reminders and other materials related to your health care or to assist in the evaluation of the quality of care you were provided. Your PHI may be communicated to staff responsible for processing and delivering materials related to your health care.

For other purposes required by law: We will use or disclose PHI about you as required or limited by local, state or federal law. We may disclose PHI about you in the course of any judicial or administrative proceedings, provided that proper documentation is presented to Good Day Pharmacy. For public health risks, we may use or disclose PHI about you to a public health authority or private entity to assist in disaster relief efforts. We may use or disclose PHI about you to a government authority if it is reasonably believed you are a victim of abuse, neglect or domestic violence. We may disclose PHI about you to law enforcement officials for authorized purposes. We may use or disclose PHI about you, in good faith and consistent with any applicable law and standards of ethical conduct, to avert a serious threat to health or safety. We may use or disclose PHI about you for specialized government functions including, but not limited to; military and veteran's activities, workers compensation laws, national security and intelligence, protective services, department of state functions, and correctional institutions and law enforcement custodial situations. Good Day Pharmacy may use or disclose PHI for disaster relief purposes.

For other purposes permitted by law: We may disclose PHI after death, or prior to, and in reasonable anticipation of death, to coroners, medical examiners, and funeral directors. We may use and disclose PHI about you for research purposes with a valid waiver of authorization from the research board. Otherwise, Good Day Pharmacy will request a signed authorization by the individual for all other research purposes. If we participate in a fundraising activity, we may use demographic PHI to send you fundraising packet, or we may disclose demographic PHI about you to a business associate or an institutionally related foundation to send you a fundraising packet.

2. Other uses and disclosures of your PHI which are not described above will be made only with your written authorization: You may revoke your written authorization.

3. Good Day Pharmacy may contact you for the following purposes: (1) We may contact you to remind you of your prescription at such time they are ready to be refilled. (2) We may contact you to notify you of alternative treatments and/or products. (3) We may use your PHI to notify you of benefits and services Good Day Pharmacy provides.

4. You have the following rights with respect to your PHI: (1) You have the right to request restrictions of Good Day Pharmacy's uses and disclosures of your PHI; however, we are not required to accommodate a request. (2) You have the right to receive confidential PHI from us by alternative means or at alternative locations. Reasonable requests will be accommodated. (3) You have the right to inspect and copy PHI that is contained in Good Day Pharmacy for the duration Good Day Pharmacy maintains PHI about you, as provided by law. There may be a reasonable cost-based charge for photocopying and mailing documents. (4) You have the right to request an amendment of the PHI Good Day Pharmacy maintains about you. Under certain circumstances we may deny your request for amendment. If we do deny the request, you will have the right to have the denial reviewed by someone we designate who was not involved in the initial review. You may also ask the Secretary, United States Department of Health and Human Services, or their appropriate designee, to review such a denial. If you wish to amend your PHI files, please communicate your request with the compliance officer identified below. (5) You have the right to receive an accounting of disclosures of your PHI made by Good Day Pharmacy, as provided by law. (6) You have a right to receive additional copies of this Notice.

5. Revisions to this Notice: Good Day Pharmacy reserves the right to change the terms of this Notice and make the new notice provisions effective for all PHI that we maintain. The revised notice will be available, upon request, to all individuals. Good Day Pharmacy will also post the revised notice in the pharmacy.

6. To file a complaint: If you believe your privacy rights have been violated, you may file a complaint with Good Day Pharmacy and/or to the Secretary of Health and Human Services. If you wish to file a complaint with Good Day Pharmacy, please contact the compliance officer, Melinda O'Brien, at this pharmacy. There will be no retaliation for filing a complaint. If you wish to file a complaint with the Secretary, please write to:

The U.S Department of Health and Human Services
200 Independence Ave, S.W.
Washington, D.C. 20201

7. To contact us : You may contact us for further information at:

Good Day Pharmacy
Melinda O'Brien, Privacy Officer
2500 Rocky Mountain Ave. Loveland, CO 80538
(970) 624-1980

8. Effective Date of this Notice: April 14th, 2003

Guidelines for Medication Disposal

Halcyon Hospice believes that the proper destruction of medication is one way we can contribute in protecting our environment.

You may have heard about how medication that is not disposed of properly can be accidentally taken by someone else. It also has the potential of contaminating the environment and our water supply. The disposal of unused medication down sinks and toilets is no longer recommended.

The following are guidelines that we compiled for you from the US Food and Drug Administration (FDA) Pharmacies and other entities that regulate medication disposal.

Do not flush prescription drugs down the toilet.

If no instructions are given, you may throw the drugs in the household trash, but first:

- **Take them out of their original containers** and mix them with an undesirable substance, such as used coffee grounds or kitty litter followed by rubbing alcohol or water. The medication will be less appealing to children and pets, and unrecognizable to people who may intentionally go through your trash.
- **Tablets, Capsules, Liquid, IV Medications:** Mix with an undesirable substance, such as used coffee grounds or kitty litter followed by rubbing alcohol or water.
- **Transdermal Patches:** Remove patches from packaging. Wearing disposable gloves cut the patch in half and place in container or bag. Add undesirable substance, such as used coffee grounds or kitty litter.
- **Ointments and Creams:** Mix undesirable substance, such as used coffee grounds or kitty litter into the original container or apply the above process.
- **Suppositories:** Add to undesirable substance, such as used coffee grounds or kitty litter followed by rubbing alcohol or water.

Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.

On medication bottles, remove the label or any identifying label from all containers before you throw them out.

OR

Call your Pharmacist or Pharmacy and get information on the best way to dispose of a particular drug or medication, or if they know of a Community Drug Take-Back Program in your area.

Community Drug Take-Back Program

(Subject to change, call local pharmacy for current information)

King Soopers

- 3400 Youngfield St.,
Wheat Ridge
- 1650 30th St,
Boulder
- 4271 S. Buckley Rd,
Aurora
- 9551 S. University Blvd,
Highlands Ranch
- 2810 Quebec St,
Denver

Tri-County Health Department

- 4857 S. Broadway,
Englewood
- 4201 E. 72nd Ave. Suite D,
Commerce City

Denver Health

- Wellington E. Webb
Center for Primary Care,
301 W. 6th Ave, Denver

City Market

- 300 Dillon Ridge Rd,
Dillon
- 400 North Parkway,
Breckenridge

Halcyon

H O S P I C E

& Palliative Care



*The Kingfisher,
calm and at peace,
nested,
upon water;
quieter of restlessness.*

North

*(970) 535-0870 phone
(970) 535-0871 fax*

South

*(303) 329-0870 phone
(303) 394-0871 fax*

www.halcyonhospice.org



Accredited by the Joint Commission

Visit www.jointcommission.org for direct inquiries to the Joint Commission