

Cornell University/New York Hospital Distinguished Alumna

Barbara Coombs Lee

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I feel very honored and grateful to receive this award and to join the ranks of so many distinguished recipients. Thank you so much, Sandra, for nominating me, and to the committee for recognizing me in this way.

As you heard from Sandra's introduction, I have not practiced what you would call traditional nursing for many years. Nevertheless, I've "been a nurse" since 1970. This school is where I became a nurse in my head and in my heart, and that shapes everything I've done ever since.

Before I came to nursing school I had witnessed little or no serious illness and death. Do you remember how relatives of patients used to sometimes stay in the nursing dorm? One night I recall being awakened by the sobs of a woman in the hallway phone booth. Her grief was poignant and overwhelming, and I remember the heaviness in my chest. I thought about how I had chosen work that would likely bring me to the raw edge of human experience on a regular basis. I felt awed by that, and grateful for the fullness of life before me.

If I were to list specific traits of a nurse's head and heart, that I have tried to cultivate, have sometimes succeeded, and that have been a help to me, it would be these:

1. A clear-eyed, uncompromising willingness to witness human suffering, and not deny it exists, whether in exchange for some gain in health or longevity, for redemption, for love, or for no purpose at all.
2. An empathic attitude, a healing presence broad enough to hold joy and sorrow, rapture and grief. Nurses go to, and stay with, those crossing a threshold, like birth, in the throes of recovery, or in crisis and grief. We reveal ways to accept and cope, ways to heal if cure is not possible. This often means affirming what is

sacred in any individual life --- living well as long as possible, showing love, and honoring human individuality and dignity.

3. A deep understanding of the power of human connection and physical touch. We hold people's hands, rub their backs or sit in quiet witness to their fear and pain. We know compassion has a human face and resilience grows when people do not feel alone. It's the nurse who stays and abides with the person's physical, emotional and psycho-spiritual experience...after the gaggle of doctors leaves the room.

I went from CCU and emergency room nursing to advanced practice, spent three years in family practice and 10 years in cardiology at the Veterans Administration. I had the thrill of breaking new ground in advanced practice, as the first non-physician to perform cardiac catheterizations. But my favorite part of the procedure was always the 15 minutes afterward, alone with the patient, applying pressure to the groin wound, with nothing to do but listen to whatever story this medical procedure had made ripe for the patient to share.

At some point the tedium of routine set in and I heard a call to more education. I kept my day job and went to law school at night, while my children were in middle school. Those three years extracted a tremendous toll on my family. After graduation and bar exams, a series of forced choices and happy coincidences brought me to a staff position at the Oregon legislature.

Then one day in 1991 two paths opened for me.

When I saw a Unitarian Universalist minister testify before a legislative committee, I glimpsed my church home, and awakened to advocacy for end-of-life choice. Neither call was fully conscious, but within a few years both came to fullness, and my church home and life's work were entwined.

New to this advocacy, I was proud and privileged to join those meeting weekly to draft a law to allow terminally ill, mentally capable adults to receive medication they could self-administer, at a time of their own choosing, if a prolonged or agonized dying process became unbearable. I became the chief spokesperson through two statewide ballot

campaigns, battles in the Oregon legislature and Congress, a challenge from the U.S. Attorney General and litigation up to the U.S. Supreme Court twice.

My organization, Compassion & Choices, (C&C) served as stewards of the new law, and 25 years later we lead a national movement for care and choice at life's end. Aid in dying is authorized as a medical practice in 5 states, Oregon, Washington, Montana, Vermont and California. The movement aims to improve the end-of-life experience for everyone, not only those who may want to access medical aid in dying.

I have seen availability of aid in dying improve the quality of end-of-life care, physician education and patients' sense of their own agency. C&C also works to improve pain and symptom management, make advance directives more effective, and reduce unwanted tests and treatment. We're building tools to help people navigate the difficult shoals of advanced illness, when tests and treatments yield diminishing returns for an individual's investment of energy, pain, side effects and other burdens.

This is a consumer movement to transform how Americans approach the end of life, whether they get to live their values and beliefs to the end. It springs from a nurse's head and heart. We all know that too often, as patients get sicker, a medical-industrial imperative takes over, momentum builds on itself and overwhelms the person's role as decision-maker. Often the priorities of intensive medicine prevail and people die in places and in ways they would not choose if they realized what was happening.

In spite of all the advances of palliative care in the last 20 years, indicators of treatment intensity in the last 6 months of life are rising. More people die in hospice than ever before, but more people spend days of waning life in ICU's, too. They go to hospice too late, and only after suffering through excessive tests and treatments.

I believe change must come from consumers' changing expectations, from individuals who come to the physician armed with tools to build trust, foster candor about the pros and cons of tests and treatments as illness progresses, and assert our own values and priorities for life's final chapter. We are in the midst of designing that social change campaign and building those tools.

A nurse's call to stand in empathy with those living with agony or suffering through loss, and help them cope, continues in this advocacy role. I'm grateful for the nurse in me that still owns my head and my heart.

Thank you very much.