

Hospice Care Guide

When a Loved One Resides in a Senior Living Community

Training, guidance, support,
questions answered, and medication FAQs.

24/7
Patient Care
Team
316-219-1750
800-767-4965

HARRY HYNES
Memorial Hospice



Our Story

Our agency was founded by community volunteers in 1983 as a non-profit hospice. In 2002, we changed our name from Hospice Inc. to Harry Hynes Memorial Hospice to honor one of our founders, Dr. Harry Hynes. Four decades later, Harry Hynes Memorial Hospice continues to be the leading provider of end-of-life care in South Central and Southeast Kansas.

Our agency began and continues to operate with a mission-driven focus based on the belief that listening to the needs of our patients and families is essential. This allows us to provide care that focuses on supporting the individual needs of each patient for their comfort, diginity, and quality of life.

Our mission is to enable people to live with dignity and hope while coping with loss and terminal illness.

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



Welcome

We Are Here for You

Thank you for choosing Harry Hynes Memorial Hospice. It is a privilege to care for you and your loved one. Hospice is not a place, but personalized care that supports the mind, body, and spirit. We always strive to support our patients and their families by providing control over their lives with a focus on comfort, dignity, and peace of mind.

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

We are here to give you more. It's not just our job, it's 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

This Training Guide will guide you toward an understanding of 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 or however this guide is worded, 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 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 care for 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 you to live each day to the fullest as comfortably and dignified as possible.

Contacting Hospice

Your loved one's hospice nurse will visit at least once a week and the other hospice care team members will visit according to your loved one's individual care plan.

We will work in conjunction with the senior living community staff to address any pain and or symptoms.

If you have questions or concerns or if you feel that your loved one's pain or other symptoms are not controlled, please call us.

A hospice nurse is available 24 hours a day, seven days a week by phone to address any issues or problems that may arise and hospice care team members will visit as needed.

We can provide the best comfort for your loved one, work more efficiently with the physician, senior living community staff, and families, when we are aware of all pain, symptoms and concerns.

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

Outside of office hours, the 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 a 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 9-1-1 OR GOING TO THE ER, PLEASE CALL US FIRST. WE CAN HELP.

Office Locations and Phone Numbers

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

Coffeyville
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

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

Oswego
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

Parsons
1750 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

Pittsburg
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

Winfield
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 C
929 N St Francis
Wichita, KS 67214
Phone: 316-261-3131
Fax: 316-261-3161

Hospice Care in a Senior Living Community

Hospice care can be provided wherever patients call home, whether in their own home, a family member's home, a nursing home, assisted living or home plus.

Hospice care in a senior living community provides the patient and their family with an extra layer of support, including expert management of pain and other symptoms, spiritual counseling, care planning, and grief support.

Some people may ask why they need another nurse when the nursing home provides one. You can compare the support provided by hospice as a specialty service. Much like a resident might receive therapy services in a nursing home, hospice is an additional service that specializes in care at end of life.

Hospice does not replace the wonderful staff in the senior living community — hospice care adds a specialized team that joins the facility staff in providing extra support for a patient and their family.

Hospice and facility staff collaborate on a plan that will meet the patient's and family's needs. Together, they can provide support to keep the resident comfortable and address symptoms as they arise.

Your Harry Hynes Hospice team helps by providing:

- Regular visits by a hospice Registered Nurse.
- Hospice aide visits to provide additional personal hygiene care, such as bathing.
- Consultations by a specialized hospice physician as needed.
- Expert management of pain and other symptoms such as problems breathing or swallowing.
- Education for facility staff, patients and families about patients' condition, symptoms, medications, and how to best care for patients' medical needs during this journey.
- Medications and supplies related to the patient's terminal illness.
- Coordinates the patient's care and medications across all of the patient's medical providers, including the patient's own doctors, hospice doctors, hospice nurses, hospice aides and all facility staff.
- Hospice care can also support with care planning, including connecting clients and families with additional resources, and help with navigating financial concerns.

Hospice care is an extra layer of care that works in conjunction with the care you already receive. The senior living community continues to provide your same daily level of nursing care, and/or any other additional services you are currently receiving such as bathing, meals, medicines, and staff support.

Also, unique to hospice care is the spiritual and emotional support you and your loved ones will receive. Grief and bereavement services are available for up to 13 months.

The Medicare hospice benefit does not cover the cost of daily room and board. However, these costs may be covered by Medicaid benefits or other benefits you have.



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Your Care Team



Your hospice interdisciplinary team consists of professional hospice staff providing expert medical care, pain management, and emotional and spiritual support. This individualized care is tailored to each patient's personal goals and needs. In addition, care and support is available for family and caregivers. Hospice volunteers can also be essential in providing the level of care and support that patients and their loved ones expect and deserve from hospice care.

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 care for the patient when we are not there.

Doctor(s): _____

_____

Referral RN: _____

_____

RN Case Manager: _____

_____

Hospice Health Aide: _____

_____

Social Worker: _____

_____

Chaplain: _____

_____

Volunteer: _____

_____

Hospice Team

Caregivers

Caregivers and family are essential to hospice care. Several people may work together to provide care, although at least one person or entity needs to be designated as the primary caregiver. If a patient lives in a senior living community, the staff of the facility are the primary caregivers, responsible for overseeing the day to day care and collaborate on decisions regarding care.

When the hospice team makes their regularly scheduled visits to the community, they teach facility caregivers how to care for the special and unique needs of a patient with a terminal illness. Although the hospice team provides guidance and support, it is not intended to take the place of the family or facility caregivers. Hospice 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 medical 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 needs and developing your plan of care. If you choose your PCP to be the Attending Physician, they may choose to continue to direct your medical care or defer to the hospice physician because of their specialized training and knowledge.

Hospice Physician

The hospice physician specializes in comfort care and becomes a partner with your physician (if they are the 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 to ensure your needs are being met.

Nurses

There are both Registered Nurses (RN) and Licensed Practical Nurses (LPN) on the hospice team. They work together to ensure the patient's needs are being met and that the issues and concerns identified in the patient's care plan are addressed. A nurse will complete a thorough assessment a minimum of once a week and can make other 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 the 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

The patient is assigned a Registered Nurse who serves as the Case Manager. This nurse is responsible for the overall coordination of care and services. The responsibility of a Case Manager is to ensure that the patient's care needs are being met. The RN works closely with the attending physician and the hospice physician, and assists in coordinating counseling and supportive services.

Licensed Practical Nurse (LPN)

Licensed Practical Nurses 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. Do not hesitate to call regardless of the time of day or night.

Hospice Health Aide

Your hospice health aide is an expert in making daily living tasks easier. They can help patients maintain dignity by assisting with bathing and personal hygiene. They can provide education on safe transfer and ambulatory techniques and range of motion exercises. 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 personal coach that helps the patient and family cope with the challenges presented by the illness. They are trained to listen without judgement and anticipate problems that may limit the patient and family's ability to meet their goals of care. They will help address and develop solutions to caregiving concerns, relationship difficulties and fears about the future. The social worker also works closely with the other members of your hospice care team.

Chaplain

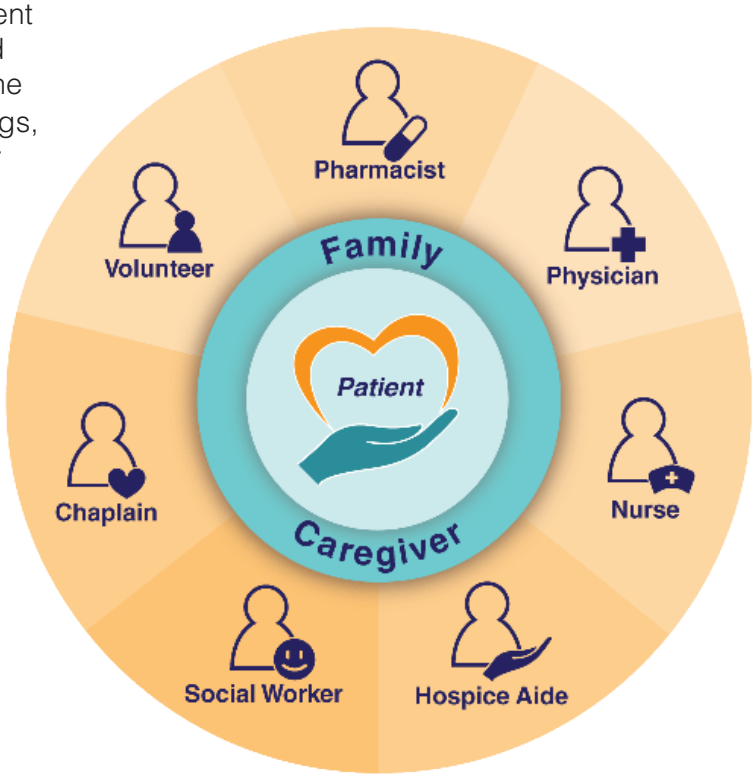
Your hospice chaplain will encourage the patient to embrace their personal spiritual beliefs and practices. Based on the individual wishes of the patient — music, scripture, inspirational readings, prayer, meditation, sacrament and even humor are some of the ways a chaplain can provide support. A chaplain can provide comfort even if the patient does not belong to a faith community. They will not try to change beliefs and values as they are all non-denominational. They are here to meet the patient where they are on their own spiritual journey.

Volunteers

Hospice volunteers are a unique service available to you and your caregivers. Our volunteers are specifically trained for hospice care and although they cannot administer medications or provide direct patient care, they do provide companionship and extra presence when family and friends can't. You can request a volunteer through your patient care team or call Harry Hynes Hospice to speak with our volunteer department. A volunteer placement specialist will then work with you to identify what you need, when and how often. Volunteers typically visit once or twice a week for a few hours. When possible, please request a volunteer 48 hours in advance.

Pharmacist

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



Hospice Services

What You Can Expect

Family caregivers often worry about their own ability to care for their loved one during a serious illness. The Harry Hynes Hospice team supports caregivers as they explain and demonstrate techniques that allow them to become more capable, confident, and supportive caregivers.

If your family member lives in a senior living facility, such as a nursing home, assisted living or home plus, they are being cared for by experienced caregivers. We work with these caregivers, supplementing your loved one's care. Together we focus on their special, individual, and unique needs.

Our hospice team will visit regularly and address pain and symptoms, while adding an extra layer of support, comfort, and care for your loved one.

The first week will likely be the busiest, delivering and getting equipment in place, and introducing your hospice team members. Your team members may include: the attending physician and/or hospice physician, nurses, hospice health aide, social worker, chaplain, and volunteers.

Your hospice team will evaluate for medical, emotional, or spiritual needs, and stabilize your loved one's symptoms as needed. Visits from team members will be scheduled according to the plan of care, so you will know when visits will be made. Your team is comprised of skilled, compassionate, and knowledgeable staff who can answer questions or get answers for you.

Your team will be in continual communication with your loved one's physician and/or the hospice physician to discuss their medical history, current physical symptoms, goals of care, and preferences. They will maintain a personalized and updated plan of care that addresses the needs, goals and traditions of your loved one and their 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. Harry Hynes Hospice will be with you every step of the way, bringing hope for a fulfilling life, even as the journey nears completion.



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 residence, 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 a registered nursing available 24 hours a day to provide direct patient care.

3. **Continuous Home Care** is care provided for between 8 and 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 98 percent of hospice care is provided at the **Routine Hospice Care** level.

**A group of health care professionals with various areas of expertise who work together toward the goals of their patients and their families.*

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 you (patient) or your loved one (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 we may support you. We will be available by phone (24 hrs/day, 7 days/wk) to answer questions and provide guidance during your travels. At times, our agency may also contact a hospice in the vacationing/visiting area 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 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.

Top Medications and 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.

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.

Your nurse will review the medications with you to ensure you understand the reason for each one. The nurse will also go over the possible side effects and the desired results. This information can also be found on pages 12-13 of this **Hospice Care Guide**. 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. The patient's senior living community staff will give the medications as scheduled.

Your hospice nurse is responsible for ordering and refilling medications filled by Kansas Palliative Pharmacy.*

**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 the patient is taking. This would include anything ordered by their 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.

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 or facility staff. The hospice care team will be responsible for monitoring the amount of any drug given and the length of time between refills.

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).

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.

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.



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. You may feel frightened, confused and overwhelmed.

Emotionally you may feel:

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

Physically you may:

- Tremble
- Shake
- Sweat
- Experience shortness of breath
- Feel like your heart is pounding in your chest
- Have an upset stomach, headaches, change in appetite, nausea or 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 conversation and priceless moments of time together. We hope this information will provide reassurance as you walk through this 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 physical 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 or anxiety, 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.
- If you are concerned or feeling overwhelmed contact your hospice social worker.
- 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 more than just a series of care choices. Anticipating the feelings you may have walking the path of a serious illness for a loved one, to grieving and ultimately healing.

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 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 your loved one and the senior living facility staff 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.

Many 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 have the best possible quality of life.

In addition to managing physical pain, the hospice pain management plan will assess and address the patient's emotional and spiritual pain.



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.

Symptom Management

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.

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.

Signs and symptoms may include being worried or scared. The mind is "racing" or "going around in circles." They may have in inability to rest or sleep at night. May feel "jittery" or "panicked" even when resting, "shaky" or short of breath, or heart is pounding or racing. Although not as common, dizziness and nausea can occur with anxiety.

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.

Confusion and 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.

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.

The signs and symptoms may include sleeping more hours out of the day, unable to perform normal activities because they are "just too tired." They may have changes in appetite because they simply do not have the energy to eat, and with less activity their nutritional needs decrease. 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.

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.

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.

Constipation

Your loved one's bowel movements may be smaller and less frequent and/or 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 use of a laxative is almost always required to prevent constipation in patients with decreased activity level and/or taking pain medication.

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.

Changes in 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.

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.

Signs and symptoms of restlessness may include moaning sounds that are not associated with pain. The patient may experience involuntary muscle twitches, hallucinations, picking or pulling at clothing or the air, or irritability. Some patients have experienced a sudden surge of energy.

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 provide for your loved one's comfort. As death approaches you may want to contact 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 family and friends should continue to speak words of comfort, even if the loved one does not appear to 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 them 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 personal 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. Or just angry that this is happening to our loved one. 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 if 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
- May be a loss of bladder or bowel control

What You Should Do

- If you are present with your loved one and see the above signs, contact the staff of the senior living facility. They will contact our hospice team.
- Although it may be your first instinct, it is NOT necessary to call 911 unless instructed by the facility staff to do so. The facility staff will be in conversations with you about this topic. Contacting 911 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. Please discuss your loved one's and your wishes with your hospice team.

At the Time of Death, Your Facility Staff and Hospice Nurse Will Want to Know

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

What You Can Expect

- A member of our 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 facility staff and/or hospice staff will prepare your loved one to be picked up.
- The other members of your hospice team will be notified.

You can have the funeral home come right away or choose to wait a period of time before calling. Let the facility staff and hospice nurse know your preference so this can be communicated to the funeral home. When the funeral home arrives, 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.

"All deaths are sudden, no matter how gradual the dying may be."

– Michael McDowell



After A Loved One Dies

After your loved one has passed, take the time you 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 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 made. 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 a few 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 Department of Veteran Affairs: 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, 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 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, and/or dependency compensation. It may also include Veterans Mortgage Life Insurance (VMLI). Call 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 Consumer Credit Counseling Service, Inc. To find the closest location call 800-279-2227.
- **Continue Health Coverage** – If insurance was through the deceased's employer, health insurance may 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 estate/case.

Grief

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
- Lacks of enegy
- 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 easier 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 or longer after the death
- Doubts as to whether your experiences and reactions are normal

For more information, please call our Bereavement Department at (316) 265-9441 or (800) 767-4965 or visit hynesmemorial.org.

Grief Services

Our goal is to help family members and loved ones find hope and healing. We recognize that everyone grieves differently. Our wide range of grief services allows you to choose those you are comfortable with.

- **Rising Sun** – A quarterly letter with information about common experiences, helpful ways to cope and a calendar listing special events and groups.
- **Individual and Family Counseling** – Counseling focuses on adjusting to the death of a loved one. Counseling is available for persons of all ages and can be in person or over the phone.
- **Grief Companion** – A trained volunteer provides phone support.

Grief Support Groups Include:

- **Companions in Grief** – Monthly group with information, sharing and fellowship.
- **Seasons of the Heart** – Participants learn about common grief reactions and healthy coping skills in this four-session series.
- **Coping with the Holidays** – Sessions to assist in preparing for holidays without a loved one.
- **Coping with the Death of a Parent** – A series designed for adults who have experienced the death of a parent. Participants learn about the unique aspects of dealing with their loss.
- **Death of a Spouse/Partner** – A support group for those that have experienced the loss of a spouse/partner.

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 and your loved one 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.

- Donna VanLiere



Celebrate and 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 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 a loved one.

Planned Gifts and Endowments

Create a personal legacy by designating Harry Hynes 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.

Gifts of Time

Please know that your gift to Harry Hynes 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 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, 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 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
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.

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

Two options to access a PDF digital version of this guide:

- Visit www.hynesmemorial.org. Select “Caregiver Support”, then select the last option “Hospice Care Guide.”
- Scan the QR code below.

HARRY HYNES
Memorial Hospice

Providing Comfort, Support, and Peace of Mind.

hynesmemorial.org • 800-767-4965

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