

Hospice Care Guide

Support for Patients and Families



HopeWest

(866) 310-8900 • HopeWestCO.org

Dear Patient and Family,

We are honored you have trusted HopeWest to care for you and your loved ones at this most profound time. Please know you are well cared for, and we will walk alongside you every step of the way.

At HopeWest we are here as your care team, to help you to feel comfortable, confident, safe, and respected while supporting you throughout the journey ahead.

Your hospice team of caregivers will manage symptoms that often cause discomfort at end of life, and assist with your emotional, spiritual, and psychosocial needs. This team may include nurses, certified nursing assistants, social workers, chaplains, and volunteers. We will assess your needs regularly, and will provide visits, supplies, and equipment as you need them. The team will also teach loved ones useful tools for confidently supporting in care.

This Care Guide is intended to review common hospice information, and answer some of the questions that may arise. Please place this in a handy location where you can use it often. When you have questions or need guidance, this is a useful tool that will provide quick and easy answers. Your team may also refer to information in this important Care Guide during visits, to ensure you have the information and support needed.

We want to provide you and your loved ones with an exceptional experience. Our visits are intentionally designed to ensure that you have what you need, when you need it. Our focus is on supporting your feeling of exceptional care by providing you with a high-quality, reliable experience. We call this "The HopeWest Way." This drives our mission - through creativity, volunteerism and philanthropy, we profoundly change the way our community experiences aging, serious illness and grief - one family at a time.

It is our most profound honor and privilege to serve you and your family during this important time.

Sincerely,

A handwritten signature in black ink that reads "Cassie Mitchell". The signature is written in a cursive, flowing style.

Cassie Mitchell
President and CEO

If you have a concern or need, or want to ask a question, please call our Patient Services Line at (866) 310-8900 — anytime, day or night. Remember, your hospice care team is only a phone call away.

Table of Contents

HopeWest Programs..... 1

Regional Offices
Generosity Inspires Hope

Hospice Care..... 4

Professional Care Team
Getting Organized
Medication Safety and Disposal
Frequently Asked Questions

Handling Emotions 13

Five Senses of Caring
When Death is Near
Grief Support Programs

Patient and Family Rights and Responsibilities..... 19

Notice of Non-Discrimination
For Concerns or Complaints

Resources 26

Symptom Management Education Sheets

- Oxygen Safety
- About Your Medication
- Agitation and Restlessness
- Sadness and Depression
- Confusion and Disorientation
- Changes in Appetite
- Nausea
- Constipation
- Pain
- Shortness of Breath
- Worry and Anxiety
- Insomnia

HopeWest Programs

Palliative Care

Medical care for people with serious and potentially life-limiting illness. Unlike hospice services, palliative care may be provided at an earlier stage of illness and alongside curative or active treatment.

PACE (*Program of All-Inclusive Care for the Elderly*) – an innovative approach to aging, providing whole-person, wrap-around care for the elderly as a team of professionals work with each individual to make sure needed services are coordinated.

Hospice

Specialized, compassionate care focusing on alleviating symptoms, relieving pain, and making patients comfortable wherever they are – home, hospital, nursing home, assisted living facility, or the Ferris Care Center.

Ferris Hospice Care Center

Located in Grand Junction, Ferris Hospice Care Center and its trained staff provide short-term care in a home-like setting in the most difficult times. Our approach to care includes comprehensive physical, emotional, social, and spiritual support.

HopeWest Kids


Designed to support children and teens as they explore, understand, and express their personal grief experience. Our expert team members create a safe and welcoming environment while utilizing techniques that best fit each child and teen.

Family & Adult Bereavement Care

Helps adults, who have experienced a loss, through grief groups and counseling services. Services are open to anyone in our community who has suffered the death of someone close to them.

HopeWest Quality Survey Results

The family caregiver survey asks family members or friends about the patient’s hospice experience and if they would recommend that hospice to someone else. The survey ratings can be used to compare hospices using a 5-star scale, with more stars indicating better quality care.



	HopeWest	National Average	Colorado Average
Willingness to recommend this hospice	94%	84%	82%
Rating of this hospice	87%	81%	78%
Treating patient with respect	94%	90%	89%
Percentage of patients who received visits from a registered nurse or social worker at least 2 of the final 3 days of their life	78.6%	49.2%	64.5%

Source: Centers for Medicare & Medicaid Services Hospice Compare

HopeWest Regional Offices - Services Offered

HopeWest serves western Colorado in Mesa, Delta, Montrose, Ouray, and Rio Blanco counties with a collection of programs to meet the needs of patients and their loved ones.



Palliative Care



PACE



Hospice



Grief Support
for Adults



Grief Support
for Kids & Teens

Delta County



(970) 874-6823

195 Stafford Lane, Delta, CO 81416

Our Delta county staff work from two offices located across from the hospital in Delta, which were remodeled thanks to gifts from local supporters.

Meeker



(970) 878-9383

617 Main Street, Meeker, CO 81641

Our Meeker team is specially designed to serve a rural population. All services can be provided without charge thanks to fundraising, volunteers, and community collaboration.

Grand Junction



Mike & Kay Ferris Care Center

(970) 241-2212

3090 North 12th St., Grand Jct., CO 81506

Located in the Fairmount Health Park, the Mike and Kay Ferris Care Center is a 13-bed care center that provides state of the art acute hospice care. Our Grand Junction administrative offices are also housed at the Care Center.

Herb & Laura May Bacon Center for Living Your Best

(970) 241-2212

2754 Compass Drive, Grand Jct., CO 81506

Our hospice teams who serve people at home and in facilities are based at the Herb & Laura May Bacon Center for Living Your Best. This location is also home to our Clinic, the Center for Hope and Healing grief counseling program, and the PACE Day Center.

Montrose & Ouray Counties



(970) 240-7734

725 S. 4th Street, Montrose, CO 81401

Our staff in Montrose work from The Montrose Center for Hope, built in 2015 through the support of our generous community.

Plateau Valley & De Beque



(970) 487-3844

58128 Hwy 330, Building B - First Floor

PO Box 294, Collbran, CO 81624

Our tightknit Plateau Valley community generously donates time and talent to ensure anyone in need of care has a place to turn during some of life's most difficult times.

Generosity Inspires Hope

Because HopeWest is a charitable, nonprofit organization, each gift is appreciated and ensures exceptional care for families now and in the future.

It is the generosity of our community that enables us to do the best thing for our patients and families, far beyond what insurance pays for. Additionally, many of our essential programs and services such as palliative care and adult & youth grief support programs, rely on philanthropy to sustain them.

There are many ways to make an impact.

Honoring Your Loved One With A Special Tribute. Complimentary obituaries are a lasting way to remember your loved one. An optional donation in honor of your loved one enables HopeWest to provide the same compassionate care and comfort to patients and families like yours.

Memorial Opportunities are a timeless way to remember those who have touched your life. Pathway Bricks and Plaques | Garden Ornaments | Aspen Leaves | Other Personalized Options
(Opportunities vary by location)

Families Often Designate Hopewest To Receive Donations in lieu of flowers when their loved one has passed. We offer complimentary memorial opportunities to these families as an expression of our gratitude.

Monthly Giving is a simple way to make a remarkable difference. The **Circle of Hope** is our monthly giving program and an opportunity for you to support HopeWest and sustain quality care in your community.

HEIRLOOMS

· FOR HOSPICE ·

Located on Main Street in Grand Junction, Delta, and Montrose, our upscale resale stores are filled with purpose and one-of-a-kind items. Proceeds from these stores support the mission of HopeWest. We are always accepting donations and offer complimentary pick up of large items.

Call your local store for more information or visit HeirloomsForHospice.org.

Delta
(970) 874-5251

Grand Junction
(970) 254-8556

Montrose
(970) 252-3648



Learn more about how you can support HopeWest by calling (970) 257-2365 or by visiting HopeWestCO.org.

Hospice Care

HopeWest is here for you when someone you love is suffering with a serious illness and you aren't sure where to turn for help. This booklet was written to answer some of the questions people ask once they have chosen hospice services. As you read this booklet, we encourage you to mark the sections important to you. If you have further questions, feel free to talk with any of your team members or call HopeWest.

Hospice is a unique form of care that encompasses both patients and their families. This specialized, compassionate care focuses on alleviating symptoms, relieving pain and making patients comfortable wherever they are – home, hospital, nursing home, assisted living facility, or the Ferris Hospice Care Center.

Hospice is a benefit of Medicare, Medicaid, and most insurance plans. Most insurance covers 100% of the cost of hospice care including drugs, medical equipment, treatments, oxygen, and other needs are covered at no cost to the patient. Hospice advocates that people need to be able to live as fully as possible every day of their life. HopeWest is dedicated to supporting that principle and making it possible through our total care perspective.



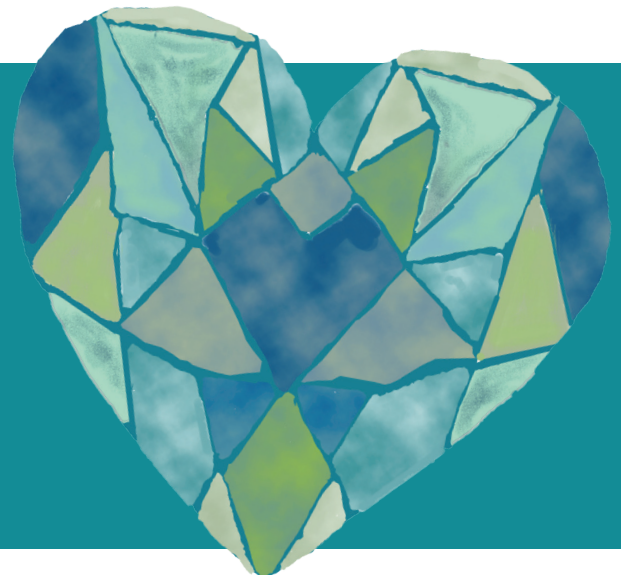
Some basic components of this concept that are unique:

- The patient and the family are the focus of care.
- Care must be provided by a team of people with different skills and backgrounds: nurses, physicians, nursing assistants, counselors, social workers and spiritual support professionals.
- Care must be organized by a **Plan of Care** that the patient and family guide and contribute to.

Many aspects of care at HopeWest are made possible by the generosity of our volunteers.

Volunteers receive specialized training to support hospice patients and families. For many, volunteers become significant support during this experience.

Volunteers can sit with patients and provide company, they can run errands, or sometimes provide music or a visit from a furry friend.



A Professional Team Meets Each Person's Needs

Every patient and every family is unique. Hospice care is holistic, considering the patient and family as the complete picture. Therefore, care will be designed specifically for the patient and their unique situation or needs.



PHYSICAL NEEDS

Our hospice team of nurses, physicians and certified nursing assistants meet the physical needs of patients. We also ensure the patient has access to other professionals when the need arises such as dietitians, occupational therapists, speech therapists, or physical therapists.



SOCIAL & EMOTIONAL NEEDS

When people are ill, they often lose a lot of social connections, which can further inhibit their health. They also face a number of challenging emotions they may not expect. In addition to other social or emotional needs, family communication can break down. Our social workers are especially helpful in these areas and can assist when needed.



PRACTICAL NEEDS

Practical needs always arise when someone experiences an illness, and this time is no exception. Some of the practical needs can be met through visits by our certified nursing assistants. Volunteers are willing to meet many practical needs as well. Our social workers can connect patients and families to other resources they may not be familiar with.



SPIRITUAL NEEDS

As people approach the end of life they often have many spiritual questions and needs. Others are very connected to a church or religious group that meets those needs. Our chaplains are people who bring an interdenominational approach to all patients and families. They have advanced education and special training to be spiritual support chaplains in a health care setting. They can also connect people to their church of choice.

Hospice Care at Home

We know most people prefer to be at home. HopeWest stands ready to help patients be comfortable and well-cared for at home. Some of the ways we can help include:



Nurse Practitioner and Physician house calls and coordinated care with the family doctor.



Making sure the patient has the medical supplies and equipment needed - usually without additional charge.



Helping plan for how various professionals and others can be of assistance during this time.



24-hour RN telephone consultations and advice.



Nurses and other team members who can come to the home on a scheduled basis and when there is an urgent need at any time, all week long.



Pharmacy delivery of routine medications and ensuring access to medications when an urgent need arises.



Being there to listen when people just need to talk it out, voice concerns, or have questions.



Volunteers go into the home to provide support, transportation, and many other needs.



Teaching how to make home a safe environment for patient care.

Hospice Care in a Nursing Home or Assisted Living Facility

Many aspects of hospice are similar when care is provided in a facility. HopeWest has collaborative relationships with area nursing homes and assisted living residences, and that allows for smooth coordination of care.



Nurse Practitioner and Physician house calls and coordinated care with the family doctor.

The team social worker who provides both support and practical resource help is particularly helpful when facility care is required. The team chaplain providing spiritual support is also very valuable.



24-hour RN telephone consults and advice to the facility staff members and patient's family.



Nurses and other team members visit the patient on a scheduled basis and when there is an urgent need at any time, all week long.



Helping you make a plan for how various professionals and others can be of assistance during this time.



Being there to listen when you just need to talk it out, voice concerns, or have questions.



Volunteers go into the facility to provide support, transportation, and many other needs.



We work with the facility regarding medications and ensuring access to medications when an urgent need arises.

Getting Organized

It is really helpful to pause and get organized as care begins.

Patient Records

- Driver's license
- Social Security card
- Insurance cards
- Veterans ID and discharge papers
- Banking and credit union records
- Other investment documents
- Patient's will
- Mortgage or leasing records
- Other bills like utilities, cable & phone
- Retirement account records

Phone Numbers & Addresses

It would be helpful to make an easy to reach list of important phone numbers and addresses.

Power of Attorney

It may be helpful to speak to your attorney or the hospice social worker regarding how a power of attorney over financial matters works if and when the patient is no longer able to take care of their own financial record keeping and bill paying. This is a different document than the Medical Durable Power of Attorney.

Advanced Care Planning

Planning for the kind of health care we want when the unexpected event occurs is important. We want to be sure that as health care providers we know and follow what the patient wants done in an emergency. We ask our patients to complete a Medical Durable Power of Attorney that names a person the patient trusts to make decisions regarding health care if they cannot. We will also ask about specific desires regarding resuscitation.



Take care of things you may have put off such as completing a simple will.

Supplies & Equipment

The HopeWest team will review your medical history and current status, and will make recommendations based on your diagnosis & personal needs. If the patient is under the Hospice Medicare or Medicaid benefit, medical equipment is rented on your behalf by HopeWest on a monthly basis.

Storage of Medical Supplies

Supplies should be stored in an area close to the patient care area for ease of use, but not clutter the patient area.

Disposal of Medical Supplies

Supplies such as dressings and tubing that is soiled with body fluids must be disposed of properly to prevent contamination or exposure to others. Supplies that have been exposed to a body fluid such as urine, feces, saliva, or blood can be double bagged while wearing gloves and disposed of in the regular trash. Oxygen tubing and masks can be disposed of in the trash.

Medical Equipment

For patients who are receiving hospice care, most medical equipment is a covered service and will be handled, ordered, and delivered by HopeWest without any copay. Medical equipment is often referred to as DME (durable medical equipment), and includes things like wheelchairs, walkers, etc..

Call your HopeWest team if you are having any problems or malfunction with any equipment.



If you have unopened plastic wrapped supplies, the items can be donated to a company who processes them for those in need. Your care team can provide information on this process.

Medication Safety & Disposal

The medical team will review patient's medical history and medications.

Medication Safety Tips

Check to make sure the correct name and correct dose are listed on the medication bottle/container. Read and understand the instructions listed on the medication and the purpose of the medication. Medication should be administered exactly as prescribed.

Disposal of Medications at Home

- Do not flush medications down the toilet or sink, as they will end up in our rivers and drinking water.
- Using a ziplock bag or other plastic container with a lid:
 - Empty all pills, liquids or suppositories into the bag or container
 - Squeeze any prescription ointments or creams into the bag or container
 - Add kitty litter, coffee grounds, dirt or sawdust to the bag or container followed by a small amount of water, soda, or vinegar. *(This will make the medication unusable.)*
 - Place the bag or container inside an unmarked paper/plastic bag into your regular trash.
- Use a marker to cross out the name on the prescription bottle and dispose of the empty bottles in regular trash.

The Colorado Medication Take-Back Program



The program accepts and destroys unused and expired over-the-counter and prescription medications generated by households. All locations accept prescribed medications.

You may keep the medications in their original container (use a marker to cross out the name) or empty all medications into a plastic ziplock bag and seal it.

All medications EXCEPT marijuana, illicit drugs, chemotherapy, used Fentanyl patches, needles, or syringes are accepted.

To see a list of all available locations near you, visit the website:

[www.Colorado.gov/pacific/cdphe/
Colorado-medication-take-back-program](http://www.Colorado.gov/pacific/cdphe/Colorado-medication-take-back-program)

Do not bring medications to a HopeWest office or the Ferris Care Center as these are NOT approved disposal locations.

HopeWest is committed to helping you be safe. We have volunteers and other means of assisting with any adaptations you may need for the safety of the patient. Please just ask.

Avoid Infections

- Always cough in your sleeve.
- Wash hands often. Have hand sanitizer available that has at least 65% alcohol. When washing hands, to be effective, sing the “happy birthday song” at least once.
- Keep disposable gloves nearby for handling any item with blood or any other body fluid.
- Keep surfaces that have contact with food clean and use a disinfecting product to clean tables and counters.

Avoid Fires

- No open flames, cigarette smoking, or candles lit with oxygen in use. If someone is going to smoke, not only should the oxygen be turned off, it needs to be in another room.
- Take extra care to ensure that frail patients are not operating ovens, microwaves, or stoves without knowing they are capable.
- Make sure things are not left on top of the stove unattended.
- Check for frayed cords on lamps, and do not overload extension cords.

Avoid a Fall on Stairs

- Keep stairs well lit, and eliminate any clutter.
- Install handrails – ideally on both sides of stairs.
- Avoid using stairs while wearing only socks or smooth-soled shoes to avoid slipping.



Avoid a Trip or Slip

- Loose rugs, runners, and mats should be secured to floor with double-sided adhesive or rubber matting. It’s best to avoid small area rugs altogether.
- Carpet edges should be tacked down so no one will trip over the edge.
- Be cautious of pets. Pets are the number one cause of falls in the home.

Avoid Slips in a Bathroom

- Tubs and showers should have a textured surface or nonskid mats or strips to avoid falls.
- Grab bars to assist with transfers should be installed in the tub, shower, and toilet areas.
- Check water temperature with your hand before entering the tub or shower.
- A night light should be used in the bathroom.
- Use a non-skid bathmat to avoid slipping on flooring.

Frequently Asked Questions

Regarding the Hospice Medicare Benefit

Why does the informed consent state that the patient is not pursuing curative treatment?

The Medicare benefit is an all-inclusive benefit that is capped at a certain amount for every hospice. It is not designed to include expensive therapies that are aggressive or curative such as dialysis, radiation, chemotherapy, or major surgeries.

Why doesn't the benefit cover room and board in a hospice facility?

Because the benefit was designed for people in their own residence, it does not pay for room and board in ANY facility of any kind.

Could the patient go back to regular Medicare or Medicaid after "electing" the hospice benefit?

A patient can return to regular Medicare or Medicaid and discharge from hospice at any time. This is called a revocation. A paper must be signed stipulating the patient desires to leave hospice benefit coverage and return to the other payer.

Why would a patient be discharged from hospice?

This would be in the circumstance of getting better and no longer being eligible because of a prognosis greater than six months if the disease ran its normal course. Patients may also be discharged if the conditions of caring for the patient are a danger to the hospice staff.

What is a Medicare Summary Notice?

The Medicare Summary Notice is mailed to patients at intervals from the Center for Medicare and Medicaid Services. It often is a confusing statement of what was charged for your care. It actually misrepresents the services because it only states certain costs and not others. It appears as though HopeWest was paid thousands of dollars in a month for a few staff visits and a few medications when many other costs covered by HopeWest during that same period are not reflected. These costs include things like hospital beds, oxygen, after-hours visits, doctor visits, ambulance rides, emergency room visits, and many others. It does not include visits by our chaplains, our nursing assistants, or our volunteers. These are just a few. Every year Medicare pays us the same for every patient regardless of their costs and HopeWest has to fundraise to make up the difference. You are not responsible for the difference or anything listed as a "non-covered charge."

Medicare Summary Notice for Part A (Hospital Insurance) Page 1 of 5

JENNIFER WASHINGTON
TEMPORARY ADDRESS NAME
STREET ADDRESS
CITY, ST 12345-6789

THIS IS NOT A BILL

Notice for Jennifer Washington

Medicare Number	XXX-XX-1234A
Date of This Notice	September 16, 2011
Claims Processed Between	June 15 - September 15, 2011

Your Deductible Status
Your deductible is what you must pay each benefit period for most health services before Medicare begins to pay.
Part A Deductible: You have now met your \$1,068.00 deductible for inpatient hospital services for the benefit period that began May 27, 2011.

Be Informed!
Welcome to your new Medicare Summary Notice! It has clear language, larger print, and a personal summary of your claims and deductibles. This improved notice better explains how to get help with your questions, report fraud, or file an appeal. It also includes important information from Medicare!

Your Claims & Costs This Period

Did Medicare Approve All Claims?	YES
Total You May Be Billed	\$2,062.50

Facilities with Claims This Period

June 18 - June 29, 2011	Otero Hospital
July 1 - July 18, 2011	Lexington Health Center

¿Sabes que puede recibir este aviso o uno tipo de ayuda de Medicare en español? Llame y habla con un agente en español. 中文或台語服務專線, 請電 800-633-4227 或 800-MEDICARE (1-800-633-4227)

Jennifer Washington THIS IS NOT A BILL | Page 2 of 5

Making the Most of Your Medicare

How to Check This Notice
Do you recognize the name of each facility? Check the dates.
Did you get the claims listed? Do they match those listed on your receipts and bills?
If you already paid the bill, did you pay the right amount? Check the maximum you may be billed. See if the claim was sent to your Medicare supplement insurance (Medigap) plan or other insurer. That plan may pay your share.

How to Report Fraud
If you think a facility or business is involved in fraud, call us at 1-800-MEDICARE (1-800-633-4227).
Some examples of fraud include offers for free medical services or billing you for Medicare services you didn't get. If we determine that your tip led to uncovering fraud, you may qualify for a reward.
You can make a difference! Last year, Medicare saved tax-payers \$4.2 billion—the largest sum ever recovered in a single year—thanks to people who reported suspicious activity to Medicare.

How to Get Help with Your Questions
1-800-MEDICARE (1-800-633-4227)
Ask for "hospital services." Your customer-service code is 05535.
TTY 1-877-486-2048 (for hearing impaired)
Contact your State Health Insurance Program (SHIP) for free, local health insurance counseling. Call 1-555-555-5555.

Your Benefit Periods
Your hospital and skilled nursing facility (SNF) stays are measured in **benefit days** and **benefit periods**. Every day that you spend in a hospital or SNF counts toward the benefit days in that benefit period. A benefit period begins the day you first receive inpatient hospital services or, in certain circumstances, SNF services, and ends when you haven't received any inpatient care in a hospital or inpatient skilled care in a SNF for 60 days in a row.
Inpatient Hospital: You have **56 out of 90 covered benefit days** remaining for the benefit period that began May 27, 2011.
Skilled Nursing Facility: You have **63 out of 100 covered benefit days** remaining for the benefit period that began May 27, 2011.
See your "Medicare & You" handbook for more information on benefit periods.

Your Messages from Medicare
Get a pneumococcal shot. You may only need it once in a lifetime. Contact your health care provider about getting this shot. You pay nothing if your health care provider accepts Medicare assignment.
To report a change of address, call Social Security at 1-800-772-1213. TTY users should call 1-800-325-0778.
Early detection is your best protection. Schedule your mammogram today, and remember that Medicare helps pay for screening mammograms.
Want to see your claims right away? Access your Original Medicare claims at www.MyMedicare.gov, usually within 24 hours after Medicare processes the claim. You can use the "Blue Button" feature to help keep track of your personal health records.

Jennifer Washington THIS IS NOT A BILL | Page 3 of 5

Your Inpatient Claims for Part A (Hospital Insurance)

Part A Inpatient Hospital Insurance helps pay for inpatient hospital care, inpatient care in a skilled nursing facility following a hospital stay, home health care, and hospice care.

Definitions of Columns
Benefit Days Used: The number of covered benefit days you used during each hospital and/or skilled nursing facility stay. (See page 2 for more information and a summary of your benefit periods.)
Claim Approved: This column tells you if Medicare covered the inpatient stay.

Non-Covered Charges: This is the amount Medicare didn't pay.
Amount Medicare Paid: This is the amount Medicare paid your inpatient facility.
Maximum You May Be Billed: The amount you may be billed for Part A services can include a deductible, coinsurance based on your benefit days used, and other charges.
For more information about Medicare Part A coverage, see your "Medicare & You" handbook.

June 18 - June 21, 2011
Otero Hospital, (555) 555-1234
PO Box 1142, Manati, PR 00964
Referred by Jesus Sarmiento Forasté

Benefit Days Used	Claim Approved?	Non-Covered Charges	Amount Medicare Paid	Maximum You May Be Billed	See Notes Below
4 days	Yes	\$0.00	\$4,886.98	\$0.00	
Total for Claim #20905400034102				\$0.00	\$4,886.98

June 29, 2011
Otero Hospital, (555) 555-1234
PO Box 1142, Manati, PR 00964
Referred by Carlos Santiago Diaz

Benefit Days Used	Claim Approved?	Non-Covered Charges	Amount Medicare Paid	Maximum You May Be Billed	See Notes Below
1 day	Yes	\$0.00	\$6,583.00	\$0.00	
Total for Claim #20909690033902				\$0.00	\$6,583.00

Continued →

Notes for Claims Above
A Days are being subtracted from your total inpatient hospital benefits for this benefit period. The "Your Benefit Periods" section on page 2 has more details.

Handling Emotions

It is hard to always be conscious of the ways people cope when under stress and when facing loss. Often there is a sense of grief that comes long before a loss – in anticipation of the loss. We hope to help people understand that these emotions are common, and we encourage you to talk over some of these feelings with one of your HopeWest team members.

Shock & Denial

When it comes time for hospice, often some of the shock of the situation of serious illness has started to wear off. But sometimes the coping mechanism of denial creeps in. One person in the family may be having trouble coping and taking in the fact that they are losing someone close and just shut down. Sometimes there are days people need that denial to just cope, and it may disappear the next. This is a time of up and down emotions.

Anger

When someone is near the end of life, emotions can arise that we may not expect, such as anger. Sometimes people suffering from an illness are fine, but the person close to them may be angry or scared at how life will be without the person they love. Typically, when someone feels or expresses anger it is toward the situation they are in and not directed towards someone. Understanding that this anger will likely be temporary and talking through these emotions with someone you trust can be helpful.

Distraction & Detachment

Sometimes the only way loved ones can cope with the realization that their worst fear could be coming true, is to detach or try to stay busy, looking for a distraction. It is not uncommon for a wife of 70 years to continue cleaning and cooking despite her ill husband asking her just to sit close. These emotions may be upsetting for some, but for others it may be a means of dealing with the situation. You may see detachment happen by both patients and people close to them.

Role Confusion

When a person suddenly becomes seriously ill, roles can change within the family unit. Sometimes this is seen as a daughter who has to suddenly care for a mother, or a wife who has to start paying bills and taking care of household issues her husband had always taken care of, or a husband who has to start cooking. All of these changes in roles take some adjustment and may lead to irritability and anger. These feelings are normal and can take time to work through.

Guilt & Regret

Throughout the course of an illness, people may feel guilty or full of regret. These emotions may be felt differently and at different times, but most people do face these feelings at some point throughout the illness. There are four statements that may help manage the feelings of guilt or regret when said to the person who is dying—

Please forgive me. I forgive you. Thank you. I love you.

The Five Senses of Caring

These caregiving tips are organized by our five senses. It is often amazing to see how little things can make all the difference.

Vision

Vision is often the first sense to be affected by serious illness.

- Keep glaring lights away from the patient's eyes
- Allow patient to rest their eyes frequently
- Stand or sit in a place where the patient can easily see you
- Use pillows or roll the bed to a position where it is easier for the patient to see
- Offer to assist with glasses
- Give the patient permission to close their eyes when you are visiting with them



Smell

Smell is one of the senses that stays the longest and is often highly sensitive until the very end of life. Many times it is a scent that brings back a host of memories. Sometimes, when people cannot speak or hear, smell can provide comfort. Remember, scents should be VERY light and it is best to avoid mixing scents.

- Lavender can be a calming scent
- Diffusers with pleasant fragrance
- Fresh flowers
- Citrus air fresheners
- Special "memory" fragrances like apple pie

Taste

The sense of taste often leaves when a person is ill. This can be difficult to cope with when we are accustomed to showing our love by sharing food. It is tempting to try to make a person eat to regain their strength or feel better. Unfortunately, patients may have no appetite or food makes them feel worse. It is sometimes helpful to share small amounts of a patient's favorite food... a small piece of candy, juice, a favorite beverage, or just a bite of a favorite food or dessert. Good, frequent mouth care can sometimes help and is an important comfort measure.

Hearing

Hearing is almost always the sense that remains present even when someone is unable to speak or appears to be asleep.

- Make sure the person wears their usual hearing device if they are accustomed to having one and it is comfortable.
- If one ear is better than the other, remember to conveniently position the person so their good ear is nearest to you.
- Speak clearly in a distinct tone.
- Try to be aware of other sounds or noises that may interfere with the person's hearing, like several people talking across the room.
- Talking to those we love, even very close to death, is very comforting. Often, they can hear us in ways we may not even understand. Don't be afraid to share your feelings and encouragement. You likely will be heard.

Touch

Touch is usually the very last sense to be diminished. Even when a person is close to death, the skin around the face and neck is particularly sensitive to touch. A touch of the hand or gently massaging the skin with warm lotion can be very comforting. Some people love to have their feet massaged with lotion. Others appreciate a cool cloth to the forehead or behind the neck. Sometimes, people don't want to be touched, particularly if they are in pain.

At other times, people may be withdrawing from those they love, perhaps making it easier to separate. Sometimes, just touching one finger is all that can be tolerated, accepted, or received. It is helpful to ask permission to touch. Watch carefully for a response. You will be fine if you move gently and with love.



*Caregiving often calls us to lean into
love we didn't know possible.*

- Tia Walker, author

When Death is Near

Each person is unique and it is hard to predict exactly what may be encountered as our loved ones approach the end of life. Often, there are physical, mental, and spiritual signs that death is near. The following are things that may be observed.

One to Three Months

- There may be a withdrawal or detachment from people and activities
- There may be less communication
- Eating and drinking less
- Sleeping More

One to Two Weeks

- People can seem to have periods of disorientation or confusion
- We see use of symbolic language like "I want to go home"
- Often people see others not present in the room who have passed before them. At times patients may be observed talking to the people they see.
- Physical changes may include:
 - Changes in pulse
 - Decrease in blood pressure
 - Changes in skin color
 - Irregular breathing patterns
 - Changes in body temperature
 - Eating and drinking less

Days to Hours

- People may sleep a good part of the time
- Sometimes a day or two before death people experience a surge in energy that may seem as if they are getting better
- Restlessness may occur
- Difficulty swallowing and even choking can happen. Be aware when giving liquids or medicines by mouth
- Increased changes in skin color
- Breathing changes with long pauses between breaths
- Gurgling sounds when breathing may occur
- Pulse weakens
- Lower blood pressure
- Decreased urine output
- Sometimes eyes appear to not close completely

Hours to Minutes

- Longer time between breaths
- Breathing may be shallow
- Mouth breathing rather than through the nose
- Patient may be unable to arouse

At Time of Death

The time of death may come when the patient is in their own home or in a facility. What happens at home is different than when a patient is in a facility or the Ferris Care Center. No matter where the death occurs, HopeWest wants to support the family.

If the Patient is at Home

- Call us at (866) 310-8900. That number goes directly to an RN and let them know you believe the patient is close to death or has died. You do not need to call 911. A nurse will be notified and make a visit to your home.
- The nurse will verify the death and call the physician to pronounce the patient. If necessary, in some areas, the coroner will be notified.
- The nurse will be happy to arrange for the patient's body to be transferred to the mortuary of your choosing. The timing of removal is up to you and can be as long as 24 hours.
- The nurse will assist in preparing the body for the mortuary, and will instruct you on the proper destruction procedures for medications. If there is equipment in the home they will assist by calling the medical supply company for removal.

For Patients in Any Setting

- The nurse will visit.
- The social worker can assist in calling family members, if desired.
- The social worker or chaplain may visit to assist and provide support.

Hospice Closure Visit and Bereavement Support

Members of your hospice team will contact you after the death of your loved one. This is a time to review all you have been through together and set the stage for the future. They will ask you about your interest in participating in our grief programs, and assist you with other issues that might arise.

There are no good-byes for us. Wherever you are, you will always be in my heart.

-Ghandi

Grief Support Programs

The journey of grief is unique to everyone. Learning about grief and sharing your experience with others can help provide comfort after the loss of a loved one. Grief is a natural, necessary, and highly personal experience. While grief does not follow a timetable, it does ease over time. Facing grief and working through it can result in newfound peace, strength, and purpose.

HopeWest offers an array of support groups where families and loved ones can learn how to cope with grief and connect with others who share a common bond. Groups are a community service provided by HopeWest and most are free of charge.

Programs include:

- Individual & Family Counseling
- The HopeWest newsletter, Grief's Journey, is available online
- Special grief counseling for children which includes grief camps, groups, and one-on-one counseling
- Telephone support
- Various grief groups

Counseling is available to anyone who has experienced the death of a loved one or those connected to someone facing serious illness and may be experiencing anticipatory grief.

Contact your local HopeWest office to talk with a trained, experienced, and credentialed grief counselor about the individual and additional group offerings to support you.

Online Grief Support Resources



HopeWest has a variety of online grief support resources that can be accessed at [HopeWestCO.org/Grief-Support](https://www.hopewestco.org/Grief-Support).

Grief's Journey Newsletter

Grief's Journey is a 12-issue newsletter that combines general information about loss and grief with proven tips and coping strategies.

Recommended Reading

View a comprehensive list of helpful books for those experiencing grief and loss.

Patient and Family Rights & Responsibilities

Your Basic Rights

You have the right to:

- Receive quality care regardless of race, religion, color, national origin, gender, age, physical or mental disabilities, marital status, sexual orientation, gender identity, socio-economic circumstances, source of payment or ability to pay.
- Be given safe, considerate care that is ethical, in your best interest, and respectful of your life values and religious preference, and offers dignity and individuality.
- Be provided information about the rules and regulations of our organization and inpatient facility that apply to you.
- Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.
- Be advised of the availability of the toll free Home Health Agency & Hospice Hotline in Colorado (800) 842-8826 to register complaints or ask questions regarding home health care or hospice services.
- For Medicare/Not Medicaid Beneficiaries: If you have a complaint for care you receive, you may place your complaint in writing and send it to:
KEPRO
5201 West Kennedy Blvd., Suite 900
Tampa, FL 33609
(844) 888-317-0891

Your Medical and Physical Care

You have the right to:

- Be informed of the hospice concept, admission criteria, services to be provided, options available, and any charges which may be incurred.
- Know the name and qualifications of your physician and others who care for you.
- Receive care by professional staff and volunteers adequately prepared for the level of service they provide.
- Choose your attending physician.
- Receive effective pain management and symptom control.

- Receive information about your illness including diagnosis, prognosis and your treatment in terms you can understand, enabling you to participate in developing the plan of care and give informed consent for all treatments and procedures.
- Actively participate in decisions involving your health care, including the refusal of any service or treatment offered or withdrawal from the HopeWest program.
- Present any complaints you may have without fear of reprisal.
- Sign an advance directive such as a living will.
- Know before your discharge or transfer about the continuing health care that you may require.

Privacy and Confidentiality

You have the right to:

- Privacy in treatment and in caring for all personal needs, to the extent possible.
- Privacy with family, visitors and phone calls.
- Information about proposed experimental procedures or research included as part of care, and the right to refuse to participate in the experiment or research without jeopardizing your continuing care.
- Have all property treated with respect.
- Have a confidential clinical record.
- Information about the uses and disclosures of your health information as outlined in HopeWest's Notice of Privacy Practices and your rights with regard to your health information.

Financial Issues

You have the right to:

- Be informed orally and in writing prior to receiving HopeWest care of all items, services and scope of services furnished by HopeWest or by arrangement for which payment shall be made, and any charges that the individual may have to pay, and any changes in these charges.
- Receive an explanation of any bill, regardless of the source of payment.
- Receive, upon request, information relating to financial assistance available through HopeWest.

The patient and family have these responsibilities:

- Provide complete and accurate medical history to the best of your knowledge.
- Participate in decisions involving your care.
- Make it known whether your proposed plan of care is understood and things expected of you are understood.
- Follow the mutually developed plan of care.
- Provide information about complications or symptoms in a timely manner.
- Be considerate of the rights and property of HopeWest staff and volunteers.
- Provide information to your HopeWest team regarding any treatment plans that change during the course of care.
- Provide accurate and timely information about sources of payment and ability to meet financial obligations.

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 this information carefully.

Our Responsibilities

- We are required by law to maintain the privacy and security of your protected health information.
- We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information.
- We must follow the duties and privacy practices described in this notice and give you a copy.
- We will not use or share your information other than as described here unless you tell us we can in writing. If you tell us we can, you may change your mind at any time. Let us know in writing if you change your mind.
- There are both Federal and State laws about protecting your medical information. If a State law is more protective or provides you with greater access to your information, then we will follow State law.

Our Uses and Disclosures

How do we typically use or share your health information? We typically use or share your health information in the following ways:

Treat you

We can use your health information and share it with other professionals who are treating you.

Example: A doctor treating you for an injury asks another doctor about your overall health condition.

Bill for your services

We can use and share your health information to bill and get payment from health plans or other entities.

Example: We give information about you to your health insurance plan so it will pay for your services.

Run our organization

We can use and share your health information to run our practice, ensure that you receive quality care, assess the quality of your care, and contact you when necessary.

Example: We use health information about you to manage your treatment and services.

Health Information Exchange

We currently use Quality Health Network (QHN) for the electronic sharing of healthcare information. If you need medical treatment in other places, QHN allows doctors or hospitals to contact us about your care. If you do not want us to share your information on QHN, please let us know in writing or during the enrollment or admission process.

Other Uses and Disclosures

We may also use or disclose your information for certain purposes such as:

- Help with public health and safety of you and others, including to report immunizations.

- When required by law to report suspected abuse, neglect, or report crimes.
- For workers' compensation reasons when allowed by law.
- To respond to audits.
- As requested by a court order.
- For health research if certain conditions exist.
- To coroners, funeral directors, or organ donation organizations.
- If state or federal laws require it, including with the Department of Health and Human Services if it wants to see that we're complying with federal privacy law.

Your Choices

For certain health information, you can tell us your choices about what we share. If you have a clear preference for how we share your information in the situations described below, talk to us. Tell us what you want us to do, and we will follow your instructions.

In these cases, you have both the right and choice to tell us to:

- Share information with your family, close friends, or others involved in your care.
- Contact you to provide appointment updates, we may leave voice messages unless you tell us not to.
- Share information in a disaster relief situation.
- Include your information in a hospice directory.
- If you are not able to tell us your preference, for example if you are unconscious, we may go ahead and share your information if we believe it is in your best interest. We may also share your information when needed to lessen a serious and imminent threat to health or safety.

In these cases, we never share your information unless you give us written permission:

- Marketing purposes
- Sale of your information
- Most sharing of psychotherapy notes

In the case of fundraising:

We may contact you for fundraising efforts, but you can tell us not to contact you again.

Students

- Students/interns in health service-related programs work with us from time to time to meet their educational requirements or to get health care experience. These students may observe or participate in your treatment or use your health information to assist in their training. If you do not want a student or intern to observe or participate in your care, please let us know.

Your Rights

When it comes to your health information, you have certain rights. This section explains your rights and some of our responsibilities to help you.

Get an electronic or paper copy of your medical record

- You can ask to see or get an electronic or paper copy of your medical record and other health information we have about you. Ask us how to do this.
- We will provide a copy or a summary of your health information, usually within 30 days of your request.
- We may charge a reasonable, cost-based fee.

Ask us to correct your medical record

- You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this.
- We may say "no" to your request, but we'll tell you why in writing within 30 days.

Request confidential communications

- You can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address.
- We will say "yes" to all reasonable requests.

Ask us to limit what we use or share

- You can ask us not to use or share certain health information for treatment, payment, or our operations. We are not required to agree to your request, and we may say "no" if it would affect your care.

- If you pay for a service or health care item out-of-pocket in full, you can ask us not to share that information for the purpose of payment or our operations with your health insurer. We will say “yes” unless a law requires us to share that information.

Get a list of those with whom we’ve shared information

- You can ask for a list (accounting) of the times we’ve shared your health information for six years prior to the date you ask, who we shared it with, and why.
- We will include all the disclosures except for those about treatment, payment, and health care operations, and certain other disclosures (such as any you asked us to make).

Get a copy of this privacy notice

- You can ask for a paper copy of this notice at any time, even if you have agreed to receive the notice electronically. We will provide you with a paper copy promptly.

Choose someone to act for you

- If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your health information.
- We will make sure the person has this authority and can act for you before we take any action.

Special rules regarding disclosure of psychiatric, substance abuse, and HIV/AIDS

Federal and State laws may require special privacy protections that restrict the use and disclosure of certain health information, including highly confidential information about you that may include information governing alcohol and drug abuse information, genetic information, as well as state laws that often protect the following types of information:

- HIV/AIDS
- Mental Health
- Genetic testing/tests
- Alcohol and drug abuse
- Sexually transmitted disease and reproductive health information

- Child or adult abuse or neglect, including sexual assault.

If a use or disclosure of health information described above in this notice is prohibited or materially limited by other laws that apply to us, it is our intent to meet the requirements of the more stringent law.

File a complaint if you feel your rights are violated

- You can complain if you feel we have violated your rights by contacting the HopeWest Privacy Officer.
- You may also file a complaint with the Department of Health and Human Services at the below address or using the OCR online portal:

**Centralized Case Management Operations
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Room 509F HHH Bldg.
Washington, D.C. 20201**

Portal:

<https://ocrportal.hhs.gov/ocr/smartscreen/main.jsf>

We will not retaliate against you for filing a complaint.

We may change the terms of this Notice at any time. If we change this Notice, we may make the new Notice terms effective for all protected health information that we maintain, including any information created or received before issuing the new Notice. If we change this Notice, we will post the new Notice in common areas throughout our facility, and on our website.

Contact

If you have any questions, need further assistance, or would like to submit a request about this Notice, you may contact our Privacy Officer for additional information:
(970) 241-2212
3090 N. 12th St, Unit B
Grand Junction, CO 81506

Effective Date of this Notice
This Notice is effective as of April 1, 2024

Notice of Nondiscrimination

HopeWest complies with applicable federal civil rights laws and does not discriminate, treat people differently or exclude them on the basis of race, color, national origin, age, disability, sex or gender, sexual orientation, gender identity or any other protected status.

HopeWest takes reasonable steps to ensure meaningful access and effective communication is provided timely and free of charge:

- Provides free auxiliary aids and services to people with disabilities to communicate effectively with us, such as:
 - Qualified sign language interpreters (remote interpreting service or on-site appearance)
 - Written information in other formats (large print, audio, accessible electronic formats, other formats)
- Provides free language assistance services to people whose primary language is not English, such as:
 - Qualified interpreters (remote or on-site)
 - Information written in other languages

If you need these services, contact the **HopeWest Access Department** at (866) 310-8900, (970) 241-2212 or TTY (800) 659-2656.

If you believe that HopeWest has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

HopeWest Compliance Officer at (866) 310-8900, (970) 241-2212, or TTY (800) 659-2656., or via email, TWalter@HopeWestCO.org.

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, the HopeWest Compliance Officer is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf> or by mail or phone at:

**U.S. Department of
Health & Human Services
200 Independence Avenue SW.
Room 509F, HHH Building
Washington, DC 20201
(800) 868-1019, (800) 537-7697 (TDD)**



Spanish	ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-970-241-2212 (TTY: 1-800-659-2656).
Vietnamese:	CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-970-241-2212 (TTY: 1-800-659-2656).
Chinese:	注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-970-241-2212 (TTY: 1-800-659-2656)。
Korean:	주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-970-241-2212 (TTY: 1-800-659-2656)번으로 전화해 주십시오.
Russian:	ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-970-241-2212 (телетайп: 1-800-659-2656).
Amharic:	ማስታወሻ: የሚናገሩት ቋንቋ አማርኛ ከሆነ የትርጉም እርዳታ ድርጅቶች፣ በነጻ ሊያገዝዎት ተዘጋጅተዋል። ወደ ሚከተለው ቁጥር ይደውሉ 1-970-241-2212 (መስማት ለተሳናቸው: 1-800-659-2656)።
Arabic:	ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-970-241-2212 (رقم هاتف الصم والبكم: 1-800-659-2656).
German:	ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-970-241-2212 (TTY: 1-800-659-2656).
French:	ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-970-241-2212 (ATS : 1-800-659-2656).
Nepali:	ध्यान दिनुहोस्: तपाईंले नेपाली बोल्नुहुन्छ भने तपाईंको निम्ति भाषा सहायता सेवाहरु निःशुल्क रूपमा उपलब्ध छ । फोन गर्नुहोस् 1-970-241-2212 (टिटिवाइ: 1-800-659-2656)
Tagalog:	PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-970-241-2212 (TTY: 1-800-659-2656).
Japanese:	注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。1-970-241-2212 (TTY:1-800-659-2656) まで、お電話にてご連絡ください。
*Cushite:	XIYYEEFFANNAA: Afaan dubbattu Oroomiffa, tajaajila gargaarsa afaanii, kanfaltiidhaan ala, ni argama. Bilbilaa 1-970-241-2212 (TTY: 1-800-659-2656).
**Persian:	توجه: اگر به زبان فارسی گفتگو می کنید، تسهیلات زبانی بصورت رایگان برای شما فراهم می باشد. با 1-970-241-2212 (TTY: 1-800-659-2656) تماس بگیرید.
***Kru:	Dè dɛ nià kɛ dyédé gbo: ɔ jũ ké m [Bàsɔ̀-wùdù-po-nyò] jũ ní, ní, à wuɖu kà kò dò po-poò bɛ̀in m̀ gbo kpáa. Dá 1-970-241-2212 (TTY:1-800-659-2656)
Ibo:	Ige nti: O buru na asu Ibo asusu, enyemaka diri gi site na call 1-970-241-2212 (TTY: 1-800-659-2656).
Yoruba:	AKIYESI: Ti o ba nso ede Yoruba ofe ni iranlowo lori ede wa fun yin o. E pe ero ibanisoro yi 1-970-241-2212 (TTY: 1-800-659-2656).

NOTE:

*Cushite: No formal written language. Written documentation is in Oromo.

**Persian: No formal written language. Written documentation is in Farsi.

***Kru: No formal written language. Written documentation is in Bassa.

For Concerns or Complaints

Our goal is to provide patients and families with exceptional care, assistance and support. Our Quality Improvement Program is designed to seek opportunities for improving our services.

As part of a federal requirement we are mandated to issue a survey about our services. This survey, which helps ensure that we provide top quality care, is provided through a third party vendor.

Your feedback is key to our ability to provide the highest quality of service.

All concerns will be investigated by the organization with documentation recording the issue, findings and resolution. If you have any concerns, we encourage you to contact our office and speak with our Compliance Officer. You may also choose to speak with any member of the Executive Team or our President by calling (970) 241-2212. A Clinical Supervisor is also available 24 hours each day at (970) 241-2212. If your concern is not appropriately addressed, you may also wish to contact other community resources designed to help you resolve any care concerns; these include:

- Colorado Home Health and Hospice Hotline (800) 842-8826
- KEPRO (Medicare only) (888) 317-0891
TTY (855) 843-4776
- Long Term Care Ombudsman (for patients in nursing homes or assisted living facilities)
 - Mesa County (970) 248-2717
 - Montrose, Delta & Ouray Counties (970) 249-2436

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Thank you for allowing us to care for your loved one.



You will be receiving a survey in the mail regarding your loved one's hospice care.

The Centers for Medicare & Medicaid services send a CAHPS® (Consumer Assessment of Healthcare Providers & Systems) survey to the caregivers of all hospice patients nationwide after a patient's passing. HopeWest always strives to provide expert care. These surveys help us continue to provide quality care for our patients.

Please consider completing this survey as your feedback is appreciated.

Oxygen Safety

Because things burn faster and hotter in the presence of oxygen, it is very important to keep any type of flame or fire away from you and your oxygen supply.

TIPS FOR USING OXYGEN SAFELY:

- Always turn oxygen off when you are not using it.
- NEVER smoke or allow anyone else to smoke around you when oxygen is in use or turned on.
- Post “no smoking” signs in your house and on the main door as a reminder.
- Avoid any open flame – this includes cigarettes, matches, pipes, lighters, candles, fireplaces, gas burners, and pilot lights.
- Keep all oxygen tanks 5-10 feet away from any heat source or things that could create a spark. This includes: space heaters, e-cigarettes, electric razors, hair dryers, electric blankets, or friction toys.

OXYGEN CAN BE IN YOUR CLOTHING, HAIR, AND FABRICS

- Keep the door to your room open so that air circulates.
- Do not spray aerosol cans around you or your oxygen supply.
- Do not use petroleum-based lotions or creams (such as Vaseline) as they can become flammable in the presence of oxygen.
- Store your oxygen in a well-ventilated area away from direct sunlight.

OTHER SAFETY TIPS:

- Be careful where you place your tubing as it is easy to trip, especially if you or someone in the household is unsteady or has sensitive feet.
- Do not change the rate of oxygen flow without consulting your hospice nurse or physician.
- Turn the oxygen off right away if it starts making a hissing noise.

About Your Medication

KEEP YOUR MEDICATIONS SAFE:

- Keep out of the reach of children or others who should not have access to them.
- HopeWest can supply a locking box upon request.
- Keep medications in their original containers as much as possible; some pills look alike and this will help you tell them apart.
- Do not give your prescription medications to anyone else - these were prescribed by your physician ONLY FOR YOU.
- If you have been given an emergency medication kit, keep it closed in your refrigerator unless otherwise instructed by a HopeWest nurse.

PROPER USE OF MEDICATIONS:

- Take medications as directed on the label. It is important to only take the medication for the reason listed and to take the correct dose with the right timing.
- Report any signs of irritation or allergic reaction to your HopeWest nurse or physician.
- Do not take any medications that were prescribed for someone else. They may have harmful reactions with your medications.
- Never split tablets in half without asking your pharmacist or nurse first.
- When using medication patches take off the old one before applying a new one.
- Let your nurse know if you stop any medications or start any new ones.
- If someone in your household is taking your medications without your permission, please report this to your HopeWest nurse and to the police.

continued -

About Your Medication - continued

PAYMENT FOR MEDICATIONS:

- Your hospice insurance benefit may provide coverage of medications related to the reason you are in hospice care if the medications are medically useful for you. Ask your nurse if you have questions.
- For medications covered under your hospice insurance:
 - HopeWest will obtain the prescriptions and either have the medications delivered to your home or arrange for you to pick up at a local pharmacy (when needed right away)
 - The pharmacy will bill directly to HopeWest; there is no co-payment
- For medications not covered under your hospice insurance:
 - Continue to obtain these as you did prior to hospice and pay the pharmacy directly.
 - If you have Medicare D or other pharmacy benefit coverage, the pharmacy may be able to bill for medications not covered under your hospice insurance.
 - Your HopeWest nurse can still help you with obtaining the correct prescriptions.

COLORADO PRESCRIPTION DRUG MONITORING DATABASE:

- All pharmacies filling prescriptions for controlled substances in Colorado will upload information daily into the Colorado Prescription Drug Monitoring Program database. This includes patient name, address, birth date, prescription number, date prescription filled, quantity filled, and prescribing doctor's ID number. (Social security number is not included.)
- This database can be accessed by any physician or pharmacist, law enforcement, the State Board of Pharmacy and/or other regulatory boards.
- This information is provided for your information and awareness only; no action is needed.

Agitation & Restlessness

Symptom Management Suggestions

WHAT ARE AGITATION AND RESTLESSNESS?

When an individual is nearing their final days, agitation and restlessness are common symptoms. Symptoms can include an urge to move, making angry accusations, their body may jerk or twitch and they may pull at the bedding or clothing.

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom? When did it start?
- Does it appear that the patient is in pain?
- Have you noticed symptoms more frequently in the day or night?
- Has the patient started on any new medications lately?
- Has the patient had any trouble with elimination (frequency or constipation?)
- Does the patient report hearing or seeing things that you don't hear/see?
- Has the patient taken any medications that have helped this problem in the past?

TIPS TO REDUCE AGITATION OR RESTLESSNESS

- Discuss the situation with the HopeWest team. A registered nurse is available 24 hours a day to assist with symptom management.
- Keep a calm and quiet environment - avoid loud TV or music. Speak in a soft, calm voice. Try playing the patient's favorite or soothing music. Consider reducing the amount of visitors. Try adjusting the lighting in the room. Take the patient for a walk or ride in a wheelchair if they are able to tolerate activity.
- Be reassuring to the patient - you might say "I am right here with you and you are safe." It does not help to argue. Instead, try to change the subject.
- Try reading something inspirational or meaningful to the patient.
- Holding hands/light touch may be reassuring.
- Help the patient resolve issues and tasks-help them delegate unresolved tasks to a trusted person.
- Talk with the team about other interventions including the use of essential oils, medications, guided imagery, etc.

Sadness & Depression

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom? When did it start?
- Is there a history of sadness/depression before the illness?
- Is there a history of mental illness?
- Could the depression be caused by other symptoms such as pain?
- Have any medications or techniques helped with this in the past?
- Is the patient sleeping ok?
- Has the patient stated they wish to end their life/have a plan to end their life?

TIPS TO REDUCE SADNESS OR DEPRESSION

- Discuss the situation with the HopeWest team.
- If the patient expresses desire to end their life or is an imminent danger, contact 911 immediately.
- Be present for the patient and relay that they are not alone. Ensure availability of significant others or pets that can provide comfort to the patient.
- Check on the patient frequently.
- Encourage continued contacts with community, churches, friends, etc.
- Help the patient explore their belief system. The team chaplain can assist with this.
- Allow the patient to express their feelings and validate what they are feeling.
- Talk with the team about other interventions including the use of essential oils, medications, guided imagery, volunteers, etc.

Confusion & Disorientation

Symptom Management Suggestions

WHAT ARE CONFUSION AND DISORIENTATION?

People nearing the end of their life may have confusion about the time, their surroundings, and the identity of those around them. They may report seeing people or things that are not visible to others, and they may engage in conversation with others who are not visibly present or who have already passed on. Confusion and disorientation can be common symptoms at end-of-life and with some disease processes.

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom? When did it start?
- Have you noticed symptoms happening more frequently at night or after dark?
- Has the patient had any change in appetite?
- Has the patient been started on any new medications recently?
- Has the patient had any troubles with elimination (urinary frequency or constipation)?
- Has the patient had trouble sleeping?
- Does the patient have a fever or low oxygen level?

TIPS TO REDUCE CONFUSION OR AGITATION

- Discuss the situation with the HopeWest team. A registered nurse is available 24 hours a day to assist with symptom management.
- If appropriate, gently try to reorient the patient. Remind them of who you are and point out familiar landmarks in their surroundings. Provide reassurance. Give the patient time to respond to your statements. Face the patient, speak slowly and use short statements.
- Tell the patient what you are going to do with them before you do it and explain the reason behind your action. For example, say "I am going to help you out of bed to keep you safe" before you start to move the patient.
- Allow and acknowledge whatever experience the patient may be having without trying to contradict or argue it away. Avoid denying hallucinations, instead try, "You spoke with your mother? I miss my mother too."
- Keep a calm and quiet environment – avoid loud TV or music. Turn off the TV or radio during conversations or when the patient is sleeping. Sometimes limiting visitors can decrease the level of confusion or disorientation.
- Engage the patient in activities that distract them, like folding clothing or washcloths, fidget pillows, etc.
- Talk with the team about other interventions including the use of essential oils, medications, guided imagery, etc.

Changes in Appetite

Symptom Management Suggestions

WHAT DOES IT MEAN?

When a patient is near end of life, it is natural for a person to no longer be interested in food or be unable to eat or drink. The body is slowing down and they are no longer able to digest and absorb food and nutrients in the same way. Our culture symbolizes food with love so this may be distressing to some family members and they may consider giving the patient nutritional supplements, tube feedings and IV nutrition. Weight loss is expected and does not mean that the person is hungry or “being starved” by the absence of food.

Findings published in several studies report that IV nutrition or forced feedings can lead to several harmful effects in patients nearing end of life, including:

- The rate of tumor growth may increase. Feedings might actually shorten the patient’s life expectancy by providing nourishment for the tumor.
- Forced feedings may increase the patient’s gastrointestinal distress causing increased suffering.
- Serious infections may occur with the use of IV nutrition (also known as TPN).
- Weight gain is marginal and is usually associated with increased fluid retention.

WHAT YOU CAN DO

- Let the patient be the guide; he or she will let you know if food or fluids are needed or wanted.
- Liquids are preferred to solids. Some people find thickened liquids easier to swallow. Small chips of ice or frozen juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (without a needle) or dropper (ask the Hospice nurse for guidance).
- People who can’t speak will sometimes cough, bite the spoon, clamp their teeth closed, turn their heads, or spit food out to let you know they don’t want to eat.
- Respect the person’s wishes by trying not to force food or drink. Often a person near death may appear thirsty but are unable to drink water; frequent mouth care may provide comfort. Use mouth swabs to keep the mouth and lips moist.

Nausea

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom?
- When did it start?
- Has the patient had any troubles with constipation?
- Is the patient eating and drinking ok?
- Is the patient able to keep pills down without vomiting?
- What makes the nausea better/worse?

TIPS TO REDUCE NAUSEA

- Discuss the situation with the HopeWest team as soon as possible.
- Encourage the patient to drink small, frequent sips of water if able.
- Meals given should be small, frequent and eaten slowly. If nausea occurs between meals, have the patient keep something in their stomach by eating small snacks in between meals.
- Bananas, rice, applesauce, toast, saltine crackers, flat ginger ale, and tea can be easy on the stomach.
- Avoid fatty, fried, spicy or very sweet foods.
- Have the patient rest quietly while sitting upright for at least an hour after each meal.
- Create a cool breeze with a open door, window, or fan.
- Provide a cool washcloth on the forehead.
- Gentle massage of the wrist may help relieve nausea.
- Relaxation techniques such as meditation or breathing exercises can help relieve nausea.
- Try listening to soft music or watching the patient's favorite TV program.
- Place a couple drops of peppermint essential oil on a cotton ball, tissue placed in a bowl or use in a diffuser.

Constipation

Symptom Management Suggestions

WHAT IS CONSTIPATION?

Constipation is infrequent bowel movements or difficult passage of stool.

WHAT CAUSES CONSTIPATION?

Dehydration, lack of dietary fiber, decreased physical activity, and medication side effects. Constipation can also be common at end of life.

THINGS TO TELL THE NURSE OR DOCTOR:

- Is this a new symptom?
- When did it start?
- Is the patient eating/drinking ok?
- Is the patient nauseated or vomiting?
- Is the patient having abdominal pain/stomach pain?
- What does the patient's stool look like? Is there blood in the stool?
- Is there any personal or family history of digestive problems?
- Have you missed any recent bowel medication doses?
- Which medications have worked in the past for constipation? Which medications have not worked?

TIPS TO REDUCE CONSTIPATION

- Alert the HopeWest nurse if constipation is a concern.
- Discuss your fluid and fiber intake with the HopeWest nurse.
- Talk to the nurse about nonpharmacological interventions including: prune juice and butter, Yakima fruit paste, etc.
- Increase physical movement if able to do so safely.
- Keep track of your bowel movements and notify HopeWest if you are not having comfortable and regular bowel movements at least every 3 days.
- Attempt to have a bowel movement when you feel the urge to go. Waiting or holding can increase the risk of constipation.

Pain

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom?
- When did it start?
- Is there a history of pain before the illness?
- Where is the pain?
- What words would describe the pain?
- What makes the pain better/worse?
- Keep a record of when medications are given for pain

TIPS TO REDUCE PAIN

- Getting ahead of the pain means that medication must be taken before pain becomes severe. If pain is severe or increasing, it will be more difficult to control, especially after waiting for the medication to be absorbed by the body and take effect.
- Discuss the situation with the HopeWest team as soon as possible.
- Relaxation: try deep-breathing exercises and abdominal breathing with or without calming music in the background.
- Distraction: turn on the patient's favorite television show, listen to peaceful music or recordings such as waterfalls, ocean sounds, or other environmental sounds that relax the patient.
- Massage: use medicated cream or ointment as ordered by the patient's doctor or massage a favorite lotion onto the skin.
- Heat or cool-check with your doctor or nurse to ask which would be most likely to help. Never put a heating pad under the patient and never apply the heating pad or ice pack directly to the skin to avoid burns.
- Consult with the nurse or doctor before starting any over the counter pain medications.

Shortness of Breath

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom?
- When did it start?
- Does the patient have a fever or chills?
- What makes the shortness of breath worse/better?

TIPS TO REDUCE SHORTNESS OF BREATH

- Discuss the situation with the HopeWest team as soon as possible. There are medication options that can help with shortness of breath.
- If the patient wears oxygen, ensure that the oxygen is turned on and the tubing is not kinked.
- Help the patient find a position that is comfortable for them and allows their lungs to expand:
 - Have the patient sit in a chair, leaning forward with the arms and upper body supported on a table.
 - Have the patient sit with their head of bed/chair elevated.
- Help the patient focus on their breathing pattern.
 - Take slow, deep breaths with the patient.
 - When the patient breathes out, tell them to purse their lips together like they are blowing out a candle.
- Create a cool breeze by opening a window or door, or using a fan.
- Try relaxation techniques:
 - Help the patient meditate, focus on pleasant thoughts, or pray.
 - Have the patient slowly contract and relax each muscle group, one at a time.
 - Keep the environment calm and quiet.
 - Allow rest breaks between activities.

Worry & Anxiety

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom?
- When did it start?
- Is there a history of anxiety before the illness?
- Is the anxiety caused by other symptoms such as pain, nausea or shortness of breath?
- Have any medications or techniques helped with this in the past?
- Is the patient sleeping ok?

TIPS TO REDUCE WORRY AND ANXIETY

- Discuss the situation with the HopeWest team as soon as possible. The social worker and chaplain have specialized training in supportive listening that can help decrease worry and anxiety.
- Consider limiting visitors unless they can provide a supportive role to the patient.
- Listen and reassure the patient without judgment.
- Help the patient take slow, deep breaths, meditate, or pray.
- Have the patient slowly contract and relax each muscle group, one at a time.
- Read or provide reading material to the patient that is supportive or enjoyable.
- Consider other distractions such as going outside, watching an old movie or another activity such as looking through pictures or enjoying a craft.
- Consider giving the patient a relaxing massage with their favorite lotion.
- Turn on the patient's favorite music or recordings such as waterfalls, ocean sounds, or other environmental sounds that relax the patient.
- Place a couple drops of lavender essential oil on a cotton ball, on a tissue placed in a bowl, or use in a diffuser.
- Avoid caffeinated beverages such as coffee, tea, and soda.

Insomnia

Symptom Management Suggestions

THINGS TO TELL THE NURSE OR DOCTOR

- Is this a new symptom?
- When did it start?
- Does the patient have any trouble with elimination (passing urine frequently at night)?
- Is the patient having any pain/discomfort/constipation/urinary retention/anxiety?
- Have any medications worked in the past?

TIPS TO REDUCE INSOMNIA

- Discuss the situation with the HopeWest team as soon as possible.
- Talk with the nurse or doctor before giving any over-the-counter medications for sleep.
- Consider turning off the TV or other electronics prior to bedtime.
- Place a couple drops of lavender essential oil on a cotton ball, on a tissue placed in a bowl, or use in a diffuser.
- Some medications can have stimulating effects. Review the patient's medication list with the nurse and ensure you are giving the medications at appropriate times.
- Address the environment: keeping the room cool, well-ventilated and with low light at night may help. The use of a white noise machine may also help the patient sleep.
- Two hours of sunlight a day regulates sleep-wake cycles, so try keeping sunlight in the room or take the patient outside. Artificial light can inhibit sleep, so use low wattage bulbs in the bedroom.
- Maintain a consistent sleep schedule. Reduce or avoid daytime naps.
- Reduce or avoid large meals or excessive fluids at bedtime and avoid caffeine.
- Consider giving the patient a backrub or a warm bath/bed bath.



HopeWest

Providing exceptional care across the Western Slope

**Mike & Kay Ferris
Care Center &
Administrative Offices**

3090 North 12th Street
Grand Junction, CO 81506
Phone (970) 241-2212
Fax (970) 255-7277 - Clinical
Fax (970) 257-2400 - Admin

**Herb & Laura May Bacon
Center for Living Your Best**

2754 Compass Drive
Grand Junction, CO 81506
Phone (970) 241-2212
Fax (970) 257-2401

Delta County

PO Box 24
195 Stafford Lane
Delta, CO 81416
Phone (970) 874-6823
Fax (970) 874-6903

Meeker

PO Box 2132
617 Main Street
Meeker, CO 81641
Phone (970) 878-9383

**Montrose & Ouray
Counties**

725 South 4th Street
Montrose, CO 81401
Phone (970) 240-7734
Fax (970) 240-7263

Plateau Valley & De Beque

PO Box 294
58128 Hwy 330
Collbran, CO 81624
Phone (970) 487-3844
Fax (970) 487-3422

HEIRLOOMS FOR HOSPICE

Delta

532 Main Street
Delta, CO 81416
(970) 874-5251

Grand Junction

635 Main Street
Grand Junction, CO 81501
(970) 254-8556

Montrose

435 E. Main Street
Montrose, CO 81401
(970) 252-3648

SPOONS BISTRO & BAKERY

3090 N. 12th Street
Grand Junction, CO 81506
(970) 255-7237