

# Patient Education Handbook



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



Dear Patient and Family,

We appreciate the opportunity to serve as your provider of hospice care and will do everything we can so that you and your loved one feel comfortable, supported, and peaceful.

Our dedicated team of staff and medical professionals deliver hometown compassion and exceptional care by following the organization's guiding principles of service, teamwork, leadership, respect, excellence and commitment. Above all you are our top priority. Please feel free to share your requests with us, so we can personalize our service to meet your needs.

We are proud to be accredited by the Joint Commission. This accreditation is a symbol of quality that reflects the organization's commitment to meeting high performance standards. As part of our commitment to you, please know that:

- We believe that quality of life is first and foremost.
- Our staff are available 24 hours a day, 7 days a week.
- We welcome patients and employ qualified individuals regardless of race, color, creed, religion, sex, age, sexual orientation, marital status, disability, veteran status, or national origin.
- We are committed to providing care regardless of payment source or ability to pay.

We are a non-profit organization guided by a community-based Board of Directors and supported by a team of enthusiastic volunteers. We promise to deliver compassionate care that allows patients to live every moment to the fullest.

Sincerely,

Lana Ellian

Dana Killian Interim President and CEO

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# THE JOINT COMMISSION ACCREDITATION

Following a meticulous series of evaluations and procedural reviews, The Joint Commission has awarded Carolina Caring the Gold Seal of Approval<sup>™</sup> for health care quality and safety in the field of home care.

This standing demonstrates to patients, staff, and the community that Carolina Caring is committed to providing the best care possible and is dedicated to continuous compliance with The Joint Commission's state-of-the-art standards.

Founded in 1951, The Joint Commission seeks to continuously improve health care for the public. The independent, not-for-profit organization is the nation's oldest and largest standards-setting and accrediting body in health care. It evaluates and accredits more than 20,000 health care organizations and programs in the United States.

If you have general questions or concerns about patient safety or quality of care, you may reach us at the following:

Carolina Caring

- Email: info@CarolinaCaring.org
- Phone: 828.466.0466
- Website: www.CarolinaCaring.org

The Joint Commission

- E-mail: <u>patientsafetyreport@jointcommission.org</u>
- Customer service: 630.792.5800
- Fax: 630.792.5636
- Website: www.jointcommission.org
- Mail: Office of Quality and Patient Safety The Joint Commission One Renaissance Boulevard Oakbrook Terrace, Illinois 60181



Carolina Caring is a community-based health care organization serving 12 counties in North Carolina. As part of our dedicated efforts to provide you with the highest quality hospice care, we share with you our guiding principles.

# **OUR MISSION**

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

# **OUR VALUES**

We deliver exceptional care to everyone who needs us, no matter where they live, by relying on:

Service	Excellence	Respect
Leadership	Teamwork	Commitment

# **OUR SERVICE STANDARDS**

- · I make patients and families my top priority.
- I welcome your questions and will 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 specially-created patient handbook for additional details about the many services provided by Carolina Caring. Caring for you and your loved ones is why we are here.

# PATIENT RIGHTS AND RESPONSIBILITIES

Before hospice care begins, you, as a patient, must be notified verbally and in writing of your rights. To the extent allowed by North Carolina law, a legal representative chosen by you or a guardian appointed by a court may exercise your rights. Carolina Caring is obligated to protect and promote your rights, which include the following:

# RESPECT

As a patient, you have the right:

- To exercise your rights as a patient of Carolina Caring.
- To be treated with respect, consideration, dignity, and full recognition of your individuality and right to privacy.
- To be informed how to voice complaints about Carolina Caring treatment or care that is (or fails to be) furnished and any lack of respect to property by anyone providing services, to include misappropriation of patient property.
- To advise Carolina Caring of any problems or dissatisfaction with care or services without fear of discrimination or reprisal for having done so and to know how your complaint is resolved.
- To be free from mistreatment, exploitation, neglect, or verbal, mental, sexual, or physical abuse, including injuries of unknown source.
- To effective communication tailored to your age, language, and ability to understand.
- To be shown respect for your cultural, religious, and other spiritual needs.
- To receive a reasonable response to your requests of Carolina Caring.

# PRIVACY

As a patient, you have the right:

- To have information about your health, social, and financial status kept confidential.
- To expect access to, or release of, clinical records and patient information to be in strict accordance with your authorization, requirements of State or federal law, and internal Carolina Caring policy.

# QUALITY OF CARE

As a patient, you have the right:

- To receive care and services of the highest quality that are adequate, appropriate, and in compliance with relevant federal and State laws, rules, and regulations.
- To receive effective pain management and control of other symptoms related to your illness.
- To receive information about the scope of services that Carolina Caring will provide and assurance that these services support your care needs.
- To receive information about specific limitations on services by Carolina Caring, if any.
- To understand fully how to contact and utilize the on-call service.
- To receive appropriate care without discrimination.

### **DECISION-MAKING**

As a patient, you have the right:

- To choose your attending physician.
- To participate in the development and periodic revision of the plan of care.
- To accept or 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.

### **INFORMATION**

As a **PATIENT**, you have the **RIGHT**:

- To be informed about Carolina Caring's organizational status and of affiliations with any entities to which you are referred.
- To be notified within 10 days when the agency's license has been revoked, suspended, canceled, annulled, withdrawn, recalled, or amended.
- To receive information about services covered by Medicare, Medicaid, and all applicable thirdparty payors.
- To be informed of charges not covered by Medicare, Medicaid, or your third-party payor.
- To receive a written statement of services provided by the agency and the charges you may be liable for paying.
- To be informed about advance directives, applicable North Carolina law, and Carolina Caring's patient care policies.
- To be informed of the acceptance and 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 remain under your physician's care while receiving hospice services.
- To provide hospice with a complete and accurate health history that includes current medications.
- To be informed of and participate in your plan of care.
- To inform hospice staff when instructions are not understandable.
- To accept the consequences for any refusal of treatment or choice of non-compliance.
- To provide a safe home environment in which your care can be given.
- To cooperate with your doctor, hospice staff, and other caregivers.
- To treat hospice staff with respect and consideration.
- To notify hospice when you are unable to keep appointments.
- To arrange for a family member or another person to assist you with your care as necessary.
- To provide all requested insurance and financial records to the agency.
- To sign the required consents and releases for insurance billing.

Carolina Caring's **PROMISES** to **YOU** and **YOUR FAMILY** include:

- All hospice medical services are provided in accordance with physician's orders.
- A plan of care will be developed by you, your family, your physician, and the hospice team that specifies services to be provided and the frequency of those services.
- All medically-related services are provided by appropriately trained professional staff who will wear proper picture identification on all visits.

**QUESTIONS** or complaints may be registered with any staff member in person, by phone, by email, or in writing. If your concern or question is not resolved, notify Carolina Caring's CEO.

Carolina Caring 3975 Robinson Road Newton, NC 28658 828.466.0466 info@CarolinaCaring.org

For unresolved problems, you may contact The Carolinas Center, a state association, (800.662.8859), NC Division of Health Service Regulation Complaint Intake Unit (800.624.3004), or The Joint Commission (800.994.6610). Reports about quality of care for services covered by Medicare can be reported to Kepro, the Quality Improvement Organization (Toll-Free 888.317.0751, TTY 855.843.4776). Kepro will determine if additional action is warranted. Carolina Caring (CC) complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Carolina Caring does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Carolina Caring:

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

If you need these services, contact our compliance officer.

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

Compliance Officer 3975 Robinson Road Newton NC 28658 828.466.0466 828.466.8862 (fax) info@CarolinaCaring.org

You can choose to file a grievance in person or by mail, fax, or email. If you need help filing a grievance, our compliance officer is available to help you.

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

US Department of Health and Human Services 200 Independence Avenue SW Room 509F, HHH Building Washington, DC 20201 800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html.

Please refer to the following text for language-specific instructions:

ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المعماعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1 6466-466 828 (رقم هاتف المم والبكم: 1-666-4666).

# ប្រយ័ត្ន៖ បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតឈ្នួល គឺអាចមានសំរាប់បំរើអ្នក។ ចូរ ទូរស័ព្ទ 1-828-466-0466។

注意:如果您使用繁體中文,您可以免費獲得語言援助服務。請致電 1-828-466-0466。

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-828-466-0466.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement.

Appelez le 1-828-466-0466.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur

Verfügung. Rufnummer: 1-828-466-0466.

सुथनाः को तमे गुकराती जोलता छो, तो निःशुल्ड लाषा सखाय सेवाओ तमारा माटे ઉपलज्ध छे. झेन डरो 1-828-466-0466. ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-828-466-0466 पर कॉल करें।

LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-828-466-0466.

注意事項:日本語を話される場合、無料の言語支援をご利用いただけます。1-828-466-0466 まで、お電話にてご連絡ください。

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-828-466-

0466 번으로 전화해 주십시오.

ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັຽຄຳ, ແມ່ນມີ

ພ້ອມໃຫ້ທ່ານ. ໂທຣ 1-828-466-0466.

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-828-466-0466.

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-828-466-0466.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-828-466-0466.



# **Notice of Privacy Practices**

### THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU, AS A PATIENT, MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO YOUR INDIVIDUAL IDENTIFIABLE HEALTH INFORMATION. PLEASE REVIEW THIS NOTICE CAREFULLY.

### **USE AND DISCLOSURE OF HEALTH INFORMATION**

We are required by law to maintain the privacy of Protected Health Information (PHI). We are required to provide this Notice of Privacy Practices to you by the privacy regulation issued under the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA). This notice describes how we protect the PHI we have about you that relates to your medical information. PHI is medical and other information about you, including demographic information, that may identify you and that relates to your past, present or future physical or mental health or condition and related health care services. This Notice of Privacy Practices describes how we may use and disclose to others your PHI to carry out payment or healthcare operations and for other purposes that are permitted or required by law. It also describes your rights to access and control of your PHI.

### HOW WE MAY USE AND DISCLOSE PROTECTED HEALTH INFORMATION ABOUT YOU

The following describes the ways we may use and disclose health information that identifies you. Except for the purposes described below, we will use and disclose health information only with your written permission. You may revoke such permission at any time by writing to our Privacy Officer.

#### **To Provide Treatment**

The organization may use your PHI to coordinate care within the organization and with others involved in your care, such as your attending physician, member of the organization interdisciplinary group and other health care professionals and volunteers who have agreed to assist the organization in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The organization also may disclose your PHI to individuals outside of the organization involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or supplies and other health care professionals that the organization uses in order to coordinate your care.

#### **To Obtain Payment**

The organization may include your PHI in invoices to collect payment from third parties for the care you may receive from the organization. For example, the organization may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or the organization. The organization also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for organization care and the services that will be provided to you.

#### **To Conduct Health Care Operations**

The organization may use PHI for its own operations in order to facilitate the function of the organization and as necessary to provide guality care to all of the organization's patients. Health care operations includes such activities as:

- · Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners in health can learn under supervision.
- Fundraising for the benefit of the organization and certain marketing activities. You have the right to opt out of fundraising communications from the organization and the organization cannot sell your PHI without your permission.

#### To Contact You

We may use and disclose PHI to contact you to remind you that you have an appointment with us. We also may use and disclose PHI to tell you about treatment alternatives or health-related benefits and services that may be of interest to you.

### To Contact Individuals involved in Your Care

Unless you object, we may share your PHI with a person who is involved with your medical care or payment for your care, such as your family, a close friend or any other person you identify. We also may notify your family about your location or general condition. If you are unable to agree or object to such a disclosure, we may disclose such information as necessary if we determine that it is in your best interest based on our professional judgment.

# To Conduct Research

Under certain circumstances, we may use and disclose PHI for research. For example, a research project may involve comparing the health of patients who received a treatment to those who received another, for the same condition. We also may permit researchers to look at records to help them identify patients who may be included in their research project or for other similar purposes, as long as they do not remove or take a copy of any PHI.

### To Coordinate Services with Business Associates

We may disclose PHI to our business associates that perform functions on our behalf or provide us with services if the information is necessary for such functions and/or services. For example, we may use another company to perform billing services on our behalf. All of our business associates are obligated to protect the privacy of your PHI and are not allowed to use or disclose any information other than as specified in our contract.

### To Communicate in Disaster Relief Situations

We may disclose your PHI to disaster relief organizations that seek your PHI to coordinate your care, or notify family and friends of your location or condition in a disaster. We will provide you with an opportunity to agree or object to such a disclosure whenever we practically can do so.

### SPECIAL SITUATIONS

### As Required by Law

We will disclose PHI when required to do so by international, federal, state or local law.

### For Lawsuits and Disputes

The organization may disclose your PHI if you are involved in a lawsuit or a dispute. We may also disclose PHI in response to a court or administrative order, subpoena, discovery request, or other lawful process by someone else involved in the dispute, but only if efforts have been made to tell you about the request or to obtain an order protecting the information requested.

### For Law Enforcement Purposes

The organization may disclose your PHI to a law enforcement official for law enforcement purposes as follows: (1) In response to a court order, warrant, subpoena, summons or similar process; (2) Limited information to identify or locate a suspect, fugitive, material witness or missing person; (3) when you are the victim of a crime even if under certain limited circumstances, we are unable to obtain your agreement; (4) About a death we believe may be the result of criminal conduct; and (5) In an emergency to report a crime, the location of the crime or victims, or the identity, description or location of the person who committed the crime.

### To Coroners and Medical Examiners

The organization may disclose your PHI to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by laws. This includes disclosure of PHI for the purposes of whole body and organ donation.

### **To Funeral Directors**

The organization may disclose your PHI to funeral directors consistent with applicable laws and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, the organization may disclose your PHI prior to and in reasonable anticipation of your death.

### In the Event of a Serious Threat to Health or Safety

The organization may, consistent with applicable law and ethical standards of conduct, disclose your PHI when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person.

# Data Breach Notification Purposes

The organization may use or disclose your PHI to provide legally required notices of unauthorized access to or disclosure of your health information.

#### Organ and Tissue Donation

The organization may use or release health information to organizations that handle organ procurement or other entities engaged in procurement, banking or transportation of organs, eyes or tissues to facilitate organ, eye or tissue donation and transplantation.

#### Military and Veterans

The organization may release health information as required by military command authorities if you are a member of the armed forces. We may release health information to the appropriate foreign military authority if you are a member of a foreign military.

### **Public Health Risks**

The organization may disclose PHI for public health activities. These activities generally include disclosures to prevent or control disease, injury or disability; report deaths; report abuse or neglect; report reactions to medications or problems with products; notify people of recalls of products that they may be using; a person who may have been exposed to a disease or may be at risk for contracting or spreading a disease or condition; and the appropriate government authority if we believe a patient has been the victim of abuse, neglect, or domestic violence. We will only make this disclosure if you agree or when required or authorized by law.

### **Health Oversight Activities**

The organization may disclose PHI to a health oversight agency for activities authorized by law. These oversight activities include, for example, audits, investigations, inspections, and licensure. These activities are necessary for the government to monitor the health care system, government programs, and compliance with civil rights laws.

#### **National Security and Intelligence Activities**

The organization may release PHI to authorized federal officials for intelligence, counter-intelligence, and other national security activities authorized by law.

### Protective Services for the President and Others

The organization may disclose PHI to authorized federal officials so they may provide protection to the President, other authorized persons or foreign heads of state or to conduct special investigations.

#### Inmates or Individuals in Custody

If you are under the custody of law enforcement, we may release your PHI to the correctional institution or law enforcement official. This release would be if necessary: (1) for the institution to provide you with health care; (2) to protect your health and safety or the health and safety of others; or (3) the safety and security of the correctional institution.

### For Worker's Compensation

The organization may release your health information for worker's compensation or similar programs.

### AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

We are required to abide by the terms of this Notice of Privacy Practices. Other than as stated above, the organization will not disclose your PHI, except with your written authorization. Other uses and disclosures of Protected Health Information not covered by this Notice or the laws that apply to us will be made only with your written authorization. If you or your representative authorizes the organization to use or disclose your PHI, you may revoke that authorization in writing at any time. However, disclosures made in reliance on your authorization before you revoked it will not be affected by the revocation.

#### YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your PHI that the organization maintains:

### **Right to Request Restrictions**

You have the right to request a restriction or limitation on the PHI we use or disclose for treatment, payment, or health care operations. You may also have the right to request a limit on the PHI we disclose to someone involved in your care or the payment for your care, like a family member or friend. We are not required to agree to your request unless you are asking us to restrict the use and disclosure of your PHI to a health plan for payment or health care operation purposes and such information you wish to restrict pertains solely to a health care item or service for which you have paid us "Out-of-pocket" in full. If we agree, we will comply with your request unless the information is needed to provide you with emergency treatment. If you wish to make a request for restrictions, please contact the Privacy Officer. **Out-of-Pocket Payments** 

If you paid out-of-pocket (or in other words, you have requested that we not bill your health plan) in full for a specific item or service, you have the right to ask that your PHI with respect to that item or service not be disclosed to a health plan for purposes of payment or health care operations, and we will honor that request.

### **Right to Receive Confidential Communications**

We will accommodate any reasonable request you might make to receive communications of PHI from us by alternative means or at alternative locations. The request for a confidential communication must be received in writing and specify how or where you wish to be contacted. The organization will not request that you provide any reasons for your request and will attempt to honor your reasonable request for confidential communications.

### **Right to Inspect and Copy Your Health Information**

You have the right to inspect and copy your PHI, including billing records. A request to inspect and copy records containing your PHI may be made to the Privacy Officer. If your PHI is maintained in an electronic format (known as an electronic medical record), you have the right to request an electronic copy of your record be given to you or transmitted to another entity. We will make every effort to provide access to your PHI in the form or format you request, if it is readily producible in such form or format. If the PHI is not readily producible in the form or format, a readable hard copy form. We may charge you a reasonable, cost based fee for the labor associated with copying, assembling, and/or transmitting the PHI associated with your request. We will not charge you a fee if you need the information for a claim for benefits under the Social Security Act or any other state or federal needs-based benefit program. You will be asked to sign a receipt for your PHI. The organization has the right to deny access to PHI in certain specified situations, such as when a health care professional believes access could cause harm to the individual or another. If denied, you have the right to have such denial reviewed by another licensed health care professional who was not directly involved in the denial of your request, for a second opinion.

### Right to Get Notice of a Breach

You have the right to be notified upon a breach of any of your unsecured PHI.

#### **Right to Amend Health Care Information**

If you or your representative believes that your health information records are incorrect or incomplete, you may request that the organization amend the records. That request may be made as long as the information is maintained by the organization. A request for an amendment of records must be made in writing to the Privacy Officer. The organization may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied that PHI was not created by the organization, if the records you are requesting are not part of the organization's records, if the PHI you wish to amend is not part of the PHI you or your representative are permitted to inspect and copy, or if, in the opinion of the organization, the records containing your PHI are accurate and complete.

#### Right to an Accounting of Disclosures

You or your representative have the right to request an accounting of disclosures of your PHI made by the organization for any reason other than for treatment, payment or health operations for the previous six years if records are maintained in paper form. You have the right to receive an accounting of all disclosures made from the electronic medical record during the three years prior to the date of request. The request for an accounting must be made in writing to the Privacy Officer. The request should specify the time period for the accounting. The organization will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

#### **Right to a Paper Copy of This Notice**

You have the right to a paper copy of this notice. You may ask us to give you a copy of this notice at any time. Even if you have agreed to receive this notice electronically, you are still entitled to a paper copy of this notice. You may obtain a copy of this notice at our website, www.CarolinaCaring.org. To obtain a paper copy, please contact the Privacy Officer. **Change in Notice** 

We may change the terms of our notice at any time. The new notice will be effective for all PHI that we maintain at that time. This notice may also be revised if there is a material change to the uses or disclosures of PHI, your rights, our legal duties, or other privacy practices stated in this notice. Following a material revision to this notice an updated Notice of Privacy Practices will be posted on our website. Additionally, upon your request, we will provide you with any revised Notice of Privacy Practices by calling the Privacy Officer at 828.466.0466 and requesting that a revised copy be sent to you in the mail. The notice will contain the effective date on the bottom of the last page.

#### **Complaints**

If you think that we have violated your privacy rights, you have the right to file a complaint with us or with the Secretary of the US Department of Health and Human Services. The organization will not retaliate against anyone that files a complaint. To file a complaint with us, please contact Privacy Officer, Carolina Caring, 3975 Robinson Road, Newton, North Carolina 28658. Telephone: 828.466.0466.

#### **Effective Date**

This Notice becomes effective September 16, 2013.

# **HOSPICE CARE & SERVICES**

Hospice emphasizes quality of life. Its broad range of comprehensive services is specifically designed to support you and your family and to promote your rights to choice and control in decision-making.

Hospice care is based on a team approach. The hospice team includes professionals and volunteers trained specifically to work with you, your family, and each other to coordinate care. It is the role of the hospice team to present and discuss options with you and your family and to assist you in making informed decisions.

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

A **Nurse** comes to you for regular visits and is available for emergency needs 24 hours per 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 you for regular visits to help with personal care such as bathing, grooming, skin care, etc.

A **Medical Social Worker** helps you and your family maintain a supportive care system that ensures your safety and comfort through education and counseling.

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

A **Counselor** provides additional support for family and friends dealing with grief and loss before and after the death of a loved one. Grief services are available for 13 months following the loss.

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

A **Pharmacist Consultant** manages your pharmaceutical care and provides drug information and education to you, your family, and the hospice staff.

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 you to maintain your maximum level of independence. Carolina Caring 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.

# FOUR LEVELS OF CARE

Depending on your needs, we can provide various levels of care to maximize your comfort and treat your illness. The level of care that's best for you may also change as your illness changes.

### **Routine Home Care**

- Hospice care is provided to people wherever they call home, including in a private residence, nursing home, or assisted living facility.
- You will receive routine visits from your team.

#### **General Inpatient Care (GIP)**

• Short-term, round-the-clock care in one of our two hospice houses or in an inpatient setting. Designed to manage acute symptoms and return people to wherever they call home.

#### **Continuous Care**

- High-level care provided in the home by a dedicated care team to manage acute medical symptoms. Used during periods of crisis.
- Goal is to manage pain and symptoms.

### **Respite Care**

• Up to five days of care that offer family members or caregivers a break from the demands of caregiving. Available in our hospice houses, as space allows, or in an approved facility.

#### **Inpatient Care**

Our inpatient facilities provide skilled care when your pain or symptoms can no longer be managed in the home (General Inpatient Care).

Respite care can also be provided for up to five (5) days.

Both of these services are covered under the Medicare/Medicaid Hospice Benefit.

#### Catawba Valley Hospice House – Foothills Campus

3975 Robinson Road, Newton, NC 28658

#### Sherrills Ford Hospice House – Lake Norman Campus

7475 Sherrills Ford Road, Sherrills Ford, NC 28673

Our inpatient facilities also provide:

- · Private rooms with a home-like setting
- · Visitation at any time
- Pet visitation
- · Family rooms, sun porches, meditation room
- Vending machines for visitors
- Nutritious meals and snacks
- Designated outdoor smoking area (only at Catawba Valley Hospice House)
- Residential care (available on a limited basis)

# WHY US?

Care is our priority. Everything we offer promotes quality of life.

# **CLINICAL EXPERTISE**

- · 24-hour service and support
- Rapid response times for admissions and ongoing care needs
- · First hospice in NC to offer specialized programs for patients with COPD and CHF
- Expanded care for advanced illness, including a palliative medicine practice
- Two state-of-the-art hospice houses with a trained clinical team to serve patients throughout 10 counties
- · Hospice physician availability
- · Care teams hired from local communities
- · Help with private insurance verification
- · Respite services when caregivers need a break

# QUALITY

- Longstanding relationships with hospitals, skilled nursing facilities, and assisted living facilities in our 12-county service area
- Voluntary participation in The Joint Commission accreditation, the gold standard of quality review

# OUR TEAM

- · 40 years of in-the-field hospice experience
- · 220 employees devoted to the hospice mission
- Physicians, nurses, social workers, chaplains, and counselors to support both family and patient
- · 445 dedicated and available volunteers to promote quality of life

# **PAYMENT FOR SERVICES**

Most hospice services offered by Carolina Caring are covered by Medicare, Medicaid, and commercial insurance carriers.

Carolina Caring bills Medicare, Medicaid, or your commercial insurance company on your behalf.

Payments made by third-party payors to Carolina Caring are accepted as payment in full with the exception of any deductibles and coinsurance you are responsible for paying. We will contact your insurance company to verify benefits.

Specific charges for all hospice services are available on request.

A flexible billing policy, based on need, is available for individuals without insurance coverage. Thanks to strong community support, no one is ever denied care because of inability to pay.

You may request services or products not covered under hospice benefits provided by Medicare, Medicaid, or commercial insurance programs.

You will be advised in advance of the costs and whether Carolina Caring can provide or arrange for the services or products you request.

You will be responsible for payment of non-covered services and products.

Note: Our staff are available to help with private insurance verification for all insurance providers.

Since 1979, Carolina Caring has lived out our mission of providing world-class, compassionate care to all individuals and their families.

We sincerely believe in the value of end-of-life care and the comfort it brings, so we make this care available regardless of a patient's financial circumstances, including lack of insurance or inability to pay for hospice services.

Our patients have been, are, and always will be our top priority.

# **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 changes to any of the following:

- Your condition
- *Any* medications you may be taking (including over-the-counter medications, supplements, vitamins, etc.)
- · Equipment or supplies you may need
- Caregiver
- Physician
- Insurance coverage
- Address

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!** 



The green information sheet that we have provided you tells how we can be reached and should be placed on your refrigerator where your family and caregivers can refer to it during times of need.

Always tell hospitals, physician's offices, and 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.





# 866.466.9996(Toll Free)

# WHEN TO CALL

- Any Time You Think You Need to Go to the Hospital or Emergency Room
- Any Time Your Health or Medical Condition Changes Significantly

HOW TO CALL

You Can Get Help from Hospice 24 Hours a

Day

Special Line for Patients Only 828-466-9996

If there is no answer, call 828-466-0466 and press 1.

YOUR CARE TEAM Your primary nurse is:

Your social worker is:

Other team members:

# WHAT TO KNOW

- Carolina Caring should be your first point of contact during emergency situations.
- You are **never** bothering us.
- We have a nurse and doctor on call **24 hours a day** to help manage your symptoms at home and direct your care in times of need.
- If you do go to the emergency room, **call us immediately**. If we aren't notified, you may be responsible for costs of the ambulance and/or emergency room visit.

# WHAT ARE MY RIGHTS?

### Who decides about my medical care or treatment?

If you are 18 or older and are able to make and communicate health care decisions, you have the right to make decisions about your medical and mental health treatment. You should talk to your physician or other health care or mental health provider about any treatment or procedure so that you understand what will be done and why. You have the right to say *yes* or *no* to treatments recommended by your physician or mental health provider. If you want to control decisions about your medical and mental health care even if you become unable to make decisions or to express them yourself, you should be sure to tell your physician or mental health provider and your family and friends what you want, but you should also have an *advance directive*.

### What is an advance directive?

An *advance directive* is a set of directions you give about the medical and mental health care you want if you ever lose the ability to make decisions for yourself. North Carolina has three ways for you to make a formal advance directive. These include 1) a *living will*, 2) a *health care power of attorney*, and 3) an *advance instruction for mental health treatment*.

# Do I have to have an advance directive, and what happens if I don't?

Making an *advance directive* is your choice. If you become unable to make your own decisions and you have no advance directive, your physician or mental health care provider will consult with someone close to you about your care. Discussing your wishes for medical and mental health treatment with your family and friends now is strongly encouraged since this will help ensure that you get the level of treatment you want when you can no longer tell your physician or other health care or mental health providers what you want.

# LIVING WILL

### What is a living will?

In North Carolina, a *living will* is a legal document that tells others you want to die a natural death if you 1) become incurably sick with an irreversible condition that will result in your death within a short period of time, 2) are unconscious and your physician determines that it is highly unlikely you will regain consciousness, or 3) have advanced dementia or a similar condition that results in a substantial cognitive loss and it is highly unlikely the condition can be reversed. In a living will, you can direct your physician not to use certain life-prolonging treatments such as a breathing machine (*respirator* or *ventilator*) or to stop giving you food and water through a tube (*artificial nutrition or hydration* via feeding tubes and IVs).

A *living will* goes into effect only when your physician and one other physician determine that you meet one of the conditions specified in the living will. Discussing your wishes with family, friends, and your physician now is strongly encouraged so that they can help make sure that you get the level of care you want at the end of your life.

# HEALTH CARE POWER OF ATTORNEY

# What is a health care power of attorney?

A *health care power of attorney* is a legal document in which you can name a person(s) as your health care agent(s) to make medical and mental health care decisions for you if you become unable to decide for yourself. You can say what medical or mental health treatments you would want and not want. You should choose an adult you trust to be your health care agent. Discuss your wishes with that person(s) before you put them in writing. Again, it is always helpful to discuss your wishes with your family, friends, and your physician or eligible psychologist. A *health care power of attorney* will go into effect when a physician states in writing that you are not able to make or communicate your health care choices. If, due to moral or religious beliefs, you do not want a physician to make this determination, the law provides a process for a non-physician to do it.

# ADVANCE INSTRUCTION FOR MENTAL HEALTH TREATMENT

### What is an advance instruction for mental health treatment?

An *advance instruction for mental health treatment* is a legal document that tells physicians and mental health providers what mental health treatments you would want and what treatments you would not want, should you later become unable to decide for yourself. You also can name a person to make your mental health decisions at that time. Your *advance instruction for mental health treatment* can be a separate document or combined with a *health care power of attorney* or a *general power of attorney*. An *advance instruction for mental health* may be followed by a physician or mental health provider when your physician or an eligible psychologist determines **in writing** that you are no longer able to make or communicate mental health care decisions.

# **OTHER QUESTIONS**

# How do I make an advance directive?

You must follow several rules when you make a formal *living will, health care power of attorney*, or an *advance instruction for mental health treatment*. These rules are to protect you and to ensure that your wishes are clear to the physician or mental health provider who may be asked to carry them out. A *living will, a health care power of attorney, and an advance instruction for mental health treatment* must be 1) written, 2) signed by you while you are still able to make and communicate health care decisions, 3) witnessed by two qualified adults, and 4) notarized.

# Who is a qualified witness?

A *qualified witness* is a competent adult who sees you sign, is not a relative, and will not inherit anything from you upon your death. The witness cannot be your physician, a licensed employee of your physician or mental health providers, or any paid employee of a health care facility where you live or that is treating you.

### Are there forms I can use to make an advance directive?

Yes. Forms for a *living will*, a *health care power of attorney*, and an *advance instruction for mental health treatment* may be obtained from the North Carolina Secretary of State website at <u>www.secretary.state.nc.us/ahcdr</u>. These forms meet all the rules for a formal advance directive. For more information, visit the website, call 919.807.2167, or write to Advance Health Care Directive Registry, Department of the Secretary of State, PO Box 29622, Raleigh, NC 27626-0622.

# What happens if I change my mind?

- You can cancel your *living will* any time by communicating your intent to cancel it in any way. You should inform your physician and those closest to you about your decision. It is also a good idea to destroy copies of it.
- You can cancel or change your *health care power of attorney* while you are able to make and communicate your decisions. You can do this by executing another one and telling your physician and each health care agent you named of your intent to cancel the previous one and make a new one, or by communicating your intent to cancel it to the named health care agents and the attending physician or eligible psychologist.
- You can cancel your *advance instruction for mental health treatment* while you are able to make and communicate your decisions by telling your physician or mental health provider that you want to cancel it.

# Who should I talk to about an advance directive?

You should talk to those closest to you about an *advance directive* and your feelings about the health care you would like to receive. Your physician or health care provider can answer medical questions. A lawyer can answer questions about the law. A trusted advisor or clergy member may be able to help with more personal questions.

### Where should I keep my advance directive?

Keep a copy in a safe place where your family members can get to it. Give copies to your family, your physician or mental health providers, your health care agent(s), and any family members or close friends who might be asked about your care should you become unable to make decisions. Always remember to take a copy of your *advance directive* with you for hospital admissions, emergency room visits, clinic visits for cardiac procedures, etc. so it can be put into your chart. Also consider registering your advance directives with the North Carolina Advance Health Care Directive Registry at www.secretary.state.nc.us/ahcdr.

### What if I have an advance directive from another state?

A *living will* or *health care power of attorney* created outside of North Carolina is valid in North Carolina if it appears to have been executed in accordance with the applicable requirements of the place where it was created or of this State. You may also choose to make an advance directive in North Carolina or have your lawyer review the advance directive from the other state as well.

### Where can I get more information?

Carolina Caring staff are happy to help you get more information about advance directives. Ask us personally, call us at 828.466.0466, or email us at info@CarolinaCaring.org.

You may also contact an attorney or visit the North Carolina Department of the Secretary of State Advance Health Care Directive Registry website at www.secretary.state.nc.us/ahcdr.

# Are other forms available that will help ensure my health care decisions are known and followed?

Other forms that you may want to be aware of include the following:

• An Authorization to Consent to Health Care for a Minor is a legal document that allows parents with sole or joint legal custody of a minor (under 18) to authorize another adult to make certain health care decisions for their child or children in their absence.

- An Organ Donor Card is a document that allows you to donate your organs. You can become an organ donor by expressing your desire to donate in your will, by authorizing the NC Division of Motor Vehicles to put an organ donor symbol on your driver's license or identification card, by completing an organ donor card or other document, or by authorizing that a statement or symbol be included on the NC Organ Donor Registry.
- A *Portable Do Not Resuscitate (DNR) Order* is a medical order that can be followed by emergency medical responders or other health care providers that tells them not to attempt cardiopulmonary resuscitation (CPR) if your heart and breathing stop (cardiopulmonary arrest). Since it is portable, it can be followed in different settings (for example, in your home, in a nursing home, or in a hospital).
- A *Medical Order for Scope of Treatment*, called a MOST form, is a medical order that can be followed in different settings, such as in the home, nursing home, hospital, etc. A MOST form contains instructions for CPR and also addresses other end-of-life treatments that you may or may not want to receive. For example, a MOST can tell emergency medical responders and other health care providers what level of treatment you would like to receive, whether you would like to receive antibiotics, and what your wishes are regarding artificial nutrition and hydration.



The staff of Carolina Caring are available to provide you with more information on any of these topics. Carolina Caring strives to honor each person's decisions about their medical care and treatment. We will comply with requirements concerning advance medical directives by providing education, literature, and an opportunity for patients to execute an advance medical directive. Carolina Caring will not discriminate against individuals nor condition the provision of services on the presence or absence of advance directives. If no advance directive exists, staff will discuss health care choices with the patient and/or responsible party and will document the patient's verbal medical directive choices.

This document was developed by the North Carolina Division of Medical Assistance in cooperation with the Department of Human Resources Advisory Panel on Advance Directives 1991. Revised 1999. Revised 2009.



# **LEGAL DOCUMENTS**

In the state of North Carolina, four legal documents allow you to put your health care decisions in writing.

# 1. Advance Directives for North Carolina (a two-part document)

- A. Health Care Power of Attorney (HCPOA) aka Health Care Surrogate/Agent This legal document lets you appoint up to three individuals to speak on your behalf if you cannot speak for yourself. The order in which you name the individuals determines who will be the primary spokesperson. The document must be signed in the presence of a Notary Public and two witnesses. (The document only addresses power over health care issues.) Any person with decision-making capacity who is 18 or older may complete one. The ability of your appointed Health Care Power of Attorney to make decisions for you only occurs if you do not have the capacity to make decisions on your own.
- B. The North Carolina Living Will (NCLW) aka Declaration for a Natural Death The NCLW discusses artificial feedings, nutrition, and extraordinary means (ventilator support) if you cannot maintain life naturally. The document must be signed in the presence of a Notary Public and two witnesses to be valid. Any person 18 or older who has the ability to make decisions may complete an NCLW. Creating an NCLW does not prevent you from speaking for yourself as long as you're able to do so.

# 2. Do Not Resuscitate (DNR)

This yellow document informs health care professionals that you desire **not** to be resuscitated or to be revived in any manner if your heart stops. This order prohibits CPR, shock, or intubation (a tube is inserted down your throat). The DNR is a physician order and must be signed by your medical doctor. No other signature is necessary. Only the original form is honored – **copies are not valid**. A DNR is for people who have a serious, chronic, or terminal illness. You may obtain the DNR form from your health care provider or at <u>www.dhhs.com</u>.

# 3. MOST (Medical Order for Scope of Treatment)

This hot-pink form is also a physician's order and requires your signature or the signature of your Health Care Power of Attorney (or responsible party). MOST forms are typically needed only if you have a serious or chronic health issue. The MOST addresses numerous health care choices in detail. It is valid from the date of issuance until revised or revoked. Notarization is not required, but your medical doctor or nurse practitioner must review and sign the document for it to be valid.

# **MEDICATION DISPOSAL**

- 1. Hospice staff will educate you and your family on the safe disposal of medications to decrease diversion and the potential contamination of the public water supply.
- 2. Upon the discontinuation of a medication or the death of a hospice patient, the hospice nurse will instruct the family in the medication disposal procedure for purposes of safety.
- 3. Disposal of narcotics and other medications with high potential for misuse or abuse will be strongly encouraged, and the response to this teaching will be documented in the electronic record.
- 4. In the home setting, if the hospice nurse participates in the medication disposal procedure, the nurse will record the name of the medication(s) to be disposed of in the medical record.
- 5. Disposal of unused medications shall occur by placing the medications in a sealable plastic container (zipper bag or bottle) containing clumping kitty litter, white vinegar, or coffee grounds and adding a sufficient amount of water to render the medications non-retrievable. The sealed container will be placed in the household trash. This practice is used to protect the environment and to ensure unused medications are not taken by anyone else.
- 6. Specific disposal guidelines include:
  - a. A transdermal patch can be folded over onto itself and placed in kitty litter or placed in a sharps container.
  - b. A PCA bag can be emptied by adding the liquid contents to the kitty litter.
- 7. If you or your family refuses to dispose of the medication, the nurse will instruct you/your family to secure the medications in a safe place and will document this response in the clinical record.
- 8. As an alternative, medications may be disposed of at approved drop-off locations. To find a nearby location, simply visit www.americanmedicinechest.com, and enter your zip code. A list of options will appear for you to consider.

# **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 you, your family, and hospice staff.

# **GENERAL SAFETY INFORMATION**

- Emergency phone numbers (including Carolina Caring's) should be posted by each telephone.
- If you are bed-bound, a bell, buzzer, or appropriate noisemaker should be kept within easy reach at all times.
- A bell, buzzer, or appropriate noisemaker should be kept in the bathroom for emergency use.
- 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 your reach.
- Do not operate heavy equipment or drive when using medications that make you drowsy or dizzy.

# 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.
- 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 adapters if necessary.

# FIRE SAFETY

- Make sure everyone in the home understands how to call 911 for help.
- Check fire extinguishers periodically according to the manufacturer's guidelines.
- Unplug and throw away appliances that smell like they are burning or produce smoke when used.
- Use space heaters according to the manufacturer's guidelines.
- Never leave space heaters on when you are not home.
- 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.)
- If your home has an upstairs, keep a fire ladder in each bedroom. (May be purchased from hardware stores.)
- Make sure all your windows open easily.
- Do not wear long/loose clothing around open flames or stoves.
- Do not smoke in bed after taking medications that make you drowsy.
- Never smoke around oxygen equipment.

- If you live in an apartment building, make sure you know where all potential exits are.
- 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 bed-bound 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.
- Do not use oxygen around open flames or heat sources.
- Keep matches and lighters out of children's reach.

\*If a patient is bed-bound, one or two persons can get him/her 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.
- Minimize or limit alcohol consumption.
- 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.

# **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 the 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 reach of children and any adult with cognitive impairments.
- 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 them 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 labels.
- Keep the names of all your medications written down, and show the list to your doctor, pharmacist, and other health care providers so they can assess them for potentially dangerous interactions. (Make sure to include prescription medications, over-the-counter medications, home remedies, and nutritional supplements as well.)
- 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 medications.
- Do not crush medications without first checking with your pharmacist, doctor, or nurse.
- Dispose of old medications. (See medication disposal guidelines on page 25.)
- Do not use alcohol when you are taking medications.
- Keep all medications away from children and any adult with cognitive impairments.

# **MEDICAL EQUIPMENT SAFETY**

Carolina Caring can provide you with the medical equipment you may need through our provider for durable medical equipment (DME). Medicare, Medicaid, and most insurance companies usually cover the costs of medical equipment through the hospice benefit. Your nurse will continuously evaluate your needs for medical equipment, check with your payor 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 team members, as well as the medical equipment company 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 the directions.
- Keep phone numbers for equipment providers accessible in case you have problems with the equipment.
- If back-up equipment is provided (for example, oxygen back-up tanks), 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 being used for medical equipment.
- Keep oxygen equipment away from open flames.
- Do not smoke around oxygen.
- 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 you, your family, and staff. Safety tips include:

- Smoking materials should be removed from all areas where oxygen is used.
- All family members should be personally warned about smoking in an area where oxygen is used.
- You and your family members should assume responsibility for preventing visitors from smoking 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 you and/or your caregiver when the equipment is delivered by our durable medical equipment (DME) company. These care instructions will also be reinforced by hospice staff.
- Electrical equipment and heat sources must be kept 6 feet away from the oxygen equipment. This includes candles, kerosene lamps or heaters, open flames of any kind (such as lighters or matches), or electric heaters in which 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

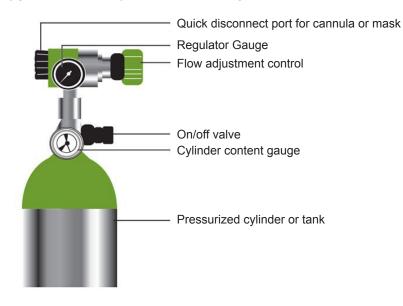
- Oxygen cylinders should be placed in a location where they will not be subject to mechanical or physical damage, heat, or electrical circuits to prevent possible explosion or fire.
- Caution must be used to keep oxygen cylinders at least 10 feet away from fireplaces, woodburning stoves, or other open sources of flame.
- Cylinders should be on carriers or strapped in a stationary way to prevent tipping.
- When oxygen cylinders are not in use, their 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 10 feet from combustible materials. Cylinders should not be covered with combustible items such as blankets, quilts, or paper, and they should never be stored in a closet or under furniture.

# SAFETY OF OXYGEN CONCENTRATORS

- A concentrator needs to "breathe" to operate properly. It should be kept at least 12 inches away from drapes, bedspreads, and walls, and no items should ever be stacked or stored on top of the device.
- Electric 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 lessen the noise and vibration.
- Concentrators should not be plugged into an extension cord, multi-outlet adapter, power strip, or into 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:

- 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.

TROUBLESHOOTING OXYGEN REGULATORS Common problems associated with oxygen regulators include failure of oxygen to be delivered and oxygen leaks. When these problems occur, follow the troubshooting tips below.				
Symptoms	Possible causes	Solutions		
Failure of oxygen to be delivered	<ul> <li>Cylinder valve isn't open.</li> <li>Oxygen tank is empty.</li> <li>T-handle or regulator attachment screw is loose.</li> </ul>	<ul> <li>Verify that the cylinder has been turned on; if not, open the cylinder valve.</li> <li>Check the contents indicator on the cylinder; switch cylinders if indicated.</li> <li>Tighten the T-handle or regulator attachment screw</li> </ul>		
Oxygen is leaking from where the regulator attaches to the cylinder	<ul><li>Plastic washer is still on the cylinder post.</li><li>Washer is actually needed to prevent the leak.</li></ul>	<ul><li>Remove the plastic washer.</li><li>Replace the washer.</li></ul>		



If you are unable to correct the problem yourself, switch to your back-up supply of oxygen and call your hospice nurse or your equipment provider.

# **PREPARING FOR AN EMERGENCY**

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

You should also assemble and keep a disaster supply kit in your home with the following items:

- 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
- cigarette lighter or matches
- · enough food and drinking water for at least 3 days

For additional information about preparing a disaster supply kit, visit www.ready.gov/build-a-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 Carolina Caring. If our phone lines are not working properly, you should do the following:

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

# TORNADO

A tornado is a violently rotating column of air that extends from the base of a thunderstorm to the ground. Tornados are 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 you are bed-bound, have a caregiver move the bed as far away from windows as possible. Cover yourself with pillows, blankets, foam padding, etc. Be sure to protect your head, and make sure your airway is not blocked. After the caregiver has protected you, her/she should go to a safe area as described above.

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 outrun a tornado in a car.
- If there is no shelter nearby, lie flat in a ditch with your hands protecting your head.

# WINTER STORM

A winter storm can include heavy snow, blizzard conditions, extreme ice, freezing rain, and/or sleet. These storms are often accompanied by extremely low temperatures. Areas that typically have mild winters can be hit by major winter storms and result in blocked roads, downed power lines, and loss of electricity to large areas. The following supplies, along with your disaster supply kit, can help you prepare for a winter storm:

- Extra blankets
- · Fuel for heating sources if power is off
- Clothes you can layer
- · Mittens/gloves (mittens keep your hands warmer), hats, and coats

# FLOOD/HURRICANE

According to the American Red Cross, "floods are among the most frequent and costly natural disasters." Flooding can occur after 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.

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

- Secure your home for evacuation.
- Move important items to the upper floors or attic of your house.
- Clean the bathtub 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 few as six inches of moving water can knock you off your feet.

### DISASTER PREPAREDNESS FOR PATIENTS AND FAMILIES

- Follow weather updates prior to an 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 available.
- Have a plan for emergency heat during the winter.
- If you have to leave your home:
  - a. Notify Carolina Caring at 828.466.9996.
  - b. Take all your medications with you.

Hospice staff may not be able to visit when road conditions are unsafe, but they 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.

# HANDWASHING GUIDELINES

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

# SIGNS AND SYMPTOMS OF A POSSIBLE 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)

### INFECTION PREVENTION

Contaminated items – also known as medical waste and including things like 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 team members can provide you with a Sharps container to keep in your home. When the container is full, secure it with sturdy tape and throw it away with your regular trash.
- Never remove, re-cap, or break needles.

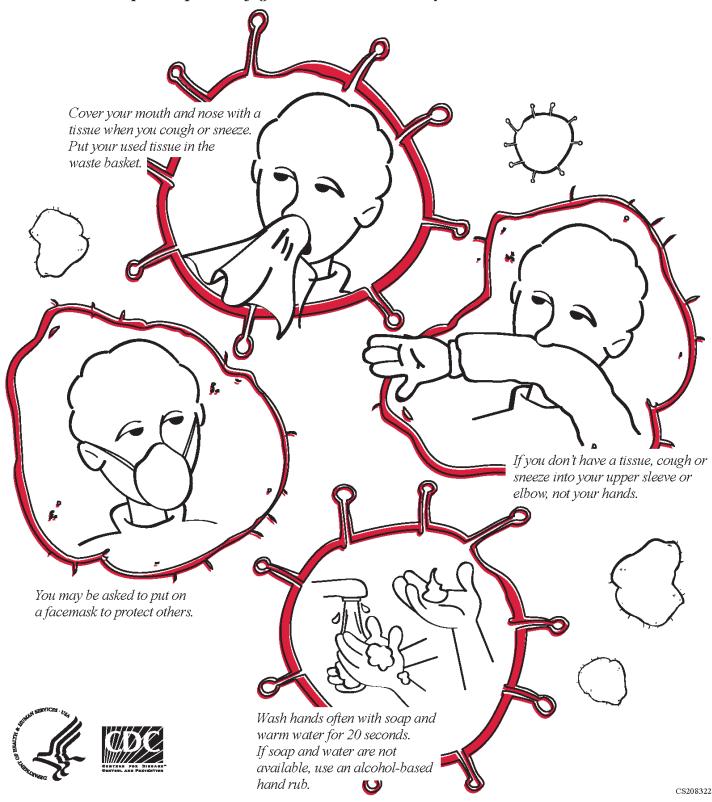
- Place soiled dressings, gloves, paper towels, and other disposable items in a plastic trash bag. Tie off the trash bag and throw it away with your regular trash.
- Flush body waste, such as urine from a catheter or feces from a diaper, down the toilet.
- Soiled laundry should be washed separately in 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 the regular trash.



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



Stop the spread of germs that can make you and others sick! -



### **MANAGING PAIN**

What is pain? There are many different definitions of pain, and they vary from person to person. One of the most common descriptions suggests that pain is whatever an individual says it is. Each person views and tolerates pain differently. Some patients think that they are supposed to have pain and should just "grin and bear it." Others fear that having an increase in pain means that their disease is worsening. Many patients also worry about becoming addicted to medications. Your hospice nurse can help you deal with any concerns that may arise from your pain.

The assessment and treatment of pain 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 about your pain can help your team effectively control it.

- 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 Carolina Caring team can do to manage 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. Two types are typically used: non-narcotic and narcotic. 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 lessen the pain:

- Relaxing activities such as soaking in a warm bath, listening to soft music, or picturing relaxing things can help take your mind off the pain.
- Watching television, playing a game, or doing other activities can distract you from your pain.
- Deep breathing exercises.
- Applying heat and cold (such as a heating pad, warm compress, or ice pack). Caution: Use a heating pad only on the low setting, and check your skin often to be sure it is not becoming reddened from too much heat.

#### SIDE EFFECTS OF PAIN MEDICATION

It is possible for you to experience side effects with any medication. Listed below are several of the most common side effects of pain medications, along with various ways you can minimize the discomfort they cause:

- **Dry mouth** Drink fluids often, consider using artificial saliva, suck on hard candy, or chew gum to combat the dryness.
- 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 he or 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. It you do not have an anti-emetic (nausea medication), ask your nurse, who 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.



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

## **PROVIDING SKIN AND MOUTH CARE**

### **SKIN CARE**

There are many things that can be done on a daily basis that will help protect your skin.

- Check each day for reddened areas or breakdown.
- · Keep skin clean and dry.
- Keep bed linens dry.
- Remove wrinkles from the 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 skin daily with an emollient cream or lotion.
- Be careful using soap, which tends to dry out the skin.

Many times as your disease progresses you become weak, lose weight, and do not eat as well. These conditions cause skin problems. In addition, when you remain in a chair or bed for an extended period of time, bedsores or decubitus ulcers may occur. The most likely areas for skin problems are the sacrum (tail bone), elbows, hips, and heels; these 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 you 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 follow to insure good oral hygiene.

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



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

## **MANAGING NUTRITION ISSUES**

Nutrition is feeding the body with food and fluids. Hydration is giving liquids to the body. Often, patients find that they lose their appetite and eat less as their health declines. Since most patients are taking in smaller quantities of food and liquids, families are often concerned about nutritional needs. Tell the hospice team if you:

- Are unable to eat or drink
- Have trouble swallowing
- · Have a dry mouth or tongue
- · Lose more than five pounds in a week
- Have less urine output
- · Become confused or drowsy at unexpected times

### COPING WITH DECREASING APPETITE AND REFUSAL TO EAT

The hospice team will discuss possible reasons and treatments for diminished intake. It is normal for patients to have a decreased appetite and to drink less as their disease progresses. In some cases, eating and drinking may become uncomfortable. Since food is one of the ways we show love to people, caregivers must also face the emotional aspect of a patient's refusal to eat and drink. Treatment choices will depend on your own wishes and on your illness. Things a caregiver 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
- 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
- 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
- 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
- If dentures do not fit well, consulting a dentist

## MANAGING NAUSEA AND VOMITING

We all know that unpleasant, queasy feeling in the back of our throat or stomach just before we throw up. Unfortunately, nausea and vomiting are common symptoms for many hospice patients. The good news is that a lot can be done to relieve and manage the uncomfortable symptoms. First, it's important for you or your loved one to note the amount and frequency of nausea and vomiting you are having and to tell your nurse. You also need to be able to describe the vomited fluid, which will help your hospice team identify the underlying cause of the problem and determine 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 as well as to what decreases those feelings. (Write down these triggers and share with others as necessary.)
- Sip carbonated drinks that have gone flat.
- Avoid acidic juices such as cranberry, grape, or apple.
- Drink sports drinks such as Gatorade. Use Pedialyte with children.
- · Avoid fried foods, milk products, or foods 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's a feeling of not being able to catch your breath. It may feel like the room is closing in or there's not enough air available.

However a patient describes it, shortness of breath is a personal experience. You should contact your hospice team if any of the following happen in regard to shortness of breath:

- You can't do what you want to do.
- You or your family become fearful, anxious, nervous, or restless.
- Your lips, nose, fingers, or toes become blue-ish in color.

### WAYS TO MANAGE SHORTNESS OF BREATH

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

- Record what makes you feel short of breath and what decreases it.
- Open a window or turn on a fan to increase air movement.
- Keep the room cool.
- Put a cool cloth to the face, turn on an air conditioner, or place a bowl of ice in front of a fan.
- Keep a quiet environment, which helps 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 medication as prescribed.

### **BREATHING TECHNIQUES**

You can do two breathing techniques that allow you to take in more oxygen-rich air. These can be effective when you experience increased shortness of breath. You can control your breathing. Take the time to do the following exercises, and don't panic. You and your family should practice these exercises together when you are not feeling short of breath so together you can work through an acute episode.

- 1. Inhale slowly through your nose for two counts, and then put your lips together (as if you were blowing out a candle or whistling) and exhale slowly through your mouth for four counts. Repeat this 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 your breathing rate down.



#### Call your Carolina Caring nurse if your shortness of breath is not relieved.

## **MANAGING CONSTIPATION**

Due to the effects of some medications, physical inactivity, and other difficulties, hospice patients often experience constipation. An uncomfortable condition, 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 Carolina Caring 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 the 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 able to notice 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 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 the 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 you may be restless include:

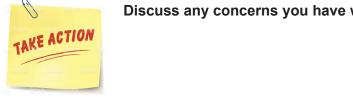
- Muscle twitching
- Moving around without a known reason
- · Pulling at the sheets or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

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, and things that decrease it, such as soft music. Share any concerns you may have as a caregiver, and let the hospice team know if spiritual support is needed. It's especially important to report any potentially unsafe situations, such as a bed needing side rails to keep the patient secure and to 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 relaxing activities if the patient is alert.
- Play soothing music.
- Keep the room guiet 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 which may include:

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

It's 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 – worries about money, concerns about the illness, fears of dying, etc. – and then share that information with the hospice team. Relationship problems with family or friends and spiritual concerns also can sometimes cause anxiety.

It is also not uncommon for the caregiver to experience anxiety when providing care for their loved one. Let the hospice team know if additional support is needed.

### **COPING WITH ANXIETY**

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

- Do 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 the environment calm.
- Limit visitors.
- Play soothing music.
- Massage arm, back, hand, and foot.
- Take/give medications as ordered.

Carolina Caring offers all families chaplain and counseling services for added support. If you're interested in receiving these services, contact a member of your hospice team.



If the signs and symptoms of anxiety get worse, call the hospice nurse.

## **MANAGING SADNESS OR DEPRESSION**

Sadness is a human emotion that all people feel at certain times during their lives. Feeling sad is a natural reaction to situations that cause emotional upset or pain. There are varying degrees of sadness. But, like other emotions, sadness is temporary and fades with time.

Depression is an illness that makes you feel sad and miserable over a long period of time. People who are depressed have difficulty coping with everyday life and may event feel suicidal. Depression is associated with a wide range of symptoms and can be treated.

Depression is a result of disturbances in your body chemistry. These disturbances can be triggered by traumatic or stressful events, such as long-term health conditions, relationship problems, financial difficulties, and/or other significant stressful events.

Possible symptoms of depression:

- Feeling sad or having a depressed mood
- Loss of interest of pleasure in activities once enjoyed
- Trouble sleeping or sleeping too much
- Loss of energy or increased fatigue
- Feeling worthless or guilty
- Weight loss or gain; over or under eating
- Difficulty thinking, concentrating or making

decisions

- Irrational fears
- Bursts of anger or impatience
- Physical aches and pains
- Suicidal ideas (feeling life is not worth living)
- Delusions and/or hallucinations
- Feelings of emptiness, helplessness or loneliness

Ways to copy with sadness or depression

Your hospice team will try to help you manage your sadness or depression with medical and nonmedical interventions. Depression can be treated with counseling and/or antidepressants.

Here are a few things you can do to help yourself and the hospice team:

- Inform your hospice team of any feelings of sadness that you experience, particularly if you have thoughts of harming yourself.
- Use relaxation exercises, meditation or aromatherapy to relieve the tension, anxiety, and irritability of depression.
- If antidepressants are prescribed, take them regularly as it can take a few weeks to have an effect. Then continue your medications and do not stop them suddenly.
- Report any medication side effects such as dry mouth or nausea to your hospice nurse.
- A hospice social worker or chaplain is available to offer support and counseling. Request this team member if you are interested.
- Avoid smoking, illegal drugs, and alcohol. These may give you a short-term "high" but are not helpful in the long run.
- Stay occupied through reading a book or watching television. You will dwell on your depression when inactive, making you feel worse.



# Call your hospice team if your symptoms worsen or you need additional assistance.

## SUPPORTING THE WORK OF HOSPICE

It is an honor and privilege to be on this journey with you. Our hope is that our team provides you with the compassionate, personalized care that enables you to "live each day with purpose" and enjoy precious time with your loved one. Thanks to the generosity of those who have experienced our care, no one in need of hospice care is turned away because of financial insecurity. We hope that you will pass along the same meaningful care you receive by donating in the following ways:

Carolina Caring Foundation 3975 Robinson Road Newton, NC 28658 828.466.0466 www.CarolinaCaring.org/our-foundation

#### MEMORIALS AND HONORARIUMS

Gifts can be designated in honor or memory of someone who touched your life. Please consider passing on the meaningful care that you receive by requesting memorial gifts to Carolina Caring Foundation in lieu of flowers in funeral notices.

#### PATHWAYS OF PROMISE

Placing an etched brick in our Pathways of Promise creates a lasting tribute in honor or memory of your loved one. These personalized bricks line the walkways of our Robinson Road and Sherrills Ford campuses. You can also purchase one for yourself to keep as a memento.

### LIGHT UP A LIFE CELEBRATION

Experience our campus aglow in special tribute to your loved one by purchasing a luminary and attending this annual event in December.



### **LEGACY GIVING**

You can leave a legacy by naming Carolina Caring Foundation as a beneficiary in your estate plan or as a recipient of your IRA or life insurance policy.

Legacy donors are recognized as members of our Circle of Life Society.

\*Please contact our Foundation for more information about giving opportunities\*





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Each patient experiences illness differently, so the information contained in this handbook is not all-inclusive. If you have a concern about something that you don't find mentioned here, please call the hospice staff for guidance. Our goal as an organization is to promote quality of life, and we are available as a resource for you at any time.

828.466.0466