



# Hospice *Currents*

Vol.13, No. 1

Spring 2005

## LIVE TELECONFERENCE: *Ethical Dilemmas at the End of Life*

Members of the community, hospice volunteers, and health care professionals, gathered at the high school on April 20th for Hospice Foundation of America's 12th live teleconference. In this year's conference, "Ethical Dilemmas at the End of Life", a distinguished panel of ethicists, educators, gerontologists and hospice experts tackled values, ethics and law in the health care decisions, and included a discussion on the recent Terri Schiavo case, as well as other prevalent end of life dilemmas.

Produced annually by the Hospice Foundation of America, this national program was moderated by Michael Putney, Senior Political Reporter for Channel 10, ABC News, Miami. A local discussion followed the 2.5 hour broadcast. Participation in this timely conference was of immense value to health and human service professionals and to the community at large, as we all try to deal with these complicated issues. We were fortunate to have had a program of such national importance available to us on a local level.

(Please see related articles *As the World Kept Vigil*, and *Advance Directives*)

## HANDS ACROSS THE WATER

Since our last newsletter, we've become a "twin" hospice with newly developing Cradock Hospice in South Africa, and have been most impressed with all that they do, faced with such tremendous obstacles and so many sick and dying people. As you may recall, our National Hospice & Palliative Care Organization has partnered with the U.S. based Foundation for Hospices in Sub-saharan Africa, and has encouraged U.S. hospices to join the effort.

Last year, we raised \$1900 at our auction, and an additional \$550 was sent from individual donations at Christmas time. In a surprise coincidence, the Mission Board of the United Methodist Church, had made a \$500 donation to the Foundation for Hospices in Sub-saharan Africa, and, after we informed them of our Nantucket connection to a specific hospice, was happy to have their donation earmarked for Cradock. Our money has helped in the development of a day care program for the fifty-six children they care for, children who've been orphaned, most of whom are infected with HIV themselves.

The dedicated staff of Cradock is most appreciative of our support, not only for the donations that have been sent, but also, for just being acknowledged and cared about by an American community. We've all enjoyed our dialog and have learned so much from one another's experiences. Our hope is to help facilitate their access to other sources of information and financial support which may be available through other organizations.

Recently, since they were faced with so many people who'd been cut off from government aid and had no food, we informed them of a program called "Seeds for Africa," which supplies seeds for food gardens to African organizations. In the future, we hope to create an initiative that might help them access much needed medications for treatment of their patients.

If anyone is interested in participating in these efforts or in making a donation for Cradock Hospice, please let us know.



## As the World Kept Vigil

by

Charlene Thurston, Hospice Director

Several years ago, because technology had reached the point of keeping people alive, even when their ability to be conscious and functional was severely limited, there was a public outcry for individuals to have the right to forego or stop aggressive medical interventions, and to be allowed to die. Such was the impetus behind the "right to die" movement, heightened by the high profile cases of Karen Ann Quinlan, and, several years later, Nancy Cruzan, two young women whose families fought to withdraw treatments when it was felt that there was no hope of a return to even basic mental or physical functioning.

After much adjudication and a strong grassroots effort by ordinary citizens who felt they would not want to be kept alive in such a state, connected to machines and/or tubes, Congress enacted the Patient Self-determination Act. This act requires that health care organizations ask patients about whether they have any Advance Directives, and, if not, provide them with information about their right to have them.

Presently, patients have the right to refuse any treatment, including, IV's, tube feedings, respirators (ventilators), medications, cardiopulmonary resuscitation, etc. If an individual is unable to communicate his or her wishes about any proposed treatment, a "health care proxy," appointed in advance by the individual, has the legal authority to make such health care decisions on the patient's behalf. The intention behind the Health Care Proxy legislation was to keep health care decision making in the hands of patients & their appointed proxies, and out of the courts. If an individual does not appoint a health care proxy, such decisions fall to the next of

kin, beginning first with the spouse.

With that background in mind, let us look at the situations which unfolded recently as two people, who touched us all deeply, died. In both cases, as we had the opportunity to witness how end of life decisions might be made, many of us began to think about, and, as importantly, inform our families about, our own values and wishes for end of life care.

In the case of Terri Schiavo, since she became unconscious, and, therefore, was unable to speak on her own behalf, and, since she had not left a written advance directive, conflict ensued as her husband and her parents disagreed over what health care decisions should be made. Although her husband, who had legal authority to act on her behalf, stated that she had

previously informed him of her wish not to be kept alive in a state such as that which developed, her parents contested that testimony, and further contested that her husband should have legal authority as her guardian. Although the courts disagreed with the parents, the parents' appeals to the public, the state and federal legislatures, and the president caused much conjecture about the appropriateness of the laws and guidelines that have been guiding end of life decisions over the past 10-15 years. Opinions were passionately debated by ordinary citizens about which family member should have guardianship; whether tube feedings should be considered extraordinary measures; whether only written (vs. verbal) advance directives should be honored.

(continued on page two)

## Welcome new staff member

We are delighted to announce that Nan Strelnitski, R.N., M.A., M.S., has joined the Hospice staff part-time as a nurse counselor. Nan received an M.A. in nursing from N.Y.U., an M.S. in marriage and family therapy from the University of Bridgeport, and has had many years' experience as a nurse and therapist. Earlier in her practice, she also worked in oncology, geriatrics, orthopedics, and in nursing education.



In addition to her nursing and counseling background, Nan is also a certified yoga instructor, and will be available to offer Hospice clients and caregivers individualized yoga and Thai Shiatsu sessions, if they'd enjoy such supportive complementary therapies. Please join us in welcoming Nan to our staff.

*(Director, continued from page 1)*

Regardless of how you felt about this very sad situation, most people would agree that the wishes of the patient should be honored. Therefore, the most important lesson from this case should be for us all to give ourselves and our families the gift of completing an advance directive and of communicating our wishes to everyone who might be involved in making decisions on our behalf - our spouse, children, parents, siblings, and doctors. As can be seen in Terri's case, this should be done from young adulthood onward. She was only 26 years old.

Only two days after Terri's death, we were all again witnessing the dying of another public figure, Pope John Paul II, the beloved pope of the Roman Catholic Church. Coincidentally, he'd had a feeding tube inserted a few days before he ultimately died, but the goal at that time was to provide additional needed nutrition to help him increase his strength, as he attempted to recover from a series of illnesses. Unfortunately, soon thereafter, he developed a urinary tract infection, which led to septic shock, and his fragile systems began to collapse.

In contrast to Terri Schiavo's situation, Pope John Paul was conscious, and therefore, was able to continue to make his own health care decisions. After having tried vigorously to recover from many illnesses unsuccessfully, he ultimately decided to forego further hospitalization and aggressive treatment, and to remain at home to die, in the presence of those he loved, including the thousands gathered outside his window. He was also able to choose to be kept as lucid as possible and to request the types of spiritual assistance that would sustain him on his journey through death - various prayers, meditation, and the reading to him of specific scriptural passages that he had chosen.

As we look at these two very public deaths, we should first be grateful for the privilege of having been allowed to witness and learn from their experiences. In the case of Pope John Paul, we learn the value of being conscious enough to make our own health care decisions as an illness unfolds, rather than needing others to make those decisions on our behalf. We learn that, after a formidable battle to try to recover proved unsuccessful, he chose to forego further aggressive treatment and to be allowed to

die naturally and peacefully. In his case, the pope exerted his right not to have such further interventions as certain medications, a respirator, dialysis, hospitalization in I.C.U. etc. And, we learn the importance of preparing spiritually - considering and requesting that which would help us as we transition from this life to whatever comes next.

In the case of Terri Schiavo, we see how much suffering can occur if we should become unable to communicate our own health care decisions and haven't clearly informed those we love of what our wishes would be. We learn that, without written advance directives, competing members of families, as well as the public and the legal system, often fight to have their choices carried out, whether or not they'd be ours, and that those choices will affect how we're treated.

In thinking about future legislative or legal directions that would best serve our nation, it's important that our law makers respond very carefully now, not only considering right to life issues, but also remembering right to die issues. The laws which were developed after the Quinlan and Cruzan cases were directed at keeping the decision making with patients and families, versus the courts or healthcare organizations, whenever possible. While some review and reconsideration may be in order, creating new laws that would insist that people without written advance directives have treatments, such as i.v.'s, feeding tubes, respirators, etc., would undo all the good work that's been done over the past 20 years. The underlying foundation on which decisions should be made is patient autonomy - the right of individuals to make their own decisions and the right to have those wishes followed, within the law.

Let us hope that, as the world has kept vigil, we've all learned the importance of exploring our own values and communicating our wishes to those who will be entrusted to make life and death decisions on our behalf.

Visit our website @  
[www.hospiceofnantucket.org](http://www.hospiceofnantucket.org)

## Remembering Louise Wareham

This winter Hospice Care of Nantucket lost one of its star pioneers and strongest advocates – Louise Wareham. Louise was a beautiful woman with a wonderful and quick smile, a loving heart, and the serenity and grace of a person with deep wisdom. She truly touched the spirit of everyone in her path, from little children to the very elderly.

For our Hospice, Louise was one of the people who conceived of the idea for starting a program for Nantucket. She and several friends sat around her kitchen table on Hussey St., came up with a plan, and brought the idea forward to the hospital. Thereafter, she, Nancy Minus and Joan Altreuter, who were also part of the founding group, volunteered every day for the first five years of the service, to offer the then all volunteer program to the people of Nantucket. We thank them all for the work they've done.

Louise continued to teach us, even during her illness and approaching death, both of which she approached with acceptance and grace. As her daughter, Joanne, sat with her during her final hours, she was moved by many statements her mother made, which I suggested she write down. With her permission, and with our sincere gratitude, we share

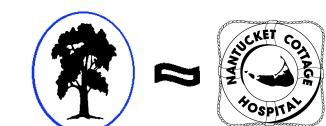
*As always we sincerely thank those families who have directed that memorial contributions be made to Hospice Care of Nantucket Foundation or to the Marla Ceely Lamb Transportation Fund. Because of these donations we are able to continue to provide services free of charge.*

them here, because they give us so much insight into the process of dying, when people very often speak of visions and experiences they are having.

Joanne writes, "The last few days before my mother's death were difficult, but, as she came closer to the end, she felt a great peace. I recorded her words as she seemed to move back and forth between the two worlds. She spoke forcefully and convincingly. Here are some things she said: 'The music is in the air. They set up the chairs and after the concert was over, they took the chairs down. But the music is still in the air.' ... 'Life is beautiful and all those people, you think they're gone, but they're still there.' ... 'I feel wonderful. All that awful feeling is gone.' ... 'I love you so much, from the first moment I knew you were coming.' ... She then said something I didn't understand and I asked her what she'd said. She seemed surprised and replied, 'If I said something, it was peaceful, and I feel I can deal with it now. Yesterday, I felt I couldn't deal with it.' Then she said, 'Love reaches out everywhere.'"



As we go to press, we honor the family and friends of Marla Ceely Lamb for their hard work towards their annual Mothers' Day Dinner and Auction. That event, in addition to the Tennessee Hoe-Down fundraiser this winter, and donations to the MCL Transportation Fundraiser throughout the year, helps maintain the support for patients with cancer who must travel off island for treatment.



### A Partnership in Caring

Funded by the Hospice Care of Nantucket Foundation, the hospice program is operated as a department of the Nantucket Cottage Hospital. Hospice is a specialized health care program, dedicated to providing excellent physical, psychological, social, and spiritual care to persons with life-threatening illness and their families.

## ADVANCE DIRECTIVES

Advance Directives are documents that you can choose to complete in order to provide directions for your health care, if you should become unable to communicate your wishes yourself, at the time that a health care decision must be made. There are two types of advance directives, sometimes combined in one document: health care proxies and living wills. In Massachusetts, health care proxies are legally binding, while living wills are not. However, if you feel strongly about having, or not having, certain treatments if there's no hope for recovery, it's still advisable to create a living will to help your health care proxy and physicians understand what your wishes would be. Advance directives are only used during the period in which you are unable to speak for yourself.

A health care proxy (or durable power of attorney for healthcare) is a person whom you appoint to make healthcare decisions on your behalf, if you should become unable to speak for yourself. Health care proxy forms are available at all healthcare organizations and attorneys' offices, and may be completed by anyone over the age of 18. They are simple to complete, need only be witnessed by two people, and copies are as valid as the original documents. It's probably a good idea for everyone over age 18 to appoint a health care proxy, but you must be sure to update it whenever you'd change your choice of proxy, for instance, when you marry or divorce. Without the appointment of a health care proxy, health care decisions generally fall to your next of kin in a specific order - spouse, adult children, parents, siblings.

A living will is a document in which you state your wishes regarding end of life treatments, which you do or do not want, if you should become unable to speak for yourself. While living wills are not legally binding in Massachusetts, they do serve to guide your health care proxy and your doctors, and are used as evidence of what your wishes would be.

Beyond the documents themselves, it's most important that you think about your values and wishes, and that you talk about them to your families, proxies, and physicians. It's also important that you continue to think about and talk about these issues regularly over the years, so that, if things change, everyone is kept informed of your wishes.

Copies of any advance directive documents should be given to your family, your proxy, and your physicians, as well as being kept in an easily accessible location in your home. In Nantucket, we also put a copy into your medical record at the hospital.

While not required, advance directives can really help relieve your family of the burdens inherent in end of life decisions if a crisis occurs. They can also ensure that you receive the type of care you desire.

If you'd like more detailed information about advance directives, you may call our Hospice Office at 508-825-8325. Written information, videos, and free educational consultations are available. Physicians, hospital and nursing home nursing and social service departments, and attorneys also have forms and can provide information and guidance about advance directives, as do the following websites: [www.caringinfo.org](http://www.caringinfo.org), [www.healthcareproxy.org](http://www.healthcareproxy.org), or [www.agingwithdignity.org](http://www.agingwithdignity.org).

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## ALZHEIMER'S DISEASE: *Educational Consultations for Caregivers*

Through a small grant from Elder Services of Cape & Islands, Hospice Care of Nantucket is able to arrange for Suzanne Baybutt, R.N., a nurse specializing in Alzheimer's, to come to the island monthly to help families understand how to care for loved ones with this disease. She can provide two-hour, private consultations and answer a variety of questions, from what medications are commonly used, to how to handle difficult behaviors. Caregivers can opt to have the consultations in the home or in our Hospice office. Examples of topics can include advance care planning (legal documents), eating, medications, bathing, wandering, and/or an overview of the disease process.

This service is free of charge. The grant will end in September, so those interested are encouraged to contact us as soon as possible to schedule a session.

A two-part, 6 hour training this winter, was also partially funded by the grant and Hospice Care of Nantucket. Suzanne Baybutt provided twenty professionals from the hospital staff and other community agencies with comprehensive information about Alzheimer's disease and other dementias as well as helpful tools to help support family caregivers.

## Tapestries Children's Grief Support

The spring session of *Tapestries*, our new supportive program for grieving children, teens, and their families, began in March with an Introductory Night for interested families. Group sessions, for both the children and the adults, facilitated by bereavement professionals and specially trained volunteers, will continue every other Tuesday evening through June 7th, then resumed in the fall.

*Tapestries*, like all of our Hospice programs, is free of charge, and funded through donations to Hospice Care of Nantucket Foundation. We extend our sincere thanks to the First Congregational Church for generously providing a space, especially since the program is not affiliated with the church.

For further information or to register, please call 508-825-8325 or email: [hospice@ackhosp.org](mailto:hospice@ackhosp.org).

## Upcoming & Ongoing...

### Dreamcatcher Dinner & Auction:

June 12, 2005 at the Galley on Cliffside Beach

**Coping with Cancer Support Group:** every other Monday, 1-2:30 PM, for persons with cancer and those who love them

### Caregivers' Support Group:

the 2nd Thursday of the month

**Spirituality & Health Conference:** coming this fall... watch for details

## Remember FAMILY CAREGIVERS' SUPPORT GROUP

***The second Thursday of each month***  
***All family caregivers are welcome***

*This program is part of the  
Caregivers' Connections Program*

*(practical assistance and support for family caregivers  
of persons with chronic illness or disability)*

## Hospice Care of Nantucket Foundation

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