

Palliative & Supportive Care of Nantucket

Currents

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Change: a letter from the new Program Director

By Dianne Bein, MSN, FNP-BC, ACHPN Program Director/Clinical Manager

Whether we like change and welcome it, or watch it arrive while we rant against it, it often comes in spite of us. For better or worse, some change is inevitable, and we are challenged daily to embrace it and find positive meaning.

It has been nearly a year since my return to the Island — after a twelveyear absence. This time, I came from a large, well-supported, not-for-profit hospice in Northern Virginia that covered a large territory in the beautiful Shenandoah Valley. I saw hospice patients in the rural backwoods and hollows of the Blue Ridge Mountains, as well as on horse farms where Kentucky Derby winners are bred, and in the fox-hunting hamlets west of Washington, DC. I drove 36,000 miles a year in this beautiful farm country — where new vineyards spring up each year and locals fight to protect the land from suburban "house farms." Northern Virginia, like our wonderful island, struggles with the changes and challenges that more people and new development bring to the land and our lives.

While the land stewards in Virginia fought to leave the land unchanged, the lives of those I served in hospice were being constantly upended. My time was mostly spent managing the evolving symptoms of very ill patients or defending a patient's entitlement to continued hospice services from Medicare. Being "On Call" every third week meant often overseeing the needs of some 240 end-of-life patients, typically in crisis, and often by phone in

the middle of the night. I saw my mission as the relief of suffering wherever possible, and that is still my mission. As with each new role we undertake throughout life, I learned a great deal working in hospice in Virginia. I

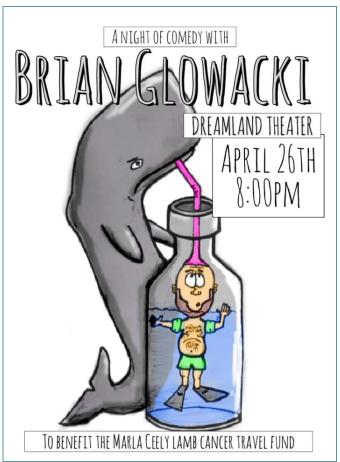
look at significant relationships and life's preciousness and fragility in a different way now. After eight years of hospice work, I was ready to return to a simpler life closer to the sea (and perhaps some time spent outside my car). The timing happened to be right.

I am grateful to return to a community I love, to do the palliative work of helping patients live as well as possible, and often longer, because of better symptom management and emphasis on the whole person — physical, mental, and spiritual. This also includes caring for those relationships

Continued on page 6







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 group or private educational sessions focusing on caregiver issues and stresses, positive self-care, and techniques for coping;
- 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

*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.



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National Health Care Decisions Day was officially on April 16th, but it's still important to know that anyone over the age of 18 should think about their Advance Directives.

Advance Directives can help your family with decisions should a crisis occur and ensure that you receive the type of care you desire.

Most adults say they prefer to die at home, yet only about one-third have an advance directive expressing their end-of-life care wishes.

* Pew, 2006; AARP, 2008

Educate yourself and begin the conversation today.

Most Americans (71%) believe it is more important to enhance quality of life for seriously ill patients – even if it means a shorter life – than to extend the life of seriously ill patients through every medical intervention possible.

Advance Directives

* Regence, 2011

Documents you can complete to provide directions for your health care, should you become unable to communicate your wishes. Advance Directives are not just end-of-life decisions, they are important to have should you become unable to speak for yourself, even if only temporarily due to an accident.

Health Care Proxy/Durable Power of Attorney for Healthcare

A person you appoint to make healthcare decisions on your behalf, should you become unable to speak for yourself.

Living Will

A document stating your wishes regarding treatments, those you do or do not want, should you become unable to speak for yourself. This document serves to guide your health care proxy and your physicians. It can be used as evidence of what your wishes would be, were you able to speak.

MOLST

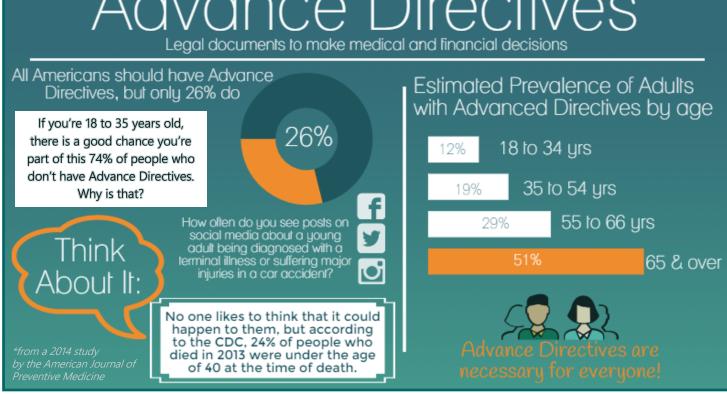
Unlike the Advance Directives described above, which are intended for everyone over 18, the bright pink MOLST (Medical Orders for Life Sustaining Treatment) forms (often placed on refrigerators for EMT responders) are intended only for patients with advanced illness. These are actual medical orders that you can request a physician to sign at any time after discussion with you during advanced illness. A MOLST is completely voluntary. Its purpose is to give health care providers immediate orders for emergency treatment in the event of a cardiac or respiratory arrest. It would be honored by all health care staff, including EMT's, nurses, physicians, etc., in any setting. The back side of a MOLST form addresses preferences for other treatments such as intubation, ventilation, dialysis, and tube feedings.

Please call or email our office for more detailed information about Advance Directives or MOLST. Written information, videos, and free educational consultations are also available. Physicians, hospital social service departments, nursing home staff, and attorneys also have these forms and can provide information and guidance.

Facing the Elephant logo and statistics courtesy of BEGINTHE CONVERSATION ORG

66% of family disputes about aging or end-of-life issues that end up in court could have been avoided if a family had clearly discussed and documented wishes in advance.

Home Instead Senior Care, U.S. Research Report, 40/70 Rule



DREAM TICKETS

Concert Experience of a Lifetime

You and 3 Friends

ANY concert ANY where ANY time

Endless Possibilities!

Airfare & Hotel included

Only 200 will be sold • \$100 each

Winner to be drawn at the Dreamcatcher Auction June 9th. Needn't be present to win. Terms & Conditions at www.pascon.org

On Sale Now at the Following Locations:

- Glidden & Glidden, PC (37 Centre St)
- Great Point Properties (1 N Beach St)
- Nantucket Island Resorts (10 Amelia Dr)
- PASCON Office (Sherburne Commons)
- Yates Island Gas (20 Arrowhead Dr)
- Or EMAIL US info@pascon.org

Please join us for the 26th Annual



PASCON NANTUCKET 2019

Sunday, June 9th

6-9 pm Nantucket Yacht Club

Sip & Bid Auction

Hors D'oeuvres & Raw Bar

Dinner & **Dancing**

Advance purchase required. Tickets on sale now.

If you're not able to attend, please consider underwriting or contributing auction items.

info@pascon.org to get involved.





Letter (continued from page 1)

our patients find meaningful, through individual and family counseling, community education, and support groups. And while PASCON is not "hospice," I cherish our ability to better serve many of our patients by supporting, working with, and often counting on the Cape Visiting Nurse Association's ability to provide hospice nurses and home health aides to those who are end-of-life. In returning to the island, I have also witnessed the community change of building a new hospital. There is a sense of loss that comes with watching the dismantling of the old Nantucket Cottage Hospital, a place where generations of Nantucketers have experienced some of life's biggest events. But I have also witnessed the excitement and pride of watching the rise of our new state-of-the-art facility, built from incredible community generosity -and without a mortgage! As we watch the slow demise of the old building, there are new opportunities emerging and evolving in health care here on the Island because of this change.

As we move forward, the hospital will provide PASCON with a permanent home in the Anderson Building, Dr. Butterworth's old office on the NCH grounds. The upcoming remodel will give us new opportunities to help design our own space in a way that our patients, clients, and staff have told us will make them feel most comfortable. It will reflect the way we use the space in times of crisis, to offer support when there are new threatening diagnoses, caregiver struggles, or grieving family members left behind. Our goal is to make it homelike, rather than medical.

Our closer proximity to the hospital, but not IN the hospital, will also make staff visits to the emergency room, the medsurge floor, or the oncology clinic more convenient and timely. It will allow those we work with to avoid yet another visit in a medical facility, which can stir understandably strong emotions. We look forward to this change in our environment, offering us new opportunities.

During this past year, I have also learned a great deal about PASCON, including its revered place here on the island for more than thirty years, rightfully secured under the very able direction of my predecessor, Charlene

Thurston. Through the support of my Board of Directors, I was able to work beside Charlene for six months before her retirement. Since then, I have continued to hear story after story from Islanders appreciative of the support PASCON has given their families through illness, loss, and grief recovery over the years. Change is difficult, but change also gives us new opportunities — the ability to see things through different lenses, or the opportunity to face new challenges in new ways. Whatever the future brings, we will be forever indebted to Charlene for her contributions to this Island's welfare. Like Charlene, I am fully committed to the good stewardship of this wonderful Foundation, and it has been humbling to be entrusted with the care of such a well-loved organization.

Moving forward, we anticipate continued increases in the numbers of patients referred to PASCON. This is partly due to national trends in palliative care — as patients, medical providers, and the medical community at large increasingly recognize quality of life that is gained through palliative support, and partly due to our growing and graying

population — one that is expected to live longer with chronic conditions that require management. We will also continue to work closely with the wonderful oncology team I have come to love at NCH.

As people become more familiar with the relatively new medical branch called "Palliative Care" and the services we can provide, we will face even more growth and change in this organization. We want Nantucket to continue to reach out to us for personal and family support during life-changing, life-threatening illness or events. That's why Palliative and Supportive Care of Nantucket was started some 30 years ago, long before "Palliative Care" existed and way ahead of its time.

Change will come despite us. There is wisdom in how we react to that change, and whether we accept it, embrace it, manage it, look at it from different angles, and attempt to find a positive meaning in it. It is ultimately up to each of us to make the most of life and the changes that drive it — by supporting each other, relieving suffering wherever we can, and finding room for joy, peace, and contentment.

Marla Ceely Lamb Cancer Transportation Fund

The Marla Ceely Lamb Fund has provided assistance to cancer patients for over 26 years, but it's still unknown to many. We want to be sure island residents know that the fund is here for them.

Any island resident needing to travel off island for cancer-related treatment is eligible. The fund is not an insurance reimbursement, nor is it a state or federal grant. It is totally supported by the generous and hard-working members of the Nantucket community.

Thanks to all who have sustained the fund since our fall newsletter:

- Meredith Lamb & her friends and family and Faregrounds for the success of their annual fundraiser
- Akimbo's *Make a Pair Donate a Pair* earring project
- The Boyd Family Foundation

- the creative fundraising efforts of Rogers & Gray Insurance
- Sharon and Frank Robinson
- Brian Glowacki
- St. Mary's Conference, St. Vincent de Paul Society
- families who named the fund as a beneficiary
- generous unsolicited individual community gifts
- Poets Corner Press
- Cape Air
- Hy-line Cruises

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. We urge anyone who is a cancer patient or who knows a cancer patient to take full advantage of this fund.



NANTUCKET ISLAND OPEN WATER SWIM SATURDAY, AUGUST 17TH, 2019

NORTH SHORE, NANTUCKET | 4-MILE SWIM



NANTUCKET ISLAND OPEN WATER SWIM SATURDAY, AUGUST 24TH, 2019

JETTIES BEACH KIDS' SPLASH | 1/4-MILE, 1/2-MILE AND 1-MILE SWIM OPTIONS

REGISTER TO SWIM, VOLUNTEER OR DONATE AT: SWIMACROSSAMERICA.ORG/NANTUCKET

BENEFITTING:









Spirit-Lifting Day at Sea

Once again, patients and their caregivers or guests are invited to "escape for a spirit-lifting day at sea" this summer, courtesy of Nantucket Community Sailing. For details on scheduling a fabulous time out on the water, please contact our office at 508-825-8325.

Foundation Elects New Members

PASCON Foundation is pleased to announce the election of Cathy Lennon, James Meehan, and Sherry Rowsey to its Board of Directors. Cathy is a registered and licensed dietitian/nutritionist at the hospital. James is a retired attorney and executive most recently with Arrowpoint Capital. Sherry is a retired physical therapist and pharmacist. "These three individuals bring new points of view and new experience that will help support the Foundation's mission to raise money for vital programs and services and to educate the community about PASCON and palliative care in general," according to Board President Mike Misurelli.

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 program offices at Sherburne Commons.

(508) 825-8325 for more info.

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

Why talking matters

Sharing your wishes for end-of-life care can bring you closer to the people you love. It's critically important. And you can do it. **Consider the facts:**

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project National Survey (2013)

60% of people say that making sure their family is not burdened by tough decisions is extremely important.

56% have not communicated their end-of life wishes.

Source: Survey of Californians by the California HealthCare Foundation (2012)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7% report having had this conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing.

23% have actually done it.

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.

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 & 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.