

HEAL Project



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Community Outreach Program in Education (COPE) Series

A Case in Point:

Christine Longaker, author of Facing Death & Finding Hope, became a caregiver in 1976 when her husband, Lyttle, was diagnosed with acute leukemia at the age of 24. After trying for a year to cure the illness, he died. Her life after caregiving created a new hospice program in Santa Cruz, CA.

In the summer of Lyttle's 25th year of life, he was not feeling well and was diagnosed with acute lymphocytic leukemia. The disease had infiltrated his brain and sexual organs, two places where chemotherapy would have no effect. The year that ensued was very difficult for them. They soon learned that it was best to seize the moment, acknowledge with honesty what was happening, no matter how difficult, and to speak clearly from their hearts.

She remained at his side until he died. Her caregiving experience, bearing witness to his death and the 2-year bereavement period that followed, all profoundly affected the direction of her life. She said that the most invaluable gift which came from Lyttle's suffering and death was that she could now help families understand how they could best use the time when a person is dying, and thereby alleviate much of the unnecessary suffering of dying and death.

She further states that volunteering to work with those who are ill, suffering, or dying as either professional or lay caregivers can help us to know ourselves better, to speak the truth with kindness, and to uncover our own wholeness, or "holiness."

Case study adapted from:
Facing Death & Finding Hope
by Christine Longaker

Caring for a Terminally-Ill Loved One: Life After Caregiving



This is the final issue in *Series I*, the first of the *COPE InfoLetter* series. It is a natural response for friends or family members to assume the responsibility for care of their dying loved ones, yet many do so without knowledge of what such a journey entails. We hope that this series has given you some insight into that journey so that your loved one's death experience may be better than it would have been otherwise. It has been our goal to provide the public with an educational resource relating to compassionate caregiving for the dying that was to the point and easy to understand. Feedback from our readers indicates that we have accomplished that goal. We will begin publishing *Series II* very soon. Visit our website for details.

Continuing Life as a Caregiver for Others - this issue discusses how some caregivers find that they would like to serve others as a volunteer after their loved one has died. While caregiving for a terminally ill family member or a friend can be emotionally draining, it can also be a very fulfilling and life-changing experience. Many hospice volunteer caregivers have chosen to become volunteers because caring for the dying has taught them how to be more present in their own lives, to be more appreciative of what life has to offer and to live more fully. This is counter-intuitive to most who have not had the experience. Death is a profound teacher that reaches the deepest places within us.

Empathy Transforms Altruism into Caregiving – our essential nature is to have concern for the welfare of others but it is our empathy that transforms this altruism into compassionate action. Empathically serving others requires an openness or a presence that does not judge. Hospice volunteers have the benefit of not knowing beforehand the "baggage" that dying people have accumulated through life and are carrying with them. This gives volunteers an opportunity to serve with an empathic presence that is not impeded by a judgmental barrier, which can prevent a volunteer from being fully present with the dying person.

Grieve First then Become a Volunteer Caregiver – the grief of a bereaved individual manifests itself in many ways and this should be considered before someone who has had a recent loss decides to become a hospice caregiving volunteer. The heightened emotions from the loss can be the primary impetus for making the choice to become a volunteer. While such an inspiration seems innocuous, the bereaved individual's grieving process can be complicated by their involvement as a caregiver for another person who is dying. It also can interfere with the person's ability to be fully present with the dying person they are supporting. The conventional wisdom is to wait at least one year after your loss before considering becoming a hospice caregiving volunteer.

Series II starts in 2005 – The next series we plan to begin publishing in early 2005 is *Caring for a Child with a Life Threatening Illness and Keeping the Family Together*. Families that are caring for a dying child face formidable emotional, psychological and spiritual challenges. This series will focus on the family's journey and how the stress of these challenges can be minimized.

Your joy is your sorrow unmasked. And the selfsame well
from which your laughter rises was oftentimes filled with your tears.
Kahlil Gibran, The Prophet