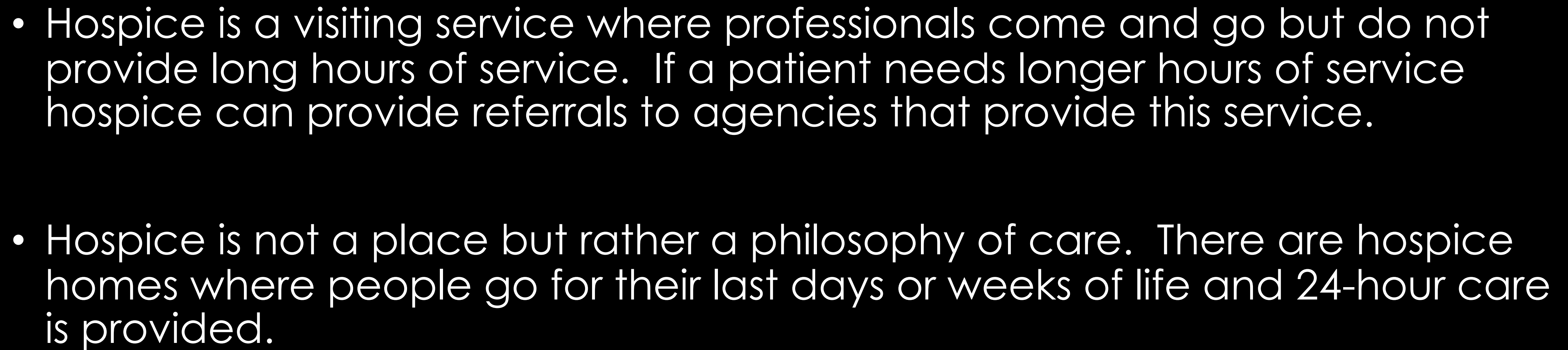
DISPELLING THE
MYTHS OF
HOSPICE

Hospice is a philosophy of care that focuses on quality of life. The goal of hospice is to honor the wishes of the patient and family and bring the best quality of life to the time the patient has left, whether that is for hours, days, months or even sometimes years.

Hospice teams of professionals and volunteers also address the emotional, social, and spiritual needs of the patient and the whole family.

Overseeing all patient care is the hospice medical director who may also serve as the attending physician.

Alternatively, the patient's own physician may continue in this role, in coordination with the hospice team and its plan of care.



- Hospice is a visiting service where professionals come and go but do not provide long hours of service. If a patient needs longer hours of service hospice can provide referrals to agencies that provide this service.

- Hospice is not a place but rather a philosophy of care. There are hospice homes where people go for their last days or weeks of life and 24-hour care is provided.

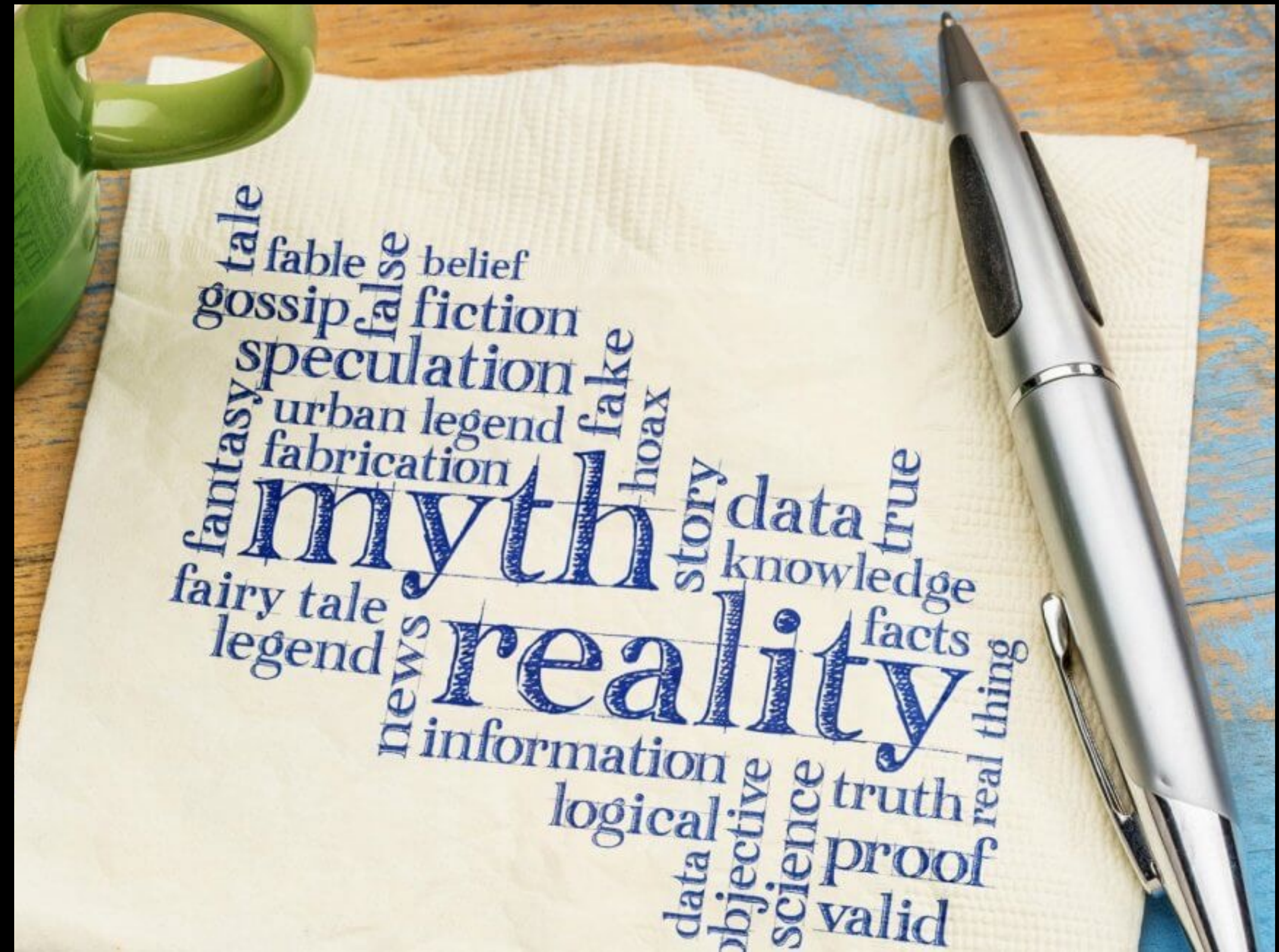
WHAT IS THE DIFFERENCE BETWEEN HOSPICE AND PALLIATIVE CARE?

Palliative care is similar to hospice care in that the same principles of pain management and symptom control are applied.

Palliative care can be used prior to a patient entering hospice to help people manage symptoms, avoid hospitalizations, maintain optimal levels of health and guide patients on when it may be time to consider hospice and make that transition.

Multiple studies have shown that the average number of emergency department visits of terminally-ill patients is reduced when patients are receiving palliative care services. This further substantiates that palliative care not only alleviates suffering, but also will prevent avoidable visits to the ER in the future for your loved one.

WHAT DO YOU BELIEVE?



MYTH #1: HOSPICE IS THE SAME AS EUTHANASIA

- Hospice neither hastens death nor prolongs dying. Hospice care honors both life and the natural process of dying, assuring as much comfort and function as possible within the limits of the disease.

MYTH #2: HOSPICE IS DEPRESSING

- While it is always sad to realize someone you care about is facing the end of their life, hospice helps that person and family discover ways to create meaning, find healing, share stories and leave a legacy and make the most of the days and months that remain. This is life affirming and can be as filled with laughter as it can with tears. Hospice is a guide for the journey to lessen fear and promote communication and quality of life.

MYTH #3: HOSPICE IS ONLY FOR OLD PEOPLE

- Although most hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care. Almost 20% of hospice patients are under 65 years of age.

MYTH #4: HOSPICE IS ONLY FOR DYING PEOPLE

- We are all dying. As a family-centered concept of care, hospice focuses as much on the family as on the patient who knows they are nearing the end of life. Most hospices make their bereavement and support services available to the community at large, serving schools, churches and the workplace.

MYTH #5: *HOSPICE IS FOR PATIENTS WHO DO NOT NEED A HIGH LEVEL OF CARE*

- End-of-life care is extremely complex. The interdisciplinary team is composed of specially trained physicians, pharmacists, nurses and therapists who can provide comprehensive medical care. Their efforts are complemented by a team of other trained professionals and volunteers who offer a full range of support services, which help the entire family.

MYTH #6: *HOSPICE REQUIRES FAMILY MEMBERS TO PROVIDE CARE TO PATIENTS*

- In many instances, hospice staff trains family members to assist in the care of their loved ones. Family members can call the nursing helpline— 24/7/365 for assistance. In cases where the patient lives alone or family members are unable to assist with care, the hospice social worker can assist families with a plan of care that is appropriate for the patients needs, including hiring in home care, transfers to assisted living, memory care, nursing home or end of life hospice homes

MYTH #7: HOSPICE IS ONLY FOR PEOPLE WHO CAN ACCEPT DEATH

- While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences. Hospice staff are readily available to discuss all options and to facilitate family decisions. Palliative care teams can assist with these discussions as well.

MYTH #8: HOSPICE PAYS FOR ALL YOUR MEDICATIONS

- Hospice pays for any medication related to the terminal illness and any medications for pain and symptom management to keep the patient comfortable.

MYTH #9: HOSPICE IS NOT COVERED BY MANAGED CARE

- While managed care organizations (MCOs) are not required to include hospice coverage, Medicare beneficiaries can use their Medicare hospice benefit anytime, anywhere they choose. They are not locked into the end-of-life services offered or not offered by the MCOs. On the other hand, those under 65 are confined to the MCOs services, but most provide at least some coverage for hospice.

MYTH #10: AN IMMENSE AMOUNT OF PAIN IS JUST A PART OF DYING. IT'S UNAVOIDABLE.

- While pain often is part of many disease processes, hospice care professionals are trained to be experts in managing pain at the end-of-life. Hospice doctors, nurses, and other professionals are able to recognize what stage of the end-of-life process the patient is at and adjust their care accordingly.

- While hospice services are required to have volunteers available, the actual care is provided by medical professionals, chaplains, and licensed social workers. This hospice myth is simply false!

MYTH #12: IT IS HARD TO ENROLL IN A HOSPICE PROGRAM

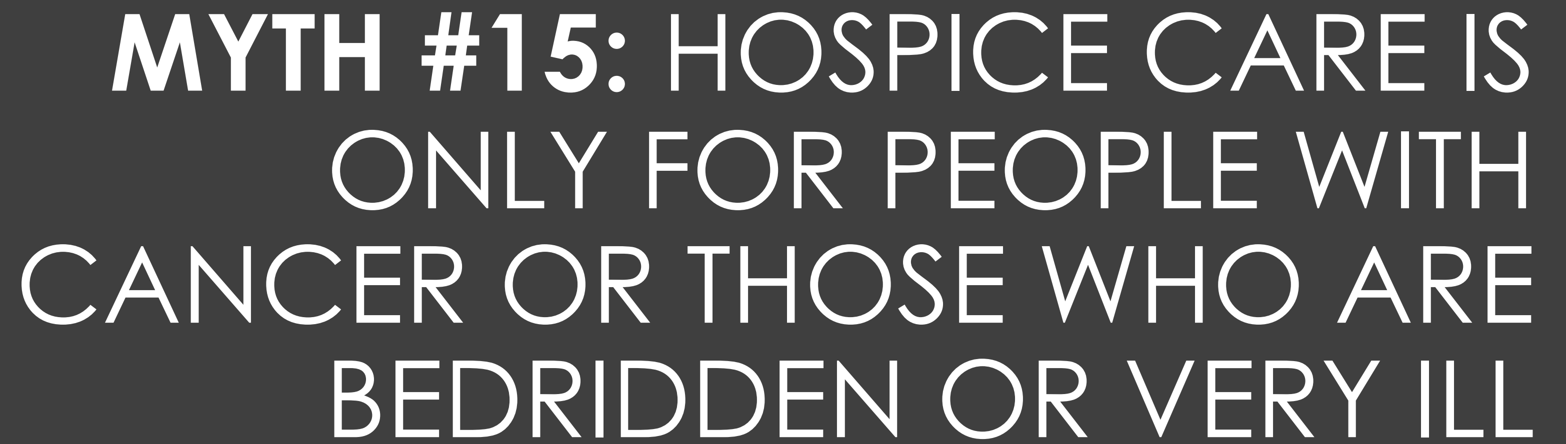
- For most hospices, it only takes a phone call for care and services to be arranged. A hospice information session can be scheduled to teach families about hospice care, free of charge. When a patient or family is ready, a team of a nurse and social worker typically come to the home and and sign forms to elect hospice care which then begins immediately. This usually takes 1-2 hours to complete, depending on a family's comfort level and questions.

MYTH #13: IT MUST BE HORRIBLE WORKING IN A HOSPICE

- **REALITY:** All of us in hospice care are immensely proud not only of what we do but of what hospice care is and consider it a privilege to be here for people at the most difficult time of their lives.

MYTH #14: HOSPICE TAKES OVER YOUR DECISIONS AND ALL YOUR MEDICATIONS

- The goal of hospice is to honor patient/family decisions. Hospice staff educate on all medications based on many factors including if the medication is working, necessary, difficult to swallow, costly to the family, or causing more harm than good as a person nears the end of life. The final decision rests in the hands of the patient and family and is transparent.



MYTH #15: HOSPICE CARE IS ONLY FOR PEOPLE WITH CANCER OR THOSE WHO ARE BEDRIDDEN OR VERY ILL

- Although many patients do have cancer, many hospices serve terminally ill patients of all ages, with all types of progressive and chronic diseases.
- About 40 percent of U.S. hospice admissions now involve patients with end-stage heart disease, dementia, lung disease or stroke.
- Many of these patients are actually able to enjoy life longer when on hospice. This fact is especially true if care is accessed early in their illness. Patients are seen by trained healthcare professionals who can address their medical conditions and support family members.

MYTH #16: HOSPICE CARE IS EXPENSIVE

- Not so for the patient. Medicare, Medicaid and most other insurances cover the cost of hospice care. The requirements for Medicare to cover hospice is that your loved one must be eligible for Medicare Part A (Hospital Insurance) and a doctor and the hospice medical director must certify that your loved one is terminally ill with a prognosis of 6 months or less if the disease runs its normal course. Care must be provided by a Medicare-approved hospice provider. Hospice care is actually less expensive than care provided in a traditional medical setting.

MYTH #17: HOSPICE PATIENTS REQUIRE A "DO NOT RESUSCITATE" STATUS PRIOR TO ADMISSION

- False. A POLST (providers orders for life-sustaining treatment previously known as a DNR) is discussed at the time of every hospice admission, if not before. Patients are educated on what occurs in a real-life resuscitation (not what they see on TV). The choice remains with the patient and family.
- Medicare-certified hospices do not require a DNR order, since it is understood by the patient and family that the patient will be receiving palliative, not curative, care. If the patient is not in agreement with palliative care vs curative care, then they are likely not ready for hospice.
- If a full-code status is chosen families understand that the patient will be required to go to the hospital and be vented if needed as partial or discontinued codes do not occur at home.

MYTH #18: ONCE YOU GO TO HOSPICE, YOU CAN'T CHANGE YOUR MIND OR SEEK A CURE

- Hospice patients always have the right to return to medical care that focuses on curing their disease at any time and for any reason.
- If a condition improves or the disease goes into remission, a patient can be discharged from hospice and go back to aggressive, curative measures.
- This is based on patient choice. If a discharged patient wants to return to hospice care, there is not a limit to the length of service if the patient still meets criteria (showing decline in their condition).

MYTH # 19: HOSPICE PATIENTS CANNOT LIVE LONGER THAN SIX MONTHS

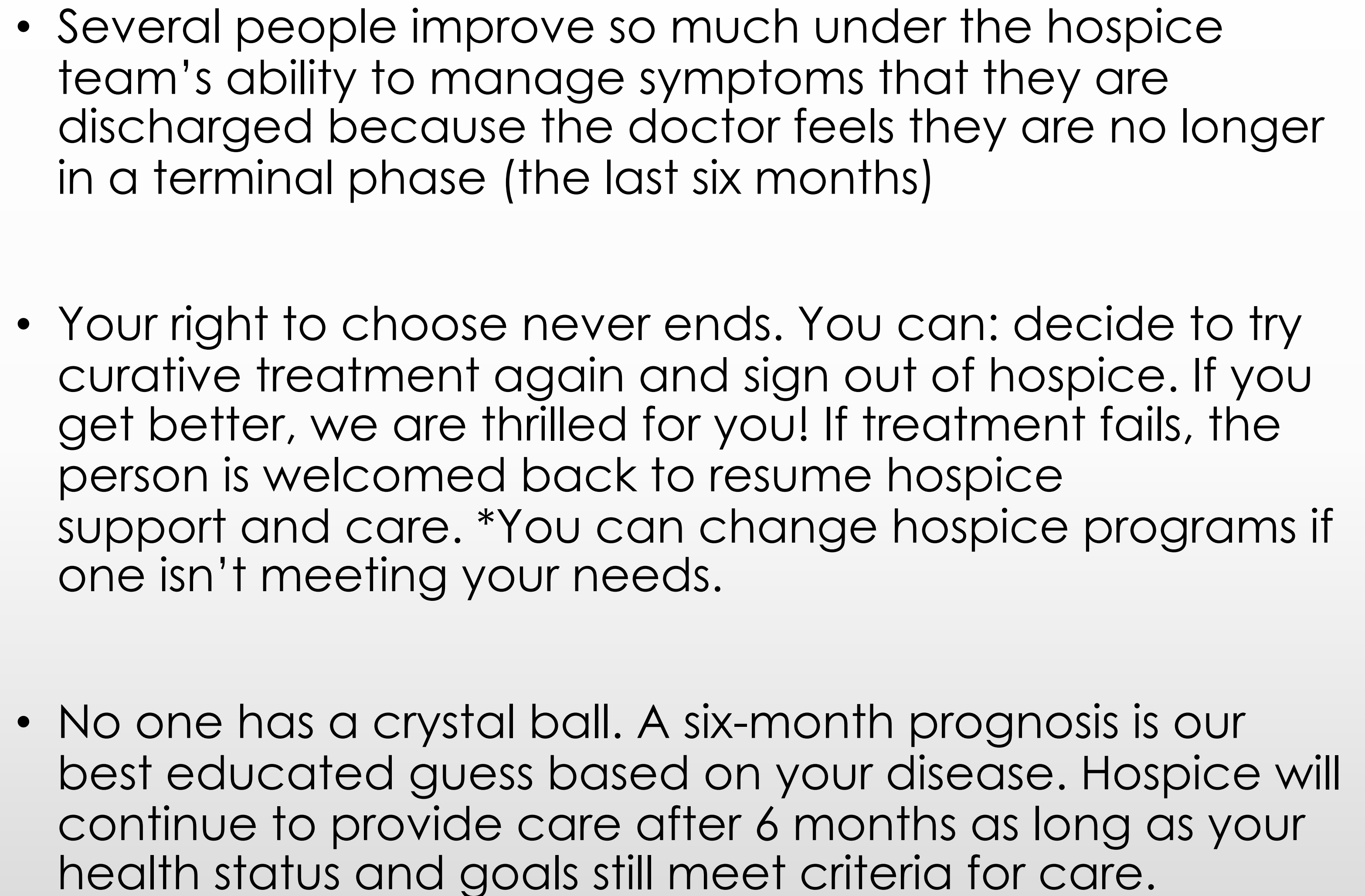
- Once on hospice, patients continue to receive services unless they are no longer necessary or appropriate, or the patient chooses to stop, by signing a revocation form.

- If the patient lives longer than 6 months, service continue for as long as the hospice doctor re-certifies that the patient is terminally ill.

- Patients have lived up to 3 years on hospice

DID YOU KNOW THIS ABOUT HOSPICE?

- Services are available 24 hours a day, 7 days a week with intermittent visits by the hospice team.
- Your doctor remains in charge of your care unless you choose otherwise or if he or she feels you will get the best care with a physician who specializes in comfort care.
- Most people can remain in their own homes until death.
- Studies show that people actually live longer under hospice care due to good symptom control and decreased aggressive treatment that may occasionally hasten the end of life.


• Several people improve so much under the hospice team's ability to manage symptoms that they are discharged because the doctor feels they are no longer in a terminal phase (the last six months)
• Your right to choose never ends. You can: decide to try curative treatment again and sign out of hospice. If you get better, we are thrilled for you! If treatment fails, the person is welcomed back to resume hospice support and care. *You can change hospice programs if one isn't meeting your needs.
• No one has a crystal ball. A six-month prognosis is our best educated guess based on your disease. Hospice will continue to provide care after 6 months as long as your health status and goals still meet criteria for care.

WHO IS ON THE HOSPICE TEAM?

- Medicare requires that and RN and Medical Social worker see every hospice patient. The nurse sees them 1-3 times per week but can be up to daily if needed and there is a nurse and physician on-call 24/7/365
- The MSW typically sees a patient 2-4 times per month and as needed for support and help with coordination of care, paperwork, family needs etc.
- HHA- Home Health aides are optional for personal cares and light housekeeping
- Chaplains, music and massage therapists are all optional to the patient and/or family.
- Hospice volunteers are optional. They do not provide hands on care but can provide many supportive and helpful services.

SPECIFIC SERVICES HOSPICE PROVIDES:

- On-call nurse availability 24/7
- Walkers, wheelchairs, a hospital bed, bedside commode, shower chair, oxygen, Hoyer lifts, etc.
- Medical supplies, such as wound-care supplies.
- Incontinent supplies: adult briefs, wipes, gloves, under-pads, etc. in some cases
- Personal-care services: bathing, light housekeeping and activities of daily living.
- Respite and in-home patient care, as needed.
- Symptom and pain management to keep our patients comfortable.
- All medications related to your primary diagnosis, and comfort medications, delivered to your home.

EMOTIONAL AND SPIRITUAL SUPPORT

The fear of death is often due to the fear of pain and abandonment. Hospice staff includes bereavement and spiritual counselors who help patients and families come to terms with dying. They assist patients in finishing important tasks, saying their final goodbyes, healing broken family relationships, distributing precious objects, and completing a spiritual journey.

Following a patients passing, bereavement care is made available to families for up to13 months.

MEDICAL CARE

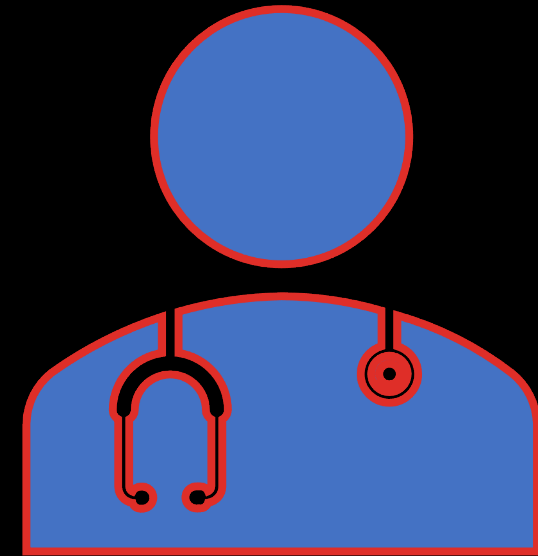
- Pain management is of particular concern for a patient with a life-threatening illness. Hospice staff are the experts in state-of-the-art pain treatments, helping patients feel comfortable with pain management alternatives. If administering pain medication requires a new skill, family members can count on the hospice staff for training and guidance.
- Most medical treatments needed to make a terminally ill patient physically comfortable can be provided at home. Recent technological advances allow for a wide variety of equipment to be installed in the home, thus reducing the need for hospitalization, except in the most complicated cases. In rare cases when symptoms cannot be controlled at home, inpatient facilities are available.

HOW DO I KNOW IF I QUALIFY FOR HOSPICE?

- Have you had frequent hospitalizations or trips to the ER?
- Have you had frequent or reoccurring infections?
- Do you have reduced desire to eat, leading to significant weight loss and changes in body composition?
- Have you had rapid decline in health over past six months, even with aggressive medical treatments?
- Do you have uncontrolled pain, shortness of breath, nausea or vomiting?
- Have you had decreasing alertness, withdrawal, increased sleeping or mental confusion?
- Have you had inability to perform tasks of daily living, such as eating, walking, using the bathroom, personal cleaning or getting dressed?
- Have you decided to focus on quality of life, instead of aggressive treatments?

IF YOU ANSWERED YES TO MANY OF THESE QUESTIONS…

It would be beneficial for you to bring up the conversation about hospice with your doctor. Often doctors are waiting for the patient or family to ask about hospice as they do not want to appear to be giving up or take away hope. The sooner the conversation begins, the better educated you will be to decide if hospice is right for you or your loved one.



Thank you for joining us! I welcome any questions you might have.