

# Patient and Family Handbook



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### **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 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.

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### **Join Us Online**

Connect with EveryStep on Facebook, via Twitter @everystep or on our website, **everystep.org**.



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**EveryStep is formerly known as HCI Hospice Care Services and Hospice With Heart.**

# 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

know she won't be able to include the watercolor, but would fear that's You and your family decide on the services right for you, and your hospice care team works to help with your needs. Your hospice care team nurse works with you and your family to create a customized plan for your care. The plan 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 the plan.

## Members of the 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 the patient bathe, walk and get in and out of bed; remind the patient to take medications; assist with meals; and change linens and do 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 family and 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, help with running errands or preparing light meals, assist with care, offer relief for caregivers and rides to medical appointments.
- **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.

# 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 homemaking tasks and outdoor work.

## Errands

Volunteers can help run errands.

## Transportation

Your volunteer can 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 served our country. If you are a Veteran, a specialized Veteran-to-Veteran volunteer can provide companionship and understanding.

## Music

Volunteers can sing or play music for your enjoyment.

## Life Review

A specially trained volunteer can interview the patient about the patient's life. The conversation is recorded and given to the patient/family as a gift for a long-lasting memory.

## Story Book

A specially trained volunteer assists the patient by recording the patient reading a story that can then be shared for generations to come. The patient and family are given the CD and the book as a keepsake.

## 11th Hour Program

Specially trained volunteers can provide a quiet presence during the final hours of life, providing companionship and support for family members through our 11th Hour Program.



# Special Support for Veterans

EveryStep recognizes the unique needs of America's Veterans and their families. As an official Level 3 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 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 singing of "God Bless America," 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.

## 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.



WE HONOR VETERANS



# 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.



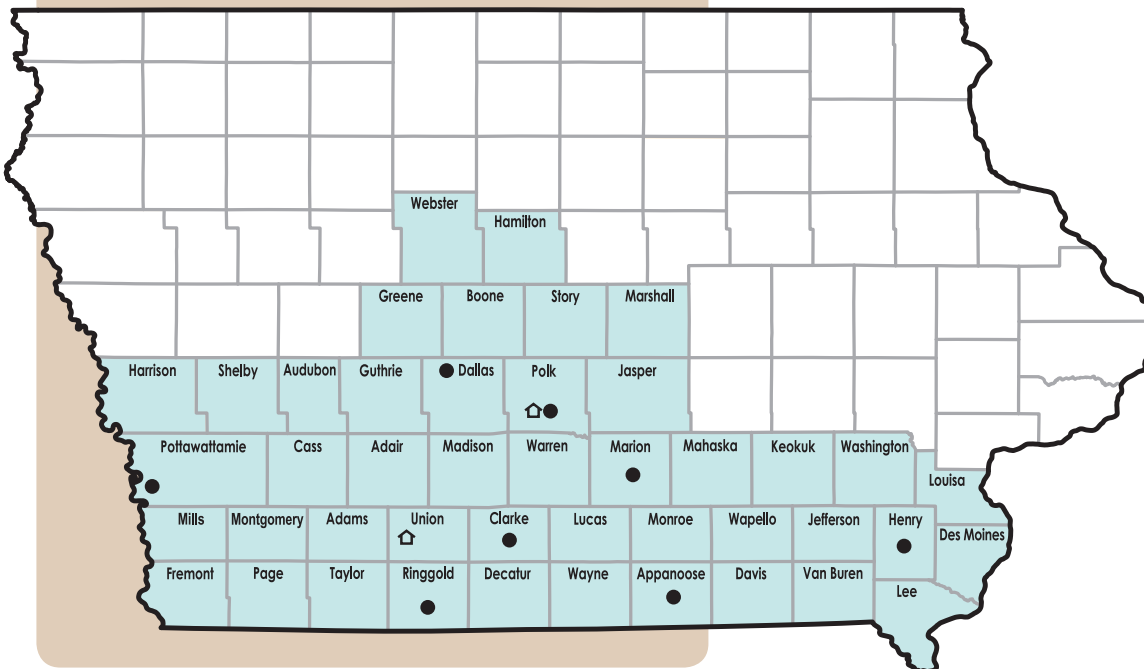
**Kavanagh House** in Des Moines opened in 1993. It was one of Iowa’s first residential hospice facilities and serves up to 15 individuals in private rooms.



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



# 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 the terminal illness. *See pages 18-33 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 the 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 our 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. Our 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 **foundation@everystep.org**.



# 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 to be 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, is maintaining alertness, even if it means being in some pain, more important to you?

# Advance Directives

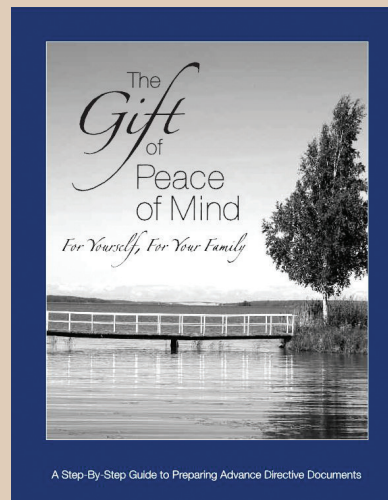
A living will, durable power of attorney for healthcare and IPOST are documents known as “advance directives.” Your physician, health care delegate (also known as your health care agent) and hospice team must follow the guidelines outlined in your advance directives. If you are hospitalized and you stop breathing or your heart stops beating, the facility’s health care staff are always obligated to follow your advance directives — whatever they may be.

## When paramedics are called to a scene, their duty is to resuscitate the individual unless:

- You have an IPOST form signed by your doctor, nurse practitioner or physician’s assistant that tells them to not resuscitate you.
- There is an Out-Of-Hospital Do-Not-Resuscitate (OOH DNR) order or uniform OOH DNR identifier that instructs them otherwise.

## Free Advance Directive Packets

EveryStep offers free advance directive forms. Contact your hospice care team for these and other helpful resources.





# Advance Directives Policy and Procedure

EveryStep respects the right of patients to make decisions regarding their own health care, including the right to accept or reject certain recommended care and the right to formulate, execute, revoke, or modify advance directives.

EveryStep recognizes a person's right under Iowa law to execute an advance directive in accordance with the requirements of the laws of the state in which it was executed.

All patients and/or their representative(s) will receive written information on advance directives, including a description of applicable State law.

EveryStep will document in a prominent part of the patient's medical record whether or not the individual has executed an advance directive.

EveryStep will not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive.

EveryStep will not coerce or place covert influence or pressure on any patient to execute or change an advance directive.

EveryStep shall provide for the education of staff and the community, individually or with others, on issues concerning advance directives.

EveryStep will inform patients at the time of initial receipt of hospice care that it is not required to provide care that conflicts with a valid advance directive, and that it is not required to implement an advance directive if, as a matter of conscience, it cannot implement an advance directive and Iowa law allows it to conscientiously object.

EveryStep will seek to honor a patient's wishes as expressed in an advance directive duly recognized under Iowa law. An advance directive which fails to meet the requirements of the laws in the state in which it was executed may not be binding under Iowa law, but expressions of intent by the patient in those documents may be helpful in guiding the patient's care where the patient is incompetent.



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Where a patient is, either through the legal system or by their attending or hospice physician, determined to not be competent to make their own health care decisions, EveryStep will seek direction regarding continued care from the individuals identified in the order specified under State law. If one exists, an attorney-in-fact, appointed under a duly executed and valid power of attorney for healthcare, is primary.

**“Advance Directive” means a written instruction, such as a living will or durable power of attorney for health care, recognized under the law of the state in which it was executed that is related to the provisions of health care when the person is incapacitated.**

This policy should be implemented in a manner to ensure compliance with Iowa law regarding advance directives.

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# Out-of-Hospital DNR

An Out-Of-Hospital Do-Not-Resuscitate order (OOH-DNR order) is a legal form which says that if your heart stops beating or you stop breathing, you do not want any kind of machine or medication to be used to try to start your heart or breathing. For the document to be legal, you must complete the form and have it signed by your doctor.

## What does it mean to have an OOH-DNR order?

By completing an OOH-DNR order, you are saying you do not want any medical intervention that uses mechanical or artificial means (machines) to sustain, restore or replace a normal and important part of being alive, like breathing or having a heart beat. "Mechanical or artificial means" might include:

- **Chest compressions** – when a person presses on your chest to force blood around your body when your heart is not beating.
- **Defibrillation** – when a machine is used to try to make your heart start to beat after it has stopped beating by using small amounts of electricity.
- **Esophageal/tracheal airway; endotracheal intubation** – when a tube is placed in your mouth or nose to push air into your lungs when you are not breathing.
- **Emergency drugs to alter cardiac or respiratory function to otherwise sustain life** – medications can sometimes be used to try to make your heart beat again after it has stopped or to make you start to breathe again if you have stopped breathing.

With the OOH-DNR form you can talk with your doctor about each of these things and write down which you want and do not want. This form is important because if your heart or breathing stops and someone calls 911 for help, police, fire and ambulance staff will use some or all of these things to try to restart your breathing or heart. If you have completed the OOH-DNR form they will follow your directions.

## What if you change your mind?

You can change your mind whenever you want. You can start or stop an OOH-DNR order. If you do not have one and would like one, simply talk to your doctor and

complete the form. Your family or hospice nurse can help you complete this form. If you have completed a form but would like to change it or end the order, all you need to do is talk with your doctor. Our hospice nurses are always available to help you with these forms. You may change your mind whenever you want, as many times as you want.

## What if family members disagree with what you decided on the OOH-DNR order?

This is your choice, as long as you are able to make your own decisions. If your family disagrees with your choices or doesn't understand them, talk with your hospice nurse. They can always help you talk with your family. The personal wishes of family members or other individuals not authorized in the OOH-DNR order to act on the patient's behalf do not override a valid OOH-DNR order.

## How do I make sure everyone knows my wishes?

Talk to your family and loved ones. If you want help, your hospice nurse can always help you explain your choices to your family. Keep the OOH-DNR order or an OOH-DNR identifier available and easy to find. If police, fire or ambulance staff arrives they must see either the OOH-DNR or the OOH-DNR identifier immediately so they know what to do. Keep the OOH-DNR form on your refrigerator or wear an OOH-DNR identifier.

## What is an OOH-DNR identifier?

An OOH-DNR identifier is a durable and easily removable unique identification (such as a MedicAlert® bracelet). It is approved by the Iowa Department of Public Health and worn by a patient who has an OOH-DNR order. The identifier has specific words engraved on it which either tells emergency responders that a do not resuscitate (DNR) order exists and MedicAlert® has the order on file, or the engraving will act as a DNR order.

You can purchase an OOH-DNR identifier by completing a MedicAlert® application, available from your doctor, or by calling (800) 432-5378. Send MedicAlert® a copy of your OOH-DNR order along with your completed MedicAlert® application.

# 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 the 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 to your story and to help create the kind of ending you and your loved ones hope for.



# Caring for the Caregiver

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

According to the Family Caregiver Alliance, caregivers report sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when sick and failure to make it to their own medical appointments. This emotional toll, the physical demands of providing care and the demands on time and resources can be stressful. Your hospice team can always help by sharing ideas, tips, and offering respite.

## Caregiver Support

**To find a caregiver support group near you, refer to:**

- Your local United Way; ask for a list of community information and referral sources, including help for caregivers
- Area Agency on Aging
- Your local hospital's senior services
- The phone directory, under "community services"
- Religious service agencies, clergy or parish nurses
- Community health or mental health clinics
- Newspaper event calendars



# Emergency Preparedness



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

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.

## Lightning

### IF YOU ARE INSIDE:

- Avoid using bathtubs, faucets and sinks — metal pipes conduct electricity and may be dangerous.
- Do not go near windows.
- Avoid using land lines (phones with cords) except in an emergency.

### IF YOU ARE OUTSIDE:

- Avoid natural lightning rods such as trees in open areas.
- Stay away from anything metal such as metal buildings, flagpoles or vehicles.

## Power Outages

If you attempt to call us for help during a power outage and our phone lines are not working:

- Call 911 or go to the emergency room if you have an emergency.
- Call your closest relative or neighbor if it is not an emergency.

## Floods

Make sure you know the potential for flooding in your area, especially if you live near water, downstream from a dam or in a low-lying region. We often think of flooding as taking days to occur, but flash floods can produce extremely fast-moving water in minutes. It only takes 6 inches of moving water to sweep you off your feet.

If you must walk in a flooded area, avoid moving water. When walking, use a stick or similar object to test if the ground is firm in front of you.

Move important items upstairs and be ready to leave your residence if a flood watch is issued. Fill a clean bathtub with water in case the local water supply becomes contaminated or is shut off. Turn off your home's utilities at the main valves if you are told to do so. Do not touch electrical equipment if you are wet or standing in water.

## Tornado

If you see a tornado, immediately go to an interior room on the lowest floor of the structure. Good places to take shelter include basements, rooms and halls with no outside walls, bathtubs and under the staircases. Many public buildings have designated shelter areas. Do not remain near windows, doors and outside walls. Get under a sturdy item such as a large table and protect your head by covering yourself with a blanket and pillow. Remain there until the tornado passes.

If the patient is confined to bed, move the bed as far away from the windows as possible. Place heavy blankets and pillows on the patient to protect their head and face from flying debris.

If you are in a vehicle, trailer or mobile home, get out immediately and go to a solid structure. If you cannot find one close by, lie down in the nearest ditch and cover your head. Never try to outrun a tornado in a vehicle. They move very fast and change direction quickly.

## Winter Storm

Large snowstorms, ice and extreme cold can make travel impossible in some areas. Roads may become blocked and power lines can fall any time it is cold or snowy. Be prepared to be isolated in case of a storm. To stay warm, wear layers of loose, lightweight clothing rather than one heavy layer. Hats and coats should be tightly woven and water repellant. Mittens provide more warmth than gloves.



## Excess Heat

Heat-related illness can occur during summer months. To decrease your risk:

- Drink water or nutritious fluids
- Avoid caffeine
- Avoid alcohol
- Avoid sitting in hot, closed vehicles.
- Remain indoors during hot/daytime hours.
- Use air-conditioning or fans to circulate the air.
- Mist water or use a cool cloth to cool your skin.

If symptoms of heat-related illness occur, such as nausea, headache or dizziness:

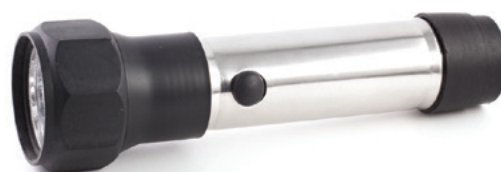
- Rest in a cool place.
- Drink a cool beverage.

If you cannot find relief from your symptoms, call your hospice nurse.

## Home Emergency Kit

Always be prepared for an extreme weather event — keep an emergency kit in your home that includes the following items:

- Lamps or flashlights
- A battery-powered-radio
- Extra batteries
- Medications
- Blankets
- Water in clean, sealed containers
- Food that is ready to eat
- A manual can opener
- Cups, plates and utensil
- Rock salt/ice melt and sand for walkways
- Extra fuel



## Emergency Shelter Supplies

If you must evacuate your residence and relocate to an emergency shelter, be sure to bring the following items:

- A one to two-week supply of your medications
- Medical supplies and oxygen
- Any assistive devices you need such as a wheelchair, walker, cane, etc.
- An air mattress or cot and bedding
- A lightweight, folding chair
- Special dietary foods and a can opener
- Extra clothing, eyeglasses and toiletries such as toothpaste, toothbrush, deodorant, etc.
- Important papers
- A valid ID with your name and current address
- Your hospice patient folder

Most emergency shelters will have power. Bring your electrical device (such as an oxygen concentrator).

## Pets

Planning ahead can make a difference in whether your pet survives a disaster. Remember, if it is not safe for you, it is not safe for animals. Some important things you can do include:

Make sure your pet can be identified. Talk to your local vet about microchipping your pet. If you and your pet become separated, a veterinarian or animal shelter will be able to scan and ID them. Make sure your pet is wearing a securely fastened collar with a tag that includes up-to-date contact information (preferably a cell phone number in case you are not able to use your land line). Birds should be caged with identification attached to the cage.

Assemble an emergency kit for your pet. Include the following items:

- For each pet, include food and water for at least 5 days
- Bowls and a manual can opener
- Medications and medical records, including vaccination schedules
- Leashes, harnesses and carriers
- Your cat's litter box, litter and scoop
- Paper towels and garbage bags (for pet waste)
- Current photos of you with your pet to prove ownership should you become separated
- Written information about feeding schedules, medical conditions and behavioral issues

Plan to take your pets with you if you need to evacuate. It is not safe for you or for them to stay!

Locate a pet-friendly refuge in advance. With the exception of service animals, pets are typically not allowed in shelters. Know the local hotels that will allow your pet(s) to stay in your room, or ask if a no-pets policy can be waived in an emergency. Make a list of those hotel phone numbers and call ahead for reservations if you know you will need to evacuate. Identify friends, boarding facilities, animal shelters or veterinarians that may be able to temporarily care for your pets. Your pets may be more comfortable together, but be prepared to house them separately if needed.





# Medication Management

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 that you take. This includes prescription medications, 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 or nurse practitioner. Your hospice nurse will review and answer any questions you may 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.
- 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.
- Avoid drinking alcohol while taking prescription medications.
- Do not share your medication with others, and do not take medications prescribed to someone else.

# After the Death of a Loved One

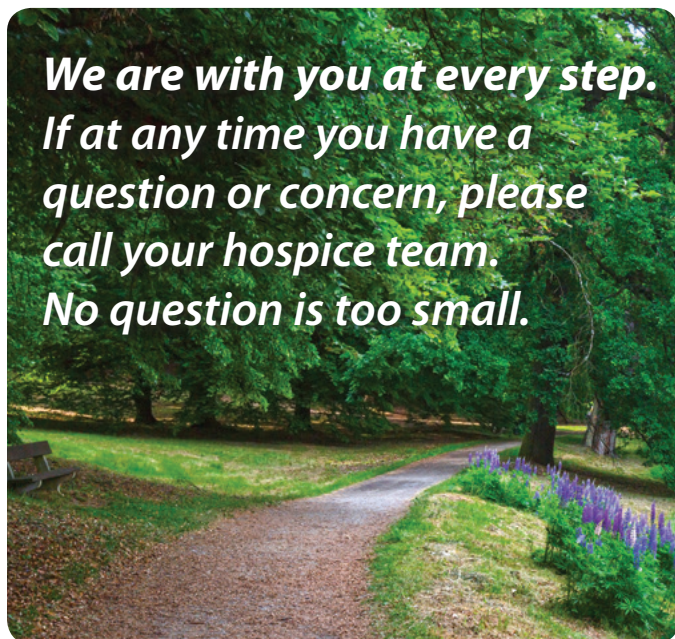
Call your hospice team nurse when your loved one dies, even if it is in the middle of the night. **You do not need to call for an ambulance or the police.**

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
- Bathe and clean your loved one if needed and desired
- Remove any tubes and turn off oxygen
- Put in dentures or ensure they are available to funeral home staff
- Contact the funeral home
- Contact other members of your hospice team
- Contact medical equipment vendor
- Complete proper documentation
- Contact your loved one's insurance company
- Dispose of unused prescription medications, as required by law



# 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/GriefandLoss](http://everystep.org/GriefandLoss) for more information.

## Memorial Events

Throughout the year, EveryStep hosts memorial events to honor the individuals we have served. These events offer an intimate setting 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 family nights, camps and other activities.

For more information about all of our bereavement services, visit [everystep.org](http://everystep.org)

# 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.



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## 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.

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## When a patient resides at one of our hospice houses:

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.

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## 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.

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## What is a Medication "Take Back" Program?

Some communities have a place where leftover 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](http://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 and pets.
- Deter misuse by teenagers and adults.
- Avoid health problems from accidentally taking the wrong medicine, too much of the same medicine, or a medicine that is too old to work well.



# Medicare Hospice Benefits

This **official government** booklet includes information about Medicare hospice benefits:

- ★ Who's eligible for hospice care
- ★ What services are included in hospice care
- ★ How to find a hospice provider
- ★ Where you can find more information



## Welcome

Choosing to start hospice care is a difficult decision. The information in this booklet and support from a doctor and trained hospice care team can help you choose the most appropriate health care options for someone who's terminally ill. Whenever possible, include the person who may need hospice care in all health care decisions.



The information in this booklet describes the Medicare Program at the time this booklet was printed. Changes may occur after printing. Visit [Medicare.gov](http://Medicare.gov), or call 1-800-MEDICARE (1-800-633-4227) to get the most current information. TTY users can call 1-877-486-2048.

Paid for by the Department of Health & Human Services.

## **Hospice care**

Hospice is a program of care and support for people who are terminally ill (with a life expectancy of 6 months or less, if the illness runs its normal course) and their families. Here are 7 important facts about hospice:

- Hospice helps people who are terminally ill live comfortably.
- Hospice isn't only for people with cancer.
- The focus is on comfort (palliative care), not on curing an illness.
- A specially trained team of professionals and caregivers provide care for the "whole person," including physical, emotional, social, and spiritual needs.
- Services typically include physical care, counseling, drugs, equipment, and supplies for the terminal illness and related conditions.
- Care is generally given in the home.
- Family caregivers can get support.

### **Palliative care**

Palliative care is the part of hospice care that focuses on helping people who are terminally ill and their families maintain their quality of life. If you're terminally ill, palliative care can address your physical, intellectual, emotional, social, and spiritual needs. Palliative care supports your independence, access to information, and ability to make choices about your health care.

## Care for a condition other than a terminal illness

Your hospice benefit covers care for your terminal illness and related conditions. Once you start getting hospice care, your hospice benefit should cover everything you need related to your terminal illness, even if you remain in a [Medicare Advantage Plan](#) (like an HMO or PPO) or other [Medicare health plan](#).

After your hospice benefit starts, you can still get covered services for conditions not related to your terminal illness. [Original Medicare](#) will pay for covered services for any health problems that aren't part of your terminal illness and related conditions. However, you must pay the [deductible](#) and [coinsurance](#) amounts for all Medicare-covered services you get to treat health problems that aren't part of your terminal illness and related conditions.

**Important:** If you were in a Medicare Advantage Plan before starting hospice care, and decide to stay in that plan, you can get covered services for any health problems that aren't part of your terminal illness and related conditions. You can choose to get services not related to your terminal illness from either your plan or Original Medicare. What you pay will depend on the plan and whether you follow the plan's rules, like seeing in-network providers. If your plan covers extra services that aren't covered by Original Medicare (like dental and vision benefits), your plan will continue to cover these extra services as long as you continue to pay your plan's [premiums](#) and other costs.

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## How your hospice benefit works

If you qualify for hospice care, you and your family will work with your hospice provider to set up a plan of care that meets your needs. For more specific information on a hospice plan of care, call your state hospice organization. Visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to find the number for your state hospice organization. TTY users can call 1-877-486-2048.



You and your family members are the most important part of a team that may also include:

- Doctors
- Nurses or nurse practitioners
- Counselors
- Social workers
- Pharmacists
- Physical and occupational therapists
- Speech-language pathologists
- Hospice aides
- Homemakers
- Volunteers

In addition, a hospice nurse and doctor are on-call 24 hours a day, 7 days a week, to give you and your family support and care when you need it.

A hospice doctor is part of your medical team. You can also choose to include your regular doctor or a nurse practitioner on your medical team as the attending medical professional who supervises your care.

The hospice benefit allows you and your family to stay together in the comfort of your home, unless you need care in an inpatient facility. If your hospice provider decides you need inpatient hospice care, your hospice provider will make the arrangements for your stay.

## Who's eligible for the hospice benefit

If you have [Medicare Part A](#) (Hospital Insurance) **AND** meet all of these conditions, you can get hospice care:

- Your hospice doctor and your regular doctor (if you have one) certify that you're terminally ill (you're expected to live 6 months or less).
- You accept palliative care (for comfort) instead of care to cure your illness.
- You sign a statement choosing hospice care instead of other Medicare-covered treatments for your terminal illness and related conditions.

**Note:** Only your hospice doctor and your regular doctor (if you have one) can certify that you're terminally ill and have 6 months or less to live.

## Finding a hospice provider

To find a hospice provider, talk to your doctor, or call your state hospice organization. Visit [Medicare.gov/contacts](https://www.medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to find the number for your state hospice organization. TTY users can call 1-877-486-2048.

You can also visit [Medicare.gov/hospicecompare](https://www.medicare.gov/hospicecompare) to find hospices that serve your area and compare them based on the quality of care they provide.

Medicare only covers your hospice care if the hospice provider is Medicare approved. Check with your doctor, the hospice provider, your state hospice organization, or your state health department, to see if the hospice provider you're looking at is Medicare approved.

If you belong to a [Medicare Advantage Plan](#) (like an HMO or PPO) and want to start hospice care, ask your plan to help you find a hospice provider in your area. Your plan must help you locate a Medicare-approved hospice provider in your area.

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## What Medicare covers

You can get a one-time only hospice consultation with a hospice medical director or hospice doctor to discuss your care options and management of your pain and symptoms. You can get this one-time consultation even if you decide not to get hospice care.

Once your hospice benefit starts, [Original Medicare](#) will cover everything you need related to your terminal illness, but the care you get must be from a Medicare-approved hospice provider.

Hospice care is usually given in your home, but it also may be covered in a hospice inpatient facility. Depending on your terminal illness and related conditions, the plan of care your hospice team creates can include any or all of these services:

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Prescription drugs
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term [respite care](#)
- Any other Medicare-covered services needed to manage your terminal illness and related conditions, as recommended by your hospice team

## Respite care

If your usual caregiver (like a family member) needs rest, you can get inpatient respite care in a Medicare-approved facility (like a hospice inpatient facility, hospital, or nursing home). Your hospice provider will arrange this for you. You can stay up to 5 days each time you get respite care. You can get respite care more than once, but only on an occasional basis.



## What your hospice benefit won't cover

When you start hospice care, you've decided that you no longer want care to cure your terminal illness and related conditions, and/or your doctor has determined that efforts to cure your illness aren't working. Medicare won't cover any of these once your hospice benefit starts:

- **Treatment intended to cure your terminal illness and/or related conditions.** Talk with your doctor if you're thinking about getting treatment to cure your illness. You always have the right to stop hospice care at any time.
- **Prescription drugs** (except for symptom control or pain relief).
- **Care from any provider that wasn't set up by the hospice medical team.** You must get hospice care from the hospice provider you chose. All care that you get for your terminal illness and related conditions must be given by or arranged by the hospice team. You can't get the same type of hospice care from a different hospice, unless you change your hospice provider. However, you can still see your regular doctor or nurse practitioner if you've chosen him or her to be the attending medical professional who helps supervise your hospice care.
- **Room and board.** Medicare doesn't cover room and board. However, if the hospice team determines that you need short-term inpatient or **respite care** services that they arrange, Medicare will cover your stay in the facility. You may have to pay a small **copayment** for the respite stay.
- **Care you get as a hospital outpatient (like in an emergency room), care you get as a hospital inpatient, or ambulance transportation,** unless it's either arranged by your hospice team or is unrelated to your terminal illness and related conditions.

**Note:** Contact your hospice team **before** you get any of these services, or you might have to pay the entire cost.

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## **Hospice care if you're in a Medicare Advantage Plan or other Medicare health plan**

Once your hospice benefit starts, [Original Medicare](#) will cover everything you need related to your terminal illness, even if you choose to remain in a [Medicare Advantage Plan](#) or other [Medicare health plan](#). If you were in a Medicare Advantage Plan before starting hospice care, you can stay in that plan, as long as you pay your plan's [premiums](#).

If you stay in your Medicare Advantage Plan, you can choose to get services not related to your terminal illness from either providers in your plan's network or other Medicare providers.

For more information about Original Medicare, Medicare Advantage Plans, and other Medicare health plans, visit [Medicare.gov](https://www.Medicare.gov) or call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

## **Information about Medicare Supplement Insurance (Medigap) policies**

If you have a [Medigap policy](#), it will cover your hospice costs for drugs and [respite care](#). Your Medigap policy also will help cover health care costs for problems that aren't part of your terminal illness and related conditions. Call your Medigap policy for more information.

To get more information about Medigap policies, visit [Medicare.gov](https://www.Medicare.gov) or call 1-800-MEDICARE.

## What you pay for hospice care

Medicare pays the hospice provider for your hospice care.

There's no **deductible**. You'll pay:

- **Your monthly Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance) premiums.**
- **A copayment of up to \$5 per prescription for outpatient prescription drugs for pain and symptom management.** In the rare case your drug isn't covered by the hospice benefit, your hospice provider should contact your Medicare drug plan (if you have one) to see if it's covered by **Medicare prescription drug coverage (Part D)**.
- **5% of the Medicare-approved amount for inpatient respite care.**

For example, if Medicare approves \$100 per day for inpatient respite care, you'll pay \$5 per day and Medicare will pay \$95 per day. The amount you pay for respite care can change each year.

**Important:** Once your hospice benefit starts, **Original Medicare** will cover everything you need related to your terminal illness. Original Medicare will also pay for covered services for any health problems that aren't part of your terminal illness and related conditions. See pages 4–5 for more information.

**Note:** If you need to get inpatient care at a hospital for your terminal illness and/or related conditions, your hospice provider **must** make the arrangements. The cost of your inpatient hospital care is covered by your hospice benefit, but paid to your hospice provider. They have a contract with the hospital and they work out the payment between them. However, if you go to the hospital and your hospice provider didn't make the arrangements, you might be responsible for the entire cost of your hospital care.

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## How long you can get hospice care

Hospice care is for people with a life expectancy of 6 months or less (if the illness runs its normal course). If you live longer than 6 months, you can still get hospice care, as long as the hospice medical director or other hospice doctor recertifies that you're terminally ill.

**Important:** Hospice care is given in benefit periods. You can get hospice care for two 90-day benefit periods followed by an unlimited number of 60-day benefit periods. At the start of the first 90-day benefit period, your hospice doctor and your regular doctor or nurse practitioner (if you have one) must certify that you're terminally ill (with a life expectancy of 6 months or less). At the start of each benefit period after the first 90-day benefit period, the hospice medical director or other hospice doctor must recertify that you're terminally ill, so you can continue to get hospice care. A benefit period starts the day you begin to get hospice care and it ends when your 90-day or 60-day benefit period ends.

**Note:** You have the right to change your hospice provider once during each benefit period.

## Stopping hospice care

If your health improves or your illness goes into remission, you may no longer need hospice care.

You always have the right to stop hospice care at any time. If you choose to stop hospice care, you'll be asked to sign a form that includes the date your care will end.

You shouldn't be asked to sign any forms about stopping your hospice care at the time you start hospice. Stopping hospice care is a choice only you can make, and you shouldn't sign or date any forms until the actual date that you want your hospice care to stop.

If you were in a [Medicare Advantage Plan](#) (like an HMO or PPO) when you started hospice, you can stay in that plan by continuing to pay your plan's [premiums](#). If you stop your hospice care, you're still a member of your plan and can get Medicare coverage from your plan after you stop hospice care. If you weren't in a Medicare Advantage Plan when you started hospice care, and you decide to stop hospice care, you can continue in [Original Medicare](#). If you're eligible, you can go back to hospice care at any time.

**Example:** Mrs. Jones had terminal cancer and got hospice care for two 90-day benefit periods. Her cancer went into remission. At the start of her first 60-day period, Mrs. Jones and her doctor decided that, due to her remission, she wouldn't need to return to hospice care at that time because she no longer has a life expectancy of 6 months or less. Mrs. Jones' doctor told her that if she becomes eligible for hospice services in the future, she may be recertified and can return to hospice care.

**Here's another way to look at Mrs. Jones' situation:**

- ▶ Mrs. Jones got hospice care.
- ▶ She started her 1st 90-day benefit period.
- ▶ Her doctor recertifies that she's terminally ill and she starts her 2nd 90-day benefit period.
- ▶ At the start of her 1st 60-day benefit period, Mrs. Jones and her doctor decide she no longer needs hospice care.
  - ▶ She continues in **Original Medicare**.
  - ▶ If Mrs. Jones becomes eligible for hospice in the future, she can return to hospice care.
- ▶ Mrs. Jones would resume hospice care with a new 60-day benefit period. She has an unlimited number of 60-day benefit periods.

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## Your Medicare rights

As a person with Medicare, you have certain guaranteed rights, including:

- The right to get care that meets professionally recognized standards. If you believe that the care you're getting is below this standard, and you're dissatisfied with the way your hospice provider has responded to your concern, you have the right to contact a [Beneficiary and Family Centered Care Quality Improvement Organization \(BFCC-QIO\)](#). You can visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to get the phone number for your BFCC-QIO. TTY users can call 1-877-486-2048.
- The right to ask for a review of your case. If your hospice provider or doctor believes that you're no longer eligible for hospice care because your condition has improved, and you don't agree, you have the right to ask for a review of your case. Your hospice provider should give you a notice that explains your right to an expedited (fast) review by a BFCC-QIO. If you don't get this notice, ask for it. This notice lists your BFCC-QIO's contact information and explains your rights.

To see a full list of your rights and for information about how to file a complaint about the hospice providing your care, visit [Medicare.gov/claims-and-appeals](https://www.Medicare.gov/claims-and-appeals), or call 1-800-MEDICARE.

**Note:** If you pay out-of-pocket for an item or service your doctor ordered, but your hospice provider refuses to give it to you, you can file a claim with Medicare. For more information on filing a claim or an appeal, visit [Medicare.gov/claims-and-appeals](https://www.Medicare.gov/claims-and-appeals) or call 1-800-MEDICARE.



## For more information

You can get official Medicare publications and find helpful phone numbers and websites by visiting [Medicare.gov](https://www.Medicare.gov) or calling 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

To learn more about Medicare eligibility, coverage, and costs, visit [Medicare.gov](https://www.Medicare.gov).

To find a hospice provider, talk to your doctor or call your state hospice organization. Visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE to find the number for your state hospice organization.

For free health insurance counseling and personalized help with insurance questions, call your [State Health Insurance Assistance Program \(SHIP\)](#). To find the contact information for your SHIP, visit [shiptacenter.org](https://www.shiptacenter.org) or call 1-800-MEDICARE.

For more information about hospice, contact these organizations:

- **National Hospice & Palliative Care Organization (NHPCO)**—Visit [nhpco.org](https://www.nhpco.org), or call 1-703-837-1500.
- **Hospice Association of America**—Visit [nahc.org](https://www.nahc.org), or call 1-202-547-7424.
- **VNAA**—Visit [vnaa.org](https://www.vnaa.org), or call 1-888-866-8773.
- **Hospice Foundation of America (HFA)**—Visit [hospicefoundation.org](https://www.hospicefoundation.org), or call 1-800-854-3402.

## Definitions

**Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO)**—A type of QIO (an organization of doctors and other health care experts under contract with Medicare) that uses doctors and other health care experts to review complaints and quality of care for people with Medicare. The BFCC-QIO makes sure there is consistency in the case review process while taking into consideration local factors and local needs, including general quality of care and medical necessity.

**Coinsurance**—An amount you may be required to pay as your share of the cost for services after you pay any deductibles. Coinsurance is usually a percentage (for example, 20%).

**Copayment**—An amount you may be required to pay as your share of the cost for a medical service or supply, like a doctor's visit, hospital outpatient visit, or prescription drug. A copayment is usually a set amount, rather than a percentage. For example, you might pay \$10 or \$20 for a doctor's visit or prescription drug.

**Deductible**—The amount you must pay for health care or prescriptions before Original Medicare, your prescription drug plan, or your other insurance begins to pay.

**Hospice**—A special way of caring for people who are terminally ill. Hospice care involves a team-oriented approach that addresses the medical, physical, social, emotional, and spiritual needs of the patient. Hospice also provides support to the patient’s family or caregiver.

**Medicare Advantage Plan (Part C)**—A type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Part A and Part B benefits. Medicare Advantage Plans include Health Maintenance Organizations, Preferred Provider Organizations, Private Fee-for-Service Plans, Special Needs Plans, and Medicare Medical Savings Account Plans. If you’re enrolled in a Medicare Advantage Plan, most Medicare services are covered through the plan and aren’t paid for under Original Medicare. Most Medicare Advantage Plans offer prescription drug coverage.

**Medicare health plan**—Generally, a plan offered by a private company that contracts with Medicare to provide Part A and Part B benefits to people with Medicare who enroll in the plan. Medicare health plans include all Medicare Advantage Plans, Medicare Cost Plans, and Demonstration/ Pilot Programs. Programs of All-inclusive Care for the Elderly (PACE) organizations are special types of Medicare health plans that can be offered by public or private entities and provide Part D and other benefits in addition to Part A and Part B benefits.

**Medicare Part A (Hospital Insurance)**—Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.

**Medicare Part B (Medical Insurance)**—Part B covers certain doctors’ services, outpatient care, medical supplies, and preventive services.

**Medicare prescription drug coverage (Part D)**—Optional benefits for prescription drugs available to all people with Medicare for an additional charge. This coverage is offered by insurance companies and other private companies approved by Medicare.

**Medigap policy**—Medicare Supplement Insurance sold by private insurance companies to fill “gaps” in Original Medicare coverage.

**Original Medicare**—Original Medicare is a fee-for-service health plan that has two parts: Part A (Hospital Insurance) and Part B (Medical Insurance). After you pay a deductible, Medicare pays its share of the Medicare-approved amount, and you pay your share (coinsurance and deductibles).

**Premium**—The periodic payment to Medicare, an insurance company, or a health care plan for health or prescription drug coverage.

**Respite care**—Temporary care provided in a nursing home, hospice inpatient facility, or hospital so that a family member or friend who is the patient’s caregiver can rest or take some time off.

**State Health Insurance Assistance Program (SHIP)**—A state program that gets money from the federal government to give free local health insurance counseling to people with Medicare.

## Notice of Accessible Communications

To help ensure people with disabilities have an equal opportunity to participate in our services, activities, programs, and other benefits, we provide communications in accessible formats. The Centers for Medicare & Medicaid Services (CMS) provides auxiliary aids and services, like publications, documents and communications, in Braille, large print, data/audio CD, relay services and TTY communications.

**CMS provides free auxiliary aids and services to help us better communicate with people with disabilities. Auxiliary aids include materials in Braille, audio/data CD or other accessible formats.**

**Note:** You can get the “Medicare & You” handbook electronically in standard print, large print, or as an eBook.

For Medicare publications, call us at 1-800-MEDICARE (1-800-633-4227).  
TTY: 1-877-486-2048.

For all other CMS publications and documents, you can:

1. Call 1-844-ALT-FORM (1-844-258-3676). TTY users can call 1-844-716-3676.
2. Send a fax to 1-844-530-3676.
3. Send an email to [AltFormatRequest@cms.hhs.gov](mailto:AltFormatRequest@cms.hhs.gov).

4. Send a letter to:  
Centers for Medicare & Medicaid Services  
Offices of Hearings and Inquiries (OHI)  
7500 Security Boulevard, Room S1-13-25  
Baltimore, MD 21244-1850  
Attn: Customer Accessibility Resource Staff

**Note:** Your request for a CMS publication or document should include:

- Your name, phone number, and the mailing address where we should send the publications or documents.
- The publication title and CMS Product No., if known.
- The format you need, like Braille, large print, or data/audio CD.

### **If you’ve already sent in, or want to follow up on, a request:**

To follow up on a previous accessibility request or if you have questions about the quality and timeliness of your previous request, you can contact the Customer Accessibility Resource Staff:

- Call 1-844-ALT-FORM (1-844-258-3676). TTY users can call 1-844-716-3676.
- Send a fax to 1-844-530-3676.
- Send an email to [AltFormatRequest@cms.hhs.gov](mailto:AltFormatRequest@cms.hhs.gov).
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7500 Security Boulevard, Room S1-13-25  
Baltimore, MD 21244-1850  
Attn: Customer Accessibility Resource Staff

## Medicare.gov accessibility & compliance with Section 508

Medicare.gov is committed to making its electronic and information technologies accessible to people with disabilities. If you can't access any content or use any features on this website due to a disability, visit [CMS.gov/about-cms/agency-information/aboutwebsite/policiesforaccessibility.html](https://www.cms.gov/about-cms/agency-information/aboutwebsite/policiesforaccessibility.html).

## Nondiscrimination Notice

CMS doesn't exclude, deny benefits to, or otherwise discriminate against any person on the basis of race, color, national origin, disability, sex, or age in admission to, participation in, or receipt of the services and benefits under any of its programs and activities, whether carried out by CMS directly or through a contractor or any other entity with which CMS arranges to carry out its programs and activities.

## How to file a complaint

If you believe you've been subjected to discrimination in a CMS program or activity, there are 3 ways to file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights:

1. Online at [hhs.gov/civil-rights/filing-a-complaint/complaint-process/index.html](https://www.hhs.gov/civil-rights/filing-a-complaint/complaint-process/index.html).
2. By phone: Call 1-800-368-1019. TDD users can call 1-800-537-7697.
3. In writing: Send information about your complaint to:

Office for Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Room 509F, HHH Building  
Washington, D.C. 20201

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### U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Medicare & Medicaid Services  
7500 Security Blvd.  
Baltimore, MD 21244-1850

Official Business  
Penalty for Private Use, \$300

CMS Product No. 02154  
Revised March 2018



This booklet is available in Spanish. To get your copy, call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

Esta publicación está disponible en Español. Para obtener una copia, llame al 1-800-MEDICARE (1-800-633-4227). Los usuarios de TTY pueden llamar al 1-877-486-2048.

# Notice of Patient Rights

EveryStep policy PF-0109 on Patient Rights states that every patient has the right:

1. To be informed of his or her rights, and EveryStep must protect and promote the exercise of these rights.
2. To exercise his or her rights as a patient of EveryStep;
3. To have his or her property and person treated with respect;
4. To voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of EveryStep; and
5. To not be subjected to discrimination or reprisal for exercising his or her rights.
6. Receive effective pain management and symptom control from the hospice for conditions related to the terminal illness;
7. Be involved in developing his or her hospice plan of care;
8. Refuse care or treatment;
9. Choose his or her attending physician;
10. Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with the privacy and security provisions of the Health Insurance Portability and Accountability Act (HIPAA--45 CFR parts 160 and 164).
11. Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property;
12. Receive information about the services covered under the hospice benefit;
13. Receive information about the scope of services that the hospice will provide and specific limitations on those services.

If a patient has been adjudged incompetent under state law by a court of proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf. If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient's rights to the extent allowed by state law.

## 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.**



# Notice of Privacy Practices

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

## Use and Disclosure of Health Information

EveryStep may use your health information for purposes of:

- Providing you treatment
- Obtaining payment for your care
- Conducting health care operations

The following are examples of times under which your health information may be used or disclosed after you sign the written consent.

### For Treatment

To coordinate care within EveryStep. This includes sharing your health information with your attending physician, the interdisciplinary group and other health care professionals who assist EveryStep in providing your care. EveryStep may also share your health information with individuals outside of EveryStep such as family members, clergy whom you designate, pharmacists, medical equipment suppliers and other health care professionals who are used in the coordination of your care.

### To Obtain Payment

EveryStep may include your health information in invoices to insurers (private insurance, Medicare and/or Medicaid) to collect payment for services you have received. EveryStep may need prior approval from your insurer and may need to explain to them your need for care and the services that will be provided to you.

### To Conduct Health Care Operations

EveryStep may use and disclose your health information for our own operations and as necessary to provide quality care to all EveryStep patients and clients. These include functions like: quality improvement activities, protocol development, professional review and performance evaluation, training programs for students, accreditation, licensing, medical review, legal services, business planning, cost management, administrative activities of EveryStep, fundraising for the benefit of EveryStep and certain marketing activities (unless you tell us you do not want to be contacted).

If you are a patient at one of our hospice houses, certain information about you (name, general health status, religious affiliation, and room number) may be disclosed while you are receiving care in that facility. EveryStep may disclose this information to people who ask for you by name. Please inform us if you do not want this information disclosed.

### For Fund Raising

EveryStep may use information about you (name, address, phone number, and dates of care) to contact you or your family to support EveryStep with a contribution. This information may be released to the EveryStep Foundation. If you do not want EveryStep Foundation to contact you or your family, notify the Foundation director at (515) 271-1309 and indicate that you do not wish to be contacted.

### For Marketing

EveryStep may send to you or your family members communications informing you of EveryStep activities. If any personal health information and/or photos are to be included in this material, EveryStep will obtain a specific authorization from you before using your information/photos. In addition, any disclosures that constitute a sale of personal health information for marketing purposes requires a specific authorization from you.

### **When Legally Required**

EveryStep will disclose your health information when it is required to do so by any Federal, State or local laws. EveryStep may release your health information in response to a court order or other valid legal processes. In addition, EveryStep may release your health information to identify or locate a missing person, fugitive or suspect, if EveryStep suspects your death was the result of criminal conduct, in order to report a crime or when you are the victim of a crime.

### **When There Are Risks to Public Health**

EveryStep may disclose your health information for public health activities such as: prevention or controlling a disease, reporting death, reporting of adverse events or product defects. EveryStep may disclose your health information, in good faith, if we believe that such disclosure is needed to prevent an imminent threat to your health or safety or to the health and safety of the public.

### **To Report Abuse, Neglect or Domestic Violence**

EveryStep is allowed to notify government authorities if EveryStep believes a patient or client is a victim of abuse, neglect or domestic violence. EveryStep will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

### **To Coroners and Medical Examiners**

EveryStep may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

### **To Funeral Directors**

If necessary to carry out their duties with respect to your funeral arrangements.

### **For Organ, Eye or Tissue Donation**

To organ procurement organizations or those involved in procuring, banking or transplanting to comply with patient or family wishes.

### **For Research Purposes**

Before EveryStep discloses any of your health information for research purposes; the project will be subject to an extensive approval process. EveryStep will ask your permission if any researcher will be granted access to your individually identifiable health information.

### **For Worker's Compensation**

EveryStep may release your health information to worker's compensation or similar programs.

For all other uses and disclosures not described in this Notice of Privacy Practices document; including must uses and disclosures of psychotherapy notes (where appropriate); a specific authorization from the individual will be required.

## Your Rights with Respect to Your Health Information

You have the following rights regarding your health information that EveryStep maintains:

### Right to Request Restriction

You may request restrictions to certain uses and disclosures of your health information. You may request a limit on EveryStep's disclosure of your health information to someone involved in your care or in the payment of your care. EveryStep is not required to agree to your request. In addition, you may restrict certain disclosures of your personal health information to a health plan if you pay for a service in full and out of pocket. If you wish to make a request for restriction, please contact the EveryStep Privacy Officer at 515-271-1313.

### Right to Receive Confidential Communications

You may request that EveryStep communicate with you in a certain way. For example, you can request that EveryStep communicate health information to you privately with no family members present. If you wish to receive confidential communications in an alternative manner, please contact the EveryStep Privacy Officer at (515) 271-1313. EveryStep will not request that you provide any reasons for your request and will attempt to honor your reasonable request for confidential communications.

### Right to Inspect and Copy Your Health Information

A request to inspect and copy your health records or your billing records may be made to the EveryStep Privacy Officer at (515) 271-1313. If you request a copy of your health information, EveryStep may charge a reasonable fee for copying and assembling costs associated with your request.

### Right to Amend Health Care Information:

If you or your personal representative believes that your health records are incorrect or incomplete, you may request that EveryStep amend the record. This request applies to information maintained by EveryStep. A request for amendment must be made in writing to the EveryStep Privacy Officer at (515) 271-1313. EveryStep of Iowa may deny the request if it is not in writing or does not include a reason for the amendment. The request may also be denied if your records were not created by EveryStep or are not a part of EveryStep's records, if the health information you wish to amend is not part of the health information you are permitted to inspect and copy, or if in the opinion of EveryStep, the records containing your health information are accurate and complete.

### Right to Opt out of Fundraising Communications

EveryStep may contact you or your family to raise money for EveryStep. The communication you receive regarding this will include an "opt out" selection for you if you do not wish to receive further communications.

### Right to an Accounting

You or your personal representative may request an accounting of disclosures of your health information made by EveryStep for any reason other than for treatment, payment or health operations. The request must be made in writing to the Privacy Officer. The request must include the time period for the accounting starting no sooner than 2012. Accounting requests may not be made for periods of time in excess of six years. EveryStep will provide the first accounting during any 12-month period without charge. Subsequent accounting requests are subject to a reasonable cost-based fee.

## Right to a Paper Copy of this Notice

You or your personal representative has a right to a separate paper copy of this notice at any time even if you or your representative received this notice previously. To obtain a separate paper copy, please contact the EveryStep Privacy Officer at (515) 271-1313.

## Right to be Notified of a Breach

In the event there is an unsecured breach of your health information, EveryStep will notify you as required in the Breach Notification Rule (45 CFR Parts 160 and 164).

## Contact Person

The EveryStep contact person for all issues regarding patient privacy and your rights under the State and Federal Privacy Standards is: EveryStep Privacy Officer at (515) 271-1313. Please call for address information.

## Duties of EveryStep

EveryStep is required by law to maintain the privacy of your health information and to provide to you and your personal representative this notice of its duties and privacy practices. EveryStep is required to abide by

the terms of this notice as may be amended from time to time. EveryStep reserves the right to change the terms of its notice to make the new notice provisions effective for all health information that its maintains.

If EveryStep changes its notice, EveryStep will provide a copy of the revised notice on their website or by request to the EveryStep Privacy Officer at (515) 271-1313. You or your personal representative has the right to express complaints to EveryStep and to the Secretary of Health and Human Services if you believe that your privacy rights have been violated. Any complaint to EveryStep should be made in writing to the Privacy Officer.

EveryStep encourages you to express any concerns you may have regarding privacy of your information. You will not be retaliated against in any way for filing a complaint.

# 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](mailto:ethics@everystep.org), fax your request to (515) 333-5801, or mail your request to:

### EveryStep

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

# 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** \_\_\_\_\_



Care. Give. Shop.

EveryStep   
**Giving Tree**

**We're always accepting gently used donations.**

You can help support our mission by donating to our thrift store in Urbandale, IA. Quality furniture, clothing and home goods are always needed to keep our showroom stocked. Sales benefit our hospice patients and families who don't have insurance or other resources to pay for care. For a list of items we accept, visit [everystepgivingtree.org](http://everystepgivingtree.org) or call **(515) 270-2414**.

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

**3330 100th Street, Urbandale, IA 50322**



**(515) 270-2414 | [everystepgivingtree.org](http://everystepgivingtree.org)**

**EveryStep**   
Hospice

**1 (800) 806-9934 | [everystep.org](http://everystep.org)**

Accredited by Community  
Health Accreditation Partner

**CHAP**  
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