



Catawba Regional Hospice

Patient Education Handbook

Follow instructions to read handbook:

- Go to www.CatawbaRegionalHospice.org
- Scroll to the bottom of the page (to blue section)
- Find “Patients & Families” column
- Click on “Download Patient Handbook”

NOTE: The information contained in this document is provided for general information purposes and is not intended to take the place of advice from a medical professional. Please consult with your personal physician for specific questions or information related to your illness.



Dear Patient and Family,

Thank you for selecting Catawba Regional Hospice as your hospice provider. We are a non-profit organization currently serving ten counties in North Carolina and are dedicated to providing you with the highest quality hospice care. The entire staff would like to share with you the following:

MISSION

Our mission is to provide world-class, compassionate care by engaging all individuals and their families to enhance living.

VALUES

Our guiding principles for the delivery of exceptional care to everyone who needs us where they live are:

Service	Leadership	Excellence
Teamwork	Respect	Commitment

SERVICE STANDARDS

Our service standards are the spirit that drives the provision of care at all levels:

- I make patients and families my top priority.
- I welcome your questions and do my best to anticipate your needs.
- I am approachable, friendly, and sincere.
- I make you feel important by treating you with respect and without judgment.
- I listen to you with compassion and work hard to ensure understanding between us.
- I am professional in my appearance, words, and actions.
- I am knowledgeable and trustworthy while providing an experience that exceeds expectations.
- I use technology and innovative thinking to create opportunities for improvement.

Please review this ***Patient Handbook*** for important facts and helpful tips about the care provided to you by Catawba Regional Hospice.

Sincerely,

Catawba Regional Hospice Staff

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PATIENT RIGHTS AND RESPONSIBILITIES

Before hospice care begins, patients **must** be notified verbally and in writing of their rights. To the extent allowed by North Carolina law, a legal representative chosen by the patient or a guardian appointed by a court may exercise the patient's rights. Catawba Regional Hospice is **obligated** to protect and promote the rights of our patients, which include the following:

Respect: Patients have the right:

- To mutual dignity and respect for person and property
- To exercise his/her rights as a patient of Catawba Regional Hospice
- To voice grievances without fear of discrimination or reprisal for having done so
- To be informed how to voice complaints about Catawba Regional Hospice treatment or care that is (or fails to be) furnished and any lack of respect to property by anyone providing Catawba Regional Hospice services, to include misappropriation of patient property
- To know how their complaint is resolved
- To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source

Privacy: Patients have the right:

- To have information about their health, social, and financial status remain confidential
- To expect access to, or release of, clinical records and patient information to be in strict accordance with patient authorization, requirements of the law, and internal Catawba Regional Hospice policy

Quality of Care: Patients have the right:

- To receive care of the highest quality
- To receive effective pain management
- To receive effective control of other symptoms related to their illness
- To receive information about the scope of services that Catawba Regional Hospice will provide and assurance that these services support that patient's palliative care needs
- To receive information about specific limitations on services by Catawba Regional Hospice, if any
- To understand fully how to contact and utilize the on-call service
- To receive appropriate care without discrimination

Decision Making: Patients have the right:

- To participate in the development and periodic revision of the plan of care
- To refuse care or treatment and be advised of the consequences of refusing care
- To be advised of the care to be furnished, the types (disciplines) of caregivers providing care, and the frequency of the care to be provided
- To choose their attending physician

Information: Patients have the right:

- To be informed about Catawba Regional Hospice's organizational status
- To be informed of affiliations with any entities to which the patient is referred
- To receive information about services covered by Medicare, Medicaid, and all applicable third-party payers
- To be informed of charges not covered by Medicare, Medicaid, or their third-party payer
- To be informed of the charges for which they will be liable
- To be informed about advance directives, applicable North Carolina law, and Catawba Regional Hospice's patient care policies
- To be informed of the acceptance/continuation of service process, eligibility determinations, and discharge procedures
- To be informed of supervisory accessibility and availability
- To be informed of anticipated outcomes of care and of any barriers in outcome achievement

As a patient, you have the responsibility to:

1. Remain under the doctor's care while receiving hospice services.
2. Provide hospice with a complete and accurate health history that includes current medications.
3. Provide all requested insurance and financial records to the agency.
4. Sign the required consents and releases for insurance billing.
5. Participate in your plan of care.
6. Inform hospice staff when instructions are not understandable.
7. Accept the consequences for any refusal of treatment or choice of non-compliance.
8. Provide a safe home environment in which your care can be given.
9. Cooperate with your doctor, hospice staff, and other caregivers.
10. Treat hospice staff with respect and consideration.
11. Advise hospice of any problems or dissatisfaction with its services without being subject to discrimination or reprisal.
12. Notify hospice when you are unable to keep appointments.
13. Arrange for a family member or another person to assist you with your care as necessary.

HOSPICE IS A TEAM

The Hospice Team is a group of professionals and volunteers trained specifically to work with the patient, the family, and each other to coordinate care.

Medical Care is provided to the patient by his or her primary physician in consultation with the **Hospice Medical Director**. The doctor is in charge of the patient's care, which includes orders for hospice services, medicines, treatments, equipment, etc.

A **Nurse** comes to the patient for regular visits and is available for emergency needs 24 hours a day, 365 days of the year. The nurse provides care ordered by the physician and teaches caregivers how to give medicines and recognize changes as they occur.

A **Nurse Aide** comes to the patient for regular visits to help with personal care such as bathing, grooming, skin care, etc.

A **Medical Social Worker** helps patients and families maintain a supportive care system that ensures the patient's safety and comfort through education and counseling.

A **Volunteer**, trained to assist patients and family members, can provide companionship, give a break to the caregiver, fix a meal, or help in many other ways.

A **Counselor** provides special support for family and friends dealing with grief and loss before and after the death of a loved one.

A **Chaplain**, specially trained to help with spiritual issues arising from your illness, is available for support and guidance.

A **Pharmacist Consultant** manages the pharmaceutical care of hospice patients and provides drug information and education to the hospice staff, patients, and their families.

In addition to comfort care and symptom management provided by the Hospice Team, other special services may include:

Medicines	Integrative Therapies
Medical Equipment	Physical Therapy
Medical Supplies	Occupational Therapy
Special Counseling for Children	Speech Therapy
Home Visits by a Doctor	Dietary Counseling

These special services are not always covered by all insurance programs and must be approved by Hospice prior to their arrangement in order to assure payment.

Our goal is for all patients to maintain their maximum level of independence. Catawba Regional Hospice has contracts for DME (durable medical equipment) and therapies to assist with this goal. Hospice staff will help you and your family determine your habilitation and rehabilitation needs.

CARE MANAGEMENT

Your hospice team will work with you, your family, and physician to manage and customize your care. An individualized Plan of Care will be developed for you based on your physician's orders, personal goals, problems, and needs as they arise, and environmental requirements. We count on you to participate in your Plan of Care by providing us information to ensure we meet your individual needs. Your Plan of Care is updated and reviewed as your needs change.

Please let one of your Hospice Team members know about any of the following:

- Changes in your condition
- Changes to **any** medications you may be taking (including over-the-counter medications, supplements, vitamins, etc.)
- Changes in equipment or supplies you may need
- Caregiver changes
- Physician changes
- Changes in your insurance coverage
- Address changes
- Problems with any equipment, supplies, or medications

Emergency room visits can be long and extremely tiring. We want to help you stay out of the hospital/emergency room by controlling your symptoms in the home. If you or your family recognizes that your symptoms are worsening, **CALL HOSPICE FIRST!**

Always tell hospitals, physician offices, testing centers (laboratory, X-ray departments, etc.) that you are a hospice patient. Pre-authorization for services like these is required when you have elected the hospice Medicare, Medicaid, or third-party insurance benefit. Failure to obtain prior authorization could result in unexpected expenses for you and your family.

Many supplies you may need can be provided by hospice. When supply needs arise, notify one of your team members before you purchase them.

SAFETY AT HOME

Most accidents in the home can be prevented. Therefore, special precautions need to be taken to ensure safety. Please check your surroundings for potential hazards. Accidents are a major cause of injury and death in the home, particularly for people over 60. Our staff may assess your home for electrical, fire, and general safety requirements necessary to operate any equipment you may need, as well as maintain a safe environment for patients, families, and hospice staff.

GENERAL SAFETY INFORMATION

- Emergency phone numbers (including hospice) should be posted by each telephone.
- Keep your doors and windows locked.
- Don't let strangers into your home. If you do not know a person, ask for identification.
- Keep outdoor areas well lit around your home.
- Wheels on beds, stretchers, wheelchairs, etc. should be locked when stationary.
- Electric beds should be kept in low position except when providing patient care.
- The hand control of an electric bed should be kept within the patient's reach.
- If a patient is bedbound, a bell, buzzer, or appropriate noisemaker should be kept in easy reach of the patient at all times.
- A bell, buzzer, or appropriate noise maker should be kept in the bathroom for emergency use.

ELECTRICAL SAFETY

- Repair or replace broken, frayed, or damaged electrical cords.
- Do not place cords under rugs, near heat sources, through doorways, or across walkways.
- Do not operate heavy equipment or drive when using medications that make you drowsy or dizzy.
- Keep cords away from sinks, bathtubs, showers, and any other areas where water is present.
- Do not touch electrical equipment/cords with wet hands or while standing in water.
- Always grab the head of the plug to remove from an outlet. Never pull from the cord.
- Don't overload outlets with plugs. Use appropriate adaptors if necessary.

FIRE SAFETY

- Make sure everyone in the home understands how to call 911 for help.
- Have 2 fire escape routes, and make sure everyone in the home knows where to meet.
- Make sure there is a working smoke alarm on each floor.
- Check your smoke alarm batteries twice a year. (Do this when you change your clocks in the Fall and Spring.)
- Make sure all your windows open easily.
- If your home has an upstairs, keep a fire ladder in each bedroom. (May be purchased from hardware stores.)
- Do not smoke in bed after taking medications that make you drowsy.
- Never smoke, use e-cigarettes or vapes, or engage in vaping around oxygen equipment.
- Do not use oxygen around open flames or heat sources.
- Keep matches and lighters out of children's reach.

- Use space heaters according to the manufacturer's guidelines.
- Never leave space heaters on when you are not at home.
- Unplug and throw away appliances that smell like they are burning or that produce smoke when used.
- Do not wear long/loose clothing around open flames or stoves.
- If you live in an apartment building, make sure you know where all potential exits are.
- Check fire extinguishers periodically.
- If your only way out of a building is cut off, remain calm, close the door, and block areas where smoke may enter. Go to the window and signal for help.
- Make sure everyone knows to "Stop, Drop, and Roll" should the body or clothing catch on fire.
- If a bedbound patient is left in the home alone for any period of time, make sure a neighbor or friend has access to the home and is available if intervention is needed.

*If the patient is bedbound, one or two persons can get the patient to safety by placing the patient on a blanket and pulling/lifting/dragging the patient out of the home.

FALL PREVENTION

- Make sure you know and understand the side effects of medications you are taking.
- Use night lights.
- Make sure stairwells are well lit and have hand rails.
- Never leave objects on the stairs.
- Keep a flashlight with good batteries next to your bed.
- Remove throw rugs from traffic areas.
- Do not place cords across pathways or under rugs, and keep them away from traffic areas.
- Use rubber mats in baths and showers.
- Install grab bars in bathrooms if necessary.
- Wear shoes that fit and have non-skid soles.
- Sit up on the edge of the bed or chair before rising.
- Stand up for a few seconds before taking a step to ensure balance.
- Clean up spills immediately.
- Use a cane, walker, or wheelchair if you feel unsteady.
- Store items you may need within your reach to avoid climbing on stools or chairs.
- Minimize or limit alcohol consumption.

BATHROOM SAFETY

- Use non-skid mats or strips in all tubs and/or showers
- Install grab bars on the walls by the tub and toilet
- Set the water heater below 120°F to prevent scalding
- Use night lights to brighten the way to the bathroom
- Use a tub or shower chair if you have difficulty getting in and out of the tub or shower

SAFE OUTSIDE AREAS

- Make sure steps and walkways are in good condition and free of clutter
- Make sure porches and balconies have railings to prevent injury
- Have all dead limbs removed from large trees
- Keep your outside areas well lit

POISONS AND HAZARDOUS ITEMS

- Store any hazardous items in their original containers
- Make sure you know how to contact poison control
- Do not mix products that contain chlorine or bleach with any other chemical products
- Keep cleaners and chemicals out of children's reach
- Make sure you store hazardous items according to recommendations on the label
- If insecticides are being used in the home, read the manufacturer's safety instructions and follow carefully

MEDICATION SAFETY

- Make sure you know the name, purpose, and dose of all the medications you are taking
- Make sure you know whether you should avoid any foods, drinks, or activities while taking certain medications
- Never take medications that are prescribed for someone else
- Read and follow the instructions provided with your medications
- Make sure the light is on when you take your medications so you can see the label
- Keep all your medications written down, and show the list to your doctor, pharmacist, and other health care providers (make sure to include prescription medications, over-the-counter medications, home remedies, and nutritional supplements) so we can assess any potential dangerous interactions between them
- Make sure someone updates your medication list as medications are added, changed, or stopped
- Don't stop or change medications without your doctor's approval, even if you are feeling better
- Report any medication side effects you have
- Keep your medications in their original containers
- Store your medications in a cool dry place according to instructions provided with the medication
- Do not crush medications without first checking with your pharmacist, doctor, or nurse
- Dispose of old medications
- Do not use alcohol when you are taking medications
- Keep all medications away from children

MEDICAL EQUIPMENT SAFETY

Catawba Regional Hospice can provide you with medical equipment you may need through our provider for durable medical equipment (DME). Medicare, Medicaid, and most insurance companies usually cover the cost of medical equipment through the hospice benefit. Your nurse will continuously evaluate your needs for medical equipment, check with your pay source, and order the equipment

and/or supplies for you. Our DME provider will deliver the equipment to you, set it up, and show you and your family how to use it safely. The provider will also leave written instructions with you. Your hospice staff, as well as the medical equipment company's staff, can assist you at any time with safety and usage information.

The following guidelines can help assure safety when using medical equipment:

- Keep instructions for medical equipment with or near the equipment, and follow them
- Keep phone numbers for equipment providers accessible in case you have problems with the equipment
- If back-up equipment is provided (oxygen back-up tanks, for example), make sure you know how to use it in the event of an emergency
- If your medical equipment uses batteries, make sure they are checked according to the manufacturer's suggestions
- Do not overload power outlets that are being used for medical equipment
- Keep oxygen equipment away from open flames
- Do not smoke around oxygen, and do not use e-cigarettes or vapes or engage in vaping
- If you use electrically powered equipment such as oxygen, you should register with your utility company

OXYGEN SAFETY

Oxygen safety techniques should be observed at all times to provide a safe environment for patients, families, and staff. Failure to comply could result in removal of equipment. Safety tips include:

- Smoking materials, including e-cigarettes and vapes, should be removed from all areas where oxygen is used
- All family members should be personally warned about smoking or vaping in an area where oxygen is used
- Patients/Family members should assume responsibility for preventing visitors from smoking or vaping in the patient's area or in an area where oxygen is used.
- A "No Smoking" sign should be displayed on the door of any home where oxygen is being used
- Care of equipment and methods for cleaning filters will be explained to the patient and/or caregiver when supplies are delivered by our durable medical equipment company and will be reinforced by hospice staff
- Electrical equipment and heat sources must be kept 3 feet away from oxygen equipment
- Do not burn candles, use kerosene lamps or heaters, have open flames of any kind (such as lighters or matches), or use electric heaters in a room where oxygen is being used
- Never oil any oxygen equipment or handle oxygen equipment with oily hands or rags
- Products containing oil or petroleum jelly (Vaseline) should not be used with oxygen
- Never cut your oxygen tubing
- Be aware that oxygen tubing can be a trip hazard

SAFETY OF OXYGEN CYLINDERS:

- To prevent possible explosion or fire, oxygen cylinders should be placed in a location where they will not be subject to mechanical or physical damage, heat, or electrical circuits.
- Use caution to keep oxygen cylinders at least 20 feet away from fireplaces, wood-burning stoves, or other open sources of flames.
- Cylinders should be on carriers or strapped in a stationary way to prevent tipping.
- When oxygen cylinders are not in use, the main valve should be tightly closed. Any valve protection devices, such as caps or guards, should remain securely in place.
- Cylinders should be stored in a dry, well-vented area at least 20 feet from combustible materials. Cylinders should not be covered with combustible items such as blankets, quilts, or paper and should never be stored in a closet or under furniture.

SAFETY OF OXYGEN CONCENTRATORS:

- A concentrator needs to "breathe" to operate properly. It must be kept at least 6-12 inches away from drapes, bedspreads, and walls, and items should never be stacked or stored on top of the device.
- Electrical cords from oxygen concentrators should be grounded.
- Thick carpets and padding may cause the concentrator to run poorly or at a higher temperature, which could lead to malfunction.

- Concentrators can be noisy if they are placed on tile or wood floors; however, a small rug placed under the device can help the noise and vibration.
- Concentrators should not be plugged into an extension cord, multi-outlet adaptor, power strip, or an outlet or circuit that has other major appliances plugged into it. Doing so can create a fire hazard, result in blown fuses or circuit breakers, or create possible damage to the concentrator.

USING YOUR BACK-UP SYSTEM

- If you experience a power outage or the concentrator stops working, you should use your back-up tanks.
- Take your tubing off the concentrator and attach it to the back-up tank regulator.
- Turn the back-up tank knob on top of the tank counterclockwise to turn it on.
- There is a small black knob on the back of the regulator called the flow meter. Turn the flow meter knob to adjust your oxygen liter flow to your normal setting.

OXYGEN CONCENTRATOR TROUBLESHOOTING

If your oxygen concentrator is not working properly, follow the guidelines below. If you are unable to correct the problem yourself, switch to your back-up supply of oxygen and call your hospice nurse.

- Make sure your concentrator is plugged in and turned on
- Make sure your flow meter is set to your prescribed flow
- Make sure there are no kinks in the tubing
- Make sure the nose piece or cannula is connected to the tubing
- Make sure your tubing is connected to your concentrator

RESTRAINT USE

Every effort will be made to manage the needs of patients without using physical or chemical restraints. When required, and when less restrictive interventions are ineffective, restraints can be utilized with a physician's order. Restraints are never used as a means of coercion, discipline, convenience, or staff retaliation.

PREPARING FOR AN EMERGENCY

An emergency is an event such as a power outage, tornado, electrical storm, winter storm, hurricane, or flood that will result in an interruption in the care and service provided to you. Everyone should have an emergency/disaster plan for their household. Assemble an emergency kit that contains the following:

- Portable radio with batteries
- Cigarette lighter or matches
- Flashlight and extra batteries
- First aid kit

POWER OUTAGE

Sudden power outages can be frustrating and scary, especially if they last a long time. If you lose power in your home and require assistance, you can contact Catawba Regional Hospice. If our phone lines are not working properly, you should do the following:

- If you are in an emergent situation, call 911 or go to the nearest hospital emergency department.
- If you are not in any emergent/life-threatening situation and need assistance, call a close relative or neighbor.

Someone from the hospice team will contact you as soon as possible.

TORNADO

A tornado is a violently rotating column of air that extends from the base of a thunderstorm to the ground. It is capable of completely destroying structures, hurling objects through the air, and uprooting trees. When a tornado has been sighted in your area, find shelter and stay away from doors, windows, and outside walls of your home.

In a house or small building:

- Go to the basement or cellar if there is one
- If you do not have a basement or cellar, go to a room in the middle of your house that does not have windows
- Stay on the lowest level possible
- Protect your head and get under a sturdy object if possible. Stay there until the tornado has passed
- If the patient is bedbound, move the bed as far away from windows as possible. Cover the patient with pillows, blankets, foam padding, etc. Be sure to protect the patient's head, and make sure you do not block their airway. Go to a safe area as described above after you have protected the patient.

In a high-rise building:

- Go to an interior room on the lowest floor possible. Use the same guidelines outlined for a house or small building above.

In a vehicle, trailer, or mobile home:

- Try to go to a sturdy structure if possible
- Do not try to out-run a tornado in a car
- If there is no shelter nearby, lie flat in a ditch with your hands protecting your head

FLOOD/HURRICANE

According to the American Red Cross, “floods are among the most frequent and costly natural disasters.” Flooding can occur from several hours or days of heavy, steady rain that saturates the ground. Flash floods are caused by rapidly rising water along streams or low-lying areas and occur suddenly.

You should assemble and keep a disaster supply kit in your home. The following items should be included: battery-operated radio, flashlight with extra batteries, first aid kit, medications and medical items (hearing aids with batteries, glasses, syringes, contact lens, etc.), extra oxygen, and enough food and drinking water for at least 3 days.

If local authorities issue a flood watch, be prepared to evacuate by gathering the above supplies and:

- Secure your home for evacuation
- Move important items to the upper floors or attic of your house
- Clean the bath tub and fill it with water in case the local supply becomes contaminated or water service is cut off
- Turn off utilities at the main switch if needed

If there is an actual flood, do not walk through any moving water. As little as six inches of moving water can knock you off your feet.

WINTER STORMS

A winter storm can be heavy snow, blizzard, extreme ice, freezing rain, and/or sleet and is often accompanied by extremely low temperatures. Areas that typically have mild winters can be hit by a major winter storm, resulting in blocked roads, downed power lines, and loss of electricity to large areas. The following supplies can help you prepare for a winter storm:

- Battery-powered radio
- Food that you can easily open and don't have to cook
- Medications
- Extra blankets
- Water stored in large containers
- Flashlights with extra batteries
- Fuel for heating sources if power is off
- Extra oxygen tanks
- Clothes you can layer
- Mittens/gloves (mittens keep your hands warmer), hats, and coats

DISASTER PREPAREDNESS FOR PATIENTS AND FAMILIES

- Follow weather updates prior to approaching disaster
- Check medications to be sure you have an adequate supply in the event of an emergency
- If you use oxygen, make sure you have full tanks to use
- Have a plan for emergency heat in the winter time
- If you have to leave your home:
 - Notify hospice at 828-466-9996
 - Take all your medications with you

Hospice staff may not be able to visit when road conditions are not safe but can often give advice and instructions to you over the phone. We will take care of emergency situations in the safest manner possible.

INFECTION: PREVENTION AND CONTROL

Germs that cause infection can be hiding in many places throughout your home: tabletops, doorknobs, telephones, money, and even on your pets. These germs can enter your body and cause infection. **Washing your hands is the single most important thing you and the people around you can do to prevent the spread of infection.** The suggested steps for proper hand washing are as follows:

- Remove all jewelry from your hands and wrists
- Wet your hands under running warm water
- Lather your hands and wrists with soap (liquid soap is much better than bar soap)
- Be sure to scrub between your fingers and under your fingernails while washing
- Try to scrub for at least 20 seconds (sing *Happy Birthday* or *Mary Had a Little Lamb*)
- Thoroughly rinse your hands in the running water
- Dry your hands with a clean paper towel
- Use a paper towel to turn off the faucet

Patients, family, friends, and caregivers should wash their hands:

- Before and after providing any care to the patient (even if gloves were used)
- Before handling or eating food
- After using the toilet
- After changing a diaper and/or handling soiled linens
- After touching a pet
- After coughing, sneezing, or blowing their nose

There are many signs and symptoms you may experience if you are developing an infection. Please notify your nurse if you have any of the following:

- Painful urination
- Nausea/vomiting/diarrhea
- Fever or chills
- Sore throat/cough
- Increased weakness
- Pain/tenderness/redness or swelling of any body part
- Inflamed skin/rash/sores/ulcers
- Pus (green or yellow drainage)

Contaminated items, also known as medical waste, such as bandages, dressings, needles, syringes, or gloves can spread infection and/or harm the environment. These items need to be disposed of properly so they don't cause injury to others. The following guidelines should be used to dispose of medical or hazardous medications and waste:

- Dispose of needles, syringes, and other sharp objects in a Sharps Container or sturdy plastic bottle. Your hospice staff can provide you with a Sharps Container to keep in your home. When container is full, secure with sturdy tape and throw away with regular trash.
- Never remove, re-cap, or break needles.

- Place soiled dressings, gloves, paper towels, and other disposable items into a plastic trash bag. Tie off the trash bag and throw it away with your regular trash.
- Flush body waste such as urine from a catheter or feces from a diaper down the toilet.
- Soiled laundry should be washed separately in hot water.
- Medical equipment should be cleaned according to the instructions provided by the medical equipment supplier.
- If blood or other body drainage is spilled, wear gloves and wipe up the spill with paper towels. Disinfect the area of the spill with a solution of 1 teaspoon of bleach to 2 cups of water or another antibacterial cleaning solution. Allow the area to air-dry completely. Put the soiled paper towels in double plastic bags and discard in regular trash.
- Unused prescription drugs should be mixed with kitty litter and placed in a sealable bag and thrown away. This practice is used to protect the environment and to ensure unused medications are not taken by anyone else.

Be sure to wash your hands after performing any of the above guidelines.

PAIN

What is pain? There are many different definitions of pain, and they vary from person to person. One of the most common descriptions of pain is that pain is whatever the individual says it is. Each person views and tolerates pain differently. Some patients feel that they are supposed to have pain and just need to “grin and bear it,” while others fear that if they admit their pain is increasing, then their disease is worsening. Many patients also worry about becoming addicted to medications. Your hospice nurse can help you deal with any issues that may arise concerning your pain.

The assessment and treatment of pain will vary. It is your right as a patient to have your pain assessed and treated, and it is our goal to manage your pain and help you achieve the highest quality of life possible.

Members of your hospice team will ask you about your pain every time they visit you in your home. Communication is the key to effective pain management. Recognizing and talking about your pain to the hospice team is important. Being able to answer some of the following questions can help your team effectively control your pain.

- Where is your pain?
- Do you have pain in more than one place?
- Which pain bothers you the most?
- Can you point to areas where you have pain?
- When did the pain begin?
- Did anything happen that may have caused the pain?
- Has the pain changed over time?
- How often does the pain occur?
- Is the pain better or worse during certain times of day?
- What does the pain feel like?
- What words describe your pain?
- What number would you give your pain right now on a scale of 0-10? (10 being the worst)
- What number would you consider a comfortable level of pain on a scale of 0-10?
- Does anything make your pain better?
- Does anything make your pain worse?

The good news is there are many things you, your caregiver, and the hospice team can do for managing pain. They will find the reason for the pain and discuss treatment options with you and your doctor.

Medications are often necessary to relieve pain, and two types are typically used: non-narcotic and narcotics. Ibuprofen, acetaminophen, aspirin, naproxen, etc. are all examples of non-narcotic pain medications. Morphine, hydrocodone, oxycodone, methadone, fentanyl, hydromorphone, etc. are medications classified as narcotics.

In addition to medications, there are other things you can do to help make the pain better:

- Relaxing activities such as soaking in a warm bath, listening to soft music, or picturing relaxing things to take your mind off the pain
- Watching television, playing a game, or doing any other activity can distract you from your pain
- Deep breathing exercises
- Applying heat and cold (such as a heating pad, warm compress, or ice pack)

SIDE EFFECTS OF PAIN MEDICATION

It is possible for you to experience side effects with any medication. Some common side effects of pain medications include:

- Dry mouth
- Increased heart rate
- Constipation
- Nausea and vomiting
- Drowsiness

Please let your nurse know if you experience any side effects from your pain medication.

The following suggestions may help control some of the side effects your medications may cause:

- Dry mouth – Drink fluids often, artificial saliva is available, sucking on hardy candy or chewing gum could be helpful.
- Increased heart rate – This will often change on its own within a few days as your body adjusts to a new medication. If you are uncomfortable, notify your nurse and she will talk to your doctor.
- Constipation – Your nurse should provide an order from your physician to begin a laxative/stool softener with any new narcotic medication for pain. Talk to your nurse if you do not have something for constipation.
- Nausea and vomiting – Medication for nausea can be taken a half-hour before your pain medication to reduce the risk of nausea. If you do not have an anti-emetic (nausea medication), ask your nurse. She can secure an order from your doctor.
- Drowsiness – This will usually stop after 1 to 3 days of starting a new medication or changing your dosage.

SKIN AND MOUTH CARE

SKIN CARE

Many things can be done on a daily basis to help protect your skin:

- Check each day for reddened areas or breakdown
- Keep skin clean and dry
- Keep bed linens dry
- Remove wrinkles from sheets or any padding on the bed
- Turn or reposition every 2-3 hours
- Use a folded sheet or pad to turn, lift, or reposition
- Use pillows to support arms, legs, and back
- Moisturize the skin daily with an emollient cream or lotion
- Be careful using soap, which tends to dry out the skin

Many times as a person's disease progresses, they become weak, lose weight, and do not eat as well, thus causing skin problems. In addition, when someone remains in a chair or bed for an extended period of time, bedsores or decubitus ulcers may occur. The most likely problem areas of the skin are the sacrum (tail bone), elbows, hips, and heels and should be inspected often. Keep in mind that in spite of all efforts, a bedsore may develop. If this happens, your hospice nurse will help decide the best way to treat the area.

MOUTH CARE

Regular mouth care may help prevent sores, improve the taste of food and fluids, and create an overall feeling of comfort. Here are some tips to ensure good oral hygiene:

- Use a soft toothbrush or a soft cloth wrapped around a finger to brush teeth and/or gums
- Do mouth care at least 2 times a day
- Remove dentures and clean them
- Keep lips moist with lip balm
- Do not perform mouth care with patient lying flat

If any mouth sores or discomfort develops, notify your hospice nurse.

MANAGING NUTRITION ISSUES

Nutrition is the feeding of our body with food and fluids. Hydration is giving liquids for the body. Patients tend to lose their appetite and eat less as their health declines. Since most patients are taking in less food and fewer liquids, families are often concerned about the patient's nutritional needs. Tell the hospice team 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 output
- Becomes confused or drowsy at unexpected times

COPING WITH DECREASING APPETITE AND REFUSAL TO EAT

The hospice team will discuss possible reasons and treatments with you. It is normal for patients to have less appetite and drink less as the disease continues. In some cases, eating and drinking also may become uncomfortable for the patient. Since food is one of the ways we show love for our families, there is also an emotional aspect to nutrition for the caregiver. Treatment choices will depend on your wishes and the patient's illness. Things you can do to help include:

- Offering favorite foods and drinks
- Offering drinks or sips often (at least every two hours), unless the patient has trouble swallowing
- Cleaning the mouth often
- If dentures do not fit well, consulting a dentist
- Encouraging the patient to rest before and after a meal
- Making mealtime a quiet and pleasant experience
- Offering small meals and using smaller dishes
- If nausea is a problem, serving small portions of salty (not sweet), dry foods and clear liquids
- Finding other ways besides food and drink to show the patient you care, such as offering a massage or looking through a picture album together
- Never putting food or drink in the mouth of a patient who is not responding to you
- Supporting the patient's decision not to eat or drink
- Helping other family members and friends understand why eating and drinking may cause the patient to be uncomfortable

MANAGING NAUSEA AND VOMITING

We all know that unpleasant, queasy feeling in the back of our throat or stomach just before we throw up or vomit. Unfortunately, nausea and vomiting are common symptoms for many hospice patients. The good news is that much can be done to relieve and manage the uncomfortable symptoms. First, it is important for you or your loved one to note the amount and frequency of nausea and vomiting you are having and tell your nurse. You also need to be able to describe the vomited fluid, which will help your hospice team in identifying the underlying cause of the problem and determining the best way to help you. Here are a few suggestions that often help with nausea and vomiting:

- Pay attention to what causes you to feel nauseated or makes you vomit and what decreases those feelings.
- Sip carbonated drinks that have gone flat.
- Avoid acid juices such as cranberry, grape, or apple.
- Drink sports drinks such as Gatorade. Use Pedialyte with children.
- Avoid fried foods, milk products, or those with strong smells.
- Try small, frequent amounts of food that the patient requests. Avoid large meals that can be overwhelming.
- Avoid eating after vomiting.
- Try sips of water or ice chips before eating again.
- Provide frequent mouth care.
- Maintain a comfortable room temperature.
- Avoid constipation.
- Use medications as directed.

Be sure to contact your hospice nurse if nausea/vomiting continues.

MANAGING SHORTNESS OF BREATH

Some patients describe it as not being able to get enough air. Others say it is a feeling of not being able to catch your breath. It may feel like the room is closing in or doesn't contain enough oxygen. However a patient describes it, shortness of breath is a personal experience for each individual. You should become worried about shortness of breath and contact your hospice team for any of the following:

- It stops you from doing what you want to do.
- It causes you or your family fear, anxiety, nervousness, or restlessness.
- Your lips, nose, fingers, or toes become bluish in color.

WAYS TO MANAGE SHORTNESS OF BREATH

There are steps you can take to manage shortness of breath. Here are a few:

- Record what makes you feel short of breath and what decreases the feeling.
- Open a window or turn on a fan to increase air movement.
- Keep the room cool.
- Applying a cool cloth to the face, using an air conditioner, or placing a bowl of ice in front of a fan can also help.
- Keep a quiet environment to help decrease anxiety.
- Elevate your head or sit in a chair or recliner.
- Relax with spiritual support, yoga, calming music, massage, or whatever works for you.
- Focus on your breathing – take slow, deep breaths or use breathing exercises your hospice team has taught you.
- Use oxygen as directed by your health care team.
- Take medications as prescribed.

Call your hospice nurse if your shortness of breath is not relieved.

BREATHING TECHNIQUES

The following two breathing techniques allow you to take in more air that is oxygen-rich. They can be effective when you experience increased shortness of breath. **You can control your breathing.**

Take the time to do the exercises and don't panic. You and your family should practice them together when you are not feeling short of breath so you can work through an attack together.

1. Inhale slowly through your nose for two counts, then put your lips together (as if you were blowing out a candle or whistling) and exhale slowly (for four counts) through your mouth. Repeat this sequence until your shortness of breath decreases.
2. Sit down and lean slightly forward with your arms resting on a table. If you are standing and have no place to sit down, simply lean against a wall. Start by breathing in through your nose and out by putting your lips together as described above. Little by little, breathe out for longer periods of time. As your breathing gets easier, concentrate on slowing down your breathing rate.

MANAGING CONSTIPATION

Due to the effects of some medications, physical inactivity, and other difficulties, hospice patients often experience constipation. The discomforts associated with constipation can also be a sign of other issues, so it is important to keep the bowels moving as regularly as possible. Constipation results when bowel movements occur less often than they normally do, when there is a hard stool, and when there is increased difficulty with moving the bowels. You should report the following conditions to your hospice team so they can work to discover the underlying cause and determine the best course of treatment for you:

- No bowel movement in two days or a change in frequency
- Pain, cramping, or tenderness
- A feeling of fullness or bloating
- Nausea and/or vomiting
- Blood in stools
- Diarrhea or oozing of stools

WAYS TO HELP WITH CONSTIPATION

There are ways to reduce the likelihood and/or effects of constipation. Here are a few that often work well with hospice patients:

- Record when your bowel movements have occurred so you will know your personal habits and be aware of a change, should one occur.
- Drink plenty of fluids. Many patients say drinking warm liquids helps.
- Eat more fruits and drink fruit juices.
- Increase physical activity if possible. Even walking short distances can help.
- Sit upright on the toilet, commode, or bedpan.
- Establish routine times for toileting.
- Take laxatives/stool softeners as ordered by your health care provider.

Call your hospice nurse if constipation continues.

MANAGING RESTLESSNESS

Restlessness is an inability to rest, relax, or concentrate. Extreme restlessness is sometimes called agitation. Restlessness can occur at any time during an illness. Nearly half of all patients experience some degree of restlessness during the last 48 hours of life. Signs that a patient may be restless include:

- Muscle twitching
- Moving around without a known reason
- Pulling at the sheets or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

You should call your hospice team if you see any of the above signs or if the patient is having difficulty swallowing medications. Also take note of things that make the restlessness worse, such as loud music, along with those things that decrease it, such as soft music. Share any concerns you may have as a caregiver, and let the hospice team know if there is a need for spiritual support. It is especially important to report any situations that might be unsafe, such as the need for side rails to keep the patient in bed and prevent falls.

WAYS TO COPE WITH RESTLESSNESS

Your hospice team will try to find the reason for the restlessness and talk with you about treatments. Here are a few things you can do to help:

- Take/give medications as directed
- Offer frequent reassurance to the patient
- Offer relaxation activities if the patient is alert
- Play soothing music
- Keep the room quiet and limit the number of visitors
- Do gentle massage, comforting touch, or other things that calm the patient
- Keep the patient safe

Discuss any concerns you have with the hospice nurse.

MANAGING ANXIETY/UNEASY FEELINGS

Anxiety is a feeling or deep sense that things are not right. Anxiety shows itself through a number of symptoms that may include:

- Fear
- Worry
- Sleeplessness
- Confusion
- Rapid breathing
- Tension
- Shaking
- Inability to relax or get comfortable
- Sweating
- Problems paying attention or concentrating

It is not unusual for patients to experience anxiety at various points during their illness. One way caregivers can help is to be aware of what may be causing the anxiety (such as worrying about money, having concerns about the illness, or fearing dying) and then sharing that information with the hospice team. Relationship problems with family or friends and struggles with spiritual concerns can also cause anxiety. If the signs and symptoms of anxiety get worse, call the hospice nurse.

COPING WITH ANXIETY

Your hospice team will work with you and your family to determine the cause for the anxiety so that treatment can be as individualized as possible. Things you and/or your caregiver can do to help the situation include the following:

- Continue doing the things that have helped you relieve anxiety in the past.
- Write down your thoughts and feelings.
- Treat physical problems, such as pain, that cause anxiety.
- Do relaxing activities.
- Keep things calm.
- Limit visitors.
- Play soothing music.
- Massage arm, back, hand, and foot.
- Take/give medications as ordered.

Catawba Regional Hospice offers chaplain and counseling services for additional support. If you are interested in receiving these services, contact a member of your hospice team.



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