

The Madison-Deane Initiative

presents

**The Palliative Care Option:
Living Fully in the
Face of a Life-Threatening Illness**



Participant's Guide

Madison-Deane Initiative: Resources for Quality End-of-Life Care
A Program of the Visiting Nurse Association of Chittenden and Grand Isle Counties, VT



The Madison-Deane Initiative is a program of the Visiting Nurse Association's End-of-Life Care Services promoting quality end-of-life care through awareness, information and education for medical professionals, other care providers and the general public.

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The Palliative Care Option: *Living Fully In The Face Of A Life-Threatening Illness*

An Educational Presentation sponsored by The Madison-Deane Initiative: Resources for Quality End-of-Life Care

Thank you for your interest in this presentation. The Madison-Deane Initiative, which began in 1997, is committed to providing educational information and resources related to quality end-of-life care. The content of this presentation is intended to increase awareness about Palliative Care, and to create a dialogue both within and between the healthcare community and the community at large.

Our goal is to:

- Provide a basic understanding of Palliative Care.
- Offer opportunity for dialogue both within and between the healthcare and the lay communities.
- Create expectations for quality care when facing a life-threatening illness.
- Reinforce the practice of “whole person care.”

If you would like more information, or have a group that would benefit from this program, please contact:

The Madison-Deane Initiative
Visiting Nurse Association
1110 Prim Road
Colchester, VT 05446
802-860-4419
www.vna-vermont.org

If you or a family member are in need of clinical services from the Hospice or Palliative Care Program at the VNA, please call (802) 658-1900.



Visiting Nurse Association of Chittenden and Grand Isle Counties Comparison of Palliative Care and Hospice Services

Topic	Palliative Care	Hospice
Objectives of Care	Symptom control in the face of life-threatening illness.	To provide dignity and quality during the last months of life.
Diagnosis	Must have a life-threatening illness.	Must have a life-threatening/terminal illness.
Life Expectancy	No requirement.	Less than six months.
Caregiver	None required; importance increases if goal is to remain at home.	Must have primary caregiver or caregiving system identified; available to provide care as needed.
Treatment	Aimed at pain and symptom control; may receive life-prolonging treatment.	Aimed at pain and symptom control; focus is on comfort care; treatment is not life prolonging.
Homebound Status	Homebound status required by Medicare and some other insurance companies.	* Homebound status is not required.
Skilled Nursing Visits	Visits as indicated by plan of care. There must be a skilled nursing need based on medical necessity. Focus on symptom management.	Visits as indicated by plan of care. Frequency of visits increases or decreases based on control of symptoms and change of functional status.
Licensed Nursing Assistant Visits	As indicated by functional assessment; supervision by palliative care nurse.	As indicated by functional assessment; supervision by hospice nurse.
Social Work Visits	Coverage determined by an individual's insurance plan.	As indicated by the doctor's referral. Hospice Team assessment and stated in plan of care.
Chaplain Visits	Spiritual needs identified and referred to local sources as needed or an "as available" basis..	*Visits by Hospice Chaplain and/or coordination with own clergy.
Volunteers	Not offered at present time.	* Trained hospice volunteers available.
Medications Covered	Coverage varies with insurance policy.	* Medications covered that are related to terminal diagnosis.
Medical Equipment	Coverage varies with insurance policy and medical necessity.	* Medical equipment covered related to terminal diagnosis (commode, hospital bed, etc.).
Emergency Care	24 hour on-call coverage. Plan for emergency needs developed with patient and family.	VNA Hospice is available 24 hours/day; 7 days/week.
Bereavement Care	Usually not covered; exceptions made on an individual basis.	* Bereavement support for family for up to one year following the death.

* Specific benefits of hospice care

Living Fully in the Face of a Life-Threatening Illness

Guide for Participants

Often, the questions and uncertainties of a life-threatening illness are not fully realized until we, or someone we know, have been confronted with such a diagnosis. This 17-minute video is intended to serve as a catalyst for meaningful dialogue and discussion about the benefits of Palliative Care. We hope the information contained within these handouts will improve your understanding of Palliative Care, both in its practice and as a philosophy of care.

PALLIATIVE CARE is comprehensive care that is offered to individuals and their families as they experience the challenges of living with a life-threatening illness. Palliative Care provides whole person care for the body, mind and spirit. By providing hope, comfort and support, a skilled Palliative Care team can help guide patients and families as they make the transition through the changing goals of care while ensuring the best quality of life possible.

The goals of Palliative Care include:

- Management of pain and other symptoms
- Working closely with your physician
- Complementing other active treatments
- Centering care around the patient and their family
- Encouraging advance care planning

While Palliative Care services are relatively new, they can be found in a variety of settings including:

- The Patient's Home
- Assisted Living or Retirement Homes
- Hospitals
- Nursing Homes

Palliative Care and Hospice Care both emphasize comfort and quality of life. Hospice Care is a specific program that is available to patients when the goal of care shifts from cure to comfort, usually during the last 6 months of life, and the patient is no longer seeking life prolonging treatments.

Important Contacts for End-of-Life Care in Vermont

VNA's Madison-Deane Initiative

1110 Prim Road
Colchester, VT 05446
(802) 860-4419
www.hospicepioneers.org

Visiting Nurse Association of Chittenden and Grand Isle Counties

Hospice and Palliative Care Services
1110 Prim Road
Colchester, VT 05446
(802) 860-4410
www.vna-vermont.org

Fletcher Allen Health Care

Inpatient Palliative Care Program
111 Colchester Avenue
Burlington, VT 05401
(802) 847-0000 for general information
(802) 847-5156 Palliative Care Program
www.fach.org

Vermont Ethics Network

VEN, 64 Main Street, Room 25
Montpelier, VT 05602
(802) 828-2909
www.vtethicsnetwork.org

Hospice and Palliative Care Council of Vermont

10 Main Street
Montpelier, VT 05602
(802) 229-0579
www.vnavt.com

The Vermont Assembly of Home Health Agencies

10 Main Street
Montpelier, VT 05602
(802) 229-0579
vahha@together.net

Quill, Timothy E. *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life*. Baltimore: Johns Hopkins University Press, 1996. There are nine patient narratives that demonstrate the personal and ethical challenges of a life threatening illness.

Ray, M. Catherine. *I'm With You Now*. Bantam, 1997 (out-of-print but available on Amazon.com). A guide to help better control the journey through a life-threatening illness. Each chapter lists in bullet form thoughts and concerns that may arise.

Remen, R.N. *Kitchen Table Wisdom: Stories that Heal*. 1996 NY: Riverhead Books. Eloquent and touching, simple stories and real life parables written by someone who is a physician, therapist, professor of medicine and long term survivor of chronic illness.

Simmons, Philip. *Learning to Fall: The Blessings of an Imperfect Life*. New York: Bantam Books, 2002. In twelve essays, the author describes his search for peace in the face of life's mysteries and a life threatening illness. Poetic, philosophic, humorous yet down to earth, the book is spirit renewing.

CHILDREN

Fry, Virginia. *Part of Me Died Too*. 1995. Dutton Books. Ten graceful studies of children and teenagers in mourning, written with compassion and admiration of the resiliency of the young subjects.

Grollman, Earl. *Talking About Death: A Dialogue Between Parent and Child*. 1991 Boston. Beacon Press. This book is intended to help parents explain death to their children.

Schwiebert, Pat and DeKlyen, Chuck. *Tear Soup*. 2001. This book provides the essential, supportive message that it's okay to grieve in your own way, in your own style, and for as long as you need to grieve. The drawings are wonderfully detailed and fun for young children to explore, but the message of this book is one for readers of any age.

Varley, Susan. *Badger's Parting Gifts*. 1992. HarperTrophy. Old badger prepares for his death, leaving lessons for those who survive him. A touching, deft treatment of this complicated subject.

DEATH AND DYING

Byock, Ira. *Dying Well: the Prospect for Growth at the End of Life*. New York: Riverhead Books. 1997. A hospice physician tells the stories of twelve people of various ages and backgrounds as they move through the dying process. A good appendix has set of questions and answers to help families talk about dying, help ease symptoms, deal with doctors and the medical system and care for a dying child.

Kubler-Ross, Elisabeth. *On Death and Dying*. New York: S&S Trade, 1997. Stories of clients in their final stages of life. Designed to show how caregivers can empower patients to die on their own terms with dignity. The book also identifies the five stages of grief.

Webb, Marilyn. *The Good Death: the New American Search to Reshape the End of Life*. New York: Bantam Books, 1997. Personal narratives by patients and families about living at the end of life are integrated with an historical account of the evolution of the American way of death over the last thirty years.

The following statements will enhance my ability to receive the best health care possible when I am facing a life-threatening illness:

- I understand the importance of discussing my wishes for care with my loved ones when I am facing a life-threatening illness.
- I will complete my Advance Directives for Health Care (Living Will and Durable Power of Attorney).
- I will discuss my needs and wishes for Palliative Care with my physician.
- I will actively participate in all decisions regarding my health care.
- I have the right to request a referral to the hospital's Palliative Care Service and/or the Palliative Care Program at the VNA.
- I understand that for any life-threatening illness, Palliative Care is available to me in my home, an assisted living facility, a hospital or a nursing home.
- I expect that my pain and symptoms will be treated effectively.
- I know that my spiritual, social and/or financial concerns can be addressed when I am facing a life-threatening illness.
- I know that I can receive guidance in any of the above areas by calling Madison-Deane Initiative: Resources for Quality End-of-Life Care (860-4419).

GLOSSARY OF TERMS

ADVANCE DIRECTIVE: A statement made by a competent individual about his/her preferences for future treatment if that person is unable to make decisions at the time. "Advance Directive" is often used to describe the two forms that most states recognize as legally important - the Living Will and the Health Care Proxy (or Medical [or Durable] Power of Attorney for Healthcare). Forms vary from state to state.

ADVOCATE: A person, often a family member, who speaks with healthcare providers in support of or on behalf of a patient. This term does not refer to one who has legal authority to make decisions for another. The terms that describe this role with legal status are healthcare proxy, medical power of attorney and agent.

COMFORT CARE: Care that is focused on quality of life through pain control, symptom management, support and relief of any form of suffering. Comfort care is not cure focused.

COMPLEMENTARY THERAPY: Methods and practices of healing used in addition to mainstream medical care. Complementary therapies may include chiropractic treatment, aromatherapy, massage, music therapy, meditation, reflexology and others.

DO NOT RESUSCITATE (DNR) ORDER: A physician's explicit written instruction to healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest.

HEALING: To restore to health; to mend; to become whole again. Healing may occur physically, emotionally or spiritually, and may include feelings and relationships.

HOSPICE CARE: A program that provides quality whole person care (physical, emotional, psychosocial and spiritual) for those who are terminally ill and in the last six months of their life. Support of the patient's family and bereavement care are important aspects of the care provided.

LIFE-THREATENING ILLNESS: An illness in which medical intervention may or may not prove successful and carries a substantial possibility of premature death; an illness that confers great vulnerability.

LIVING WILL: A document stating an individual's instructions for treatment to be used when that person becomes unable to express his/her wishes for healthcare treatment.

MEDICAL POWER OF ATTORNEY: A method of giving another person legal power to make medical decisions when one is no longer able to do. The written form used to appoint a proxy is often called "Durable Power of Attorney" for healthcare decisions. A separate legal power for overseeing financial matters is called "Durable Power of Attorney for Finances."

PALLIATIVE CARE: Comprehensive care for people with a life-threatening illness.

PROGNOSIS: A prediction of the probable course and outcome a disease/illness will take.

TERMINAL ILLNESS: A disease/illness that leads ultimately to death.

PALLIATIVE CARE SUGGESTED READINGS

Albom, Mitch. *Tuesday's with Morrie*. Doubleday, 1997. A true story of a college professor with ALS who teaches his former student lessons about how to live fully while dying.

Doka, Kenneth. *Living with a Life-Threatening Illness*. 1998. Lexington Press. Offers alternative models to understanding life-threatening illness, its tasks and phases.

Dunn, Hank, *Hard Choices for Loving People*. A & A Publishers, Herndon, VA 20172. 703 707-0169, fax 703 707-0174. Website: www.hardchoices.com A short, easy to read booklet that is a practical guide to helping families and patients make decisions in the face of a life threatening illness.

Light in the Shadows: Meditations While Living with a Life-Threatening Illness. A&A Publishers (see above). A collection of thoughts and stories to help with spiritual struggles when facing a life-threatening illness.

Groopman, M.D., Jerome. *The Measure of Our Days*. Penguin, U.S.A. 1998. Described as "a spiritual journey of questioning and self awareness....a compelling portrayal of what is to be learned when life itself can no longer be taken for granted."

Groopman, M.D., Jerome. *The Anatomy of Hope: How People Prevail in the Face of Illness*. Random House, 2003. An inspiring and profoundly enlightening exploration of one doctor's discovery of how hope can change the course of illness. Groopman presents stories based on his patients and his own debilitating back injury. Through these moving if somewhat one-dimensional portraits, he reveals the role of memory, family and faith in hope and how they can influence healing by affecting treatment decisions and resilience.

Grollman, Earl. *In Sickness and In Health: How to Cope When your Loved One is Ill*. Beacon Press, 1987 (out-of-print but available on Amazon.com). Short phrases tell you it's OK to feel the way you're feeling, offer you support in meeting your family's and your own needs.

Jevne, R. and Miller, J. *Finding Hope*. 1999. Willowgreen Publishing. A wonderful means of finding hope, even in the most difficult times. Each page is a short description of how to find hope in those around you and through what you do.

Larson, Dale G. *The Helper's Journey: Working with People Facing Grief, Loss and Life-Threatening Illness*. 1993, Champaign, IL. Research Press. A tremendous resource blending appropriate research and practical suggestions for understanding yourself and being a better caregiver.

Lynn, Joanne, Harold, Joan and the Center to Improve the Care of Dying, George Washington University. *Handbook for Mortals: Guidance for People Facing Serious Illness*. New York: Oxford University Press, 1999.

Meyer, Maria. *The Comfort of Home*. 2002. Care Trust Publications. A very thorough, easy to read guide for caregivers, addressing issues from how to set up the home, financial planning, establishing a plan of care how to assist with activities of daily living, and even protection from elder abuse and fraud.