

National Healthcare Decisions Day 2008

On April 16th, Hospice joined with many organizations across the country in highlighting the importance of advance care planning for everyone, young and old, healthy and ill. Charlene Thurston, R.N., A.N.P., offered an educational presentation for the public at the Nantucket Cottage Hospital, as well as individual consultations to assist people with how to complete health care proxies and living wills. The importance of designating a health care proxy (the person who would make health care decisions for you if you were unable to make them yourself) was emphasized.

April 16th will be National Healthcare Decisions Day every year, in an effort to remind people to think about and, when necessary, update their advance directives annually, the day after taxes are due.

All adults of all ages should have a health care proxy, to designate the person whom you've chosen to make health care decisions on your behalf, should you become unable to communicate your wishes - even in the short term, due to an accident or serious illness.

Anyone in need of assistance in preparing advance directives, free of charge, may call our office or the Social Services Dept. of the hospital. Forms and instructions may also be downloaded on several websites, including

Funded by the Hospice Care of Nantucket Foundation, the hospice program is operated as a department of the Nantucket Cottage Hospital, which is an affiliate of Massachusetts General Hospital, and a member of Partners HealthCare, Inc. 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.

Hospice Care of Nantucket Foundation

57 Prospect Street, Nantucket, MA 02554 508-825-8325 hospice@ackhosp.org www.hospiceofnantucket.org

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by Charlene Thurston, RN, ANP,
Director of Hospice

“You matter because you are. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to help you live until you die.”

-Dame Cicely Saunders, M.D.

Founder of the present day hospice movement

How do we attend to persons who have lost their ability to communicate with us in language or behaviors with which we're familiar? Does it matter whether or not we visit with loved ones who may not remember us or who may forget we've visited five minutes after we've left? Should we continue correcting our loved ones with dementia when they think it's the wrong day, place, person, etc? How should we interact with people whose thinking ability and memory no longer function normally? These are all questions that leave us searching for answers as we try to care for loved ones with dementia or other conditions that affect cognition or consciousness.

Recently in hospice, we have been trying to address the issue of how to improve the quality of life for patients and families faced with dementia. To date, most of our efforts have focused on how to support family members who provide care for their loved ones, while encouraging them also to care for themselves. Learning how best to interact in ways that keep both patients and families calm and loving is a difficult task, but one which would be enormously beneficial to all. As many of our readers know, we've worked closely with Alzheimer's Services of the Cape and Islands and Elder Services of the Cape and Islands to bring information and support to caregivers of persons with dementia. Also, over the past several weeks, we at HCON have been learning about a program developed in Seattle, Washington, to help caregivers



The fifteenth Annual Dreamcatcher Dinner and Auction will be held at The Nantucket Yacht Club on Sunday, June 15, 2008 with Peter and Sarah Monaco as our Honorary Chairpersons for the event. This fabulous evening will begin with a welcome cocktail and Spanky's ever-popular raw bar. The cocktail hour will be followed by dinner served in the ballroom at the Yacht Club. The gourmet dinner, prepared by Executive Chef, Robert McGowan, will be served with wines that have been selected to complement each course. This year we are once again including a Silent Auction which will start at the beginning of the cocktail hour...don't forget to stop by and place your bids. The main event will be the Live Auction and once again Rafael Osona will lend his wit and powers of persuasion to the task of raising funds for our Nantucket Hospice. Offerings include many unique Nantucket experiences, dinners at local restaurants, a special item dedicated to our sister hospice in South Africa as well as trips to many exciting destinations including a BACKROADS trip to the Croatian Riviera, and a great getaway to California Wine Country. A few new and exciting items being auctioned this year include a fabulous Children's Playhouse for your yard; a luxury vacation in Turks and Caicos and a brilliant painting by Katie Trinkle Legge. Be sure to make your reservations as this will be an evening not to be missed. We look forward to seeing you in June at The Nantucket Yacht Club!

Michael Varbalow

effectively manage difficult behaviors.

Beyond managing behaviors, however, is the importance of remembering that, although the person with dementia may be difficult to recognize in his/her present state of functioning, (s)he is the same person. Locked within is the essence of the person, no matter how unrecognizable because of the symptoms of the disease. While (s)he may not be able to think, communicate, or function normally, the person is still there and still has value, just because (s)he exists.

How to reach or touch this loved one in a way that enhances his/her well-being is a task that we must all learn. This is uncharted territory for most of us, including health care professionals, in some ways similar to the challenge of reaching children with autism.

A whole new set of skills might be warranted, that we've never thought of before, since words and actions may not always be appropriate in communicating or in understanding the person's needs. We

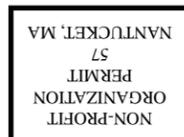
must learn this new "language," taking clues from non-verbal behaviors, body language, facial expressions, etc. We might find that using music, touch or massage, aromas, art supplies, and movement are helpful in enhancing pleasure, releasing tension, and making connections. The use of photographs and memory boxes often help stir familiar memories.

Exercise helps to maintain physical strength and to reduce anxiety and tension. Connecting with nature, plants, pets, and using familiar religious prayers and rituals can often be soothing and comforting. Having family, friends, or paid caregivers who understand how to be present and care for your loved one in a calm and competent manner can provide enjoyment for the patient and time out for the family caregiver.

Most importantly, we must dramatically change our expectations for how to relate to someone we love who has dementia.

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Hospice Currents

*Honoring the Person Within:
Being There for a Loved One with
Dementia*

As President of the Foundation...

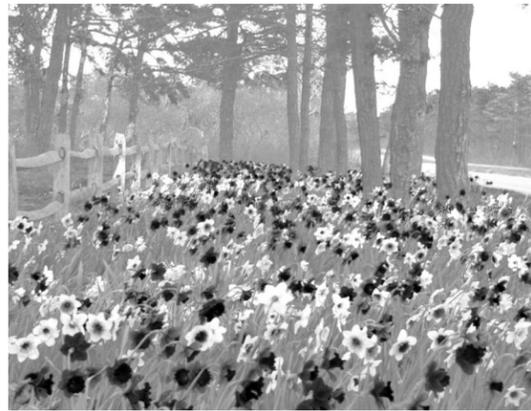


A Partnership in Caring









While first ensuring that an appropriate diagnosis has been made by qualified physicians, that treatable and reversible causes of dementia have been ruled out, and that treatments available to help forestall progress of the disease as much as possible have been put in place, we must begin to adjust to the fact that life as we knew it has changed. The person, as we knew him/her has been profoundly altered, and, although this is the same person, we must relearn how to relate to him/her.

We have every right to grieve this loss with our whole heart and soul. It is truly grievous. We should get help, get support, and use whatever coping strategies help us. And then, when we can begin to put one foot in front of the other again, we must learn how to deal with what's before us; learn what we need to know to care for this person whom we love and to care for ourselves. Following are some helpful suggestions for the journey:

- *Accept what is and learn how to relate to who this person is now.
- *Live in and relate to this person in the present moment. (That's all any of us really has anyway.)
- *Let go of your expectations and your need to be acknowledged by the person. Simply be present, without an agenda.
- *Don't feel hurt or insulted because of the person's comments or behavior toward you. Remember that the disease is causing this change, not you.
- *Learn about the disease itself, including what to expect, how to relate and communicate, and how to handle difficult behaviors.
- *Create pleasant moments, perhaps drawing on some of the ideas mentioned above. It doesn't matter whether or not the person remembers them. They're still experienced at the moment and bring comfort and joy.
- *Learn about resources that are available to help you and use them.
- *Remember that you need care also, and that you must attend to taking care of yourself as much as you take care of your loved one. One person is not more important than the other.

Above all, remember that your loved one is still the same person, just a person with an illness. No matter how profoundly changed (s)he's become, there is some level of awareness of your presence. Just being there for him/her is one of the greatest gifts you can offer, and the awareness that you're able to be there, without expectations, will be one of your greatest rewards.



Before: children & parent volunteers from the Nantucket New School plant the bulbs in 2007
photo by Rob Benchley

Thousands & Thousands of Daffodils

Hospice Care of Nantucket extends sincere thanks to the children and parent volunteers from the Nantucket New School and the crews of G&M and Champoux Landscapers in addition to the Nantucket Garden Club and the growers who donated the 8,500 bulbs:

Down to Earth, Ernst Land Sesign, G&M Landscape, David Champoux Landscaping, Gregory Raith Landscaping, Nantucket Landscapes, Ryan Landscaping, Sconset Gardner, as well as to the Dreamcatcher Auction guests whose generous bids raised over \$20,000 to help hospice continue to serve the Nantucket community free of charge. It is the wish of the auction committee that each spring the beauty of the daffodils will bloom with new hope and gratitude.



After: our flowers in bloom this year near the Serengetti on Milestone Road
photo by Quint Waters

Over the past year, we've been saddened by the deaths of three individuals who were extremely instrumental in making our Hospice what it is today. All gave countless hours of time, creativity, and energy and we're truly grateful for their contributions.

Nancy Minus was one of the original founders of our program, who, together with Louise Wareham, who died a few years ago, and Joan Altreuter, ran the hospice program, which at that time was totally volunteer. Through her dedication and hard work, the underpinnings of our present program were developed and provide a sound foundation for the values which we continue to honor, particularly those of compassion and a desire to be helpful to all who need us. Saying "yes we can" was the motto she lived by whenever a request for assistance was made, and we continue to strive to follow that to this day.

Dorothy Holland was a dedicated member of the Board of Hospice Care of Nantucket Foundation for six years. Among many other valuable contributions she made to our program, Dorothy, together with then board member Kate Stout, created our first annual fundraising event, the Dreamcatcher Fantasy Auction and Dinner, which we've continued since that time. A lovely, gracious woman, Dorothy was truly a woman of substance with a keen mind, boundless energy, great ideas, and the talent to get things done. The Dreamcatcher Auctions have made it possible for us to continue to expand our services and to deliver them free of charge.

Bill Muehling was one of our early patient care volunteers, and continued in this role for many years. Bill's quiet, easy going, and affable personality offered a comforting presence and enduring friendship to the patients and families he served, and his eagerness to help our program in any way he could was of great benefit to us.

As we go forward in the years to come, we'll always be grateful to these early, esteemed pioneers of our organization for the strong foundation they provided in both structure and values for what we've become today.

We offer our sincere sympathy to their families during this time of grief, and express our gratitude for their most valuable contributions to our program.

In a recent e-mail from our "twin" hospice in Cradock, South Africa, we were delighted to hear that they had received a second shipment of supplies from Direct Relief International, a U.S. medical relief organization that sends medical supplies to underserved areas throughout the world. As many of our readers may remember from previous newsletters, one of the most significant things we've been able to do for Cradock Hospice has been to facilitate a connection with them and DRI. In receiving this second cargo shipment, they were overwhelmed by the supplies they received and the incredible difference they've made in what they've been able to provide for their patients.

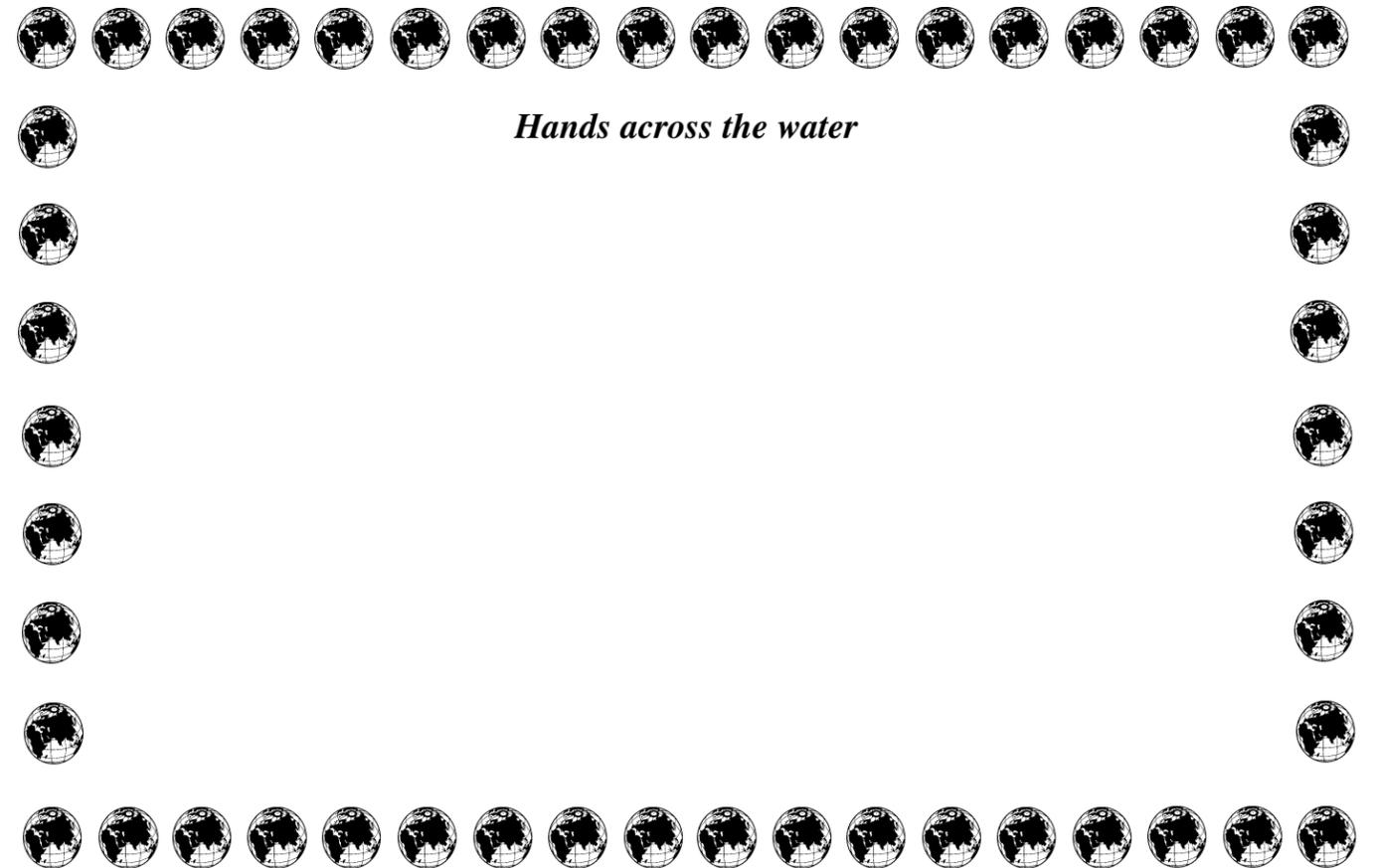
In other recent e-mails, they've also discussed their progress with other initiatives we've enabled. They're now fully certified as an independent hospice, which allows them to qualify for some government funding. The palliative care nurse, whom we helped them hire and train, has now completed her training, passed her certification exam, and reportedly has made an enormous difference in the level of care they're able to offer their patients. Lastly, with the money that we donated last year, they were able to renovate the interior of their building, which was in desperate need of up-grading in order to use it appropriately for staff and patients. All of these efforts were made possible by modest funds that we've donated over the past four years, amounting to an average of about \$6000/year, from a few private donors and from money which has been raised specifically for Cradock Hospice, at our annual Dreamcatcher Auction. (In raising these funds, it is clearly stated up front that they will be directed to benefit Cradock Hospice, so that only donors interested in that cause participate.)

We're delighted to continue this relationship with our "twin," and are inspired by the work they do, despite the most difficult circumstances. For those of you who might be interested in donating to Cradock Hospice, please contact our office for information on how to do so.

Honoring the Person Within...continued from page one



Saying Good-bye to three HCON Pioneers



Hands across the water







Children's Grief Support

Tapestries is a program where young people may come together in groups or individually to gently process their grief. Through talking, artwork, play, quiet time, and high energy activities, they have a chance to remember their loved one. Individual education and counseling to parents of children in grief are also available. Also, this year Hospice has spent a great deal of time working with the schools, hospital, and other community organizations in responding to children's and community needs.

Since so many children have been affected by grief over the past year, we thought it might be helpful to again include the following excerpt from Facts for Families from the American Academy of Child & Adolescent Psychiatry on Children and Grief:

"...children react differently from adults. Preschool children usually see death as temporary and reversible, a belief reinforced by cartoon characters who die and come to life again. Children between five and nine begin to think more like adults about death, yet they still believe it will never happen to them or anyone they know.

Children who are having serious problems with grief and loss may show one or more of these signs:

- an extended period of depression in which the child loses interest in daily activities and events
- inability to sleep, loss of appetite, prolonged fear of being alone
- acting much younger for an extended period
- excessively imitating the dead person
- repeated statements of wanting to join the dead person
- withdrawal from friends, or
- sharp drop in school performance or refusal to attend school

If these signs persist, professional help may be needed. A child and adolescent psychiatrist or other qualified mental health professional can help the child accept the death and assist the others in helping the child through the mourning process. "

We'd also like to make our readers aware of several Bereavement Camps we've heard about for the summer season:

Stepping Stones: A weekend retreat open to any children and families who have experienced the death of someone close to them; free of charge (except for a nominal registration fee); July 12th & 13th; Wenham, MA

Circle of Tapawingo: for girls ages 8 - 12 who have experienced the death of a parent; free of charge; August 24-29; Sweden, ME contact: www.circleoftapawingo.org; Cathy Spear, 781-820-3388

Camp Phoenix: A weekend camp for grieving families with children from infants to age 21; free of charge; September 12, 13, & 14th ; Meredith, NH

Camp Erin: Children & Teens Grief Support Camp; ages 6 - 17; free of charge; June 27-29 Assonet, MA.

For more information or for help with transportation expenses to and from the camps, please call our Hospice office at 508-825-8325.

We thank Nantucket Children's Charity Foundation for the generous gift to partially fund Tapestries.

Upcoming & Ongoing...

1st Annual Walk to benefit The Marla Ceely Lamb Travel Fund: Saturday, June 14th, 10:00 AM

Hospice Dreamcatcher Dinner & Auction: June 15, 2008, 6:00 PM at the Nantucket Yacht Club

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

"Time Out" for Caregivers: Every 2nd and 4th Tuesday of the month, 1:00-2:30PM

Bereavement Camps for Children: See above listings

We Can Weekend: A retreat for adult cancer patients & their families: June 6-8, South Hadley, MA; & August 1-3, Nashua, NH; \$35; Contact the American Cancer Society at 1-800-227-2345

As always we sincerely thank those families who have directed that memorial contributions be made to Hospice Care of Nantucket Foundation.

Because of these donations we are able to continue to provide services free of charge.

Hospice Care of Nantucket offers private consultations, in the home or our office, with a nurse practitioner, for family members who help care for a family member or friend who needs some assistance due to illness, disability, or frailty.

Caregivers can request an overall evaluation of their situation, including an assessment of the person they help care for, and can receive information, support, and education about various topics, e.g., the disease process (including Alzheimer's Disease); managing medications; giving personal care; maintaining safety; planning for future health care needs; caring for themselves while caring for someone else; etc. Referrals for other services may also be made. This program is part of our Caregivers' Connections Program which also includes:

***Volunteers** - can provide 1 1/2 - 2 hour/week for respite breaks for caregivers, or can help with errands, transportation, etc.

***Time Out** - stress reduction education and/or counseling, in the home or office, which may include talking, learning relaxation techniques, yoga, etc. Thai Shiatsu massage is also available.

***Caregivers Support** - one on one consultations

***Alzheimer's Disease Educational Consultations** for caregivers of persons with the disease

***Lending Library** of caregiver-related topics.

All our services are free of charge! For more information or an appointment, please call our Hospice Office at 508-825-8325.

This program is offered with the assistance of a Title III grant from Elder Services of Cape Cod & the Islands.



Hospice Director, Charlene Thurston and student, Molly MacKay

During this past school year, we've been blessed with a Nantucket High School student intern! Molly Mackay, a high school senior, who was interested in having an experience in psychology, chose Hospice as her School to Work placement, and has worked with us for 4 hours a week throughout the year. During her time with us, Molly has accompanied staff on their ongoing visits to several patients (with their consent of course), and is now able to make some visits independently to a resident of Our Island Home. She's also had opportunities in other hospital departments such as Visiting Nurses, Social Services, Med Surg, Maternity and the ER. When asked about her experiences, Molly says, "I couldn't have asked for a better experience or better mentors. This program has done so much for me, including giving me the confidence

and desire to want to learn and pursue a profession in health care. Charlene and others have definitely instilled a love and passion in me for helping others for which I am so thankful."

We'll be sad to see Molly leave us, but wish her great success as she pursues her college education in *nursing*. The nursing profession will be richly rewarded by her contributions.

As we go to press, we honor Marla's family and friends for their hard work towards their 16th annual **Mothers' Day Dinner and Auction** fundraiser. Proceeds from that event, in addition to generous donations throughout the year, go entirely to the fund. This year the fund supported 73 patients with cancer who needed to travel off island for treatment. Thanks to all who make donations.

DID YOU KNOW.....

that our hospice, unlike other hospices, not only provides care to the terminally ill, but also provides education, support, and coaching to help persons with curable life-threatening illnesses?

COACHING FOR CAREGIVERS

Molly MacKay, our Student Intern

The Marla Ceely Lamb Fund

*The 1st Annual Walk to benefit The Marla Ceely Lamb Travel Fund
Saturday, June 14, 2008*

*Faregrounds Restaurant to Surfside Beach & Return 8:00-10:00 AM Registration Walk begins @ 10:00
Pledge cards available at: Faregrounds Restaurant, The Hub, Nantcuet Cottage Hospital,
Yates Gas & Wannacommet Water Company*