



Thank you for choosing Suncoast Hospice, a member of Empath Health. We are honored to serve you and your family. Should you have any questions or concerns we are available to you 24 hours a day, 7 days a week.

Call us anytime at **(727)467-7423** and ask for your team.

**SUNCOAST**  
HOSPICE



**[SuncoastHospice.org](http://SuncoastHospice.org)**

## When Should You Call?

### A Checklist

You may wonder when it is appropriate to call your Suncoast Hospice team if you have a concern. There are a number of factors that are definite signals to call us. Even if your question or concern is not on the list below, we encourage your call—day or night, weekends or holidays. We are here for you.

**Call (727) 467-7424, 24 hours a day, 7 days a week**

#### Examples of when it is important to call:

##### Always Call if You

- Fall - even if minor
- Are considering going to the hospital or calling 911
- Change locations (e.g. hospital to home, nursing center to home, home to hospital, etc.)

##### When New or Increased

- Pain
- Shortness of breath
- Bleeding
- Nausea/vomiting
- Confusion
- Anxiety/restlessness
- Feelings of being sad or overwhelmed
- Fever
- Chills
- Sweating
- Coughing
- Weakness
- Skin sores/broken areas
- Swelling (e.g. legs, arms, abdomen, etc.)

##### Any Difficulties With

- Breathing
- Clearing throat
- Sleeping or staying awake
- Urination
- Diarrhea, constipation or no bowel movement in three days
- Worrying

##### Any Changes In

- Ability to eat or drink
- Desire to eat or drink

##### Have Questions Related to

- Medications
- Oxygen
- Medical equipment
- Treatments
- Expected deliveries or visits
- Advanced care planning (help with a living will, health care surrogate, etc.)
- Additional caregiving services (information on private hire, respite care, assisted living/nursing facility care)

**We strive to return calls within 30 minutes.  
If it has been longer, please call again.**



# Table of Contents

## Section 1 Your Documents

- |   |  |          |
|---|--|----------|
| <a href="#">1-1 Disaster Evacuation Plan</a>                          | <a href="#">1-15 Family/Caregiver Instructions for Medication Disposal</a> | <b>1</b> |
| <a href="#">1-4 Special Needs Shelter Medical and Equipment List</a>  | <a href="#">1-16 What's Important?</a>                                     |          |
| <a href="#">1-5 Notice of Privacy Practices for Suncoast Programs</a> | <a href="#">1-17 Practical Matters</a>                                     |          |
| <a href="#">1-10 Statement of Advance Directives</a>                  |  |          |
| <a href="#">1-10 Patient Rights and Responsibilities</a>              |  |          |
| <a href="#">1-11 Medicare Hospice Benefits</a>                        |  |          |

## Section 2 Frequently Asked Questions

- |   |   |          |
|---|---|----------|
| <a href="#">2-1 What to Expect</a>            | <a href="#">2-3 Suncoast Hospice Care Centers</a> | <b>2</b> |
| <a href="#">2-2 Children and Families</a>     | <a href="#">2-6 Grief Support</a>                 |          |
| <a href="#">2-2 Medications</a>               | <a href="#">2-6 Reimbursement</a>                 |          |
| <a href="#">2-3 Honoring Veterans</a>         | <a href="#">2-6 Medicare and Medicaid</a>         |          |
| <a href="#">2-3 Organ and Tissue Donation</a> | <a href="#">2-8 Reporting Concerns</a>            |          |
| <a href="#">2-3 As Care Needs Change</a>      | <a href="#">2-8 Thanking Your Team</a>            |          |
|   |   |          |

## Section 3 Your Team & Volunteers

- |                                       |          |
|---------------------------------------|----------|
| <a href="#">3-1 Your Hospice</a>      | <b>3</b> |
| <a href="#">3-1 Your Care Team</a>    |          |
| <a href="#">3-2 Your Volunteers</a>   |          |
| <a href="#">3-3 Making Memories</a>   |          |
| <a href="#">3-3 Personalized Care</a> |          |

## Section 4 Your Comfort

- |  |   |          |
|--|---|----------|
| <a href="#">4-1 Pain</a>                 | <a href="#">4-7 Shortness of Breath</a>   | <b>4</b> |
| <a href="#">4-3 Pain Medications</a>     | <a href="#">4-8 Nausea and Vomiting</a>   |          |
| <a href="#">4-5 Weakness and Fatigue</a> | <a href="#">4-10 Promoting Comfort</a>    |          |
| <a href="#">4-6 Constipation</a>         | <a href="#">4-14 Your Comfort Journal</a> |          |

## Section 5 Your Decisions

- |   |          |
|---|----------|
| <a href="#">5-1 Advance Directives</a>            | <b>5</b> |
| <a href="#">5-5 Funeral and Memorial Services</a> |          |



# Table of Contents

Continued

## Section 6 Tips For Patients and Caregivers

- [6-1 Practical Tips from Other Caregivers](#)
- [6-1 Talking with Children](#)
- [6-2 Finding Your Support System](#)
- [6-3 Warning Signs for Caregivers](#)
- [6-4 More About Caregiving](#)

6

## Section 7 Tips for Care and Safety

- [7-1 Preventing and Controlling Infections at Home](#)
- [7-4 Biomedical Waste Guidelines](#)
- [7-5 Falls Prevention Checklist](#)
- [7-6 Giving Medications](#)
- [7-7 Providing Personal Care](#)
- [7-9 Mobility](#)
- [7-11 Bladder and Bowel Care](#)
- [7-14 Fire and Oxygen Safety Checklist](#)
- [7-14 Caring for Someone in Bed](#)

7

## Section 8 Loss & Grief

- [8-1 Common Expressions of Grief](#)
- [8-2 Suncoast Hospice Grief Services](#)
- [8-2 Helping Grieving Children](#)

8

## Section 9 Resources

- [9-1 Suncoast Hospice Community Lending Libraries](#)
- [9-1 Suncoast Hospice Resale Shops](#)
- [9-2 Local and Governmental Resources](#)

9

## Section 10 Suncoast Hospice Foundation

- [10-1 Circle of Caring](#)

10



# Your Documents

1

- 1-1 Disaster Evacuation Plan
- 1-4 Special Needs Shelter Medical and Equipment List
- 1-5 Notice of Privacy Practices for Suncoast Programs
- 1-10 Statement of Advance Directives
- 1-10 Patient Rights and Responsibilities
- 1-11 Medicare Hospice Benefits
- 1-15 Family/Caregiver Instructions for Medication Disposal
- 1-16 What's Important?
- 1-17 Practical Matters



# Section 1 Your Documents

## **Disaster Evacuation Plan**

Events during the past few years have highlighted the importance of being prepared for emergency situations. Because we live in Florida, most of our disaster planning efforts involve preparing for hurricanes. It is important to remember that hurricanes are not the only disasters that could strike our area. Power outages, tornadoes, localized flooding, acts of terrorism and fire are all examples of possible threats to normal living.

Having an evacuation strategy, an emergency kit in your home, written contact numbers and anticipating what loss of electricity would mean to your household will help you to be better prepared for any unexpected threat.

***Your Care Team will help you develop a disaster plan that fits your care needs and your living situation. Please contact your care team if you would like to discuss a change in your care needs or established plan. Plan may be updated to reflect changes in location/condition.***

### **You and Your Family**

1. Make a family plan and be sure your hospice care team knows your plan. Inform your care team any time your plan changes.
  - Develop a disaster supply kit – If not evacuating, include a 14-day supply of non-perishable food, 1 gallon of water per person per day and a 14-day supply of medications and supplies.
  - Anticipate what loss of electricity might mean for you and your family.
  - Make plans to protect your home before any storm.
  - Purchase a battery powered weather radio.
  - Be sure to have a landline, non-electric phone.
  - Inventory your possessions and store important papers such as insurance, title and ID in a safe, dry place. Send copies to a friend or relative outside the area.
  - Review your insurance policies for your home and possessions.
  - During hurricane season (June-November) work with your care team to be sure you have at least a two-week supply of medications on hand.

### **2. My evacuation level is \_\_\_\_\_.**

3. If you live in an evacuation zone or are electrically dependent on medical equipment (i.e. continuous oxygen, suction) make a plan now for where you and your family will evacuate.

Your physical condition and needs should guide you in determining where you would need to go and how you would get there. Options to discuss with family and your care team are listed below.

- Family or friends in a non-evacuation zone
- Host homes

- Hotel in a non-evacuation zone
- Special need shelters staffed by Suncoast Hospice
- Public shelters (We strongly encourage the above options instead.)
- Other options based on condition and needs – skilled nursing facility or hospital
- Considering the timing and reason for the evacuation need, such as during a pandemic, staying in a community evacuation shelter and social distancing are difficult to do safely together as shelters typically have very limited space. Please remember it is important to bring your own Personal Protective Equipment (masks).

**My Evacuation Destination Is:** \_\_\_\_\_

☐ Patient resides in an ALF or Skilled Nursing Facility, evacuation destination per facility.

**Contact Name/Location:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Phone Number(s):** \_\_\_\_\_

**My Transportation will be:**

☐ Self   ☐ Family   ☐ Registered with Special Needs Transport

☐ Other: \_\_\_\_\_

**\*Special Advice for Evacuees to Special Needs Shelters**

- Please note that special needs shelters are intended to be a place of last refuge and that the conditions in a shelter may be very stressful.
- It is recommended that a caregiver accompany an evacuee to the special needs shelter and remain with him or her. Other family and friends may be able to accompany an evacuee to a special needs shelter as well. Please note that if space is limited only one caregiver will be able to stay with the special needs registrant and the rest of the family and friends will be asked to stay in the general population area of the shelter.
- Hospice staff will be present to provide support and care (in addition to shelter staff)

**Special Advice for Evacuees to Skilled Nursing Facilities or Hospitals**

- Patients with special needs (oxygen greater than 4 liters flow per minute, ventilators, specialized IV medications and those that are bedbound) need evacuation plans to a non-evacuating skilled nursing facility or hospital.
- Your care team will help you register for transportation to the skilled nursing facility or hospital with Pinellas County Emergency Management if that should be needed.

**Recommended List of Items to Take to a Special Needs Shelter, Skilled Nursing Facility or Hospital**

- Personal identification showing current address
- Any personal important papers and contact information

- Your “Patient & Family Guide” notebook, including your:
  - Plan of Care
  - Medication, Supply and Equipment List (provided by Suncoast Hospice)
  - Advance Directives
  - Contact Numbers
- 14-day supply of prescription and non-prescription medication
- Oxygen – take your concentrator
- Bedding, folding lawn chair, air mattress, linens and sleeping supplies
- Special diet items, non-perishable food for 72 hours and 1 gallon of water per person per day
- Glasses, hearing aids and batteries, prosthetics and any other assistive devices
- Personal hygiene items
- Extra clothing for 72 hours
- Flashlight and batteries \_\_\_\_\_
- Entertainment and comfort items – books, magazines, games
- During a pandemic additional items for personal protection are recommended (masks, hand sanitizer)

## A Word about Pets

A pet-friendly shelter should be your last choice in the event of an evacuation with your pet. These are **not** equipped as special need shelters.

Pinellas County does have three pet-friendly shelter options. Please note the following:

- Space is extremely limited. These shelters will only be open for mandatory evacuations and may only accommodate a portion of citizens who dwell in mobile homes.
- Priority is given to mobile home residents and then by evacuation zone.
- Pets must be pre-registered with Pinellas County Animal Services 727-582-2150.
- Cats and dogs only.
- Pets must have a current license and rabies vaccination.

Contact Numbers	
Hospice	
Physician	
Family	

## After an evacuation

After the danger has passed and authorities have notified you that you can return to your residence or reenter an affected area please know that our staff will be attempting to make contact with you as soon as possible. We would ask that you call us at \_\_\_\_\_ to update us on your condition and whereabouts so that we can make contact with you as soon as possible.



## Special Needs Shelter Medical and Equipment List

<input type="checkbox"/>	Briefs	<input type="checkbox"/>	Bi Pap Machine
<input type="checkbox"/>	Chuxs	<input type="checkbox"/>	E regulator for E & D tanks
<input type="checkbox"/>	Diapers	<input type="checkbox"/>	E Tank
<input type="checkbox"/>	Dressings	<input type="checkbox"/>	E cylinder bag
<input type="checkbox"/>	Hand Sanitizer	<input type="checkbox"/>	Nasal Cannula
<input type="checkbox"/>	Hand Soap	<input type="checkbox"/>	O <sub>2</sub> Tubing
<input type="checkbox"/>	Gauze Dressings	<input type="checkbox"/>	Wheelchair
<input type="checkbox"/>	Gloves (sterile)	<input type="checkbox"/>	Wheelchair Standard foot rest
<input type="checkbox"/>	Dressing Tape	<input type="checkbox"/>	Wheelchair Wedge Pillow
<input type="checkbox"/>	Rubber Gloves	<input type="checkbox"/>	Wheelchair Gel Cushion
<input type="checkbox"/>	Syringes	<input type="checkbox"/>	Wheelchair head support
<input type="checkbox"/>	Medication Box	<input type="checkbox"/>	Wheelchair E tank bag
<input type="checkbox"/>	Thermometer	<input type="checkbox"/>	Walker
<input type="checkbox"/>		<input type="checkbox"/>	Cane
<input type="checkbox"/>		<input type="checkbox"/>	
<input type="checkbox"/>		<input type="checkbox"/>	
<input type="checkbox"/>		<input type="checkbox"/>	
<input type="checkbox"/>		<input type="checkbox"/>	
<input type="checkbox"/>		<input type="checkbox"/>	
<input type="checkbox"/>		<input type="checkbox"/>	

**DO NOT BRING:** Bag balm or Chapstick. **Avoid using petroleum based products in the presence of oxygen. Bring water based products only.**

# **NOTICE OF PRIVACY PRACTICES FOR SUNCOAST PROGRAMS**

## ***"PROTECTING THE PRIVACY OF YOUR HEALTH INFORMATION"***

**THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.**

Suncoast Hospice offers a variety of programs in its continuum of care. This Notice of Privacy Practices applies to one or more of those programs including ASAP, Suncoast Hospice, Suncoast Homecare, and Suncoast PACE. Suncoast Hospice shall hereafter be referred to as **Suncoast**.

Please be aware that only a patient or patient representative can request copies of medical records. Florida Statutes stipulate patient records may otherwise only be released with a court order. Please contact a member of your care team for assistance if you will be requesting copies of your medical records.

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

Suncoast may use your health information for purposes of providing you **treatment**, obtaining **payment** for your care and conducting health care **operations**. Suncoast has established policies to reasonably protect health information as defined in the Health Insurance Portability and Accountability Act (HIPAA) Privacy and Security Rules.

### **THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH YOUR HEALTH INFORMATION MAY BE USED AND DISCLOSED:**

**To Provide Treatment.** Suncoast may use your health information to coordinate care within Suncoast and with others involved in your care, such as your attending physician, members of the Suncoast interdisciplinary team and other health care professionals who have agreed to assist Suncoast in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. Suncoast also may disclose your health care information to individuals outside of Suncoast who are involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

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

**To Conduct Health Care Operations.** Suncoast may use and disclose health information for its own operations in order to facilitate the function of Suncoast and as necessary to provide quality care to all of Suncoast's patients. For example, Suncoast may use or disclose your health information to perform quality assessment activities or evaluate the performance of its staff.

Suncoast may use your health information to contact you as a reminder regarding a visit to you, or contact you as part of general fundraising and community information mailings (unless you tell us you do not want to be contacted).

If you are in a Suncoast inpatient or residential facility, Suncoast may disclose certain information about you in a Suncoast directory, including your name, your general health status, your religious affiliation and your location while you are in the facility. Suncoast may disclose this information to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.

**For Fundraising Activities.** Suncoast may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for Suncoast. Suncoast may also release this information to a related Suncoast foundation. If you do not want Suncoast to contact you or your family, notify the Vice President of Planning at 5771 Roosevelt Blvd., Clearwater, FL 33760 or at 727-586-4432 and indicate that you do not wish to be contacted.

**For Appointment Reminders.** Suncoast may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

**For Treatment Alternatives.** Suncoast may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

## **OTHER USES OR DISCLOSURES OF YOUR HEALTH INFORMATION:**

**Business Associates:** Suncoast provides some services by using outside vendors (business associates). Suncoast may share your information with them so that they can perform the job Suncoast has asked them to do. To protect your information, Suncoast requires the business associate to contractually agree to appropriately safeguard your information.

**When Legally Required.** Suncoast will disclose your health information when it is required to do so by any Federal, State or local law.

**When There Are Risks to Public Health.** Suncoast may disclose your health information for public activities and purposes like reporting vital events such as birth or death, tracking medical devices or reporting communicable diseases.

**To Report Abuse, Neglect Or Domestic Violence.** Suncoast is allowed to notify government authorities if Suncoast believes a patient is the victim of abuse, neglect or domestic violence. Suncoast will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

**To Conduct Health Oversight Activities.** Suncoast may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. Suncoast, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

**In Connection With Judicial And Administrative Proceedings.** Suncoast may disclose your health information in the course of any judicial or administrative proceeding, in response to court or administrative order or in response to a subpoena, discovery request or other lawful process, but only when Suncoast makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

**For Law Enforcement Purposes.** As permitted or required by State law, Suncoast may disclose your health information to a law enforcement official for certain law enforcement purposes such as to report:

- Certain types of wounds, or
- To help identify or locate a suspect, fugitive, material witness or missing person, to report a crime; or
- If Suncoast has a suspicion that your death was the result of criminal conduct including criminal conduct at Suncoast.

**To Coroners And Medical Examiners.** Suncoast may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

**To Funeral Directors.** Suncoast may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. Suncoast may disclose your health information to funeral directors prior to and in reasonable anticipation of your death, if deemed necessary to fulfill their duties.

**For Organ, Eye Or Tissue Donation.** In the event you have chosen to be a donor, Suncoast may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

**For Research Purposes.** Suncoast may, under very select circumstances, use your health information for research. Before Suncoast discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.

**In the Event of A Serious Threat To Health Or Safety.** Suncoast may, consistent with applicable law and ethical standards of conduct, disclose your health information if Suncoast, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

**For Specified Government Functions.** In certain circumstances, the Federal regulations authorize Suncoast to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

**For Workers' Compensation.** Suncoast may release your health information for workers' compensation or similar programs.

## **AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION**

Other than as stated above, Suncoast will not disclose your health information other than with your written authorization. You may revoke that authorization in writing at any time. However, Suncoast is unable to take back any disclosures it has already made with your permission and that Suncoast is required to retain for its records of care.

Your written authorization is required for most uses and disclosures of psychotherapy notes; uses and disclosures of health information for marketing purposes; and disclosures that are a sale of health information. You may revoke your authorization in writing at any time except to the extent that we have taken action in reliance upon the authorization.

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

You have the following rights regarding your health information that Suncoast maintains. If you wish to exercise this right, you may contact the Vice President of Planning. The contact information is shown at the end of this Notice.

- **Right to request restrictions.** You may request restrictions on certain uses and disclosures of your health information. You have the right to request limit on Suncoast's disclosure of your health information to someone who is involved in your care or the payment of your care. In most cases, Suncoast is not required to agree to your request. If we do agree, we will comply with the request unless the information is needed to provide you with emergency treatment. Also, we cannot agree to restrict disclosures that are required by law. You have a right to request that we not disclose PHI to health plans because you paid for services or items out of pocket and in full. If you wish to make a request for restrictions, please tell Suncoast:

- (1) what information you want to limit;
- (2) whether you want to limit Suncoast's use, disclosure, or both; and
- (3) to whom you want the limit to apply (e.g. spouse).

If you think you should be classified as a self pay patient, please note that as well. However, you should be aware that if you choose to use a medical expense reimbursement/flexible spending account (FSA) or a health savings account (HSA) to pay for the health care items or services that you wish to have restricted, those plans will still require you to provide the necessary substantiation of the expenses in order to receive reimbursement.

- **Right to receive confidential communications.** You have the right to request that Suncoast communicate with you in a certain way. For example, you may ask that Suncoast only conduct communications pertaining to your health information with you privately with no other family members present. Suncoast will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.
- **Right to inspect and copy your health information.** You have the right to inspect and copy your health information, including billing records. If you request a copy of your health information, Suncoast may charge a reasonable fee for copying and assembling costs associated with your request. If you wish to receive electronic copies of your information, please put this in the request.
- **Right to an Electronic Copy of Electronic Medical Records.** If your protected health information is maintained in an electronic format, you have the right to request that an electronic copy of your record be given to you or transmitted to another individual or entity. We will make every effort to provide access to your protected health information in the form or producible in the form or format, you request your record will be provided in either our standard electronic format or if you do not want this form or format, a readable hard copy form. We may charge you a reasonable, cost-based fee for the labor associated with transmitting the electronic medical record.
- **Right to amend health care information.** You or your representative has the right to request that Suncoast amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by Suncoast. Suncoast may deny the request if it is not in writing or does not include a reason for the amendment. The request will be denied if your health information records were not created by Suncoast, if the records you are requesting are not part of Suncoast 's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of Suncoast, the records containing your health information are accurate and complete.
- **Right to an accounting.** You or your representative have the right to request an accounting of disclosures of your health information made by Suncoast for certain reasons, including reasons related to public purposes authorized by law and certain research. The request must specify the time period for the accounting which may not be longer than six (6) years and may not include dates before April 14, 2003. The request should describe the accounting you wish to receive (e.g. a list of disclosures to a certain person or for a certain reason). Suncoast will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a cost-based fee.
- **Right to a paper copy of this notice.** You or your representative have a right to a separate copy of this Notice at any time even if you or your representative have received this Notice previously. You may also obtain a copy of the current version of Suncoast's Notice of Privacy Practices at its website, [www.SuncoastHospice.org](http://www.SuncoastHospice.org)
- **Right to receive notice of breach of Protected Health Information.** In the event of any unauthorized acquisition, access, use or disclosure of Protected Health Information by Suncoast, we shall fully comply with the breach notification requirements, including any and all regulations which have been or may be promulgated, which will include notification to you of any impact that breach may have had on you.

## DUTIES OF SUNCOAST

Suncoast is required by law to maintain the privacy of your health information and to provide this Notice of its duties and privacy practices to you or your representative. Suncoast is required to abide by the terms of this Notice as may be amended from time to time. Suncoast reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If Suncoast makes material changes to its Notice, Suncoast will make a copy of the revised Notice available to you or your appointed representative. You have the right to express complaints to Suncoast and to the Secretary of DHHS if you believe that your privacy rights have been violated.

***Complaints to Suncoast should be made in writing to the Vice President of Planning, 5771 Roosevelt Blvd., Clearwater, Florida 33760. Suncoast encourages you to express any concerns you may have regarding the privacy of your information and offers its assurance that you will not be retaliated against in any way for filing a complaint.***

## CONTACT PERSON

Suncoast has designated the Vice President of Planning as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. To make a request or ask a question, you may contact the Vice President of Planning at 5771 Roosevelt Blvd., Clearwater, FL 33760 or at 727-586-4432.

**EFFECTIVE DATE**

Effective April 14, 2003  
Updated September 18, 2013

**Our employees and volunteers respect your right to privacy and are committed to safeguarding the privacy of your protected health information!**

Notes:

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

## **STATEMENT OF ADVANCE DIRECTIVES**

Suncoast Hospice recognizes under Florida Law that all adult persons have a fundamental right to make decisions relating to his/her own medical treatment, to accept or refuse medical care and treatment, including whether to continue medical treatment that would prolong life artificially. Encouraging individuals and their families to participate in decisions regarding care and treatment is the policy of Suncoast Hospice. Valid advance directives such as **Living Wills, Durable Power of Attorney for Health Care and Do Not Resuscitate (DNR)** orders will be followed to the extent permitted and required by law. Our staff will discuss advance directives with you at time of admission and ongoing and furnish copies of the documents for your convenience.

You have the right to change your mind about any treatment or revoke an advance directive. If you wish to revoke your advance care directive, the best way to do so is by destroying all copies of the directive and notifying your health care providers of your decision. You may also revoke your directive by informing your attending physician or health care providers that you wish to revoke your directive.

If you have a Living Will containing your personal directions about life-prolonging treatment or a Durable Power of Attorney for Health Care or Health Care Surrogate designation form, please provide a copy of the document to the Hospice nurse or social worker. This will be kept in your Hospice medical records. Keep the original in a safe, accessible place and be sure that family members and the Hospice nurse know where to find it. DNRO forms are recommended to be visible at the home such as on the refrigerator, so Emergency Medical personnel can easily discover your wishes.

Should an individual wish to receive cardiopulmonary resuscitation, the Hospice staff members including, physicians, ARNP's, RN's, LPN's, home health aides/CNA's, respiratory therapists, physical therapists, occupational therapists and speech therapists will initiate CPR. All other staff/volunteers will respond by notifying 911 for patients who have identified that they wish to be resuscitated.

In the absence of advance directives, Suncoast Hospice will provide appropriate palliative care according to the treatment plan authorized by the attending physician and the Hospice interdisciplinary team. Suncoast Hospice will not condition the provision of care or otherwise discriminate against an individual based on whether or not he/she has executed an advance directive and a DNR statement is not required for admission to the program.

Note: The legal basis for these rights can be found in the Florida Statutes: Life-Prolonging Procedure Act, Chapter 765; Health Care Surrogate Act, Chapter 765; Durable Power of Attorney, Section 709.08; and Court Appointed Guardianship, Chapter 744; and in the Florida Supreme Court decision on the constitutional right of privacy; GUARDIANSHIP OF ESTELLE BROWNING, 1990.

## **PATIENT RIGHTS AND RESPONSIBILITIES**

Patients have the right to be informed of their rights and obligations before hospice care begins. Consistent with Florida law, patient's family/representative may exercise the patient's rights when the patient is unable to do so. Suncoast Hospice wishes to protect and promote the rights of their patients.

### **AS A SUNCOAST HOSPICE PATIENT YOU HAVE THE RIGHT TO:**

- exercise your rights as a patient of Suncoast Hospice;
- have your property and person treated with respect;



- voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for your property by anyone who is furnishing services on behalf of Suncoast Hospice;
- exercise your rights without being subjected to discrimination or reprisal;
- receive effective pain management and symptom control from Suncoast Hospice for conditions related to your hospice diagnosis;
- be involved in developing your hospice plan of care;
- refuse care or treatment;
- choose your attending physician;
- have a confidential clinical record; access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164;
- be free from mistreatment, neglect or verbal, mental, sexual, and physical abuse including injuries of unknown source and misappropriation of patient property;
- receive information about the services covered under your hospice benefit;
- receive information about the scope of services that Suncoast Hospice will provide and specific limitations on those services.

### **QUESTIONS/CONCERNS:**

Please tell us right away if you are not pleased with your care or wish to recommend changes in your plan of care. You may discuss questions/concerns with your nurse or social worker, or you may phone Suncoast Hospice at (727) 467-7423. To report neglect or exploitation, you may phone the State toll-free ABUSE line at 1 (800) 96-ABUSE (1-800-962-2873).

### **PATIENT/FAMILY RESPONSIBILITIES INCLUDE:**

- provide an accurate medical history
- select a physician and remain under medical care
- provide accurate insurance/financial information and notify Suncoast Hospice of any changes in coverage
- notify Suncoast Hospice of all other care received with health care providers (hospital, physicians, etc.) to assure coordination of care
- notify Suncoast Hospice staff if you wish to cancel services or if you will be unavailable for scheduled visits
- inform staff about changes in your health status, medications, treatments and/or advance directives
- inform staff if you are unable to secure medications, equipment or supplies ordered for your care/treatment
- notify Suncoast Hospice staff if you are displeased with your care

## **MEDICARE HOSPICE BENEFITS**

*A special way of caring for people who are seriously ill*

### **HOW DO I CLAIM MY HOSPICE MEDICARE BENEFITS?**

Your hospice benefit is provided under Part A (hospital insurance). To receive hospice care in connection with your Medicare benefits:

- Your physician and your hospice's medical director certify that you have a serious, life-limiting illness and have six months or less to live if your illness runs its normal course



- You sign a statement indicating that you choose to have hospice care instead of other Medicare covered benefits to treat your terminal illness
- Your care is provided by a Medicare approved hospice program, such as Suncoast Hospice.
- Medicare will still pay for covered benefits for any health problems that are not related to your hospice diagnosis.

## WHAT SERVICES WILL I RECEIVE WITH THE HOSPICE MEDICARE BENEFIT?

Your doctor and the hospice interdisciplinary team will work with you and your family to set up a plan of care that meets your needs. Your plan of care includes hospice services that are covered by Medicare. For more specific information on a hospice plan of care, call your state or the National Hospice and Palliative Care Organization (NHPCO – 1-800-658-8898). When you qualify for hospice care you will have a specially-trained hospice team and support staff available to help you and your family cope with your illness. A wide variety of services are covered by the hospice Medicare benefit. Most costs are paid for under the benefit. You may expect to receive the following when included in your plan of care:

- Doctor's visits when necessary
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Medication that controls symptoms/relieves pain
- Short-term inpatient care when necessary
- Home health aides and homemaker services
- Physical and occupational therapy
- Speech therapy
- Social work, counseling and pastoral care
- Dietary counseling
- Specially-trained hospice volunteers
- Grief and loss counseling for you and your family

You will only have to pay part of the cost of outpatient drugs and inpatient respite care if routinely billed by your hospice.

### What is respite care?

Respite care allows a patient's caregiver time to get some rest while someone else assumes the role of caregiver. As a hospice patient, you may have one person who takes care of you each day, perhaps a family member. But occasionally your caregiver might need to tend to things that need to be done or just get some rest. During a period of respite care, you will be looked after in a Medicare approved center, such as a hospital or nursing home.

## WHAT IS NOT COVERED UNDER THE HOSPICE MEDICARE BENEFIT?

**When you choose hospice care, it is important for you to know that Medicare will not cover any of the following under the hospice benefit:**

- **Treatment intended to cure your serious, life-limiting illness.** You should talk with your doctor if you are thinking about getting treatment to cure your illness. As a hospice patient, you always have the right to stop hospice care at any time and get the Medicare coverage you had before you chose hospice care.

- **Prescription drugs to cure your illness rather than for symptom control or pain relief**
- **Care from any hospice provider that was not set up by the hospice team.** You must get hospice care from the hospice provider you chose. All care that you get for your hospice diagnosis must be given by or arranged by the hospice team. You cannot get the same type of hospice care from a different provider, unless you change your hospice provider.
- **Room and board are not covered by Medicare** if you get hospice care in your home or if you live in a nursing home or a hospice residential facility. However, if the hospice team determines that you need short-term inpatient care or respite services that they arrange, your stay in the facility is covered. You may be required to pay a small co-payment for the respite care.
- **Care in an emergency room, inpatient facility care, or ambulance transportation, unless it's either arranged by your hospice team or is unrelated to your hospice diagnosis.**

## WHAT YOU PAY FOR HOSPICE CARE

**Medicare pays the hospice provider for your hospice care. You may be asked to pay the following:**

- No more than \$5 for each prescription drug and other similar products for pain relief and symptom control.
- Five percent of the Medicare approved amount for inpatient respite care. For example, if Medicare pays \$100 per day for inpatient respite care, you may pay \$5 per day.

## HOSPICE CARE IF YOU ARE IN A MEDICARE ADVANTAGE PLAN

All Medicare-covered services you get while in hospice care are covered under the Original Medicare Plan, even if you are in a Medicare Advantage Plan (like an HMO or PPO) or other Medicare Health Plan. However, your plan will continue to cover you for any extra services not covered by the Original Medicare Plan (like dental and vision benefits). If you choose to stay in your Medicare Advantage Plan while getting hospice care, you must continue to pay your plan's monthly premium.

## CARE FOR A CONDITION OTHER THAN YOUR HOSPICE DIAGNOSIS

You should continue to use the Original Medicare Plan to get care for any health problems that are not related to your hospice diagnosis. The hospice team determines whether any other medical care you need is or is not related to your hospice diagnosis so it will not affect your care under the hospice benefit. You must pay the deductible and coinsurance amounts for all Medicare-covered services. You must also continue to pay Medicare premiums, if necessary.

For more information about the Original Medicare Plan, Medicare Advantage Plans, Medigap and other Medicare Health Plans, look in your copy of the "Medicare and You" handbook mailed to every Medicare household in the fall. If you do not have the "Medicare and You" handbook, you can visit [www.medicare.gov](http://www.medicare.gov) on the Web. You may also get a free copy by calling 1-800-Medicare.

## FOR MORE INFORMATION ON THE HOSPICE MEDICARE BENEFIT:

1. Call national hospice associations or visit their websites.
  - National Hospice and Palliative Care Organization (NHPCO)  
1731 King Street  
Alexandria, VA 22314 1-800-658-8898  
[www.nhpco.org](http://www.nhpco.org)

- Hospice Association of America  
228 7th Street, SE  
Washington, DC 2003 1-202-546-4759  
[www.nahc.org](http://www.nahc.org)

2. Visit [www.medicare.gov](http://www.medicare.gov) on the web.

- Call 1-800-MEDICARE (1-800-633-4227)  
TTY users should call 1-877-486-2048

Note: At the time of printing, these telephone numbers and web addresses were correct. Telephone numbers sometimes change. To get the most updated telephone numbers, call 1-800-633-4227. TTY users should call 1-877-486-2048. Or, visit [www.medicare.gov](http://www.medicare.gov) on the Web. Under "search tools" select "find helpful telephone numbers."

Notes:

---

---

---

---

---

---

---

---

---

## Family/Caregiver Instructions for Medication Disposal

Suncoast Hospice staff will assist you directly with the disposal of unneeded medications. In the event additional medication is discovered at a later time, please dispose using the following options:

**Preferred Option: Bring all found medications to a drop-off location in Pinellas County or use a mail-back medication disposal bag purchased at your local pharmacy. Several drop-off locations can be found below:**

- Pinellas Sheriff's Office <https://www.pcsoweb.com/operation-medicine-cabinet>
- Walgreens <https://www.walgreens.com/topic/pharmacy/safe-medication-disposal.jsp>
- CVS <https://www.cvs.com/content/safer-communities-locate>

**Alternate Option: Dispose of your medications at home following the instructions below:**

1. Separate out the medications listed below. These should be immediately flushed down the toilet when no longer needed and a take-back option is not readily available. These medicines may be especially harmful and, in some cases, fatal with just one dose.

Active Ingredient	Found in Brand Name
<b>Buprenorphine</b>	Belbuca, Bunavail, Butrans, Cassipa, Suboxone, Subutex, Zubsolv
<b>Fentanyl*</b>	Abstral, Actiq, Duragesic (patch), Fentora, Onsolis
<b>Diazepam</b>	Diastat/Diastat AcuDial rectal gel
<b>Hydrocodone</b>	Anexsia, Hysingla ER, Lortab, Norco, Repraxin, Vicodin, Vicoprofen, Zohydro ER
<b>Hydromorphone</b>	Dilaudid, Exalgo
<b>Methadone</b>	Dolophine, Methadose
<b>Methylphenidate</b>	Daytrana transdermal patch system, Ritalin
<b>Morphine</b>	Arymo ER, Avinza, Embeda, Kadian, Morphabond ER, MS Contin, Roxanol
<b>Oxycodone</b>	OxyContin, Percocet, Percodan, Roxicet, Roxicodone, Targiniq ER, Xartemis XR, Xtampza ER, Roxybond
<b>Oxymorphone</b>	Opana, Opana ER
<b>Tapentadol</b>	Nucynta, Nucynta ER

- \* Fentanyl patches should be handled with gloves and never touched after opened with a bare hand. They should be cut and then flushed down the toilet.
2. Any medications not listed above should be poured from the original containers into a sealable plastic storage bag.
    - a. Remove or mark through any personal information on the now empty containers and throw away in the trash.
    - b. Add kitty litter, coffee grounds or flour to the bag with the medication.
    - c. Add a small amount of water to the bag
    - d. Throw away the bag into the trash. Do not place in the recycle bin.

**Please call Suncoast Hospice with any questions (727) 467-7423.**

## **What's Important?**

We are frequently asked, "What do I do now?" There is no right or wrong. Focusing on those things that are most important to you can make this time more meaningful. It seems simple but this big picture can so easily get lost in the practicalities and strains of living with an illness.

What matters right now? You may want to spend more time with friends or family or take a trip or celebrate a special occasion. You may feel the need to get the details of living in order, to take care of business, to set things straight.

Take a moment to write down the things that are important to you. Is there something weighing on your mind or heart? Use your list to guide you and your hospice team in making the most of each day.

### **What is important to you?**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Is anything keeping you from doing what is most important to you? If so, what is it?

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

Consider sharing your answers with the people closest to you and with your hospice team members. They want to help you achieve your goals.

## **Practical Matters**

Are you concerned about having things in order? You may be wondering where to start. The following list can be used as a worksheet to help locate important items and keep track of them. It may help to keep these documents in one place.

Things to Find	Check When Found	Location of the Information
Planning and Advance Directives:		
Living will (Documents indicating wishes regarding end-of-life care)		
Health care surrogate (designated person to make health care decisions when you can no longer make your own)		
Power of attorney (Legal document indicating who is able to make financial decisions on behalf of another person)		
Memorial, funeral, or other arrangements (arrangements for final resting place and service)		

Identification:		
Birth certificate (Provides accurate record of date of birth, maiden name, parents information, etc. Helpful to write obituary.)		
Social Security number (needed for death benefits)		
Passport, immigration and naturalization certificate		
Marriage license (divorce certificate if applicable)		
Guardianship papers (Legal document indicating who has been given the right to make decisions for a person who cannot make decisions for him or herself)		

Things to Find	Check When Found	Location of the Information
Insurance policies: health, accident, disability, life		
VA claim number or honorable discharge certificate (Important for getting death benefits)		
Affiliations		
Social or religious (Clubs, Lodges, church, Hall, Mosque, Synagogue etc)		
Spouse(s), children, family members, clergy, friends employer or business colleagues (list their names, phone number and address)		
Education and military records		

Things to Find	Check When Found	Location of the Information
Assets/Debts		
Banking: checking accounts, money market accounts, savings accounts, IRAs, CDs (certificate of deposit), others?		
Annuities, mutual fund shares, stocks, bonds, others?		
Safe deposit box (location of box and key)		
Last will and testament and lawyer's/executor's name, phone number and address		
Loans: credit cards, installment payments (list where to send payments, amount of payment, for how long, and when payments are due), others?		
Income: insurance policies, trusts and benefits (life, casualty, death benefits, military, Social Security, credit union, 401 (k) plan, monies received via wills/trusts, etc.), others?		
Income tax records- (federal, state, local)		

Real Estate		
Mortgages or rent information (debts on home, office, apartments, condominiums, businesses), others?		
Location of family treasures, jewelry, other items?		
Certificate of ownership for property, cars, boats, etc. and keys for these items		
Insurance policies (flood, real estate)		
Certificate of ownership, contract for cemetery plot		
Bills: utilities, phone, cable TV, internet services, taxes, etc.		

Notes:

[illegible]



# Frequently Asked Questions

- 2-1 What to Expect
- 2-2 Children and Families
- 2-2 Medications
- 2-3 Honoring Veterans
- 2-3 Organ and Tissue Donation
- 2-3 As Care Needs Change
- 2-3 Suncoast Hospice Care Centers
- 2-6 Grief Support
- 2-6 Reimbursement
- 2-6 Medicare and Medicaid
- 2-8 Reporting Concerns
- 2-8 Thanking Your Team



## Section 2 Frequently Asked Questions

### **What to Expect**

#### **What kind of care should I expect from Suncoast Hospice?**

Whether you are experiencing a serious illness or caring for someone who is, you may expect to be treated with dignity and respect. Every effort will be made to:

- Ease pain and discomfort
- Provide emotional and spiritual support
- Partner with your doctors to provide care planned specifically for you
- Assist you in achieving your personal goals
- Honor your choices

#### **May I keep my own physician?**

Yes. You do not need to leave the care of your own physician to receive care from Suncoast Hospice. Your hospice care team works in partnership with your physician and other health care providers.

If for some reason your physician is unable to continue providing your care, a Suncoast Hospice physician who specializes in palliative (comfort) care is available to visit you and consult with your care team if you so choose.

#### **What does “palliative” mean?**

The word palliative is used to describe care that is focused on comfort rather than on cure. It is about:

- Enhancing quality of life
- Preventing and relieving pain and other symptoms
- Promoting peaceful life closure

#### **What if I need special equipment, such as a wheelchair or electric bed?**

Medical equipment and disposable medical supplies are available to you through your care team and can be delivered directly to your home. Talk with your care team members about what would be helpful. They will be able to explain what is available and how any costs will be handled.

#### **Does Suncoast Hospice provide care in hospitals, assisted living and nursing facilities?**

Yes, Suncoast Hospice works in partnership with most Pinellas hospitals, assisted living and nursing facilities. Talk with your care team whenever you have concerns about where you will receive care or the kinds of care you need.

#### **How do I choose the kinds of care I want to receive?**

From the time of your first visit with your Suncoast Hospice team, your choices will guide your care. Hospice care is meant to support your well-being as a whole person. As your needs or priorities change, you may find that your choices about your care change as well. We respect your choices and will do our best to provide personalized care that works for you.

**Will I always have the same team?**

While under the care of Suncoast Hospice the identifying color of your team may change. Be assured your care will not be interrupted. Suncoast Hospice staff will continue to meet your care needs.

**Does Suncoast Hospice provide 24-hour care?**

You have access to skilled, knowledgeable Suncoast Hospice staff 24 hours a day, 7 days a week by calling (727) 467-7423. Nurses, counselors or social workers, spiritual care coordinators and volunteers are available to respond to your needs whenever you call.

Regular visits by your care team are meant to assist you in caring for yourself and your loved one. Under certain circumstances, such as uncontrolled symptoms or a sudden change in condition, you may receive longer visits from additional team members. Talk with your care team about how we can best serve you.

**Children and Families****What services are available to support children, teens and families?**

A variety of services organized specifically for children, teens and their families are offered through Suncoast Hospice's family of programs. Support is available from the time of diagnosis, throughout an illness and during the grieving process. Support groups and weekend retreats that combine fun and emotional healing are available as well. For more information, ask your care team or call (727) 467-7423 and ask for the community counseling department.

**Medications****How will I receive my medications?**

When you are admitted to our care, the nurse will talk with you about which pharmacy or pharmacies you will be using for your medications. Your hospice nurse will contact your physician for new prescriptions as needed. Please let your hospice nurse know when your medication supply gets low.

If you are using the Suncoast Hospice Pharmacy, the pharmacy team will work with you, your nurse and your physician to make sure your needs are met. The pharmacy staff and volunteers care about your safety and are pleased to be part of your care team. All of your prescriptions filled at the Suncoast Hospice pharmacy will be delivered to your home. Before delivering medications, a pharmacy representative will call you to arrange an acceptable time. Please let your nurse or our pharmacy representative know if you want to request any special days and/or times for deliveries. We will do our very best to honor your requests.

When using any pharmacy, please take a moment to look over your medications carefully when a prescription is filled. Check to make sure your name is on each medication container. Contact your Suncoast Hospice nurse if you have any questions about any medication's appearance, purpose or directions for use.

**How should I dispose of unused medications?**

See **"Your Documents"** section of this guide for specific instruction regarding medication disposal. Talk to your care team before disposing of any medication. The proper disposal of medications is extremely important for health and safety reasons.

Your care team will assist you to make sure medications are disposed of properly and safely. If the medications you receive are no longer needed or you move from your private home to a facility, all Suncoast Hospice-provided prescription medications should be destroyed and recorded as disposed of with the assistance of your hospice nurse or other hospice team member. A family member may be asked to witness the disposal of certain medications. If you are a patient being cared for in a Suncoast Care Center or other facility, any medications you no longer need will be disposed of according to that facility's policies. Nurses and other healthcare workers are not allowed to transport medication in their vehicles.

## **Honoring Veterans**

### **How does Suncoast Hospice honor the service of military veterans?**

If you have served in the military, Suncoast Hospice recognizes the contributions and sacrifices you and your family have made. Please tell your care team about your service in the military. Available are:

- **Veterans Serving Veterans** – specially trained Suncoast Hospice volunteers who are military veterans are paired with veterans receiving hospice care
- **Military Service Recognition Ceremonies** – veterans receive certificates of appreciation for their service and specially-crafted pins from The Hospice-Veteran Partnership of Florida
- **Lifetime Legacies** – available to all Suncoast Hospice patients and families, Lifetime Legacies can assist veterans in creating a written, video or audio legacy as an opportunity for reflection and as a keepsake for future generations
- **Partnerships with VA medical centers** and other veterans service organizations

## **Organ and Tissue Donation**

### **Am I able to choose to be an organ or tissue donor?**

Everyone is a potential donor of tissue or organs, based on your physical condition, for either transplant, research or education. Regenerative Biologics, Inc., is a resource that Suncoast Hospice staff can utilize to help answer questions you may have about your options or you can contact them directly at 1-866-432-1164 or at [www.donorcare.org](http://www.donorcare.org).

## **As Care Needs Change**

### **What if my care needs change?**

Please be assured that Suncoast Hospice is your partner in care and will work with you, your family and your physician to provide the right care at the right time. The following information will help you better understand some of the options available and help make those transitions go smoothly.

## **Suncoast Hospice Care Centers**

Consistent with Suncoast Hospice's mission, the staff and volunteers at the Care Centers combine excellent skilled care with compassion and a commitment to honor the hopes, wishes and needs of the patients and their loved ones. For patients who need focused skill and attention for management of pain or other symptoms, a short stay in a Care Center may prevent an unwanted hospitalization. For more information about Suncoast Care Centers, ask your care team or view the virtual tour(s) on our website [SuncoastHospice.org](http://SuncoastHospice.org).

### Things I should know about the Care Center.

- Transportation will be coordinated by your Suncoast Hospice care team.
- Items to bring with you to the Care Center include:
  - o DNRO (Do Not Resuscitate Order) if applicable
  - o Special personal toiletries of choice (soap, lotion, deodorant)
- Items not to bring with you to the Care Center include:
  - o Suncoast Hospice medical equipment
  - o Valuable items (electronic devices, jewelry) medications
- Medication, medical equipment and supplies will be provided at the Care Center during your stay.
- If this stay results in changes in your financial responsibility due to stabilization of symptoms, your care team will discuss those changes with you.

### What happens when I'm ready to return home from the Care Center?

The Care Center team will assist you to make the transition as smooth as possible. The Care Center staff will provide a current medication list including instructions for taking your medication. Any medical equipment needed at home will be ordered for you. There will need to be someone in the home to receive the delivery of equipment and medications. The Suncoast Hospice Care Team will continue to support you at home and will coordinate care team visits with you.

### Crisis Care?

Crisis Care is short-term care focused on alleviating uncontrollable pain and symptoms. If there comes a time when your medical needs temporarily require an increase in focused care, skill and attention, your hospice care team will talk with you about the possibility of providing crisis care staffing in your home or care facility. Crisis care is care provided for only brief periods of time to provide additional support to reduce uncontrolled discomfort and symptoms.

#### What if my symptoms cannot be managed at home?

Please notify your Suncoast Hospice care team when symptoms occur which you believe might need immediate attention.

- Call the Suncoast Hospice switchboard at (727) 467-7423. Give your name and your team color. The Care Team will contact you to assess your symptoms and make recommendations for care.

#### What if I need to go to the hospital?

Please notify your Suncoast Hospice care team as early as possible when symptoms occur which you believe you might need to go to the hospital.

- Call the Suncoast Hospice switchboard at (727) 467-7423. Give your name and your team color.
- Your Suncoast Hospice team will contact you to assess your needs and offer choices **such as the Suncoast Hospice Care Center**. If hospitalization is necessary, your team will notify your physician.
- Your team will discuss and/or coordinate transportation if necessary.
- Items to bring with you to the hospital or Care Center include:
  - o DNRO
  - o Updated medication list

- Items to not bring with you to the hospital or Care Center include:
  - o Medical equipment
  - o Valuable items
- Upon arrival at the hospital, please be sure to tell the hospital staff that you are a Suncoast Hospice patient.
- During your stay at the hospital, a representative of Suncoast Hospice will visit, provide support and work with hospital staff. Your Suncoast Hospice representative will also work with the hospital staff to plan for your discharge from the hospital.
- Changes in your financial responsibilities will be discussed with you by the Suncoast Hospice representative and/or hospital staff.

### **What if I need to receive care in a nursing home?**

Your Suncoast Hospice team will work in partnership with you and the facility to coordinate your care.

- Items to bring with you to the nursing home include:
  - o DNRO
  - o Updated medication list
  - o Clothes and toiletries
- Items to not bring with you to the nursing home include:
  - o Medications
  - o Suncoast Hospice medical equipment
  - o Valuable personal items
- Suncoast Hospice will coordinate with the facility to provide equipment and supplies.
- Suncoast Hospice team members will continue to visit and be involved in your care.
- Your Suncoast Hospice care team will discuss any changes in financial responsibility, including transportation costs.

### **What happens when I'm ready to return home from a nursing home or hospital?**

We want to work with you to make the transition as smooth as possible.

- Please notify your Suncoast Hospice care team when you anticipate discharge to home by calling (727) 467-7423. The facility discharge planner and staff, along with your Suncoast Hospice care team, will coordinate transportation.
- Request your original DNRO back from the facility.
- Obtain a copy of your discharge orders.
- Discuss additional medical equipment needs with your Suncoast Hospice representative.
- Expect contact from your care team within 24 hours of hospital discharge.
- Your Suncoast Hospice team will arrange for any medications and medical equipment that are related to your hospice diagnosis to be provided at home.
- Your Suncoast Hospice care team will let you know of prescriptions you will need to have filled at your pharmacy of choice.
- Please notify your team when you arrive at home by calling (727) 467-7423.

### **What happens if I no longer need hospice care?**

When illness stabilizes or improves, some patients no longer require traditional hospice care services. If this becomes true for you, a Suncoast Hospice team member will help you explore other care options that may be available to assist you.

## **Does Suncoast Hospice make funeral arrangements?**

While Suncoast Hospice does not make such arrangements, your care team can assist you in locating the information you need to make such decisions and will support you in the choices that feel right to you.

In the Your Decisions section of this book, you will find more information about making funeral plans. A spiritual care coordinator, social worker or counselor with your care team is available to help as you sort through options and make decisions.

## **Grief Support**

### **What kind of care does Suncoast Hospice offer to help me while I am grieving?**

Hospice care continues for surviving family members, friends and caregivers as they adjust to life after the death of a loved one. The kinds of grief support Suncoast Hospice provides and how long Suncoast Hospice remains involved will depend on what feels most comfortable to you. Someone from our hospice will check in with you periodically to offer information and support. You will also receive information about support groups which can help you cope with the changes that come with grieving. Different types of groups are available to meet particular needs. Ask a member of your care team or call The Center for Loss and Healing at (727) 467-7423 anytime for more information about grief services.

## **Reimbursement**

### **How is Suncoast Hospice reimbursed?**

There are many ways Suncoast Hospice care is paid for. It is important to know that no person in Pinellas County who needs hospice care is turned away from Suncoast Hospice. Medicare and Medicaid along with most major insurance companies and managed care providers offer coverage for hospice services. People may also pay out of pocket for services to the extent that they are able. Through the generous financial support of this community, your not-for-profit Suncoast Hospice offers care to all regardless of their ability to pay.

If at any time you have questions about billing, payments, or reimbursement, please do not hesitate to ask your care team.

## **Medicare and Medicaid**

### **What are the Hospice Medicare and Hospice Medicaid benefits?**

The Hospice Medicare benefit is a federal benefit that helps to pay for eligible hospice care and services. The Hospice Medicaid benefit is a state and federal partnership that helps to pay for eligible hospice care and services.

### **How do I know if I have Hospice Medicare and/or Medicaid?**

Everyone who is eligible for traditional Medicare and/or Medicaid is eligible for the Hospice Medicare and/or Medicaid benefit if they meet certain end-stage disease-related conditions.

You or your designated person must sign an election form to start using your Hospice Medicare and/or Medicaid benefit. Neither can be started without your permission.



## **May I have both Hospice Medicare and/or Medicaid and Traditional Medicare and/or Medicaid?**

Your Hospice Medicare and/or Medicaid benefit only covers those services, hospitalizations, equipment, treatments and medications that are related to your end-stage disease diagnosis. Your traditional benefit continues to cover your other healthcare needs as it did prior to your admission to hospice.

## **How will a hospital or doctor know which type of Medicare or Medicaid to bill?**

This is where we need your help. It is very important that your Suncoast Hospice care team is notified as soon as you do anything new that affects your care. With timely and correct information, we can communicate with you and your health care providers to ensure that you have optimal access to your Medicare or Medicaid benefits. If you go to the hospital, to a new doctor, to a nursing home, or plan to start a new treatment, it's very important that you let your team know right away.

## **What are my responsibilities as a Medicare or Medicaid beneficiary?**

At Suncoast Hospice, we are committed to coordinating your care in the best manner possible to ensure that your needs are met with compassion and excellence and in a timely manner. In order for us to do that, we need your help.

***It is your responsibility to notify Suncoast Hospice any time you go to the hospital, plan for or receive a new treatment, change your location of care, or consult a new health care practitioner.***

Including your care team in the planning process will help us better meet your needs and ensure that you have the fullest spectrum of Medicare or Medicaid benefits available to you.

## **What if I go to the hospital or receive treatments without letting Suncoast Hospice know?**

Our commitment to your care includes being committed to using the Hospice Medicare/Medicaid benefit according to laws and regulations. Therefore, it is possible that we may not be able to cover the cost of services that you receive without our knowledge or involvement.

If anything new happens with your care, call your Suncoast Hospice care team. We are grateful for the opportunity to be a partner in your care.

## **What if my hospice care is paid for by another source?**

It's still very important that your Suncoast Hospice care team is informed and involved in every aspect of your care. Your team wants to support you in accessing and coordinating the care that feels right to you.

## **How can I learn more about how the Hospice Medicare and Medicaid benefits work?**

Start by asking your Suncoast Hospice care team. Your social worker or counselor is familiar with how reimbursement for hospice care works and can help you find the information you need. Periodically, the Center for Medicare and Medicaid Services sends beneficiaries a statement called a Medicare Summary Notice. This notice provides a snapshot of Medicare's reimbursement for hospice services for a specific period of time. It is not a bill. If you receive a Medicare Summary Notice and have any questions, your care team will be happy to review it with you.

You can also contact Medicare directly by calling 1-800-MEDICARE. For more information about Medicaid, contact the Pinellas Area Medicaid Office at 727-552-1191, extension 276.



## **Reporting Concerns**

### **What do I do if I have a concern or am unsatisfied with my care?**

Providing our patients and families with the best possible care is a top priority. If you have any concerns about the care you received, please speak with your nurse or call (727) 467-7423 and ask for one of the Patient Advocates in our Quality Department. They will be most willing to assist you.

If you are still not satisfied that your concerns have been addressed, you may contact Florida Agency for Healthcare Regulation (AHCA), or The Joint Commission, as both agencies oversee the quality of care administered by licensed healthcare agencies.

- AHCA can be contacted by calling (888) 419-3456/(800) 955-8771 (Florida Relay Service TDD number), emailed at CAU@AHCA.MyFlorida.com or at their website AHCA.MyFlorida.com/Contact and completing their Healthcare Facility Complaint online form. Their mailing address is: Agency for Health Care Administration; 2727 Mahan Drive, Tallahassee, FL 32308.
- The Joint Commission can be contacted by calling (800) 994-6610 or at their website: JointCommission.org and scrolling down to "Submit a New Safety Event." Their mailing address is: The Joint Commission, Office of Quality and Patient Safety; One Renaissance Blvd, Oakbrook Terrace, IL 60181.

## **Thanking Your Team**

### **How can I say thank you to my care team?**

We consider it an honor and privilege to be of service to you. If you are pleased with the care you have received, please consider:

- **Telling** those who have made a difference that you appreciate their care.
- **Writing** a note directly to those you wish to thank or sending it to your care team coordinator.
- **Talking** with your friends about Suncoast Hospice so they will feel more comfortable and confident if they need care in the future.
- **Making a donation.** Suncoast Hospice is a not-for-profit organization and welcomes financial contributions, all of which support its many programs and services. Donations of clothing, household items and furniture may be made to Suncoast Hospice Resale Shoppes. Suncoast Hospice Community Lending Libraries gratefully accept books and other publications.
- **Becoming a volunteer.** There are many opportunities to support Suncoast Hospice by assisting patients and families, helping out in offices or resale shops and more.

***What questions do you have? Please call us at (727) 467-7423 anytime. We will gladly answer your questions.***



# Your Team & Volunteers

3-1 Your Hospice

3-1 Your Care Team

3-2 Your Volunteers

3-3 Making Memories

3-3 Personalized Care



## Section 3 Your Team & Volunteers

### **Your Hospice**

Suncoast Hospice is your not-for-profit community hospice. As a patient, family member, friend or caregiver, your concerns and preferences will guide your care plans.

Care from Suncoast Hospice is...

- accessible at any time – 24 hours a day, 7 days a week.
- aggressive in preventing and managing pain and symptoms.
- committed to your physical, emotional and spiritual well-being.
- focused on helping you live your way.

### **Your Care Team**

Suncoast Hospice services are provided by care teams. Because illness affects much more than physical health alone, care teams are made up of people with different kinds of training and skills. Members of your team will visit regularly. Together you will decide who visits and how often. All of the members of your team share responsibility for providing care of the highest quality.

#### **Your care team includes:**

- You – and your family, friends and caregivers – are the center of your care team.
- Your physicians are valued members of your Suncoast Hospice care team. Your care team will actively work with your primary and/or consulting physicians to provide treatment options, prevent complications, manage pain and symptoms and monitor changes related to the illness. In addition, Suncoast Hospice physicians are also available to visit you and consult with your doctors about your plan of care.
- Your nurse will focus on providing skilled care and support related to your physical condition, level of comfort and learning needs. Your nurse will perform physical assessments, ask for your input on planned treatments and medication changes, communicate with your physician and help you find answers to your questions. Your nurse is an excellent source of information about medications, treatments, disease processes, equipment use, hands-on care and other topics of concern.
- Your counselor or social worker is dedicated to helping you deal with the many ways that illness affects your life. Counselors and social workers can assist you with accessing community resources, making decisions, discussing difficult topics, finding emotional support and coping with loss. They strive to help you, family members, friends, or caregivers do the things that are important to you now.
- Your aides make your personal care and comfort their highest priorities. Their care may include grooming, bathing, mouth care, skin care, and repositioning. Visits with your aide may also be a good time for a walk, wheelchair ride outside or other activity that is difficult without assistance. Aides are valuable sources of practical information and encouragement.
- Your spiritual care coordinator is available to offer spiritual support in any way that is comfortable for you whether or not you practice any particular faith or religion. Your spiritual care coordinator's care is non-judgmental and focuses on your personal concerns or requests. The spiritual care provided by a spiritual care coordinator may include assistance in thinking through decisions, support in healing relationships, offering prayers, performing requested rites or rituals, and assisting in planning and providing memorial services. If you are a member of a congregation or have your own clergy, your hospice spiritual care coordinator is available to work with whomever you choose to meet your needs.

- Your volunteers are specially trained to provide assistance and support in many ways. From companionship to transportation to running errands, their roles are guided by your needs. You can ask for a volunteer by talking with any member of your care team. Please see How Volunteers Might Help later in this section for more ideas.
- Your overnight and weekend care teams ensure that you have access to skilled, knowledgeable Suncoast Hospice staff 24 hours a day, 7 days a week. Any time you call, there is a nurse, counselor or social worker, spiritual care coordinator and volunteer coordinator available to respond.
- Specialized team members are also available to meet your particular needs.
  - Registered Dietitians work collaboratively with the team to make nutrition, hydration, and feeding recommendations consistent with the patient's plan of care.
  - Child and Family Support Program counselors and social workers specialize in meeting the needs of children, teens and families during times of illness and grief. They offer counseling and support in homes and at school.
  - Equipment specialists deliver assistive devices such as wheelchairs and oxygen tanks, and offer information to promote safe use.
  - Pharmacists work with you and the rest of your team to skillfully manage your medications. Knowledgeable and experienced in controlling pain and other symptoms, they are committed to giving you the best care.
  - Physical and occupational therapists offer information, exercises and equipment that promote safety, independence, and mobility.
  - Respiratory therapists provide treatments, exercises, and teaching that promote comfort for people with respiratory symptoms.
  - Speech Language Pathologists work corroboratively in the areas of communication, chewing, and swallowing function consistent with the patient's plan of care.

As your situation changes, you may find that your needs for different members of your care team change as well. If you have any questions, ask your team or call (727) 467-7423 anytime and ask to speak with your care team coordinator.

## **Your Volunteers**

Volunteers can be a great source of assistance and support. They are the history and heart of hospice care. Suncoast Hospice's volunteers are a group of highly trained, motivated, caring individuals with a broad range of life experience. Many have been touched by personal experiences with illness and caregiving.

### **Volunteers are:**

- Committed to maintaining your privacy.
- Respectful of your choices.

### **What Can Volunteers Do?**

The beauty of care provided by Suncoast Hospice's volunteers is their dedication to finding ways to enrich your quality of life. The list of possibilities expands constantly as new volunteers offer their talents and skills. Could a volunteer be helpful to you?

- Companionship – friendly conversation or a listening ear
- Time with patients so caregivers can rest or go out for a while

- Transportation for errands, appointments, worship services or other outings
- Letter writing or journaling
- Help with small jobs around the house
- Assistance with hobbies or crafts
- Help with organizing paperwork, bills to be paid or balancing a checkbook
- Grocery shopping
- Light housekeeping
- Assist with preparing a meal
- Deliver small treats like a favorite ice cream
- Care for a pet or walk your dog
- Watch TV with you – bring videos or DVDs to watch
- Record you or your family's story on tape or video
- Play music for you
- Record audio tapes to send to family and friends
- Play games – checkers, cards, puzzles
- Bring a pet to visit
- Celebrate special occasions
- Create photo memory albums
- Write down your special stories or memories
- Share camaraderie veteran-to-veteran
- Fill your special request – tell us what would bring peace, comfort or joy to your life

Each team has a volunteer coordinator who specializes in matching volunteers to your requests. Simply ask your care team or call (727) 467-7423 to request volunteers.

### **Making Memories**

If you would like a chance to record your family history, your most cherished memories or special words of wisdom, volunteers are ready to help. Through Lifetime Legacies, specially trained high school age volunteers under the direction of Suncoast Hospice staff will work with you to create your personal legacy. You choose to record your story in a video, written journal, or photo memory album and they make it happen. If you would like family and friends to participate, they are welcome. If you are interested or would like more information, please tell your care team.

### **Personalized Care**

You are the leader of your care team. The knowledge, experience and compassion of your Suncoast Hospice staff and volunteers help you live your life your way and make the choices that feel right to you. Call anytime. (727) 467-7423.

# Your Comfort

- 4-1 Pain
- 4-3 Pain Medications
- 4-5 Weakness and Fatigue
- 4-6 Constipation
- 4-7 Shortness of Breath
- 4-8 Nausea and Vomiting
- 4-10 Promoting Comfort
- 4-14 Your Comfort Journal



## Section 4 Your Comfort

### Managing Pain and Other Symptoms

Your comfort is our priority. There are many ways to prevent and manage symptoms effectively. In this section you will find information about:

- Pain
- Weakness and fatigue
- Constipation
- Shortness of breath
- Nausea and vomiting

You will also find information about medical and non-medical ways to relieve distress and promote comfort. Your care team is always available to help. Call anytime. (727) 467-7423.

### Pain

Physical pain affects people in many ways. Does pain keep you from being active, sleeping well, enjoying family and friends, or from eating? Pain can also trigger or intensify feelings like sadness, helplessness, fear, or anger. If you are in pain, please talk with your care team. Tell them how it is affecting your life and what you hope for in treating it.

***Remember, pain can be controlled.***

#### Facts about Pain Treatment

Many people have questions and concerns about pain and its treatment. Here are some facts that may answer your questions.

***Concern: If I complain too much, I am not being a good patient.***

**Fact:** Controlling your pain is an important part of your care. Tell your nurse or another member of your care team if you have pain, if your pain is getting worse, or if you are taking pain medicine and it is not working. They can help you get relief.

***Concern: I will become “hooked on” or “addicted to” pain medicine.***

**Fact:** When a person has pain, the body uses medication differently than if he or she were taking the drug to get high. Remember, it is important to take pain medicine regularly to keep pain under control. Studies show that getting hooked on or addicted to needed pain medicine is rare.

***Concern: If I take too much medicine or if I take it too early, it won't work if my pain gets really bad.***

**Fact:** The medicine will not stop working, but sometimes your body will get used to it. This is called tolerance. Tolerance is not usually a problem with pain treatment because the amount of medicine can be changed or other medicines can be used in combination. Keeping track of how long your pain medicine works for you and telling your hospice nurses or physician will help them know if changes need to be made in your medicine or medication schedule. Using Your Comfort Journal found in this notebook will help.

**Concern: The pain medicine can cause side effects. I don't want to be drowsy or have an upset stomach.**

**Fact:** Many pain medicines do have side effects but most of them go away after a few days when your body becomes used to the medicine. When starting a new pain medication, your physician or care team may offer advice or prescribe other medications to help prevent side effects such as nausea or constipation. It is important to let your care team know if you have any problems taking your medications.

**Concern: I can only take medicine or use other treatments when I have pain**

**Fact:** Do not wait until pain becomes severe to take your medicine. Pain is easier to control when it is mild than when it is severe. Your doctors and nurses may suggest that you take your pain medicine routinely. This means taking it on a regular schedule around-the-clock. Preventing pain by taking your medicine on a regular schedule may even lower the amount of medicine you need each day to manage your pain. Taking your medicines on a regular schedule may also decrease the chance of having side effects from the medicines.

Pain is usually treated with medicine but other treatments can be used along with medicine to give even more pain relief. Relaxation and breathing exercises, cold packs, moist heat, and other non-medical techniques may help to control your pain. Your care team can talk with you how these other treatments might help.

The above information has been adapted from the Agency for Health Care Policy and Research Patient Guide for Managing Cancer Pain, Consumer Version Clinical Practice Guideline Number 9. The guideline was written by a panel of private sector experts.

## Talking About Pain

One of the most important things you can do to help manage pain is talk about it. You are the expert on how you are feeling. Your hospice care team members need and want you to tell them when pain is happening, how bad it is, and what it feels like. Your care team will ask many questions about your pain to determine:

- What type of pain you are having
- What treatments will be most effective

Your care team members will ask questions such as these to guide them in managing any pain that you are having. Try using Your Comfort Journal in this notebook to keep track of changes in your pain.

- **Where is the pain?** Pain can be in more than one place. Let your health care team know all of the painful areas. Which site of pain is the most severe or bothersome?
- **What does the pain feel like?** Your description of your pain is important in helping your care team decide which medications or treatments would work best. Which of the following words describe your pain?
  - Aching
  - Searing
  - Stinging
  - Burning
  - Sharp
  - Tearing
  - Cramping
  - Shooting
  - Throbbing
  - Cutting
  - Squeezing
  - Tingling



- o Crushing
- o Stabbing

- **How intense is the pain?** A number scale is frequently used to rate pain. The scale most often used is a 0-10 scale, with 0 being no pain, and 10 being the worst pain you can imagine. You can also describe pain with words like, none, mild, moderate, severe, or worst possible pain. This helps your team know how well your treatment plan is working and what changes need to be made.
- **How does pain change your activity?** Letting your Suncoast Hospice team know how pain affects your day-to-day life is very helpful. For instance, are there things you cannot do because of the pain: walking, eating, sleeping, riding in the car, turning over in bed, sitting up, bathing, going to the bathroom, talking?
- **What makes the pain better and worse?** Some things may make pain increase or decrease. For example, using heat or cold on the place that hurts, sitting or lying in different positions, urinating or moving bowels, and walking may affect your level of pain. Pay attention to those things that trigger and relieve the discomfort.
- **When do you notice pain?** When is pain the worst? Is there a pattern to your pain? When are you most comfortable?
- **If you are taking medication for pain, how well is it working?** Describe how well the treatment is working by using the 0-10 scale. Or, you can say how much of the pain is relieved – all, almost all, none, etc. Let your care team know how quickly the medication takes effect and how long it lasts. For instance, does it work well for 2 hours, but wear off before the next dose is scheduled to be taken?
- **Are you having side effects from the medications that you are taking?** Most, if not all, side effects from pain medicines are preventable or treatable. Make sure you let your care team know if you are having side effects or problems. Some common side effects that can be managed are: constipation, nausea and vomiting, sleepiness, itching and confusion.
- **Has the pain changed?** Pain may change over time. It may get better or worse or feel different. For example, the pain may have been a dull ache at first and has now changed to a burning, tingling feeling. Please report any changes. Changes in pain do not necessarily mean the illness is getting worse.

 **Tip: Use the Comfort Journal provided in this section to keep track of your symptoms and determine which treatments work best for you.**

## Pain Medications

Medications work differently for each individual. Some people get relief right away, while it takes a bit longer for other people to feel relief. While you are being treated for pain, tell your care team members how you feel and if the medications help. The information you give will help them find the best medicines, the most effective doses and the right schedule to help you get maximum relief.

- **Type of Medication and Type of Pain** Many different types of medicine are used to treat pain. Your treatment depends upon the type of pain that you are having. Ask your doctor or nurse to tell you more about the medicine you are taking. Suncoast Hospice pharmacists and physicians are also available for consultations regarding your comfort and medication options.
- **Choosing Pain Medication** Your care team, physician and pharmacist will work very hard to find the pain medicine that best meets your needs. You can help by talking with them about:
  - o Pain medicines you have taken in the past and how well they have worked for you.

- o Medicines (including health foods, vitamins, and other treatments) you are taking now. This is important because some treatments and medicines do not work well together. Your doctors and nurses can find medicines that can be taken together.
- o Complementary therapies and treatments you have tried in the past or are using now and how they work for you. This may include various techniques such as relaxation, meditation or guided imagery, massage, humor, exercise, aromatherapy, music and prayer.
- o Fears and concerns that you have about the medicine or the treatment. Talk about your fears and concerns. Your care team will use that information to make treatment decisions and answer your questions.

## How and When to Take Your Pain Medications

To help your pain medicine work best:

- Make sure you have the right medication, the right dose, and that you are taking it at the right time.
- Take your medicine as directed. It is usually recommended that you take your medicine on a regular schedule (by the clock). Taking medicine regularly and as your nurse or physician suggests helps to keep pain under control.
- Do not skip a dose of medicine or wait for the pain to get worse or come back before taking your medicine. The best way to control pain is to prevent it.
- Check with your doctor or nurse before starting a new medication. Some medications work well with others and some do not. Your nurse or doctor can provide you with information about new medications.
- Ask your nurse or doctor how and when to take extra medicine. If some activities, such as riding in a car, make your pain worse it may help to take an extra dose of pain medicine before these activities or as soon as possible after these activities. The goal is to prevent the pain.

Treating pain is important, and there are many medicines and treatments that can be used. If one medicine or treatment does not work, there are others that can be tried. Also, if a schedule or way that you are taking the medicine does not work for you, changes can be made. Talk openly to your hospice nurse or physician so you can work together to find the pain medicine and treatments that can help you the most.

## Possible Side Effects of Pain Medication

All medicines can have some side effects. Not all people get side effects from their medications, and some people have different side effects than others. Most side effects can be managed.

Many side effects happen in the first few hours of treatment and gradually go away. Do not stop taking your pain medicines. Call your hospice nurse if you experience side effects because many things can be done to help prevent or treat them.

### Some of the most common side effects of pain medicines are:

- **Constipation** Pain medications can slow down the bowel allowing too much water to be absorbed from the waste matter. This leads to hard and/or infrequent stools. When taking pain medication, your health care professional may also recommend a “bowel regimen” that includes a stool softener and/or a laxative. It is important to:
  - o Take stool softeners and laxatives routinely as prescribed to prevent and treat constipation.

- o Drink as much water, juice, and other liquids as possible.
- o Eat more fruits and vegetables if you are able.
- o Call your hospice nurse if you have not had a bowel movement in 3 days.

- **Nausea and vomiting** When this happens, it usually only lasts for the first day or two while the body adjusts to the medication. A medicine to control nausea and vomiting can be prescribed to help.
- **Sleepiness** Some people who take pain medicines feel drowsy or sleepy when they first take the medicine. This usually only lasts two to three days while the body adjusts to the new medication.

More serious side effects of pain medicines are rare. To help prevent serious side effects, the amount of medicine that will be prescribed will depend upon your age, height, and weight as well as how much pain you are having and what other medicines you are taking. If you have any side effect from any medication you are taking that concerns you or does not go away, please tell your care team right away.

## Disposing of Pain Medications

Out of concern for the safety of children, pets and other adults as well as the environment, proper disposal of all medications is extremely important. If you no longer need a medication, please talk with your hospice team before disposing of it.

Your care team will assist you to make sure medications are disposed of properly and safely. If the medications you receive are no longer needed or you move from your private home to a facility, all hospice-provided prescription medications should be destroyed and recorded as disposed of with the assistance of your hospice nurse or other hospice team member. A family member may be asked to witness the disposal of certain medications. If you live in a Suncoast Hospice residence or other facility, any medications you no longer need will be disposed of according to that facility's policies. Nurses and other healthcare workers are not allowed to transport medication in their vehicles.

Please see the Guidelines for Proper Disposal of Medications included in the Your Documents section of this notebook. The guidelines offer specific information about disposing of particular types of medication safely and responsibly.

## Weakness and Fatigue

Weakness and lack of energy are common complaints with most serious illnesses. Talk with your care team about strategies for understanding and living with these symptoms.

### What You Can Do

- Schedule rest periods between activities.
- Create an environment that helps you sleep well at night.
- Eat small, frequent meals throughout the day.
- Focus energy on activities that are important to you. Consider saving energy by letting a hospice home health aide assist with hygiene, bathing, and dressing.
- Avoid activities such as driving, cooking and handling machinery when drowsy or dizzy.



- Prevent falls by:
  - o Changing positions slowly. When moving from a prone position, sit first and let feet dangle for a minute or two before standing.
  - o Using adaptive equipment such as a cane or walker.
  - o Keeping objects and loose throw rugs out of walkways.
  - o Using adaptive equipment such as elevated toilet seats and shower benches in the bathroom.
- Ask about occupational or physical therapy aimed at maintaining strength and independence.

**Call your care team if:**

- You fall.
- Weakness or dizziness comes on suddenly.
- Weakness is accompanied by heart palpitations, difficulty breathing, dizziness, or chest pain.
- There is any sign of bleeding.
- There is a change in your ability to move around.
- There is a change in your ability to eat and drink.

Your ability to take care of those things that are important to you matters very much to your hospice care team members. Please talk to them about your worries or concerns so that they will know how to help.

## **Constipation**

Constipation is a symptom that should be taken very seriously. Changes in bowel function are common during illness. Many factors can lead to slowed bowel function and hard, infrequent stools. Don't be embarrassed to talk to your care team about this problem – it can be treated.

### **Causes of Constipation**

- Changes in diet – low fiber, lack of fluids
- Medications
- Decreased activity
- Changes in the intestinal lining or mobility

If you are experiencing constipation or taking medications that can lead to constipation, your hospice care team will work with you to create an effective bowel regimen.

### **What You Can Do**

- Talk openly with your hospice nurse about any current or past problems with your bowels.
- Tell your hospice nurse what has worked – and not worked - to relieve such problems for you in the past.
- Drink water, juice, and other liquids as you are able to tolerate.
- Take stool softeners and/or laxatives as prescribed.
- Keep track of the frequency of bowel movements and share that information with your hospice nurse.

**Call your care team if:**

- Stool is hard and difficult to pass.
- It has been 3 or more days since your last bowel movement.
- Your abdomen is tender, painful, or distended.
- Constipation is accompanied by nausea and/or vomiting.
- There is blood in the stool.
- The only stool is a small smear or liquid.

**Establishing a Bowel Regimen**

Your nurse may discuss creating a bowel regimen. A bowel regimen is a plan for preventing and managing constipation. Starting a plan, sticking to it, and evaluating it together will help you and your care team know what works well for you. The Your Bowel Plan worksheet found in this notebook can be used as a guide.

**Shortness of Breath**

Shortness of breath is also called dyspnea or breathlessness. Feeling out of breath is very uncomfortable and tiring. It can also cause feelings of fear, nervousness, sadness, helplessness, anger and frustration.

**Signs of Shortness of Breath**

Shortness of breath may occur during activity and even during rest. Some of the signs of shortness of breath include:

- A restless or anxious feeling.
- A feeling of not getting enough air.
- Fatigue.
- A faster breathing rate.
- Being winded when talking.

**Some things that may cause or increase feelings of shortness of breath include:**

- Anxiety.
- Movement.
- Talking.
- Exercise.
- Posture.
- Cough.
- Secretions.
- Climate, especially heat and humidity.
- Infection.
- Illness-related changes in the lungs.

**What You Can Do**

There are many different ways to help decrease feelings of shortness of breath. Treatments for shortness of breath work differently for different people.

- **Medications** Many different types of medicines can be used to help improve shortness of breath. Your physician may give you one or more of them to take. The types of medicine that will be suggested will depend upon the symptoms you are having and what is causing them.



- **Oxygen Therapy** Not everyone needs or will benefit from using oxygen. Ask your care team or physician if oxygen would be helpful in your situation.
- **Respiratory Therapy** A respiratory therapist may visit to assess your breathing and make recommendations for your treatment plan.
- **Helpful Hints** Medications and other treatments may work better and give more relief when combined with these suggestions:
  - Eliminate allergens, such as smoke, dust and mold.
  - Use a cool mist humidifier to increase the moisture in the room.
  - Use a small fan to keep air circulating.
  - Keep the room cool.
  - Elevate the head with pillows.
  - Request an adjustable bed.
  - Certain positions can help with chest expansion. Sitting upright and leaning forward helps air to move in and out of the lungs. Breathing while lying on one side may be easier than while lying on the other.
  - Breathing through the mouth may cause dryness. Ice chips or a cold, moist washcloth may relieve feelings of dryness of the mouth.
  - Conserve energy. Rearrange the environment to reduce exertion. For example, move the phone next to the chair or bed.
  - Plan activities to conserve energy. Schedule activities to include rest time. For example, eat first, then rest and then bathe.
  - Try to conserve energy to do those things that are enjoyable. For example, let someone assist with dressing and bathing so you feel up to doing more pleasant activities.
  - Minimize emotional upsets.
  - Try relaxation techniques, music and visualization.
  - Be sure clothing around the neck and chest is loose and light weight.

Your care team wants to help you breathe as comfortably as possible. If shortness of breath comes on suddenly or causes distress, please call your care team immediately at (727) 467-7423.

**Tip: Use Your Comfort Journal in this section to keep track of your symptoms and determine which treatments work best for you.**

## **Nausea and Vomiting**

Nausea and vomiting are distressing symptoms. Fortunately, there are effective ways to prevent and treat these symptoms. If you feel nauseated or are having episodes of vomiting, please tell your care team. Your care team will work with you and your physician to identify what is causing these symptoms and develop a treatment plan.



**Nausea and vomiting may be caused by:**

- Medications, such as chemotherapy, antibiotics, aspirin, and pain medications.
- Damage to the stomach and intestinal lining from disease or treatments.
- Anxiety
- Uncontrolled pain
- Motion sickness (travel-related)
- Some infections
- Constipation or diarrhea
- Coughing -- thick secretions and/or coughing may trigger vomiting
- Some foods and/or strong odors

**What You Can Do**

- Eat small, frequent meals
- Try foods such as:
  - Toast and crackers
  - Sherbet
  - Pretzel
  - Angel food cake
  - Chicken without skin (baked or broiled)
  - Fruits or vegetables that are soft or bland (potatoes, canned peaches)
  - Ginger or herbal remedies. Be sure to check with your nurse or pharmacist to be certain herbal remedies do not interact with prescribed medications
- Try to avoid these foods:
  - Fatty, greasy and fried foods
  - Spicy, hot foods
  - Dairy products such as milk or ice cream
  - Foods with strong odors
  - Citrus foods such as oranges and grapefruit
  - Foods containing caffeine such as coffee and chocolate
- Eat foods at room temperature or cooler. Hot foods may trigger nausea.
- Suck on ice chips or take frequent sips of a liquid such as ginger ale.
- Use disposable plates, napkins, silverware and cups
- Avoid drinking liquids with meals.
- Enjoy a quiet, relaxing, pleasant atmosphere for meals. Avoid eating in a room that is stuffy, too warm or has cooking odors or smells.
- Try relaxation techniques such as deep, controlled breathing and focusing on pleasant thoughts.
- Don't eat favorite foods when nauseated. This may cause a permanent dislike of those foods.
- Rest after meals - activity may slow digestion. It is best to rest sitting up, for about one to two hours after meals.



- If nausea is a problem in the morning, try eating dry toast or crackers before getting out of bed (keep a supply next to the bed).
- If nausea occurs during chemotherapy or radiation therapy, avoid eating for 1-2 hours before treatment.

**Ask your hospice nurse about medications to help control nausea. Use Your Comfort Journal in this section to keep track of when nausea occurs and what causes it (specific foods, events, surroundings). This information will help your nurse and physician determine the most effective treatments for you.**

## Managing Nausea & Vomiting

### *If vomiting occurs:*

- If lying down, turn head to the side to prevent choking.
- After vomiting, rinse the mouth out with water, brush the teeth, and/or rinse the mouth with a mouth rinse.
- Place a damp, cool cloth on forehead, neck and wrists.
- Do not eat or drink anything until the vomiting has stopped.

### *Once vomiting stops:*

- Try small amounts of clear liquids such as apple juice, bouillon and gelatin. Begin with a teaspoonful every 10 minutes. Gradually increase the amount to 1 tablespoonful every 20 minutes and then try 2 tablespoonfuls every 30 minutes. If unable to tolerate any fluids, call your care team.
- Once able to keep down clear liquids, try non-clear liquids. Gradually work up to a regular diet.
- Ask your hospice nurse or physician about specific medications to help control nausea.

### *Call your care team immediately if:*

- Vomiting happens more than two times in two hours.
- Vomit looks like coffee grounds or looks like it is bloody.
- Symptoms include weakness, dizziness and/or thirst.
- You are unable to keep down or swallow medication prescribed to control nausea and vomiting.

Much can be done to prevent and treat nausea and vomiting. Please talk with your care team about your concerns (727) 467-7423.

## Promoting Comfort

There are many ways to help relieve distressing symptoms. Medications, properly chosen by your physician, are the mainstay of pain and symptom management. There are also ways to relieve distressing symptoms that go beyond taking medication.

Ask your care team what non medical treatments might be helpful to you. Your hospice care team can coach you – as a patient or caregiver - in learning more about these techniques. They can also let you know what types of complementary therapies can be provided by specially trained hospice staff and volunteers.



Do not stop taking your medications. These treatments are meant to be used with – not instead of – medication. These treatments can help your medications work more effectively and may also relieve other symptoms such as anxiety. Before trying any new treatment, always check with your care team to be sure it is safe and recommended.

## Using Heat and Cold

Applying heat or cold to painful areas works because the nerves at the surface of the skin send their signal to the brain more quickly than the nerves that send the painful signal. In effect, this “tricks” the brain because it can only process one signal at a time.

This technique works best on pain that aches, throbs and is muscular in nature. If you can point to the pain, and say “it hurts right here” then consider using hot or cold compresses.

### Remember:

- Do not use heat or cold on an area that has open wounds or broken skin.
- Do not use cold on areas with poor circulation or decreased sensation.

### Where to Use Heat or Cold:

- At the site of the pain.
- On the opposite side of the body as the pain (if the right shoulder aches, try applying to the left shoulder).
- Between the pain and the brain (if your foot is aching, apply to calf or thigh).

### Heat

Warmth increases blood flow and can help reduce joint stiffness.

- Protect skin by placing towel between heat and skin.
- Do not use on skin that has received radiation treatments.
- Apply for 20-30 minutes.
- Try alternating with cold application (20 minutes each) for skeletal muscle spasm.
- Avoid use with oil or menthol containing products which may irritate skin.

### Equipment

- Microwavable hot packs (available at most drug and health stores)
- Warm moist towels (use hot tap water or heat moist towel briefly in microwave)
- Hot water bottles
- Electrical heating pads – moist heating pads best
- Warm baths/showers or whirlpool treatments

### Cold/Ice

Cold decreases blood flow to skin and reduces inflammation and decreases local sensation.

- Avoid cold if skin pales and then turns red after application, this indicates poor circulation to the area.
- Avoid using on abdomen and stomach area.
- Protect skin by wrapping cold source in towel.
- Apply for 20-30 minutes.

## Equipment

- Gel packs – can be purchased at drug stores
- Cold or frozen damp towel
- Ice packs (sealed plastic bag with 1/3 alcohol and 2/3 water frozen until slushy)
- Bag of frozen peas/corn (separate for flexibility)

## Simple Gentle Massage

A simple back rub can be comforting and relaxing. It assists with sleep and is a simple way to show care. Hand massage is simple and can be soothing.

- Don't rub an area that is painful or reddened.
- Use lotion or oil if desired.
- Use long stroking motion up and down the back and use large circular motions at the upper and lower back.
- Massaging hands and feet can be less intrusive to the person and is also comforting and very relaxing.
- Avoid deep massage of the lower legs.

## Caring Touch

The use of soft touch with a full hand that communicates compassion, nurturing and attention. Caring/Comfort Touch shifts attention from discomfort and stress to physical and emotional comfort.

## Integrative Medicine Clinic

The environment of the Suncoast Hospice Integrative Medicine Clinic promotes comfort, safety, relaxation, and a sense of peace. Treatments in the clinic focus on the mind, body, spirit and emotions and may include Acupuncture, Reiki, Breathwork, and other complementary therapies. You can request a clinic appointment through your care team.

## Palliative Arts

The following therapies and techniques are relaxing and may help to relieve such symptoms as pain, anxiety, nausea and vomiting, shortness of breath, and difficulty sleeping. Many volunteers and staff have been specially trained to administer these services. You can request the following through your care team.

- **Massage Therapy**

The use of "hands on" techniques delivered by a licensed massage therapist can promote relaxation, reduce anxiety/agitation, and create a sense of peacefulness.

- **Meditation**

Meditation, progressive relaxation, and guided imagery are effective techniques for promoting peace, relaxation, and relief of suffering. Meditation and progressive relaxation audio guides can be purchased online or at your local bookstore. Guided meditations are also found on YouTube and other music streaming sites such as Spotify.

- **Spiritual Care**

Finding comfort in prayer, sacred readings or familiar rituals can be a healing and hopeful way to find peace and strength. Inspirational reading, poetry and music may soothe and comfort. Consider requesting a visit from a hospice spiritual care coordinator. A spiritual care coordinator's nonjudgmental, compassionate care can be reassuring and calming.

- **Reiki**

A gentle technique where practitioners apply either a light touch or hold their hands just above the body. It is an energy treatment that brings about a sense of deep relaxation and well-being.

- **Music**

The idea that music can comfort and provide relief is familiar to everyone. Lowering the lights and playing music you find relaxing can ease a difficult moment or day. Familiar music has the best effect for comfort, and music without words can ease restlessness.

- **Humor**

Laughter is proven to be good medicine. Plato and Socrates used laughter as a remedy for colds and depression; Freud appreciated the benefits of laughter in releasing tension and reducing anxiety. Studies have documented the benefits of laughter. There are many books, videos, CDs and cartoons that can lift the spirits and ease suffering.

- **Aromatherapy**

The use of essential oils to promote the health of the body, mind and spirit is an ancient practice. Essential oils affect chemicals in the brain in ways similar to the ways medications work. They can help to relax the body, relieve nausea, reduce unpleasant odors and promote restful sleep. Aromatherapy oils and blends can be diffused into the air, applied to cotton balls and placed near the nose, used in lotions and bath water, or used in a spritzer.

- **Pet Visits**

Pet visits honor the value to human well-being that companion animals provide. Interactions with pets uplift the spirit, promote a sense of connection, and reduce loneliness.

**Ask your Suncoast Hospice team today about nonmedical options available through the Palliative Arts program. Other patients and families have told us these non-medical treatments decreased their pain and anxiety while increasing their feelings of peace.**

**Remember, your comfort is our priority.**

### **References:**

Agency for Health Care Policy and Research. Patient guide for managing cancer pain, consumer version clinical practice guideline number 9. Author.

*“The human spirit is stronger than anything that can happen to it.”*

- C.C. Scott



**4-14**

## Your Comfort

- © copyright 06/2019, Suncoast Hospice | Empath Health

© copyright 06/2019, Suncoast Hospice | Empath Health

© copyright 06/2019, Suncoast Hospice | Empath Health

© copyright 06/2019, Suncoast Hospice | Empath Health

© copyright 06/2019, Suncoast Hospice | Empath Health

## 0-10 Rating Scale

[illegible]

## 0-10 Rating Scale

[illegible]

Your Pain Control Plan

If you are having pain or discomfort, your hospice care team will work with you and your physician to create an effective pain control plan. Share your answers to the following questions with your care team. This information will help determine which treatments will work well for you.

- In the past, what has worked to reduce your pain? What has not worked?

---

---

- Are you satisfied with your level of comfort? How could it be better?

---

---

- Would you consider changing your pain medications or treatments?

---

---

- Is there anything you don't understand about your pain control plan? If so, what?

---

---

- Does the timing of your medications work for you?

---

---

- Are you having any difficulty taking (or giving) any medication?

If yes, please describe.

---

---

- What side effects are you having?

---

---

- Is the medicine or treatment causing any problems?

---

---

- What nonmedical treatments are working and which are not?

---

---

- Would you like to talk about other nonmedical treatments that might help?

---

---



Please call your care team at (727) 467-7423 right away when you have a question or concern about your comfort. Skilled professionals are available 24 hours a day, 7 days a week to assist you. Your comfort is important to us — ***please do not wait.***



## Medication Record

If keeping track of scheduled times to take medications is a challenge, try using one of these medication records. Talk to your care team about setting up a system that works for you. Medication boxes that can be filled with the correct medications to take at certain times also can be helpful.

**Weekly Medication Record:** On this page is a chart for keeping track of medications weekly. In the first column, list medications according to the time they should be taken. Include any special reminders such as "before meals" or "with food." In the next columns, write in the time and make a check mark or note to show whether or not that medication was taken.

	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
<b>Date:</b>							
<b>Morning:</b>							
Example — Medication A Take with food	8:00 ✓	8:00 ✓	8:00 ✓	8:00 ✓	Did not take	8:00 ✓	8:00 ✓
<b>Mid-day:</b>							
<b>Evening:</b>							
<b>Bedtime:</b>							

©2005 The Hospice of the Florida Suncoast

**Daily Medication Record:** On this page is a chart for keeping track of medications daily. In the first column, list medications and the instructions for when and how they should be given. Include any special reminders such as "before meals" or "with food." In the next columns, write the time each medication should be taken. Make a check mark or note to show whether or not the medication was taken as prescribed.

[illegible]

If you have any questions about your medications, please call your care team anytime at 727-586-4432



**Your Bowel Plan**

Constipation is a common but uncomfortable side effect of some illnesses and medications. To prevent or treat constipation, your Suncoast Hospice care team will work with you and your physician to create a plan — a bowel regimen — that is effective for you.

**Please tell your care team about:**

- Any past problems with constipation or diarrhea.
- What has worked to alleviate bowel problems for you in the past.
- What has not worked for you.
- Any concerns or questions.

**Call Suncoast Hospice if:**

- Stool is hard or difficult to pass.
- It has been 3 or more days since you had a bowel movement.
- Your abdomen is tender, painful or distended.
- You feel nauseated or are vomiting.
- There is blood in your stool.
- The only stool is a small smear or liquid.

**Bowel Plan**

Date:

- ☐ Stool Softener(s):
- ☐ Laxative(s):

Instructions:

---

---

---

---

---

---

Notes:

---

---

---

---

---

---

---

---

---

---

**Suggestions (if checked by nurse)**

☐ Increase fluid intake by drinking:

- ☐ Water
- ☐ Fruit juices
- ☐ Vegetable juices
- ☐ Other: \_\_\_\_\_

---

---

---

---

---

---

---

---

☐ Other: \_\_\_\_\_

---

---

---

---

---

---

---

---

---

---

---

---

Keeping track of bowel movements will help you and your care team decide what treatments work the best.

Date	Bowel Movement ✓	Comments (soft, hard, watery, cramping, etc)	Notes (change in medications, used enema, called nurse, etc)

**When you have any questions, please call your hospice team at (727) 467-7423**



# Your Decisions

5-1 Advance Directives

5-5 Funeral and Memorial Services



## Section 5 Your Decisions

### Making and Communicating Your Choices

Whether you are ill or are caring for someone who is, you may find yourself facing many choices. In this section you will find information about:

- Factors to consider in making medical decisions
- Having important conversations with your loved ones and writing down your choices so others will know your wishes
- Thinking about what is most important in the last days of life
- Planning ahead for meaningful memorial or funeral services

### **Advance Directives**

Once you have made decisions about treatments you do and do not want, talking about them and writing them down helps to ensure that your wishes are honored. Advance Directives reflect decisions – in advance – about health care and medical treatments. These instructions go into effect **ONLY** if you are no longer able to make decisions or communicate your wishes yourself.

While no one is required to prepare advance directives, all health care providers are mandated by Florida law to make patients and families aware of them. Suncoast Hospice supports your right to make the treatment choices that are right for you. Any advance directives that you completed when you began hospice care can be kept in the front or back pocket of this book.

### **Living Will**

- Tells others what kind of medical treatment you do or do not want to receive – it makes your wishes known
- Should be discussed with your family, friends, clergy, and a physician
- Goes into effect only if you are no longer able to make decisions or communicate your wishes yourself and when you are diagnosed as having:
  - A terminal condition from which there is no reasonable probability of recovery, or
  - An irreversible end-stage condition that has resulted in permanent and severe deterioration, or
  - A persistent vegetative state or irreversible condition of unconsciousness with no voluntary action or ability to communicate purposefully.

### **Designation of Health Care Surrogate Document**

- States that you authorize another person to make medical decisions, based on your desires, in the event that you are not capable of doing so.
- May include specific instructions based on your particular medical conditions.
- Goes into effect if and only if you are unable to communicate your wishes.
- If a situation you did not cover in this document or in your living will occurs, your surrogate will be asked to make a needed decision for you.

- The person you designate as your Health Care Surrogate can:
  - o Give informed consent
  - o Review medical records
  - o Talk with your physicians and health care providers
  - o Authorize transfers to different health care facilities
  - o Apply for public health care benefits
  - o Consent to organ and tissue donation according to your wishes
- The best person to select as your health care surrogate is a competent adult who knows and respects your values, religious beliefs and preferences regarding medical treatment.
- You may want to list alternate surrogates as well in case your first choice becomes unable or unwilling to carry out your wishes.
- Let your health care surrogates know you have chosen them to assume this role if the need ever arises.

### **Without a Living Will and Designated Health Care Surrogate**

If you have not indicated who will speak for you if you become incapable of communicating your health care choices, the law designates the following people in this order:

- Court appointed guardian
- Spouse
- Adult child
- Parent
- Adult sibling
- Adult relative
- Adult friend who knows you well
- A licensed clinical social worker

It is important to communicate your wishes to your family and friends because they may be asked to make your health care decisions.

### **Do Not Resuscitate (DNR) Orders: Making Decisions about CPR**

You have probably seen cardiopulmonary resuscitation (CPR) on television or in the movies. CPR includes a series of emergency procedures used when breathing stops and/or the heart stops beating. Mouth-to-mouth resuscitation or the use of a device called an Ambu-bag temporarily restores air flow to the lungs. When the heart stops, chest compressions are delivered by hand until emergency personnel or medical staff can use electrode paddles to “shock” the heart. Intravenous medications are also used to help stabilize the heart's rhythm. If these initial attempts are successful in restarting the heart but breathing does not resume, a ventilator may be used to continue delivering oxygen.

You can choose whether or not you would want to receive CPR. While CPR can be a life-saving intervention for some, studies have shown that it is rarely effective for persons who have advanced illness. If you have questions about the use of CPR in your situation, ask your care team and physician to explain the procedures in detail and to outline the potential risks and benefits.



## Making Your Wishes Known Regarding CPR

For your wishes to be followed, it is important that each person involved in your care know what you have decided regarding CPR. The abbreviation DNR stands for Do Not Resuscitate.

If you do want to receive CPR, tell the people around you and your hospice team. Emergency care workers and healthcare workers in facilities are required to perform emergency resuscitation procedures if you stop breathing or your heart stops beating.

Talk to your physician and care team about:

- What results you expect from CPR
- What your goals for recovery would be
- Why your choice feels right to you
- Any situations that would change your decision

### **If your decision is to allow natural death rather than receive CPR, it is important to complete a Do Not Resuscitate (DNR) form.**

- In the state of Florida a specific Do Not Resuscitate (DNR) form is required so that emergency medical services (911) and other health care providers know not to perform CPR – even if your living will states your choices.
- The DNR form is a bright yellow form signed by you and your physician. Your health care surrogate can sign the form if you are cognitively incapable of making your wishes known.
- Without the DNR form, emergency care workers are required to begin emergency resuscitation procedures if you stop breathing and/or your heart stops beating. This can apply to healthcare workers in facilities as well. In some cases, a physician who is acting on your wishes can write a DNR order in a facility medical chart without the yellow form.
- Treatments and care planning will focus on providing optimal comfort and preventing distress rather than on restarting your breathing or pulse.

### **To feel prepared and confident in making and honoring this decision, please keep in mind that:**

- You will want to keep the original yellow form in an easy-to-find place - usually on the refrigerator at home or in the chart at a facility or hospital so that emergency care providers will know your wishes.
- The original form needs to go with you when seeking care in a hospital or other facility. The yellow form is required for providers to honor your wishes.
- When you choose not to receive CPR, your caregivers will be taught to call Suncoast Hospice right away in the event of respiratory and/or cardiac arrest.
- Your care team will work with you and your caregivers to make a plan that focuses on your comfort.

### **Changing or Canceling your Living Will, Healthcare Surrogate or DNRO**

- It is a good idea to review your advance directives periodically to make sure they continue to reflect your wishes.
- You may change or cancel your Living Will, Designated Health Care Surrogate, and Do Not Resuscitate Order (DNRO) at any time. You can do this by:
  - Preparing new documents and having them witnessed
  - Destroying your old forms





- Stating your new choices to your doctor and health care surrogate(s).
- Make sure you tell your hospice care team about changes in your wishes and give them copies of any new documents.

Making decisions about what might happen can be hard. Your care team has experience with helping people sort out what choices feel right. Talk with them. Ask questions. For more on Advance Directives, see "Your Documents" section of this document.

### AICD Magnet

Patients with an Automatic Implantable Cardiac Defibrillators (AICD) may have firing of the device which may cause pain and discomfort. Your hospice team will discuss with you and your family whether you wish to turn off the AICD and what this would mean for your care and treatment. While you are deciding whether you wish to turn off your AICD, it is the policy of Suncoast Hospice to supply you with a magnet that can be used in an emergency situation if your device is firing inappropriately. This magnet should be kept in a location in your home which can be easily accessed and is known to all caregivers. You should keep the magnet at least one foot away from the patient with the AICD, unless you are going to use to turn off the device. Your nurse will circle the instructions below to follow if your device needs to be turned off in an emergency. Please note that in most cases, the device will only be turned off during the time that the magnet is held over the device, and that the device will return to normal function once the magnet is removed. If you want to turn your device off permanently, please contact Suncoast Hospice so that we can arrange for an AICD company representative to come and do this. To turn off the AICD in an emergency situation, hold the magnet over the device. Specific information regarding types of AICDs are provided below:

#### Medtronic

- It will not permanently change any device settings
- All settings go back to normal when removed
- No effect on pacemaker-pacing, pacing mode, rate, and interval remain programmed
- May produce audible tones initially

#### St. Jude (Ventrivex)

- It will not make a beeping noise
- It will not permanently change device settings
- Once magnet is removed the device is activated again
- Can be programmed to not respond to magnet use

#### Biotronic

- It will not make any noises
- It will not permanently change device settings
- Once magnet is removed the device is activated again

#### Guidant (CPI) / Boston Scientific

- Device is inactive as long as tones are heard
- If, after 30 seconds a change in tone is heard (beeping to long tone), detection has been turned off and you must reactivate the device later by reapplying the magnet and listening for the beeping tones to return (if a change in tone does not occur, the device cannot be changed with a magnet)

- ***The magnet can permanently change the device settings***

## **Funeral and Memorial Services**

Do you have strong feelings about how you would like to be remembered after your death? Do you as a family member or friend want to plan a memorial that honors your loved one? For some people, planning the funeral, memorial service or celebration of life is comforting and provides an opportunity to finish unfinished business. Others, quite understandably, would rather avoid the topic completely.

If you are thinking about memorial planning, the following questions may help you decide what is important to you and share that information with friends or family members who will be involved in making decisions. Use the questions to start a conversation or as a worksheet to guide you in writing down your ideas.

What are some of the things you would like your friends and family to remember about you?

---

---

Would you like an obituary in the newspaper, church bulletin, etc.? What would you like it to say or include such as place of residence, occupation, school attended, memberships in associations or clubs, religion, interests, survivors, contributions, or place of burial?

---

---

After your death, how would you like to be memorialized (funeral, memorial service, celebration of life, etc.)? Do you have specific wishes about how you would like it to be carried out?

---

---

Have you made (final, funeral, memorial service) arrangements? Have you made arrangements for your final resting place?

---

---

If yes, with which mortuary/funeral home did you make these arrangements? Where is the paperwork?

---

---

If not, where would you like your final resting place to be (cemetery, scatter ashes, urn and kept with family, memorial garden)? What about this place is important to you?

---

---

Do you prefer cremation or burial? Do you have a burial plot?

---

---

---

Are there any special clothes you would like to wear for burial/cremation?

---

---

If burial, is there anything you would like with you?

---

---

If burial, do you already have a headstone? Do you want a headstone, and if so, what would you like it to say?

---

Is there any special person(s) you want present at your funeral/memorial service?

---

---

Do you have a place of worship where you would like the funeral/memorial service to occur?

---

---

Do you have a preference for clergy?

---

---

Who would you want to read your eulogy?

---

---

What would you want to be said in your eulogy?

---

---

Do you have favorite songs, prayers, readings, rituals or sacraments that would honor your life and help people remember you?

---

---

Do you want flowers? Would you like donations to be given to a charity in your honor?

---

---

If flowers, what is your favorite?

---

---

If you choose donations, to which charity should the donations to be made?

---

---



Table of  
Contents

5



Do you have any other final wishes? Any special wishes?

---

---

### **Your Suncoast Hospice Care Team Can Help**

Your hospice care team is available to support you in considering all of your options for treatments and advance planning. We can provide information, counseling, and encouragement and will respect your values and priorities. We are here to help you live your life your way. Call anytime. (727) 467-7423.

#### **Resources:**

Hospice of the Florida Suncoast. (2004). It's Time to Talk About It. Clearwater, FL: Author.  
Hospice Institute of the Florida Suncoast. (2003). Caregiving at Life's End: The National Train-the-Trainer Program. Clearwater, FL: Author.  
Morris, V. (2004). Talking about Death. Chapel Hill, NC: Algonquin Books.  
National Cancer Institute. (2010). Last days of life: Patient version. Bethesda, MD: Author.  
Von Gunten, C.F. (1991). CPR in Hospitalized Patients. American Family Physician, 44, 2130-2134.

# Tips For Patients and Caregivers

6

6-1 Practical Tips from Other Caregivers

6-1 Talking with Children

6-2 Finding Your Support System

6-3 Warning Signs for Caregivers

6-4 More About Caregiving



## Section 6 Tips For Patients and Caregivers

### **Practical Tips from Other Caregivers**

Consider your hospice care team a partner in meeting the changing needs of the person who receives your care. Your nurse, home health aides, counselor or social worker, spiritual care coordinator, and volunteers will work with you to provide the best care possible while also trying to give you and the person you are caring for some quality time together. Knowing that practical care needs are met can give you the peace of mind to be able to focus on making the most of each day.

- Protect your quiet time – use the answering machine to screen calls, hang a do not disturb sign on the front door when resting.
- When cooking, make simple meals and twice as much, freeze the extras.
- Use paper goods to shorten clean up time.
- Cut down on shopping trips by buying extra supplies of items you know you will need.
- Create a schedule. You might not follow it exactly, but knowing what the plan is for the day can reduce anxiety and help you both feel more in control.
- Pick your battles – ask yourself if something is really worth an argument or cross word.
- Keep a small amount of cash on hand so that you can easily reimburse helpful friends and neighbors when they run an errand.
- Establish “visiting hours” so that you can have both support and privacy.
- Pick a willing family member or friend to be in charge of relaying updates by phone or e-mail to others who are concerned.
- Use this care guide or another notebook as a centralized place to keep track of phone numbers, medications, appointments, etc.

### **Talking with Children**

If there are children in your life, you may be wondering how to talk with them about what is happening. Before having these conversations, ask yourself:

- What does the child need to know?
- What does the child want to know?
- What can the child understand?

**Begin at the Child's Level**

- Think about what the child will be able to understand.
- Tell the truth.
- Provide concrete information about the illness – the correct name, symptoms and how the illness is contracted.
- Emphasize that nothing the child did caused the illness.
- Focus on what is being done to promote comfort, control symptoms or treat the illness.

**Be Guided By the Child's Questions**

- Create opportunities for the child to feel safe and able to ask questions.
- Take time to clarify questions so that you understand what the child really wants to know.

**Provide Opportunities for the Child to Share His or Her Feelings**

- Encourage the child to find ways to show love for the person who is sick – drawing pictures, writing poems, letters, or stories, telling the person that he or she is loved.
- Ask the child how he or she feels about what is happening. Teach healthy ways to share difficult feelings like sadness, fear and anger. Encourage expression through talking, writing, art, exercise, dance, etc.

**Remember the Basics**

- Plan to make sure the child's needs are met.
- Keep the child's routine as normal as possible.
- Children count on the adults in their life to provide reassurance, love, care, honesty, routine and structure.
- Set aside uninterrupted time to let the child know that you are available to talk about what is happening.

**Use Resources**

- There are many books, videos, and websites available for additional information. Some of these are listed in the "More Resources" section of this book.
- Suncoast Hospice community libraries have materials about illness and grief for children and for the adults in their lives. Visit the libraries at Suncoast Hospice's community service centers or call (727) 467-7423 for more information.

Suncoast Hospice offers supportive counseling services for children, teens and their parents during the serious illness or death of a loved-one. Your care team's licensed social worker can help guide you and your family during this difficult time. Call your care team for more information.

**Finding Your Support System**

Another key to staying active as a caregiver is combating the sense of isolation. Ask your care team for recommendations of caregiver support that may be available to you.

Once you know who your supporters are don't be shy about asking for their help and encouragement. Remember that your hospice care team wants to be part of your support system.

Often people want to help but don't know how to be helpful. Be ready to answer when someone says, "Is there anything I can do?"

The next time someone offers to help, I will ask them to please...

- Bring a meal
- Go grocery shopping
- Go to the:
  - Bank
  - Post office
  - Discount store
  - Hardware store
  - 
  - 
  -
- Drive me/us to \_\_\_\_\_
- Pick up \_\_\_\_\_
- Clean the \_\_\_\_\_
- Fix the \_\_\_\_\_
- Visit \_\_\_\_\_
- Call \_\_\_\_\_
- Stay with the person I care for while I go \_\_\_\_\_
- Help me take the person I care for to \_\_\_\_\_
- Sort through \_\_\_\_\_

### **Warning Signs for Caregivers**

The strain of caregiving can lead to exhaustion – physically, mentally, emotionally, and spiritually. Such exhaustion, sometimes called “burnout”, can cause compassionate, involved caregivers to feel detached and become unable to continue giving good care.

Warning signs:

- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless, and helpless
- Changes in appetite, weight, or both
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to hurt yourself or the person for whom you are caring
- Feeling emotionally and physically exhausted
- Irritability



Help is available. Call your care team at (727) 467-7423 or your personal health care provider if you are experiencing any of the signs listed above. If your safety or the safety of someone else is at risk, call 911 for emergency assistance.

## **More About Caregiving**

There are many good sources of information available about topics related to caregiving. In addition to your care team, Suncoast Hospice Community Library is available to help you find books, Web sites, community resources and other materials that might be useful. We invite you to browse through the library at your neighborhood hospice community service center. If you are unable to stop by, call the library at (727) 467-7423 or ask a member of your care team to request information directly. Our dedicated team of library volunteers can help by locating materials and working with your care team to deliver them to your home. You can visit the library's website by going to [SuncoastHospice.org](http://SuncoastHospice.org) and clicking on the library link.

Please see the **More Resources** section of this notebook for more information about organizations, websites and materials that may be of interest to you as a caregiver.

### **References:**

Hospice Institute of the Florida Suncoast. (2003). Caregiving at Life's End: The National Train-the-Trainer Program. Largo, FL: Author.  
National Alliance for Caregiving, AARP. (2004). Caregiving in the U.S. Washington: Author.

# Tips for Care and Safety

- 7-1 Preventing and Controlling Infections at Home
- 7-4 Biomedical Waste Guidelines
- 7-5 Falls Prevention Checklist
- 7-6 Giving Medications
- 7-7 Providing Personal Care
- 7-9 Mobility
- 7-11 Bladder and Bowel Care
- 7-14 Fire and Oxygen Safety Tips
- 7-14 Caring for Someone in Bed



## Section 7 Tips for Care and Safety

Living with an illness means adapting to changing care needs. This section offers helpful hints for promoting safety, independence, comfort and dignity.

### **Your care team will help you...**

- Understand any changes that are happening
- Get helpful medical supplies and medical equipment
- Learn needed skills
- Adjust to changes in ability and mobility

The general information in this section is intended as a quick reference. Please ask your hospice nurse for instructions tailored to your particular situation.

Remember that Suncoast Hospice aides are available to assist with a variety of personal care needs. They specialize in providing excellent, respectful care.

### **Consider accepting their help with:**

- Grooming
- Mouth care
- Skin care
- Bathing
- Positioning

**Tip: Are you wondering if visits from a home health aide would be helpful? Ask your care team to schedule a one-time visit. Start slowly with simple care tasks like skin care and grooming. The choice is always yours.**

## **Preventing and Controlling Infections at Home**

Illness and stress make everyone more vulnerable to getting infections. There are many steps you can take to prevent and control the spread of infections in the home.

Infections are caused by germs getting inside the body. Our hands have many opportunities to come in contact with germs. Some germs get on your hands when you handle money, use the toilet or touch door handles. Some germs are in the air and can be passed to another person, especially through coughing or sneezing. Other germs are passed from one person to another through blood and other body fluids. Infection prevention is everyone's responsibility.

### **Personal Hygiene: Keep your Skin Healthy**

Your skin is your body's first line of defense against germs. Caring for your skin can prevent infections. If your skin starts getting dry or starts cracking, apply moisturizing cream to keep skin soft.

- Bathe regularly.
- Wash hair at least once a week.
- Brush teeth after every meal and before going to bed.
- Change the water in the denture cup every day.
- Trim fingernails and toenails weekly or as necessary (Do not trim nails of someone with diabetes, loss of sensation or lack of circulation in feet or hands. Consult a physician.)
- Wear clean, laundered clothes.
- Change soiled clothing and bed linens promptly.
- Do not share towels, washcloths, toothbrushes or razors.

### **Hand Hygiene: Keep Your Hands Clean**

**Washing your hands frequently is the most important thing you can do to prevent infections.** Since it can sometimes be hard to get to a sink, keep an alcohol-based hand sanitizer handy. Don't forget to wash the hands of the person you are caring for too.

- Wash hands frequently with soap and water. Or, use hand sanitizer if hands are not visibly soiled.
- Wash hands before preparing, eating or serving food.
- Wash hands after using the toilet or changing diapers, blowing or wiping your nose, contact with your own or another person's body fluids, taking out the trash or any outdoor activities.

### **How to Wash Hands with Soap and Water**

- Wet your hands with clean running water and apply soap. Use warm water if it is available.
- Rub hands together to make a lather and scrub all surfaces, including around the nails.
- Continue rubbing hands for 40-60 seconds.
- Rinse hands well under running water.
- Dry your hands using a paper towel or clean cloth towel. If possible, use your paper towel to turn off the faucet, and then throw it in the trash. Used cloth towels can transfer germs back onto your hands.

### **How to Wash Your Hands with Hand Sanitizer**

- Use a hand sanitizer for routine hand cleaning only if your hands aren't visibly dirty.
- Apply product to the palm of one hand.
- Rub hands together for 30 seconds.
- Rub the product over all surfaces of hands and fingers (including nails) until hands are dry. It takes this long to kill the germs.

### **Protecting Others from Coughs and Sneezes**

Illness and disease can be spread by coughing, sneezing, and unclean hands. A procedure called respiratory hygiene/cough etiquette should be followed to prevent the spread of all respiratory infections, including influenza (flu). Use the following infection control measures if you know or suspect someone may be infected.

To help stop the spread of germs:

- Cover your nose/mouth with a tissue when you cough or sneeze.

- Put your used tissue in a waste basket and clean your hands.
- If you do not have a tissue, cough or sneeze into your upper sleeve, not your hands.
- Wash your hands with soap and water after coughing or sneezing. If soap and water are unavailable, use an alcohol-based hand sanitizer to clean your hands.

Please inform your team if you have symptoms of a respiratory infection and please practice respiratory hygiene/cough etiquette.

## **Taking Care of Cuts, Scratches and Wounds**

Your skin is your armor against harmful bacteria. Use moisturizing cream to prevent dryness and cracking. An open wound leaves an easy way for germs to enter your body. Keep all cuts, scratches and wounds clean and protected with a clean, dry bandage. Don't 'let it breathe' unless your nurse directs you differently. If any wound is not healing, let your nurse know.

### **To Care for Wounds**

- Clean your hands before and after changing wound dressings even if you wear gloves.
- Take special care with IV lines or other medical devices inserted into the body. If you must touch them, clean your hands first.
- Follow any specific instructions from your doctor for the care of your wounds.

## **Cleaning and Disinfecting the Environment**

A clean environment can help protect every person in your household from developing an infection.

- Do not share towels, dishes or personal items with someone who has an infection.
- Clean and disinfect as soon as possible after spills/accidents
- Remove soiled laundry and wash separately from other laundry as soon as possible.
- The diarrheal infection "C.Diff." requires disinfection with a bleach solution after cleaning.

## **General Cleaning Tips to Prevent Infection**

Routine cleaning can greatly reduce the risk of picking up germs from surfaces around the house.

- Ventilate with fresh air when possible.
- Dust and vacuum regularly – weekly if possible.
- Remember to clean commonly touched things such as doorknobs, phones, and TV remotes.
- Use a clean, dry cloth or paper towel to clean and dry all surfaces. Wiping with a dirty dishcloth, sponge or towel will only spread germs.
- Mop kitchen and bathroom floors weekly and after spills.
- Clean the inside of the refrigerator routinely with soap and water.
- Wear gloves and wash hands when cleaning birdcages, litter boxes, aquariums, etc.
- Clean soiled household items and medical equipment thoroughly. After cleaning, equipment can be disinfected with a 70% alcohol solution or a solution of one part bleach to nine parts water. Make sure the product you use will not damage the equipment.
- Add a teaspoon of vinegar to each quart of water or saline used for humidifiers or dehumidifiers.

- Clean the kitchen and bathroom counters and other surfaces with bleach-based cleaners or disinfectant cleaners.
- Clean soap dishes, denture cups, etc. weekly.
- Do not use the same cleaning cloth to clean the bathroom and kitchen.
- Do not pour mop water down the kitchen sink.
- Do not clean rags or mops in the kitchen sink.
- Disinfect mops weekly by soaking in a one part bleach to nine parts water solution for 5 minutes.
- Flush body wastes down the toilet.
- Do not clean bedpans, potty seats, urinals, etc in the kitchen sink.

### **Isolation Precautions**

Some infections require special care to prevent the spread of germs. The nurse/HHA may need to use a gown, gloves, or a mask to protect themselves and their other patients. If you have been asked to follow “isolation precautions”, please follow the instructions you receive. You may want to limit visitors until the infection is healed. Please remind your visitors to wash their hands at the beginning of the visit and before they leave.

### **Caring for your Medical Supplies**

Please:

- Do not store boxes of medical supplies on the floor.
  - o If medical supplies must be kept on the floor, please remove the supplies from the box, line the box with a clear plastic bag, and replace the supplies. This will protect them from becoming wet.
  - o Medical supplies may also be stored in clean plastic bins or clean plastic bags (not grocery bags).
- Keep the supplies clean – please wash your hands before touching them.
- Keep the supplies dry – protect them from getting wet.
- Protect the medical supplies from children, pets, and insects.
- Do not store supplies in direct sunlight.
- Do not open packages or wrappers until the item will be used.

Please notify your nurse if you received any damaged supplies or if you have any questions.

### **Cleaning and Disinfecting Medical Equipment**

Keeping medical equipment clean is an important step you can take to prevent the spread of germs. Please follow the directions provided by your care team. All medical items should be stored in covered containers off of the floor. Blood pressure cuffs, crutches, side rails, etc. can be cleaned with detergent and then disinfected.

### **Biomedical Waste Guidelines**

Some items you use while caring for yourself or your family member cannot be put in the regular trash at your house. There are two different ways to dispose of the medical trash, depending on what it is.

## Sharps Container

Florida has laws about what needs to go into a special red box, called sharps containers. These sharps containers are used for anything that could poke, stick, or cut your skin. Some examples of these items are:

- Diabetic lancets
- Razors
- Glass medicine vials

No paper, used alcohol pads, or wrappers should go in this container.

## Biomedical Waste Bags (Red Bag)

The red trash bag is for soft items that have blood or body fluids on it. Soiled bandages or items saturated such as a towel, bed sheet, or washcloth are examples of what type of items would need to be placed in the red bag.

When either the sharps container or the red bag is full, you cannot place these in your regular trash collection with the city or county. Instead, contact your nurse. The nurse will remove these items from your home or arrange for our biomedical waste company to pick them up. Please talk to your nurse if you have questions regarding biomedical waste.

## Falls Prevention Checklist

### Floors:

- ☐ Have clear pathway to walk, arrange furniture (especially low coffee tables) and other objects so they are not in your way when you walk
- ☐ Remove rugs or use double sided tape or a non-slip backing so rugs won't slip
- ☐ Pick up things that are on the floor
- ☐ Coil or tape cords and wires next to the wall
- ☐ Make sure sofas and chairs are the right height for you to get in and out of easily
- ☐ Don't walk on newly washed floors

### Stairs and Steps:

- ☐ Pick up things on the stairs
- ☐ Fix loose or uneven steps
- ☐ Have light on top and bottom of stairs
- ☐ Have light switch at top and bottom of stairs
- ☐ Make sure carpet is firmly attached to each step and attach non-slip rubber treads to stairs
- ☐ Fix loose handrail or put in new ones, have handrails on both sides of stairs
- ☐ Place strip of brightly colored duct tape to top and bottom steps

### Kitchen:

- ☐ Move items to lower shelves
- ☐ Do not climb on step stools or chairs, have someone else get items from upper shelves
- ☐ Remove throw rugs

### Bathrooms:

- ☐ Have professional mount grab bars near toilets and on both the inside and outside of your tub and shower
- ☐ Put a non-slip rubber mat or self-stick strips on the floor of the tub or shower
- ☐ Turn on night lights
- ☐ Use bedside commode/urinal/elevated toilet seat/shower chair
- ☐ Use incontinence devices
- ☐ Take medication to reduce urgency
- ☐ Remove throw rugs

### Bedrooms:

- ☐ Place lamp close to the bed where it's easy to reach
- ☐ Have night light to see way from bedroom to bathroom
- ☐ Keep phone next to bed
- ☐ Use low bed
- ☐ Place mattress on the floor or use concave mattress
- ☐ Use bed alarm

### Other things to prevent falls:

- ☐ Get up slowly after you sit or lie down
- ☐ Don't attempt to walk if you are feeling dizzy
- ☐ Always use your assistive device (walker, cane) as ordered by your healthcare provider
- ☐ Wear shoes both inside and outside the house, avoid going barefoot or wearing slippers
- ☐ Improve the lighting in your home. Put in brighter light bulbs. Florescent bulbs are bright and cost less to use
- ☐ Have uniform lighting in a room
- ☐ Keep items you use often within easy reach, including the telephone
- ☐ Use a reach stick or ask for help in reaching items that are up high or down low.
- ☐ Know where your cat or dog are, put bell on collar
- ☐ Keep emergency numbers in large print near each telephone
- ☐ Drink fluids
- ☐ Rise slowly from bed or chair
- ☐ Use Personal Alarm Device
- ☐ Ask for help when walking or getting up
- ☐ Meet with Occupational or Physical Therapist
- ☐ Wear glasses and make sure they are clean
- ☐ Manage foot problems
- ☐ Limit alcohol
- ☐ Manage pain/symptoms

### Giving Medications

Do you have questions about medications? Your hospice nurse and pharmacy are great resources for learning more about the medications and how to safely use them.



### Helpful Tips:

- Call your hospice nurse right away if you have any doubts about how to use a medication. Remember that there is a nurse available at Suncoast Hospice to answer your questions 24 hours a day, 7 days a week.
- Keep all medications out of the reach of children, pets and adults who are unable to take them safely.
- Remember the 5's:
  - **Right person** – Medications should only be taken by the person for whom they are prescribed. People living together in the same household may want to keep their medications in separate places to avoid mix-ups.
  - **Right medication** – Double check that the medication that you are taking is the one you think you are taking.
  - **Right route** – By mouth? Rectally? Under the tongue (sublingually)? Injection? Make sure you know how a medication is intended to be used.
  - **Right dose** – Sometimes dosing measurements can be confusing and instructions hard to read. Always double check. Also, talk with your nurse before crushing a pill or opening up a capsule because doing so may affect the dosing, effectiveness and safety of the medication and cause unintended side-effects.
  - **Right time** – Timing is important. Take medications at the time prescribed and following any specific directions such as “with food.”
- Tell your hospice nurse right away if you are considering stopping, starting or changing a medication. Your nurse can help you to do so safely.
- Try a medication chart or medication box to help keep track of what medications you should be taking and when.

Daily and weekly medication records can be found in this guide. Try one or create your own to see if it makes keeping track of medications a little bit easier.

## Providing Personal Care

### Skin Care

Good skin care is especially important for anyone who spends a lot of time sitting or lying down. Good skin care increases comfort and helps prevent pressure wounds and infection.

### Helpful Tips:

- Add extra cushioning to favorite chairs.
- Use a special mattress – ask your care team for more information.
- Keep bed linens dry and wrinkle free.
- Use pillows to support the body in comfortable positions.
- Use heel and elbow protectors.
- Keep skin clean and moisturized.
- Avoid rubbing reddened areas.
- Change positions in bed by turning from side to side every two hours. If able, get out of bed and sit in a chair.

- Change damp or soiled linens and clothing promptly.

#### **Signs of Skin Irritation:**

- Redness or other discoloration
- Warmth or heat
- Cracks, blisters, scrapes
- Drainage
- Bruising
- If you notice these or any other changes, please tell your hospice nurse as soon as possible.

## **Mouth Care**

Keeping the mouth moist and clean is important for comfort. The membranes of the mouth and the lips are very sensitive. Good mouth care may help prevent bad breath, dryness, infections, irritation, may help increase appetite and will surely increase comfort.

### **What You Can Do**

- Drink fluids with meals, after meals and between meals.
- Eat cold, soft, bland foods, such as ice cream, yogurt or applesauce. Try popsicles, shaved or crushed ice or frozen juices,
- If swallowing is difficult, place ice chips or frozen juices in a washcloth and suck on the washcloth.
- Avoid alcohol products, tobacco, rough foods such as hard bread, toast, or pretzels, spicy foods and citrus juices.
- Chew sugarless gum or suck on hard candy.
- Rinse mouth frequently with water.
- Apply water-based (such as KY jelly) or lanolin-based moisturizers or artificial saliva to lips every few hours.
- Avoid petroleum-based products due to concerns about infection and flammability.
- Avoid lemon glycerin swabs which can dry the mouth.
- Clean mouth and teeth using the guidelines below.
- Mouth care every morning, after meals and at bedtime may help prevent infection and soreness and help increase appetite.
  - o Check the inside of the mouth regularly for anything unusual, including:
    - Pain or tenderness
    - Redness or sores
    - Bleeding gums, rash or pinpoint dots on the mouth or tongue
    - Odors
    - Dryness
    - White patches on tongue or inside the mouth
    - Difficulty swallowing
- If you are assisting someone else with his or her mouth care, these tips might help.
  - o Gather supplies, including:
    - Soft toothbrush or toothette (pink tooth sponge)
    - Non-abrasive toothpaste
    - Small bowl or basin
    - Wash cloth
    - Glass of water, alcohol-free mouth wash or mouth solution

- o Raise the head of the bed to prevent choking on fluids.
- o Offer a sip of water to moisten the mouth.
- o Use a soft toothbrush or toothette and gentle, non-abrasive toothpaste to gently brush the teeth, gums and tongue.
- o If teeth cannot be brushed, use a mouth rinse. Avoid mouth rinses with alcohol as they can increase soreness and cause dryness. You may want to try using a solution of 1/2 teaspoon of baking soda and 1/4 teaspoon of salt in a glass of warm water to rinse the mouth.
- o Ask the person to rinse well and spit in the bowl or basin.
- o Apply lubricant, such as KY jelly, to lips every 2 hours.
- For dentures:
  - o Brush or soak in denture cleaner in the morning, after meals and at bedtimes.
  - o Replace the dentures and check the fit. Loose dentures can cause irritation in the mouth. If dentures are causing sores, remove the dentures; consult your nurse and dentist.

If you have any questions or concerns about daily mouth care or notice any unusual symptoms, call your hospice nurse.

## **Mobility**

If weakness and fatigue are making moving from place to place difficult, the following tips can help you prevent injury. Before assisting with transferring from one place to another, think through the process and break it down into simple steps. Your hospice nurse can make suggestions specific to your situation and help you find ways to promote safety and independence.

We strongly encourage you to consider your own health, strength, and safety when assisting another. Do not try anything that you aren't sure your body can handle. Even if you want to do it all, there may be limits to what you can reasonably and safely do. If you are a caregiver, keep in mind that an injury to you will not be helpful to the person in your care.

The tips here are general information and not meant as medical advice or specific instructions. Your care team will help you adapt to specific changes as they happen. Do not hesitate to call when you have a doubt, question or worry.

### **Using a Cane or Walker**

- When a person is using a cane, walk on the side opposite the cane. The cane should be used on the side of the weak leg.
- When a person is using a walker, walk behind him or her for support.
- Make sure the walker is placed within his or her reach when you leave.
- Remind the person not to grab the walker handles to help get up from a chair. The walker may tip over. He or she should always push up from the chair using the chair arms and then move his or her hands over to the walker handles after standing up.

### **Using a Wheelchair**

A wheelchair can come in handy when weakness, fatigue, or other symptoms reduce stability and endurance. Using a wheelchair can prevent injuries from falls and save energy for pleasurable activities.

### Helpful Tips:

- Remember to apply the wheelchair brakes before getting in or out of the chair.
- Rotate the leg rests and fold up the foot rests so they are out of the way before transferring someone into or out of the chair.
- Release the brakes before pushing the chair.
- When going down an incline, position the chair facing up the incline and walk backwards with it.

### Helping Someone Stand

If someone needs help getting in and out of a chair or bed, give him or her a minute or two to rest sitting on the edge before standing. Observe his or her color and facial expression. You should not help a person up if you notice any of the following:

- Suddenly pale complexion
- Excessive perspiration
- Complaints of feeling dizzy, faint, too weak or too tired

To help someone stand:

- Assist to a sitting position with feet placed flat on the floor.
- Ask him or her to scoot buttocks as far as possible to the edge of the chair or bed.
- Ask him or her to place hands firmly on the bed or the arms of the chair they are sitting in and push with his or her arms while you steady him or her with one arm around the back. It helps if the person leans his or her head forward as they stand.
- If more assistance is needed, stand in front of the person and wrap your arms around the person under his or her arms. Ask him or her to put their arms around your waist.
- Remember to use your leg muscles – not your back or neck - to do most of the lifting.

### Transferring

The following technique may be used in assisting a person to move from bed to wheelchair, to bedside commode chair or to a regular chair. Transferring someone requires strength and balance. If you have health limitations or aren't sure that you can safely offer assistance, please do not attempt it without talking to your hospice nurse or your personal health care provider. Your safety and the safety of the person you care for is at risk. Remember that as a caregiver your well-being is vital to the care of the person you are assisting.

- Position the chair as close to the bed as possible with the side arm parallel to the bed. Remember to set the brake on bed and wheelchair.
- Lower the side rail and position the bed at a level that will allow the feet to rest flat on the floor. Assist the person to stand using the suggestions above.
- Provide support as needed and turn so the backs of the legs are close to the chair. Move with the person as they ease down into the chair.
- Avoid twisting your back or trunk – take small steps to turn in place.
- Make sure his or her hips are all the way back in the seat.
- Adjust the leg/foot rests on a wheelchair to support the legs.

## **Bladder and Bowel Care**

Incontinence is the inability to control urination and/or bowel movements. Managing incontinence can prevent discomfort, skin problems and possible infection. Your care team will help you get needed supplies and equipment and offer advice specific to your situation.

### **What You Can Do:**

- Routinely offer assistance in getting to the bathroom.
- Ask the person if he or she needs to use the urinal, bedside commode or bedpan every few hours. Keep these items close by. Place in a cabinet or cover with a towel to maintain privacy.
- Use disposable briefs, pads, shields and/or protective bed pads to contain body waste.
- Check for wetness every couple of hours.
- Change soiled briefs, pads and linens as soon as possible to prevent skin irritation and breakdown.
- Clean the genital area with soap and water after each episode. Gently dry well. A barrier cream will help to protect skin.
- If taking diuretics that increase urine output, ask your nurse or physician about scheduling them early in the day to prevent the need to urinate frequently during the night.
- Ask your nurse or aide about ordering a bedside commode.

### **Using a Bedside Commode**

A bedside commode is a portable toilet that can be placed wherever it is most convenient.

- Position the commode at an angle to the chair or bed.
- Disposable pads or newspaper can be placed under the commode to protect flooring.
- Place a small amount of mild soapy water or scented disinfectant in the disposal bucket to aid in disposal and clean up after use.
- Make sure tissue or toilet paper is handy. Offer supplies for washing up genital area and/or hands after use.
- Remember to use gloves when assisting in washing and when disposing waste. Wash your hands after removing gloves.

### **Assisting with Using a Bedpan**

- Wash hands and put on gloves.
- If the person you care for is in a hospital bed, lower the head of the bed.
- Have the person roll onto one side; if applicable, make sure side rails are up on that side.
- A little powder or cornstarch sprinkled onto the lip of the pan helps it slide under the person.
- Place bedpan against buttocks with small end of pan toward the small of the back.
- Help roll onto his or her back. Bedpan will be underneath him or her.

- Raise the head of the bed or assist the person to as close to a sitting position as tolerable. Assist in bending the knees and planting the feet on the bed. Remember to leave some toilet paper.
- Provide privacy but stay nearby.
- When removing bedpan, lower head of bed and place one hand on the mattress near the bottom of the bedpan and push down on the mattress.
- With the other hand hold the pan level and pull the pan from under the person as you ask him or her to lift slightly.
- If he or she is unable to lift up, help turn over slightly, in the direction away from you, as you slide out the bedpan.
- Assist with washing thoroughly, drying and applying lotion or cream.
- Dispose of gloves and wash hands.

### Urinary Catheter Care

A urinary catheter drains urine continuously from the bladder through a plastic tube and into a collection bag. The catheter is held inside the bladder by a small balloon filled with sterile saline. The catheter eliminates the need to use a bedpan or toilet for urination, but a bedpan is still needed for a bowel movement. The following tips can provide comfort and help to prevent bladder infections.

- Wash your hands with soap and water before and after handling the catheter, tube or bag.
- Keep the bag below the level of the bladder at all times.
- Check to be sure there are no kinks or loops in the tubing and that the person is not lying on the tubing.
- Don't pull or tug on the catheter tubing.
- Wash around the catheter entry site with soap and water twice each day and after each bowel movement.
- Do not use powder around the catheter entry site.

### Emptying the Catheter Bag

The collection bag should be emptied as often as needed or at least every 12 hours. Leg bags should be emptied every 3-4 hours.

**Supplies:** Gloves, container to collect urine, alcohol swab

- Wash your hands and put on gloves.
- Remove the drainage tube from its sleeve, and point it into the container.
- Unclamp the drainage tube. Try not to touch the end of the tube to any surface when emptying the collection bag.
- Let the urine drain into a container.
- Reclamp the tube.
- Clean the tip of the drainage tube with an alcohol swab.
- Reinsert the tip of the drainage tube into the sleeve.
- Dispose of gloves and wash hands.

## Urinary Catheter Questions and Concerns

Many people have questions and concerns about urinary catheters. Some of these concerns and what you can do are listed below.

**Concern:** After catheter insertion, the person feels mild burning or a need to urinate. This is a common feeling and will diminish.

### What you can do:

- Try deep breathing, relaxation exercises or diversion activities, such as watching TV or visiting with family and friends.
- Call your nurse if these symptoms persist more than a day.

**Concern:** The urine in the collection bag is dark or amber colored. This can be caused by some medicines, some illnesses or not taking in much fluid.

### What you can do:

- Encourage and increase the fluids you offer if the person can tolerate the increased intake.
- Let your nurse know, especially if there is any increased discomfort and ask him or her to discuss reasons for this.

**Concern:** The urine in the collection bag is cloudy or foul smelling.

### What you can do:

- Let your nurse know.
- Watch for and report any other changes including fever, chills, confusion, fatigue, flank pain, burning, vomiting and restlessness.

**Concern:** No urine has drained into the tubing or bag.

### What you can do:

- Be sure the tubing is not caught under the person, kinked or looped.
- Straighten the catheter tubing. Change the person's position.
- Help him or her roll onto one side or sit up if able. Check to be sure the bag is below the level of the bladder.
- Check for wetness (leaking) around the catheter entry site.
- Check to see if the person feels pressure or pain in the lower abdomen.
- Call your nurse if there is leaking, pain or pressure or if you have tried all of the above and you still see little or no urine in the bag 6 to 8 hours after you emptied it.

## Fire and Oxygen Safety Checklist

Oxygen makes things burn much faster. When you use oxygen in your home, you must take extra care to stay safe. Here are some safety instructions to follow.

- ☐ Know the correct oxygen liter flow that your doctor ordered and do not change the setting. \_\_\_\_\_
- ☐ Do not smoke or allow others to smoke within 10 feet of you when oxygen is in use.
- ☐ NO SMOKING SIGNS should be posted in all areas of oxygen use. We can supply extra signs.
- ☐ For fire safety you need working smoke detectors. Checking them monthly may save your life. Change the batteries in alarms every year.
- ☐ Working and non-expired fire extinguisher(s) are very important to have available. If the oxygen is in use in multiple rooms, you may want to have more than one. Make sure everyone in your home knows where it is located and how to use it. When using the extinguisher remember "PASS"- Pull the pin, Aim hose at base, Squeeze the handle, Sweep across the base of fire.
- ☐ Make a plan for fire safety and escape. Keep exits clear and know two exits from any room.
- ☐ Getting out is your first priority in a fire. Staying out and safe is the second.
- ☐ Oxygen user needs to stay at least 10 feet away from all open flames or heat sources. *Examples: stoves, candles, fireplaces, space heaters, electric razors, hair dryers, cigarettes, lighters, matches....*
- ☐ Do not use flammable or petroleum-based products on your face or upper body. Water based products may be used such as K-Y jelly or Aloe Vera. **Do not use: Vaseline, Chapstick, bag balm, rubbing alcohol, paint thinners, nail polish.**
- ☐ Change the nasal cannula every 14 days and as needed if soiled or damaged.
- ☐ Oxygen concentrator needs to be placed in area of good ventilation at least 12 inches from walls, furniture, draperies, and heating sources.
- ☐ The concentrators filter should be cleaned/brushed off/vacuumed every 7 days and as needed.
- ☐ Always use distilled water in the oxygen reservoir/humidifier.
- ☐ Make sure you can hear the concentrators alarms and know how to resolve possible problems.
- ☐ Keep oxygen tanks out of the way in well ventilated areas-upright in a stand or on its side. Do not place anything flammable around any tank (example: cardboard boxes). Ask for an extra stand to keep tanks safe.
- ☐ Using Green oxygen extension tubing can help minimize tripping hazards. Always check where your tubing is before you begin to walk.

## Caring for Someone in Bed

When someone is spending most or all of the time in bed, it can be a challenge to provide basic care. Like with most things, practice does help. Remember that safety has to be a primary concern. Do not do anything that you think might cause injury to you or the person you are assisting. Know your limits and talk with your hospice nurse and home health aide about what those limits are and how to ensure the best care.



### **Electric or “Hospital” Bed**

It can be difficult to decide whether or not to try an electric or “hospital” bed. Each situation is unique.

An electric bed does offer some practical advantages in improving comfort and making care easier. Caregivers can raise or lower the bed to provide bedside care at a comfortable and safe working height. Adjusting the height can make transfers easier and safer. The head and foot of the bed can be raised and lowered for the comfort of the person in bed. Also, some people choose to put the bed in the family or living room area so that the person using the bed is included in daily activities.

### **Tips for Using an Electric Bed**

- For optimal safety, the bed should stay in the lowest position possible except when raised while giving care.
- Placement of the bed in a room should allow for movement of caregivers on at least 3 sides of the bed.
- Bedside rails should be up for those who are confused unless a caregiver is at the bedside.
- For inclusion in household activities, place the bed in a family or living room. For maximal privacy and quiet try a bedroom. Do what works for you.
- Don't let the bed be a barrier to personal contact. If you have been enjoying physical closeness and intimacy, there is no need to stop now. If the bed is too narrow for two, try positioning it next to another bed and lowering the rail on that side.

### **Moving a Person Up in the Bed**

A person in bed will often slide down toward the foot of the bed and need assistance moving up toward the head of the bed. To move a person to the head of the bed, use the following guidelines:

- Ask the person if you can help reposition him or her in bed.
- Raise the bed to a height that lets you keep your back straight.
- Lower the head of the bed.
- Remove the pillow from under the person's head.
- Have him or her bend at the knees and grasp side rails with both hands.
- Bend your knees and hips – not your waist. Stand with feet shoulder-width apart.
- Put one arm under the neck and shoulder, the other arm under the thighs.
- On the count of 3 have the person in bed push up while you slide him or her up toward the head of the bed.
- Replace the pillow and adjust the bed to a comfortable position.

### **Using a “Draw-Sheet”**

Using a draw sheet can make repositioning easier when caring for someone who is unable to move without help. A draw-sheet is a bed sheet that has been folded in half and laid across the bed on top of the fitted or bottom sheet. The draw sheet is positioned under the heaviest part of the torso of the person so that it can most easily assist you in moving him or her around in the bed.

### **To roll someone to the side:**

- Stand on the side of the bed that you want him or her to face.
- Ask the person to bend the knee that is away from you. If he or she is not able, it may help if you slide the leg to a bent position.
- Reach across and lift the draw sheet on the opposite side. Slowly lift and pull toward you, gently rolling the person toward you.

- Make sure the side rail is raised. Cross to the other side of the bed.
- Prop the person in a comfortable position by placing pillows under the draw sheet behind the back.

#### **To move someone up in bed:**

- Find someone to help. This is a two person job even with a draw sheet.
- If the person has a catheter bag, make sure that the tubing will not be pulled during repositioning.
- Tell the person what you are going to do.
- Caregivers stand across from each other on opposite sides of the bed.
- Lower the head of the bed.
- Remove any pillows.
- If able, help the person in bed bend at the knees and place his or her feet firmly on the bed. Ask the person to assist by pushing with their feet.
- Ask the person to fold his or her arms over his or her chest and tuck his or her chin.
- Each of the caregivers will then roll the sides of the draw sheet up close to the person's sides and grasp firmly.
- Bend your knees. Try not to bend at your waist.
- On the count of 3, you and the person assisting you lift up, shift toward the head of the bed and then lower.
- Reposition comfortably.

#### **Changing Sheets**

If the person you are caring for becomes too weak to get up safely, you may need to change the linens with him or her in the bed. It is helpful to think of the bed in two halves. You change one half of the bed while the person lies on the other. Then, you move him or her onto the clean half and change the other half. It is important to wear gloves if the bedding is soiled.

- If the person you are caring for can tolerate it, remove all but one pillow and make the bed as flat as possible.
- Raise the bed to height that is comfortable for you while you work at the bedside.
- Help the person roll to one side of the bed. Use the draw sheet if you have one on the bed. Be sure the rail on that side is up so he or she will not fall.
- Go to the side where you are facing his/her back. Loosen all the bedding on that side.
- Roll the soiled bedding and tuck it under the person's torso and legs.
- Put the clean linens on that side of the bed and tuck in the top, bottom and sides. If you are using a draw sheet or incontinence pad, place that on top of the sheet. Fold and tuck the clean linen underneath the roll of linen you are removing.
- Pull up the side rail on the side you've been working from and help the person roll over the roll of linen onto the clean side of the bed.
- Move around to the other side of the bed, lower the rails and pull out the dirty linen.
- Unroll the clean linen and tuck in.
- Reposition the person comfortable and cover with linens.
- Dispose of gloves and wash hands

#### **Changing a Disposable Brief or Pads for Someone in Bed**

**Supplies:** latex gloves, incontinent pads, disposable brief, clean linen if needed, wash basin and cleaning supplies or pre-moistened wipes

- Change soiled diapers, pads or linens promptly to prevent skin breakdown.
- Explain to the person in bed what you are going to do.
- Cover torso with a sheet and unfasten diaper tabs, roll the person onto one side. If the person is in an adjustable hospital bed, raise the side rail on the side away from you. The person can use the rail to help roll to the side and hold steady.
- Remove soiled materials and clean area with a mild soap and warm water.
- Apply a barrier ointment or cream.
- Place clean sheet, pad and/or diaper underneath the hip area, roll the person back onto the clean linen and fasten diaper.

## Bathing Someone in Bed

For someone who is weak or unable to get out of bed, a bed bath can be refreshing and soothing. It is also a good way to save energy for other activities and keep the skin in good condition.

Still, the idea of giving or receiving a bed bath for the first time can be intimidating. Remember, bathing is something we all do; there is no right way or wrong way. These suggestions might help make both of you more comfortable.

### Before you start:

- If pain is a concern, give pain medication and wait until it has had a chance to start working before beginning.
- Take a moment to think or talk about ways to make bath time more pleasant.
  - Music?
  - Warm towels?
  - Favorite soaps or lotions?
  - Things to talk about – old memories, funny stories, something important?
- Gather any supplies you might need before beginning. This will save you steps and time and help prevent falls.
- Prevent chilling and protect privacy by keeping any areas that are not being washed covered with towels or soft blankets. A flat flannel sheet is a good choice.
- Encourage the person receiving the bath to participate as much as possible.
- Place a laundry bag or hamper close by.
- Hold onto your sense of humor.
- Ask your hospice nurse or aide for helpful tips and supplies.

### Supplies:

- Basin
- Warm water
- Bath gel or other clean rinsing soap
- Wash cloths
- Towels
- Clean sheets
- Lotion
- Clean clothes

**Bathing:**

- Fill a basin about 2/3 full with warm water and place on a table near the bed on the side you will work from first. Place a clean wash cloth in the basin.
- If possible, adjust the bed to a comfortable working level. Adjust the head and foot to a comfortable level and lower the side rail.
- Help the person move toward your side of the bed.
- Begin with the face while the water is clean. Wash one area at a time – rinsing and drying thoroughly.
- Remove the clothing from the upper body and cover with a towel or light blanket. Wash the neck and upper body, rinse, pat dry and cover.
- Support the arm with your hand under the elbow. Wash shoulder, armpit and arms using long circular strokes. Rinse, pat dry, and cover.
- Wash the hand and gently clean under fingernails.
- Repeat with the other arm and hand.
- If the water has cooled, replace now with fresh warm water.
- Remove clothing from the lower body. Keep covered with towels, sheet, or light blanket. Uncover only the area being washed.
- Put a bath towel under the legs. Bend the knee and hold the leg with one arm. Wash with long, light strokes, rinse, pat dry and cover. Wash, rinse and dry the foot. Repeat with the other leg and foot.
- Help the person turn on his or her side facing away from you. Wash back and neck with light, long circular strokes. Rinse, pat dry, and cover. Apply lotion.
- Place a towel underneath the buttocks and roll onto the back. Wash or assist the person you are caring for in washing the genital area. Rinse, pat dry, remove damp towels, and cover.
- Apply lotion to skin or powder skin folds.
- Apply deodorant.
- Put on clean clothes and change the bed as needed.
- Offer mouth care and help brushing or combing hair.
- Lower the bed. Adjust the bed and pillows for comfort and raise any side rails.
- Wash your hands after completing the bath.

***Be sure to report any areas of concern to your hospice nurse as soon as possible. Do not rub any reddened or discolored areas.***

**Learning New Care Skills**

Just like any new skill, learning to assist someone else with hands-on personal care takes practice. Be patient with yourself. Ask lots of questions. Consider letting your Suncoast Hospice aides help out and share with you the lessons they have learned by caring for others. Remember not to do more than you feel safe doing. If you have any questions or worries, call your care team at (727) 467-7423. Anytime.

# Loss & Grief

- 8-1 Common Expressions of Grief
- 8-2 Suncoast Hospice Grief Services
- 8-2 Helping Grieving Children



## Section 8 Loss & Grief

Suncoast Hospice recognizes that this is a difficult and life-changing time. We are here to support you and your loved ones.

Keep in mind that everyone grieves in their own way, in their own time. There is no “right” way to express grief. It is a personal experience that is unique to each of us and presents itself differently each time we go through it.

Many things influence how we grieve. Our past encounters with loss and death influence our feelings. Our culture, faith, gender, and background affect how we grieve.

Take your time. Nurture yourself. Grief work is good, honest, hard work that takes time and attention.

### **Common Expressions of Grief**

Grief is personal and individual. You may go through some or all of the feelings described below.

- **Shock or Numbness**
- **Longing**
- **Sadness**
- **Regret and Guilt**
- **Anger**
- **Sleeplessness**
- **Forgetfulness**

*“I went through all the phases of grief – sometimes I still get depressed. The counselor at Suncoast Hospice helped me deal with all those feelings. She reassured me that my feelings are normal and that I was making progress when I couldn’t tell I was...”*

 Stephanie Dove

## **Suncoast Hospice Grief Services**

### ***Does Suncoast Hospice offer support and counseling services to help me cope with change and loss?***

Hospice care involves counseling support to help you and your family adjust to many changes you and they may be experiencing. Many people anticipate feelings of loss and will need support through the journey and so individual counseling is available at Hospice. After a loss, grief support services such as mailings, phone calls and visits are available as desired. These services may be accessed by contacting your team counselor.

## **Helping Grieving Children**

Illness and death affect all members of the family – young and old. Children also experience grief and need opportunities to mourn. Keep in mind that children are not miniature adults. Because of the developmental differences between children and adults, children show their grief differently. Understanding these differences will help you support the child who is grieving.

Between the ages of birth and two, children have no real understanding of a death, but they will have a sense of the parent's loss. They can also sense the emotional changes in the home. Typically, a child this age will show signs of irritability, changes in eating, crying or bowel and bladder habits.

From ages 3 to 5, children begin to have a limited concept of death. They still don't see death as being permanent and will often ask the same questions repeatedly to begin to make sense of the loss. It is important for the adults in the child's life to continue to "tell" the story as often as needed. Pre-school age children are typically capable of showing sadness for only short periods of time. It is also not unusual to see a return to earlier behaviors such as thumb sucking or clinginess. Young children also may become more fearful and have a great need for security. It is particularly important to keep their same routine.

Older children, ages 6 to 10, can better understand the finality of death and have a great need for truthful information, but they are often unprepared for the length of the grief process. Children this age may also begin to understand other possible consequences of death, such as loss of a home or other financial problems. When coping with the loss of a significant person, these children may have angry outbursts and act out in socially inappropriate ways. It is also not unusual to see children who perform well in school have school related problems.

Pre-adolescent and adolescents understand very well the finality of death and the impact of the death on the family. Developmentally, these children are beginning to separate emotionally from their family and do not always talk about their feelings with adults. They may show signs of depression or anger. They may also return to earlier stages of behavior or become involved in dangerous behaviors such as substance abuse. With this age group, in particular, it is important to seek out counseling assistance, if warranted.

### **Talking with Children about Loss and Grief**

Children need clear, simple and honest answers to help them cope with loss and grief. Children can thrive when given information and support that is appropriate for their age and development. Too much information will confuse them and create anxiety. Ask children questions in order to figure out what they already know or believe. Encourage them to talk openly and ask questions.

- **Begin at the child's level**
  - Be aware of the developmental level of the child and how this affects his/her reasoning and understanding.
  - Tell the truth; honesty fosters trust and security. Involving children in the situation and letting them know what is happening can be very supportive and lead to improved coping skills.
- **Be guided by the child's questions**
  - Create an environment in which the child feels safe and secure and is able to ask questions.
  - Take time to clarify what question was asked.
  - Provide opportunity for the child to express his/her feelings.
  - Encourage the child to identify feelings related to the death, memories of loved ones and hopes for the future.
- **Encourage feedback**
  - Develop a plan to make sure the child's needs are met.
  - Keep the child's daily routine as normal as possible. Children need reassurance, love, care, honesty, consistency and structure.
  - Set aside time when you will not be interrupted.
  - Let the child know that you have plenty of time to listen.

There are many creative ways to help children express their feelings. Most children respond to warm loving adults who listen to their feelings and provide a warm, safe, nurturing environment. Books and story telling help children understand the many different ways that a "story" may end. Popular literature, as well as books specific to death and dying, are helpful. Art in many forms helps children express themselves. For example, children can draw a picture of the funeral, how they are feeling now, their family, or anything else that would help express a feeling. Music and puppetry help with re-telling the story and are particularly useful with young children.

- Ask what they know and what they want to know. Don't assume.
- Be honest about the reason for your tears and sadness.
- Focus on reality – their vivid imaginations create answers that can be far worse.
- Make time just for them.
- Watch their play for clues about how they are feeling.
- Expect that expressions of their feelings will come and go depending on many factors including age and attention span
- See the Resources section of this care guide for a list of books, videos, and Websites that you might find helpful. Also, Suncoast Hospice community libraries have books for grieving children and for the adults who care for them. Visit the libraries at Suncoast Hospice's community service centers or call (727) 467-7423 for more information.



# Resources

- 9-1 Suncoast Hospice Community Lending Libraries
- 9-1 Suncoast Hospice Resale Shops
- 9-2 Local and Governmental Resources



## Section 9 Resources

This section lists some of the many resources available locally. If you have any questions, please ask a member of your care team for information.

### **Suncoast Hospice Community Lending Libraries**

**The libraries are available to anyone in our community who needs information and resources for living with illness, coping with grief or support for caregiving.**

The libraries offer materials on a variety of subjects including:

- Aging
- Advance Care Planning
- Caregiving
- Spirituality & Inspiration
- Grief & Loss
- Books for Children
- Books about Children's Concerns
- End of Life
- Complementary Therapies

The libraries are supported by community book drives. Community members may suggest books that they have found helpful or meaningful and may even write reviews to share with others.

We invite you to visit the library at your Suncoast Hospice Community Service Center. The libraries are open Monday through Friday from 9 a.m. to 5 p.m. Our team of volunteers and staff will be happy to help you browse our resources and find the materials you need. If you need assistance with transportation, please ask your care team.

#### **Suncoast Hospice Community Service Center Library Locations:**

5771 Roosevelt Boulevard, Clearwater, FL 33760

2675 Tampa Road, Palm Harbor, FL 34684

3050 1st Avenue South, St. Petersburg, FL 33712

If you have a question about the library, book drives or resources available, please call (727) 467-7423 and ask for the library staff.

### **Suncoast Hospice Resale Shops**

If you are looking for budget-friendly clothing and household items or are looking for a way to help support care for our community, stop by and visit the volunteers at one of our three Resale Shops. The Resale Shops offer a way for the Suncoast Hospice Foundation to provide service to hospice families in need and raise funds to support the many programs offered by Suncoast Hospice and Empath Health.

#### **Resale Shop Locations**

26252 US Highway 19 North, Clearwater, FL 33761 (727) 286-4483

1478 South Belcher Road, Clearwater, FL 33764 (727) 538-4483

3533 49th Street, St. Petersburg, FL 33710 (727) 527-4483

## **Local and Governmental Resources**

The following organizations are listed as a guide to some of the services available in Pinellas County. Suncoast Hospice does not endorse or recommend any specific products or services provided by public or private organizations listed on the following pages.

**Call Suncoast Hospice at (727) 467-7423. Anytime.**

### **Tampa Bay Cares: 24 Hour Information and Referral**

**Dial 2-1-1 [www.tampabaycares.org](http://www.tampabaycares.org)**

#### **Abuse/Domestic Violence**

CASA (Community Action Stops Abuse) ..... 895-4912  
Florida Abuse Hotline ..... 1-800-962-2873

#### **Counseling/Mental Health**

Pinellas Emergency Mental Health Services ..... 541-4628  
Gulf Coast Community Care Geriatric Crisis Response Team ..... 538-7460  
Suncoast Hospice Community Bereavement Programs ..... (727) 467-7423

#### **Disability Services**

Deaf and Hearing Connection ..... 399-9983  
Pinellas Association for Retarded Children ..... 345-9111  
Upper Pinellas Association for Retarded Citizens ..... 799-3887  
Division of Blind Services, State of Florida ..... 893-2341  
Goodwill Industries ..... 523-1512  
Lighthouse of Pinellas for the Blind and Visually Impaired ..... 544-4433

#### **Elder Services**

American Association of Retired Persons ..... 1-888-687-2277  
Area Agency on Aging ..... 570-9696  
Gulf Coast Jewish Family Services ..... 538-7150  
Neighborly Senior Services ..... 573-9444  
Senior Helpline of Florida ..... 1-800-963-5337  
Social Security Administration ..... 1-800-772-1213

#### **Emergency Shelter/Food/Assistance**

American Red Cross, North Pinellas ..... 446-2358  
American Red Cross, South Pinellas ..... 898-3111  
The Salvation Army ..... 822-4954  
St. Vincent dePaul Society, Clearwater ..... 461-9598  
St. Vincent dePaul Society, St. Petersburg ..... 825-0725  
United Way of Tampa Bay ..... 535-3545

#### **Pinellas County Department of Social Services**

Clearwater ..... 464-8400  
St. Petersburg ..... 582-7781

#### **Health**

AIDS Services Association of Pinellas ..... 328-3268  
Alzheimer's Association ..... 1-800-772-8672  
Suncoast Hospice ..... (727) 467-7423  
Pinellas County Health Department ..... 842-6900

## **Organ and Tissue Donation**

Southeast Tissue Alliance (SETA) ..... 1-866-432-1164

## **Recovery**

Alcoholics Anonymous ..... 530-0415  
Al-Anon ..... 548-6811  
Narcotics Anonymous ..... 547-0444

## **Suicide Hotlines**

2-1-1 Tampa Bay Cares ..... Dial 211  
National Suicide Prevention Lifeline ..... 1-800-273-TALK (1-800-273-8255)

## **Transportation**

American Red Cross ..... 898-3111  
DART Dial-A-Ride Transit ..... 540-1800  
PSTA Pinellas Suncoast Transit Authority ..... 540-1900

## **Veteran Services**

VA Benefits Information ..... 1-800-827-1000  
Bay Pines VA Healthcare Center ..... 398-6661  
James A. Haley Veterans' Hospital ..... 813-972-2000

## **211 Tampa Bay Cares**

Dial 211 or visit [www.211tampabaycares.org](http://www.211tampabaycares.org). 24-hour information and crisis helpline that will help connect you to local services such as support groups, respite providers, etc.

## **Elder Helpline of Florida**

### **Florida Department of Elder Affairs**

Starting point for local information and referral to agencies and organizations providing needed services to elders. 1-800-963-5337 (1-800-96-ELDER)

For information about or referral to a service provider outside of Florida, contact the Eldercare Locator Service 1-800-677-1116. [www.eldercare.gov](http://www.eldercare.gov)

## **Florida's Disabled Parking Program**

[www.hsmv.state.fl.us](http://www.hsmv.state.fl.us)

## **Lighthouse of Pinellas for the Blind and Visually Impaired**

727-544-4433 in Largo [www.lighthouseofpinellas.org](http://www.lighthouseofpinellas.org)

## **Long-Term Care Ombudsman Program, Dept. of Elder Affairs**

Protects the rights of residents of long-term care facilities and assures that residents receive fair treatment and quality care.

1-888-831-0404

## **Medicaid Office Area 5 (Pasco-Pinellas)**

### **Agency for Health Care Administration**

1-800-299-4844

***To report suspected Medicaid fraud, you are asked to call toll-free 1-888-419-3456.***

***The Agency for Health Care Administration describes Medicaid Fraud as follows:***

Medicaid fraud means an intentional deception or misrepresentation made by a person with the knowledge that the deception could result in some unauthorized benefit to him or her or some other person. It includes any act that constitutes fraud under applicable federal or state law as it relates to Medicaid. The office of the Inspector General at the

Agency for Health Care Administration accepts complaints regarding suspected fraud and abuse in the Florida Medicaid system by phone at 1-888-419-3456 or on the Agency web site at [http://ahca.myflorida.com/Executive/Inspector\\_General/complaints.shtml](http://ahca.myflorida.com/Executive/Inspector_General/complaints.shtml)

### **Nursing Home Compare**

Provides detailed information about the past performance of Medicare and Medicaid certified nursing homes in the U.S. 1-800-MEDICARE [www.medicare.gov](http://www.medicare.gov) click on "Site Updates" then "Compare Nursing Homes in Your Area"

### **Pinellas County Talking Book Library**

1330 Cleveland St.  
Clearwater, FL 33755  
727-441-9958  
TDD 727- 441-3168  
<http://www.pplc.us/tbl>

### **Senior Helpline**

#### **Florida Department of Elder Affairs**

Starting point for local information and referral to agencies and organizations providing needed services to elders. 1-800-963-5337 (1-800-96-ELDER)  
For information about or referral to a service provider outside of Florida, contact the Eldercare Locator Service 1-800-677-1116. [www.eldercare.gov](http://www.eldercare.gov)

### **Suicide Prevention**

#### **211 Tampa Bay Cares**

Dial 211 or visit [www.211tampabaycares.org](http://www.211tampabaycares.org). 24-hour information and crisis helpline that will help connect you to local services such as support groups, respite providers, etc.

#### **National Suicide Prevention Lifeline**

24-hour information and crisis help. [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org) or 1-800-273-TALK (1-800-273-8255)

### **United States Department of Veterans Affairs**

Information about benefits and programs for US military veterans and their families. 1-800-827-1000 [www.va.gov](http://www.va.gov)

# Suncoast Hospice Foundation

10-1 Circle of Caring

SUNCOAST HOSPICE  
FOUNDATION



10



## Section 10 Circle of Caring



### Empath Health Circle of Caring

#### A Grateful Family Program

We are honored to care for your loved one.

At Empath Health, we care for people often during some of the most difficult and complicated times in their lives. And we know there is a special connection formed between our care teams and their patients, clients or participants. Sometimes the care team becomes part of your family. This is why we created the **Circle of Caring – A Grateful Family Program**.

It is natural and healing to want to say thank you. Thank you for **caring**. Thank you for providing **compassionate care**. Thank you for providing **hope through innovative services**. Thank you for providing **inspiration through endless encouragement**.

Our care teams members are humbled by the many ways they are thanked by those they have cared for or their loved ones.

We encourage you to send a token of your thanks and become a part of Empath Health's Circle of Caring in support of your loved ones care and in recognition of the care team. Your words of kindness and appreciation are priceless.

Empath Health is proud of the life-changing care our teams provide. A monetary donation in memory of your loved one is greatly appreciated and we will always share your words of gratitude with the team.

**Visit [CircleOfCaring.org](http://CircleOfCaring.org) or use the  
envelope provided in the back of this handbook  
to recognize your caregivers**