

Palliative & Supportive Care of Nantucket

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

Currents

Vol. 26, No. 2

Fall 2018

The Importance of Letting Go

*By Charlene Thurston, RN, ANP,
Program Director*

In our spring newsletter, I wrote about how patients and families could make the decision to stop treatment and allow natural death, especially important when serious illness so compromised the patient’s quality of life that life felt no longer worth living. After writing that article, I realized that an additional article needed to be written to help families understand the importance of allowing their loved ones to let go, to give them permission to let go and die when it was their time. This is such a hard thing for families to do because we want to keep our loved ones with us as long as possible; but it is so important.

So often we see very, very ill patients struggling and suffering because they don’t want to let their families down. This can become very difficult as their bodies don’t have the energy to persevere. As hard as it is, as family members, we must come to terms with our own pain of grief and not impose our needs on the patient who is so fragile and vulnerable and needing to be released. Patients try to take care of their loved ones, even during their dying, so if loved ones are clinging and holding on, the dying person keeps trying to hold on for them until they feel they’ll be okay and can give them permission to go.

When we’re working with patients and families through this period, we try to help them prepare to let go by completing their relationships in a meaningful way. Ira Byock, MD, a highly respected physician in the hospice and palliative care field, wrote a book, “The Four Things that Matter Most,” and we try to help our patients and families by following those teachings. They can be summed up as saying

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Tree of Remembrance Service

**Sunday, November 18th - 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.

A Letter from Outgoing Program Director Charlene Thurston

As I write my final newsletter as the Program Director of Palliative & Supportive Care of Nantucket, I’m reminded of all the wonderful years I’ve had serving in this role, and all of the truly amazing people I’ve met throughout this time. All of our patients and families have touched my life in ways they’d never imagine. Though I was there to help them, what I’ve received from them was even more profound. While my role was to offer them comfort and support along their often very painful journeys, I learned so much from them. I learned how people can come face to face with intense sadness and despair, yet persevere and grow strong again, even when death is the outcome. I learned that the human spirit is so much more resilient than we ever imagined; that even in the face of tremendous adversity, we can adapt, and cope, and heal. I’ve also learned that all people are good and loving and caring, even when they do things that hide those qualities. And that we still have a caring and generous community, even amidst all the



Program Directors Charlene Thurston and Dianne Bein

growth and changes; a community of people who are always there for each other, who rally around those in need, and who share their love and their resources to help those in need carry on. It has been a privilege for me to be allowed into the lives of patients and families we’ve served during these very intimate moments and I’m deeply grateful.

Leaving would be much more difficult if I hadn’t found an exceptional person to assume this role as my successor. Many of you may

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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 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 bimonthly in our office. Call for details.
- 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



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Palliative Care Counselor

Ginnie Faria
Volunteer Coordinator

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**The Caregivers' Connections Program of PASCON is funded in part by the MA Executive Office of Elder Affairs and the Federal Administration for Community Living by a contract from Elder Services of Cape Cod and the Islands.*

25th Annual Dreamcatcher Dinner and Auction - June 3rd



All photos by Becky Zadroga Photography

Annual Daffy Planting

Our Annual Daffodil Planting took place Tuesday, November 6th along Main Street in Sconset. Thanks to Jamie and Hollie Holt for their dedication to beautifying the area and their work securing planting sites. We can't wait to see how it looks this spring.

Thank you to Mike Misurelli of **J & M Landscape Services** and Ben and Dave Champoux of **Champoux Landscape** who make this possible year after year! They donate all the bulbs, fertilizer, and equipment and have amazing crews who can plant thousands of daffys in no time flat!

Great Art.
Great Value.
Great Cause.



9th Annual Art Show

Thursday, Nov. 29 - Saturday, Dec. 1

Hosted by Quidley & Company
26 Main Street • Nantucket

Sealed bidding begins at noon on Thursday
Winners announced at 4 pm on Saturday

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

- | | |
|---------------------------|-----------------------|
| Ginger Andrews | • Valeri Arnold-Osley |
| Nikoline Bohr | • Susan Briskman |
| Dan Brown | • Susan Coyne |
| Julija Mostykanova Feeney | • Elle Foley |
| Dottie Gennaro | • Katie Hemingway |
| G.S. Hill | • Sharon Woods Hussey |
| Diana Dunbar Northrop | • Stephen Pitliuk |
| Sharon Farrell Robinson | • Sergio Roffo |
| Penny Scheerer | • Nancy Simonds |
| Donald Van Dyke | • Loretta Yoder |

*List as of press time. Check our website for current list.

Swim Across America

Another terrific Island Swim took place August 25th, thanks to the dedicated efforts of event co-chairs Jim Pignato and Jill Roethke, their committee, and hundreds of swimmers, volunteers, and donors! So many people turned out to show their support for this amazing annual event which raises funds for cancer treatment and care through both PASCON and Nantucket Cottage Hospital. Their grand total exceeded expectations with over \$435,000! PASCON and the entire community are so grateful to everyone involved.

We'd like to give special recognition to our own PASCON Team's top fundraisers who went above and beyond, raising over \$18,000 between them.

Caitlin Marcoux	Phil Wattles	Sabine Koch
Robin Rowland	Lou Gennaro	Maria Zodda



Marla Ceely Lamb Fund

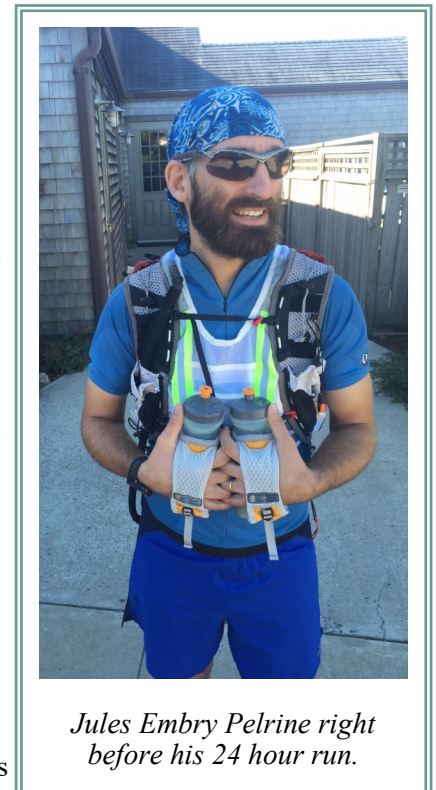
When a family member, friend, or neighbor receives a cancer diagnosis, one of the things they can count on to lighten their burden is the Marla Ceely Lamb Fund. Thanks to a generous community, the fund continues to provide financial assistance for off-island treatment.

On behalf of the 50 cancer patients served over the last 6 months since our spring newsletter, we want to whole-heartedly thank the generous supporters who keep this fund available:

- Meredith Lamb, Faregrounds, volunteers, and everyone who donated items and services for the Annual Fundraiser happening tomorrow!
- Akimbo Beads & Things whose weekly earring making class created 500 pairs for donation to the fund
- Jules Embry Pelrine who raised \$2,500 with his 6th Annual 24 Hour Run over Columbus Day weekend
- Nantucket Whaler teams and coaches, Nantucket Booster Club, and donors contributing to the Play in Pink Games throughout October
- Quidley & Co. and artists contributing to the Stroll Art Show
- Dorothy Harrison Egan Foundation
- families who made the fund a beneficiary
- unsolicited individual gifts
- Poets Corner Press
- Hyline Cruises



SAA photos by Joelle Bouchard, Suzette Brown, Ron Lynch, and Becky Zadroga



Jules Embry Pelrine right before his 24 hour run.

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

Letting Go (cont. from p. 1)

“I love you”; “I’m sorry - please forgive me”; “I forgive you”; and “Thank you”. Ultimately, we try to help people say “Good-bye - We love you, we’ll miss you, but, when you’re ready to go, do so, knowing that we’ll be ok.” We’ve found that helping people come together in this way brings much peace of mind to both patients and their families.

When there are loved ones who live far away or, for other reasons, won’t be able to return to see the person who is dying, we encourage families to arrange a way for them to say their good-bye’s by phone, letter, or email, so that their relationships can be completed. This has great value for both patients and their loved ones. Even in the final moments, a phone can be held to the patient’s ear and the words can be said.

Helping children say their good-bye’s in some way is also extremely important. This is very difficult for families. However, preparing children for the fact that the patient is very ill and will die soon, and giving them a way to visit, if they’d like to, or helping them express their love or good-bye in some other way, like through a note, drawing, or phone, etc., allows them to prepare for the loss and to feel included in the family. There are many helpful websites that can provide guidance. The American Cancer Society’s section on helping children when a family member has cancer has excellent suggestions for helping children and is appropriate for any illness, not just cancer.

How we end our relationships when faced with death is one of the most important things we can do. It will greatly impact both how peaceful the patient can feel in the dying process, and how his or her loved ones will carry on for the rest of their lives. Taking the opportunity to let each other know how much we’ve meant to one another, what we’ve given to one another, how much we forgive one another, and how we’ll remember and move on to live our lives is the gift that can be given and received when death comes from terminal illness. It’s the opportunity that is greatly missed when a loved one dies from a sudden fatal illness or accident since in those cases, there was no time to prepare.

A poem that has brought comfort to many families when a loved one has died is included here in the hope that it might bring comfort to our readers.

Gone from my Sight

- Henry van Dyke

*I am standing upon the seashore. A ship, at my side,
spreads her white sails to the moving breeze and starts
for the blue ocean. She is an object of beauty and strength.
I stand and watch her until, at length, she hangs like a speck
of white cloud just where the sea and sky come to mingle with each other.*

Then, someone at my side says, 'There, she is gone'

Gone where?

*Gone from my sight. That is all. She is just as large in mast,
hull and spar as she was when she left my side.
And, she is just as able to bear her load of living freight to her destined port.*

Her diminished size is in me - not in her.

*And, just at the moment when someone says, 'There, she is gone,'
there are other eyes watching her coming, and other voices
ready to take up the glad shout, 'Here she comes!'*

And that is dying ...

*Death comes in its own time, in its own way.
Death is as unique as the individual experiencing it.*

Letter (cont. from p. 1)

remember Dianne Pitman, a nurse practitioner who worked in Dr. Tim Lepore’s practice for several years until she left about ten years ago to marry and live in Virginia. Now she’s Dianne Bein and, for the past 8 years, has worked for Blue Ridge Hospice, a large hospice in Virginia. I’d heard over the years from Tim that Dianne has always loved Nantucket and hoped to return, so, last fall, when I considered that I might like to retire from this position this year, I asked her whether she’d be interested in returning and was delighted to hear that she was. We’ve had Dianne working with us now since June, so that we might have a very smooth transition, and she’s brought her excellent skills and loving presence to all our patients. I stepped down just two weeks ago, but am not leaving the island, so will be able to answer any questions that might arise. Meanwhile, I am confident that the program will be in excellent hands. We are so fortunate to have someone with Dianne’s skills, compassion, and love for the island take on this position!

PROGRAM OFFICE MOVE

Our offices have moved during construction of the new hospital.

Now at Sherburne Commons.

Mailing still 57 Prospect St.

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 today.

Support Groups

Coping with Cancer • Grief Support Group • "Time Out" for Caregivers

All groups meet in our office at Sherburne Commons.

(508) 825-8325 for days/times and more info.

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

Black Friday. Cyber Monday.

#GIVINGTUESDAY™

November 27, 2018

DOUBLE YOUR IMPACT



**SUPPORT WHAT MATTERS
MOST TO YOU AND YOUR
ISLAND COMMUNITY.**

Drop off, mail in, or go online to
make your year-end contribution
by Tuesday the 27th and your
gift will be MATCHED.

www.pascon.org

Thank you

#GIVINGTUESDAY™

HONORING
26
Years

26th Annual Fundraiser

for the

Marla Geely Lamb Cancer Travel Fund

Friday, November 16th, 2018

at

Faregrounds Restaurant

Starts at 5pm

Hors d'oeuvres • Silent Auction

50/50 Raffle • Live Auction

Suggested Donation at the Door

\$20.00

Live Music

The Shepcats

For more info, please call

508.317.7679



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**PALLIATIVE & SUPPORTIVE
CARE OF NANTUCKET
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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.