

“You matter because you are you, and you matter to the end of your life.”

Most people today have heard of hospice and have a basic idea of what it is and who it serves. Confusion, however, exists as to when to call hospice. All too often, calls are made at a point when family caregivers are exhausted beyond belief and when their loved one has a very short time left to live. Niagara Hospice, like hospices across the country, report that many patients come into the program with only a week, a few days or even less to live. While loving, expert care and support is provided to every hospice patient and family, staff know that there is so much more they could do when calls come earlier.

The hallmark of hospice care is an emphasis on quality of life. The hospice team of doctors, nurses, social workers, therapists, pharmacists, spiritual care counselors, aides and volunteers work in concert to achieve as much quality as possible given the circumstances. Each patient and family receives an individualized plan of care that best suits their specific needs. Every effort is made to control the patient's pain and other symptoms be they of a physical, emotional or spiritual nature. Attention focusing on caregivers is designed to ease stress as much as possible. This may include, but rarely be limited to, education and strategies to lighten caregiver strain, opportunities for respite, a listening ear and/or a shoulder on which to cry. When caregivers are less harried, it often has the benefit of reducing some of the worry and guilt patients may be experiencing.

Once patient symptoms are controlled and caregiver stressors lessened, there is opportunity to again experience some of the things that bring enjoyment, that achieve a sense of quality and thus allow individuals to truly live until they die. Living the last of life with quality while under hospice care occurs in any number ways. A few that I've observed over the years include: being able to travel to a sister's new home in another state, experiencing a sense of awe while watching glorious sunsets, fussing over the roses growing in the backyard, laughing while reminiscing with good friends, being emotionally moved by exquisitely beautiful music, continuing to feel valued by helping a granddaughter select her prom dress, feeling needed by an adult son seeking advice on parenting teenagers, attending weekly coffee gatherings with fellow retirees, enjoying the spa at hospice house at two in the morning. One of my favorite examples, though, comes from a hospice patient with whom I volunteered to play cards and board games. One day in the heat of a particularly close game, she suddenly exclaimed, "I'm having fun! I'm having fun!" Prior to being on hospice care, she had all but given up on being able to still experience enjoyment.

Having been involved in the early hospice movement, I vividly recall when there was little, if any, specialized, compassionate care for dying persons and their family members. My heart still aches for my aunt and for a friend who spent the last of their lives in physical and emotional agony. They and their families felt abandoned by the health care system having been told there was no hope, there was nothing more to be done.

Hospice does not cure but it does offer hope that one's life continues to have meaning and value throughout those last days, that quality of life is still possible. There is always more that can be done. As Cicely Saunders, MD and founder of the modern day hospice movement said, "You matter because you are you, and you matter to the end of your life. We will not only help you to die peacefully but to live until you die."

If you or someone you know is uncertain as to whether or when to call hospice, I encourage a call to Niagara Hospice at (716) 439-4417 or 716-HOSPICE. The staff will answer your questions and help you determine the best course to take. You won't be sorry. Calling sooner rather than later can make the difference to living with quality during the last of life.

Patricia L. Evans

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