



Hospice & Community Care

Caring for Life





Confident Caregiver and Patient Guide

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Street address:

Hospice & Community Care
2275 India Hook Road
Rock Hill, SC 29732

Mailing address:

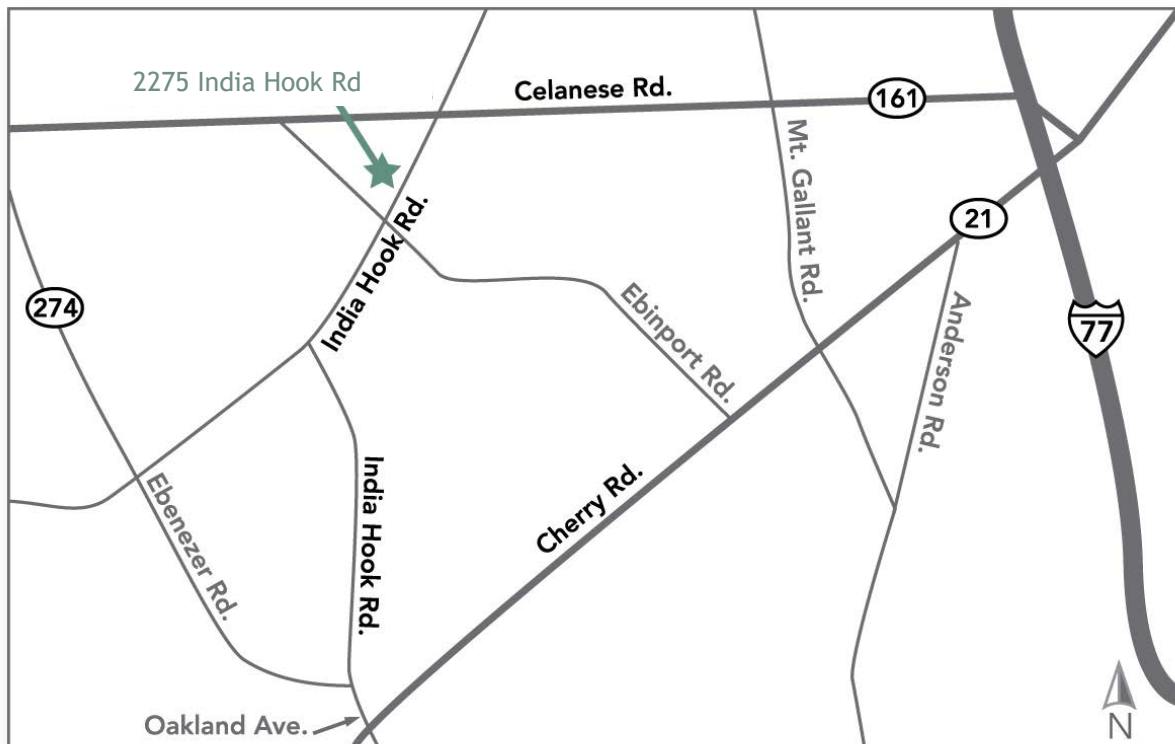
Hospice & Community Care
PO Box 993
Rock Hill, SC 29731

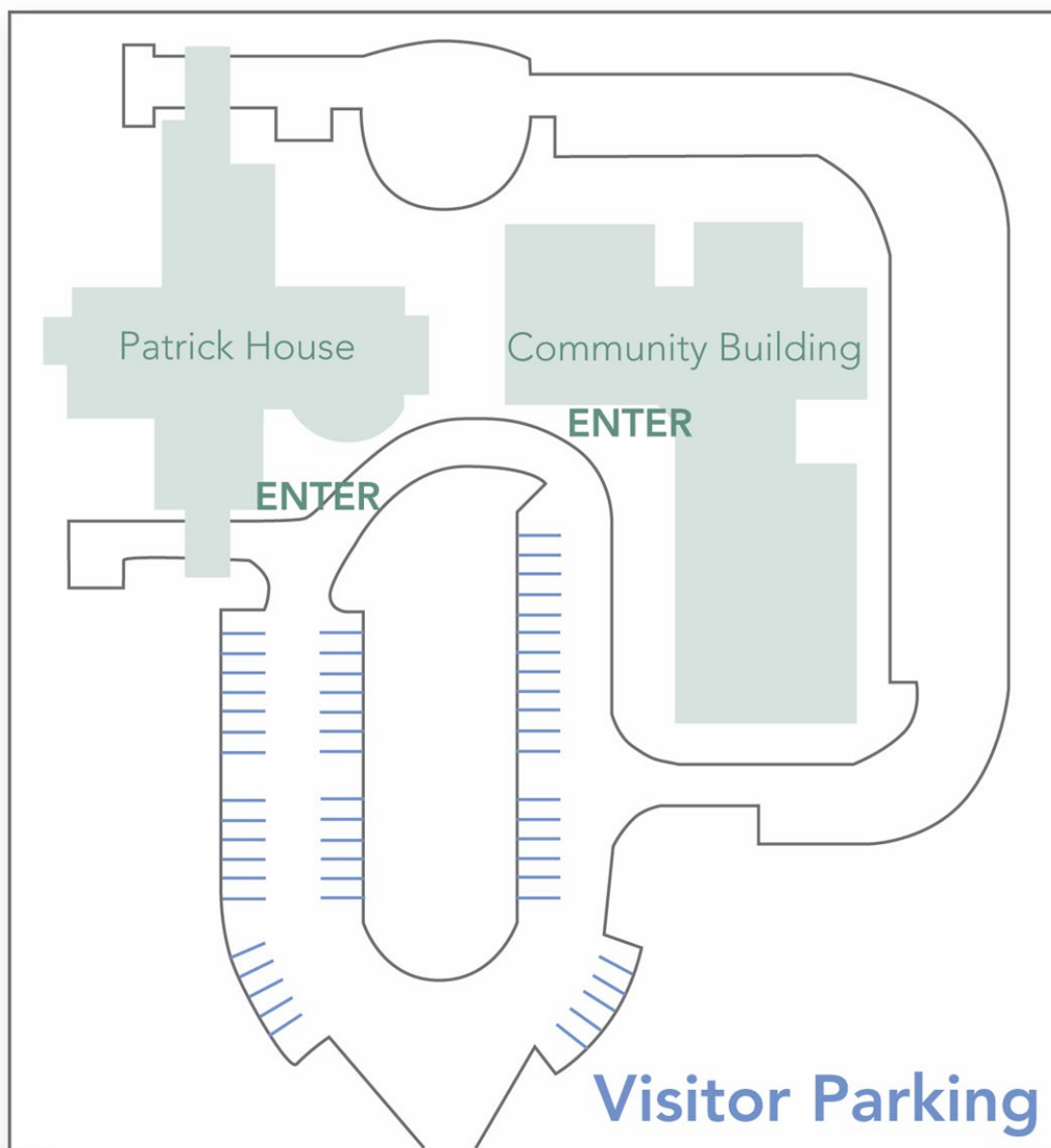
Phone: 803-329-1500 or 1-800-895-CARE

Directions to Hospice & Community Care and Wayne T. Patrick Hospice House from I-77 North/South:

Exit 82C to Hwy. 161/Celanese Rd. toward York. Travel 2.5 miles to the intersection of Celanese Rd and India Hook Road. Turn left onto India Hook Rd. Travel .3 mile and turn right at stone wall entrance to Hospice & Community Care driveway located beside Catawba Animal Clinic.

The first building on the right is our Administrative & Community Building. The second building is the Wayne T. Patrick Hospice House.







A Message from Jane

Dear Friend,

Thank you for the privilege of allowing Hospice & Community Care to serve you and your family. This booklet will help explain what to expect as a patient and family served by Hospice & Community Care.

Our care is designed to enable you to live as fully as possible, as long as possible. We have nurses who are under the direction of a medical director. They will work with you to ensure that you have the right medications, equipment, and supplies for your comfort. We also have team members who are able to provide you and your family emotional and spiritual support, and who will ensure that you have the resources you need. Additionally, we can provide you with aides to assist in your personal care if desired. As a team, we will provide teaching to family/caregivers to ensure that you well cared for and comfortable.

The Hospice & Community Care team is available 24 hours a day, seven days a week to assist you. We are here to help. Don't wait to call us – we don't want small problems to turn into bigger ones.

Our goal is to provide excellent care. If you believe we are not meeting this goal, please call me at 803-329-1500. We want this process to be one that provides you with positive experiences and respect for you and your family.

Thank you for choosing Hospice & Community Care.

Jane Armstrong, RN MN
CEO, Hospice & Community Care

Notice of Nondiscrimination & Accessibility for Individuals

Hospice & Community Care complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Hospice & Community Care does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Hospice & Community Care provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Hospice & Community Care provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact Jane Armstrong, CEO 803-329-1500.

If you believe that Hospice & Community Care 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 by mail, fax, or email with:

Jane Armstrong, CEO Hospice & Community Care
PO Box 993 Rock Hill, SC 29731
803-329-1500 or 1-800-895-CARE
Jane@HospiceCommunityCare.org.

If you need help filing a grievance, Hospice & Community Care 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 and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)
Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-803-329-1500

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 1-803-329-1500

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-803-329-1500

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-803-329-1500

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-803-329-1500

LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. 1-803-329-1500

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги Hu гауперевода. Звоните 1-803-329-1500

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sawika nang walang bayad. Tumawag sa 1-803-329-1500

સચુ ના: જો તમે ગુજુ રાતી બોલતા હો, તો નન:શલ્કુ ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-803-329-1500

ប្រយ័ត្ន: បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, បសវន៍នួយខ្លួនកកាសា បោយមិនគិតគូរ គឺអាចមានសំរាប់បើអ្នក។ ជូរ ទូរស័ព្ទ 1-803-329-1500

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-803-329-1500

ध्यान द:ेे यदद आप ह िंदी बोलते हैं तो आपके ललए मफुु त में भाषा सहायता सेवाएं उपलब्ध हाैं 1-803-329-1500

ໂປດຊາບ: ຖ້າວ່າທ່ານເວົ້າພາສາລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສຍຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທ 1-803-329-1500

注意事項:日本語を話される場合、無料の言語支援をこゝ利用いたたゝけます。1-803-329-1500 までゝ、お電話にてこゝ連絡くだゝさい。

The Hospice Care Team

You and Your Family

You are the most important member of your care team. The services offered by your Hospice & Community Care team are based on your specific goals, your questions, and your concerns. Your care team respects your privacy, personal choices, cultural and/or religious customs, and family traditions.

Nurse/Case Manager

Case managers are registered nurses who are experts in pain control and management of physical symptoms that cause distress or interfere with patient comfort. Your case manager will regularly evaluate your physical symptoms and care needs. He or she can help with concerns or questions about managing your pain, other symptoms, how to use your medications, and the stages of your illness. Your nurse will also coordinate the care of your entire care team and will frequently talk with your doctor. A nurse is available 24 hours a day, 7 days a week.

Social Worker

Your Social Worker can help you identify your primary goals and concerns, to help you strengthen your coping abilities in times of stress, and support your family and significant relationships. He or she can provide useful information about planning for your care, solving problems, community and financial resources, and support for your caretakers. Your Social Worker can also arrange visits with Hospice & Community Care Volunteers. A Social Worker is available 24 hours a day, 7 days a week.

Hospice Aide

As you or your caregivers need additional assistance to meet your personal care needs, a Hospice Aide/Certified Nurse Aide will become part of Your Care Team. The Aide will compassionately and respectfully help you with bathing, grooming, dressing, toileting, nutrition, and skincare needs in collaboration with your Nurse.

Physician

Physicians play an essential role in the care of Hospice patients. Patients and their families can choose to have their own physician follow them or use our board-certified Hospice physicians to develop and oversee the patient's plan of care. Physicians regularly communicate with the Hospice team to ensure that the patient's medical needs are taken care of during their time with Hospice.

Spiritual Care Counselor

Spiritual care counselors provide non-denominational, non-judgmental support if requested. They respect all faiths and traditions, work with patients of all belief systems, and help with questions and concerns regarding your faith, ethical issues, or purpose in life. They can also support your search for meaning and hope, assist with alleviating spiritual distress, read sacred and inspirational writings, pray with you and your family, address ceremonial or ritual needs, help with grief, suffering, and the many emotions that surround facing a terminal illness, and assist with funeral or memorial services.

Bereavement Team

In addition to the ongoing support provided by your Care Team throughout your hospice care, the Bereavement Team is comprised of chaplains and social workers who have specialized training in grief and loss. Members of the Bereavement Team are available to offer support throughout the transition toward the end of life and also to help navigate the grief process after a loss.

Volunteers

A Volunteer can become a member of your Care Team. Your Volunteer is selected based on similar interests, hobbies and geographic proximity. Your Volunteer could talk with you about topics that interest you, read to you, assist you in writing letters, stay with you for a while so your family caregiver may run errands, and many other possibilities.

Hospice & Community Care relies on a dedicated group of Volunteers to provide special services to our patients and families. Our Volunteers truly give from the heart and in doing so provide not only physical and emotional support to our patients but also peace of mind to family members. Many of our Volunteers know what it's like to be on the receiving end of hospice services, which makes them an invaluable member of your Care Team.

Hospice & Community Care Volunteers:

- Receive extensive training classes
- Are evaluated regularly
- Are committed to maintaining your privacy
- Adhere to the Hospice & Community Care's Mission and Values
- Bring a great deal of life experience
- Add quality of life to the patient's journey

What Volunteers Can Do for Patients and Families:

- Companionship – socialization, friendly conversation, or a listening ear
- Respite – staying with a patient while a caregiver runs errands or takes a break
- Pet Therapy – bringing a registered pet to visit in a facility
- Pet Grooming – taking a patient's pet to be groomed
- Transportation
- Grocery Shopping and Errands
- Letter Writing
- Life Review – recording you or your family's story on tape or video
- Helping to organize paperwork
- Helping to celebrate a special occasion
- Helping with special requests

If you have a special request, please talk with your Social Worker. The above list is not inclusive of all the services that our Volunteers can provide. Let us know how we can make your journey more comfortable and we may have the perfect Volunteer who can help meet your needs.

Other Care Team Members

Your Care Team may contract with other qualified healthcare providers for services necessary for your optimal function and symptom management.

These may include:

- Physical Therapy
- Speech Therapy
- Dietary Consultant
- Occupational Therapy
- Respiratory Therapy

You may contact any team member by calling 803-329-1500 or 1-800-895-CARE

Hospice & Community Care staff and volunteers wear photo identification badges at all times and will introduce themselves to you. From time-to-time, there may be other members of the Hospice & Community Care team who visit to care for you and your family. All Hospice & Community Care team members are highly trained and will always wear a Hospice name badge. If you are concerned about the identity of an employee, please call 803-329-1500.

We provide 24-hour assistance, seven days a week.

Normal agency hours are Monday - Friday 8 a.m. to 4:30 p.m. Our on-call staff is highly qualified and available after hours and on weekends.

Care Locations

Care at Home

Our staff provides care in a setting that best meets the needs of each patient and family. The most common being a patient's or relative's home. At a patient's home, the care team is able to provide comprehensive management of the patient's physical, emotional, social and spiritual needs. We aim to achieve the best possible quality of life through relief of suffering and control of symptoms.

Care at the Patrick Hospice House

Hospice & Community Care's Wayne T. Patrick Hospice House is the area's ONLY free-standing inpatient hospice facility. The Patrick House provides hospice patients with expert care for pain control and symptom management, respite for caregivers, and a place for patients who may need the safety and security of residential hospice care. The Patrick House does not replace any of our home-based hospice programs, rather it adds another facet to what we are able to offer patients in need of hospice care. The Patrick House features 16 private suites, each designed with the physical and psychological comforts of home in mind. The Patrick Hospice House is open 24-hours a day, 365 days a year. There are unlimited visiting hours for family members of patients at the Patrick Hospice House.

Wayne T. Patrick Hospice House Admission criteria:

- General in Patient (GIP) – Pain and Symptom Management; when symptoms need more intense attention than can be managed at home, GIP care at the Patrick Hospice House may benefit the patient.
- Respite Care – A period designed to relieve the family member or caregivers for the patient. Respite care is offered on an occasional basis for no more than five consecutive days at a time.
- Residential - Occasionally a patient may need the safety and security of residential hospice care. Residential care is offered to the patient and family at a pre-determined rate. To learn more please contact your Hospice Care Team.

Care at Long Term Care Facilities

Hospice & Community Care has the privilege of partnering with several long-term care and assisted living facilities in our community to provide care to patients in their facilities. Collaborating with facility staff, Hospice & Community Care's comprehensive team provides the same level of care to patients and families in facilities as in private homes.

Calling Your Team

We are committed to helping our patients and families by being continually available. Please call if you have questions, concerns or fears. We are here for you.

Our number is 803-329-1500 or 1-800-895-CARE.

When to call during the office hours (8 a.m. - 4:30 p.m.):

- You have a question or message for one of your care team members.
- You need medication refills, medical supplies, or medical equipment outside of regularly scheduled home visits.
- You need to arrange for the pick-up of medical equipment or supplies.
- You need to cancel a scheduled visit.
- You need to discuss a problem with a supervisor.

When to call after hours, on weekends, or holidays:

- You have questions or concerns about a change in symptoms, such as increased pain or agitation.
- You see an unexpected change in the patient's physical or emotional condition that concerns you.
- You observe symptoms such as increased breathing difficulty, discomfort or agitation.
- You have malfunctioning medical equipment.
- You believe your loved one's respirations have changed.

What happens when I call after hours?

- The answering service staff will ask the patient's name, your name and relationship, and telephone number.
- The on-call nurse will be contacted and call you as quickly as possible. If you do not hear from the nurse within 30 minutes, please call again.
- When the nurse returns your call, explain your concern. You and the nurse will then determine a plan of action.
- If your needs are not met to your satisfaction, please request a supervisor.

When to call Hospice & Community Care

1. The patient is taking prescription pain medicine and pain is not controlled to your satisfaction.
2. The patient's pain has changed in strength, intensity, or duration and is not controlled with medication.
3. The patient has less than a three-day supply of medicines supplied by Hospice.
4. The patient's doctor has ordered a new medicine for you.
5. The patient has not had a bowel movement in three days.
6. The patient has fallen – even if they can get up and think they are not hurt, the fall should be reported to the nurse.
7. The patient has increased breathing difficulty.
8. The patient has bleeding from any location.
9. The patient starts having nausea, begins vomiting, or develops diarrhea.
10. The patient is experiencing confusion, agitation, anxiety, sleeplessness, or seizures.
11. As a caregiver, you are fearful or stressed and need someone to talk to about the situation.
12. The patient is planning on going out of town.
13. If you feel the need to call 911 for any reason you are encouraged to speak with the Hospice & Community Care nurse first.

Frequently Asked Questions

What is hospice?

Hospice is a philosophy of care for people facing a life-limiting illness. Designed to provide comfort care while ensuring respect for the quality of life, it supports patients with pain and symptom management needs who have chosen comfort rather than curative care. Hospice serves the patient and family together, caring for their physical, emotional, spiritual, and practical needs.

Who qualifies for hospice care?

Patients whose physicians have given a prognosis of approximately six months or less, if their disease follows its normal progression, may qualify for hospice care.

What if the patient lives longer than six months?

As long as the physician continues to certify the appropriateness of the patient for hospice care and the patient meets the guidelines, hospice care will continue after six months.

Who pays for hospice services?

Hospice services are paid by Medicare, Medicaid, and most private insurance plans.

Where is hospice care provided?

Hospice can be provided in the patient's home, long term care facility, and our Wayne T. Patrick Hospice House. Your insurance plan may provide specific coverage guidelines.

Does hospice cover equipment and supplies?

Eligible medical equipment may include hospital beds, wheelchairs, certain supplies, and medications that are related to the terminal illness. The equipment given to your family is the property of Hospice & Community Care. In the event the equipment is no longer needed, it is to be returned to Hospice. Please call us at 803-329-1500 to schedule a pick-up time and time or talk with your Hospice team. Non-eligible items may include nutritional supplements, over-the-counter medications, and personal hygiene items such as tissues, lotion, and shampoo.

How do we get medications?

The Hospice nurse will obtain an order for the medication from the physician. The Hospice & Community Care contracted pharmacy provides the medicines that are related to the patient's primary diagnosis and are included in the hospice formulary. A 14-day or less supply is ordered at one time. All new medications require approval from Hospice & Community Care. The nurse will review your medication supply with you on home visits to ensure you have the medications you need. It is unlawful for staff to transport medications.

Hospice & Community Care's Commitment to Quality

Hospice & Community Care is committed to providing the highest quality care to patients and their loved ones, and we believe in collecting feedback from those we serve because we continually strive to improve our performance. If at any time during our service you would like to express a concern, complaint, or compliment, we encourage you to speak directly with one of your care team members, call our office or contact us by mail.

Hospice & Community Care
PO Box 993
Rock Hill, SC 29731
803-329-1500 or 800-895-CARE

We also seek to improve our services by conducting satisfaction surveys with our patients and their loved ones. These surveys will be mailed to you by Deyta, our contracted associate, in an effort for your response to remain anonymous. When responding to our surveys, we hope that you will offer honest feedback concerning the ways we can improve our services. Your comments help us provide care that is sensitive to and addresses the needs and wishes of our patients and their loved ones.

Patient Privacy

Hospice & Community Care Staff, volunteers, and outside providers will uphold the patient's privacy and security.

At times our staff may take photos for medical information purposes only. Any photographs taken will be filed in the permanent medical record with Hospice & Community Care. Photographs will not be used for any publication and are used for the sole purpose of information for the agency. The patient and family have the right to refuse any photography.

If you have any privacy and security concerns, please notify us.

Mission

The mission of Hospice & Community Care is to give hope, comfort, and compassion to our community when needed most.

History

Locally, hospice care began in 1985 stemming from community leaders' response to one woman's struggle with cancer and her desire to remain at home until her death. Hospice & Community Care has heard similar stories during our 35-year history of serving thousands of patients and their families. Today, Hospice & Community Care serves residents of six counties: York, Chester, Lancaster Cherokee, Fairfield, and Union. Governed by a volunteer Board of Directors, Hospice & Community Care currently uses a vast team of professional staff and more than 250 community volunteers to compassionately care for more than 100 patients each day. In 2008, Hospice & Community Care moved to the campus in Rock Hill, which houses the Administrative & Community Building, and the Wayne T. Patrick Hospice House.

Funding

We are honored to serve you and your family during this time. Hospice & Community Care is a nonprofit organization owned by our community. We would be grateful if you would consider supporting Hospice & Community Care by spreading the word about our services, volunteering your time, or making a gift to our organization. Each year it takes thousands of donors and hundreds of volunteers to cover unreimbursed care for hospice patients in our community.

We can't do it without you. Your generous support can benefit others.

You may mail donations to:

Hospice & Community Care
PO Box 993
Rock Hill, SC 29731

To donate online or learn more about volunteer opportunities visit HospiceCommunityCare.org

Hospice serves patients and their families without regard to race, color, national origin, religion, sex, age, disability, sexual orientation, marital status, military or veteran status, or ability to pay.



Safety in the Home

As an illness progresses, you may need to take certain safety and health precautions in your home. Most importantly, you will need to identify hazards, plan for emergencies, and make changes to better fit your needs.

Help Hospice visits be most effective by creating a safe environment for our team and volunteers by following these guidelines:

Smoking

For the safety and health of your Hospice team, please have smokers refrain from smoking in the home when a team member is present. If you have oxygen in the home, have smokers go outside to reduce the chances of an explosion.

Firearms

To ensure a safe environment for Hospice team members, all firearms in the home must be kept in a locked and secure place when a team member is present in the home.

Pets

Please secure all pets in a room other than where the Hospice team is visiting the patient. Barking dogs make it hard to talk, biting pets are dangerous, and curious pets may interfere with medical equipment and patient care. Please be aware of potential hazards and address them appropriately to ensure patient safety.

Telephone

Maintaining communication between the patient, the Hospice team, and others involved in patient care is important. Therefore, a telephone (landline or cell phone) needs to be accessible for the patient at all times. It is also important to keep contact information for family and neighbors within reach.

Universal/Standard Precautions

- Avoid direct contact with blood and body fluids. Wear disposable gloves when there is a possibility of exposure to blood, body fluids, feces, or urine. Also, wear disposable gloves when handling soiled linens and cleaning spills of blood, urine, vomit, and feces.
- When clothing or bare arms are likely to be in contact (during bathing or cleaning a patient) with secretions/excretions, wear a gown, smock, or water-protective barrier gown.
- Wear a mask when caring for a patient diagnosed with a suspected or actual communicable, respiratory disease. Your nurse will let you know if this is needed.
- Wear eye protection, goggles, or glasses when splashes of secretions may occur (i.e. when suctioning patient)
- Store bedpans and urinals away from clean items, in a designated space; handle with gloves.
- Wash your hands well with soap and water before and after contact with the infected patient, even if gloves are worn. Use alcohol-based hand sanitizers when unable to wash your hands with soap and water. To keep skin from becoming dry and cracked, apply lotion after each washing. If you have open sores on your hands and arms, wear gloves and adequate clothing, and wash hands after contact.
- Keep your hands away from your mouth and face while caring for the patient. Wash your hands before eating.
- Clean patient care area daily.
- Family members should wash their hands before and after using the bathroom, before handling food, and before providing care to the patient.
- Use liquid soap in the bathroom to wash hands. Use a disposable cloth, paper towel, or tissue over the faucet to turn off the water. Each family member should use his or her own toothbrush and drinking glass.
- Wash dishes in a dishwasher or using hot, soapy water.

Home Infection Control

Hospice patients are at a higher risk for infections because their bodies' natural defenses against germs are weak. Hospice team members follow standard infection control practices to protect the patient, family members, guests, and themselves against spreading germs.

Hand washing

Liberal use of soap and water is the best way to prevent the spread of infection. Wash hands thoroughly before and after all patient care, self-care, meal preparation, and upon arrival and departure from the patient's home. Rub hands for at least 30 seconds with soap and warm water; scrub between fingers and under nails. Rinse with running water, dry hands with paper towels, and use the paper towels to turn off the faucet.

If you cannot get to a sink with soap and water, clean your hands with waterless alcohol rub by applying a walnut-sized amount into your hand and rubbing until dry before touching anything.

Also, remember to wash the patient's hands frequently.

Personal hygiene

Caregivers and patients should bathe or shower regularly. Refer to the Caregiving Tips area of this manual for details on bathing a patient.

Disposable items/equipment

Double bag all paper, plastic, and non-reusable items in waterproof bags and fasten securely. Dispose of bags in a trash receptacle. Make sure animals cannot get into your trash.

Non-disposable items

Change bed linens on a regular schedule and when soiled. Put soiled linens in a plastic bag until laundered. Wash soiled patient laundry separately from other household laundry.

When soiled use diluted bleach (1/2 cup Clorox bleach to 1 gallon of water) or disinfectant, clean equipment used by the patient. Wash hands after cleaning non-disposable items.

Spills

If you encounter spills of blood, body fluids, urine, or feces put on gloves before attempting clean up. Use a disinfectant and paper towels for initial clean up; then wipe the area again using a cleaning solution of 1/2 cup of bleach to 1 gallon of water. After 24 hours, discard the unused bleach solution. Double bag paper towels and dispose of them in a trash receptacle. Wash hands thoroughly after removing gloves.

How to Prevent Infection

Avoiding contagious diseases like the common cold, strep throat, and the flu is important to everyone. Here are easy things you can do to fight the spread of infection.

Clean your hands

- Use soap and warm water. Rub your hands for at least 30 seconds; scrub palms, nails, in between your fingers, and the backs of your hands.
- Or, if there is no soap and water available, clean hands with alcohol-based hand sanitizers. Rub the sanitizer all over your hands, especially under your nails and between your fingers, until your hands are dry.
- Wash your hands before touching or eating food. Wash your hands after you use the bathroom, take out the trash, change a diaper, visit someone who is ill, and play with a pet.

Cover your mouth and nose

Many diseases are spread through sneezing and coughing. When you sneeze and cough, germs may travel three or more feet! Be sure to cover your mouth and nose to prevent the spread of infection to others.

- Use a tissue! Keep tissues handy at home, work, and in your pocket. Discard used tissues and clean your hands after coughing or sneezing.
- If you don't have a tissue, cover your mouth and nose with the bend of your elbow or shoulder, avoiding your hands. If you use your hands, clean them right away before you touch anything.

If you are sick, avoid contact with others

- If you are sick, stay away from other people or stay home. Avoid shaking hands or touching others.

Get shots to avoid disease and fight the spread of infection

Make sure your vaccinations are current—even for adults. Check with your doctor about shots you may need. Vaccinations are available to prevent these diseases: Chicken Pox, Measles, Tetanus, Shingles, Mumps, Diphtheria, Hepatitis, Meningitis, Flu (also known as influenza), Whooping cough (also known as Pertussis), German measles (also known as Rubella), Pneumonia (*Streptococcus Pneumoniae*), and Human papillomavirus.

Medical Equipment

Ensure that you are familiar with the equipment in the home and know the appropriate use of each item.

- Manufacturer's instructions for specialized medical equipment should be kept with or near the equipment and should be followed for patient safety.
- Perform routine and preventive maintenance according to the manufacturer's instructions.
- Equipment should be cleaned and maintained after each use.
- Have available equipment service provider phone numbers in case you experience equipment problems or failure.
- Ensure backup equipment is available when needed. Provide training in the event the equipment must be used during a power outage.
- Determine adequate electrical power is provided for medical equipment such as oxygen concentrators and other equipment.
- Have an adequate service person check equipment batteries regularly.

Reducing Risk of Falls

Each year, millions of people are injured by falls. People at risk of falling include nursing home residents and those recovering from an illness or injury at home. Below are tips and actions that can be taken to reduce the risk of falling, whether at home or in a medical facility.

Why do falls happen?

- Person is weak, tired or ill
- Person is not physically fit
- Person may have problems seeing
- Medicines may cause weakness, sleepiness, confusion, or dizziness
- Slippery or wet floors or stairs
- Obstructed pathways
- Darkness

How to Reduce the Risk of Falling

Take care of yourself

- Keep as active as possible.
- Stay hydrated. Dehydration may make it easier to lose your balance.
- Regularly have your eyes checked.
- Talk to your doctor if your medicine makes you sleepy, light-headed, sluggish, or confused. Ask how to reduce these side effects or if you may take another medicine.

Take extra precautions

- Turn on the lights when you enter a room. Do not walk in the dark.
- Make sure your pathway is clear.
- Use the handrails on staircases.
- Sit in chairs that do not move and have armrests to help when sitting down and standing up.
- Wear shoes that have non-slip soles.
- Do not wear shoes that do not have backs on them.
- Replace the rubber tips on canes and walkers when they become worn.

Make small changes to your home

- Install timers, “clap-on”, or motion sensors on your lights.
- Use night lights in your bedroom, bathroom, and hallway leading to the bathroom.
- Keep the floor and stairs clear of objects such as books, tools, papers, shoes, and clothing.
- Remove small area rugs and throw rugs that can slip. Rubber mats are a good replacement.
- Put frequently used items in easy-to-reach places that do not require using a step stool.
- Make sure your bed is easy to get in and out of.
- Apply non-slip treads on stairs.
- Apply non-slip decals or use a non-slip mat in the bathtub or shower.
- Install grab bars near the toilet and the bathtub or shower.

A home care agency, personal care and support agency, or community program may be able to help make changes to your home if you live alone and need help.

*Falls information is provided in partnership with The Joint Commission

Oxygen Safety

When oxygen is in use in the home there are greater risks of fire. It is important everyone follow safety precautions to prevent injury, damage, or even death. While oxygen alone will not burn, oxygen makes things burn faster and ignites easier.

Home oxygen therapy increases the amount of oxygen in the environment. It will saturate clothing, fabric, hair, beards, and anything in the area. Even flame-retardant clothing can burn when the oxygen content increases.

People on home oxygen therapy should plan and practice home fire drills. Also, make sure the home is equipped with working smoke detectors.

Oxygen is a drug and must be prescribed by a physician. Do not change the amount of oxygen the patient is using without discussing it with your Hospice nurse.

When people continue to smoke where oxygen is present, the risk of a fire increases to a deadly level. If the patient, you, a family member, or caregiver smoke, you are encouraged to **stop** immediately from smoking indoors.

Oxygen is very safe to use when you create the proper conditions.

Recommendations for Oxygen Safety

- Do NOT smoke when oxygen is in use.
- Post at least one NO SMOKING sign in a prominent place near the entrance of the home.
- Warn visitors not to smoke in the home while using oxygen.
- Stay at least 15 feet away from gas stoves, candles, fireplaces, and other open flame and heat sources.
- Store oxygen cylinders in well-ventilated areas (avoid closets, behind curtains, trunks of cars, under beds) and away from direct sunlight, heaters, and electrical appliances. Oxygen should not be allowed to freeze or overheat.
- Use a properly grounded wall outlet for the oxygen concentrator.
- Do not place electrical cord/oxygen tubing under any object, including rugs or furniture.
- Do not use flammable products (cleaning fluids, paint thinner) or aerosol sprays (hairspray) while using oxygen.
- Keep all grease, oil, and petroleum products (many hand/body lotions) and flammable materials away from oxygen equipment. Use water-based lubricants on your lips and hands instead.
- Avoid using electric razors, hairdryers, electric blankets, and space heaters while using oxygen.
- Avoid static electricity - Do not use bedding/clothes made of wool, nylon or synthetic fabrics that may produce static electricity. Use a humidifier in winter to add moisture to dry air in your home.

- Do not allow children or untrained individuals to handle or operate oxygen equipment.
- Ensure an all-purpose fire extinguisher is close by and familiarize yourself with its use.
- In the event of power failure, know how to connect the backup oxygen system and notify Hospice & Community Care.
- If you have electrically powered equipment such as oxygen, you should notify your local utility company. In case of a power outage, the utility company will know to make certain your service is restored as soon as possible.
- Follow instructions provided by the medical equipment company for safe oxygen use.

Ordering Oxygen

If you use portable oxygen and need to order an additional tank:

- Call your Hospice nurse at least 24 hours in advance to place an order.
- Check the supply of portable oxygen supply before the weekend to ensure you have enough.

Call your Hospice & Community Care Team if:

- Oxygen equipment does not seem to be working correctly.
- Patient is short of breath and is not improving.
- Patient has nose or ear irritation that sometimes can be caused by the oxygen, the mask or the tubing.

Fire Prevention and Electrical Safety

Help prevent fires by checking for hazards and correcting problems. Install smoke alarms as the first line of defense for early fire warnings.

- Establish an evacuation plan for you and your family in the event of a fire. Have at least two escape routes, ensure all windows can easily open, and designate a meeting place outside.
- Notify the fire department if a disabled person is in the home.
- Ensure fire extinguishers are in key areas and working order.
- Call 9-1-1 if you smell or see smoke.
- If you must exit through smoke, CRAWL on the floor where the air is better. If clothing catches fire, STOP, DROP, and ROLL or smother the fire with a blanket.
- If your escape route is cut off, remain calm, close the door, and seal cracks to hold back smoke. Signal for help at the window.
- If the fire is contained and small, you may be able to use your fire extinguisher until the fire department arrives.
- Test smoke and carbon monoxide alarms to ensure they are in working order. Install in hallways, sleeping areas, and on each level. Test devices regularly and change batteries twice a year when you set clocks forward in the spring and back in the fall.
- Have the heating/cooling system checked and cleaned regularly by a qualified technician.
- Provide deep ashtrays for smokers and wet all cigarette butts before discarding.
- Keep matches and lighters out of reach of children and people who are confused.
- Repair frayed and damaged electrical cords. Avoid overloading electrical outlets.
- Do not use electric blankets.
- Maintain space heaters and use only according to the manufacturer's specifications. Keep space heaters at least three feet from anything that may burn. Turn off space heaters when leaving the home.
- Unplug appliances after use. Repair or throw away an appliance that smokes or smells as if it is burning.
- Keep electrical items away from sinks, tub, and shower area.
- Move pot handles to the back of the stove. Make sure burners and oven are off when not in use.
- Keep doors free from obstruction.
- Keep lamps, extension cords, and telephone cords out of walkways.
- Do not stack old papers or clothing.

To evacuate a bed-bound patient:

Have one or two people place the patient on a sturdy blanket and pull/drag the patient as gently as possible out of the home.

Inclement Weather/Disaster Information

A disaster is an emergency situation that will result in an interruption of your services. Having an emergency plan is important and should be practiced periodically, especially when a substitute caregiver occasionally assists in the home. In case of emergencies, know how to operate any back-up equipment in the home.

Disaster preparedness plan for patients and families

- Keep an emergency kit in the home that contains:
 - Portable radio with batteries
 - Flashlight and batteries
 - Battery-powered lantern
 - First aid kit
 - Fire extinguisher
 - Blanket
 - Canned food and manual can opener
 - Drinking water
 - Extra clothing
- Listen to weather updates on the storm's approach as well as business closings and shelter locations.
- Check medication regularly to ensure an adequate supply in the event of an emergency.
- Have a plan for emergency heat.
- If the patient leaves their home due to an electrical outage or natural disaster:
 - Notify Hospice & Community Care
 - Take all medications with the patient.
 - Keep your phone with you. During bad weather, your Hospice nurse may call to maintain contact.
- Always notify the Hospice & Community Care before you need to connect the last tank of oxygen during a power outage so they have plenty of time to make additional deliveries if road conditions change.
- Nurses may not be able to visit when road conditions are dangerous, but advice and instruction may be given by phone. Emergency situations will be taken care of in the safest manner possible.

Power outage

During a power outage, if the patient and/or caregiver requires assistance and our agency phone lines are down, do the following:

- If you are in a crisis or have an emergency, call 911 or go to the nearest hospital emergency room.
- Use Hospice & Community Care backup telephone line for power outage emergencies only - 803-326-9978

Flood/Hurricane

Floods are the most common and widespread of all-natural hazards. Some floods develop over a few days, but flash floods can result in raging waters in just a few minutes. Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam.

If local authorities issue a flood watch, prepare to evacuate by:

- Ensuring the patient's safety.
- Securing your home. Move essential items to the upper floors of your house.
- Turning off utilities at the main switches or valves, if instructed. Do not touch electrical equipment if you are wet or if you are standing in water.
- Cleaning the bathtub and filling it with water in case your supply becomes contaminated or water services are cut off.
- Have an evacuation plan and know where to go if you are told to do so.

If there is a flood:

- Do not walk through moving water. Six inches of moving water can knock a person off their feet. If you must walk in a flooded area, walk where the water is not moving.
- Use a stick to check the firmness of the ground in front of you.
- Do NOT drive around barricades.

Tornado

Tornados are nature's most violent storms. When a tornado has been sighted, go to a shelter or predesignated safe location immediately. Stay away from windows, doors, and outside walls. Listen to local radio or television stations for current storm news.

Tornado Watch - a tornado is possible in your area.

- Be alert to changing weather conditions.
- Blowing debris and the sound of an oncoming tornado may alert you.

Tornado Warning - a tornado has been sighted and may be headed for your area.

- If inside, go to a safe place in the home.
- If outside, hurry to the nearest sturdy building and seek a safe place.
- If outside and unable to get indoors, lie down in a ditch or low-lying area.
- Listen to the radio for news and instruction.
- Use flashlights to inspect the home for damage before turning the power back on.

In a house or small building:

- If the patient is bed-bound, move the patient's bed as far away from windows as possible. Cover the patient with heavy blankets or pillows, being sure to protect the head and face. Then go to a safe area.
- Go to the basement or storm cellar. If there is no basement, go to an interior room on the lower level closets, interior hallways.
- Get under a sturdy table, hold on, and protect your head. Stay there until the danger has passed.

In a nursing home, hospital, or shopping center:

- Go to predesignated shelter areas. Interior hallways on the lowest floor are usually safest. Stay away from windows and open spaces.

In a high-rise building:

- Go to a small, interior room or hallway on the lowest floor possible.

In a vehicle, trailer or mobile home:

- Get out immediately and go to a more substantial structure. Do not attempt to out-drive a tornado. They are erratic and move swiftly.

If there is no shelter nearby:

- Lie flat in the nearest ditch or ravine with your hands shielding your head.

After a tornado

- Watch for fallen power lines and do not approach them.
- Do not go into damaged areas.

Emergency Disaster Plan for Hospice & Community Care

An emergency is defined as a natural or man-made disaster that significantly:

- Disrupts the environment, buildings, homes, or grounds due to thunderstorms, wind, ice/snow, flooding, explosion, fire, or bomb.
- Disrupts care and services, such as the loss of utilities (power, water, or telephone), floods, snow/ice storms, severe thunderstorms, hazardous chemical spills, and accidents.
- Results in a sudden change or increase in demand for Hospice services such as communicable disease outbreak and/or community mass casualty event.

Hospice will coordinate efforts with area emergency management agencies such as the local health department, law enforcement, and office of emergency management. Patient families are encouraged to make emergency preparation plans such as those listed below:

- Ensure additional food, water, medications, and supplies (batteries, flashlights, etc.) are available and accessible.
- Notify Hospice staff if additional patient equipment is needed.
- Ensure a system for communicating with others such as cell phones.
- Ensure safety equipment such as smoke detectors and fire extinguishers are in working order.
- Develop a family emergency plan. Practice carrying out the plan regularly.

In the event of an emergency, Hospice & Community Care's response center will be located on the Hospice Campus at the Wayne T. Patrick Inpatient Facility. Should the Inpatient Facility require evacuation, the alternative command center is located at Piedmont Medical Center, 111 South Herlong Ave. Rock Hill, SC 29732 803-329-1234.

Hospice & Community Care staff will implement the emergency operations plan if needed. Staff will make every effort to ensure the safety of patients who are not likely or capable of evacuating without assistance if evacuation becomes necessary. During an emergency, staff will primarily communicate by phone with patients and families to update on operation/evacuation status as needed.

Hospice will communicate with and inform appropriate state or local authorities to assist patients in need of evacuation due to an emergency. Hospice will comply with HIPPA Privacy Regulations as appropriate when communicating such information.

If Hospice staff is not able to perform home visits as a result of the emergency, patients would be instructed to use local hospital emergency rooms.

The Hospice will return to normal business operations as soon as possible.

Hospice's Emergency Plan is tested and evaluated annually.

Emergency phone numbers

- Police and Fire (all cities) 9-1-1
- Duke Energy 1-800-769-3766
- City of Rock Hill Utilities 803-329-5500
- York Electric Cooperative 1-866-374-1234
- York County Natural Gas 803-323-5304
- Lockhart Power Company 864-545-2211
- Lancaster County Water & Sewer 803-285-6919

It is also important to keep contact information for family members and neighbors close by.

Call your Hospice & Community Care Team if:

- You experience a power outage that may impact the care or safety of the patient, such as electrical medical equipment, lack of water, etc.
- You have to leave your home due to fire, power failure, etc. Let us know where the patient is so we can continue caring for the patient with you.



Providing Day-to-Day Care

Hospice Aides make regular visits to provide personal services to the patient such as help with bathing, dressing, and personal care. When aides are absent personal care may need to be provided by family members and loved ones. Below are some practical suggestions on caring for your loved one while maintaining privacy and respect.

Bathing

Bathing often feels good for the loved one who is bed-bound. This activity provides cleanliness and helps to refresh the body and spirit. It may also stimulate circulation, provide movement and exercise, and allow you to look for any skin problems. Most people do not need a daily bath. If bathing is difficult, do it only as often as necessary. Do make sure that the hands and face are washed every day.

Bathing tips

- Keep things as pleasant and relaxing as possible.
- If movement is painful, provide pain management one hour before the bath.
- Begin washing the face and work down to the feet.
- Gently soap the skin, rinse and pat dry. Too much soap may increase skin dryness.
- Keep the room comfortably warm. Bathe only a small area at a time to avoid chills.
- Provide plenty of privacy.

If the person can get into a tub or shower:

- Ask the patient to sit on the edge of the tub. Put both legs into the tub before standing. Reverse the process when getting out.
- Make sure the floor is dry when helping the patient in or out of the tub.
- Lower the water temperature in the house to 120 degrees.

Bathing Assistive Devices

For concerns about getting in or out of the tub, a bath bench or hand-held shower attachment may be helpful. There are a variety of other assistive devices that make bathing safer including: grab bars, long-handled sponges, wash mitts, hair washing devices, a non-slip mat, a bath thermometer to ensure the water is not too hot, an inflatable bathtub, and rinse-free bath products.

Shaving

- Use an electric shaver when shaving another person – it's safer and easier. Anyone taking blood-thinning medication should use an electric razor.
- If the patient wears dentures, place in his mouth before shaving.
- Shave the patient in a sitting position, if possible.
- Move slowly and with little pressure.
- Shave the most tender areas of the face (the neck area below the jawbone) first, then move up to the tougher areas of the face between the ears, nose, and mouth.

Skin Care

It is important to keep the skin healthy. Changes in the skin are often concerning to the patient and the caregiver. Unfortunately, as the body becomes weaker, skin breakdown is difficult to prevent. Early recognition and prevention of problems are important.

Daily Care

- Keep skin clean and dry.
- Examine the patient's body daily for dryness, blisters, red areas, cracks, or tears.
- Reduce pressure on bony areas as often as possible.
- Avoid over-padding the foam mattress.
- Keep bed linens clean, dry and wrinkle-free.
- Use a flat sheet folded in half or quartered (draw sheet) under the trunk of the body to turn and position the patient.
- Offer more fluids. Juices and vegetable drinks provide vitamins and minerals.
- Offer foods high in calories and nutrition.

Call your Hospice & Community Care Team:

- If you have questions or concerns about bathing or grooming, or if you need more help with bathing the patient.
- You notice reddened areas that do not fade open areas or blisters on the skin.
- You have any other questions or concerns about giving care.

Mouth Care

Consistent mouth care helps prevent sores and may improve appetite. The patient should sit upright to prevent choking. Use a soft toothbrush or a soft cloth wrapped around a finger to provide the best cleaning results. A toothbrush dipped in water or mouthwash will do a good job of cleaning the teeth, gums, and tongue. You may also use a foam-covered stick. Avoid putting the toothbrush too near the back of the patient's throat to prevent gagging.

Daily Mouth Care

- Remove the patient's dentures after eating for cleaning or if gums and mouth are sore.
- As individuals lose weight, dentures may not fit properly and may cause mouth sores. A denture adhesive may be needed to avoid slipping.
- If the patient is unconscious, remove dentures.
- Brush dentures to remove food debris. Avoid soaking dentures. If eating, clean dentures twice a day with a denture brush and nonabrasive denture cleaner.
- After a meal, rinse the mouth area with clean water to help remove food particles caught in the teeth or gum lines.
- Apply lip balm or petroleum jelly to the patient's lips for moisture often. **(Caution: Do not use oil-based products like petroleum jelly if the patient is using oxygen.)**

Dry Mouth

- Have the patient sip on fruit juices.
- Offer foods high in water content (well-cooked vegetables, canned fruits, gravies, soups, and sauces).
- Offer tart foods like lemon to stimulate saliva.
- Offer hard candy, popsicles, and ice chips.
- Avoid mouthwash products that cause dryness.
- For severe dry mouth, a saliva substitute may be needed. Ask your hospice nurse.

Sore Mouth

- Avoid salty or tart foods, crackers, or hard foods that may cut or rub sore areas. Also avoid extremely hot or cold food or liquids.
- Frequent antibiotic use may result in thrush, a condition that causes soreness and white patches. Eating yogurt daily replaces the "good" bacteria lost when taking antibiotics.
- Avoid acidic food and beverages including orange juice, tomato juice, and citrus fruits.
- Offer easy-to-swallow foods like soup and liquid meals).
- Cold foods like ice cream, yogurt, and popsicles can be soothing.
- Have the patient use a straw to prevent liquids from coming in contact with sores.

Call your Hospice & Community Care Team:

- Any soreness in the patient's mouth area.
- Discoloration or white patches in the mouth.

Skin Breakdown

Immobility is the primary cause of skin breakdown. People who stay in bed or a wheelchair for long periods are at the greatest risk. Areas of skin breakdown may include spine, ears, elbows, hips, ankles, and heels.

It can be caused by:

- Friction when the skin is rubbed against or dragged over a surface.
- Dryness and cracking.
- Age.
- Irritation by urine or feces.
- Lack of good nutrition or not drinking enough fluids.
- Certain chronic conditions or diseases – especially those that limit circulation.

Daily Care

To provide comfort and decrease skin irritation:

- Avoid friction such as rubbing the patient's skin on the sheets when moving the patient.
- Reposition the patient every two hours or as tolerated. If the patient is able, remind them to reposition. This applies to the bed and chairs.
- Avoid sitting for long periods.
- Use mild soap and warm water on the skin. Rinse and dry well – pat dry without rubbing.
- Gently clean away urine or feces immediately. Always clean the front area before cleaning the rectal area.
- Use pillows to support the patient's arms, legs, and back.
- Use lotions containing lanolin to replace moisture loss due to reduced fluid intake.

Call your Hospice & Community Care Team if:

- Changing position causes pain or if the patient refuses to turn.
- Changes occur in the ability to turn or change the patient's position.

Nutrition, Fluids, and Drink

Eating may be time-consuming, especially if the patient must be fed. When someone is ill, their appetite decreases. The body's need for calories and protein-rich foods is altered due to decreased activity. Fluids are necessary to keep the skin healthy, the mouth moist, and help the body remove waste products. If we "listen" to our body, it tells us exactly what is needed to sustain life.

Daily Care

- Offer food and drink, do not force – eating is the choice of the individual.
- Small, frequent meals are more likely tolerated.
- Remove unpleasant odors.
- Offer pleasure or comfort foods.
- Mouth care before mealtime may stimulate the appetite.
- Breakfast may be the best meal of the day - appetites tend to decrease later in the day.
- Avoid straws as the patient may swallow air and become more nauseated.
- Offering ice chips, jello or popsicles may be helpful.
- All fluids and food should be stopped when the patient can no longer swallow.
- Use plastic utensils if the metallic taste is an issue.

Call your Hospice & Community Care Team if:

- You notice an increased difficulty in swallowing or incidents of choking.
- The Patient experiences increase nausea, vomiting, or other eating difficulties.
- The Patient is suffering from abdominal cramping or pain.
- You notice significant changes occurring in the patient's appetite or amount of food eaten.

Elimination

Urine and stool are natural ways for the body to remove waste. Loss of control of bladder and bowels may occur as the muscles begin to relax. Elimination problems may cause discomfort, anxiety, and embarrassment. Bedpans, urinals, a bedside toilet, and disposable adult briefs may be helpful. Catheters may help to drain the patient's bladder. Medications and inactivity may lead to constipation.

Daily Care

- Provide as much patient privacy as possible while maintaining safety.
- Keep a bedpan or urinal within the patient's reach.
- Use bedside toilets to avoid long distances to the bathroom, especially at night.
- Place waterproof pads under the patient to draw any moisture from leakage away from the patient's skin.
- Encourage the patient to drink fluids, eat fiber, fruits and vegetables as tolerated.
- Always wear gloves and wash your hands after assisting with toileting, handling the bedpan, urinal, and emptying a bedside toilet.
- Always wash hands before and after working with the catheter or drainage bag, even when wearing protective gloves.
- Empty the drainage bag at least twice a day.
- Check the drainage tubing for kinks and loops, and ensure the bag is below the level of the patient to allow for drainage by gravity.
- Clean the area around where the catheter enters the body. Your Hospice nurse will teach you how to clean the catheter.

Call your Hospice & Community Care Team if:

- Patient has not had a bowel movement for three days, even with very little or no eating.
- Patient has not urinated or emptied bladder for 12-18 hours.
- Patient experiences abdominal pain or burning when urinating or emptying the bowel.
- Patient's abdomen becomes hard or swollen.
- Patient's urine is discolored, dark, or contains blood.
- Patient is unable to control urination.
- Patient has 2-3 episodes of diarrhea within 8 hours.
- If there is catheter leakage.

Body Mechanics

Moving patients unable to move themselves requires skill, knowledge, and strength. Proper body mechanics are essential to avoid injury from lifting patients. When a patient is confined to bed, frequent changes in the patient's position are important.

Daily Care

- Explain to the patient what you are about to do to prevent fear and encourage cooperation.
- Use a “pull pad” when needed.
- Support arms and legs with pillows and rolled towels.
- Check all tubing to ensure it will move freely.
- Move the patient to the side of the bed beginning with the head, shoulders, and trunk, then legs and feet.
- Consider using two people when moving a patient.
- Avoid lifting, especially if you can push or pull.
- Stand firmly on the floor and as close to the patient as possible. Always flex your knees when lifting. Avoid twisting or turning your back. Stand directly in front of the patient when transferring the patient on or off the bed.
- Never lift with your back and use your legs.
- When transferring a patient on and off of the bed, always lock the wheelchair, assist the patient to the edge of the bed and stand in front of the patient. Wrap your arms around the waist and bring the patient to a standing position. Pivot and assist the patient to sit while bending your knees. Position the patient's arms and legs appropriately.

Safety with Transfers

- If the patient cannot help with the transfer at all, you need special training to lift and move them.
- Never try to lift someone heavier than yourself unless you've had proper training.
- If you feel a strain in your lower back, stop the transfer and get help.

Call your Hospice & Community Care Team if:

- Patient experiences any difficulty with transferring or repositioning. Staff can assist you in learning proper techniques to prevent injury.

Lifting and Moving a Patient

Making an Occupied Bed

Making a bed with someone in it can be difficult. Your care team will instruct you on how to make an occupied bed. They may refer you to additional instructional videos found on YouTube for further reference.

Moving a Patient in Bed

With repositioning, some people find it easiest to move a patient in bed using a draw sheet. A draw sheet helps to avoid friction and irritations to the patient's body. A draw sheet is a pad or a sheet folded over several times and placed under the patient. The draw sheet should be large enough to cover the area from the thigh to the upper back.

If the patient can help:

- Elevate the bed to your height.
- Remove all pillows from under the patient's head.
- If the patient is in a hospital bed make sure the bed is flat (be sure the patient can tolerate having the head of the bed flat).
- Put one hand under the patient's shoulder and the other under the upper thigh.
- Ask the patient to bend their knees with feet firmly braced against the mattress.
- Stand with your feet at least shoulder-width apart, pointing your feet to the center of the bed.
- Bend your body from the hips, facing the patient.
- On a count of "one, two, three," have the patient push their body toward the head of the bed with their hands and feet while you shift weight.
- If the patient cannot help, two people are needed to use a draw sheet with one on each side of the patient.

Handling Difficult Behaviors

Confusion or Disorientation

Persons near end-of-life may seem confused about the time of day, where they are, and even the identity of people around them. The patient may report hallucinating and seeing things or people that are not visible to you. These symptoms may occur as the body's metabolism slows down.

Recommendations

- Limiting visitors may decrease the level of confusion.

Call your Hospice & Community Care Team if:

- There are any changes in the patient's condition.

Restlessness and Agitation

The patient may become restless (i.e. pulling at clothing and bed linens, or engage in repetitive movements). This often occurs when there is a decrease in oxygen to the brain or can be a symptom of physical discomfort or pain. Unresolved emotional or spiritual concerns may also be worrisome.

Recommendations

- Minimize distractions including loud noises, television, and ringing phones.
- Use soft music and low lighting.
- Have someone sit with the patient.
- Use a sound/camera monitor while outside of the room.

Call your Hospice & Community Care Team if:

- There are any concerns about the patient's condition.

NOTES



Medication Management

The patient's comfort is our primary goal. Keeping track of medicines and knowing how and when to take them is critical to a patient's health. The following are guidelines to ensure medications are appropriate, current, and used to benefit the patient.

Your hospice nurse will initially review the patient's clinical needs with the patient, family, attending physician, and hospice medical director to determine which medications will best manage symptoms and provide comfort.

During each visit, the hospice nurse will check that all medications are taken as ordered by the physician. Any changes in medications must be approved by the physician. Please notify the hospice nurse if there are changes in the patient's condition, patient needs medication refilled, or there are any questions.

Please note, Hospice staff are not allowed, by law, to bring to or remove medications from a patient's home or living facility.

Medication Safety Tips

- Know the name, dosage, method for taking, and reason for each medication.
- Be familiar with possible side effects and when to report them to the nurse.
- Keep a current list of medications, possible side effects and pharmacy telephone number. Use the medication sheet in this book.
- Take medications only as prescribed.
- Maintain a daily log of when medication is taken.
- Talk with the Hospice nurse before stopping any medication or skipping doses.
- Tell the Hospice nurse of any over-the-counter medications the patient is taking, including aspirin, Tylenol, cold or sinus medication, vitamins, and herbal supplements.
- Report medication allergies or side effects to the Hospice nurse immediately.
- Look at the medication – if it does not look like what is normally taken, ask why. It could be a generic brand or it may be the wrong medication.
- Dispose of expired and discontinued medications.

- At all times, keep medications in a secure, private location and out of the reach of children, confused adults, and pets.
- Keep medications in original containers if possible. The Hospice nurse may recommend a pill planner
- Store refrigerated medications with proper labeling and away from food items.
- Periodically, gently shake bedsheets to check for any medications that may have been overlooked or dropped.
- Do not allow others to take or borrow medication.
- Consider using a locked box to store controlled medicine to prevent it from being stolen or taken by anyone other than the patient.

Hospice Medication Disposal Policy

Federal law prohibits the transfer of prescription medications to any person other than the person for whom it was prescribed.

When medications prescribed by Hospice are no longer needed, the Hospice & Community Care nurse will safely dispose of them.

Disposal of medications (including controlled substances)

- Upon death of a patient receiving services from Hospice, ownership of unused medications related to the care of the patient shall transfer to the Hospice for immediate disposal.
- Upon death of a patient receiving services from Hospice, in the presence of a witness, the Hospice shall record in the medical record the name and quantity of each unused controlled substance. The Hospice nurse then shall conduct immediate disposal at the site of care by complying with EPA and DEA guidelines for safe disposal. When conducting immediate disposal at the site of care, the nurse shall perform the disposal in the presence of a witness, who shall sign a document indicating their witnessing of disposal.
- The Hospice nurse will dispose of medications by mixing prescription drugs with an undesirable substance, such as used coffee grounds or kitty litter, and put them in an impermeable, non-prescript container, such as empty cans or sealable bags, to further ensure the drugs are not diverted. Disposed medications will be left in the patient's home and family will be encouraged to permanently dispose of any waste. Hospice employees must not remove any medications from the site of service.
- If family members express an interest in utilizing disposal for non-narcotic or other non-hospice prescription medication, the Hospice nurse will educate families about how they may take advantage of medication disposal programs and community pharmacy take-back programs that allow the public to bring unused drugs to central location for proper disposal. Some communities have pharmaceutical take-back programs or community solid-waste programs that allow the public to bring unused drugs to a central location for proper disposal.

Additional Medication Disposal Sites

Below is a listing of drop-off locations for any unwanted medications. These locations offer free, environmentally-save disposal and may serve as an additional option to biannual DEA drug take back days. If your area is not included in this list, check back periodically to see if new locations have been added.

Chester County

Chester County Sheriff's Office
2740 Dawson Dr. Chester
803-581-5131

Call to inquire

Fairfield County

Fairfield Co Sheriff's Department
350 Columbia Rd. Winnsboro
803-635-4141

Drop off Mon-Fri 8:30 – 5:00

Lancaster County

Lancaster County Sheriff's Department
1520 Pageland Hwy. Lancaster
803-283-3388

Drop off 24/7

Lancaster County - Indian Land Sub
8290 Charlotte Hwy. Indian Land
803-283-3388

By appointment

Union County

Union County Sheriff's Department
220 W Main St. Union
864-429-1612

Drop off Mon-Fri 8-5

York County

York County Sheriff's Department
1675-24 York Hwy (Moss Justice Center)
803-628-3059

Drop off 24/7

Clover Police Department
112 Bethel St, Clover
803-222-9494

Drop off 24/7

Fort Mill Police Department
111 Academy St. Fort Mill
803-547-2022

Drop off 24/7

Tega Cay Police Department
7705 Tega Cay Dr, Tega Cay
803-548-0340

Drop off 24/7

Rock Hill Police Department
120 E. Black St, Rock Hill
803-329-7282

Drop off 24/7

Winthrop Police Department
523 Myrtle Dr, Rock Hill
803-323-2211

Drop off 24/7

York Police Department
12 N Roosevelt St, York
803-684-3886

Drop off 24/7

If you have any questions or concerns about the disposal of unused or expired medications, contact the above sites or Hospice & Community Care at 803-329-1500.

Symptom Management

Your comfort is our primary concern. All members of your hospice team will frequently ask about your comfort and whether you are experiencing any pain. It is important to always report any pain or symptoms that are new right away so your Hospice nurse can follow up. Because pain is such an individual experience, it is impossible to know what another's pain feels like. By understanding how pain affects you, we can work with you and your doctor to make you more comfortable.

Most types of pain may be treated safely and effectively using various types of treatment including medications and many non-drug options.

Facts about pain medication

MYTH: Pain medicine should be saved and used only when pain is severe.

FACT: Pain medication should be given regularly and as ordered so there is a stable amount of medicine in the body to keep the pain away. By taking medication before the pain becomes unbearable, the patient can get better relief with lower doses and fewer side effects.

MYTH: The patient will develop a tolerance to his/her medication and will have to keep taking more and more until he/she is immune to it and it no longer works.

FACT: Tolerance to opioid drugs may occur and is seldom a clinical problem. Tolerance means that taking the drug changes the body in such a way that the drug loses its effect over time. Most patient's doses are gradually increased by the physician until pain relief is obtained, then the dose is stabilized for a while. If doses need to be increased because the pain returns, it is more commonly related to the disease than drug tolerance.

MYTH: If the patient takes narcotic medications, he/she will become addicted.

FACT: Addiction is characterized by the overuse of drugs. It is rare for patients with pain and have no history of substance abuse to become addicted to pain medication.

MYTH: If the patient no longer needs the medication, he/she will go through severe withdrawal when trying to stop it.

FACT: Withdrawal is a physical response to the sudden absence of something the body has gotten used to having. All people who take opioids for some time can have this withdrawal syndrome if the drug is stopped or suddenly lowered. This can be easily prevented by slowly lowering the dose of drugs over several days and is usually not a problem.

MYTH: Pain is only a physical issue.

FACT: Hospice recognizes that people are more than a collection of symptoms. People nearing the end of their lives often face emotional and spiritual distress. They are dismayed as their physical abilities begin to fail. They do not want to be a burden on their families. They worry about how their loved ones will manage without them. Sometimes, they feel deep regret about things they have done or said – or things left undone and unsaid. Hospice spiritual care providers and social workers are trained to be active listeners and to help patients and families work through these concerns so that they can find peace and emotional comfort in their final days.

Suggestions for pain management

- Take your medication exactly as prescribed and don't wait until the pain is intense before taking your medicine.
- Make sure that you have a three-day supply of pain medication available at all times. Call your Hospice nurse for another prescription before the last dose of medicine is given.
- Report your pain accurately. Your nurse will want to know – When did the pain start? Is this a new pain? How long have you had this pain? Where is the pain located? On a scale of 0-10 (0 being no pain; 10 the worst pain you could imagine). How would you rate your pain? Is there anything that makes you feel better or worse? When did you take your pain medication?
- Caregivers should always believe a patient who reports pain. However, not all patients can verbalize what they are feeling. In those cases, the caregiver should watch for signs of pain. Sometimes frowning, moaning, general restlessness, short rapid breathing, muscle tensing and/or resistance to turning or positioning are symptoms of pain. Report and log your observations for the Hospice nurse or any team member.
- When the patient is experiencing pain, you may want to limit visitors. Usually a patient can rest better if the temperature of the room is comfortable, the lights are dimmed and clothing is loose. Try changing the body position. Don't sit or lie in the same position for more than two hours. You may want to use pillow under your arms, legs or feet.
- Try relation breathing – Breathe in slowly and deeply through the nose expanding the belly with air and breathe out through the mouth emptying the belly and letting it relax. These techniques can be demonstrated by the caregiver along with the patient. Your Hospice social worker can help with relaxation techniques.
- If the patient likes to be touched, hold the patient's hand or gently massage hands or feet.
- Try to focus on something besides the pain. Watching a movie, reading or having someone read aloud, listening to music, visualizing a pleasant place or meditating are some ideas that may help.
- Sometimes heat and cold, such as heating pads and ice packs, may be used for 15 – 30 minutes over the area of pain. Use a light cloth between the heat or cold and the skin, and be sure to check the skin frequently. Talk to the Hospice nurse to see if this method could help relieve pain.

Anti-Anxiety Medication

Anti-Anxiety Medications are a type of prescription medication used to treat symptoms of acute anxiety. Experts point out that it is perfectly natural to feel sad, scared, and anxious about terminal illness. That is because people are facing something that they have never dealt with before. Anti-anxiety medications can help.

Other uses for this group of medications are paranoia, wandering, hallucinations, restlessness, and irritability. These problems can interfere with normal daily activity and sleep and may increase the risk of harm to the person.

These medicines cause a drowsy, calming effect. They provide relatively fast relief for individuals who suffer from acute anxiety and panic attacks. For individuals that have trouble sleeping, anti-anxiety medications help.

Names of Medicines your doctor may order:

- Alprazolam (Xanax)
- Clonazepam (Klonopin)
- Lorazepam (Ativan)
- Diazepam (Valium)
- Restoril (Temazepam)

How do I use anti-anxiety medications effectively?

Use the medicine dose and frequency as directed by your doctor or nurse. If this dose does not help, talk to your nurse. Talk to your doctor, nurse, or pharmacist any time you have a question.

What are the side effects of anti-anxiety medicines?

- Drowsiness
- Dizziness or light-headedness
- Headache
- Dry mouth
- Fatigue

Anti-Nausea & Vomiting Medication

Anti-Nausea and Vomiting Medications are a type of prescription medication used to treat the symptoms of nausea and vomiting. Nausea is an uneasiness of the stomach that often accompanies the urge to vomit. Vomiting is the forcible emptying of stomach contents through the mouth. Although nausea and vomiting are usually harmless, it can be very uncomfortable and stop people from eating or drinking.

Names of Medicines your doctor may order:

- Promethazine (Phenergan)
- Prochlorperazine (Compazine)
- Metoclopramide (Reglan)
- Ondansetron (Zofran)

How to prevent nausea and vomiting:

- Eat small meals during the day, instead of three large ones
- Eat slowly
- Rest after eating with your head elevated about 12 inches above your feet
- Drink liquids between meals rather than during meals
- For vomiting: slowly drink small amount of clear liquids and avoid solid food until the vomiting episode has passed

How do I use anti-nausea/vomiting medications effectively?

Use the medicine dose and frequency as directed by your doctor or nurse. If this dose does not help, talk to your nurse. Talk to your doctor, nurse, or pharmacist any time you have a question.

What are the side effects of anti-nausea/vomiting medicines?

- Drowsiness
- Dizziness or light-headedness
- Headache
- Dry mouth
- Constipation

Constipation

Constipation is a condition that results in having fewer bowel movements than normal for the patient. Stool may be painful or hard to pass. Constipation is also a common side effect of certain pain medications. Patients taking pain medications may need to make changes in their diet or take regular doses of laxatives to prevent constipation. It is important to let your nurse know if you have not had a bowel movement in 2 or 3 days.

Non-medicine treatment for constipation:

- Eat high-fiber foods, like fruits, vegetables, and whole grains (if possible)
- Drink lots of liquid (if possible)
- Warm liquids may help

Names of Laxatives your doctor may order:

- Docusate (Colace)
- Senna (Senekot)
- Bisacodyl (Dulcolax)

How do I use the laxatives?

Use the medicine dose and frequency listed on the label. If this dose does not help, talk to your doctor. Talk to your doctor, nurse, or pharmacist any time you have a question about a medication.

What are the side effects of laxatives?

- Gas
- Bloating
- Cramping
- Diarrhea
- Nausea

Diarrhea

Diarrhea is a condition that results in having frequent, loose, and watery bowel movements. There may also be abdominal cramps and a greater volume of stool. Some medications, cancer treatments, stress and anxiety, or other medical conditions may cause diarrhea. It is important to let your nurse know if you have diarrhea that lasts longer than two days, or if you have bloody or black stools.

Non-medicine treatment for diarrhea:

- Eating small, frequent meals
- Drink lots of liquid (if possible), especially sports drinks, broth, or caffeine-free soft drinks
- Avoid food and drinks that cause gas and are high in fiber
- A diet of bananas, rice, apples, and toast (BRAT)

Names of medications your doctor may order:

- Loperamide (Imodium)
- Over the Counter Kaopectate
- Over the Counter Lomotil

How do I use these medications?

Use the medicine dose and frequency listed on the label. If this dose does not help, talk to your doctor. Talk to your doctor, nurse, or pharmacist any time you have a question about a medication.

What are the side effects of these medications?

- Gas
- Bloating
- Constipation
- Stomach Pain

Shortness of Breath/Dyspnea Medication

Shortness of breath is unpleasant or uncomfortable breathing. It is experienced and described differently by patients depending on the cause. People describe shortness of breath in different ways. When you experience shortness of breath, you should pay attention to the sensations you feel and try to be as specific as possible when describing these sensations to your doctor or nurse. Some people say they feel “hungry for air”, others say they feel as though they “cannot breathe deeply enough”. Shortness of breath may be related to lung, heart, and other causes, which vary by acuity of onset.

The most common causes of shortness of breath include:

Asthma	Pneumonia
COPD	Heart Attack
Weakness	Cancers

The most common cause of shortness of breath in patients with COPD, heart disease, or cancer is the worsening of their disease

Treatment and Medication Regimen your doctor may prescribe:

- Oxygen Therapy by nose 1 – 4 liters/minute as needed for air hunger
- Roxanol 0.25mg to 1mg every 1 – 2 hours for pain or air hunger
- Albuterol (Ventolin) 2.5mg via nebulizer every 4 hours as needed for wheezing

How do I use shortness of breath medication?

Use the medication dose and frequency listed on the label or as directed by your doctor or nurse. If this dose does not help, talk to your nurse. Talk to your doctor, nurse, or pharmacist any time you have a question about a medication.

What are the side effects of medicines ordered for the treatment of dyspnea?

- **Oxygen Therapy**
 - Nasal irritation
- **Albuterol/Ventolin**
 - Nervousness
 - Headache
 - Uncontrollable shaking of a body part
 - Hives/rash
- **Roxanol**
 - Refer to the Pain Medication Handout for side effects

Pain Medications: Narcotics & OTC

It will be important for doctors and nurses to constantly ask about your pain. This is because pain changes over time or your pain medicine may need to be adjusted. You will be asked to describe how bad your pain is on a scale of 0 to 10 with 10 being the worse pain. They may use other pain scales that use words, colors, faces or pictures if indicated. Tell the nurse and/or doctor if you are unable to sleep or do things like dressing or moving without pain. The more they know about where you hurt and your pain level, the better they will be able to treat it.

Narcotics

Narcotics (also called pain relievers) are used only for pain that is severe and is not helped by other types of pain relievers. When used carefully and under a doctor's direct care, these medications can be effective at reducing pain. Pain medicines work by binding to receptors in the brain, which blocks the feeling of pain.

Names of Pain Medicines your doctor may order:

- Hydrocodone (Vicodin)
- Roxanol (Oxycodone, OxyContin)
- Morphine (MS Contin)
- Fentanyl (Duragesic) – available as a patch
- Tramadol (Ultram)

Over the Counter

Over the Counter (OTC) pain relievers/fever reducers (the kind you can buy without a prescription) are safe and effective when used as directed. There are two categories of over the counter pain relievers/fever reducers: acetaminophen (Tylenol) and nonsteroidal anti-inflammatory drugs (NSAIDs) (Ibuprofen or Advil). Acetaminophen is used to relieve headaches, muscle aches and fever. Over the counter NSAIDs are used to help relieve pain and reduce fever. Both of these medications may be found in many other medicines, such as cough syrup and cold and sinus medicines.

OTC Pain reliever/fever reducer medications your doctor may order:

- Acetaminophen (Tylenol)
- Aspirin
- Naproxen
- Ketoprofen
- Ibuprofen

How do I use the pain relievers?

Use the medicine dose and frequency listed on the label. If this dose does not help, talk to your doctor. Talk to your doctor, nurse, or pharmacist any time you have a question about a medication.

What are the side effects of pain medicines?

Constipation	Nausea
Vomiting	Itching
Sleepiness	Drowsiness
Dizziness	Urinary retention



Hospice & Community Care

Approaching End of Life

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

Dr. Ira Byock, palliative care physician and long-time public advocate for improving care through the end of life, says that these four sentences carry enormous power. In many ways, they contain the most powerful words in our language. He also says that these four phrases provide us with a clear path to emotional wellness, and they guide us through the thickets of interpersonal difficulties to a conscious way of living that is full of integrity and grace.

Anticipatory Grief

Grieving usually begins soon after the diagnosis of a life-limiting illness is made. Patients, families, and friends grieve for the physical changes the patient is experiencing for the things they can no longer do, and for the shortened time they have with those they love.

Grief is natural. It is our human response to change or loss. It is painful.

How the pain of grief moves through the body, mind, and spirit is unique to each person. Sometimes you don't know why you feel empty, hurt, or sad. It helps just to say the words out loud to yourself and feel the emotion.

"Why me?"
"Where is God?"
"I don't want to talk to anyone."
"If the doctors and nurses had just done their job."
"I can't stop crying."
"I hate him."
"It hurts."
"I can't believe this is happening."
"Where did I go wrong?"
"Someone should be able to fix this."
"I hate what this is doing to me."
"What do I feel?"
"Why can't things just be the way they were?"

"Why now?"
"It can't be true."
"How can she leave me now?"
"I can't cry."
"Why can't I say what I feel?"
"What's the use?"
"I'm so empty, so numb."
"Is God punishing me?"
"I don't know what to do."
"When will the pain go away?"
"I feel so overwhelmed."
"I'm so tired."

Talk with someone. Call your social worker or chaplain, and say, “Help me understand my feelings. Where are they coming from?” These emotions are powerful and sometimes frightening. Talk and cry with someone. Crying helps move the feelings through the body. Tears are normal and precious.

Caregiving

Caring for yourself during this time is as important as the care you provide to others. We encourage you to utilize *all* members of your team; we find that families benefit if they allow all the team members to be involved.

When a family member develops a terminal illness, the entire family is affected. Additionally, the primary caregiver may experience increasingly stressful situations. Because of this, caregivers must develop methods of self-care to protect their own physical and emotional well-being. Small things can make a big difference.

Self-Care Suggestions

- Set priorities – complete the most important tasks first. Perform others as energy and time allow.
- Practice deep-breathing several times a day. Bringing more oxygen to every cell can refresh both body and mind.
- Take time for yourself. Ask friends to sit with the patient, and get out of the house on a regular basis.
- Be intentional about getting outside, even if just a few minutes each day. Walk around your yard, sit in your garden. Finding a quiet place allows you to relax for short periods.
- Continue to exercise regularly to help with stress management and boost your energy. Walking and stretching routines may be especially helpful.
- Eat a well-balanced diet. You may find it challenging to eat well if your loved one cannot. Remind yourself that food is fuel and you need it to stay strong.
- Drink plenty of liquids, especially water.
- Limit caffeine and alcohol as they may further drain your energy.
- Get adequate rest. Sleep is essential; nap and lie down when you can to re-energize.
- Determine if people visiting is helpful or creates more stress. It is okay to ask people to limit their visits. Ask your Hospice & Community Care team to help limit visitors, if needed.
- Allow friends to help with household duties such as dusting, changing beds, preparing meals, grocery shopping, and laundry.
- Make a new habit of writing down as much as possible. Even with the best intentions, you may make communication mistakes. Make notes on everything—phone messages, comments from friends, and questions you may have for the Hospice team.
- Get away. If you have a hobby, try to get to it at least twice a week. Run errands, go to a movie, take a walk, take a nap, and get out of the house. When you return, you will be better prepared to help your loved one.

- Share your feelings with someone you trust and who will listen - your minister, a friend, neighbor, family member, or your Hospice social worker. Sometimes you may feel frustrated, tired, and angry. Refrain from expressing those to the patient. Seek other support. Feelings expressed are feelings relieved.
- Do not be afraid to ask questions when you are unclear about care and safety instructions, medication management, etc. No question or concern is too small. You are a valuable member of your loved one's care team, and your concerns are valid.

Signs of caregiver stress

- Experiencing fatigue a great deal of the time
- Feeling overwhelmed, irritable, and out-of-sorts
- Sleeping far more or less than usual
- Noticeable weight fluctuations
- Losing interest in activities you enjoy

Too much stress, especially over a long time, may harm your health. As a caregiver, you're more likely to experience symptoms of depression or anxiety. Also, you may not get enough physical activity or eat a balanced diet, which increases your risk of medical problems.

Strategies for dealing with caregiver stress

The emotional and physical demands involved with caregiving can strain even the strongest person. These strategies may help you manage caregiver stress:

- **Accept help.** Prepare a list of tasks others may perform to help. One person may enjoy taking the patient on a walk a couple of times a week; another may pick up groceries or provide a meal.
- **Focus on what you are able to provide.** Don't give in to guilt. Feeling guilty is normal, and no one is a "perfect" caregiver. Do your best and let go of the rest. Housework and chores may have to wait; meals may consist of leftovers. Adjust your expectations for yourself and your surroundings.
- **Seek social support.** Make an effort to stay emotionally connected with family and friends. Set aside time each week for socializing, even if it is a walk with a friend. Many have identified that maintaining a strong support system is the key to managing stress associated with caregiving.

Dealing with Criticism

Receiving criticism is never a pleasant experience. Whether it is a sibling judging how you care for a relative or complaints from the person you are caring for, you may feel suddenly flooded with difficult emotions – perhaps anger, shame, or confusion.

We can't stop others from giving criticism. But we can become wiser about how to deal with it. Try these tips:

- **First, pause.** Criticism can feel like an attack. To avoid saying something you'll regret, stall with a remark such as, "Hmmm. That's an interesting comment."
- **Then, explore.** Without denying it or buying into it, get clarification. "Just to be sure I understand, you are concerned about how I ____?" or, "You would like me to ____?"
- **Consider what may be true.** Is Mom's checkbook actually a mess? Instead of crumbling in shame or being defensive, acknowledge what's yours. That sets a constructive tone. Say you'll look into some solutions. Or ask them to join you in finding solutions. Do they have specific suggestions about what to do differently? (Privately, remind yourself about all that you are doing well, too.)
- **Consider what may be theirs.** Is your sister's lashing out really deflecting her shame about doing so little for your mom? Or possibly, your dad's fault-finding represents his frustration with poor health. If so, disregard what's unfair and let it go. Calmly acknowledge the comment by saying, "Gotcha, Dad. I'll give that some thought."
- **Maintain appropriate boundaries.** Valid criticism focuses on something you've done, not on who you are. Meanness, such as being told, "You're lazy," is never okay. Set a limit: "I am happy to listen to feedback about how I do things, but not to judgments about me."
- **Turn it into an opportunity.** Ask the person who is criticizing to help with solutions by sharing or taking on the task himself or herself.

Respite Care

What is respite care?

There are times when caregivers need a break. Respite (or rest) care gives the caregiver the opportunity for time off or to attend a family event. Respite care supports the caregiver and

is part of the benefit provided by Medicare, Medicaid, and most insurances. Trained volunteers can provide respite care on a weekly or as-needed basis.

How is respite obtained?

The inpatient respite level of care is available to patients in a contracted facility or Hospice & Community Care's Patrick Hospice House on an as-needed basis. Situations indicating a need for respite care may include, but are not limited to, injury or impairment of the caregiver or the caregiver requests an interval (5 days or less) of rest or relief from providing regular care to the patient. The social worker or RN case manager assesses the need for respite care, arranges inpatient respite care with a contracted facility, arranges transportation if needed, and informs the rest of the team and necessary agency departments.

Respite can last up to 5 days and is offered as needed. The patient will receive all medications and treatments based on the hospice plan of care. The physician may stop by, but this is not necessary since team members will provide the facility with all necessary care instructions. Remember, when using respite care, the setting is different, but the care does not change.

How should the patient/caregiver prepare for respite?

Bring all medications (except narcotics) in labeled medicine bottles. Bring supplies, such as diapers, ostomy supplies, and dressing supplies. Pack the patient's belongings (brush, comb, toothbrush, etc.) as well as any clothing the patient wants.

How should the patient get to the facility?

If at all possible, the family should take the patient and pick them up. If this isn't possible, discuss transportation needs with the social worker and RN case manager on your team.

Preparing for Death

When people begin to accept their mortality and realize death is approaching, they may start to withdraw from their surroundings. Thus begins the process of separating from the world and those in it.

As each of our lives are unique, so are our deaths. Because of this, it is hard to predict specifics about what will happen at a person's death. As a caregiver, you may wonder about what will occur. The members of the Hospice team can help you prepare.

During the weeks and days before death, a person's condition typically declines. While it may be difficult for you, the patient is usually unconcerned about these changes. Some people exhibit a decline, then for some unexplained reason, may "rally" and their condition seems to improve a little. These roller-coaster changes can be emotionally and physically exhausting for the caregivers.

The dying process occurs in its own time, neither hastened nor slowed. The patient will continue to live until the body has completely shut down. As the body begins to deteriorate, a person simultaneously works through emotional and spiritual issues. This behavior is a normal and natural way a person prepares to die.

Following is only an outline of what you may expect as death approaches. We encourage you to talk freely with Hospice team members and use them as resources to explain what is happening to your loved one. Gathering information may reduce your anxiety and prepare you for the changes that will inevitably occur with your loved one.

One to two month:

- Social withdrawal - it is common for people to begin to withdraw from friends, family, and the world around them. They may engage less in conversations and activities they once enjoyed. This behavior may begin weeks before death as they feel the need to release themselves from their attachments. While the body is shutting down, emotional and spiritual work occurs. This work is natural as a person prepares to die. During this time, caregivers may feel helpless and begin their grieving.
- Less eating and drinking – As altered body chemistry produces a mild sense of euphoria, the body does a wonderful thing. The patient is neither hungry nor thirsty and is not suffering from this. Do not become anxious about this as it is an expected part of the end-of-life journey.
- Increased sleeping – As the body shuts down, the act of sleeping and resting increases. You may continue to talk and gently touch your loved one, even when you can see no reaction. Hearing is the last sense to leave the body.

One to two weeks

- Disorientation and confusion – Patients may talk to people who are not present. Let them talk about who they see or hear, as this could be meaningful to them. Be calm and reassuring. Too many visitors may become overwhelming.
- Physical changes that may occur:
 - changes in blood pressure and pulse
 - temperature
 - increased sleeping, yet still able to wake
 - eating or drinking less
 - tiredness and feeling of heaviness
 - pale or bluish skin
 - shallow or rapid breathing
 - chest congestion

Days to hours

- Sleeping the majority of the time, unresponsive/coma-like state
- An unexplained surge of energy – Patients often suddenly muster all their energy, and their condition appears to improve. Typically a short-lived event and should not be seen as the patient getting better. The rally is a final experience.
- The skin may become cold to the touch on feet, hands, and legs. Hands and feet may become purplish, and knees and elbows may become blotchy (mottled.) The patient may appear pale, grayish blue around lips and under the nail beds. Blood circulation is decreasing to the body's extremities. Provide warm blankets to keep the patient comfortable.
- Weak blood pressure and pulse.
- Darkened and less frequent urination – The patient may become incontinent and soil the bed.
- Mouth and eyelids no longer close completely, eyes become glassy.
- Respirations will change. The average is 16-20 breaths per minute.
 - Dyspnea or shortness of breath is rapid – heavy breathing.
 - Apnea is long pauses, 10 – 30 seconds between breaths may occur.
 - Cheyne-Stokes is alternating periods of apnea and deep, rapid breathing. This kind of breathing is not uncomfortable for the patient and is a response to the body's weakening condition. To help, elevate the head of the bed, turn the patient to one side, and use a fan to move air softly without blowing directly onto patient. Speak gently and offer reassurance.

- Long pauses between breaths - Changes in breathing and congestion tend to come and go. One minute these symptoms may be present, and the next minute it may be gone. The change in symptoms is normal. Talk to your Hospice team if you feel panicky or concerned.
- When you notice congestion, gently turn the patient's head from side to side to allow gravity to drain secretions. Avoid suctioning as it may cause discomfort.
- There may be moist sounding respirations and gurgling when breathing. Secretions collect in the back of the throat when the person has become weak and cannot swallow their saliva. While it may sound distressing, it does not indicate the patient is in pain or suffering.
- Fever and flushing - As the body becomes weaker, so does the temperature control center. The weakening may cause a fever and sweating. Gently wipe with a cool moist cloth. The patient may indicate feeling too warm and remove covers. If the patient is sweating, change the gown and sheets to keep dry. Consider opening a window or using a fan.

It may be helpful to clean the patient's lips and mouth several times a day. It is important to keep the lips and mouth as moist as possible. Use lip balm and not petroleum jelly.

Also, you may clean their eyes, face, and hands with a clean, warm, moist washcloth.

Saying "Goodbye"

Each person will have his or her own way of saying goodbye.

- It is okay to lie in bed with your loved one, holding hands and saying all the things you need to say. Love, kindness, and support are most important to your loved one.
- Take time to simply be still with your loved one. Be a good listener, be kind, honest, flexible, and patient.
- Tears are normal, let them flow. Take time for yourself away from the patient if you feel out of control.
- Let your loved one know he or she will be missed and not forgotten.
- Say goodbye in the manner you wish – do not worry about what you say or do.
- Continue to sit with the patient, maintaining a touch or holding the patient's hand, even when there seems to be no awareness.
- Consider music for the environment.
- Dying may take hours or days. The signs may appear and disappear.
- You are not alone. Hospice can offer extra support during this difficult time. Talk with your Hospice team about options.
- As the last moments approach, give your loved one permission to go when ready.

Signs of death

You will know your loved one has died when:

- Breathing stops – When breathing has nearly ceased, your loved one could have an infrequent gasp of breath.
- There is no pulse.
- There is no response to your voice or touch.
- Eyes and mouth may become slightly open – you may wish to close the eyes and prop the head up on a pillow.
- Loss of bowel and bladder control.

When Death Occurs

1. When you notice significant changes or the signs of death, call Hospice & Community Care 803-329-1500 or 800-895-2273. A Hospice nurse will respond to your call at the time of death. Please try to keep the phone line clear until the nurse returns your call. The nurse will visit to confirm that death has occurred and will assist you with additional relevant needs.

Do not call 911 or emergency services. If an emergency crew responds, they will attempt to resuscitate the patient and may transfer the patient to the local hospital.

2. When the Hospice nurse arrives, she will examine the patient, confirm the patient has died, and make the necessary notifications. The doctor does not visit, nor is the patient's body taken to the hospital. You do not need to notify any authorities. The nurse will call the coroner's office and the doctor. Deaths that occur in the home require a coroner visit.
3. Your loved one can stay in the home until everyone is ready for the funeral home to come; the Hospice nurse will place the call to the funeral home also.
4. You may wish to call family members, neighbors, and friends. The Hospice nurse can help you with this
5. The Hospice nurse will prepare your loved one's body by bathing and removing any tubes.
6. The nurse or Hospice team member will remain with you until the funeral home staff come to take the patient's body to the funeral home if desired. At that time, the funeral home will set a time with you to make final arrangements unless previously completed.
7. The Hospice nurse will gather supplies and small equipment that was brought to your home (to get it out of the way, so you don't have to be concerned about returning it.) The nurse will call the equipment company to arrange a pick up for any large equipment. Equipment companies will call in the following days to arrange a convenient time to pick up equipment. If you do not get a call from the equipment company within two days, call Hospice.

8. Hospice is responsible for the medication in the home that Hospice purchased. It is our responsibility to count any medications left and destroy them (a family member will need to witness this and sign that it was completed.)
9. After the death of a loved one, A Hospice bereavement counselor will be available during your time of grief. The bereavement counselor will call to give you support and schedule an appointment to meet if you would like. Grief takes its own time and expresses itself differently in each person. Your counselor can help you understand and deal you're your feelings and experiences. A choice of grief education is available to you.

The Following Days

We strive to provide exceptional care. Once you're loved one no longer needs Hospice care, you will receive a survey from the Consumer Assessment of Healthcare Providers and Systems (CAHPS.) Developed by the Centers for Medicare & Medicaid Services, it measures your satisfaction relative to our quality of service. Healthcare First, our survey partner, is the company that sends you the survey. *Your opinion is important to us, and we would appreciate your feedback.*

Grief and Bereavement

Hospice & Community Care Bereavement Services

After the death of a loved one, you may experience many feelings and emotions. It is now time to take care of you, knowing that you gave a gift of dying with dignity and integrity to your loved one. We commend you for all you have done to surround the patient with understanding, comfort, and calm, enabling them to leave this world with a sense of peace and love.

Our Bereavement Team will continue to provide services to you, as the caregiver and to other family members as needed. Services consist of supportive correspondence and educational materials sent out at intervals during the first thirteen months of bereavement.

In addition, we provide support groups and grief seminars. These groups nurture you as you enter a new phase of your life, offering guidance, tactics for managing grief, fellowship, and understanding. They are free and open to anyone who has suffered a loss.

If you are the parent, grandparent, older sibling, or close family friend, you play an essential role in helping a child/teen cope with death. Guiding children/teens toward understanding and accepting their feelings surrounding death may promote healing from their grief. Hospice & Community Care can offer additional support, so please notify a staff member if a child or teen might benefit from these services.

Hospice & Community Care can be a resource for you and your family after the death of a loved one. Our bereavement counselors offer the following services:

- Listening and talking with you
- Grief support groups
- Education and information about grief and the healing process
- Community workshops and programs on grief and loss
- Special services and activities for children and adolescents

After you have completed the Hospice & Community Care grief support program (about 14 months following the death), Healthcare First will mail you another survey called the Family Evaluation of Bereavement Services. This survey is written by the National Hospice and Palliative Care Association. Your feedback will help us to better understand the needs of our families and our ability to address them.

To learn more about the services of our bereavement services, call 803-329-1500 or email info@hospicecommunitycare.org

Visit our website HospiceCommunityCare.org for additional online grief resources.

NOTES



ADDITIONAL RESOURCES

This section offers additional resources that may be helpful while receiving hospice services. If you or any family members have questions, please ask the Hospice & Community Care staff to explain the information and assist in utilizing this section.

As a part of Hospice & Community Care's regulations and accreditation, from time to time, you may be asked for a surveyor to be present for a visit. Please be aware this is to help us ensure the highest quality of care possible. Before the visit, you would be asked for permission, and the surveyor would also present an identification badge upon arrival.

Hospice & Community Care is committed to providing the highest quality care to patients and their loved ones, and we believe in collecting feedback from those we serve because we continually strive to improve our performance. If at any time during our service you would like to express a concern, complaint, or compliment, we encourage you to speak directly with one of your care team members, call our office or contact us by mail.

We also seek to improve our services by conducting satisfaction surveys with our patients and their loved ones. These surveys will be mailed to you by Deyta, our contracted associate, in an effort for your response to remain anonymous. When responding to our surveys, we hope that you will offer honest feedback concerning the ways that we can improve our services. Your comments help us provide care that is sensitive to and addresses the needs and wishes of our patients and their loved ones.

Hospice & Community Care
PO Box 993
Rock Hill, SC 29731
803-329-1500 or 800-895-CARE

Advance Planning

As an adult, you make decisions every day, from simple to complex choices about your home, career, and life. You plan for a special vacation, a birth or a wedding, or a trip to the grocery store. An important choice that you might not have thought about is your choice for health care in the future. Technology and medical advances have given us more and more options.

How would you like to be treated if you are seriously ill? Decisions like these are best made before there is a health crisis. Advance Care Planning includes:

- Understanding possible future health care decisions
- Thinking about choices in light of what is important to you
- Talking with your loved ones and healthcare providers
- Putting your plans in writing

Planning for this choice—now, while you are able—is a gift you can give to yourself and those you love. Having a plan will make it easier for you, your doctor, and your loved ones if decisions about treatment ever need to be made at a time when you are unable to do so.

Thinking about your living and dying brings opportunities to leave a legacy, strengthen relationships, and grow spiritually. Some ideas for leaving a legacy include teaching a skill to a young person, writing about your beliefs or life lessons, and making a video of stories about your childhood, family event, and memories.

Your preparation for your final phase of life may include becoming more familiar with your traditions surrounding the end of life. Talking with religious leaders, respected elders or loved ones may give ideas for making this time rich with meaning.

Conversations with those you love and care for you are important as you make decisions about your health care. Decisions should be based on your wishes and values, but they need not be made alone.

The patient, to start a conversation, could say to the family: “This is hard for me to talk about, but I need to tell you what I would and would not want in specific situations.”

Or, the family could begin by saying: “This is hard for me to talk about, but I really want to respect and carry out your wishes. I need to know what you want me to do in certain situations.”

Once the dialogue begins, plans can be made. You may find that this is a very special time of family sharing. After decisions are made, there is a sense of relief, and you can focus on living as fully and comfortably as possible.

Your Hospice & Community Care medical social worker can help guide you through this process.

Financial Matters

Important financial activities may include establishing a will, appointing a power of attorney, and gathering information about bank accounts, life insurance, deeds and titles to property, other assets, outstanding loans, and information regarding military service. Your medical social worker can provide additional information.

Health Care Directives

Advance Directives

Advanced Directives is a common term for several documents completed by a patient describing treatments that should or should not be given, or identifying a person(s) who can make medical decisions in the event the patient is unable to speak for him or herself.

Health Care Power of Attorney

Health Care Power of Attorney, also referred to as a health care proxy or medical durable power of attorney, is a legal form that authorizes a person of the patient's choice to make health care decisions for the patient if he/she is unable to do so.

Living Will

A Living Will is a guide to help others determine what medical treatments you would or would not want if you were dying. Technology and medical advances have given us more and more choices. It is important to understand the benefits and burdens of treatment decisions and make a decision based on your value system.

The Hospice team will ask to view these advance care documents if you already have them in place. If you have not completed them and would like to do so, your social worker can help. It is important to note that you can always change your mind about future choices. As long as you are able to make decisions, your plans can be changed. Our program does not require that you have these documents.

Do Not Resuscitate

A Do Not Resuscitate (DNR) form is another document that the Hospice team will ask you about. It is a document that specifically tells a health care team not to attempt CPR (cardiopulmonary resuscitation) if your heart and breathing stop. It is particularly important to have this document to show Emergency Medical Services (EMS) personnel and to take it with the patient in the event of ambulance transportation if CPR is not desired.

We suggest a copy be placed near the head of the patient's bed or on the refrigerator for quick access.

While decision-making capacity and communication are clear, you should discuss feelings about dying at home. While the majority of individuals and families want death to occur at home, some may prefer the time of death occur in a hospital, Hospice Home, or nursing home, if possible. Share your feelings with the Hospice team. We will do our best to have your wishes honored.

Sometimes those who are ill want to help plan their **obituary** and **funeral** in great detail while others provide little input. Often families find they are better at making sound decisions about final arrangements before the death occurs.

And finally, it may be helpful for the caregiver to be informed about what to expect in the last few weeks of life so that you can prepare. Although it is difficult to predict precisely when a terminally ill person will die, a combination of signs and symptoms can signal the time is getting close. Not all symptoms will appear at the same time, and some may never appear. However, many caregivers find that it is helpful to understand what to expect and to know a symptom is common during the dying process.

For additional information about advance directives including downloadable forms, visit www.caringinfo.org

Additional Resources

Five Wishes

Five Wishes communicates your wishes to family, friends, and health care providers, including your choice to receive or decline specific treatments, what you want loved ones to know, and who you want to designate to make sure your wishes are followed.

The Health Care Power of Attorney and Living Will

These documents are available at no cost from a variety of organizations including <https://aging.sc.gov/programs-initiatives/legal-assistance-seniors>

Grief Words

HospiceCommunityCare.org contains access to various articles on grief and loss. These articles are free for access to the community.

Veteran Benefits

Hospice & Community Care patients that are Veterans may desire additional information about Veteran benefits. Your care team is available to help families navigate Veteran benefits that they may be eligible for as a result of their service.

Hospice Resale Shops

Your loved one's personal and household belongings are special, and parting with them can be one of the hardest things to face after their death. Sorting through and deciding what to do with clothing, furniture, and other items, while part of the grieving process, is often emotional and can be overwhelming. We are here if you need help.

For your convenience and support, Hospice & Community Care can help by picking up large furniture, appliances, boxed household items, and bagged clothing for donation to the Hospice Resale Shop. Donating items to the Hospice Resale Shop is a great way to honor the memory of your loved one and ensure that the items will continue to be valued and cared for in the future. And your donations make a difference in the lives of others as all proceeds from the Hospice Resale Shop are used to make care possible for other Hospice & Community Care patients and their families.

The Hospice Resale Shop accepts donations during business hours at the store in downtown Rock Hill and Lancaster from 10 a.m. to 5 p.m., Monday through Friday and Saturdays from 11 a.m. - 2 p.m. For assistance with large item pick-up or for more information on how we can help, please call or email us at 803-329-1500 or info@HospiceCommunityCare.org

Rock Hill Resale Shop

145 E. White Street
Rock Hill, SC 29732
803-980-5200

Lancaster Resale Shop

121 S. Main Street
Lancaster, SC 29730
803-283-1101

Medicare Hospice Benefits

Your Medicare hospice benefit covers your care, so you shouldn't have to go outside of hospice to get care (except in very rare situations). Once you choose hospice care, your hospice benefit should cover everything you need.

All Medicare-covered services you get while in hospice care are covered under Original Medicare, even if you were previously in a Medicare Advantage Plan (like an HMO or PPO) or other Medicare health plan.

You must pay the deductible and coinsurance amounts for all Medicare-covered services to treat health problems that aren't part of your terminal illness and related conditions. You also must continue to pay Medicare premiums, if necessary.

If you have Medicare Part A (Hospital Insurance) **AND** meet these conditions, you can receive hospice care:

- Your hospice doctor and your regular doctor (if you have one) certify that you're terminally ill (with a life expectancy of 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.

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.

Medicare will cover the hospice care you get for your terminal illness and related conditions, but the care you get must be from a Medicare-approved hospice program.

Important: Once you choose hospice care, your hospice benefit should cover everything you need. Original Medicare will still pay for covered benefits for any health problems that aren't part of your terminal illness and related conditions, but this is very rare.

Hospice care is usually given in your home. 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 (such as a family member) needs a 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 it is only provided on an occasional basis.

What Medicare Won't Cover

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

- **Treatment intended to cure your terminal illness 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** – There are exceptions 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 receive 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 provider unless you change your hospice provider. However, you can still see your regular doctor 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 in an emergency room, inpatient facility care, 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.

Medicare Advantage Plan or Other Medicare Health Plan

A Medicare Advantage Plan (like an HMO or PPO) is a type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance) benefits.

Original Medicare covers all Medicare-covered services you get while in hospice care, even if you were previously in a Medicare Advantage Plan or other Medicare health plan. Once you choose hospice care, your hospice benefit should cover everything you need. Original Medicare will still pay for covered benefits for any health problems that aren't part of your terminal illness and related conditions (this is very rare).

You can choose to get Medicare-covered services that aren't part of your hospice care through your Medicare Advantage Plan or Original Medicare. 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 additional services as long as you continue to pay your premium.

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 should call 1-877-486-2048.

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 will also 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:

- **A copayment of up to \$5 per prescription for outpatient prescription drugs for pain and symptom management.**

In the rare instance your medication isn't covered by the hospice benefit, your hospice provider should contact your Medicare drug plan to see if it's covered under 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.

How Long You Can Get Hospice Care

Hospice care is intended for people with a life expectancy of 6 months or less (if the disease 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 (with a life expectancy of 6 months or less).

Important: Hospice care is given in benefit periods. You can get hospice care for two 90-day periods, followed by an unlimited number of 60-day periods. At the start of each period, the hospice medical director or another hospice doctor must recertify that you're terminally ill (with a life expectancy of 6 months or less), 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 period ends. **Note:** You have the right to change providers 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 discontinue hospice care at any time for any reason.

If you stop your hospice care, you'll get the type of Medicare coverage you had before you chose a hospice program, like Original Medicare, a Medicare Advantage Plan (like an HMO or PPO), or another type of Medicare health plan. If you're eligible, you can go back to hospice care at any time.

Example: Mrs. Jones has 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. 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 returns to 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.

Your Medicare Rights

People with Medicare have certain guaranteed rights. If your hospice program 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 should give you a notice that explains your right to an expedited (fast) review by an independent reviewer hired by Medicare, called a Beneficiary and Family Centered Care Quality Improvement Organization (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.

You can also 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 should call 1-877-486-2048.

Note: If you pay out-of-pocket for an item or service your doctor ordered, but the hospice refuses to give it to you, you can file a claim with Medicare. If your claim is denied, you can file an appeal.

For more information on appeals, visit [Medicare.gov/appeals](https://www.medicare.gov/appeals) or call 1-800-MEDICARE.

For information about how to file a complaint about the hospice that's providing your care, visit [Medicare.gov/claims-and-appeals/file-a-complaint/complaints.html](https://www.medicare.gov/claims-and-appeals/file-a-complaint/complaints.html) or call 1-800-MEDICARE.

For More Information

You can get 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 should 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 program**, 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.
- **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 [Medicare.gov/contacts](https://www.medicare.gov/contacts) or call 1-800-MEDICARE.
For more information about hospice, contact these organizations:
- **National Hospice & Palliative Care Organization (NHPCO)**—Visit nhpco.org, or call 1-800-646-6460.
- **Hospice Association of America**—Visit naahc.org/haa, or call 1-202-547-7424.

Definitions

Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO)

A type of QIO (a group of doctors and other health care experts under contract with Medicare) that reviews 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.

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.

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, 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, it is 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)

Part D is 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

It is Medicare Supplement Insurance sold by private insurance companies to fill “gaps” in Original Medicare coverage.

Original Medicare

Original Medicare is fee-for-service coverage under which the government pays your health care providers directly for your Part A and Part B benefits.

Premium

Premium is a 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)

SHIP is a state program that gets money from the federal government to give free local health insurance counseling to people with Medicare.

TTY

A TTY (teletypewriter) is a communication device used by people who are deaf, hard-of-hearing, or have a severe speech impairment. People who don’t have a TTY can communicate with a TTY user through a message relay center (MRC). An MRC has TTY operators available to send and interpret TTY messages.

Area hospice organizations

South Carolina

Carolinas Center for Hospice & End-of-Life Care

1-800-662-8859

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Medicare & Medicaid Services 7500 Security Boulevard
Baltimore, Maryland 21244-1850

PATIENT/FAMILY RIGHTS

“A patient has the right to be informed of his or her rights, and the hospice must protect and promote the exercise of these rights.”

Hospice Medicare Conditions of Participation (CFR 418.52, Subpart C, 418.52)

Hospice & Community Care “Hospice” shall comply with all relevant federal, state, and local laws and regulations related to patient care and protections, *e.g.*, Title VI, Section 601 of the Civil Rights Act of 1964, Americans with Disabilities Act (ADA), and ensure that there is no discrimination with regard to source of payment, recruitment of potential patients, location of patients, or provision of care, treatment, and services to patients. Care shall not be discontinued or diminished due to the inability to pay for the care until provisions can be made for the transfer of the patient.

You have the support and protection of all basic human, civil, and legal rights in all care that Hospice & Community Care provides. You have the right to receive appropriate, respectful, and professional hospice services/treatment regardless of race, religion, color, sex, age, disability, ethnic background, diagnosis, or ability to pay. The patient’s family or guardian may exercise the patient’s rights if the patient has been judged incompetent.

Quality end-of-life care will be provided. The following rights shall be guaranteed to the patient/family, and, at a minimum, Hospice & Community Care shall provide a written and verbal explanation of these rights:

Hospice Care and Services

- Choose a hospice provider.
- Exercise one’s rights as a patient of the Hospice and be free of discrimination or reprisal for exercising those rights.
- Be fully informed of one’s responsibilities.
- Receive information about the services covered under the hospice benefit.
- Choose an attending physician or another authorized healthcare provider.
- Be informed of care to be provided and the opportunity to participate in care and treatment and to be informed about, and updated on changes in condition.
- Receive information about the scope of services that Hospice will provide and specific limitations of those services.
- Freedom from mistreatment, abuse (physical, verbal, sexual, or mental) including injuries of an unknown source, neglect, and exploitation.
- Freedom of physical restraint through the use of medications unless they are prescribed by a physician.
- Participate in the development and periodic revision of the Plan of Care.
- Be informed of anticipated outcomes of care and any barriers in achieving the outcomes.
- Be fully informed in advance about care/service to be provided, including the disciplines that furnish care and the frequency of visits, as well as any modifications to the Plan of Care.

- Have one's property and person treated with respect, consideration, and recognition of the patient's dignity and individuality.
- Respect and security for the patient's property and in a hospice facility for the patient to keep personal possessions as space permits, unless it interferes with the rights and safety of other patients;
- Receive effective pain management and symptom control from Hospice for the terminal illness and related conditions.
- Receive appropriate service/care without discrimination in accordance with physician orders.
- Refuse care or treatment after the consequences of refusing care or treatment are fully presented.
- Refuse to participate in experimental research.
- Be able to identify visiting personnel members through proper identification, and upon request, receive information about the relation to Hospice or other agencies.
- Respect and dignity in receiving care, including privacy in receiving treatment or personal care.
- Be informed of Hospice's twenty-four-hour on-call service.
- You have the right to any information necessary to assist in making decisions about your care and the right to participate in consideration of ethical issues that may arise.

Language Services

- Receive verbal and written notice of the Patient's Rights and Responsibilities in a language and manner that is understandable.
- Receive interpretative services when the predominant language of the community is not spoken or understood.
- For a minor or a patient needing assistance in understanding these rights and responsibilities, both the patient and the parent, legal guardian, or other responsible representative are fully informed of these rights and responsibilities.

Advance Directives

- Be informed, both orally and in writing, of patient rights under South Carolina law to formulate Advance Directives.
- You have the right to formulate an advance directive without fear of discrimination. Staff will discuss and provide written information about the organization's policies and procedures on advance directives. You have the right to be informed of Hospice & Community Care policies about resuscitative services and aggressive treatments.

Privacy

- Confidentiality and privacy of all information contained in the patient record and of Protected Health Information.
- Be advised of the Hospice's policies and procedures regarding the disclosure of clinical records.
- Receive a copy of Hospice's Notice of Privacy Practices.

Charges

- Be informed, both verbally and in writing, in advance of care being provided, of the extent of charges, including payment for care/service expected from third parties and any charges for which the patient will be responsible.
- Be informed of any financial benefits when referred to a Hospice.

In the Patrick Hospice House

- To choose meals/food as desired.
- Immediate access to family members, other relatives, or responsible party without restriction or unreasonable delay
- Privacy in visits, including the right to associate and communicate privately with people of the patient's choice, including spousal visits of a conjugal nature.
- Receive visitors at any reasonable hour, including small children.
- Privacy when sending or receiving mail. The Hospice shall not open and read mail without patient permission either when received or prior to being mailed.
- To share a patient room, unless contraindicated by their attending physician.
- To receive a refund based on the actual number of days a patient is physically in the hospice facility (along with bed-hold days). The patient or responsible party shall be informed of the refund policy in writing at the time of admission and shall be notified in writing anytime the policy is changed.
- Patients being transferred or discharged for medical reasons or the welfare of the patients or the welfare of other staff or patients must be given written notice of not less than ten (10) days prior to transfer or discharge. When the health, safety, or well-being of the patient or other patients in the facility would be endangered by the ten (10) day notice requirements, the time for given the notice shall be that which is practicable under the circumstances. A patient being transferred or discharged due to a change in his or her condition and who no longer qualifies for hospice care shall be given written notice of not less than forty-eight (48) hours.

Grievances

- Voice complaints regarding treatment that is (or fails to be) furnished on behalf of the Hospice and lacks respect for property.
- Have grievances/complaints regarding treatment or care that is (or fails to be) furnished and lack of respect of property investigated.
- The Hospice shall inform the patient or responsible party in writing of the grievance procedure should the patient consider one or more of his or her rights violated.
- Voice grievances and recommend changes in policy, staff, service or care without recrimination. This can be done by contacting the Chief Executive Officer (CEO) of Hospice & Community Care. You may also complete the Patient/Family Grievance Form and mail it to the Hospice & Community Care CEO. An investigation will be completed in regards to the concern.

Hospice & Community Care

2275 India Hook Road

Rock Hill, SC 29732

803-329-1500 or 800-895-CARE (24 hours/7 days)

- The patient rights, the grievance procedure, and other notices as required by law shall be prominently displayed in public areas of the hospice facility. Included in the grievance procedure shall be the address and phone number of the Department of Health and Environmental Control - Bureau of Health Facilities Licensing.
- If you do not have your grievance resolved with Hospice & Community Care, contact the **SC Department of Health and Environmental Control, Bureau of Health Facilities Licensing, 2600 Bull Street, Columbia, SC 29201-1708 or call the Hotline at 1-800-922-6735 or 803-545-4370**. A grievance can be mailed to the above address or call the office during normal business hours, or use the Hotline number. The purpose of the Hotline is to receive complaints and to answer questions about local Home Care agencies. The Hotline may be called 24 hours a day.
- The Hospice shall not retaliate against a patient who exercises his or her right to complain about a violation of his or her rights, such as, increasing charges, decreasing the services received; taking away any privileges; use of abuse, threatening language, or trying to force a patient to discontinue Hospice care or leave a Hospice Facility.

Patient/Family Responsibilities

- Name a person available to serve as the primary caregiver or commit to establishing a plan with Hospice to ensure caregiving needs are met. Inform Hospice of changes in persons providing care for the patient.
- Provide accurate financial, medical history, and other information to Hospice.
- Inform Hospice of any changes in the patient's medical condition and new appointments with physicians or treatments/medications.
- Cooperate with Hospice in efforts to plan and provide safe care for the patient.
- Provide a safe environment in which Hospice can deliver appropriate care.
- You are responsible for following the agreed-upon Plan of Care or for discussing any changes that you may desire in the plan with your nurse or social worker.
- Inform Hospice of plans to leave the service area so that preparations can be made to ensure continuity of care.
- Treat all persons providing Hospice care with dignity and respect, refraining from the use of profane and foul language, inappropriate gestures or touch, and threatening language or behavior.
- Inform Hospice of any changes in insurance or financial status that may affect the patient's financial responsibility for Hospice charges. You are responsible for making payment for services not provided by Hospice & Community Care.
- You are responsible for the duties identified as yours in the care planning process. These duties will be explained as they arise.

Revised: 05/08, 10/08, 09/11, 02/13, 02/17

Privacy Practices

THIS NOTICE DESCRIBES HOW HEALTH INFORMATION ABOUT YOU AS A PATIENT OF HOSPICE & COMMUNITY CARE MAY BE USED AND DISCLOSED, AND HOW YOU CAN GET ACCESS TO YOUR INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION. PLEASE REVIEW THIS NOTICE CAREFULLY.

Protecting the privacy and security of information about your health is a responsibility we take very seriously. We are committed to the practices and procedures established by *Hospice & Community Care* to protect the confidential nature of information about your health.

USES AND DISCLOSURES OF INFORMATION ABOUT YOUR HEALTH WITHOUT YOUR AUTHORIZATION

The following categories describe different ways that we may use and disclose the minimum necessary amount of information about your health without your written authorization. We are including examples. Although we have attempted to make this thorough, not every use of disclosure in a category can be listed.

TO PROVIDE TREATMENT

Your protected health information may be used to provide, coordinate or manage your health care and any related services by *Hospice & Community Care* team members such as your physician, pharmacist and suppliers of medical equipment, and other healthcare professionals who have agreed to assist *Hospice & Community Care* in coordinating your medical care. Your protected health information may be disclosed

to individuals involved in your care, such as family members and clergy whom you have designated. We also contact our patients' families about support services and educational opportunities.

TO OBTAIN PAYMENT

Hospice & Community Care may use your protected health information to collect payment for the care that you received from us. For example, we may be required by your health insurer to provide information regarding your health care status so the insurer will reimburse you or Hospice. We also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for Hospice care.

TO CONDUCT HEALTH CARE OPERATIONS

To facilitate the function of Hospice and provide quality care to all Hospice patients, we may use and disclose protected health information for our own operations. Health care operations include, but are not limited to: agency administrative activities, training programs in which students learn under supervision, audits, licensing reviews, quality assessment, and performance improvement activities, for notification and disaster relief purposes, and employee review activities.

For example, Hospice may use your protected health information to evaluate its performance, combine your protected health information with other hospice patients in evaluating how to serve all hospice patients more effectively, disclose your protected health information to members of the hospice workforce for training purposes, contact you as a reminder regarding a visit, or

contact you as part of general fundraising and community information mailing (unless you tell us you do not want to be contacted). We may share your protected health information with third-party business associates that perform administrative and other services (i.e., billing or transcription services) for *Hospice & Community Care*. Whenever an arrangement between our office and a business associate involves the use or disclosure of your protected health information, *Hospice & Community Care* will have a written contract with each of the business associates containing terms requiring them to protect the confidentiality of your information to the same extent *Hospice & Community Care* is required to protect the privacy of your protected health information.

FOR MARKETING & FUNDRAISING ACTIVITIES

Hospice & Community Care may use information about you, including your name, address, dates you received care, name of attending physician, insurance status, and other demographic information to contact you or your family for financial support of the organization. If you do not want the organization to contact you or your family, notify the development department at (803) 329-1500 or (800) 895-2273 or by email at info@hospicecommunitycare.org and indicate you do not wish to be contacted.

IN THE PATRICK HOSPICE HOUSE FACILITY

In the Patrick Hospice House facility, *Hospice & Community Care* may disclose certain information about you, including your name, your general health status, religious affiliation, and room location. We may disclose this information in the Patrick Hospice House Directory to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.

WHEN LEGALLY REQUIRED

When required to do so by any Federal, State or local law, Hospice will disclose your protected health information. Your information may be disclosed to the Department of Health and Human Services for HIPAA investigative and enforcement purposes.

WHEN THERE ARE RISKS TO PUBLIC HEALTH

Hospice & Community Care may disclose your protected health information in order to report disease, exposure to a communicable disease, injury, disability, vital events such as birth or death, adverse events, or product defects. It may also be disclosed to track products, enable product recalls, repairs, and replacement, and in compliance with requirements of the Food and Drug Administration.

TO REPORT ABUSE, NEGLECT OR DOMESTIC VIOLENCE

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

TO CONDUCT HEALTH OVERSIGHT ACTIVITIES

Hospice & Community Care may disclose your protected health information to a health oversight agency for activities including audits, civil, administrative or criminal investigations, inspections, licensure, or disciplinary action. Hospice, however, may not disclose your protected health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

IN CONNECTION WITH JUDICIAL AND ADMINISTRATIVE PROCEEDINGS

If you are involved in a lawsuit or a dispute, *Hospice & Community Care* may disclose your protected health information in response to a court or administrative order. We also may disclose this information in response to a subpoena, discovery request, or other lawful processes by someone else involved in the dispute. We will make reasonable efforts to either notify you about the request or to obtain an order protecting your protected health information.

FOR LAW ENFORCEMENT PURPOSES

Your protected health information may be disclosed to

a law enforcement official in response to a court order, warrant, summons, subpoena, or similar process. We may also release information about your health to law enforcement for certain types of physical injuries, to identify or locate a suspect, fugitive, material witness, or missing person, under certain limited circumstances when you are the victim of a crime, if *Hospice & Community Care* has the suspicion that your death was the result of criminal conduct, or in an emergency to report a crime.

TO CORONERS AND MEDICAL EXAMINERS

Hospice & Community Care may disclose your protected 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

Hospice & Community Care may disclose your protected health information to funeral directors consistent with applicable laws and, if necessary, to carry out their duties with respect to your funeral arrangements. If necessary, Hospice may disclose your protected health information prior to and in reasonable anticipation of your death.

FOR ORGAN, EYE OR TISSUE DONATION

Hospice & Community Care may use or disclose your protected health information to cadaveric organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for whom you have designated.

FOR RESEARCH PURPOSES

Under very select circumstances, we may use your protected health information for research. *Hospice & Community Care* will ask your permission if any researcher will be granted access to your individually identifiable health information.

IN THE EVENT OF A SERIOUS THREAT TO HEALTH OR SAFETY

Consistent with applicable laws and ethical standards

of conduct, *Hospice & Community Care* may disclose your protected health information if we, in good faith, believe that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or the health and safety of the public.

FOR SPECIFIED GOVERNMENT FUNCTIONS

In certain circumstances, federal regulations authorize *Hospice & Community Care* to use or disclose your protected health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations, and inmates in law enforcement custody.

WORKERS' COMPENSATION

We may release your protected health information as authorized to comply with worker's compensation laws and other similar legally-established programs.

USES AND DISCLOSURES OF INFORMATION ABOUT YOUR HEALTH WITH YOUR AUTHORIZATION

Other than what is previously stated, *Hospice & Community Care* will only disclose your protected health information with your written authorization. You may revoke that authorization in writing at any time. If you revoke your authorization, we will no longer use or disclose your protected health information for the reasons covered by your written authorization except to the extent that action has already been taken. Please understand that we are unable to rescind any disclosure already made under the authorization.

YOUR RIGHTS WITH RESPECT TO YOUR PROTECTED HEALTH INFORMATION

You have the following rights that are listed below.

All requests must be in writing and submitted to:

Privacy/Security Officer

Hospice & Community Care

P.O. Box 993

Rock Hill, SC 29731.

RIGHT TO REQUEST RESTRICTIONS

You may request restrictions and limitations on certain uses and disclosures of your protected health information. You have the right to request a limit on the organization's disclosure of your protected health information to someone who is involved in your care or the payment of your care. *Hospice & Community Care* must comply with an individual's request to not disclose protected health information to a health plan for payment where *Hospice & Community Care* has been paid in full, out-of-pocket, at the time of services. *Hospice & Community Care* may not be able to meet your request and may break the agreement in specific emergencies.

RIGHT TO RECEIVE CONFIDENTIAL COMMUNICATIONS

You have the right to request that *Hospice & Community Care* communicate with you in a certain way. For example, you may ask that Hospice only conduct communications pertaining to your protected health information with you privately, with no other family members present. If you wish to receive confidential communications, please notify *Hospice & Community Care*. We will not request that you provide any reasons for your request. *Hospice & Community Care* will attempt to honor your reasonable requests.

RIGHT TO INSPECT AND COPY YOUR HEALTH INFORMATION

You have the right to inspect your protected health information, with limited exceptions. To access your information, you must submit a written request detailing the information you would like to access that specifies whether you would like to inspect or obtain a copy of the information. If you request a copy of your protected health information, Hospice may charge a reasonable fee for copying and assembling costs associated with your request. You have a right to receive your protected health information electronically. *Hospice & Community Care* may deny your request for access under limited circumstances.

RIGHT TO AMEND HEALTH CARE INFORMATION

If you or your representative believes that your protected health information records are incorrect or incomplete, you may request that *Hospice & Community Care* amend the records. That request may be made as long as your record is maintained by Hospice. *Hospice & Community Care* 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 protected health information records were not created by the organization, the records you are requesting are not part of the Hospice's records, the protected health information you wish to amend is not part of the health information you or your representatives are permitted to inspect and copy, or, in the opinion of the organization, the records containing your protected health information are accurate and complete. Individuals can submit a statement of disagreement if *Hospice & Community Care* refuses to change the medical record.

RIGHT TO AN ACCOUNTING OF DISCLOSURES

You or your representative have the right to request an accounting of disclosures of your protected health information made by *Hospice & Community Care* for any reason other than for treatment, payment, or health operations. This request for an accounting must be made in writing to the Privacy/Security official and should specify the time period for the accounting. Requests may not be made for periods in excess of six years. We will provide the first accounting you request during any 12-month period without charge. Subsequent requests may be subject to a reasonable cost-based fee.

RIGHT TO RECEIVE NOTICE OF A BREACH

Hospice & Community Care will notify you if your protected health information has been acquired by an unauthorized party.

RIGHT TO A PAPER COPY OF THIS NOTICE

You or your representative have the right to obtain a paper copy of this Notice from us at any time. You or your representative may also obtain a copy electronically or view the current version of the organization's Notice of Privacy Practices at www.HospiceCommunityCare.org

DUTIES OF HOSPICE & COMMUNITY CARE

Hospice is required by law to:

- *Maintain the privacy & security of your protected health information
- *Provide to you and your representative this Notice of our duties and privacy practices
- *Abide by terms of this Notice, as subject to amendment from time to time

CHANGES TO THIS NOTICE

Hospice & Community Care reserves the right to change this Notice. If we change this Notice, *Hospice & Community Care* will provide a copy of the revised Notice to you or your appointed representative. The Notice will contain the effective date.

TO FILE A COMPLAINT

You or your representative have the right to express complaints to *Hospice & Community Care* and the Secretary of Health and Human Services if you or your representative believe that your privacy rights have been violated. Any complaints to *Hospice & Community Care* should be made in writing to the Privacy/Security Officer. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against for filing a complaint.

All issues regarding patient privacy and your rights under the Federal Standards should be directed to our Privacy/Security Officer:

Jane Armstrong

PO Box 993

Rock Hill, SC 29731

Phone: (803) 329-1500 or (800) 895-CARE.

You may also contact the Department of HHS:
US Department of HHS,

Attn: OCR Regional Manager, Sam Nunn
Atlanta Federal Center, Suite 16T70

61 Forsyth Street S.W., Atlanta, GA 30303-8909
Phone: (800) 368-1019.

This notice is effective beginning September 23, 2013.

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