

Continuing Education—September 2012
Just Plain Stephie: Conversations at the End of Life
By J. Scott Janssen, MSW, LCSW

“I know what it looks like, Scott, but we aren’t here today to talk about dying.”

Stephie, a 60-year-old woman with a terminal lung disease, straightened her back, her voice suddenly firm as though mustering what little of her strength remained to emphasize her point. I’d simply observed that she appeared to be going downhill fast—no appetite, increased weakness, needing help to get into and out of her chair. Fluid was causing swelling in her legs and belly, filling her lungs. Each inhale was accompanied by audible congestion; each exhale accompanied by a slight cough. She also had a hard time staying awake.

It wasn’t the first time she’d used the phrase. I’d heard it the day I introduced myself as her hospice social worker. “We’re not going to waste time talking about dying when you come out here,” she instructed, “because I’m getting better. I’m not going to die.”

Then, in case I needed further instruction, she told me what we were going to talk about during my visits: living and all that made life meaningful to her, such as her faith, friends, and family; her ability to laugh and carry on no matter what; and the simple affirmation that each day, however hard, brought something for which to be thankful.

I heard the sentiment months later when Stephie called a family meeting to make sure that everyone, especially her son, Will, and her brother, Russ, were on the same page.

At Stephie’s request, the hospice nurse started the meeting by outlining the likely trajectory her illness would take and what it would mean in terms of increased care needs. Once the picture was drawn and before I could offer those gathered a chance to ask questions or speak about what Stephie’s situation meant to them, Stephie abruptly changed direction. “We know what’s coming,” she said fiercely, pausing as much for the sheer drama as to let it sink in. “But we aren’t going to spend the rest of our time here today getting all teary-eyed and talking about dying because I don’t care what the medical folks say, I’m planning on getting better. I’m not going to die.”

That “we know what’s coming,” along with several variations of the phrase “it’s all in God’s hands” and “nobody lives forever” were about as close as I ever heard Stephie come to acknowledging she might die. In spite of mounting evidence to the contrary, she typically insisted she was getting better. She had to; she had “important things” to do. There were people to encourage, young folks to teach, prayers to be offered, and at least one or two folks who needed a good piece of her mind.

And, of course, there were stories to be shared. Stories from what many would have considered a hard life, stories about back-breaking labor as a housekeeper, raising a son by herself, taking care of family members as they got sick and died. There were stories of paychecks that were too small and bills that were too big, about toughness and sacrifice. There were funny stories, sad stories, stories about folks who were above the ground and those who were beneath it, along with stories about coming together and about being ripped apart. And there were stories about times when the wind got knocked out of her, but she kept going forward anyway.

And so things went, Stephie forbidding talk of death, asserting she would get better, laughing, crying, and telling stories. Some end-of-life counselors and medical professionals would have said she was in denial or exhibiting avoidance. Some would have expanded such conclusions with theories about the anxiety, anger, or fear that must surely lay hidden just under the surface of Stephie’s unrealistic assertions and defenses. Such terms as “denial” would have made Stephie laugh. I can almost hear her say, “I’m in denial because I don’t want to spend my time talking about dying? Because I have hope? Because I want to live? Because I ask God to heal me?”

The Lessons of Language

Over the years, I've heard many caring professionals use words such as "denial" or "avoidance" or "false hope" as though we know best what people should think and what stance they should take regarding their illness and mortality. We use words such as "appropriate" and "noncompliant" and "unrealistic" as though we know best how they should behave. We use buzzwords such as "closure," "forgiveness," and "acceptance" as though it's all so simple. We assess stressors, levels of support, and coping styles to calculate the potential for depression or caregiver burnout. We analyze risk factors to ascribe bereavement scores to the broken hearts of loved ones left to grieve. How could Stephie ever find closure (that elusive chimera) if she didn't follow the blueprint of accepting her mortality, processing things appropriately, and saying good-bye?

There's nothing inherently wrong with such language. It is understandable that caring professionals would see denial in Stephie who says she's not dying. We must search for words to make sense of what we are seeing and, as we do so, these words may be the best we can do in response to the situation. Finding language to illuminate the deep waters our patients and their families are navigating is difficult, and we try our best to do so in a way that brings peace.

But when we become too comfortable with a certain way of speaking, we can fall into unexplored habits of language and seeing from a fixed, even rigid, perspective. This can lead us to focus on questions that are more important to us than they are to our patients—questions such as whether a person is in denial or grieving appropriately. When we do this we may miss or discount things that are important to them, such as hope and maintaining some semblance of normality.

One problem with habitual, repetitive language is that it can appear far more precise and authoritative than it actually is, and words can quickly become labels that are hard to see beyond. Language is the foundation of the stories we tell ourselves as we formulate ideas about how to help our patients and their families. Left unexamined, we may become so enraptured with the familiar rhythms and enticingly precise-sounding tone of our words that we begin to believe there is only one way toward that holy grail of hospice care—the so-called good death—and that we, the "experts," know the way better than those who are actually making the journey. And in our eagerness to use our knowledge to help, we may force our mental blueprint in a way that inadvertently conflicts with another well-worn and time-tested concept: patient autonomy and self-determination.

Naturally, it is good to be sensitive to emotionally and psychologically loaded topics that patients such as Stephie would rather not discuss. Perhaps denial is as good a word as any for some of these situations, but caring professionals need to consistently examine our linguistic habits and the assumptions that grow from them, working to truly see things from our patients' perspective in their language and meaning systems. When we do so, we often find that they have the wisdom and courage to find the best way forward, whether it conforms to our ideas about what they should do or not.

To see mainly avoidance or denial in Stephie's refusal to talk about death and her assertions that she would get better would have risked missing the life force and the affirmation of living that infused everything she did. To demand that she be more realistic and begin finding ways to accept her terminal status and say good-bye would have missed the power in her heart to continue reaching out and engaging with others no matter how constricted her world became or how inexorably that moment of separation loomed. To ask her to start letting go of roles and tasks instead of endlessly uncovering important things she needed to do would have missed the immense meaning and joy these gave her.

Stephie knew how she wanted to live the last part of her life, and it had nothing to do with acceptance, saying good-bye, or letting go. It had to do with packing as much in as she could and building as big a head of steam as possible before illness finally stopped her in her tracks. She wasn't afraid of dying; she just didn't want to waste time talking about it, planning for it, or letting it slow her down any more than necessary.

Her family understood this. Several times when Will and Russ were around, I invited them and Stephie to talk about what was in their hearts. Were there things they wanted to say? Questions they wanted to ask? Had they thought about how they wanted to spend what time remained? Each time they declined such invitations.

Privately, they spoke about "time running out" but felt no urgency to alter the descending arch of their lives together to make a place for explicit conversations about separation, forgiveness, and gratitude. They felt no need for verbal encapsulations of Stephie's legacy and the impact her death would have. These were implicit in the daily comings and goings of family and friends, in the laughter, the occasional awkward silences, prayers for healing, and the quiet adaptation to new roles and boundaries as Stephie needed and received more help with activities and managing her medications. As her son put it, "It's all about love right now, all the way to the end."

I thought that as things wound down Stephie might finally turn toward death and begin to process, say good-bye, let go. Many people equally fierce in their determination to live begin such conversations as their bodies tell them they are not getting better. Such was not the case with Stephie. That visit when she straightened her back and said, "I know what it looks like, Scott, but we aren't here today to talk about dying" turned out to be our last. I could see she was dying and so could her brother and son, but Stephie wanted to talk about something else.

"Well, what are we going to talk about then, Stephie?" I asked.

She pointed at a dog-eared Bible. "Get me that Bible and I'll tell you what we're going to talk about."

I did as she asked. She thumbed through till she found the right page. "We're going to talk about Will," she said as she handed me the Bible and asked me to read. The book had been interspersed with modern poems and stories. She'd stopped on a poem about sons and the hopes a parent holds as her child grows and learns, the pride she feels as her son becomes a man, and the way her spirit shines from her son's heart and survives there long after she is gone.

Tears formed in the corners of her eyes as I read the poem out loud. She smiled. I invited her to discuss what the poem meant to her and why she had asked me to read it, but she was too tired. Her eyes closed, and she said only, "You know what it means."

We sat silently for a moment before I asked a few final questions.

"Stephie, how are you feeling about what's happening now?"

"I'm at peace." Her eyes remained closed.

"Is there anything in your mind or your heart right now that you want to ask or talk about?"

She shook her head no.

"Is there anything that you feel is important for your family to know? Anything you want to say?"

She shook her head again. There was another silent pause.

“Down the road, Stephe, when you’re not here and when we think about you, what do you want us to remember?”

Her eyes remained closed as she responded, “I’m not dying, Scott.” She opened her hand for me to hold. When I did, she said, “Just remember how I always tried to treat people. Tried to treat them the way they wanted to be treated. Just remember plain old Stephe.”

By the time I left that day, she was fast asleep. She didn’t have a long way to go. She died about a week later. She knew the way. She always did.

— J. Scott Janssen, MSW, LCSW, has been a hospice social worker for 20 years and currently works for Duke Hospice in Durham, NC. He is author of the book *The Dawn Is Never Far Away: Stories of Loss, Resilience, and the Human Journey*.

Reprinted with the permission of Social Work Today©. Great Valley Publishing, Co.