

MCDES History: 1977 –2017

by Sharon Dardis

Minnesota Coalition for Death Education and Support is celebrating its 40th anniversary! This places us in good company with other entities also commemorating milestones this year, including Minnesota Public Radio (50 years), the attack on Pearl Harbor (75 years), my own graduating high school class reunion (50 years), and even the release of the movie Bonnie and Clyde (50 years)

Anniversaries are cause for reflection. For us to be here to witness, to remember and share stories is a privilege. We testify to the occasion or organization's value in our lives. Reflection in turn gives weight and meaning, underscoring our ability to connect meaningfully with others in the world. Hooray for us, hooray for MCDES! We've survived and prospered for 40 years!

The Formative Early Years

Thanks to long-time board member, Paul Johnson who dug through a stash of MCDES archives and found the original brochure about the beginning of MCDES. Written by Larry Beresford, and published March, 1983, "Five Year History of the Minnesota Coalition for Terminal Care," demonstrates the foresight the MCDES board had to commission this historical booklet. Beresford, a San Francisco free-lance writer and editor in the health field, held "many roles within the hospice movement," including hospice support staff, newsletter editor, and patient care volunteer. Originally from Minnesota, he was a Coalition staff member from 1978- 1979 when he was enrolled in the University of Minnesota's School of Journalism.

Names listed under "special thanks" include respected death and dying educators and networkers you may recognize: Don Irish, Mary Ellen Grobe, Joanne Lucid, Peter Thoreen and Greg Owen, as well as John Brantner, Doug Wallace, Howard Bell, Hugh Harrison, Carmiam Seifert, Bob Slater, Mary Ann Anglim, Gail Noller, Robert Green, and Paul Riddle.

Initial Purpose

The initial purpose for the Coalition was "to improve the care and services available to persons confronting death and to individuals and groups in supportive relationships to these persons." The purpose noted in March of 1983 had not changed since the organization's inception in 1977, when it was first conceived by a University of Minnesota YMCA program director who was interested in coordinating the emerging work in the areas of death, dying, and terminal care. Even then, the goals were "to provide opportunities for communication and sharing and to promote and provide education in support of people involved in the care of those confronting death." The focus was later expanded from just the Twin Cities to encompass all of Minnesota.

The Story Begins

In the words of Beresford: "The story begins with Howard Bell, founder and first director of the Coalition. In 1971, while at Yale University Divinity School in New Haven, CT, Howard enrolled in an interdisciplinary course about the chronically ill. This class had been created by Edward Dobihal, Director of Religious Studies at the Yale-New Haven Hospital, and was an early educational effort in the issues of death, dying, and terminal care. Howard found his attention naturally focused on this field, and when he came to the University of Minnesota YMCA in 1972, he explored it further.

New Ideas About Death and Dying

There were at this time many new ideas springing up in health care. Elisabeth Kubler-Ross, a psychiatrist working in a Chicago hospital, had begun listening to dying patients; feelings and experiences. She formulated the concepts of five stages a dying patient may experience and presented them in her book, *On Death and Dying* (McMillan, 1969). Another new idea being presented was hospice, a philosophy of wholistic palliative care for dying patients and their families. Well-known English hospice programs, St. Joseph's and St. Christopher's, influenced hospice programs in this country, beginning with the Connecticut Hospice, Inc. in New Haven and the Hospice of Marin in California.

During this time, Robert Slater, a professor of Mortuary Sciences at the U of MN stated, "Outside of Harvard Uni-

versity and Massachusetts General Hospital, there is no greater concentration of death and thanatology experts than in the Twin Cities.” Slater followed new developments in death and dying because of their importance to mortuary science students. Other Minnesota experts included Robert Fulton, who established the Center for Death Education and Research at the University in the late 1960’s, nursing professor Delphi Fredlund, the late professor of psychiatry George Williams, and psychology professor John Brantner, all of the University of Minnesota.

First Meetings and Conferences

The University had three large meetings on death between 1967–1969, largely due to Fulton and Slater. In 1972, a conference entitled “Death and Attitudes Towards Death” was sponsored by the U of M’s Bell Museum of Pathology. Another nucleus for death education had been the Sociology Department at Hamline University in St. Paul. Professors Don Irish and the late Betty Green organized a 1970 conference, “Death Education: Preparation for Living.”

Don Irish said, “When we printed the program, we planned for 300 participants. Ten days beforehand, we already had 600. For a subject supposed to be taboo, the conference drew over 1200 people to the Hamline Fieldhouse!” It was broadcast on a local public radio station and the proceedings were published the following year in a book with the same title (edited by Betty Green and Donald Irish: Schenkman, 1971). Betty’s interest in the issues prompted her husband, Robert, a St. Louis Park oncologist, to learn more about death and dying and together, he and Betty gave talks to educate the public.

New Ways of Caring for the Dying

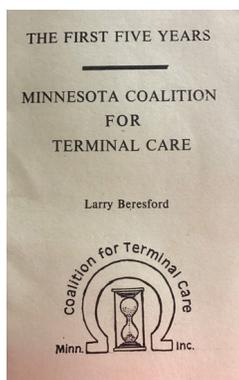
Accompanying educational efforts such as these were new ideas for providing care to dying patients. Ida Martinson, a professor of nursing at the University, obtained a grant to study home care for the child with cancer. Preliminary work was done in ’74 and ’75. Mary Ann Anglim, University nursing professor was also a long time supporter.

In January, 1975, Gail Noller, Director of Social Services at Mount Sinai Hospital in Minneapolis, was asked by the chief of medical staff to respond to a complaint about a poorly handled death in the hospital. That same month, Gail’s father had surgery and was dying. As a result, she became actively involved in creating a committee to explore the way the hospital dealt with death and dying. The committee evolved into the Program Concerned with Death and Dying, and eventually included support groups for patients and families, grief groups for the bereaved, and a committee that discussed problem cases, legal and ethical issues, and policy decisions for the hospital on issues such as do-not-resuscitate orders. One outcome was an administrative decision allowing nurses to attend funerals of their patients!

Another Twin City area hospital developing innovative programs for cancer patients was North Memorial Medical Center in Robbinsdale, whose home care department cared for Senator Hubert Humphrey during his terminal illness in 1977. Judi Johnson and Pat Norby developed the “Share and Care” and “I Can Cope” programs which were distributed nationally by the American Cancer Society. Both programs served people expected to survive their illness as well the terminally ill. As a result, North Memorial developed home care as well as in-patient support services which later evolved into a hospice program.

Howard Bell’s interest in death education and work with the University YMCA, provided a receptive environment for new ideas and challenging programs. Doug Wallace, Executive Director at the YMCA helped develop “Eight Weeks to Live — Eight Weeks to Die.” This experimental program was offered in the spring of 1975. The idea was to ask healthy college students to confront their own mortality by simulating the experience of a terminal illness through a variety of learning techniques. Participants role-played encounters with student nurses, doctors, clergy and morticians. Participants said the program had a major impact on their lives. One of the students in that first course was Peter Thoreen, who said, “I got hooked on the issues; on the realness of it.” Peter stayed with the program as a volunteer student leader and after graduation, directed it for two years.

The Eight Weeks program strengthened Bell’s relationships with death and dying experts. Bell said, “They were all saying, “Why don’t you organize something?” One idea was to establish a hospice program in the Twin Cities, using Montreal’s Royal Victoria Hospital Palliative Care Unit as a model. The catalyst was a student named Michelle Holtze, who had been referred because of her interest in death and dying. Bell continued, “I asked her to help me draft a proposal. We sat



down and dreamed up the Coalition for Terminal Care.”

First Working Proposal

The first working proposal by Bell and Holtze, dated March 1977, was mailed to a dozen leaders in the field. The idea was to bring them together for an exchange of ideas and information. The first organizational meeting was held June 10, 1977 at Fairview Lutheran Deaconess Hospital. Forty invitations were sent; 77 attended and was the beginning of the Coalition for Terminal Care. The first home care hospice in Minnesota and one of the first in the United States, was opened in August of 1977 by Bethesda Lutheran Medical Center in St. Paul. Their hospice leaders also joined the Coalition.

State-wide, much excitement was generated and collaboration was sparked. Others contributing to the early efforts of the Coalition were Carmian Seifert, Robert Brown, and Robert Ryndes, Jim Platten, Caryl Range and Reverend James Diamond. The Coalition represented a “neutral force in the competitive health care community of the Twin Cities. It did not represent any single health care institution nor limit itself to hospice service development.” It was to provide “communication and collaboration” among individuals and institutions wanting to establish hospice programs.” At this time, it was officially an adjunct program of the University YMCA and so permitted Howard Bell to operate outside of potentially competitive health care organizations providing leadership in the developing death and dying field.”

Early Objectives, Structure, Surveys”

In Larry’s words: On October 21, 1977, the Coalition sponsored a second quarterly meeting that featured reports about the objectives and organizational structure of the Coalition and the results of two opinion surveys conducted by Peter Thoreen, one on the care of the terminally ill in the U of M Hospitals and the other on the overall quality of care for the terminally ill in the Twin Cities. The Coalition’s goals were to stimulate community support for making available the concept of hospice care to terminally ill patients, to provide a mechanism for communication among persons involved in the caring for the terminally ill, to encourage community educational projects that would broaden support and knowledge of death and dying issues, to support efforts at collaboration where total care and services could be enhanced and to develop new approaches to service delivery. A membership fee was established, a steering committee was organized and other projects were identified, including a newsletter, liaison with a physician’s group called the Foundation for Health Care (then studying terminal care) and hospice exploration through a task force under the leadership of Gail Noller.

“If Money Were No Object...”

One more component was needed to make the Coalition an organization that would have an impact on development of care for the terminally ill, and that was provided in the fall of 1977. A meeting was held at the University YMCA with Bell, Thoreen, Wallace and a philanthropist named Hugh Harrison. Harrison had made his fortune in the mining industry on Minnesota’s northern Iron Range and had been involved in both philanthropy and philosophical explorations.

“I’ve been interested in life—its meaning and its possibilities,” Harrison explained in a recent phone interview from his home in Oregon. “In the death experience, there was a kind of window opening up around the world, now, to think about why we’re here and what’s it’s about.” This interest has led Harrison to invest in “Continuum: the immortality principle,” a traveling exhibit that explores various religious and scientific perspectives on the possibilities of immortality. Harrison was also involved with many innovative programs at the “Y,” donating money, making sure the money was well spent, and offering suggestions for programs such as Eight Weeks.

At the meeting held in the fall of 1977, ostensibly to review the Eight Weeks program, Harrison asked the “Y” staff about their dreams for coordinating the death and dying field if money were not an object. He wanted to make a donation to this field and he asked the “Y” staff to develop proposals for Eight Weeks and the Coalition. Shortly thereafter, a check for \$50,000 arrived in the mail.

“I don’t know how much money is given out by foundations each year,” Harrison explains. “Precious little of that gets teamed up with the kind of dedication, originality and talent of those two guys (Bell and Thoreen). The evidence is this Coalition. What Harrison got for his money was a newly formed organization in the midst of the developing death and dying community in the Twin Cities. He provided funding to pay staff salaries for supporting and coordi-

nating this movement to improve the care of the terminally ill. The Coalition, from its neutral position, could bring together leaders in the field and provide them with education and other tools. Specifically, Harrison provided a grant to pay Howard Bell's salary as Coalition Director, "Y" staff person at Bethesda Hospital's hospice. The grant also enabled Bell to spend a week with Richard Lamerton at St. Joseph's Hospice in London, to attend the National Hospice Organizations (NHO) first annual meeting in Washington, D.C., to teach a death education course at the Twin City Institute for talented youth. Thoreen was to be paid as Associate director of the Coalition and as a program director at the University YMCA, working with programs such as "Eight Weeks to Live—Eight Weeks to Die." Harrison's grant also funded a half-time secretary for the Coalition and office expenses. The one-year grant was to begin July 1, 1978.

A "Hallmark in Minnesota Hospice Development"

During the funding negotiations, a planning committee was preparing a terminal care conference. "Concepts of Care for Persons With Limited Life Span" was held February 3 and 4, 1978 at L'hotel Sofitel in Bloomington, and is still talked about as a hallmark in the history of hospice development in Minnesota. Over 259 participants heard several national experts, including many from Minnesota.

The following month the Coalition's first newsletter was distributed, highlighting the February conference. This newsletter also described the work of the hospice task force chaired by Gail Noller and the formation of the Coalition's Steering Committee. The nine members of the steering committee were Bell, Anglim, Green, Noller, Platten, Seifert, Barbara Dixon of Hamilton Associates, Sadi Proehl of Transition Counseling Services, Inc. and John Hill, a physician at Abbott-Northwestern Hospital. Future issues of the bimonthly Coalition newsletter covered....the creation of a National Hospice Organization, a visit to St. Paul by Richard Lamerton, Medical Director of St. Joseph's Hospice in London, the opening of a hospice in-patient unit at Bethesda, a burial society at Adath Jeshurun Synagogue in Minneapolis to honor the dead in the traditional Jewish manner, a meeting between Coalition representatives and state legislators, and the Coalition's Spring Meeting, attended by 70 people...where the topic discussed was the Ethical and Legal Issues of Terminal Care.

The Saga Continues

After the early years of MCDES, it is surprising to find there was a time when MCDES came very close to extinction! There was a discussion among a number of the board members in 1994 that the organization be disbanded, and, as the story goes, five folks on the board stepped up to help decide how to keep MCDES alive. Thanks to Paul Johnson, Ben Wolfe, Barb Force, Paula Dickie, and Gail Noller, it was agreed those who did not want to continue would resign from the board, and the five then put their heads together and agreed to divide responsibilities and carry on. Another interesting twist is, it was during this time that Verla, working at the U of MN Hospital and Clinic, was asked to help with conference certificates, and eventually, the organizational data base. As the saying goes, "...and the rest is history!"

Early November of 1994 found MCDES at a crossroad. Board members were divided regarding the direction and viability of the Coalition. Surveys were distributed to gain insights on how to proceed; one sent to members, the other to board members, some of whom thought the best approach might be to "dissolve funds and disperse to another organization." As a result, a transitional board of five members remained to help determine if MCDES would and could continue: Paula Dicke (secretary), Gail Noller (treasurer), Paul Johnson (program coordinator), Barb Force (membership), and Ben Wolfe (newsletter editor). Options to consider included moving forward with new vigor or dissolving MCDES.

So, in late November, a detailed survey was sent to a diverse 310 members, asking for input. Dues at the time were \$15 or \$10 for students and seniors. Questions posed related to programing and services, such as how important education, networking, and support were to members. A call was issued for additional board members. Voluntary participation from the membership would prove to be key to MCDES's survival.

In January 1995, a pledge for a "new beginning" was offered. The response to the board survey was "overwhelmingly positive," with additional board individuals to be presented for a vote at the March annual meeting. 83% of respondents had requested MCDES keep the member directory; 97% asked to continue receiving the newsletter. Dr. Jim Miller from Indiana would speak at the March meeting, "The Transforming Mystery: Spirituality, Loss, and Grief." Plans were also well-underway for a spring conference in May. New board members who stepped forward to help included Lisa Eiche, Mary Ann Miller, Kay Johnson, Ricky Rask, Tricia Jorke, Ralph Rickgarn, Hella Lange, and Sharon

Spear. It was an exciting “new beginning” for MCDES.

Instead of an executive board, it was decided to designate a Chairman. In March of 1995, Ben Wolfe, still editor of the bi-monthly newsletter, accepted a larger leadership role. A June 1995 notice revealed the start of an idea which continues today, the MCDES Scholarship Fund. A “Small Grants Award” idea was also presented as a way to involve, motivate, and encourage membership.

It was also during this time Verla Johansson first became involved with MCDES. As Verla recalls, she was working at the U of MN Hospital and Clinics when Paula Dicke came “waltzing into the office and asked if I would do her a favor.” Paula needed certificates for an upcoming conference. Verla said, “Yes.” Months later, Verla was asked to do a data base for the same group. Again, thankfully, Verla said “yes” and so, over time, she became the membership person, then began formatting brochures, laying out newsletters, and taking conference registration.

An interesting note in August of 1995 mentioned “MCDES board fantasies.” Happily, several of these fantasies are reality today: 1) that members “somehow actually get to know each other both professionally and personally. 2) that when we say “MCDES or the word, Coalition,” everyone knows who we are! 3) Camaraderie—a “place” for those of us who do “this work” to share and create about it.

With continued involvement from members and the Board, MCDES will continue its mission well into the future. Thanks to everyone along the way who enabled this important organization to flourish and serve the needs of the bereaved and those dedicated to helping them. The MCDES crossroads is reminiscent of Robert Frost’s Road Not Taken. “I shall be telling this with a sigh, somewhere ages and ages hence, two roads diverged in a wood, and I—I took the one less traveled by, and that has made all the difference.