

Missoula leading the way in care for those at life's end

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During the past decade public awareness about end-of-life issues has dramatically increased and with it higher expectations for care and family support during times of illness, family caregiving, dying and grief. People are gradually becoming more assertive in pursuit of those expectations. National medical and nursing and hospital organizations have adopted progressive professional standards, developed new education and training programs and have (finally) begun revising Board certification exams and hospital accreditation procedures to include pain management, ethical decision-making and basic communication with seriously ill patients and their families. Still, we have a long way to go. Current research still paints a dismal picture of the way many Americans die. This past November the Last Acts Campaign published a national report, which ranked states on 8 parameters pertinent to end-of-life care. It contains sobering information about the proportion of people whose last days are at home (36% at best), the shocking percentage of nursing home residents in persistent pain (33% at best and over 50% at worst!), the continued under use of hospice, and the number of doctors and nurses certified in palliative care (infinitesimal, but growing).

Since the mid-1990's Missoulians have been actively contributing to national efforts to improve the situation in unique and critically important ways. The Life's End Institute, formerly the Missoula Demonstration Project, began with the perspective that illness, personal caregiving, death and grief are not solely medical problems, but instead, fundamentally, are parts of the lives of individuals, families and our community. Drawing from clinical and social sciences, we have developed and published research methods that open up these aspects of community experience to scientific inquiry. Drawing on organizational change theory and pragmatic business approaches, we have created community-based quality improvement strategies that really work.

Missoula's efforts have placed us in the national spotlight. The Robert Wood Johnson Foundation's new Rallying Points program (www.rallyingpoints.org) is rooted in Missoula's groundbreaking work. The Life's End Institute was selected as Rallying Point's Regional Resource Center for community-based, end-of-life care coalitions in 14 western states. In the process of responding to peoples' needs, we are assisting coalitions to build "social capital," strengthening naturally occurring communities of schools, service groups, places of work and places of worship, and neighborhoods.

Typical of Missoula, we have made a practice of thinking globally while acting locally. The Missoulians who comprise Life's End Institute's Board of Directors, staff, committees and task forces recognize that the most valuable contribution we can make is to get things right, right here, where we live. We have the advantage of having wonderful health care in Missoula. But in matters of illness, caregiving and grief, it takes a community to "get it right." By taking the best care possible for one another, we can set an example of what is possible elsewhere. A spirit of enlightened self-interest suffuses the serious work we do, making it all surprisingly upbeat.

This week Life's End Institute is publicly launching the Choices Bank. It's the latest collaborative project involving Missoula 's health care community, aging services, faith communities, legal community and many individuals in many walks of life. The project advances a core value of Americans – the ability to control key life choices, even if we become too ill to speak for ourselves. Choices Bank specifically addresses the perplexing challenge of retrieving a person's advance directive – their living will or power of attorney for health care documents – urgently, whenever and wherever they are needed.

Think for a moment: Could you find your own living will or power of attorney forms in a hurry if you had to? Could your spouse? And could you find his or hers? For most people the answers are No.

Having previously practiced emergency medicine for 15 years, I know all-too-well that these critical documents are often not available when they are needed most – when a car accident or stroke or heart attack forces families to make life and death decisions. As the person named on my mother's and sister's advanced directives, until Choices Bank I could never be sure I could produce those documents if, God forbid, a crisis occurred. What if it happened when I was out of town? Now that their documents are deposited, I can, anytime, anywhere.

In typical Missoula fashion, we have brought local ingenuity, energy and community pride to attacking a national problem. In typical Life's End Institute fashion, we brought nearly half a million federal grant dollars to Missoula to support the effort.

Choices Bank is the first community-owned and operated scanned-document repository for people's advance directives. It enables people to find their own, or their loved ones advance directives within 5 minutes, from anywhere with Internet access or even a phone and fax machine. Health care providers have access 24/7 with appropriate identifying information – and they have the assurance of knowing that the documents are current and valid. Privacy is maintained and, because these documents cannot be altered on line, the documents are secure. You can bank on it.

There are plenty of other challenges ahead in the quest to improve the quality of care, social support we all need – and deserve – as we approach life's end. In addition to honoring people's choices, controlling and enhancing communication and spiritual support, we must tackle thorny issues of housing and transportation for the most ill, aged and frail members of our community.

Of course, all these problems exist in every community. Locally, Life's End Institute will continue to engage Missoulians in bringing novel, community-based approaches to continually solving these problems locally, and offering our experience to colleagues and communities around the country and around the world. You can bank on that too!

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