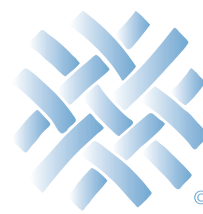




OHSU CENTER *for* ETHICS *in* HEALTH CARE



A Life of Sharing

One family's painful story illustrates critical need for improved POLST communication system

There was a graceful elegance to Elizabeth Hirsch – an innate poise enlivened by her radiant warmth that in some ways belied the exquisite attention she gave to the details of life, her own and those of her countless cherished friends.

After her death in 1999, Portland's First Unitarian Church was full to the brim as people paid tribute to her remarkable humanity and the myriad ways in which she had contributed to her community. Her son, Bob Conklin, recalls of that day: "I think half the people there considered my mother to be their best friend. And they were right."

Such was the depth of her capacity for friendship and service. To this life calling she brought many qualities: boundless compassion, vigorous intelligence and intuitive insight. Her greatest desire was to enrich the lives of others, and her gifts for this purpose were both imaginative and prolific.

Underlying these gracious gifts of self, though, was her deep understanding of how the details of daily life can be the language of caring. Books and ideas shared, civic organizations served, special days remembered, friends brought together, dinner tables beautifully tended, letters written and phone calls made. These details were the currency of her life, spent freely and wisely to nourish her vast circle of friends and wider community.

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photo on cover:
Bob Conklin,
Elizabeth Hirsch's
son, relives painful
memories as he shares
his mother's story

(continued from cover)

It was Elizabeth Hirsch who, as wife of White Stag executive Harold Hirsch, suggested that the leaping reindeer on the company's sign at the west end of the Burnside Bridge should sport a red nose during the holiday season. This brilliant gesture has provided decades of holiday joy for an entire city – vividly illustrating how she regularly created magic through her loving attention to even the smallest detail.

It was quite fitting, then, that as she advanced in years and her health declined she would pay careful attention to the details of her wishes for end-of-life care. A long-time supporter of the Center for Ethics in Health Care at OHSU and always an unshrinking realist, she knew all too well how important it was to address these crucial issues and to ensure that her desires were known to others.



Elizabeth Hirsch was a
woman of rare elegance
and grace

To that end she met with her doctor to fill out a POLST (Physicians Orders for Life-Sustaining Treatment) form – designed for people in frail health as a detailed, dependable means of communicating end-of-life care wishes, and more effective than an Advance Directive because it constitutes actual medical orders. Her wishes were abundantly clear. “Do Not Resuscitate.” “Limited Interventions,” which specifically meant that she did not wish to be put on a breathing machine in an intensive care unit.

None of this came as a surprise to her family and close friends, who knew how deeply this woman of regal bearing would want at the end of her life to avoid the medical interventions she viewed as indignities.

Tragically, though, events unfolded in a way that diverged drastically from the course that Elizabeth Hirsch had charted.

Shortly after her 88th birthday, when she was frail but otherwise active and cheerfully engaged in life, she experienced a sudden catastrophic medical event that left her on the brink of death with no hope of recovery. Three cruel twists of fate made this dire circumstance even worse. Her son and daughter-in-law – her primary advocates – were out of the country. The POLST form she had so carefully completed was not found at the scene. And the hospital she was taken to had no record of her POLST.

In the absence of medical orders to tell them otherwise, emergency medical professionals have no choice but to do everything possible to sustain life, irrespective of the prognosis for recovery. In Elizabeth's case, that meant extensive medical treatments – numerous interventions that contravened her deeply-held desire for a dignified and peaceful death and, practically, could serve only to prolong her dying process. She died two days later connected to a maze of life-support equipment and other medical technology in an Intensive Care Unit, the end she dreaded most.

The suffering this created for her family members is still felt years later. While they bear no malice toward the emergency personnel who were simply doing their job, they feel profound sadness that Elizabeth's wishes were not met.



As her son Bob puts it: “She had carefully considered how she wanted to be cared for in a situation like this, and she did everything she could to ensure that would happen. It’s heartbreaking to know that in her last days she was subjected to interventions that she had tried so conscientiously to avoid. The system failed her.”

Unfortunately, as an Oregon study reveals, in approximately 25% of cases where POLST forms have been completed, the brightly colored form cannot immediately be found at the scene of a medical emergency. This leaves emergency personnel obligated to provide any and all lifesaving treatment, however unwanted it might be – a conundrum that presents a critical gap in the effectiveness of the POLST program to give patients control of their own health care.

In answer to this distressing reality, Oregon’s POLST Task Force proposes to develop and test a centralized electronic POLST Registry for the Portland metro area. This sophisticated system will provide emergency health care professionals with immediate access to medical orders that reflect individual wishes for care, ensuring that critical decision making is no longer subject to the uncertainties of whether or not the right piece of paper can be found at the scene.



Dying in an Intensive Care Unit was what Elizabeth Hirsch dreaded most

“Unwanted medical intervention at the end of life can cause terrible and totally needless suffering for both patients and families.” Susan Tolle, MD

Such electronic records technology was not available at the time of Elizabeth Hirsch’s need. But it will be transformative in its ability to save others from the tragic communication gap that led to her ordeal.

“The POLST program has dramatically improved the way we are able to honor patients’ wishes at the end of life, and it is vital that we now address the critical and very practical issue of how to ensure that these medical orders are immediately available to emergency personnel when needed,” says Susan Tolle, MD, director of the Center for Ethics. “Unwanted medical intervention at the end of life can cause terrible and totally needless suffering for both patients and families. A centralized POLST Registry is a crucial next step to help keep end-of-life medical decisions in the hands of the patient.”

For Bob Conklin, there is comfort – even amidst the painful memories – in sharing his mother’s story to illustrate the urgent need for a POLST Registry.

“Mother made her body available for research after her death. And this story is another part of that contribution. Serving other people was her whole life, and she would have gladly offered her experience as a way to help prevent this kind of suffering for others.”

The OHSU Center for Ethics is currently raising funds to support the building and testing of an electronic POLST Registry for the Portland Metro area to serve ultimately as a model for the state and beyond. The POLST program – initiated by the Center in partnership with a broad consortium of health care professionals in 1995 – now serves numerous communities throughout the nation. More information about the POLST program is available at www.polst.org.



A message from
Center for Ethics in Health Care
donors Cornelia Hayes Stevens and
Lisa Andrus-Rivera

*As our last newsletter story illustrated, much of the work of OHSU's Center for Ethics in Health Care focuses on education and the vital role it plays in improving the way health care is delivered to patients. But sometimes problems in health care require a different kind of approach. When the problem stems not from individual shortcomings that can be remedied by more and better teaching, but from a systems failure – where good people with good skills and good will are trapped in a flawed system – the only effective approach is **policy change** to address the system itself.*

Elizabeth Hirsch's heartrending story is a powerful example of that kind of need. When her POLST documents could not be found, her wishes for care could not be honored – a devastating outcome, and a clear indication that the system did not function as it was intended to do. Only a policy change, in this case the creation of an electronic POLST Registry, can remedy this kind of system failure so that end-of-life care decisions remain where they belong, in the hands of the patient.

This issue has a special resonance for me (Lisa). For fourteen years I have been haunted by the memory of emergency personnel trying to resuscitate the lifeless body of my own father – an outcome that he absolutely did not want and would have wished to avoid at any cost. In contrast, my mother – who died after the POLST program was available – died a very peaceful death, just as she wished. The contrasting stories of my parents' deaths explain my deep commitment to the Center's work.

My own experience also confirms for me how much trauma and sadness there is for the families of patients like Elizabeth Hirsch for whom – despite careful preparations, and the caring response of emergency personnel – the system failed so dramatically.

We are deeply grateful to Bob Conklin for his courage and generosity in telling his mother's story, and we believe wholeheartedly that the POLST Registry is the policy change that can prevent this kind of needless suffering for others. We hope very much that you will want to partner with us to bring this critical change to fruition.

UPCOMING *events*

OCTOBER 3, 2007

*Daniel Labby Senior Clinician's Seminar:
"HPV Vaccine: Who Should Get it and
When? When Science and Emotion Collide"*
MacDonald Auditorium, OHSU Casey Eye
Institute, 10:00 AM to Noon

NOVEMBER 7, 2007

Annual MAC Luncheon
MAC Club, Portland, OR, 12:30 PM to 2:30 PM

APRIL 10 & 11, 2008

*18th Annual Kinsman Statewide
Ethics Conference: "Something's Gotta Give"
Importance of Ethics in Oregon
Health Care Reform*
Co Host: Asante Health System
Smullen Center, Medford, Oregon

JUNE 13, 2008

Statewide Palliative Care Conference
Co Host: Adventist Hospital, Portland, OR



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