



HOSPICE

PATIENT AND FAMILY RESOURCE BOOK



CORNERSTONE VNA
HOME • HEALTH • HOSPICE

603-332-1133

HOSPICE

PATIENT AND FAMILY RESOURCE BOOK

This book was made possible thanks to individual donors.
We welcome your feedback to help support
other hospice patients and families.

Published May 2025

Cornerstone VNA
178 Farmington Road
Rochester NH 03867
603-332-1133
www.cornerstonevna.org



Contents

1 Welcome

- 1 Greetings from our Hospice Care Director
- 2 Your Feedback Is Important
- 2 About Hospice

3 Always Supported with Cornerstone VNA Hospice

- 4 Hospice 24-Hour Support System
- 5 Your Hospice Care Team
- 5 Hospice Care Team Roles

8 Commonly Asked Questions

11 Home Safety and Equipment

- 14 Durable Medical Equipment (DME) and Medical Supplies

15 Support for Caregivers in Providing Care and Comfort

- 16 Providing Direct Care
- 19 Taking Care of Yourself
- 21 Understanding Signs and Symptoms
 - 21 Pain
 - 22 Anxiety/Agitation (Extreme Restlessness)
 - 23 Appetite
 - 24 Breathing Pattern Changes
 - 25 Confusion
 - 26 Elimination/Toileting
 - 27 Emotional, Spiritual, or Mental Changes; Unusual Communication
 - 28 Fatigue/Drowsiness/Increased Sleeping
 - 28 Nausea
 - 29 Restlessness
 - 30 Skin Temperature Changes
- 31 Medications Used for Pain and Symptom Management
 - 32 Narcotics
 - 33 Hospice Comfort Kit

34 Honoring Goals and Wishes

- 34 Advance Care Documents

36 End-of-Life Care

- 36 Transformations At The End Of Life
- 38 Seeing Your Loved One's Body
- 38 Proper Disposal of Medication

39 Continued Support for Caregivers

- 39 Grief and Bereavement
- 40 The Grieving Process
- 41 Pre-death Gathering of Important Documents and Information
- 43 Post-death List of Actions

For videos on specific caregiving procedures visit
<https://cornerstonevna.org/hospice-resources>





Greetings from our Hospice Care Director

Thank you for choosing Cornerstone VNA. As a nonprofit organization, we are proud to provide compassionate home health and hospice care in New Hampshire and Maine.

Our Hospice Care team is here to support you and your loved ones, ensuring comfort and dignity during this time. You'll have access to a dedicated team of professionals, including Hospice Physicians, Nurse Practitioners, Nurses, Chaplains, Social Workers, Nursing Assistants, and Volunteers. Together, we'll work to manage your symptoms and enhance your quality of life.



Your care plan will be personalized to meet your needs, with regular reviews and adjustments as necessary. We are committed to delivering care at the appropriate level, whether through visits during business hours or 24/7 emergency support. Hospice care covers medications and items related to your diagnosis, as deemed medically necessary.

Your satisfaction is our priority, and we welcome any feedback to help improve our services. We strive to provide exceptional care and to always be here to meet your needs. It's an honor to care for you and your family.

Sincerely,

Lisa Nichols, RN, MSN, CCM
Hospice and Palliative Care Director

Your Feedback Is Important

Your Cornerstone VNA Hospice Care team will coordinate all aspects of your care, including arranging for medical equipment, supplies, and medications based on your hospice diagnosis and medical needs. We strive to provide the highest quality services to each patient and their families.

We rely on your feedback to let us know what we're doing right and what could be improved. We welcome your comments or questions at any time, including feedback regarding the content in this *Hospice Patient and Family Resource Book*. You can speak to a member of your Hospice Care team or contact the Hospice Care Director by calling 603-332-1133.

Another way we receive your feedback is through a national hospice survey. Caregivers will receive this survey in the mail a few weeks after care ends. Please complete the survey, even if you feel the care we provided was exceptional. We recognize that the needs of each patient and family are unique, and our goal is to always meet those needs and provide the support each patient deserves, with compassion and dignity.

About Hospice

Hospice is a program of care and support for people who are terminally ill. Here are some important facts about hospice:

- Hospice helps people who are terminally ill live comfortably.
- The focus is on providing comfort, not on curing an illness.
- A specially trained team of professionals and caregivers provide care for the whole person, including their physical, emotional, social, and spiritual needs.
- Services may include physical care, support, medications, equipment, and supplies for the terminal illness and related condition(s).
- Care is generally provided in the home.
- Hospice isn't only for people with cancer.
- Family caregivers can get support from the Hospice Care team members.

Additional information, forms, and state required notices can be found in the back pocket of this resource book. If you have any questions, please do not hesitate to ask – we're here for you.



Choosing hospice care is an important decision, and we understand that patients and families often have many questions. This resource book is designed to support patients, with a focus on the role of family members or caregivers. It aims to reinforce your discussions with the Hospice Care team and provide additional information about the journey ahead.

We hope this resource book helps you feel supported and confident, both in receiving and providing care. Most sections address caregivers, though some directly speak to patients. We encourage caregivers to include patients in healthcare decisions.

Hospice care focuses on compassionate, expert care, honoring patients' wishes, and helping them live fully. It's a time for strengthening relationships and finding peace, with each day as an opportunity to experience life one more time. In addition to managing pain and symptoms, hospice supports both patients and families, offering emotional care and grief support.

Our priority is to honor the goals and wishes of our hospice patients. Advance care directives, which are explained in this book, will help guide decisions, ensuring care aligns with patient preferences, such as managing pain and being cared for at home.

Your hospice team cares for patients where they are, most often at home, but also in hospitals, skilled nursing facilities, assisted living, or Hyder Family Hospice House in Dover, NH.

Role of Caregivers

In hospice care at home, family caregivers are vital partners in our mission to provide compassionate care. Your observations and communication make a difference.

- Please share any pain or symptom concerns with us so we can address them quickly. Our team is available 24/7.
- Contact us at 603-332-1133 with any concerns or changes in medical status.
- If you are not present during a hospice visit, we encourage you to call us if you have any questions.

Care at home can be rewarding but also overwhelming. Our team is here to guide, listen, and support you. You'll remain under the care of your primary doctor while working with the hospice team to create a personalized care plan.

Hospice 24-Hour Support System

In case of emergency, **please do not call 911**. Call Cornerstone VNA Hospice at 603-332-1133 first, even if you feel the need to call 911 or an ambulance. Hospice staff will help you manage the medical crisis and, whenever possible, remain at home. If a visit to the hospital is determined to be needed, Cornerstone VNA Hospice will help you navigate the hospital systems to best honor your wishes and get you the care you need.

Cornerstone VNA Hospice has nurses and providers who are on call 24 hours a day to meet your needs and those of your caregivers. Even when your primary nurse case manager is off duty, there is always a knowledgeable registered nurse available to answer your questions or make a visit. Please call Cornerstone VNA Hospice at 603-332-1133 at any time for questions, clarifications, or to report changes in patient status, including death.

Please call us if:

- there is a **significant change** in the patient's condition
- the patient **falls**
- there is **heavy bleeding**
- the patient has new or persistent **severe pain**
- **death occurs**

Call us any time, day or night. 603-332-1133



Your Hospice Care Team

Hospice Director: Lisa Nichols, RN, MSN, CCM

Medical Directors: Patrick Lanzetta, MD and Peter Saikali, MD

Nurse Case Manager: _____

Nursing Assistant: _____

Social Worker: _____

Chaplain: _____

Bereavement Coordinator: _____

Volunteer: _____

Hospice Care Team Roles

Hospice Medical Director: Your hospice medical director is specially trained in end-of-life care and may consult with your doctor and the hospice team to ensure that your care is meeting your changing medical needs.

Nurse Practitioners: A nurse practitioner who has advanced training in hospice and palliative care may assist the hospice team or physician with symptom management.

Nurse: Your hospice nurse manages your care, in consultation with your primary physician and other members of your hospice team. Your nurse will:

- monitor your condition
- coordinate all aspects of your care
- teach you and your caregivers about:
 - medications
 - end-of-life care
 - symptom management
 - decision making
 - use of equipment
 - other individualized topics as needed

Social Worker: Your social worker can help you determine your goals of care at the end of life and may:

- offer emotional support to you and your loved ones
- facilitate family meetings to address your care and comfort and to help resolve any conflicts or stressful situations
- provide information on healthcare decision making (Do Not Resuscitate - DNR, Advance Directive, and Health Care Proxy - see page 34)
- provide referrals to other community resources, financial assistance, and funeral arrangements

Chaplain: The chaplain meets patients where they are on their spiritual journey. Having a specific religion or faith is not a requirement for chaplain support. The chaplain provides a spiritual connection and guidance for the patient and family through listening, prayer, music, or other methods that meet the needs. Chaplains do not replace your current spiritual support, but are additional support specific to the hospice experience. Chaplain care can:

- provide support for issues such as faith, fear, loss, forgiveness, anger, or spiritual questioning
- provide space for listening, processing, and end of life conversations
- contact or coordinate with the clergy of your faith community if you have one

Nursing Assistant: The nursing assistant can assist with personal care and will:

- help with bathing, eating, dressing, and personal grooming
- perform light homemaking such as changing the patient's linens, assisting with the patient's laundry and meal preparation
- communicate their observations to the nurse case manager

Nursing assistants **cannot:**

- cut toenails, under any circumstances
- do heavy work such as washing floors, walls, windows, or curtains, or spring or fall house cleaning
- do heavy weekly laundry or any laundry other than the patient's own items
- transport people in their car or the patient's/family's car
- perform care or services for other family members, friends, or neighbors
- accept money, tips, or personal gifts (Cornerstone VNA is a non-profit organization and can accept donations)
- give their telephone number or address to patients or families

Primary Caregiver: Hospice at home means people receive most of their care from a loved one or friend who is an integral member of the hospice team. Primary caregivers provide basic physical care and emotional support, including bathing, giving medications and special comfort measures, and reporting issues and observations to the hospice team.

Companion Volunteer: A volunteer can visit on a regular basis or for a one-time need. Volunteers have extensive hospice volunteer training and can offer services such as:

- **Listening and offering a supportive presence:** Volunteers can provide companionship through attentive listening and meaningful conversations.
- **Engaging in activities:** Volunteers may read to the patient, play soothing music, or assist with writing letters or other creative activities.
- **Providing caregiver relief:** Volunteers can give caregivers a short-term break by staying with the patient and ensuring their comfort.
- **Sitting vigil:** Volunteers are available to stay quietly with the patient, especially during nighttime hours, offering peace and presence.
- **Assisting with daily tasks:** Volunteers can help with running errands and preparing simple meals.

We Honor Veterans Volunteers: Our participation in the national We Honor Veterans Program allows us to offer additional services to veterans and their families, such as assisting with VA benefits, military funeral and memorial planning, supporting persons with Post-Traumatic Stress Disorder, and providing a veteran-to-veteran volunteer.



Therapy Dog Volunteer: Our therapy dog can lend its compassionate presence and unwavering support to Hospice patients. Moreover, it will play a special role in bereavement sessions and group grief support meetings, offering comfort and solace to those in need.



Pet Peace of Mind Volunteers: We understand the importance of your pet(s) in your life. People bond with their pets in much the same way they bond with people. Pets are loved like family members and comfort their owners much like a close friend or relative. At the end of life, for some people, pets may be the sole source of companionship, comfort and love. As an illness progresses, people may require assistance to care for their beloved pet(s). We can help during this challenging time. We have trained volunteers who love animals and who will be happy to come to your home to help ensure your pets are well cared for. Pet Peace of Mind Volunteers can provide assistance with:

- dog walking, playtime, clean up waste, brushing/combing
- cat playtime, litter box cleaning, brushing/combing
- costs of pet food, grooming or medication
- boarding or pet-sitting if a patient is hospitalized or transferred to a facility and other options have been exhausted
- placing pets after a patient's death



Commonly Asked Questions

What does it mean when you say you provide “care and comfort”?

In hospice this is a rather standardized term for palliative, not curative treatment – care that improves a person’s quality of life by relieving suffering and providing practical, emotional, and spiritual support.

What if something is not covered by Medicare or commercial insurance?

When a person elects to use the hospice benefit portion of their insurance, financial responsibility is defined primarily by the insurance company. Most define this as medically necessary items, services, and drugs related to the reason for hospice.

- Hospice provides equipment, medications and supplies based on best practice standards of care using a formulary with contracted vendors.
- If a patient wants equipment or medication that is not medically reasonable or necessary for their terminal diagnosis, then the patient is responsible for the cost.

Does hospice pay for all services a patient needs?

While it is exceptional and unusual, there might be times when the hospice will determine that items, services, and drugs are unrelated to your terminal illness and related conditions; if this happens, those items, services, and drugs would be covered by your insurance as they were before electing hospice.

How does a hospice program measure success?

As an agency we always want to meet your needs and hear from you to improve your experience. Hospices measure success by the responses from patients and their families or caregivers. One specific way we measure success is by the day-to-day feedback from patients during care. Another way we measure success is the Family Experience Survey required by the Centers for Medicare and Medicaid services. The survey asks questions to determine if the hospice was **always** meeting the needs of the patient and family.

How much input do I have regarding my care?

You **always** have a say in your care! If you ever have questions, we want to hear from you. Please reach out any time by calling 603-332-1133 and ask to speak with hospice leadership.

Is hospice always available to provide direct care?

Hospice has a team of professionals who can teach care of the patient and support the patient and the family. Hospice is available by phone 24/7 and can provide intermittent visits for emergency situations.

Does hospice put the patient on sedating medications?

Hospice sometimes needs to put patients on pain medications that can be sedating. However, in order for the patient to remain alert and able to interact with friends and family, hospice uses the lowest dose possible to control the pain.

How does morphine effect the patient at the end of life?

Hospice provides a pack of emergency medications, called a Comfort Kit, which often includes morphine. Morphine can be used to help symptoms that may develop, such as shortness of breath or pain. Morphine does not postpone or hasten death.

If things get too hard at home, can patients immediately go to a hospice house?

Admission to a hospice house depends on certain criteria being met. It is meant to be short term for symptom control and depends on bed availability.

If things get too hard at home, can patients immediately go to a nursing facility?

Nursing facilities may not have a bed available – placement in a facility can sometimes take months, especially if there is a wait time for Medicaid approval.

- The Medicare hospice benefit does cover respite for 5 days in order to give caregivers a rest (timing is dependent upon bed availability).

Does a dying person who becomes dehydrated feel extreme thirst, pain, and distress?

Dehydration in a terminal frail patient is not painful. Terminal frail and especially elderly patients have a blunted sense of thirst characterized by increased sleepiness and decreasing alertness without discomfort. Perceived thirst in a dying patient is easily relieved by moistening the lips or giving ice chips or very small amounts of liquids.

Does a dying person who stops eating/drinking starve to death painfully?

Usually terminally ill patients stop eating/drinking because the illness has progressed to a point where the body can no longer process food or fluids. In this situation, nutrition/hydration will likely cause the patient to feel bloated, cause nausea, vomiting and diarrhea. Studies have shown that the vast majority of dying patients do not experience hunger.

Isn't artificial nutrition/hydration needed for wound healing?

For terminally ill patients there is no evidence showing improved wound healing with IV hydration or artificial nutrition. Increased fluids in incontinent individuals can increase skin breakdown due to the constant exposure to moisture.

Shouldn't patients with cancer cachexia (wasting syndrome) receive IV nutrition and hydration to maintain weight and strength?

No scientific evidence exists that artificial nutrition and hydration is beneficial to dying patients with this syndrome. It neither stops weight loss nor improves strength and energy.

If the dying person does not feel thirst, are there any benefits to dehydration?

Beneficial effects of end-of-life dehydration include:

- decreased secretions, so congestion, coughing, and gagging are reduced
- reduced swelling and discomfort associated with edema and fluid accumulation
- reduced fluid volumes in the digestive tract prevent or reduce nausea, vomiting, and bloating
- decreased urinary and stool output reduces the frequency with which the terminally ill patient must be moved, which is often uncomfortable



Staff Safety

For the safety of our staff, please take these precautions when they are visiting your home:

- After dark, please turn on your outside lights near the door and house number.
- Secure pets when hospice staff is in the home.

If staff feels unable to enter your home safely, they will call you to determine other ways to help.

Home Safety

Our goal is to optimize your safety at home. The following recommendations and guidelines will help you and your caregivers to maintain a safe environment in your home.

Medical Waste

- Household medical waste (such as bloody or soiled bandages and dressings, catheters, colostomy bags, disposable sheets and clothing, disposable gloves, etc.) should be placed in a plastic bag and securely closed before you place it in your regular trash.
- Liquid body fluids such as blood, vomit, or urine can be poured into your toilet and flushed or washed down the drain with hot water.
- To clean spills contaminated by blood or body fluids, wash the area with hot, soapy water using disposable gloves.
- Wash soiled laundry apart from other laundry in hot, soapy water.

Fall Prevention

- **Bathroom**
 - Place a nightlight in the bathroom.
 - Provide easy access in and out of the tub.
 - Install grab bars around the bath and shower.
 - Use a shower bench or chair in the tub or shower.
 - Remove loose scatter rugs from the bathroom floor and replace with a non-skid mat near the tub and toilet secured with suction cups or non-slip adhesive strips.
 - Always make sure that the floor is dry.
 - Position the toilet at a convenient height. Use a raised toilet seat or commode, if necessary.

- **Hallways**

- Keep walls free from heavy paintings and objects that can be knocked down.
- Install railings or grab bars on the walls.
- Install a nightlight.
- Remove scatter rugs from the floor.
- Eliminate clutter from hallways and other areas.

- **Bedroom**

- A lamp or light switch should be within reach of the bed.
- A phone should be within reach of the bed or close to the floor in case of emergency.
- Install a nightlight.
- Eliminate scatter rugs from the floor.
- To prevent the patient falling out of the bed, consider installing padded bed rails or ask your hospice team to get a hospital bed.
 - Keep hospital bed in low position, except during times of direct care. Keep side rails up, except when a caregiver helps reposition the person or provides personal care.
- If using a commode or urinal, make sure they are always within reach. Encourage the patient to ask for assistance when getting out of bed, as medications and dehydration can cause dizziness.
 - Consider using a baby monitor if you're concerned that the patient may not remember to ask for assistance to get out of bed.
 - Check the patient's legs for numbness or weakness before they stand or get out of bed.

- **Stairways**

- Have handrails on both sides of the stairwell.
- Keep the stairways well lit, clear of objects, and carpeting well secured. Apply a non-slip surface to stairs without carpeting.
- Assist the patient up and down the stairs, if necessary.

Hand Washing

Always wash your hands thoroughly, for at least 20 seconds:

- Before and after giving any care to the person (even if wearing gloves).
- Before and after eating or preparing food.
- When handling soiled linens or cleaning objects soiled with urine, feces or blood.
- Before and after going to the bathroom, touching pets, coughing, sneezing or blowing your nose.
- Before you put gloves on and then again when you take them off.

Wear Disposable Gloves

Always use protective gloves when:

- you will come into contact with saliva, urine, feces or blood or give care to the mouth or genitals
- you change disposable pads, tabbed briefs, or sanitary pads, and when you empty commodes or bedpans
- you clean contaminated surfaces, such as bathrooms or soiled laundry
- you have a rash, cut or open area on your skin
- you give care to a person with open wounds or breaks in the skin

Procedure to properly remove protective gloves:

- Using a gloved hand, grasp the palm area of the other gloved hand and peel off first glove.
- Hold removed glove in gloved hand.
- Slide fingers of ungloved hand under remaining glove at wrist and peel off second glove over first glove and discard.
- Immediately wash your hands or use an alcohol-based hand sanitizer if your hands get contaminated during glove removal.

Oxygen Safety

- Never smoke while using oxygen.
- Post “No Smoking” signs.
- Keep all sources of fire away from an oxygen canister and its tubing. Fire sources include open fires, cigarettes, stoves, candles, gas heaters, and combustible materials (such as oils, grease, aerosol sprays, lotions, and solvents).
- Never use petroleum-based products (such as Vaseline or A&D ointment) in and around your nose. Mixing these with oxygen may cause burns. Instead, use water-based products (such as K-Y jelly).
- Store oxygen tanks in an open, well-ventilated area that is stable and secure. **Turn off your oxygen when it is not in use.**
- Use caution to prevent kinks in the oxygen tubing, and do not lay objects on the tubing.
- Do not leave the tubing in your bed or under the furniture cushions. If you leave the oxygen unit on while you are not using it, the oxygen will leak into these items. A spark or flame could cause a fire.
- Portable oxygen tanks should be transported in the back seat or trunk of the car.

Durable Medical Equipment (DME) and Medical Supplies

Hospice DME refers to specialized equipment and supplies essential in providing comfort, assistance, and symptom management for hospice patients.

DME is crucial in maintaining a patient's dignity, independence, and quality of life while in hospice care. These equipment items are designed to alleviate pain, facilitate mobility, aid in daily activities, and address specific medical needs that arise in the context of hospice care.

DME may include:

- Hospital Beds (adjustable beds)
- Wheelchairs (manual wheelchairs)
- Oxygen Equipment (oxygen concentrators or portable oxygen tanks)
- Mobility Aids (devices such as walkers, canes)
- Lifts and Transfer Equipment (patient lifts, transfer boards)
- Pressure Relieving Mattresses (specialized mattresses)
- Enteral Feeding or Infusion Therapy (IV) Equipment (feeding or IV pumps)
- Bathroom Safety Equipment (raised toilet seats, commodes, shower chairs, and bath transfer benches)

It's important to note that Medicare has specific guidelines and requirements for coverage of DME in hospice care. The hospice team must deem the equipment medically necessary and be directly related to the patient's terminal illness or related conditions.

Cornerstone VNA uses a specific DME provider who will deliver and set up the equipment and then review with you how it works. Your hospice team can also provide training and answer questions about the equipment. If at any time you need more training or information, please reach out to the hospice team.

When the DME equipment is no longer needed, the hospice team will notify the DME provider to arrange for pickup. If there is a delay in the equipment being picked up, please call the hospice team.

If you have any unopened medical supplies that are no longer needed, most items can be donated back to Cornerstone VNA. Although we do not take back unused medication, you can contact our hospice team to discuss the items you'd like to donate.

Support for Caregivers in Providing Care and Comfort



Being a caregiver can be rewarding and meaningful, but it can also be stressful. It's normal to feel overwhelmed by this responsibility and not equipped to provide medical care. Additionally, now that the goal of care has shifted from cure to comfort, you may also feel confused about how to best meet the patient's needs. It is our hope that this resource book will assist you and help boost your confidence when giving care. Please be assured that you are not alone. Your Hospice Care team will review each of following topics with you. If you have questions, you always can call 603-332-1133 for phone support or request an extra visit.

The entire Hospice Care team has expertise in providing end-of-life care and will help you create a plan that works for you and your person. Your nurse case manager will coordinate your hospice team to meet your needs. Cornerstone VNA Hospice staff is available 24 hours a day to support you and answer your questions.

Hospice staff will call you if a scheduled visit must be canceled or changed.

Caregivers at Home Are Essential

Hospice care at home relies on family and friends to provide the majority of day-to-day care for the patient. To provide daily care, you do not need any special medical skills, and you will find that you are more than qualified to perform these tasks. If more complicated procedures are needed, your hospice nurse will be able to assist you or provide training or education. In general, it may help to remember that the aim of hospice care is always to improve the quality of life.

It is helpful to keep a few general rules in mind when providing care:

- **Communication** - Open and clear communication is always important when providing care, and allowing them to share their feelings about what is happening - sharing their thoughts on dying can be a comfort to them.
- **Independence** - It's hard to relinquish all control and become completely dependent on others for help. When possible, let them make decisions and be involved in their care and daily routine.
- **Stress Relief** - Look for ways to make things easier and to relieve the stress, including yourself.
- **Respect** - It's important to maintain dignity and privacy. Always ask permission before starting personal care and let them know what you are doing. Keeping them covered and knocking on the door before you enter their room is important as well.

Providing Direct Care

Providing direct care may involve many new tasks and procedures, but they oftentimes do not require any special skills, except patience and understanding. Make sure you involve the patient in their care and allow them to participate as much as they can, and ask them how they would like something done. Be flexible – their needs may change depending on how they feel that day. Make sure you provide them with appropriate privacy, whenever possible. The following sections provide tips to help you perform common tasks safely. If you have any questions on how to perform a task or procedure, please ask your hospice nurse or LNA to demonstrate it and guide you through the procedure or process. **We also have compiled a page with helpful videos explaining specific procedures at <https://cornerstonevna.org/hospice-resources>.**



Moving/Transfer Safety Tips

Before you attempt to move the patient, remember the following tips to avoid injury from lifting:

- Wear practical shoes and comfortable clothes.
- To avoid hurting your back, keep your feet apart and bend at the knees, not at the waist.
- When you are moving them, remember that it is easier to pull than to push.
- When moving your person up towards the head of the bed, put the head of the bed down, and the foot of the bed up (if using a hospital bed). Using a draw sheet can help you pull them up towards the head of the bed. Refer to the next page for instructions on using a draw sheet, or scan the QR code for video guidance.
- If the patient is bedridden and is using a hospital bed, raise the hospital bed to a comfortable working height prior to providing care. Remember to lower the bed after care is completed.
- Sometimes, when people first stand up, they can get dizzy. Give them a moment to stand before walking to be sure they have regained their equilibrium.
- When walking with the person, keep your hands on them so that you can be ready to support them if they begin to fall.

Personal Grooming

Being freshly bathed and shaved can make a positive difference in how a person feels. If they are strong enough, they may be able to handle most grooming unassisted. Unless they can shave themselves, we strongly recommend using an electric razor to reduce the risk of cutting or skin irritation. For sanitary and safety reasons, razors should not be shared.

Giving a Bed Bath

Ask your hospice team if the patient requires some premedication prior to care to provide pain or anxiety relief and added comfort. Here are some tips to providing a bath in bed:

- Assemble all the items you need at the bedside:
 - Gloves
 - Two large bowls for warm water and soapy water, respectively
 - Two towels, two washcloths, and soap
 - Lotion
 - Blanket to cover the person
 - Except for the part of the body that you are washing, keep them covered and warm with a sheet or blanket.
- Container for soiled disposable underwear
- Wash one part of the body at a time, starting with the upper body and moving downward. Wash the genital area last.
- When you are washing their back and/or buttocks have them turn away from you in the bed.
 - If the bed has side rails, make sure they are up on that side.
- Pat-dry all areas to prevent chafing and apply lotion.

Making an Occupied Bed

- Prepare the (Hospital/Homecare) bed: Ensure the bed is locked at a comfortable working height and raise the side rail on the opposite side of the bed.
- Position the patient: Turn them to the side of the bed opposite from where you're working.
- Remove soiled linens: Roll the soiled bottom sheet, draw sheet, and bed pad toward the patient and tuck them under the patient.
- Put on a clean sheet: Place a fitted sheet on the half of the bed you're working on.
- Draw sheet: Fold a flat sheet in half lengthwise. Place the sheet on top of the fitted sheet so that the top and bottom of the draw sheet go across the bed (perpendicular to the bed). Position the draw sheet between the person's shoulders and knees.
- Roll the fitted sheet with the draw sheet lengthwise then tuck them under the patient.
- Roll the patient: Assist the patient to roll over toward you.
- Pull the rolled fitted sheet with the draw sheet to the other side of the bed.
- Gently roll the patient back to the center of the bed and secure the corners of the fitted sheet.

The process gets easier the more practice you have! Ask your nurse or LNA to provide a demonstration, they will be glad to help.

Caring for the Skin

- A person who spends most of the time in bed can develop breakdown of the skin, resulting in bedsores.
- Watch closely for skin irritation or places where there is contact, such as knees rubbing together when lying on one side.
- Change their position every couple of hours by moving them from side to side or onto the back. Place a pillow against their back to keep them in position.
- Massaging or padding pressure points (knees, elbows, feet, hips, shoulders, tailbone) can help prevent irritation. Heels are particularly prone to skin break down and can be raised off the mattress by placing pillows under each calf.
- Certain areas of the skin seem to be more prone to breakdown. Depending on their position in bed, you should massage these vulnerable areas with any hypoallergenic lotion, such as Lubriderm, after warming it your hand:
 - If they are frequently on their side, massage the ear, shoulder, ankle, and hip.
 - If they are on their back, massage the back of the head, shoulder blades, spine, elbows, and heels.
 - If a bed sore is found, such as any persistent red or dark area, or if any open area is found, please notify your hospice nurse or call the Cornerstone VNA hospice team for further guidance.

Feeding

Since food is often associated with caring and nurturing, our instinct is to encourage a person to eat to get stronger or because we don't want the person to starve. As difficult as it may be, it is important to respect their wishes related to eating and drinking. Do not try to force food or drink or encourage them into eating or drinking. This could cause choking or increase their discomfort or guilt. We always suggest to families that they offer, but don't push food and drink. It is a normal part of the dying process for a person to eat and drink less as the body shuts down. End-of-life dehydration produces a mild euphoria, so the only discomfort related to not eating/drinking may be caused by a dry mouth. Small ice chips or lip moisturizers may keep the mouth and lips comfortable.

Caring for the Mouth

A sore mouth or gums usually impairs a person's ability to eat. When caring for the mouth:

- Position the person upright. Place a towel under their chin.
- Help them rinse their mouth with water.
- Gently brush their teeth with a soft-bristled toothbrush taking care not to irritate the gums. If this is too irritating, use a sponge-tipped applicator (Toothette). Use toothpaste, tooth-powder, or baking soda and water to clean the teeth.
- Help them rinse their mouth by placing a small basin under the chin.

Changing Disposable Underwear/Adult Briefs

The idea of wearing disposable underwear may be very difficult to accept and they may be embarrassed, requiring your utmost understanding. Many people wear disposable pull-up underwear on a daily basis. When a person is able to stand, pull-up underwear works well to contain minor incontinence. If a person is fully bedridden or is incontinent of large amounts of stool or urine, disposable tabbed briefs are a better option for managing incontinence.

Procedure for changing tabbed briefs in bed:

- Assemble the needed items:
 - Disposable gloves
 - Clean disposable underwear/briefs - opened and set aside
 - 2 bowls of warm water - 1 for soap/1 for water or wipes
 - Soap, moisturizer, and barrier cream (A&D ointment, Calmoseptine), if needed
 - 2 washcloths and towels
 - Container/trash bag for the used underwear
- Procedure:
 - Put on disposable gloves.
 - Make sure that the bed rail is raised (if equipped) on the opposite side from where you are standing.
 - While the person is on their back, remove both side tabs of the briefs and tuck the briefs' side that is away from you under the person's backside.
 - Fold the front of the briefs inward towards the person and tuck it between the legs.
 - Clean and dry the genital area.
 - Have them turn on their side away from you, leaving the soiled briefs if possible.
 - Clean and dry the perineal area. Position them so that you have easy access to the perianal area. Clean and dry the area and apply moisturizer if needed. Also, you may wish to apply barrier cream if indicated by your nurse.
 - Place the disposable briefs in a trash bag and throw away.
 - Once the person is clean and still on their side, place the new opened tabbed briefs along the back. Tuck it under and then have them return to their back.
 - Bring the front of the tabbed briefs up between their legs and secure the adhesive tabs to the sides; if needed, have the person roll slightly so you can access both side tabs.
 - If there is a change in toileting needs, ask for assistance from the hospice team to discuss equipment needs.

Taking Care of Yourself

Caring for yourself is the best way to ensure that you, as a caregiver, will be able to manage the emotional and physical strain that is commonly experienced by those who care for people receiving hospice. Caring for yourself can include eating a well-balanced diet, a good night's sleep, taking a nap while the person rests, exercise, and taking time for yourself. Accept help from friends and family or ask the hospice social worker about hospice volunteers or other community resources.

Your Hospice Care team is here to support your entire family. We have resources to help you talk to children about the end of life. Please talk to your social worker or chaplain if you see this need within the family. Keeping in touch with loved ones and friends while also managing a healthcare challenge can be difficult, but staying connected can be comforting and a way to relieve stress for both the patient and caregiver. Make intentional efforts to engage family members and friends.

Understanding Signs and Symptoms

Pain

Physical suffering or discomfort caused by illness or injury. Pain, or some form of discomfort, is not uncommon for a person with a terminal illness.

Possible causes

- Timing of medication
- Medication side effects
- Body position
- Joint stiffness

What to do

- Listen carefully to the patient and help them describe the pain – is it sharp, dull, achy, constant?
- Give ordered medication on time. Medication given late can result in the pain reaching a point that is difficult to bring back under control.
- Keep a close record of the time and dosage of the medication given, the effect it has and how long the effect lasts. Each person's pain is different, and it may take some initial adjustments to determine the best dose and schedule.
- Ask your nurse what side effects to watch for.
- Help the patient find a comfortable position; use pillows or small cushions to relieve pressure or stiffness.
- Hot or cold packs may help joint or muscle pain. Ask your nurse how to apply these safely.
- Give a massage to help relieve discomfort and relax the person.

The hospice nurse should be notified if:

- medication does not seem to have an effect
- the pain can't be eased by the comforting actions described above
- the patient complains that they don't get relief; if they can't verbalize their pain because of weakness or confusion, watch for the following signs:
 - Facial grimacing or wincing with movement, heavy breathing, furrowed brow, increased irritability, restlessness or inability to sleep, decreased appetite
 - Avoidance of movement – staying in bed and not getting dressed

Anxiety/Agitation (Extreme Restlessness)

State of uneasiness that can be seen in physical changes

Possible causes

- Pain
- Shortness of breath
- Temperature changes/patients often feel warm
- Too much stimulation
- Change in environment

What to do

- Administer medication as directed by hospice team members or physician.
- Offer light massage to hands or forehead.
- Provide companionship.
 - Stay with the person until the medication begins to work.
- Speak softly and calmly.
 - Keep your speech clear, simple, direct, and reassuring.
 - Don't say too much at once (they often get overstimulated).
- Pay attention and respond with reassurance.
- Eliminate extra noise, turn off TVs and radios during conversations.
- Play music softly that you know they enjoy.
- Walk with them around the house or room if they are able and then return them to bed.

The hospice nurse should be notified if:

- the anxiety, agitation or restlessness is new or suddenly increased
- medication is not effective after one hour
- the patient is at risk for injury
- you cannot keep the patient from wandering or leaving the home

Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let a Hospice Care team member know if you or your family member needs to see the social worker or chaplain more often.

Appetite

Any change in desire for food, changes in amount or frequency of food or fluid intake

Possible Causes

- Natural part of end of life

What to do

- Offer choices and allow the patient to choose what, when, and how much to eat. Forcing or encouraging them to eat can cause discomfort.
- Honor requests for special foods.
- Give small amounts.
- Offer ice cream, ice chips, or popsicles.
- Offer frequent mouth care - sponge mouth and gums with oral care swabs, use lip balm.

The hospice nurse should be notified if:

- the ability to swallow suddenly changes
- vomiting or diarrhea occurs that continues for more than 24 hours
- the patient's level of alertness significantly changes

Breathing Pattern Changes

Breathing patterns change in several ways as someone approaches death, including:

- **Cheyne-Stokes respirations:** A common pattern of breathing that alternates between deep, rapid breaths, shallow breaths, and periods of no breathing. This pattern is usual and expected.
- **Noisy breathing:** Mucus can build up in the throat and lungs, causing a gurgling or rattling sound when breathing. The dying person usually isn't aware of the noise, but it can be upsetting to family and friends.
- **Slower breathing:** Breathing may become slower and quieter in the final moments of life.
- **Irregular breathing:** Breathing may become less regular, with longer pauses between breaths.

Possible Causes

- Pain
- Respiratory illness distress
- Anxiety/fear
- Dying process
- Increasing weakness and inability to swallow secretions

What to do

- If breathing is noisy, gurgling, or requires extra effort, change patient's position by elevating their head with pillows or raising the head of the bed.
- Administer medication as directed by hospice team members or physician.
- Increase air circulation with a small fan blowing gently towards the face.
- Open windows or doors.
- Sit with the patient.

The hospice nurse should be notified if:

- there is a significant change in breathing
- medication is ineffective after one hour

Confusion

Confusion and other changes in thinking and behavior that can occur at the end of life are often caused by delirium or terminal agitation/restlessness. It can be a dramatic personality change and cause sudden agitation, anxiety, anger, or confusion.

Possible Causes

- Pain
- Lack of sleep
- Decreased oxygen
- Physiological changes that occur during the dying process
- Medication side effects

What to do

- Administer medication as directed by hospice team or physician.
 - Stay with the patient until the medication begins to work.
- Provide companionship and reassurance.
- Announce yourself, speak softly and calmly.
 - Keep your speech clear, simple, direct, and reassuring.
 - Don't say too much at once.
 - Eliminate extra noise.
 - Turn off TVs and radios during conversations.
- Do not touch the patient unexpectedly.
- Offer light massage to hands or forehead.
- Be alert and watch for their safety.

The hospice nurse should be notified if:

- confusion is new or suddenly increases
- the patient is at risk for injury
- you can't keep the patient from wandering or leaving the house
- you feel unsafe in any way

Elimination/Toileting

Decrease in urine output

Possible Causes

- Urine output decreases due to decreased fluid intake and slower circulation through the kidneys.
- Some medications or other issues can cause urinary retention (body holds the urine making a person unable to urinate)

What to do

- Position the patient on the toilet or bedpan in a fully sitting position.
- Run water while the patient attempts urination.
- If catheterized, check tubing for kinks and position drainage bag below the level of body.

The hospice nurse should be notified if:

- The patient is unable to urinate, or if catheterized, has no urine in the bag.
- The patient is uncomfortable.

Constipation, defined as three or fewer bowel movements in one week and possibly hard and dry stool. People who eat very little will still produce stool. This stool comes from sources within the body, not from food. Even patients with liquid stool can have constipation. Constipation can be uncomfortable.

Possible Causes

- Pain medications (narcotics)
- Decreased appetite and fluid intake
- Decreased activity

What to do

- Make sure the patient drinks as much as they can tolerate.
- Encourage the patient to walk as much as possible, when able.
- Administer medication (such as a laxative) only as directed by a hospice team member or physician.

The hospice nurse should be notified if:

- the patient has severe abdominal pain
- the patient does not have bowel movements for three days

Emotional, Spiritual, or Mental Changes

Behavior that is out of character

Possible causes

- Transitioning through the end of life
- Possible precursor to confusion

What to do

- Offer acceptance
- Sit with the patient
- Talk
- Listen

Decreased socialization/ withdrawal

Possible causes

- Transitioning through end of life can progress to seemingly coma-like state

What to do

- Allow them to limit visitors and assist by acting as gatekeeper
- Offer support
- Continue to speak soothingly

End-of-life dreams and visions

Possible causes

- Patient may see or hear things you cannot see or hear

What to do

- Offer acceptance
- Affirm experiences and do not argue or explain visions
- Soothe them if they seem frightened by it

The hospice nurse should be notified if:

- you are distressed by what you are seeing
- the patient appears to be uncomfortable

Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let a Hospice Care team member know if you or your family member needs to see the social worker or chaplain more often.

Fatigue/Drowsiness/Increased Sleeping

Increased sleeping is a common sign that someone is approaching the end of their life. Patients may become drowsy or fall asleep while talking. They may also have difficulty waking up. They may become less interested in what's going on around them and have less energy.

Possible causes

- Activity usually decreases significantly and it's natural to sleep more
- Transitioning through end of life
- Metabolic changes
- Medication side effects

What to do

- It's OK to let them sleep
- Sit with them
- Hold their hand
- Offer light massage to hands or forehead if desired

The hospice nurse should be notified if:

- the patient has sleeplessness at night

Nausea

Vomiting. A sick feeling in the stomach typically precedes retching or throwing up.

Possible Causes

- Metabolic changes
- Medication side effects

What to do

- Administer anti-nausea medications as directed by a hospice team member or provider
- Have the patient take slow deep breaths
- Drink clear, cold flat fluids
- Keep an easy to hold container and a towel nearby

The hospice nurse should be notified if:

- vomiting of blood occurs (more than just a few streaks)
- the patient has sudden onset severe pain, nausea, or vomiting
- you notice blood in the stool or black tarry stool
- the patient has foul smelling vomit

Restlessness

Behaviors that can occur in the days leading up to death may include kicking legs, picking at bedsheets and clothes, reaching out in the air, pulling on IV lines, sudden anger or hostility, anxiety, and confusion.

Possible Causes

- Pain
- Inability to urinate
- Lack of oxygen
- Metabolic changes
- Medications side effects

What to do

- Administer medications (anxiety-reducing or pain medications) as directed by a hospice team member or provider
- Sit with them
- Hold their hand
- Offer light massage to hands or forehead if desired
- Speak softly and calmly
 - Keep your speech clear, simple, direct, and reassuring

The hospice nurse should be notified if:

- you are distressed by what you are seeing
- the patient appears to be uncomfortable

Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let a Hospice Care team member know if you or your family member needs to see the social worker or chaplain more often.

Skin Temperature Changes

As a person gets closer to death, their body's ability to control their temperature might shift significantly. Both high and low temperature episodes may occur, but generally speaking, the body temperature will decrease. The person's temperature may fluctuate, and their hands, feet, and legs may feel cool to the touch at times, while at other times they may feel hot and clammy.

Possible Causes

- Darker or splotchy looking patches on skin
- Decreased circulation
- Decreased metabolism
- Tumor activity
- Infection

What to do

- If the patient's skin feels warm to the touch, remove blankets and just use a light sheet.
- If the skin feels cool to the touch, add a light blanket.
- Keep the heat in the room at a comfortable temperature.

The hospice nurse should be notified if:

- you are distressed by what you are seeing
- the patient appears to be uncomfortable

Medications Used for Pain and Symptom Management

With any medication, the more information you have, the better able you are to prevent errors.

The hospice admission nurse will consult with the hospice medical director to obtain appropriate medications needed to keep them comfortable. Upon request from your hospice nurse, the attending physician will prescribe symptom management medications as needed for pain, nausea, breathing issues, and agitation.

Cornerstone VNA Hospice partners with local pharmacies and with a pharmaceutical vendor to meet a patient's medication needs, 24 hours a day. Patient orders and refills are ordered either locally for family to pick up or via mail order for home delivery. **Hospice employees are not allowed to personally pick up or deliver medications to the home.** Most medications related to the hospice diagnosis are covered by the patient's hospice benefit.

The nurse will provide education about the medications, their purpose, and possible side effects. The nurse will provide a form to make it easier to keep track of which medications are to be taken for which symptoms, as well as when and how they are to be taken (see form in the back of this booklet). At each visit, the hospice nurse monitors the supply of medications to ensure timely refill. As with all medications, please keep symptom management medications out of the reach of children. Use only as directed by your hospice nurse.

The medications are intended to manage any emergent symptoms quickly and keep the person as comfortable as possible. If you have a question regarding these or other medications, ask your hospice nurse or contact the on-call nurse 24/7 at 603-332-1133.

Narcotics

Narcotics, such as morphine, are among the medications that may be recommended for controlling pain. We realize that misinformation about these drugs sometimes causes people to question their use. However, because we know that hospice patients can find great relief from pain through the closely monitored use of morphine or other narcotics, we believe it's important to dispel these myths. Please be assured that:

- Addiction to narcotics is very rare for hospice patients. If a narcotic is prescribed, it will be for the purpose of relieving pain and will not cause a person to crave the drug or become addicted.
- Narcotics do not hasten death. They are introduced gradually, allowing the body to adjust to their effect.
- Morphine and other narcotics do not typically cause breathing to slow or stop. Respiratory depression (breathing that slows or stops) is very rarely seen in patients who have morphine appropriately prescribed and administered.
- Using narcotics to control pain does not mean that the patient will be too sedated to function. They may feel drowsy for the first few days, but for most people this side effect goes away as the body builds up resistance to the sedating effects.
- Morphine is an effective pain and breathing medication at any stage of a person's illness. Give the exact dosage prescribed at the correct times, even if the patient seems comfortable or is asleep. It's vitally important to stay on the prescribed schedule in order to avoid what is known as "break through" pain. Medication given late can result in the pain reaching a point that is difficult to bring back under control.

To monitor the use of narcotics, it is helpful to keep a log or record of when medication is given, including the time and the amount given (dose). Setting a timer can be helpful as a reminder when the next dose is due.

Hospice Comfort Kit

The Hospice Comfort Kit is a small supply of medications kept in the home so that they will be available to rapidly treat symptoms that may occur in a patient with a terminal illness. Knowing how to use your hospice emergency kit is an important part of the hospice education a nurse will provide when a patient begins hospice services. Each medication is to be taken separately according to the label directions and those provided by your hospice nurse. Medications in the Comfort Kit may include:

- Acetaminophen suppositories – used to treat mild to moderate pain and to reduce fever
- Bisacodyl (Dulcolax) suppositories – used to treat constipation
- Haloperidol (Haldol) liquid – used to treat agitation, nausea, and vomiting
- Hyoscyamine SL (Levsin) tablets – used to decrease secretions and saliva production
- Lorazepam (Ativan) tablets – used to reduce anxiety, nausea, vomiting and difficulty sleeping
- Morphine sulfate (Roxanol) concentrate oral solution – used to relieve pain and shortness of breath. It also relieves pain that occurs between doses of longer-acting pain medicines.
- Prochlorperazine (Compazine) tablets – used to reduce nausea and vomiting

How to Use Your Hospice Comfort Kit

The Hospice Comfort Kit is designed to be used when a new symptom emerges or the current symptoms worsen, requiring an immediate response. Medications should only be used under the direction of Cornerstone VNA's hospice nurse. If you believe there has been a change in the patient's symptoms, you should contact the hospice team immediately. If medication needs to be administered from the Hospice Comfort Kit, a nurse will direct you on what medication to use, the correct dosage, and how to administer the medication.

Storage for all medicines in the Comfort Kit

It is recommended to store the sealed Comfort Kit on the top shelf in the refrigerator. Keep the box and contents out of the reach of children. Do not store in the bathroom or in heat or light.

Precautions for all medicines in the Comfort Kit

Medicines in the Comfort Kit should only be used when instructed to do so by the nurse or prescriber who will provide information on which medicine to take, how to take it, and when to take it.

Honoring Goals and Wishes

Making sure your wishes are known by your family and the members of your hospice team assures you will receive the care and treatment you want, where you want it.

Advance care planning helps you and your loved ones gain a better sense of your values, preferences, and wishes related to care and treatment during serious illness and at the end of life. It provides others with information about your health care wishes in case illness or injury prevents you from telling them yourself, and it relieves your loved ones of the burden of having to decide what you might want to have done.

Advance care planning is a process. It is one of the ways the Cornerstone VNA Hospice team supports you as your partner in health care. We will ask to see your advance care documents if you already have them in place. If you have not completed them and would like to do so, your hospice social worker or nurse can help. It is important to note that you can always change your mind about advance directives or amend them.

Cornerstone VNA Hospice does not require people in hospice to have these documents.

Advance Care Documents

Advance Directives

This is a common term for legal documents (statements) that are made by anyone describing treatments that should or should not be given or identifying a person who can make medical decisions in the event the individual is unable to speak for themselves. Advance Directives put your wishes in writing. They do not say “don’t treat me.” They say, “treat me the way I want to be treated” and let you specify exactly what that means to you.

Health Care Proxy

If you are at least 18 years old and competent, you may complete a Health Care Proxy form, which lets you choose another person (called your Health Care Agent) to make health care decisions for you if the day comes when you cannot. The purpose of the Health Care Proxy is to make sure that your wishes are respected if you become unable to speak for yourself. In your Health Care Proxy document, you can specify which types of care and treatment you want and which you do not want.

If you don’t have a Health Care Proxy, you have the same legal rights to accept or refuse medical care. If you become unable to make or communicate your health care decisions, you still have those same rights, but someone else must then make health care decisions for you. If you have not completed a Health Care Proxy, your family may be asked to make decisions based upon what they believe you would want. If you have no family or if there is a disagreement about what treatment you would want, a court may be asked to appoint a legal guardian to make those decisions on your behalf.

Do Not Resuscitate (DNR) Order And Comfort Care Protocol

A DNR Order is a physician's order that tells health care providers not to attempt CPR (cardiopulmonary resuscitation) if your heart or breathing stops. The DNR instructs emergency medical personnel as to your wishes prior to treatment. The topic of a DNR decision may arise at different points in your care. A DNR is not required to choose hospice care.

If you have a DNR order from your provider, the hospice team will provide both a portable DNR form and card, typically pink-colored. You can carry the card with you, and the form should be displayed in the home so that medical emergency professionals can easily see it.

Physician Orders For Life-Sustaining Treatment (POLST)

Physician Orders for Life-Sustaining Treatment are instructions about certain life-sustaining medical treatments, written by a physician, nurse practitioner, or physician assistant to other health professionals (e.g. nurses, emergency responders), based on the person's own preferences. The POLST form includes instructions about resuscitation and other life-sustaining treatments. And, unlike a DNR order, the POLST form can be used to refuse or request treatments. Talk to your hospice nurse if you would like to discuss obtaining POLST documentation.

We do not know exactly when the patient will die. However, for those with a terminal illness, the hospice team will prepare you for the signs you may see as death approaches, as described in the following section.

As life draws to a close, you may feel vulnerable, frightened, and concerned about what will happen next. Understanding the common signs of approaching death can help you prepare to say goodbye and reduce your concerns about the dying process. Though some of these signs can be distressing, knowing that they are to be expected may lessen your fears.

Transformations At The End Of Life

Though each person is unique, most people on hospice experience similar physical changes as life nears its natural end. These transformations can develop over many months, or occur in just weeks or days:

- Changes in appetite and thirst. As death nears, persons are likely to eat less and expend less energy. The body's instinct is also to dehydrate. This makes it easier to breathe and prepares the person for a more comfortable death. Please do not encourage or force them to eat or drink if they aren't hungry or thirsty.
- Increased sleep and difficulty getting out of bed. Metabolic changes now may make them feel drowsier, take more naps and sleep for longer periods at night.
- Restlessness or disorientation. Metabolic changes and decreases in oxygen circulation may also cause them to feel restless or confused. They may think or talk about seeing family members or friends who have died. Talk to your hospice nurse about medication that can help reduce restlessness.
- Decreased body temperature. As circulation slows down, they may feel cooler. Blankets will help keep them warm. Don't use an electric blanket.
- Increased body temperature. They may develop an intermittent fever because of decreased metabolism. Cancerous tumors also produce heat.
- Skin changes. End stage illness, along with decreased nutrition and fluid intake, can cause skin to weaken and become dry and sensitive. You and your hospice team should help them change positions frequently to avoid bedsores.
- Breathing changes. They may experience a change in breathing patterns, breathing more rapidly or more slowly, or pausing between breaths. Additionally, as a person becomes weaker, they can lose the ability to cough or clear secretions. This can lead to wet rattling sounds as they breathe in and out. There is no evidence that this causes discomfort. However, if they are also experiencing

discomfort or shortness of breath, talk to your hospice nurse about steps to improve comfort.

- Just as the body prepares physically for death, a dying person needs to prepare emotionally and mentally for this transition. As death approaches, they may be experiencing the following:
 - Less interest in the outside world. They may no longer have strength or the interest in regular activities of daily life or having visitors.
 - Less talkative. Talking takes energy and they may now prefer non-verbal ways of communicating.
 - Less socially interested in others. As their thoughts turn inward, they may want only a few people to be nearby.
 - Memory changes. Memories of long ago may seem more recent and they may forget what happened yesterday.
 - Focusing on loved ones who have died. They may be thinking more about deceased friends and family and may even feel like they are seeing or hearing them too.

Decreased Responsiveness

As death approaches, they may become more withdrawn and less responsive. Though you may find it challenging to communicate now, remember that hearing is the last sense to be lost, so even if they don't answer they likely do know what you are saying. This time with your loved one is very meaningful, and it's important to pay attention to everything your loved one says in these final days. You will treasure these last days together. Your family members will also want to hear about your conversations, even if they seem insignificant to you at the time.

You could ask open-ended questions like "What are you thinking or feeling now?" However, do not push for answers, if they don't reply, let it go. They may be unable to express experiences in words and may feel frustrated. You should not argue or challenge their reality. Instead, accept and validate what they say. For example, you might say, "You said you saw your grandfather here in the room talking about what comes after. Do you want to talk about it?" If you don't know what to say, it's OK to simply sit quietly with your loved one. Touching their hand or forehead lets them know you are present. You can reassure them by saying, "I am right here beside you."

For a caregiver it may not be obvious to you when death comes - the two main signs of death are no breathing and no heartbeat. There may also be a loss of bowel or bladder contents.

If you sense that the person has died, call Cornerstone VNA Hospice at 603-332-1133. You do not need to call for an ambulance or the police. **Please do not call 911.**

A hospice nurse will come to assist you and provide support for you and your family. The nurse will notify your physician and can notify a funeral home on your behalf. The funeral director will come to your home after the physician has been notified. Your loved one doesn't have to be moved until you are ready.

Seeing Your Loved One's Body

Family members may have different feelings about being with their loved one's body. Some may want to sit at the bedside or bathe the person. Others may not be comfortable with the transition. A hospice team member can assist you in preparing the body for the funeral home. If you prefer this to be a private time, the team member can leave after making the necessary calls.

How children react to death depend on their previous experiences, relationship with the person, individual personality, and stage of development. Share your feelings with them. Admit that everyone is sad and that you may cry, but assure them that you will be all right and so will they. Above all, remain attentive to their safety amidst all the distraction and activity, and offer lots of hugs and physical contact during this difficult time.

Children deserve time to experience the dying process and say goodbye. When your loved one's death is imminent, it may help to take any involved children to the funeral home so they can be prepared for the visitation and/or funeral. Then, when death occurs, consider involving the children in decisions for the funeral or memorial service as appropriate for their age and sociocultural background. Please ask a member of your hospice team if you would like additional resources for your children.

Proper Disposal of Medication

Proper disposal of medication in the form of pills, liquids, patches and suppositories is important. Here is a quick list of what to do with unused medication, but you can find our policy and a more detailed guide in the back of this book.

- Place medication in a ziplock bag.
- Mix with a little liquid (e.g. hot water or soda).
- Add liquid medications to the bag.
- Add patches or suppositories to the bag (remove backing to patches, use gloves).
- Add cat litter, coffee grounds, or flour.
- Close bag, and optionally secure with duct or packing tape for additional safety.
- Dispose of medication in regular trash; do not place it in recycle bin.

You can also contact the local police department about the location of the closest drug drop box.



Grief and Bereavement

Cornerstone VNA has an extensive bereavement program. We provide support throughout your grieving process, which starts as soon as the person is admitted to hospice care. Our staff offers individual grief counseling and group support, as well as opportunities to remember and celebrate your loved one. We also have resources you can utilize as you work through the grieving process. Following the death of your loved one, a member of our staff will contact you by phone, letter, or visit to provide support, as requested, throughout the first 13 months of your loss.

Grief impacts our emotions, our physical selves and even our spirituality. Grief is from any loss and that loss often begins long before our loved one dies. Symptoms often happen gradually, such as the loss of independence, the loss of physical activities, the loss of memories, the loss of having to move and each one of these losses creates layers for both the patient and caregiver. This loss can impact every aspect of your life. Each relationship is unique, and so is the grieving process.

Anticipatory Grief

Grief often begins with the diagnosis of a terminal illness. The feelings of loss you and your family may be experiencing before the death occurs is called anticipatory grief. This is a normal process and may affect different people in different ways. This is being continuously assessed by your hospice team to help both the patient and loved ones process. Emotionally, you might feel a wave of emotions, such as sadness, anger, fear, depression or shock. Many people do not expect the physical symptoms that come with grief. You may have trouble sleeping, stomach issues, headaches, exhaustion or aches and pains. There may be fear of the unknown regarding finances or resources, which may trigger anxiety. It is important that you talk to your team if you begin to experience some of these symptoms.

Anticipatory grief can help you prepare for a loss by giving you time to absorb the reality of the loss over time and the ability to set boundaries to help support you and your family. Here are some helpful suggestions:

- Discuss any issues with the patient, such as regrets, what you are thankful for, clearing up misunderstandings and saying a meaningful goodbye.
- Take care of yourself physically and emotionally and accept help.
- Lean on those closest to you and your hospice team for support.
- Be patient with yourself.

Grief is a personal journey that can take unexpected paths. Taking the time to nurture the relationship before the patient's death can help family and friends in the grieving process.

The Grieving Process

Grieving can be very painful, even overwhelming. People respond to grief in a variety of ways. Everyone grieves differently because everyone and every relationship is different. Many people feel numb and as if it hasn't happened. Our diet can change and we may want to numb the pain. It is common to wrestle with guilt or feel conflicting emotions such as relief alongside sadness. People may want to "do" something and won't let themselves slow down, whereas others may not want to do anything but cry. Brain fog is VERY common and makes it difficult to concentrate. You will be impacted emotionally, but our bodies also feel grief, sometimes intensely.

It is important to monitor how you feel and notify your doctor if you experience something significantly different. You will go through special occasions and holidays, which may be very difficult after losing someone. Some people will have significant financial changes and may have to move, but the recommendation is, whenever possible, don't make any major decisions within that first year and seek professional advice on assuring financial security. You may also find that you focus on the last few weeks, days, or moments at the end of your loved one's life. This can change with time, but it is not uncommon to feel stuck in that time frame and unable to remember other times or memories. It is not uncommon to be upset with people around you, God, or the loved one you lost. Though we view tears as a sign of grief, anger is a very real part of grief in certain circumstances. Grief is a difficult process, and people often feel very alone. Please know you are NOT alone, and although we can't stop the pain of your loss, we're here to support you in any way we can.

Pre-death Gathering of Important Documents and Information

We recommend using a personal notebook or folder to organize and gather important documents and information and storing them in a safe or lock box. Use the following checklist as a guide.

Personal Information

- ☐ Full legal name, date and place of birth
- ☐ Location of certificates and identification such as birth and death certificates, certificates of marriage, divorce, citizenship, adoption, passport, and driver's license
- ☐ Location of education and military records, including DD214 for veterans, connected benefits, account numbers, usernames, and passwords
- ☐ Contact information (name/address/phone/email) for spouse, child(ren), relatives, friends, doctors, lawyer(s), financial advisor(s), religious groups, and membership organizations

Financial Information

When applicable, keep track of usernames and passwords.

- ☐ Sources of income and assets (pension from employer, IRAs, 401(k)s, interest, etc.)
- ☐ Social Security information card, including benefits
- ☐ Insurance information (life, long-term care, home, auto) including company name, policy number, agents' names, and phone numbers
- ☐ Bank information (checking, savings, credit union) including bank name and account numbers
- ☐ Credit and debit card names and numbers
- ☐ Digital wallet/payment information such as Paypal, Venmo, Bitcoin, Apple Pay, etc.
- ☐ Recurring bills (utilities, fuel, mortgage, insurances, credit cards, internet, cable, subscriptions and digital services, etc.), including payment method, frequency, and amount
- ☐ Investment income (stocks, bonds, property), including stockbrokers' names and phone numbers
- ☐ Copy of most recent income tax return, including name and phone number of tax preparer/office
- ☐ Location of current will with an original signature
- ☐ Liabilities (property tax, mortgages, debts/loans), including what is owed, to whom, when payments are due and how they are paid
- ☐ Location of original deed of trust for home, car title(s) and registration(s)
- ☐ Location of safe deposit box and key

Health Information

- ☐ Living will, durable power of attorney for health care, any medical orders or forms such as a Do Not Resuscitate (DNR) order
- ☐ Organ donation status
- ☐ Health insurance provider(s), including policy and phone numbers(s)
- ☐ Funeral home, cremation, burial, or other arrangements, such as songs, prayers, officiant, and obituary

Other Information

- ☐ Pets: Include who will care for them and veterinarian contact information, any special diets or medication(s)
- ☐ Vehicles (cars, trailers, other motorized transportation): Include registration/inspection dates, garage/mechanic, title, and any outstanding loans
- ☐ Home Maintenance Contacts: handyman/carpenter, plumber, electrician, HVAC, landscaping (plowing/lawn care), pool maintenance, fire wood/pellet supplier
- ☐ Home Maintenance: location of electrical panel, generator, AC, smoke/carbon monoxide detectors, sump pump; main shut off for water, furnace/boiler, water heater; septic system information
- ☐ Digital Presence: phone unlock code, computer password, email address(es) and password(s), social media account(s) and password(s). Setting up a legacy contact on your social media account(s) will allow the designated contact to manage or close the accounts after the death.

Post-death List of Actions

We recommend using a personal notebook or folder to keep track of your progress and actions completed. Use the following checklist as a guide.

☐ **Funeral Home/Cremation Society**

A hospice nurse will come to the home to pronounce that the person has died. When appropriate, they will call the funeral home who will come to pick up your loved one. The family may request more time before they arrive. The family will then connect with the funeral home to finalize arrangements.

☐ **Death Certificates**

Typically, the funeral home will file the death certificate. 10-15 certified copies are recommended and will be part of your funeral expenses. A few entities will accept photocopies of the death certificate. Additional copies can be picked up at the town/city hall of the municipality where the patient passed.

☐ **Social Security**

Notify your local Social Security Office of the death. Often they will have been notified, but you may want to check. Payments to your loved one stop at time of death. You may want to check on potential benefits for yourself and any children.

☐ **Health Insurance Company/Employer**

Call to terminate coverage for your loved one and check on any continued coverage for you and children.

☐ **Life Insurance Policies**

If your loved one had any policies, the insurance will need a certified copy of the death certificate and the policy numbers. An insurance agent will be able to provide you with claim forms and help you navigate the process. If there are policies listing your loved one as the beneficiary, it will be helpful to have that changed.

☐ **Pensions, Retirement Plans, Union Death Benefits**

If your loved one was working, their employer can help access these funds. A certified copy of the death certificate will be required.

☐ **Credit Cards**

Contact credit card companies, provide certified copy of death certificate to cancel the card and close the account, or, for joint accounts, update the account.

☐ **Tax Returns**

Tax returns must be filed for the year your loved one died. Keep bank statements of all individual and joint accounts noting the balances at the time of death. Copies of recent tax returns and W-2 forms are important. A tax advisor or accountant can be helpful.

☐ **Joint Bank Accounts**

A customer service representative at your bank can help you to change joint accounts into your name only.

☐ **Stocks And Bonds**

Ensure beneficiaries are current and correct.

☐ **Vehicle Ownership**

If your loved one owned a car, once you have legal authority to transfer ownership, contact your town or city clerk's office to apply for a new title.

☐ **Paying Current Bills**

Continue to pay important bills and make sure accounts are closed or transferred (ex. mortgage, electric, heat, etc.)

☐ **Mail**

If appropriate, arrange for mail to be forwarded.

☐ **Veterans**

If loved one was a veteran, contact your local VA office. You will need a copy of veteran's DD214. The VA can help with any benefits you may be eligible for.

Goodbyes are only for those
who love with their eyes.
Because for those who love
with heart and soul,
there is no separation.

Rumi