



How to Work with Hospice (and Palliative Care)

Hospice and Palliative Care are both services designed to make end of life conditions as comfortable and meaningful as possible for both the patient and loved ones. The difference between them is in time of service and extended scope of service.

Hospice requires a Physician's expectation that death will occur within a 6-month period.

Palliative Care is adopted when a person's condition is considered terminal but not immediate.

Both services focus on comfort and care, not on healing and rehabilitation. This difference is critically important for families to understand. When it is medically determined that an illness, injury or condition has reached a point where returning to a healthy quality of life appears to be an unrealistic goal, the focus of care needs to shift from trying to force restorative care to helping to provide the best quality and comfort in care possible – whether that is for Hospice (with a life expectancy of 6 months or less) or Palliative Care (usually a longer period of care).

Knowing what to expect and what questions to have answered can help the experience of care be more complete and satisfying to everyone. Here are a few questions to consider:

Will someone always be there? Many people are afraid of dying alone – or of allowing their loved one to die alone. They worry that their loved one might pass while they are at work or even during a quick trip to the store to get more milk. They can become too afraid to leave the house. Ask your provider if they have a plan to make sure your loved one is never left alone. If they do not, ask them to help you develop one.

What services are offered? Hospice workers can do more than provide pain medication and help with feeding and bathing. They can actually provide many types of therapeutic care that can ease physical pain and help soothe a patient mentally and emotionally. Music therapy is a popular choice for many families, as is massage therapy. Most Hospice providers have volunteer programs to help provide visits and other services. Be specific and ask what is available and how to schedule that help.

Ask what therapeutic care (medically related care) they can provide. Emergency room visits, aggressive medical treatments and efforts to “cure” are not part of the services you can expect. Be clear on understanding what is available and appropriate.

Ask what assistance with the activities of daily living (ADL) care is available. [bathing, dressing, wound care, medication management, oxygen etc.] Ask how often these services will be provided.

Ask how to access care support – by telephone, by text, by email and which is available 24/7.

Ask about religious or spiritual care services. Every Hospice has a Chaplaincy program and works to meet the spiritual needs of every faith for both the patient and family. Ask how often a Chaplain will visit.

Ask about the medical oversight plan. How often will a Doctor or Registered Nurse visit? What Physicians are involved. Who do you call if you have a concern about the medical care?

Ask what happens when death occurs? Who to call? What information is needed? What happens to the body? There are excellent resources to help you understand the actual dying process.

Ask about support services following a death. Most Hospice agencies provide Spiritual and practical support to help with the grieving process. Some even hold annual memorial events to honor your loved one and provide you a meaningful way to move from grieving into remembrance.

As always, if you need help arranging for care, working with coordinating Hospice or Palliative Care and managing the many legal, financial and household affairs accompanying caring for someone who is facing Hospice or Palliative Care or coordinating any level of care someone may need, contact us at The Caregiver Foundation at 808-625-3782 or email info@thecaregiverfoundation.org

Our thanks to American Hospice and Palliative Care of Phoenix (<https://americarehospice.org/>) Kokuia Mau of Hawai'i (<https://kokuia.org/>) and Pacific Health Ministry of Hawaii (<https://www.phmhawaii.org>) for their help in preparing this article.

The Caregiver Foundation's How-To series is designed to provide you with tools and tips for caregiving. External authorship is cited where known. Neither the authors nor TCF is engaged in providing medical, legal, or financial advice. You should always check with your own professionals before taking action on any ideas presented in this series.