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# Caring for the Human Spirit<sup>®</sup> magazine

SPRING / SUMMER 2016

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## From Our Readers

*I am impressed greatly by your magazine since it brings CPE theory and practices up to date—meeting the current issues we face in chaplaincy.* —Chaplain W. Ray Bailey, Bonner Springs, Kan.

*The [fall 2015] issue with its emphasis on pediatric spirituality is a wonderful resource for spiritual care providers in all venues. I plan on sharing it!* —Bob Swope, M.Div., RN, Fairbanks, Alaska

## Comments? Suggestions? Contact us at

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Vol.3, No.1 Caring for the Human Spirit® magazine is published semi-annually: spring/summer, fall/winter. All rights reserved. This publication may not be reproduced in whole or in part without permission from HCCN. ©HealthCare Chaplaincy Network



# Love in Liminal Space

**A Hospice Social Worker Helps a Grieving Family Express What's on Their Minds and Hearts**

By **Scott Janssen, M.A., MSW, LCSW**

Rick's\* eyes were fixed on the gray sky as he glared angrily out the kitchen window. Everyone was giving him a wide berth. A physically powerful man, he's intimidating on a good day and with his 27-year-old daughter Jen's lifeless body upstairs, this was one of the worst.

I cleared my throat to let him know I was standing behind him. As I approached, I made sure he could hear each footstep. I stood beside him silently, hardening my eyes, and we glared together at the autumn sky.

After several minutes I softened my face and looked at him. He swallowed hard, forearms and shoulders clenching as though bracing against a wave of unspeakable pain. When he looked at me, his eyes glassy with tears, I visualized sending him a silent pulsation of courage and love. Spontaneously, he began telling me a story about the day Jen was born.

"When the nurse brought her

in, my wife held her in her arms repeating the words, 'I love you' over and over. I asked what the hell she thought she was doing," he recalled.

Tears welled in the corners of his eyes as he cleared his throat, explaining, "She told me she wanted the very first thing Jen ever heard to be a message of love."

"What'd you do?" I asked.

"I picked her up and said 'I love you' over and over," he replied.

He returned his gaze to the window, his face lost in remembering. After a few minutes of silence he said he needed to get some air and disappeared out the kitchen door.

\*\*\*

This time I had not followed him. After years as a hospice social worker I know that not everyone who is suffering wants to talk about it. Sometimes people want silence; sometimes they want space.

Though aware of the blueprint hospice professionals often use

to help people prepare for such moments—encouraging them to say and do all the right things—I've come to believe that there really is no "right thing"; there are only imperfect, often frightened human beings with human hearts doing their best to deal with painful situations and, however awkwardly, express love.

Not all messages of love are as clear as the one Rick delivered to Jen the day she was born. Sometimes love is expressed in barely recognizable gestures: a momentary softening in the eyes, a pause to catch one's breath rather than respond with frustration, the touch of a hand, an unspoken prayer.

Such expressions are easily missed or mistranslated amidst the stormy surface of difficult events, swallowed beneath the tempest of intense emotions, stress and fatigue.

One of my jobs as a hospice social worker is simply being attentive to the ways love gets overshadowed or goes unrecognized, and finding ways to call people's attention to these messages even as physical decline and impending separation press down on the nerves. Helping patients and their families connect with what some clinicians call their deep or core selves, what others call their souls, and to express this felt sense of love has become a central part of my practice.

\*\*\*

As I watched Rick light a cigarette and kick his work boots against the brick foundation of the carport, I thought about the visit I had with him and Jen a couple of weeks earlier. She was declining rapidly and had asked both of us to come at the same time.

When we were all there, Jen straightened her back, raised her voice, and told Rick she was fed up with his bullying anyone who tried to speak honestly about her decline. She'd had it with his denial. Rick

## Ode to Chaplain Friends

Since chaplains are an indispensable part of any hospice team, I have worked with quite a few over the years. And I have learned from my chaplain friends more than I could ever articulate.

Chaplains have helped me understand that every person, whether having religious faith or not, has a profoundly spiritual dimension; and that this dimension may be transformative during times of struggle such as often occur at the end of life.

They have sensitized me to the deep self, the spirit, within each individual, and reminded me to listen closely for the inner voice of this deep self, whatever pain or suffering may be roiling the surface.

And they have helped me learn to cherish the mystery of life, accept that some things are unknowable, and trust that love, after all, really is more powerful than death.

—Janssen

responded defensively, accusing her of surrendering to negativity and giving up without a fight. It was a rough and heated conversation.

When things had settled, I asked him to tell Jen what he'd been trying to communicate by shutting down any conversation about her dying. Tears washed down Jen's face as he told her that he'd been trying to protect her and motivate her to fight harder to live.

"Why is it important to you that Jen fight?" I asked.

He started crying, and then, in an unusually soft voice, declared, "I don't want you to die Jenny-bear."

He leaned forward as if in physical pain, his shoulders shaking, and sobs erupting from his massive frame. Jen reached out for one of his hands as he balled the other into a fist.

Beneath Rick's ferocity had been an impulse to protect. Beneath his intimidating behavior had been the fear of a father whose heart was breaking and whose anger masked deep sadness.

When Jen had tried explaining what it was like to be in a body battered by metastatic cancer, why she was tired of fighting, it was too much for him. He raised his hands and demanded she stop, launching into a discourse on why she shouldn't feel the way she felt—always a recipe for disaster.

I interrupted him mid-stride and asked to him to be quiet, to leave his thoughts and let himself feel, however scary, what was going on inside him at that moment.

"What's the bottom line Rick?" I whispered, tapping the center of my chest. "From the heart this time."

\*\*\*

Outside in the morning cold, Rick flicked away his spent cigarette and put his hands in his pockets, anger chiseled into his face.

I thought about how he had told Jen he loved her, how he would have traded places with her if he could have, how ashamed he was that he

couldn't keep her safe. I remembered how he had asked for her forgiveness, the way they had hugged. In my mind's eye I can still see the look in Rick's eyes as she said, "I love you, Papa-bear."

I left the kitchen and walked upstairs to Jen's room. The room was packed with friends and family. When they saw me everyone fell silent and, as if on cue, quickly filed out, leaving me alone with Jen's husband, Steve, who was sitting on the bed next to Jen's body.

Mindful that the funeral home was going to arrive soon, I asked Steve if he would like me to leave too so he can have a few final moments alone with his wife. He motioned for me to sit next to him.

As he held Jen's hand he shared a few simple memories, which contained deep, eternal truths. I asked what he thought she would most want him to remember now and in the days ahead. In a breaking voice, he said, "She'd tell me I did enough. I did my best."

He said he knew she was dying. The hospice nurse had gone over the little blue book that outlines the signs of approaching death, but he hadn't needed the book. He knew.

"I held her hand for I don't know how long," he said. "I just kept saying, 'I love you.' I said it until her heart stopped. It was the last thing she heard."

*\*Names have been changed to protect confidentiality.*

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**Scott Janssen, M.A., MSW, LCSW**, of Hillsborough, N.C., has been a hospice clinical social worker for more than 20 years and currently works at Hospice and Palliative Care Center of Alamance-Caswell, Burlington, N.C.