

One often thinks of needlecraft as women's work; as conservative; as exemplifying the values of diligence, tradition, patience and thrift. The Life Quilt for Breast Cancer does not contradict these values so much as it reconfigures them, just as a diagnosis of cancer reconfigures one's life. The small canvas of a quilt square seems to help contain the search for meaning in the chaos of disease. One contributor died a week after she completed her square; her commentary was supplied by a friend:

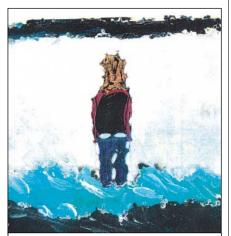
Celeste chose the crazy quilt pattern, because that's exactly what her cancer diagnosis did to her life — turned it upside down and crazy. It forced her and all of us around her to face questions about our lives and deaths that we usually put off until much later. She found herself asking the unanswerable whys and whens. We all did. We had to look deep within ourselves to find courage and commitment, far greater than we ever thought we'd need.

Anne Marie Todkill Editor, The Left Atrium

Reference

 Givner J. Unfortunate incidents. Ottawa: Oberon; 1989. p. 95.

More information on the Life Quilt for Breast Cancer can be obtained from: Box 38101 King Edward Mall PO, Vancouver BC V5Z 4L9; tel 604 310-1184; fax 604 310-1114.



Lynn walked into the sea.

Anonymous



When I was first diagnosed with breast cancer, everything seemed dark and hopeless. It was a while before I allowed myself to trust the future enough to hope again. Not to hope for a cure, but to hope to live without fear.

Mary Juengel, Sherwood Park, Alta.

Room for a view

Reading, writing and resuscitation

nce a month I travel from Lethbridge to Edmonton for day-long meetings with a dozen of my health care colleagues. We ascend to the 8th floor of a downtown highrise and take our seats around a rectangular array of tables. An occupational therapist sits to my left, an internist across the way, a pharmacist in the opposite corner and a hospital administrator a few seats over, tucked between a licensed practical nurse and a kinesiologist. For the past couple of years we've provided "technical assistance" to the Provincial Health Council, a group charged with providing a citizens' perspective on health care reform.

At first I wasn't sure what an emergency physician would contribute to the group's deliberations. But my experience resuscitating the nearly dead was soon required. Early into our second meeting I could feel growing inside me the sense of urgency that is a familiar part of my ER work. It was the day we were struggling to "state our mission" while simultaneously trying to "focus our vision" and "shift our paradigm." Words began to lose their meaning. We retreated in quiet desperation to the mantra of health care reform that had been included in the orientation package given to committee members. Someone with proven ability to "talk the talk" chanted in reassuring tones that our task was to assess the reform of a health care system that should be Consumer-Focused, Integrated, Affordable, Accessible and Appropriate. Repeat after me: "See-eff-eye-triple-A."

I looked around the table and was alarmed to see some of my colleagues' heads beginning to nod in a way that suggested they were no longer responding to verbal stimuli. I managed to catch the attention of the committee chair. I felt a little out of my element. I was without my customary high-tech tools: no reflex hammer, not even a stethoscope. As I was given the floor, I grabbed the nearest thing at hand: a book.

No ordinary book, this volume was given to me by a friend the previous evening when I told him about my new committee appointment. "You'll need this," he said, and slipped the book into my case. *Hard Travel to Sacred Places* by Rudolph Wurlitzer is written in prose that is vital, compact and jewel-like in its clarity. I felt that the excerpt I'd read before going to bed might serve as an antidote to the jargon-induced torpor that had settled over the room.

I held up the book and indicated that Wurlitzer had something to say to us as we embarked on the difficult journey to the sacred place of health care reform. I read the passage slowly. Around the table a few people shook themselves, like hypothermics momentarily distracted from the comfort of the snow bank. From his travels to



Buddhist sites in Southeast Asia, Wurlitzer writes about Tham Krabok, a rehabilitation monastery and detoxification centre in Thailand for people with addictions. There he contemplated some of the central tenets of Buddhism:

I am subject to disease, and I cannot escape it.

I am subject to death, and I cannot escape it ...

I am the owner of my deeds. Whatever deed I do, good or bad, I shall become heir to it.

These observations revived us until the coffee break.

At the next meeting the committee chair caught me nodding off and asked if I had brought another reading to share. Somewhat sheepishly I pulled out a copy of Uwe Poerkson's *Plastic Words*. I read a fragment from chapter

4, "Experts as functionaries who make reality":

The expert understands something of his field; but he derives his strongest authority from the *language* belonging to it, from the stance of the nonpartisan scien-

tific specialist. He throws the mantle of scientific language over himself and disappears beneath it; he gains distance from the lay person and through this distance wins effectiveness.²

The readings became an unwritten part of the agenda. My literary guests joined the

parade of visiting consultants who helped us write our reports. They donated a few dozen eloquent words to the process of public consultation and our examination of the so-called citizens' perspective on health care reform. What they had to say was seldom di-

rectly related to the business at hand. This contributed not only to their popularity but also, paradoxically, to their relevance. They enhanced our depth perception and widened our peripheral vision.

While we struggled with funding formulas, John Allen Paulos reminded us of the consequences of mathematical illiteracy. Our discussion of the impact of health workers' issues on patient care was contrasted by the *Guardian Weekly*'s observations of

emergency relief operations in Sudan. As we considered issues of primary care, injury control and the adequacy of measures and standards for the health care system, Primo Levi informed us:

A good part of our malaise comes ... from the extreme unknowability of the future, which discourages every long-term project of ours."³

George Woodcock sent us a short letter from the Khyber Pass. John McKnight shared strong words on medicine's hegemony. Rick Salutin provided a functional analysis of the Canadian ministry of propaganda. Umberto Eco described in detail how a business person can travel with a salmon. Kalle Lasn from *Adbusters* spoke about oppositional cultures and sent along the provocative image of camel Joe Chemo.

When our language grew vague, Doris Lessing, George Orwell and Susan Sontag warned us of what can happen to revolutions, even health care revolutions, when words go soft. The clarity of their writing inspired, entertained and sustained us. Keep them in mind when you're selecting *ex officio* members for future committees.

Vincent M. Hanlon, MD

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References

- Wurlitzer R. Hard travel to sacred places. Boston: Shambhala; 1994. p. 46-7.
- Poerkson U. Plastic words. University Park, PA: Pennsylvania State University Press; 1995. p. 80.
- Levi P. Other people's trades. London: Abacus; 1989. p. 64.

Illness and metaphor

Breast cancer

"Wait," I say, "I'll do it. I'll cure you. What we need here is something custommade. You've never been a made-for-the-masses type." I stand up, hold my hands over her head, one above the other, make a low singing sound. It sounds sort of Native American. Maybe I've tapped into something I didn't know I knew. I squeeze my eyes shut, imagine walking in suddenly on Ruth's cancer. It is caught now, frozen like an animal in headlights. Now that it is seen, its plans spread out and revealed before it, I can tell it to stop, that's all. I remember meeting a man with cancer who told me that when he was diagnosed he came home, stood naked before his mirror and wept. Then he screamed, "Come out where I can see you! Let me see you!" And I do this now, see Ruth's outlaw cells, all of them, everywhere. They are asymmetrical, ragged-edged, leering. Their colors are dark red and purple, the colors of abuse. They are slippery and quick and divide and divide and divide. But now I see them and I tell them to stop. That's all. Just stop. Why not? Why can't an ending to all this be subtle and arbitrary, when the beginning was that way? Her, sitting at a restaurant with me, with her bacon cheeseburger halfway up to her mouth, saying, "Oh, I've got another lump. Want to come with me to have it biopsied? Don't worry, they're never anything."

I open my eyes. Then I hug her. She is so thin now, like a suggestion of her former self. You have to be careful. I don't squeeze too hard, but I push a lot of feeling across the space between us. "There," I whisper. "Now you will start to heal."

She looks up at me and smiles and I see that she believes this might actually help. It is there as a slice of light in her eyes. She thinks this might actually help! And there's more: I believe it too, because it is all we have left. Oh, the stubbornness and the strength of hope. Every day that I am with her lately, I learn another staggering lesson. Everything about her is too much to bear: the delicacy of her wrist, the arrangement of her living-room furniture, the notices to renew magazine subscriptions that she gets in the mail. And yet we do bear it. She does, especially.

From Elizabeth Berg, Talk Before Sleep
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