

Guide to Palliative Care Resources

For Chittenden and Grand Isle Counties, Vermont

Information for Individuals, Families and Caregivers



Madison-Deane Initiative

Changing the Face of Dying

In Collaboration with the Vermont Ethics Network and the Fletcher
Allen Health Care Community Health Resource Center

Available online at www.vnacares.org

A Publication of the Madison-Deane Initiative, a program of the
Visiting Nurse Association of Chittenden and Grand Isle Counties.



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About us....

The Madison-Deane Initiative (MDI) was formed following the death of Dr. James F. Madison, a respected and beloved local physician. Jim lived with pancreatic cancer for only four months. In deep appreciation of the care he received from VNA's Hospice of the Champlain Valley prior to his death in December of 1996, he requested that donations in his memory be made to Hospice. He hoped these resources could be used to educate both the general public and health care professionals about quality care at the end of life.

In August of 1997, Dr. Robert S. Deane, esteemed mentor in surgical intensive care to several generations of physicians and nurses, and a colleague of Dr. Madison, was also diagnosed with pancreatic cancer. He asked Joan Madison if contributions in his memory could be used to support Jim's cause.

The first James F. Madison Memorial Lecture, "Pain Control at the End of Life," was presented by Dr. Zail Berry, in September of 1997. This lecture addressing the complex challenges of pain management was followed by a series of presentations covering other aspects of care for the dying.

After Dr. Deane's death in September of 1997, a group of dedicated and passionate individuals came together and *The Madison-Deane Initiative: Resources for Quality End-of-Life Care* was born. This volunteer-based advisory council became a program of the Visiting Nurse Association of Chittenden and Grand Isle Counties in 2002. MDI works closely with other community organizations to fulfill the wishes of Drs. Madison and Deane by providing educational events and information directed toward health care providers and the general community on issues related to end-of-life care.

The mission of the Madison-Deane Initiative has further been realized by the creation of this ***Guide to Palliative Care Resources***. It is the sincere hope of the Madison-Deane Initiative that this guide will serve to inform and empower individuals as they face the many complex decisions that may lie ahead.

Collaborators...

Vermont Ethics Network

Vermont Ethics Network (VEN) is an educational non-profit organization. Its purpose is to increase understanding of ethical issues, values and choices in health care by engaging the public in dialogue about these issues.

VEN publishes and distributes the booklet *Taking Steps to Plan for Critical Health Care Decisions*. The booklet contains Vermont’s legal advance directive forms: the Terminal Care Document (often referred to as the “living will”) and the Durable Power of Attorney for Health Care, which allow for appointment of an agent to make health care decisions for incapacitated adults.

VEN plans and conducts workshops on a variety of subjects dealing with ethical choice in end-of-life care as well as topics as diverse as health care privacy, genetic testing and technology and doctor/patient communication. Most recently, VEN has published a booklet called *When You Must Make Medical Decisions for Someone Else*. VEN is not an advocacy organization, but rather one that exists to promote greater dialogue about health care issues that involve choices at all levels.

For more information, call (802) 828-2909 or visit the website: www.vtethicsnetwork.org

**The Community Health Resource Center
Office of Community Health Improvement
Fletcher Allen Health Care**

If knowledge is power, the Community Health Resource Center affords the power of health knowledge to everyone. The Community Health Resource Center at Fletcher Allen Health Care can help individuals get the answers they need to health questions.

The Community Health Resource Center is staffed by a librarian who can assist patients, their family members and community members in their health-related research. Patrons may use either the computers at the resource center or ask the librarian to conduct a search for them. The results can be e-mailed, faxed or sent via US mail to the patron.

The Resource Center serves thousands of individuals each year, offering free, easy, guided access to the world’s most accurate health-related information. Stop by the Resource Center at Fletcher Allen Health Care, visit the website at www.fahc.org/Health_Improvement/Resource_Center/resource_center.html, or call (802) 847-8821 for more information.

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I. Palliative Care Defined

The World Health Organization defines Palliative Care as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other physical symptoms, and of the psychological, social and spiritual problems of patients is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.”¹

Palliative care:

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement

The word “palliative” is derived from the Latin word for a long scarf worn once by medieval priests, the “pallium.” Compassionate clergy would customarily remove this extravagant accessory and wrap it around those they encountered who were in need of warmth. The gift of the pallium held other symbolic values that always referenced the care of others. While the gift of a pallium did not chase away the cold, it provided relief from it. Centuries later, we reflect the spirit of this word as we employ it to refer to medical care that focuses on comfort, which does not seek to cure but to care for the body in pain. When people choose palliative care, they do so for a variety of reasons. Chiefly, they recognize the value of comfort care.

Palliative Care:

- Can be provided from the point of diagnosis of a life-threatening, chronic or terminal illness—not just in the last days or weeks of a person’s life
- Is an approach to care that is foremost patient-centered and addresses patient needs within the context of family and community
- Assists patients in establishing goals of care, clarifying priorities, promoting informed choices and providing an opportunity for negotiating a care plan with providers
- Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patient and family
- Uses a team approach to caring for a patient and his or her family with attention to the physical, spiritual, psychosocial and emotional aspects of living with a life-threatening condition
- Allows active treatment, such as chemotherapy, to continue

Palliative care means taking care of the whole person—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.

¹ www.hopkinsmedicine.org/palliativecare.html

II. An Explanation of the Guide

If you or a loved one have a life-threatening illness, you may be wondering for the first time how to plan for needed health care and support services, how to make decisions regarding complex medical, financial and legal considerations, or how to cope with the realities of living with a chronic or life-threatening condition. You may be uncertain about what questions to ask or what resources are available.

This guide has been created to provide information about decisions that you may have to face, and the choices available to patients and their families when confronted with a life-threatening illness. Further, it is the goal of this guide to assist individuals, families and caregivers in locating services and resources to improve the quality of life for patients and their families. It is our hope that the information provided in this guide will enlighten and empower everyone with the knowledge necessary for informed decision-making.

Finding us on the Web

In order to provide you with the most current information possible, this *Guide to Palliative Care Resources* can also be found on the internet as a .PDF file at www.vnacares.org, where it will be updated as new services and information become available.

Additional Copies of the Guide

If you would like additional copies of this *Guide to Palliative Care Resources*, please contact the Madison-Deane Initiative: Resources for Quality End-of-Life Care at (802) 860-4419.

III. Taking Control: Talking with Physicians, Family and Caregivers

Living with a life-threatening illness is always difficult. Often many complex medical, legal, financial and emotional challenges and decisions need to be made.

The following questions arise frequently for people facing a life-threatening illness. More specific information on the issues addressed below can be found throughout the guide.

Patient Questions

Q *What do I need to think about or address as I face the diagnosis of a life-threatening illness?*

Medical

Are you working with health care providers you trust, who listen to your questions and concerns, and provide you with enough information to make informed decisions?

Advance Care Planning

Have you had detailed conversations with those you love about your values, preferences and wishes, to help you make decisions about care that you do and do not want? Have you appointed a healthcare agent by completing a Durable Power of Attorney for Healthcare and signing it along with two witnesses?

Legal

Have you completed a will? Does your family know where it is? Do they know where you keep your other important papers and valuables? Have you talked with a lawyer about other issues, such as a durable power of attorney for financial issues?

Financial

Are you familiar with the health benefits available to you through your private insurance plan, Medicare or Medicaid? Do you have a list of all insurance plans (health, life and disability) and does your family know where to find the list?

Support

Are you using your support system of family and friends for physical (assistance in caregiving) and emotional support? Are you aware that support can be found through support groups or faith-based institutions?

Q *How can I communicate effectively during visits with my (or my loved one's) doctor?*

- Keep a list between appointments of issues you want to report and questions you want to ask. Take the list with you to appointments.
- Tell your doctor at the beginning of the appointment that you have a list of issues to discuss so that you won't run out of time before getting all of your questions or concerns answered.
- If you haven't received or don't understand an answer to your question, ask it again, or ask for a simpler explanation.
- If you have many concerns, ask to schedule a longer appointment.
- When you are likely to address emotionally difficult issues or those about which significant medical decisions need to be made, take someone with you to the appointment. If you don't have a family member or friend to go with you, let your doctor know you would like to tape record the session and take along a tape recorder with you.

Q *What specific questions are helpful to ask the doctor or nurse?*

- What are my treatment options, and what are the pros and cons of each of these?
- What are the typical problems that could arise with this illness over time?
- Are there symptoms I should be particularly concerned about?
- What support services are available?
- Whom should I talk to for comprehensive information on services available to help with care?

Family and Caregiver Questions

Q *It is difficult to begin conversations with my loved one about his/her wishes and feelings about end of life care. What are sensitive ways to approach this conversation?*

- "I want to make sure you always get the best care possible, or the type of care that you want, so these are the things we should talk about..."
- "I've been wondering if there are things that you want me to know about your beliefs or wishes that would help me be sure you get the care you want..."

- "Since none of us knows what the future will bring, there are some things that I think we should talk about..."
- "If I am ever in a position where I need to make some healthcare decisions for you, I'll be best able to take care of you if I really know what you want..."

Q *What are the signs that it is time to get more help in caring for my loved one, or even to think about living situations where more care is provided?*

- It seems like no matter what you do, it isn't enough.
- You are not sure you can keep your loved one safe.
- Family relationships are becoming problematic due to the stress of care giving.
- You are exhausted or developing frequent illnesses yourself.
- You feel generally overwhelmed.
- You do not have time for yourself.
- Caregiving responsibilities are controlling your life to an unacceptable degree.
- You are not taking care of yourself or are acting in self-destructive ways, such as drinking too much alcohol, over- or under-eating, or not sleeping.

Q *How do I help my children as we face a life-threatening illness in the family?*

- Give children simple, honest explanations appropriate to their age.
- Allow children to participate in caring for their ill loved one in ways appropriate to their age.
- Assure children that they are safe, and that they will be cared for.
- Assure children that there is nothing they did to cause the illness, and there is nothing they can do to cure it. Tell them there is much they can do to offer caring and comfort to the ill person they love.
- Help children express their feelings in appropriate ways.
- Seek help from others.

member or primary caregiver by addressing pain and symptom management on a continuous basis and by providing comprehensive support to the patient and family or significant others in their chosen location – home or facility – through the dying process, including bereavement. Bereavement services for the family or significant other can continue for up to a year after the death of a hospice patient.

Comprehensive hospice care is covered in Vermont under Medicare, Medicaid and other third party payors.

Palliative Care and Hospice services are available to children as well as adults.

Resources

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

1110 Prim Road
Colchester, VT 05446
(802) 860-4410
www.vnacaes.org

- Palliative Care Program
- Hospice of the Champlain Valley
- Camp Knock Knock (Family Bereavement Camp)
- Madison-Deane Initiative: Resources for Quality End-of-Life Care
- Vermont Respite House
- Maternal and Child Health's Pediatric Supportive Care Service

Vermont Respite House

99 Allen Brook Lane
Williston, VT 05495
(802) 879-0943
www.vnacaes.org

- A home-away-from-home for terminally ill individuals. Vermont Respite House provides room, board and personal care as needed. VNA's Hospice staff provide case management and medical services.

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.fahc.org

- The Palliative Care Team provides consultative services to any person with a life-threatening medical condition who might benefit from attention to specific needs affecting their quality of life.

American Cancer Society Hope Lodge

237 East Avenue
Burlington, VT 05401
(802) 658-0649
www.cancer.org/hopelodge

- Hope Lodge provides free, comfortable, homelike lodging for cancer patients and their families who must travel far from home for cancer treatment. It is located next to Fletcher Allen Health Care's MCHV Campus.

Related Health Care and Support Services

Living with a life-threatening medical condition or caring for an ill loved one is challenging and emotionally draining. Meeting the physical and emotional needs of a loved one in times of illness, combined with the demands of daily living, can often become overwhelming. Many services are available to help those with life-threatening medical conditions and their caregivers. You will find some of these services described below. Eligibility information can be found by contacting the service directly for more information.

Home Health and Home Care Services

Traditional home health services provide short term, recuperative care and support for patients in their homes. However, many agencies provide a wide range of high-quality care for people of all ages with acute and long-term illnesses. Home care involves patients and their families and includes a comprehensive plan of treatment and rehabilitation. The treatment plan is determined through collaboration with the patient, the family, the nurse and the physician.

Home care services can include nursing services, licensed nursing assistants (home health aides), personal care, homemaker assistance, respite care, physical therapy, speech and occupational therapy, medical social service, Medicaid Waiver (means of providing personal care attendant for those who qualify) and other related services. Home care is paid for by a variety of sources: private and public insurance programs, including Medicare and Medicaid, and individuals or their families. Vermont home health agencies accept contributions from individuals, corporations, towns and cities and the United Way. For those whose insurance does not cover home care, all Vermont agencies offer sliding scale fee schedules so that a family need pay only what it can afford.

Adult Day Programs/Respite Care

Certain types of illnesses, such as Alzheimer's disease, may require more supervision or stimulation than is available at home. Adult day programs provide enriching activities and help with personal and health care needs for individuals of all ages in a safe, home-like setting. Nursing and personal care services are provided on-site, along with activity specialists and dedicated volunteers. Adult day programs can also provide a much-needed break for family caregivers.

Private Home Care Services

Some agencies provide a wide variety of private, or "fee for service," in-home services which allow people to obtain the care they need in extended blocks of time. The care plans are flexible to meet individual needs and preferences. These services are personally designed for people who are not eligible for home health services traditionally covered by Medicare or other health insurance policies. They are also used by people seeking to supplement the services covered by their health insurance policies.

This type of care can be provided in the home, including private residences, apartments, shared housing and assisted living facilities. Care is usually available 24 hours a day, seven days a week with a minimum visit of three hours. Private home care services can include homemaker services, personal care, nursing care, companionship, transportation and respite for family members and other caregivers.

Resources

Visiting Nurse Association of Chittenden and Grand Isle Counties

1110 Prim Road, Suite 1
Colchester, VT 05446
(802) 658-1900
www.vnacares.org

- *Adult Home Care Program:* Nurses work as case managers to coordinate patient-centered home health services.
- *Community Care Connection Private-Duty Nursing:* This program provides a wide variety of private in-home services which allows people to obtain the care they need in extended blocks of time (802-860-4440).
- *Adult Day Program:* Community-based day program for elders, adults with disabilities and individuals with Alzheimer's or other memory disorders.

Champlain Valley Agency on Aging

The Chace Mill
1 Mill St.
Burlington, VT 05401
Mailing Address:
PO Box 158
Winooski, VT 05404
(802) 865-0360
www.cvaa.org

- Providing information, referral and advocacy services for people 60 and older and younger adults with disabilities.
- Meals on Wheels available.

The Memory Center

Neurology Health Care Service
Fletcher Allen Health Care-Fanny Allen Campus
Medical Office Building
792 College Parkway, Suite 205
Colchester, VT 05446
(802) 847-1111 or (800) 358-1144
www.fahc.org

Professional Nurses Services

94 West Canal Street
Winooski, VT 05404
(802) 655-7111
www.pronurses.com

- Provides nursing IV and infusion services, licensed nursing aides for personal care services, health care assistants, case management services and life skills aides serving people with traumatic brain injury.

Armistead Caregiver Services

145 Pinehaven Shores Road, Suite 2151
Shelburne, VT 05482
(802) 288-8117
toll free 1-866-284-1912
www.armisteadinc.com

- Provides personal care, bathing, companion care, medication reminders, meal preparation and homemaker services.

HomeShare Vermont

412 Farrell St.
So. Burlington, VT 05403
(802) 863-5625
www.homesharevermont.org

- Provides home sharing, live-in caregiving and hourly caregiving.

Home Instead Senior Care

41 IDX Drive, Suite 230
South Burlington, VT 05403
(802) 860-4663

- Non medical care only.

Extended Care Facilities

As a person's health declines, it may be inadvisable or impossible to continue living at home. There are several types of extended care facilities that provide different levels of care for residents.

- **Nursing Homes**

Nursing homes provide long-term care for elderly, chronically ill and disabled individuals. Services include nursing care, personal care and rehabilitative care, such as physical, occupational and speech therapy. An increasing number of nursing homes also provide specialized services for people with Alzheimer's disease and other forms of dementia. Most nursing homes contract with Hospice programs to provide Hospice services to residents.

Nursing homes may also provide short-term care for patients who have been hospitalized and need a brief period, usually up to a month, for rehabilitation or medical monitoring before returning home. Finally, some nursing homes provide respite care to enable caregivers to have time off.

- **Assisted Living/Residential Care**

Assisted living residences provide resources for the elderly or disabled individuals who need more supervision and services than living in a private home can provide, but do not need 24-hour nursing or rehabilitative care. Assisted living residences generally offer a range of services including meals, social activities, assistance with personal care, coordination of healthcare services, medication management and emergency response. Assisted living can be found as freestanding residential complexes or within continuing care retirement communities that provide multiple levels of residential support and care.

- **Vermont Respite House**

Vermont Respite House was founded in 1991, as a home-away-from-home for people with terminal illness. This home for the terminally ill uses the expertise of skilled VNA caregivers and volunteers who are dedicated to providing a warm, caring, and personalized environment for people in the final stages of life. Vermont Respite House is a unique model in health care today. Neither a hospital, nursing home nor institution, this is truly a supportive home-away-from-home for its residents and their family and friends. Vermont Respite House is the first, and currently only, Medicare-certified inpatient hospice resident in Vermont.

Resources

Vermont Respite House

99 Allen Brook Lane
Williston, VT 05495
(802) 879-0943
www.vnacares.org

- A home-away-from-home for terminally ill individuals. Vermont Respite House provides room, board and personal care as needed. VNA's Hospice staff provide case management and medical services.

State of Vermont

Agency of Human Services
Department of Aging & Disabilities
103 South Main St.
Waterbury, VT 05671
(802) 241-2400
www.dail.state.vt.us

- Provides a listing of all Nursing Home, Assisted Living and Residential Care Facilities

Frymoyer Community Health Resource Center

Fletcher Allen Health Care
Level 3, Main Pavilion
Ambulatory Care Center
111 Colchester Avenue
Burlington, VT 05401
Hours: Mon-Thu 9 am - 5:30 pm, Fri 9 am - 5 pm
(802) 847-8821
(802) 847-3013 (fax)
ResourceCenter@vtmednet.org
www.fahc.org/chrc

- The Community Resource Center provides current listings of all support groups in the local area and other consumer health information.

V. Relevant Palliative Care Information

Advance Care Planning

Advance Directives and Related Resources

It is helpful to loved ones and increases your autonomy to communicate in advance what kind of medical care and related support services you desire to have near the end of life.

Advance Directives are documents that are prepared in advance which express your wishes and desires about health care. There are two types:

Terminal Care Document (Living Will) is a simple one-page form that expresses your wish to die a natural death with just comfort care measures and other forms of pain and symptom management when your condition is terminal and will result in death in the near future;

Durable Power of Attorney for Health Care is a document in which you can appoint someone to speak for you, called a *healthcare agent*, in choosing health care options when you are in a critical care situation (not just terminal) and can no longer speak for yourself.

It is important to think about and discuss these documents with your family and loved ones before you are actually critically ill or dying. Worksheets have been designed to help you consider what type of care or treatment you might want, based on your values and beliefs. You may also want to consider an **organ donor card** specifying your willingness to donate some or all suitable organs and tissues at the time of your death.

Advance Directives can be as general or specific as you wish, but to the extent that you can share specific feelings about life-sustaining treatments like breathing machines, or artificial feeding and hydration through tube feeding, this will be very helpful for your health care professionals and family to know in advance. If you have a chronic or progressive illness, it is important to inform yourself of the likely changes you will experience over time and to know and share ways in which this influences the kind of health care you may want at different stages in the process.

Be sure that your advance directives are properly filled out, signed and witnessed and that your *healthcare agent*, your family and health care professionals have copies. It is a good idea to send a copy to your nearest hospital and ask that it be made a part of your *permanent medical record* there.

More specific medical care orders such as ***Do Not Resuscitate Orders*** (sometimes called “DNR” or “DNAR” Orders) need to be signed by your physician and placed in your chart or given to you to post at home before they can be honored.

A new publication of the Vermont Ethics Network has been designed to help health care agents, family members and guardians with understanding how to make medical decisions for a loved one or someone for whom they are now responsible. It is called *When You Must Make Medical Decisions for Someone Else*.

Resources

Vermont Ethics Network

VEN, 64 Main Street, Room 25
Montpelier, VT 05602-2951
(802) 828-2909
www.vtethicsnetwork.org

- *Taking Steps to Plan for Critical Health Care Decisions*
- *When You Must Make Medical Decisions for Someone Else*

Champlain Valley Agency on Aging

The Chace Mill
1 Mill Street
Burlington, VT 05401
Mailing Address:
PO Box 158
Winooski, VT 05404
(802) 865-0360
www.cvaa.org

- Senior Helpline: 1-800-642-5119
- Case managers and volunteers provide assistance and support with a variety of health and social service needs and can assist with advance care planning and the preparation of advance directives.

Department of Disabilities, Aging, and Independent Living

103 South Main Street
Waterbury, VT 05671
(802) 241-2663

- Houses the program called the **Office of Public Guardian**.
- The Department oversees the *Guardianship Services Program* for adults with developmental disabilities.

Pain and Symptom Management

People with a life-threatening condition may have fears or concerns about pain or other symptoms associated with their illness, particularly as their disease progresses. However, with the recent and continuing advancements in treatments, pain and other distressing symptoms can be minimized. For those with pain, there are many different kinds of medicines, ways to receive the medicine, and non-medicine methods that can relieve the pain people may have.

Pain Management

Unrelieved pain due to certain illnesses or their treatments can cause needless suffering and diminish an individual’s quality of life. Pain can lead to decreased physical activity, disrupt appetite and sleep, and affect a person’s emotional well-being. It can also weaken the immune system and interfere with one’s ability to heal. Fortunately, most pain associated with life-limiting illness can now be adequately controlled through the appropriate use of a variety of pain medications or a combination of medications and non-drug therapies.

Good pain management relies on good communication between the patient and the caregiver. Patients must:

- Tell the physician or nurse about their pain, where it hurts and what it feels like
- Describe how it affects their ability to do certain things
- Discuss how well the treatments are working
- Patients must also speak up about any fears or concerns they may have regarding pain and/or pain treatments

Successful palliative care with good pain management occurs when health care professionals are knowledgeable and skilled in the strategies of managing pain, and patients and families are diligent about communicating with the caregiver about their fears, needs and concerns.

Patients with pain should not accept pain as a normal part of having an illness or undergoing a treatment. When people are free of pain, they can sleep and eat better, enjoy the company of family and friends, and continue with their work and hobbies.

Other Symptoms

Some illnesses and their treatments can cause symptoms other than pain that are equally distressing. These symptoms may include shortness of breath or difficulty breathing, anxiety, depression, weakness, fatigue, altered mental state, constipation, diarrhea, nausea and vomiting. These symptoms may greatly affect a person’s quality of life.

Just as with pain management, it is important to describe any of these symptoms to the individual's health care provider, since most can be minimized or controlled.

Resources

Fletcher Allen Health Care Pain Management Center

62 Tilley Drive
South Burlington, VT 05403
(802) 847-3737
(802) 847-2965 fax
www.fahc.org

- A comprehensive anesthesiology-based evaluation and treatment program for patients with acute, chronic and cancer related pain.

Fletcher Allen Health Care Inpatient Palliative Care Program

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

- The Palliative Care Team provides consultative services to any person with a life-threatening medical condition who might benefit from attention to specific needs affecting their quality of life.

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

1110 Prim Road
Colchester, VT 05404
(802) 860-4410
www.vnacares.org

- *Palliative Care Program*: provides skilled management of pain and other symptoms

MindBody Medicine Clinic

1 South Prospect Street
Burlington, VT 05401
(802) 847-2673

- Provides a support group which meets 90 minutes weekly for 11 weeks, one time a week for 90 minutes. The group uses cognitive behavioral therapy.

American Cancer Society

Vermont Office
121 Connor Way Suite 240
PO Box 1460
Williston, VT 05495
(802) 872-6300
www.cancer.org

- “*I Can Cope*” program for addressing pain issues, resources of books, pamphlets and videos, educational information through the national call center 1-800-ACS-2345

Frymoyer Community Health Resource Center

Fletcher Allen Health Care
Level 3, Main Pavilion
Ambulatory Care Center
111 Colchester Avenue
Burlington, VT 05401

Hours: service hours are expanding. Call for specific times

(802) 847-8821
(802) 847-3013 (fax)
ResourceCenter@vtmednet.org
www.fahc.org/chrc

- Provides health information, services and resources for Chittenden and Grand Isle Counties.

Complementary and Alternative Medicine (CAM)

Research indicates that the use of complementary and alternative therapies is increasing. Complementary and alternative medicine (CAM), also referred to as integrative medicine, includes a broad range of healing philosophies, approaches and therapies. A therapy is generally called *complementary* when it is used *in addition to* conventional medical treatments; it is often called *alternative* when it is used *instead of* traditional medical treatment.

Integrative medicine, as defined by the National Center for Complementary and Alternative Medicine (NCCAM), combines traditional medical therapies and CAM therapies for which there is some high quality scientific evidence of safety and effectiveness.

NCCAM classifies CAM therapies into five general categories:

- **Alternative Medical Systems:** These are traditional practices in medicine that are recognized by other cultures. One common therapy today is acupuncture, which is part of traditional Eastern medicine.
- **Mind-Body Interventions:** Mind-body medicine uses a variety of techniques designed to enhance the mind's capacity to affect bodily function and symptoms. Such techniques include meditation, prayer, mental healing, and therapies that use creative outlets such as art, music or dance.
- **Biologically-Based Therapies:** These treatments include herbal medicine, dietary supplements and other biological therapies.
- **Manipulative and Body-Based Methods:** These methods are based on manipulation and/or movement, including chiropractic and massage therapies.
- **Energy Therapies:** These techniques involve the theory and use of energy fields from internal or external sources.

Questions when considering CAM Therapy

While some scientific evidence exists regarding the effectiveness of various CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies. Therefore, it is important to ask the following questions when considering CAM therapy:

- Has there been research on the safety and effectiveness of this treatment?
- What are the potential side-effects?
- What are the risks associated with this CAM therapy?
- What are the benefits that can be expected from this therapy?
- Will the therapy interfere with conventional/traditional medical treatments?
- Is the therapy covered by health insurance?

Resources

National Center for Complementary and Alternative Therapies

National Institutes for Health
9000 Rockville Pike
Bethesda, MD 20892
1-888-664-6226
www.nccam.nih.gov

National Foundation for Alternative Medicine

1325 G Street, Suite 500
Washington, DC 20005
(202) 463-4900
www.nfam.org

Alternative Medicine Foundation: www.amfoundation.org

Office of Cancer for Complementary and Alternative Medicine (OCCAM):

www.cancer.gov/cam/

American Chiropractic Association: www.amerchiro.org

Vermont Secretary of State Office of Professional Regulation

National Life Building
North FL2
Montpelier, VT 05620-3402
888-287-5006
www.sec.state.vt.us

Legal Issues

When a person is faced with a life-threatening illness, concerns about legal issues may arise. Issues could include medical decisions, financial decisions and/or caring for dependents. There is also the possibility that a person may reach a point where they are unable to make or communicate decisions for themselves. Planning in advance for these circumstances will give greater assurance that a person's health care choices and financial decisions will be carried out as they wish.

Legal Options for Decision-Making on Behalf of a Living Person

Healthcare Proxy

A healthcare proxy or Durable Power of Attorney for Health Care (an advance directive) is a document in which a person appoints an *agent* (surrogate) and an *alternate agent*, to make medical decisions in the event, for any reason or at any time, they are unable to do so. A healthcare proxy, medical proxy or Durable Power of Attorney for Health Care is not the same thing as a living will which does not authorize a person to act as the individual's agent. Living wills are used in cases of terminal illness and do not delegate legal authority to an agent for healthcare decisions. *Living wills are used only in cases of medically certified terminal illness, and do not delegate authority to an agent for healthcare decisions.*

Powers of Attorney

A common method of planning for incapacity is to use powers of attorney. These are popular for several reasons. First, powers of attorney can be drafted well ahead of when they are needed. People who draft powers of attorney can feel confident that they have planned for the future. Second, they are convenient and inexpensive because they can be done without going to court. Third, powers of attorney are an alternative to involuntary guardianship. A power of attorney allows a person to choose how their financial affairs will be handled and give specific instructions for about what they want done.

A power of attorney is a legal document that allows one person to give another person the authority to handle financial and personal decisions. The person who appoints the agent is called the "principal." The person given the authority to act is known as the "agent" or "attorney-in-fact." A power of attorney can authorize an agent to perform a single act or to perform a variety of acts for a long period of time or indefinitely. The power of attorney document defines the extent of the agent's authority. When an agent acts within the authority specified by a power of attorney, his or her actions are legally binding on the principal just as if the principal took the same action.

Durable Power of Attorney

A Durable Power of Attorney (DPA) is a legal document that allows a person (the *princi-*

pal) to give authority to another person (an *agent* or *attorney-in-fact*) to make financial/legal decisions and financial transactions on the individual's behalf. It is called "durable" when, by its terms, it remains effective even if the principal becomes incapacitated or mentally incompetent. If a power of attorney is not durable, the authority of the agent automatically ends when a principal becomes incapacitated and is no longer capable of handling his or her own affairs. *If an individual is executing a power of attorney to allow the agent to handle their financial affairs or personal decisions for when they are unable to do so themselves, they need to be sure to create a "durable" power of attorney.* Under Vermont law, in order to create a durable power of attorney a person's power of attorney document must contain the following or similar words: "This power of attorney shall not be affected by the subsequent disability or incapacity of the principal."

Ordinarily, a DPA is effective on the day that it is signed or executed. However, the appointment of the agent can be structured so that it doesn't go into effect until the principal actually becomes incapacitated or mentally incompetent. This is referred to as a "springing" DPA. A good example is the Durable Power of Attorney for Health Care.

Guardianship

A guardian is someone who has the power and responsibility to help people with their personal, medical and financial affairs when they can no longer manage on their own. There are two different ways to initiate a guardianship. A person can ask the probate court to appoint someone to help them manage their affairs. This is called a **voluntary** guardianship. Or, someone who is concerned about their welfare can ask the probate court to appoint a guardian to make decisions for them. This is called an **involuntary** guardianship. In either case, the guardian can have either **total** power to make all decisions for a person or **limited** power to make decisions about specific aspects of their life. For example, a limited guardian may only have the power to handle their finances or to decide where they will live.

For more information about guardians and health care decisions, one may want to consult that section of the Vermont Ethics Network's booklet *When You Must Make Medical Decisions for Someone Else*.

Conservatorship

If a person has not taken any advance care planning action, a court may appoint an agent to make decisions on their behalf. A conservator is a court-appointed agent responsible for only financial decisions. Usually a court will only appoint a guardian or conservator after a person is unable to make decisions or communicate their own wishes, and have failed to put into place or have revoked a healthcare proxy or DPA.

Resources

Vermont Ethics Network,

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

- *Taking Steps to Plan for Critical Health Care Decisions*
- *When You Must Make Medical Decisions for Someone Else*

Champlain Valley Agency on Aging

The Chace Mill
1 Mill Street
Burlington, VT 05401
Mailing Address:
PO Box 158
Winooski, VT 05404
(802) 865-0360
www.cvaa.org

- Senior Helpline: 1-800-642-5119
- Case managers and volunteers provide assistance and support with a variety of health and social service needs and can assist with advance care planning and the preparation of advance directives. Meals on wheels available.

Department of Aging and Independent Living (DAIL)

(802) 241-2401
www.dail.vermont.gov

- The Department houses the program called the **Office of Public Guardian** (802-241-2663).

Department of Mental Health

(802) 652-2000
www.healthvermont.gov

- The Department oversees the *Guardianship Services Program* for adults with developmental disabilities.

Agency of Human Services

Call 211 (toll-free) from anywhere in Vermont for community, regional, state and faith based human services information.

Vermont Long-Term Care Ombudsman Project

Vermont Legal Aid
264 North Winooski Ave.
Burlington, VT 05401
Mailing address:
PO Box 1367
Burlington, VT 05402
1-800-889-2047

- Project provides individual advocacy to people in nursing homes and residential care homes. The goals are to educate consumers and providers on long-term care (LTC) issues and monitor regulations and laws that might affect LTC consumers

Adult Protective Services

Department of Aging and Disabilities
Division of Licensing and Protection
103 South Main Street
Waterbury, Vermont 05671-2306
1-800-564-1612
(802) 241-2354

Legal Services Lawline of Vermont, Inc.

264 N. Winooski Ave.
Burlington, Vermont 05401
(802) 863-7153 or 1-800-639-8857

Senior Citizens Law Project

Vermont Legal Aid, Inc.
264 N. Winooski Ave
Burlington, VT 05401
802-863-5620
1-800-889-2047

Lawyer Referral Service

1-800-639-7036
jspoone@vtbar.org
Open Monday-Friday, 8 am - 4 pm

Spirituality

The decision to concentrate on comfort care propels a patient and family into the last chapter of a life-story. This can be a useful time for “tying up loose ends” in terms of financial and other matters, but importantly, it can also provide a family and patient with relational and spiritual opportunities.

The distinction between the concepts “spirituality” and “religion” is important; people who do not consider themselves religious still have spiritual needs as they face death. “Spirituality” can be defined as the way in which one makes meaning of life, develops a world view, and adopts values and principles which have given one’s life impetus and energy. “Religion” is a way in which one may express his or her spirituality by involvement in a faith community, and through various rituals and practices. So, even the person who is not “religious” will likely be dealing with his or her spirituality during the course of a life-threatening illness.

This can be a time to recall the wealth of experiences shared by the patient and his or her family and friends, including the humorous and even ridiculous moments remembered with laughter. Story-telling also can be an important way to connect a person to the meanings and values of his or her life journey. Some may see this as more explicitly involving a spiritual perspective and additionally, for some, it will be an opportunity to participate in appropriate religious rituals or sacraments to celebrate life and anticipate what might lie beyond this life.

For family and friends, story-listening can be a precious gift of concentrated attention to the person near the end of life. This time also can be used to heal injuries and rifts which may have occurred during life’s journey. The initiative for amends may come from the patient or others wishing to “set things right” with the patient “while there is still time.” Forgiveness and reconciliation can heal old wounds and contribute to a sense of peace and closure for all.

There are times when people are not alert enough to interact with family and friends due to their illness or the sedative effect of painkilling medication. Even under such circumstances, the reminiscing of family members around the bedside, their verbal expressions of love and caring (spoken in normal tones, not whispers), and for the explicitly religious, offering of prayers and reading of psalms, poetry or other meaningful writings can surround the unconscious patient with a level of caring up to the very moment of death.

Resources

Visiting Nurse Association of Chittenden and Grand Isle Counties

End of Life Care Services
1110 Prim Road, Suite 1
Colchester, VT 05446
(802) 860-4410
www.vnacares.org

- Hospice Chaplain Services

Fletcher Allen Health Care Pastoral Care (Spiritual Resource Center)

Baird 223 MCHV Campus
111 Colchester Avenue
Burlington, VT 05401
(802) 847-2770 (office); (802) 847-0000 (on call)
Chaplain on-call 24 hours/day, 7 days/week
www.fahc.org/Spiritual/index.html

- Chapels at Fletcher Allen Health Care are located on the MCHV Campus on McClure 1, across from the Pharmacy, and on the Fanny Allen Campus between the Convent and the Hospital. Roman Catholic and Interfaith services are held on a regular basis.

Northeast Center for Holistic Medicine

501 Riverway Place
Bedford, NH 03110
(603) 647-0600
www.northeast-holistic.com

- providing comprehensive and individualized natural healthcare that combines ancient traditions and modern scientific discoveries.

Living with Losses

Receiving the diagnosis of a life-threatening illness can often trigger the feeling of loss. Besides any physical loss associated with the disease, there can be losses associated for individuals and their families as they think about the future, as they start a new course of treatment or when they perhaps discover that a treatment is not working the way they had hoped. Losses are individual so it is difficult to list those that may be present with illness. Some losses may be temporary but they are still difficult.

Grief is a normal and natural response to loss. Many people associate grief only with the death of a loved one but grief can be acutely felt with other, less traumatic, losses. Grief is the individualized response to real, perceived or even anticipated losses. The reactions to grief can be physical, emotional, psychological and spiritual. The psychiatrist, Elisabeth Kubler-Ross who studied and wrote about grief, death and dying, describes five emotional responses that people experience as they come to terms with their losses. These responses are:

1. Denial: often the first response to news of a life-threatening illness. “There must be some mistake! This cannot be!”
2. Anger: at the doctor, at the world, at God, at anyone who isn’t sick. “Why me?”
3. Bargaining: an attempt to change what is by making promises (to God or whatever higher, more powerful spirit).
4. Depression: sorrowing over our losses, mourning and sometimes giving up to grief.
5. Acceptance: Kubler-Ross describes this stage often as the final stage of those who are dying and who have worked their way through all of the previous stages and are quietly reconciled to their coming end.

These five stages are not accomplished in any particular order but can be seen as fluid – one does not necessarily lead to the next – most people will experience most of the stages at one time or another in accepting their losses.

What are some of the other ways people react to loss? In coping with losses, individuals are likely to be easily distracted or have more difficulty concentrating. They may find themselves searching for answers, feeling hopeless or helpless, questioning their faith, or turning to their faith more strongly. They may also find that their assumptions about the world have changed. It is common to feel like they are “not themselves” – that this is all happening to someone else. Children often respond to losses by “acting out” or regressing to younger

behaviors.

Reactions to loss are individual and can vary tremendously even with people who are grieving the same losses. Since everyone grieves differently, it is important for a person not to compare themselves to others. They should pay attention to their own feelings and needs, giving themselves time alone to adjust to a loss or expressing their need to gather others around them. Individuals should trust their own feelings.

Grieving losses is hard work and requires considerable emotional effort. One may find it helpful to talk with others who have experienced similar significant losses; support groups can be beneficial. Many different types of community-based support are available. Some are self-help or mutual help groups, which are facilitated by someone who has experienced the same type of loss, while other support groups are facilitated by mental health professionals. An individual’s personal support network, such as friends, coworkers, or family, as well as his or her faith community, or individual counseling, can also help in coping with losses.

It is important to acknowledge the losses that come with the diagnosis of a life-threatening illness. These feelings of loss and the grief reactions are real. Coping with the losses requires time and understanding; the intensity of the feelings can be surprising.

Resources

Visiting Nurse Association of Chittenden and Grand Isle Counties End of Life Care Services

1110 Prim Road
Colchester, VT 05446
(802) 860-4410
www.vnacares.org

- *Camp Knock Knock* - A weekend bereavement camp held in June for families with children who have experienced the death of a loved one.
- Bereavement services for families whose loved one has died. Monthly support groups.

Cancer Patient Support Program

Hematology/Oncology Clinic
Ambulatory Care Center
Level 2, Main Pavilion
111 Colchester Ave.
Burlington, VT 05401
(802) 847-4848
1-800-358-1144 ext 4848

- Counseling, nutritional support, emergency fund.

Frymoyer Community Health Resource Center

Fletcher Allen Health Care
Level 3, Main Pavilion
Ambulatory Care Center
111 Colchester Avenue
Burlington, VT 05401
Hours: Monday-Thursday, 9 am - 5:30 pm; Friday, 9 am - 5 pm
(802) 847-8821
(802) 847-3013 (fax)
ResourceCenter@vtmednet.org
www.fahc.org/chrc

- The Community Resource Center provides current listings of all support groups in the local area and other consumer health information.

Compassionate Friends

www.compassionatefriends.org
www.vtcompassionatefriends.org

- A self-help organization offering friendship and understanding to bereaved parents and families who have suffered the loss of a child.

HowardCenter

208 Flynn Ave, Suite 3J
Burlington, VT 05401
(802) 488-6000
(802) 488-6001
www.howardcenter.org

- HowardCenter serves more than 14,000 people a year in child, youth and family services; developmental services; and mental health and substance abuse services.

Health Insurance Information

The United States has developed a variety of ways to pay for health care. Some systems are publicly-funded through taxpayer dollars and others come from private sources or individuals. The present system for financing health services is built upon payments by four different groups: the federal government, state government, employers and individual consumers. Both nationally and in Vermont, government pays the largest portion of the cost of health services.

Government Health Insurance Programs

- *Medicaid* is a state-sponsored health insurance plan paid for by state and federal taxes. In order to qualify for Medicaid you must meet certain income eligibility requirements. Vermont's Medicaid programs include **Dr. Dynasaur** (coverage for children), the **Vermont Health Access Plan (VHAP)**, **The Catamount Health Plan** (coverage for uninsured low-income Vermonters), and the **Medicaid program** (coverage for low-income families with children or people who are disabled). The Office of Vermont Health Access will determine which program is most appropriate for your needs.
- *Medicare* is a federally-funded insurance program for people age 65 and older and certain disabled people under age 65. Medicare provides broad coverage of basic benefits, but does not cover outpatient prescription drugs or long-term care. Medicare has two parts (and is initiating a third, a prescription drug plan):

Part A covers inpatient hospital charges, skilled nursing facility benefits, home health visits following a hospital or skilled nursing facility stay and hospice care.

Part B covers physician and outpatient hospital services, annual mammography and other cancer screenings, and services such as laboratory procedures and medical equipment.

If a person is eligible for Medicare, there are several coverage choices:

Medicare alone. One may choose not to buy additional coverage. This means the person will be asked to pay out of his or her own pocket for services that are not covered by Medicare.

Medicare plus a Medicare supplemental (Medigap) insurance policy. In addition to Medicare coverage, a person can buy a Medicare supplemental insurance policy, which may pay for some bills not covered by Medicare Parts A and B. The exact items paid for by a Medicare supplemental policy depends on which type of plan is purchased.

A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in Original Medicare Plan coverage. Medigap policies help pay some of the health care costs that the Original Medicare Plan doesn’t cover. If you are in the Original Medicare Plan and have a Medigap policy, then Medicare and your Medigap policy will pay both their shares of covered health care costs.

Generally, when you buy a Medigap policy you must have Medicare Part A and Part B. You will have to pay the monthly Medicare Part B premium. In addition, you will have to pay a premium to the Medigap insurance company. You will need to choose from several types of coverage under the Medigap plans offered.

Medicare plus Medicaid. Even if a person has Medicare, he or she may still be eligible for Medicaid coverage for services not covered by Medicare.

If a person is a Medicare beneficiary and is not sure what choice is best, he or she should call the Health Insurance Counseling and Assistance program (HICA) at 800-642-5119 or check the HICA web site at www.medicarehelpvt.org.

Other Types of Insurance

Disability insurance: Disability policies provide replacement income, a set schedule of payments, or coverage for expenses if the person is unable to work.

Long-term care insurance: Long-term care insurance policies help pay for the costs of nursing home, home health, adult day care and other similar types of care.

Employer Insurance Coverage

Most Vermonters get health insurance coverage through their employers. Employers choose how much of the cost for this insurance they will pay and how much (if any) their employees will pay.

Individual Consumer Insurance Coverage

Individual consumers pay whatever their health insurance plans (whether through an employer or a government program) do not pay for. This includes premiums for coverage they buy for themselves as well as all other out-of-pocket costs, such as deductibles, co-insurance, co-payments, and services they receive that are not covered by their plans.

Resources

Vermont Department of Banking, Insurance, Securities and Health Care Administration (BISHCA)

1-800-631-7788

www.bishca.state.vt.us

- Offers a consumer guide to health insurance

Office of Vermont Health Access: 1-800-250-8427

- Eligibility for and information about state-sponsored health insurance (VHAP, Medicaid, Dr. Dynasaur).

Office of Health Care Ombudsman: 1-800-917-7787

- A free statewide program to help Vermonters resolve problems with and complaints about their health insurance. Advocates are available to assist in the resolution of problems.

Health Insurance Counseling and Assistance: 1-800-642-5119

- Free, private health insurance counseling for people who receive (or will be receiving) Medicare.

Vermont Department of Health: 1-800-464-4343

Vermont Department of Labor and Industry: (802) 828-2286

- Help with Workers’ Compensation issues.

U.S. Dept. of Labor, Boston Regional Office: (866) 444-3272

- Assistance with questions about continuation of health insurance benefits through the federal COBRA law, and self-insured employer-sponsored health plans under the ERISA law.

Health Care Financing Administration: 1-800-MEDICARE

- Information on Medicare.

Vermont Secretary of State, Office of Professional Regulation: (802) 828-2386

www.sec.state.vt.us

- Provider licensing, concerns about provider quality of care.

Vermont Board of Medical Practice: (802) 657-4220

- Concerns about physicians' conduct and practice.

Governor's Information and Referral Office: 1-800-649-6825

VI. Other Services and Resources

The Vermont Assembly of Home Health Agencies

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

Vermont Cancer Center

University of Vermont
Health Science Complex
Burlington, VT 05405
(802) 656-4414
www.vermontcancer.org

Excellent Collaboration at the End of Life (EXCEL)

Vermont Program for Quality in Healthcare, Inc.
132 Main St - PO Box 1356
Montpelier, VT 05601
(802) 229-2152
fax: (802) 229-5098
patty.launer@vpqhc.org

ExCEL is comprised of individuals and organizational representatives statewide with a wide range of experiences and perspectives regarding end of life care in Vermont. Our mission is to serve as a network of groups and individuals in Vermont working together to improve end of life and grief experiences for everyone, through education and the sharing of resources. ExCEL is a project of the Vermont Program for Quality in Health Care, Inc.

Alzheimer's Association

Vermont Chapter Headquarters
172 North Main Street
Barre, VT 05641
Business line: (802) 477-7000
www.alz.org/vermont

Provides support, assistance, and education for those with Alzheimer's disease or related disorders, their families, professionals and the general public.

ALS Association
VERMONT Chapters
Northern New England Chapter
(Serving Vermont, New Hampshire & Maine)
Champlain Mill Suite 13
Burlington, VT 05401
(802) 862-8882
(866) 257-6663 (toll free)
fax: (802) 862-2138
www.alsanne.org

vt@alsanne.org (e-mail for services person)

Provides programs, services and support to individuals with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) to help maintain their quality of life and independence.

Community of Vermont Elders (COVE)

79 River Street
Heritage II Building, Suite 1
Montpelier, VT 05602
(802) 229-4731
www.vermontedlers.org

National Multiple Sclerosis Society

Vermont Division
100 Dorset Street, Suite 12
South Burlington, VT 05403
(802) 862-0912
Phone: 1-800-FIGHT-MS/ 800-344-4867
Fax: (802) 864-6509
Email: vtn@nmss.org <mailto:vtn@nmss.org>
www.nationalmssociety.org/vtn

Provides information, referrals to community resources, programs for people with MS and their families and other special events.

Hospice and Palliative Care Council of Vermont

10 Main Street
Montpelier, VT 05602
(802) 229-0579
Email: vahha@together.net
www.vnavt.com

A state-wide organization of all the hospice programs in Vermont. The goal is to provide education about end-of-life care issues, and to collaborate with other groups interested in providing excellent care.

American Parkinson Disease Association (APDA)

APDA Information and Referral Center
University of Vermont

FAHC-UHC Campus, Neurology Department
1 South Prospect Street
Burlington, VT 05401

Jean Baker, RN, Coordinator
(802) 847-3366 or (888) 763-3366
(802) 847-5918 fax

Email: Jeanette.Baker@vtmednet.org

Vermont Cares

P.O. Box 5248
Burlington, VT 05402
(802) 863-2437
1-800-649-2437
(802) 864-7730 (fax)
www.vtcares.org

The non-profit organization's mission is to improve the quality of life of people affected by HIV/AIDS, create compassionate communities, and prevent the spread of HIV.

VT 211

95 St. Paul Street, Suite 210
Burlington, VT 05401
211 (except for cell phones)
1-866-652-4636 (in-state toll free)
(802) 652-4636 (from out of state)
www.vermont211.org

A program of the United Way of Vermont.

A free confidential information and referral phone line to provide information about state-wide non-profit and human service agencies.

United Way of Chittenden County

412 Farrell Street, Suite 200
South Burlington, VT 05403
1-800-545-0446
info@unitedwaycc.org

United Way of Chittenden County works to mobilize human and financial resources to improve lives in Chittenden County. Based on human care needs prioritized by the community, United Way volunteers study community problems and recommend investments in programs and partnerships that work toward solutions.

VII. Online Resources

[Aging With Dignity](#)

Advice on making health care decisions and what you want your loved one to know. Publishers of Five Wishes, an advance directive form in everyday language that talks about your personal, emotional, and spiritual needs as well as your medical wishes. www.agingwithdignity.org

[Alliance of State Pain Initiatives](#)

ASPI is a national organization dedicated to promoting pain relief nationwide by supporting the efforts of state and regional Pain Initiatives. www.aspi.wisc.edu

[American Academy of Hospice & Palliative Medicine](#)

The American Academy of Hospice & Palliative Medicine is the only organization in the United States for physicians dedicated to the advancement of hospice/palliative medicine, its practice, research and education. www.aahpm.org

[American Hospice Foundation](#)

The American Hospice Foundation provides training and education programs in the workplace, in public and private schools, and in the health care system, with the goal of improving services for grieving and dying Americans of all ages. www.americanhospice.org

[Cancer Pain and Palliative Care Links](#)

This site provides links to other pages on the website that provide resources for those dealing with cancer. <http://www.cancerindex.org/clinks4u.htm>

[Center to Advance Palliative Care \(CAPC\)](#)

CAPC is a resource to hospitals and other healthcare settings interested in developing palliative care programs. CAPC is a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine. www.capc.org

[City of Hope Pain/Palliative Care Resource Center: Beckman Research Institute \(COHPPRC\)](#)

The purpose of the COHPPRC is to serve as a clearinghouse to disseminate information and resources to assist others in improving the quality of pain management and end-of-life care. The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, end-of-life resources, research instruments and other resources www.cityofhope.org/hom.htm

[Dying Well: Defining Wellness Through the End of Life](#)

This website provides written resources and referrals to different organizations for people who are dealing with life-limiting illness. There are also resources for their families and for professional caregivers. www.dyingwell.org

[End-of-Life Nursing Education Consortium \(ELNEC\)](#)

ELNEC offers courses for undergraduate faculty, clinical end-of-life care educators and other continuing education/staff development educators. The ELNEC project, a comprehensive, national education program to improve end-of-life care by nurses, is funded by a major grant from The Robert Wood Johnson Foundation. Primary project goals are to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care. www.aacn.nche.edu/elnec

[Euthanasia and the Right To Die](#)

Legal, medical, and ethical issues involved in palliative care, assisted suicide and euthanasia. www.trinity.edu/~mkearl/dtheuth.html

[Fletcher Allen Health Care](#)

The website provides links to over 175 recommended internet health education/resource sites. www.fahc.org/Health_Improvement/Resource_Center/health_links_all.html

[Growthhouse.org: Improving Care for the Dying](#)

Our primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Our search engine gives you access to the Internet's most comprehensive collection of reviewed resources for end-of-life care. www.growthhouse.org

Hospice Foundation of America

HFA is a nonprofit organization that promotes hospice care and works to educate professionals and the families they serve in issues relating to caregiving, terminal illness, loss and bereavement. www.hospicefoundation.org

Hospice and Palliative Nurses Association (HPNA)

The purpose of the HPNA is to exchange information, experiences, and ideas; to promote understanding of the specialties of hospice and palliative nursing; and to study and promote hospice and palliative nursing research.

www.hpna.org

National Hospice and Palliative Care Organization

The heart of this site is a database of hospices in the United States. Search by state, then county. Provides Web site address if available as well as address and contact information. In addition, there is basic information related to hospice care, a FAQ, and an annotated list of links to other hospice information on the Web. www.nhpco.org

VIII. Suggested Books

Albom, Mitch. *Tuesdays 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.

Byock, Ira. *Dying Well: The Prospect for Growth at the End of Life*. New York: Riverhead Books, 1997.

Ira Byock, M.D. is a hospice physician in Montana who has specialized in care for the dying since 1985. In *Dying Well* he tells the stories of twelve people of various ages and backgrounds whom he has helped in the process of dying. Each chapter focuses on a particular aspect of human development or personal growth that is associated with this final stage of life. The appendix has a set of questions and answers from a variety of cases to help families talk about dying, help ease symptoms, deal with doctors and the medical system, and care for a dying child.

Callahan, M. and P. Kelley. *Final Gifts*.

Written by two hospice nurses, this is an emotionally moving book on how to gain insight into the dying person's last words and what those words mean.

Dunn, Hank, *Hard Choices for Loving People* (4th edition, 2001), A & A Publishers, Inc. P.O. Box 1098, Herndon, VA 20172-1098

Voice Mail (703) 707-0169; FAX (703) 707-0174

Website: www.hardchoices.com Email: Aapublish@aol.com

Write or call for information on purchasing bulk copies.

Kiernan, Stephen P. *Last Rights: Rescuing the End of Life From the Medical System*. New York: St. Martins Press 2006.

The author tells the stories of people who experienced the best of care at the end of life and people who received substandard care and why. He provides a hopeful, profound vision for patients, doctors and families and spells out ways to give comfort and compassion to those we most love as they are dying.

Kubler-Ross, Elisabeth. ***On Death and Dying***.

The author shares the stories of clients in their final stages of life. She states that the text is intended to show how we as caregivers can empower patients to die on their own terms with dignity by creating a mutually gratifying experience for all parties involved. The book also identifies the five stages of grief.

Kubler-Ross, Elisabeth. ***The Wheel of Life: a memoir of living and dying***. New York: Touchstone, 1998.

The world-reknowned medical doctor, psychiatrist, and author of *On Death and Dying* writes an account of her life, including her experiences working with terminally ill children, AIDS patients, and the elderly.

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

This book aims to help those who face serious chronic illness that will eventually cause death. Professional caregivers, scholars, and ordinary citizens have collaborated to provide practical information, coping strategies, personal stories, and inspiring quotations. An annotated list of organizations and books is also included.

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 from the author's practice that demonstrate the personal and ethical challenges of dying. Each narrative is followed by a brief commentary on the central themes that emerged and a list of references for more in-depth study. The last chapter provides a synthesis of what was learned in the stories and a set of eleven challenges for providing a comprehensive system of care for the dying.

Tobin, Daniel, R. ***Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life***. Reading, MA: Perseus Books, 1999.

Peaceful Dying is based on the FairCare program founded by Dr. Tobin at the VA Hospital in Albany, New York. The book discusses the 26-step program that is directed primarily to those who are currently facing end-of-life situations and secondarily to their loved ones. The

text of each step includes practical suggestions and illustrations from the experiences of dying patients with whom the the author has worked. The appendix includes sample living wills and health care proxy forms.

Webb, Marilyn. ***The Good Death: The New American Search to Reshape the End of Life***. New York: Bantam Books, 1997.

The author provides an historical account of the evolution of the American way of death over the last thirty years that focuses on the persons involved and their families. Her approach integrates landmark legal cases, personal interviews with experts from a variety of disciplines and points of view, literature reviews from pain management, hospice, law, and medical ethics, and personal narratives by patients and families with firsthand experience.

Vermont Ethics Network, ***Taking Steps to Plan for Critical Health Care Decisions*** (7th printing, 2002), and ***When You Must Make Medical Decisions for Someone Else*** (2003) VEN, 64 Main Street, Room 25, Montpelier, VT 05620.

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Write or call or e-mail for single copy or bulk purchase information of the booklets.

IX. Acknowledgments

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This was truly a collaborative project from inception to completion. The initial printing is still considered a work in progress. Since our goal is to provide the most accurate information and comprehensive listing of local resources for healthcare providers, individuals, families and the community, we will rely on your feedback to make further improvements or add new sections.

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X. References

Portions of this guide were taken from the following sources:

National Center for Complementary and Alternative medicine; nccam.nih.gov/health/decisions/index.htm

National Cancer Institute; cis.nci.gov/fact/9_14.htm

Massachusetts Resource Guide for End of Life Services; Massachusetts Commission on End of Life Care, 2002. www.endoflifecommission.org

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Precepts of Palliative Care; Developed by the Task Force on Palliative Care, Last Acts Campaign, Robert Wood Johnson Foundation; *Journal of Palliative Medicine*, Volume 1, Number 2, 1998.

When You Must Make Medical Decisions For Someone Else, Vermont Ethics Network, 2003.