



AN EXEMPLAR OF EXCELLENCE IN END-OF-LIFE CARE

Life sometimes offers us opportunities we'd prefer not to have had and lessons we'd much rather not needed to learn. As also happens so often, however, episodes of this nature can give us invaluable insights that can be gained only by living through such events. In this editorial, I'd like to share a very personal experience that relates to the end-of-life theme of this issue.

Foreground to End-of-Life Care

Nearly 2 years ago, my brother-in-law's rapidly deteriorating cardiac status precipitated his transfer to the Cleveland Clinic, where my husband and I were afforded a first-hand opportunity to not only witness but to marginally interact with a team of heart failure specialists who pulled our family member back from his mortal precipice to a functionally narrowed yet reasonably normal life lasting many months past its anticipated projection. I describe our participation as marginal only because it was both late on the scene, as it took a few days before we were able to rearrange our schedules and drive from Maryland to Cleveland, and brief, because within a few days following our arrival, this team of physicians and nurses had stabilized our family member's status sufficiently to enable his transfer from the heart failure intensive care unit to the coronary care unit, where he remained for only a few more days before his discharge. In the interim, however, my husband, a retired radiologist, and I were able to communicate with the Cleveland Clinic nurses and physicians to fill in some gaps in my brother-in-law's health history owing to incomplete

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doi: 10.4037/ccn2010686

records sent upon his transfer, encourage our family member to relate an accurate history of his current condition, correct a number of misperceptions regarding adherence to his prior medical regimen, and translate medical discourse and the revised plan of care into language intelligible to this 75-year-old bachelor. We appreciated the invitation and respect accorded to our participation, enabling us to clarify a few points regarding our family member, including the following:

- No, they were not missing his health records from before 3 years ago. Since his discharge from the military in the 1950s, our family member had a single physical examination performed by a physician who had died decades ago. Otherwise, his health monitoring consisted of an occasional blood pressure and cholesterol check at the county fair.
- We were not aware that he had primary cardiac disease, rather he had developed cardiomyopathy and heart failure following chemotherapy and radiation therapy a few years earlier for pulmonary and mediastinal lymphoma.
- Regarding his response to his home town cardiologist's medical plan for the 12 months preceding his admission to the Cleveland Clinic, our telephone calls over that period suggested that our family member often slept through his medication schedule, failed to renew prescriptions when they ran out, misplaced medications in his house, stopped taking his diuretic owing to the annoyance of frequent voiding, stopped

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taking all 5 of his medications about 3 months earlier due to persistent nausea, and neglected to inform his cardiologist about any of these issues.

- Regarding his weight loss of nearly 100 pounds over the past year, although it may have been attributable to extension of his oncologic condition, related contributing influences over that period included chronic anorexia, nausea, and inability to shop for groceries or stand long enough to make a meal.

Transition to End-of-Life Care

Despite his declining vigor over 9 to 12 months following discharge from Cleveland Clinic, this lifelong bachelor refused any category of health care worker visiting him at home to assist with his care and vehemently opposed proffered alternatives including nearby assisted living facilities, nursing homes, or hospice services. It wasn't until he literally could not stand on his own that he agreed to enter a health care facility. By that time, he was not just eligible, but long overdue for hospice care. Rather than that relocation from home to an inpatient hospice facility reflecting the end of a long, sad, family tale, however, those 4 weeks of hospice care afforded an opportunity to both witness and fully participate with a small town's team of hospice nurses, who provided world class end-of-life care to both my brother-in-law as well as to all members of his extended family.

Experience With Inpatient Hospice Care

At our initial visit to this inpatient hospice facility, we were warmly greeted and introduced to not only the nurse assigned to my brother-in-law, but to all of the nurses and staff on duty and given a brief overview of our loved one's status since admission. We were then gently interviewed to determine our priorities, preferences, and immediate needs, as well as to identify the circumference of inner circle friends and family who could visit at any time.

Although my husband and I have been health care professionals throughout our careers, neither of us had first-hand experience with hospice care. As a result, our initial expectations for this type of care were optimistic yet generic, that is, we hoped that staff would provide supportive care that would ensure minimal discomfort and maximal peace for all of his remaining days and anticipated that our needs would be met by seeing that our family member's needs had been met. Our experience

with care at this inpatient hospice center surpassed every expectation for our loved one, his closest friends, and ourselves. The most poignant aspects of the hospice care we experienced included the following:

- **Primacy of the patient's wishes and needs.** All aspects of care were dictated first by the patient's expressed preferences. When nursing staff were unaware of his wishes, they inquired directly from him. When he could no longer provide that information, staff then inquired from the immediate family; if we were not present, they asked his closest friends. If none of these sources was available, they based decisions on a collective judgment of nurses who had provided care to him or, as a last resource, on facility protocol. Numerous clinical decisions were made every day for our loved one's care; no decision reflected thoughtless rendering.
- **Openness.** Throughout my brother-in-law's hospice stay, each time we entered his nursing unit, the nurse assigned to him not only shared her own assessments and impressions, but enjoined her colleagues and any visiting friends to supplement, modify, contrast, or otherwise enhance her appraisals to ensure accurate and timely portrayal of the patient's condition and his response to interventions and to help determine whether changes in the plan of care were warranted. This embracing approach to patient assessments reflected a partnership in care we had never previously participated in.
- **Sensitivity.** At our initial meeting with the hospice nurses and intermittently thereafter, we were asked how much we were interested in knowing about our family member's condition; how much detail we wished to hear about his physical, emotional, and spiritual needs; how active a role we wished to take in his care; how much time we would like to be with him; any special cultural or spiritual practices we would like to be observed; and many other inquiries that represented exquisite sensitivity to a myriad of small and large issues.
- **Nonjudgmental attitude.** Although a member of the clergy was one of my brother-in-law's close friends, our family member's and our dissimilar religious backgrounds, preferences, and spiritual beliefs were solicited for clarification, but not assumed and never acted upon without first verifying concurrence with the patient's or our wishes.

From talking with these nurses over a few weeks, it seemed apparent that they also held diverse religious and spiritual beliefs, yet none imposed or provided overt spiritual or religious interventions unless these were requested.

- **Continual striving for best practices.** Even when their interventions for sedation, hydration, nutrition, repositioning, or pain relief appeared to be effective, these hospice nurses never seemed to be wholly satisfied, as they frequently sought reaffirmation that improvement was achieved. Spending 20 minutes to find the optimal position for facilitating ventilation while relieving back pain and preventing pressure areas was not uncommon. Neither was frequent and increasingly refined adjustment of the analgesic-sedative mix to elicit the desired effects. Music from the patient's favorite selections was played softly, with room lighting and blinds adjusted to achieve maximal comfort. Except for the devotion to continually improving and verifying the effectiveness of care, no aspect of nursing interventions remained static.
- **Far-reaching support for the patient, family, and close friends.** In addition to the anticipated admonitions to family and friends to take time for themselves and to get adequate rest, the hospice staff extended an open-ended offer to secure "anything the patient wants or needs at any time of the day or night." Although our family's needs did not require testing this offer, we heard stories of other fulfilled patient and family wishes that demonstrated this was no empty promise. Even for our small group, however, the nursing and social service staff exerted extraordinary efforts to provide fully cooked meals, snacks, nourishments, computer access, chairs for visiting, beds for naps or overnight stays, private spaces for reflection or solace, assistance with local or regional resources, explanations of Medicare charges, transportation, and the like.
- **Blend of traditional and alternative health interventions.** My brother-in-law was a traditional, Midwestern man, who needed a few weeks, a steadily declining health status, and nurses especially skilled in building patient rapport before he slowly became comfortable with nurses taking care of his needs. Despite his lifelong aversion to securing even minimal traditional primary health care, the hospice nursing staff astounded both family and

friends by gently yet frequently enlisting this man to try massage therapy and hydrotherapy. A week before he died, he finally agreed to some massage to his neck and shoulders and requested a second appointment for a back massage that he was not able to keep. Likewise, the hydrotherapy machine was not operating at the time he agreed to try it. The noteworthy point here has everything to do with the nursing staff's commitment to finding all available approaches to improving the quality of life his life even as it ebbed away.

I don't know what's going to happen with the future health care system in the United States as politicians continue to debate the merits of "fixing" our current system's weakest links, but I do pray that one little corner of northwestern Ohio is protected from any fixes that would detract from the care currently available at the Van Wert Area Inpatient Hospice Center. As you can see from this copy of our letter thanking the nursing staff at that facility (see Figure), our first experience with end-of-life care was truly exemplary, so I don't want any "fixes" to change care that needs to be meticulously preserved. CCN



Grif Alspach, RN, MSN, EdD
Editor

Dear Angie K, Melissa, Teresa, Laura, Tonya, Angie M, Barb, Kristie C, Val, Kristie W, Cris, Deb, Tricia, Karen, Jenn, Erika, Kim, Joyce, Deb, and Tia,

There are few things in life as painful as accompanying a loved one's passage from life. Thank you for the abundance of compassion, communication, thoughtfulness, support, respect and tenderness you bestowed upon John and all of us in his family during his final weeks. The only thing that could have improved upon our experience at the Van Wert Inpatient Hospice Center would have been delivering John into your gentle hands much earlier than he was willing to arrive.

You are the personification of the best that hospice support can offer. As family members who are also a physician and nurse, you left us not only grateful for your care, but exceptionally proud to be healthcare professionals.

Please know that your competency and kindness created a legacy of memories that transformed the sadness of John's death into the joy of being with you each day on that journey.

*Our enduring gratitude,
Rodger and Grif Alspach*

Figure Letter of appreciation

Critical Care Nurse

The journal for high acuity, progressive, and critical care

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Grif Alspach

Crit Care Nurse. 2010;30: 10-13 doi: 10.4037/ccn2010686

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