



Palliative & Supportive Care of Nantucket Currents

Vol. 26, No. 1

Spring 2018

Allowing a Natural Death Understanding Your Rights

By Charlene Thurston, ANP,
Program Director

By now, most people are aware of the fact that they have a right to forego emergency attempts at life-extending measures like cardio-pulmonary resuscitation (CPR) if they have a cardiac arrest. DNR orders (Do Not Resuscitate) are very familiar in the public jargon, and many people have strong feelings about what their wishes would be. We've written in past newsletters about the importance of having advance directives like living wills and health care proxies, and of discussing one's wishes and completing a MOLST (Medical Orders for Life-Sustaining Treatment) with one's physician or other clinician when living with a serious illness. People are also often aware of their right to have a respirator discontinued, and many family members have been faced with the decision of "pulling the plug" when a loved one has been on a respirator but it was felt that there was minimal chance of meaningful survival. However, people often do not really understand that they have a right to stop *any* treatment, even medications or oxygen, if they feel that their quality of living is so poor that they'd rather not continue living.

Please let me be clear that I'm not encouraging patients to do so. This is a very personal decision and patients need to think about their own values and those of their families. My purpose in writing this article is purely to ensure that patients understand their rights.

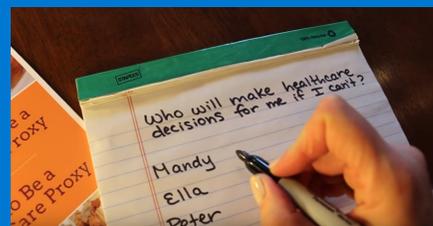
Over the past year, we've had a few patients express their wish that they could move to a state with so-called "death with dignity" acts. In these

states (Calif., Colorado, Oregon, D.C., Vermont, Washington), it is legal for a physician to prescribe a lethal dose of medication that can be taken by a resident with a terminal illness and a life expectancy of 6 months or less. In Massachusetts and in several other states, this is not legal, but bills are in committee.

However, patients with serious illness who are dependent upon life-sustaining medications, oxygen, tube feedings, dialysis, pacemakers, defibrillators, etc. should be aware that they do not need to move to a state with such acts. They already have the right, in any state in which they reside, to stop treatments without which they could not live. There are no laws which compel competent adults to accept treatment or continue treatment. If living with such illness has

Continued on page 4

Have you Completed Your
Advance Directives?



National Healthcare Decisions
Day was April 16th.

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

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.

Spreading a Message of Hope and Renewal Across Nantucket

PASCON has planted over 100,000 daffodils along
Nantucket's roadsides since 2007.
We plant in honor of our volunteers and the caregivers
who improve lives every day.



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

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



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Ginnie Faria
Volunteer Coordinator

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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★

**NANTUCKET ISLAND OPEN WATER SWIM
SATURDAY, AUGUST 18TH, 2018**

NORTH SHORE, NANTUCKET | 4-MILE SWIM

OUR
ISLAND • FAMILY • SWIM • CAUSE •

**NANTUCKET ISLAND OPEN WATER SWIM
SATURDAY, AUGUST 25TH, 2018**

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

SWIM
ACROSS AMERICA
★ MAKING WAVES TO FIGHT CANCER ★

BENEFITTING:



PALLIATIVE & SUPPORTIVE
CARE OF NANTUCKET

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Understanding Your Rights (continued from page 1)

become intolerable, you should discuss this with your family and health care proxy, and discuss with your physician what your values and goals are, what medications and treatments you're taking, what you might experience if such treatments were discontinued, and what further treatment you would or would not want.

When I was thinking about various patients we've cared for over the years, I thought about how some patients would cling to life, even one in which they were gasping for breath during much of the day, whereas others were wishing that death would take them, even when they seemed to have much less physical suffering. I'm not speaking here of people who are depressed and feeling suicidal. I'm also not talking about people with cancer who are deciding whether or not to accept further aggressive treatment, although much of this may apply. I'm speaking here of people with very advanced chronic illness whose illness has left them with such a limited existence that life has no meaning. And therein lies the crux of the issue - some people

may continue to find meaning and purpose, even in the midst of extreme suffering or minimal ability to engage in life, while others may not; for them, living is essentially over.

Many books have been written about the topic of finding meaning. Man's Search for Meaning, by Viktor Frankl, a survivor of an Auschwitz concentration camp, is one of the most well-known. One contemporary author I came upon was Emily Esfahani Smith, who wrote, The Power of Meaning, and who also gave a TED Talk on YouTube called, "There's More to Life than Being Happy." She states that, although happiness may come and go, it is really a lack of meaning that can make life feel empty, and goes on to describe four pillars that bring life meaning. Belonging (feeling part of a family or community), purpose (using our strengths to serve others), transcendence (connecting with something that lifts us beyond our everyday world), and storytelling (the story we tell ourselves about ourselves). She goes on to talk about how many people who have suffered tremendous hardship, have been able to find meaning by turning

their hardship into a positive endeavor, and how this purpose then sustains them. How people can often change their story from one that brings them nothing but sadness and depression, to one of growth and fulfillment – the redemptive story.

In our work with patients with life-threatening illness then, I want to be sure patients are informed about their right to discontinue treatments if they are subjected to much suffering and misery and if life seems futile. If your decision is to stop life-sustaining treatment, you have a right to request comfort measures so that you will not suffer when those treatments are discontinued. Such comfort measures include medications to decrease pain, shortness of breath, or other symptoms, as well as physical, emotional, and spiritual support for yourself and your family throughout the end of life. If care is needed in the home, palliative care and hospice care are available to help you, and if care is needed in the hospital or nursing home, our palliative care team is available to follow you there as well.

But I also want to encourage patients to really examine their lives and explore possible avenues of fulfillment before making such decisions. It is incumbent upon us as healthcare providers to help them in both circumstances. To help them truly examine their lives and explore opportunities for growth and meaning, and, also, to ensure that they are supported and kept comfortable if they decide to stop treatment and allow natural death.

Marla Ceely Lamb Fund

Every other day a new or returning cancer patient calls and asks if it's possible to get assistance for off-island treatment. And thanks to a community that was even more generous this year, we can say yes.

On behalf of the 55 cancer patients served since our last newsletter in November, we want to give a whole-hearted thank you to those generous supporters who keep this fund available:

- Meredith Lamb & her friends and family, and the Faregrounds Restaurant for the extra efforts towards the success of their 25th Anniversary Fundraiser
- Nantucket Middle and High School staff and student athletes
- families who named the fund as a beneficiary
- generous unsolicited individual community gifts

- the creative fundraising efforts by Rogers & Gray Insurance staff
- The Downyflake for once again donating the proceeds from the dining room sales of its closing day of the season - and to the crowd of diners!
- The Boyd Family Foundation
- Nantucket Platform Tennis
- Nantucket Grange
- St. Mary's Conference, St. Vincent de Paul Society
- Sons of the American Legion
- Poets Corner Press
- Cape Air
- Hyline Cruises

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

A 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 about how to schedule a fabulous time out on the water this summer, contact our office at 508-825-8325 or email pascon@partners.org.

25th Annual Dreamcatcher Dinner & Auction

Sunday, June 3rd at the Nantucket Yacht Club

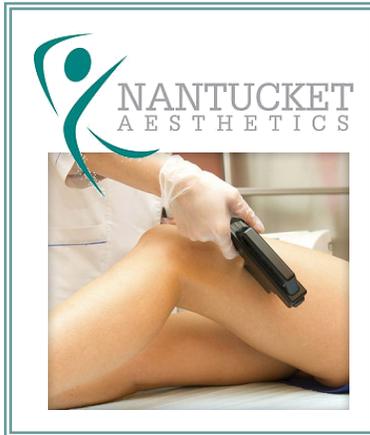


Tickets still available and online bidding is open. Visit our website for details on the items below and many more.

BID



Follow us online and check back over the next few weeks as we add more great items! Bidding on some LIVE packages opens May 1st.



Support Groups

All groups meet at PASCON program office on 99 Goldfinch.
(508) 825-8325 for more info.

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

- | | |
|----------------------------------|-----------------------------|
| <i>Coping with Cancer</i> | every other Mon., 1-2:30 pm |
| <i>Grief Support Group</i> | 1st & 3rd Wed., 1-2:30 pm |
| <i>"Time Out" for Caregivers</i> | 2nd & 4th Wed., 1-2:30 pm |

PASCON Adds to Board



PASCON Foundation is pleased to announce the election of Duncan Macallister to its Board of Directors. Duncan is Vice President, Nantucket Manager for Cape Cod Five Cents Savings Bank.

Dream Tickets On Sale Now!

CONCERT EXPERIENCE OF A LIFETIME

You and 3 Friends

Only 200 will be sold
\$100 each

ANY Concert * AIRFARE
ANYwhere & HOTEL
ANYtime included

(508) 825-8325 or info@pascon.org

Winner to be drawn at
Dreamcatcher on June 3, 2018.
Needn't be present to win.

ENDLESS Possibilities !

www.pascon.org for full terms and conditions



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.