



Palliative & Supportive Care of Nantucket

(formerly Hospice Care of Nantucket)

Currents

Vol. 24, No. 2

Fall 2016

Serious Illness Care Planning

By Charlene Thurston, ANP,
Program Director

In past newsletters, we've discussed the fact that all people over 18 years of age should choose a Health Care Proxy in an advance directive, and we've encouraged people to have conversations with their families and physicians about their wishes if facing a life-threatening situation. For the educational article in this edition of our newsletter, we'll focus more specifically on the importance of advance care planning for people who are already dealing with a serious illness like an advanced stage of cancer, heart disease, lung disease, kidney disease, dementia and other neurologic disease, etc.

When patients have such serious illnesses, it's important for them to plan with their physicians how much aggressive treatment they'd want as their disease advances, so that their health care team will know how to proceed in a manner that honors their wishes. It's particularly important to have such information available at times of crisis, when a trip to the emergency department or admission to the hospital will have patients being cared for by physicians who very likely will not be familiar with them. Without clear and readily available directions for what patients want, or don't want, for aggressive treatment, full emergency procedures will be implemented. If this conforms to what the patient desires, all is well, but if it does not, it creates disruption and turmoil for the patient and his or her



loved ones. The goal in having plans in place ahead of time is to have the treatment that's provided be aligned with the patient's wishes.

Though most patients assume that their physicians will tell them what they need to know when the time is right, when it comes to planning for what should happen when serious illness progresses, many physicians are often hesitant about starting the conversation due to concerns about distressing their patients. However, there's a great effort now being made by such leaders as Dr. Atul Gawande and Dr. Susan Block connected with Harvard Medical School's Center for Palliative Care and Ariadne Labs, to educate physicians and other practitioners about the value to patients of having such discussions. They have developed the "Serious Illness Conversation Guide," which can be used to help physicians learn from their patients what's important to them, and, on that basis, make recommendations that meet their patients' values, goals, and wishes.

In case you'd like to think about your

own situation, we thought we'd list the questions from the guide, so that you could think about your own values and wishes, and, if desired, initiate discussions with your own physician.

Questions to ponder:

- ◆ "What is my understanding of my illness now?"
- ◆ "What would I like to know about my illness and what lies ahead?"
- ◆ "If my health condition worsens, what are my most important goals?"
- ◆ "What are my biggest fears and worries about the future with my health?"
- ◆ "What gives me strength as I think about my future with my illness?"
- ◆ "What abilities are so critical to my life that I can't imagine living without them?"
- ◆ "If I become sicker, how much am I willing to go through for the possibility of gaining more time?"
- ◆ "How much does my family know about my priorities and wishes?"

Continued on page 6

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.*

Nancy Chase's Legacy

This fall we, along with several other island organizations, were presented with early Christmas presents from the estate of Nancy Chase by her sister Susan Ottison. Through her will Nancy made extremely generous contributions to both our Palliative & Supportive Care Program and to the Marla Ceely Lamb Fund, for which we're most grateful.

Several years ago, Nancy had served as a long-term member of our board and was always most helpful and generous to our program, both in spirit and in treasure. In addition to the work she did for our program, she extended herself wherever was needed to improve the lives of the people of Nantucket. It was so wonderful of her to continue her legacy of caring for our island residents for many years to come by providing such meaningful financial support to community organizations that care for them. We're most grateful and honored that she chose us to be among them.

Nancy's gift reminds us of how we can continue to care for our community even after our death. For anyone who's interested in the idea of legacy giving, a good resource is available at www.leavealegacy.org.



This past weekend we held our Annual Tree of Remembrance Service in the JC House Gazebo Garden with a reception following at Dune.

Thanks so much to everyone who turned out to take part in this special and most meaningful ceremony before the holiday season gets truly underway.

If you weren't able to make it Sunday, you're welcome to add an ornament to the tree at any time this holiday season. Stop by our office for a shell on which you can write your loved one's name.

Special thanks to Rev. Gary Klingsporn, Mollie Glazer, and Michael Getter.

Sailing Heals Helps Patients and Caregivers

Have you ever noticed how different you feel when you're on the water? Whether it's on a pond in a kayak or on the deck of the ferry, stress seems to melt away as a sense of well-being takes over. This magical state was experienced this summer by many of our patients and caregivers who participated in the **Sailing Heals** program.

Begun five years ago in partnership with Nantucket Community Sailing, **Sailing Heals** provides a free day or afternoon of relaxing sailing for patient guests - those who are undergoing treatment for cancer or dealing with the effects of a serious illness - as well as their caregivers.

This year 26 patients and caregivers spent an afternoon on Nantucket Sound aboard a 35 foot keelboat with Nantucket Community Sailing, and on a

classic yacht with its volunteer captain one day during the Opera House Cup week.

After an afternoon in the harbor one patient told us "it put the wind back in my sails". Another said how much she loved the magnificent storm cloud when asked if the cloudy weather had put a damper on the sail. Still another shared, "That was a wonderful afternoon. I was a helm hog and sailed, and sailed, and sailed. What a wonderful opportunity..." Still another shared how she could feel her mind slowing down and the stress almost disappear.

Wallace J. Nichols, a marine biologist, believes that we all have a "blue mind" - as he puts it, "a mildly meditative state characterized by calm, peacefulness, unity, and a sense of general happiness and satisfaction with life in

the moment" - that's triggered when we're in or near water.

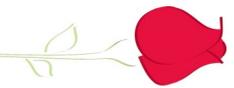
"We are beginning to learn that our brains are hardwired to react positively to water and that being near it can calm and connect us, increase innovation and insight, and even heal what's broken," Nichols writes in *Blue Mind: The Surprising Science That Shows How Being Near, In, On, or Under Water Can Make You Happier, Healthier, More Connected, and Better at What You Do*. And thanks to the efforts of those at Nantucket Community Sailing and Sailing Heals who coordinate and sustain the **Sailing Heals** Program, our patients and caregivers have an opening into this 'blue mind' state.

To learn more about these organizations, visit sailingheals.org and nantucketcommunitysailing.org

Our Annual Daffodil Planting took place November 12th along Old South Rd across from Fairgrounds. Look out for the beautiful blossoms this spring. Thank you to everyone who came out to help plant, especially Nantucket New School students and staff and the crews of **J & M Landscape Services** and **Champoux Landscape** who make this possible year after year! Thanks also to Ernst Land Design for their donation.



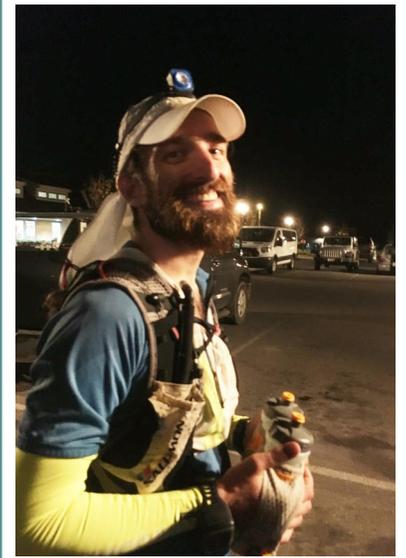
Marla Ceely Lamb Fund



What a community, what a cause!

After 24 years the Marla Ceely Lamb Fund continues to serve over 90 people with a cancer diagnosis who need to travel off island for treatment. We are blessed with a generous community of donors whose gifts sustain this valuable fund. Since our last newsletter, the Fund has been supported by:

- 24th Annual Fundraiser at Faregrounds by Marla's family and friends
- NHS Class of 2016
- Caitlin Marcoux and Nantucket Island Resorts/Yoga Benefit
- Play in Pink Games/Nantucket Public Schools
- Rogers & Gray Insurance Company's Pinktober Committee
- Pink4Purpose by Nantucket High School staff
- Estate of Nancy A. Chase
- Jules Embry Pelrine's 24 hour Run
- Brian Glowacki's Comedy Show/Nantucket Dreamland Foundation
- Photographers Alliance of Nantucket
- Dorothy Harrison Egan Foundation
- Nantucket Yacht Club
- Sons of the American Legion
- Memorial & Honor tributes from community members



When we asked Jules what inspired him to pick the Marla Ceely Lamb Fund as beneficiary of his 24-hour run, he told us that when his older brother had a cancer scare, he was able to ride on the "T" for his treatments, so it made sense do something to help islanders who need to go to so much expense to go off island for treatment. And when we asked what gets him through the night, he said that actually, that long run is nice and quiet and peaceful...and though he says he has no problem with sleepiness, that gift of ice coffee around the half way mark, sure helps him get through to the end of the run!

Playing in Pink

Nantucket High School athletes celebrated a week of Whaler pride last month when they participated in the 5th Annual Play in Pink games.

Athletes from all fall sports worked together with the Booster Club, coaches, and community members to raise money for a cause that is near and dear to many.

Shae and Paige Albertson (top right) were approached by the Booster Club to lead this year's fundraising efforts and said that the student athletes really enjoy supporting this cause.

Over \$8,000 was raised this year, bringing the five year total to nearly \$40,000!



The Marla Ceely Lamb Cancer Transportation Fund continues to be managed and administered by Palliative & Supportive Care of Nantucket so that every dollar raised can go directly towards patient travel expenses.

What Patients Say

“Knowing I have the transportation cushion for my trips to Dana Farber gives me immeasurable courage. I feel the support of those who make these trips possible for me. Not worrying about having sufficient funds to visit the Dana Farber oncology team ensures that I am faithful to their life-saving regimen. Sitting in the Dana Farber Breast Oncology waiting room, named in honor of our fellow Nantucketer, Dr. David Nathan, makes me proud of him, his prodigious accomplishments, and our island and islanders. We look after each other. Thank you, Marla Ceely Lamb Fund, for prolonging my life and giving me hope.”



“The Marla Ceely Lamb Fund has always held a special place in my heart, as she was a friend. I watched her struggle to go to Hyannis for treatment, as there was no discount or fund when she was ill. Happy to contribute to her fund, I never thought I would be a hands-on user. Finding out I had cancer, and that the treatment was in Boston, I was faced with a financial dilemma. The Marla Ceely Lamb fund gave us peace of mind, as our medical costs were mounting. Ginnie and all of the Palliative and Supportive Care staff are accommodating, sympathetic, and encouraging as I asked for assistance. I will be forever grateful for all the generosity and caring.”



“The Marla Ceely Lamb Fund has been a bright light in the dark cancer tunnel I involuntarily entered 5 years ago. It makes my travel to Boston for annual check-ups easy and worry free. Accessing the fund is very discreet, and doesn't require a lot of paperwork. It takes the financial burden off your shoulders, so that you can focus on your health instead. Thank you!”



“I was diagnosed seven years ago with CML, Chronic Myelogenous Leukemia, and through the assistance and support of the Marla Lamb Fund, you have made my experience with cancer much more manageable, as words can't express my thanks. I continue taking chemo daily and there is currently not a cure, but I'm hoping that one day there will be a cure and I'm truly grateful for everyone's assistance”.



“I recently started participating in the Lamb Fund as I need to travel to Boston frequently for my doctors appointments. The cancer has caused me to cut back on my work, thus my income has dropped. Through the Lamb Fund I receive financial assistance that helps me with my travel arrangements. I am very grateful for it!!”

“People tend to forget that most folks also need to bring along a spouse/ partner/friend for support. That doubles the cost of travel. Thank you for all you do to help us.”



“The Marla Lamb Fund was just a ‘concept’ for a long time. But when my diagnosis became a reality, it was so comforting to walk into the office, make a request, and have it honored with a smile.”



“The fund allows cancer patients to concentrate on getting to their treatments/appointments without having to worry about the associated travel expenses...one less worry when your mind is already overloaded. Ginnie convinced me to take advantage of the funds even though I said I didn't need it. I feared appearing ‘needy’. It was part of my cancer bravado -- which was truly all a façade. She suggested I donate back to MCL when I felt better. That worked for me -- made me not feel like I was taking from someone who needed it more than me. And those travel costs added up so fast it was astonishing. Aside from all the chemo trips to Boston, there were multiple trips for PET scans, MD appointments, staging appointments, pre-op testing and surgery.”



“The Marla Lamb travel fund saved my life. Weekly sometimes bi-weekly trips to MGH would have been put on credit cards because I wasn't working while I was healing from surgery and then heading over to Hyannis for radiation. You don't realize how draining it can be on your finances even if you have medical insurance. There are all the extra expenses and the travel is monumental when you live 30 miles out at sea.”



“I had been aware of the fund for years. I had contributed to some of the fundraisers, but I didn't know too much about it. I now know that so many people, too many, have to make the personal, professional, and financial arrangements necessary to deal with cancer, a situation exacerbated from living on an island. It wasn't until I was in a position to be on the receiving end of this fund that I appreciated the breadth and depth of this organization. The support is more than financial. The fund was a help with the added financial burden associated with treatments, but was also a window into the generous nature of our community. Cancer touches so many in our community and the community responds.”



“Having any cancer is emotionally stressful and expensive. The Fund helps defray the cost of treatments and the cheerful administration helps reduce the corresponding stress.”

Congratulations to Our Palliative Care Counselor, Bonnie Fitz-Gibbon!



Please join us in congratulating our Palliative Care Counselor, Bonnie Fitz-Gibbon, LMHC, for earning her Ph.D. in Psychology from Saybrook University's College of Humanistic & Existential Studies.

Bonnie has worked tirelessly towards this degree for several years, in addition to carrying out her work for PASCON and her private clinical practice.

She was such an outstanding student that she received the prestigious Rollo May Award last year, as the person who exemplifies outstanding and scholarly achievement at the college.

We're so happy for Bonnie and so proud to have her as a member of our staff!



Serious Illness Care Planning (cont. from p. 1)

We encourage patients to think about these issues and any other questions or thoughts they'd like to share, and to request an appointment with their primary care physicians or primary specialist, who know them best, to discuss them and to create a plan for future care. After discussing the information, your physician should be able to understand more clearly what's important to you and make recommendations of care that best meet your goals. The plan should be documented in your medical record, and, if desired, a MOLST form can be created, with a copy for you and for your medical record. MOLST stands for Medical Orders for Life Sustaining Treatment, and is a set of doctor's orders which can be used in emergencies to direct your care.

Remember that the purpose of this planning is to help patients think about their situation and to help them engage in discussions with their physicians about the best way to proceed. Ultimately, this process will keep patients and families in control and will help health care staff understand your wishes and provide care that conforms to your wishes. Your primary care physician or, at times, your primary specialist knows you best and can best help you plan for your future treatment. Don't hesitate to request a special appointment to have this discussion. Also, please don't hesitate to call upon us at PASCON to discuss this idea further or to request help.



Swim Across America's
Nantucket Island Swim
- August 27, 2016 -

Mark Your Calendars:
August 26, 2017

www.swimacrossamerica.org



23rd Annual Dreamcatcher Dinner and Auction - June 12, 2016



All photos by Rebecca Love Photography



Photos by Joelle Bouchard, Kit Noble, Becky Zadroga



Bidding Friday and Saturday
Final Bids 4 pm Saturday



Quidley & Co., 26 Main Street

Benefits PASCON & Marla Lamb Fund

Annual Auction

Original Works from 30+ artists including:

- | | |
|---------------------------|-------------------------|
| Joan Albaugh | Miki Lovett |
| Colin Berry | Jan Purdy Metcalf |
| Stephen Coyle | Diana Dunbar Northrop |
| William Davis | Anthony Panzera |
| Julija Mostykanova Feeney | Forrest Rodts |
| Julie Gifford | Sergio Roffo |
| Tine Kirkland Graham | Christine Sanford |
| Louis Guarnaccia | Sage Goldsmith Tremaine |
| Tracey Harris | Jocelyn Urban |
| T.S. Harris | Peter Van Dingstee |
| Greg Hill | Donald Van Dyke |
| Megan Hinton | Meg Weeks |
| Sharon Woods Hussey | Neeltje Westerlund |
| Maryann Jones | Sid Willis |
| Oriana Kacicek | Michael Wodynski |
| Ken Layman | Karen Woods |
| Sue Lingeman | Linda Zola |

Hosted by Quidley & Co.

Support Groups

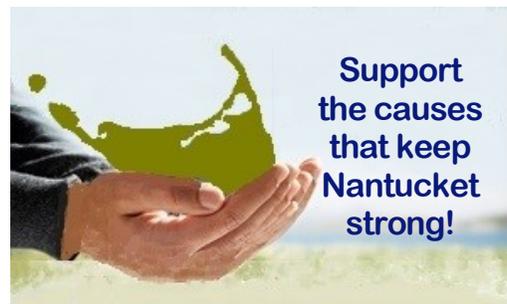
- *Coping with Cancer* - every other Mon., 1-2:30pm
For those with any stage of cancer, as well as family members or friends of those with cancer, to discuss concerns and share ideas in a safe and welcoming environment. Information, support, and stress management strategies.
- *Time Out” for Caregivers* - 2nd and 4th Wed. of each month, 1-2:30pm
A stress reduction program for family caregivers focused on helping identify stress factors in their lives, learn about the impact of stress, and experience specific techniques to help relieve stress.

All groups meet in our office at 99 Goldfinch. Call us at (508) 825-8325 for more information. Trained volunteers available to sit with loved ones while caregivers attend.

Black Friday. Cyber Monday.

#GIVINGTUESDAY™

November 29, 2016



Support the causes that keep Nantucket strong!

Double your donation to PASCON!
Donate online Tuesday the 29th and your gift will be MATCHED.

www.pascon.org



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.