The Difficult Spiritual Journey of a Patient and the Patient’s Loved Ones

“The art of living well and the art of dying well are one.” — Epicurus

Pain can be either physical or spiritual or both. Words that signal inner, spiritual pain include:

- Alienation
- Loneliness
- Separateness
- Abandonment
- Despair
- Meaninglessness
- Fearfulness

The caregiver, in order to understand the source of this pain needs to know that:

1. Understanding the source of pain is more about listening than fixing. The primary role for the caregiver is to be a compassionate, empathic “mirror” to the patient to articulate what the caregiver is hearing. The role is to not to try to fix it or tell your own story.

2. Spiritual suffering and physical pain are interrelated. The whole being is affected by an imbalance in body, mind, or spirit.

There are four timeless sources of spiritual pain.

1. Lack of meaning or personal identity — “How can I live when everything of value is slipping away?”
   a. Possible courageous questions from a caregiver to a patient:
      i. “What brings you joy or peace or energy now?”
      ii. “What matters most to you right now?”
      iii. “Is there something beyond this familiar world that you know and love?”
      iv. “Are there spiritual traditions that you would like to honor or experience now?”
      v. “In remembering your past, is there any way that memories of past life experience can remind you of those ‘things of value’ that could support you now?”

2. Lack of forgiveness — of another or of oneself
   a. Forgiveness is not condoning or excusing ignorant or evil behavior. It is not denial of hurt or about inviting an abuser back into our lives. It is not forgetting real wounds and betrayal.
   b. Possible courageous questions from a caregiver to a patient:
      i. “What does forgiveness mean to you?”
      ii. “How have you received forgiveness in the past? “How have you forgiven others?”
      iii. “What does forgiveness look like to you in this case?”

3. Loss of relationship — regarding the patient him/herself or the patient’s loved ones
   a. Possible courageous questions from a caregiver to a patient:
      i. “How are you coping with the changes that you are experiencing?”
      ii. “How are you and your loved ones communicating right now?” “How would you like it to be different?”
      iii. “How have you gotten through other past struggles or situations?”

4. Loss of hope — giving up, unable to articulate any positive future
   a. Possible courageous questions/responses from the caregiver to the patient:
      i. “What is most important or most meaningful for you right now?”
      ii. “What is the most powerful thing in your life?”
      iii. “Have you ever gone through a time in your life when you just wanted to give up? What got you through that time?”
      iv. Being present, light physical touch, contact with nature, rituals like lighting candles, massaging the body, playing gentle music.

Adapted from The American book of Dying: Lessons in Healing Spiritual Pain by Richard F. Grovers and Henriette Anne Klauser
Material assembled by Hospice Austin, August, 2013.
TOP TEN MYTHS ABOUT HOSPICE:

1. HOSPICE IS A PLACE.
2. ALL HOSPICES ARE THE SAME...LIKE WAL-MART.
3. HOSPICE MEANS GIVING UP.
4. HOSPICE IS ONLY FOR THE LAST FEW DAYS OF LIFE.
5. HOSPICE IS THE KISS OF DEATH.
6. IF YOU TALK ABOUT END-OF-LIFE ISSUES YOU'LL DIE SOONER.
7. HOSPICE IS OVERLY RELIANT ON PAIN MEDICATION.
8. HOSPICE WORK IS REALLY DEPRESSING.
9. THERE ARE NO DIFFICULT PATIENTS OR FAMILIES ON HOSPICE CARE.
10. HOSPICE WILL FINALLY ANSWER ALL MY QUESTIONS ABOUT DEATH AND DYING.
Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's critically important. And you can do it.

Consider the facts.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.