

HOW TO CHOOSE A HOSPICE

Deciding to explore hospice services may be difficult and challenging; it means that you (or someone you care about) are actively considering their end-of-life choices. Hospice admission, your particular insurance coverage, and the specifics of where and how care will be delivered will all be particular to you. Once you are enrolled in a hospice care program, there will be significant support, understanding and guidance. This is always something that can be done to help you.

It is important that you choose a program that meets your needs. Because hospice is a distinct approach to managing your health care, some of the language and care concepts may be foreign to you. Take as much time as you need when you are interviewing hospices. Even basic services may be delivered differently by each hospice. This is one of the most important decisions you can make, and you have the right to have all of your questions answered to your satisfaction.

The entire focus of hospice care is *customized comfort care*—helping you to feel calm, supported and informed about what is really going on as changes happen. The ultimate goal is to help you to be comfortable enough that you can address the things you want to make sure you complete and have time to celebrate your life.

Comfort means.....

- knowing that pain and symptom management, as you define them, are top priorities.
- getting information about what is happening in clear understandable language.
- having professionals respond to your needs in your home, wherever that is.
- being able to call with emergencies or concerns 24 hours a day and getting an immediate response from someone who will know what to do.
- having help locating resources you need to navigate this journey.
- working with professionals who understand that your dignity and emotional and spiritual well-being are as important as your medical status.

Your family will have a team of hospice staff who have expertise in dealing with all the concerns and tasks that arise when you are getting ready to say goodbye. As you read about their roles, think about what three things and which team members your family needs the most at this time.

- **Medical team members** will work immediately and regularly with any kind of pain or symptoms you have, and will adjust pain and symptom management medications as often as you need.

Other members of the team should be as available to help your caregivers learn to care for you with confidence, and to support you while dealing with non-medical matters of importance, such as fears, regrets, concern about being a burden, or the well-being of family left behind. Beyond the requirement for a regular assessment, you will always be able to choose which services you need or don't need.

- **Social workers** can help you identify community resources, facilitate family meetings to help everyone understand what's going on for each person, plan for the future, problem-solve, and provide emotional support, especially in completing life closure tasks, leaving legacies and saying goodbye.
- **Chaplains** are sometimes discounted because people assume they are religiously focused. Hospice chaplains are trained in many religious traditions but they are often there primarily to explore the questions of meaning that come up when you are facing the end of your life. They can also help connect you to your beliefs or your faith community in supportive ways if desired, as well as design and facilitate memorial services and funerals.
- **Grief Counselors** can help your family deal with the feelings and responses to letting go at every phase of the process as well as provide support for 13 months after their loss.
- **Certified Nursing Assistants (CNAs)** can give personal care, such as bathing, washing hair, changing beds, helping people toilet, and and may provide light massage and housekeeping.
- **Volunteers** may be available to help with a variety of tasks, such as shopping, sitting with you so your family can get a break, styling hair, and doing chores such as lawncutting. Some hospices may also provide **complementary therapies** such as aromatherapy, art, pet and music therapies, acupuncture, cranial sacral work, and Comfort Touch.

Some hospices have separate palliative care programs (palliative means that the focus is on pain relief and quality of life), which allow you to continue to pursue medical curative treatments while also having your pain managed expertly. This is an important option so ask each hospice for information about how they support palliative care.

**IN HOSPICE CARE, YOU MAKE YOUR OWN DECISIONS
ABOUT THE KIND OF CARE YOU WANT,
SO IT'S IMPORTANT TO UNDERSTAND WHAT YOUR WISHES AND NEEDS ARE.**

Here are some questions that will help you choose the kind of care you want because hospices have different types of programs. I suggest that you and your caregivers interview several hospices. There is a tool on the Medicare website that will help you compare different hospices services. (<https://www.medicare.gov/hospicecompare/>) If there is no time for several interviews, choose a hospice that is referred to you by someone you trust.

- How is hospice care paid for and what does it include? Will Medicare or my insurance pay for your hospice? (Not all insurance companies pay for care in all hospices.)
- What if I have no way to pay?
- When is the right time to talk to hospice and how do I start?
- Can you provide palliative care if I'm not quite ready or eligible to go into hospice yet? Tell me about your palliative care services.
- Can I continue with my regular doctor, and my treatments, therapies and medications?
- Are your physicians board certified in Hospice and Palliative Medicine? How much experience in hospice do they have?
- Where can I receive hospice care? If I move, can I stay with the same team?
- How long can I be in hospice? What happens if I feel better or my health improves?
- Who are the members of my team?
- Will there be volunteers also available and what can they do to help us?
- How often will a physician, nurse and the rest of the team come to my home to visit?
- Can I have a CNA visit every day if I need one? What is the maximum amount of CNA visits available per week?
- Will I have the same team all the time?
- What is your team caseload (how many families does one team work with) right now?
- Tell me how you work with pain. Will I get enough pain medication to make me comfortable? Can I take too much?
- If we have a pain crisis in the middle of the night, how long will it take you to come to us?

- How do you respond to after-hours requests or needs? Will I get a live person on the phone if I call? Will it be a clinician who has access to our medical records?
- If we need someone to come out to help us, how long does it take for you to respond?
- If I live in a facility that I call home, do you have an established and good relationship with this facility and how do you communicate with each other on a regular basis so I have consistent and organized care?
- Can we get 24-hour care in our home for a little while if things feel out of control? Which team members will come to our home and how do they work with us? How much staff do you have to do this?
- If I need help with pain management that can't be achieved at home, where will I go? Do you have a hospice in-patient facility with hospice staff that we can go to? If not, do you contract with a nursing facility? Do you have an established relationship with the facility?
- Is my whole team available every day and night of the week? What does "available" mean?
- How can you help us if we begin to feel frightened, overwhelmed or hopeless?
- What kind of grief support can you provide to us before and after the death?
- If we find ourselves dealing with unexpected complicated medical or emotional issues that we need objectivity to solve, can you help us? (Do you have access to an ethics committee if the situation becomes too complex to resolve with just our team?)
- How do you address the needs of people of different ages, cultures or faith traditions?
- Can you send someone out to my workplace or church to support the other important people in our lives before and after this loss?
- What is your position on the Colorado End-of-Life Options Act (Medical Aid in Dying)? What kind of support will you provide my family and me if I want to access it? What kind of support have you decided not to provide?
- What makes your hospice the one I should choose?

(This document was compiled by Kim Mooney with help from three different hospices.) 1-22-18