

EveryStep 
Hospice

Patient and Family Handbook



everystep.org



Our Mission

We empower individuals, support families and strengthen communities.

Our Values

We act with INTEGRITY and RESPECT.

We serve with COMPASSION.

We lead through EXCELLENCE.

We unite through TEAMWORK.

EveryStep Administrative Office

3000 Easton Boulevard
Des Moines, IA 50317

Join Us Online

Connect with EveryStepIowa on Facebook and Twitter, or visit our website at everystep.org.



EveryStep offers its services to all hospice-eligible people without regard to race, creed, color, religion, gender, physical or mental disability, marital status, sexual orientation, veteran status, national/ethnic origin, age, diagnosis, ability to pay or any other characteristic.

Contents

- Your Hospice Care Team 3
- Volunteers: Caring and Sharing 4
- Special Support for Veterans 5
- Our Hospice Houses 6
- Focusing on What Matters Most at the End of Life... 7
- Dying is Still Living 7
- Improving Quality of Life 7
- Emergency Preparedness 8
- Caring for the Caregiver 8
- Directing Your Care 9
- Out-of-Hospital DNR 9
- Advance Directives 9
- Hospice Coverage and Payment Options 10
- A Foundation of Care 10
- Caring For Your Loved One**
- Maintaining Dignity 11
- Avoiding Falls 11
- Preventing Infection 12
- Preventing Bedsores 12
- Moving About 13
- Eating and Drinking 14
- Oral/Dental Care 15
- Using the Bathroom 16
- Using a Bedpan 17
- Bathing 18
- Getting Dressed 19
- Managing Anxiety 20
- Managing Constipation 21
- Managing Delirium 22
- Managing Dyspnea 23
- Managing Pain 24
- Managing Medications 25
- Behavioral Changes 26
- Signs and Symptoms at the End of Life 27
- After the Death of a Loved One 28
- Grief Support 28
- Disposing of Medications 29
- Patient Rights & Privacy Practices 30
- Our Ethics Program 30
- Staff/Important Phone Numbers 31
- EveryStep Giving Tree Thrift Store 32

Your Hospice Care Team

The goal of hospice care is to help you live comfortably with a life-limiting illness.

At EveryStep, we always help you live your remaining time to the fullest. We help you find quality of life by providing relief from the pain, discomfort and stress of living with your illness.



Hospice care manages your symptoms, helps with daily needs and supports your family members and caregivers.

You and your family decide on the services that are right for you, and your hospice care team works to provide care that meets your needs. Our staff will create a customized plan for your care, which details the services you and your family receive.

Your care plan can be changed at any time, depending on your needs. Talk to a member of your hospice care team if you would like to make changes to your plan.

Members of the EveryStep team visit patients in their home or at our hospice houses. Your EveryStep team may include:

- **Patients and their Families**
- **Patient's Physician and/or an EveryStep Team Physician or Nurse Practitioner**

- **Nurses**

Nurses work with the patient's physician to manage comfort and teach family members how to care for the patient.

- **Hospice Aides**

Hospice aides help with personal cares and activities of daily living such as bathing, walking, getting in and out of bed and reminding the patient to take medications. In some cases, an aide may also help with meals, changing linens and light housekeeping.

- **Social Workers**

Social workers help the patient and family manage ongoing challenges related to end of life. They offer emotional support and education on finances, caregiving and end-of-life planning.

- **Spiritual Care Counselors**

Spiritual care counselors connect patients and caregivers with spiritual resources that support the dignity and comfort of each individual to help the human spirit in its search for peace and meaning.

- **Pharmacists, Therapists, Dieticians**

Other professionals offer special skills, therapies and knowledge to meet the unique needs of patients and their families.

- **Volunteers**

Our caring volunteers provide company and understanding, may help with running errands or providing rides to medical appointments, preparing light meals, assist with care, offer relief for caregivers

- **Bereavement Counselors**

Bereavement counselors are available to families throughout the end-of-life journey. They can provide educational materials and learning opportunities, and offer support to the family for up to one year following the loss of a loved one.



More information about your hospice team can be found in the [Hospice Admissions Booklet](#).

Volunteers: Caring and Sharing

Hospice volunteers are available to patients and families, offering company, care, support and compassion. Our volunteers have completed training and passed thorough background checks. Talk to your hospice care team about the many support services our volunteers can offer.



Companionship

Volunteers can offer you company, read to you, play cards, or just offer a comforting presence.

Respite

Your volunteer can sit with you while your family members take a break from caregiving.

Homemaking Duties

Volunteers can assist you with light housework and outdoor work.

Errands

Volunteers can help run errands.

Transportation

A volunteer may be able to take you to your doctor appointments and deliver supplies.

Veteran-to-Veteran Program

Our Veteran-to-Veteran Program is a special service pairing Veterans who are volunteers with patients who have also served our country. If you are a Veteran, a specialized Veteran-to-Veteran volunteer can provide companionship and understanding.

Music

Some volunteers can sing or play music for your enjoyment.

Life Review

A specially trained volunteer can interview you about your life. The conversation is recorded and given to you or your family as a gift for a long-lasting memory.

Story Book

A specially trained volunteer records the patient reading a story that can then be shared for generations to come. You and your family are given a copy of the recording and the book as a keepsake.

Additional Support

11th Hour Program

Specially trained volunteers can provide a quiet presence during the final hours of life, providing companionship and support.

Pet Visitors

Specially-trained volunteers and certified therapy dogs are often available to visit you. Pet visitors bring joy and other emotional and physical benefits to our patients.

Special Support for Veterans

EveryStep recognizes the unique needs of America's Veterans and their families. As an official Level 4 partner in the Department of Veterans Affairs' national "We Honor Veterans" collaboration, EveryStep provides specialized care, recognition, volunteer support, community education and resources to Veterans and their families. Ask your hospice care team about the many support services our volunteers can offer.



Veteran-to-Veteran Volunteer Program

EveryStep's Veteran-to-Veteran Volunteer Program pairs patients who have served our country with Veterans who are trained volunteers. EveryStep recognizes that there are some issues Veterans only feel comfortable sharing with fellow Veterans. Our Veteran-to-Veteran volunteers provide companionship and understanding, helping patients come to terms with past events and find peace. The volunteers also participate in special events and ceremonies which recognize the service of Veterans in our care.

Veteran Pinning Ceremonies

EveryStep employees and volunteers also honor those who have served our country through "Veteran pinning" ceremonies — special recognition events which are typically hosted in the patient's place of residence. Conducted by the EveryStep team and volunteers, these ceremonies may include the Pledge of Allegiance, a prayer of thanks, the awarding of a Veteran service flag pin, the playing of the theme song from the military branch in which the patient served, the playing or singing of other patriotic music, a reading of "What is a Veteran" and the presentation of a certificate of recognition. These events honor Veterans for their patriotic service and help connect families to their loved ones' history.



WE HONOR VETERANS

Veteran Recognition

With permission from and when desired by the Veteran and family, EveryStep may also submit articles and photos about Veterans' pinning ceremonies to local media, celebrate their service in EveryStep's newsletters, and/or share their service stories via EveryStep's social media channels. These recognition opportunities provide yet another way for the patient's family and community to celebrate and honor the Veteran's service to our country.

Our Hospice Houses

Most hospice care happens in people’s homes. However, when a patient needs around-the-clock hospice care, including pain and symptom management, EveryStep’s hospice houses are available.

Our hospice facilities provide a home-like atmosphere with private bedrooms, living rooms, family kitchens, meditation rooms and other family accommodations. Patients and families can enjoy being outdoors, where they are surrounded by nature and scenic gardens. Respite care, a period of time up to five days in which the primary caregiver is relieved of caregiving, is also available. To learn more, please talk with your hospice care team.



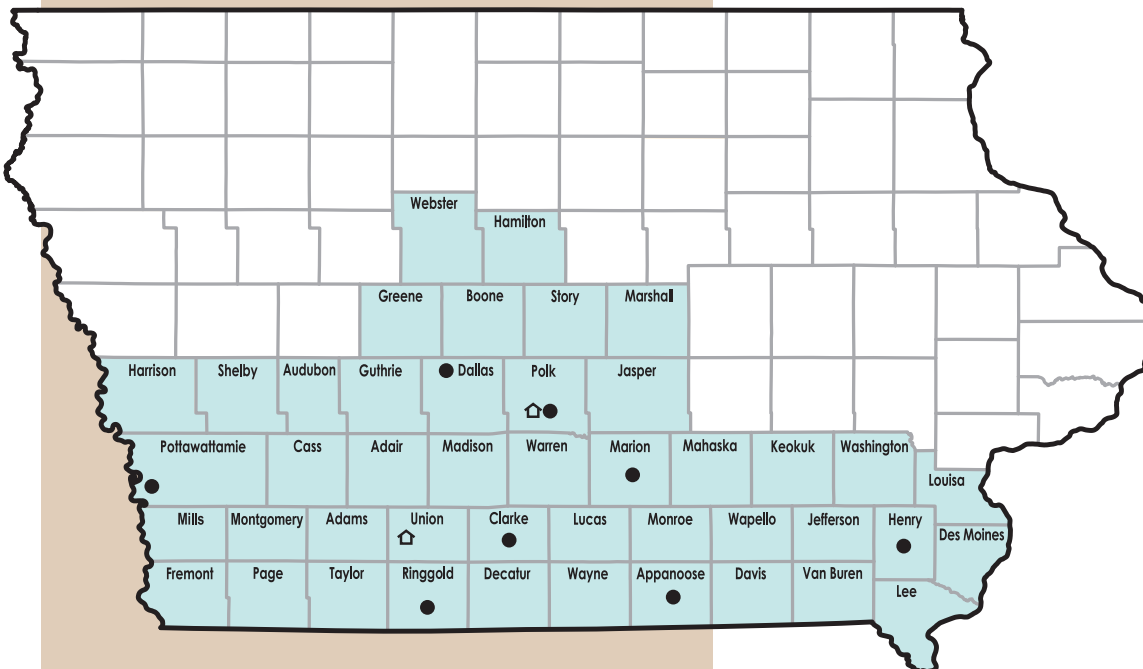
Kavanagh House on 56th Street in Des Moines opened in 1993. It was one of Iowa’s first residential hospice facilities and serves up to 15 individuals in private rooms.



Greater Regional Hospice Home in Creston opened in 2008. It features six private suites, a complete family kitchen, a meditation room, children’s play areas and a whirlpool therapy spa for patient care.

Our Service Area

EveryStep provides home hospice care to patients and families in 44 counties from multiple locations and at our hospice house facilities in Des Moines and Creston.



Focusing on What Matters Most at the End of Life

The journey toward death isn't easy. It can be filled with ups and downs, but the way in which we care for someone during this time can bring a sense of peace to the process.

EveryStep Hospice helps those living with serious, life-limiting illness make the best out of every day by managing pain and symptoms, helping with daily needs and providing emotional and spiritual support. This supportive approach to care is intended to bring peace of mind to patients and their families so they can focus on what matters most.

Dying is Still Living

The end of your life, or the life of a loved one, may be coming sooner than you expected. Perhaps many months or years have been spent fighting an illness or hoping for a recovery. You may feel confused and scared. However, there is still much to be hopeful for:

- Living final days and months in comfort and dignity
- Finding peace of mind
- Gaining comfort with pain and symptoms well-managed
- Working through conflicts and repairing relationships with loved ones
- Looking back on your life and finding meaning

The dying process is unique to each individual. Your EveryStep team is always here to listen and to help create the kind of ending you and your loved ones hope for.

Improving Quality of Life

A life-limiting illness can take away much of a person's independence. Some patients may experience a diminished sense of self-worth because they are no longer able to perform tasks they once could such as gardening, going to the store, or simply making the bed. As a result, a person may become depressed or feel trapped.

However, there are things that patients, families and caregivers can do to maintain quality of life for as long as possible.

Some things you can do:

- Play music.
- Listen to audiobooks together. Family members and caregivers can also read aloud to their loved one.
- Watch movies together.
- Assemble puzzles or play games.
- Continue religious traditions if that is important to you or your loved one. Ask for one of our spiritual care counselors to visit you.
- Talk about fond memories; look at family photos.
- Write letters or use a phone to record and send messages to friends and family.

Think about any activities that bring you joy and use that time to bond.





Caring for the Caregiver

Caregiving is a tremendous responsibility. Most caregivers find the experience emotionally rewarding, but many also feel scared, alone, overwhelmed or worried. Caregivers spend so much time taking care of others; they often fail to take care of themselves.

Caregivers often report sleep deprivation, poor eating habits, failure to exercise, failure to make it to their own medical appointments and failure to rest when sick. The emotional and physical demands of providing care can be stressful. **Remember, you must take care of yourself to be a good caregiver.** Call us if you are struggling to provide care for yourself or your loved one. Your hospice team can always help by sharing ideas, tips, and offering respite.

What You Can Do

- Find a caregiver support group. Contact your local United Way, Area Agency on Aging, religious organizations, hospitals, community health clinics or mental health services.
- Keep in contact with family and friends. Ask for their help. Invite them over or talk on the phone or online.
- Maintain your sense of humor.
- Try to find time for a relaxing activity, such as taking a bath or reading a good book.
- Try to stay positive. Take it one step at a time.



Emergency Preparedness

If your area experiences a natural disaster, severe weather or other emergency, we will make every effort to meet your medical needs.



For more information about [Emergency Preparedness](#), refer to your [Hospice Admissions Booklet](#).

We have a plan to continue crucial patient services. Home visits will be made unless it puts our staff at risk. When roads are too dangerous, our staff will call you (if possible) to let you know that they are unable to visit you that day.

All patients are assigned a priority level that is updated throughout the course of their care. A patient's level assignment determines our response time in case of an emergency. That level assignment, along with other important information which may be helpful to emergency responders, is kept with the patient's file. Below are the levels and response times:

Level I (high) – Within 24 hours

Level II (medium) – Within 24-48 hours

Level III (low) – Within 48-72 Hours

In case of a weather event or other situation that might prevent our staff from visiting you, turn to your local radio or TV station. Please notify our office if you leave your residence and move to another location or emergency shelter.

Directing Your Care

One of the best things you can do for your family is to plan for and discuss your end-of-life care. You may want to ask yourself these questions:

- **What would you like the last day of your life to be like?**

What would you be doing? Would you want special music played, spiritual passages read to you, letters shared with your loved ones?

- **Where do you want to be at the end of life?**

Will you want to be in a hospital, a nursing home, one of our hospice houses, or your own home? Some people may feel being at home creates too great a burden for their family. For others, being in the comfort of their own home gives them peace of mind.

- **Who do you want with you when you die?**

To some, being surrounded by family and friends is important; others envision the company of one or two loved ones or a spiritual care counselor.

- **How do you feel about pain management?**

Would you want as much as necessary, even if it meant making you unconscious or unresponsive? Or, is maintaining alertness, even if it means being in some pain, more important to you?

Advance Directives

Not only will planning ahead help alleviate stress and burdens on your family, it will also help you regain a sense of control and empowerment. Starting the conversation about your end-of-life care can be a positive, life-affirming experience. It's about sharing your thoughts, hopes and dreams with the people you love, and it helps ensure peace of mind for yourself and your family.

Advance Directives are legal documents that allow you to give directions for your medical care, should you become unable to speak for yourself. You can use advance directives to request or refuse treatment and to express feelings about other healthcare issues. Advance directives ease the burden on family members, who can carry out your wishes as you have specified, rather than make difficult decisions for you.

Your physician, health care delegate (also known as your health care agent) and hospice team must follow the guidelines outlined in your advance directives. If you are hospitalized and you stop breathing or your heart stops beating, the facility's health care staff are always obligated to follow your advance directives — whatever they may be.



For more information about Advance Directives, refer to your Hospice Admissions Booklet.

Free Advance Directive Packets

EveryStep offers a free advance directive packet which includes "The Gift of Peace of Mind," forms and in-depth information to help you make end-of-life decisions.

Contact your hospice care team for this and other helpful resources.

EveryStep  **Planning for the Future:** Talking about your end-of-life care and completing advance directives

Hospice

One of the best things you can do for your family is to plan for your end-of-life care. Not only will planning ahead help alleviate stress and burdens on your family, it will also help you regain a sense of control and empowerment. Starting the conversation about your end-of-life care can be a positive, life-affirming experience. It's about sharing your thoughts, hopes and dreams with the people you love, and it helps ensure peace of mind for yourself and your family.

Talk about the Tough Questions
Decisions about end-of-life medical treatments are personal and should be based on your values and beliefs. When you talk to your family about how you would want the end of your life to be, try to answer the following questions:

- What would you like the last day of your life to be like? What would you be doing? Would you want special music played, spiritual passages read to you, letters shared with your loved ones?
- Where do you want to be at the end of life? Would you prefer to be in a hospital, a nursing home, a hospice house, your own home? Some people may feel being at home creates too great a burden for their family; for others, being in the comfort of their own home gives them peace of mind.
- Who do you want with you when you die? To some, being surrounded by family and friends is important; to others, having one or two loved ones or a spiritual counselor nearby is what they envision.

It is impossible to foresee every type of circumstance that might occur. What is important is that your loved ones understand what "quality of life" means to you. Additional questions to ask yourself and tell your loved ones include:

- How do you feel about pain management? Would you want as much as necessary, even if it meant making you unconscious? Or, is maintaining alertness, even if it means being in some pain, more important to you?
- If you could no longer swallow, would you want artificial feeding tubes used?

Advance Directives
Advance directives are legal documents that allow you to give directions for your medical care, should you become unable to speak for yourself. You can use advance directives to request or refuse treatment and to express feelings about other healthcare issues. Advance directives ease the burden on family members, who can carry out your wishes as you have specified, rather than make difficult decisions for you.

Advance directives usually take effect only if you have a terminal condition and are unable to make decisions. If you are lucid and able, you can make your healthcare decisions, even if they contradict your advance directives. You can change or revoke the documents at any time. There are two types of advance directives: living wills and durable power of attorney for healthcare. Both forms are available from EveryStep.

Living will, also known as a "medical directive" or "declaration relating to use of life-sustaining procedures," provides written instructions to your physician. It explains your wishes for healthcare in the event you can't communicate as a result of a terminal condition or irreversible coma. Often these documents say whether you want life-sustaining procedures to be withheld or withdrawn under certain circumstances or in certain situations.

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Coverage for Hospice Care

Hospice care from EveryStep is covered by Medicare, Medicaid, most private insurance plans and with assistance from our Foundation, if needed.

Hospice Payment Options

Patients and families served by EveryStep can receive a wide variety of services. These services are covered by Medicare, Medicaid and most private insurance plans. For those who qualify, Medicare Hospice Benefits cover most of the health care costs related to a terminal illness. *See the Hospice Admission Booklet for details about Medicare Hospice Benefits.*

Common Questions and Answers

If I select Medicare Hospice Benefits, do I continue seeing my own physician?

Yes. Your doctor continues to be your doctor. He or she approves the plan of care, and the hospice team works with your physician to provide that care. EveryStep's chief medical officer and hospice team physician offer extra support, if needed.

If I choose to receive Medicare Hospice Benefits, can I stop hospice care and pursue curative treatment again?

Yes. You are not "locked in." You can choose to stop coverage under Medicare Hospice Benefits at any time. If you do, routine care for your illness is covered by regular Medicare benefits as before your hospice care. There is no penalty. You can also re-enroll in the Medicare Hospice Benefits at any time, as long as you are eligible.

How long can I receive hospice care?

You can choose to receive hospice care for as long as you desire *and* your physician certifies that you are terminally ill.

If I don't have Medicare, can I still receive hospice care from EveryStep?

Yes, we work with many types of insurance and also serve people who don't have insurance. Your team social worker can help you review your financial coverage options, such as:

- **Private insurance** – Most private insurance companies offer coverage for hospice care. Our team will review your plan's benefits with you.
- **Medicaid** – For those who qualify, Medicaid is a health insurance program that helps pay for prescription medications, respite care costs and other hospice services related to a terminal illness.
- **EveryStep Foundation** – If you don't have insurance, our team will work with you to understand your needs and help you enroll in a plan or apply for support through EveryStep Foundation. Our foundation assists families who are financially in need. Ask your social worker for more details.

A Foundation of Care

EveryStep is committed to keeping our care affordable and accessible, and our patients comfortable and making the best of every day. We recognize that health care funding is ever-changing, and those entering hospice may find that their resources are not only depleted, but that their insurance may not pay for particular components of their care.

In 1986 our organization established its own foundation to meet the growing need for financial assistance for our patients and their families. EveryStep Foundation offers a number of programs which help reduce financial barriers for those who do not have

insurance or other means to cover the cost of their care and comfort. Patient support is available for our patients who qualify.

Because of the generosity of our communities and friends, EveryStep can provide quality end-of-life care to those who need it, regardless of their ability to pay. Memorial gifts made in honor of loved ones and contributions to our mission make it possible for us to serve all who need our care. For more information on supporting our Foundation please contact our offices at **(515) 271-1335** or email giving@everystep.org.

Caring for Your Loved One

Our hospice team is here to make sure your loved one receives the care he or she needs to be comfortable at the end of life. Because we are not able to provide around-the-clock care in a patient's home, family members or close friends are called upon to provide certain caregiving tasks when hospice staff are not present.

Your loved one may need help with everyday tasks known as "activities of daily living" (ADLs). These might include eating, drinking, toileting, bathing, dressing or simply moving about. Some of these activities are very personal in nature, and your loved one may be embarrassed accepting your help. Be sensitive and understand how difficult this time is for him or her. Always ask if it is okay to help, and let them do as much as they can on their own, for as long as they are able.

Maintaining Dignity

One of the greatest fears people have about dying is losing their sense of dignity and independence. Your loved one may need help with everyday tasks that were once simple, including toileting and other personal hygiene routines. This sudden dependence on others can threaten a person's sense of self-worth.

Helping your loved one maintain his dignity is one of the most caring things you can do throughout the dying process. Other things you can do include:

- Talk openly and truly listen. Be honest and involve him in decisions.
- See things from his perspective and consider how you would want to be spoken to or treated. With specific tasks, ask how he would like to be cared for.
- Allow him to do as much for himself as he wishes, as long as he is able.
- Be flexible and do what you can to accommodate his requests.
- Verbal communication will become more difficult. Have patience and avoid becoming frustrated. Find alternative, non-verbal ways to communicate.
- Learn about what your loved one is going through physically and emotionally. The following sections will help you know what to expect and understand the person's journey.

Avoiding Falls

Hospice patients are often prone to falls, sometimes resulting in serious injuries. Age, poor eyesight and medications all play a factor in falls, but there are things you can do to help prevent an accident.

- Always keep walking aids such as canes or walkers near your loved one.
- Patients should wear non-skid socks or lightweight shoes with good, gripping soles.
- Hearing aids and glasses should always be worn.
- Make sure the inside of the home is well lit, as well as any outside walkways. Use nightlights.
- Make sure stairways are safe and handrails are sturdy. Placing a strip of brightly colored grip tape on the edge of each step is helpful.
- Be sure the floor is free of clutter or anything that may cause the person to trip. Use non-skid mats in slippery areas.

Call us immediately if a fall happens and the person is injured or can't move.

If the patient is not injured, get help to lift him. If he can pull himself up, place a sturdy chair nearby for support.

Caring for Your Loved One

Preventing Infection

Cleanliness is extremely important in preventing infection. Remember to always:

- Keep yourself, your loved one and the home environment clean.
- Use disposable gloves when performing certain household tasks such as cleaning the bathroom or when handling soiled items. Gloves should also be worn when helping with toileting and bathing. Change gloves between tasks.
- Wash your hands often with soap and warm water.
- Wash soiled items with soap. Use bleach water for wiping down surfaces — 1 teaspoon of bleach per 1 gallon of water.



For more information about preventing infection, refer to your Hospice Admissions Booklet.

Preventing Bed Sores

Sitting or lying in one place for long periods of time can cause sores to develop. This is especially true with certain medical conditions and the elderly, whose skin is fragile. Bed sores can be extremely painful and can easily become infected. To prevent bed sores:

- Remind (or help) the patient to change her position every few hours. If she cannot move, place pillows under pressure points and change the position of the pillows often.
- Gently massage pressure points such as elbows, knees, feet, hips, shoulders and tailbone.
- Check for damage to the skin. You may see tears, scabs or dark marks. If marks do not fade after removing pressure, inform your hospice nurse or aide.
- Check your loved one often if she is having trouble with bladder or bowel control. Staying clean and dry will help reduce bed sores and infection.

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We can be reached 24 hours a day, 7 days a week.



Moving About

Getting around from room to room or up out of a chair is most likely becoming difficult for your loved one. You or another caregiver may need to assist with transferring her from one place to another.

Special training and equipment is required for this type of assistance. Our staff will show you how to do this safely. A few things to consider:

- Make sure chairs are sturdy and do not slide.
- Have a cane or walker within arms reach.
- Wheelchair brakes should be on.

How to Transfer to a Standing Position:

1. Talk to the person while you are helping. Stop if the individual tells you she is in pain or is lightheaded.
2. If you are helping someone out of bed, ask her to sit up (or help her sit up). Swing her legs over the edge of the bed.
3. If the person is in a bed, have her place her palms on the bed. If seated in a chair, have her place her hands on the arm rests. **A person should never place arms around your neck**, as this can cause injuries to both of you.
4. Stand close to the person. The individual's legs should be between yours. Make sure her feet are firmly on the floor and she is wearing shoes or non-skid socks.
5. Bend with your knees and "hug" the person around the waist. On the count of three, have her push off the floor with her feet while you lift.
6. Keep your back, neck and shoulders aligned as you lift. Your legs should be doing the work. If you feel any pain or strain, stop and get help.
7. Make sure the individual is steady on her feet before giving her a cane or walker.



How to Transfer to a Chair:

8. Perform steps 1-6. After the person is standing, and while you are still holding her, turn her back toward the chair. **Always shuffle your feet to turn. Do not twist.** Shuffle until her legs touch the back of the chair.
9. Bend at the knees, again keeping your back, neck and shoulders aligned while letting your legs do the work. As you lower the individual into the chair have her use the arm rests for support if she is able.
10. Be sure the individual is comfortable in the chair. Help her adjust her position if needed.

Speak to a hospice nurse or aide before attempting any task for the first time.

Our staff can demonstrate techniques and give you tips for performing the task safely. If any task causes the person pain, please contact us.

Eating and Drinking

You will most likely notice changes in your loved one's eating and drinking habits. A person who feels weak may eat less. While it may be upsetting to you, try not to pressure him to eat more. You may notice weight loss, but it doesn't mean he is starving. Your loved one is digesting food more slowly now.

1. Ask the patient what you should buy at the store. His tastes may have changed and he may want different foods than before.
2. Allow the person to eat on his own for as long as he is able. Special dishes and utensils can make it easier, such as flexible straws and sectioned plates.
3. Don't tell the person he isn't eating enough. Instead, serve smaller portions if needed.
4. Let him decide when he wants to eat. Don't put a time limit on meals. Small meals throughout the day may be better than a few larger meals.

Tips for Staying Hydrated

It is important for your loved one to stay hydrated, as long as he wants fluids and is able to swallow.

- Always keep fresh water within reach.
- Don't limit liquids, even if incontinence is an issue. Dehydration can cause bladder infections.
- Provide a full glass of water when giving medications.
- Provide liquids in different forms such as juice, jello, soups and fruits. Avoid caffeine and alcohol.
- When the time comes that your loved one can no longer drink liquids, you can use a swab dipped in water to moisten lips and the inside of the mouth every few hours. Small ice chips are also an option.

NEVER force a person to eat or drink. This may cause choking. Contact us if swallowing has become difficult.

Always have the person sitting up while eating and continue sitting up for 20 minutes afterward.

NOTES

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We are available 24 hours a day, 7 days a week.

Oral/Dental Care

Oral care is not just about the prevention of cavities. Because of this, it is sometimes overlooked by family members when caring for the dying. Control of oral conditions can help with a person's comfort, dignity and quality of life by preventing mouth sores and other conditions that may cause discomfort.

1. Mouth care should be done in the morning, evening and as needed. Follow the same cleaning schedule for dentures and store them properly when not in use.
2. Help your loved one to the bathroom and let her brush her own teeth if she is able.
3. Gently wipe and dry her mouth if she needs help. Use lip balm if needed.

How to Brush a Bed Bound Patient's Teeth:

For this process you will need a glass of water, a small basin, a hand towel, non-latex medical gloves, a soft-bristled toothbrush, toothpaste (or baking soda) and dental floss.

1. Put on the gloves. Provide a small glass of water for the individual to rinse her mouth and have her spit the water into a small basin.
If she cannot rinse, wet the toothbrush with water and swab the inside of the mouth first.
2. Apply toothpaste or baking soda and gently brush the teeth.
3. Have the person rinse if able, or swab the inside of the mouth with a clean, wet toothbrush until traces of toothpaste are gone.
4. Gently wipe and dry the mouth and chin. Floss once each day and use lip balm if needed.

Contact us if the person cannot swallow.

Use only a pea-size amount of toothpaste to prevent choking.

NOTES

Caring for Your Loved One

Using the Bathroom

If your loved one has difficulty controlling bladder or bowels, you will need to help him with getting to the bathroom. This can be embarrassing for both of you at first. It's best to be very matter-of-fact about the process.

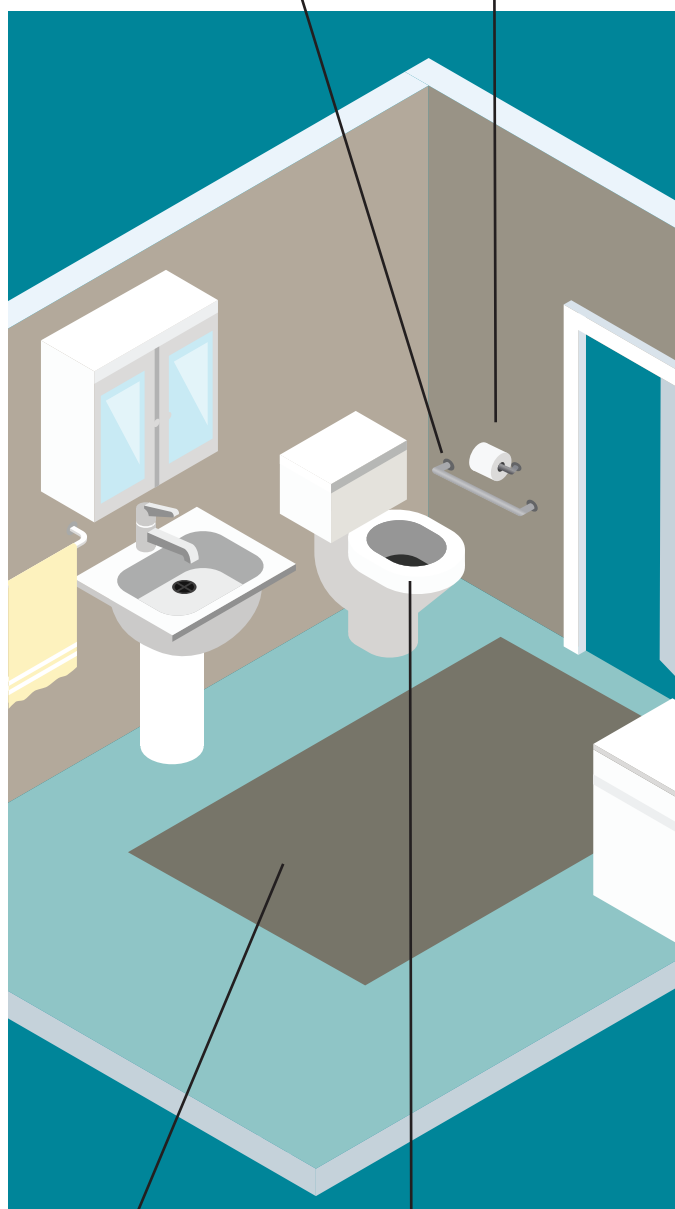
1. Set a schedule for bathroom trips every 2-3 hours. Your loved one will appreciate not having to ask for help each time, and it will reduce the number of accidents. If he does ask for help, respond right away.
2. If your loved one has an accident, let him know it is okay.
3. Move the bed closer to the bathroom if possible. A bedside commode may also be helpful.
4. Help the person walk to the bathroom for as long as he is able. Leave the bathroom if he is safe to be alone. If not, turn away to provide as much privacy as possible.
5. If incontinence is a regular issue, you may need to place pads under the person while in bed and while seated in a chair. Disposable briefs are also an option. It is important to always keep your loved one clean and dry.

Contact your hospice team if there are a lot of accidents. It could be a sign of an infection.

BATHROOM SAFETY

Are there grip rails by the toilet to help return to a standing position?

Is the toilet paper within easy reach?



Is the floor dry, or is there a non-slip mat on the floor?

Is the toilet too low? If it is, special, raised toilet seats that fit over the existing seat are available.

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We are available 24 hours a day, 7 days a week.

Using a Bedpan

If a person is bed bound, it will be necessary to use a bedpan or urinal. To use a bedpan you will need:

- Bedpan or urinal bedpan (for men)
- Talcum powder or corn starch
- Non-latex medical gloves
- Bed pad(s)
- Toilet paper
- Washcloths, water and soap
- Towels
- Disinfectant soap
- A toilet brush
- Bleach

NOTES

1. First dust powder on the rim of the bedpan. This will allow the person to slide onto it.
2. Provide privacy by closing the door. Put on gloves and help the individual slide their clothing down.
3. Place a bed pad under the person. As she is laying on her back, have her lift her hips so you can slide the pad under her.
4. Ask the individual to lift her hips again. While supporting the lower back, slide the bedpan underneath. If she cannot lift her hips, roll her to one side. Place the bedpan on the pad and then roll the person onto the bedpan.
5. Help the individual to a sitting position with knees bent if possible. Prop her up with pillows if needed.
6. When finished, help the person lay back down. Have her roll to one side off the bedpan. Remove the bedpan and place it on the floor and out of the way.
7. As the person is on her side, wipe the buttocks with toilet paper. For women, wipe front to back to prevent a urinary tract infection.
8. If needed, clean with a washcloth, warm water and soap. Pat dry the skin and remove the bed pad.
9. Empty the bedpan into a toilet. Scrub it with hot soapy water and a toilet brush. Empty the pan again into the toilet and rinse. Pour five capfuls of bleach into the pan. Rinse with hot water and let dry.
10. Throw the gloves in the trash. Wash your hands with soap and water.

Bathing

A bath or shower may be relaxing, but it can also be exhausting for your loved one. Give baths when he has the most energy. If the individual is tired, hair can be washed another day. Dry shampoos or no-rinse shampoos may be used in between washings as needed.

A full bath may not be necessary every day, but the face, hands and private areas should be washed daily.

Place non-slip mats inside and outside of the bath. Installing grab bars and using a shower chair will also help prevent falls.

How to Give a Bed Bath

If your loved one cannot get out of bed, a bed bath will be necessary.

1. Fill a basin with warm water and place on a table next to the bed.
2. Put on medical gloves. Remove the person's clothes and cover him with a blanket.
3. Begin with the head using a wet (not dripping), unlathered washcloth. Wipe the eyes, from the nose towards the ear.
4. Work a small amount of **mild soap** such as Dove or baby soap, into the cloth and continue washing the face and neck. Be careful to avoid the eyes.
5. Rinse the washcloth and remove soapy residue from the skin; dry well.
6. Uncover and wash one body part at a time, starting with the shoulders, then arms, hands, chest/ abdomen, legs and feet. Help the person roll to his side to wash his back. **Wash buttocks and private areas last. This will prevent the spread of germs.**
7. After each part is washed and dried, re-cover with the blanket.
8. For dry skin, apply lotion as needed.

How to Wash a Person's Hair in Bed

You will need:

- Several large towels
- A washcloth
- A large trash bag
- A plastic cup
- A 2-gallon basin of warm water
- Mild shampoo

1. Cover the pillow with a towel. Roll up another towel and place it under the person's neck.
2. Open the trash bag and roll the sides down about halfway. Line the inside of the bag with 2 or 3 towels to catch and absorb the water.
3. Place the opening of the bag under the head and under the rolled towel.
4. With the washcloth over the person's eyes, use the cup to scoop water and wet the person's hair.
5. Work the shampoo into the hair and scalp.
6. Rinse shampoo out completely with water using the cup.
7. Carefully remove the trash bag without spilling.
8. Dry the hair with a hair dryer or a towel.

Getting Dressed

Getting dressed each day can help a person maintain their dignity and provide a sense of normalcy. Help your loved one get dressed each day for as long as possible.

Tips for Providing Help With Dressing

- Choose clothes that are easily removed. Shirts that open in the front will be easier than tops that must be pulled over the head. Elastic waistbands will make going to the bathroom easier.
- Give your loved one a few clothing options, then let her choose what she wants to wear each day.
- If the person has a weak side, place clothing on that side first.
- Allow the person to dress herself as much as she is able.



NOTES

Caring for Your Loved One

Managing Anxiety (Worries and Fears)

What is Anxiety?

Anxiety can be described as an uncomfortable feeling of worry, unease, helplessness or fear. For hospice patients, symptoms of anxiety are common given the uncertainties of illness and approaching death. While many patients have worries and fears, they do not rise to the level of an anxiety disorder. However, for other patients, fear of uncontrolled symptoms or dependency can result in significant anxiety.

Signs and Symptoms:

- Inability to relax or get comfortable
- Difficulty paying attention or concentrating
- Confusion
- Sleeplessness
- Rapid breathing or heartbeat
- Tension
- Shaking
- Sweating

How You Can Help:

- Write down thoughts and feelings
- Treat physical problems such as pain that can cause anxiety
- Do relaxing activities like deep breathing, yoga, or playing soft music
- Keep things calm and limit visitors
- Reach out to family and friends
- Massage back, arms, hands or feet
- Take medications as prescribed

Tell Your Care Team About:

- Feelings that may be causing anxiety (for example, fear of dying or worrying about finances)
- Concerns about the illness
- Problems with relationships with family or friends
- Spiritual concerns
- Signs and symptoms that the anxiety is getting worse
- A known history of anxiety, being on medication for anxiety, or counseling for anxiety

MEDICATION INFORMATION

What is the name of the medication?

What do I use the medication for?

How do I use the medication?

What are the normal side effects of the medication?

When should I call you?

Other Notes

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We are available 24 hours a day, 7 days a week.

Managing Constipation (Difficulty Pooping)

What is Constipation?

Constipation can be described as bowel movements (BMs), stools or pooping, occurring less often than usual. Constipation may be embarrassing to discuss, however, it is very important for your care and comfort.

Many medications (such as morphine) can cause constipation. A plan to prevent this should be started as soon as these medications are prescribed. Your care team will discuss this with you.

Signs and Symptoms:

- BMs that are dry, hard and difficult to pass
- BMs that are less frequent than usual
- Straining during BMs or incomplete BMs
- Bloating or swelling in the abdomen
- Cramping, nausea, vomiting, and reflux/heartburn

How You Can Help:

- Increase physical activity if possible — walking can be beneficial
- Eat food with plenty of natural fiber, like whole grains, fruits and vegetables
 - Do not take fiber supplements like Metamucil unless instructed by your care team
- Drink as much (non-alcoholic and caffeine-free) fluid as is comfortable, up to 8 glasses per day
- Drink warm fluids with or after meals to stimulate the bowel
- Sit upright after meals — this helps with digestion
- Take laxatives or stool softeners as prescribed
- Set a BM schedule and sit on the toilet or bedpan at the same time every day
- Keep a record of your BMs: list the day and time of your BM, describe what it looked like and if you had any problems during the BM.

Tell Your Care Team About:

- Change in usual frequency and/or consistency of BMs (hard, soft, liquid)
- Pain, cramping, bloating or tenderness
- An urge but inability to have a BM
- Nausea and/or vomiting
- Bloody or runny stools (diarrhea)

MEDICATION INFORMATION

What is the name of the medication?

What do I use the medication for?

How do I use the medication?

What are the normal side effects of the medication?

When should I call you?

Other Notes

Caring for Your Loved One

Managing Delirium (Severe or Sudden Confusion)

What is Delirium?

Delirium can be described as a state of **sudden** confusion. The symptoms are often severe but can be temporary and reversible if attended to appropriately. It develops quickly, usually in hours to days. Delirium is common at the end of life, and can be caused by many conditions. It is most often caused by the body's changes in the last days or hours of life.

Delirium is not dementia. Dementia is a progressive condition with a slow onset that cannot be reversed.

Signs and Symptoms:

- **Sudden** changes in mood, personality, language or speech
- Restlessness or agitation
- Inability to sit still, getting up and down
- Hallucinations or seeing, hearing or feeling things that are not there
- Inability to recognize familiar people and surroundings
- Difficulty focusing attention, disorganized thinking, jumping from one topic to another
- Changes in sleep patterns

**Symptoms fluctuate, which means they come and go*

How You Can Help:

- Provide a safe, peaceful environment. Limit the number of visitors. Remove obstacles that may cause falls or injuries. Maintain a comfortable room temperature. If the patient enjoys it, play familiar, soothing music. Keep a nightlight on at night with familiar objects nearby.
- Remind the patient who you are and offer spoken reassurances such as, "I am right here with you."
- When confused about time and place, do not argue with the individual.

- Avoid asking a lot of questions or offering complex choices.
- Try to maintain the patient's normal routine. Explain everything you are going to do before you do it, for example, "I am going to help you sit up in bed now."
- Provide glasses and/or hearing aids if the patient can use them safely.

Tell Your Care Team When:

- You identify any signs or symptoms – **call immediately**
- You begin to feel overwhelmed, fearful or anxious about the symptoms

MEDICATION INFORMATION

What is the name of the medication?

What do I use the medication for?

How do I use the medication?

What are the normal side effects of the medication?

When should I call you?

Other Notes

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We are available 24 hours a day, 7 days a week.

Managing Dyspnea (Shortness of Breath)

What is Dyspnea?

Dyspnea can be described as an uncomfortable feeling of having difficulty breathing, not getting enough air, or not being able to catch your breath.

How You Can Help:

- Sit in a chair or elevate your head on pillows when lying in bed.
- Sit with your hands on your knees or on the side of the bed leaning over the bedside table.
- Practice pursed lip breathing by taking slow, deep breaths, breathing in (inhale) through the nose and then breathing out (exhale) slowly and gently through pursed lips (lips that are puckered as if you were going to whistle).
- Increase air movement in the environment by opening a window or using a fan.
- Keep cool by using air conditioning, a bowl of ice in front of a fan, or by applying a cool cloth to the head or neck.
- Keep the environment quiet and peaceful to decrease any feelings of anxiety.
- Take medications as prescribed.
- Use oxygen as instructed by the hospice care team.
- Use relaxing activities like playing soft music, massage, meditation or prayer.

Tell Your Care Team When:

- Your shortness of breath is not relieved or gets worse
- It stops you from doing what you want to do
- It causes you or your family fear, anxiety, nervousness or restlessness
- It causes your skin to look bluish, especially on the face, nose, fingers or toes

MEDICATION INFORMATION

What is the name of the medication?

What do I use the medication for?

How do I use the medication?

What are the normal side effects of the medication?

When should I call you?

Other Notes

Managing Pain

What is Pain?

Pain can be described as an uncomfortable feeling of hurting or discomfort caused by physical, emotional or spiritual distress. Pain is what the individual says it is. It is an experience that can only be felt and described by the person with the pain. The good news is that there is much you and your care team can do for managing pain.

Signs and Symptoms:

- Children may express pain by sleeping more, becoming irritable, or having other behavior changes – they may use words like ‘owie’ or ‘boo-boo’ to describe pain.
- Adults may describe pain as aching, burning, gnawing, grabbing, discomfort, or soreness.
- Patients who are confused, have cognitive impairment, or cannot speak for themselves may have behavior changes such as pacing, moaning, agitation, grimacing, or a furrowed brow.

How You Can Help:

- Take medications as prescribed.
- Use relaxing activities like playing soft music, light massage, soaking in a tub of warm water, or guided imagery (picturing enjoyable and relaxing scenes to take your mind off the pain).
- Use distracting activities like watching TV, playing a game, or just thinking of other things.
- Use heat or cold such as a heating pad, warm compress, or ice pack.
- Use aromatherapy (pleasant smells of certain plants or fragrances such as lavender).
- Try storytelling, drawing or writing.
- Practice deep breathing.

Tell Your Care Team About:

- Where the pain is located and what the pain feels like (burning, sharp, stabbing).
- If the pain is constant or if the pain comes and goes.
- What makes the pain worse and what makes the pain better.
- How severe or intense the pain is on a scale of 0 to 10, mild to severe, or using pictures – ask your nurse about options for reporting pain.
- If you are becoming irritable from lack of sleep because of the pain.
- How often you are taking pain medication and how well the medication is working.

MEDICATION INFORMATION

What is the name of the medication?

What do I use the medication for?

How do I use the medication?

What are the normal side effects of the medication?

When should I call you?

Other Notes

If you ever have a concern or a question about how to care for your loved one, please contact your hospice care team. We are available 24 hours a day, 7 days a week.

Managing Medications

Medication management is key to medication safety. It is important to develop a safe system to organize and identify your medications. Your hospice nurse will work with you to create an effective medication plan.

To Safely Manage Medications:

- Keep a list of all medications you take. This includes prescriptions, medications you buy without a prescription, vitamins and herbal supplements.
 - Store all medications in their original, clearly marked containers.
 - Take medications exactly as directed by your physician. Your hospice nurse will review and answer any questions you have. If a medication or dosage looks different than you expected, notify your nurse.
 - Drug names can look or sound similar. To avoid errors, make sure you can clearly read the medication label for name, dosage and any warnings. Ask the pharmacy for larger print on the label if possible. Turn on a light so you can check the label before taking any medication.
 - Notify your hospice nurse promptly if you notice a new symptom or side effect from your medication.
 - Discuss with your physician and nurse the purpose of taking the medication, the results you should expect and possible side effects.
 - Stick with the recommended treatment plan.
 - Do not stop or change your medicine without your doctor's approval. If you think a change needs to be made to a medication, talk to your hospice nurse first. The nurse will work with you and your physician to create a plan that works best for you.
 - Use a pill planner or create a schedule for your medications.
- Keep all medication out of the reach of children, pets or others who may be harmed, such as people with dementia.
 - Avoid drinking alcohol while taking prescription medications.
 - Do not share your medication with others, and do not take medications prescribed to someone else.



See page 29 for information on medication disposal.

Signs and Symptoms Near the End of Life

While dying is a natural part of life, it is never the same for any two people. We can't predict when or how it will happen for our patients, but we can work to understand the process and provide them with comfort and kindness.

Withdrawal

Preparing for death comes in many forms. For many patients, the acknowledgement that death is near may include withdrawing from their world around them. Your loved one will stop participating in the things they once enjoyed. This is a time for internal reflection and he or she may begin to nap more frequently. While there may be less verbal communication during withdrawal, touch and silence begin to take on more meaning. While your loved one may not be able to respond, he or she can still hear you.

Changes in Breathing

As the end of life nears, a person can experience changes in breathing patterns. Often, breaths take on a faster, shorter pace followed by periods of no breath, usually lasting five to 30 seconds. "Rattling" sounds may also accompany breathing.

Other Changes

You will notice changes in eating, drinking, body temperature and bowel/bladder functions. Other symptoms may include confusion, restlessness and anxiety. Your loved one may express confusion about time, places and people. In some cases, he or she will talk of things they see but others can't, or speak with people who are not actually there. Let your loved one speak freely and limit the number of visitors to make him or her more comfortable.

A surge of energy may come in the days before death. This might come as a shock to a caregiver, but it's a common occurrence in the dying process. This sudden change can often give a false impression that the patient's health is improving, but it is unlikely. Use this opportunity to talk to your loved one and say goodbye.

For more information about what to expect when death is near, refer to the booklet titled *The Final Journey*. If you need a copy, please ask a staff member.

A Timeline of the Dying Process

The dying process is unique to everyone, but there are a number of changes and signs that indicate death is near. The following is a basic timeline of the dying process.

One to Three Months

- Disconnecting from the physical world
- Talking less
- Disinterest in eating and drinking
- Less alert, more rest

One to Two Weeks

- Disorientation
- Speaking to those not in the room
- Physical changes, such as slower breathing, skin color changes, heartbeat increase, fluctuation in body temperature, and eating or drinking less or not at all.

Days to Hours

- Continuous sleep
- Surge of energy
- Increased restlessness
- Difficulty swallowing
- Changes in breathing and skin tone
- Weak heartbeat
- Changes in bodily functions; less or no urination
- Changes in breathing pattern; rattling in chest

Minutes

- Short breaths with longer breaks between
- Mouth open
- Non-responsive



After the Death of a Loved One

Death can seem like a shock, even if you felt prepared. Call your hospice team nurse when your loved one dies, even if it is in the middle of the night. **You do not need to call for an ambulance or the police.** Your hospice nurse will know what to do and will assist you and your family.

Spend as much time with your loved one as you would like, and include anyone you would like at the bedside. Your hospice team nurse is always available to help you and your family during this time.

Your hospice team will:

- Contact your loved one's physician
- Remove any tubes and turn off oxygen
- Bathe and clean your loved one if needed and desired. Some families honor their loved one by performing this task themselves. Please let us know if this is your wish.
- Ensure that dentures are given to funeral home staff
- Contact the funeral home. We will ask you when you would like their staff to arrive so that you have as much time with your loved one as you would like.
You can choose to be there when they prepare to transport your loved one, or you may wait in another part of the home.
- Contact other members of your hospice team
- Contact the medical equipment vendor
- Complete proper documentation

We are with you at every step.
If at any time you have a question or concern, please call your hospice team.
No question is too small.

Grief Support

The loss of a loved one is a heart-wrenching experience, but it is not one you have to face alone. We care for our patients and their loved ones. Part of that care includes our grief and loss services. Our professionals offer insight, understanding and helpful information. You will receive educational resources throughout the first year following your loss, including invitations to the following events.

Grief Support Groups

EveryStep offers grief support groups for adults throughout the year. These meetings are free and open to anyone who has lost a loved one. Please ask our bereavement counselor, call our office or visit everystep.org/services/grief-loss for more information.

Memorial Events

Throughout the year, EveryStep hosts memorial events to honor the individuals we have served. These events offer a way for family members, the public and our staff to remember loved ones and celebrate their lives.

Amanda the Panda

Amanda the Panda is a special program within our family of services that helps restore grieving children and families back into the mainstream of their lives. Support is provided through fun days, camps and other activities.

For more information about all of our bereavement services, visit everystep.org/services/grief-loss

Survey

A few months following the death of your loved one, you may receive a survey in the mail from our survey administrator, Strategic Health Care Programs (SHP).

If you receive this, you will be asked to evaluate the care you and your loved one received from EveryStep. **We encourage you to complete and return the survey.** Your feedback is important to us and it will help ensure that future patients receive the best possible care.

Disposing of Medications

Families are often concerned about leftover medications. When a medication is no longer needed or has expired, it should be disposed of safely. There may be a "take back" drop off site in your area. Your hospice nurse will discuss the safe disposal of medication and will work with you to destroy hospice medications that are no longer needed. This is in accordance with our policy and procedure, as well as state and federal guidelines, which were provided in the admission folder.



When a patient resides in the

HOME ENVIRONMENT

Medications are the property of the patient. They do **not** belong to EveryStep. No medications will be removed from the home by a hospice staff member.

When a patient resides at a

HOSPICE HOUSE

Medications will be disposed of at our hospice houses in partnership with the pharmacy that provided the medication. All federal and state guidelines will be followed.

When a patient resides in a

LONG-TERM CARE FACILITY OR HOSPITAL

The hospice nurse will follow the facility's policy for disposing of patient medications.

What is a Medication "Take Back" Program?

Some communities have a place where leftover or expired medications may be taken where they will be disposed of safely.

Check with your local pharmacy or law enforcement agency

to see if they have a medication "take back" program.

For more information, visit www.iarx.org/EcoReturns

Proper disposal of leftover medication protects you and others!

By getting rid of medicine the right way, you:

- Prevent poisoning of children, pets or others who may be harmed, such as people with dementia.
- Deter misuse by teenagers and other family members.
- Avoid health problems from accidentally taking the wrong medicine, too much of the same medicine, or a medicine that is too old to work properly.

Patient Rights and Responsibilities

Providing quality care requires a partnership between you and your health care professionals. You need information to make appropriate decisions about your care. Your health care professionals need your involvement to ensure you receive appropriate and effective care. Mutual respect and cooperation are essential to this partnership.

It's important to know what you can expect and what we need from you when you receive care from us.

Notice of Our Privacy Practices

EveryStep is required by law to maintain the privacy of Protected Health Information ("PHI") and to provide you with notice of our legal duties and privacy practices with respect to PHI.

The notice explains the ways EveryStep is allowed to use your health information and lists the rights you have with respect to your health information.



To read our [Patients Rights and Notice of Privacy Practices](#), refer to your [Hospice Admissions Booklet](#).

Our Ethics Program

Our organization promotes a culture providing patient-focused and family-centered, compassionate care. We recognize that ethical questions may arise during the course of care which may be difficult for patients and families to address.

EveryStep's Ethics Committee serves as a resource in such situations, offering consultative services and information to assist patients and families facing difficult decisions.

To initiate an ethics consultation, please first contact the Ethics Committee chair at (800) 806-9934. You may also send an email to ethics@EveryStep.org, fax your request to (515) 333-5801, or mail your request to:

EveryStep

Attn: Ethics Committee Chairperson
3000 Easton Boulevard
Des Moines, IA 50317-3124

You Have a Voice

EveryStep is committed to acting with integrity and respect — not only in how we provide care but also in how we conduct business. We invite you to connect with us and share your suggestions for how we can improve our services. Please contact us if you have questions or concerns about the care you or your loved one is receiving.

Our Compliance Program

EveryStep's corporate compliance program is designed to strengthen our organizational culture by promoting ethical conduct and preventing and detecting non-compliance with the law.

Please report any perceived misconduct of our employees or volunteers, including actual or potential violations of laws, regulations, policies, procedures or our standards or codes of conduct. We protect the anonymity of all individuals who report compliance concerns, and concerns may be voiced without fear of reprisal or discrimination.



For more information, please call our compliance hotline: (888) 933-4274.

Your Hospice Staff



Hospice Nurse's Name _____

Hospice Aide's Name _____

Social Worker's Name _____


Spiritual Care Counselor's Name _____


Other _____


If you need to reach a hospice nurse or aide, please call: _____


Important Phone Numbers


Patient or family to complete.


 Ambulance/Police/Fire **911** or _____


 Hospital _____


 Doctors _____


 Non-Emergency Transportation _____


 Pharmacy _____


 Poison Control **1-800-222-1222** or **911** _____

 Medical Equipment (Oxygen) _____

 Electric Company _____

 Phone Company _____

 Water Company _____

 Family _____

EveryStep Giving Tree Thrift Store

Shop. Donate. Volunteer.

Sales and donations help EveryStep's patients, clients and their families.

You can help support our mission by donating to our thrift store in Urbandale. Quality furniture, clothing and home goods are always needed to keep our showroom stocked. Sales benefit our patients and families who don't have insurance or other resources to pay for care.

3330 100th Street, Urbandale
(515) 270-2414
everystepgivingtree.org

Visit our website for store hours, a list of items we can accept and to sign up for our newsletter.



Volunteers also play a vital role in our store operation. If you are interested in volunteering a few hours each week, please call today!



EveryStep

Hospice

1 (800) 806-9934 | everystep.org

Accredited by Community
Health Accreditation Partner

CHAP
EST. 1965