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
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-Gibbion, 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

*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

Swim Across America’s Nantucket Island Swim - August 26, 2017

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

Photos by Becky Zadroga Photography
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 25th anniversary fundraiser that Marla’s daughter Meredith and her family and friends celebrated at Faregrounds Restaurant on Veteran’s Day weekend, and the 5th 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.
Reflections (cont. from p. 1)

youself 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 re-prioritize 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.
- The Four Things that Matter Most, by Ira Byock, M.D.
- theconversationproject.org
- mettainstitute.org
- deathoverdinner.org
- agingwithdignity.org
Palliative & Supportive Care of Nantucket Foundation

6 www.pascon.org

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.

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.

PASCON Foundation News

New Member
Emily Molden

Retiring Members
Rick Beaudette • Gussie Beaugrand
Carolyn Durand • Heidi Daniels Girvin
Peggy Tramposch

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!

Great Art.
Great Value.
Great Cause.

8th Annual Art Show

Thursday, Nov. 30th - Saturday, Dec. 2nd
Hosted by Quidley & Company
Sponsored by Cape Cod Five Cents Savings Bank
26 Main Street • Nantucket

Sealed bidding begins at noon • Thursday, November 30th
Winners announced at 4PM • Saturday, December 2nd

Joan Albaugh
Ginger Andrews
Valeri Arnold-Osley
Colin Berry
Nikoline Behr
Susan Biskman
Stephen Coyle
Susan Coyne
William Davis
Julia Mostykanova Feeley
Sandra Flavin
Bobby Frazier
Paul Galschneider

Tracey Harris
Greg Haynes
G.S. Hill
Sharon Woods Hussey
Patricia Jones
Donald Jurney
Carol Kenne
Gary Korin
Paul La Paglia
Ken Layman
Jan Purdy Metcalf
Diana Dunbar Northrop
Anthony Panzena

Scott Prior
Cate Raphael
Forrest Rodts
Sergio Raffo
Christine Sanford
Jess Hurley Scott
Aleta Rossi Steward
Don Van Dyke
Kathleen Kasmar Van Lien
Meg Weeks
Bill Welch
Karen Woods

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

A Partnership in Caring

PALLIATIVE & SUPPORTIVE CARE OF NANTUCKET FOUNDATION

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