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HEAL Project

Community Outreach Program in Education (COPE) Series

A Case in Point:

This case illustrates a situation that is difficult not because physical, emotional, and spiritual caring were neglected but because the patient's personal characteristics and values were not responsive to this caring. The point is not to blame patients or caregivers but to caution against regarding what appear to be unfortunate outcomes as necessarily the result of failures in care.

Andrew Lindts was a 45-year-old business executive who suddenly noticed some weakness in his left leg and intermittent fatigue. A hard-driving personality, he ignored these symptoms. He was diagnosed with a high-grade, malignant brain tumor with a likely prognosis of less than one year.

Mr. Lindts appeared to accept his diagnosis not as a fatal illness but as a problem that he could overcome, just as he had overcome a variety of business setbacks. Despite cautions by specialists, he demanded the most aggressive curative therapies. He brushed off the physicians and friends who compassionately and sensitively tried to help him understand his medical situation and prognosis. As his symptoms worsened, he became increasingly depressed and wondered whether religion might help. Drawing on his status and connections, he talked with several prominent religious leaders and was baptized.

Mr. Lindts lost consciousness and died, with his family present, 11 months after the diagnosis. Family and friends were relieved but felt guilty about his reaction to the whole process.

It is important to realize that people approach death along many different paths. Despite our best intentions to assist and guide them, they will die in their own way. As a caregiver you need only let your heart guide you and then know that your loved one will be eternally grateful for your kindness, love and compassion.

Case Study adapted from
Approaching Death –
Improving Care at the End of Life

Caring for a Terminally-Ill Loved One:

Comfort Management

The ***National Hospice Organization*** identified a distinct set of needs for people who are dying: 1) to be free from pain; 2) to retain feelings of self-worth and dignity; 3) to receive love and affection. In a recent study on improving end-of-life care, the ***Institute of Medicine*** found that too many dying people were suffering from pain and other distresses that could have been prevented or relieved with existing knowledge and therapies.

Managing physical pain – a new field of medicine has grown out of the hospice movement called ***Palliative Care (PC)***. Great strides have been made in this field, which focuses on treatment that will enhance the comfort and improve the quality of life of the dying person. PC strives to control the physical pain of the dying person as opposed to treating the underlying disease. This is an important distinction that places the comfort of the dying person as the primary consideration for treatment.

In the hospice environment pain medications are most commonly taken orally in a pill or liquid form. Those who have trouble swallowing can be given medications rectally. Another effective alternative for those unable to swallow is the *transdermal* patch. The patch is placed on the chest or back where it transfers the medication through the skin.

Psychological and social considerations – it is important for the caregiver to understand that *comfort management*, in the broadest sense of the term, includes physical, psychological, social and spiritual considerations. This perspective reflects the reality that there are many other sources of human pain besides the physical. There is an explicit need to care for the dying person as a living person.

The psychological needs generally focus around feeling secure, maintaining a sense of autonomy and the desire to continue to experience life. These needs are satisfied by assuring them that you will be there for them, by allowing them some degree of decision-making participation and by providing ways to retain their personal dignity in the process.

The social needs involve sustaining key personal & family relationships while at the same time facing the impending loss of those relationships. The caregiver needs to be aware that their loved one may seek closure on many of these key relationships in an effort to close the circle of communication to a select few they desire to be with them until the end. Unwillingness of others to face your loved one's death can complicate this process. Hospice staff members can be used to assist you in resolving such issues.

Spiritual considerations – satisfying spiritual needs revolves around identifying, developing, or reaffirming sources of spiritual energy that can encourage faith or hope in the dying person. It is not a time to convert them to a new faith. More importantly it is a time to affirm where their faith lies…more on this topic in a subsequent issue.

The need for comfort by the dying is not that much different from the living. Perhaps the most significant difference between the two perspectives is that the dying are looking back, trying to make sense of it all while the living are looking forward wondering what life has in store for them. This realization can help us to more adequately understand the needs of the dying while acting as caregivers.

> Whenever your life ends, it is all there.
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> The advantage of living is not measured by length, but by use.
>
> Some men have lived long, and lived little; attend to it while you are in it.
>
> It lies in your will, not in the number of years, for you to have lived enough.
>
> *Michel Eyquem deMontaigne*

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