

Narrative Medicine: Adding Color to Life's Final Chapter

Meg Wise, PhD MLS

How do people survive and thrive in the face of life-threatening illness? How do they simultaneously hold joy and sorrow, embrace life, and let go? These questions nagged at me as I conducted patient-needs assessments to develop comprehensive eHealth programs.

Yes, patients were shocked, scared, and angry. They needed to know about their illness and treatments. They needed help dealing with emotional and psychosocial stress. But their uninvited illness also highlighted what was right about them, distilled the clutter, and underscored that, as time goes by, the fundamental things apply more than ever. Consequently, I believed assets-focused tools would activate peoples' stereoscopic vision so they could live fully in the face of life-threatening illness.

In June 2004 I began to interview people with advanced lung cancer. At about the same time, my father started 24-7 oxygen for chronic obstructive pulmonary disease. I went back home to visit several times that summer. We fell into a pattern—afternoons at the breakfast table, I with my interview transcripts and four bright highlighters and he with a bowl of fruit, fine-tipped brushes, and a full palette of paints. His eyes and hands moved masterfully as fluid and beautiful still lifes emerged from blank 8 in. x 10 in. panels. Painting was his life's calling. It was calming and in stark contrast to the messy tangle of alien, colorless oxygen tubing—an uninvited leash, an unnatural lifeline. Meanwhile beautiful, complex, and fluid life stories of mastery and purpose, sorrow and joy, and love and life—heightened in the shadow of death—emerged from my interviews. Dad's life story was converging with my lived work experience.



Bowl of Fruit, 2004, 8 in. x 10 in., acrylic on panel. © 2004 by the estate of Roland Wise. Reprinted with permission.

My research interviews elicited cancer and life stories that exemplified assets built over a lifetime. The interviews, which frequently were accompanied by photographs, provided an eloquent interpretive reflection on the meaning of life and death. People thanked me for the opportunity to talk about their experience (the first time for many) and asked for a copy of the transcript. Their stories were assets containers; the research interview itself was the intervention.



Interior, Victoria, Madrid, 1976, 42 in. x 42 in., acrylic on canvas. © 1976 by the estate of Roland Wise. Reprinted with permission.

In fall 2004 I designed an online narrative intervention study. Following the example set by the end-of-life review work of Chochinov¹, interviewees would receive an edited transcript of their interview and access to a life-review education Web site that enhanced their life stories with audiovisual features. In December I helped my father tell his story, "A Life of Making Art." My husband David did the videotaping, and we spent the 2005 New Year's holiday editing and pulling in still photos of his work.

On November 19, 2005, Dad had just returned home from yet another pneumonia-induced hospitalization. He was on megadoses of prednisone, and he was furious. He wanted to have our end-of-life conversation, but, in stark contrast to the integrative cancer care available to our research participants, neither Dad's doctor nor his home health nurses would endorse his participation in my project.

"The patient's vitals are fine," these practitioners said in front of my father, who was fully lucid. The family tried to live in this unsettling state of denial. Meanwhile, I sat and listened to Dad as he turned away from worldly matters to reflect on a life well lived and other side musings. Three days later the family could no longer endure the denial. We called in hospice home care, and it was a gift. Dad gave us many more gifts in return. He sketched, blessed us with his wisdom and love, and slept more and more.

On December 2, David, my two sons, and an uncle arrived. While Dad slept, they photographed many paintings in the soft, clear light that was bathing the room in the unseasonably mild weather. On December 3, David placed a computerized slide show on dad's lap. Dad, never a computer user, got such a kick out of seeing his "old friends" while reminiscing about his 6 decades of creating art. Most of all, he loved what he saw and was ready to sign the painting that had long sat on an easel in his downstairs studio. As he requested, we gathered the fine-pointed brush and charcoal grey tube of paint. Dad, now exhausted, said, "Maybe tomorrow. But if I don't get around to it, just have someone forge it." He fell asleep smiling and died peacefully (thanks to palliative medicine) 24 hours later at 1 am on December 5.




Self Portrait, 1970, 18 in. x 24 in., acrylic on canvas. © 1970 by the estate of Roland Wise. Reprinted with permission.

For New Year's 2006 we created a Web site devoted to showcasing Dad's life's work with clips from the movie we had made exactly 1 year earlier. The depth, breadth, and beauty of his work have continued to assuage the enormity of our loss. The Web site can be viewed at <http://rolandwiseart.com>.

Today, our online life-story project continues to enhance meaning and relationships in the lives of patients with advanced cancer and their loved ones. Why is narrative so powerful? According to the research, stories allow us to express and understand the complexity and the contradictions of our lives. As authors of our own



Last Painting (unsigned), 2005, 34 in. x 40 in., acrylic on canvas. © 2005 by the estate of Roland Wise. Reprinted with permission.

stories, we play out life's struggles, share our legacy, and write the final chapter. 

Reference

1. Colchinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA*. 2002;287(17):2253-2260.

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Palliative Care Nurse Practitioner

Full-time Nurse Practitioner to provide direct patient care and Palliative Care Consultation Service to patients on an ongoing basis as directed; Nurse Practitioner with current N.C. license; 3 years recent clinical experience; 2 years hospice or home health experience; Hospice nurse certification preferred; Knowledge of MS office suite and other clinical programs; 1300 St. Mary's Street, Raleigh, NC 27605; email: hr@hospiceofwake.org; fax: 919-719-0398. EOE.

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Geisinger Medical Center seeks a second full-time, ABHPM certified or fellowship trained ABMS certification eligible physician to join our physician-led Palliative Medicine Department. Geisinger's Department of Palliative Medicine was established in 1999. Our service currently provides inpatient and outpatient care for about 700 new consults a year. This position will work closely with all clinical services in our hospital and network/share an active roll in the education of students, physicians in training, staff physicians and other health care providers. Community directed educational programs are also offered. This opportunity offers a role in future program expansion, including system wide outreach, development of an inpatient unit, increased hospice association and institution of a palliative medicine fellowship program. Development of special interests in the field of palliative medicine will be encouraged. Research opportunities are available through The Weis Center for Research and Geisinger Center for Health Research, both of which reside on the campus of Geisinger Medical Center.

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