





COMPASSIONATE PURPOSE

A GLOBAL HOSPICE EXPERT, J. DONALD SCHUMACHER '72, PSYD, EDUCATES CONGRESS AND THE PUBLIC TO ENSURE HIGH-QUALITY END-OF-LIFE CARE FOR ALL AMERICANS.

Story: Kristin E. Etu '91 Photos: Susana Raab

One truth has become painstakingly clear to **J. Donald Schumacher '72, PsyD.**

"People often wait until it is too late to engage in meaningful conversation with or to settle strained relationships with their loved ones," says the president and CEO of the National Hospice and Palliative Care Organization (NHPCO). "We try to help dying patients and their families realize that in life, saying 'goodbye' is just as important as saying 'hello.'"

Schumacher knows all too well the problems caused by unresolved grief. In the early 1970s as an undergraduate student at Canisius College, Schumacher lost his close friend, Jim, to leukemia. His beloved grandmother succumbed to cancer.


"Back then, there were no hospice programs in place," says Schumacher. "Dying people were essentially isolated in hospitals and people did not have the opportunities or support to have important discussions with loved ones."

Schumacher believes that because of the advances made in hospice care, which include pain management and compre-

hensive support, there is a greater acceptance of the inevitability of death.

"People can have a more engaged dying experience when they are not separated from their loved ones," he adds. "A main goal of hospice is to keep the dying person with his family until death."

British physician Dame Cicely Saunders, MD, founded the first modern-day hospice in London in 1967. Based on the belief that each person has the right to die pain-free and with dignity, hospice and palliative care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support tailored to the person's needs and wishes. Doctors, nurses, home health aides, social workers, chaplains, counselors and trained volunteers work together to focus on the dying person's needs. Hospice care can be provided in the person's home, in freestanding hospice centers, hospitals and nursing homes and other long-term care facilities.



Today, there are nearly 5,000 hospices centers across the United States. As NHPCO president, Schumacher oversees a staff of 65 and leads the largest non-profit organization that represents hospice organizations and professionals around the world. Schumacher is a globally-recognized authority on hospice and palliative care, and lectures nationally and internationally on the topic. Based in Alexandria, VA, NHPCO is responsible for public policy, education, legislation, regulatory issues and fundraising.

Schumacher's calling as a leader in the hospice field was not always so apparent. As an English major at Canisius, he intended to become a college professor. But his advisor, **Kenneth M. Sroka '65, PhD**, professor of English, recommended that Schumacher teach for awhile first to see if he actually enjoyed the classroom atmosphere.

"Don is caring, compassionate and has a sympathetic temperament that makes him well-suited to work with people in severe need, such as the terminally ill or those who have lost a loved one," says Sroka.

hospices in the United States, where he did extensive counseling work with dying patients and their families.

Schumacher returned to Buffalo in 1989 to become president and CEO of Hospice Buffalo. He led the development of an integrated hospice campus, launched a variety of hospice-related organizations including nursing homes, mental health and pediatric care facilities, as well as an exceptional bereavement program. When Schumacher started, Hospice Buffalo took care of 28 patients at a time. When he left 13 years later, its patient census numbered more than 600. Today, it serves nearly 1,000 and is one of the 20 largest hospice and palliative care programs in the nation.

Gretchen Brown, president and CEO of Hospice of the Bluegrass and chair of the board of directors for NHPCO, believes that Schumacher's transition from the local to the national level was a natural one.

"Don has the ability to see what the broad-range service possibilities are, such as international outreach, organizational collaboration, education and advocacy," she says. "As a national leader, you can affect positive change with so many more people

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Sroka's advice turned out to be spot on. Schumacher taught English at Mount St. Joseph's Academy for three years (1972-1975). In the spring of 1975, he attended a lecture in the college's Grupp Fireside Lounge by renowned Swiss psychiatrist Elisabeth Kübler-Ross, MD, author of the groundbreaking book *On Death and Dying* and creator of "The Kübler Ross Model" on the five stages of grief.

"When she spoke about the potential experiences between a dying person and their loved ones, I knew right away what had been missing when my grandmother and Jim died," says Schumacher. "I didn't have a chance to say goodbye to either one of them and they essentially died alone."

Kübler Ross befriended and mentored Schumacher. He went on to obtain his master's degree in counseling psychology from the State University of New York at Buffalo in 1977 and his doctorate in psychology from the Massachusetts School of Psychology in 1986. In 1987, Schumacher founded The Hospice of Mission Hill in Boston, MA, one of the first AIDS

and encourage it in a much wider arena."

As NHPCO president, Schumacher now dedicates a great deal of time to the nation's healthcare reform, most recently, Section 1233 of the House Ways and Means Committee version of the bill. It contains a new Medicare provision that allows patients coverage for a voluntary "Advance Care Planning Consultation" with their physician when faced with a life-threatening or terminal diagnosis, admission to a long-term care facility, a skilled nursing facility or a hospice program. Schumacher and NHPCO work diligently to dispel the rumor that such proposals would create government-sponsored "death panels" to decide which patients live or die.

"This issue has unfortunately become politicized and has absolutely nothing to do with the legislation," notes Schumacher, who has been interviewed on the topic by more than a dozen national news outlets, including *Newsweek*, *US News & World Report*, *The New York Times*, *The Washington Post*, ABC News and CNBC.



"Americans deserve the right to have a conversation with their doctors about what kind of plans that they might want if they become terminally ill. It is common sense in my mind," he adds.

Schumacher regularly addresses hospice professionals and others about end-of-life issues.

"Don has the unique ability to work with a variety of publics," says Galen Miller, NHPCO executive vice president. "He is equally comfortable with donors, the media or politicians on Capitol Hill as he is with patients and families."

Schumacher's vision for expansion of hospice services includes enhancement of pediatric care options and international services for those afflicted with AIDS.

In 2005, The Diana Princess of Wales Foundation, in cooperation with the Franklin Mint, awarded NHPCO a \$3.5 million grant. In spring 2009, Schumacher presented a final report on the work of the National Hospice Foundation's Diana Legacy Fund to staff at the Diana, Princess of Wales Memorial Fund. The grant was used to increase NHPCO's global initiatives, fuel a capital campaign and improve public awareness and access to hospice and end-of-life care. He also had the opportunity to meet the Queen of England at St. James Palace during the 25th anniversary of Help the Hospices. "The Queen is very supportive and knowledgeable

about hospice and we had a fascinating discussion about hospice programs in the United States," says Schumacher. "It was the one of the highlights of my life."

Schumacher continues to reach out to Canisius English majors as a regular speaker at their annual banquet, where he encourages students to use their degrees to serve others, no matter what their career choice.

"Through literature you learn how the psyche works, how people connect and how people communicate," he says. "My English education was wonderful preparation for what I do now."

And Schumacher was able to benefit from what he learned through years of experience. When his parents were gravely ill in the 1990s, he had productive conversations with them before they died. He adds that his spirituality, which was nourished by his Jesuit education at Canisius College, serves as the basis for his work.

"I have a strong belief in the afterlife and in a loving God," says Schumacher. "I think the most important reason we are here on Earth is to support each other through life and certainly in the process of dying. It is critical not to reject or walk away from a person who is dying but to stay with them. I think that is what God asks of us." ■