



Palliative & Supportive Care of Nantucket

(formerly Hospice Care of Nantucket)

Currents

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Whole Person Care A Hallmark of Our Services

By Charlene Thurston, ANP,
Program Director

“The secret to the care of the patient is in caring for the patient.”

-Francis Peabody

There's a new phrase in healthcare these days called “whole person care.” Used and promoted by healthcare leaders who hope to transform our healthcare system into one that is more empathic and sensitive to the needs of a person's mind and spirit as well as to the body and disease, it really just represents good patient care, but care that is too often missing.

Fortunately for those of us who specialize in hospice and palliative care, tending to our patients holistically and extending our services to include their families have always been central to the care we provide. Recognizing that a patient is not just a disease or broken body part to be fixed, but rather a complex human being with emotional, social, and spiritual, as well as physical needs, the interdisciplinary teams of hospice and palliative care programs include nurses, doctors, social workers, counselors, chaplains, and lay volunteers who can help address patients' needs in a more complete way.

All of the services we offer through our PASCON program are delivered with this core value in mind. Whether patients are coming to us for a brief consultation, attending a group,

accessing our caregiver or bereavement services, or are comprehensive care patients that we care for intensively through advancing illness and dying, they can expect us to be available to offer counseling, education, and support to help them cope, as well as care to relieve their pain and other physical symptoms.

We also spend a great deal of time with our patients. Since this depth of care can't be delivered in the typical fifteen minute visits so common throughout much of healthcare, our visits are often an hour or more to allow patients and families the time they need to discuss their concerns and receive the support that's warranted in the setting of their choice – office, home, hospital, or nursing home. Many of our patients and families receive over fifty hours of our services through the course of their illness, and all of our care is free of charge.

Much of our work over the past year has been focused on more fully developing our cancer care services, thanks to the funding raised through our Swim Across America event in Nantucket, a charity that's focused on cancer.

While our PASCON services are available to patients with any life-threatening illness, not just cancer, some of the initiatives that are being developed in the field of cancer survivorship can serve as a great catalyst for transforming healthcare overall. For instance, recognizing the devastating

Tree of Remembrance Service



**Sunday, November 22nd - 4 pm
JC House Gazebo Garden**

Please join us and share in this very special event marking the beginning of the holiday season. Scallop shells are provided to write names of those we wish to remember and are then placed on the tree. This brief but moving interfaith ceremony is a peaceful and special way to memorialize and honor loved ones who have died. All are welcome. A reception follows at *Dune*, 20 Broad Street.

emotional toll that can affect cancer patients and their families, even if the patient's disease is cured, the Institute of Medicine has created new standards that require all comprehensive cancer centers to include services that address the patient's and family's distress, both during and after treatment, and to provide patients with cancer survivorship care plans after treatments have ended, so that they can receive appropriate follow-up for long term effects of their treatment that may develop over the

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Our Services at a Glance

Individualized Comprehensive Care

Through consultations and follow-up care, we offer a broad range of physical, psychological, social, and spiritual care for persons with life-threatening illness and their families. Services are provided by our interdisciplinary team of professionals and volunteers and are aimed at providing education, support, and symptom control from the time of diagnosis through cure or, if cure is not possible, through advancing illness and end-of-life. All of our services are provided in the most appropriate setting for our patients' needs – in our office, at home, in the hospital, or in the nursing home.

Caregiver Support

- Coaching for Caregivers – one-on-one consultations with our Nurse Practitioner on any aspect of care; individualized assessment of needs and individualized plans for support;
- Time Out – a professionally led support group – every 2nd and 4th Wed. of the month, 1-2:30 pm, in our office;
- De-Stressing to Cope* – a group or private educational session focusing on caregiver issues and stresses, positive self-care, and techniques for coping;
- Lending Library of caregiver-related topics.

Grief and Bereavement

Support, education, counseling, and referral for anyone coping with the grief of one's own illness or the illness or death of a loved one. Help individuals:

- Understand the grief process;
- Actively do one's grief work;
- Handle issues including finances, legal/business affairs, housing, insurance, wills;
- Optimize wellness through diet, exercise, stress reduction, mind/body modalities, coping strategies;
- Attend to spiritual/existential issues and enhance meaning-making and growth;
- Cope healthily and effectively;
- Ultimately, recover from grief and adjust to a life in which the deceased loved one is absent.

Cancer Survivorship Program

Working collaboratively with a person's physician(s) and other health care practitioners, we provide an extra layer of support to help deal with the cancer and its impact on body, mind, and spirit through:

- Education, counseling, and support
- Patient navigator services
- Pain and symptom control
- Stress/distress management
- Mind/Body education and care
- Advance care planning
- Comprehensive care as needed
- Coping with Cancer Support Group
- Marla Ceely Lamb Cancer Fund
- Look Good Feel Better Program
- Survivorship Services
- Referrals as needed
- End-of-life care as needed

Children's Services

- Direct care to children with life-threatening illness and family support;
- Guidance for parents of children coping with the illness of a loved one;
- Education and support for families of children grieving the death of someone close;
- Group support sessions for grieving children and their parents/guardians when enough families are interested;
- An extensive library of resource materials available for loan.

Volunteer Aid/Companionship

Trained volunteers are available to help patients and families and can:

- Provide respite breaks to caregivers
- Drive to doctor's appointments
- Assist with household chores
- Do errands
- Take patients on outings
- Help record personal history
- Play music
- Listen to their story
- Provide companionship
- And more



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**De-Stressing to Cope is partially funded through a Title IIIB grant of Elder Services of Cape Cod and the Islands.*

Whole Person Care (cont. from p. 1)

course of their lives. Oncologists are also encouraged to refer their patients to palliative and supportive care early in the course of their disease, since studies show that doing so can help them live better and often even live longer than not having this support during treatment.

While so many people think that palliative care is only used at end of life, the fact is that when started early, even when cancer is curable, it helps patients cope not only better emotionally, but also physically, and helps them tolerate their treatment better. Moreover, since it is well known that stress reduces the immune system's ability to fight disease, the work done within these programs to reduce stress improves patients' chances of regaining their health and well-being.

To better appreciate this, consider the case of one of our patients who was so fearful about having chemotherapy that she almost chose not to have it. She'd gone to her first oncology appointment and was so distressed that she came to our office in near panic about the idea of needing chemotherapy. She was immediately able to access our counseling and support, and, after about an hour's care, felt somewhat less anxious and better educated about what would happen.

Attending our cancer support group a few days later, she received further support and encouragement from other patients who'd gone through chemotherapy. Although still frightened, she felt empowered to make some decisions about her care that better met her needs, and after a few more private and group visits, ultimately completed her series of treatments.

She frequently tells us that without our help, she would never have been able to get through this treatment; that, in fact, she well might not have had it.

Another one of our patients had been diagnosed with an incurable form of cancer several years ago and was told that her prognosis was perhaps no

more than two years. She started attending our cancer support group and requested guidance in learning about how to live with the idea of facing death in the not-so-distant future.

Through coaching and guidance over many months, she was able to change her way of looking at life and considering the importance of living her life in a way that was more true to her authentic self. She made many, many changes in her life throughout the next couple of years and felt truly transformed by the experience in a very positive way.

While she has received excellent care by her oncologists and has been on a variety of chemotherapy regimens, she credits the treatments with *saving* her life and the counseling and support she's received through our program with *enriching* it.

While the above discussion focused on care of cancer patients, as mentioned previously, the care of any patient with any diagnosis is provided with the focus on the whole person. Our goal is to reduce patients' suffering and to strengthen and restore them to a higher level of well-being in which healing may be enhanced.

Often, the coaching and support we provide for family caregivers creates a level of assistance that diminishes the stress they must endure and makes a vital difference in the patient's and family's experience, further increasing the opportunity for healing.

So what is whole person care? It is care that recognizes that patients are more than their bodies and their diseases, that recognizes that they are human beings with lives and relationships and that every aspect of their lives is impacted by their illness.

Patients need the good biomedical care focused on curing their disease with technological approaches; but they also need much more. They need another dimension of care focused on helping them adjust to what their disease and its treatments are causing to happen and on how their lives and

Join us Nov. 12th
6-8 pm

for
Ladies
Night




Kick off the holiday season
with a fun night at the farm!

Dozens of vendors to shop local.

Festive drinks, tasty treats,
a Chinese auction, and more!

Suggested Donation \$10

All proceeds benefit
the Marla Ceely Lamb Fund.

Are you dealing with the loss
of a newborn or infant?
You're not alone.

Nantucket Cottage Hospital's
Newborn and Infant Loss
Support Group

meets the 2nd Friday of every month
from 5-7 pm in the Founder's Bldg.

Next meeting November 13th.

the lives of people they love are being disrupted by the illness.

As health care providers we must do these two things simultaneously – cure the disease, when cure is possible, and help our patients heal (become whole), whether their disease is curable or not.

Our work at PASCON is to bring this aspect of care to our patients and to add this additional level of care and support to the disease-focused care they're receiving from other members of their healthcare team. By working together in this way, our hope is that our patients will receive the best care possible.

The People of the Marla Ceely Lamb Fund

When new patients come in to apply for assistance from the Marla Ceely Lamb Cancer Transportation Fund, one of the things they learn is that the funds are all raised by the community ... grassroots efforts separate from the hospital and having nothing to do with insurance. It's many of their friends, neighbors, and colleagues, in addition to several community grants, who organize and sponsor the fundraisers and projects that keep the Fund going year after year.

When the Fund began 23 years ago, it was the family and friends of Marla Ceely Lamb who took on this grassroots effort of fundraising. Since that time, more and more friends and neighbors have joined the effort.

A community member like Ashlie Emery who, along with her teenage nieces, established MAD MIA bags and pillows designed from recycled jeans and shirts to sell at flea markets gives a portion of the proceeds to the fund.

Hospital employee and marathon man, Jules Embry-Pelrine, recently completed a 24-hour long run covering over 100 miles of the island to support the fund for the third

consecutive year. His efforts have raised \$4,000 to date!

Since the publication of our last newsletter in May, family and friends of Kelly Culkins West organized the 8th Annual Walk for Transportation in her memory, once again becoming one of the major sustainers. The Trustees of the Dorothy Harrison Egan Foundation understood the fund's mission to meet the needs of the community and contributed a generous grant as another major sustainer.

In honor of Breast Cancer Awareness month, Nantucket Island Resorts donated one dollar for every "Like" on their White Elephant Facebook page in October. Nantucket Health Club helped celebrate the month by holding more than a dozen donation classes for members and non-members alike. And Nantucket High School athletes and the Nantucket Booster Club once again organized a number of Play for Pink games.

Marla's family and friends have planned their 23rd annual fundraiser for November 13th at Faregrounds Restaurant. And for the second year in a row, Bartlett's Farm will donate all proceeds from its Ladies' Night fundraiser to the Fund. Last year they raised over \$4,000!

Several families named the Fund as beneficiary for memorial gifts, and we are very grateful. Poet's Corner Press ran a special promotion throughout the year and donated \$1 for every carton of copy paper sold. We're also grateful to people like Kim Corkran of Cape Air, Liz Holland of Hy-Line Cruises, Cheryl Caradonna of Island Airlines, and Gina Barboza of the Steamship Authority, who went out of their way to advocate for patients and helped make discounted tickets possible. And we love those PALS (Patient Airlift Services) pilots like Chris McLaughlin, who volunteer their time and fuel to fly patients for free.

This past year over \$75,000 worth of tickets and related travel reimbursements were dispersed thanks to the generous hearts and dollars of fellow community members who supported the Marla Ceely Lamb Fund.

We couldn't end these thanks without also mentioning those individuals and businesses who have so generously given their support in the past: Anne Stearns, Betsey Minihan, Chris Quidley of Quidley & Company, Wayne Petty and Laura Anderson of Nantucket Frame Center, Cape Cod Five, Island Gas, and The Hospital Thrift Shop.

There is a list of over 100 people who count on this fund to help with their travel off-island for treatment and check-ups. So far this year over 85 patients have come into the PASCON office for help with travel for treatment, and they always express how grateful they are for the generosity of their fellow community members.

23rd Annual Fundraiser
for the
Marla Ceely Lamb
Cancer Travel Fund

Friday, November 13th, 2015
at
Faregrounds Restaurant
6pm - 10pm

Hors d'oeuvres • Silent Auction
50/50 Raffle • Live Auction

Suggested Donation at the Door
\$10.00



Music by
The Offshore Blues Band



For more info, please call
508.317.7679



Photo by Kindflow Productions

Galley Beach once again provided the perfect venue for our Annual Dreamcatcher Dinner and Auction on May 31st and Auctioneer Tommy Bresette inspired guests to raise their paddles high and often for PASCON.



Photo by Brian Sager

The Nautican Foundation had a fabulous turnout for its 8th Annual Summer Soiree on August 8th! Guests gathered at the Whaling Museum for a fun night of cocktails and live music. The Nautican Foundation aims to motivate the island's young professionals to connect with and give back to the community. Their tremendous efforts raised over \$20,000 for PASCON!

PASCON Staff Recognized

Congratulations to our Program Director, Charlene Thurston, who was chosen as one of Nantucket Bank/Blue Hills Bank's Hometown Heroes and will appear in their 2016 calendar. And to our Palliative Care Counselor, Bonnie Fitz-Gibbon, who received the 2015 Rollo May Award for her outstanding scholarship as a doctoral student at Saybrook University. This is the highest honor the university awards.



Photos by Barbara Clarke, Beverly Hall, and Jane Ziesing
Swim Across America's Island Swim was a huge success thanks to the hard work of its event committee, co-chairs Jim Pignato and Jill Roethke, and the dedicated fundraising efforts of over 350 swimmers and volunteers! They reached an astounding total of \$325,000 which will go to Nantucket Cottage Hospital and PASCON to help support cancer patient treatment and care on island.

Mystery Art Auction



Silent Auction
to benefit
PALLIATIVE & SUPPORTIVE
CARE OF NANTUCKET
and
THE MARLA CEELY LAMB FUND

December 4th - 5th
Closing Bids Saturday at 4 pm
Quidley & Company
26 Main Street

New Night
New Format
Same Fabulous Works

Confirmed Artists include:

Joan Albaugh
Susan Briskman
Robert Frazier
Greg Hill
Whitney Krebs
Julija Mostykanova
Donald Van Dyke
Neeltje Westerlund



De-Stressing to Cope

By Bonnie Fitz-Gibbon, MEd, LMHC

In my position as the counselor for PASCON, I have the opportunity to engage with people going through all stages of illness and bereavement. This is a time that is often deeply challenging and personally transformative, and I am continually reminded as I witness this heroic journey that there is no limit to the possibilities for growth even in the face of such hardship.

Much of my work in this past year has been focused on the many needs of caregivers. These are the people who have the complex task of caring for loved ones, while also faced with how to take loving care of one's self. This dual existence is not easy to maintain and it requires a keen attention to a multitude of needs.

Stress, whether it be acute or chronic is the most familiar domain of the caregiver. For not only is one often caring for another on a round-the-clock basis, he or she is confronted with the dilemma of how to make sure they stay in shape, remain up to the task, be forever tireless, and be always willing and available. This is no simple undertaking.

Thanks to a grant from Elder Ser-

vices of Cape Cod & the Islands, we've added a new dimension to our caregivers' services this year called "De-Stressing to Cope."

Adapted from a national program called "Stressbusters," we have been educating caregivers in the many ways of self-care.

Techniques such as visualization, meditative breathing, journaling, specific body relaxation techniques, and art therapy are some of the resources we have used to help caregivers work with everyday stress. Time outs and time away (if possible) are also part of the "medicine" that enables caregivers to keep giving the best they can.

Along with this, we have introduced Reiki sessions to help all our patients and caregivers with relaxation.

Reiki is a traditional Japanese technique used for stress reduction that promotes healing. It is administered by a "laying on of hands" and is based on the idea that life force energy flows through us, and when this energy is low we are more likely to feel stress.

Reiki treats the whole person and in this way can affect the physical body and emotions to create a sense of peace

and well-being in the recipient. It can be done in any setting, whether lying down or sitting in a chair. In many hospitals across the country Reiki is now being used as part of patient care and has been found to help with a variety of conditions.

Hospitals such as MGH, Brigham & Women's, Beth Israel, Children's Hospital, and the Dana Farber/Harvard Cancer Center are some of the in-state medical centers that are routinely using Reiki as part of their wellness care.

Whether one is a caregiver or living with illness, stress is a natural part of life. The challenge that is upon one in this difficult time is learning how to sustain a sense of balance without letting stress become overwhelming to the point of debilitation. This requires a focus that is often hard to juggle when one is also managing the common everyday stressors of existence.

The task here is to be pro-active with self-care as much as possible. Sometimes a helping hand or a listening ear can jumpstart that process.

At PASCON it is our priority to help people not just by listening, but also by reminding and educating them about the many ways to cope with stress.

Our next "Time Out" Caregiver Support Group meeting is on Wed., November 25th. Please join us.

Upcoming Events

- Ladies Night at Bartlett's* - Thursday, November 12th - page 3
- 23rd Annual Marla Lamb Fundraiser* - Friday, November 13th - page 4
- Tree of Remembrance Service* - Sunday, November 22nd - page 1
- Giving Tuesday* - Tuesday, December 1st - details online
- Mystery Art Show* - Friday-Saturday, December 4th-5th - page 5

Support Groups at PASCON office

- Coping with Cancer*
every other Mon., 1-2:30
- "Time Out" for Caregivers*
every 2nd & 4th Wed., 1-2:30



**PALLIATIVE & SUPPORTIVE
CARE OF NANTUCKET
FOUNDATION**

A Partnership in Caring



**NANTUCKET
COTTAGE HOSPITAL**
MASSACHUSETTS GENERAL HOSPITAL AFFILIATE

Funded by the Palliative & Supportive Care of Nantucket Foundation, the palliative & supportive care 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.