HARRY HYNES
Memorial Hospice

Welcome

We Are Here for You

Thank you for choosing Harry Hynes Memorial Hospice. It is an honor to care for you and your loved one. While hospice is designed for those with an advanced illness, hospice is not about giving up, but rather shifting focus from curative treatment to comfort and quality of life. It offers specialized care that allows patients to live fully with less pain and stress, often providing more meaningful time with loved ones.

At Harry Hynes Memorial Hospice, we are driven by the belief that hospice is not about losing life but adding to it. We believe you deserve to get the most out of every day no matter where you are in life's journey, and have more opportunities to create memories and moments of joy. We believe in less pain and more quality of life and that your wishes should be respected.

We are here to give you more. It is not just our job, it is our calling. And we wouldn't have it any other way. Thank you for allowing us to serve you. Our goal is to help you make the most of your time together, so that each day can be lived to its fullest.

Training Guide

In this Training Guide we will help you understand what hospice care is, what you might expect in the days, weeks, or months ahead, and how we can support you and your family. We make every effort in this guide to speak to both the patient and the family. Please know that whichever category you are in, the material here can provide you with important information and insight.

We suggest that you look through this guide page by page. Please ask us to clarify anything you don't fully understand or anything you would like to know more about. It is also important that you communicate all symptoms, responses to medications, or voice any concerns you may have to your hospice team.

Nursing visits are scheduled regularly and a hospice nurse is available by phone 24 hours a day to answer questions and address concerns. Care team members will visit as needed and teach caregivers the skills necessary to provide for the special needs of the patient when we are not there.

Hospice care focuses on supporting you and your loved one during an advanced illness, with emphasis on comfort and quality of life, rather than finding a cure. This specialized care enables patients to live each day to the fullest as comfortably and dignified as possible.

When to Call Hospice

Your nurse case manager will visit at least once a week, increasing frequency as needed. But please call us if questions or concerns need to be addressed prior to your nurse's visit, or if you feel that your loved one's pain or symptoms are not controlled. A nurse is available by phone 24 hours a day, 7 days a week to address any issues or problems that may arise, and your hospice care team members will visit as needed.

Please call us if you have concerns about:

- increased pain
- agitation
- any bleeding
- increased restlessness
- any injury
- trouble breathing
- slurred speech
- a change in mental alertness
- unusual sweating
- nausea or vomiting
- inability to urinate
- constipation or diarrhea
- problems with equipment
- a change in food / fluid intake
- medication questions

Our hospice staff can provide the best comfort for the patient, work more efficiently with the physician, and ease the caregiver's stress when we are aware of all pain and symptoms.

Office hours: Monday-Friday, 8 am-5 pm

Outside of office hours, our answering service will take your call and notify the on-call nurse. That nurse will return your call within 15 minutes. On the rare occasion that a return call from a nurse is not received within 15 minutes, please call and ask that the nurse be paged again.

If at anytime you call 800-767-4965 and do not get an answer or there is a fast busy signal, please call the hospice answering service directly at 316-261-8168.

Since hospice is comfort care with the hospice acting as the primary care provider, hospice patients and caregivers are asked to contact hospice before calling 911 or going to the emergency room. If you have any questions, please don't hesitate to call us.

**IF YOU ARE CONSIDERING CALLING 911
OR GOING TO THE EMERGENCY ROOM,
PLEASE CALL US FIRST.
WE CAN HELP.**

Call us 24/7 at 800-767-4965

Notes

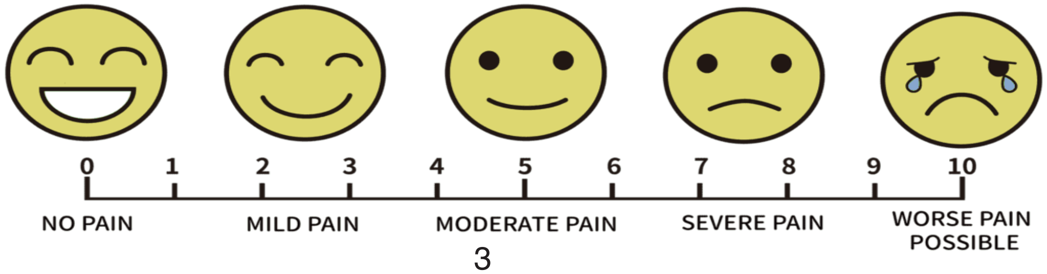
HARRY HYNES
Memorial Hospice

As Needed Medication Log

Write down medications given with date, time and dose.

Please mark “X” if you have issues or concerns in any of the areas listed.

DATE & TIME	PAIN 1-10 Pain scale at bottom of page	MEDICATION GIVEN	DOSE GIVEN	Trouble breathing Pg. 28	Skin and/or temperature change Pg. 28	Food and/or fluid intake Pg. 29	Bladder and/or bowel elimination Pg. 29	Anxiety and/or depression Pg. 30	Sleeping and/or fatigue Pg. 31	Agitation and/or restlessness Pg. 32



HARRY HYNES
Memorial Hospice

Medication List

Medication	Notes	Covered Y/N

Contents

Welcome 1
When to Call Hospice 2
As Needed Medication Log 3
Medication List 4

Hospice Support TAB

- Your Care Team 7
- Locations and Phone Numbers 8
- Hospice Services: What You Can Expect . . . 9
- Hospice Team 10
  - Caregivers 10
  - Physicians 10
  - Nurses 10
  - Hospice Health Aide 11
  - Social Worker 11
  - Chaplain 11
  - Volunteers 11
  - Pharmacist 11
- Hospice Levels of Care 12
  - Traveling on Hospice Services 12
  - Discharge from Services 12
  - Serving Veterans 12
- Infection Control 13
- Home Safety 14
- Physical Assistance 15
  - General Rules 15
  - Ambulating Your Loved One 15
  - Assisting From Bed to Chair 15
  - Assisting Sitting to Standing 16
  - Assisting Using a Commode 16
  - Caring for Bedbound Patient 16
  - Pulling Up a Loved One in Bed 16
  - Assisting Using a Bedpan 17
  - Positioning Your Loved One 17
  - Giving a Bed Bath 17
  - Skin Care 17
  - Providing Mouth Care 18
  - Changing Bed Sheets 18
  - How to Use a Gait Belt 18
  - Assistive Equipment Use 18

More on other side.

Medication TAB

Medications 19
  Medications Refills 19
  Controlled Substance Requirements 19
  Home Use & Disposal of Controlled Substances . 20
Attention Medicare Part D Participants 21
Top Medications and Side Effects 22
Disposal by Flushing 24

Caregiving TAB

Taking Care of Your Loved One 25
Pain Management 26
  Comfort Care Kit 26
  Morphine Q & A 26
  Signs and Symptoms of Pain. 27
Symptom Management. 28
  Trouble Breathing 28
  Skin and Temperature Changes. 28
  Nutrition and Hydration 29
  Bladder and Bowel Elimination 29
  Constipation 30
  Anxiety 30
  Fatigue and Sleep 31
  Confusion / Disorientation 31
  Restlessness and Agitation 32
  Withdrawal 32
Final Days 33
Saying Goodbye 34
When Your Loved One Dies 36

Grief and Loss TAB

After a Loved One Dies. 37
  Collect Important Information 37
  Apply for Death or Disability Benefits 37
  If Dependent on Income from Deceased 37
  Preparing for the Future 38
Grief Support 39
  We Value Your Opinion 39
Celebrate and Honor Life 40
  Opportunities for Giving 40

Patient Rights and Privacy 41

Your Care Team

Hospice is a holistic approach to end-of-life care that addresses the physicial, social and spiritual needs of patients. The interdisciplinary team is commiteed to providing the highest possible quality of care and support for patients and families.

The care provided by your experienced hospice team will be customized to meet your specific goals and needs. Hospice volunteers can also be essential in providing the level of care and support that is expected from hospice.

Your nursing visits will be scheduled regularly and a hospice nurse is available by phone 24 hours a day to answer questions and address concerns. All care team members will visit as needed and teach caregivers the skills necessary to care for the patient when we are not there.

Doctor(s): ______________________________

____

RN Case Manager: ______________________

____

Hospice Health Aide: ____________________

____

Social Worker: _________________________

____

Chaplain: _____________________________

____

Volunteer: ____________________________

____

Our History

Founded by community volunteers in 1983 as a non-profit local hospice, Harry Hynes Memorial Hospice has grown to be the leading provider of end-of-life care in South Central and Southeast Kansas. In 2002, we changed our name from Hospice Inc. to Harry Hynes Memorial Hospice to honor one of our founders, Dr. Harry Hynes (middle, back row, in photo).

Our agency began and continues to operate with the mission of enabling people to live with dignity and hope while coping with loss and serious illness. That belief is based on listening to the needs of our patients and families, while focusing on comfort, quality, and dignity of life.

To learn more about our mission and history, please visit hynesmemorial.org.

Locations and Phone Numbers

Wichita Office

313 S Market St
Wichita, KS 67202
Phone: 316-265-9441
800-767-4965
Fax: 316-265-6066
Counties: Butler, Harper, Kingman, Sedgwick

Coffeyville Office

1503 W 11th St
Coffeyville, KS 67337
Phone: 620-251-1640
866-865-2154
Fax: 620-251-2130
Counties: Chautauqua, Elk, Greenwood, Montgomery, Wilson, Woodson

Pittsburg Office

3 Med Center Cir
Pittsburg, KS 66762
Phone: 620-231-7223
866-584-5498
Fax: 620-235-7801
Counties: Allen, Anderson, Bourbon, Cherokee, Crawford, Labette, Linn, Neosho

Newton Office

120 W 6th St Suite 140
Newton, KS 67114
Phone: 316-283-1103
800-767-4965
Fax: 316-283-1106
Counties: Harvey, Marion, McPherson, Reno, Rice, Sedgwick

Oswego Office

1010 S Commercial St
Oswego, KS 67356
Phone: 620-281-7030
866-584-5498
Fax: 620-281-7060
Counties: Allen, Anderson, Bourbon, Cherokee, Crawford, Labette, Linn, Neosho

Winfield Office

109 W 10th Ave
Winfield, KS 67156
Phone: 620-705-5150
800-767-4965
Fax: 620-705-5375
Counties: Cowley, Harper, Sedgwick, Sumner

Hospice Center Inpatient Unit

Ascension Via Christi
St. Francis Campus
NW Corner, 8th Floor,
Elevator Bank A
929 N St Francis
Wichita, KS 67214
Phone: 316-261-3131
Fax: 316-261-3161

Parsons Office

1720 Main St
Parsons, KS 67357
Phone: 620-423-3863
866-584-5498
Fax: 620-423-0441
Counties: Allen, Anderson, Bourbon, Cherokee, Crawford, Labette, Linn, Neosho

Hospice Services

What You Can Expect

Family members sometimes have concerns about their own ability to care for a seriously ill loved one at home. Please be assured that your Harry Hynes Hospice team will make regularly scheduled visits and support you as they explain and demonstrate techniques that allow you to become a more capable and confident caregiver.

After signing onto hospice, the first week will likely be the busiest - getting equipment in place and meeting the hospice team. Team members visiting may include your nurse, hospice health aide, social worker, and chaplain. Volunteers may also visit for comfort and companionship for your loved one.

When members of your team begin visiting, please know they are there to help take care of the patient and family, not to take over. They will stabilize the patient's pain and symptoms as needed, and evaluate for medical, emotional and spiritual needs.

Visits from hospice team members will be scheduled according to the plan of care, so you know whom to expect and when. Your team of skilled and knowledgeable healthcare experts will be available to help the patient and family as they navigate a serious illness. They will also be available to answer questions or find answers for you. We encourage you to ask whatever is on your mind.

Your hospice team will be in continual communication with the patient's physician and/or the hospice physician to discuss the patient's medical history, current physical symptoms, goals of care, and preferences. This will assist your team in maintaining a personalized and updated plan of care that addresses the needs, goals and traditions of the patient and family.

As everyone's journey is unique, none of us can say for certain exactly what's to come. However, we can say the moments remaining hold many opportunities to share memories, make amends, deepen relationships, express love and hope, and simply be together.

Our goal is that you find comfort in knowing Harry Hynes Memorial Hospice will be with you every step of the way, bringing hope for a fulfilling life, even as the journey nears completion.

Hospice Team

Caregivers

Caregivers and family are essential to hospice care. Several people may work together to provide care, although at least one person needs to be designated as the primary caregiver. Primary caregivers are responsible for overseeing the care in the home and are included in decisions regarding care. We value the commitment primary caregivers make to their loved ones.

When the hospice team makes their regularly scheduled visits, they teach caregivers how to care for the special and unique needs of a patient with a terminal illness.This includes physical care as well as extending emotional and spiritual support to the patient. This care is not intended to take the place of the family and/or primary caregiver. Team members depend on the observations of caregivers for daily progress and needs.

Physicians

Attending Physician

The Attending Physician is the doctor identified by the patient as having the primary role in the determination and delivery of their hospice care. This may be a doctor of medicine or osteopathy, a nurse practitioner, a physician assistant, or the Hospice Physician.

Primary Care Physician (PCP)

With extensive knowledge of your health history and often a long-standing relationship, we recognize that your PCP is an integral person in identifying your medical needs. If you choose your PCP to be the Attending Physician, they may direct your medical care OR choose to defer hospice care coordination to the Hospice Physician because of their specialized training and knowledge.

Hospice Physician

The Hospice Physician specializes in comfort care. They can be your Attending Physician if you wish. Or they can work closely with your Attending Physician in planning and directing your care. Hospice physicians are available 24 hours a day, 7 days a week. The Hospice Physician oversees the hospice team and your care plan.

Nurses

There are both Registered Nurses (RN) and Licensed Practical Nurses (LPN) providing hospice care. They work together to ensure your needs are being met and that the issues and concerns identified in your care plan are addressed. A nurse will complete a thorough assessment weekly and will make additional visits throughout the week as needed.

Your hospice nurses are experts in symptom management, disease processes, identifying care needs, and providing education and support. They are responsible for managing your medications, including ordering and refilling as needed. The nurses communicate all assessment findings, questions, and concerns to the attending physician or hospice physician as appropriate.

Registered Nurse (RN)/Case Manager

You are assigned a Registered Nurse who serves as your Case Manager. Your Case Manager is responsible for the overall coordination of your care and services, and to ensure that your care needs are being met. Your Case Manager works closely with your Attending Physician and/or the Hospice Physician and assists in coordinating medications as well as counseling and supportive services.

Licensed Practical Nurse (LPN)

The Licensed Practical Nurses on the team work closely with the RN Case Managers. Like an RN, they are skilled and knowledgeable in end-of-life and comfort care. The LPN will communicate all assessment findings, questions, and concerns to your RN Case Manager.

After-Hours Nurses (Triage)

Both RNs and LPNs are a part of the team of nurses available to assist you after hours. These after-hours nurses are available evenings, nights, weekends, and holidays. Team members are scheduled and available to receive calls and respond to questions or make visits 24 hours a day, 7 days a week.

Hospice Health Aide

Your Hospice Health Aide is an expert in making daily living tasks easier. They can help patients maintain dignity and independence by assisting with bathing, personal hygiene, and light household duties related to your care. They can provide education on safe transfer and ambulatory techniques, and exercises for range of motion. Hospice Aides also serve to provide companionship and often alert the physician, nurse, and other team members of care issues that may require attention.

Social Worker

Your Hospice Social Worker is a licensed professional who provides support to patients and their loved ones during a difficult time. They offer a range of supportive services, including assessing social, emotional, and spiritual needs, helping to develop the patient's care plan, individual and family support counseling, and education about community resources and referrals. Additionally, social workers may help with cultural and language barriers, team conferencing, grief and loss counseling, and assistance with applying for financial resources. They may also connect patients with caregiving services, help with advance directive planning, and assist with funeral arrangements.

Chaplain

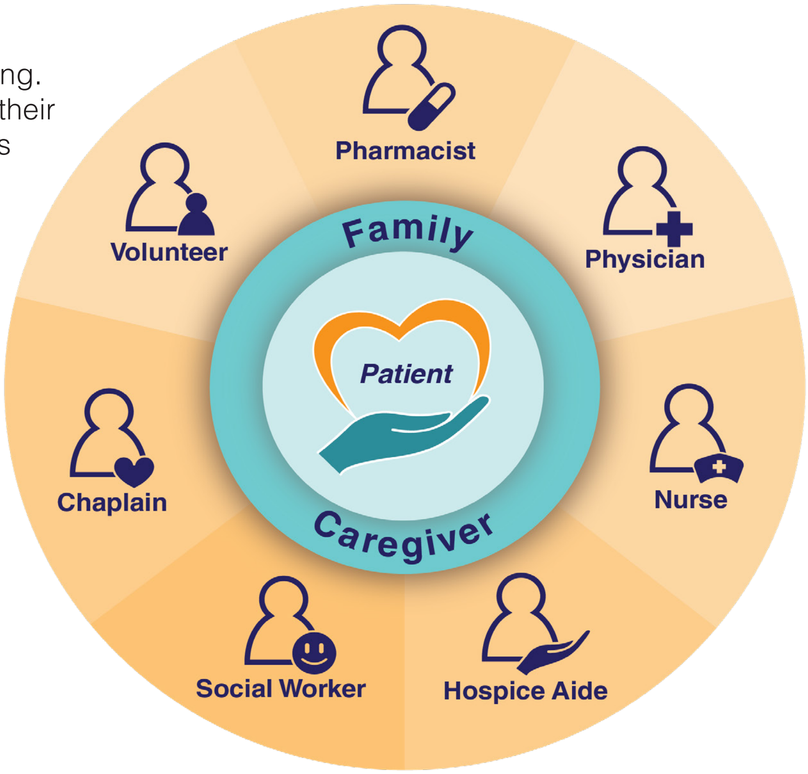
Your Hospice Chaplain is a non-denominational spiritual counselor with specialized clinical training. They serve as a guide to honor our patients and their loved ones' unique emotional and spiritual needs during end-of-life care. Drawing from the patient and family faith tradition, beliefs, and values, chaplains play a vital role in ensuring the patient and family are treated with dignity, compassion, and respect while finding inner strength, peace, and spiritual well-being. Some of the services that chaplains provide are spiritual counseling, grief and loss counseling, companionship, collaboration with local clergy or pastoral care, and funeral planning.

Volunteers

Hospice volunteers are a unique service available to patients and their caregivers. Our volunteers are specifically trained for hospice care. They can visit with the patient, read or play soothing music, or just sit quietly at the bedside. You can request a volunteer through your patient care team. When possible, please request a volunteer 48 hours in advance. A volunteer placement specialist will work with you to identify your needs. Volunteers can not administer medications or provide direct patient care, but they can allow caregivers an opportunity to leave the home for a short time, comfortable in the fact that their loved one is in good hands.

Pharmacist

Harry Hynes Memorial Hospice has an in-house pharmacy with dedicated pharmacy staff. Your hospice pharmacist helps coordinate many aspects of your medication management and are a valuable resource to your hospice team. At admission and throughout the course of your care, the pharmacist reviews your list of medications for appropriateness, effectiveness, proper dosing, side effects, drug interactions, and any necessary lab monitoring for therapeutic levels. They also provide guidance on new medications or changes in current medications.



Hospice Levels of Care

All Medicare-certified hospices are required to offer four levels of hospice care depending on patient and caregiver needs, due to the fact that patients may require differing intensities of care during the course of their disease.

1. **Routine Hospice Care** is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their home, which can include a private residence, assisted living facility or nursing facility.
2. **General Inpatient Care (GIP)** is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms have been ineffective. GIP can be provided in a Medicare-certified hospital, hospice inpatient facility, or nursing facility that has registered nursing available 24 hours a day to provide direct patient care.
3. **Continuous Home Care** is care provided for between 8 to 24 hours a day to manage pain and other acute medical symptoms. Continuous home care services must be predominately nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis.
4. **Inpatient Respite Care** is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long-term care facility that has sufficient 24-hour nursing personnel present on all shifts to guarantee that patient's needs are met. Respite care is provided for a maximum of five (5) consecutive days.

Payment for each level covers all aspects of the patient's care related to the terminal illness, including all services delivered by the Interdisciplinary Team, medication, medical equipment and supplies. Over 90 percent of hospice care is provided at the Routine Hospice Care level.

While hospice patients may be admitted at any level of care, the progression of their illness may require a change in their level of care. Although the Medicare and Medicaid Hospice Benefit is designed to offer patients care where they live (including nursing homes), a hospice may transfer a patient to inpatient GIP care if necessary, for pain and symptom management.

Sources: NHPCO National Data Set and/or NHPCO Member Database. 2021. 42 CFR 418. Hospice Conditions of Participation. 2008.

Traveling on Hospice Services

There may be occasions when the patient needs to travel outside our service area. Please inform your RN Case Manager if the patient will be making such a trip. Whether it's over the weekend or longer, it's important we have knowledge of your plans in advance, so that we may support you. We will be available by phone 24 hours/day, 7 days/week to answer questions and provide guidance. At times, our agency may also contact a hospice in the visiting area to be accessible to provide hospice services if needed. In most cases, the patient will not need to terminate hospice services by planning in advance.

Discharge from Services

Harry Hynes Hospice may discharge a patient if:

1. The patient moves out of our service area or transfers to another hospice;
2. We determine that the patient is no longer terminally ill;

or

3. We determine that the delivery of our care or ability for us to operate effectively is seriously impaired.

Serving Veterans

Harry Hynes Memorial Hospice is proud to provide compassionate, quality care to veterans in our community. We have a strong commitment to honoring our veteran patients in all branches of service for the sacrifices they made to preserve the freedoms we all cherish. We strive to meet their unique needs, including help with PTSD and navigating their medical benefits. Veterans on our service are recognized with a ceremony of appreciation and an Honored Veteran Pin.

Infection Control

Hospice patients are at an increased risk for infections because their body's natural defenses against illnesses may be weakened. All members of the hospice team will follow standard infection control policies to protect you, your family, caregivers, and themselves.

Handwashing

Hand hygiene is important not only for anyone providing care to the patient but also for the patient themselves. Handwashing should be done before and after any contact with the patient, such as feeding, repositioning, or assisting with toileting or other elimination needs. Handwashing should also be done after contact with personal items such as bedding or personal care supplies. Handwashing should follow any time you blow your nose, cough or sneeze.

Center for Disease Control (CDC) guidelines for how to wash your hands:

1. Wet your hands with clean, running water (warm or cold), turn off the tap, apply soap.
2. Lather your hands by rubbing them together. Be sure to lather the backs of your hands, between your fingers and under your nails.
3. Scrub your hands for at least 20 seconds. You should be able to hum the "Happy Birthday" song beginning to end twice.
4. Rinse hands well under clean, running water and dry with a clean towel.

Hand Sanitizers – Information from the CDC:

- Washing hands with soap and water is the best way to reduce the number of germs. If you must use a hand sanitizer, use an alcohol-based hand sanitizer that contains at least 60% alcohol (ethanol or ethyl alcohol) or 70% isopropyl alcohol.
- Alcohol-based hand sanitizers can quickly reduce the number of germs in most situations. They do not eliminate all types of germs.
- Hand sanitizers are not as effective when hands are visibly dirty or greasy.

General Hygiene

Keeping the patient's skin clean and dry is important. It helps prevent infection and maintain skin integrity. Personal items such as toothbrushes or razors should never be shared.

Cleaning Medical Supplies

Bedpans, urinals, and commodes should be cleaned on a regular basis with soap and water. For a more thorough cleaning, you may use 1:10 bleach solution. This can be made by mixing 1 cup of bleach with 10 cups of water. The dirty water should be poured down the toilet and not the sink.

Soiled Linens and Clothing

Place the soiled linens and/or clothing in a separate container or trash bag until you can wash them. Avoid shaking the items in the air prior to washing, as this can spread germs. Wash as soon as possible after soiling and wash separately from other linens. If the material is colorfast you may add one cup of bleach and use hot water if possible.

Sharp Objects

Needles, syringes and razor blades should be placed in a puncture-proof container and labeled as contaminated waste. Your hospice team can provide you with a puncture-proof container for your sharps. Never recap needles and do not attempt to break or bend needles. Always dispose of the unit as a whole. Never overfill the containers, and containers should be appropriately disposed of once they are ¾ full. Staff can bag them in a designated bag for contaminated materials and then remove them from the home to dispose of them in the appropriate manner.

Spills in the Home

Blood and body fluids need to be cleaned by putting on gloves and wiping up fluid with paper towels. Use a cleaning solution of household bleach and water (1 cup of bleach to 10 cups of water) and wipe the area again. Bag the used paper towels and dispose of them in the trash.

Visitors

Discourage those who have cold or flu symptoms from visiting. Encourage visitors to wash their hands before and after the visit.

Home Safety

Safety is a concern for all of us. Remember these important tips:

- Our staff and volunteers will call to schedule visits, so you will know when to expect them.
- Our staff and volunteers will wear a photo badge that identifies them as being from Harry Hynes Memorial Hospice.
- Please turn on outside lights when expecting a visit after dark.
- Keep pets in a safe area so they do not become upset when outsiders come into the home.
- Stow and secure all weapons.

Fall Prevention

- Keep pathways clear from clutter, trash and electrical cords.
- Avoid the use of throw rugs and runners.
- Use handrails when available.
- Keep the home well lit, especially hallways.
- Follow the manufacturer's recommended use of assistive equipment.

Bathroom Safety

- Use non-skid mats
- Keep floors dry
- Avoid slippery surfaces
- Use grab bars in shower or tub
- Use a stool riser if needed
- Set hot water tank at a medium setting to avoid burns.

Electrical Safety

- All electrical cords should be in good repair with no frayed or exposed wires.
- Do not overload circuits or extension cords.
- Cover outlets appropriately when not in use.

Disaster Safety

Ask yourself and your family these questions:

- If there were no power, what would I need to stay safely at home?
- If the roads were blocked for several days and no one could reach my neighborhood, who would check on me that lives close by?

Fire Safety

Smoking

- NO SMOKING OR OPEN FLAMES WHEN OXYGEN IS IN USE.
- Do not smoke in the presence of oxygen tubing or the oxygen concentrator.
- Smoke only in well-ventilated areas.
- Allow waste to cool before disposing in an appropriate trash can.

Candles

- Do not use candles when oxygen is in use.
- Do not leave burning candles unattended.

Smoke Detectors

- Have a working smoke detector on every floor of the home.
- Test batteries monthly to assure they are working.
- Change batteries twice a year. A good way to remember is to change batteries when daylight savings time changes.

Space Heaters

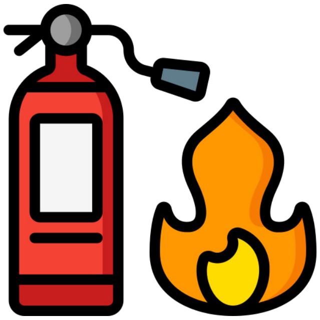
- Keep the area around the heater free from clutter. This includes rugs, blankets and paper.

Fire Extinguishers

- Have a working fire extinguisher in your home and know how to use it.
- Keep the extinguisher in an easily accessible area in the home.

Escape Route

- Know your escape route from the home.
- Have a planned meeting area outside the home.
- Practice the escape plan each year with everyone living inside the home.

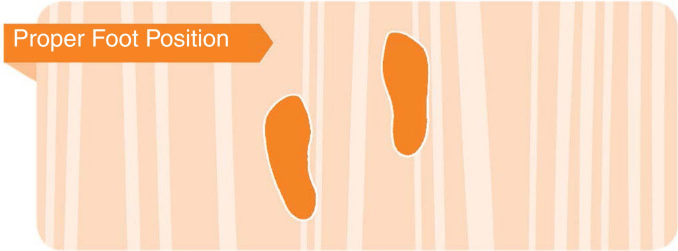


Physical Assistance

Safe body mechanics ensures caregiver and patient safety, places less stress on the body, decreases risk for injury, and conserves energy through more efficient use of the body.

General Rules

1. Never lift more than you can comfortably handle.
2. Create a base of support first. Stand with your feet at shoulder width apart and place one foot a half-step ahead of the other.
3. DO NOT use your back to do the heavy lifting. The back muscles are not your strongest muscles. USE YOUR LEGS.
4. If the bed is low, place one foot on a footstool. This will relieve the pressure on your lower back.
5. Consider getting a back support belt to protect your back.
6. Consider a gait belt when the patient has mobility or balance issues. (See page 18)

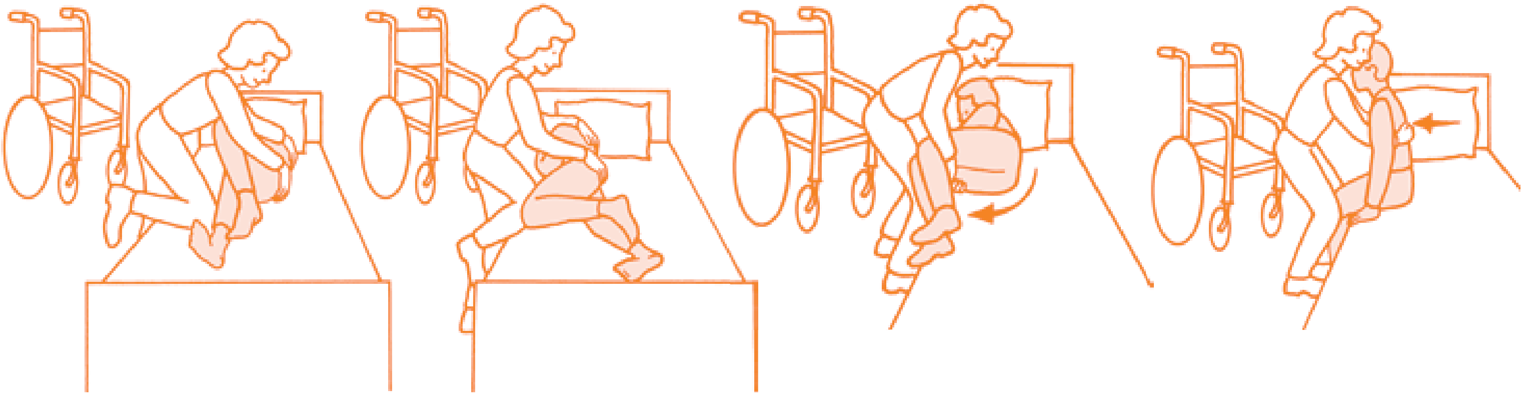


Ambulating Your Loved One

1. Always stand on the person's weaker side when assisting with ambulation.
2. Place your hands around their waist to guide the person gently and offer support.
3. If the person should fall, guide them slowly to the ground and sit with them. Keep your hands around their waist to guide their center of gravity to the floor landing on their bottom.

Assisting from Bed to Chair

1. Have the person scoot to the side of the bed they will be sitting on.
2. Raise the head of the bed completely.
3. Allow the person to rest with their head elevated to avoid lightheadedness as their body gets used to sitting up.
4. Bring the person to a sitting position on the side of the bed.
5. Allow the person to dangle their legs off the side of the bed. Move slowly and allow time for the blood to circulate to avoid becoming lightheaded as someone changes position.
6. Place appropriate footwear on the person's feet to offer stability.
7. Face the person and place your right foot between the person's feet.
8. Bend your knees to ensure you are assisting the person using your legs and not your back.
9. If needed, use the draw sheet to help pull the patient to a standing position.
10. The person should not grab you around your shoulders as this could injure you. The person can hold on to your waist.
11. The person receiving help can push off the side of the bed or hold on to a walker, wheelchair, or arms of chair.
12. Once standing, pivot slowly, and hold on to the gait belt (if applicable) or draw sheet until they feel the surface of the chair behind their knees.
13. Have the person reach with both hands back to the arms of the chair or continue to hold the caregiver's waist.
14. Bend your legs to help lower the person as they slowly sit.
15. Gently guide the person by their waist (or gait belt if applicable) to sit.



Assisting Sitting to Standing

1. Assist the person to the edge of the bed or chair.
2. Face the person with feet shoulder-width apart.
3. Reach under the arms, with their arms on your shoulders, with your knees bent and back straight.
4. Hug your loved one gently while raising to a standing position; allow them to pull on your shoulders for stability.
5. Do NOT let go until you are sure the person is stable while standing.

Assisting Using a Commode

1. When moving with a person, it is essential to explain the purpose, goal and what you will do with the person before starting the task.
2. Ambulate with a person to the commode until the patient feels the surface of the commode behind their knees.
3. Lower their pants and make sure the commode lid is open.
4. Have the person reach both hands back to the arms of the commode or continue to hold the waist of the caregiver.
5. Bend your legs when you help lower the person as they slowly sit. Be sure they are sitting squarely on the commode. Gently guide the person by their waist to sit.
6. Give them toilet paper and a warm washcloth to clean themselves, if they are able.
7. Allow privacy if needed.
8. After using the commode, offer hand sanitizer and anything else needed to clean up.
9. Help to stand after using the commode by first placing their feet in a comfortable position in front of the commode. On a count of three help to a standing position. Be sure the person gets their bearings prior to taking a step.

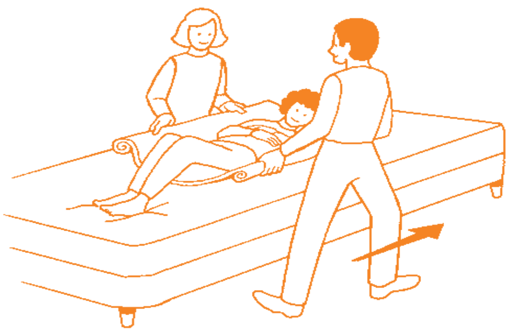
Caring for a Bedbound Patient

1. **When caring for a bedbound patient it is essential to prevent pressure sores or skin tears. Turning or repositioning every two hours is the most effective prevention.**
2. A natural tendency is to raise someone's feet, however, it can be harmful to their buttocks if their head is raised above 30 degrees and their feet are elevated at the same time. This position will cause skin breakdown on buttocks from the skin being pulled in opposite directions.
3. Another prevention strategy when caring for a bedbound person is to keep skin clean and dry.
4. If there are areas that promote sweating such as on the back, buttocks and under the breasts, clean and pat dry those areas daily A common "hospice intervention" is to apply antiperspirant under the breasts to help prevent skin breakdown from sweating.

Pulling Up a Loved One in Bed

--This is a two-person task--

1. If using a hospital bed, start by lowering side rails.
2. Raise the bed to the top of your hips to avoid bending over the person - bending over could cause back strain which you want to avoid.
3. Lower the head of the bed so they lie flat.
4. Stand between the person's hip and shoulder and grab and roll the draw sheet with palms facing down. Be sure the draw sheet is between the person's nipple line and mid-thigh.
5. Have the person bend their knees and dig their heels to help push with their legs to move up in bed. Remind them to do this on the count of three.
6. Remove the pillow from under their head.
7. Further direct the person to hug themselves and lower their chin to avoid skin tears.
8. Both caregivers turn their front foot forward toward the head of the bed and bend at knees.
10. On the count of three, pull the person up in bed.
11. Both people lift at the same time, using leg strength and not their backs, to move the person up in bed.
12. Gently replace the person in bed, straighten pillow and sheets and flatten any wrinkles that could be uncomfortable for the person to lie on.



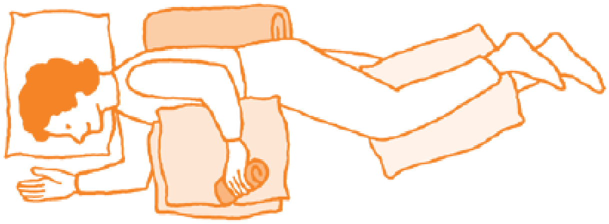
Assisting Using a Bedpan

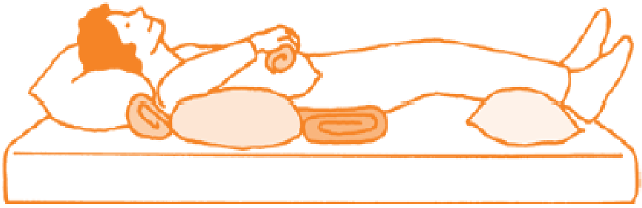
When assisting someone to use a bedpan, gloves are always recommended.

1. Explain to the person what you're planning to do.
2. Lower the bed into a flat position.
3. Help the person roll to one side in the bed.
4. Place the bedpan squarely under the buttocks.
5. Roll the person back on top of the bedpan.
6. Double-check the bedpan is in the right position.
7. If able, place the person into a sitting position.
8. Place toilet paper or a warm washcloth next to the person.
9. Give the person some privacy but stay close (outside the door) to hear if help is needed.
10. When they are done, lay their head down and carefully roll the person to one side to remove the bedpan.
11. Help cleanse the area if assistance is needed and pat dry.
12. Dispose of waste into toilet and clean the bedpan.
13. Remove gloves and wash hands.

Positioning Your Loved One

1. If using a hospital bed, start by raising the side rail on the side of the patient that they will be turning toward.
2. Raise the bed to the top of your hips to avoid bending over the person.
3. Remove all pillows.
4. If they are able, have the person bend their legs to help them roll to the side. The person should always roll to their weaker side so the strong arm pulls their body over.
5. Ask the person to reach and grab the bed rail to the best of their ability while you gently guide the person on to their side.
6. Consider placing a pillow, blanket or towel between the knees and ankles to offer additional comfort and prevent bone resting on bone while lying on their side.
7. Place a pillow behind the back for support and to hold the side-lying position.
8. There should not be any weight on the shoulder or knees. Be sure to keep bony prominences protected.
9. Raise the head of the bed a little, just enough to provide comfort to the patient.
10. Place a small pillow under the person's head.
11. Place a small pillow lengthwise under the calf of the weak leg. Let the heel hang off the end of the pillow to relieve pressure. If the person needs a blanket, make sure the blanket does not create pressure on the toes.





Giving a Bed Bath

1. Gather the following supplies if giving a bed bath: wash basin, soap, lotion, washcloths and towels, gloves and clean clothes.
2. Place warm water in the basin and add soap to the wet washcloth.
3. Wash, rinse, then dry one area at a time using very little soap (to avoid drying out the skin). Cover each cleaned area with a towel or blanket before moving to the next area. A common strategy is to start with the extremities and wash the trunk last.
4. Consider changing the water halfway through washing the patient so that it remains warm.
5. Check for dry skin and be sure to use moisturizing soap and lotion if you notice this.
6. Call the nurse if you notice any red areas that do not go away after several hours.
7. Keep sheets dry and wrinkle-free to prevent pressure sores.

Skin Care

Keeping the skin moisturized and clean with frequent position changes (every two hours) is important during illness. Specific things to keep in mind about proper skin care:

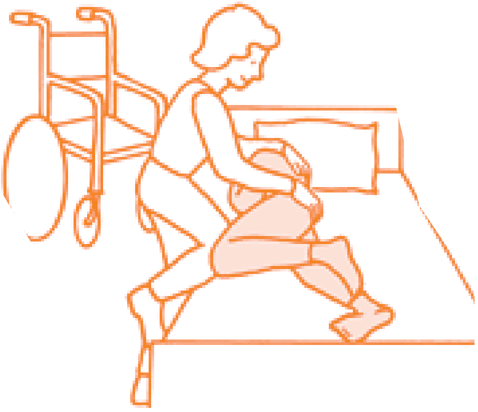
- If the skin is very dry, use moisturizing soaps and lotions.
- After bathing, make sure soap is rinsed off completely and the skin is thoroughly dried.
- Avoid rubbing reddened areas.
- Everyday bathing may not be appropriate for all patients.

Providing Mouth Care

1. Gather the following supplies for mouth care: soft toothbrush, toothpaste, cup of water, dish to spit into. Additional items such as K-Y jelly to moisturize lips (Vaseline should never be used with oxygen because it is flammable); 1 tsp of baking soda in 8 oz. water can help with dry mouth.
2. Have the patient sit up if possible.
3. Check for redness or white patches.
4. Rinse mouth and dentures after meals.
5. Remove dentures before bed.
6. Notify your hospice care team if you notice white patches on the person's gums, tongue or throat. Also, notify the hospice care team if the person is having difficulty swallowing.

Changing Bed Sheets

1. If using a hospital bed, raise the side rails first.
2. Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain.
3. Lower the head of the bed so they lie flat.
4. Stand between the hip and shoulder of the person. This is where you will grab the draw sheet to move the person onto their side.
5. Ask the person to reach and grab the bed rail—if they are able—while you gently guide the person onto their side.



6. Place the pillow behind the back for support and to hold the side lying position. Position the person's arm out of the way to avoid shoulder discomfort while the person is lying on their side.
7. Begin to change the sheets by rolling the used sheets (including the fitted sheet) under the person along the length of the person's body.
8. Attach the top and bottom corners of the clean fitted sheet and flat sheet. Smooth the clean sheet out under the patient.
9. At this time a draw sheet can also be placed under the patient and folded with the clean sheets under the patient. A draw sheet is necessary for someone who is bed bound.
10. To complete making the bed with clean sheets, roll the person to their opposite side, helping them to gently roll over the used sheets and newly placed clean sheets.
11. Once the person is re-positioned on the opposite side with pillows for stability, pull out the used sheets. Place used sheets into the laundry bin.
12. Pull the clean sheets tight and attach the final two corners, making sure wrinkles are flattened.

How to Use a Gait Belt

Put the belt around the person's waist over their clothing with the buckle in front. Thread the belt through the teeth of the buckle. Put the belt through the other two loops to lock it. Be sure the belt is snug with just enough room to get your fingers under it.

When helping someone stand, if possible, the person should be encouraged to push down on the chair or bed, while you lean forward and grasp the belt on both sides. The person should be held at the waist instead of the arms or shoulders.

Lift or move the person with your arm and leg muscles. Do not use your back muscles. Do not twist your body when you move or lift the person. When you are done moving or walking with the person, remove the gait belt.

Assistive Equipment Use

Using assistive equipment: walkers, canes, wheelchairs, bath benches and shower seats, etc.

- Assistive equipment should not be used alone until the patient has been shown how to use it.
- If the patient is unsteady, a walker or cane should not be used without some assistance during walking.
- Equipment can be cleaned using soap and water and towel-dried before the next use
- A pad or pillowcase on the wheelchair seat will also help keep it clean.
- Make sure the chair or bench is secure and dry in the tub/shower before using the equipment
- Removing all throw rugs will reduce falls.

Call your Hospice Care Team if:

- The patient has fallen.
- The equipment is cracked or broken.
- There are any questions about the proper use of the equipment.

Medications

Medications come in different forms, including: pills, liquids, inhalants, patches, suppositories and ointments. Medications may be changed into different forms depending on the patient's needs, such as if they may have difficulty swallowing. Let your hospice team know if you have less than a 7-day supply of any current medication.

Your nurse will review your medications with you to ensure you understand the reason for each one. The nurse will also go over how and when to take the medication along with the possible side effects and the desired results. In addition, our pharmacist will review the medications for any possible side effects or interactions. Your nurse will then visit with you, your caregivers and your physician if there are suggested changes in medications.

Things to Remember

- Take or give the medications as scheduled.
- Use a pillbox to organize the medications. A pillbox helps to ensure you are using the medicine correctly and at the right time. Upon request, your nurse can fill your pillbox each week.
- Keep a log of the medications you take or give. This log will help your nurse know how to best control symptoms and help you track the medications.
- Your nurse can assist you in the disposal of medications when they are discontinued or are no longer needed.
- Prescribed medication is only for the intended person and should only be used as directed by the doctor.
- Keep medicine in a safe, secure location, and out of the reach of children.
- Needles should be disposed of by placing the uncapped needle directly into an appropriate container. Your care team will provide a disposal container for your use.

Medication Refills

- Your hospice nurse is responsible for ordering and refilling medications filled by Kansas Palliative Pharmacy.*
- Your nurse will review and count medications to ensure you have enough. If needed, your nurse can assist you in ordering refills of your other medications from the pharmacy of your choice.
- Some medications require special conversation and paperwork with your physician, which may cause some delay in receiving them in your home.

**Kansas Palliative Pharmacy is owned by Harry Hynes Memorial Hospice and the pharmacists and technicians work with your nurses and physician(s) to help you have the best care possible. They are dedicated to your symptom management and care throughout your time with our hospice.*

We Can Best Serve You When

- We know all medications you are taking. This would include anything ordered by your physician, over the counter medications and any vitamins, herbals or supplements.
- Let us know any changes in pain or symptoms.
- Call us before you fill any outside prescriptions.
- Please help us in evaluating your medication and other supply needs for nights, weekends and holidays.

Controlled Substance Requirements

Harry Hynes Memorial Hospice adheres to a controlled drug reporting system. Controlled substances are distributed only to the patient or his/her legal representative. The hospice care team will be responsible for monitoring the amount of any drug given and the length of time between refills. Medication lock boxes can be used when appropriate. If the patient/family refuses to dispose of any controlled substance, the physician and pharmacist are informed, and the nurse will document the refusal.

In addition, our pharmacists participate in the online Prescription Monitoring Program known as K-TRACS (Kansas Tracking & Reporting of Controlled Substances). The system collects prescription data on ALL Schedule II, III, and IV controlled substances and drugs of concern dispensed in or into the state of Kansas. (pursuant to K.S.A. 65-1681 through 65-1693).

Home Use and Disposal of Controlled Substances

PURPOSE

To ensure the appropriate use and disposal of controlled substances, in accordance with applicable state and federal regulations.

POLICY

Harry Hynes Memorial Hospice, Inc. voluntarily adheres to a controlled drug reporting and disposal process. Note: This policy is applicable to sample medications if utilized.

PROCEDURE

1. Controlled substances will be distributed directly to the patient or his/her representative. The interdisciplinary group will be responsible for monitoring the amount of drug issued and the length of time between renewals.
2. The Admitting Nurse/Case Manager will provide a copy of the written policies and procedures on the management and disposal of controlled drugs to the patient/representative and family. The Admitting Nurse/Case Manager will verbally discuss this policy in a language and manner that they understand to ensure the safe use and disposal of controlled drugs. The Admitting Nurse/Case Manager will document in the clinical record that the patient/representative and family have received a copy of the policies and procedures.
3. The Admitting Nurse/Case Manager will outline an informal documentation procedure for the patient and family/caregiver when hospice personnel are not present in the home.
4. Organizations will monitor for suspected drug diversion, including opioids, depressants, hallucinogens, stimulants, and anabolic steroids.
5. The Admitting Nurse/Case Manager will document in a clinical note who is responsible for the disposal of the drugs.

Disposal of Controlled Substances – Family

1. When a hospice patient no longer has a need for a controlled substance, the Case Manager will instruct the patient and family/caregiver regarding proper disposal of the drugs in accordance with federal, state and local law/regulation.
2. The Admitting Nurse/Case Manager will document in the clinical record that the patient and family/caregiver were given the written policies and procedures for managing controlled drugs and discussed the disposal of medications and took responsibility to do so.
3. The hospice nurse, social worker, or chaplain attending the death of a hospice patient will inform the family/caregiver of their responsibility to dispose of all the patient's prescribed medications and will document this instruction in a clinical note. If the family/caregiver requests assistance with the disposal, the hospice employee will observe and provide verbal assistance as the family/caregiver properly dispose of the prescribed medications. The disposal will be documented in a clinical note.

Disposal of Controlled Substances – Hospice

1. In the event a hospice patient no longer has a need for a controlled substance, a hospice nurse, physician, or physician assistant, employed by or under arrangements of a qualified hospice program, acting within the scope of employment, may handle any controlled substance that was lawfully dispensed to the person receiving care for the purpose of disposal of the controlled substance in accordance with Federal, State, Tribal and local law/regulation.

A. The disposal occurs after the death of the patient.
B. The controlled substance is expired.
C. The hospice patient no longer requires the controlled substance because the plan of care has been modified.

2. If the family choses to dispose of the controlled substances, the hospice nurse may assist the family with this task. Our nurses have the supplies necessary to make this an easy process. Documentation may include the following information.

A. The type of controlled substances
B. Dosage
C. Dosage form (i.e, tablet, patch, vial, etc.)
D. Route of administration
E. Quantity disposed of
F. Time, date and manner of disposal
G. Who witnessed the disposal

Disposal of Controlled Substances – Long Term Care Facilities (LTCF)

A. Per federal controlled substance law, all controlled medications (DEA class II, III, IV, and V) that have been accepted into the facility-controlled substance log must remain in the LTCF. To aid in the identification of a a controlled substance, Kansas Palliative Pharmacy will stamp medication labels with a red “C” or a “CII”.
B. A direct physician order will permit a patient to leave the LTCF with patient specific controlled medications, but many LTCFs have a policy prohibiting this transfer.
C. All medications, controlled or non-controlled, that are removed from their packaging or opened are to be disposed of by the consulting pharmacist per the LTCF protocol.
D. Medications that are sealed and not controlled may be returned to the pharmacy that dispensed them. Kansas Palliative Pharmacy may not legally accept medications dispensed from other pharmacies.

Disposal of Controlled Substances – Hospice Center

A. If patient medications are brought to the Hospice Center, the unit nurse must assist the family in the disposal of the controlled substances, or the medications can be returned to the home by the family. The Hospice Center may not accept controlled substances that have been taken to the patient’s home. Patient’s family members may not bring medications to the Hospice Center for disposal after the patient dies. Additionally, the patient specific controlled substances may not be returned to the pharmacy for disposal.

Attention Medicare Part D Participants

It is our responsibility as your hospice provider to work with your physician and your pharmacy to determine which medications we will cover under the Medicare Hospice Benefit, which ones will be covered under your Part D plan, and which medications are determined to be no longer medically necessary. If these medications will be continued, they would become your financial responsibility. If you receive a new prescription from your physician, notify us immediately so we can determine if the new medication will be covered by hospice or by your insurance plan. If you have any questions or concerns about medications and/or your Medicare Part D coverage, please contact your hospice team.

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

Medicare

Top Medications & Side Effects

Medications	**Common Side Effects**	**Severe Side Effects** (Call Harry Hynes Hospice)
For Pain		
Acetaminophen	• Headache • Upset stomach	• Allergic reactions • Breathing problems
Opioids • Morphine • Hydrocodone • Oxycodone • Hydromorphone • Fentanyl • Methadone	• Constipation • Dry mouth • Nausea / vomiting • Drowsiness • Blurred vision • Fentanyl patch (itching, redness, rash where patch is applied)	• Allergic reactions — skin rash, itching, hives, swelling to face, lips, tongue • Breathing problems
Gabapentin (for nerve pain)	• Constipation • Tiredness • Weight gain • Dizziness / lightheadedness	• Seizures • Swollen glands / flu symptoms • Severe tingling / numbness • Allergic reactions • Breathing problems
For Anxiety and Agitation		
Benzodiazepines • Lorazepam • Alprazolam • Temazepam • Clonazepam • Diazepam	• Drowsiness/ dizziness • Impaired coordination/unsteadiness • Weakness	• Hallucinations • Severe depression • Severe drowsiness • Breathing problems • Allergic reactions
Quetiapine	• Constipation • Drowsiness / dizziness • Stomach upset • Dry mouth • Weight gain	• Difficulty swallowing • Uncontrolled / unusual movements of face, lips, mouth, tongue, arms, legs • Allergic reactions • Breathing problems • May cause rise in blood sugars
For Excess Secretions or Gastrointestinal Spasms		
Hyoscyamine	• Drowsiness / dizziness • Decreased sweating • Constipation • Altered taste • Dry mouth and/or dry skin • Blurred vision	• Fast / irregular heartbeat • Mental / mood changes (confusion, unusual excitement) • Allergic reactions • Breathing problems
For Nausea and Vomiting		
Ondansetron	• Constipation / diarrhea • Headache • Lightheadedness / dizziness	• Fast / irregular heartbeat • Stomach pain • Muscle spasms / stiffness • Allergic reactions • Breathing problems
For Constipation		
Bisacodyl	• Bloating • Cramping / lower stomach discomfort • Discolored urine (oral tablets) • Rectal itching, burning, or swelling	• Rectal bleeding • Severe / persistent diarrhea • Severe bloating/stomach distension • Allergic reactions • Breathing problems

For Constipation		
Polyethylene Glycol (Miralax)	• Bloating or gas • Cramping / lower stomach discomfort • Nausea	• Diarrhea • Severe bloating, pain, stomach distension • Allergic reactions • Breathing problems
Sennosides / Docusate	• Bloating • Discolored urine • Cramping / lower stomach discomfort	• Allergic reactions • Breathing problems • Rectal bleeding • Severe / persistent diarrhea • Severe bloating or distension of stomach
For Depression or Anxiety		
SSRIs • Citalopram • Escitalopram • Sertraline • Fluoxetine • Paroxetine	• Nausea • Loss of appetite • Diarrhea • Problems sleeping • Drowsiness • Anxiety / irritability	• Chest pain / rapid heartbeat • Allergic reactions • Breathing problems
For Stomach Acid / Gastrointestinal Protectant		
H2 Blockers • Famotidine • Ranitidine	• Constipation • Diarrhea • Headache • Dizziness	• Agitation / confusion • Hallucinations • Allergic reactions • Breathing problems
Proton Pump Inhibitors • Omeprazole • Pantoprazole	• Constipation • Dry mouth • Headache • Loose stools • Nausea	• Bone, muscle, or joint pain • Allergic reactions • Breathing problems
For Shortness of Air / Bronchospasm		
DuoNebs (Albuterol / Ipratropium)	• Shaking (tremors) • Blurred vision • Cough • Headache • Stuffy or runny nose • Unusual taste • Stomach upset	• New / unusual wheezing, choking, or other breathing problems • Chest pain or rapid heartbeat • Allergic reactions • Breathing problems
For Decreasing Inflammation, Pain, and Nausea / Vomiting		
Steroids • Dexamethasone • Prednisone	• Trouble sleeping • Headache • Nausea / vomiting • Weight gain • Skin issues (acne /dry /thinning skin) • Changes in shape or location of body fat	• Allergic reactions • Breathing problems
For Decreasing Fluid Retention		
Loop Diuretics • Furosemide • Bumetanide	• Increased urination • Thirst • Muscle cramps • Weak / dizzy / lightheaded	• Dehydration • Ringing in ears / hearing loss • Allergic reactions • Breathing problems

Additional Counseling of Side Effects: (1) For medications that cause sleepiness / drowsiness / dizziness, do not drive, operate heavy machinery or other dangerous activities until you know how the medications will affect you. (2) Do not drink alcohol or take other drugs that may make you sleepy or dizzy without talking to your hospice nurse. (3) For medications that cause dizziness / lightheadedness, these may increase the risk of falling, so remember to rise slowly from a sitting or lying position.

Disposal by Flushing

FDA Required Medication Disposal by Flushing

This list from the U.S. Food and Drug Administration (FDA) tells you which medicines you should flush when they are no longer needed. To download clickable links in the list below that direct you to medicine information for consumers that includes specific disposal instructions on the web search: "Medicines recommended for disposal by flushing - FDA."

Active Ingredient	Found in Brand Names
Benzhydrocodone/ Acetaminophen	Apadaz
Buprenophine	Belbuca, Bunavail, Butrans, Suboxone, Subutex, Zubsolv
Diazepam	Diastat/ Distat AcuDial Rectal Gel
Fentanyl	Abstral, Actiq, Duragesic, Fentora, Onsolis
Hydrocodone	Anexsia, Hysingla ER, Lortab, Norco, Represain, Vicodin, Vicoprofen, Zohydro ER
Hydromorphone	Dilaudid, Exalgo
Meperidine	Demerol
Methadone	Dolophine, Methadose
Methylphenidate	Daytrana Transdermal Patch System
Morphine	Arymo ER, Embeda, Kadian, Morphabond ER, MS Contin, Avinza
Oxycodone	Combunox, Oxaydo (formerly Oxecta) OxyContin, Percocet, Percodan, Roxicet, Roxicodone, Roxybond, Targiniq ER, Xartemis XR, Xtampza ER
Oxymorphone	Opana, Opana ER
Sodium Oxybate	Xyrem Oral Solution
Tapentadol	Nucynta, Nucynta ER

FDA believes that the known risk of harm, including death, to humans from accidental exposure to the medicines listed above, especially potent opioid medicines, far outweighs any potential risk to humans or the environment from flushing these medicines. FDA will continue to conduct risk assessments as a part of our larger activities related to the safe use of medicines. For disposal information, specific to another medication you are taking, please visit Drugs@FDA. Once there, type in the medication name and click on search. Then click on the label section for that specific medication. Select most recent label and search the word "disposal."

Taking Care of Your Loved One

For each person and each family member or caregiver, the journey through end of life is different. Many who are caring for a terminally ill person, or experiencing the journey of a serious illness, have never done so before.

Emotionally you may feel:

- Tense
- Worried
- Agitated or irritable
- Easily distracted
- Helpless
- Overwhelmed
- Alone
- Wondering if you are doing the right/ wrong thing

Physically you may:

- Tremble or shake
- Sweat
- Experience shortness of breath
- Feel like your heart is pounding in your chest
- Have an upset stomach, nausea, or change in appetite
- Have headaches
- Have difficulty sleeping

Experiencing a serious illness, and/or caregiving for someone who is, can be emotionally taxing. But it can also be an opportunity for meaningful conversations and priceless moments of time together. We hope this infomation will provide reassurance as you walk through the journey with your loved one.

What You Can Do

- The hospice social worker can provide techniques that might help reduce anxiety: controlled breathing, relaxation, a quiet place, exercise, intentional focus.
- Limit caffeine (coffee, tea, colas, chocolate) and avoid alcohol.
- Make sure to rest. Lack of rest can increase the level of emotional and physicial stress you are experiencing.
- Talk with your physician. Let them know about any anxiety or worry you are experiencing or feeling.
- Talk with your family and friends about your needs and accept help as offered.
- Continue participation in your favorite activities or hobbies.
- Take time alone. This can include walking, reading, listening to music, taking a bath, praying, gardening, etc.
- Continue to eat well and drink plenty of water.
- If you have fears, anxiety, or are feeling overwhelmed contact your hospice team.
- Take comfort in your spiritual or religious beliefs. If you need help with spiritual support, contact your hospice team. Remember, we are here for you too.
- Family members may react differently. It is important to talk with each other regarding expectations and how to best provide care. Your hospice team is available to facilitate a family meeting if needed.
- Allow yourself to feel and express the variety of emotions that you may experience.

Ensuring a loved one's final months, weeks or days are as good as they can be may require not only making medical decisions but also attending to their emotional, spiritual and social needs. This includes creating a supportive environment that prioritizes their comfort and dignity beyond just physical care.

As a person gets closer to death, the body goes through some natural changes. It is our goal to provide as much comfort and support to you and your loved one as we possibly can during this time of change.

There is no set path or sequence that will occur at end of life. Each person is unique and depending on the nature of the illness and the patient's circumstances, they may exhibit only a few symptoms or maybe numerous symptoms. And, symptoms may occur in a matter of weeks or may occur in just a few hours.

Pain Management

Pain is a complex symptom accompanying many life-limiting illnesses and managing pain is very important. Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does. People can experience all types of pain: physical, emotional and spiritual. Your hospice team will work with you and your loved one to identify what type of pain is being experienced and determine the most appropriate treatment.

Physical pain is experienced by most people with a terminal illness. The goal is to control the pain while keeping your loved one as alert as possible. Although pain cannot always be controlled completely, it can be kept at a minimal level. Only your loved one truly knows the severity or extent of the pain.

Some people report less pain than they are having for fear of addiction to the pain medication. We encourage patients to be honest about their pain. Hospice pain management means keeping the patient comfortable and addressing their symptoms, so they may have the best possible quality of life.

There are different tools available to help your loved one rate their pain. A numeric scale can be used if your loved one is alert, oriented and able to communicate. Ask your loved one to choose the rating that best describes their pain level using a 0-10 scale with 0 being no pain and 10 being the worst pain they have ever had. If your loved one is unable to use the numeric scale, you can ask them to identify the face that best describes how their pain makes them feel. (*See page 27 for pain scale.*)

If your loved one can't communicate, look for the followng signs of discomfort and speak on behalf of your loved one to the care team: **Moaning, Frowning, Restlessness, Tension, and/or Tears.**

Tell your team what makes the pain better or worse, and how well pain medications are working. We encourage you to write down any and all questions you have. Then share them with your care team during visits, or call anytime.

Comfort Care Kit

Upon admission, we may issue a "comfort care kit" containing emergency medications to be used in a time of crisis. This sealed package contains a small quantity of several medications historically needed on an urgent basis for many patients with symptoms such as constipation, pain, anxiety, nausea or vomiting.

When uncontrolled symptoms occur, please contact us. A nurse will listen to your situation, and may then instruct you to open and use a medication from your comfort care kit. The kit should remain sealed until you are instructed to open it. Please keep the kit in a safe place. Instructions can also be found in the kit.

Morphine Q & A

The decision to use morphine is one that a patient and family often have questions about. Although morphine can carry some stigma and fears, the benefits to a hospice patients' quality of life are greatly improved when morphine is administered responsibly.

Is morphine dangerous?

Some people fear or have heard that morphine will cause the patient to stop breathing. However, this common hospice medication is very safe when given orally at the dose needed for symptom control and increased slowly as needed for pain relief. Patients typically start at a very low dose, which is gradually increased if needed until the person feels comfortable.

Will morphine cause me to feel sleepy all the time?

Morphine can cause some sleepiness or sedation initially, but with continuing doses this effect decreases within a few days.

Will taking opioids make me addicted?

No. Morphine will be prescribed for either pain or shortness of air. Addiction generally occurs when people continue to take pain meds for a euphoric feeling after the reason for taking them has resolved. This is not the case in a hospice patient.

Doesn't morphine stop the patient's breathing?

Our hospice doses are closely monitored by the nurse, pharmacist, and physician. When our hospice patients are experiencing shortness of breath, they are usually taking fast ineffective breaths. The morphine slows the breathing rate down so that the breaths are more effective and allow for increased oxygen intake.

Will taking morphine hasten my death?

Morphine does not hasten death. Having to live with pain can hasten death. Morphine can aid in a more comfortable death, not a quicker one. There is no evidence that opioids such as morphine hasten the dying process when used at the right dose to control the symptoms a patient is experiencing.

Does starting morphine mean that death is near?

No, it is the degree of pain or shortness of breath that dictates when morphine should be initiated. When morphine and other opioids are started at a low dose and increased as needed, these medications have been proven safe and effective in the management of comfort.

Does hospice give morphine to help people die?

No. Properly prescribed opioids do not cause or hasten death but can make the patient more comfortable and improve quality of life. Appropriate use of these pain relievers does not shorten life.

Signs and Symptoms of Pain

The following signs and symptoms may or may not be present. Remember that everyone copes with pain in their own way and that pain is what the person says it is. If your loved one is awake and alert, ask them about their pain. If your loved one is unable to tell you about their pain, look for one or more of the symptoms listed below. Your hospice nurse can help you identify how your loved one shows signs and symptoms of pain.

Common Pain Indicators

- Verbal expressions of pain
- Furrowed brow
- Clenched jaw
- Fidgeting or restlessness
- Moaning or crying out
- Withdrawn or quiet

What to Report to your Hospice Team

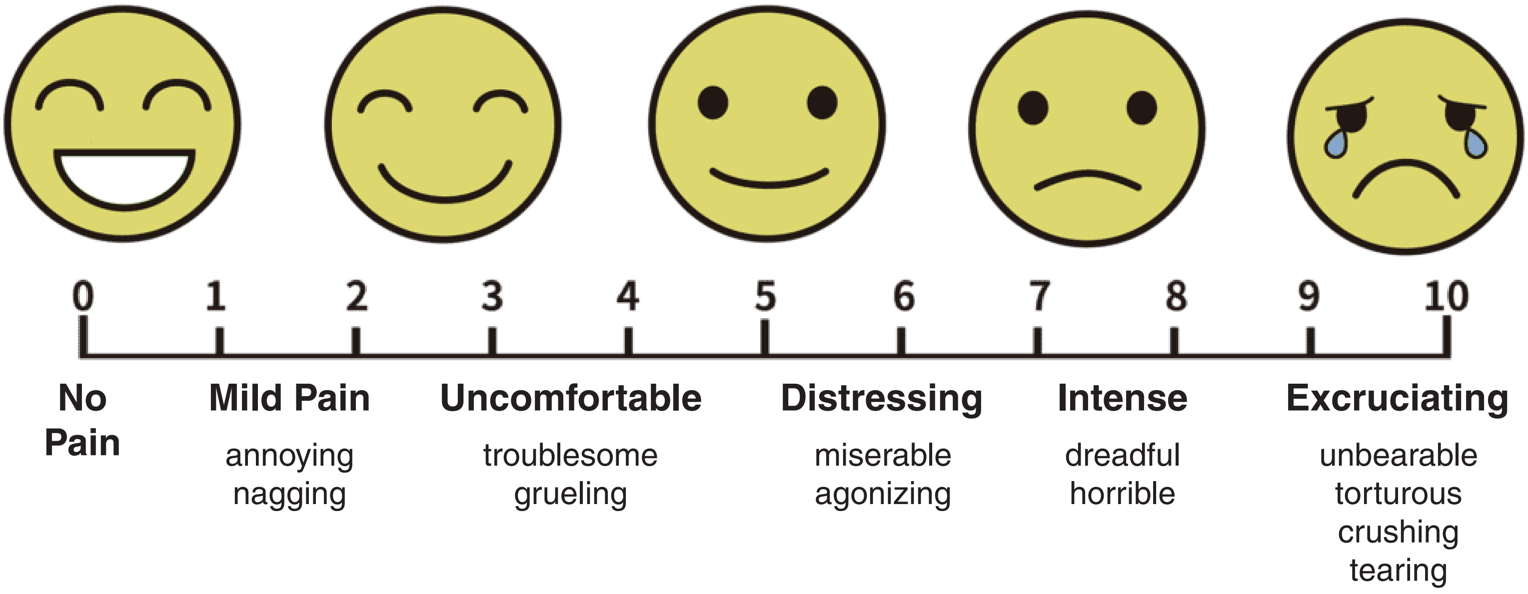
- Verbal complaints of pain not relieved with prescribed medications.
- Increased use in pain medications.
- Pain that is interfering with your loved one's ability to sleep or participate in activities.
- If your loved one is unable to swallow the medications, there may be some alternative ways it can be given. Your hospice nurse will work closely with you on any questions you may have about the medication.

What You Can Do

- Keep a medication log to keep track of times and amounts given.
- Give medication at scheduled times. It may require more medication and take longer for the pain medication to work if it is not given as scheduled.
- Give pain medications prior to activities.
- Set an alarm to remind you when medication is due.
- Keep medications organized either in a pillbox or in their original bottles.

Other options may include:

- Many people with chronic pain report that concentrating on something other than pain may help. Some things to try: watching television or movies, reading, listening to music, writing, painting or other activities or hobbies of enjoyment.
- Meditation, relaxation, and breathing exercises may help reduce muscle tension.
- The patient may find prayer, visualization and/or focused deep breathing helpful.
- Gentle massage, body rubs or simply a soft touch can be soothing.



Please call Harry Hynes Hospice if your loved one has any significant changes in their pain.

Symptom Management

Trouble Breathing

As a patient nears death, it is common for their breathing patterns to change. These patterns can happen very quickly, or can occur over many hours or even days. The rate of breathing might change, becoming very rapid or very slow. There can be a puffing or a blowing of the lips with exhaling. There may be long pauses between breaths which is called apnea. This kind of breathing is not uncomfortable for your loved one. It is a natural response to the body's weakening condition. If breathing seems labored, medications may be prescribed to ease the breathing and help provide comfort.

As a patient becomes weaker and/or loses consciousness, they can lose the ability to clear their throat or swallow. Secretions in the mouth may increase and collect in the back of the throat causing a "rattling" sound. Suctioning may cause more discomfort than good, but if secretions are visible in the mouth, gentle suctioning may be an option. This "rattling" sound may be distressing to hear but it does not indicate the person is suffering.

What to Report to your Hospice Team

- Verbal complaints of difficulty breathing or inability to "catch their breath"
- Persistent cough
- Rapid breathing
- Long periods without breathing followed by several quick, deep breaths
- Moist breathing or a congested "rattling" sound
- Wheezing or gasping
- Chest pain

What You Can Do

- If breathing patterns change notify Harry Hynes Hospice.
- Provide a calm and reassuring environment.
- Raise the head of the bed or use pillows to elevate the head and shoulders.
- Turn the head and shoulders to the side to help drain secretions from the throat.
- Ask your nurse about using oxygen and medications that can provide comfort.
- Use a cool mist humidifier to increase humidity in the room as oral secretions increase.
- Use a fan in the person's room to circulate the air.
- Use oral swabs to cleanse the mouth and moisturizer on the lips. This can help relieve the dryness that occurs with mouth breathing as well as help to remove secretions.

Skin and Temperature Changes

Often the body loses the ability to regulate its temperature. Your loved one may develop an increase in temperature, but this is not necessarily a sign of infection. Your loved one may feel cooler to the touch. These changes to skin temperature often go unnoticed by your loved one. The skin may also become a bluish gray or have a patchy appearance; this is called mottling. You may notice it first in the nail beds, kneecaps and feet. Sometimes the skin may turn a pale yellow or have a waxy appearance. There may be increased perspiration often with clamminess.

What to Report to your Hospice Team

- Fever
- Chills associated with fever
- Turning a blue hue around the nose, lips, mouth, fingers and toes
- Skin may have spotting with patches of color (sometimes called "mottling")
- Hands, arms, feet and legs that are cool to the touch

What You Can Do

- For a fever, apply a cool, damp cloth to the forehead and back of neck.
- Provide ice chips or cool sips of water if your loved one is alert and able to swallow.
- Give your loved one a lukewarm sponge bath for an elevated temperature or clamminess.
- Administer fever reducing medications as directed by your hospice team.
- As the fever lowers, your loved one may perspire requiring a change of bedding and/or clothing.
- Listen to your loved one. Apply or remove blankets as requested. Your loved one may be warm even when you feel cold.

Nutrition and Hydration
(Food and / or fluid intake)

One of the most difficult changes for you as a family to witness may be your loved one's loss of appetite and decreased desire to eat. The body's need for food and water decreases as the body is concentrating on conserving energy for the major organs to maintain life. Weight loss is expected and does not mean the person is hungry or that the body is being "starved" by the absence of food. The body also conserves fluid, which decreases the need for fluid intake.

If your loved one is unable to swallow, it is not necessary for food and fluid to be given by machines and tubes. Often this is the body's natural way of saying it no longer needs food and water. Artificially feeding a person's body can often cause a great deal of discomfort when it no longer needs the nutrition.

What to Report to your Hospice Team

- Decreased appetite
- Refusing meals
- Nausea or vomiting
- Difficulty swallowing

What You Can Do

- Give food and fluids by mouth at your loved one's request. Your loved one will let you know if food or fluids are desired.
- Respect your loved one's wishes by not trying to force food or drink.
- Offer small portions at regular intervals.
- Serve your loved one's favorite foods as requested. A person's appetite may decrease as the day or time progresses.
- Avoid foods with strong odor which may cause or increase nausea.
- Provide ice chips or small sips of fluid to relieve dryness.
- Use mouth swabs and moisturizer to relieve dryness and provide comfort.
- Soothe chapped lips by applying moisturizer.

Bladder and Bowel Elimination

Problems with elimination can cause your loved one anxiety, embarrassment, and discomfort. Along with a decrease in food and fluids, there is a normal decrease in urine output. Urine may gradually appear darker in color and become cloudy and/or have a strong odor. This is the normal response to decreased fluid intake as well as decreased circulation through the kidneys. As the muscles of the body relax, there may be loss of control of the bladder and bowels. This is a natural process but should be attended to promptly, as urine left on the skin can lead to irritation and odors.

What to Report to your Hospice Team

- Bladder and/or bowel incontinence
- Non-stop oozing of stools
- Burning, pain or discomfort with urination
- Change in amount, color or odor of urine
- Skin irritation

What You Can Do

- To minimize embarrassment, do not draw unneeded attention when your loved one needs to be cleaned and changed.
- Keep your loved one clean and dry.
- Wear protective garments.
- Use barrier creams to protect the skin.
- Wash hands before and after providing personal care.
- Establish a toileting routine to help decrease incontinence and constipation.
- Provide ample time and privacy during toileting.
- Make it easier to use the bathroom by moving your loved one closer to the toilet or using a bedside commode, urinal or bedpan.
- Avoid foods that can act as laxatives and may even cause dehydration. These include caffeinated beverages, alcohol, diet soda and beverages with artificial sweeteners.
- Talk to your nurse about a catheter. In some situations, a catheter can be used to keep your loved one's skin from being constantly wet.
- When providing personal care, gently touch them and explain what you are doing prior to doing it.

Constipation

Your loved one's bowel movements may be smaller and less frequent. They may also become hard, dry, and difficult to pass. Frequency of bowel movements is not the critical factor. Comfort is most important.

When taking pain medications on a regular basis, it is common for constipation to occur. Since pain medication can slow down bowel activity, prevention is the best treatment. It is important to use laxatives as directed by your care team.

Bowel function is also affected by activity, diet, and fluid intake. A medication regimen that includes the use of a laxative is almost always required to prevent constipation in patients with decreased activity level and/or taking pain medication.

What are the Signs and Symptoms

- Dry, hard stools/straining with bowel movements
- Incomplete passage of stools
- Bloating and distention of the abdomen
- Cramping, nausea, vomiting, reflux, or heartburn
- Nonstop oozing of loose stools

What to Report to your Hospice Team

- Problems with passing stool such as straining, incomplete passage of stool, diarrhea or bleeding
- Bloating, distention, cramping, nausea, vomiting, reflux, or heartburn

What You Can Do

- Keep a record of bowel movements. List the day and time and describe what the stools look like. List any problems your loved one had passing the bowel movement.
- Ask your nurse for a form to record bowel movements.
- Give a laxative as directed by your care team.

A daily bowel regimen should be followed just as carefully as your physician's other instructions. The overall goal is to have a bowel movement at least every 2-3 days. Because responses vary, use these guidelines to find a regimen that works best for you. If at any time the dosage of your pain-relieving medication is changed, you may need to increase your daily dosage of laxative.

Preventing Constipation (follow as directed by your hospice care team):

1. Take 2 Senna-S tablets at bedtime. If you do not have a bowel movement in the morning;
2. Take 2 Senna-S tablets after breakfast. If you do not have a bowel movement by evening;
3. Take 3 Senna-S tablets at bedtime. If you do not have a bowel movement in the morning;
4. Take 3 Senna-S tablets after breakfast.

If you do not have bowel movement by morning after step 4, consult your hospice nurse.

Anxiety

It is not uncommon for people with a serious illness to experience anxiety. Anxiety is a reaction to stress that has both psychological and physical features. Heart and breathing rates can increase, muscles can become tense and the mind might have a difficult time slowing down. Your loved one may or may not let you know they are anxious.

What are the Signs and Symptoms

- Being worried or scared
- Mind is racing or going around in circles
- Inability to rest or sleep at night
- Feeling jittery or panicked even when resting
- Feeling shaky
- Feeling short of breath
- Feeling like your heart is pounding or racing
- Although not as common, dizziness and nausea can occur with anxiety

What to Report to your Hospice Team

- Any of the thoughts, feelings or behaviors mentioned above

What You Can Do

- Provide a calm environment.
- Use distraction by focusing on something else: have them count slowly to 25 or more, have them slowly open and close their fists or slowly recite the alphabet. If they are able, do something they enjoy like playing a game, listening to music or watching television.
- Call your hospice team. There may be medications that can help with anxiety. Your social worker and other team members can help with behavioral techniques that may decrease anxiety. The social worker and chaplain can also address underlying fears or concerns and provide emotional and spiritual care to your loved one.

Fatigue and Sleep

Feeling weak and having less energy is common. It is important to recognize your loved one may not have the energy to participate in previous activities. Some people have difficulty sleeping at night because they fear they may not awaken in the morning. Napping throughout the day is common and may result in a loss of sense of time and interfere with normal sleep patterns.

Your loved one may become less responsive to visits and stimuli and may begin sleeping more. It is okay to let your loved one sleep when they are tired. Even though they may be sleeping more, it is important to continue to communicate with them. People continue to hear what is happening around them and what is being said in their presence even after they no longer open their eyes or speak. Your loved one might speak less, then perhaps not at all; sight may gradually fail.

What are the Signs and Symptoms

- Sleeping more hours out of the day
- Unable to perform normal activities because they are "just too tired"
- Changes in appetite may occur because your loved one simply does not have the energy to eat, and with less activity their nutritional needs decrease

What to Report to your Hospice Team

- Any of the behaviors described above
- What makes the fatigue increase or decrease
- Any concerns you have as the caregiver about fatigue
- Spiritual concerns around food and water intake
- Major changes in appetite
- Any distressing symptoms that are not controlled

What You Can Do

- Help your loved one prioritize activities and eliminate or postpone activities that are not a priority.
- Plan activities and visits for times of the day when your loved one seems most alert.
- Assist with daily activities such as eating, moving or bathing.
- Encourage your loved one to rest when tired.
- Plan rest times or naps for late morning or early afternoon. Sleeping later in the day could interrupt nighttime sleep.
- It is okay to lie beside them. Your presence may be comforting.
- Even if your loved one appears to be sleeping, remember not to say anything in front of them that you would not say if he or she were awake.

Confusion / Disorientation

Your loved one may become confused by the surroundings and the people around them. They may not recognize familiar faces. There may also be a time when your loved one describes people and places that are not visible to you. Your loved one may talk about past people or events or talk to people who have already died. They may hear conversations and music that you cannot hear. This is all very real to them. People near the end of their life will sometimes talk about traveling or taking a trip. They may say such things as "I want to go home," "I need my keys," or "My bags are packed." This type of conversation is symbolic and may be one of the ways your loved one is letting you know they are preparing for death. In other words, trying to say goodbye.

What are the Signs and Symptoms

- Speaking to people who are not present
- Talking about leaving or taking a trip
- Confusion

What to Report to your Hospice Team

- Any of the behaviors described above

What You Can Do

- If appropriate, gently try to reorient your loved one. Remind them of who they are, who you are and what you will be doing.
- Reassure your loved one of where they are and that they are in a safe place.
- Allow your loved one to share these experiences without attempting to bring them back to reality.
- Do not deny or try to refute what your loved one is telling you. This may cause increased restlessness or frustration.
- Share memories or stories with your loved one about the person they are "seeing."
- Sometimes limiting visitors can decrease the level of confusion.
- Introduce people when they come to visit.
- Identify yourself by name when you speak. Tell the person what you are going to do before you do it. For example, "Susan, this is Bob. I am going to clean your mouth now."

Restlessness and Agitation

Restlessness is very common. It may be caused in part by a slowing down of circulation. This causes less oxygen to flow to the brain. Your loved one may appear agitated. You may observe involuntary muscle twitches. Your loved one may be unable to lie or sit for more than a few moments at a time before wanting to change position. Sometimes restlessness or agitation can be a symptom of physical pain or discomfort. It may also be a sign of emotional or spiritual concerns. Your loved one may make restless or repetitive motions such as pulling at bed linens or "picking" at things in the air that are not visible to you. They may also become overly sensitive to touch and seem irritated when you touch them. Your loved one may also make audible noises such as sighing, humming or moaning. This does not necessarily mean something is wrong.

What are the Signs and Symptoms

- Moaning sounds that are not associated with pain
- Sudden surge of energy
- Involuntary muscle twitches
- Hallucinations
- Picking or pulling at clothing or the air
- Irritability

What to Report to your Hospice Team

- Any of the behaviors described above. There may be medications that can help your loved one rest better.

What You Can Do

- Provide a calming environment. This may include low lights, quiet music, and/or limiting visitors.
- Remove objects that could potentially cause harm to your loved one.
- Speak in a quiet, natural way.
- Continue with the medications prescribed by the doctor.
- Keep a light on in the room. Your loved one cannot see well and may be scared by the darkness and shadows.
- Do not try to restrain your loved one.
- Consider the use of a baby monitor while out of the room.
- Offer a soft blanket or stuffed bear to hold.
- Utilize the hospice social worker or chaplain to address underlying concerns and provide emotional and spiritual support.
- If your loved one is irritated by touch, do not stroke or rub their skin. You might try a more solid touch.
- Lightly massage the forehead, read to the person or play soothing music if this is comforting to them.
- The restlessness may be a reaction to sudden stimulation, even if your loved one is unconscious.
- Supporting your loved one in a more upright position, turned slightly to one side, can reduce or eliminate this feeling.

Withdrawal

As your loved one becomes aware they are dying, they may begin to withdraw from friends and family. They may even decline visits from them. They may no longer be interested in the outside world. This includes television, radio, newspaper and current events. This process may begin a few weeks before death. Touch and silence can take on more meaning as your loved one withdraws and has less desire to communicate verbally.

What to Report to your Hospice Team

- Your loved one has withdrawn from people and has little to say
- No longer initiating conversation; only speaking when asked direct questions

What You Can Do

- Try not to take it personally as this is a natural process.
- Limit visitors to one or two at a time and for short periods of time.
- Speak to your loved one in a normal tone of voice.

Final Days

No one can predict the moment of death. However, physicians and nurses involved in end-of-life care know that certain symptoms are usually associated with the body's shutting down. These signs of approaching death are specific to the natural dying process, apart from the effects of illnesses the person may have.

As your hospice team observes and assesses these symptoms, they will provide assurance that these signs are common occurrences and review the steps you can take to provide for your loved one's comfort. As death approaches call people who would like to say goodbye or be present at the time of death. They may have some last thoughts or words of love to share. They can also provide support to you during this time. Remember that hearing is the last sense to go so continue to talk to your loved one even if they do not respond.

Signs of Natural End-of-Life Process

- Increased pain or discomfort
- Decrease in food and fluid intake, difficulty swallowing or not wanting to eat or drink at all
- Excessive fatigue and sleep or increased physical weakness
- Changes in breathing
- Increased secretions – your loved one may have gurgling and rattling sounds coming from their chest. These sounds may become loud.
- Changes in urination and/or loss of bowel or bladder control
- Urine output decreasing or becoming darker in color
- Swelling in the feet and ankles
- Withdrawal – your loved one may be mostly unresponsive or appear to be in a comatose-like state
- Mental confusion or disorientation
- Vision-like experiences – your loved one may reference speaking to someone who has already died or may report recently being places they have not
- Restlessness or anxiety – performing repetitive and restless tasks
- Unusual communication – conversations seemingly out of character or unclear statements, gestures or requests
- Cold feet, hands, arms and legs – often become very cold to the touch. Their skin may also become pale and look blotchy or mottled.

Let Your Hospice Team Know

- If there is a need for spiritual support or guidance for the patient or family
- If you have any questions or concerns
- If there are religious, cultural or ethnic traditions important to you or your family

Surge of Energy

Your loved one may exhibit a sudden surge of unexplained energy. This is usually temporary and does not mean the person is getting better. They may become unexpectedly alert and aware of their surroundings. They may ask to eat when they have not eaten for days or weeks. This does not happen to everyone and if it does, it may not be this dramatic. It can be more subtle, such as being awake when they have been sleeping most of the time. It is easy to see how this surge of energy can be misunderstood and give false hope that your loved one is getting better. Make the most of this time and use this time with your loved one to say goodbye.

What You Can Do

- Explore with the social worker or chaplain your fears about saying goodbye.
- Take advantage of the times when your loved one is alert to share.
- You may gently hold your loved one's hand while talking. If you are both comfortable with it, lying in the bed with the person may be helpful.
- If you are concerned about past wrongs that may have been done, apologizing or asking for forgiveness can begin steps to healing.
- If you are concerned about your future, share your concerns with the social worker.

Final Thoughts

- Write down what your loved one says. This may be a source of inspiration and comfort to share with other family members and may bring you comfort later.
- Consider including the children in your family in the experience of your loved one's death.
- Tears often occur when saying goodbye and are a normal reaction.
- Remember that hearing is one of the last senses to fade. Tell your loved one goodbye with cherished memories or making amends. These will be important to you and your loved one even if they do not respond.
- Death is a unique experience for each person Sometimes a loved one may want everyone gathered at the bedside when death occurs so that they are not alone.
- Remember that simple acts of kindness like holding a hand, sharing memories or just being with your loved one can be very helpful.

Saying Goodbye

Saying Goodbye: When a Loved One is Dying

by Debra Voth, LSCSW

Though we are all aware that death is a natural part of life we cannot help but feel shock and great sadness when faced with the death of someone close to us. Exactly what we feel and how we choose to cope with these feelings will vary depending on our situation and the history we bring to our current circumstances.

This information is meant to offer some general guideposts for this difficult journey. Many of these thoughts come directly from people who have said goodbye to loved ones and reflected on the challenges they faced. You may find yourself able to relate to some points but not to others.

Above all, be gentle with yourself. These are days of sorrow as well as precious joy. The moments you share with your loved one now will be remembered for many years to come.

The Task at Hand

When a loved one is dying, we are faced with the difficult task of preparing ourselves to separate from this special person while continuing to stay involved. Sometimes this period of time involves intense caregiving responsibilities which demand intimate, personal closeness. The challenge is to remain involved with our dying loved one while beginning to consider a life without him or her.

An early change that often occurs is a shift in the usual roles each person plays. This may mean that the "in charge" person may no longer be able to make decisions of the "chief cook and bottle washer" and can no longer accomplish daily chores. When possible, it may feel comforting to maintain the familiar household routines as much as possible.

The "roller coaster effect" is a phrase used by some to describe the extreme ups and downs that can be typical of this time. One day our loved one is energetic and positive and the next day our loved one is hurting and sad. We may sense that death is very near one day and the next seems far away. We might even begin to consider "we can beat this yet." Amid such uncertainty it can be helpful to scale back our view of the future and take one day at a time.

If we are spending much of our time and energy caring for our loved one, we may experience a deep sense of isolation. Some caregivers have used the words "the walls are closing in on me." It can be extremely helpful to seek outside support from friends or family to maintain our perspective and our own health.

What We May Feel

It is not possible to describe the wide range of feelings we may encounter during this time. However, people have identified some general themes.

The first of these is the feeling of numbness. Our hearts can only take so much bad news. It is okay to let ourselves understand both the awfulness and the enormity of our situation a little at a time.

Another difficult feeling may be anger. Maybe we feel angry at our loved one for being so sick and causing us such anguish or at the physician for not curing them. Perhaps we even feel angry at God for our feelings of being abandoned. These feelings can be quite disturbing. They may also lead us to feelings of guilt and helplessness.

No matter what we do or how hard we try to make things better, our loved one is still dying.

Laughter and pleasure can still be a part of our lives. We can permit ourselves positive feelings even during these difficult circumstances.

Dealing with Intense Feelings

To love deeply is to open ourselves to the pain of separation. Often the intensity of this emotional pain surprises even the most stoic and well-prepared individuals. Many people feel uncomfortable with these feelings since they are so seldom experienced. Expressions such as "breaking down" or "losing control" may lead us to see these feelings as threatening and dangerous. However, intense sadness is a natural part of saying goodbye, and the emotional release of these feelings is also natural.

Sharing sad feelings and tears with our loved one can be very healing. However, this is not always possible. Perhaps our loved one can no longer respond or does not want to talk about these difficult feelings. A private time and place where we can shed our tears alone or with trusted friends can be a way of coping with intense feelings.

Some people find journaling or keeping a diary helpful. Others have used a creative project as a means of expressing the pain and sorrow of their loss, such as writing a song or poem for the memorial service, building the burial box or casket, or creating a picture book of the loved one's life.

By finding an outlet for these intense emotions, we are taking care of our own emotional well-being. We are also less likely to distance ourselves from our dying loved one out of fear or discomfort.

When Family is Involved

If we are experiencing this loss as a member of a larger family, we will no doubt experience the rewards and challenges that come with family interactions. These times may call for increased flexibility and tolerance of personal differences among family members. It may also be helpful to keep in mind family history of dealing with difficulties or crisis situations. These past experiences can teach us how to best cope with the current crisis.

Family can be a source of great strength and courage. When other agendas are put aside, and energies are focused on these special last days with our loved one, these times can be a family's "finest hour."

When the End Comes

Inevitably the moment comes to bid our loved one farewell. We say our goodbyes. We reassure our loved one that we will manage without them and then we release them to God.

These profoundly moving moments can be made less anxious and frightening if we been able to do some planning. Sometimes just thinking through what these moments might be like will help prepare us. Who would we like to have with us? Who will need to be called? There is no need to rush. We have all the time we need to say a prayer of farewell or wait for family to arrive. We know that the funeral director will arrive soon and our deceased loved one will finally leave our side.

One journey has ended. Another is just beginning. In the weeks, months and years ahead we will slowly rebuild our lives and discover our loved one's final gift to us. They have taught us how to say goodbye when it is our time to die.

Dr. Ira Byock has identified five statements needed for relationship completion:

"I forgive you."
"Forgive me."
"Thank you."
"I love you."
"Goodbye."

When Your Loved One Dies

Even though you have been with your loved one throughout the dying process, the moment of death may be very powerful and emotional.

Signs That Death May Have Occurred

- Absence of breathing for more than 5 minutes
- No heartbeat or pulse
- No physical response
- Relaxed jaw with mouth slightly open
- Eyes may appear fixed on a certain spot and may be slightly open
- There may be a loss of bladder and bowel control

What You Should Do

- Call Harry Hynes Memorial Hospice. Call even if you are not sure but suspect that death has occurred.
- Although it may be your first instinct, it is NOT necessary to call 911 unless instructed by the hospice team to do so. This may be the case if your loved one remained a full code and does not have a Do Not Resuscitate (DNR) order signed and you wish to have them resuscitated.
- If your loved one dies after hours, on the weekend or a holiday remember that when you call you will get the answering service. Inform the operator of your loved one's death and the operator will then contact a hospice nurse. The hospice nurse will call you prior to coming to your home.

At the Time of Death, Your Hospice Team Will Want to Know

- The name of the funeral home you want to use.
- The names and numbers of family, should you desire us to assist you in notifying them.

What You Can Expect

- A member of your care team will make a visit.
- A nurse will confirm the time of death.
- A member of the hospice team will contact your loved one's doctor and mortuary of your choice
- The hospice team may assist in cleaning your loved one and remove any catheters, etc.
- A nurse will assist you in properly disposing of all unused medications prescribed to your loved one. They will arrange for medical equipment to be picked up.
- A nurse will notify the other members of your hospice team.

You can have the funeral home come right away or choose to wait a period of time before calling. Let the hospice nurse know your preference so this can be communicated to the funeral home. When the funeral home does arrive, you can decide whether you want to be present when they take your loved one or wait in another area.

Families honor the passing of their loved one in a variety of ways. Some choose to gather at the bedside for prayer or join in inspirational song. Others may recite a favorite poem, play special music, or tell stories and share fond memories.

After A Loved One Dies

After your loved one has passed, take the time you may need with them and let the grieving process begin. There will be time for you to exercise any religious or cultural customs that need to be done. You may also want to notify family and close friends.

Death must be officially pronounced, and a hospice nurse will be available for this. Many people decide to use a funeral director to help with arrangements of how they would like the body of their loved one cared for. Costs vary significantly based upon the decisions you make. If finances are a concern, ask your social worker to assist you. Your social worker can also assist you by providing information on available funeral and mortuary services.

A funeral or memorial service is a meaningful way for family and friends to remember the person who has died. These services can be at a funeral home, church or even your own home. Our chaplain is available to assist you with planning or conducting the funeral or memorial service if you desire.

Collect Important Information

- A **Certified Death Certificate** is required by insurance companies before benefits can be paid. Information for ordering can be found at Kansas Office of Vital Statistics - kdhe.ks.gov/1193/death-certificate. You may also ask the funeral director to order the certificates(s) for you. You may need more than one and it may take two or three weeks to receive.
- Gather all **Insurance Policy Documents** including life, health, home mortgage, and accident. Contact your insurance agent for claim or replacement forms.
- **Social Security number of the deceased.**
- **Military discharge papers (DD-214)** – Call the Department of Veteran Affairs at 800-827-1000.
- **Marriage certificate** – Contact the District Court of the county the marriage took place.
- **Deceased's will or estate plan.**
- **Deceased's most recent federal income tax return** – Contact the deceased accountant or the Internal Revenue Service for assistance.
- **If survivors include dependent children,** you will need the children's birth certificates and Social Security numbers.

Determine Ownership of

Insurance policies, cars and other property, house, bank accounts, safe deposit box, and credit cards.

Apply for Death or Disability Benefits

- **Personal life insurance.**
- **Employee life insurance** – Check with the company's human resources department.
- **Social Security** – Surviving spouses and sometimes ex-spouses caring for dependent children, surviving spouses over age 50, children under age 18, and dependent parents over 62 may be eligible for monthly benefits. A small, one-time death benefit may also be available. Call Social Security Administration at 800-772-1213 or apply online at www.ssa.gov.
- **Active military or veterans' benefits.** A surviving spouse or child of an active-duty member or a retired veteran may be eligible for benefits. Benefits may include funeral expenses, medical care and use of commissary, exchange, dependency compensation. It may also include Veterans Mortgage Life Insurance (VMLI). Call the Department of Veterans Affairs at 800-827-1000 to apply.
- **If state benefits were received, such as Medicaid**, call the local Department for Children and Families office and ask about the Estate Recovery Program at 316-337-7000.

If Dependent on Income from Deceased

- **Develop an emergency budget.** Identify current income and try not to spend more than received. Money may be tight until survivor benefits begin. Social Security may take six weeks to three months for benefits to arrive. Veterans benefits may take six to nine months.
- **Pay Bills** – A good credit record is important. If bills and credit are a concern, please contact the local Credit Counseling Services, Inc. office. To find the nearest location call 800-279-2227.
- **Continue Health Coverage** – If insurance was through the deceased's employer, health insurance can be bought through the company. The employer must be contacted within 30 days of the death.

Settle the Estate

Generally, nine months from the date of death is given to pay the deceased's debts and divide the estate to those named in the will. If there is no will, Kansas law requires that probate court settle the case.

When someone you love dies, it hurts. Sometimes the hurt goes deeper than you ever imagined. The sadness and pain are part of grief. You and your family are now beginning to adjust to living without your loved one.

Grief is a normal response to loss. Each person grieves in their own way. Grief can be expressed through thoughts, feelings, physical symptoms and behaviors. Some common expressions include:

Thoughts

- Disbelief
- Inability to make decisions
- Confusion
- Preoccupation with the deceased
- Forgetfulness

Behaviors

- Withdrawal from usual activities
- Being overactive or keeping busy
- Being talkative
- Being overly dependent on others

Feelings

- Anger
- Sadness
- Anxiety
- Numbness
- Guilt
- Fear
- Irritability

Physical

- Sleeping more or less
- Eating more or less
- Tears
- Headaches or stomach aches
- Lack of energy
- Muscle aches

Preparing for the Future

- Feelings change during grief so try not to let them influence important decisions.
- Develop a long-term budget.
- Revise your emergency budget as income and expenses may not be easy to determine.
- Use benefits wisely. They may be needed to cover basic living costs.

What You Can Do

- Give yourself permission to grieve
- Try to get plenty of rest, exercise and eat healthy foods
- Get a checkup with your family physician
- Avoid alcohol as it is a depressant
- Share stories about the deceased
- Consult with a trustworthy person before making any major changes in your life
- Ask for help from caring people
- Be willing to try new ways of coping by attending a support group, reading about grief and reaching out to help others

Contact your Hospice Bereavement Team When Experiencing

- Thoughts of suicide or self-harm
- Increased use of alcohol or drugs
- Isolation from other people
- Inability to sleep for several days
- Frequent and intense grief reactions that continue beyond two months after the death
- Doubts as to whether your experiences and reactions are normal

Grief Support

Harry Hynes Memorial Hospice offers grief support for families and caregivers of those we have served and to the community at large. Our bereavement staff supports people in finding healing, growth, and renewed hope for living. We want to provide support to you in a manner that is comfortable for you.

Services we offer include:

- **Rising Sun** – A quarterly grief and loss newsletter with articles about common experiences and helpful ways to cope. A calendar listing special events and bereavement groups is included. Newsletters can be mailed electronically, by postal service, or viewed on our website at hynesmemorial.org.
- **Grief Support Groups** – Support groups where you can find help and healing after losing a loved one.
- **Grief & Loss Counseling** – Counseling that focuses on adjusting to the death of a loved one.

For more information contact the Harry Hynes Memorial Hospice Bereavement Department at (316)-265-9441 or (800) 767-4965 or visit hynesmemorial.org/grief-and-loss-support/.

We Value Your Opinion

Approximately three months after your loved one has passed, you will receive a survey from the Centers for Medicare & Medicaid Services. The Consumer Assessment of Healthcare Providers and Systems Hospice Survey (CAHPS®) is a national survey of family members or friends, who cared for a patient that died while under hospice care.

The CAHPS® survey contains questions covering topics of interest to family caregivers. Survey results are published as part of **Hospice Compare** on the Medicare.gov website.

By completing the survey, you will help our agency improve the care we give to future families. We encourage, appreciate, and value your input.

Thank you for allowing us the privilege to serve you during your journey.

> Grief never ends…but it changes. It's a passage, not a place to stay. Grief is not a sign of weakness, nor a lack of faith. It is the price of love.
>
> -Author Unknown

Celebrate & Honor Life

Opportunities for Giving

Those who are touched by Harry Hynes Memorial Hospice often ask about ways to honor their loved ones. As a non-profit organization, Harry Hynes Hospice relies on individual contributions and memorials to provide medical, emotional and spiritual support to patients and their families in our care. Donations also provide bereavement support for family members after the loss of a loved one.

Memorials or Honorarium Gifts

A gift made to Harry Hynes Memorial Hospice, in memory or honor of your loved one, can serve as a meaningful and lasting tribute that lives on through care and service to others. Your gift will be acknowledged with a letter sent to the person honored or the family of the memorialized individual. The amount of your gift will remain confidential.

Memory Garden

Our Memory Garden is at **The Collective** located near East 21st Street and K-96 in Wichita. The garden is a beautiful, serene place to visit, with walking paths and benches. The purchase of a brick or paver is a unique opportunity for families and friends to honor and remember their loved one.

Planned Gifts and Endowments

Create a personal legacy by designating Harry Hynes Memorial Hospice in a trust, gift, land, endowment, bequest, or appreciated security. Tailor a gift to fit your financial, estate, or tax plans, or to gain tax rewards and maintain financial security.

Giving Events

The **Lanterns of Life** and **Lights of Life** are annual, community events that allow personalized recognition in memory or honor of someone special.

Gifts of Time

Please know that your gift to Harry Hynes Memorial Hospice does not need to be monetary. We offer many volunteer opportunities, including patient companionship, writing notes or letters to patients, office work, clinical support, fundraising and annual events support.

General and Sustaining Donations

Whether it is a gift of $25, $50, $100 or more, or as a one-time or recurring gift, your donation allows us to provide numerous programs and services to our patients and their families, including medical supplies and medicine, and spiritual and bereavement support.

Named Gifts

Donors often look for ways to make a significant impact by providing a gift to name a specific project or program. Contact our Director of Donor Development to learn more about the current opportunities or to create a custom plan.

Matching Gifts and Workplace Giving

Many companies offer matching gift programs to their employees that may double an original donation. Some companies also match gifts made by retirees and/or their spouses. If your employer offers a matching gift program, please see your company's human resources department to request the form to submit with your donation.

For more information, to donate, establish a memorial, or opt out of fundraising efforts, please contact Donor Development at 800-767-4965 or email: donations@hynesmemorial.org, or visit hynesmemorial.org/donate.

Patient Rights & Privacy

Advance Directives

The purpose of Advance Directives is to allow you to make your wishes known when you are unable to voice them yourself.

If you have an Advance Directive, please give a copy to your care team. If you want to complete an Advance Directive or if you have questions, ask your care team. We are happy to provide the forms for you.

Advance Directives Include:

Durable Power of Attorney for Health Care Decisions (DPOA-HC)

- Allows you to designate another person to make medical decisions for you.
- This person makes medical decisions on your behalf only when you are unable to do so.
- It is important that you discuss your wishes with your DPOA-HC, so they can speak on your behalf.

Do Not Resuscitate (DNR) Order

- A DNR order means a person dies a natural death. You will still receive optimal comfort care.
- A DNR order is not required to begin care, except when care is provided at our Hospice Center at Ascension Via Christi St. Francis.
- If you do not want resuscitation attempted, ask your doctor to write a DNR order and keep a copy of that order in your home. Your hospice team can also help you obtain this.

Living Will

- Takes effect when a person is unable to make decisions regarding healthcare.
- Applies only to questions of treatment related to a terminal condition and only applies to medical decisions.
- Advisable to specify your wishes regarding medical care choices in writing.

Bill of Rights

You have the right to:

Dignity and Respect

- Receive information about the services covered under the hospice benefit.
- Receive information about the scope of services that we provide and the limitations of those services.
- Be notified in writing of your rights and responsibilities before care begins.
- Request information about your diagnosis, prognosis, treatment and alternative care in terms you can easily understand so you can give informed consent.
- Receive care without discrimination as to age, race, religion, creed, sex, handicap, national origin or the ability to pay.
- Be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown sources and misappropriation of your property.
- Voice grievances and suggest changes in service or staff without fear of reprisal or discrimination.
- Contact the Kansas Department of Health and Environment that collects, maintains and updates information on Medicare participating home care agencies. The toll-free hotline is 800-842-0078. This service is available between 8:00am-4:00pm Monday-Friday, excluding state holidays.
- Be referred to another agency (if denied service for any reason).

Decision Making

- Be involved in the development of your care plan and be informed in advance of any change in care.
- Refuse care or treatment to the extent allowed by law, and to be informed of the possible consequences of your decision.
- Choose what will happen with your medical care and communicate that choice with your caregivers and doctors.
- Choose your attending physician.

Privacy

- Confidentiality of written and verbal communication.
- Have information released only with your prior written authorization or as required by law.

Financial

- Be informed of the extent to which payment may be expected from Medicare or other sources and the extent to which payment may be required from you.
- Be informed of our ownership status and our affiliation with any entities are referred to.

Quality of Care

- Receive effective pain management and symptom control for conditions related to your terminal prognosis.
- Receive physical, emotional, social, spiritual and supportive services.
- Receive care of the highest quality.

Grievance

You have the right to voice a complaint and suggest changes in service or staff without fear of retaliation or discrimination. As a first step, talk to your care team directly or contact the Director of Community Based Services. Other options include:

- Contacting the Vice President of Clinical Services, who will investigate your complaint and make every effort to resolve the concern.
- Should you wish to pursue the complaint further, contact the President of Harry Hynes Memorial Hospice.
- If your complaint remains unresolved to your satisfaction you can file a formal complaint with the Kansas Department of Health and Environment by calling 800-842-0078.

Patient Responsibilities

You have the responsibility to:

- Actively participate in planning your care.
- Follow the care plan developed by you, your caregiver and your care team.
- Provide full information about medicines, treatments and concerns.
- Inform your care team when you do not understand the care plan or instructions.
- Be considerate of the rights of team members and respect their property.
- Contact your care team when you have questions or concerns.

Privacy Notice

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

Your Rights

Get an electronic or paper copy of your medical record

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

Ask us to correct your medical record

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

Request confidential communications

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

Ask us to limit what we use or share

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

Redisclosure Notice

- Protected health information disclosed in accordance with HIPAA may be subject to redisclosure by the recipient and once redisclosed, may no longer be protected by HIPAA.

Get a list of who we have shared information

- You can ask for a list (accounting) of the times we have shared your health information for six years prior to the date you ask, who we shared it with and why.
- We will include all the disclosures except for those about treatment, payment, healthcare operations and certain other disclosures (such as any requests you made). We will provide one accounting a year for free but will charge a reasonable, cost-based fee if you ask for another one within 12 months.

Get a copy of this privacy notice

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

Choose someone to act for you

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

File a complaint if you feel your rights are violated

- You can complain if you feel we have violated your rights by contacting us at the address listed on this notice.
- You can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, or by calling 877-696-6775, or by visiting hhs.gov/ocr/privacy/hipaa/complaints/.
- We will not retaliate if you file a complaint.

Your Choices

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

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

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

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

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

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

Our Uses and Disclosures

How do we typically use or share your health information?

- Your treatment: We can use your health information and share it with other professionals who are treating you.
- Hospice organization: We can use and share your health information to run our practice, improve your care and contact you when necessary.
- Billing for your services: We can use and share your health information to bill and get payment from health plans and other entities.

Special Protections for Substance Use Disorder Information

Certain health information related to substance use disorder diagnosis, treatment, or referral for treatment is subject to additional federal protections under applicable law. We may not use or disclose substance use disorder records except as permitted by law, and such information is subject to more stringent confidentiality requirements than other protected health information.

Substance use disorder records may only be used or disclosed with your written consent, unless otherwise permitted or required by law.

Use of Substance Use Disorder Records in Legal Proceedings

We are prohibited from using or disclosing substance use disorder records in civil, criminal, administrative, or legislative proceedings against you without your specific written consent or a valid court order, as required by law.

Respond to Lawsuits and Legal Actions

We may share health information about you in response to a court or administrative order, or in response to a subpoena, discovery request, or other lawful process, as permitted by law. However, substance use disorder records will not be disclosed for these purposes without your written consent or a court order that meets applicable legal requirements.

How Else Can We Use or Share Your Health Information

We are allowed or required to share your information in other ways – usually in ways that contribute to the public good, such as public health and research. We must meet any conditions in the law before we can share your information for these purposes.

Help with Public Health and Safety Issues
We can share health information about you for certain situations such as:

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

Do research
We can use or share your information for health research.

Comply with the Law
We will share information about you if state or federal laws require it, including the Department of Health and Human Services if they audit for compliance with federal privacy law.

Respond to Organ and Tissue Donation Requests
If you happen to be an organ donor, we can share information about you with organ procurement organizations.

Work with a Medical Examiner or Funeral Director
We can share health information with a coroner, medical examiner or funeral director when an individual passes.

Address Workers Compensation, Law Enforcement and Other Government Requests
We can use or share health information about you:

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

Respond to lawsuits and legal actions
We can share health information in response to a court or administrative order or in response to a subpoena.

Our Responsibilities

- We are required by law to maintain the privacy and security of your protected health information.
- We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information.
- We must follow the duties and privacy practices described in this notice and give you a copy of it.
- The organization reserves the right to change the terms of its notice and make the new notice provisions effective for all protected health information that it maintains. The notice will describe how the new information will be provided to individuals.
- We will not use or share your information other than as described here unless you tell us we can in writing. If you tell us we can, you may change your mind at any time. Let us know in writing if you change your mind.

Fundraising

We may contact you for fundraising purposes. Each fundraising communication will provide a clear and conspicuous opportunity for you to opt out of receiving future fundraising communications. You may opt out at any time, and your decision will not affect your treatment or payment for services.

Discrimination is Against the Law

Non-Discrimination Policy

Harry Hynes Memorial Hospice complies with applicable Federal civil rights laws and does not discriminate or exclude or treat individuals differently on the basis (prohibited by Section 1557) of race, color, national origin, age, disability, or sex (including pregnancy, sexual orientation, and gender identity). Community resources are available to help with the cost of hospice care. Acceptance criteria and provisions of care criteria are applied equally. Harry Hynes Memorial Hospice non-discrimination policy applies to all procedures, practices including the use of artificial intelligence, clinical algorithms, predictive analytics, and other tools.

Harry Hynes Hospice provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Harry Hynes Hospice provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact your hospice team or call 800-767-4965.

If you believe that Harry Hynes Hospice has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance in person or by mail, fax, or email:

Quality and Compliance Department
313 S Market Street, Wichita, KS 67202
Phone: 316-265-9441   Fax: 316-265-6066
Email: info@hynesmemorial.org

If you need help filing a grievance, the Quality and Compliance Department is 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
1-800-368-1019 800-537-7697 (TDD)

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

- If you speak English, language assistance services, free of charge, are available to you. Call 316-265-9441 or 800-767-4965.
- ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-316-265-9441 or 1-800-767-4965.
- CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-316-265-9441 or 1-800-767-4965.

Health Information Management

Your Rights Regarding Electronic Health Information Exchange (HIE)

Harry Hynes Memorial Hospice participates in Electronic Health Information Exchange (HIE). New technology allows a provider or a health plan to make a single request through a Health Information Organization (HIO), to obtain electronic records for a specific patient from other HIE participants for purposes of treatment, payment or health care operations. HIOs are required to use appropriate safeguards to prevent unauthorized uses and disclosures.

You have two options with respect to HIE. First, you may permit authorized individuals to access your electronic health information through an HIO. If you choose this option, you do not have to do anything.

Second, you may restrict access to all your information through an HIO (except access by properly authorized individuals as needed to report specific information as required by law). If you wish to restrict access, you must complete and submit a specific form available at www.KanHIT.org. You cannot restrict access to certain information only; your choice is to permit or restrict access to all your information.

If you have questions regarding HIE or HIOs, please visit KanHIT.org for additional information.

Even if you restrict access through an HIO, providers and health plans may share your information directly through other means (e.g. facsimile or secure e-mail) without your specific written authorization.

If you receive health care services in a state other than Kansas, different rules may apply regarding restrictions on access to your electronic health information. Please communicate directly with your out-of-state health care provider regarding those rules.

Change to the Terms of this Notice

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

If you have any questions regarding this notice, please contact:

Privacy Officer at Harry Hynes Memorial Hospice
313 S. Market Street
Wichita, KS 67202
316-265-9441 or 800-767-4965

Effective Date of this Notice: January 23, 2026

For more information visit: hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html.

Family Disaster Planning

Preparedness Disaster Plan for people who may need assistance and their caregivers

Harry Hynes Memorial Hospice understands the importance of preparing families for disaster events. The information below will help with developing Family Disaster Plans and we encourage you to learn more about how to be prepared.

Disaster can strike quickly and without warning. It can force you to evacuate your neighborhood or confine you to your home. What would you do if basic services such as, water, gas, electricity or telephone were cut off? Local officials and relief workers will be on the scene after a disaster, but they cannot reach everyone right away.

Families can and do cope with disasters by preparing in advance and working together as a team. Follow the steps listed below to create your family's disaster plan. Knowing what to do is your responsibility for your best protection.

Four Steps to Safety

1. Find Out What Could Happen to You
    - Contact your local Red Cross chapter or emergency management office, be prepared to take notes.
    - Ask what types of disasters are most likely to happen. Request information on how to prepare for each.
    - Learn about your community's warning signals: what they sound like and what you should do when you hear them.
    - Ask about animal care after a disaster. Animals may not be allowed inside emergency shelters due to health regulations.
    - Find out how to help elderly or disabled persons, if needed.

    Find out about the disaster plans at your workplace, your children's school or day care center and other places where your family spends time.

2. Create a Disaster Plan
    - Meet with your family and discuss why you need to prepare for disasters. Explain the dangers of fire, severe weather and earthquakes to children. Plan to share responsibilities and work together as a team.
    - Discuss the types of disasters that are most likely to happen. Explain what to do in each case.
    - Ask an out-of-state friend to be your "family contact." It is often easier to contact someone who is away. Other family members should call this person and tell them where they are. Everyone must know your contact's phone number.
    - Discuss what to do in an evacuation. Plan how to take care of your pets.
    - Pick two places to meet:
        - o Right outside your home in case of a sudden emergency like a fire.
        - o Outside your neighborhood in case you cannot return home. Everyone must know the locations address and phone number.

3. Complete this Checklist
    - Post emergency telephone numbers by phones (fire, police, ambulance, etc.).
    - Teach children how and when to call 9-1-1 or your local Emergency Medical Services number for emergency help.
    - Show each family member how and when to turn off the water, gas and electricity at the main switches.
    - Check if you have adequate insurance coverage.
    - Teach each family member how to use the fire extinguisher and show them where it is kept.
    - Install smoke detectors on each level of your home, especially near bedrooms.
    - Conduct a home hazard hunt.
    - Stock emergency supplies and assemble a Disaster Supplies Kit.
    - Take a Red Cross first aid class and CPR class.
    - Determine the best escape routes from your home. Find two ways out of each room.
    - Find the safe spots in your home for each type of disaster.

4. Practice and Maintain Your Plan
    - Quiz your children every six months so they remember what to do.
    - Conduct fire and emergency evacuations.
    - Replace stored water every three months and stored food every six months.
    - Test and recharge your fire extinguisher(s) according to instructions by the manufacturer.
    - Test your smoke detectors monthly and charge the batteries at least once a year.

For more information on Family Disaster Planning, visit the Federal Emergency Management Agency's (FEMA) website for family disaster planning at READY.gov.

Emergency Plan - Hospice Center

If an emergency were to occur at our Via Christi Hospice Center, Harry Hynes Memorial Hospice staff will follow the Ascension Via Christi St. Francis Disaster Plan Instructions.

If evacuation is warranted, families can take their loved one (the patient) home or can follow the Ascension Via Christi plan of moving the patient to the Caritas Center at 1400 S. Sheridan, Wichita.

Centers for Medicare & Medicaid Services provides a

Medicare Hospice Benefits booklet

This official government booklet includes information about Medicare hospice benefits:

- Who's eligible for hospice care
- What services are included in hospice care
- How to find a hospice provider
- Where you can find more information

Options to access the PDF version:

- Visit Medicare.gov/publications and search for "Hospice".
- Open your preferred search engine. (Google, Bing, etc.) Search "Medicare Hospice Benefits Booklet". Select the medicare.gov pdf link.
- Scan the QR code below.

If you would like a hard copy of the booklet, please ask your RN Case Manager.

HARRY HYNES
Memorial Hospice

Notice to Caregivers:

Consumer Assessment of Healthcare Providers and Symptoms (CAHPS*) Hospice Survey

The Centers for Medicare and Medicaid Services (CMS) developed a family of surveys to be utilized by hospices, hospitals, surgical centers, home health, and other healthcare providers. CMS requires each hospice to use approved vendors to administer the survey on their behalf, and Harry Hynes Memorial Hospice has contracted with Strategic Healthcare Programs (SHP) to administer the survey.

The Hospice CAHPS survey gathers information on the experiences of hospice patients and their caregivers' perspectives of the hospice services provided to their loved one. The survey allows for fair comparisons across hospices throughout the nation and is used to calculate quality measures related to topics such as communication, timeliness of care, emotional support, spiritual support, respectfulness, symptom management, training, and overall rating of care. Hospices utilize the survey responses and feedback for quality improvement purposes.

If your loved one receives hospice services in a hospital or resides in a nursing home or assisted living facility, Harry Hynes Memorial Hospice staff works closely with the staff in these facilities to ensure appropriate care and support is provided. However, the Hospice CAHPS Survey is intended for responses to be solely about the staff and services of hospice; not the hospital, long-term care, or assisted living facility staff.

We encourage you to complete the survey as the feedback provides valuable insight into the services and care we provide.

If you have any questions regarding the care you are receiving from us or want to share what we can do to improve the care and support of both you and your loved one, please contact us at 800-767-4965.

Thank you for trusting in our compassionate staff, and please know we are here for you.

HARRY HYNES
Memorial Hospice