

# West of the Rockies

## The power of words

### How the labels we give patients can limit their lives

Rachel Naomi Remen, Institute for the Study of Health and Illness, Commonweal, Box 316, Bolinas, CA 94924, [drachel@igc.org](mailto:drachel@igc.org)

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I have had Crohn's disease for more than 48 years. In my experience, professionals tend to underestimate the emotional and physical capacity of people who are chronically ill. Anyone living with significant physical problems is not a weak person, and many find ways to use what capacity they have to reach their goals. Sometimes, we can best help people by remembering that what we believe about them and their potential may affect them profoundly. The attitude of an expert is contagious and can become limiting.

I once experienced what it is like to be disempowered by being labeled. Because I had not seen a doctor for some time, I set up a consultation with Dr Z, a recognized expert in Crohn's disease, to get his opinion on the management of my condition. In advance of my visit, I sent him a 40-page summary of my extensive medical and surgical records.

His office was formal and traditional. After shaking my hand, he sat on one side of his huge desk and indicated that the chair on the other side was for me. From across a large stretch of mahogany, he began to take a careful history. Then, he asked a truly wonderful question: "Tell me the story of your illness from the beginning." In all these years, no one had ever asked me this before.

So I began my story, which involves years of intensive therapy with toxic drugs and eight major surgical procedures. I told him about being in coma for 6 months after a massive gastrointestinal bleed. I told him about high-dose continuous steroid therapy that altered my appearance so completely that my father, when picking me up at the airport, did not recognize me until I spoke his name. I told him of bones that fractured spontaneously and of years of constant pain and weakness. I also described how many of my present physical limitations were the long-term

effects of my treatment—problems that my physicians years ago had not expected me to live long enough to experience. I had never put all of these experiences together like this before, and it was overwhelming.

My story took some time to tell, and he listened attentively without interrupting. When I finished, he leaned forward and in a kind voice asked me if I was still able to practice medicine a little. Shocked, I told him I had a full and busy practice. He seemed acutely embarrassed and changed the subject.

But his remark awakened in me a sense of self-doubt. Many years before this consultation with Dr Z, other physicians had told me that I would be dead long before now. If this man, so expert in the management of my disease, thought that I could not possibly be an active and contributing member of society given my situation, was it reasonable to suppose that I might not become an invalid tomorrow? Did my life, as I knew it, have any stability?

In the weeks following this visit, I began to worry over physical problems I had lived with comfortably for years. I canceled travel plans because I did not feel safe 3,000 miles away from doctors who knew my case. Finally, one of my colleagues asked me why I seemed so stressed. Almost in tears, I told him what had happened. "May I hear the story?" he asked, and so I told it again. Like Dr Z, he listened thoughtfully without interrupting, but he heard something different. When I finished speaking, he healed me with a single sentence. "My God, Rachel," he said with admiration, "I had no idea who you really are."

People with chronic illness may become as limited and diminished by their beliefs about themselves as by their disease. A diagnosis of a chronic illness is always an encounter with





Possibility and strength in the face of adversity

the unknown. Perhaps we can best serve our patients by offering them our sense of possibility. This sense may be communicated in many ways—by tone of voice, facial expression, or choice of words.

We can also communicate our sense of possibility by our willingness to touch others in ways that are simply human. At age 29, much of my intestine was removed and I was left with an ileostomy. As a result of this surgical procedure, I felt hopelessly different: shut out of the world of femininity I had

once inhabited. While I was in the hospital, stoma therapists who were young professional women like myself called on me daily to change my appliance. On entering my room, they would don gown, mask, apron, and gloves. After they changed my appliance, they would strip off all of this protective clothing and carefully wash their hands. This elaborate ritual humiliated me and I felt shamed. I did not feel that I could live with this change in my body. In my despair, thoughts of suicide crossed my mind.

But one afternoon, a young woman whom I had never met came in to help me. It was late and she was not wearing her white coat. She went to the sink and, as she washed her hands, she asked if she might change my appliance for me. When I nodded, she took a fresh appliance from my bedside table and, in the most natural way possible, removed the old one and replaced it, without even putting on gloves.

My first thought was “How unprofessional!” But as she continued to chat with me in a warm way, as if we were at lunch together, I began to notice her hands. They were soft and feminine. Her jewelry was delicate and her nails were painted a pale pink. Suddenly, a deep and unexpected feeling arose within me and I knew that I was going to be alright. Her willingness to touch me had a profound effect. In 10 minutes, she did more than tend my body—she reminded me of my strength.

Physicians too may be limited by the ways in which we think about ourselves. Our medical expertise may not be the only thing of value that we can offer to others, especially people who live with chronic illness. Enabling someone to heal and become more whole despite physical illness may require stepping beyond the limitations of our “professional image” to re-own our full power as human beings.

Who we are may affect our patients as deeply as what we know. We can often heal with our understanding and our presence things we cannot cure with our scientific knowledge. The power to make a lasting difference in another’s life may ultimately be a function of the heart as well as of the mind.

**Author:** Rachel Naomi Remen is clinical professor of family and community medicine at the UCSF School of Medicine, cofounder of the Commonweal Cancer Help Program ([www.commonweal.org](http://www.commonweal.org)), and author of *Kitchen Table Wisdom* (1996) and *My Grandfather’s Blessing* (2000), both published by Riverhead Books.

### **Creativity and chronic disease Sergei Rachmaninov (1873-1943)**

Rachmaninov’s exceptionally large hands may have been a manifestation of Marfan’s syndrome. With his long, tapering fingers, the tall and slender pianist could easily play his own concertos, which demanded an unusually long reach at the keyboard. The gene for Marfan’s syndrome has now been identified.

Paul Wolf, *Clinical professor of pathology*, University of California, San Diego, VA Medical Center, San Diego, [paul.wolf@med.va.gov](mailto:paul.wolf@med.va.gov)