

2017 Marks MCDES 40th Anniversary

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!

This is **Part One** of the history of MCDES. For the next few issues, we'll do a bit of reminiscing! We hope you'll join in and contribute your own recollections. (Submit to the editor: sdardis@aol.com.)

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 Coali-

tion 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 Thorn 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

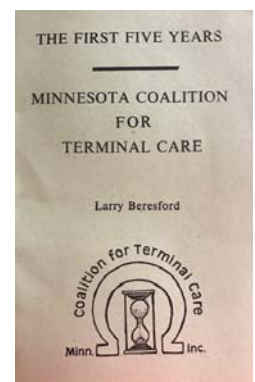
early educational effort in the issues of death, dying, and terminal care. Howard found his attention naturally focused on this field, and when he came to the University of Minnesota YMCA in 1972, he explored it further.

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 University 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

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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**,

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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.”

To Be Continued in the June Issue