



Palliative & Supportive Care of Nantucket

Vol. 24, No. 1

Currents

Spring 2016

Having the Conversation

By Charlene Thurston, ANP,
Program Director

If something happened to you and you were nearing the end of your life, either due to a sudden accident or illness or a long term progressive disease, what would your wishes be? Have you thought about that? Have you told anyone about them? Do you know what your family members would want?

There's an international movement in the healthcare field to try to help people think about what they'd want and to encourage them to communicate their wishes to their families and their healthcare providers. Prompted by authors like Dr. Atul Gawande (Being Mortal), Dr. Angelo Volandes (The Conversation), and many others, and by efforts like The Conversation Project and the now reimbursable doctors' visits to discuss advance care planning, people are finally beginning to understand the importance of having these discussions before emergencies arise, so that when something does occur, everyone knows what to do.

Several months ago, I'd seen a TEDMED Talk by Michael Hebb, who came up with the idea of starting a campaign to get people talking about their wishes over dinner parties. Hebb describes how he'd been sitting in a train with two physicians he'd just met, and, in the course of their conversation, they'd described how incredible it was that people approached the most significant event of their lives totally unprepared, and how their families were often left to make life and death decisions for loved ones without any idea of what they might want. He mentions being unpleasantly surprised to

hear that the vast majority of American bankruptcies are related to end of life expense, and that, although 75% of people say they want to die at home, only 25% do. In the course of the conversation he asked, "Do you agree that how we end our lives is the most important and costly conversation we're not having?" To which the physicians emphatically agreed. He then asked, "Do you think that, if we started a national campaign called, "Let's Have Dinner and Talk about Death," there'd be wide support by physicians, hospitals, and the public?" and both said, "Absolutely! You must do this."

Since then he and his colleagues developed the idea of starting a grass-roots movement where people would gather around a dinner table with family and friends for the purpose of discussing what was important to them and what they'd want or not want if a life and death situation occurred. The dinner party idea came from his thoughts that people sitting together in friendship breaking bread in a relaxed way was how we most comfortably share thoughts and feelings about important matters in life.

Out of this, an organized platform
Continued on page 4

Please join us for a FREE web streaming video program

“Managing Conflict, Finding Meaning - Supporting Families at Life’s End”

Saturday, May 21st
9 - 11:30 am
Founder’s Building
Nantucket Cottage Hospital

A panel of experts will discuss how to support families as a family member is dying and while grieving after a death as well as how to manage sources of conflict that may emerge.

This program is geared towards professionals, but all are welcome. CEUs will be available.

To register or for more information:
508-825-8325/ pascon@partners.org

Part of Hospice Foundation of America's Living With Grief Program

Have you Completed Your Advance Directives?

National Healthcare Decisions Day was April 16th.



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

Visit our website or call for more information and help with advance care planning.

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



Foundation

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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

Rev. Linda Simmons
Chaplain

Ginnie Faria
Volunteer Coordinator

Contact Information

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Nantucket, MA 02554

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(508) 825-8211 FAX

pascon@partners.org
www.pascon.org

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

SWIM TO FIGHT CANCER ON NANTUCKET★

OUR

★ ISLAND ★ FAMILY ★ SWIM ★ CAUSE ★



NANTUCKET ISLAND OPEN WATER SWIM

AUGUST 27, 2016 8:00AM

1/2 Mile and 1 Mile Swim, Kids' Splash

Jetties Beach

WEEK OF AUGUST 23, 2016

4 Mile Swim

North Shore, Nantucket

BENEFITTING:  **NANTUCKET COTTAGE HOSPITAL**
MASSACHUSETTS GENERAL HOSPITAL AFFILIATE

 **PALLIATIVE & SUPPORTIVE CARE OF NANTUCKET**

SWIM
ACROSS AMERICA
 ★ MAKING WAVES TO FIGHT CANCER ★

REGISTER TO SWIM, VOLUNTEER OR DONATE:

WWW.SWIMACROSSAMERICA.ORG/NANTUCKET

 @SAANANTUCKET

Serving Our Cancer Patient Community

We are so grateful to Swim Across America for the opportunity to raise funds for cancer care on the island each year.

The amount received by PASCON in 2015 has helped us further develop our Cancer Survivorship Program and has enabled us to serve nearly 200 patients and families dealing with cancer through over 800 visits with our Nurse Practitioner, Palliative Care Counselor, and Program Assistant.

Thank you so much to everyone who helped make our 2015 Nantucket Swim such a tremendous success! We hope everyone will join us again on August 27th.



Patients and their guests are invited to “escape for a spirit-lifting day at sea” this summer courtesy of Sailing Heals and Nantucket Community Sailing.

Those who’ve gone out other years have thoroughly enjoyed their afternoon in the harbor.

For details, contact our office at 508-825-8325.

Marla Ceely Lamb Fund

In Memoriam

We'd like to express our sincere sadness over the death of family member Sally Roberts and to offer our deepest sympathy to her family. Sally was Marla's sister-in-law and has been such a staunch advocate and hard worker in support of this fund over the years. We're so grateful for all that she's done to help so many others.

Continuing Community Support

Since the publication of our newsletter in November, extraordinary community support continues to make it possible for the Marla Ceely Lamb Fund to assist those who need to travel off-island for cancer treatment and care.

Marla's family and friends donated scores of treasures and worked many hours to raise over \$25,000 at their Annual Dinner and Auction November 13th. Thanks to Kim and Bill Puder for once again hosting the event at Faregrounds. Kim and Bill also deserve thanks and congratulations for being chosen and then donating their \$1,000 *Hometown Hero* award from the Blue Hills Bank Foundation.

Practically every lady on island came together for a fun night of shopping at Bartlett's Farm in November. This year's

Having the Conversation (continued from page 1)

was created so that people could access it for free online to create their own dinner parties. At deathoverdinner.com, you can see the format, and, if interested, register and create your own dinner party. They've included excellent resource material for guests to read and great prompt questions to guide your discussions. They've even developed invitations you can email your guests. You can watch the 17 minute TEDMED Talk online by searching "TEDMED Death Over Dinner".

We strongly encourage you to try it, even with just a small group of family or friends, and promise that the conversation and effort will be rewarding. Afterwards, continue the process by communicating your wishes to your family and healthcare

Ladies' Night event raised over \$7,000! Thank you ladies, Bartlett's Farm, and all the volunteers.

It was heartwarming to receive the surprise gift generated by high school student athletes at their *Play in Pink* games. Callaghan Bartlett led this year's effort and raised \$5,000. Thank you to the athletes and their families, fans, and businesses who showed support and made this such a success.

For the second year in a row, the *Downyflake* donated all proceeds from dining room sales on their last day of the season and raised \$2,600. Thank you to owners, Ron and Patty, and to all the winter closing day diners.

Nantucket and Duxbury's women paddle tennis players continued their rivalry and generosity, donating \$2,500 in support of their teammates this year!

The Photographers Alliance of Nantucket is holding a small works exhibition at The HandleBar Café through tomorrow, May 13th. All proceeds benefit the Fund.

The Marla Ceely Lamb Fund is totally supported by the community and is managed and administered by PASCON so that every dollar raised can go directly to patient travel expenses.

providers, creating your Health Care Proxy, and, if desired, creating a Living Will. Although Living Wills are not legally binding in Massachusetts, they are used to guide your family and healthcare providers as to your wishes. Healthcare Proxies, however, are legally binding, and allow you to appoint a person to make healthcare decisions on your behalf should you become unable to communicate your wishes.

Please remember that you can call on us at any time to answer questions, obtain forms, or help you develop advance care plans. Visit our site or call (508) 825-8325.

Other useful resources include:

www.theconversationproject.org
www.begintheconversation.org
www.caringinfo.org

A Lasting Legacy



An ethical will is a personal written or dictated record of your family stories, philosophic thoughts, legacy, and goals.

Ethical wills allow you the opportunity to share your values, achievements, words of wisdom, blessings, life's lessons, hopes and dreams for the future, love, and forgiveness with your family, friends, and community.

Ethical wills are not new. Initially, ethical wills were transmitted orally. Over time, they evolved into written documents.

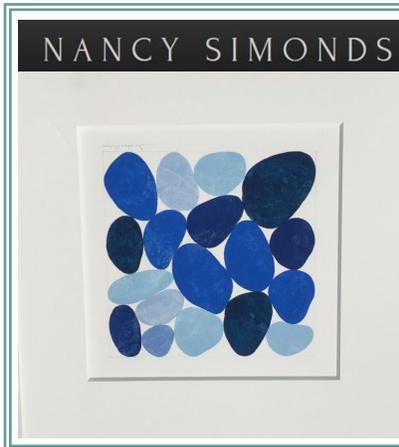
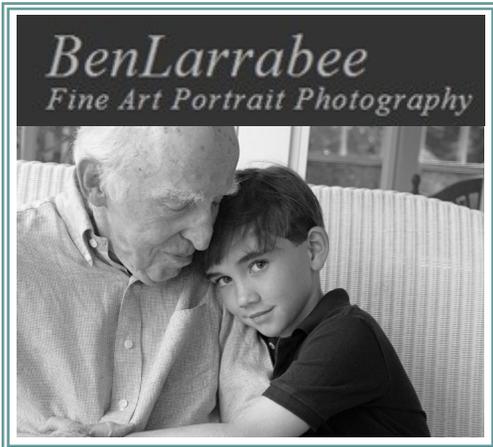
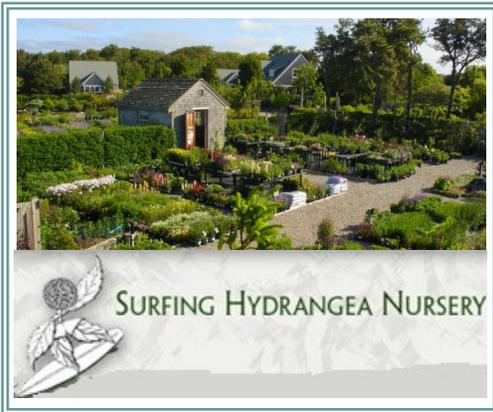
The Hebrew Bible first described ethical wills 3,000 years ago (Genesis Ch. 49). References to this tradition are also found in the Christian Bible (John Ch. 15 -18) and in other cultures.

Intended for succeeding generations, the ethical will may be your most valuable legacy. Many people leave precious jewelry or other keepsakes, but it is your stories, values, and wishes for the family that last a lifetime.

An *ethical will* is not a legal document like one's *last will and testament*, but rather a means to pass on stories and values to future generations.

Dreamcatcher Online Auction Open to All

Here are just a few of our generous auction contributors.
To view their offerings and more visit www.pascon.org



 Follow us online and continue to
 check back throughout the month
 as we add more awesome items.

Thank You to Our Donors

Our second annual Giving Tuesday initiative raised over \$40,000 thanks to donations from nearly 100 generous individuals and the amazing matching gifts of 5 of our greatest supporters!

Thank you to Great Point Properties for letting us sell Dream Tickets in front of their Sconset office over Daffy weekend and to the Dreamland for letting us sell them during our Dreamland Gives bACK screening on May 5th. And thanks to Petticoat Row for the delicious daffy cookies for our Daffy weekend setup.

Our own Program Director, Charlene Thurston, was selected by the Blue Hills Bank Foundation as one of their 2016 Hometown Heroes and received \$1,000 to benefit PASCON. Blue Hills also awarded a generous grant of \$2,500 to help pay for the production of our last newsletter!

Our Annual Art Show at Quidley & Co. over Stroll was hugely successful thanks to the fabulous works of 40 generous artists. Over \$22,000 was generated and split between PASCON and the Marla Ceely Lamb Fund. Thanks to Don Van Dyke, Chris Quidley and staff, Wayne and Laura of Nantucket Frame Center, Stacey Perry, and Cape Cod Five for making this such a wonderful success!

Lastly, we thank the Nantucket Platform Tennis Association for making us the beneficiary of this year's charity paddle tournament.

Since 2007, we have planted over 75,000 daffodils in honor of our volunteers and caregivers.

Thanks to everyone who has made this possible, especially

**Champoux Landscape
J&M Landscape Services**

2016 DREAM TICKET

4 Seats. Any Concert. Anywhere. Anytime.

Airfare and Accommodations included

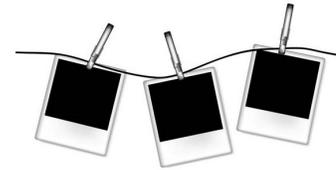
Only 200 chances. \$100/chance

www.pascon.org for details



A small works photography exhibit.

Presented by Photographers Alliance of Nantucket.



Gallery at **The HandleBar Cafe**

Opening Friday April 29th 5:30-7:30 PM
And runs through May 13th.

ALL PROCEEDS BENEFIT THE MARLA LAMB FUND



www.nantucketphotographers.net

Upcoming Events

- Small Works Big Cause* - through Friday, May 13th - page 6
- Supporting Families Webinar* - Saturday, May 21st - page 1
- Dreamcatcher Dinner & Auction* - Sunday, June 12th - page 5
- 5th Annual Island Swim* - Saturday, August 27th - page 3
- Harbor Sails for Patients* - various dates - page 3

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**

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.