

# 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 potential for 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 SinceYouCare® — 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.<sup>1</sup>

## 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, Dame Cicely Saunders.<sup>2</sup> 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.<sup>3</sup> Today there are more than 4,000 hospice programs operating in the United States.<sup>4</sup> 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 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 he or she has 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 an 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 focused on the dignity, comfort and wishes of the care recipient.

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.<sup>5</sup>



### ***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.<sup>6</sup>

### ***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 rather 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, clergy and volunteers to assist both the patient and his or her caregivers.

### ***Remaining Eligible for Hospice Services***

During hospice care, a nurse periodically recertifies the eli-



gibility 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 are given needed support at home, 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 appropriate 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, homemakers, clergy, volunteers, therapists, dietary counseling and bereavement services for survivors.<sup>7</sup> 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.<sup>8</sup> In order to receive hospice benefits under Medicare an individual must:

- be eligible for Medicare Part A (hospital benefits)
- have a certification from his or her doctor and the hospice medical director that he or she is terminally ill and has 6 months or less to live if the illness runs its normal course
- sign a statement choosing hospice care instead of other Medicare-covered benefits to treat the terminal illness (Medicare would still pay for covered benefits for any health problems not related to the terminal illness.) and
- receive care from a Medicare-approved hospice program.<sup>9</sup>

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.

An individual who has selected hospice has the right to change his or her mind and return to receiving regular Medicare benefits at any time.<sup>10</sup>

The admission form that a person reads and signs when admitted to hospice care or hospice should outline 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.<sup>11</sup>

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.<sup>12</sup>

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."<sup>13</sup>

## 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 eligible. 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.<sup>14</sup>

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. For reimbursement under Medicaid, respite is provided as an inpatient stay in a Medicare approved nursing or hospice facility. There is a 5% co-insurance the beneficiary must pay based upon the Medicare payment schedule. The co-insurance cannot exceed the Part A deductible which was \$952 in 2006. This amount is subject to change.<sup>15</sup>

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.

## 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 his or her role and responsibilities regarding the care plan and any accommodations they may need to make.
- Research the disease; know

what it's about, treatments available, 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 with your family member his or her views on end-of-life care. If he or she does not have an advance directive (described below), he or she may want to consider having one drawn up by an attorney so that care will be delivered according to his or her wishes.

## Advance Directives

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

There are two types of advance directives.

### 1) *Living Will*

This type of advance directive puts in writing an individual's wishes regarding medical treatment if he or she is incapacitated or unable to communicate. 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."<sup>16</sup>

### 2) *Medical Power of Attorney*

This document appoints someone that an individual chooses to make medical decisions for him or her, should he or she be 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."<sup>17</sup>

Individuals 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 advance directive. Each state will regulate the use of advance 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, 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*

**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.  
\$16.00 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.  
\$17.95 ISBN: 0195146018

## **On Death and Dying**

This groundbreaking book by respected psychiatrist and author Elisabeth Kubler-Ross introduces and explores five stages that individuals go through related to death and dying.

Kubler-Ross, E. (1997). Scribner.  
\$14.95 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 <http://www.caregiving.org/pubs/brochures/palliativecare.pdf> or by calling 301-718-8444.

## **Internet Sites**

### **Five Wishes**

Aging with Dignity  
PO Box 1661  
Tallahassee, FL 32302-1661  
850-681-2010 Fax: 850-681-2481  
Five Wishes is a living will and a durable power of attorney for health care, valid in the majority of states, that addresses not only an individual's medical wishes, but also his or her personal, emotional and spiritual needs. It is easy to understand and use. (Check with your state to see if they will honor the Five Wishes document.) The project was supported by a grant from The Robert Wood Johnson Foundation. To order, write to Aging with Dignity, call toll free: 888-5-WISHES (888-594-7437), or go to [www.agingwithdignity.org](http://www.agingwithdignity.org) for online ordering. Single copies are \$5.00 each; pricing for bulk orders is available.

### **Hospice Net**

Hospice Net is an independent nonprofit organization formed to provide support to individuals and families facing life threatening illnesses. The website contains information about hospice services, a link to locating local hospice services, a section specifically addressed to patients and the issues they face in end-of-life care and a section for caregivers specifically addressing caregiver issues and the concerns that accompany caring for a loved one

with a terminal illness. The site also provides grief information and has material specific to helping children and teens with the grief process. It can be accessed at <http://www.hospicenet.org/>.

### **National Association of The Area Agencies on Aging (n4a)**

The n4a at [www.n4a.org](http://www.n4a.org) 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: <http://www.eldercare.gov/Eldercare/Public/Home.asp>.

### **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.growth-house.org](http://www.growth-house.org).

### **Hospice Association of America (HAA)**

This organization represents over 2,800 hospices, caregivers and

## Hospice Assessment Checklist

### Is Hospice Care the Right Choice?

Hospice care is a choice. You may question if hospice is the best program for you. Depending on the area of the country you are in, you may or may not have options about which agency to use.

The following provides some questions you and or your family may want to ask about whether hospice is right for you and what services may be provided by the agency.

Do I want to be at home with family and friends when I am dying?

Yes  No

Is my family willing and able to help care for me at home when I am dying?

Able  Not Able

If I cannot be cared for at home, would I go to a facility?

Yes  No

If no, where would I go? \_\_\_\_\_

Is it important to me that I have the final say in my care?

Yes  No

How will my pain be controlled? \_\_\_\_\_

Who will help support my family and caregivers during this period? \_\_\_\_\_

How will I pay for the care? \_\_\_\_\_

**If you decide to use hospice services, the physician providing your care may make the referral to a hospice agency on your behalf. Medicare and some health insurance plans may specify which hospice agencies they will cover.**

### If you choose your own agency:

- Ask for your physician's suggestions.
- Check with your church or religious affiliation for recommendations.
- Ask for suggestions from friends and neighbors that have had experience with hospice. Your local area Agency on Aging may provide names of agencies in your area.
- Call the National Hospice & Palliative Care Organization (NHPCO). See *Resources to Get You Started* for contact information.



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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. Consumer materials include *All About Hospice: A Consumer Guide*, *The Hospice Patient's Bill of Rights*, *When Caring Matters Most: Top 20 Reasons for Choosing Hospice* and *A Listing of Home Care and Hospice State Associations*. Many of these publications are available as brochures and can be ordered through HAA's publications department at 202-546-4759. The HAA Web site may be accessed at <http://www.nahc.org/HAA/>.

## National Hospice & Palliative Care Organization (NHPCO)

This organization is the largest non-profit hospice and palliative care organization representing programs and professionals in the United States. The site contains a wealth of information, provides links to other resources and has a database that allows you to search for a local hospice provider.

Caring Connections is a program of NHPCO that is supported with a grant from the Robert Wood Johnson Foundation and is a national consumer initiative to improve end-of-life care. It provides free resources and information to help people

make decisions about end-of-life care and services before a crisis and helps them connect with the resources they need. The Caring Connections site which can be accessed at <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285> also provides a link to state specific information on Advance Directives and the ability to download state specific forms for Living Will and Health Care Power of Attorney.

The NHPCO toll free HelpLine at 1-800-658-8898 is available to help people looking for end-of-life information, including free brochures, advance directive information and contact information for hospice and other end-of-life organizations. The NHPCO site may be accessed at [www.nhpc.org](http://www.nhpc.org).

## Useful Tools

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

- Hospice Assessment Checklist

<sup>1</sup> *Hospice Care Enhances Dignity and Peace As Life Nears Its End*, Centers for Medicare & Medicaid Services, via the Internet at [www.cms.gov](http://www.cms.gov), March 28, 2003.

<sup>2</sup> *How Did Hospice Care Begin in America?*, National Hospice Foundation, via the Internet at [www.hospiceinfo.org](http://www.hospiceinfo.org), 2003.

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

<sup>4</sup> *Hospice Facts and Figures*, National Hospice and Palliative Care Organization, [http://www.nhpc.org/files/public/communications/out-reach/Fact-sheet\\_FactsAndFigures.pdf](http://www.nhpc.org/files/public/communications/out-reach/Fact-sheet_FactsAndFigures.pdf). Accessed 11/29/06.

<sup>5</sup> *Hospice Concept*, Hospice Net [www.hospicenet.org](http://www.hospicenet.org)

<sup>6</sup> Ibid.

<sup>7</sup> *How To Select A Hospice Program*, National Hospice Foundation, via the Internet at [www.hospiceinfo.org/public/articles/index.cfm?cat=3](http://www.hospiceinfo.org/public/articles/index.cfm?cat=3), 2003.

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

<sup>9</sup> *Medicare Hospice Benefits*, Centers For Medicare and Medicaid, CMS Pub.No. 02154, Revised July 2005. <http://www.medicare.gov/publications/pubs/pdf/02154.pdf>

<sup>10</sup> Ibid.

<sup>11</sup> *Medicare Hospice Benefit*, National Hospice Foundation, via the Internet, [www.hospiceinfo.org/public/articles/index.cfm?cat=7](http://www.hospiceinfo.org/public/articles/index.cfm?cat=7), 2003.

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

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

<sup>14</sup> *How to Select A Hospice Program*, National Hospice Foundation, via the Internet at [www.hospiceinfo.org](http://www.hospiceinfo.org), 2003.

<sup>15</sup> *Hospice Services Payment System*, Medpac, Revised September 2006, accessed via internet at [http://www.medpac.gov/publications/other\\_reports/Sept06\\_MedPAC\\_Payment\\_Basics\\_hospice.pdf](http://www.medpac.gov/publications/other_reports/Sept06_MedPAC_Payment_Basics_hospice.pdf).

<sup>16</sup> *What is a Living Will?* Partnership for Caring, via the Internet at [www.partnershipforcaring.org/advance/faq\\_set.html](http://www.partnershipforcaring.org/advance/faq_set.html).

<sup>17</sup> *What is a Medical Power of Attorney?*, Partnership for Caring, via the Internet at [www.partnershipforcaring.org/Advance/faq\\_set.html](http://www.partnershipforcaring.org/Advance/faq_set.html), 2003.



## *About the Authors of Since You Care*<sup>®</sup>

*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**

**Institute**<sup>®</sup> is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market. The Institute, staffed by gerontologists, provides research, training and education, consultation and information to support Metropolitan Life Insurance Company, its corporate customers and business partners. MetLife, a subsidiary of MetLife, Inc. (NYSE: MET), is a leading provider of insurance and other financial services to individual and institutional customers.

**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**

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues.

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*This booklet offers general advice, however, it is not a substitute for consultation with an appropriate professional. Please see a health care professional, attorney, or other appropriate professional when determining how the information and recommendations discussed in this booklet apply to your specific situation.*