

SINCE YOU CARE

A Series of Guides from **MetLife** in Cooperation with the National Alliance for Caregiving

Hospice Care

About the Subject

There are very few things in life that come with a guarantee. The sun rises and sets each day. The moon hangs high in the night sky. And sometime, sooner or later, we all must die. These are a few of life's certainties.

For many of us, contemplating death brings with it a fear of the unknown, of pain, of sorrow, and of loss. There is the loss of the ability to control our destiny and the loss of our dignity. There is also concern for family and friends who will be left behind.

As difficult as it is to discuss life's final hours, making certain that your family knows your wishes makes honoring them much easier. Many terminally ill people prefer to stay at home, surrounded by family and friends. A program called "hospice" helps people with a terminal illness choose how their final days will be spent.



MetLife

Caregivers face many challenges as they search for information and make decisions about how best to provide care to their loved ones. To help meet their needs,

MetLife offers SinceYouCaresm — a series of guides which provide practical suggestions and useful tools on a variety of specific care-related products.

Central to hospice care is the philosophy that every individual has a right to die with dignity, with compassion and comfort.¹

Things You Need to Know

What is Hospice?

Hospice is not about death, but rather, about the quality of life as it nears its end, for all concerned — the patient, family and friends, and the health professional community. Hospice is a model of care that was developed in the late 1960's by a British doctor and nun, Dame Cicely Saunders.² She developed the principles of modern hospice care that focus on a holistic approach to pain and symptom management, incorporating the spiritual, emotional, and psychological aspects of dying, and keeping the patient and family at the center of the caregiving circle.

The first U.S. hospice home care program was started in 1974 by the Connecticut Hospice.³ Today there are more than 3,000 hospices operating in the United States.⁴ Hospice is traditionally a program that is implemented and maintained in a person's home, but it can be provided in nursing homes,

some assisted living facilities, free-standing standing facilities devoted to hospice care and in some special situations, in the hospital.

Hospice is a program that had originally been associated with the terminally ill cancer patient. Current practice makes it available for any terminally ill person in the end stages of cancer, Parkinson's, Alzheimer's, heart disease, or other disease or condition. And while the majority of patients are older, the program is available to anyone—regardless of age, sex, religion or disease—who has been diagnosed by a physician as having a life expectancy of six months or less. The care that is provided is not meant to cure the person. It is palliative, which is care aimed at relieving or reducing discomfort. Hospice does not work to hasten death, but to enhance the quality of life that remains and to provide support to caregivers.

Why Choose Hospice?

Eligibility

The essential component to eligibility for hospice, whether covered by Medicare or health insurance, is that a person's physician certifies that they have a life expectancy of six months or less.

Hospice eligibility requirements are the same whether the person lives at home, in an assisted living facility or nursing home. Some nursing homes may provide their own in-house hospice services. Other nursing homes and most assisted living facilities may have contracts with hospice home care agencies that will come to the facility to supplement the needed hospice services.

When the determination to begin hospice care is made, the current plan of care to treat the illness such as cancer, with chemotherapy or radiation, is usually discontinued and care becomes palliative. The individual continues under the plan of care of his or her physician with hospice nurses and other health professionals administering care of a palliative nature to provide dignity and a good quality of life.

Hospice cares for the entire family, not just the terminally ill family member. Through services such as symptom relief for the patient and emotional, spiritual and practical support, patients and their families can prepare for death in ways that are meaningful to them. Hospice provides dignity in dying for families and their loved ones.⁵



Hospice Service Locations

While hospice care may be provided in assisted living facilities and nursing homes, the majority of care is still provided in the home. When hospice care is provided in an assisted living facility or nursing home, it generally means that the individual receives special visits from members of the hospice team such as nurses, social workers, or aides in addition to the services already

being provided by the facility. In a situation where hospice in a nursing home or assisted living facility is requested, there is generally a contract between the hospice agency and the facility. More than 80% of hospice care in the U.S. is provided in a person's own home.⁶

Freestanding Hospice Facilities

Freestanding hospice facilities or residential hospice facilities

are full-time hospice residences. Criteria for admission may vary depending on the residence, but most facilities will take residents for a few days up to a year's time, provided they meet eligibility criteria. In facilities such as these, hospice personnel provide full time end-of-life care.

Utilizing Hospice Services

Sometimes the doctor will broach the subject of hospice care, but a patient or family caregiver may also be the first to initiate the discussion. Often family is hesitant to approach the subject of hospice because, for some people, the discussion makes the terminal illness a reality.

While death is expected for those using the hospice benefit, people who live longer than the six month life expectancy needed to qualify for hospice may continue to receive hospice care provided they continue to meet eligibility criteria with subsequent evaluations.

When the family makes the decision to utilize hospice, the physician will make a referral to a hospice agency. A nurse



from the hospice agency will meet with the patient and/or family to view the hospice program and to verify eligibility. Once this is confirmed, the person can then be authorized to receive hospice services. In most cases, it is better for a patient to begin to use hospice services earlier than later, if there is a choice. This allows for the full use of services and support of the trained and experienced health care professionals, social workers, chaplains, and volunteers to assist both the patient and caregivers.

Remaining Eligible for Hospice Services

During hospice care, a nurse periodically recertifies the eligibility of the individual who is receiving hospice services. If patients experience a substantial improvement in their condition, which is possible when symptoms are effectively treated and caregivers and given home support, they may be discharged from hospice because they no longer meet eligibility criteria. At this time, the agency would assist the patient and caregivers in locating other appropri-

ate services. If another decline in health occurs later on, the patient could be readmitted when they again met eligibility criteria.

Hospice Agencies

The hospice philosophy is consistent across the country, but the agencies themselves may vary dramatically in the services available and treatments a patient may receive. Generally, hospice includes a team of professionals working together to provide medical, emotional and

spiritual supportive care for an individual.

Services

Services include medical and nursing care, medical equipment (such as a hospital bed or oxygen), pharmaceutical therapy for pain control, social workers, home health aides and homemakers, clergy, volunteers, therapists, dietary counseling, and bereavement services for survivors.⁷ In some areas of the country, availability of all these services may be restricted or limited.

Personnel

Although a nurse is available twenty-four hours a day for questions and concerns, home hospice services do not provide twenty-four hour hospice care in the home. An agency may place an aide, homemaker or volunteer to assist and support the patient and caregivers, but continuous care is provided for crisis situations only and then for a very limited time.

A large component of the hospice service team is its volunteers. They undergo special training before they are able to go into an individual's residence, whether it is a private home, an assisted living facility or a nursing home. The volunteers are of great help to caregivers because

they are trained to help with everyday tasks and have usually had personal experience with hospice.

Accreditation

There is no mandatory nationwide accreditation of hospice home care agencies. The state's department of health certifies all hospice agencies, and those agencies that are Medicare-certified are monitored by the federal government by the Centers for Medicare & Medicaid Services (CMS). An agency can voluntarily apply for accreditation by the Joint Commission on Accreditation of Healthcare Organization (JCAHO) or Community Health Accreditation Program (CHAP).

Medicare and Hospice

Medicare Eligibility for Hospice

Congress enacted the hospice benefit under Medicare in 1982.⁸ Like non-hospice Medicare, the benefit is available to retired persons who have worked 10 or more years in a job, made contributions to Medicare while working and who are over 65.⁹ The individual must have Medicare Part A, and elect services from a Medicare certified hospice program.

While on hospice, a person has certification periods or periods of care. There are two initial 90 day periods followed by an indefinite number of 60 day periods. It is at the start of each of these periods that a physician certifies a person's continued terminal illness status. As long as their physician recertifies their terminal illness status, they may continue to receive hospice care. Continuing hospice eligibility is the same regardless of a person's place of residence.

When an individual meets the eligibility requirements (six months to live or less) and elects the Medicare hospice benefit, they sign a statement upon admittance, choosing hospice care instead of routine home care.¹⁰ Signing this statement indicates that an individual is waiving the right to Medicare payments for medical treatment of those conditions relating to their terminal illness. This is reversible if the individual changes their mind and decides to pursue more aggressive treatments. The admission form that a person reads and signs when admitted to hospice care or hospice outlines all the particulars about privacy, rules, payments and other details.



If an individual is in a nursing facility and receiving hospice services, hospice services will most often be covered providing the individual uses a Medicare certified hospice agency. Room and board and accompanying expenses such as laundry or housekeeping are usually the responsibility of the patient. If residence in a freestanding hospice is anticipated, it is best to speak with the facility regarding the Medicare reimbursement policy. Discuss with the agency providing care, how and what hospice would cover if an inpatient hospital admission were necessary.

Under Medicare, full time hospice home care is not covered except in a crisis situation, and there are strict limits to providing that care. You should check with your agency to see what may or may not be covered. Also, there may be a charge for pharmacy services, up to five percent, so it is important to check with the agency upon initiation of services.¹¹

If an individual is a member of a Medicare HMO that does not provide hospice services, the HMO must, by law, inform Medicare members of agencies in the area that do provide hospice care. Patients do not

need to leave the HMO. Hospice services will be covered under Medicare.¹²

As Jon Keyserling, Vice President of public policy for the National Hospice and Palliative Care Organization (NHPCO) said, “Hospice is a no-cost item to an elderly patient and their family. It’s paid up health insurance.”¹³

Payment

If the individual is a Medicare recipient, hospice is a benefit that covers most hospice services pertaining to the terminal illness. Home care services under hospice are covered. Hospice services provided in a nursing facility will usually be covered, but room and board expenses will not. Medicaid will usually cover hospice services.

Long-Term Care Insurance

Long-term care insurance may help cover the cost of personal care services needed to supplement hospice care being provided under Medicare or other health insurance. For example, many long-term care policies may help cover the cost of a nurse’s aide.

Most private insurance companies and HMOs cover hospice costs for individuals who are eli-

gible. However, check the policy limits for payment, as coverage may vary. Some hospices have programs for individuals without insurance or who have limited income but are not covered by Medicaid. If you have insurance but are unsure of the coverage, the agency may be able to speak with your carrier to try to negotiate payment for care. Hospice traditionally has been there to provide care and services based on need, rather than on the ability to pay.¹⁴

Sometimes national organizations, such as the American Cancer Society or the Alzheimer’s Association, have programs that help to defray cost.

Your local Area Agency on Aging may have programs to assist those with limited income who desire hospice care in the home. Use the *ElderCare Locator* found in *Resources to Get You Started* at the end of this guide to locate the agency in your area.

Respite Care

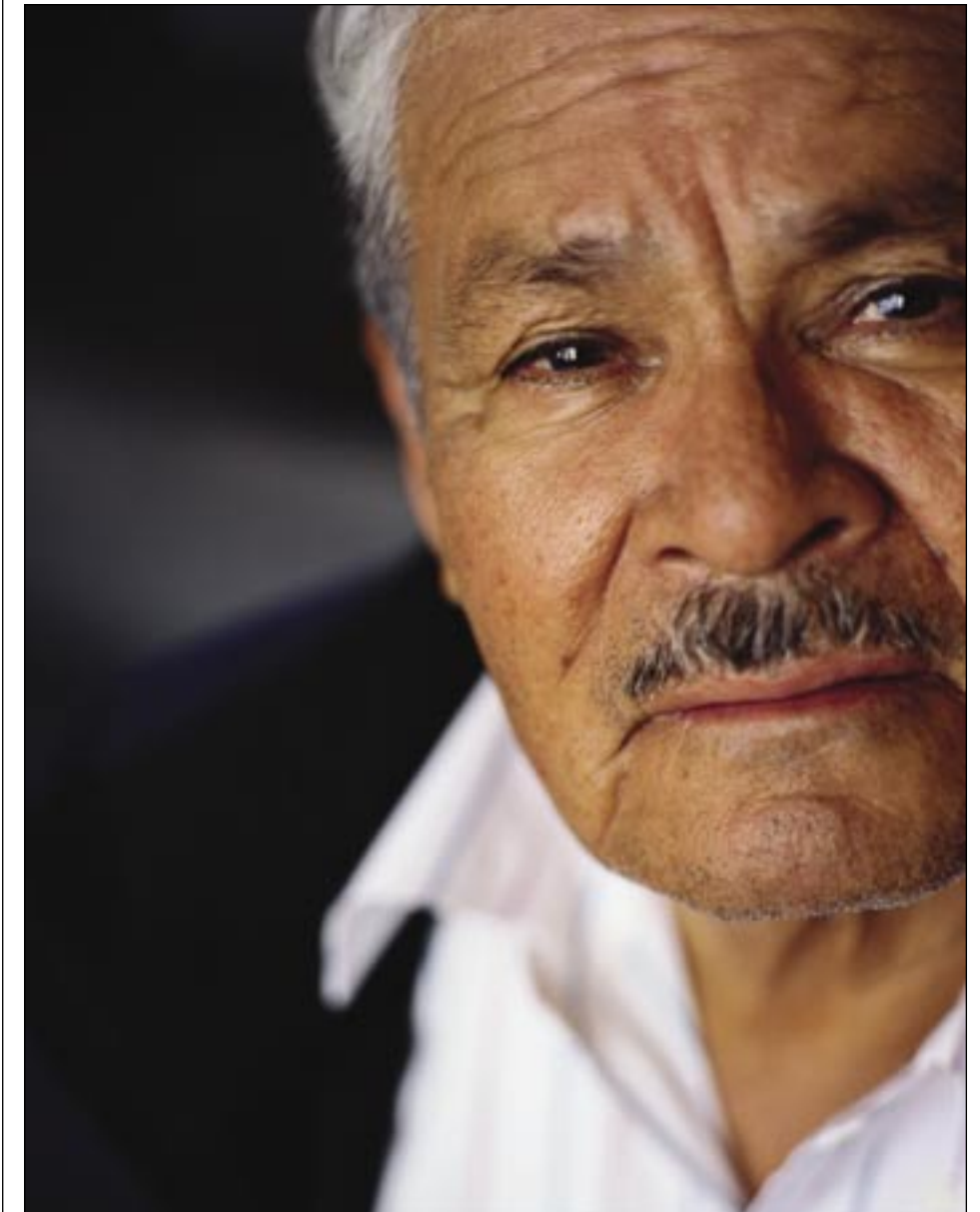
Respite care is short-term care provided at a facility or in the home so that family caregivers can take a vacation, travel on business or take a break from caregiving responsibilities.

For reimbursement under Medicare, respite is provided as an in-patient stay in a Medicare approved nursing or hospice facility. Care is usually provided for a maximum limit of five days, and is only for occasional use. There is a five percent charge based on the Medicare payment that is subject to change and can vary slightly depending on your location.¹⁵

If you plan to cover a respite stay using private health insurance or long-term care insurance, or if you’re on Medicaid, speak with your carrier or caseworker to see if there is a respite benefit and how it can be utilized. Sometimes the agency providing in-home hospice care has special contracts with other agencies for respite care in the home. Speak with your nurse or the social worker about any programs they might have.

Other respite care options include:

- Faith in Action
- National Family Caregiver Support Program
- Disease-specific groups such as the Alzheimer’s Association or the National Parkinson Foundation, Inc.



- Church groups
- Community grant programs

Some respite options are free; some are offered on a sliding fee scale. Sometimes people will provide home visits for just a few hours a week instead of a five-day minimum, which will help save money.

Helpful Hints

- If you or a family member is considering hospice, don’t be afraid to discuss with the doctor the type of care, medicines, treatments or therapies that can be provided under hospice care. Be sure everyone in the family understands their role and responsibilities

regarding the care plan and any accommodations they may need to make.

- Research the disease; know what it's about, treatments, and prognosis.
- Don't be afraid to look at the emotional and spiritual side of the issues.
- Talk to family members and prioritize those things that are important in order to make the most of the time that remains.
- Know that being afraid of dying is natural and to be expected.
- Discuss your views on end of life care before a crisis hits. If you don't have an Advanced Directive, discuss it with your family and consider having one drawn up by your attorney.

Advanced Directives

An advanced directive is written instructions regarding the provision of health care for use when an individual becomes incapacitated.

There are two types of advanced directives.

1) Living Will

This type of advanced directive puts in writing your wishes regarding medical treatment if you are incapacitated or unable to communi-

cate. The state defines when it may go into effect and there may be limits to it. It may also be called "Directive to Physician," "Declaration" or "Medical Directive."¹⁶

2) Medical Power of Attorney

This document appoints someone you choose to make medical decisions for you if you are unable to do so. It may also be called "Health Care Proxy," "Appointment of Health Care Agent" or "Durable Power of Attorney for Health Care."¹⁷

You do not need to have a terminal diagnosis to draw up a Living Will or Medical Power Of Attorney. Everyone, regardless of age, should have an advanced directive. Each state will regulate the use of Advanced Directives differently, and not all states require both types of directives listed, so be sure to check your state's requirements.

Remember The Caregiver

- If you're feeling overwhelmed about providing care for someone who is terminally ill, reach out to support groups, the nurses involved in your loved one's care, and friends and family. Caregiving can be an



isolating experience.

- If you have questions about how to provide basic caregiving, such as making an occupied bed, or taking someone to the bathroom, the American Red Cross can provide information on caregiving classes. If a home care agency is providing care to a family member, talk to the home care agency about teaching you these caregiving skills.

- Don't be afraid to acknowledge anger, frustration, fear, or anxiety.

When the caregiving ends, don't feel guilty about being a bit relieved. It's a normal reaction to a stressful situation.

Resources to Get You Started

Books and Publications

Caregiving: Hospice-Proven Techniques for Healing Body & Soul

This book, appropriate for family and agency caregivers, was written by a hospice director and provides a multitude of caregiving ideas, tools, checklists and much more. A wonderful book about the quality of com-

passionate care for those who are dying.

Smith, D. (1997). MacMillan General Reference. \$14.95 ISBN: 0028616634

Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying.

The authors, who are hospice nurses, share their intimate experiences with patients. They offer practical advice for family members and professionals on recognizing, understanding and responding to a dying person's messages.

Callanan, M., & Kelley, P. (1997). Bantam Books. \$13.95 ISBN: 0553378767

Handbook for Mortals — Guidance for People Facing Serious Illness

Comprehensive, authoritative guide written by specialists and authorities in the field of end of life care. It should be read by anyone providing care for a seriously ill family member.

Lynn, J., Harrold, J., forward by Rosalynn Carter (2001). Oxford University Press. \$34.00 ISBN: 0195146018

On Death and Dying

This groundbreaking book by respected psychiatrist and author Elisabeth Kubler-Ross

introduces and explores five stages of approaching death. Kubler-Ross, E. (1997). Scribner. \$13.00 ISBN: 0684839385

Palliative Care: Complete Care Everyone Deserves

This booklet provides an overview of palliative care and provides strategies caregivers can use to ensure that family members receive the palliative care they need in a variety of settings. National Alliance for Caregiving and FRIA (Friends and Relatives of Institutionalized Aged) (2003). Available at www.caregiving.org/care.pdf or by calling 301-718-8444.

The Hospice Handbook: A Complete Guide

An excellent introduction to hospice care. Covers basic concepts of palliative care, how hospice functions, suggestions on choosing a hospice and more. Beresford, L. (1993) Little Brown & Co. \$16.99 ISBN: 0316091383

National Hospice & Palliative Care Organization (NHPCO)

Booklets explaining and discussing Do-Not-Resuscitate (DNR) orders and advanced medical directives can be ordered by calling 703-837-1500 or by accessing their Web site at www.nhpco.org.

Internet Sites

Five Wishes

This template for a living will makes it easy for individuals to state their wishes for how their medical, personal, emotional, and spiritual needs should be addressed if they become unable to speak for themselves. A 25-minute video explaining Five Wishes is also available. *Aging With Dignity* (2001). Available at www.agingwithdignity.org or by calling 1-888-5-WISHES. Single copies \$5.00. Orders of 10 or more \$2.00 each. Video \$19.95.

National Association of The Area Agencies on Aging (n4a)

The n4a is the umbrella organization for the 655 Area Agencies on Aging throughout the United States which provide information and services, and coordinate and administer programs for older adults. The federally-funded Eldercare Locator, administered by n4a, provides callers with information about local services, including hospice, by zip code. Call 800-677-1116, 9:00 a.m.-8:00 p.m. ET, or access it at: www.n4a.org.

GrowthHouse

Growth House, Inc. is located in San Francisco, CA. This site provides educational, informative, comprehensive resources

for end-of-life care. It offers guides related to specific disease processes, online book resources, groups, and much more. It may be accessed at www.growthhouse.org.

Hospice Association of America (HAA)

This organization represents over 2,800 hospices, caregivers and volunteers engaged in caring for the terminally ill. HAA is an affiliate of the National Association for Home Care (NAHC). The site has information on current hospice trends, how to choose a hospice, publications and helpful links. It may be accessed at www.nahc.org/HAA/

Last Acts Partnership

Last Acts Partnership is a national non-profit organization that resulted from combining the programs of Partnership for Caring, a national non-profit organization dedicated to improving care and caring near the end of life, and Last Acts, a national campaign with the same goal.

The Last Acts Partnership Web site contains information for consumers, medical and health professionals and end-of-life care advocates. Additionally, Last Acts Partnership maintains a

Website containing publications, free downloads of living wills and medical powers of attorney and a variety of educational materials. You may reach them by calling 202-296-8071, or call their 24-hour, 7 day per week crisis number at 800-989-WILL (800-989-9455).

www.lastacts.org

National Hospice & Palliative Care Organization (NHPCO)

This organization was established in 1978 as the National Hospice Organization and changed its name in 2000. It is the largest non-profit hospice and palliative care organization representing programs and professionals in the United States. The site is a wealth of information about resources, education and links within the same site to the National Hospice Foundation. This site provides for state specific hospice searches. It may be accessed at www.nhpco.org.

Useful Tools

Included is a checklist to help you evaluate if hospice is the right choice at this time.

- Hospice Assessment Checklist

¹ *Hospice Care Enhances Dignity and Peace As Life Nears Its End*, Centers for Medicare & Medicaid Services, via the Internet at www.cms.gov, March 28, 2003.

² *How Did Hospice Care Begin in America?*, National Hospice Foundation, via the Internet at www.hospiceinfo.org, 2003.

³ Leukenotte, A., *Gerontological Nursing*, 2nd Ed., Mosby, St. Louis, pg. 791, 2000.

⁴ *Aid Programs: Getting Help in On Our Own Terms: Moyers on Dying: Discussion Guide*, 2000: Thirteen/WNET New York Educational Broadcasting Corp & Public Affairs T.V., Inc.

⁵ *Hospice Concept*, Hospice Net www.hospicenet.org

⁶ bid.

⁷ *How To Select A Hospice Program*, National Hospice Foundation, via the Internet at www.hospiceinfo.org/public/articles/index.cfm?cat=3, 2003.

⁸ *Hospice Facts & Statistics*, National Association for Home Care, via the Internet, <http://www.nahc.org/Consumer/hpcstats.html>, November, 2002.

⁹ *Aid Programs: Getting Help, in On Our Own Terms: Moyers on Dying: Discussion Guide*; 2000: Thirteen/WNET New York Educational Broadcasting Corp. & Public Affairs T.V., Inc.

¹⁰ *Hospice*, via the Internet at 222.cms.hhs.gov/medlearn/refhospice.asp, 2003.

¹¹ *Medicare Hospice Benefit*, National Hospice Foundation, via the Internet, www.hospiceinfo.org/public/articles/index.cfm?cat=7, 2003.

¹² Leukenotte, A., *Gerontological Nursing*, 2nd Ed., Mosby, St. Louis, pg. 792, 2000.

¹³ *What Hospice Is: Not a Place, But a Philosophy of Care*, State Initiatives in End-of-Life-Care, Issue 11, pg.4, August 2001.

¹⁴ *How to Select A Hospice Program*, National Hospice Foundation, via the Internet at www.hospiceinfo.org, 2003.

¹⁵ *Medicare Hospice Benefit*, via the Internet at www.hospicenet.org, 2003.

¹⁶ *What is a Living Will?* Partnership for Caring, via the Internet at www.partnershipforcaring.org/advance/faq_set.html.

¹⁷ *What is a Medical Power of Attorney?*, Partnership for Caring, via the Internet at www.partnershipforcaring.org/Advance/faq_set.html, 2003.

About the Authors of Since You CareSM

Since You Care guides are prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Nurse Care Managers.

MetLife Mature Market InstituteSM is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market.

MetLife Nurse Care Managers are available to MetLife's long-term care customers and their caregivers, on a daily basis, to help identify and resolve caregiving questions and concerns through counseling and referral.

National Alliance for Caregiving is a non-profit coalition of 38 national organizations that focuses on issues of family caregiving.

Mature Market Institute MetLife

57 Greens Farms Road
Westport, CT 06880
E-Mail: MatureMarketInstitute@metlife.com
www.maturemarketinstitute.com

National Alliance for Caregiving

4720 Montgomery Lane,
Fifth Floor, Bethesda, MD 20814
www.caregiving.org

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