

WHEN IS IT TIME?

...to consider Hospice Care



Illnesses can seem to come out of nowhere, or they come and stay like uninvited guests. Either way, hearing the words “terminal illness” is never easy, but knowledge may make it less difficult.

As one begins to deal with the challenges and contemplate care options, every person with a life-limiting illness should consider hospice care. For some, “hospice” might evoke fear because it involves the end of life. But when a final journey is at hand, hospice care can be one of the greatest blessings a patient and their loved ones will experience together. The best hospice care will relieve pain, preserve dignity, restore or provide a sense of peace (emotionally and spiritually), give back a sense of control and help with getting one’s affairs in order – allowing patients to focus on a meaningful life during the journey with a life-limiting illness.

Care does not end with a terminal illness. Care changes to a different type that can make all the difference in the world at the end of life, *when a difference is needed most.*

How does one know when it is time for hospice?

This guide is for anyone facing this question, and many other questions that come with it.

1 What is hospice care?

“Hospice” is a word many people have heard but are not very familiar with compared to other kinds of health care. Hospice care is a *medical* specialty that was developed especially for the journey at the end of our lives – with a different goal: maintaining or improving quality of life for people whose illness, disease or condition is unlikely to be cured. It alleviates suffering by focusing on the needs of the total person: not only the physical, but also the emotional and spiritual. Each hospice patient is served by a highly skilled and compassionate team of specialists including physicians, nurses, hospice aides (*certified nurse technicians*), social workers, chaplains (*multifaith spiritual counselors*) and volunteers.

Contrary to a common misperception, not all individuals admitted for hospice care have a cancer

diagnosis. Approximately one-third **are** cancer-related, and other disease diagnoses include neurologic, heart, lung, stroke or coma, kidney, liver, motor neuron, various other diseases and terminal illnesses, and often admission results from a combination of life-limiting conditions.

Sometimes the terms are confusing:

Hospice care is **always** palliative (*pain and symptom management focused on comfort*), but when **only palliative care** is offered, it is **not** hospice care – which also includes comprehensive, compassionate individual **and** family-centered care provided by a highly skilled interdisciplinary team that includes physicians, nurse practitioners, nurses, social workers, chaplains, hospice aides, and volunteers.

2 When does hospice care come into the picture?

Many people are surprised to learn that hospice care can begin **months** before the end of life comes, they are **entitled** to receive this specialized care when certified as eligible. People with a life-limiting diagnosis (*or multiple diagnoses*) who are rendered terminally ill are eligible for hospice care, and physician(s) must certify this status according to condition-specific eligibility guidelines.

When to elect hospice care is a very personal decision based on an individual's values and can be made when they are emotionally ready. Ideally,

the election occurs as a fully-informed decision with a physician that curative measures are no longer likely to be effective, or are no longer desired.

Hospice care is not only for the last weeks or days of life. There is no reason a person should not be given the benefits of hospice care for the maximum time possible. There is no time limit, as long as eligibility guidelines are evaluated periodically and the person remains eligible.

3 How do I know we have done everything we could to beat this illness?

This is one of the most difficult questions for many, many people. It is natural to want to know they've done everything that could be done; that no option was left unexplored; that there was not something more that could have made all the difference.

Conversations with one's physician are vital to the decision-making process, and an open, frank discussion can be helpful. Physicians are highly skilled at knowing how illnesses change over time and how effective a treatment will be given an individual's condition. One of the factors a physician will take into account is the benefit (*given a terminal illness diagnosis*) vs. the burden of treatments. While curative treatments are meant to extend life, in many cases, continued treatments may instead prolong

suffering once the illness reaches a certain point. Patients and their loved ones may want to ask questions about the consequences of treatment (*intended or unintended*), the alleviation of pain and discomfort (*such as shortness of breath and agitation*), and how treatments will affect the ability to live independently. At some point, the burden of treatments can outweigh the benefit and can result in poor *quality* of life for the remaining *quantity* of life.

A patient's care is a physician's highest priority. Sometimes, what is best for an individual may be measures that may extend life for a time. And sometimes, what is best is care that offers the best quality of life when a cure is no longer an option. The key is talking through the options together, defining one's goals of care and deciding on the best course of action based on those goals and personal values.

4 Does it mean I am giving up if I choose hospice?

The journey of life is filled with many paths, and as human beings, we are planners. If something happens, we want to know what comes next. A terminal prognosis is never easy to accept, and what follows this diagnosis is for each person and their loved ones to decide. Choosing hospice care does not mean giving up hope. **Hospice care gives hope – a different kind of hope.**

Hospice gives hope for:

- Quality of life even in the last months and weeks of life – with all of the physical and emotional comfort and support needed for the time remaining.
- The comfort of knowing a team is there with specialized training and expertise to help any time of the day or night to relieve pain, and help restore or provide a sense of peace – emotionally and spiritually.
- Upholding a sense of personal control while preserving dignity. This sacred time of a life nearing its end is a natural process, and the multifaceted considerations about how that time is spent are each person's to make.
- Support for individuals *and* their loved ones to help them cope emotionally and spiritually, within the beliefs of *their own* faith and culture. Hospice considers both the person who is ill and their caregiver(s) to be “the patient.” This extra help can mean one gains meaningful moments with family and friends.
- The best chance at living fully and meaningfully during the end-of-life journey, making the time remaining the best it can possibly be.

5 What do I do now?

The best way to make an important decision is with plenty of clear information. A conversation with a physician may be helpful.

Sometimes, conversations are most productive when they're not occurring in the midst of a crisis. Asking questions as soon as one is ready is a very helpful step.

Loved ones may also be fearful and stressed, so it can help considerably to include them in the discussions as early as possible. **In fact, the most frequent comment from patients and families is that they wish they had experienced hospice care earlier in the illness.** One should also consider personal religious and/or cultural beliefs, and support system(s) or lack thereof.

Every adult is well advised to utilize **Advance Care Directives** to establish personal preferences for end-of-life care. Doing so provides peace of mind and is one of the greatest **gifts** that can be given to loved ones. Studies show that when loved ones are willing to talk to each other and medical providers about quality of life, care options and individual preferences, people are more likely to have a peaceful death and family members are less likely to suffer from prolonged grief and depression. Conversations about death and dying can be difficult... Beginning to think about one's values and what is most important is extremely beneficial.

For more information, visit thegiftinitiative.org.

Polls have revealed that 9 in 10 adults would prefer to die in their homes, free of pain, surrounded by family and loved ones.

Hospice works to make this happen. All individuals deserve quality care at the end of life – it is a fundamental part of living. Hospice care is the model of high-quality, compassionate care that helps people and families live as fully as possible, and provides the care Americans have said they want.

Want more information?

Have a conversation with your doctor and your loved ones, and Alive Hospice welcomes your call at any time 24/7. We will provide information and help you to make an informed decision.

About Alive Hospice

Founded over 40 years ago in 1975, Alive Hospice is Middle Tennessee's oldest and largest hospice care provider, and offers the most comprehensive care for terminally ill patients and their families in the region. We are here to answer questions and serve as a resource for patients and their loved ones, health care professionals, and the community at large.

Alive Hospice's Mission

We provide loving care to people with life-threatening illnesses, support to their families, and service to the community in a spirit of enriching lives.

Alive Hospice is a 501(c)(3) charitable nonprofit health care provider licensed in the following counties: Bedford, Cannon, Cheatham, Coffee, Davidson, DeKalb, Dickson, Robertson, Rutherford, Sumner, Williamson, Wilson.

Alive Hospice is accredited by the Joint Commission and holds its Gold Seal of Approval. Additionally, Alive Hospice is accredited by the National Institute For Jewish Hospice. Alive Hospice is a Level 4 partner of the We Honor Veterans program in collaboration with the National Hospice and Palliative Care Organization and the U.S. Department of Veterans Affairs.



Make the best of every day
you are given

Choose Alive Hospice

We welcome your call at any time – 24 hours
a day, 7 days a week

For more information, visit

AliveHospice.org or call 615-327-1085

TheGiftInitiative.org for Advance Care Planning

*(All the Advance Care Planning documents you need
in a packet which is downloadable)*

Other brochures available include:

- *10 Things That May Surprise You About Hospice Care*
- *How Do I Choose a Hospice Care Provider?*
- *Is there such a thing as "a good death"?*
HOSPICE CARE 101: Who and Where

CONTACT US

Alive Hospice Offices

Main Office:

1718 Patterson St., Nashville, TN 37203

Main Phone (24/7): 615.327.1085

For admission information or Physician referrals:
615.250.1348

Other Field Offices:

Madison

Murfreesboro

Dedicated Hospice Facilities

Nashville Residence (30 beds)

1710 Patterson St., Nashville | 615-963-4800

TriStar Skyline Madison (15 beds)

500 Hospital Dr., 2nd Fl, Madison | 615-860-6407

(New Residence Coming Soon to Murfreesboro)

Note: Over 90% of Alive Hospice's care is provided in private homes.

Alive Hospice Grief Support

Alive Hospice Griefline: 615.963.4732

Grief support available at our Nashville, Madison and Murfreesboro Offices.

Youth Grief Camps in La Vergne, Murfreesboro, and White Bluff

alivehospice.org

