



# *Freedom Hospice* *LLC*

Patient and Caregiver  
Handbook

# Your Freedom Hospice Team

Office Toll Free Number: (844) 760-3733  
Office Phone Number: (785) 740-1705

Your RN: \_\_\_\_\_

Your Medical Director: \_\_\_\_\_

Your Social Worker: \_\_\_\_\_

Your Chaplain: \_\_\_\_\_

Your Hospice Aide(s): \_\_\_\_\_

Your Volunteer Coordinator: \_\_\_\_\_

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# Our Most Valued Relationship

Thank you for choosing Freedom Hospice. It is a privilege to partner with you and your loved ones during this final journey of life.

We will do all that we can to serve you with the dignity, respect and the compassion that you deserve. Our experienced, dedicated team is here for you and your loved ones, and we will do our best to provide education, support and guidance during this difficult time.

This handbook was created in an effort to help you better understand our services and how you can most benefit from all that hospice has to offer. While this handbook is filled with helpful information, we understand that it may not address every question that you have. Please know that we welcome any question and are available to you day and night.

Thank you for believing in the work we do. Thank you for entrusting your loved one to our care. You truly are our most valued relationship. If there is anything more we can do for you, please don't hesitate to ask us.

# Freedom Hospice

## **Mission Statement**

Freedom Hospice strives to provide a comforting atmosphere for end-of-life care that **focuses on the individual as well as the families**. Our hometown approach to self-determination for the patient and furthered support for their families afterward is what makes local hometown care the best option.

## **Vision**

Through compassionate care for our friends and neighbors, Freedom Hospice **puts the patient first**. Their rights of self-determination give them the choice of how they want their life to progress. Freedom Hospice is more than willing to be your network for quality competent care that focuses on all phases of end-of-life care, to include physical, emotional, and spiritual care in an **atmosphere of sensitivity and respect**.

## **Values**

Hometown Atmosphere, Self-Determination, Respect & Compassion, Empathy, Integrity, Teamwork

# Freedom Hospice Staff and Services

## **The Interdisciplinary Team**

The Freedom Hospice interdisciplinary team works together to develop a plan of care based on your individual needs. We will work with you and your family or designated caregivers to schedule visits that are right for you. We will respect your house rules and privacy. You choose how each person can assist you in the care you request. Our interdisciplinary team members include:

## **RN Clinical Supervisors**

The clinical supervisor is responsible for ensuring that patient care is coordinated and managed appropriately. The Clinical Supervisor is responsible for ensuring that care and services are delivered appropriately and for the supervision of clinical personnel.

## **Registered Nurse (RN)**

At the time you are admitted to Freedom Hospice, you will be assigned an RN. This nurse will provide visits, support and education as needed to you and your caregiver(s). He/she will coordinate your care while on our services. Visits are scheduled to monitor your terminal illness, pain control or other symptoms you may experience. The frequency of these visits may change, depending on your needs.

## **Licensed Practical Nurses (LPN)**

During the course of your stay with Freedom Hospice, a LPN may assist the RN in providing care for you. The LPN under the direction of the RN may provide patient services under the scope of their license. Visits are scheduled under your specified plan of care. Along with the RN, frequency of the visits may change, depending on your needs.

## **Hospice Medical Director**

This doctor is the hospice physician; he/she provides advise and direction for the hospice team. This doctor attends hospice meetings and works with your primary doctor to ensure that the medical care you are receiving is closely monitored and meets your ongoing needs. He/she or a Nurse Practitioner is required to have a “face-to-face” visit with you after your second benefit period (180 days) and then every 60 days thereafter to assess for continued hospice eligibility.

## **Your Attending Physician**

Your doctor remains your doctor, unless you choose otherwise. Your nurse will be in communication with your doctor to ensure he/she is aware of changes in your condition or needs. Your physician will continue to prescribe your medications and will be responsible for approving any changes in your plan of care.

## **Social Workers**

Freedom Hospice social workers are available to discuss the emotional challenges of serious illness and offer support when you and/or your caregiver need it. They can also assist you with healthcare decisions, funeral plans or legal matters, and put you in touch with other community resources you request. A social worker will visit you after your hospice admission to get to know you and your caregivers, and determine how to be most helpful to you.

**Chaplain**

Our non-denominational chaplains provide spiritual care. When requested by you and your caregivers, they can help discuss spiritual issues such as fear, loss, forgiveness or anger, or address spiritual questions. They can also help you get in contact with your local church to arrange a visit by your priest, rabbi, minister or spiritual advisor.

**Hospice Aide**

Hospice aides are provided as requested by you or your caregivers to give personal care as directed by the RN. They are assigned based on care needs identified in your plan of care.

**On-Call Nurse**

A nurse is available 24 hours a day to answer any questions you may have. If needed, an on-call nurse will visit you to resolve any concerns that may occur during nights and weekends.

**Hospice Volunteers**

Freedom Hospice volunteers provide services to support our patients and their families. They offer companionship and assist with errands or other tasks as needed. We also welcome volunteers in non-direct care activities, such as office help and public relations services. Freedom Hospice requires and provides orientation and ongoing training for all volunteers.

**Bereavement Counselors**

Freedom Hospice bereavement counselors provide ongoing support to caregivers and family members. They make calls, visits, send mailings and offer support groups to provide encouragement and comfort to those experiencing loss. Bereavement counselors continue to support families/caregivers for 13 months following the patient's death.

**Additional Services**

Freedom Hospice also has additional therapy services that may include but not limited to: Massage, Music, Pet, Occupational, Physical and Speech. These services are provided when your plan of care suggests you would benefit from the service.

Nutritional Counseling is available.

# The Patient and Family Team

While our hospice team has members with years of experience, the patient and family/caregiver(s) are the heart of our team. A big part of the plan of care will be determined by you. While this may seem intimidating, know that we stand beside you and are available even when we are not there with you. We will help the family develop a plan for ongoing support in sharing the workload. In the event, you or your caregivers are no longer able to carry out certain responsibilities, we will work with you to determine a plan that meets the needs for your safety and medical care.

## When Children are Involved

Our social workers are also available to help children cope with questions and fears as it relates to illness, death and grief. Should you wish to include children, our team will work to support them.

## Freedom Hospice: An Overview of Benefits

Hospice is a comprehensive program of supportive care for persons with terminal illness. The goal of hospice is not to cure but to reduce any symptoms of the disease and to provide emotional, spiritual and physical support to the patient and family

Many families and friends are comforted and strengthened by hospice. Frequency of visits by appropriate hospice team members will evolve to meet the changing needs of the patient. The team will work with the family and friends to adjust support as needed

## Services

Freedom Hospice provides necessary services for the patient, family and caregivers during the patient's life-limiting illness. These services as related to the terminal diagnosis include:

- Physician care, nursing, hospice aide and continuous care nursing in times of symptom crisis.
- Social services, spiritual care and volunteer support for patients and caregivers.
- Physical therapy, occupational therapy, nutritional counseling, speech therapy, massage therapy, music therapy and laboratory analysis.
- Medications, medical supplies, x-rays, durable medical equipment, palliative radiation/chemotherapy and certain surgical procedures when needed for pain and symptom management.
- Short inpatient stays for respite or symptom management.
- Bereavement services continue for family or friends for 13 months following the patient's death.

All services above are provided in accordance with the plan of care. A plan of care is developed and continually evaluated by the hospice team, including the patient, primary physician and primary caregiver. It is essential that any changes to the plan of care be done in consultation with the patient, family, physician and hospice team members.

Freedom Hospice completes a comprehensive assessment to determine the need for medications, medical supplies and equipment related to the hospice diagnosis. Freedom Hospice coordinates delivery of the medications, equipment and supplies related to the hospice diagnosis. This includes 24-hour emergency services as needed. It also includes medication monitoring, planning and education. Freedom Hospice will assist with disposal of medication that are no longer needed.

Freedom Hospice primarily provides care for patients in their homes, assisted living communities and/or nursing facilities. However, if temporary inpatient care is needed for symptom control or respite care, it is available if authorized in the plan of care. Freedom Hospice is contracted with several local inpatient facilities to provide care for Freedom Hospice patients.

It is essential that patients and family members arrange all care needs through Freedom Hospice including hospitalization.

### **Changing or Canceling Hospice Services**

A patient may choose to revoke hospice services at any time. Patients must notify Freedom Hospice of the decision to discontinue hospice services or the decision to choose to seek treatment outside of the hospice plan of care. A revocation statement must be completed.

A patient can choose to receive hospice services from another provider at any time. Freedom Hospice must be informed so that transfer arrangements can be made. The patient must notify Freedom Hospice of the date he/she wishes to discontinue receiving care from Freedom Hospice, the name of the new hospice and the date the care will start with the new hospice. The patient loses no benefit days by changing to another hospice program. A transfer request must be completed.

### **Discharge Policy**

You may be discharged from hospice if you no longer are eligible for the hospice benefit, or we are unable to safely provide care to you in your home. Discharge could also occur if you move outside of the service area for Freedom Hospice. Discharge planning will be discussed with you prior to discharge.

# Payment for Hospice Services

## Patients with Medicare

Patients are eligible for the Medicare hospice benefit when:

- You have Medicare Part A.
- Your doctor and hospice medical director certify that you are terminally ill, and probably have less than six months to live.
- You sign a statement choosing hospice services instead of routine Medicare covered benefits for your terminal illness.
- You receive care from a Medicare approved hospice program.

## Patients with Medicaid

The state Medicaid program determines your eligibility, which is limited to individuals who fall into certain categories. Medicaid is a state-administered program and each state sets its own guidelines regarding eligibility. The hospice service benefit is an optional benefit, which states may choose to make available under the Medicaid program.

Freedom Hospice will provide services for care of the patient's life-limiting illness directly or through contracted services. During the patient's hospice benefit period, Freedom Hospice, through Medicare or eligible Medicaid programs, will cover the patient's full financial responsibility for these services, except under any of the following circumstances:

- If the patient decides to pursue a curative, non-palliative course of treatment.
- If the patient enters an inpatient facility without prior authorization from Freedom Hospice.
- If the patient enters an inpatient facility for a condition unrelated to his/her primary hospice diagnosis.
- If the patient enters an inpatient facility that does not have a contract with Freedom Hospice to provide care to Freedom Hospice patients.

In each of the above cases, the patient has the option to revoke his/her hospice election and return to traditional Medicare or Medicaid coverage, and consequently forfeit the remaining days within the benefit period.

The Medicare and Medicaid hospice benefits provide for four levels of care: Routine Home Care, General Inpatient, Respite Care and Continuous Care. Any changes in a patient's level of care must be approved by Freedom Hospice.

The Medicare and Medicaid benefit is divided into benefit periods. The first two periods are for 90 days each. There are additional unlimited 60-day benefit periods, provided the physician and hospice team determine that the patient continues to be eligible.

## For Patients residing in a Skilled Nursing Facility

Medicaid reimbursement, related to hospice services, can cover certain services that Medicare does not. When a Medicaid hospice patient resides in a nursing facility the hospice agency may be responsible to bill the state for the room and board charges and submit payment to the facility. For patients pending Medicaid approval, hospice will not be responsible to bill or pay room and board charges until coverage has been approved, at that time hospice will retroactively pay going back to the coverage effective date or date of hospice admit, whichever is later.

## **For Patients with Other Insurance Coverage**

Various types of insurance plans cover many of the professional services offered by Freedom Hospice. A Freedom Hospice social worker is available to discuss insurance and assist the patient to receive the maximum available coverage for needed services. By speaking to your insurance company directly, Freedom Hospice can better help the patient know exactly what is covered and what, if anything, will remain the financial responsibility of the patient. You will be informed orally and in writing before care is initiated regarding the extent of which charges the patient may have to pay.

After the insurance company makes its payments, if there is an uncovered balance payable to Freedom Hospice, our staff will discuss this with the patient or family and charges will be billed directly. If a statement of services sent to a third-party payer is not paid within 90 days of it being mailed, or if there is no third-party payer that will reimburse Freedom Hospice for services rendered, the patient will be expected to pay the outstanding balance.

Freedom Hospice will never discontinue services because of a proven inability to pay.

## **Patient Responsibility**

While you are receiving care and services from Freedom Hospice, we expect you to assume certain responsibilities for your own care including the following:

1. To provide clinician's complete and accurate information about medical services you are receiving or about to receive.
2. To provide accurate insurance and financial information and provided timely notification of any changes in this information.
3. To inform all clinicians of all medications, including prescribed and over-the-counter medications, herbal supplements and any homeopathic medications or treatments that you are receiving.
4. To have a responsible caregiver available who is capable and willing to assist with your personal needs, between visits from our agency's staff, when indicated.
5. To inform staff of any changes in your condition so that the physician and clinicians can make accurate decisions concerning the type of care or services you require.
6. To follow the plan of care developed for you.
7. To have adequate facilities in your home that will assist in the provision of safe and appropriate care.
8. To promptly notify us in advance of any home visit you must cancel.
9. To be courteous and respectful of all agency staff.
10. To know that any signs of suspected abuse, neglect or misappropriation of financial assets will be reported to the appropriate authorities.

# Medical Care, Medications, Equipment and Supplies

## Medical Care

The Freedom Hospice Team is dedicated to providing pain control and symptom management based on the highest level of accepted standards of practice.

## Medications

Side effects of medications depend upon the medication and the person taking it. Some side effects can be very minor, and others may require the substitution of another medication. Read all labels on medication and consult your nurse or pharmacist if you have any questions. Report any side effects or allergies to your hospice nurse and/or your doctor.

Tell your nurse and pharmacist about all medicines you are taking, including over-the-counter and homeopathic drugs to prevent harmful interactions.

Many people have more than one disease or disorder, requiring the use of different medications. Always know what you are taking and why.

Follow instructions for using medications safely. Many medications can react harmfully when taken together. One medication may make another more powerful, or keep it from working at all. They may even combine to create serious side effects.

Please call Freedom Hospice immediately if you experience an unpleasant or unusual reaction to medication.

## Safe Medication Practices

- Take your medications at correct times. If you miss a dose, ask your nurse what you should do.
- Do not take medications in the dark. Turn on the lights in order to avoid taking the wrong medicine.
- Take the exact dosage prescribed. Too much medicine can cause an overdose; too little can keep the medicine from doing its job.
- Follow recommendations regarding foods you should take or avoid while on certain medications.
- Do not take medications unless you understand all instructions for taking them safely.
- Refill your prescriptions early so you do not run out. Your nurse will ask you to show her the medications, and will call in refill orders as needed.
- Do not stop taking your medications or change the dose without talking to your nurse or doctor.
- Do not take another person's medications, or let them take yours.
- Do not put pills into another bottle unless told to by the pharmacist.
- Never take labels off of bottles.
- Keep medications away from children or confused adults by keeping them out of the reach and out of sight.
- Store medications properly in a clean area.
- Always read the label special storage instructions.
- Do not take expired medications.
- Do not mix medications with alcohol. Many medications contain at least one substance that reacts with alcohol.

## **Managing and Disposing of Controlled Drugs in the Home**

Controlled drugs must be secured and managed to ensure your comfort and safety. The nurse will instruct you on how to store your controlled medications. When a controlled substance is discontinued, the nurse will facilitate and instruct on the disposal of the amount remaining. Freedom Hospice nurses follow state and federal guidelines for the disposal of controlled medications.

## **Medical Equipment Safety**

Whenever medical equipment is delivered to your home, the supplier will demonstrate the use and safety of all equipment.

- Beds should always be in the lowest position, unless care is being provided. Check to ensure the bed's wheels are locked in place.
- Wheelchairs should be locked when at a standstill, or when not in use.
- Medications and supplies should be kept out of reach of children and confused adults.
- There should be **NO SMOKING** while oxygen is in use.

## **Home Oxygen Tips**

Oxygen is a drug and is effective and safe **ONLY** when used as prescribed by your physician. Never change your oxygen liter flow without first consulting your physician.

### **Fire Safety**

- Oxygen is not flammable and will not explode. However, oxygen does support combustion. This means that oxygen makes things burn faster and ignite easier.
- Use and/or store oxygen in a well-ventilated area because oxygen accumulates around the user and immediate surroundings.
- **NEVER** use or store oxygen in a confined space such as a cabinet or closet.
- **DO NOT** use petroleum-based ointment or lotions in or around your nose, such as Vaseline, Vicks, Chapstick, etc. Oxygen can react violently with these oily substances and can cause burns.
- Keep all oxygen equipment at least 15 feet from any type of open flame. Take care to avoid open flames while using oxygen, including matches, fireplaces, barbeques, stoves, space heaters, candles, etc.
- **DO NOT SMOKE** within 15 feet of the oxygen set-up or an oxygen patient.
- Avoid using electrical appliances that produce sparks, such as electrical heaters, electric razors, hair dryers, friction toys, remote toy cars, etc.
- Use of a smoke detector or fire extinguisher is highly recommended when using oxygen in the home.
- Plan an evacuation route for you and your family in the event of a fire.

### **Oxygen Storage and Handling**

- Oxygen tanks should be stored in a stand or cart to prevent tipping and falling. Store extra, unsecured tanks by placing them flat on the floor. Do not allow tanks to stand or lean in an upright position while unsecured.
- **DO NOT** store oxygen systems in unventilated areas such as closets or cabinets.
- **NEVER** drape clothing over oxygen systems.
- **DO NOT** store oxygen systems near heat or ignition sources.
- **DO NOT** store oxygen systems in the trunk of your car.
- While transporting oxygen in a vehicle, ensure containers are secure and positioned properly.
- Oxygen should be transported in the passenger compartment of the vehicle with the window open slightly (2-3 inches) to permit adequate ventilation.

### Concentrator Safety

- Concentrators are electrical devices that should only be plugged into a properly grounded or polarized outlet.
- DO NOT use extension cords.
- DO NOT use multi-outlet adaptors such as power strips.
- Avoid using power sources that create heat or sparks.
- Use a power supply or electrical circuit that meets or exceeds the amperage requirements of the concentrator.

### Liquid Oxygen Safety

- Avoid direct contact with liquid oxygen as it can cause severe burns due to its extremely cold temperature.
- Avoid touching any frosted or icy connectors of either the stationary reservoir or portable unit.
- Avoid contact with any stream of liquid oxygen while filling portable units.
- Keep the portable unit in an upright position. Do not lay the unit down or place on its side.

## ► Smoking While Using Oxygen Is Extremely Dangerous ◀

### Infection Control in your Home

- Hand washing is the most effective way to prevent the spread of infection. Wash hands before and after meals, before preparing meals, and after using the bathroom.
- Wash utensils and dishes in hot soapy water or run them through a dishwasher.
- Always wear gloves when cleaning, urine, feces or blood. Remove gloves and wash hands.
- Wash areas often that have the potential to be splashed with urine, feces or blood with one part bleach mixed with nine parts water. The same solution can be used for soiled sheets and bedding. A new batch of cleaning solutions should be made every 24 hours.

### Disposal of Medical Supplies

- Needles should be disposed of in a puncture-proof container. Do not place sharp objects in any container that will be recycled.
- Used dressings and medical supplies should be handled using gloves and placed in a plastic bag. Tie bag and place in another bag, tie bag tightly and dispose of bag directly into the garbage. Remove gloves and wash your hands.

If plastic bags are not available, newspaper can be used to dispose of dressings contaminated with visible blood by placing materials on several layers of newspaper. Saturated materials with a solution of one part bleach and nine parts water. Wrap with additional newspaper and secure tightly, and throw into garbage. Remove gloves and wash hands.

### Basic Hygiene

When patients are unable to bathe themselves, they may need you to bathe them. Gather supplies and follow these suggestions:

- Administer medications (if needed) before beginning the bath.
- Explain everything you are doing to the patient, even if he/she is not able to respond to you.

- Wash, rinse and dry one area at a time to provide warmth and comfort.
- Inspect skin for reddened areas.
- Tell your hospice nurse of any skin conditions (rash, open areas or redness).
- Apply lotion and other products as ordered to protect skin.

### **Oral Care**

Mouth care is important. A moist mouth may prevent complications and reduce comfort.

If the patient is not able to brush his/her teeth, mouth care should be provided two times daily. If it causes pain or discomfort or if patient is not responsive, using moist mouth swabs will help with dryness. If the patient is unresponsive or unable to swallow, be sure to use any minimal amounts of water on swab, making sure the swab is almost dry.

Avoid using mouthwashes, as many of them contain alcohol which will increase mouth dryness.

## **Emergency Planning**

### **24-Hour Availability**

A hospice nurse is available to you by phone 24 hours a day, 365 days a year. In the event of emergency, call your local Freedom Hospice office at (785) 740-1705 or (844) 760-3733. If you call during business hours, the receptionist will contact your RN, or put you in contact with someone who can help you.

If you call between 4:00 PM and 9:00 AM or anytime on weekends, you will reach Freedom Hospice's on-call nurse and he/she will assist you. If you have questions or concerns related to a patient, do not hesitate to call.

**IT IS ALSO IMPORTANT THAT YOU CALL FREEDOM HOSPICE FIRST FOR DIRECTION OR ASSISTANCE BEFORE YOU CALL 911.**

### **Inclement Weather**

Freedom Hospice is dedicated to providing services to you regardless of weather conditions. In the event of severe weather or other emergencies, our agency will be operational and patients in need of visits will be seen by available staff as soon as possible.

The RN assigned to you will assist you in planning ahead for potential emergencies. Here are some things you can do to be prepared for an emergency:

- Keep important numbers close to your phone. These will include the numbers for Freedom Hospice's office, local police, fire department, ambulance services and electric and gas companies that service your community.
- When possible stock up on emergency supplies including water, canned food, a handheld can opener, flashlights, candles, first aid kit, medications and baby wipes.
- Ensure you have installed smoke detectors and check batteries.
- Properly maintain your car and keep it filled with gas.
- Be sure your car has emergency supplies: snack bars, blankets, flashlight, shovel, ice scraper and flares.
- Ensure you have batteries for flashlights and radios. A battery-operated radio will allow you to hear important information related to your community when you have no electricity.

## **Emergency Preparedness**

These are some things you can do to plan ahead for an emergency:

- Contact your local emergency management office or Red Cross chapter to learn about emergency preparedness.
- Learn about available emergency shelters in your area.
- Disabled people may need to plan ahead in arranging transportation to a shelter.
- Learn, plan and practice evacuation routes that may be designated in your community.
- Assemble a disaster supply kit to survive on your own for a minimum of three days, including water, food and emergency supplies.
- Store water for sanitation purposes.
- Store hand-washing supplies (waterless products like baby wipes).

## **Patient Health Information**

### **Advanced Directives**

You have the right to make an advance directive such as a living will or durable power of attorney for health care. If you have one, we will ask for a copy. If you need information about advance directives, we will provide this in your admission packet. Admission to Freedom Hospice is not contingent on having an advance directive including a DNR (Do Not Resuscitate) status. We will provide care to you based on your physician orders and in accordance with our policies.

## **Protected Health Information- Notice of Privacy Practices Your Information. Your Rights. Our Responsibilities.**

### **Your Rights**

You have the right to:

- Get a copy of your paper or electronic medical record
- Correct your paper or electronic medical record
- Request confidential communication
- Ask us to limit the information we share
- Get a list of those with whom we've shared your information
- Get a copy of this privacy notice
- Choose someone to act for you
- File a complaint if you believe your privacy rights have been violated

### **Your Choices**

You have some choices in the way that we use and share information as we:

- Tell family and friends about your condition
- Provide disaster relief
- Include you in a hospital directory
- Provide mental health care
- Market our services and sell your information
- Raise funds

## Our Uses and Disclosures

We may use and share your information as we:

- Treat you
- Run our organization
- Bill for your services
- Help with public health and safety issues
- Do research
- Comply with the law
- Respond to organ and tissue donation requests
- Work with a medical examiner or funeral director
- Address workers' compensation, law enforcement, and other government requests
- Respond to lawsuits and legal actions

## Your Rights

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

Get an electronic or paper copy of your medical record

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

Ask us to correct your medical record

- You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this.
- We may say “no” to your request, but we’ll tell you why in writing within 60 days.

Request confidential communications

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

Ask us to limit what we use or share

- You can ask us to **not** to use or share certain health information for treatment, payment, or our operations. We are not required to agree to your request, and we may say “no” if it would affect your care.
- If you pay for a service or health care item out-of-pocket in full, you can ask not to share that information for the purpose of payment or our operations with your health insurer. We will say “yes” unless a law requires us to share that information.

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

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

accounting a year for free but will charge a reasonable, cost-based fee if you ask for another one within 12 months.

Get a copy of this privacy notice

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

Choose someone to act for you

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

File a complaint if you feel your rights are violated

- You can complain if you feel we have violated your rights by contacting us using the information on page 1.
- You can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue SW, Washington, DC 320201, calling 1-877-696-6775, or visiting [www.hhs.gov/ocr/privacy/hipaa/complaints/](http://www.hhs.gov/ocr/privacy/hipaa/complaints/).
- We will not retaliate against you for filing a complaint.

## Your Choices

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

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

- Share information with your family, close friends, or others involved in your care
- Share information in a disaster relief situation
- Include your information in a hospital directory

If you are not able to tell us your preference, for example if you are unconscious, we may go ahead and share your information if we believe it is in your best interest. We may also share your information when needed to lessen a serious and imminent threat to health or safety.

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

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

In the case of fundraising:

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

## Our Uses and Disclosures

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

**Treat you**

We can use your health information and share it with your professionals who are treating you. Example: A doctor treating you for an injury asks another doctor about your overall health condition.

**Run our Organization**

We can use and share your health information to run our practice, improve your care, and contact you when necessary. Example: We use health information about you to manage your treatment and services.

**Bill for your Services**

We can use and share your health information to bill and get payment from health plans or other entities. Example: We give information about you to your health insurance plan so it will pay for your services.

**How else can we use or share your health information?** We are allowed or required to share your information in other ways—usually in ways that contribute to the public good, such as public health and research. We have to meet many conditions in the law before we can share your information for these purposes. For more information see: [www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html](http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html)

**Help with public health and safety issues**

We can share health information about you for certain situation such as:

- Preventing disease
- Helping with product recalls
- Reporting adverse reactions to medications
- Reporting suspected abuse, neglect, or domestic violence
- Preventing or reducing a serious threat to anyone's health or safety

**Do research**

We can use or share your information for health research

**Comply with the Law**

We will share information about you if state or federal laws require it, including with the Department of Health and Human Services if it wants to see that we're complying with federal privacy law.

**Respond to organ and tissue donation requests**

We can share health information about you with organ procurement organizations.

**Work with medical examiners or funeral director**

We can share health information with a coroner, medical examiner, or funeral director when an individual die.

**Address workers' compensation, law enforcement, and other government requests**

We can use or share health information about you:

- For worker's compensation claims
- For law enforcement purposes or with a law enforcement official
- With health oversight agencies for activities authorized by law
- For special government functions, such as military, national security, and presidential protective services.

## **Respond to lawsuits and legal actions**

We can share health information about you in response to a court or administrative order, or in response to a subpoena.

Note: We do not create or maintain a hospital directory

## **Our Responsibilities**

- We are required by law to maintain the privacy and security of your protected health information.
- We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information.
- We must follow the duties and privacy practices described in the notice and give you a copy of it.
- We will not use or share your information other than as described here unless you tell us we can in writing. If you tell us we can, you may change your mind at any time. Let us know in writing if you change your mind.

For more information see:

[www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html](http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html)

## **Changes to the Terms of this Notice**

We can change the terms of this notice, and the changes will apply to all information we have about you. The new notice will be available upon request, in our office, or on our website.

## **Concerns and Grievance Process**

In order to provide quality services, Freedom Hospice encourages you to express all concerns to a member of your care team, without fear of reprisal. Concerns will be resolved at the level of management best able to bring about your satisfaction. If the concern continues to be unresolved, you can escalate your concern to the CEO in person, by phone or in writing.

To contact the CEO, please utilize the address and telephone number provided and you will be directed to the appropriate person:

1705 Oregon Street  
Hiawatha, KS 66434  
(785) 740-1705

It is the policy of Freedom Hospice to provide service to all persons without regard to race, color, national origin, disability, or age in compliance with 45 CFR Parts 80, 84, and 91, respectively. The same requirements are applied to all and there is no distinction in eligibility for, or in the manner of, providing services. All services are available without distinction to all program participants regardless of race, color, national origin, disability or age. All persons and organizations having occasion either to refer persons for services or to recommend our services are advised to do so without regard to the person's race, color, national origin, disability or age. Concerns of the discriminatory nature must be submitted in writing to the CEO providing your service within 30 days after becoming aware of the alleged discriminatory act.

The CEO is the Section 504 Coordinator who will ensure a speedy, equitable resolution. The CEO shall issue a written decision determining the validity of the complaint no later than 30 days after its filing.

Your nurse can indicate other agencies and phone numbers you may wish to utilize as appropriate to your service, including the U.S. Department of Health and Human Services Officer for Civil Rights in your area. You may also contact the Medicare Hotline by using the information below:

Centers for Medicare & Medicaid Services  
Medicare Service Center  
800-MEDICARE (800-633-4227)  
TTY: 877-486-2048

## Primary Caregivers Responsibilities

Freedom Hospice requires that each person have a primary caregiver at the time the patient is no longer able to care for him/herself. This is a very important role. This individual is the person with whom the hospice team coordinates the care of the patient, especially when the patient is no longer able to make decisions.

The hospice team will provide instructions to the primary caregiver on how to care for the patient at home. The primary caregiver is responsible for the day-to-day care in the home. If this person is not able to provide the care with the help of relatives and friends, he/she is responsible for arranging for this care.

The hospice team will assist with arranging for additional care, but the primary caregiver is responsible for the final decision-making and the payment of services.

## Family Guide to Patient Care

### How can I help my loved one?

Some practical suggestions are:

- Offer choices. Allow them to have as much control as possible.
- Be there. Touch and eye contact are vital.
- Maintain respect and privacy.
- Encourage sharing of stories and memories.
- Allow them to express fears, concerns and feelings without denying or minimizing them.
- Allow for silence and quiet moments.

### Care for the Caregiver

Providing care at home for a loved one with a serious illness is a wonderful gift you give, and at times, you may feel tired or overwhelmed. Taking time for yourself is very important to help keep you as strong as you can be.

- Be aware of your own needs, they are important too!
- Keep in contact with supportive friends and family—even brief times away can really help.
- Make sure you get as much rest as you need.
- Eat small meals several times a day.
- Ask for help when you need it!
- Do something you enjoy.
- Expect “unexpected feelings.”
- Give yourself permission to feel.
- Give voice to what you feel by talking to a friend, writing in a journal, crying when you feel like it, etc. It will provide release.

- Forgive yourself and others

Sometimes the caregiver is trying to meet so many needs and this can result in frustration. Caregivers are trying to give the best care while meeting all the expectations of their loved ones, family and life. All caregivers and family members need time to relax.

### **Here Are 10 Warning Signs of Caregiver Stress:**

We thought this may be a tool to assist you in identifying and discussing with your hospice team areas of concerns that you may have.

1. DENIAL about the disease and its effect on the person who has been diagnosed. “I know he/she will get better.”
2. ANGER at the person with the illness or others. “There is no effective treatment. People just don’t understand what is going on.”
3. SOCIAL WITHDRAWAL from friends and activities that once brought pleasure. “I don’t care about getting together with neighbors anymore.”
4. ANXIETY about facing another day and what the future holds. “What happens when he/she needs more care than I can provide?”
5. DEPRESSION begins to break your spirit and affects your ability to cope. “I don’t care anymore.”
6. ENHAUSTION makes it nearly impossible to complete necessary daily tasks, “I’m too tired for this.”
7. SLEEPLESSNESS caused by a never-ending list of concerns, “What if he/she falls? What if I don’t hear him/her?”
8. IRRITABILITY leads to moodiness and triggers negative responses and reactions. “Leave me alone.”
9. LACK OF CONCENTRATION makes it difficult to perform familiar tasks. “I was so busy, I forgot we had an appointment.”
10. HEALTH PROBLEMS begin to take a toll, both mentally and physically. “I can’t remember the last time I felt good.”

## **Additional Support and Resources**

Your social worker can provide a list of community resources that may offer help. Please ask your social worker for assistance in the following areas or for additional information.

### **Respite**

Please ask a team member about respite care that may be available under the hospice benefit.

### **Transportation by Ambulance**

Coverage for the cost of ambulance trips depends on how hospice services are paid. If you have private insurance, coverage depends on the insurance policy. **If you are utilizing the hospice benefit, ambulance rides are not routinely covered. The patient is responsible for ambulance charges if it is the result of a 911 call not authorized by hospice.** Cost of transportation to and from doctor appointments, treatment or respite stays are the responsibility of the patient.

### **Family Meetings**

The hospice team believes having family meetings allows the patient and family members to ask questions or verbalize concerns with the hospice team. It also allows for open communication. This gives everyone a chance to problem solve, think of creative caregiving, connect with one another and discuss loss and grief concerns, as well as consider long range planning for care.

### **Children: Emotional Support/Education**

Hospice team members are able to work with families to provide information and suggestions regarding preparing children for the grief and loss of a parent, grandparent, or other family member.

### **Lifeline/Life Alert**

This is a device that is installed in the home. If your loved one lives alone, he/she is able to connect with someone to ask for assistance. There is a one-time charge for installation and a monthly service fee.

### **Meals on Wheels**

A social worker can assist you with making arrangements for these services, if needed.

### **Blocks of Hours/Private Hours**

If a family member is looking for additional hours of care that exceed the hospice benefit, private agencies may provide blocks of hours on a fee-for-service basis.

### **Companionship Services**

This service helps with everyday tasks that allow individuals to live independently in their homes on a fee-for-service basis. They may provide meal preparation, medication reminders, light housekeeping, laundry and errands, including shopping.

### **Nursing Home/Alternative Placement**

Your social worker is available to discuss and assist in arranging alternative living arrangements for your loved ones.

## **Hospice Pain and Symptom Management**

Freedom Hospice is dedicated to helping relieve any pain, discomfort or side effects in the least invasive manner. Our nurses have received specialty training in pain and symptom management.

### **Pain Management**

Pain management is an important part of your care. When you are in pain or are uncomfortable, it can affect the way you feel both physically and emotionally. The longer the pain goes untreated, the harder it is to relieve. Effective pain management can ease your pain. Don't wait, talk to your care team when pain first starts.

At every visit by every member of our team, the patient will be asked if they are having pain, discomfort or any changes in condition. We strongly advocate that a patient's pain is what he/she says it is.

At the time of your admission assessment, the nurse will ask you to rate your pain at its best, at its worst and presently. The patient will also be asked to score their desired level of relief. All patients are different and acceptable pain levels can vary.

Freedom Hospice uses two pain scales. One is the pain rating scale of 1-10. A score of 0 is no pain; a score of 10 is the worst pain the patient has ever had.

The PAINAD scale is used for patients who are unable to verbalize their pain or discomfort. The nurse assessed the patient in the following areas to determine a pain score: Breathing independent of vocalization, negative vocalization, facial expressing, body language and consolability.

### **Questions for the Doctor or Nurse:**

You have the right to expect accurate information about pain prevention and pain relief measures.

1. What will you be given for pain?
2. How will medication be taken?
3. When should medication be taken?
4. What should be done if the medication doesn't seem to be working?
5. What are common side effects of the medication?

### **Spiritual/Emotional Pain**

Sometimes pain is reflected in feelings, such as sadness, loneliness, regret, fear and despair. At times, physical pain may be triggered by such feelings. When one feels these emotions, it may be helpful to talk with a trusted friend or professional. Your own clergy or spiritual caregiver may also be of help.

Freedom Hospice staff is available to listen and support you through such emotional/spiritual pain. Such staff includes clinical social workers and chaplains.

### **Alternative Pain Management**

There are many treatments to manage pain. Ask a doctor or nurse for more information regarding: relaxation techniques, guided imagery, paced or rhythmic breathing, hot or cold packs, massage, elevation or support-position changes or music.

Pain can be relieved! If you have questions or concerns, please do not hesitate to call us.

## **Common Fears about Pain Medication**

There are some people who are reluctant to take medications because they are afraid they will become addicted. Studies show that addiction is extremely rare when people are using medications to treat pain. Other people do not want to tell others they are in pain, as to not bother anyone. It is important for you to know that you have the right to ask for pain relief. Please tell us when you are in pain.

## **Symptom Management**

### **Withdrawal**

With withdrawal comes less of a need to talk. Touch and silence take on more meaning. People at this point may not respond to you or may look like they're in a coma. This may be their way of getting ready to let go.

### **Changes in Eating**

Changes in eating can be one of the hardest things for caregivers to accept. Food is the way we feed the body. As the body begins to slow down, it no longer digests food in the same way. Weight loss is common. Keep in mind, this does not mean that the person is hungry or being starved.

### **Changes in Toileting**

“Incontinence” is the loss of bladder and bowel control. This can happen as muscles in the lower body start to relax. Incontinence can be embarrassing for many people. Always keep the person clean, dry, and comfortable. The overall goal is the person's dignity.

## Changes in Breathing

Breathing patterns often change for people at the end of life. Breathing may slow down. Or there may be fast, short breaths followed by periods of no breathing. These periods can last 5 to 30 seconds, or up to a full minute. Breathing this way is not uncomfortable for the person.

## Changes in Body Temperature

*FEVER:* The brain loses control of body temperature when the body is weak. Sometimes he or she may get sweaty with or without a fever. Let the nurse know if the person has a fever.

*COOLNESS:* As your loved one becomes weaker, blood flow slows down. Legs and arms might feel cool to the touch. Skin color may change. The hands and feet may look a little purple. The knees, ankles, and elbows may look spotty.

## Confusion

People nearing the end of life may seem confused at times. They may not know what time it is, where they are, or who you are. They may say they see things no one else can see. They may talk to people who are not there, or who have already died. Let the hospice nurse or other care team members know if the person is confused. They will show you how to best support the person at this time.

## Freedom Hospice Bereavement

Freedom Hospice Bereavement Program provides bereavement support to families for 13 months following a death of a patient. Educational programs are offered to help people understand their grief. Bereavement calls or visits will be offered to family members for 13 months following the death. Referrals to grief groups and grief therapists can be made when appropriate.

## Donations to Freedom Hospice

Freedom Hospice accepts donations in order to help care for patients and families. Many of the families we service designate memorial gifts to Freedom Hospice. Donations are appreciated but certainly not expected. If you would like to support Freedom Hospice financially, your contribution will be used to support the vision and programs of Freedom Hospice. Your generosity provides quality care for patients and families facing the end-of-life process. Every **financial contribution** to Freedom Hospice makes a difference in the lives of those we service. And remember, by supporting Freedom Hospice, your gift always stays close to home.

Ask us how you can be part of our **Legacy Flag** by calling (785) 740-1705 or (844)760-3733.

If you would like to make a **donation**, please send a check payable to Freedom Hospice at 1705 Oregon, Hiawatha, KS 66434







# *Freedom Hospice* LLC

(785) 740-1705

OR

(844) 760-3733

[www.FreedomHospice.net](http://www.FreedomHospice.net)