

CAREMATTERS

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The 'H' in AseraCare Hospice Stands For Hope

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Our promise to our community is simple—to provide the best care possible—24 hours a day, seven days a week—for all whose lives are affected by an illness that is expected to lead to death. Comfort and compassion are our guiding principles. Please call your local AseraCare Hospice anytime we can be of assistance to you or your patients.

Many physicians have told me that they don't refer to hospice earlier because they don't want to deprive their patients of hope. This feeling is understandable but *only* if one believes that hope is exclusively dependent upon only physical realities.

A hospice patient of mine, who was 80 years old and clearly dying of pancreatic cancer, told me, "I anxiously open the newspaper every morning hoping that some new drug or treatment will come out that will cure me." When I asked him if there were any other hopes he had at this stage of his life, he just shrugged and said, "Nope, all my hopes are in you guys—the medical profession." He died three weeks later, tragically clinging to tomorrow's news.

The Hope for a Cure

The hope for a cure is a natural one. Initially, it is

a healthy belief, which can result in a positive attitude and nurture healing. But false hopes—once seen for the illusions or mirages that they are—can devastate the patient and family. It may alienate the patient from the doctor, cause loss of trust, precipitate depression and set off a chain of events that can negatively affect the patient's family for years.

Some physicians, who sincerely believe that they are doing something good, act in collusion with patients as they cling to false hopes. These physicians allow patients to believe that they will be cured, will live five more years, will be helped by that fourth chemo regimen or will be healed by God. They are fearful that the patient will get discouraged and lose hope. And they are right.

Initially hearing the words "incurable" or "hospice" is difficult. The patient may become anxious or depressed. Our job as

physicians and healthcare workers should be to rebuild and redirect the patient to a new hope. But this hope must be based on truth—not falsehoods and unrealistic expectations.

In the Netherlands, according to Dr. PJ van der Maas, euthanized patients noted hopelessness as the single most important reason for requesting physician-assisted suicide. "Physical pain only" was the motivator mentioned by only three percent.¹

Robert Frost said it well: "Hope does not lie in a way out, but in a way through." The way *through* for the terminally ill is the way of truth—with compassion, empathy and hope.

True Hopes

True hopes are based on the truth that there is always more to do for the patient—even when there is nothing more to do from a medical standpoint. Redirecting hope should

TABLE 1**The Three Stages of Hope**

The Hope for a Cure

The Hope for Prolongation of Life

The Hopes of the Dying

be an end-of-life goal for both the physician and the patient. It helps for physicians to understand the three stages of hope (Table 1). Thus, hope can be changed, realigned, refocused and redefined. True hope for a patient who is dying can take many forms and involves the last two hopes in our table.

There is the hope of being reconciled with one's past. I have witnessed countless families brought back from estrangement during the final months. At AseraCare Hospice we often do life review—allowing a patient to find meaning and set goals from the past.

There is the hope to love and be loved. Many want to see their friends and family to give and receive forgiveness, thankfulness and love. This may require time and planning. Sadly, I have seen many patients not experience this healing because false hopes led them to be unaware of how sick they truly were

and they simply ran out of time.

Some have the hope of attaining specific goals. At hospice one of our initial questions is, "What goals do you have for your remaining days?" These are the types of answers we often hear:

"I hope to attend the wedding of my granddaughter, Juli."

"I hope to see Joseph, my new grandson."

"I hope to see another Christmas."

At AseraCare Hospice, we encourage the patient to set realistic goals.

Some patients simply hope that they will be able to remain at home and die with family and friends around. Others hope to get their financial affairs in order for their spouse and children. Others have a strong desire to transmit wisdom and words of knowledge to their children.

Don't forget spiritual hopes. I have seen many patients talk excitedly

about heaven and what expectations they have. And there is the hope that, just as one might find meaning in life, one might find meaning in the mystery of death. As a hospice physician, I have witnessed a truth that was not as apparent to me when I was in private practice: As patients near the end of life, their spiritual and religious concerns are often awakened and intensified, and this gives hope.

The hopes that I listed above are true hopes—rooted in the strong soil of integrity. Vaclav Havel said, "Hope is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out." All of the above hopes help a person make sense of life and sickness and death.

When Patients Hope for a Miracle

These can be difficult cases for physicians. The key, as I see it, is to maintain your integrity while taking the spiritual journey with the patient. You may want to consider one of these responses:

"I wish you could be the one who receives a miracle, but I also

know that you would want me to be completely honest with you. I have never seen anyone with your disease recover at this stage."

"I hope you do receive a miracle. I would love to see one ... but in my experience, they are pretty rare."

By handling the patient's belief this way, you affirm the patient's faith and you maintain your credibility as a scientist and a physician.

Factors That Increase and Decrease Hope

Multiple studies have identified factors that increase and decrease hope in the terminally ill (Table 2).

Hospice Increases Hope

These findings have clearly helped me to reaffirm the framework upon which AseraCare Hospice has been based: physician, nursing, counseling and spiritual care. Studies have shown that hospice care fosters hope—and hope actually increases as death approaches. Many doctors have voiced disbelief at such a notion. Interestingly, in my experience, this

TABLE 2

Factors That Influence Hope in the Terminally Ill ^{2 3 4}

Increase	Decrease
Feeling valued	Feeling devalued
Realistic goals	Lack of goals
Spiritual beliefs	Lack of faith
Pain and symptom relief	Unrelieved pain
Meaningful relationships	Poor support
Hospice	Isolation

increase in hope as death approaches is a common occurrence—provided that adequate care and comfort are provided in all the dimensions of a person’s life. I think of a recent patient of mine who, before he died, visited all of his children in Indiana, celebrated his last wedding anniversary on a cruise ship, reconciled with an estranged brother, took communion for the first time, and died in his home surrounded by family and friends and hospice.

physician is to help our patients die with hope. AseraCare Hospice can help your patients do that.

Until next month,



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Golden Living

All too often, I have seen patients undergoing futile therapy, clinging to false hopes, avoiding hospice and never finding the true hopes that give death its dignity and meaning. Soren Kierkegaard, the great philosopher, said, “To die well is the height of wisdom.” I believe that one of our most important “callings” as a

References:

- ¹ Van der Maas PJ, van Delden JSM, Pijnenbuy L, *Euthanasia and other medical decisions concerning the end of life* (New York: Elsevier, 1992), 43–45.
- ² Herth K, “Fostering hope in terminally ill people,” *Journal of Advance Nursing*, (1990;15): 1250–9.
- ³ Frankl, VE, *Man’s Search for Meaning* (New York: Washington Square Press, 1984).
- ⁴ Cherny NI, Coyle N, Foley KM, “Suffering in the advanced cancer patient: a definition and taxonomy,” *Journal of Palliative Care*, (1994;10): 57–70.

