

Issue: 4/3/13 Vol. 10 No. 5

Articles

Fred Grewe **Healing in Hospice**

There will, I hope, still be opportunities to go on trips, play with the kids, do the dishes, pay the bills, listen to music, help with the homework, attend a couple of football games, go to movies, do a little bit of writing, share happy moments with my wife and family, renew friendships with some people and reach closure with others, search for spiritual meaning in and acceptance of the life I have lived, and search for healing even in the absence of cure.

- **Dr. Paul Cazier** (voicing his hope as he was dying from a cancerous brain tumor)¹

I meet people right where they sleep. Often unconcerned about their appearance, I find them lying on or sitting on their beds in homes, adult foster homes, assisted living facilities, nursing homes, or memory care units. A doctor has told them they have less than six months of life. Many require aid to simply breathe. During my visit a respirator frequently swooshes in the background delivering needed oxygen through a plastic tube into the cannula placed at the entry of their nostrils.

I am a hospice chaplain.

Often the people I meet are overwhelmed. Overwhelmed by the dire news given by their doctor. Overwhelmed by pain and/or the side effects of the narcotics they are on – or both. Often constipated. Overwhelmed by the invasion of hospice workers who have five working days to complete government mandated initial assessments. Overwhelmed by the same questions over and over again. Overwhelmed by the shock and tears of loving friends and family. Overwhelmed by the knowledge that soon they will cease to be.

The waiting is awful. They know something is going to happen ... something not good ... and they don't know when. They know it's coming, just not when it's coming.

Some folks try to take care of as many personal life details as possible. Some get angry. Some just give up. Many just stare out the window in shock, trying to make sense of so many stitched together memories into something that resembles meaning.

In the past nine years I have journeyed with more than 1,000 folks who have died. On an average week I visit 20 to 25 terminal patients and in my current job I see about 50 different people each month. Two hundred fifty of my patients die each year.

Far and away the most common issue I encounter causing distress with these brave souls is the existential pain caused by the loss of meaning.

My first experience in observing the intense pain caused by a loss of meaning came long before my career as a chaplain began, however, it came from watching my mother die.

She was only 44 and had battled cancer for seven years. It started in her breast, then went to the ovaries, then finally and painfully into her bones. Double mastectomy, chemo, radiation, the indignity of all her beautiful black hair falling out, her caring face mooning up from the medications – none of it worked. For the last year of her life she basically lay in pain on the couch in our family room and had to let my three sisters, my father, and myself take care of her.

The greatest pain she endured though was not being able to be our mom anymore. She often told me she hated having everyone wait on her. She felt like such a burden to us. For all our life she had cared for and nurtured us – now she could only lie on that damn couch.

I remember one evening during her last year, she and I were home alone. I was lying on the floor in the family room watching TV and she asked me, “Do you want some ice cream?” Half jokingly I said, “Yeah, right.”

A short while later she labored to get up off of the sofa, grabbed her crutches and started up the seven stairs from the family room to the rest of the house. I thought she was just going to the bathroom. She returned gingerly balancing a bowl of ice cream in her right hand, walking with the crutches, and cautiously making her way back down the seven stairs. I felt so ashamed and yet she looked so happy. For just a few moments, she told me she felt like a mom again.

Conversely, those were some of the richest moments in my life. I had just graduated from college and moved home to help care for her. Those last several months of tending to my mother were an opportunity for me to give back to this beautiful woman who had given me and our family so much of herself. Serving her pulled a kindness and sensitivity out of me that I didn’t even know was there. I was a better human being as a result of those months caring for my dying mother.

Ironically, letting us serve her as she was dying was the final gift our mother gave us. Her care filled our lives with deep meaning. Now I’m not suggesting it was easy, or that it made us happy, but it did make our living very rich. Not infrequently I share this insight with those I serve who also suffer from a loss of meaning as they lay dying. I suggest even confined to the hospital bed, unable to care for themselves in any way, the dying patient can still teach the rest of the family how meaningful life can be as we serve others.

Nearly 40 years later, the impact of those months has never left me. The experience of caring for my dying mother was a major consideration in my life choice to become a hospice chaplain.

Healing vs. Cure

In my practice as a hospice chaplain there is no more pressing work than helping patients reframe their sense of meaning at the end of their lives. So many people I meet are more afraid of losing their meaning than they are of dying.

The existential pain inflicted by the loss of meaning is often exacerbated for the dying by its confrontation with our cultural idol of independence. The great North American mortal sin is to become a burden to others. So for the dying person, who can find no reason to continue living, the thought of being a burden to their loved ones by requiring the family’s resources of time and money for their care is pain unbearable. This is suffering pharmaceuticals can’t touch. This is soul suffering.

As a chaplain, one of my aims is to help alleviate this soul suffering. One method that brings relief is by simply bearing witness to it. One of the key elements of suffering’s pain is that it isolates the sufferer. By patiently sitting with the dying person, honestly talking in non-judgmental ways about the loss of meaning and the fear of being a burden to others, I have witnessed a lessening of this excruciating existential pain. Simply naming it, looking at it square in the eye, and not running from it, has incredible therapeutic value.

But we can do more to help heal this end-of-life existential pain. In our efforts to create meaning the importance of our roles and relationships cannot be overstated. John Pilch in his insightful work, [Healing in the New Testament](#), does a masterful job of differentiating cure from healing. Cure is a medical term limited to eliminating a spot from an x-ray, or cutting out diseased tissue, or using pharmaceuticals to destroy unwanted bacteria. Healing, on the other hand, requires a much broader understanding. Healing may involve cure, but it also includes restoring the sick person to their familial relationships and roles in the broader community when needed.

In the Palestine of the first century, sick people were often quarantined to limit the exposure of such dreaded diseases as leprosy from spreading to the larger population. Diseased folks were often segregated, forced to live at the margins of the community, and yell “unclean” if others approached to keep healthy people at a safe distance. Folks with certain diseases weren’t permitted to live in their own homes, engage in commerce with local merchants, or go to work.

These conditions only increased the isolation and suffering of the afflicted persons.

This is the reason, Pilch points out, Jesus frequently told people he healed to “go show yourself to the priest.” Showing oneself to the priest was the entry way back into the life of the community. Once you were no longer deemed contagious (that is a threat to the welfare of the larger community) by the priest, you could move back into your home to resume your role as mother or father relationally, and you could go back to work to resume your role in helping the entire community survive. This is the biblical meaning of healing.

Thus it is possible to be healed without obtaining a cure. Pilch adds a further insight,

Healing is also effective when the individual experience of illness has been made meaningful, personal suffering shared, and the individual leaves the marginal situation of sickness and is reincorporated — in health or even death — back into the social body.

I like to say in hospice work our cure rate runs at about 0%, but we’re pretty good at healing.

How is this accomplished?

Meaning Making Ideas

In my practice to help dying persons suffering from a loss of meaning at the end of their lives, I rely on several approaches to help them reframe meaning given their current terminal circumstances. For some, we talk about teaching their loved one’s how to die. This is particularly appropriate for dying parents and grandparents. They’ve already given much of their lives to teaching their progeny how to live, now they can teach them how to die. This approach reinforces the dying person’s role in the family structure and it also provides a wonderful gift as many folks in our culture are terrified of death. Teaching others to die without fear, without regret, is an incredible gift. [Henri Nouwen](#) shares,

If I die with much anger and bitterness, I will leave my family and friends behind in confusion, guilt, shame, or weakness. When I felt my death approaching, I suddenly realized how much I could influence the hearts of those whom I would leave behind. If I could truly say that I was grateful for what I had lived, eager to forgive and be forgiven, full of hope that those who loved me would continue their lives in joy and peace, and confident that Jesus who calls me would guide all who somehow belonged to my life – if I could do that – I would, in the hour of my death, reveal more true spiritual freedom than I had been able to reveal all the years of my life. I realized on a very deep level that dying is the most important act of living. It involves a choice to bind others with guilt or set them free with gratitude. ³

I find this insight of Nouwen’s to be incredibly inspirational. How beautifully rich it can be to teach those you love how to die. In a world that offers so much impersonal social media, plastic gizmos, and answers for everything – sharing the vulnerable uncertainties of the dying process is such an intimate invitation to

love. It can also be a powerful source of meaning to help dying persons endure the numerous indignities involved with residing in a body that is simply giving out.

Another approach in reframing meaning is to consider how the dying person might bless their loved ones. Based on a biblical approach to blessing, [Gary Smalley and John Trent](#) have identified five basic elements in an effective blessing: meaningful touch, spoken words, expressing high value, picturing a special future, and offering an active commitment to see that future become reality.⁴ Helping dying patients consider how they might want to bless their loved ones in casual or more ritualized ways provides a rich vein of possibilities laden with meaning. It is also a simple and beautiful gift one human can offer to another – noticing how special someone is and celebrating it before death.

Finally, with some of my patients I talk about giving the gift of receiving. As in the story about my mother's dying, by her letting us care for her I was able to discover gifts within me I didn't know I had – gifts like kindness and tenderness. Receiving is so difficult in our culture, but it can afford those who love you an opportunity to express their love in creative and tangible ways--ways that may change the givers forever.

Summary Questions

- How might we help create community (a sense of relatedness) for those who are dying all alone?
- What ideas have you discovered in helping to reframe meaning at life's end for those you serve?
- What gives meaning to your life?

Footnotes

1. Paul R. Cazier, "Stealing the Reaper's Grim: The Challenge of Dying Well," *Dialogue: A Journal of Mormon Thought*, v32, no. 4 (Winter, 2000): 120.
2. John Pilch, *Healing in the New Testament: Insights from Medical Mediterranean Anthropology* (Minneapolis: Fortress Press, 2000), 34.
3. Henri Nouwen, *Mornings with Henri J. M. Nouwen: Readings and Reflections* (Cincinnati, OH: Servant Books, 2005), p.106
4. Smalley and Trent, *The Gift of the Blessing*, (New York: Inspirational Press, 1993).



Rev. Fred Grewe is a Board Certified Chaplain (Association of Professional Chaplains) with a Master's Degree in Pastoral Care from the Aquinas School of Theology in St. Louis and an ordained Congregationalist minister working for Providence Hospice in Medford, Oregon. His interest in working with the dying began in the early 1990's with the death of his best friend who succumbed to AIDS. In January of this year, Rev. Grewe began working towards a doctoral degree on the topic of this article.

User Comments

Alice Tremaine 4/3/2013 10:02:50 AM

Beautifully written. I love the notion of offering the "gift of receiving." So many of the hospice pts I encounter feel like a burden, and I try to help them find meaning in receiving. We all want to hold onto our independence, but to me there is something beautiful about interdependence as well.