

Upcoming & Ongoing...

2nd Annual Walk to benefit the Marla Ceely Lamb Cancer Travel Fund in memory of Kelly Culkins West: Saturday, June 13th
Hospice Dreamcatcher Dinner & Auction: June 14, 2009, 6:00 PM at Galley Beach
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 listings in the Tapestries article on page 2

*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.*



A Partnership in Caring



Funded primarily by the Hospice Care of Nantucket Foundation, the palliative and supportive 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. Palliative and Supportive Care 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

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Hospice Care of Nantucket Foundation is a not-for-profit tax exempt public charity.

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Hospice Currents

Vol. 17, No. 1

Spring 2009

**Heading upstream -
 expanding our services and
 changing our name**

By Charlene Thurston, RN, ANP

We have come to a crossroad in the evolution of our program and have had to make a decision about whether to become a “Medicare-certified” hospice or to continue to move upstream in the patient’s disease progression to offer more services to patients who are *not* terminally ill. For many reasons, we have never felt that becoming a *Medicare* hospice was in the best interest of the program or of the people of the island, and we have consistently tried to offer services beyond the confines of such a program and prided ourselves in being *different* from other hospice programs. Our goal, since we first developed our program, has been to consistently broaden our reach to serve patients from the time of diagnosis onward, not just at end of life.

However, as much as we’ve tried to encourage patients to use our services early in their disease, many, many patients who could benefit have not accessed them because of the “terminal illness” connotation of the name hospice. In light of all these reasons, we’ve decided to change our name and to continue to expand in directions we feel will better serve our community, rather than becoming a “Medicare-certified” hospice and restricting our services to the terminally ill - a move that we feel would be going backwards.

While this has been a difficult decision, when we really looked at what we were offering and what organizational structure we’ve felt was best for our program, we realized that offering palliative and

From the President of the Foundation...

The sixteenth Annual Dreamcatcher Dinner and Auction will be held at Galley Beach on Sunday, June 14, 2009. This fabulous evening will begin with a welcome cocktail and Spanky’s ever-popular raw bar. Many exciting Silent Auction items will be on display during the cocktail hour when you will have a chance to stop by and place your bids. The cocktail hour will be followed by dinner served al fresco in a gala tent on Cliffside Beach. The gourmet dinner, prepared by the Galley’s Chef de Cuisine, will be served with wines that have been selected by hosts David and Geoffrey Silva to complement each course. 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 Program. A few new and exciting items being auctioned this year include 4 tickets for second-row seats at the September 20th U2 concert at Gillette Stadium, a chance for 12 people to race in the Opera House Cup in August as well as two stunning pieces of jewelry. We will also have several of your favorite Nantucket experiences and, of course, a special item dedicated to our efforts for South Africa. And for something totally new...the classy, sophisticated and stylish band of eight talented artists, Kahootz, will provide music during the cocktail hour and again after dinner for dancing. 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 Galley Beach!



Geoffrey Silva

supportive care is what we’ve always been striving for. We’ve never wanted to restrict ourselves to end of life care, because we’ve always recognized that the same services that were available at end of life (defined by Medicare as the last six months of life) should be available to patients and families from the moment a patient is diagnosed with a life threatening illness. Moreover, we’ve been trying to develop services to help patients get well again in their efforts towards cure, a program component that no other hospice I’m aware of offers.

After much consideration, the new name of our program will be Palliative and Supportive Care of Nantucket. While this is quite long, we wanted to be sure that our name would be inclusive of all we plan to offer, and not be restricted again as regulations change over the years. We feel that this name will accurately reflect our program of services and our overall goals, and we’re hopeful that it will also pose less of a barrier for patients who fear the “end of life” connotation of hospice. It’s important to realize that all of our present services will continue just as they are. We will continue to offer excellent end of life care, in exactly the same way as we always have, but, in addition, we will expand our reach to offer more services to patients in earlier stages of illness. We’re very hopeful and excited to try to promote this aspect of our program. Most importantly, all of our services will continue to be offered free of charge.

Spotlight on: Supportive Care during Early Illness

When first diagnosed with any life threatening illness, whether curable or not, patients and their families are often thrown into a chaotic period of distress, questions, and fear while, at the same time, being required to understand much new technical information and to make critically important decisions about treatment. While their physicians are often excellent at making the diagnosis, explaining it, and suggesting treatment alternatives, patients and families greatly benefit from additional resources and support.

Through our Supportive Care Program, we offer many services to help patients through this period, as they strive to deal with their illness and get well again. Private sessions are available for patients and their families with a nurse practitioner, nurse counselor, and/or social worker, and include education, counseling and support, consultations about symptom control, and mind/body sessions to decrease stress and enhance well-being. Volunteers are also available to help patients and families with practical assistance and/or companionship.

The focus of our care during this period is on helping patients get as well as possible by:

- *Understanding their disease process and treatment options; making decisions about care; advance care planning;
- *Coping with the emotional and spiritual/existential impact of illness;
- *Enhancing overall wellness through stress reduction, mind/body modalities, increasing resiliency;
- *Handling social issues, e.g., employment, finances, legal/business affairs, housing, insurance, wills, relationships; travel for treatment;
- *Symptom management as necessary (due to disease and side effects of treatments);
- *Caregiver education and support;
- *Referrals to other services as needed.

All of our services are provided free of charge.

Tapestries

Children are often considered the forgotten grievers, and we've always worked hard to ensure that families of our patients are aware of the impact which the death of a loved relative, friend, or pet could have on their children. Several years ago, we developed Tapestries as our supportive program for grieving children and their families. Through this program, education is provided to families about how children at various ages understand death and how they might process their grief. When enough families are interested to form a group, we offer bi-weekly support sessions in which children may come together to gently process their experiences, while their parents or guardians meet separately to discuss their own reactions to grief and/or their concerns about their children. We also have an excellent library of resource materials which are available for loan. Please be aware that our services provide education and support, not mental health therapy or psychiatric care.

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 small registration fee); July 11th & 12th; 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 Manitou: for boys ages 10-12; August 23rd -28th

Camp Erin: Children & Teens Grief Support Camp; ages 6 - 17; free of charge; June 26-28 Assonet, MA.

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

All services which we offer directly are free of charge.

Support for Family Caregivers

Through our Caregivers' Connections Program, family caregivers of persons with any long term illness or disability can access education, support, and practical assistance from our staff, in their efforts to provide care for their loved one as well as remembering to take care of themselves. Services include:

- * **Coaching for Caregivers** - one on one consultations with our Nurse Practitioner on any aspect of care;
- * **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;
- * **Volunteers** - can provide 1 1/2 hour/week for respite breaks for caregivers, or can help with errands, transportation, etc.;
- * **Lending Library** of caregiver-related topics

All our services are free of charge! For more information or an appointment, please call our Office at 508.825.8325

Hands Across the Water

The Director of our sister hospice, Good Samaritan Cradock Hospice in South Africa, reminded us recently that one of the most significant things that her "twin" hospice in Nantucket had provided was the connection that we facilitated with Direct Relief International, the U.S. medical relief organization that sends medical supplies to underserved areas throughout the world. She had been overwhelmed by the supplies received from Direct Relief International and the incredible difference it's made in what they've been able to provide for their patients. This year the Foundation for Hospices in Subsaharan Africa signed a Memorandum of Understanding with Direct Relief International to expand DRI's supply of palliative care provisions to patients in the Eastern Cape of South Africa. This focus on palliative care was an effort initiated by members of our staff and board, an exciting example of how a small agency such as ours can have such an impact on the quality of life and care of these patients and families.

For those of you who might be interested in donating to Cradock Hospice or Direct Relief, please contact our office for information on how to do so.

Make Your Wishes Known

Since the importance of Advance Directives has received so much national attention, we thought it might be helpful to include some information here about the importance of making your healthcare wishes known to loved ones and healthcare providers, regardless of your age or current health.

Advance Directives are documents that tell healthcare providers who it is that you wish to make medical decisions for you and what treatments you would want or not want, if you are ever not able to tell care providers what you would want in a medical emergency or life-limiting illness. 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 you want your doctors, family, and friends to know about your wishes, and what gives your life the most meaning, 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 health-care 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.

While not required, advance directives can really help relieve your family of the burdens inherent in health care decisions if a crisis occurs. They can also ensure that you receive the type of care you desire. It's important to take steps to ensure that your choices are known and protected. This process does not take long and is free.

If you'd like more detailed information about advance directives, or would like copies of the documents or assistance completing documents, you may call our Office at 508-825-8325. 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, www.healthcareproxy.org, or www.agingwithdignity.org.

The Marla Ceely Lamb Fund

As we go to press, we honor Marla's family and friends for their hard work towards their 17th 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 90 patients with cancer who needed to travel off island for treatment. Thank you to all who make donations.

*The 2nd Annual Walk for Travel to benefit The Marla Ceely Lamb Cancer Travel Fund
In memory of Kelly Culkins West
Saturday, June 13, 2009*

9-11:00 AM Registration

Faregrounds Restaurant to Surfside Beach & return

Walk begins at 11:00 AM