Dear friends,

Since we, at Hospice, have participated in recent nation-wide efforts to raise awareness about the effects of Alzheimer’s Disease on patients and families, we thought that creating a guide of readily available resources for residents of the island might be helpful. Our hope is that people will be able to easily determine how to access help and support, from the time in which symptoms develop and throughout the course of the illness.

When concerns about memory develop, the best things to do are to make a doctor’s appointment for an evaluation, and to learn about Alzheimer’s and other dementias through books, websites, & various organizations. www.alz.org and www.alzcapecod.org are two good websites. Our Hospice website (www.hospiceofnantucket.org) lists several good books, which we’ve donated to the Saltmarsh Senior Center for loan, and also lists links to other resources.

If a diagnosis of Alzheimer’s Disease or other dementia is made, your physician will prescribe treatment and follow up visits as necessary. You & your family will probably want to continue learning about the disease process and many of the situations which can arise, so that preparations may be made for how to handle them. Putting legal affairs in order and doing advance care planning (living wills, health care proxies, etc.) are important tasks to complete early in the disease process, while memory and reasoning abilities are good. Tending to other priorities, such as work or business affairs, relationships, travel, documenting your life’s story for your family, preparing a legacy, and doing everything that gives your life meaning are also important. Keeping our affairs, including our relationships, in a state of completion is a principle by which all of us should live, whether sick or well, since none of us knows what tomorrow may bring.

As President of the Foundation...

I would like to remind you to join us for the Eleventh Annual Dreamcatcher Dinner and Auction to be held on Sunday, June 13, 2004 at the Galley on Cliffside Beach. This fabulous evening will begin with aperitifs and Spanky’s ever popular raw bar. The cocktail hour will be followed by dinner served al fresco in a gala tent on Cliffside Beach. The delicious four-course dinner, prepared by the Chef de Cuisine, will be served with wines that have been selected by hosts David and Geoffrey Silva to complement each course. This year we are once again including a Silent Auction which will start at the beginning of the cocktail hour. The many exciting items will be on display in the main tent with something for everyone – don’t forget to stop by and place your bids. The main event will be the Live Auction and once again Rafael Osona will lend his wit and power of persuasion to the task of raising funds for our Nantucket Hospice. Offerings include many unique Nantucket experiences, dinners at local restaurants and other venues as well as trips to many exciting destinations including a BACKROADS cooking school in Italy; golf for a week at St. Andrews in Scotland; a week in Maui and a week in the Bahamas.

Reserve your tickets now as this will be an evening not to be missed.

As time passes, education and support for handling various concerns may be needed, such as, management of memory problems, behavioral concerns, safety issues, emotional impact; medication management; caregiving. It’s important to know that there are many services in the community that can be very helpful, and that patients and caregivers will cope much better if they utilize the support which is available to them. Following is a list of community resources.

By contacting any of the following organizations, you should be able to receive support and guidance in how to proceed.

Alzheimer’s Services of Cape & Islands: information, education and support for patients & caregivers. (508-775-5656) (www.alzcapecod.org)

Island and Consultant Physicians – provide diagnostic evaluation and ongoing treatment

Nantucket Cottage Hospital – provides full services as an acute care hospital; physical, occupational, & speech therapy evaluations and treatment are available through Rehab. Services Dept. (508-228-1200)

* Social Services Dept.—provides information, support, and assistance with a variety of issues, such as, health insurance, accessing Free Care Program of NCH, advance directives, referrals for various services including private home care aides, patient/family support, assistance for non-English speaking clients. All services are free of charge.

Lifeline, a personal emergency response system, is available for $35/month. (508-825-8195)

* Hospice Care of Nantucket—in early stages of illness and throughout, provides education, counseling, & support for patients and/or families; assistance with advance directives; monthly support groups for family caregivers; volunteers for up to 2 hours, twice/week; lending library. During the terminal stage of illness, comprehensive hospice services - physical, emotional, & spiritual care in home, hospital, or nursing home setting. Bereavement support is available to families for a year after the death of a loved one. All services are free of charge. (www.hospiceofnantucket.org)

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Farewell...

In April of this year, longtime Hospice Spiritual Counselor, Rev. Ted Anderson, retired from this volunteer role that he's served in since 1988, with just a brief hiatus while he returned to school. "Ted has been a pivotal member of our patient care team", says Charlene Thurston, Hospice Director, "offering true insight into how to best meet the needs of our patients. He's been constantly available, at a moment's notice, for a patient or family in need of support, and his relationships with members of the community bring them great comfort. We are eternally grateful to have had Ted on our team for all these years, and wish him well in his retirement.

Welcome...

While saying farewell to someone who's served us so well is always difficult, we are blessed to be welcoming Rev. Joel Ives, rector of St. Paul's Episcopal Church, to take over the reins to serve in this role. Joel has been on the island for five years now, and evokes nothing but praise for the work he has done for his congregation. Over the years we have had many opportunities to work together with Joel as we've cared for mutual patients and families, and have seen what an impact he makes on those to whom he ministers. His compassion, prayers, and practical assistance have provided invaluable support during times of need. We look forward to having Joel on our patient care team for many years to come.

(continued from page one)

* Community & Home Health Dept. – certified home health agency that provides nursing, physical, occupational & speech therapy, home health aides, social service, and nutritional counseling. Rehabilitation therapists evaluate the patient and the home to improve functioning and safety. Insurance coverage, if eligible, or fee for service. Free consultations available. (508-825-8300)
* Cottage Care Unlimited - provides homecare nurses, geriatric care management, home health aides, homemakers on a private fee for service basis. (508-825-8333)
Elder Services of Cape & Islands - for individuals who are 60 years old or older and meet financial eligibility, offers case management, family caregiver education & support, homemaking, personal care, respite care, chore services and referrals. Low fees, based on income. Meals on Wheels provides daily meals to homebound elders. Suggested $2 voluntary donation. (508-228-4647)
* Our Island Home: Monthly support group for caregivers. (Free of charge.) Full residential nursing home - costs are covered by Mass. Health, if eligible, or private fees on a sliding scale. (508-228-0462)
* Adult Community Day Center: supervised social day care program, located at the Teen Center. Open 3 days/week. Subsidized by Elder Services, for those who qualify, or fee for service. (508-325-5349)
Nantucket Behavioral Health Service - full service counseling center, which includes supportive counseling for caregivers. Costs are covered by insurance, if eligible, or fees on a sliding scale. (508-228-2689)
Churches - pastoral counseling and support available through most churches, usually free of charge.
Isle Return - a registry for persons with memory impairment who are at risk for wandering. (Sponsored by the Nantucket Sheriff, Police and Fire Depts., Community and Home Health, and Elder Services.)
Private services: in addition to the above organizations, numerous services are offered through private counselors, personal care aides, and complementary therapists, on a private fee for service basis. (Complementary therapies include a variety of modalities which often enhance overall well being of patients & caregivers and may improve functioning. Some examples are massage, reiki, yoga, tai chi, art therapy, music therapy, movement therapy, chiropractic, jin shin jyutsu, acupuncture, aromatherapy.)
Please don’t hesitate to call upon us. We're here to serve you. Charlene Thurston

Visit our website @ www.hospiceofnantucket.org
Volunteers...our most priceless treasures

By Ginnie Faria, Volunteer Coordinator

When our hospice began over 20 years ago, the initial operation was completely run on a voluntary basis. The hospice movement internationally began with a strong foundation of volunteering. Even today, Hospices are still required by regulatory mandate to offer volunteers in addition to professional care.

Hospice Care of Nantucket volunteers provided over 500 hours of direct care service to patients and families over the past year. Additionally, board members and auction volunteers of the Foundation, also provided many more hours and were responsible for all of the fundraising which supports our program.

According to the National Hospice and Palliative Care Organization, approximately 500,000 people volunteer in the nation’s 3200 hospice organizations, and provide more than 10 million hours of service annually.

This year, as we expanded our hospice program to include support for caregivers of chronically ill and disabled individuals, we also expanded and increased our corps of volunteers. This winter we completed a 26-hour training program that now qualifies 10 new volunteers to provide support for family caregivers and their care recipients. We now have over 30 trained and qualified volunteers able to serve patients and their families.

Some of the services that our volunteers provide are: respite for caregivers, companionship to patients, outings for the homebound patient, transportation, errands, and shopping for either the patient or family, and other non-medical practical assistance. Some of our volunteers are also professionals who volunteer their services such as massage and other therapies. Volunteers also serve on working committees of our Board of Trustees.

Volunteers come to the program for different reasons: some simply have a desire to help others or to give back to their community; others have had a positive experience with the care and support a loved one might have received from Hospice, while others appreciated the help they received from Hospice during the grieving process. We are fortunate here on Nantucket to be blessed with so many people who are willing to volunteer in so many capacities and on so many levels.

I asked several of our volunteers what brought them to this work:

“I wanted a chance to be of service. I’ve actually taken away new learning experiences and have made new and unique friends”

“I’d always admired what Hospice does and saw the training opportunity in the newsletter”

“I feel it’s a privilege …someone is opening up his or her life to you”

“I sleep better knowing I’ve helped someone else”

Thank you Volunteers!

Upcoming & Ongoing...

Dreamcatcher Dinner & Auction
June 15, 2004 at the Galley on Cliffside Beach

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

Caregivers’ Support Group 
the 2nd Thursday of the month

Spirituality & Health Conference – coming this fall...watch for details

As we go to press, we honor the family and friends of Marla Ceely Lamb for their hard work towards their annual Mothers’ Day Dinner and Auction fundraiser. That event, in addition to the donations to the MCL Transportation Fund throughout the year, helps cover costs for cancer patients who must travel off island for treatment.
Live Teleconference: Alzheimer’s Disease

Thirty-five members of the community, hospice volunteers, and health care professionals, gathered at the high school on April 28 for Hospice Foundation of America’s 11th live teleconference. This year’s topic was Alzheimer’s Disease (see our Director’s Resource Guide on page 1). The 2 ½ hour live broadcast (simulcast on channel 18) covered issues ranging from medical conditions and symptoms, services and educational opportunities available to caregivers, the anticipatory grief and mourning associated with the disease, and public policy issues, including advocacy for increased funding to support much needed research. Throughout the broadcast, “voices” of patients with Alzheimer’s as well as those of caregivers provided first hand insight into the challenges of the disease and the positive steps taken along the way. Some issues highlighted by members of our own community included assistance and services for the caregiver, concerns about early onset, and questions about treatments and medications. The program will be re-broadcast on channel 18 and a video is available for loan from our office upon request.

As always we sincerely thank those families who have directed that memorial contributions be made to Hospice Care of Nantucket Foundation or to the Marla Ceely Lamb Transportation Fund. Because of these donations we are able to continue to provide services free of charge.

Health Care Proxies, Living Wills

Health Care Proxies are legal documents that do not require a lawyer. Remember that Hospice is available to help you with Advance Care Planning, so don’t hesitate to call our office for assistance—free of charge.

Hospice Care of Nantucket Foundation

Board of Trustees: Augusta Beaugrand, President...Jo Zschau, 1st Vice President...David Boyce, 2nd Vice President...Eugene Collatz, Treasurer...Keith Krewson, Secretary...Rev. Mark Bruce...Martha Butler...Gloria Grimshaw...Beatrice Knox-Johnston...Keith Krewson...Wendy McCrae...Leslie Ottinger, MD...Michael Varbalow...

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.