



HOSPATUS
HEALTH®

Care Guide



888-295-4239 | HOSPATUSHEALTH.ORG



CAHPS Awareness Initiative

(Consumer Assessment of Healthcare Providers and Systems)

Hosparus Health is grateful for the opportunity to care for your loved one and to share this journey with you. It is our hope to exceed your expectations of your family member's care and service.

We encourage you to assist us in improving the quality of our care by sharing your comments and experience with us.

Following our service delivery, you may receive a survey, we would greatly appreciate if you would take the time to complete this important questionnaire. We realize this may be a difficult time and reflecting on your loved one's last weeks and days may be emotional for you, but we hope when you are ready, you will respond.

If you have any questions, call the Patient Care Line at 888-295-4239.

This booklet was written to answer some of the questions people ask once they have chosen hospice services. As you read this booklet, mark the sections important to you. If you have further questions, feel free to talk with any of your team members or call Hosparus Health.

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INTRODUCTION

Welcome to Hosparus Health

You, or a person in your life, has been admitted to Hosparus Health for hospice care and services. We know this can be a very stressful and emotional time for you. You receive a lot of information at the time of admission, which may be overwhelming. This Care Guide is intended to review some of that information and to answer questions you may have in the future. Please keep this Care Guide in a handy location where you can refer to it often. Your team will refer to this important Care Guide during visits to assure you have the information and support needed for this journey. In addition to this Care Guide, helpful information can be found in the our *Overview of Our Services* booklet, and on our website www.HosparusHealth.org.



Hosparus Health wants you to be comfortable, confident, safe and feel respected as you are cared for or as you provide care. We will help you focus on a comfortable and meaningful life experience as you go through this difficult time. Hosparus Health will manage symptoms that often cause discomfort for those at the end of life, and assist with your emotional, spiritual, and psychosocial needs. Our mission is to enhance your quality of life through our core values:

- **G**ratitude
- **R**espect
- **A**ccountability
- **C**ompassion
- **E**mpowerment
- **S**ervice Excellence

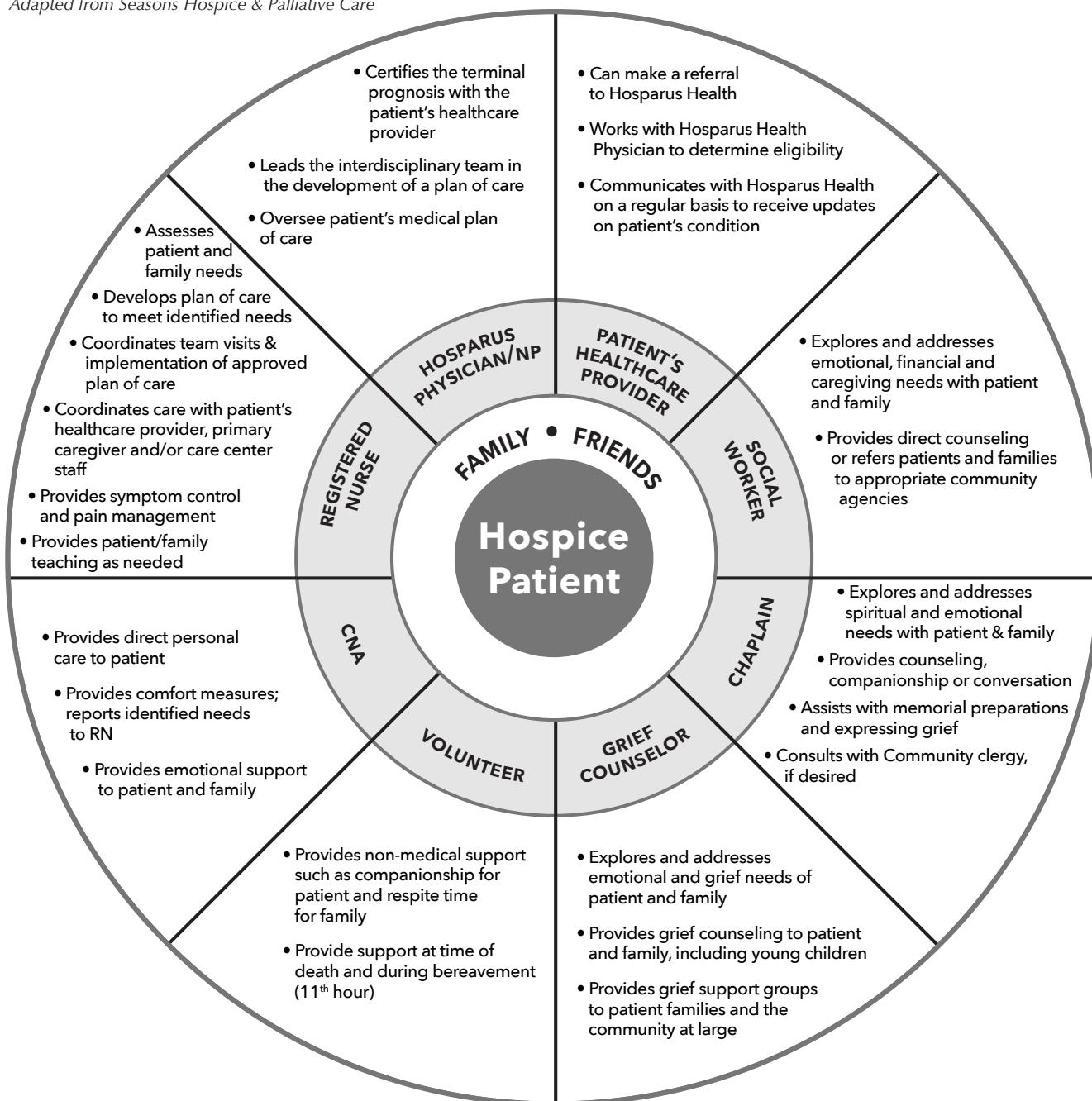
Our goal is to understand and respond to your unique needs and exceed your expectations. We are committed to honoring differences and providing excellent service.

Settings of Care

Hosparus Health care primarily focuses on home care. Whether your home is in a private residence, in an Assisted Living Facility (ALF), a Personal Care Facility (PC) or a nursing home we will be there to support you with care and services. When home care isn't possible, we can provide services to you in the Hosparus Health Inpatient Care Center (HICC) or in a hospital in your community or symptom based care. This guide will discuss hospice care and services unique to each of these settings.

The Hosparus Health Team Circle of Care

Adapted from Seasons Hospice & Palliative Care



This Care Guide will offer you guidance in working with your Hosparus Health team so that you will feel confident and prepared for situations that may arise.



The Plan of Care

Your Hosparus Health team will talk to you and your family about your wishes and goals, as well as any problems or needs you may have related to living comfortably and safely with your illness. You and your team will work together to determine the most appropriate actions to address problems, issues, and opportunities. Hosparus Health calls this your Plan of Care. Each of your team members will review your plan with you on their visits and together you will evaluate how well the actions are working. Your plan of care will be revised as needed. It is very important that you talk to your Hosparus Health team about your concerns, as well as any fears or wishes you have, and to always let your team know what you need and what you expect. They will work with you in developing a Plan of Care that assures confidence and satisfaction with our services and attention. Our goal is to always provide excellent care and services.



Services

In addition to your Care Team, your hospice benefit most often allows Hosparus Health to provide durable medical equipment (DME), supplies, medications and treatments which are necessary for comfort and care related to your hospice diagnosis. Some of these services need to be pre-authorized by Hosparus Health. Always be sure you let the nurse on your team know of any new medications, treatments, lab work, x-rays, other medical tests and physician appointments. Some of your medications, tests and procedures may not be related to your hospice diagnosis and therefore will not be covered by Hosparus Health or your hospice benefit. The Hosparus Health Pre-Authorization Department will work with you and your Care Team to be sure care and services are provided and payment is determined and explained to you in a timely manner.

Your Hosparus Health Team

Your Hosparus Health Care Team along with you, your family, and your doctor, develops your Plan of Care.

Your Hosparus Health nurse, social worker and/or chaplain will contact you and visit you within five days of your admission to Hosparus Health. If certified nursing assistant (CNA) services were arranged at the time of the admission, you may receive a call from your CNA. If you need to speak to someone from your team and have not heard from anyone, please call Hosparus Health Customer Support at the Patient Care Line number for your area listed on page 9. They will assist you with your need or will contact the appropriate team member to return your call.

After that first visit with your team, each member of your team will contact you regularly and provide care based on your goals and needs, usually during core business hours: Monday - Friday, 8:30 a.m. – 5:00 p.m. **Hosparus Health Customer Support is available 24 hours a day, 7 days a week to answer questions or meet urgent needs when your Hosparus Health team is not available.**

We Want to Hear From You

You will soon receive a satisfaction survey regarding Hosparus Health services. We appreciate your feedback so that we can continue to improve our services to patients and families.

What If We Have A Concern or Complaint

Our team members want to provide the very best quality of care and we invite your comments about our services. Often we use surveys or interviews to get your feedback, but you can also call us at any time. We strive for you to be very confident in our services and want to know when you are not.

If you have concerns, questions or suggestions, please talk with any Hosparus Health Team member or call the Patient Care Line at 1-888-295-4239. Our team members are trained to listen with respect and appreciation for your willingness to help us improve. You do not need to worry about a negative response from us or about getting anyone in trouble. We are here to serve you and want you to feel very satisfied with the service you receive. If after discussing your problem with us you are still not satisfied, you may call:

The Compliance Line

If you have concerns about patient care or safety, report your concerns to The Compliance Line at 1-866-842-7172. The Compliance Line is operated by an independent third party administrator. You can feel confident calling The Compliance Line. Your call can be anonymous and will be reported to Hosparus Health.

In Kentucky
Kentucky Licensure and Regulation
502-595-4079

In Indiana
Indiana State Department of Health
1-800-227-6334

If your concerns are not resolved through the organization, you may contact Joint Commission's Office of Quality Monitoring by phone at 1-800-994-6610 or email complaint@jointcommission.org.

Hosparus Health complies with all state and federal regulations related to hospice benefits. Please call the Patient Care Line at 1-888-295-4239 and ask for our Vice President of Compliance and Organizational Excellence, if you have questions or concerns related to our compliance regulations.

Contacting Hosparus Health - Important Numbers and Emergency Information

Your Patient Access Code and Your Privacy

At the time of admission to Hosparus Health, you were given your patient access code. This code is written on stickers and/or cards the Admission Nurse gave you. This code is used to assure your protected health information (PHI) is safeguarded at all times. Anytime you or anyone else calls Hosparus Health for information about you, Hosparus Health staff members will ask for your access code. You must provide the Patient Access Code when you call. Please keep this code confidential and in a safe place. Share it only with those people you want to be able to receive your health information. If you have questions, please speak to your Hosparus Health team or a Customer Support Team member.

Hosparus Health Help is Only a Phone Call Away

Customer Support Team members are in the office to help you 24 hours a day, 7 days a week. They can address an urgent need or get a message to a member of your team.

You can always reach someone by calling the

Patient Care Line – 1-888-295-4239 or:

- | | |
|--|--------------|
| <input type="checkbox"/> Hosparus Health Bowling Green: | 270-796-2076 |
| <input type="checkbox"/> Hosparus Health Campbellsville: | 270-763-4239 |
| <input type="checkbox"/> Hosparus Health Elizabethtown: | 270-763-4239 |
| <input type="checkbox"/> Hosparus Health Louisville: | 502-813-2659 |
| <input type="checkbox"/> Hosparus Health Southern Indiana: | 812-542-2811 |



When you call us with a question or need assistance, please be prepared to provide us with the patient access code, the patient's name, your name and a contact number for you, the caller (in case we get disconnected or need to return a call). From there, please be prepared to describe the need or problem. The Customer Support Team member will ask additional clarifying questions in order to provide you with the best care and services to meet the need. This will assist us in helping you quickly and ensure you feel very confident with our services.

Only Use the Phone Numbers Listed Above to Contact Your Team Members

When your Hosparus Health Team members call you, their cell phone may show up as an unknown or blocked number or an alternate office number may show up on your caller ID. Please do not use these numbers to reach your team members as your call may be missed if they are off-duty or out of cell phone range. Always use the Patient Care Line numbers listed above to reach your Hosparus Health Team members so we are assured your needs are met promptly.

Patient Care Line

Your Hosparus Health Team will discuss your routine visit needs with you and schedule those visits. At times, you may have an urgent or unanticipated need that cannot wait for a call or a visit from your Hosparus Health Team. If this happens, please call the Patient Care Line at 1-888-295-4239. A Hosparus Health Customer Support Team member will discuss the situation with you and work with you to determine how to best meet your needs.

Call Hosparus Health First and Not 911!

We can often treat sudden pain or other symptoms at home and avoid unnecessary trips to the emergency room. If we cannot take care of the problem, we will notify your doctor and discuss other options. Talk to your Hosparus Health Team about things you can anticipate arising that would make you feel you need to call 911. Things to think about include: What would an emergency look like to you? What is your greatest fear? What is it that keeps you awake at night?

Your team can usually prepare you for handling these incidents and give you steps to take if needed. They can help you understand what to expect and remind you how to contact them or the Customer Support Team. Hosparus Health can usually spare you unplanned and uncomfortable trips to the hospital emergency room where you may encounter long waits and unwanted procedures. Please give us a chance to help you in your home first.

SUGGESTIONS FOR WHEN TO CALL HOSPARUS HEALTH CUSTOMER SUPPORT



Call Hosparus Health immediately if:

- You think you need to call 911.
- Death occurs.

TEAR OUT
↑

Your Team: _____ Patient Care Line: 1-888-295-4239

Nurse: _____

Social Worker: _____

Chaplain: _____






CNA: _____











Volunteer: _____

Customer Support answers calls “24/7” and are an important part of your team.

“When To Call” Guide

This plan is only a guide and may not apply to all situations. This plan is not intended to override your decisions in seeking care. Examples of when to call Hosparus Health:

CONCERN OR NEW SYMPTOM	CALL HOSPARUS HEALTH WHEN:
 I have trouble breathing	<ul style="list-style-type: none"> • Swelling (of hands, feet, abdomen) is getting worse • Cough is worse • Harder to breathe when lying flat • Changed color, thickness, odor of sputum (spit)
 I see blood	<ul style="list-style-type: none"> • Change in urine color or foul odor, or urine appears bloody • Bleeding, such as from gums, nose, mouth, rectum or surgical site • Unusual bruising
 Trouble thinking	<ul style="list-style-type: none"> • Confusion or difficulty concentrating • Restless or agitation
 I feel sick to my stomach	<ul style="list-style-type: none"> • Throwing up – if a new symptom • Nausea unrelieved by medication
 I hurt	<ul style="list-style-type: none"> • New pain or pain is unrelieved by medication • Unusual bad headache

CONCERN OR NEW SYMPTOM	CALL HOSPARUS HEALTH WHEN:
 I have fever or chills	<ul style="list-style-type: none"> • Temperature is at or above 101 degrees F • Any fever lasting 72 hours • Chills / can't get warm
 I am dizzy	<ul style="list-style-type: none"> • Trouble with balance
 I fell	<ul style="list-style-type: none"> • Any fall whether injured or not • If I fall and can't get up, I will also contact my "call buddy": (name)_____ (phone)_____ <p>If I fall and can't get up and call an outside agency such as the Fire Department or EMS, I am aware that this service may not be covered by the hospice benefit.</p>
 Bowel troubles	<ul style="list-style-type: none"> • Diarrhea – more than 3 times/day • Black/dark OR bloody bowel movement • No bowel movement in 3 days • No ileostomy output in 24 hours • No colostomy output in 3 days
 Trouble Urinating	<ul style="list-style-type: none"> • Leaking catheter • No urine from catheter in 12 hours • No urine (passed water) in 12 hours • Burning feeling while urinating • Belly feels swollen or bloated and urge to urinate
 I am anxious or depressed	<ul style="list-style-type: none"> • Always feeling anxious • Trouble sleeping • Increasing confusion • Increasing agitation • Increasing hopelessness
 My wound changed	<ul style="list-style-type: none"> • Change in drainage amount, color or odor • Increase in pain at wound site • Increase in redness/warmth at wound site • New skin problem • Temperature is above 101 degrees F
 I am suddenly unable to move	<ul style="list-style-type: none"> • Unable to move arm or leg • Sudden drooping of one side of face, or drooling
 I have extreme swelling	<ul style="list-style-type: none"> • Sudden or extreme swelling of the neck, upper chest, and/or face
 I am thinking about suicide or self harm	<ul style="list-style-type: none"> • Thoughts of suicide or self harm

WHAT IF I LIVE IN A FACILITY?

I Live in an Assisted Living Facility

Hosparus Health provides the same level of care and service to you in an Assisted Living Facility (ALF), as is offered to people living in a private residence. Your Hosparus Health Team is familiar with your ALF and will discuss what the facility staff can provide in the way of care and support as ALFs vary in the services provided by them. Generally, residents and their families are responsible for their own day to day care.

It is important that you and your family discuss with your Hosparus Health Team your plan to provide additional caregiving as your needs increase. Your team will work with you, your family, friend or other primary caregiver to teach them how to provide your care as change occurs in your situation and work with you and the facility to decide other options that may be available to you.



I Live in a Personal Care Facility

Hosparus Health provides the same level of care and service to you in a Personal Care Facility, as is offered to people who live in a private residence. Personal Care Facility regulations can vary from state to state, and your Hosparus Health Team can discuss with you and the facility the requirements for living there as a Hosparus Health patient. Personal Care Facilities will have professional nursing staff who can give you medicine and provide more care than in an ALF. Please talk to your team about your plan for caregiving when your needs increase.

I Live in a Nursing Home Facility

Hosparus Health provides the same level of care and service to you in a Nursing Home Facility, as is offered to people who live in a private residence. Your Hosparus Health Team will work with you and the facility staff to optimize your care and support in the facility. Hosparus Health services enhance the care you are already receiving from the facility staff. Hosparus Health serves as a resource for facility staff in pain and symptom management and addressing emotional and spiritual issues you or your family may encounter.

Hosparus Health is available 24 hours a day, 7 days a week for pain and symptom consults and visits. Your team will include the facility staff in their care planning with you and your family. Your Hosparus Health Nurse will consult with and make recommendations to your facility doctor for medication changes that will keep you comfortable. You will be offered a Hosparus Health CNA to provide personal care in addition to what the facility staff provide. Your Hosparus Health Social Worker and Chaplain will provide support and counseling to you and your family and will communicate with facility staff to improve your quality of life.

The Hosparus Health Physician is available for consultation with your facility doctor, and Hosparus Health Volunteers may be assigned for companionship.

Hosparus Health will see that you have the medication, equipment, and supplies appropriate for your care. Your Hosparus Health Team will attend care plan meetings at the facility and will visit you routinely to monitor your care and comfort.

WHAT DOES THE HOSPARUS HEALTH TEAM DO WHEN THEY VISIT?

The Visit

Every visit is important and Hosparus Health wants you to know what to expect so you are prepared and feel your visits are meaningful and helpful to you. We suggest that you write down questions you have before the visit. This Care Guide provides pages in the back for you to jot down questions or concerns. Having this Care Guide close at hand during the visit will also help as your team discusses certain topics with you.

The team member will call you to schedule your visit. He/she will ask how you are feeling and if you have any concerns today. The team member will also ask if you need any supplies or equipment. Your first visit will usually last an hour to an hour and a half. Other visits will be shorter, usually less than one hour.



- Your Hosparus Health Team members visiting you should have a Hosparus Health ID badge. Your team members will always wear a Hosparus Health ID badge. If this is a first visit, they will introduce themselves to you and will tell you a little bit about their experience and their role in your care. They will also let you know how long they plan to be with you and what they will focus on during the visit.
- If they do not have an ID badge or if you are unfamiliar with that person, call the Patient Care Line at 1-888-295-4239 to confirm their identity.
- Your team members will have a hand-held device which contains Hosparus Health's most recent information about you and your care. Throughout the visit, the team member will refer to the computer for information and will enter new information as needed. This is very important so that all team members have accurate and up to date information about you and your care.
- The team member will ask how you are feeling, what you feel you need today, and what is your greatest concern right now. Your Hosparus Health Team is there to listen to you, so please share anything you feel is important for them to know about you and how you are feeling. A team member may discuss how other members of your team can be of assistance and can review how to contact them or place a call directly on your behalf to request team member assistance.
- Each team member will complete an assessment based on their training and expertise. This assessment helps to identify whether your current plan of care is addressing your needs or identify needed adjustments.
- Your CNA will provide personal care, such as bathing, and may teach those caring for you how to provide personal care, such as how to manage toileting needs.
- Your nurse may check your blood pressure, observe for any swelling or skin problems, and ask about your appetite, sleep or any pain. You will be given instructions on medication and shown how to provide certain care. A medication record will be left in your home and your nurse will review your medicines with you.
- Your social worker and chaplain may ask about your emotional, spiritual or other support and practical needs.
- Other than your caregiver/s or Hosparus Health Nurse, no one else is authorized to handle or organize your medications. Ask anyone who handles your medicines to do so in front of you.
- At the end of the visit, your team member will review important points from the visit, may review the process for reaching Hosparus Health for any concerns, and will schedule your next visit. At any time you need to reschedule a visit, call the Patient Care Line at 1-888-295-4239 and the Hosparus Health staff will notify your team member so your team member can contact you.
- A nurse practitioner or physician may visit you to evaluate your condition.

- A Hosparus Health Manager may visit with your Hosparus Health Team member to observe the care you receive. During this visit, the manager may ask a few questions or participate in providing care. These managers are part of your Hosparus Health Team. Their visits help to ensure that your team has the knowledge, support and resources they need to provide exceptional care.

Working with Your Team

Since your primary Hosparus Health Team knows you and your family best, please review the following questions and concerns with them so you can prepare or prevent emergency situations:

- Do I have enough medicines to last for the next four days?
- Do I have enough supplies to last for the next four days?
- How long does it take for the medicines (for pain, nausea, shortness of breath, etc.) to work? What should I do if these symptoms continue?
- How often can I give/take medicines for pain, nausea, shortness of breath, etc.?
- If there is a sudden change in condition, what should I do?
- When do I call Hosparus Health, and when do I call my doctor or 911?
- When will the nurse, social worker, chaplain be out to visit again?
- Other questions?

By having these answers, you can feel very confident in your care and spend more time with family and friends. We want to provide excellent service to you.

Please share and describe to us any ways your condition has changed in the past few months.



WHAT IF I WANT TO TRAVEL OR TAKE A VACATION?

Your team will assist you with plans so that you have the services you need as you travel, including coordination with a local hospice, as well as any medications or supplies you might need.

Notify your team about your travel plans as far in advance as possible. Advance notice will allow Hosparus Health to continue meeting your needs and make arrangements with providers in the area you will visit.

WHAT TO EXPECT AS YOU MOVE THROUGH THIS JOURNEY



We recognize that the end of life can be a roller coaster of physical, emotional and spiritual issues. There is no right or wrong way to experience this. Our goal is to find out what is most important to you and help you reach your goals. Just as we tend to your physical needs, we know that you will need emotional and spiritual support to deal with grief, loss, and the changes this experience brings. We want you and your family to feel very confident about your care. Our trained professional teams are experts and are here to listen, support and guide you and your family through this experience. This is your journey and we honor your unique values, wishes and needs.

For the Caregiver

Getting enough rest and nourishment is beneficial for caregivers. It requires a lot of energy to provide care through this time. Allow friends and family to help and remember it is okay to ask for help. Your team social worker can assist you with identifying support, coping and self-care strategies to help you continue to find the energy and strength to provide caregiving in a way that is also healthy for you.

Hosparus Health would like to thank you for the privilege of assisting you with the care of your loved one.

TO BE ABLE TO TAKE CARE OF ANOTHER, YOU MUST FIRST TAKE CARE OF YOURSELF.

Tips of taking care of yourself:

- Get enough rest, perhaps naps during the day. Conserve your energy.
- Exercise and take breaks. Even a short walk helps sleep and gives energy.
- Make sure you are eating.
- Pay attention to what your body is telling you. Is it tired, stressed, tense?
- Nurture your spiritual side. Pursue those things that are uplifting to you.
- Avoid unrealistic expectations of yourself.
- Allow others to help you.
- Set limits. It's OK to say "no" sometimes.
- Recognize your needs and limitations.

Additionally, respite care may be available for you. Respite care is short-term inpatient care provided to the individual, when necessary, to relieve the family members or other persons caring for the individual at home. Your team members can provide more information.

As death nears, it's okay to say good-bye. This is a very personal time with no rights or wrongs. Saying good-bye might be as simple as saying I love you, thank you, or saying a prayer. Be aware that feelings of sadness, anger, helplessness, depression, guilt and fear are normal. Talking with a friend or Hosparus Health Team member about your feelings can be helpful.

We realize that reading this information may be difficult. Hosparus Health wants you and your family to feel very confident, know what to expect during this time and know you are doing a great job!

End of Life – The Last Stages

As the body prepares itself for the final stage of life, there is a process of “shutting down” that is natural but can be frightening if you are unprepared. We want to provide information and support that will help you know what to expect at the time of death and help your family feel very confident during this time. Some of the changes discussed here will come and go and may not occur in the order listed or even within the same time frame. We all live each stage of our life in a unique way, and that includes our dying.

Activity – Withdrawal from normal activities may be noticed. It is not unusual for past interests and hobbies to be set aside. This may include less verbal communication. A person may experience an unexpected surge of energy and become more alert asking for a favorite food or activity. This experience is usually brief.

Oral Intake – There may be a decrease in appetite and thirst. This is part of the natural dying process as the body begins to shut down. Ice chips or frozen juice may be refreshing, but do not force someone to eat or drink. Good mouth care is very important at this time.

Alertness – More time may be spent sleeping with less time talking. It is important to continue conversation, but speak softly and naturally, and ask simple questions that have an easy response, like a nod. It may be comforting to simply share time sitting quietly holding hands.

Restlessness – A person may become restless, picking at the air or bedclothes, or have difficulty sleeping. A person who has been bedfast may even try to get out of bed and walk. Your Hosparus Health Team can recommend medication or make other suggestions.

Breathing Pattern – Breathing often becomes irregular and may vary from very shallow to very deep. Breathing may stop for 10-30 seconds; with breaths coming only 2-3 times per minute for a long period of time. This is a natural part of the dying process. Mucous can gather in the back of the throat and cause a rattling sound that may be very disturbing to you. Raising the head of the bed or turning from side to side or placing in recovery position may help. Let your Hosparus Health Team know because there may be medications that can help.

Temperature – Body temperature may increase or decrease. As circulation slows down, arms, legs, and the underside of the body may take on a blue-purple color.

Bowel/Bladder Elimination – Urine output lessens, often becoming darker with a strong odor. Bladder and bowel control may be lost. If this occurs, it is important to keep skin clean and dry.

Pain – Everyone experiences pain differently. Pain may lessen or become more intense.

More Signs and Symptoms of the Dying Process

The following signs and symptoms may come and go, may not occur in the order listed, or even within the same time frame. Not everyone experiences all of these signs or symptoms:

Final One to Three Months

- decrease in appetite
- less communication and conversation
- increase in sleep
- withdrawal from normal activities

Final One to Two Weeks

- changes in skin color
- changes in breathing pattern
- congestion, “rattling” breathing sounds
- unable to clear saliva
- decrease in appetite or refusal to eat
- change in body temperature
- may become bedbound or have a marked decrease in activity
- unable to swallow pills or refusing regular medications

Final Days to Hours

- erratic or irregular breathing pattern or pauses between breaths
- restless or no activity
- decreased urine output
- changes in bowel/bladder function
- may have a day of renewed energy and activity, called a “rally” day
- change in skin color
- high fever with minimal discomfort
- eyes remain half-open
- may stop talking/responding but probably able to hear
- rapid heart rate
- may see or talk to people who aren’t there, including people who have previously died
- swelling of hands, arms, legs
- family pets may act differently

When death occurs

- breathing and heartbeat stop and do not resume
- sometimes there is a release of bowel and bladder
- the person cannot be awakened
- the jaw is relaxed and the mouth may be open
- eyelids may be open

At the time of death, call the Patient Care Line at 1-888-295-4239. A team member will be sent to your home to provide support and help make the necessary phone calls to the funeral home. If residing in a nursing facility, please remind the facility staff to call Hosparus Health.

Further Resources to Support You

Your loved one's favorite readings, music, photos or other items of meaning may be comforting.

Visit our website to learn more about resources available www.HosparusHealth.org

Ceremonies of Passage – Reading and Rituals to Enrich the Dying Experience. Ask your team chaplain for a copy of this.

Dying Well. By Ira Byock, MD. (1998). NY: Riverhead Books. ISBN 1573226572. Available through any bookstore.

Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying. By Maggie Callanan and Patricia Kelley. (1997). NY: Bantam Books. ISBN 0553378767. Available through any bookstore.

Guiding Your Children and Teens

Children have the same needs as adults for information, inclusion and closure with their loved one. Young people who are included in the family process experience less anxiety and have an easier time in bereavement than children who are not involved during this important time in their family. Grief counselors are available for children.

For more information on how to support your children and teens, ask your Hosparus Health Team for a copy of *“Staying Connected At the End of Life: A Guide for Parents”*.



What about Medications?

Our nurses are specially trained in assessing pain and other symptoms and will consult with your physician to find the best medicines for comfort while honoring your wishes. “Related medications” are prescribed for your specific hospice condition, are part of your plan of care, and are usually covered by your hospice benefit and provided through Hosparus Health. There may be medications you are taking that are “not related” to your hospice condition. Hosparus Health does not cover these medications and you should continue to get these medications from your local pharmacy or mail order service.



Medications not related to your hospice condition are paid for in the same way they were paid for prior to starting hospice services. We will review your related and non-related medications with you. Your Hosparus Health Team needs to know about all the medications you are taking including current and active prescriptions, over-the-counter medications (including herbals and vitamins), oxygen, tube-feeds, peripheral and central line flushes, and skin and wound care products.

Your Hosparus Health Team will provide you with information about your medications. We recommend that medications not be discussed with anyone other than your immediate family or someone providing care. Please store medications safely out of sight and out of children’s reach in the Hosparus Health Medication Box (see page 26 for more information).

When a medication is no longer needed, we will guide you to dispose of it safely (see page 27 for more information). **In accordance with federal law, Hosparus Health staff will never hand deliver, pick up, transport or accept medications.**

Pharmacy Services

Living at Home or in an Assisted Living Facility

To meet your special needs as a hospice patient, you may receive some of your hospice related medications from local pharmacies and some will be delivered to your home by a leading delivery service from a national pharmacy that specializes in hospice medications.

If a hospice related medication is needed right away, a local pharmacy can provide a limited supply of the medication until a supply can be sent from the national hospice pharmacy. You

will be given a prescription card to show the local pharmacy when you pick up medications. There is no co pay or charge to you for most hospice related medications. Your nurse will order refills from the national hospice pharmacy that will be delivered by a leading delivery service.

Your physician may recommend keeping a Comfort Pak in your home. The Comfort Pak is a sealed box sent to you by the national hospice pharmacy which contains a few doses of medications that you may need later. If you receive this box in the mail, **please do not open it.** Please let your nurse know that you have received it so that he/she can then explain the use and contents. Place the entire box in the refrigerator out of reach of children. **Assisted Living Facilities have individual policies about delivery and storage of Comfort Paks. Your Hosparus Health nurse will discuss with you the policy for your ALF facility.**

Living in a Personal Care or Nursing Home Facility

To meet your special needs as a hospice patient, you will continue to receive most medications from your facility pharmacy with occasional exceptions. The exception would be if the facility pharmacy does not stock a medication your physician has ordered. In these cases, your Hosparus Health Nurse will arrange for delivery of the medication from a national pharmacy that specializes in hospice medications. The delivery will be to the facility pharmacy to be dispensed to you with your other medications. Your Hosparus Health Nurse will work with the facility nurses to be sure your medications are available and refilled by the facility pharmacy. Comfort Paks are not necessary in Personal Care or Nursing Home Facilities.

Taking Your Medication Safely at Home or in an Assisted Living Facility

The physician orders your medication to help treat your condition. It is important to take it safely. Here are some good rules to follow:

- Read the labels and information that come with your prescriptions.
- Always check the label on the bottle to be sure you are taking the right medicine.
- Keep your medicine in its original bottle, away from children and pets.
- The nurse will work with you to keep track of the number of pills you have. If you find you are short any medications (a four day supply or less) let your Hosparus Health Team know immediately.
- Do not share your medicines with family members or friends and do not take medications that have not been prescribed for you.
- All Hosparus Health Team members visiting you should have a Hosparus Health ID badge. If they do not have one or if you are unfamiliar with that person, call Hosparus Health to confirm their identity.
- Keep your medicine in the provided medication box in a cool dry place. Refrigerate medicine if it says to do so (your team will give you a second box for medications that require refrigeration).
- Don't take medicine that doesn't look right or has passed the expiration date.
- Don't take over-the-counter drugs without checking with your Hosparus Health Nurse or Physician.

- If you forget to take a dose or several doses, follow your nurse's instructions or call Hosparus Health for directions.
- Use gloves when applying topical (on the skin) medications.
- If you have any questions about symptoms you have after taking your medicine, talk to your Hosparus Health Nurse, physician, or pharmacist.
- We have provided two examples of ways to document the medication doses to control symptoms and keep you comfortable. It is helpful to copy one of these forms in a notebook to track your doses of medications taken on an as needed basis (see page 71).
- Ask your Hosparus Health Nurse what to do with medicines you are no longer taking. We will provide you with a bag labeled "discontinued" if needed.
- If you suspect that someone is taking your medications, tell your Hosparus Health Team.
- Be aware of those around you when prescriptions are picked up or delivered.
- When leaving the home carry enough medication with you. You should have a small supply of medication in case it is needed while you are out of the home. If planning to travel, notify your Hosparus Health team.

In Assisted Living Facilities, if you need assistance with taking your medications safely, ALF staff may be able to assist. Your Hosparus Health Nurse will discuss with you and your family the policy for your facility.

Taking Your Medication Safely in a Personal Care or Nursing Home Facility

Facility nurses are trained to give your medication safely; however, your Hosparus Health Nurse will discuss your medications with the facility nurses at each visit. They will review the medications you are taking, any changes to your medications, any new medications your physician has prescribed, and any precautions that should be taken for safely giving your medication. If you notice that your medication looks different or has changed in any way, you should ask the facility nurse if there has been a change. If you are uncertain about taking any medication, ask the facility nurse or a family member to call the Patient Care Line at 1-888-295-4239 before taking the medication.

Do not ask your family or friends to bring in medications, prescription or over the counter, from home. It is very important that the facility nurses and your Hosparus Health Nurse know all of the medications you are taking to prevent medication complications. If you feel you need a medication you are not receiving, talk to your Hosparus Health Nurse. If a medication does not seem to be "working" as it once did, or if you are experiencing unusual side effects of any medication, please report this to the facility nurse and have someone contact your Hosparus Health Nurse to discuss.

Administration of Liquid Medicines

If swallowing is a problem, your Hosparus Health Nurse will train you on an alternative way to administer medications. Liquid medications or crushed pills dissolved in liquid may be placed under the tongue, between the lip and gum, or in the cheek area. Your Hosparus Health Nurse will advise you on how to crush pills if this should become necessary.

Administration of Rectal Medicines

Rectal administration of medication is sometimes necessary to best control your symptoms. Your Hosparus Health Nurse will instruct when this administration is necessary.

To give medications rectally, you need the medication, gloves and some **water-soluble gel** such as KY Gel. Please do **not** use Vaseline or Petroleum Jelly. This could keep the medication from working. In some cases, a Macy catheter may be used.

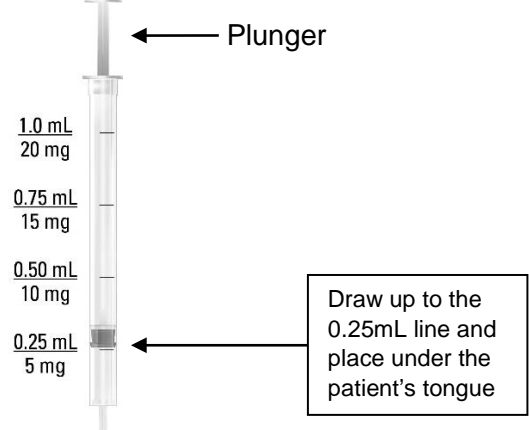
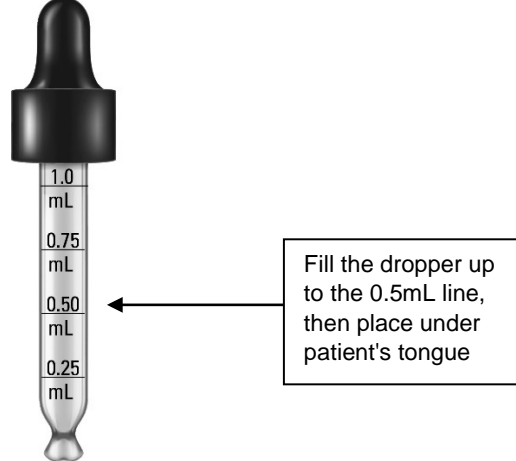
Follow these steps:

- Wash your hands.
- Put on gloves.
- If the medication is a suppository, remove the foil wrapper.
- A pill or capsule can be put directly into the rectum or the medication may first be put into a gelatin capsule and then put into the rectum (talk to your Hosparus Health Nurse about where to get these).
- Put a large daub of gel on the suppository, capsule or pill.
- If possible, position the patient on the left side with his/her knees pulled to chest.
- Instruct the person to take a few deep breaths and relax as medicine is gently inserted into the rectal opening with a gloved finger.
- Push the medication in as far as it will go and place it against the rectal wall (if the rectum is full of stool, a bowel movement is necessary before the medicine is placed in the rectum).
- There may be the need or sensation to have a bowel movement after the medication is put in the rectum (hold the medication in for at least 20 minutes so that it will be taken in by the body).
- Take off the gloves.
- Wash your hands.

Remember:

- The Hosparus Health Nurse will train you which medications should be given rectally.
- Report any problems to your Hosparus Health Nurse.
- Your confidence in giving medications is very important to us. Please ask your Hosparus Health Nurse for more information if needed.

Comfortpak Medicines Instruction Sheet

<p>Morphine Sulfate 20mg/mL <i>What is it for?</i> Pain or Shortness of Breath <i>Side Effects:</i> Drowsiness, dizziness, upset stomach, itching, constipation</p> <p style="text-align: center;">Give 5mg (0.25mL) under the tongue every 3 hours as needed</p>	
<p>Haldol / Haloperidol liquid 2mg/mL <i>What is it for?</i> Agitation, Restlessness, Nausea/Vomiting <i>Side Effects:</i> Dry mouth, constipation, drowsiness, dizziness, restlessness</p> <p style="text-align: center;">Give 1mg (0.5mL) under the tongue every 6 hours as needed</p>	
<p>Hyoscamine SL Tablets <i>What is it for?</i> Secretions <i>Side Effects:</i> Dry mouth or eyes, blurred vision, constipation, dizziness, drowsiness</p> <p style="text-align: center;">Give 0.125mg under the tongue every 4 hours as needed</p>	<p>Ativan / Lorazepam Tablets <i>What is it for?</i> Anxiety, Shortness of Breath <i>Side Effects:</i> Drowsiness, dizziness</p> <p style="text-align: center;">Give 0.5mg Tablet by mouth every 4 hours as needed</p>
<p>Compazine / Prochlorperazine Tablets <i>What is it for?</i> Nausea/Vomiting <i>Side effects:</i> Headache, dizziness, drowsiness</p> <p style="text-align: center;">Give 10mg by mouth every 6 hours as needed</p>	<p>Bisacodyl Suppository <i>What is it for?</i> Constipation <i>Side effects:</i> Diarrhea, stomach cramps</p> <p style="text-align: center;">Give 10mg by rectum every day as needed for constipation</p>
<p>Acetaminophen Suppository <i>What is it for?</i> Fever, Mild Pain</p> <p style="text-align: center;">Give 650mg per rectum every 6 hours as needed</p>	<p>If you have any questions, or the patient is experiencing any of these symptoms please call the Patient Care Line at 1-888-295-4239.</p>

Hosparus Health's Responsibilities Related to Medications

Opioids and other narcotics, sedatives and tranquilizers have potential for abuse. Because of this, there is strict accountability to protect public health and safety. To do this Hosparus Health must:

- Assure your medications are safe. This is our first responsibility to you, our patient. To do this, we may ask you several questions, such as:
 - “Are you allergic to anything?”
 - “How much medication are you taking?”
 - “How often?”
 - “How well is it working?”
 - “How alert do you want to be, even if that means more pain?”
- Comply with laws and regulations. The laws require that we only provide medications that will be used for a medical reason and in amounts that are acceptable based on medical standards. If a medication is not helping, we will help find one that works for you.
- Practice in an honorable, ethical and professional manner. This means prescribing and providing the right medications, for the right reasons and making sure that they get to the right person.
- Consider the use of medications as part of your well-being. This includes physical, spiritual, social and emotional well-being.

Patient's Responsibilities Related to Medications

Provide Hosparus Health with complete and accurate information concerning your care. This includes the amount and frequency of all medications taken.

Medication Storage in the Home or Assisted Living Facility – The Hosparus Health Medication Box

We want you to be very confident about the use, storage, and disposal of medications. To assure that all medications are properly stored, please follow the Hosparus Health Medication Box (plastic shoe box provided by Hosparus Health) instructions:

1. Keep ALL medications (prescribed, over the counter, vitamins, supplements, herbals) that the Hosparus Health patient is currently using in the Hosparus Health Medication Box.
2. Keep your current medication list in the Hosparus Health Medication Box.
3. Any changes in medications will be reviewed and documented by the nurse at each visit. For example:
 - If a medication is discontinued, remove it from the Hosparus Health Medication Box and place it in the bag labeled “discontinued medications.”
 - If a medication is added, store it in the Hosparus Health Medication Box.
 - If the frequency and/or dosage are changed, please tell your nurse.

Since some medications can't be easily stored in the Hosparus Health Medication Box, please indicate on the Hosparus Health Medication Box if any of the circumstances below apply to your situation:

- Some medications are in the refrigerator
- Some medications are stored in a lock box
- Patient has tube feedings
- Patient requires flushes
- Patient requires inhalers/nebulizer treatments

We hope this Hosparus Health Medication Box is very helpful to you. Your Hosparus Health nurse will ask to see the Hosparus Health Medication Box during each visit. Please call your team for any questions.

Proper Disposal of Prescription Medications

By law, medications cannot be returned and must be destroyed in accordance with the state regulation. Medications should be destroyed in accordance with the Office of National Drug Control Policy guidelines (see below for the destruction of unused, unneeded, or expired prescription medications). In accordance with state and federal law, Hosparus Health staff will never hand deliver, pick up, transport or accept medications for destruction. Also, medications cannot be accepted at any location.

In most instances, your Hosparus Health Team will dispose of medications no longer needed in your home. However, when your Hosparus Health Team is not present to provide assistance, medications may be destroyed in the following ways:

- Remove unused, unneeded, or expired prescription medications out of their original containers and throw the container in the trash.
 - Protect yourself from identity theft by removing or destroying medication labels or making them unreadable on any containers before throwing them in the trash.
- Mix prescription medications with an undesirable substance.
 - Place medications in a strong zip lock bag containing used coffee grounds, kitty litter, or liquid soap. Add a small amount of warm water to dissolve the medications, seal the bag, and squeeze bag to mix well. Toss the bag into the regular trash.
- Return unused experimental chemotherapy medications to your physician's office or chemotherapy clinic.



COMMON SYMPTOMS AND COMFORT MEASURES

Pain

Not everyone experiences pain, but when it occurs, it is a very personal experience that is different for everyone. The person experiencing pain knows the most about it and should be trusted to describe it.

The cause of pain varies. It may occur because of your illness or from various treatment methods. Whatever the cause, Hosparus Health can help lessen or relieve pain.

It is important for you to discuss pain with your nurse and physician – very openly and honestly – so that everyone can work together to keep you comfortable.

Is Pain a Problem?

If you are taking care of someone, you may wonder how to know if he/she is in pain. Here are some suggestions:

Ask: Are you uncomfortable? Do you hurt or ache anywhere? How much are you bothered by pain right now? Where is your pain? What do you think causes your pain? Which word(s) describe your pain?

*sore, burning, heavy, cramping, sharp, aching,
dull, stinging, shooting, tingling or pressing*

If your loved one has difficulty talking, look for actions that are unusual for him/her that may show pain such as:

- Face–grimacing, frowning, blinking, tightly closed or widely open eyes
- Voice–moaning, crying, groaning, calling out, screaming
- Body movements–hitting, biting, rigid posture, increase in head movements, rocking, tugging legs, guarding part of the body, change in walking
- Daily activities–more rest periods, less social activity, sudden stop of routines, sleep changes
- Mood–more irritability, confusion, more withdrawn or agitated

Your Comfort and Confidence with Pain Medications is Important to Us

We understand that this can be a difficult time and any discomfort can make it more difficult. Pain medications may provide relief when someone is uncomfortable. While using pain medications, our goal is to train you to feel confident about the side effects of the pain medications and when to give more medication. See the following helpful information.

You may expect to see:

- Drowsiness for up to the first 3 days after starting on certain pain medications.
- Increased sleeping may possibly occur because of relief from pain or anxiety. If this continues or if you have concerns about this, talk to your nurse.
- Light headedness/dizziness when getting up suddenly.
- Nausea that should subside within 48 hours. Nausea does not necessarily mean an allergic reaction but can be a temporary side effect while the body is adjusting. There are medications that can be given to help if this occurs.

You should NOT expect to see:

- Change in behavior (outside of normal behavior), i.e., increased confusion, restlessness, or delirium.
- Drowsiness that persists or worsens after the first 3 days.
- Dramatic changes that concern you.

If you notice these things, please discuss your concerns with one of your Hosparus Health team members. There may be other reasons besides the medications. Knowing the reasons will help you be confident and at ease with what to expect. Together, we will help you achieve your comfort goals.

Pain Medication Facts

FACT: Medication to control pain is different for each person. The amount of medication you need to take will be decided by you, your nurse and physician and will depend on:

- your wishes for pain control
- your disease
- your age, height and weight
- how much pain you have
- other medications you are taking
- side effects of the medication

The amount and type of medication you need to take may change at times to give you better pain control.

FACT: Taking medications as prescribed for pain will not make you a drug addict. You may need larger doses as time goes on and your body gets used to the medication. Increasing the amount of the medication to relieve pain does not mean you are becoming addicted.

FACT: You may be drowsy or sleepy up to the first 3 days after starting new medication. Talk to your Hosparus Health Team if this is a concern for you.

FACT: There will always be medications that can help reduce your pain. You do not have to worry about a limit to the amount of medication you need. Many people take large doses of pain medications so they can be comfortable and they are able to get up, walk around and perform normal activities. Combinations of different types of medications can also be helpful to control pain.

FACT: The same medication that is used for pain can sometimes be used for other reasons, like difficulty breathing, even though there is no pain. If you are unsure, ask your Hosparus Health Nurse or physician why a medication has been ordered.

FACT: Taking your medications as prescribed will more likely assure that your pain can be controlled safely.

FACT: Roxanol or morphine sulfate concentrate are forms of liquid morphine that work quickly and are absorbed in the mouth. It doesn't need to be swallowed to work. It provides the same pain control as other forms of morphine.

Trouble Breathing

Lung disease, pneumonia, anxiety, or fluid in the lungs may make it difficult to breathe easily. Problems include chest pain, wheezing, a pale or blue skin color, sweating, a fast pulse or breathing rate.

Medications including oxygen may be used to reduce shortness of breath; however, there are instances where the use of oxygen is not always helpful. Sometimes lungs are so damaged that the extra oxygen can't be absorbed. Discuss its use with your physician or Hosparus Health Nurse. Using oxygen can dry out a person's nose, mouth and throat. People may even become more anxious with oxygen tubing on their face.



If trouble breathing should happen:

- The most important thing is to remain calm.
- Breathe in gently through the nose. Purse your lips as if you were whistling when you breathe out. Try not to let your cheeks puff out.
- Try slow, deep breathing.
- If using oxygen, be sure that there is no kinking in the tubing and all connections are tight.
- It is easier to breathe in a cooler room. A fan may help.

- Take medications if ordered.
- Play music softly.
- Try distractions such as TV, books or other things of interest.
- Raising the head of the bed may help.
- Keep number of people in the room to a minimum.
- Keep person facing the door/window.
- Lean forward and put elbows on a table. This can expand the lungs.

Feelings of Anxiety or Sadness

Emotions are common symptoms as you near the end of life. Anxiety is a subjective feeling of apprehension, tension, insecurity and uneasiness, usually without a known specific cause, and is a common symptom in individuals nearing death. Anxiety and stress can affect individuals differently and can range from mild to severe.

Anxiety can be caused by:

- Certain medications
- Lifestyle changes
- Financial Concerns
- Dependency on others
- Confronting family conflicts
- Fear of approaching/nearing death

Management of anxiety may include:

- Listening
- Support
- Accurate and clear information
- Relaxation activities
- Collaborating with Hospice Health Nurse to see if medication is needed
- Simple calming distractions, such as watching TV or listening to music
- Medications
- Essential Oils

Restlessness and Agitation

Restlessness and agitation are common symptoms as a person nears death. Our goal is to train you to feel confident in recognizing signs of restlessness and agitation. A person is restless when they are unable to stay still or quiet. They may appear worried, anxious and uneasy. They may thrash about the bed, pick at the air or their clothes, and have difficulty sleeping. Agitation may be a result of restlessness. A person who is agitated may appear disturbed, be easily aroused, or be very excitable. They may demonstrate profound mood changes such as irritability, anger or depression.

Treatment of Restlessness and Agitation may include:

- Medications
- Reorientation
- Relaxation
- Distraction
- Rest or sleep

Appetite/Nutrition

Eating is usually a pleasure, yet during an illness, eating may take special effort. Not being able to eat, drink or share in meals as before can stir deep emotions. So much of life revolves around eating and drinking: daily life, holidays, major life events and even religious ceremonies.

Many changes may take place during your illness that may affect your food intake. You may lose your appetite, have no interest in food, or experience nausea, vomiting, diarrhea or constipation. Your mouth or throat may be sore and you may have a difficult time swallowing. Any of these problems may make eating difficult or undesirable. Often, these symptoms are temporary.

A general rule of thumb though is to understand that when you are ill, good nutrition cannot be measured by the amount of food you eat or the number of calories you take in. Even people who eat well may continue to lose weight. So do **not** feel guilty if you are unable to eat. **If you are the caregiver, don't force unwanted food.**

Some tips that may help include:

- Eat when you feel like it and as much as you want.
- Eat whatever interests you – any foods that sound good or look appetizing.
- Try small portions or plates – a blender or food processor can make foods easier to swallow.
- Keep snacks or finger foods handy for nibbling. Store in individual containers.
- Avoid strong cooking odors or unpleasant smells. Fried and fatty foods may be more difficult to digest.
- Improve the taste of some foods or add calories by adding fruits or ice cream to milk shakes or liquid supplements.
- Serve colorful foods on favorite dishes or with flowers.
- Eat in your favorite room or place.
- Eat when you feel the best – free from pain, relaxed, rested.
- Give yourself several selections to choose from, as well as different amounts.
- Notice eating habits. If the person forgets to eat or chew, they may need gentle prompting.

Nutritional Supplements

It is sometimes hard to eat enough food to give your body the calories needed to keep energy levels up. There are ways to boost the amount of calories you take in without having to eat more food. Commercially made nutritional supplements are available at pharmacies and grocery stores. Your hospice benefit does not pay for nutritional supplements.

The following suggestions and recipes can help you add calories (and energy) with common ingredients.

Fortified Milk

- 1 cup powdered milk to 1 quart whole milk
- Use fortified milk in shakes, puddings, sauces, etc.

Instant Breakfast

- variety of flavors
- add ice cream, whipped cream
- use fortified milk

Instant Puddings

- add whipped cream
- use as a thickener in milk drinks

Instant Potato Flakes

- add to cream soups for more calories and/or thickening

Fruit Purees or Baby Food Fruits

- use applesauce to thicken fruit juices
- add blended fruits to shakes or instant breakfast
- freeze juices in ice cube trays to use in tea, lemonade, etc.

Sweeteners

(to change the taste and add calories)

- add extra sugar to tea, juices, jello
- use condensed sweetened milk in hot drinks
- use Karo syrup or honey in foods or drinks
- use crushed up candy bars in milkshakes to increase calories

Thickened Liquids

- thickened liquids move down the throat slowly and help to avoid choking
- instant puddings, instant potato flakes, applesauce, jello or gelatin may be added to foods/fluids
- drink boiled custard
- jello can be allowed to warm to room temperature, stir gently and serve as a thickened liquid

Recipes

Strawberry Smash

- 1/3 cup strawberry drink mix
- 1/4 cup applesauce
- Vanilla ice cream

Mix drink mix with applesauce then stir with the ice cream. Add carbonated water if desired.

Strawberry Flip

- 1/4 cup strawberry drink mix
- 1 tablespoon lemon juice
- 1/3 cup cold water

Stir briskly. Add 2 scoops lemon sherbet.

Pudding Shake

- 1 box instant pudding (flavor of choice)
- Mix with milk as package directs
- Add 1-1/2 cups ice cream

Blend. Thin to desired consistency with more milk.

Orange/Pineapple Shake

- 1 pint orange sherbet
- 3 cups orange/pineapple juice

Blend with crushed ice.

Chocolate Peanut Butter Soda

- 1/3 cup quick chocolate flavored drink mix
- 1 tablespoon peanut butter
- 1/4 cup fortified milk
- 2 scoops vanilla ice cream

Blend together.

Spicy Chocolate Frosty

- 1/4 cup quick chocolate flavored drink mix
- 1 cup fortified milk
- 1/4 teaspoon cinnamon

Add 1 scoop vanilla ice cream.

Strawberry Soda

- 1/3 cup strawberry flavored drink mix
- 1/2 cup fortified milk
- 2 scoops vanilla ice cream

Blend. Add carbonated water if desired. Top with whipped cream.

Quick Breakfast Drink

- 1 ripe banana frozen (peel and place in plastic bag overnight)
- 1 tablespoon wheat germ
- 3/4 cup fortified milk
- 2 teaspoons honey
- 1/4 teaspoon cinnamon

Blend together.

Banana Malt

- frozen banana
- 3/4 cup fortified milk
- 3 tablespoons chocolate malted milk powder

Blend till smooth.

Banana Shake

- 2 ripe bananas sliced
- 14 ounces condensed milk
- 1 cup cold water
- 1/3 cup lemon juice concentrate

Mix together or use blender (if blender is used, add 2 cups ice cubes).

Power Pudding (can also be used to help with constipation)

- 1/2 cup prune juice (if needed to blend)
- 1/2 cup wheat bran flakes
- 1/2 cup prunes (canned, stewed prunes)
- 1/2 cup applesauce
- 1/2 cup whipped topping (like cool whip)

Blend ingredients, cover and refrigerate (keep as long as one week). Take 1/4 cup portion of recipe with breakfast.

**diabetics may use “no added sugar” and “light” whipped topping*

Difficulty Swallowing

Difficulty swallowing is a common problem when the body is weak. Sometimes coughing or choking occurs during eating or drinking. This also can make taking medications difficult.

Some tips that may help include:

- While taking foods or liquids, sit up in bed or in a chair.
- Before taking foods or medications, try drinking small sips of water.
- If choking is a problem, tilt your head forward and tuck your chin into your chest while swallowing.

- Thicker liquids (see Nutritional Supplements) are sometimes easier to swallow. Drinking milk shakes or adding gelatin to liquids may help.
- A blender may be used to puree foods. Other soft foods, such as puddings, mashed potatoes, applesauce or jello are good.
- Some medications can be crushed and taken in soft foods to make swallowing easier. Please check with the nurse before crushing medications since some medications should not be crushed. Sometimes, medications come in liquid, gel or suppository form if swallowing is difficult.
- If your loved one is coughing or choking, don't panic or slap the person on the back. Turn them on their side or sit them up more.

Nausea, Vomiting, Dry Heaves

Nausea, vomiting and dry heaves are usually temporary and can be successfully treated. Symptoms may be caused by illness, strong odors, treatments and some medicines.

Your Hosparus Health Nurse and physician will work with you to obtain relief. Some medications may relieve and control nausea and taking these medications 30-60 minutes before meals may allow you to enjoy eating without being sick.

Some tips that may help include:

- Eat slowly and chew food thoroughly.
- Eat small amounts more often.
- Eat whenever and whatever you feel like.
- Try cool, clear liquids such as Kool-Aid and carbonated drinks.
- Drink liquids before and after meals. Too much liquid during meals can cause you to feel too full.
- Suck on mints or hard candy.
- After eating, rest in a semi-reclining or sitting position.
- Avoid fried or fatty foods because they are more difficult to digest.
- Eat foods such as crackers, jello, toast and juices because of their higher carbohydrate content. These types of foods digest more easily.
- Avoid any offensive or strong odors or foods that cause nausea.

Constipation

“Constipation” means a change in normal bowel movements that are:

- Less frequent
- Smaller, drier or harder
- Difficult to pass

Causes of constipation include:

- Decreased activity
- Decreased food and/or fluid intake
- Illness
- Some medications

Some tips that may help include:

- If you have not had a bowel movement in three days, contact your Hosparus Health Nurse
- Talk with your Hosparus Health nurse to develop a plan to minimize constipation
- Use medicines recommended by your Hosparus Health Nurse or physician on a regular schedule
- If possible try:
 - warm prune juice or other fruit juices
 - increase water intake
 - increase activity
 - fresh fruits
 - fresh vegetables (especially raw, green leafy)
 - whole wheat or bran cereals and breads
- Power Pudding Recipe (see Recipes)

Dehydration

Dehydration can occur when there are not enough fluids taken in or excessive fluids are being lost from the body. Causes may include loss of appetite, difficulty swallowing, nausea or vomiting, diarrhea, use of water pills, or excessive sweating. The skin may become dry and flaky, membranes in the nose and mouth may be sticky, lips may crack, and urine may be darker and strong smelling with a decreased amount. Weakness and confusion may occur.

Dehydration often occurs as part of the natural dying process. Research shows that the body releases its own natural painkillers when the body begins to dehydrate.

It is often difficult to watch someone not eating or drinking as much as before. As the illness progresses, the body processes begin to slow down and the desire for food and fluid naturally decreases.

IV fluids at this time may stress the body's heart, lungs, and kidneys causing increased swelling, vomiting and lung congestion.

Diarrhea

Diarrhea includes frequent, liquid bowel movements with or without discomfort. The most common causes are:

- a blockage of stool in the rectum (an impaction)
- medication or laxatives
- infection
- tumors
- side effects from chemotherapy or radiation

If suffering from diarrhea, it may help to:

- Eat foods that are high in protein and low in fiber such as cottage cheese, baked potatoes, boiled white rice, cooked cereal, bananas, pasta, white toast, apple sauce and yogurt.
- Drink clear liquids.
- Add nutmeg to food. It will slow down the intestine.
- Rest.
- Clean the rectal area with mild soap and warm water after each bowel movement. Rinse well and dry. Apply a water repellent ointment to the area such as A&D Ointment or Desitin.
- Take a warm tub bath. That may help relieve the discomfort of rectal irritation.

Avoid:

- caffeinated or alcoholic beverages
- milk/milk products
- very hot/very cold liquids
- tobacco products

Call the Patient Care Line at 1-888-295-4239 if these things occur:

- New onset of diarrhea
- Blood in the stool
- Diarrhea causing cramping
- Diarrhea with fever or a fever above 101° that doesn't respond to acetaminophen (Tylenol)
- There has been constipation and then changes to passing small amounts of liquid from the rectum

Confusion

A person who is confused has trouble understanding and reacting or responding to their environment. It is difficult for them to think and act with their usual speed and clarity. As a caregiver, this can be challenging at times.

Confusion can be caused by:

- Normal illness progression
- Tumors
- High fever
- Intense pain
- Some medications
- Unfamiliar surroundings

Some tips that may help include:

- Always identify yourself.
- Stay within a few feet of the person while talking. If appropriate, touch the person during conversation.
- Face the person when you speak. Talk slowly and use short statements. Avoid loud speech.
- To orient – remind the person of the date/time and other important information. Keep a clock and calendar, as well as familiar objects nearby.
- Explain, step-by-step, anything you will be doing such as dressing, bathing or changing bed linens.
- Provide comfortable lighting.

To help protect from injury:

- Don't leave the person alone for long periods of time
- Help him/her go to the bathroom or to another room
- Label – with pictures – commonly used items, such as a picture of a flame over the stove
- Avoid leaving medications within reach

Call the Patient Care Line at 1-888-295-4239 if:

- The confusion begins suddenly or worsens
- The person becomes violent
- Injury occurs

Seizures

People sometimes have seizures as a result of their illness or medications. They may be followed by loss of consciousness, periods of sleepiness, and/or confusion.

Look for:

- Eyes rolling back or blank stare
- Sudden loss of bladder or bowel control
- Jerking movements, especially arms and legs, usually lasting less than five minutes

Some tips that may help include:

- Stay calm
- Stay with the person
- If possible, prevent falling by easing the person to the floor

During the seizure:

- Don't restrain or try to stop any movements.
- Turn the person on his/her side, to prevent choking.
- Don't restrain or try to stop any movements.
- Remove any hard or sharp objects from the area.
- Loosen any tight clothing such as a collar or belt.
- Place something soft and flat under the person's head. You can use a folded blanket or pillow.
- Never force anything into the person's mouth.
- Ask unnecessary visitors to leave the area.
- Dim the lights.

After the seizure:

- Let the person lie quietly.
- As the person begins to wake up, gently call by name and tell where he/she is and what has happened.
- Don't give food, liquid, or medicine until the person is fully awake.
- If the person is hurt, bleeding or new onset of seizure, call the Patient Care Line at 1-888-295-4239 immediately.
- Write down what you remember about the seizure – such as how long it lasted, what the person was doing before the seizure and the type of movement during the seizure. Report this to Hosparus Health.

Sweating

Heavy perspiration, especially at night. Sweating can be caused by a fever, the body's reaction to a tumor, infection or hormone changes.

- Take medications as ordered to reduce fever.
- Use layers of clothing with a cotton layer next to the body. Cotton absorbs moisture and pulls it away from the skin.
- Change wet clothing as soon as possible.
- Change bed linens if they become wet.
- Choose a comfortable amount of blankets.
- Avoid becoming chilled.
- Don't let the room temperature become too hot/too cold.
- Anxiety can cause sweating, so try to keep calm.

Call the Patient Care Line at 1-888-295-4239 if:

- A fever above 101° doesn't respond to ordered medications
- Chills continue

Gurgling or Rattling Breathing

Often during the last days of life, people may be too weak to clear secretions or drainage in the airways. Air moving through these secretions can cause a rattling sound that is sometimes called the "death rattle."

Knowing what to expect and being trained on what you can do may help you feel more comfortable and confident if this happens. Although these sounds may be upsetting to others, the person is usually in a coma-like state and is not aware that it is happening. The gurgling or rattling does not cause distress for the patient. Sometimes, placing a patient in recovery position may aide in minimizing the sound and facilitating drainage of the secretions.

Recovery position: The mouth is downward so that secretions can drain from the airway. The chin is up to keep the throat opened. The arms and legs are locked to stabilize the position.



Using a suction machine will not help in this situation. It may actually increase secretions due to stimulation.

What you can do:

- Keep the head of the bed raised as this may help him/her to breathe easier.
- Turn the person from one side to the other every 2-3 hours so secretions can drain.
- Keep the person as comfortable as possible.
- Clean the person's mouth as needed.
- Do not try to force the person to swallow fluids.
- Let Hosparus Health know. There may be medications available to lessen this.

Insomnia

Sleeplessness lowers pain tolerance and exhausts the person and caregiver. Insomnia may occur as part of the disease process.

Some tips that may help include:

- Sometimes simple remedies, such as lighter blankets or a nightlight can help.
- Sleep when tired or feeling sleepy. When awake and able, participate in activities of interest or meaning.
- Have someone read to you.
- Drink warm milk.
- Rest at the same time each day.
- Take medications if prescribed to help sleep or relax.
- Relax the body with back rubs or foot massages.
- Use relaxation techniques as suggested by your Hosparus Health Team.
- Let Hosparus Health know if you or your caregiver isn't sleeping well at night.
- Avoid caffeinated beverages (coffee, tea, cola) or foods such as chocolate.
- Don't ignore pain. Give medications as prescribed.
- Lower the lights and limit the number of people in the room.

Itching

Itching can be caused by dry skin, allergies, side effects of medications, and chemotherapy or radiation therapy.

Look for:

- Dry, red, rough, flaky skin
- Skin with yellow color
- Rash
- Scratch marks
- Skin sores

Some tips that may help include:

- Apply soothing creams or ointments, as ordered, such as Cortisone, Benadryl, Calamine or Caladryl. Apply skin creams 2-3 times a day.
- Use warm, not hot, water for bath. Add baking soda, bath oil or treatments (Aveeno packets/oatmeal based products) to bath water, especially at bedtime.
- Keep nails clean and short.
- Dress in loose clothing made of a soft fabric (cotton or flannel).
- Change bed linens regularly if bedfast.
- Keep the room cool.
- Drink plenty of fluids.
- Take medications as prescribed by your physician. Damp skin, especially in skin folds, can become infected if skin is broken during scratching. This should be treated with a medicated lotion or powder prescribed by the physician.
- Keep attention away from itching by watching TV, listening to the radio or tapes, reading a book or visiting with company.
- Cover hands with cotton socks or cloth gloves.

Avoid:

- Scrubbing skin
- Using harsh detergents
- Using scented or alcohol-based products on skin

Call the Patient Care Line at 1-888-295-4239 if:

- Itching doesn't improve
- A rash develops or becomes worse after using creams or ointments
- Hives, welts, or open sores develop

HAND HYGIENE AND CONTROLLING GERMS



You will notice Hosparus Health Team members washing their hands or using hand sanitizer during their visit with you. Hand hygiene is the most important thing we all can do to reduce the spread of germs.

When to wash your hands:

- Before and after close contact with people who are sick.
- After contact with body fluids or things with body fluids on them, such as towels and sheets.
- Before and after providing care, such as emptying a urine bag or emptying a bed pan.
- After using the restroom.
- Covering a cough, sneeze or blowing your nose.
- Before and after wearing gloves while giving care.
- Before preparing or eating meals or preparing medications.
- After contact with pets.

How to wash your hands:

- Use warm, not hot, running water.
- Wet hands and use soap, liquid if possible.
- Scrub hands for at least 15 seconds.
- Be sure to include fingernails and between fingers and thumb. If you wear rings, spend extra time scrubbing them.
- Rinse hands well.
- Dry hands gently with paper towel or clean cloth towel.
- Turn the water off with the towel, not your clean hands.
- If soap and water are not available, use a 62% alcohol-based hand rub as directed.

Do not use 62% alcohol-based hand rub if using oxygen – consult Hosparus Health.

Wear Gloves

Gloves should be worn with any direct contact with body fluids: mucous, blood, vomit, urine or stool and when handling soiled items.

Cover Your Cough

To help stop the spread of germs and respiratory illnesses spread by coughing, sneezing or unclean hands:

- Cover your mouth and nose with a tissue when you cough or sneeze.
- If you do not have a tissue, cough or sneeze into your upper sleeve or elbow. Your hands should be a last resort.
- Wash your hands after coughing/sneezing.
- You may be asked to put on a face mask to protect others.

ASSISTANCE WITH DAILY LIVING TASKS

Skin Care

Basic skin care is important when someone is ill. Regular hygiene, such as bathing or showers, shampoos and lotion for dry skin, should continue as long as you are moving without help. Sitting for long periods of time or staying in bed most of the time requires special skin care. Skin breakdown and pressure sores often occur when nutrition is poor or with prolonged periods in bed. Buttocks, shoulders, heels, elbows, hips and other bony parts are particularly at risk for developing pressure problems.

Guidelines to Prevent Pressure Problems:

Inspection

- Check skin for reddened areas daily (focusing on heels, elbows, buttocks, hips and shoulders).
- Call the Patient Care Line at 1-888-295-4239 if you see reddened or broken skin.

Hygiene

- Keep skin clean and dry.
- Change pads soiled with urine or stool as soon as possible.
- Gently wash the genital area with mild soap. Rinse with warm water.
- Keep dry, flaking skin lubricated with lotion.
- Skin-to-skin contact areas (between legs, under breasts, in folds of abdomen) can cause irritating wetness. Dry these areas thoroughly.

Turning and Positioning

- Turn or change position every 2 hours as tolerated
- Prop up with soft pillows
- If sitting, shift weight frequently

Ask Hosparus Health about things that may help prevent pressure problems.

Mouth Care

Keeping the mouth moist and clean provides comfort.

- Cool liquids are soothing. Ice chips, shaved ice and popsicles may provide comfort.
- Rinse mouth frequently with cool tap water or a mild salt solution (1 tsp. salt to a quart of water).
- Citrus fruits, spicy foods or alcohol may irritate the mouth/throat.
- Use a soft toothbrush or sponge to clean the mouth. If using mouthwash, mix it with water (1 tbsp. mouth wash in 1/2 cup water). Some commercial mouth washes contain alcohol and may burn.
- Clean the mouth, teeth, gums and tongue at least 2 or 3 times daily. Use petroleum jelly or lip balm to help keep the lips moist. **Do not use petroleum jelly for mouth care if using oxygen – consult Hosparus Health.** If dentures are worn, take them out before cleaning the mouth.

Massage

Massage often helps a person feel more relaxed. You might use simple massage to:

- Reduce stress and anxiety
- Distract a person
- Relax muscles
- Increase energy
- Improve alertness
- Increase blood flow

How to massage:

- Ask the person where they would like the massage. Some people like back massage while others like their feet or hands massaged.
- Put warm lotion on the person's body or your hands.
- Move hands softly across the body.
- Move hands in gentle circles to improve blood flow.
- Wear gloves if there are open sores on the person's skin or your hands
- Keep the person warm and comfortable. Keep the rest of the body covered and warm while massaging another part of the body.

Bed Bath

To avoid spreading germs, always wash your own hands before and after giving a bath. Tell the person that you will be bathing him or her and ask for as much help as possible. At each step, tell the person what you are about to do.

1. Make sure the room is warm and comfortable.
2. Gather supplies, such as gloves, mild soap, washcloth, wash basin, lotion, comb, razor, shampoo and clean clothes.
3. Use good body mechanics. Keep your feet separated, stand firmly, bend your knees, and keep your back in a neutral position.
4. Offer the bedpan or urinal before beginning bath.
5. If possible, raise the bed to a level that is comfortable for you.
6. Have the person lie as flat as possible.
7. Test the water temperature in the basin with your hand.
8. Remove clothing and the blanket. Cover the person with a towel or light blanket. Keep the person covered during the bed bath, uncovering only one area at a time while washing it.
9. Have one washcloth for soap, one for rinsing, and a dry towel. Have the wash cloth very damp, but not dripping.
10. Very gently wash the face first. Pat dry.
11. Wash the front of the neck. Pat dry.
12. Wash the chest and, for females, under the breasts. Pat dry.
13. Wash the abdomen and upper thighs. Pat dry.
14. Clean the navel with a little lotion on a cotton swab.
15. Wash upward from the wrist to upper arm to stimulate circulation. Pat dry.
16. Wash the hands and between the fingers. Check the nails. Pat dry.
17. Place a towel under the buttocks and legs.
18. Flex the knees.
19. Wash the legs. Pat dry.
20. Wash the feet and between the toes and dry well. Use lotion on dry feet. Do not put lotion between toes. This area must be kept dry and clean to prevent fungal infection.
21. Wash the pubic/private area. If possible, allow the person to wash his or her own genitals.
22. If a male is uncircumcised, retract the foreskin, rinse, dry and bring the foreskin down over the head of the penis again. For the female, wash the genitals thoroughly by spreading the external folds. (This must be done at least daily.)
23. Pat the genitals dry.
24. Change the bath water.
25. Roll the person away from you.
26. Tuck a towel under him or her.
27. Wash the back from the neck to the buttocks.
28. Rinse. Dry well.
29. Give a back rub with lotion to enhance circulation.
30. Dress the person.
31. Change the bed linens (see next section).

Changing Linens While Someone Remains in Bed

When changing linens, follow the guidelines below:

- Never move or position the person in a way that will endanger his or her health.
- Move the patient gently and smoothly. Rough handling can cause injury.
- Throughout the procedure, explain what you plan to do before you do it.

Remove the top bedding:

- If you have a hospital bed, raise the height of the bed.
- Lower the head and foot of the bed to make it flat, if tolerated.
- Remove the blankets and pillows, leaving only the bottom, draw and top sheet.
- Raise the bed rail on the side opposite of where you will be working so the person cannot fall out of the bed.
- Help the person roll on his or her side facing the rail.
- Leave the top sheet over the person or replace it with a bath blanket.

Change the bottom sheet and drawsheet:

- A drawsheet can be a folded sheet or an inexpensive plastic tablecloth with a flannel backing (flannel side up). Place the sheet under the person from the shoulders down to the thigh area.
- Loosen the sheets on all sides.
- Move to the other side of the bed and roll the used bottom sheeting toward the person.
- Place the clean sheets on the bed with the middle fold running along the center of mattress right beside the person's body.
- Unfold the clean sheet and bring enough of it toward you to cover half of the bed.
- Gently lift the mattress and tuck the free edge of the draw sheet under the mattress on your side of the bed.
- Raise side rail on the side of the bed the person is turning toward.
- Help the person roll over toward you onto the clean side of the bed.
- Move to the other side of the bed and lower the side rail.
- Remove the used linen and put in hamper.
- Unfold the clean bottom sheet. Pull it tightly so that it is smooth and tuck the sheet in.
- Unfold the clean drawsheet. Pull it tightly until smooth and tuck in.
- Change the pillowcases.
- Help reposition the person in the center of the bed.

Apply or complete the top bedding:

- Spread the top sheet over the person and ask him/her to hold the sheet or tuck it under the shoulders while you pull the bath blanket or used top sheet away.
- Complete the top of the bed with any extra linens needed.
- Position the person in the bed until comfortable.

Ensure continued patient safety:

- Before leaving the bedside, place the bed in the low position.
- Put items the person uses within easy reach.

Positioning or Moving a Person Using Good Body Mechanics

As a caregiver, it is important to use good body mechanics to avoid strain and injury.

Good body mechanics:

- When lifting keep your back straight, bend your knees, and lift with your legs.
- Stand as close as possible to the person. Keep your feet spread apart for a firm balance.
- Use the muscles of the arms/legs to move the patient. Avoid using your back muscles.
- If transferring the person from bed to a chair, turn with your entire body. Do not twist.

Helpful hints:

- Encourage the person to help as much as possible.
- Explain to the person what you are going to do, even if you aren't sure that the person can hear you.
- Change position every 2 hours as tolerated.
- Be aware of any catheters, tubings or dressings before moving.
- Loosen blankets, remove pillows, and, if person is in an electric bed, lower the head of the bed. Raise the bed to waist level.
- If the patient is weak on one side of his/her body, move him or her away from the weak side.

How to move a person who cannot help:

- Two people or a drawsheet can be helpful.
- Lower the head of the bed or remove the pillows.
- Cross the person's arms over the chest and bend knees if possible.
- Say "1,2,3, go" then pull and lift toward the head of the bed with the lift sheet.

If you move a person by yourself:

- Lower the head of bed and remove pillows.
- If the drawsheet is tucked, then loosen it.
- Stand at the head of the bed and grasp the drawsheet as close to the person's shoulders as possible.
- Slide/pull the person upward.

Transferring From the Bed to a Chair

To move the person out of bed:

1. Position chair next to the bed.
2. Slide the person's body to the edge of the bed.
3. Help the person to a sitting position in bed.
4. Stand facing the person. Steady the person's knees with your knees. Have the person place arms on your shoulders with your arms around the waist.
5. On the count of three, help the person to a standing position.
6. Pivot around to the chair and slowly lower the person down into the chair.
7. Always remember to turn your entire body.
8. Do not twist at your waist, doing so can injure your back.

To move from a wheelchair or bedside commode to the bed:

1. Position the person in the wheelchair or commode next to the bed and lock it in place.
2. Stand directly in front of him/her.
3. Spread your feet the width of your shoulders.
4. Position your knees on either side of his/her knees in a straddle position.
5. Keeping your back straight, bend slightly at your knees.
6. Place your arms around the person's upper chest, beneath the armpits (in a hug-like position).
7. Straighten your legs to lift them.
8. Turn your entire body when moving them. Do not twist at your waist. Doing so can injure your back.
9. Slowly lower the person to a sitting position on the bed by bending your knees. Support her/him while s/he slowly lies down.

HOME EQUIPMENT

How Do We Get Equipment?

Your Hosparus Health Team makes arrangements for medical equipment, such as a hospital bed, bedside commode, wheelchair or oxygen if necessary. In Personal Care and Nursing Home Facilities, your nurse will work with facility staff and determine what the facility will provide and what Hosparus Health will have delivered.

Prior to delivery, select the location for the equipment carefully. If equipment or furniture needs to be moved, your hospice benefit does not cover the cost of this. **Ask your team members about circumstances that may lead to charges (not covered by Hosparus Health). For instance, Durable Medical Equipment (DME) companies will not move furniture or patients from one location to another.**



Hosparus Health follows Medicare Guidelines regarding provision of medical equipment.

We want you to be very satisfied with our service, so, to report equipment problems at home or in an Assisted Living Facility (ALF), please call the Patient Care Line at 1-888-295-4239 first. In a Personal Care or Nursing Home facility, notify the nursing home staff and your Hosparus Health Team.

Note: It is important to let your team know when you are no longer using a piece of equipment or if you need some other piece of equipment.

Equipment Safety

Some medical equipment can improve safety, comfort, and quality of life. In the home or ALF, the company that supplies your equipment gives you information. **We encourage you to read it.** Each piece of equipment should have a sticker that includes the date of the last inspection. Notify your Hosparus Health Team if the inspection occurred more than one year ago or if the sticker is missing. If you have any questions, contact your Hosparus Health Team.

In Personal Care or Nursing Home facilities, the facility staff have received education on equipment safety and will provide routine maintenance and inspections. If you notice any problem or malfunction of any equipment, notify the facility staff immediately. You may also

call the Patient Care Line at 1-888-295-4239 of the problem, and they will work with the facility to correct the problem and assure that you have safe equipment.

In addition to the company's instructions, we offer the following information:

Hospital Beds

- For safety, keep bed wheels locked.
- If the bed is electric, plug into a properly grounded outlet.
- Adjust the bed's height to reduce bending, stooping, and for transfers to and from a chair or bedside commode.
- Never permit anyone (including pets) under the bed.
- Keep moving parts free of obstruction (don't pinch oxygen tubing, blankets, cords, etc.).
- Do not attempt to take the bed apart for any reason.

Wheel Chairs

- Always lock wheels before getting in or out of the chair. When possible have someone assist.
- Be careful of hands when going through doorways.
- Perform basic safety checks as directed by the company.
- Look over all nuts, bolts and hardware for proper tightness.
- If any unsafe conditions are found, discontinue use and contact your Hosparus Health Team.

Walkers

- Be sure to have the walker adjusted to the proper height before using.
- If you have been instructed by a physical therapist, follow their instructions explicitly.
- If you are using a walker for the first time, have someone with you until you get used to it.
- Always take short steps, being careful not to step all the way into the front of the walker frame.
- Inspect the rubber tips on the walker regularly. Immediately replace worn or damaged tips.
- The same goes for handgrips. Handgrips that turn during use can cause a fall.
- Do not use walkers on stairs.

Bedside Commodes

- Exert force only straight down in a vertical direction when getting up or down or transferring to prevent the commode from tipping over.
- Most commodes are adjustable so be sure the seat height is at the most functional level for the user.

- If the height is adjusted, check to ensure that the lock secures tightly afterwards.
- Sit down on the seat, centered over the opening, rather than sitting on the front edge and sliding back.

Bath and Shower Seats

- Exert force only straight down when sitting, rising or shifting positions to prevent tipping the seat.
- These items are slip resistant but not slip proof. Initially and periodically, clean the rubber feet or suction cups with alcohol to remove any oil, grease or talc and to enhance the slip resistant characteristics of the material.
- If the seat is adjustable, be sure that the legs are locked after any adjustment.
- Keep the tub or shower floor clean and free of soap film to prevent slipping.
- A hand-held shower usually works best with these seats.

Oxygen Safety

In some cases, oxygen can make breathing easier, giving you energy to do the things that are important to you. But it is important not to change the amount of oxygen (liter flow) you are getting without talking with your Hospirus Health Nurse or physician. **More is not better and can actually be harmful.**

Different machines are used to deliver oxygen and safety is important. In the home and ALF, the company that provides your oxygen will give you information about:

- The company, including how to contact them
- Fire and safety precautions
- How to operate the equipment
- How to properly clean
- A “No Smoking-Oxygen in Use” sign to post

If you did not receive this information, please contact the company and request it.

The use of oxygen presents a fire risk, so proper use is critical. Here are some reminders when using oxygen in any setting:

- **DO NOT SMOKE AROUND OXYGEN. SMOKING AROUND OXYGEN IS A SERIOUS THREAT TO SAFETY BECAUSE OXYGEN IS VERY FLAMMABLE.**
- Place “No Smoking – Oxygen in Use” signs at entrances to your home.
- Keep all oxygen at least 10 feet from open flames, including candles, space heaters and stoves.

- Do not use petroleum-based products, such as Vaseline, chapstick, oily back rubs, lotions or creams, when using oxygen or handling oxygen equipment.
- Ideally, store oxygen tanks in a **secured** upright position in a well **ventilated** area. If this is not possible, you can place the oxygen tanks flat on their side in a well **ventilated** area. Do not store oxygen tanks in a confined area such as a closet or under a bed with a bedskirt.
- Do not use alcohol or alcohol-based products around oxygen.
- Do not use aerosol sprays around oxygen.
- Use the shortest length of oxygen tubing possible to prevent tripping over it.
- Change the nasal cannula every two weeks or as instructed by the company.
- Wear cotton clothing and use cotton bed linens to reduce static electricity and sparks.
- Avoid using electrical objects, such as hair dryers, electric razors, blankets or heating pads.
- Dust the oxygen system with a cotton cloth and do not cover it with any material.
- Clean the filter in the oxygen concentrator when visibly dirty or at least monthly. Your team members can provide you with instructions.
- Have a fire plan that includes an escape route.
- Have smoke detectors and a fire extinguisher in your home.

SUPPLIES

In the Home and Assisted Living Facility

Your Hosparus Health Team will order supplies related to your hospice plan of care, such as disposable pads, gloves and dressings, if needed. Hosparus Health follows Medicare Guidelines regarding provision of medical supplies. It is important to let your team know when you are running low on any hospice supply item. Review what you have and what you need at each visit. If you run out of a supply, call the Patient Care Line at 1-888-295-4239.

In the Personal Care and Nursing Home Facility

Most of your supplies will be provided by the facility. Hosparus Health reimburses the facility for supplies related to your hospice diagnosis. Any supplies that are related to the hospice diagnosis that the facility cannot provide will be ordered by your Hosparus Health Team. Any supplies needed that are not related to the hospice diagnosis will also be provided by the facility and the cost passed on to you. Hosparus Health follows Medicare Guidelines regarding provisions of medical supplies in the facilities.



Patient Safety

Hospice patients are at a greater risk for falls due to the nature of terminal illness. Assessment by your hospice team will help to determine how best to keep the patient safe.

Fall prevention for Home hospice patients primary focus is on training patients, caregivers, and family members about external fall risk factors – such as environmental hazards, assistive devices, and pets – as well as underlying fall risk factors which include acute illnesses, worsening of chronic illnesses, medications and abnormality or weakness in one or more body system.

It is very important that patients/family report every fall, including unwitnessed and near falls, to Hosparus Health so your Hosparus team can gather fall data in order to reduce the risk of patient harm resulting from falls.

Bed Safety

Most patients can be in bed safely without bed rails. Consider the following:

- Use beds that can be raised and lowered close to the floor to accommodate both patient and hospice needs.
- Keep the bed in the lowest position with wheels locked.
- Use transfer or mobility aids.
- Monitor patient frequently.
- When the patient is at risk of falling out of bed, place mats next to the bed, if this does not create a greater risk of accident.
- Anticipate the reasons patients get out of bed such as thirst, going to the bathroom, restlessness and pain; meet these needs by offering food/fluids, scheduling ample toileting, and providing calming interventions and pain relief.

When/if bed rails are used, perform an on-going assessment of the patient's physical and mental status; closely monitor. Consider the following:

- Lower one or more sections of the bed rail, such as the lower rail.
- Use a proper size mattress or mattress with raised foam edges to prevent patients from being trapped between the mattress and rail.
- Reduce the gaps between the mattress and side rails.

To Help Prevent Falls

Certain things make falls more likely, these include:

- Weakness due to illness
- Problems with balance
- Poor vision
- Medicines that may cause drowsiness or dizziness
- Hazards like slippery rugs or floors or chairs with wheels
- Disease progression
- Restlessness
- Strong desire for independence

To help prevent falls, have the person who is ill:

- Sit upright and count to 10 before standing to minimize imbalance
- Use a cane or walker if prescribed and assist them if they are unsteady
- Turn on the lights and wear glasses if needed
- Take it slow and try not to hurry, especially with turns
- Wear footwear/socks with grippers on the bottom
- Be careful on stairs

To help prevent falls, the care provider can:

- Check need for toileting at regular intervals and leaving the patient unattended.
- Before leaving the patient unattended, make sure all items the patient may need are within reach, such as remote, glasses, phone, food, drink, etc.
- Notify nurse if the person becomes restless.
- Move resting area away from stairways.
- Consider using a baby monitor.
- ***Discuss fall safety with your Hosparus Health Nurse.*** Weakness, confusion, problems with balance, disease progression, restlessness and certain medications can increase the risk of falls. Some simple changes in equipment can reduce fall risk. These may include placing bed in low position, providing a bedside commode, use of fall alarms or placement of fall mats next to the bed.

Falling is easier than you think. Prevent accidents by taking the following steps:

Floors and Walking Areas

- Keep walkways and halls free of clutter
- Keep area carpets in place with rubber pads or double-sided adhesive tape
- Avoid the use of throw rugs
- Avoid using wax on floors
- Clean up spills immediately
- Fix uneven flooring
- Replace any loose floor tiles
- Wear supportive shoes with non-skid soles

Stairs

- Secure handrails on at least one side of the stairs
- Install nonskid treads on the stairs
- Keep adequate lighting on the stairs
- Make sure carpet is firmly attached to every step

Bathroom

Since falls often occur in the bathroom, these things can make the bathroom safer:

Use special equipment, such as:

- Toilet extension seat, raised toilet seat with arms or toilet safety frame
- Grab bars on the wall
- Shower chair or bench
- Non-skid mats in the tub or shower
- Liquid soap, instead of bar soap to avoid dropping and bending over to pick up or slip on
- A hand-held shower head
- Shower shoes

Other tips:

- Leave bathroom door unlocked.
- Keep all items within reach.
- Put a large towel on the toilet or chair to have a place to sit down and dry off.
- Give the bath or shower when your loved one is not too weak or have someone else available to help, if needed.
- Check for a safe water temperature.

Lighting

Having adequate lighting can prevent many falls. For example:

- Use night lights in bedrooms, bathroom and halls; adhesive touch lights can be used as well.
- Keep a flashlight at bedside.
- Replace burned out light bulbs.
- Use highest watt bulbs that are appropriate for each light fixture to increase illumination.

Additional Tips to Reduce Falls in Personal Care or Nursing Home Facilities

- Be sure the person is oriented to the location of the bathroom in his/her room.
- Show him/her how to use the call light to call for assistance in getting up to the bathroom.
- Be sure the path to the bathroom is clear.
- Make sure eyeglasses are within reach.
- Be sure a cane or walker is used correctly. If pre-authorized by Hosparus Health, the facility Physical Therapy Department can assess this.
- The facility will have a procedure in place to reduce fall risk. Your Hosparus Health Nurse will work with you and facility staff to minimize the risk of serious injury falls, prevent injuries if a fall does occur, and discuss options for safety.

What to Do if a Fall Occurs in the Home or Assisted Living Facility

Have a plan (post it in your home, include names and phone numbers to call):

Identify a Fall Buddy - the person/s you can call to assist getting the fallen person up. Talk with your Hosparus Health team about what you should and should not do if a fall happens. This could include learning how to keep someone comfortable until help arrives, always call the Patient Care Line at 1-888-295-4239, knowing when to call EMS, and making arrangements for who to call. This will help you be confident when an issue arises.

What to Do if a Fall Occurs in a Personal Care or Nursing Home Facility

Notify the facility staff immediately. They will determine if there is an injury and will notify the physician. They will also call Hosparus Health to report the fall and any injury. If you are not sure if Hosparus Health was notified, please call the Patient Care Line at 1-888-295-4239 to be sure your team is made aware of the fall and discusses any new safety plans with you.

SAFETY IN THE HOME – OTHER SAFETY TIPS



Hosparus Health helps patients stay at home. It is important to be safe from accidents and injuries in the home. Your Hosparus Health Team will discuss the following as part of your plan of care. This section includes some tips for making your home healthy and safe and to allow you the confidence you need to be able to manage at home.

Keeping Needles, Syringes and Lancets Safe

DO

- Put used needles directly into a sharps container or a strong plastic or metal container that can't be punctured or broken. (Ex: coffee can or plastic laundry detergent container.)
- Make sure the top or lid screws on tightly to prevent spills.
- Seal the top with strong tape; when the container is full.
- When full and the top sealed tightly, place in regular trash, not recycling containers.
- Keep your container out of reach of small children and pets.

DON'T

- Throw loose needles in the garbage
- Flush used needles down the drain
- Put needles in recycling containers
- Try to bend, break, or put the cap back on your needle

Fire Safety

Take these steps to prevent a fire:

- Keep your furnace, as well as other heating equipment, in safe working order.
- Keep portable heaters 3 - 4 feet away from objects.
- Never use the burners on a gas kitchen stove to heat the house.
- Install smoke detectors. In the event of a fire, a smoke detector can save your life and those of your loved ones. They are the single most important means of preventing fire fatalities.
- Smoke detectors are very easy to take care of. There are two steps to remember:
 - Replace the batteries at least once a year.
 - Keep them clean. Dust and debris can interfere with their operation, so clean your smoke detector regularly.

Smoke detectors don't last forever. You may want to write the purchase date with a marker on the inside of your unit. That way, you'll know when to replace it. Always follow the manufacturer's instructions for replacement. If you do not have smoke detectors and cannot afford them, your local fire department may be able to help. Contact them for information about this or any questions about types or installation of smoke detectors.

Do not smoke when you are:

- Around **oxygen**
- In bed
- Feeling drowsy
- Alone

Electrical Lighting and Safety

- Check electrical cords for damage
- Do not overload outlets
- Make sure no electrical cords are placed under rugs or in walkways
- Do not use electrical appliances near the bathtub/shower area
- Unplug electrical appliances when you are not using them
- Use caution with extension cords

Emergency Preparedness Plan

In the event of a natural disaster, inclement weather, or emergency, we have an emergency plan to continue necessary patient services. We will make every effort to continue making visits to your home. Your Hosparus Health Team members will contact you when roads are too dangerous to travel. In case of bad weather or other situations that might prevent your team from reaching you, turn to your local radio and/or TV station(s). Please call the Patient Care Line at 1-888-295-4239 if you evacuate to another location or emergency shelter.

Natural Disasters

Natural disasters, such as tornados, floods and earthquakes can happen at any time. These situations can be especially threatening to people who move slowly, are bed bound, rely on medical equipment or who have other special needs. Being prepared for such disasters can help keep you safe and confident.

Tips to prepare:

- Keep supplies handy such as a battery-powered radio, at least 3 days worth of basic food including drinking water, sleeping supplies, clothing, flashlights and extra batteries, first-aid kit, suitcase of essentials in case you must evacuate, and essential medications.
- Know how to turn off your home's water, gas and electricity.
- Know the alternate power supplies for any electrical medical equipment you are using.
- Post emergency numbers by each phone.
- Keep your medications together so that, if you have to move to a safe area, you can quickly take them with you. Make sure you always have a 4-day supply.

Power Outage

If you require assistance during a power outage and local phone lines are down:

- Call your oxygen provider if there are problems accessing your emergency oxygen tanks while the power is out.
- Call the Patient Care Line at 1-888-295-4239 with any other concerns before calling 911.
- Call your closest relative or neighbor if it is not an emergency.

Flood

- Floods are the most common and widespread of all natural hazards. Some floods can develop over a period of days, but flash floods can result in raging waters in just a few minutes. Be aware of flood hazards, especially if you live in a low-lying area near water or downstream from a dam.

If local authorities issue a flood warning, prepare to evacuate:

- Secure your home. Move essential items to the upper floors of your house.
- If instructed, turn off utilities at the main switches or valves. Do not touch electrical equipment if you are wet or standing in water.
- Fill a clean bathtub with water in case water becomes contaminated or services are cut off.
- Six inches of moving water can knock you off your feet. If you must walk in a flooded area, do not walk through moving water.
- Use a stick to check the firmness of the ground in front of you.

Tornado

Tornadoes are nature's most violent storms. When a tornado warning has been issued, go to your safe area immediately. Stay away from windows, doors and outside walls.

In a house or small building:

- Go to the basement or storm cellar
- If there is no basement, go into an interior room on the lower level (closets, interior hallways)
- Get under a sturdy table and hold and protect your head
- Stay there until the danger has passed

In a high-rise building:

- Go to a small interior room or hallway on the lowest floor possible

In a vehicle, trailer, or mobile home:

- Get out immediately and go to a more substantial structure
- Do not attempt to out-drive a tornado. They are erratic and move swiftly

If the patient is bedbound:

- Move the patient's bed as far away from windows as possible
- Cover the patient with heavy blankets or pillows, being sure to protect the head and face
- Then go to a safe area

If there is no safe area nearby:

- Lie flat in the nearest ditch, ravine, or culvert with your hands shielding your head

Lightning

Inside a home:

- Avoid bathtubs, water faucets and sinks because metal pipes can conduct electricity
- Stay away from windows
- Avoid using a landline telephone, except for emergencies

If outside:

- Do not stand under a natural lightning rod, such as a tall, isolated tree in an open area
- Get away from anything metal

Winter Storm

Heavy snowfall and extreme cold can immobilize an entire region. Even areas which normally experience mild winters can be hit with a major snow storm or extreme cold. The results can range from isolation, due to blocked roads and downed power lines, to the havoc of cars and trucks sliding on icy highways.

Gather emergency supplies:

- Battery powered radio, flashlights, battery powered lamps and extra batteries
- Food that doesn't require cooking and a manual can opener
- Your medications
- Extra blankets
- Extra water in clean soda bottles or milk cartons
- Rock salt to melt ice on walkways and sand to improve traction
- Make sure you have enough heating fuel as regular fuel sources may be cut off

Dress for the season:

- Wear several layers of loose-fitting, light-weight, warm clothing rather than one layer of heavy clothing
- Outer garments should be tightly woven and water-repellent
- Mittens are warmer than gloves
- Wear a hat, as most body heat is lost through the top of the head

Earthquake

Protect yourself from falls, falling objects and crumbling buildings. It is best to stay where you are. Stay away from the outside of buildings, walls, power lines, trees, street lights and signs.

If you are inside, stay there and:

- Get under a sturdy table and protect your head.
- If you are in a wheelchair; move to a doorway, lock the wheels and cover your head with your arms.
- If you are in bed, stay there. Pull the covers up over your head.

If you are outside, stay there and:

- Stay away from the outside of buildings.

If you are in a car:

- Stop, park away from dangerous items, and stay there until the quaking stops.

Hot Weather Precautions

During the summer season there is an increased risk of heat-related illness. If you are experiencing hot weather or it is predicted, follow these guidelines:

- Never leave anyone in a closed, parked vehicle during hot weather.
- Drink plenty of water on a regular basis, even if you do not feel thirsty. Avoid drinks with alcohol or caffeine. Eat small, frequent meals.
- Stay indoors as much as possible. If air conditioning is unavailable, stay on the lowest floor, out of the sun, pull shades over windows and use fans for cross-ventilation.
- Sponge off frequently with cool water.
- Wear sun block, hats and loose, light-weight, light-colored clothing. Light colors will reflect away some of the sun's heat.
- Consult with a physician about the effects of sun and heat exposure while taking prescription drugs such as diuretics, antihistamines or other medications.
- At the first sign of heat illness (dizziness, nausea, headaches, muscle cramps), move to a cooler place. Rest for a few minutes and slowly drink a cool beverage. Call the Patient Care Line at 1-888-295-4239 immediately if conditions do not improve.

Additional Safety Information for Patients in an Assisted Living Facility, Personal Care or Nursing Home Facility

Every facility has its own plan for safety related to fires, electrical lighting, and natural disasters. Talk to your Hosparus Health Team and facility staff about your facility's procedures in the event of an occurrence. Ask questions of the staff and ask to see the facility's plan if you have any concerns.



HELPFUL INFORMATION PRIOR TO DEATH

Things To Do In Preparation For Death

1. Complete and/or locate important documents such as:
Last Will and Testament, Living Will, Durable Power of Attorney, Military Discharge Papers, Social Security Cards, Marriage License, Birth Certificates.
2. Locate Life Insurance policies to find out amount of insurance and beneficiaries on policies.

3. Locate car titles and real estate deeds.
4. Arrange for care of pets.
5. Discuss wishes for final arrangements: burial, cremation, body bequeathal, choice of funeral home, funeral services.
**Body bequeathal and cremation are best to be PRE-arranged by patient if possible.
If not pre-arranged, next of kin will have to approve.**
6. List bank accounts and other financial records.
If patient is only “owner” of bank account, accounts will likely be frozen.
7. List on-line accounts (such as email, Facebook, banking, etc.) and passwords.
8. Locate safety deposit box and keys, and information about ownership/access.
9. Address any fiduciary responsibilities the patient may hold so other arrangements can be made – examples may be POA, payee for Social Security, guardian, etc.
10. Gather information – names/relationships, military history, work history, memberships to organizations, etc. for obituary.

Helpful Phone Numbers:

- Social Security 1-800-772-1213
- Veteran’s Administration 1-800-827-1000 or www.va.gov

HELPFUL INFORMATION FOLLOWING A DEATH

The following information is offered as a general guide to help you deal with financial and/or legal issues during the first few months following death. If more information is needed, an experienced trusts and estates attorney can assist you in these matters.

Durable Medical Equipment (DME)

You may have rental DME left in your home after the death of a loved one. Hosparus Health notifies the DME company that you no longer need the equipment. If you have not heard from the DME company within two working days after your loved one’s death, please call the Patient Care Line at 1-888-295-4239, and we will follow up with the company.

If you are discharged from Hosparus Health and choose to keep your current DME, you will be responsible for the DME cost and will work with the provider directly.

Medical Supplies

Often, there is a surplus of medical supplies left in your home. If you would like to donate unused medical supplies (not medications) or equipment, please call the Patient Care Line at 1-888-295-4239 to see if a volunteer might be able to pick up what you no longer need. You may also return the supplies directly to the Hosparus Health office.

Death Certificates

Funeral homes start the process to complete a death certificate and can help you decide how many certificates are needed. Several copies are usually needed; one to keep, one for each insurance policy, checking or savings accounts, properties, stocks, bonds or mutual funds. Keep extra death certificates to send with your income tax return.

Death certificates must be signed by a physician and submitted to the appropriate state office. This process could take about three weeks. If you have not received the death certificate within three weeks, you should contact the funeral home to inquire about the process and get an estimate of how much longer it might take.

If additional certificates are needed, contact:

For Kentucky:

Vital Statistics	www.kentucky.gov
275 East Main St 1E-A	502-564-4212
Frankfort KY 40621	

For Indiana:

You can obtain additional death certificates by contacting either the health department in the county where the death occurred or:

Indiana State Department of Health
Vital Records Office
6 W. Washington Street
Indianapolis, IN 46204
317-233-1325

Applications and further information can be obtained online at www.in.gov/isdh/20444.htm.

Medical Records

There may be times when you need a copy of your loved one's medical record from Hosparus Health. For example, cancer policies often require parts of a medical record to process claims. If you need a copy of the medical record, there are a few things you must know:

- Hosparus Health must comply with federal regulations regarding the release of protected health information (medical records).
- All requests for medical records must be in writing and accompanied by a completed authorization form.

- Hosparus Health can only provide medical records to an authorized personal representative. A personal representative is a person with legal authority to act on behalf of the deceased person's estate. If the personal representative is not the spouse of the deceased, they may be asked to submit evidence that the court has established legal authority.
- The legal representative may receive one free copy of the medical record. Additional copies will be available for a fee established by Hosparus Health.
- Hosparus Health will process a medical record request within 30 working days of receipt of a completed authorization request form. To obtain a medical records form, call the Hosparus Health Medical Records Department at 502-456-6200 or 1-800-264-0521.

Medical Records authorization forms should be submitted to:

Hosparus, Inc.
ATTN: MEDICAL RECORDS
6200 Dutchmans Lane
Louisville, KY 40205-3271

Banking Information

If the account is in the deceased's name only, you will need an attorney to help you. Bank procedures vary. Do not write checks on any account, either individually or jointly held in the name of the deceased before checking with the bank. You may be required to return any uncashed checks in the name of the deceased. Check with an officer of your bank or an attorney for more information about this.

Social Security

As soon as possible after your loved one's death, call the Social Security Administration at your local office or call the national Social Security office at 1-800-772-1213 or TTY 1-800-325-0778. They will give you advice about keeping or returning the most recent check and explain other possible benefits. It is important that you retain at least the amount of the last Social Security check in the bank in case it is required to be returned. It may be necessary to make an appointment to go to the local Social Security office or it may be possible to apply by phone.

Last Will and Testament – Executor/Executrix or Personal Representative

If your loved one left a Last Will and Testament, review this legal document to determine if the deceased named an Executor/Executrix or Personal Representative to administer his/her estate. If an Executor/Executrix or Personal Representative was named, that person(s) may be responsible for filing the deceased's Last Will and Testament with the probate clerk in the county or city where the person lived at the time of death. Consult an attorney with any Will or Probate questions.

Credit Life Insurance

Some installment loans, credit union loans, etc., that are covered by Credit Life Insurance may pay off the balance owed at death. If you are left with a financed car, credit card debt, home improvement loan, etc., check to see if the debt is automatically paid off at death. If so, ask what you need to do to finalize this transaction.

Estate Advice

If you have inherited assets, you may have money you want to invest. If this is the case, you should make an appointment to consult with an experienced financial advisor and/or attorney.

Insurance and Government Benefits

Once a death certificate has been issued, life insurance, social security, railroad, union, veteran's survivor benefits, and other government benefits may be available. However, you must apply for benefits as none of them are automatic. Contact the individual companies or agencies to begin the process.

Inheritance and Estate Tax Return

Check with an attorney or financial advisor to determine if inheritance tax is due on assets left to a surviving spouse. Other exempt beneficiaries may include children, stepchildren, grandchildren, parents, siblings and grandparents. Other beneficiaries may have tax due depending on how closely they are related and the amount inherited.

If you seek professional help in filing a return you will need to take the following items with you to a meeting with your accountant or lawyer:

- (1) A copy of the Last Will and Testament (if one exists)
- (2) A list of the value of all assets owned wholly or partly by the deceased at death. Include money in the bank, credit union, or saving and loan associations, real estate, automobiles, jewelry, stocks and bonds, mortgages, life insurance payable to the estate (not to a designated beneficiary), notes, etc. On real estate, also list the latest assessed value and the balance due on any mortgage. You can list an appraised value or estimate of the fair market value.
- (3) A copy of the Trust (if one exists) and a list of the assets in the trust. If assets are in a trust, they may be subject to Inheritance Tax.



HOSPARUS HEALTH®

Hosparus Health Medication Abbreviations

Below are some medication abbreviations and what they mean. These abbreviations are commonly used when describing how medications are administered. Contact your Hosparus Health nurse with any medication questions.

Medication Abbreviations

What They Mean

PO	By mouth
Per Rectum	Rectal
SL or Sub L	Under the tongue
IM	Shot into the muscle
IV	In the vein
Topical	On the skin
SubQ	Under the skin (Subcutaneous)
Epidural	An infusion in the spine
Q	Every
Q AM	Every morning
Q Day	Once a day
BID	Twice a day
TID	Three times a day
QID	Four times a day
PRN	As needed
HRS	Hours
mg	Milligram
mcg	Microgram
ml	Milliliter
tab	Tablet
cap	Capsule

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Patient Name: _____
Patient Access Code: _____
Team: _____

[illegible]

Symptom Control Diary

[illegible]

Faces Pain Scale – Revised (FPS-R)

In the following instructions, say "hurt" or "pain", whichever seems right for a particular child.

"These faces show how much something can hurt. This face [point to face on far left] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to face on far right] - it shows very much pain. Point to the face that shows how much you hurt [right now]."

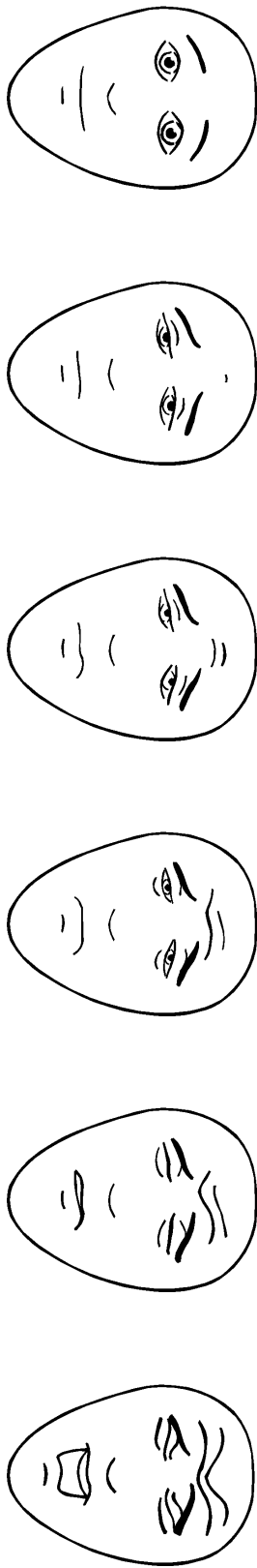
Score the chosen face 0, 2, 4, 6, 8, or 10, counting left to right, so "0" = "no pain" and "10" = "very much pain". Do not use words like "happy" or "sad". This scale is intended to measure how children feel inside, not how their face looks.

Permission for Use. Copyright of the FPS-R is held by the International Association for the Study of Pain (IASP) ©2001. This material may be photocopied for **non-commercial clinical, educational and research** use. For reproduction of the FPS-R in a journal, book or web page, or for any commercial use of the scale, request permission from IASP online at www.iasp-pain.org/FPS-R.

Sources. Hicks CL, von Baeyer CL, Spafford P, van Korihaar I, Goodenough B. The Faces Pain Scale – Revised: Toward a common metric in pediatric pain measurement. Pain 2001;93:173-183. Bieri D, Reeve R, Champion GD, Addicoat L, Ziegler J. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. Pain 1990;41:139-150.

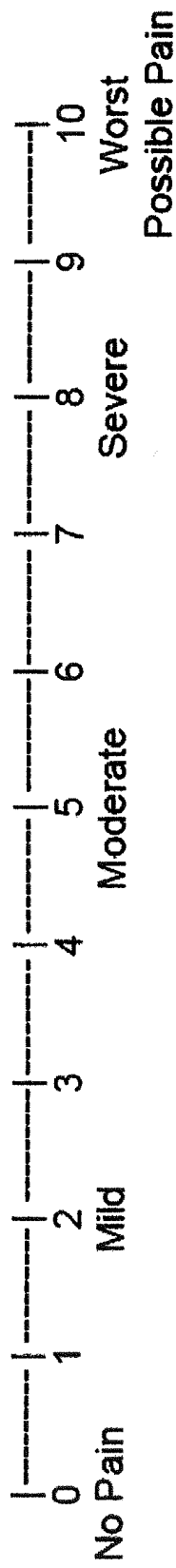
(fold along dotted line)

10 8 6 4 2 0



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Numeric Rating Scale (NRS)



When using the NRS for pain, the provider would ask, “On a scale of zero to ten, where zero means no pain and ten equals the worst possible pain, what is your current pain level?”

National Pain Management Coordinating Committee, Veterans Health Administration. Pain as the 5th vital sign toolkit, revised edition. Washington, DC: National Pain Management Coordinating Committee, Veterans Health Administration; 2000

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Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing Independent of vocalization	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respirations 	
Negative vocalization	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated troubled calling out Loud moaning or groaning Crying 	
Facial expression	<ul style="list-style-type: none"> Smiling or inexpressive 	<ul style="list-style-type: none"> Sad Frightened Frown 	<ul style="list-style-type: none"> Facial grimacing 	
Body language	<ul style="list-style-type: none"> Relaxed 	<ul style="list-style-type: none"> Tense Distressed pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out 	
Consolability	<ul style="list-style-type: none"> No need to console 	<ul style="list-style-type: none"> Distracted or reassured by voice or touch 	<ul style="list-style-type: none"> Unable to console, distract, or reassure 	
TOTAL SCORE				

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

PAINAD Item Definitions

(Warden et al., 2003)

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails, or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails, or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging, or rubbing body parts can also be observed.
5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of well-being. The person appears content.
2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is at all distressed.
3. *Unable to console, distract, or reassure* is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

Please place this on your front door following death if you are expecting medications to be delivered.

**ATTENTION:
NO DELIVERIES**

**We are refusing all deliveries
from DeltaRx or
Mullaney's Guardian Pharmacy**

Thank You

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EMERGENCY NUMBERS

Have these important numbers close by each telephone.

Hospalus Health:_____

Call buddy for falls:_____

Fire Dept: _____

Police:_____

Gas & Electric: _____

Family/Friends:

QUESTIONS FOR YOUR HOSPARUS HEALTH CARE TEAM

Date	Question	Answer / Response

INSTRUCTIONS FROM YOUR HOSPARUS HEALTH CARE TEAM

Date	Need / Concern / Issue & Instructions	What Changed?

Nondiscrimination Statement

Hosparus Health complies with applicable Federal civil rights laws and does not discriminate on the basis of race, religion, national origin, gender, gender identity, sexual orientation, age, or disability. Hosparus Health does not exclude people or treat them differently because of race, religion, national origin, gender, gender identity, sexual orientation, age, or disability.

It is Hosparus Health's policy to provide an interpreter to assist in communicating with patients who have significant hearing loss or who cannot speak, read, write or understand the English language at a level that permits them to interact effectively with our staff. We will provide all vital documents in the requested primary language. These services will be provided free of charge. If you need these services, please contact us at 800-264-0521.

If you believe that we have failed to provide these services or discriminated in another way on the basis of race, religion, national origin, gender, gender identity, sexual orientation, age, or disability, please let us know. You have the right to file a grievance also known as a complaint. If you need to file a complaint please contact: our Vice President of Compliance and Organizational Excellence. You can file a grievance in person or by mail, fax, or email. If by mail please send to Hosparus Health, 3532 Ephraim McDowell Drive, Louisville KY 40205; or call Telephone number: 1-800-264-0521 (Dial 7-1-1 or TTY number 1-800-648-6056); Fax 502-719-4215; or Email: compliance@hosparus.org. If you need help filing a grievance, we are available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at: U.S. Department of Health and Human Services, 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 or 1-800-368-1019, 800-537-7697 (TDD). Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

Nondiscrimination Notice

English

ATTENTION: If you do not speak English, language assistance services, free of charge, are available to you. Call 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

Español (Spanish) :

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

繁體中文 (Chinese):

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-800-264-0521 (TTY: 711 or 1-800-648-6056)。

Deutsch (German):

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

Tiếng Việt (Vietnamese):

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

عربي (Arabic):

ملاحظة: إذا كنت تتحدث انكليزية سفان خدمات المساعدة اللغوية متوفرة لك مجاناً. اتصل برقم 18002640521 (رقم هاتف المساعدة: 711).

Srpsko-hrvatski (Serbo-Croatian):

OBAVJEŠTENJE: Ako govorite srpsko-hrvatski, usluge jezičke pomoći dostupne su vam besplatno. Nazovite 1-800-264-0521 (TTY- Telefon za osobe sa oštećenim govorom ili sluhom: 711 or 1-800-648-6056).

日本語 (Japanese)

注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。1-800-264-0521 (TTY: 711 or 1-800-648-6056) まで、お電話にてご連絡ください。

Français (French):

Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-800-264-0521 (ATS : 711 or 1-800-648-6056).

한국어 (Korean):

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-800-264-0521 (TTY: 711 or 1-800-648-6056)번으로 전화해 주십시오.

Deutsch (Pennsylvania Dutch):

Wann du [Deutsch (Pennsylvania German / Dutch)] schwetzscht, kannscht du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: Call 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

नेपाली (Nepali):

ध्यान दनुहोस्: तपाइंले नेपाली बोल्नुहुन्छ भने तपाइंको नमितिभाषा सहायता सेवाहरू नःशुल्क रूपमा उपलब्ध छ । फोन गर्नुहोस् 1-800-264-0521 (टटिविडि: 711 or 1-800-648-6056) ।

*Cushite/ Oroomiffa (Oromo):

XIYYEEFFANNAA: Afaan dubbattu Oroomiffa, tajaajila gargaarsa afaanii, kanfaltiidhaan ala, ni argama. Bilbilaa 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

Русский (Russian):

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-800-264-0521 (телетайп: 711 or 1-800-648-6056).

Tagalog (Tagalog – Filipino):

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

Ikirundi (Bantu – Kirundi):

ICITONDERWA: Nimba uvuga Ikirundi, uzohabwa serivisi zo gufasha mu ndimi, ku buntu. Woterefona 1-800-264-0521 (TTY: 711 or 1-800-648-6056).

हिंदी (Hindi)

सुचना: જો તમે ગુજરાતી બોલતા હો, તો નઃશુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-800-264-0521 (TTY: 1-800-648-6056).

ਪੰਜਾਬੀ (Punjabi)

ਧਿਆਨ ਦਫਿ: ਜੇ ਤੁਸੀ ਪੰਜਾਬੀ ਬੋਲਦੇ ਹੋ, ਤਾਂ ਭਾਸ਼ਾ ਵੱਚਿ ਸਹਾਇਤਾ ਸੇਵਾ ਤੁਹਾਡੇ ਲਈ ਮੁਫਤ ਉਪਲਬਧ ਹੈ। 1-800-264-0521 (TTY: 1-800-648-6056) 'ਤੇ ਕਾਲ ਕਰੋ।

Nederlands (Dutch)

AANDACHT: Als u nederlands spreekt, kunt u gratis gebruikmaken van de taalkundige diensten. Bel 1-800-264-0521 (TTY: 1-800-648-6056).

Barren River - Bowling Green

101 Riverwood Avenue, Suite B
Bowling Green, KY 42103

Barren River - Glasgow

1320 North Race Street
Glasgow, KY 42141

Central Kentucky

105 Diecks Drive
PO Box 2149
Elizabethtown, KY 42701

Green River

Green River Plaza, Suite 5
295 Campbellsville Bypass
PO Box 4134
Campbellsville, KY 42718

Indiana - Jasper

225 West 41st Street, Suite C
Jasper, IN 47546

Indiana - New Albany

502 Hausfeldt Lane
New Albany, IN 47150

Louisville

6200 Dutchmans Lane
Louisville, KY 40205

Hosparus Health Inpatient Care Center (HICC)

Norton Healthcare Pavilion
315 East Broadway, 6th Floor
Louisville, KY 40202



HOSPARUS HEALTH®

OUR MISSION

Through compassion, dignity and excellence we seek to enhance the quality of life for those impacted by serious illness.

OUR VISION

To be the preferred partner for serious illness care in our region, through clinical excellence and a culture of joy and gratitude.

Since 1978, Hosparus Health, a fully accredited not-for-profit hospice and palliative care organization, has provided medical care, grief counseling, pain management and much more for people facing serious and life-limiting illnesses in Kentucky and Indiana.

800-264-0521 | HOSPARUSHEALTH.ORG | A NOT-FOR-PROFIT ORGANIZATION

Updated 10-2020