Palliative & Supportive Care of Nantucket Vol. 22, No. 1 Currents Spring 2014

What Will Be Your Legacy?

By Charlene Thurston, ANP, Program Director

When we come to our final days and look back on our life, what will we say has made it meaningful?

How can we spend whatever time we have remaining in a manner that brings satisfaction and fulfillment to our lives and to the lives of those we love?

If we were told we could die tomorrow, what would we want to be sure to pass on to those we'd leave behind? What legacy would we leave?

People often think of the tangible things they'd like to leave to others, like their property, money, and other valuables, and are usually very sure to leave a will. But what of your life's story would you like people to remember? What has given your life meaning? What lessons have you learned and what values would you like to pass on? These are the parts of *ourselves* that live on and are often much more important than the *things* we leave.

If there is any blessing to having a lifethreatening illness, it is that, in bringing one face-to-face with the possibility of dying, it provides time for pondering the questions of life's meaning and for addressing the issues which surface during this phase of life's journey.

Dame Cicely Saunders, founder of the hospice movement, said, "You matter because you are you. 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 live until you die."

We've used this quote often in articles we've written because it clearly states one *Continued on page 4*



Electric Love

On a Thursday evening in late March, nearly 100 men and women came out for a very special night of music, art, meditation, and yoga at the Dreamland studio and raised over \$3,000 to benefit PASCON.

Centered by a lovely opening meditation from Clay Twombly, participants moved to the music of DJ Pete Ahern while the beautiful and inspirational yogini Caitlin Marcoux led the practice and while Brooklyn-based graffiti artist Craig Anthony Miller created a spontaneous piece of art via simulcast.

The event was spearheaded by Caitlin who solicited the help of friends and colleagues to pull it all together. Burr Tupper of Verde Nantucket Green Build was instrumental in the night's success creating the stage and backdrop and financing the film crew in Brooklyn to stream the artist.

It was quite a night of loving and healing energy that filled the theater and touched all who participated.

We are grateful to everyone who came out to participate and show their support, especially the event organizers who gave so freely of their time, love, and energy.

We are thankful that Caitlin Marcoux has so graciously and honestly shared her experience coping with breast cancer while also advocating for support of PASCON. We are truly awed by her courage, her grace, her talent, and her generosity of spirit.

To learn more about Caitlin's journey, visit caitlinmarcoux.net where she shares information not only about her yoga, but also about her experiences facing breast cancer.



Foundation

Rick Beaudette President

Joseph Grause Vice President

Gussie Beaugrand Secretary/Clerk

Lou Gennaro Treasurer

Carolyn Durand Laura Fletcher Heidi Daniels Girvin Jeanne Hicks Mike Misurelli Nancy Moylan Peggy Tramposch Clark Whitcomb

Carrie (Glidden) Riden Executive Director

Program

Charlene Thurston, ANP *Program Director*

Timothy Lepore, MD Medical Director

Peter MacKay, MSW Social Worker

Bonnie Fitz-Gibbon, MEd, LMHC Palliative Care Counselor

Ginnie Faria Volunteer Coordinator

Contact Information

57 Prospect St Nantucket, MA 02554 (508) 825-8325 (508) 825-8211 FAX pascon@partners.org www.pascon.org

Farewell to Nan Strelnitski, Welcome Bonnie Fitz-Gibbon

It was a very sad day when Nan Strelnitski, RN, MA, MS, our wonderful palliative care counselor, announced that she'd be retiring.

After 9 years of working together and creating a role that has become so integral to our program and the care we provide, it was hard to see how we could move forward without her.

Nan brought the perfect blend of credentials in counseling, compassionate presence, and skillful care, and a background in yoga and Thai Shiatsu Massage into the role that we were trying to create for our program. Over the years she's touched the lives of so many of our clients who felt that her care for them was central to their healing. Her quiet, loving, gentle style was a great balm to all of us who worked alongside her. We will miss her greatly, but wish her well in all that she does in the future.

In considering how to move forward, we took a deep breath and followed the tenets of one of our mentors in the field of end-of-life care who suggests welcoming all change, even when it's undesirable, and seeing it as an opportunity for new growth.

Fortunately, several months earlier, a mental health counselor in the community had expressed an interest in volunteering for our organization, and we were so moved by our interviews with her and her interest in working with people who were facing life -threatening illness that she quickly came to mind as a possible candidate to fill Nan's role. To our delight, she was interested and we've now hired Bonnie Fitz-Gibbon, M.Ed, LMHC, as our new Palliative Care Counselor.

While both Nan and Bonnie have backgrounds in counseling, other aspects of their backgrounds are different and our program will evolve accordingly. We're excited to see what the future holds as we explore new possibilities.

Please join us in thanking Nan and in welcoming Bonnie.

All of our services are free and made possible by your donations. Thank you so much to all those who have contributed this year.

For Caregivers

Caring for a loved one with a long-term illness or disability is a 24 hour job! The physical and emotional stresses can be overwhelming. Through our Caregivers Connections program, we provide family caregivers education, support, and practical assistance. Services include:

 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** every 2nd and 4th Wed. of the month, 1-2 pm, stress reduction education and/or counseling in the home or office, which may include talking, learning relaxation techniques, etc.;
- **Volunteers** 1¹/₂ 2 hours/week for respite breaks or help with errands, transportation, etc.;
- Lending Library of caregiver-related topics.

All of our services are completely free of charge! Please take advantage of all we have to offer. For more information or to make an appointment, please call our office at (508) 825-8325.

Children's Services

Through our Tapestries program, we offer:

•

- Direct care to children with life-threatening illness and support for their families;
 - Parental guidance for parents of children coping with the serious 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 in forming a group;
- An extensive library of resource materials which are available for loan.

As always, these services are offered at no charge.

21st Annual Dreamcatcher Dinner and Auction June 8th

The Farmer's Almanac predicts a cool, clear evening on June 8th. Sounds like perfect conditions for a gorgeous sunset and another fantastic evening supporting PASCON at Galley Beach.

For the 13th year in a row, David and Geoffrey Silva have generously offered to host our Dreamcatcher Dinner and Auction at Galley Beach. There's no better spot in our eyes, and chef Neil Ferguson promises to deliver another award-winning meal.

After more than 20 years leading the festivities and challenging guests to raise their paddles in support of our programs and services, Rafael Osona has stepped down and turned the microphone over to Tommy Bresette. Rafael can be credited for the incredibly moving memorial sunset portion of the evening, and we are so grateful for his countless contributions over the years. While Tommy certainly



has some big shoes to fill, we're thrilled to begin this new chapter and see where it takes us!

Spanky will be back with his fabulous raw bar! And we're looking forward to offering a great mixture of old and new auction items. There will be perennial favorites like the clambake at the Admiralty and sailing in the Opera House Cup as well as some new packages like a trip to the CMA Awards in Nashville and a stay at Las Ventanas in Cabo.

Our silent auction features some items you might expect like restaurant gift certificates and manicures. But we're also excited to list some more unique items and experiences including passes to the Film Festival and the Yoga Festival.

We hope you'll consider joining us for this wonderful event. Whether you've been with us every year or are attending for your first time, we'd love to have you and are certain you'll have a great time.

Reservations are required and seating is limited. Tickets start at \$225 and are available online (www.pascon.org).

And if you can't make it this year, please take a chance on a Dream Ticket. Show your support for PASCON and maybe even win the concert experience of a lifetime!

2014 DREAM TICKET 4 Seats. Any Concert. Anywhere. Anytime.* Airfare and Accommodations included Only 200 tickets will be sold. \$100/ticket www.pascon.org for details

Winner will be selected the night of June 8th at Palliative & Supportive Care of Nantucket's 21st Annual Dreamcatcher Dinner & Auction Needn't be present to win * any concert within the continental US between 7/25/14 = 6/9/15

Legacy (continued from page 1)

of our central goals – ensuring that our patients recognize their value and dignity, no matter what state of vulnerability and weakness they might be experiencing. Supporting our patients and families as they confront the existential and spiritual issues that emerge when faced with life-threatening illness and grief is a most important aspect of our work.

Reviewing our lives, reminiscing, and sharing memories can often be very beneficial in reaffirming the value of a person's whole life. At a time when one may be feeling particularly vulnerable, it helps to remember who they've been, whom they've loved, what they've accomplished, and what they'll leave to those who survive them. In this way it helps complete their life story and share it with those they love, re-experiencing times that have brought them joy, and providing an opportunity for them to reframe, forgive, or reconcile with events or people that might have been very difficult.

For those who are well enough to do so, time may be spent on a spiritual search, looking for answers to questions about life and death and whatever follows, re-prioritizing things in their life so that they live more authentically for whatever time there is remaining, whether weeks, months, or years, and realigning their lives with their values.

For people who may be too weak or uninterested in such a pursuit, simple reminiscence with loved ones with opportunities to pass on treasured memories, values, forgiveness, and words of wisdom will be most valuable. For those with the interest, strength, and opportunity to do so, creating a documented legacy, written, audio-taped, or videotaped, can be a wonderful way to share one's life and to leave something which surviving loved ones may return to after a death, creating a tangible bond which endures for years to come.

Patients, family members, and friends can all participate in the process, and, if desired, our volunteers are available to help as well.

One of our veteran volunteers, Toby Greenberg, recalls successful life review projects with some of her patients. Using an interview tool designed in booklet form learned at a training session, she was able to help patients, even those with memory loss, tell their life stories which they remembered and enjoyed in amazing detail.

Ginnie Faria, our volunteer coordinator, recalls helping a patient friend create a photo book. Not only did the patient love having a book to enjoy and to leave for her loved ones, but a detailed story of an extraordinary family road trip from her early life as a young mother emerged from just one picture.

There are many tools that can help in the process. Some people just like to sit over photos and talk about what was meaningful. Others like to write letters to those who'll remain. Still others choose to follow guides to document their stories. We have several resources in our office which people are invited to borrow.

However it's done, reviewing one's life provides an opportunity to make meaning of the life we've lived and enhances our connection to people we love. We encourage family members and caregivers to ask about the lives of persons they're caring for and to take the time to listen attentively to what's being shared. Everyone will benefit.

Community Outreach

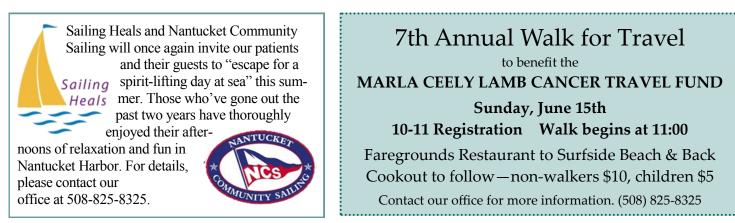
On May 10th, we were pleased to offer a free teleconference for health and human services providers as well as interested members of the community. **"Helping Adolescents Cope with Loss"** is part of the Hospice Foundation of America's Annual National Living with Grief series and focused on the issues adolescents face as they cope with loss.

Support for the Marla Ceely Lamb Fund

The Hospital Thrift Shop recently awarded the Marla Ceely Lamb Fund a grant for \$12,000! We are deeply grateful for this most generous gift. It will help countless islanders needing to travel offisland for cancer treatment and care.

Last weekend, the Marla Ceely Lamb Fund hosted its 22nd Annual Mother's Day Fundraiser at Fareground's. Thank you so much to everyone who came out to support the Fund and everyone who donated auction items.

The Marla Ceely Lamb Fund is managed and administered by Palliative & Supportive Care of Nantucket.



Swim Across America

Swim Across America is back for the 3rd Annual Nantucket Island Open Water Swim at Jettie's Beach August 23rd.

Register before June 1st for \$25. Registration goes up to \$50 after June 1st.

We need everyone's support to reach the ambitious goal of \$225,000! We know you can do it. And you need to know how important this swim is to Nantucket!

Nearly all of the money raised will remain on island and be split between Nantucket Cottage Hospital and Palliative & Supportive Care of Nantucket for their cancer programs and services.

The money raised from last year's Swim is helping PASCON further develop our Cancer Care Support Program. Our hope is to improve the quality of life for people facing cancer and their families by helping to alleviate the physical, emotional, and spiritual distress caused by the illness and its treatment and by increasing their ability to cope and thrive.

Please join in the effort this year! All are welcome. There are so many ways to participate. Swim the 1/2 mile, the 1 mile, or the kids' splash. Volunteer for registration or as a kayaker. Show up to cheer on the swimmers. And donate.

You don't have to swim to raise money. You can register as a volunteer and start fundraising right away. The competition for top fundraising team and individual is already under way. Team Roethke is the team to beat so far, but it's not too late to throw your hat in the ring!



Courtesy of Claudia Kronenberg Photography

Wine Dinner a Success

Thank you to chef Michael Getter and his staff at Dune for hosting our 2nd Annual Wine Dinner last month. Guests enjoyed a fabulous meal and wines courtesy of Brix Wine Shops, Classic Wine Imports, Jill Yeagy Bookkeeping, and several anonymous donors. Thank you to our sponsors and to each of our guests who turned out to show their support.

SWIM EASY, FIGHT HARD,

NANTUCKET ISLAND OPEN WATER SWIM SATURDAY AUGUST 23, 2014 8AM JETTIES BEACH 1/2 MILE SWIM, 1 MILE SWIM, KIDS SPLASH

HELP US FIGHT CANCER ON NANTUCKET THIS AUGUST.

Join the Swim Across America Family for the 3rd Annual Nantucket Island Open Water Swim. At Swim Across America, the money you raise stays in our community, supporting cancer treatment and patient care.

Swim with us this August and make a tangible impact on our island.

THE SWIM IS THE EASY PART.

ANTUCKI



PALLIATIVE & SUPPORTIVE

CARE OF NANTUCKET

To sign up or learn more, visit: WWW.SWIMACROSSAMERICA.ORG/NANTUCKET2014

🋫 #SAANANTUCKET 🛛 🖸 @SAANANTUCKET



Massachusetts Orders For Life-Sustaining Treatment (MOLST)

By Jason Graziadei, Public Information Officer, NCH

A new state initiative is being rolled out in 2014 to ensure that people of any age who have a life-threatening medical condition, illness, or injury can make their own choices about endof-life medical care.

Massachusetts Medical Orders for Life -Sustaining Treatment, or MOLST, are written instructions from a physician to other health care providers regarding a patient's medical care. They outline the types of emergency medical treatments a patient wants, or does not want, to be administered to keep them alive near the end of their life.

These forms, which are voluntary, can be used by a person of any age who has a serious medical condition from which they may not recover to ensure their own preferences are honored by all health care providers. Unlike written "final wishes" or a living will, MOLST forms carry greater authority and will be honored by Massachusetts medical facilities. They also differ from "Do Not Resuscitate" (DNR) orders by providing additional instructions regarding medical care. MOLST forms can be changed or voided at any time.

Nantucket Cottage Hospital and Pal-

liative & Supportive Care of Nantucket are working to educate patients, clinicians, and caregivers about the MOLST program.

Anyone with an advanced illness or injury should start discussions about advance care planning with their clinicians. The MOLST forms, which are bright pink, are filled out by a patient and their clinician, and should be kept by the patient in a location that is easy to locate, such as a refrigerator or bedside table. They should also be carried with the patient outside their home.

What are life-sustaining treatments?

These are medical treatments used to restart a person's heart or breathing if they stop, such as:

- Cardio pulmonary resuscitation (CPR), such as mouth-to-mouth breathing, forceful pressure, or electric shock to the chest. Many health care providers are legally required to use CPR if a patient's heart or breath stops, unless they have written orders with other instructions from a doctor, such as MOLST form.
- Intubation and Ventilation, when a tube is put down a person's throat and attached to a machine that pumps air into and out of the person's lungs.

MOLST forms will provide EMT's,

health care facilities, and clinicians with specific medical orders regarding treatments that are to be used or not to be used to start a person's heart or breathing in the event they stop.

If you have questions about MOLST and end-of-life care, please contact PASCON at 508-825-8325. Additional information about MOLST is available at www.molst-ma.org.



was April 16th

Did you complete or review your Advance Directives? (It's never too late. We can help.)

Do your loved ones know your healthcare wishes?

Who would decide on your medical treatment if you were not able to speak for yourself?

Be sure to choose a Health Care Proxy and make your wishes known!

Visit our website or call for more information on how to protect yourself and make your healthcare wishes known.

Upcoming Events

Dreamcatcher Dinner & Auction - Sunday, June 8th - page 3 7th Annual Walk for Travel - Sunday, June 15th - page 4 3rd Annual Island Swim - Saturday, August 23rd - page 5 Harbor Sails for Patients - various dates - page 4 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



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.