

## Message Delivered

### Planting the Seeds for an End-of-Life Journey

William M. Buchholz, MD

Harry moved to California to live with his daughter and continue treatment for myeloma after his wife died. He was a lifelong New Yorker with a thick regional accent. In addition to the side effects from chemotherapy, his biggest complaint was that he missed his garden. Because we shared a common passion, we often discussed how he could landscape his daughter's backyard now that he found himself in a different area.

We went through two years of such conversations until it became clear that his myeloma was progressing and we were running out of options. Harry confronted me during one visit and bluntly asked, "Am I dying, doc?" I nodded, and he went on in his thick Bronx accent, "Being dead isn't a problem. Now dying, *that's* a problem! I've never died before, what should I do?"

I reassured him that I could help him handle any pain and that I would see him at home if he couldn't make it to the office. Harry then asked me, "But how do I deal with being helpless, having to depend on other people, not even able to take care of my garden? I wouldn't know who I was if I couldn't be active. What would you do if you were in my shoes?"

I tried to think of an answer to that question since I know that, someday, I *will* be in his shoes. I had just read an article describing the issues facing patients at the end of life. Beyond physical symptoms, the article noted that the most commonly mentioned problems were loss of control, loss of social roles, and loss of identity. Appropriately enough, the article was titled "The Landscape of Distress in the Terminally Ill" (Chochinov et al., 2009).

It set me to thinking: How can we maintain trust in the future when we

don't have control, keep self-esteem when we can't perform our customary roles, and maintain a sense of self when our very identity as independent, self-reliant individuals has morphed into something else?

Using our common interest as a metaphor, I told Harry, "If I were landscaping my life to cope with dying, I'd have to plant something that would let me trust more in goodness, appreciate *being* more than *doing*, and be able to give something back for all the care I'd need so I wouldn't feel in debt."

Harry was Catholic, but he didn't attend church much. He accepted the metaphor, but looked confused when I spoke of goodness. "So what can I trust when I'm dying?" he asked. "I've prayed to be safe, but that's a joke when you've got cancer. And I don't like His sense of humor."

"It does seem futile to ask to be safe from harm," I replied. "What I meant is that both good and bad things happen. You have to prepare for adversity but, instead of concentrating on only the bad stuff, keep a portion of your mind open to the good. Trust that whatever happens, you can cope with it. You can trust that goodness happens too."

"Does that mean I can cover up the 'S... Happens' bumper sticker on my car?" Harry wise-cracked. "But I still can't live without doing something. All my life I've been busy. I had my business, my family, my golf, my garden. If I can't do something productive, what am I?"

Sheepishly, I confided to him, "That's my problem too. I get bound up in the same kind of things and forget that I'm a *human being* and not a *human doing*. As a busy doctor, I am rewarded with praise, social status, and material wealth. I get stressed and burned out when I overdo, but it's addictive. It's hard to say 'no' when I get rewarded so often for saying yes.

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"Yet sometimes I remember that it isn't what I do that defines me, but who I am. People will still love me even if I'm not a doctor or a father or a gardener. It isn't just smelling the roses; they are still fragrant whether I smell them or not. It's not being focused only on what I do, but noticing that the flowers are all around me."

Harry considered this and replied, "Maybe you're right, doc. I am content when I just sit and feel all the plants and nature around me. I'm part of it, too. Maybe I'm not ready to become compost yet, but I can accept that as part of living. My priest quotes Ecclesiastes where it says there is 'a time for everything under Heaven.' Maybe there is time to just be there, not having to do something.

"But when I get real sick and need something, I don't want to be a burden to my daughter or grandchildren. If I have to ask for help getting dressed or going to the toilet, I don't want to feel that they resent it. If I can't do something for them,

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