

# *Palliative & Supportive Care of Nantucket*

*For Patients, Families, and Caregivers Touched by Life-Threatening Illness and Grief*

## *Currents*

Vol. 25, No. 2

Fall 2017

## Reflections from the Bedside

By Charlene Thurston, ANP,  
Program Director

Several months ago, I had the honor of being a Sunday guest speaker at the Unitarian Universalist Church of Nantucket and shared some of the many lessons I'd learned after my almost thirty years of working with patients facing life-threatening illness. Since several parishioners found the discussion valuable, I thought it might be of interest to all our readers.

People often ask me how I can do this work, especially the end-of-life aspects of our care. I actually came into this rather accidentally. When asked some years earlier whether I'd be interested in starting a hospice program, I'd declined, but, in 1982, when asked again, I was a few years older at age 33 and taking some time off to raise our daughter, so thought it would be interesting to get involved to develop a hospice program.

During the earlier years of our program, almost all our focus was aimed at care of the dying, and one of the things that I learned quickly when starting to care for terminally ill patients was that, in order to care for the dying and their families, one had to make peace with death. I learned that I had to do my own personal growth work, examine my own beliefs and values, and develop a personal philosophy or belief system that could sustain me, in order to stand with people who are experiencing intense suffering and help them through their experience.

Working with our patients and families is beautiful work, and being allowed into a person's life during such an intimate time is truly a privilege.

This is a time when our everyday masks are off, and when we're much closer to connecting soul to soul, something few people get to experience in their everyday interactions with people. And it's awe-inspiring.

All patients and families are different and all are remarkable in their own ways, and we learn and receive from all of them. This is a very reciprocal process; while we're there to give (care), we also receive, even when things seem chaotic and difficult.

Some patients are at a place in their lives where they're able to cope with their illness with equanimity, while others are so devastated by their fear of death that they seem to shut themselves off before their illness does, often becoming paralyzed in fear and anger and cutting themselves off from their loved ones, at a time when their loved ones are trying to reach out to help them or to join in their suffering. There's nothing sadder than to see this withdrawal and one of my strongest messages to people is to humble

*Continued on page 5*

## A Very Special Tribute to Outgoing Board Member, Gussie Beaugrand

Thank you, Gussie, for 20 years of service to our foundation and organization! We have had many great board members over the years, and you truly are one of the top! Thank you for transforming our foundation and for all you've done to keep our organization financially sustainable throughout the years, so that we could continue to offer all of our services free of charge. Your leadership has been unsurpassed, and our staff, our board, our patients, and the community at large are deeply grateful.



PASCON is Proud to be  
Celebrating 35 Years of  
Caring for Nantucket!

### Program Office Move

Our offices have moved during construction of the new hospital. Now at 99 Goldfinch in Naushop. Mailing address still 57 Prospect St.

# 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 group providing education, support, and socialization with other caregivers – every 2nd and 4th Wed., 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

Education, basic counseling, and referral for persons coping with the death of a loved one.

- Private individual sessions
- Grief Support Group - led by Palliative Care Counselor Bonnie Fitz-Gibbon, Ph.D. - meets on the 1st and 3rd Wednesday of each month from 1-2:30 pm, in our office.
- Focus is on:
  - Understanding the grief process
  - Actively doing one's grief work
  - Handling issues including finances, business affairs, housing, insurance;
  - Optimizing wellness through diet, exercise, stress reduction, mind/body modalities, coping strategies;
  - Coping healthily and effectively.

## 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

Rick Beaudette  
*President*

Mike Misurelli  
*Vice President*

Gussie Beaugrand  
*Secretary/Clerk*

Lou Gennaro  
*Treasurer*

Carolyn Durand

Marianne Felch

Laura Fletcher

Kim Higgins

Sharon Woods Hussey

Emily Molden

Nancy Moylan

Nancy Newhouse

Carrie M. Riden  
*Executive Director*

### Program

Charlene Thurston, ANP  
*Program Director*

Timothy Lepore, MD  
*Medical Director*

Peter MacKay, MSW  
*Social Worker*

Bonnie Fitz-Gibbon, Ph.D., LMHC  
*Palliative Care Counselor*

Rev. Linda Simmons  
*Chaplain*

Ginnie Faria  
*Volunteer Coordinator*

### Contact Information

Mailing: 57 Prospect St  
Physical: 99 Goldfinch Dr  
Nantucket, MA 02554  
(508) 825-8325  
(508) 825-8211 FAX  
pascon@partners.org  
www.pascon.org

*\*De-Stressing to Cope is partially funded through a Title IIIB grant of MA Executive Office of Elder Affairs and the Federal Administration for Community Living.*



## 24th Annual Dreamcatcher Dinner and Auction - June 4, 2017



*Photos by  
Becky Zadroga Photography*

## Swim Across America's Nantucket Island Swim - August 26, 2017



*Photos by Joelle Bouchard,  
Suzette Brown, Pat White,  
and Becky Zadroga*





# Marla Ceely Lamb Fund



Since the publication of our last newsletter in May, over 60 cancer patients have continued to benefit from the Marla Ceely Lamb Cancer Transportation Fund. In addition to the fabulously successful 25<sup>th</sup> anniversary fundraiser that Marla's daughter Meredith and her family and friends celebrated at Faregrounds Restaurant on Veteran's Day weekend, and the 5<sup>th</sup> Annual 24-hour run by Jules Embry-Pelrine, the generosity of the donors listed below will enable the fund to continue to serve many more patients to access off-island transportation assistance:

- Nantucket Public School staff
- Nantucket Whaler athletic teams and coaches, local businesses, and the Masons for another successful Play in Pink Games fundraiser
- Poet's Corner Press
- Dorothy Harrison Egan Foundation
- The winner of the Nantucket Boys & Girls Club *Golf Ball Drop*
- Cape Airlines
- Hyline Cruises
- Brian Glowacki's Comedy Night
- Nantucket Energy
- Those families who named the fund as a beneficiary
- Community members who made memorial gifts

The Marla Ceely Lamb Fund is available to all Nantucket residents who have a cancer diagnosis. The fund is managed and administered by Palliative & Supportive Care of Nantucket so that every dollar raised can go directly to patient travel expenses.

## Fall Happenings

Caitlin Marcoux and Nantucket Island Resorts teamed up for the 2nd Annual Yoga for PASCON benefit at the White Elephant Village Ballroom on October 25th.

Our Annual Daffodil Planting took place Saturday, November 11th along the Old South Road bike path near Nantucket Meat & Fish Market. Look out for the beautiful blossoms this spring.

Thank you to everyone who came out to help plant, especially the crews of **J & M Landscape Services** and **Champoux Landscape** who make this possible year after year! Thanks also to the Nantucket Boy Scouts, students of the Bulgarian Education Center, and staff and students of the Nantucket New School for turning out on an especially chilly morning to lend a hand.

Mike Misurelli and Ben and Dave Champoux lead this effort each year, donating bulbs and fertilizer along with their crews and equipment, and coordinating it all. Ernst Land Design also donates bulbs.

Our Annual Tree of Remembrance Service took place on Sunday, November 19th 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 meaningful ceremony before the holiday season gets underway. If you weren't able to make it, you're still welcome to add an ornament to the tree at any time this holiday season. Stop by our office at 99 Goldfinch to pick up your scallop shell ornament.

Special thanks to Rev. Linda Simmons, Jessica Sanseverino, Jason Curtis at the Jared Coffin House, and Michael Getter at Dune.

## Grieving During the Holidays

The winter holidays are generally perceived as "the most wonderful time of the year." But for those facing grief after the death of a loved one, the holidays may instead be a time filled with pain and sadness.

Even for those for whom grief is not as fresh, the holidays may serve as an annual reminder of the loss - not only of that person, but of tradition and celebration.

It's important to make decisions that feel right to the grieving person and to give oneself permission to make new or different choices at the holidays.

Holidays often center on certain traditions and rituals. Continuing these traditions without a loved one may be an important way to continue sharing their memory. For others, it may be more comforting to develop new rituals to help lessen the pain and immediacy of the loss.

Holiday shopping, baking and decorating can cause added pressure and stress. Grieving people should be encouraged to prioritize what needs to be done, and focus on those projects that may bring them pleasure. Perhaps the gift list can be pared down, cards need not be sent out, or someone else can cook family dinner.

The holidays can bring opportunities to remember the person who has died in a way that is personally meaningful. Some families choose to participate in holiday events like the Tree of Remembrance Service. Others may choose to share special family stories over a meal. Some may find that making a donation to a special charity or volunteering time to help others in need may be a comforting way to honor their loved one.

Remember that we are here to help.



## Donations to Your Favorite Charity Make Perfect Holiday Gifts!

Forego the fruitcake and make a donation for everyone on your list this holiday season!  
Visit [www.pascon.org](http://www.pascon.org) today.



### Reflections (cont. from p. 1)

yourself enough to accept help from those who love you. This is a gift *you* can give *them*.

Witnessing the difference in how people cope with these diagnoses, I've come to suggest to all people that they start early, while they're well, to explore their own beliefs and values and philosophies about life and death; that they do their own spiritual search, re-visiting their own religious and spiritual beliefs, so that when the time comes that they're faced with their own illness or the illness or death of someone they love, they're better prepared to cope. We will all face death and we will all face the death of people we love. Start to build the foundation for what will sustain you early if you can.

People with life-threatening illness and those of us who work with them often find that they develop a much more intense appreciation of what really matters to them in life. They reprioritize what's important, and learn to let go of what really isn't. Realizing that each day could be your last (which should be something we all realize) informs how you live.

Living one's life authentically becomes so much more important; letting go of the "shoulds" and staying true to who you really are, not what other people want you to be.

Reconciling relationships; seeking and granting forgiveness, including forgiving ourselves.

Saying the things that matter most. Dr. Ira Byock, a leading physician in the hospice movement, states in his book, The Four Things that Matter Most, that, in completing relationships, the things that matter are saying, "I love you"; "I'm sorry, please forgive me"; "I forgive you"; and, "Thank you."

Accepting what is. When there's nothing that can be done to improve a situation, our wisest choice is to accept it and to re-direct our energy toward making the most of it vs

continuing to fight against it.

Welcoming everything; pushing away nothing. Frank Ostaseski of the Metta Institute, a world renowned leader in the field of end-of-life care, teaches that all experiences, positive and negative, are of great value in teaching us the lessons of life, helping us cope, and growing through situations that we otherwise might avoid.

At the end of the day, or at the end of a life, we want to know that our lives counted for something, that we mattered, that our lives have had meaning. Much time is spent in life review and reminiscence as we try to take stock of who we've been. What matters most to

people is not what they've accumulated, but whom they've touched; whom they've loved and been loved by.

Our work is to help our patients and their families get through their experience, whether it ends in cure or death, with as much comfort and equanimity and growth as possible.

Dame Cicely Saunders, founder of the hospice movement, has a very famous quote: "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." We, at Palliative & Supportive Care of Nantucket, try to live by those words.

## Reflecting on Your Own Wishes

Begin by sitting quietly with pen and paper and giving some thought to what would be important to you if you were facing death. It is never too early to start this process, since we all are facing death, whether now or years from now.

Think about your values, what's important to you, what you'd want to ensure was in order, what you'd like to be sure you'd accomplished.

Think about whom you'd want to make health care decisions for you if you were unable to speak for yourself and complete a Health Care Proxy. Think about what kind of care and treatment you would or would not want, and write it down, if you wish, in a Living Will. If you're already living with advanced illness, consider completing a MOLST (Medical Orders for Life Sustaining Treatment) with your physician. Most importantly, have the conversation about your wishes with your family, health care proxy, and physicians so that they understand what they are.

Your wishes may change over time, so keep your documents updated and keep everyone informed.

Participating in conversational groups like *Death Cafes*, or *Death over Dinner* can be a great way to explore your values and wishes.

Some books and websites that might be of interest include:

- The Conversation, by Angelo Volandes, M.D.
- Being Mortal, by Atul Gawande, M.D.
- Who Dies? An Investigation of Conscious Living and Consious Dying, by Stephen and Ondrea Levine
- The Four Things that Matter Most, by Ira Byock, M.D.
- [theconversationproject.org](http://theconversationproject.org)
- [deathoverdinner.org](http://deathoverdinner.org)
- [mettainstitute.org](http://mettainstitute.org)
- [agingwithdignity.org](http://agingwithdignity.org)

Great Art.  
Great Value.  
Great Cause.



## 8th Annual Art Show

Thursday, Nov. 30<sup>th</sup> - Saturday, Dec. 2<sup>nd</sup>

Hosted by Quidley & Company

Sponsored by Cape Cod Five Cents Savings Bank  
26 Main Street • Nantucket

Sealed bidding begins at noon • Thursday, November 30<sup>th</sup>

Winners announced at 4PM • Saturday, December 2<sup>nd</sup>

Joan Albaugh	Tracey Harris	Scott Prior
Ginger Andrews	Greg Haynes	Cate Raphael
Valeri Arnold-Osley	G.S. Hill	Forrest Rodts
Colin Berry	Sharon Woods Hussey	Sergio Roffo
Nikoline Bohr	Patricia Jones	Christine Sanford
Susan Briskman	Donald Jurney	Jess Hurley Scott
Stephen Coyle	Carol Keefe	Aleta Rossi Steward
Susan Coyne	Gary Korlin	Don Van Dyke
William Davis	Paul La Paglia	Kathleen Kasmar Van Lieu
Julija Mostykanova Feeney	Ken Layman	Meg Weeks
Sandra Flavin	Jan Purdy Metcalf	Bill Welch
Bobby Frazier	Diana Dunbar Northrop	Karen Woods
Paul Galschneider	Anthony Panzera	

*Proceeds benefit both the Marla Ceely Lamb Fund and  
Palliative & Supportive Care of Nantucket*

### PASCON Foundation News

#### New Member

Emily Molden

#### Retiring Members

Rick Beaudette • Gussie Beaugrand  
Carolyn Durand • Heidi Daniels Girvin  
Peggy Tramosch

Please join us in welcoming Emily and in thanking Rick, Gussie, Carolyn, Heidi, and Peggy for their many years of dedicated service to PASCON and to this community!

### 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.

#### *Grief Support Group*

1st and 3rd Wed., 1-2:30pm

For those who have lost a loved one to help understand the grief process, cope healthily, and adjust effectively.

#### *"Time Out" for Caregivers*

2nd and 4th Wed., 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.

(508) 825-8325 for more info.

Trained volunteers available to sit with loved ones while caregivers attend.



**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.*



**NANTUCKET  
COTTAGE HOSPITAL**