



Vol. 11, No. 1

# Hospice *Currents*

Spring 2003

## Caring for Family Caregivers

by Charlene Thurston, RN, ANP  
& Francina Bardsley, MS

*“Take care of the elders for they have come a long way; take care of the children for they have a long way to go; take care of those in between for they are doing the work.”* African Proverb

Since our last newsletter, we, at Hospice, have been focusing on developing a framework for a Caregiver Resource Program, a new initiative which would provide meaningful support to the many family caregivers of persons with chronic illness or disabilities in our community. Our intention is to again expand our services beyond those typically provided by hospices, so that much of the same support that is available to family caregivers of terminally ill patients, could be made available to caregivers of non-terminally ill persons.

The National Family Caregivers Association (NFCA) defines a family caregiver as “someone who has a deep personal relationship with a person who is chronically ill or disabled and whose own life has been impacted by their loved one’s condition.” The family caregiver may be an immediate or extended family member, neighbor, or friend providing care and support varying from 24 hours/day to intermittent care.

Many caregivers dedicate over 20-40 hours/week caring for loved ones, care which is often both physically and emotionally demanding. Very often care is provided by people who are elderly themselves, and it is not unusual for the caregivers to become ill and wonder whether they’ll out-survive the person from whom they’re caring.

## **From the Foundation President** *Gussie Beaugrand*

As I reflect on the first six months of my term as president, I feel truly privileged to be a part of this organization that does so much for the Nantucket community. Our Hospice Program director and our Volunteer Coordinator continue the vital work of the Hospice program with the Interdisciplinary Team and the many wonderful Hospice volunteers. Our 2002 Annual Fall Appeal has, once again, brought an overwhelming response from both from full-time as well as summer residents. In addition, the plans for the 2003 Dreamcatcher Dinner and Auction are well under way and the committee has received many wonderful donations for the auction, including the donation of six paintings with a value of over \$12,000, from the family of a former Hospice patient.

I would like to take this opportunity to thank all of you for your continued response and generosity: to those of you who offer your time, talent, and energy to serve as volunteers to serve within the Hospice Program, on the Board of Trustees and on the Dreamcatcher auction committee; as well as those of you that offer your financial support through repeated and generous donations. You all play a very important part in ensuring that the Hospice Care of Nantucket program is able to expand its initiatives and to continue to offer its services free of charge to the community.

At other times, care is provided by adult children who are trying to balance work, spousal, and childcare needs of their own, with those of a parent who needs care. Added to their caregiving burden is the grief they feel over the increasing losses in their loved one’s health. The stress, exhaustion, and financial strain that can occur put caregivers, and often their families, at risk for emotional and physical illness.

The NFCA has given form to the insights of professional and family caregivers in its “Principles of Caregiver Empowerment.” These principles are presented as guideposts in the caregiver’s search for a sense of direction and inner peace.

- *Choose to take charge of your life.* Don’t let your loved one’s illness or disability always take center stage.
- *Honor, value and love yourself.* You’re doing a very hard job and deserve some quality time, just for you. Self care isn’t a luxury. It’s a necessity.

- *Seek, accept, and, at times, demand help.* Don’t be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do.
- *Stand up and be counted.* Stand up for your rights as a caregiver and a citizen.

Since caregivers are frequently unrecognized and receive little help and support in this task, our hope at Hospice is to bring attention to their needs and to try to develop services, in collaboration with other community organizations, that help decrease their isolation and provide respite, support, education, and practical assistance. We invite you to call or write us if you have any thoughts or ideas about how we might best meet these goals.

For more information on family caregiving, see the NFCA website ([www.nfcacares.org](http://www.nfcacares.org)).

# Dreamcatcher Dinner & Auction

by Gussie Beaugrand

Please join us for the Tenth Annual Dreamcatcher Dinner and Auction to be held on Sunday, June 15, 2003 at the Galley on Cliffside Beach.

This fabulous evening will with begin with aperitifs and Spanky's raw bar, followed by a live auction and dinner served al fresco in a gala tent on Cliffside Beach. A delicious four-course dinner prepared by the Chef de Cuisine will be served with wines to compliment each course. These wines will be selected from different regions by hosts David and Geoffrey Silva and will give an international flair to the event.

Once again Rafael Osona will lend his wit and power of persuasion to the live auction. Offerings include many unique Nantucket experiences, fine dining in a number of cities in the northeast, a spectator boat for the 2003 Opera House Cup and destinations such as Alaska, Telluride, London, and the Carribean.

This year we are delighted to offer a number of paintings by two well-known Nantucket artists, Illya Kagan and Helen Sharp Potter. These paintings were generously donated to the auction by the family of a former Hospice patient.

Mark your calendars now as this will be an evening not to be missed. We look forward to seeing you in June on Cliffside Beach!

\*\*\*\*\*

## There's more to Hospice...

**Did you know** that in addition to providing comprehensive physical, psychological, social, and spiritual care to persons with life-threatening illness, and support for their families...

Hospice Care of Nantucket provides consultation, counseling, education, and volunteer services to persons with *any stage of any serious illness*, even when they are pursuing aggressive curative treatment.

### Hospice Services include:

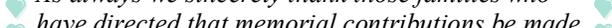
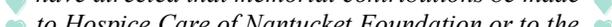
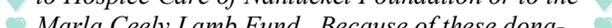
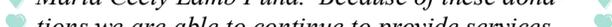
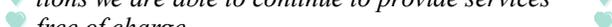
- advance care planning
- pain control and symptom management
- coping with a new diagnosis
- support when considering options for treatment
- counseling for coping and living with a chronic illness
- support and education for caregivers
- assistance with explaining illness and death to children
- coping with cancer support group

These services are provided in any setting: in the home, hospital, nursing home, or office. All Hospice services are free of charge thanks to the work and support of Hospice Care of Nantucket Foundation, a separate, tax-exempt public charity.

### Volunteer services include:

- respite breaks for caregivers
- companionship & support for patients and their families
- transportation
- errands
- other non-medical practical assistance

To request services call our office (508-825-8325) or ask for a referral by your nurse or physician.


Thank you to all of our devoted volunteers for more than 700 hours of assistance with patient care over the past year, and to our dedicated Board members and Auction volunteers, for their tireless fund raising efforts, without whom we would not have a successful Hospice program.

## Visit our website @ [www.hospiceofnantucket.org](http://www.hospiceofnantucket.org)

Our website not only contains information about our services but is a comprehensive site created to be a living resource to use in the privacy of your home. Designed to meet a variety of individual needs of both lay members of the community and professionals, some of the articles archived on the site include:

- The Nantucket Model of End of Life Care
- The Power of Personal Presence
- Spirituality Questions
- How to Help a Friend
- Pain Control - A Major Component of Hospice Care
- Bill Moyers' " On Our Own Terms" What's Needed in End of Life Care
- Advance Directives - What Are They And Who Needs Them

Some of the Internet links to other resources include:

- Advance Directives Information of Mass. Medical Society
- Alzheimer's Association
- American Chronic Pain Association
- Cancer Net
- Center for Grief Education
- Hospice Foundation of America
- National Family Caregivers Association

A free on-line course, *Finding Our Way: Living & Dying in America*, is available through our site as well. Inspired by a nationally distributed 15-part newspaper series, it includes topics such as *Caregiving, Spirituality & Faith, Last Rites, Hospice, Culture & Diversity, Advance Directives, Palliative Care* and *Widowhood*. It is funded by the Robert Wood Johnson and other foundations.

Our website also includes the list of the collection books held at both the Nantucket Atheneum and the Saltmarsh Senior Center. These collections are made available by Hospice through the Nancy Adam Hospice Education Fund.

### Hospice Interdisciplinary Team

Charlene Thurston, RN, ANP — Rev. Ted Anderson — Tim Lepore, MD— Peter MacKay, MSW — Ginnie Faria, Coord. Of Vol.

## JCAHO ACCREDITATION

We are excited to report that Hospice Care of Nantucket has again received a 3 year accreditation by the Joint Commission of Accreditation of Healthcare Organizations. JCAHO is the national organization which conducts voluntary surveys of healthcare programs to ensure that high quality service is being provided. Three years is the longest period accredited per survey. In April, all of the homecare departments of the hospital were surveyed - Hospice, Community & Home Health Dept., and Cottage Care Unlimited - and received a combined score of 92%!

## Spirituality & Health Conference

Hospice is once again participating with other community members in planning the 5th Annual Conference on Spirituality and Health. This year's conference will focus on creating and telling our life's stories. Jay O'Callahan, world reknown storyteller, will be the featured speaker, and several local and off-island experts will lead afternoon breakout sessions on various methods of expression, including art, music, drumming, movement, etc.

Recognizing and sharing the stories of our lives help us find the meaning in our experiences and those of others. Stories help us learn from and connect to one another in profound ways, and can often lead to significant personal growth and transformation.

We hope you'll all save the date of Friday, October 24th, to participate in what should be an exciting and rewarding conference!

You might also be interested to learn that the Noon Day Forums are again taking place on Tuesdays from 12:10 – 1:00 PM. These forums are open to the public and are held at the Methodist Church.

### Upcoming & Ongoing...

**Coping with Cancer Support Group** - every other Monday, 1-2:30 PM, for persons with cancer and those who love them

**Hospice Dreamcatcher Dinner & Auction** - June 15, 2003 at the Galley on Cliffside Beach

**Spirituality & Health Conference** -- October 24, 2003 at the Congregational Church

## Coping with Public Tragedy

On April 30, 2003, Hospice Care of Nantucket joined hundreds of hospices throughout the nation in locally hosting the 10th Annual Bereavement Teleconference of the Hospice Foundation of America. This year's topic, Coping with Public Tragedy, brought together an outstanding panel of experts to discuss what defines a public tragedy, what types of reactions and responses are commonly seen after such events, and what helpful interventions might key organizations provide in order to best serve their communities.

An audience of professionals, volunteers, and community members, gathered at Nantucket High School to view the teleconference and to participate in a discussion about how we might best meet the needs of Nantucket residents when such events occur.

A community panel including Rev. Ted Anderson, Dr. Tim Lepore, Supt. Alan Myers, A Safe Place Director Meg Hunter, and Hospice Director Charlene Thurston, preceded the teleconference. The effects of tragedies on first responders, helping professionals, as well as on immediate victims and the general public, were discussed.

Developing a formalized plan through which Nantucket organizations might respond to public tragedies is an idea which we've had at Hospice. Nantucket has an excellent Emergency Preparedness Plan for responding to physical disasters, such as storms, plane crashes, etc. What we feel we need now is to develop a similar preparedness plan for responding to crises which affect the public emotionally. The conference provided an excellent foundation, and we hope to participate with other organizations in the near future to continue the dialogue.

### Hospice Care of Nantucket Foundation

57 Prospect Street Nantucket, MA 02554 508-825-8325  
hospice@ackhosp.org www.hospiceofnantucket.org

**Board of Trustees: Augusta Beaugrand, President...Jo Zschau, 1st Vice President...David Boyce, 2nd Vice President... Eugene Collatz, Treasurer...Ellen Glennon, Secretary...Martha Butler...Marjorie Colley...Gloria Grimshaw...James Joynt... Keith Krewson...Wendy McCrae...Leslie Ottinger, MD...Catherine Flanagan Stover**

**Hospice Care of Nantucket Foundation is a not-for-profit tax exempt public charity.**



### A Partnership in Caring

*Funded by the Hospice Care of Nantucket Foundation, the hospice program is operated as a department of the Nantucket Cottage Hospital. Hospice 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.*