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Your guide to
hospice care

If you have an emergency, call us anytime, day or night.

Our nurses are here 24/7 to assist you. Call us anytime you need us. If you are in pain, not comfortable, feeling stressed or just need to be reassured, call us — that is why we are here. We will help coordinate your care and ensure you receive services promptly and specifically targeted to meeting your goals and keeping you comfortable.

Please call us before visiting the emergency room, seeing a physician or scheduling a test or procedure to determine if it will be covered as part of your hospice care. All services related to the terminal illness or related conditions need to be preapproved by the hospice provider, otherwise the patient will be financially responsible for those services.

Open a door to renewed hope

When most people think of hospice, the word “hope” rarely comes to mind. Novant Health Hospice is working to change that perception. By definition, hope is the feeling that what is desired is also possible, or that events will turn out for the best.

In hospice, we hear our patients and families hope for a positive outcome related to whatever circumstances they are experiencing. To us, hope for our patients means helping them live life to its fullest — spending quality time surrounded by those they love. We focus on going beyond meeting needs to creating special moments in the lives of our patients and their loved ones.

We also help prepare family and friends for the loss of a loved one and help them deal with their grief through compassion, counseling and bereavement support.



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Welcome

Thank you for choosing Novant Health Hospice. At this point in your journey, there is nothing more important to us than your comfort and the quality of life you and your loved ones experience in our care.

The hospice team includes a medical director, skilled nurses, hospice aides, social workers, hospice chaplains, bereavement counselors and many volunteers. Together we will work with you to develop a care plan that anticipates, relieves and prevents your physical symptoms, as well as addresses the spiritual and emotional stresses you and your loved ones may face.

We are dedicated to providing the same level of comfort and care that you've come to expect from Novant Health. We consider it a privilege to be involved in your care and thank you for placing your trust in us during this important stage of life.

Sincerely,

Kim Darden
Corporate director of hospice services
Novant Health

**Over 30 years of providing peace,
comfort and dignity to patients and
families facing life-limiting illness**

What is hospice and how is it helpful?

Hospice is specialized care for those who are nearing the end of life. The goal of hospice is to provide comfort to an individual with a terminal illness who no longer is seeking curative treatment. The goal is to make the most of the time that is left.

Benefits of Novant Health Hospice care

- Offering quality of life and dignity for those with a life-limiting illness. By providing services in the home, or the place you call home, you can stay close to friends and family in comfortable, familiar surroundings.
- Limiting unnecessary hospital stays and emergency room visits.
- Keeping you comfortable and free of pain.
- Involvement in all aspects of care, including important healthcare decisions.
- Treating the person, not the disease.
- Providing valuable support to loved ones during the journey.

Novant Health Hospice services

- **Pain and symptom control.** We work with you to manage your discomfort, pain and side effects to keep you as comfortable as possible, while still alert enough to enjoy the people around you and make important decisions.
- **Home and hospital care. Our goal is to keep you comfortable at home, or the place you call home, for as long as possible.** If you need to be admitted to the hospital, we will continue to stay involved in your care.

- **Spiritual care.** Whatever your spiritual and religious beliefs, our chaplains assist you directly or connect you to local resources to meet your specific needs.
- **Care conferences.** We routinely schedule conferences to keep loved ones informed about your condition and what to expect. These conferences are a time of open sharing so we can continue to learn what is important to you and your loved ones in this journey. In this way, we can best meet everyone's needs.
- **Coordination of care.** The hospice team coordinates and supervises your care seven days a week, 24 hours a day. We ensure that all those involved in your care are communicating and the care is coordinated.
- **Respite care.** If you have hospice care at home, your hospice team may offer respite care to allow your caregivers some time away. You will receive care in either a hospice facility, a hospice unit such as the Harris Hospice Unit, or in beds that are set aside in nursing homes or our hospitals. This allows caregivers to plan a mini-vacation, go to special events or simply get much-needed rest while you are safely cared for in an inpatient setting.
- **Bereavement care.** Our compassionate team works with surviving loved ones to help them through the grieving process.

Who provides my services?

Members of your Novant Health Hospice team work together with you and your loved ones to provide coordinated, compassionate care. The team includes:

- **Medical director** – Our medical director is a doctor who leads the care team.
- **Nurses** – Our hospice nurses are trained to monitor disease-related symptoms and coordinate your treatment options with your doctor. They provide teaching to caregivers, along with coaching and support.
- **Hospice aides** – Our hospice aides help you with personal care and other daily living activities, including bathing and grooming, skin care and dressing changes. They are specially trained in hospice care.
- **Rehabilitation professionals** – Our hospice care team may consult with physical, occupational or speech therapists to help you.
- **Dietitians** – Our dietitians provide nutritional consultation and guidance to assure your needs and desires are met.
- **Social workers** – Social workers provide emotional support, counseling and guidance. They can help with advance directives, medical decision-making and identifying available resources.
- **Chaplains** – Clinically trained, ordained chaplains offer spiritual support for issues dealing with personal meaning, spiritual pain, forgiveness and regret. They can provide hope to individuals of all beliefs, faiths and values. Our chaplains also serve as a liaison to your minister, priest or faith community.
- **Bereavement counselors** – Our counselors provide grief support and counseling to family and caregivers following a loved one's death.
- **Volunteers** – Our amazing volunteer team offers understanding and support to our patients and families. Our volunteers visit with patients, assist with patient transportation, run errands and help write letters. Volunteers deliver flowers to patients in their homes for special occasions and recognize our veterans through a special pinning ceremony.



How do I qualify for Novant Health Hospice services?

Anyone may request hospice care, but a doctor must confirm that you qualify for hospice. A person with a life-limiting illness can receive hospice services when a doctor believes he or she has about six months or less to live. Because it can be hard to predict the course of an illness at the end of life, some patients may live longer than six months. When that is the case, the six-month period can be extended as long as the patient still qualifies.

Where is Novant Health Hospice care provided?

Hospice is not limited to a specific place. Hospice care usually is provided in the comfort of your home, with your familiar surroundings and easy access to family and friends.

If your symptoms cannot be managed at home, or when care at your home is no longer an option, hospice care can be delivered in hospice facilities, hospitals, nursing homes and other long-term care facilities. Please consider treatment at a Novant Health hospital so that we may remain involved in your care and can better assist with discharge planning. Our area hospitals include:

- Novant Health Presbyterian Medical Center
- Novant Health Matthews Medical Center
- Novant Health Huntersville Medical Center
- Novant Health Charlotte Orthopedic Hospital
- Novant Health Rowan Medical Center

Hospice unit - If you require inpatient treatment, our hospice units at Presbyterian Medical Center and Matthews Medical Center or the Glenn A. Kiser Hospice House provide a **short-stay**, home-like environment. Guided by a specialized team, you will receive “transitional care,” with an emphasis on stabilizing symptoms while providing comfort and support — all with the goal of getting you back home for continuation of hospice care where you are most comfortable. Our hospice units’ coordinated team approach to care helps loved ones learn to provide the necessary hospice care at home while still having the guidance and support of hospital staff.

In some instances, you may be eligible for “respite care.” In a respite situation, our hospice unit may function as a **short-stay** opportunity so your family can receive short-term relief (respite) from their care responsibilities. Your hospice staff can help determine when or if respite care is needed.

Excellent care for you

What is your role in your hospice care?

We want you to have the best life throughout your whole life. Our goal is to partner with you in providing the best care possible. We recognize “the best care possible” is different for everyone — each person is unique in what they want and need. To help us meet your needs, we ask the following:

- **Share your wishes, goals, fears and desires** with your loved ones and our team so we can partner together through this journey.
- **If it is important to you, it is important to us.** Please tell us what you need — no matter how small or trivial you may think it is — and together we can find a solution.
- **Let us know if we can do something better.** We want to please you and make sure all of your needs are met. If we ever fall short of your goal, please call us and we will try to make it right.
- **Call us.** We have a team of compassionate professionals who are on call 24 hours a day, seven days a week. If you are in pain, not comfortable, feeling stressed or just need to be reassured, call us — that is why we are here.
- **Open, honest communication.** Our goal is to partner with you in this journey and support your decisions. We will not judge you.
- **Ask questions** to make sure you understand and are part of the care being provided. If you hear answers that you do not understand, ask us to clarify. We want you to understand, and we know healthcare is complicated.

Interpreter services

At Novant Health, we want to communicate with you in your preferred language. We offer interpreter and communication services at no charge, including American Sign Language (ASL) interpreters, telephone interpreters, video remote interpretation and face-to-face interpreters, as well as aid-essential equipment

and tools. Please immediately notify your care provider when you need any of these services.

If you have a complaint

While in our care, if your expectations are not being met or if you have a safety concern, please notify your hospice care team.

Our goal is to provide remarkable care to every patient. A few days after your admission to Novant Health Hospice, a representative may call you to request your participation in a phone survey regarding the quality of your care. We encourage you to provide honest feedback regarding your care.

If you would like to speak to a hospice administrator, please call Novant Health Hospice:

- Charlotte: 704-384-6478
- Salisbury: 704-210-7900

If you are not satisfied with the resolution, you have the right to report any grievance about your healthcare experience to the following agencies:

- The Joint Commission: 1-800-994-6610
- North Carolina Division of Health Service Regulation: 1-800-624-3004

Reporting abuse and neglect

We are obligated to report signs of abuse and neglect. If you have concerns or are aware of any abuse, you may contact the Department of Social Services 24 hours a day.

- Adult/protective services
 - Mecklenburg: 704-336-3150
 - Rowan: 704-216-8331
- Child abuse and neglect
 - Mecklenburg: 704-336-2273
 - Rowan: 704-216-8499



Choices and Champions[®]: Stay in control of your care

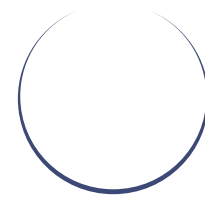
Take charge of your healthcare decisions

Life is filled with choices, and your healthcare is no exception. None of us knows what the future holds or what medical decisions may have to be made on our behalf. The most important thing you can do is choose who you trust to carry out your healthcare wishes if you're ever unable.

Choices and Champions is a free service provided by Novant Health to help guide you through the process of safeguarding your future. It is designed to help you name your healthcare champion and think about other medical choices you may face, including how to complete an advance directive to make your decisions legally binding. From talking with your loved ones to documenting your wishes, we'll help remove the uncertainty from your healthcare and make sure that everyone — you, your loved ones, your doctor and care team — understands your goals and values to make the right choices for you.

Summary of Novant Health policies

- We will follow your wishes about medical care.
- We will honor your right to agree to or refuse medical or surgical treatment, including end-of-life wishes expressed through Do Not Resuscitate (DNR) orders or Medical or Physician Orders for Scope of Treatment (often called MOST, POST or POLST).
- We can help you make treatment decisions and make those wishes known.
- There may be times when you cannot make decisions or tell us your wishes. If this happens, and you do not have an advance directive, we will follow the law regarding who may make medical decisions for you.



CIRCLE of LIFE[®]

Choices and Champions is a recipient of the American Hospital Association's prestigious Circle of Life Award. In 2020, Novant Health was one of only two programs to be nationally recognized for our innovations in end of life care.

What are advance directives?

Advance directives are legal documents about medical wishes that are used when you are not able to speak for yourself. These documents include the following:

- **Someone to speak for you.** When you are not able to speak for yourself, we need to know **whom** you want to make medical decisions for you. You may name someone to be your “agent” to make these decisions. This is done in a legal document called a “Health Care Power of Attorney” or “Power of Attorney for Health Care Decisions.” Signing a legal document naming an agent is the only way to make sure that decisions are made by the person who **you want** making decisions for you.
- **Making your wishes known.** You have the right to make decisions about the types of care that you want or don’t want at the end of your life. If you become unable to speak for yourself, a “living will” is a document that tells your wishes about treatments that keep you alive, such as breathing machines and feeding tubes.
- **Mental health treatment.** If you have special wishes about mental health treatment choices, you may prepare a document sharing those wishes. This also may be included as part of your “Health Care Power of Attorney.”
- **Organ donation.** You also may decide to be an organ donor. You may include this in an advance directive, sign an organ donation card, tell your loved ones about your wishes, or indicate that you are an organ donor on your driver’s license.

What do I need to do?

- If you have an advance directive, please give us a copy. You also should give copies to all of your doctors and loved ones.
- If you do not have an advance directive and would like to make one, please let us know. Our team has all the forms you need and is happy to help you, free of charge.

Ensure your wishes are honored

We encourage you to think about and discuss your healthcare choices. Deciding now is the only way to make sure your wishes are honored in the event of sudden illness or injury. Discussing your wishes — and making them legally binding — helps you, your loved ones and your care team because we all want you to receive the care that’s right for you.

From tips on how to start the conversation with your family and friends about the kind of care you prefer in specific situations to contemplating the appropriate advance directive forms to make your decisions official, we’re here for you every step of the way.

Frequently asked questions

Can I change my advance directive? Yes. You may change or cancel your advance directive at any time. If you make changes, it is important that you tell others that you have changed or cancelled your advance directive.

What if I have an advance directive from another state? Most states will honor an advance directive from another state. If you spend a lot of time out of state, you may wish to make an advance directive using the special forms of the state you are visiting.

Do I have to file my advance directives with a registry? No. You do not need to register your advance directive, but may if you choose. There is a national registry called U.S. Registry. Some, but not all, states also have advance directive registries. For more information on how to register your advance directives, you may visit the following websites:

- U.S. Living Will Registry — uslivingwillregistry.com
- North Carolina registry — sosnc.com

Contact us

Toll-free **1-844-677-5134**

ChoicesandChampions@NovantHealth.org

NovantHealth.org/ChoicesandChampions



Hospice patient bill of rights

What are your rights?

You have the following rights. If someone is helping you make healthcare decisions, he or she may exercise these rights for you.

Quality of care — you have the right to:

- Have quality end of life care by skilled doctors and team members.
- Be treated for your pain.
- Have treatment that is as comfortable as possible.
- Have emergency procedures without unnecessary delays.
- Ask for a second opinion, at your expense.

Safety — you have the right to:

- Have safe care.
- Know when something goes wrong with your care.
- Be free from all forms of abuse, harassment, exploitation and neglect.
- Be free from the use of restraints and seclusion unless needed for safety.

Voice and choice — you have the right to:

- Get information in a manner you understand. When it is not possible or medically advisable to provide information to you, we will provide information to your designee.
- Have help to decide the details of your care plan and make informed decisions about your care, except in emergencies.
- Refuse care.
- Make advance directives and have your medical wishes followed.
- Contact a person or agency to protect your rights.
- Have a support person with you for emotional support.

- Agree or refuse to allow pictures for purposes other than your care.
- Have religious and other spiritual services that you choose.
- Complain without fear and have your complaints reviewed.
- Choose your doctor.
- Have a medical record.
- Have information about the scope of services that hospice will provide and specific limitations on those services.

Affordability — you have the right to:

- Have a detailed bill and an explanation of that bill.
- Have information about resources to help pay for your healthcare.
- Have information about the services covered under the hospice benefit.

Authentic personalized relationships — you have the right to:

- Know the names and jobs of the people who care for you.
- Be treated with respect and dignity.
- Have access language assistance services free of charge, including an interpreter when possible.
- Have treatment without discrimination.
- Be respected for your culture, values, beliefs and preferences.
- Know when a doctor is considering you for a medical care research or donor program.
- Have visitors of your choice. We will inform you about any restrictions.
- Have personal privacy.

Easy for me — you have the right to:

- Know about rules that apply to your actions.
- Have help in planning for your care needs.
- Be transferred to another facility when medically permissible. You or your designee will first receive complete information and an explanation about why the transfer is needed and any alternatives to the transfer. Also, the facility to which you will be transferred must have accepted you for transfer.
- Be free from duplicative medical and nursing procedures.
- Have privacy, confidentiality and access to your medical information. The Notice of Privacy Practices describes your rights and our obligations related to medical information.

What is your role in hospice care?

- Be an active partner in your healthcare.
- Ask questions.
- Keep appointments.
- Be respectful to other people and their property.
- Follow the facility's rules.
- Follow your care instructions.
- Share as much health information with us as possible.
- Tell us about changes in your condition.
- Tell us when you are in pain.
- Give us a copy of your advance directive(s).
- Leave your valuables at home.
- Pay for your care.

Novant Health Hospice will coordinate your care with other agencies if:

- We lack the resources for optimum care.
- We are unable to respond to a request for service promptly.
- You no longer meet the physical criteria for continued hospice services. We will provide a 48-hour notice of discharge allowing you the opportunity to appeal if you disagree with the decision.
- You move out of our service area.
- You choose admission to a noncontracted facility, nursing home or hospital and cannot assume the financial responsibility of continuing with Novant Health Hospice.
- You decide you wish to pursue curative or aggressive treatment.
- You or someone in your home refuses to comply with hospice rules and regulations, which makes delivery of services not possible.

Requests for medical records

To obtain a copy of your medical records, you must complete and sign a medical release form.

- Request forms by mail or fax, or obtain one directly from the medical records department.
- You will be charged a reasonable fee for copies of your medical records at a rate determined by state law.
- Please allow seven to 10 working days for requested information.

For all inquiries, please call Novant Health Presbyterian Medical Center at 704-384-4000 or Novant Health Rowan Medical Center at 704-210-5000 to request the medical records department.

Managing your physical care

Medication management

- Your hospice nurse will facilitate all medications related to your hospice condition.
- Let your hospice nurse know one week before any refills are needed.
- Your hospice nurse or pharmacist will tell you when there are medication substitutions that will be covered as part of your service.
- Your hospice nurse will provide education about your medications so that you clearly understand:
 - What the medicines treat.
 - How you are supposed to take them and for how long.
 - What the side effects may be and what to do if you experience side effects.
 - If it is safe to take the medicines with other medicines or vitamins/herbs.
 - What food, drink or activities you should avoid while taking the medicines.

Medicines and food

- Medicines can interact with your diet affecting how they work.
- You may need to change certain dietary habits or avoid certain foods while taking particular medications. Your doctor will prescribe a diet for you that complements your medical care.
- Ask for more information about your diet to understand interactions, how to avoid problems and what to look for.

Bathing

- A bath seat in the tub or shower provides a safe and more relaxing experience.
- Bed baths should be given when tub or shower bathing becomes unsafe. Your hospice nurse will direct your caregiver on giving a bed bath.
- Hospice aides are available upon request to provide personal care such as bathing and grooming.

Mouth care

- Good mouth care helps prevent sores and may make food and fluid taste better.
- A soft toothbrush is best for cleaning.
- Disposable mouth swabs can also be used to clean teeth, gums and tongue.
- Clean dentures regularly and remove dentures if gums and mouth are sore.
- Lips should be kept moist by using lip balm.

If you experience dry mouth:

- Tart foods and hard candy may stimulate saliva.
- If severe, a saliva substitute may be indicated. Discuss with your hospice nurse.

If you experience a sore mouth:

- Avoid acidic foods such as fruit juices.
- Eat regular or frozen yogurt to replace good bacteria if thrush is present.
- Avoid salty foods or hard foods that can cut or rub sore areas.
- Tell us if you have any mouth soreness or white patches in the mouth.

Managing your comfort

Managing your pain

- Pain is best managed as a partnership between you and your hospice team. In this partnership, your job is to report honestly about your pain.
- Only you know how much pain you are feeling and we want to treat your pain appropriately.
- Reporting your pain helps us know how well your treatment for pain is working and if any changes need to be made with your care.
- You can use words or a pain scale to help us understand where and how much discomfort you are experiencing.

Some different ways to measure pain

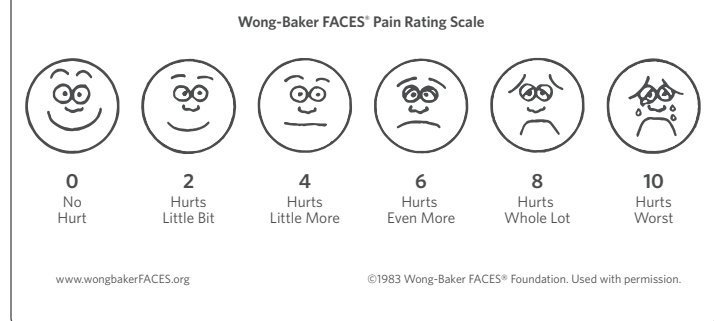
- A number scale
- Words that describe pain like mild, moderate, severe or excruciating
- Pictures that communicate pain

Wong-Baker 'faces' pain rating scale

Each face is for a person who feels happy because he or she has no pain or sad because he or she has some or a lot of pain.

Face 0 is very happy because he or she does not hurt. Face 10 hurts as much as you can imagine. Choose the face that best describes how you are feeling.

Please point to the number that best describes your pain.



Treating your pain

- It is important that you take an active part in the plan to control your pain.
- There are medicine and nonmedicine treatments for pain. Your feelings and beliefs about pain management are important, and you and your hospice team will decide which ones are right for you.
- Talk about how often you will be given pain medicines. You may get pain medicines at set times or you may need to use them as you experience discomfort.
- Ask for pain medicine when your pain first begins. It is easier to control pain if we take action at the first signs.
- If you know your pain will worsen when you get up, move around or do certain activities, ask for the pain medication first, before beginning the activity.
- We will ask you how your pain relief plan is working. If your pain is not being controlled, your plan may be changed by your doctor.
- There are limitations and side effects of pain treatment. We can discuss this with you so that you are comfortable with it.

Notify us if you experience:

- Unrelieved pain or if your pain becomes severe/intense.
- Pain that keeps you from doing your usual activities.
- Any side effects of the medication (common side effects include constipation, diarrhea, nausea, vomiting, sleepiness, dizziness, itching).
- Concerns about medications: how to take them or how to administer them.
- Irritability from lack of sleep and/or because of the pain.

Nonmedicine treatments include:

- Position change
- Posture and movement training
- Hot or cold treatments to the painful area
- Relaxation or strengthening exercises
- Guided imagery
- Meditation
- Music
- Massage
- Hobbies to distract you
- Other treatments ordered by your doctor

Pain medicine treatments may include:

- Pill
- Liquid
- Injection (shot)
- Subcutaneous (under the skin)
- Suppository
- IV (tube in your vein)
- Injection into a nerve pathway

Nausea and vomiting

Nausea is an unpleasant feeling that may occur in the back of your throat or in your stomach. Your hospice team will try to discover the underlying causes and discuss treatments with your healthcare provider.

Things you can do:

- Record what causes you to feel nauseated or to vomit and what decreases the nausea and/or vomiting.
- Sip carbonated drinks that have gone flat.
- Avoid acidic juices, such as orange, grape and apple.
- Drink sports drinks, such as Gatorade.
- Try small amounts of salty foods, such as crackers or chicken broth.
- Avoid fried foods, milk products or those with strong smells.
- Practice frequent mouth care.
- Try eating small, frequent amounts because large meals may be overwhelming.
- Avoid strong odors such as perfume and deodorizers.
- Avoid eating immediately after vomiting.
- Try sips of water or ice chips before eating again.
- Maintain a comfortable room temperature.
- Avoid constipation.
- Use medications as ordered by your healthcare provider.
- **If nausea/vomiting continues, contact your hospice care team.**

Constipation

Constipation is a very common side effect of taking a narcotic pain medicine. Early intervention is always the key to avoiding problems. If constipation is left untreated, it can become a more serious problem; pain, bloating, nausea, vomiting and impaction (blocked bowel) can occur.

Things you can do:

- Record when bowel movements have occurred.
- Drink as much fluid (liquids) as is comfortable. Drinking warm liquids has benefited many patients.
- Eat more fruits and drink fruit juices, if not nauseated.
- Increase physical activity if possible. Walking short distances can be beneficial.
- Sit upright on toilet, commode or bedpan.
- Establish routine times for toileting.
- Take laxatives/stool softeners as ordered by your healthcare provider. Use bulk laxatives only as directed by your hospice nurse.
- **Contact your hospice team if constipation continues.**

Diarrhea

Diarrhea describes bowel movements (stools) that are loose and watery. It is very common and usually not serious. Many people will have diarrhea once or twice each year. It typically lasts two to three days and can be treated with over-the-counter medicines. If diarrhea is left untreated, dehydration can occur.

Things you can do:

- Increase fluid intake of water, broth and soups that contain sodium and fruit juices.
- Take medications as ordered by your doctor.
- Until diarrhea subsides, try to avoid caffeine, milk products and foods that are greasy, high in fiber or very sweet. These foods tend to aggravate diarrhea.
- As you improve, add soft, bland foods to your diet, including bananas, plain rice, boiled potatoes, toast, crackers, cooked carrots and baked chicken without the skin or fat.

Notify hospice if you experience:

- A change in bowel movements, including no bowel movement in two days; diarrhea for more than three days; bloody, tarry or oozing stools
- Nausea and/or vomiting, especially any vomiting that prevents you from drinking liquids to replace lost fluids
- A fever of 102 degrees or higher
- Severe pain in the abdomen or rectum
- Pain, cramping or tenderness
- A feeling of fullness or bloating
- If you notice any of the following dehydration signs:
 - Dark urine
 - Small amount of urine
 - Rapid heart rate
 - Headaches
 - Dry skin
 - Irritability
 - Confusion



Providing physical care: Information for caregivers

As a caregiver, you will provide direct care for your loved one along with the hospice team. We want you to feel very confident in providing this care. Our staff will teach you everything you need to know. The following information will help guide you along the way.

Giving medicine

- Most medications are in pill form and may be taken with water or another preferred liquid.
- Elevate the head with pillows when giving medicine by mouth.
- Give a few sips of liquid before putting pills in the mouth to help prevent them from sticking.
- If nausea is a problem, offer nausea medication with a small amount of water 30 minutes to an hour before giving medicine. Allow the nausea medication to take effect before offering anything to eat or other medicines.
- **Always** ask the hospice nurse if pills that are too difficult to swallow can be crushed. If medication can be crushed, mix it with a small amount of juice, ice cream, pudding, applesauce or other soft food.
- If swallowing medication continues to be a problem, your hospice nurse will consult the doctor to obtain the medication in a liquid, cream or suppository (medications given rectally). Suppositories should be kept refrigerated.
- The doctor may consider stopping some medicines, except those needed for comfort.

Skin care

It is important to try and keep the skin in good condition.

- Common causes for skin problems and breakdown include decreased appetite, decreased fluid intake, decreased mobility and incontinence.
- Examine patient's body daily for blisters, reddened areas, cracks or tears.
- Reduce pressure on bony areas such as elbows, hips, ankles, heels, ears and spine by turning and repositioning often.
- Use flat sheet folded in half under trunk of body to turn and position patient.
- Turn patient every two hours during waking hours.
- Keep sheets free of wrinkles.
- Use pillows to support arms, legs, and back.
- Massage red areas.
- Keep skin clean and dry.
- When your loved one becomes incontinent (urine and stool), it is important to immediately clean and change him/her.
- Replace moisture to skin with lotions containing lanolin.

We want you to feel very confident in caring for your loved one. With our help, you should feel fully prepared for what to expect with your loved one's care, be able to review what will happen next during care and be able to tell us what you need during your loved one's journey.

Bowel and bladder care

The elimination of urine and stool is the body's mechanism for removing waste products. Problems with elimination can cause the patient a great deal of anxiety, embarrassment and discomfort.

Some patients will experience the inability to control urination. In other patients, the passageway for urine becomes blocked. If either of these conditions is present, it may be necessary for the nurse to place a catheter (tube) into the patient's bladder to drain the urine. This will only be done with a doctor's recommendation and following a discussion about the procedure with the patient and family. If a catheter is recommended, your nurse will put it in place and teach you how the system works and how to take care of it. If your loved one loses the ability to control bowels, your hospice team will guide you with the information on what you need to know and do.

Catheter care

- Good catheter care can help prevent infections and odors. It also will help the patient feel cleaner.
- Empty drainage bag every morning and evening.
- Do not rest the drainage bag on the floor.
- Always keep the drainage bag below the level of the bladder.
- Avoid pulling or tugging on the tubing.
- Keep skin around the tubing clean by washing once or twice a day with warm soapy water. Rinse then dry.

Immediately report any issues to the hospice nurse, including:

- Blood in the urine
- Urine leaking around tubing
- Urine not draining
- Pain and fullness in lower abdomen
- If the catheter accidentally comes out

Changing linens of a bedbound patient

- Making the bed with the patient in it can feel overwhelming, but your hospice nurse can walk you through the process.
- If you have a hospital bed, raise the bed to a height most comfortable for you.
- Remove pillows (unless the patient would be uncomfortable) and any top sheet or blanket.
- Loosen all bottom sheets.
- You will make the bed in two halves:
 - To begin, turn the patient to one side and leave the side rails up on that side.
 - Roll soiled linen to center of bed and tuck under patient.
 - Layer incontinent pad on top of a fresh sheet and roll it into the form of a log.
 - Starting with the side closest to you, roll the clean linens toward the patient and tuck the clean linens under the soiled linens as well as under the patient as far as possible. Be sure to leave enough linen on your side of the bed to tuck under mattress.
 - Roll patient toward you over the dirty and clean linens so that the patient is now facing you.
 - Put side rail up and walk to other side of the bed.
 - Lower the side rail; pull out soiled sheets.
 - Unroll the clean sheet and incontinent pad and tuck in the side, top and bottom.
 - Reposition the patient. Replace pillows, top sheet and blanket.

Providing comfort: Information for caregivers

Pain in nonverbal adults

- When patients are unable to speak for themselves, loved ones become important partners in managing pain.
- You can help the doctor and nurse become aware of any discomfort the patient may be experiencing by reporting painful conditions and what treatments worked well in the past.
- The “Checklist of Nonverbal Pain Indicators” is one tool that our staff will use to help patients in pain who are unable to speak for themselves.

Checklist of nonverbal pain indicators (CNPI)

Write a (0) if the behavior was not observed and a (1) if the behavior occurred even briefly during activity or rest.

Behavior	With Movement	Rest
1 Vocal Complaints: Nonverbal (expression of pain that is not in words, such as moans, groans, cries, gasps or sighs) +
2 Facial Grimaces/Winces (furrowed brow, narrowed eyes, tightened lips, dropped jaw, clenched teeth, distorted expression) +
3 Bracing (clutching or holding onto side rails, bed, tray table or affected area during movement) +
4 Restlessness (constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still) +
5 Rubbing (massaging affected area) <i>In addition, record verbal complaints.</i> +
6 Vocal Complaints: Verbal words expressing discomfort or pain (“ouch,” “that hurts,” cursing during movement or exclamations or protest, “stop,” “that’s enough”)
Total	=

Once you total the score, base the number on the numeric pain scale 0 to 10

(If the score totals from 10 to 12, this is considered excruciating pain.)



Difficulty breathing

Shortness of breath may occur at times. Breathing patterns may change and the rate may become irregular. You may notice pauses between breaths or periods of no breathing (apnea).

Things you can do:

- Report fever or green phlegm to the hospice nurse.
- Raise the head of the bed.
- Keep room cool — cool cloths to face, air conditioner, a bowl of ice in front of a fan.
- A fan blowing gently on the patient's face often decreases sensations of breathlessness.
- Keep environment quiet to decrease feelings of anxiety.
- Medications to manage anxiety also can help breathing.
- Use oxygen as directed by your hospice team.
- Encourage slow deep breathing.
- Plan activities to decrease exertion.

Nutrition and eating

Loss of appetite is one of the most common conditions accompanying life-limiting illness. Changes in taste or smell, nausea and vomiting, depression and the natural dying process all contribute to a loss of interest in eating. It is normal for the patient to have less of an appetite and to drink less as the disease continues.

The good news is that much can be done to support the patient during these changes. Treatment choices depend on the patient's illness and personal choices.

Things you can do:

- Encourage favorite foods and drinks.
- Offer drinks or sips often — at least every two hours.
- Clean the mouth often — a pleasant tasting mouth may make food taste better.
- Help others understand why eating and drinking may cause the patient to be uncomfortable.
- Support the patient's decision not to eat or drink.
- Encourage the patient to rest before and after a meal.
- If dentures do not fit well, consult a dentist.

Notify hospice if the patient:

- Is unable to eat or drink.
- Has trouble swallowing.
- Has a dry mouth or tongue.
- Loses more than five pounds in a week.
- Has less urine.
- Becomes confused or drowsy.



Managing your general care and safety

Following simple health and safety measures can reduce the risk of injury, harm and the spread of infection to you and others.

Medicine safety

- Inform us of any medication allergies and side effects.
- Inform us of all medicines you are taking, including prescriptions, over-the-counter medicines and dietary supplements.
- Keep a list of all medicines, including prescriptions, over-the-counter medicines and dietary supplements. Take it with you to every doctor visit and update it regularly.
- Keep all current medications together in a box (such as a shoebox). Keep medications in clean, dry areas and refrigerate if indicated on instructions.
- Keep all medications in their original containers. Write the purpose of medications on the container.
- Never put one medicine in another medicine bottle or an unlabeled bottle.
- Store discontinued medications separately.
- Never take any medications that have expired, including over-the-counter medications.
- Keep all drugs out of the reach of children and anyone lacking proper understanding of their use.
- Do not leave bottles open. If you have trouble opening the cap, ask your pharmacist for an easy open cap.
- Read prescription bottles carefully and follow all instructions.
- Medications prescribed for you are to be used only by you.
- Take medicine as ordered by your doctor. If a medicine makes you feel dizzy, report it to your hospice nurse.
- Do not change the dose or dosage schedule without a doctor's order.
- Know intended use and expected actions of medication therapy. If you have any questions, consult your pharmacist, nurse or doctor.
- Develop a system for taking your medications as ordered. Medication boxes are available at drug stores.
- Ask about the best device to measure your liquid medicines (spoon, syringe, dropper or medicine cup).
- If you miss a dose and remember within 2-3 hours, take medication. Otherwise, skip that dose and take remaining dose as scheduled. If you are unsure, please call the hospice nurse.

Safe disposal of medications

Hospice uses safe methods of drug disposal.

- Medications no longer needed should be disposed.
- A hospice nurse, accompanied by a witness, can assist in disposing medications in a manner consistent with law.
- If you or your caregiver refuses to allow medication to be destroyed, the refusal is documented in your clinical record with the name and strength of the medication and the amount remaining. Included with the documentation is your signature, or your caregiver's, attesting to the refusal and the date your doctor was notified of the refusal.



Fire safety

- Immediately notify the fire department and a medic of a bedbound person in the home. You will need to provide the person's name and location in the home for their records.
 - Fire department:
 - Charlotte 704-336-2441
 - Rowan 704-216-8916
 - Medic:
 - Charlotte 704-943-6200
 - Rowan 704-216-8160
- NEVER smoke in bed.
- Have a working fire extinguisher accessible.
 - Use PASS to operate the fire extinguisher:
 - Pull the pin.
 - Aim the nozzle at the closest edge of the fire.
 - Squeeze the handle.
 - Sweep from side to side.
- Install smoke detectors and keep batteries current.
- Remove excess clutter and paper that may burn easily and quickly in a fire.

In case of fire

- Get out of the house and stay out.
- If you are a caregiver caring for a bed-bound patient: roll the patient onto a sheet or blanket, roll patient onto the floor and drag the patient out of the house.
- Have a prearranged meeting place for your family.
- If your clothes are on fire, "STOP, DROP and ROLL."

Electrical safety

- Immediately notify the power company of any oxygen or other equipment that requires electricity.
- NEVER overload plugs or circuits.
- NEVER put furniture or rugs over extension cords.
- Use only UL-approved appliances.
- Keep space heaters clear of objects.
- Avoid liquid exposure to all electrical equipment.
- Severe weather and accidents can cause damage that can lead to power outages. If your power stays off for more than a few minutes, please contact your local energy provider. Duke Energy customers: call 1-800-POWERON (1-800-769-3766) or report an outage using the quick and easy mobile website by visiting m.duke-energy.com from any smartphone.

Oxygen safety

Using prescribed oxygen can help you avoid shortness of breath, improve sleep and mental alertness, and help you to be more active. To reduce the chances of fire and other hazards, you need to follow important safety guidelines when using your oxygen unit. Remember these Do's and Don'ts.

Oxygen DO's

Suggestions of what to do include the following:

- Do post an "Oxygen Alert Notice" so it is visible to anyone entering your home.
- Do keep sources of flame at least 10 feet away from where your oxygen unit or tank is being used or stored. This includes cigarettes, e-cigarettes, matches, candles, fireplaces, gas burners, pipes, electrical devices or anything else that could start a fire. Never smoke or use an open flame when wearing oxygen.
- Do keep the oxygen unit at least 10 feet away from sources of heat such as space heaters, electric or gas heaters, steam pipes, furnaces and radiators.
- Do ask the medical equipment company if you should keep the oxygen unit away from other appliances, such as TVs and radios.
- Do turn off the oxygen unit completely when it's not in use.
- Do have a fire extinguisher nearby. Make sure you and others in your household know how to use it.
- Do be careful not to trip over the oxygen tubing.
- Do keep the door to the room open so that air circulates and it is not stuffy.
- Do protect your oxygen tank from being knocked over. Store the oxygen tank upright in a secure, approved storage device.
- Do turn the tank off right away if it is knocked over and makes a hissing noise. If the regulator breaks or you cannot safely turn the tank off, remove the tubing and leave the room. Then call the supply company or the fire department for help right away.
- Do ask your medical supply company how often you should change your nasal cannula tubing, your cannula and your humidifier bottle, if you have one.
- Do follow the instructions for safe use as recommended by your medical supply company. Not using oxygen safely at home can put you and your neighbors at higher risk for fires and burns.
- Make sure you know what to do in an emergency. Your emergency numbers should include 911 (or your area's emergency number), your healthcare provider and your medical supply company.

Oxygen DON'Ts

Suggestions of what not to do include the following:

- Don't smoke, and don't allow others to smoke near you. This includes cigarettes, e-cigarettes, pipes and cigars. Post a "No Smoking" sign in your home.
- Don't use aerosol sprays such as air fresheners or hairspray near the oxygen unit. Aerosols are very flammable.
- Don't use vapor rubs, petroleum jelly or oil-based hand lotions, creams or lip balms. These substances can be flammable when mixed with pure oxygen. Use water-based products instead.
- Don't use oxygen while cooking with gas. Ask the medical equipment company about other types of cooking.
- Don't oil the oxygen unit. And don't use it with oily or greasy hands.
- Don't place a liquid oxygen unit on its side. The oxygen inside can evaporate. Oxygen should always be stored upright in a secured device.
- Don't use an extension cord with the concentrator.
- Don't use a hair dryer, electric razor, electric blanket or other electrical devices. It is possible, in certain conditions, that the combination of oxygen with a spark from an electric appliance could ignite and cause burns.
- Don't store your concentrator or tanks in a small storage area. The extra heat generated could damage the unit and other materials in your storage area.

Infection prevention

To reduce the chances of an infection, follow the following tips:

- Change nasal cannulas (nose tube) on an as-needed basis and between respiratory infections or colds.
- If you are on 5 LPM or greater, use distilled water only in the humidifier bottle. Clean the bottle every other day.
- When not using your nasal cannula (nose tube), store in a clean, dry place.
- When using a concentrator with a humidifier, it is important to follow instructions on cleaning the bottles and changing the water. If instructions are not followed properly, bacterial growth is possible and may pose risk for infection.

Using oxygen at home

Your healthcare provider may prescribe oxygen to help make breathing easier for you. You will be shown how to use your oxygen unit by the medical supply company. Below are some guidelines on using oxygen at home safely. Do all steps each time you use your oxygen unit.

Note: Instructions will vary based on the type of oxygen device you use.

When to call the healthcare provider

Call your healthcare provider right away if you have any of the following:

- Pale skin or a blue tint to your lips or fingernails
- Increased shortness of breath, wheezing or other changes from your usual breathing, even with oxygen in place
- Confusion, restlessness or more anxiety than usual
- Chest pain

Step 1. Check your supply

- Pressurize your oxygen tank (compressed oxygen tanks only). Other devices may simply be switched on. Make sure you follow the instructions provided by your healthcare provider or medical equipment company.
- Check the oxygen supply level on the tank to be sure you have enough. Your medical supply company will tell you when to call them to let them know that you need more oxygen. Or they will deliver your oxygen on a regular schedule.
- If you have a humidifier bottle, check the water level. When it is at or below half full, refill it with sterile or distilled water.

Step 2. Attach the tubing

- Attach the cannula tubing to your oxygen source as you have been shown.
- Be sure the tubing is not bent or blocked.

Step 3. Set your prescribed flow rate

- Set the oxygen to flow at the rate your healthcare provider has prescribed.
- Never change this rate unless told to by your healthcare provider.

Step 4. Insert the cannula

- Insert the nasal cannula (nose tube) into your nose and breathe through your nose normally.
- If you're not sure whether oxygen is flowing, place the nasal cannula in a glass of water. If the water bubbles, the oxygen is flowing.

Traveling with oxygen

Using oxygen doesn't mean you can't travel. You just need to plan ahead. Tell your hospice team and oxygen supply company where you're going and how you're getting there. They can help you arrange to have oxygen tanks ready at your destination when you arrive. Some tips to help you plan your trip include:

By car

- Avoid open flame and any sources of high heat. **Do not smoke** or allow anyone else to smoke in the car.
- Open a window.
- Don't allow anyone to smoke near you.
- Place the oxygen unit upright, either on the floor or on the seat beside you. (Do not put the oxygen in the trunk. It is too hot!)
- Secure the unit with a seat belt.
- Store extra oxygen units upright.

By cruise ship

- Notify the cruise company that you will be traveling with oxygen.
- Ask your healthcare provider to provide the cruise company with a letter that includes a brief medical history and your current oxygen prescription.
- Make arrangements for your oxygen units to be delivered directly to the cruise ship before you depart.

By plane

- Make your airline reservations several weeks ahead. Although your oxygen tank is not allowed on the plane, most airlines will supply an oxygen system for a fee.
- Send a copy of your oxygen prescription, approval for air travel, verification of need for in-flight oxygen, and a completed medical information form to the airline. Bring enough copies of this letter with you for all flights.



- Keep in mind, oxygen may only be supplied while in the plane — not in the airport. You must arrange to have oxygen delivered to your destination, as well as to any layovers during the flight. Arrange for extra oxygen tanks to be at your destination before you arrive.
- Different airlines have different requirements. Check with your airline in advance.
- Bring along your own nasal prongs or nipple adaptor.

By bus or train

- Call the carrier in advance before you depart.
- Tell them that you're traveling with oxygen and request seating in a nonsmoking area.
- Verify if you can take your own oxygen unit onboard.
- Bring extra oxygen tanks as baggage if allowed by the bus or train company.

Fall prevention

Around the house

- Always wear proper-fitting, low-heeled or flat soled shoes with nonskid soles — even if just going from bedroom to bathroom. Do not walk around while wearing only socks.
- Pick feet up off the floor when walking. Try not to slide feet along the floor.
- Place frequently needed objects at eye level. Looking up may cause dizziness.
- Use assistive medical equipment as directed by your hospice team (cane, walker, wheelchair). Lock wheelchairs when getting in and out of them.
- If using oxygen, be mindful of tubing that poses a trip hazard.
- Provide good lighting throughout your home and turn on lights before moving around the house when it's dark. Consider adding night lights.
- Be aware of your surroundings. Watch for curbs, uneven surfaces and spills. Be careful around pets.
- Arrange furniture so there is something to hold onto if walking becomes unsteady.
- Clear pathways of low lying objects such as footstools and clutter, including exposed extension cords.
- Use chairs with armrests. The seat should be high enough so that getting in and out of the chair is easy.

If a patient falls:

- 1 Call Novant Health Hospice.**
- 2 If the patient falls and cannot get up, call a nonemergency fire department in your area.**

In and out of bed

- Get out of bed slowly. Do not lean or support yourself on rolling objects such as IV poles or bedside tables.
- You are likely to feel dizzy after sitting or lying for a long time. Avoid rising quickly from either a lying or a sitting position.
- When getting up, sit in bed for a few minutes before standing. Pump your ankles up and down for a minute before standing and then rise carefully. Use a walker or cane to improve balance.
- Ask your caregiver for help if you feel dizzy or weak after getting out of bed.

Bathroom

- Create a clear path to the bathroom.
- Use nonskid rubber mats in shower or bath.
- Install grab bars or benches in the bath, tub or shower and by the commode.
- Install raised toilet seats if necessary.

Rugs and floors

- Avoid wet floors. Clean up spills immediately.
- Tack down edges of carpet completely.
- NEVER use throw rugs.
- Use only nonskid wax. Avoid highly polished floors.

Stairs

- Clear away clutter on and around stairs.
- Use nonskid treads on steps.
- Install and always use handrails.

Alcohol and effects of medication

- Avoid alcoholic beverages, especially in excess.
- Medicines like antidepressants, anti-seizure medicine, sleeping pills, laxatives, pain medicine, blood pressure or fluid pills may make you dizzy.

Infection control

- In certain situations, hospice staff may wear gloves, gowns or other protective wear when caring for you.
- Visitors who have major cold symptoms or flu should be discouraged from visiting.
- All staff, volunteers, caregivers, family and visitors should wash hands with antibacterial gel/soap and water, and dry with a clean towel before and after having ANY contact with you, including:
 - Cooking
 - Feeding
 - Toileting
 - Bedding change
- Always dispose of needles, syringes, lancets or other sharp objects in a **hard** plastic or metal container with a tightly secured screw-on lid. If you use a coffee can, reinforce the plastic lid with heavy duty tape.
- Never dispose of sharp objects in glass or thin plastic container, or in any container to be recycled or returned to a store.
- Keep all containers with sharp objects out of the reach of children.
- Always dispose of soiled bandages, disposable sheets and medical gloves in securely fastened plastic bags BEFORE putting them in the garbage.

Emergency planning

- If there is a disaster or bad weather, the hospice staff will prioritize patients and attempt to make or reschedule visits. If visits cannot be made and your condition requires care before a rescheduled visit, you have the option of going to an emergency care facility.
- If there is a disaster or bad weather, please connect with your local media for emergency information.
- If using life-support machines or oxygen, check with the equipment company about backup systems.

Medical supplies and equipment

- Medical supplies ordered by your hospice nurse will arrive by a professional delivery service.
- Disposable items, such as medical supplies and drugs, are typically ordered in smaller quantities that best cover changing needs.
- Your hospice nurse will recommend durable medical equipment (DME) designed to increase your functional level and independence.
- The medical equipment company will provide instructions on each piece of equipment.
- Do not adjust any medical equipment. Call your hospice nurse if any equipment alarms.





Emotional and spiritual care: Caring for the caregiver

Caring for a loved one with life-limiting illness can be a time-consuming and draining task, both physically and emotionally. It is important that you take care of yourself first.

Get plenty of rest

- Find time during the day to nap if your loved one's sleep schedule is disturbed at night.
- Ask your hospice team for a door sign that asks visitors to limit their time so that everyone can rest.

Eat regular meals

- Eat a balanced diet, including fruits and vegetables.
- Even if your loved one is not eating three meals a day, you need to maintain your energy.

Take a break

- Take time for yourself, whether that means going for a walk or just sitting quietly without distractions.
- Ask friends or neighbors to sit with your loved one so you can get away for a while.
- Ask your hospice team about scheduling a hospice volunteer.

Ask for help

- Make a list of tasks for friends or family members who offer to help.
- Household or yard chores, errands such as going to the post office, grocery shopping or preparing a meal are some suggestions.

Talk about it

- Stay in touch with friends or consider a support group for caregivers.
- You may find it helpful to talk with a member of the clergy or a professional counselor.
- Your hospice team is also available to provide emotional support when you need to talk.

Anticipatory grief

- Everyone touched by a life-limiting illness will experience some level of anticipatory grief.
- It is normal to have feelings of sadness, anger, frustration, depression and anxiety.
- Experiencing these feelings is natural and helps us prepare for loss.
- Denial is a healthy reaction to bad news. Our patients and their loved ones often experience denial when they are first diagnosed with a life-limiting illness and then throughout the dying process.
- Accept that your feelings may be an emotional roller-coaster. Caring for someone who feels good today and not so good tomorrow can be challenging.

Seven common fears of dying and how to help relieve them

Helping your loved one through the process of dying can be overwhelming. Your presence and attention are the most important ways to reassure your loved one. Although approaching the end of life is a very personal journey, there are seven most common fears that most people experience. Understanding these fears can help you feel more prepared for what is to come, while allowing you to help your loved one overcome them.

The seven fears of dying

1 Fear of the dying process

People are often worried as to whether death will be painful, and whether they will feel anxious or frightened. They may worry about what will happen to their bodies as death approaches, and what changes may take place.

How to help: The hospice team will work with your loved one and caregivers to meet goals for comfort. Control of pain and anxiety are priorities for the hospice team. The team is trained to understand what patients need, using verbal and nonverbal cues, while discussing benefits and drawbacks of each option. Reassure your loved one that there is support in each stage of the journey from your hospice team.

2 Fear of loss of control

Life-limiting illness gradually makes patients more dependent for daily needs. The patient and loved ones may feel more helpless and less able to make decisions about themselves and their future.

How to help: Encourage your loved one to live a normal life as long as possible. As your loved one needs more help to get through the day, ask how he or she wants things done, and honor these choices. It may help to introduce additional caregivers before they are needed, so your loved one can get to know them and feel more comfortable when additional support is needed.

3 Fear of loss of one's loved ones

Patients are often worried about what will happen to the people they leave behind. Will their family have enough money? Will the spouse be able to return to work? Will their family get along without them?

How to help: Only the patient's loved ones can relieve this fear. Discuss honestly what will happen. Help your loved one by making plans together for future care of any children or dependents. Reassure your loved one that you will be OK. And, finally, give your loved one permission to go.

4 Fear of the fear of others

Perhaps best explained by the quotation, "I never knew what fear was until I saw it in the eyes of the people taking care of me."

How to help: It's natural to feel fear and sadness when faced with the loss of your loved one. But do try to control anxiety in the patient's presence, as this will increase his or her own anxiety and worry. Make sure that all caregivers are getting enough sleep, exercise and emotional support. Your hospice team can help with resources for your self-care and help you feel confident in providing good care for your loved one. Ask your hospice team for information on what to expect and how to cope if you feel unprepared for what is to come.

5 Fear of isolation

People are often fearful of the aloneness of dying. They feel increasingly isolated as friends and family visit less frequently and healthcare professionals seem less involved as death nears.

How to help: Encourage friends and family to visit. Ask your hospice social worker about a volunteer for companionship. Your hospice chaplain may help with visits from your faith community friends. As periods of alertness allow, spend time in your loved one's presence to help him or her to feel connected.

6 Fear of the unknown

People worry about what to expect, both physically and spiritually. They may question their faith and wonder if there is life after death. If there is, what will it be like for them?

How to help: Everyone has questions like these when facing the end of life. Give your loved one permission to share his or her doubts and concerns. Even if your loved one is not religious, he or she may accept support from a spiritual leader. Ask for support from your hospice chaplain and/or your loved one's pastor, rabbi or other spiritual leader.

7 Fear that life will have been meaningless

Dying is often a time of intense self-examination. Your loved one may be asking, "What did I accomplish during my life?" or "Did I have a positive impact on the world?"

How to help: People who are leaving this world need to hear that they are valued and that they won't be forgotten. Don't miss the chance to tell your loved one how much you love them. Share memories or look through photo albums together. Even if your loved one is forgetful, long-term memory can be very strong. Ira Byock, a doctor specializing in end-of-life care, teaches that we all need to hear and say the five things that matter most:

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



Living life until the end — the final days

For most of us, death and dying are very difficult topics. We may just not feel “ready” to deal with it all. Yet death, like birth, comes whether we are ready or not. Your hospice team would like to help you prepare so your loved one can have peace and comfort until the end.

Our goal at the end of life is to provide an environment that:

- Is free of avoidable distress for the patient, the family and caregivers.
- Agrees or fits with the patient’s and caregiver’s wishes.
- Is reasonably consistent with clinical, cultural and ethical standards.

We have prepared material to help you understand what your loved one may experience at the end of life. We will address some difficult issues and choices that loved ones may have to face: emotional withdrawal, feeding and hydration. In addition, we have described some processes that your loved one may experience. Our goal is to help you feel prepared and comfortable so that you feel confident through this process.



Emotional withdrawal: Be ready to listen

Death means separation from the people and the activities that we love. Helping your loved one in this gradual process may be very painful for you. Understanding that it is natural and necessary may make it a bit easier.

Many people begin to be less outgoing one to three months before death. They may be less interested in the newspaper, TV or family activities. They may begin gradually to separate from those they love, as a preparation for their final “letting go.” Your loved one may want to be with only a very few people.

If you are not part of this small inner circle, it does not mean that you are not loved or are not important. It means you have already fulfilled your task with your loved one, and it is time for you to say “goodbye.” You may continue to help in other practical ways, such as shopping or preparing meals.

Your loved one may need to spend some time reflecting on his or her life and accomplishments. You can help with this life review, and reassure them that their life was worthwhile. Your loved one may also need to “finish business,” to let you know their wishes for the funeral arrangements or how to distribute possessions. Continue to allow your loved one to have as much control as possible.

Encourage your loved one to share his or her feelings. It is OK to say: “I’m sad that you are experiencing this, but I want you to know I will be here for you. If there is anything I can do to help you feel more at peace, I will do it.” Giving permission for your loved one to let go, without making him or her feel guilty for leaving can be difficult. This is one of the greatest gifts you can give your loved one at this time.

Nutrition: Not eating is OK

We eat to nourish our bodies and give us energy. When our bodies begin to prepare for death, it is perfectly natural that eating should stop. This is a difficult idea to accept. Our lives revolve around eating. This is the way in which we socialize and come together as communities.

When someone is seriously ill, loved ones may focus on eating as necessary for healing. They may feel guilty if they don't make sure that their loved one has nourishment. They may even question whether or not they are allowing him or her to starve. They may worry about being judged by others. Your hospice team wants to help you understand that NOT eating is a natural part of the dying process and that NOT eating even has some benefits that may make the dying process more comfortable for your loved one.

First, it is important to understand that it is a terminal disease, not starvation that is the cause of death. Your loved one is not dying because of starvation. Patients with very advanced disease take in less food and fluids. This is because of reduced ability to swallow, loss of appetite, less energy and withdrawal from all activities of daily living. These are all part of the dying process. Patients with dementia, or a disease like Parkinson's disease, lose the ability to swallow and lose interest in eating. Patients with cancer may lose interest in food because foods taste and smell different and/or their appetite is gone.

At times, your loved one may crave something, but then may eat only a few bites. Make small portions available and offer frequent small snacks, but understand that it is OK if your loved one chooses not to eat. Don't get frustrated if he or she chooses not to eat, even after requesting something. Encourage, but don't push, and don't make eating the focus of your care and support.

Second, it is important to ask yourself, if we choose to feed a dying person by tube feeding or IV (intravenously), who is really being treated? Is this something that will possibly benefit a person facing end of life, or are we choosing this because we can't bear to let our loved one go?

Finally, not eating can add to the comfort of a person who is in the final stage of a disease. The patient will enter a state called ketosis. In this state, a person does not feel hunger, but rather feels a sense of euphoria caused by the body's own natural pain relievers called endorphins. The feeling of hunger in a dying person is different than that of a healthy person. If your loved one asks for something to eat, by all means, provide it. If he or she doesn't want to eat, please don't worry.

When a person's body is shutting down, food does not benefit them. Eating may actually cause nausea, vomiting or diarrhea. This is because a dying body won't accept or can't process food. Making someone eat by a feeding tube, or forced feeding, can cause problems such as abdominal distension, bloating and aspiration, which occurs when food or fluid enters the lungs. These can result in restlessness, irritability and discomfort.

Fluids and dehydration: Benefit or burden?

- With an advanced terminal disease, it is normal to take in less fluid.
 - Benefits of artificial fluids: Acute dehydration can cause changes in the balance of electrolytes or chemicals in the body. These imbalances may cause nausea, vomiting, muscular twitching, some confusion or sleepiness. In earlier stages of an illness, fluids may help to restore balance. In later stages, if these symptoms become distressing in a dying patient, they can be treated with medications.
 - Burdens of artificial fluids: A dying body cannot process excess fluids, and dehydration may have benefits for such a patient. With less fluid going in, there will be less fluid buildup in the lungs, which means less coughing and congestion, and less burden on the heart. This may make patients more comfortable, especially those with advanced heart or lung disease. There may be less fluid buildup in the digestive tract, reducing nausea and vomiting. There may be less swelling or edema in the ankles and feet. There may be less swelling around the tumor, if one is present. All of these effects help promote comfort in patients nearing the end of life.
- Dehydration in later stages of dying may also provide a natural analgesia or pain relief. This is due to the release of endorphins, which are the body's own natural pain relievers. More sleepiness may also make your loved one less aware of the dying process. Dehydration does not cause uncomfortable feeling of thirst, as long as good mouth care is provided. Moistened oral swabs and ice chips will keep your loved one comfortable.
 - Your hospice team can help you make a decision about the benefit versus the burden of artificial fluids.
 - Medical research on artificial nutrition and artificial hydration in patients in the final stages of disease shows no improvement in functioning, survival or reduced pressure ulcers.



Changes to expect one to two weeks before death

Communication

Frequently, people who are drawing closer to death may say things that seem confused or may seem to be having hallucinations. We encourage you to listen very closely. These moments of communication often hold important meaning. Your loved one may talk to people who are not really there or have conversations with loved ones who have already died. It may be very reassuring for your loved one to feel the presence of someone who has already died. Your loved one may ask to “go home” or talk about being on a journey. Listen closely and let your loved one know that you are listening, as he or she may be asking for permission to die.

A calm, reassuring approach is most helpful. Pay special attention to safety measures. Your loved one may be impulsive and overestimate the ability to get out of the bed safely. This makes accidents more likely.

Provide a restful environment and consider having fewer visitors or limiting visits to five minutes. Speak quietly and slowly in a calm, reassuring voice. Try to convey a sense of peacefulness with your body movements. There will be times when just sitting quietly with your loved one is the best approach.

Gently respond to what your loved one says or sees to show acceptance. Ask questions and offer comments that encourage your loved one to keep talking. Try to understand the feeling that your loved one wants to express.

Offer support

If your loved one is having difficulty with letting go, acknowledge the problem and say, “Tell me what I can help you with right now.”

Reminiscing should be encouraged since long-term memory loss is often intact. Look at photo albums together and share fond memories.

Physical changes

- Blood pressure often lowers.
- Heart rate may increase and then decrease.

Days or hours before death

The body may experience temperature changes. There may be a fever that does not respond to medication. The arms and legs may be cool and grayish.

The pattern of breathing may change. There may be pauses between breaths. There may be a pattern of increasing, then decreasing in depth and rate of breaths. As the dying process continues, breathing may become more uneven and congested.

There may be rattling in the upper throat and lungs. This is from pooling of secretions which can no longer be swallowed. Unless this becomes extreme, it is not distressing for your loved one although it may be unpleasant to hear. Changes in position and some medications may help with this if it becomes a problem.

There may be a “rally” period of improved alertness. Your loved one may be able to eat and talk, and enjoy visiting with family.

There may be increased restlessness due to lower oxygen in the blood.

Your loved one may be breathing through the mouth. Mouth care and keeping the tongue, gums and oral cavity moist become even more important for comfort.

Hands, feet and legs may become purplish and blotchy.

Urine output will decrease.

Although your loved one may no longer be able to respond to you, remember that he or she can hear you and knows that you are present. Continue to offer your presence, gentle touch and reassuring voice. Provide music if this is something that your loved one enjoyed during his or her life. Reminisce about good times, and let your loved one know that it is OK to let go.

When the last breath occurs, it may be followed by several long breaths. There will be no heartbeat or pulse. Your loved one’s journey is complete. When this happens, please call Novant Health Hospice if one of your care team members is not present. Your hospice team will support you on the next steps.





The end of the journey: When death occurs

When your loved one dies

- Call Novant Health Hospice and we will send a nurse to your home for assistance.
- Try to remain calm. You may wish to call a neighbor or friend to be with you until help arrives.
- Once the hospice nurse arrives, he or she will:
 - Check for the absence of a pulse and breathing.
 - Remove a catheter if present, clean your loved one if needed and dress him or her if necessary.
 - Contact the funeral home you wish to use for burial or cremation and stay with you until they arrive.
 - Contact the doctor to report the death.
 - Call your medical equipment provider and schedule a time to have the equipment removed from the home.
 - Assist with disposal of all your loved one's unused medications.
- The funeral home will have the death certificate signed by the doctor.
- A hospice bereavement counselor will contact you approximately four to six weeks following the death of your loved one to offer grief counseling and support. Should you need support sooner, do not hesitate to call us at 704-384-6478 in Charlotte or 704-210-7900 in Salisbury.

The first days and weeks following your loss

- Arrange for appropriate child care, if needed.
- You also may wish to arrange for a trusted friend to care for your pet for a few days.
- Ask a friend to coordinate hotel arrangements for any out of town guests. It may be wise for you not to have visitors staying with you at this time, so that you can take care of yourself.
- Ask a trusted friend to oversee some of the household needs for a few days. It helps people to have a specific task and promotes healthy grieving for everyone who loved the person who has died.
- Consider who you want to be pallbearers and have someone contact them. For elderly individuals or those in poor health, you may honor them by asking them to act as honorary pallbearers.
- If your loved one had a will, contact the attorney and notify him or her of the death.
- Ask a friend to arrange for disposition of flowers following the funeral service. Consider donating them to your church, a nursing home or Novant Health Hospice's Giving Gardens program.
- Prepare a list of people you wish to contact by letter and perhaps include a copy of the obituary or memorial service program.
- Above all, strive to be emotionally present during this time and let friends and family assist you in ways that enable you to conserve energy and focus on the meaning of celebrating your loved one's life.
- In the days and weeks following the funeral, you will relive and replay in your mind all the significant moments leading up to the death. This is normal and expected and a way of helping you understand the enormity of your loss.
- Open yourself to support following the funeral. Grief counselors and support groups are available through Novant Health Hospice.



Support for family following loss

Memorial/funeral notice

- Writing the obituary is a process of remembering. Writing these important facts about your loved one's life can serve as a tribute.
- An obituary typically serves as a public notice to the community that a person has died and publishing it in a local newspaper is entirely optional. Most newspapers charge for this service, often by the line or by the word.
- Many funeral homes offer online obituaries free of charge.
- The following information serves as a template, but is not required.



Name of deceased

Address

Birthplace

Date of death Place of death

Cause of death

Occupation Employer

Education

Church/Place of worship

Community involvement/Memberships

Major achievements

Surviving family

Spouse

Children

Brothers/Sisters

Parents

Grandparents

Family members who have preceded in death

Funeral home Minister

Pallbearers

Funeral/Memorial service

Visitation

Graveside service/Burial

Memorials/Donations

Planning a funeral service

- Planning for a funeral is never an easy task, no matter how prepared a person or family may be for death.
- If planned in advance, you can include your loved one in the planning for his or her service, giving the opportunity to talk about special preferences and ease the burden of decision-making for the family later on.
- The following template can serve as a guide for your funeral home director.

Funeral home/Crematorium preferred

Address Phone

Location of memorial service (include name)

Funeral home/Crematorium Church

Graveside Other

Memorial park/Cemetery

Type of burial arrangement: Burial Mausoleum

Disposition of cremation ashes: Burial Columbarium Scattering

Other

Type of casket: Wood Metal Casket open during ceremony Closed during ceremony

Participating organizations (military, lodge, etc.):

 Flag folded Draped Presented to

Clergy

Address Phone

Type of viewing: Public Private

Pallbearers

Name Phone

Name Phone

Name Phone

Name Phone

Name Phone

Name Phone

Clothing preference

Personal articles

Item..... Stays on Return to

Jewelry Stays on Return to

Floral preference

Memorial donations made to

Music organist/Pianist Soloist

Songs/Hymns

Religious passages or readings

Eulogy by

Newspaper notices (name of paper)

Novant Health Hospice

P.O. Box 33549 ▪ Charlotte, NC 28233 or
1229 Statesville Blvd. ▪ Salisbury, NC 28144

Please note: *Many of our families choose to remember their loved one by asking for memorials to be sent to our hospice program. Donations are in honor of your loved one and a sincere compliment to our team and the care they provided. These gifts truly touch our hearts and allow us to continue*

our mission of providing remarkable hospice care in your community. Because we are nonprofit, we are required to receive donations only through our post office box as listed above — and not mailed to our physical address. Thank you for your kind consideration.

Organizing personal records

- Keep a file of important papers that may be needed at the time of death.
- Keep original documents in a fireproof box or bank safety deposit box.
- Keep copies in a manila envelope and store it in a place where others can find it easily.

Items you may need

- Will
- Insurance policies
- Real estate deeds
- Stock certificates
- Bank account numbers, with name of bank and address
- List of assets and debts
- Safe deposit key
- Income tax returns
- Birth certificates
- Marriage certificates, or proof of divorce, if applicable
- Automobile title
- Social Security number
- Military discharge papers
- Business records
- Appraisals for personal belongings, such as jewelry, antiques, etc.
- Funeral or memorial service instructions

Social Security benefits

If your loved one was receiving Social Security benefits, then you will need to contact the Social Security Administration to report the death. They will be able to work with you to determine whether benefits are available for any survivors, as well as resolve any issues related to benefits that already have been paid.

Social Security Office

Monday through Friday, 7 a.m. to 7 p.m.
1-800-772-1213

Bereavement services

- Needs do not end with the death of your loved one. Hospice will provide **free grief counseling** for up to 13 months following the death of your loved one, if you desire this help.
- All services are free and include newsletters, education, support groups and individual counseling.
- Within four to six weeks after the death of your loved one, a member of Novant Health Hospice's bereavement team will contact you to determine if there is any help we can offer with the grieving process.
- Or you can contact us **any time** you feel you need our support.

Our bereavement services include:

- Informational mailings on issues of grief throughout the first 13 months following the death of a loved one
- Individual and/or family counseling
- Support for children
- Grief support groups
- Supportive phone contacts
- Annual memorial service



Financial information

Novant Health Hospice is a nonprofit organization and a department of Novant Health Presbyterian Medical Center and Novant Health Rowan Medical Center. Services of hospice require a doctor's order and are provided for a fee. Patients may pay privately for services or, if eligible, use Medicare, Medicaid or other insurance plans.

Although subject to change, current rates for per-visit hospice services are:

- Nursing evaluation: \$160
- Nursing visit: \$150
- Social worker evaluation: \$145
- Social worker visit: \$140
- Hospice aide visit: \$60
- Chaplain visit: No charge
- Bereavement care: No charge
- Physical, occupational or speech therapy visit: \$150

Please note: *Although most insurance plans provide a hospice care benefit, care will be provided regardless of your ability to pay for services.*

Financial assistance to help with your bills

Novant Health will provide financial assistance for patients who receive medically necessary services and meet the eligibility requirements under the policy. If eligible for financial assistance, patients will receive a percentage discount or free care.

How do I apply?

Ask your hospice team for more information or to apply. Applications are available in English and Spanish. A copy of the financial assistance policy and an application will be provided.

Am I eligible?

In order to qualify for financial assistance, all of the following conditions must be met:

- The patient must be uninsured or, in certain circumstances, have limited insurance coverage.
- The patient must be unable to access other programs that would cover medical expenses.
- The patient's annual family income must be no more than 300 percent of the current year federal poverty guidelines
- The patient must not have substantial cash assets.
- The patient must not have declined health insurance through an employer.
- The patient must not be ineligible for government sponsored coverage because of noncompliance with requirements.
- The service must be considered medically necessary (generally defined as urgent or emergent).
- The patient must live in the Novant Health service area.
- The application and supporting documentation must be submitted to financial counseling department.

How will I know if I have been approved?

Once all requested documents are received, the application will be reviewed. An approval or denial letter will be mailed to each applicant. The financial assistance application and documentation must be updated every six months, or when the patient's income or other key circumstances change. Each visit within the six-month period will be reviewed for potential access to other programs.

Exclusions: This policy only applies to services rendered at a Novant Health facility. It does not apply to services rendered by any independent physicians or practitioners that are not employed by Novant Health. This includes but is not limited to anesthesiologists, radiologists and pathologists. No individual who is eligible for financial assistance will be charged more than amounts generally billed for emergency or other medically necessary care to individuals who have insurance covering such care.

How do I pay for hospice?

Medicare and Medicaid cover hospice care for patients who meet eligibility criteria. Private insurance and veterans' benefits also may cover hospice care under certain conditions. Novant Health Hospice provides services to all patients who meet eligibility criteria, regardless of their ability to pay.

The patient will sign a statement saying that he or she is choosing hospice care.

Please let us know if you have a Medicare Part D prescription plan — you will now need to coordinate with your hospice provider to have your medications filled.

Under the Medicare Hospice Benefit, Novant Health Hospice will cover all medications related to your life-limiting illness and related conditions. Our hospice doctor will coordinate with your regular doctor (if any) to determine which of your current medications are hospice-related and which medications are not related.

You may be on hospice-related medications that the hospice physician may determine are no longer medically helpful at this stage in your disease. If this is the case, hospice will work with you to discontinue them or switch to other medications that might help more. If you are in agreement, these medications will be stopped. If you choose to continue these medications, you will be responsible to cover the cost. Also, if you are currently taking a medication that has an equal in our medication formulary, or we have an equivalent medication that we believe will work well, we will suggest that you switch. If you refuse to accept the equal medication, then you will be responsible to cover the cost of the medication.

Insurance billing

- Most insurance plans pay a daily rate for hospice care to cover ongoing care and availability.
- Although you may not be visited by a hospice team member every day, hospice provides medications, equipment, supplies and 24-hour availability of nursing and social work.
- Our daily charge for routine in-home hospice care is \$201.
- Rates for respite and inpatient care may vary based on contractual agreements between the facility and hospice.
- We will make every effort to obtain benefit information and authorization for your care, as required by your insurance company.
- Every patient is responsible for contacting his or her insurance company for specific deductible, copay and authorization requirements.

Patients and their families are responsible for contacting Novant Health Hospice to obtain authorization **before** contracting any services not scheduled by our staff. If you initiate service without notifying hospice, you may be financially responsible for charges incurred.

Medicare and Medicaid

Patients with Medicare Part A or Medicaid may be eligible for the Hospice Medicare/Medicaid Benefit.

The benefit covers:

- All treatments related to your hospice illness.
- Inpatient hospitalizations.
- Routine medical equipment.
- Medications related to the hospice illness.
- Nursing care and hospice aide services.
- Social work, chaplain, volunteers and therapist visits.
- Counseling during illness.
- Bereavement services after the patient has died.
- Short-term inpatient care at hospice contracted facilities, including respite care for up to five days. Medicare patients seeking respite care are responsible for 5% copay for each day of respite care.

Hospice covers:

- Items medically necessary and related to the hospice condition.
- Items for the relief and control of symptoms related to the hospice condition.
- Items not considered curative in nature.
- Hospitalizations for Medicare and Medicaid patients, if the admission is related to the hospice condition.
- Hospice may cover ambulance transport for Medicare and Medicaid patients with prior approval and with a demonstrated medical need. To be covered, ambulance transport must be the only safe and possible way to move the patient.

Hospice benefits DO NOT cover:

- Any services not related to the hospice condition. However, these services may be covered by your medical insurance outside of the hospice benefit.
- Room and board charges for patients in nursing facilities. However, these charges may be covered by your medical insurance outside of the hospice benefit or by Medicaid.
- Routine transportation to and from hospitalizations, doctor visits and other appointments.

Billing questions and assistance

If you receive a bill from a doctor, laboratory or other medical facility for services that you believe hospice should cover, we will gladly assist you.

Simply request that the provider send a copy of the bill to Novant Health Hospice.

Charlotte:
324 N. McDowell St., Suite 200
Charlotte, NC 28204

Salisbury:
1229 Statesville Blvd.
Salisbury, NC 28144

Hospital stays are only covered for the short-term period it takes to get symptoms under control and patient comfortable enough to return to in-home hospice care.

Supporting Novant Health Hospice

To fulfill our mission of providing care to the terminally ill in our community, regardless of the patient's ability to pay, we depend on the generous financial and volunteer involvement of our community.

Novant Health foundation

A nonprofit organization, Novant Health Hospice is served by **Novant Health Foundation**. Hospice has several funds available to receive donations, including a restricted general fund specifically designed to support the growth and mission of our inpatient and outpatient programs — which may include providing financial assistance to those who cannot pay.

Donations for hospice's general fund (RHGF) can be made payable to:

Novant Health Hospice
P.O. Box 33549
Charlotte, NC 28233

or

Novant Health Hospice
1229 Statesville Blvd.
Salisbury, NC 28144

Hospice's **Giving Gardens** is a unique program that helps hospice patients celebrate special occasions and life's simple pleasures with their families during their hospice diagnosis. Creating fresh flower bouquets and delivering home-grown produce, **Giving Gardens** volunteers provide unique gifts of nature to help patients and loved ones celebrate life.

Become a volunteer

Volunteers are an integral part of the hospice philosophy and members of the care team. They are the very heart of hospice. Many of our volunteers have been a caregiver, a spouse or a helpmate to someone who has died. Each volunteer receives specialized training. Whether it's offering assistance in the office, visiting with a patient or delivering flowers to our families, volunteers are absolutely essential to our team. Volunteer opportunities include:

- Providing companionship to in-home patients — reading, writing letters or helping a patient with a journal.
- Participating in special committees, community events and fundraising.
- Serving with our **Giving Gardens** by making floral bouquets for our patients' special occasions like birthdays and anniversaries, or growing seasonal vegetables.
- Delivering fresh flower bouquets or homegrown seasonal produce to home-hospice patients or fresh-made meals to our grieving families.
- Offering emotional support to grieving families through our bereavement volunteer team.
- Providing clerical support in our office.
- Participating in our prayer ministry, music ministry or other special groups.

Your hospice team

Novant Health Hospice

Nurse: Social worker:

Hospice aide: Chaplain:

Volunteer(s):

Doctors:

Questions for my hospice team:

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Our contact number: _____

Glossary

Advance directives – A document in which you are able to state your choices for medical treatment or designate an individual who should make treatment choices if you should lose the ability to make decisions. With this document, you can ensure your wishes are honored in a legally detailed way.

Artificial nutrition and hydration – A procedure that delivers a mix of nutrients and fluids when you are unable to eat or drink. This is done through intravenous (IV) lines and feeding tubes and is not a natural process of eating food or drinking liquid.

Assisted living facility – A residential living arrangement that provides individualized personal care and health services for people who require assistance with activities of daily living.

Benefit period – The maximum period that an individual can receive benefits for a qualified long-term care event.

Bereavement – The period after a loss of life during which grief is experienced.

Cardiopulmonary resuscitation (CPR) – A medical procedure that involves chest compressions, medicines and electric shock to restart your heart if it stops beating.

Caregiver – The main person (usually a relative) who is managing and providing care for a person who is in hospice.

Confidentiality – Your right to talk with your healthcare provider without anyone else finding out what you have said.

Copayment – A type of cost sharing whereby insured or covered persons pay a specified flat amount per unit of service or unit of time and the insurer or public agency pays the rest of the cost.

Curative care – Treatments or procedures that continue to try to cure the disease.

Do Not Resuscitate (DNR) order – A medical order preventing doctors and nurses from performing CPR if your heart stops beating (cardiac arrest) or if you stop breathing (respiratory arrest).

Durable medical equipment – Reusable medical equipment including hospital bed and over-bed table, bedside commode, tub chair, walkers, bath benches, wheelchairs, oxygen, oxygen concentrator and backup tanks.

Health care agent – A person named in a Health Care Power of Attorney to make healthcare decisions for you if you ever lose the ability to make or communicate your own decisions.

Health Care Power of Attorney – A specific type of advance directive that allows you to select someone else to make medical decisions for you if you become temporarily or even permanently unable to make those decisions yourself.

Hospice – Care that focuses on comfort, pain reduction and quality of life, rather than treating or finding a cure for an illness. Hospice care can be provided at home, in a freestanding facility, in a nursing home or at a hospital.

Living will – A legal document that explains the patient’s wishes to receive or not to receive life-prolonging treatment. A living will only is effective if the patient has a terminal illness, advanced dementia or is in a persistent vegetative state. It is used when the patient is unable to make or communicate his or her own healthcare decisions.

Life-prolonging measures – Any of several medical procedures or interventions that serve only to postpone artificially the moment of death by sustaining, restoring or supplanting a vital function. Some of these interventions may include use of a ventilator (breathing machine), kidney dialysis, antibiotics, tube feeding and similar forms of treatment.

Long-term care or nursing facility – A state-licensed facility providing skilled, intermediate or custodial care for patients who need assistance with daily living due to an accident, illness, cognitive impairment or advancing age.

Medicaid – A joint federal/state program that pays for healthcare services for those with low incomes or very high medical bills relative to income and assets.

Medicare – The federal program providing hospital and medical insurance to people age 65 and older and to certain ill or disabled persons. Benefits for nursing home and home health services are limited.

Medical Orders for Scope of Treatment (MOST) – A medical order used near the end of life. The MOST form details the patient’s wishes about CPR, levels of care for other medical interventions, antibiotics, and artificial nutrition and hydration. It is signed by the patient and the doctor. MOST is a portable medical order that can be honored by any provider in any care setting, including by emergency medical providers who may be called to the home. The MOST form is used in North Carolina.

Palliative care – Specialized medical care for people with serious illnesses. Also known as supportive care, this type of care is focused on providing patients with relief from the symptoms, pain and stress of serious illness — whatever the diagnosis.

Persistent vegetative state – A permanent coma or state of unconsciousness caused by injury, disease or illness. Someone in a persistent vegetative state is not aware of his or her surroundings and is not expected to recover.

Physician Orders for Scope of Treatment (POST) – A physician’s order used near the end of life. The POST form details the patient’s wishes about CPR, levels of care for other medical interventions, antibiotics, and artificial nutrition and hydration. It is signed by the patient and the doctor. POST is a portable medical order that can be honored by any provider in any care setting, including by emergency medical providers who may be called to the home. POST forms are used in many states and currently are being piloted in South Carolina and Virginia.

Respite care – The provision of short-term relief (respite) to family members caring for their terminally ill relatives. Respite services encompass traditional home-based care, as well as adult daycare, skilled nursing, home health aide and short-term institutional care, including hospitalization.

Terminal condition – An incurable condition in which death will occur within a short time (in general, considered less than one year) and medical treatment will only prolong the dying process.

Contact information

Office hours

Monday through Friday, 8 a.m. to 5 p.m.

Call during office hours to:

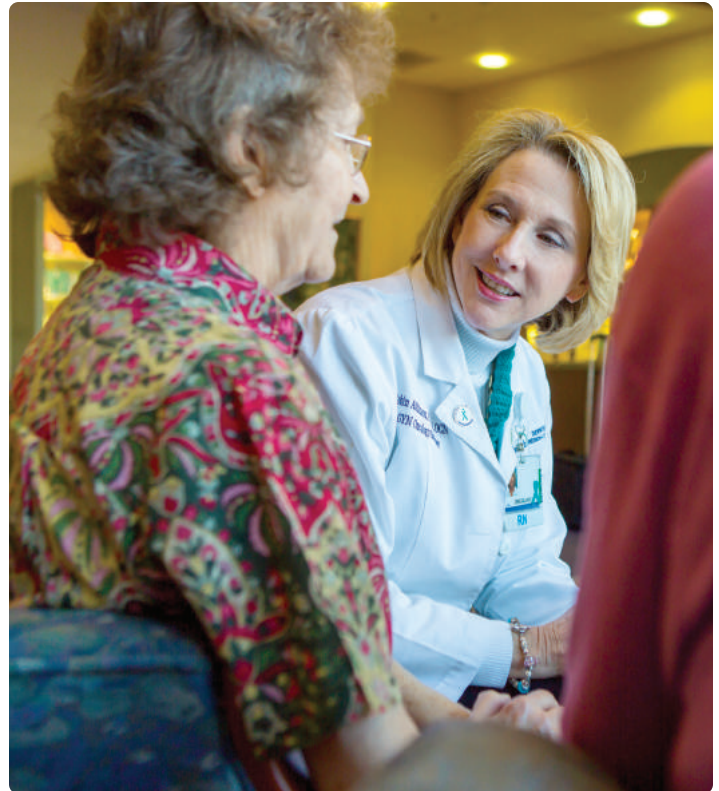
- Refill all medications.
- Leave messages for your primary nurse.
- Reach a social worker, chaplain or other hospice staff.
- Receive lab or blood work results.
- Schedule a hospice volunteer visit.
- If you need to reschedule a visit, please call at least one day in advance.

After-hours calls

Monday through Friday, 5 p.m. to 8 a.m.
24-hours-a-day, weekends and holidays.

- A hospice nurse is always available by phone after hours, on weekends and holidays.
- If the nurse is assisting another family, please leave your name (or the patient's name) and a telephone number.
- Call again if the nurse has not responded within 15 minutes.
- If the clinicians are scheduled to arrive after dark, please turn on your porch light and answer the door promptly.

Please note: *The hospice nurse does not carry and cannot administer any medications unless ordered by a doctor.*



Calling your doctor

- Please call the hospice nurse *before* calling your doctor.
- The nurse will answer your question or help you reach your doctor.

Hospitalization

- Please call the hospice nurse if you are considering hospitalization.

Please note: *Patients and their families are responsible for contacting Novant Health Hospice to obtain authorization before contracting any services not scheduled by our staff. If you initiate service without notifying hospice, you may be financially responsible for charges incurred.*

Call us, day or night, for any of these emergency situations

- Pain not responding to medication
- Difficulty breathing
- Onset of agitation or restlessness
- Falls with possible injury
- No urine output within an eight-hour period, accompanied by discomfort
- Uncontrolled nausea, vomiting or diarrhea
- Uncontrolled bleeding
- Temperature above 101 degrees not responding to medication
- Change in ability to awaken patient
- Catheter leaking
- Chest pain
- Death

We can be reached 24 hours a day, weekends and holidays.

Novant Health Hospice

Charlotte: 704-384-6478
324 N. McDowell St., Charlotte, NC 28204

Salisbury: 704-210-7900
1229 Statesville Blvd., Salisbury, NC 28144

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