



Hospice Care: A Personal Journey for Adults & Families

A conversation with Parmenter Community Health Care

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1. What is hospice care?

People have been doing hospice care before it was called ‘Hospice’. It is family, friends and the extended community taking care of a person at the last phase of life. Hospice care is for adults and children with a life-limiting illness where their doctors have determined the adult has a lifespan of 6 months or less.

Hospice is a philosophy of care where the person’s care goals change from curative treatment to pain and symptom management to keep them comfortable.

2. How does hospice care help adults and their family members?

Hospice helps adults with advanced illness transition through to the end of life, and live each day to the fullest. For instance, a woman came to us wanting to plan and manage her own hospice care, but had not yet told her family ‘as not to burden them’. In talking about services, we asked if she had considered that her family would want to be on this journey with her. She was happy to learn that hospice care is both helping adults to direct their own care, and helping family members understand and support the process. It can help families make decisions together, instead of the individual or family going through this alone.

3. Why is the statement “*I wish I started hospice sooner*”, commonly heard from adults & families?

We frequently hear that comment and what adults and families are often saying is, “I wish I understood all that hospice care had to offer sooner.” Hospice is not just one definition, but a physical, emotional, social, and spiritual empowering of adults to live as they want and as fully as they can. A team of professions- nurses, doctors, social workers, clergy, and bereavement counselors for adults and children- work together to offer comprehensive services. We care for people where they are; whether at home, in a hospital or care facility and work closely with their health care teams and families to deliver services.

4. When should you start to consider hospice care?

Hospice care is both a choice and a medical benefit. You can choose to access the benefit for 6 months if eligible. The hospice team can help adults to understand the eligibility requirement, the range of services, the cost, and talk with adults and families to see if they are emotionally ready to start hospice care. If you are not yet eligible or not ready, we offer a Bridge Program. This is for someone who has a terminal diagnosis, but perhaps is continuing to seek curative treatment or perhaps is not yet emotionally ready to choose hospice. We optimize the expertise of the hospice team, even while on Bridge (home care services) unit a time they wish to initiate hospice care.



5. When asked, most people will say they want to die at home. Tell us about that experience.

We often hear adults express that wish for themselves or when trying to honor the wishes of a parent or grandparent. For most of us the ideal is to die in a comfortable place like home, not in pain, surrounded by family, and to slip away peacefully. The reality of dying at home is often more complex for terminally ill patients. The hospice team can give you the best possible picture of what the experience of your body shutting down, or watching a loved one go through that process, might look like and the help that may be needed to make a person as comfortable as possible to die with dignity. Our hospice team tries to be present at the very end to help with that transition. We talk openly with families about when a home environment may not be adequate to realize the goal of dying in comfort and with dignity, and explore other options like a hospice residence or another appropriate facility.

6. How can hospice help you cope with the multiple stages within the last phase of life?

Adults may start this phase relatively stable, and then their health may take a downward turn followed by a plateau, and continue in this fashion. It's an active process where the hospice team is constantly evaluating and providing information so adults and families can make informed choices about their care. We find it helps to offer information in 'nuggets'. Everyone is different in defining their nugget. For instance, when one gentleman was close to the end of his life, his wife asked only to know information relevant for the next 24-48 hours so she could stay emotionally present with her husband knowing his medical needs were being taken care of. His adult children however, asked to talk through all the details both from a medical and an emotional perspective to know they were doing everything possible for their father. Either way, the hospice team can help support each person accordingly.

7. What is the difference between receiving hospice care at home or in a hospice residence?

Hospice care offers compassionate care through the challenges of advanced illness. The hospice team can provide care to patients in their home wherever they reside, or in a hospice residence. The hospice team will help families evaluate what is best for the patient and the caregiver. They help families weigh the medical needs, as well as the physical and emotional cost of being the caregiver with in-home hospice, and/or moving to a residence and letting other people manage the medical and physical needs of the patient allowing the family time with their loved one. At Parmenter we can support either choice. Families have often remarked that our residence is not a facility- "it is home". Residents create their own daily schedule, and family and friends can be found baking cookies in our community kitchen. An unexpected benefit is that a hospice residence creates a community of families who support each other.

8. Parmenter has a long standing commitment to the Metrowest Boston community. What have you learned overtime from your patients and their families?

We've learned that this is personal journey for adults and families. We try to meet people where they are and bridge services to connect them to what they need to live as they want, and as fully as they can. We ensure the individual's voice is heard, and that family members are receiving the social, emotional and spiritual support they need. Read more about Parmenter Community Health Care, www.parmenter.org