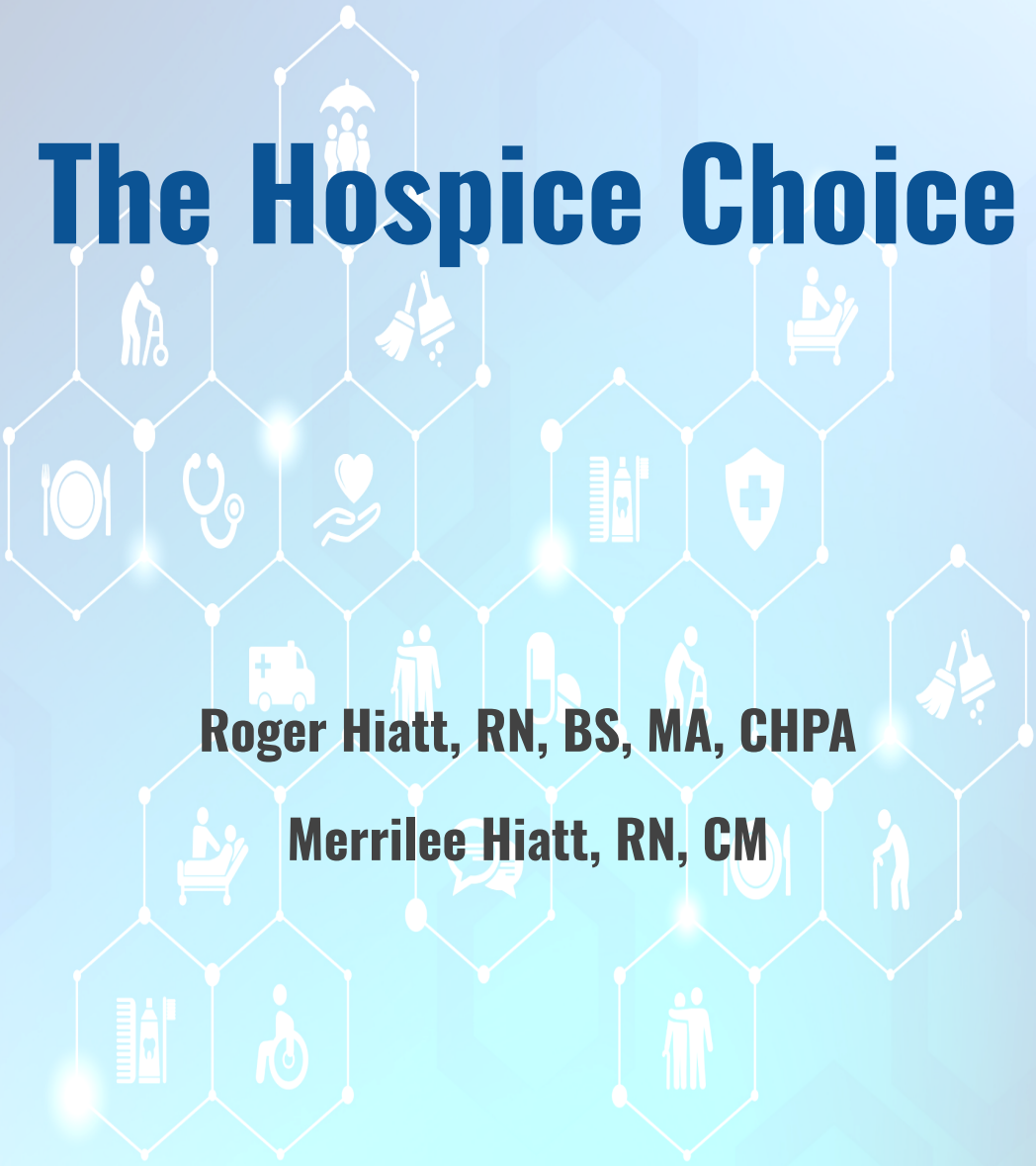
The Hospice Choice



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Introduction

For many, the term hospice is synonymous with death and dying. It is there for that of course, but it's so much more. It is a dedicated discipline in the field of medicine, but unlike the other ninety percent of medicine, hospice is about comfort and support, not curing a condition or disease.

It's also not a service to be used only at the end of life. Research has shown that most people needing hospice care receive it within the last few weeks of life, often after struggling with the pain and debilitating aspects of dealing with a terminal illness. That doesn't need to happen. If started early in the disease process, hospice can provide great physical, mental, emotional, and spiritual comfort and support, often significantly improving your quality of life.

In fact, we've seen the health and wellbeing of many people improve dramatically when placed on hospice as supportive and comfort cares have been applied - even to the point of no longer needing the service.

In ancient Roman times, a hospice was a way-station for weary travelers. We like that idea. When done right, hospice is a comforting, soothing, and supportive service allowing you to spend the end of life on your terms, with dignity, and a feeling of personal control. Good hospice care provides effective management of undesirable symptoms including pain, difficulty breathing, weakness, etc.; allowing you to focus on the things that are most important to you, including precious time spent with loved ones.

By definition, hospice care is designed to meet your medical care needs when your physician feels you have a condition or diagnosis with a life expectancy of six months or less. Typically provided in the comfort of your home, hospice accommodates your preferences with care provided on your terms. Using a multidisciplinary approach, nurses, aides, social workers, and others come together as a team to support not only you, but your family also through this time of significant change.

Hospice is intermittent in nature, meaning the nurses, aides, social worker, chaplain and volunteers visit your home as needed, and typically for up to an hour or so several times during the week. The full time care is provided by family, friends or paid caregivers. The roles and responsibilities of these caregivers are described later.

But hospice is also always available to you. There is a skilled hospice nurse available to respond to your questions or needs by phone 24 hours a day, seven days a week; or to make after-hours in-home visits if needed.

Are You Ready For Hospice?

How does hospice work?

The vast majority of hospice care is provided under the Medicare Hospice benefit, and is governed by regulatory guidelines known as Conditions of Participation (COPs). (Some insurance companies also pay for hospice services but they uniformly follow the same guidelines.) Hospice agencies who contract with Medicare to provide services are routinely surveyed to make sure they are abiding by these COPs. A guiding principle behind the COPs is to optimize the hospice experience for individuals under care, and for their families.

Medicare COPs cover basic required services such as physician oversight, skilled nursing and nurse aide cares, social work services, and spiritual care or chaplaincy services. Efficacy of treatment is also monitored in areas such as pain or other negative symptom management. Agencies are also required to continually improve their performance to make sure minimum standards of care are met.

Payment for hospice care is most often paid completely by Medicare under its Hospice Benefit, with no additional out of pocket costs. Medicare also pays for needed personal care supplies (e.g. disposal bed-pads or briefs, cleaning clothes/wipes), durable medical equipment (e.g. a hospital bed, or walker), and medications directly related to the primary hospice diagnosis or for comfort medications such as pain meds.

To qualify for hospice care, a physician is required to certify that a person has a diagnosis with a six month life expectancy. This certainly is not a hard and fast rule, and it has been liberally interpreted to mean that given the individual's clinical diagnosis of a potentially terminal disease, the existence of comorbidities (other conditions or diagnoses), and the person's overall health condition, the physician would not be surprised if the individual were to pass away within six months. If the person were to live past that time, and the physician's clinical, terminal prognosis remains the same, hospice may be continued with the physician recertifying the hospice orders.

While a physician must provide an order for hospice care to begin, the referral to a hospice agency can originate from several different sources including: the physician's office; a hospital, nursing home, a rehabilitation facility discharge planner; or you may choose an agency based on a recommendation from the above sources. Often however, you or your family are presented

a list of Medicare-certified agencies in your area without making a recommendation - so the referring medical professional can't be accused of showing a bias towards any specific agency.

As you'll soon learn, we feel VERY strongly not only about honoring "patient choice" (a current catch-phrase value in healthcare) in the choosing of a hospice agency, but also in making that choice as well-informed and useful to you as possible. It is in nailing these two objectives that this book is about.

What are your care goals now, and for the future?

The first and most important question is to determine what you want for your care now, and in the near future. Too often the hospice decision is made based on a terminal diagnosis, again, a condition or disease with a probable prognosis of six months to live or less.

Once that often frightening diagnosis and prognosis are made, the assumption is often made that hospice care is the only viable alternative. And it may be best, but in choosing hospice, you are essentially saying no to pursuing most curative treatments. This may be exactly what you want, but we've seen too often people placed on hospice without a full understanding of the limitations. Medicare will pay for comfort or palliative care under hospice, or it will pay for cuative-type care - but not both at the same time.

When receiving health care services at home, it is vital that you have a choice in the services that will best fit your care goals. Ideally, you would have someone sit down with you who can clearly describe the strengths and limitations of both Medicare-certified hospice and home health care. That same expert would ask to understand what you want to accomplish, in whatever life-time you have remaining. Do you want to continue to "fight the good fight" - exploring treatment options that might help cure whatever is ailing you? Or, are you ready to seek comfortable hospice approaches that can help you enjoy time remaining with loved ones?

There is no one "best" answer, only ones that help you live the way you choose, on your terms. You are also not stuck with a choice, if you change your mind, or if conditions change. You can opt for hospice now, then switch to home health - or vice versa - at any time.

Choose Your Caregivers First!

> Sometime ago we were called in to work with an elderly woman who was the caregiver to her spouse on hospice and who was dying from a large tumor attached to his carotid artery. The best medical guess was that this tumor would erode the artery causing him to

bleed internally and externally in large amounts. This woman seemed overwhelmed and extremely ill-prepared to deal with this pending catastrophic event.

Knowing that she needed the best possible practitioners to meet this extremely challenging case, we asked her how she chose the hospice agency that would be providing end of life care for her husband. She said she had consulted the telephone book and that the agency she was choosing was the nearest to their home. We asked what she knew about the training and hospice experience of the nurses and aides who would be supporting her and meeting her husband's critical care needs at home. She stated that "they must be good, or our doctor wouldn't have sent them."

This woman and her husband may win in the luck of the draw and get a highly experienced nurse case manager (the primary attending nurse) with abundant hospice experience and a background in critical care nursing to handle this incredibly challenging case. The primary aide assigned might likewise be experienced, have a great working relationship with the nurse case manager, and know what to look for and when to call the nurse when problems arise. The social worker and spiritual advisor (chaplain) may be useful to the patient and family in dealing with the emotional roller coaster they will go through. The hospice physician may also be available 24/7 on the nurse case manager's speed dial should any medications or other treatment modalities need to be ordered.

The likelihood of the above ideal scenario happening with the first agency chosen from a phonebook or online is extremely remote. Like the woman described above, most people assume that their physician wouldn't write orders for hospice care for any but the best (or at least the adequate) hospice providers to be sent into their home. The truth is, without careful due diligence there is no way to know who is entering your home and providing care to you, or your loved one.

Fortunately for this woman and her husband, we were able to step back and evaluate with them the proposed hospice care providers before they proceeded. We found a hospice certified nurse case manager with years of hospice experience, and a substantial background in critical care nursing. The nurse recommended an experienced hospice aide who connected well with the patient and his wife-caregiver, and who worked in tandem with the nurse. The social worker and chaplain assigned to the case were also a good fit, and not only was the hospice physician on the nurse's speed dial, but he also made frequent housecalls to oversee the case and provide direct support to the patient and his wife.

This patient's passing went smoothly, with the appropriate medication provided to keep the patient sedated and pain free, and the anticipated drainage from the ruptured artery was well managed, and the spouse was comforted and well supported.

This is what hospice can be, and should be like every time. The key is choosing the professional personnel first. Typically excellent caregivers work with good “full-service” hospice agencies, and each needs to be evaluated to make certain you are getting the best hospice care and services available. Listed below are checklists for each.

The recommended approach is to contact several hospice agencies in your area using the checklists as a guide. Then arranging to have the nurse case manager (at least), social worker, and primary nurse aide interview with you in your home. While this may seem a bit uncomfortable to you - and unusual for the hospice agency and their personnel - we feel it is a critical step in getting the best possible care and services.

It has amazed us over our 40+ years of work in healthcare how little we consumers of care know about the skills and experience of those practitioners we blithely surrender the often invasive inspection, dissection, and treatment of our most precious possessions (our bodies!) to strangers with a clinical degree or certification hanging on a wall. No right-thinking American would ever surrender their precious automobile to just any mechanic at any price without first getting a recommendation from those we trust. We typically won’t settle for anything but an “honest” mechanic with proven skills.

Checklist for Choosing Hospice Caregivers

- ☐ Nurse Case manager:
  - ☐ What are their credentials and experience?
    _____
  - ☐ Are they hospice certified?
    _____
  - ☐ Do they have a critical care (or significant medical/surgical) background?
    _____
  - ☐ What is their hospice experience?
    _____
- ☐ Hospice Medical Director:
  - ☐ Who is it?
    _____
  - ☐ What is their hospice experience?
    _____
  - ☐ How involved are they in direct patient care, and do they make house calls?
    _____
  - ☐ Are they available to the oncall nurse 24/7?

_____

- ☐ Certified Nurse Aide (CNA):
  - ☐ Will you have a primary certified nurse aide, or multiple?

    _____
  - ☐ What is their experience?

    _____
  - ☐ Does the aide have a good working relationship with the nurse case manager?

    _____
  - ☐ Once you've interviewed the primary aide, do you feel they will work well with you and your primary family caregiver? (Personality compatibility matters - especially in this role!)

    _____
- ☐ Social Worker:
  - ☐ Is the social worker licensed and certified?

    _____
  - ☐ After meeting them, do you feel you could confide in them?

    _____
  - ☐ Do they work with other social workers, or are they primary to your case?

    _____
- ☐ Chaplain/Spiritual Advisor
  - ☐ Do you feel you could benefit from the spiritual support a chaplain may offer, or are you comfortable with your current source of spiritual support (e.g. clergy, spiritual guide, meditation coach)?

    _____
  - ☐ Is the chaplain certified/trained in pastoral care?

    _____
  - ☐ After interviewing them, would you feel comfortable confiding spiritual issues with this person?

    _____

Choosing a Hospice Agency (VS Having One Chosen For You)

Checklist for Choosing a Hospice Agency

- ☐ Recognize that it's your choice.

As described earlier, the typical way patients are assigned a hospice agency is that a physician or a hospital discharge planner will refer their patient to a hospice agency they are familiar with, (or in many cases the agency for which the physician is a paid medical director).

That would be just fine, if every agency was exactly like every other agency, but they are not. Well, they are pretty much all alike in that they must all follow the same federal guidelines for services provided and for meeting minimum standards of care; but they are often wildly different in:

- Whether they are a nonprofit or a for profit agency,
- The types, number, and quality of the services they provide,
- The training and experience of their clinical staff,
- The availability and involvement of their paid medical directors, and
- Multiple other differences.

The most important point here is that the choice is yours! You want the best possible care from the most qualified providers working with the hospice agency that provides the best and most services available to you under the federal hospice benefit.

Questions to ask when choosing an agency:

- ☐ Will you see the same nurses and aides, or do they rotate different staff members through the course of care?

  _____

- ☐ Is the agency for-profit or nonprofit?

  _____

- ☐ What are their Respite (placing the person in a facility to provide the caregiver a break) and General Inpatient Admission (admitting the person into a care facility supervised by registered nurses, typically to treat an acute flareup in a medical condition) policies? Which facilities in the area do they contract with for these advanced care services?

  _____

  _____

- ☐ Do they provide volunteers? How many do they have? How much volunteer services could they reasonably provide if needed/desired?

  _____

  _____

- ☐ Do they offer personal care services? (These are typically privately paid services replacing the need for a family caregiver in the home). If not, do they recommend such an agency?

_____

- ☐ Can they help find placement in residential care (e.g., assisted living or skilled nursing facilities) if the person needs to leave the home?

_____

- ☐ What's the policy/procedure for resolving problems that may arise?

_____

_____

- ☐ How does the hospice agency address:
  - ☐ Personnel conflicts with you or your caregiver,

    _____

    _____
  - ☐ Providing durable medical equipment (e.g. hospital beds, walkers, canes, mechanical lifts, etc.),

    _____
  - ☐ Access to community-related services (e.g. Meals on Wheels)?

    _____
- ☐ What is the philosophy for providing medication for symptom relief and comfort?

_____

_____

The Caregiver

Hospice works best with a dedicated caregiver or caregivers in the home - or readily available and closeby. Typically a family member, the caregiver becomes the quarterback in managing the various aspects of hospice care. She or he is typically involved in choosing the clinical providers and hospice agency who will provide the cares, and keeps any additional family members up to date on your progress.

The caregiver role can be both rewarding and challenging at the same time. Caring for a loved one at the end of life often produces a closeness not previously experienced as the focus shifts to things that matter most - including the process of saying goodbye to family and friends.

But the physical and emotional strains on the caregiver when preparing for the impending death of a loved one can be extremely challenging as well. Over time, this can lead to caregiver burnout, often characterized by deep physical and emotional fatigue. It's important to recognize the signs of impending burnout, and to prevent that from happening. Alternate family or friend caregivers can be arranged to step in and give the primary caregiver needed breaks. When

needed, the hospice agency can move you into a care facility with a nurse available around the clock, allowing the caregiver and her family a chance for a brief respite from care.

A condition known as anticipatory grief is also common among caregivers and family members. This anticipation of the emotional loss associated with the death of someone dear to them can be difficult and even overwhelming. It's important that they have someone to talk to to help them process and work through this challenging time. The hospice agency provides both a social worker skilled in grief counseling and a chaplain available to provide spiritual support. Often, grief support groups are available for those wanting additional help and support.

An additional important service offered by hospice agencies is ongoing grief support following the death of a loved one. This varies according to the emotional and spiritual needs of the caregiver and family members, and typically includes scheduled outreaches and remembrances by the hospice grief counselor, and individual counseling support if needed. This grief support typically continues for up to one year following the death.

Typical caregiving responsibilities in hospice include:

- Providing day-to-day companionship. She becomes your "Girl Friday" coordinating schedules for the hospice staff and assisting you with day-to-day cares. The hospice nurses and aides can provide the training the caregiver may need to succeed in this role.
- Managing your medications. In addition to the routine medications your physician has prescribed for you, comfort-care medications are often prescribed, and these are provided by the hospice agency. The agency nurse will set these up and teach your caregiver how to administer and manage these medications for you. Typically included in these comfort meds are those to control pain, anxiety, or other discomforting symptoms. These can come in pill form, liquid or a patch applied to your skin.
- Working with the hospice agency to troubleshoot and address problems as they arise. The caregiver becomes the eyes and ears for the hospice nurse case manager, reporting any unmet needs, or shortcomings in care. The caregiver becomes the conduit for the hospice agency to make sure that the cares provided are optimized for your benefit.

Plan With the End in Mind

As you plan to embark on this hospice journey, there are several documents you'll want to consider to make sure your wishes are followed. These documents fall under the general umbrella term of Advance Directives and they are designed to clearly communicate your wishes

for end of life treatment and care. Some will be made available to you by the hospice agency, and the rest are pretty easily obtained online.

One great free resource for starting to think this through is the Institute for Health's *Conversation Project*. It is an intuitive, online, step-by-step questionnaire that helps you identify and communicate what's important to you in the cares you will receive as you move forward. It also allows you to identify and choose a health care proxy or advocate - someone to speak for you if you are unable to speak for yourself. Click here for the Conversation Project's Conversation Starter Guide.

The National Hospice and Palliative Care Organization (NHPCO) also offers a guide to the right forms for your state here. A hospice professional will go over this with you in detail to explain the choices and get it just the way you want it.

Conclusion

It's been argued that the federal government doesn't get everything perfectly right all the time…(pause for a smile or smirk). But the Medicare Hospice Benefit is one thing we believe it's gotten right. It's good for the government because it is an extremely cost-effective alternative to more expensive types of medical care. It's good for the individual recipient because it brings a high level of specialized care and service into your home while giving you a voice in how these services are provided. It provides optimal control and personal dignity at the end of life.

We, like many who have made hospice care a passion as well as a profession, find great purpose and meaning in helping people understand hospice, and how to make it work well for them. Feel free to reach out to us at any time if we can help answer questions or guide you through this challenging but incredibly important world of hospice.

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