New Tools Empower Patients

By Charlene Thurston, ANP, Program Director

This winter, our Palliative Care Counselor, Bonnie Fitz-Gibbon, Ph.D., LMHC and I spent many hours participating in conferences which enabled us to bring new treatment strategies back to our patients.

Bonnie attended “Transforming Trauma” with Dr. James Gordon of the Center for Mind Body Medicine, and I attended a CDC funded program at City of Hope Medical Center, entitled “Cognitive Behavioral and Related Interventions in Cancer Care.” Both conferences added many tools to our treatment toolkits, and I thought I’d share some information we acquired with our readers.

Both conferences strongly emphasized the value of relaxation/meditation skills as the backbone to improvement for both emotional and physical symptoms. In Dr. Gordon’s conference which dealt specifically with trauma, he stated that meditation served as an antidote to trauma. His program, which is a mindfulness-based stress reduction program, has helped traumatized victims in war torn areas around the world and has had amazing results restoring both children and adults to more functional lives.

City of Hope’s conference for treating cancer-related symptoms focused on the use of relaxation/meditation and other cognitive behavioral interventions for symptoms like fatigue, anxiety, depression, insomnia, and pain. Cognitive behavioral interventions focus on how we think, behave, and feel, and have been validated in study after study to show their effectiveness. Using these techniques to alleviate these cancer-related symptoms is exciting for several reasons.

First, they’re effective; second, they’re not medications, which often have side effects; and third, they are skills that patients can be taught so that they can become more empowered to take back control of their own well-being, a feeling that is often lost when facing an illness like cancer. Moreover, although the emphasis of this particular conference was on cancer care, these same skills can be learned and utilized by anyone.

The use of cognitive behavioral strategies for depression has been shown in research to be as effective as medication for the treatment of mild to moderate depression and its effects can be long-lasting. Teaching patients to look

Continued on page 3

Daffodils Pop Up in Honor of our Volunteers and Caregivers

You may have noticed our banners around the island over Daffodil Weekend. They marked the sites where we have planted daffodils over the past 10 years. For more about our continued efforts, see page 4.
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
Support, education, counseling, and referral for anyone coping with the grief of one’s own illness or the illness or death of a loved one. Help individuals:
- Understand the grief process;
- Actively do one’s grief work;
- Handle issues including finances, legal/business affairs, housing, insurance, wills;
- Optimize wellness through diet, exercise, stress reduction, mind/body modalities, coping strategies;
- Attend to spiritual/existential issues and enhance meaning-making and growth;
- Cope healthily and effectively;
- Ultimately, recover from grief and adjust to a life in which the deceased loved one is absent.

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 IIB grant of Elder Services of Cape Cod and the Islands.

Foundation
Rick Beaudette
President
Mike Misurelli
Vice President
Gussie Beaugrand
Secretary/Clerk
Lou Gennaro
Treasurer
Carolyn Durand
Marianne Felch
Laura Fletcher
Heidi Daniels Girvin
Kim Higgins
Sharon Woods Hussey
Nancy Moylan
Nancy Newhouse
Peggy Tramposch
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
New Tools (continued from page 1)

at and correct how their thinking might be distorted (e.g., jumping to conclusions, catastrophizing, etc.) helps them decrease their distress. Also, sometimes, changing behavior alone can be effective, even when not analyzing thoughts. In other words, getting out of bed, engaging in various activities, etc., despite feeling sad, can often decrease feelings of sadness and break the pattern of depression. Lastly, during research on the use of a lightbox to improve cancer-related fatigue, they found that patients also showed a decrease in depression. Further details about this appear later in this article.

Education and behavior changes have also been very effective for patients with insomnia. Dr. Ancoli-Israel from UCSD, an award-winning expert in sleep disorders, discussed how teaching people with insomnia about the sleep-wake cycle and circadian rhythms and helping them develop a plan to change their behavior by regulating their time in bed, napping, and arising has been very effective in treating insomnia.

Fatigue is one of the most frequently reported and distressing symptoms that patients with cancer face, and there have been few medications or treatments that help effectively. Therefore, to me, one of the most novel and promising presentations of the conference was on research that is being conducted on the use of a lightbox for patients with fatigue, depression, or insomnia.

People are probably familiar with the idea of using a lightbox for Seasonal Affective Disorder. Now Dr. William Redd of the Icahn School of Medicine of Mount Sinai in New York, has had remarkable results in using it for several other symptoms. In his research, patients have been using a lightbox that emits 10,000 lux of bright white light for 30 minutes/day, preferably early in the morning. The lightbox is placed on a table and positioned about arm’s length away from the face at about a 45 degree angle. (Do not look directly into the light.) That’s all there is to it.

The patient can be checking emails, reading, sitting, whatever. Eyeglasses don’t interfere, but sunglasses should not be worn during that time. Patients with mania of bipolar disease and patients with eye disorders like glaucoma, cataracts, diabetic eye damage, etc. shouldn’t use it without prior approval by their doctors, but, thus far, there have apparently been few other problems identified.

I do emphasize that this treatment is still being researched, but, so far, it is a simple intervention using an easily available and affordable lightbox and has been showing remarkable results. (There are many lightboxes on the market. The one that was used in the research discussed was the Litebook Edge.)

These have been exciting conferences offering several novel approaches to some of our patients’ most distressing symptoms. We look forward to incorporating our new learning into our practices over the coming months, and hope that, by doing so, our patients find great benefit.

If you’re interested in learning more, don’t hesitate to call on us. Also, if you’re interested in reading more about cognitive behavioral therapy overall, you might like The Feeling Good Handbook, by Dr. David Burns. For Dr. James Gordon’s work, see Unstuck: Your Guide to the Seven Stage Journey out of Depression. Finally, if you just google meditation, you’ll find numerous articles, audios, and YouTube videos available for free to lead you through various techniques.

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.

“Time Out” for Caregivers

second and fourth Wed. of each month, 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.

We would like to start a BEREAVEMENT GROUP. Please call or email if you might be interested.

Expressing Gratitude

Gratitude journaling has received a lot of attention recently as a means to help people pay attention to things in life for which they feel grateful, instead of dwelling too much on things they find distressing. It’s so easy to overlook our blessings when we’re feeling inundated by negative events in our personal lives or in the world at large. A member of our support group has started using a different approach to acknowledging her blessings, and has started writing little thank you notes to people who make a difference in her life, even when it might be just a little thing. This has the double effect of recognizing something nice that’s happened, while also letting the other person know that (s)he’s appreciated.
Spreading a Message of Hope and Renewal

Nantucket’s blooming daffodils are an island-wide sight of blankets of sunny flowers that delight natives and visitors alike. But they are more than cheerful beacons of the warm weather and sunshine to come. The history of the daffodils and what they have come to mean within our island life are truly a continuing story of community collaboration and civic pride.

It all started in the 1970’s with the late Jean MacAusland. Now in their fifth decade, she is widely credited with the inspiration and the substantial initial efforts in planting daffodils along our roads as well as instituting the attendant activities such as the antique car parade and the daffodil show.

MacAusland spearheaded the planting effort with David Champoux of Champoux Landscape. It started with planting thousands of bulbs along roads and in areas visible to walkers, bikers, and motorists alike. The hardy bulbs were a perfect choice for the island. Naturally spreading and shunned by browsing deer, they continued to return and proliferate over the decades. Supported and championed by the Nantucket Garden Club in the 1980’s and continuing to work with Champoux Landscape, the effort has just kept growing. Splotches of brilliant yellow could be seen along longer and longer stretches of bike paths and roads.

PASCON joined the effort in 2007 when board members working on their annual Dreamcatcher event decided daffodil planting would be a wonderful way to honor and recognize the invaluable efforts of the family caregivers and the PASCON patient care volunteers. And with a whole new cadre of community members becoming involved in this annual planting effort, the scope of PASCON volunteerism has grown.

Champoux Landscape continues to play an active role alongside J&M Landscape Services, and new planting is an annual fall rite for the energetic students, parents, and staff of the Nantucket New School. Between 5,000 and 7,500 bulbs are planted each year, thanks to the generous donations from Champoux Landscape, J&M Landscape Services, and several others over the years. As the island has grown with new development, so has the opportunity to find new places for those daffodils to bring their annual cheer. In addition to those early daffodils still popping up every spring, new batches have been planted along Milestone, Hummock Pond, and Old South Roads, Sconset Village, and Amelia Drive. PASCON has added more than 50,000 bulbs to the island landscape since 2007. Since the bulbs and materials are donated, any money raised in tribute to the family caregivers and the PASCON patient care volunteers goes directly to PASCON programs and services.

It is very satisfying to see a million plus bulbs come up to brighten the landscape every spring. Not only is it a beautiful sight to behold, but they also are living symbols of how a community comes together to create something special in the landscape and in the lives of island residents facing some of life’s most harrowing challenges.

These daffodil blooms each spring serve as a symbol of renewal and hope as well as a reminder of the hard work and dedication of PASCON volunteers and of the entire community.

Please consider becoming a part of the tradition of the island-wide bulb planting. Check our website for details in the fall. All are welcome to join in the planting in November.
24th Annual Dreamcatcher Dinner & Auction

Sunday, June 4th 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.

Follow us online and check back over the next few weeks as we add more great items!
Marla Ceely Lamb Fund

While Swim Across America helps support the care we provide to our cancer patients, those funds cannot be used for transportation costs. Therefore, as always, the Marla Ceely Lamb Fund helps off-set travel expenses for patients when they must travel off-island for aspects of their treatment that cannot be provided here.

Since our last newsletter, over 70 cancer patients have continued to benefit from extraordinary community support. Some events mentioned in our last newsletter hadn’t yet happened, so we wanted to mention them again.

Thank you so much to:

◊ Marla’s daughter Meredith and her family and friends who received scores of treasures from our generous community and worked many hours at their Annual Dinner & Auction on Veterans’ Day. And to Kim and Bill Puder, owners of the Faregrounds Restaurant, who once again hosted that event;

◊ Our high school athletes, led by Shae and Page Albertson, and all the businesses and fans who participated in raising funds through the Play in Pink games;

◊ Middle and high school teachers who rallied to support a colleague on a Pink4Purpose day;

◊ The Downyflake, for once again marking its last day of the season by donating proceeds from the day’s dining room sales;

◊ The Boyd Family Foundation, Rogers & Gray Insurance, The Nantucket Golf Club, St. Mary’s Saint Vincent de Paul Society, and The Union Lodge for their generous gifts.

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

Swim Across America Support

PASCON has the honor of being one of the two beneficiaries of Swim Across America Nantucket, the other being the hospital. Funds raised over the past five years have supported our Cancer Survivorship Support Program through which we provide, free of charge, counseling, education, symptom control, and support to patients and families coping with any stage of cancer.

Patients facing cancer need two things: great disease-directed treatment, like surgery, chemotherapy, radiation, etc., and great symptom control and emotional support throughout and beyond their disease process.

Supported by Swim Across America’s funding, Nantucket Cottage Hospital and Palliative & Supportive Care of Nantucket work together to bring both sides of care needed to patients and families who live on the island.

Please join us and make this year’s swim another huge success!!!!

Thank You to Our Donors

Our third annual Giving Tuesday initiative repeated the previous year’s success with donations from nearly 100 generous individuals and the amazing matching gifts of 5 of our greatest supporters!

Our Annual Art Show at Quidley & Co. over Stroll was hugely successful thanks to the fabulous works of more than 40 generous artists. Funds raised were split between PASCON and the Marla Ceely Lamb Fund. We are ever grateful to Chris Quidley and his staff for donating not only their space, but their time, energy, and connections to amazing artists. Thanks to Don Van Dyke for once again working hard to get more and more artists involved in this great event. Thank you to Stop & Shop for donating festive food and drinks and to Cape Cod Five Cents Savings Bank for sponsoring the event once more.

The 2016 Nantucket Island Swim was a terrific success yet again. We thank Co-Directors Jim Pignato and Jill Roethke, the Nantucket event committee, the folks at Swim Across America, and all of the swimmers, kayakers, volunteers, and donors who work so hard to raise money for island cancer care!

Elder Services of Cape Cod & the Islands continues to support our work through a multi-year grant, and the Dorothy Harrison Egan Foundation awarded another generous grant last year. We also received more than 50 donations from individuals and businesses in honor or in memory of someone. Every one of these contributions helps ensure that we continue to provide crucial services to this community year-round at no charge.

Thank you to Kelly Badger and Cake Nantucket for making adorable daffy cookies for us to give out with our Dream tickets over Daffy weekend. We sold some tickets, but still have plenty. See page 8 to get yours.

A Spirit-Lifting Day at Sea

Once again, patients and their guests are invited to “escape for a spirit-lifting day at sea” this summer, courtesy of Sailing Heals and Nantucket Community Sailing.

Last summer 26 patients and their caregivers enjoyed this fabulous opportunity to be out on the water.

For details, contact our office at 508-825-8325.
SWIM ACROSS AMERICA
MAKING WAVES TO FIGHT CANCER

JOIN US IN 2017
swimacrossamerica.org/nantucket
August 19: 4 mile swim
August 26: Kids’ Splash and 1/4, 1/2 and 1 mile swims

NANTUCKET BY THE NUMBERS

$1,229,000
Money raised for on-island cancer care since 2013

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>$187,000</td>
</tr>
<tr>
<td>2014</td>
<td>$225,000</td>
</tr>
<tr>
<td>2015</td>
<td>$325,000</td>
</tr>
<tr>
<td>2016</td>
<td>$342,000</td>
</tr>
</tbody>
</table>

+ $150,000 from Grant Wentworth’s record-breaking swim from Hyannis to ACK

609 miles swam

1,600 +
Total number of cancer treatments provided on Nantucket with donations from Swim Across America

2013: 258
2014: 325
2015: 529
2016: 540
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.

Dream Tickets On Sale Now!

CONCERT EXPERIENCE OF A LIFETIME

4 Seats • Any Concert
Anywhere • Anytime
Airfare and Hotel Included *
Only 200 will be sold • $100 each
info@pascon.org for how/where to buy

Winner to be drawn at Dreamcatcher on June 4, 2017.
Needn’t be present to win.

Please join us for a FREE web streaming video program

“When Grief is Complicated”
Saturday, June 17th from 9 - 11:30 am
The Design Center at Marine Home Center

A panel of experts discusses how to understand, assess, and assist those who may be experiencing complicated forms of bereavement. Begins with an overview of contemporary work on complicated grief, then explores strategies to support grievers.

This program is geared towards professionals, but all are welcome. CEUs available.

To register or for more information: 508-825-8325/ pascon@partners.org

Part of Hospice Foundation of America’s Living With Grief Program

Our offices have moved during construction of the new hospital.

Now at 99 Goldfinch in Naushop.
Mailing address still 57 Prospect.