

Frontline

This newsletter is dedicated to professional caregivers. It is our hope that this newsletter will help you give comfort and strength to those you serve.

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Confusing Terms of Grief



By Dr. Earl A. Grollman

What is hospice? What is palliative care?
How are they similar? How do they differ?

The hospice movement was started by Cicely Saunders, a nurse, social worker and physician who founded St. Christopher's Hospice in London in 1969, a shelter for the dying. Saunders approach focused on comfort and quality support for the dying patient, as well as comfort and support for family and caregivers.

St. Christopher's is based on the following principles:

- The goal: to improve the quality of life, not the quantity of years.
- Holistic care, focusing on the patient, not solely on the disease.
- Relies not only on professionals, but dedicated volunteers as well.

Saunders (soon conferred as dame), eloquently captured the mission of the hospice movement when she said, "You matter to the last moment of life, and we will do all we can do to not only help you die peacefully, but to live until you die."

Today, hospice comes in many forms. Some are home-based; others are located in a "hospice home," which provides support to terminally-ill patients in a comfortable home-like setting. Some are also based in separate units in hospitals. Some hospices are for profit; some are non-profit. Some are religious based; most are not. Some are created for a designated kind of illness.

Eligibility for hospice care is based upon two government-determined criteria:

- The patient's condition has been diagnosed as incurable.
- Life expectancy is approximately six months or less. However, hospice care does not "cut off" at the end of the initial six-month

period. Benefits continue as long as the hospice physician continues to certify a six-month life expectancy and the patient wishes to continue hospice care.

Typically, the hospice team is comprised of doctors, nurses, home health aides, social workers, chaplains, counsellors and trained volunteers. Volunteerism has been a vital part of hospice from its inception. Hospice volunteers may:

- Visit patients and serve as a companion to the dying. By holding their hand, reading to them – just by being there, volunteers offer comfort during a great time of need.
- Provide respite for family members who need time to refuel. This might involve some shopping, childcare or delivering a hot meal.
- Facilitate grief support groups. By listening and sharing, they offer hope to families in their time of need, demonstrating that there can be a meaningful life after the death of a loved one.
- Assist with administrative tasks such as answering telephone calls, preparing mailings or helping with fundraising efforts.
- Contribute special talents, whether it is knitting blankets for patients, being the handyman or upgrading computer systems.

After the death of a loved one, the bereaved often become volunteers at their local hospice. By giving back, and helping other patients and mourners, the bereaved become better able to cope with their own tragic losses. In the words of Mary Anne Radmacher, "As we work to create light for others, we naturally light our own way."

While volunteers give back in different ways, they all share something in common: they all say that they get more than they give. As one volunteer so stated, “By volunteering for hospice, I learn what’s important in life. I learn how to live in the moment. I learn to appreciate the blessings that I have. My life has gained new meaning through giving.”

While hospice has provided millions of terminally-ill patients and their families with relief from physical, emotional and spiritual suffering, the model does not fit every medical need.

Palliative Care

Recognizing a gap in services, Dr. Balfour Mount of the Royal Victoria Hospital of Montreal introduced the concept of “palliative care.” The word “palliative” is derived from Latin *palliare*, “to cloak.” Palliative care, like hospice care, offers a holistic approach to “cloak” patients with serious illness, helping them to find relief from painful symptoms and stress.

So how is hospice different than palliative care?

Here is a quiz to test your knowledge: which of these two people should receive palliative care?

- Case A: A 90-year-old man with advanced pancreatic cancer. His doctors believe he has three months to live.
- Case B: A 42-year-old woman with muscular dystrophy (a disease that causes progressive weakness and degradation of muscles) whose condition has worsened. She experiences considerable pain and has some difficulty walking. Despite these obstacles, she is still able to work while raising a family.

Most people would say, case A. But this was a trick question. Both cases should receive palliative care. With case A, hospice is one form of palliative care available to patients during the last stages of a terminal illness. Case B presents an individual with a chronic condition that gradually causes irreversible muscular deterioration that may endure for months or years. However, the individual is currently functional and strives to lead a more normal and purposeful life.

Palliative care is appropriate at any age and at any stage of a serious illness. A specially-trained team of doctors, nurses, social workers and other specialists work together to provide an extra layer of support while patients receive treatment. For example, the team can help patients and their families make informed decisions about different treatments.

How Are Hospice Care and Palliative Care Different?

Timing

Hospice care is provided for patients with a life expectancy that is approximately six months or less. Palliative care intends neither to hasten nor to postpone death.

Location

Hospice care usually is administered in the patient’s home or other designated facilities. Palliative care frequently takes place where the patient first received treatment, most often in a hospital or a facility associated with a palliative-care team.

How Are Hospice Care and Palliative Care Similar?

The goals of both hospice care and palliative care are the same: to help patients live life as fully as possible by:

- Integrating the patient’s medical, psychological and spiritual needs.
- Providing relief from pain and other distressing symptoms.
- Helping patients find meaning in their lives, and live life as fully as possible, even when they’re hurting.

One hospice and palliative care nurse at Mt. Auburn Hospital from Cambridge, MA, Lissa Rockwood, described how her mother paved the way for her own career and passion. At the age of 79, her mother was diagnosed with a rare intestinal cancer. After having major surgery, she was able to resume her usual active life. However, at the age of 84, her cancer reoccurred. Thus began an aggressive path of treatment, including radiation and weekly chemo. When the first chemo was ineffective, they tried another. The one time the family asked if this disease was terminal the oncologist’s reply was, “We don’t use that word here.” While Rockwood’s mother suffered painful side-effects and her health continued to decline, no one ever asked her what she wanted or told her what her options were.

Rockwood says, “Now every time I am with a patient and their family, I try to set a stage where I can ask them what they want should their lifespan look shortened.” They not only discuss medical treatments, but also living arrangements, end-of-life options and last wishes.

Her motivation for providing good end-of-life care comes from Dr. Atul Gawande’s quote, “We need to ask people what their priorities are ... if we don’t ask, our care isn’t aligned with what matters most to them and there is suffering. But when we ask, it’s extraordinary.”

Whether it’s palliative care or hospice care, there is a common denominator, involving the patient and their families in how they want to live and how they wish to die.

NOTE: To learn more about hospice care and palliative care, contact: <https://www.nhpco.org/>.

About the Author

Dr. Earl A. Grollman, a pioneer in crisis management, is an acclaimed writer and lecturer. In 2013, the Association for Death Education and Counseling presented him with its Lifetime Achievement Award, only the fourth time in three decades. This award honours “his national and international impact on the improvement of death education, caring for the dying person, and grief counseling.” His books on coping with bereavement have sold more than a million copies. For further information, visit www.beacon.org/grollman.

Embrace the Uniqueness of Your Grief



By Alan D. Wolfelt, Ph.D.

In life, everyone grieves. But grief journeys are never the same. Despite what you may hear, you will do the “work of mourning” in your own special way. Be careful about comparing your experience with that of other people. Do not adopt assumptions about how long your grief should last. Just consider taking a “one-day-at-a-time” approach. Doing so allows you to mourn at your own pace.

I invite you to explore some of the unique reasons your grief is what it is – the “whys” of your journey through the wilderness.

Why #1: Your relationship with the person who died

Your relationship with the person who died was different than that person’s relationship with anyone else. For example, you may have been extremely close as well as husband or wife. Perhaps you loved the person who died, but you had frequent disagreements. Or maybe you were separated by physical distance, so you weren’t as close as you would have liked.

The stronger your attachment to the person who died, the more difficult the grief journey. Ambivalent relationships can also be particularly hard to process after a death. You may feel a strong sense of “unfinished business” – things you wanted to say but never did; conflicts you wanted to resolve but didn’t.

Why #2: The circumstances of the death

How, why and when the person died can have a definite impact on your journey into grief. For example, was the death sudden or anticipated? How old was the person who died? Do you feel you might have been able to prevent the death?

A sudden, unexpected death does not allow opportunity to prepare. But are you ever ready? After a death due to terminal illness, people often tell me they were still, in a sense, shocked by the death.

The age of the person who died also affects your acceptance of the death. We usually anticipate that parents will die before their children. When a child dies, the order of the world is turned

upside down. Or your grief might be heightened when a “middle-aged” person dies in the “prime of life.”

You may also be asking yourself if you could have done anything to prevent the death. This is natural, even if it lacks logic.

Why #3: The ritual or funeral experience

Decisions you make relating to the funeral can either help or hinder your personal grief experience. There is no single, right way to have a funeral. We do know, however, that creating a meaningful ritual for survivors can aid in social, emotional and spiritual healing after a death.

The funeral is a time and a place to express your feelings about the death, thus legitimizing them. The funeral also can serve as a time to honour the person who has died, bring you closer to others who can give support, affirm that life goes on, and give you a context of meaning that is in keeping with your own religious, spiritual or philosophical background.

Why #4: The people in your life

Mourning requires the outside support of other human beings in order to heal. Without a support system, the odds are that you will have difficulty in doing this work of mourning. Healing requires an environment of empathy, caring and gentle encouragement.

Sometimes people may think that you have a support system when, in fact, you don’t. For example, you may have family members or friends who live near you, but they have little compassion or patience for you and your grief. If so, a vital ingredient to healing is missing.

Why #5: Your unique personality

Whatever your unique personality, it will be reflected in your grief. For example, if you are quiet by nature, you may express your grief quietly. If you are outgoing, you may be more expressive with your grief.

Why #6: The unique personality of the person who died

Just as your own personality is reflected in your grief journey, so, too, is the unique personality of the person who died. Personality is the sum total of all the characteristics that made this person unique. The way she talked, the way he smiled, the way she ate her food – all these and so many more little things go into creating personality. It's no wonder there's so much to miss when all these little things are gone at once.

Why #7: Your gender

Your gender may not only influence your grief, but also the ways in which others relate to you at this time. While not always true, men are often encouraged to “be strong.” Typically, men have more difficulty in allowing themselves to move toward painful feelings and often resist accepting outside support. In contrast, women sometimes have a hard time expressing feelings of anger.

We must be careful about generalizations, however. Sometimes too much is made of the differences between genders and not enough is made of the essence of the capacity to grieve and mourn.

Why #8: Your cultural background

Your cultural background is an important part of how you experience and express your grief. When I say culture, I mean the values, rules (spoken and unspoken) and traditions that guide you and your family. Often these have been handed down generation after generation and are shaped by the areas of the world your family originally came from. Your cultural background is also shaped by education and political beliefs.

Why #9: Your religious or spiritual background

Your personal belief system can have a tremendous impact on your journey into grief. You may discover that your religious or spiritual life is deepened, renewed or changed as a result of your loss. Or you may find yourself questioning your beliefs as part of your work of mourning.

Why #10: Other crises or stresses in your life

What else is going on in your life? Although we often think it shouldn't, the world does keep turning after a death. You may still have to work and manage finances. Other people in your life may be sick or in need of help. You may have children or elderly parents to care for.

Whatever your situation, take steps to de-stress your life for the time being. Now is the time to concentrate on mourning and healing.

Why #11: Your experiences with loss and death in the past

You are the sum total of all you have experienced in your life so far. Before this death, you may have had other significant losses. The more “experienced” you are with death, the less shocked you may feel this time around. Often people find that the more deaths they mourn, the more natural the cycle of life seems to them. This is not to say they aren't sad and don't need to mourn, but they do begin to integrate death and loss more seamlessly into living.

Why #12: Your physical health

How you feel physically has a significant effect on your grief. If you are tired and eating poorly, your coping skills will be diminished. If you are sick, your bodily symptoms may be more pressing than your emotional and spiritual ones.

For more information, visit centerforloss.com.

About the Author

Dr. Alan D. Wolfelt is a noted author, educator and grief counsellor. He serves as director of the Center for Loss and Life Transition in Fort Collins, Colorado and presents many grief-related workshops each year across North America. Among his newest publications are the books *The Depression of Grief* and *Finding the Words: How to Talk with Children and Teens about Death*. For more information, write or call the Center for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins, Colorado 80526, (970) 226-6050 or visit www.centerforloss.com.



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It is our hope that the information provided within this newsletter will assist you in working with families at a time of death. Your professionalism and understanding are so important to a family that has just experienced a loss.