



Finding Our Way: Living with Dying in America, a fifteen-week newspaper series begins September 10th and continues through December 17th. The series is being distributed throughout the country by Knight Ridder/Tribune Information Services. The Finding Our Way national public education initiative is focused on bringing practical information to the American public regarding end of life and its surrounding issues.

Each article in the newspaper series explores a subject that faces seriously ill Americans, their caregivers, families, and communities. The newspaper series is written by experts in the field of medicine, sociology, theology or culture and explores issues that face seriously ill Americans, their caregivers, families, and communities. The series offers compelling personal stories and up-to-the-minute proactive information and resources so that individuals, families and communities can find the help they need.

Hundreds of newspapers throughout the United States are expected to carry the series; national television and radio shows will discuss the issues covered in the articles; and there will be promotional tie-ins to National Hospice Month and National Family Caregivers Month in November.

In September 2002, *Finding Our Way: Living with Dying in America* will offer a web-based, noncredit course on the issues presented in the newspaper series. A study guide, as well as additional community activities, will be organized. The overall effort provides practical information and user-friendly resources on end-of-life issues for individuals and organizations. We hope that it will also create a demand or change among American consumers. A critical element to the success of the effort is the cumulative energy being generated across the country by community and state end-of-life coalitions.

A number of national organizations are participating in the campaign to promote *Finding Our Way: Living with Dying in America* in communities around the country. The Partnership for Caring, *Last Acts*®, The Center for Advanced Illness Coordinated Care/VA HealthCare Network, Upstate New York at Albany and the Center for Death Education and Bioethics at the University

of Wisconsin provide leadership for the effort. The Robert Wood Johnson Foundation, FanFox and Leslie R. Samuels Foundation and Charitable Leadership Foundation provide funding.

As a nation, we must move from a stance of powerlessness and avoidance to one in which this most significant life event is approached with the same kind of emotional preparedness, planning, and active involvement that we strive for in other domains of life. The *Finding Our Way* initiative seeks to make this transition a reality for Americans.

Without discussion and preparation for the end of our lives, we run the risk of denying ourselves dignity and comfort. America is ready to talk



LIVING WITH DYING IN AMERICA

What kind of health care should you expect at the end of your life?

What kind of medical treatment are you entitled to at the end of your life? The following “core principles,” developed in 1999 to guide treatment for dying patients, have been adopted by major medical organizations:

- Respect the dignity of both patients and caregivers.
- Be sensitive to and respectful of the patient’s and family’s wishes.
- Use the most appropriate measures that are consistent with patient choices.
- Encompass alleviation of pain and other physical symptoms.
- Assess and manage psychological, social and spiritual/religious problems.
- Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers).
- Provide access to any therapy that may realistically be expected to improve the patient’s quality of life, including alternative or nontraditional treatments.
- Provide access to palliative care and hospice care.
- Respect the right to refuse treatment.
- Respect the physician’s professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences.
- Promote clinical and evidence-based research on providing care at the end of life.

From The Milbank Memorial Fund’s “*Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine*,” by Dr. Christine Cassel and Dr. Kathleen Foley.

Partnership for Caring: America’s Voices for the Dying

Download forms for advance directives tailored to your state; join a consumer advocacy group focused on improving end-of-life care.

PFC Publications – Publications Office
325 East Oliver Street
Baltimore, MD 21202
Hotline: 1-800-989-9455 (option 2)

www.partnershipforcaring.org

National Hospice and Palliative Care Organization

Provides a search for hospice and palliative care, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.nhpco.org

American Academy of Hospice and Palliative Medicine

Find board-certified hospice and palliative care physicians.

4700 W. Lake Ave.
Glenview, IL 60025-1485
(847) 375-4712

www.aahpm.org

The Last Acts® Campaign

Research latest news on legislative, educational and policy initiatives from local, state and national organizations.

1951 Kidwell Drive, Suite 205
Vienna, VA 22182
(703) 827-8771

www.lastacts.org

Growth House

Excellent source for books and other publications regarding end-of-life care

San Francisco, CA
(415) 255-9045

www.growthhouse.org

Aging With Dignity

Provides Five Wishes, an advance directives planning document.
1-888-5-WISHES

www.agingwithdignity.org

AARP

Offers extensive information on and support for caregiving, illness, grief, widowhood, funerals, wills and estate planning and advance directives.

601 E St., NW
Washington, DC 20049
1-800-424-3410

www.aarp.org/endoflife

The Center for Advanced Illness Coordinated Care, in collaboration with the Veteran’s Administration Healthcare Network of Upstate New York at Albany

Find guidance on coping with the complexities of serious illness through the “Walking the Advanced Illness Road” section.

113 Holland Avenue (111t)
Albany, NY 12208
(518) 626-6088

www.coordinatedcare.net

Community-State Partnerships to Improve End-of-Life Care

Find out what individual states are doing to organize health care professionals, educators and policymakers.
(816) 842-7110

www.midbio.org

Project on Death in America

Lists innovations in the arts, social work, education and public policy.

Open Society Institute
400 West 59th Street
New York, NY 10019
212-548-0150

www.soros.org/death

Center to Advance Palliative Care

Search the latest resources in palliative care available to hospitals and health care systems.

Mount Sinai Hospital
One Gustave L. Levy Place, Box 1070
New York, NY 10029-6547

www.capcmssm.org

Missoula Demonstration Project

Research tool for communities interested in setting up models for improved care at the end of life.

320 Main Street
Missoula, MT 59802
(406) 728-1613

www.dyingwell.com/MDP.htm

Promoting Excellence in End-of-Life Care

Research innovative programs that have received grants and technical support to change the face of dying in America.

The University of Montana
1000 East Beckwith Avenue
Missoula, MT 59812
(406) 243-6601

www.endoflifecare.org

Americans for Better Care of the Dying

Track changes in public policy, as well as reforms in pain management and support for family caregivers.

4125 Albemarle Street, NW, Suite 210
Washington, DC 20016
(202) 895-9485

www.abcd-caring.org

CONVERSATIONS ABOUT THE END OF LIFE by Dale Larson

Here are tips to help you talk to doctors, loved ones — and yourself:

- **Know your stuff:** Research your disease and bring a detailed list of questions to your doctor (see below). If you need support, bring along a friend or family member. Ask to tape record the medical interview so you can remember all the details of the conversation.
- **Build teams:** When you talk to your doctor, nurses, social workers, clergy, and other care-providers, think of them as colleagues, all interested in the same thing — helping you live your life to the fullest in the time you have left.
- **Learn from others:** Call up a local hospice or hospital to find nearby support groups or educational programs for people facing the same medical or caregiving challenges.
- **Share experiences:** Get your group — say, church or senior center— to discuss the experiences (good and bad) that members have had with friends and family who have died recently.
- **Plan proactively:** Discuss a treatment plan for your remaining time with your loved ones. Discuss your medical options (living will and health care proxy) and desired funeral arrangements. Give your doctor a copy of your completed directives.
- **Don't waste time:** Share with your loved ones what you'd like to do with the remaining time in your life — travel, getting together with old friends, for example. Be realistic, but set down your plans in detail and take action.
- **Tie up loose ends:** Think about what the unresolved issues are for you with your family, and what you can do to achieve some closure. For example, tell someone you forgive him or her for a past conflict. Get closure for the unfinished parts of your life.
- **Tell your story:** Make a video or audiotape for your children or grandchildren, telling them stories of your life and candidly sharing your feelings for

them.

- **Write it down:** Think of writing as a conversation with yourself. Writing about your life in its final stages may not cure your illness, but finding words to describe what you're feeling can be emotionally comforting and help you find meaning.
- **Look for the window of opportunity:** If your illness worsens and you are trying to balance life-prolonging treatments with your quality of life, it might be time for you to consider dying as the next stage of your life. The more you talk with others and prepare, the more likely you will be able to maintain control and dignity and achieve a sense of peacefulness in the time that remains.

Questions to ask your doctor about care:

- What are my treatment options?
- What are the side effects of the treatments you are recommending? How will they affect me and my family?
- Are there any support groups available for people with my disease and their families?
- What symptoms might arise suddenly? What medicines should I have on hand for these? What plans can we make in advance for these possible complications?
- What treatments will help my symptoms even if they don't cure what I have?
- What are the likely outcomes of resuscitation or life support machines for someone with my medical problems?
- I know you can't say how long I have to live, but would it surprise you as my doctor if I died within the next year or two?
- How can you help me plan for the worst while I hope for the best?
- What is your philosophy and practice on prolonging life versus enhancing the quality of life that remains?
- If your illness is advanced, ask: "How will we know when death is near? What signs should my family look for and what can they do for me?"

Aging with Dignity

The Five Wishes Project

Offers advance directive forms that can be used by residents of 33 states.

1-888-5-WISHES

www.agingwithdignity.org

AARP

AARP's End-of-Life page. Offers information on having end-of-life conversations.

601 E St., NW

Washington, DC 20049

1-800-424-3410

www.aarp.org/maturity/sept_oct00/conversation.html

Partnership for Caring: America's Voices for the Dying

It's All About Talking page.

PFC Publications – Publications Office

325 East Oliver Street

Baltimore, MD 21202

Hotline: 1-800-989-9455 (option 2)

www.partnershipforcaring.org/Talking/index.html

WIDOWHOOD

by Myra Christopher

Every bereaved spouse has to work through grief and loss in his or her own way, but here are some general tips:

- Take control of your financial resources. If your spouse was employed, seek help from his or her company's human resources department. As soon as possible, find a financial adviser, make a budget, visit a tax accountant or lawyer. Contact the Social Security office for information and current rules about benefits for yourself and your children.
- Maintain as much stability in your life as possible for a while; don't quit your job, sell your house or move right away.
- Take care of yourself. Eat a healthy diet, exercise and get enough sleep.

Here are some questions commonly asked after the death of a spouse:

Q: Should I still wear my wedding ring?

A: There is no such thing as "wedding ring etiquette." Do what makes you most comfortable. Some widows place their wedding rings on their right hand, others remove their rings, sometimes saving them for future generations. Some have their rings fashioned into a special new piece of jewelry and others wear their ring all their life.

Q: What should I do with my husband/wife's clothes?

A: This is a special concern to most widows. Trust yourself to know when the time is right to dispense with the personal belongings. Some people give them to family and friends, others to charitable organizations. This task doesn't have to be done all at once. It usually helps to go through belongings with a friend or family member so you can share memories and stories — it may make the task less distressing.

Q: How can I get others to talk about my deceased spouse?

A: People are afraid that any mention will make you sad. They feel uncomfortable and don't know what to say. You can help them and yourself by sharing memories of your loved one with them. You might open the door by

Reprinted with the permission of Partnership for Caring. *Finding Our Way: Living with Dying in America* can be accessed at <http://www.findingourway.net/index.html>

saying, "Remember when Jim ...?" Or be direct and simply say to friends and family that you want to talk about your loved one and want others to do so, too.

Q: How can I get through birthdays, anniversaries, holidays and other special events?

A: For most people, special occasions are difficult, especially the first ones following a loved one's death. Anticipate that they may be difficult and prepare yourself. It's fine to put traditions in mothballs to be recycled when you feel stronger, or to create new traditions. Try a diversion, such as a family trip or volunteering time at a social service agency that helps others during the holidays. Visit the cemetery or site where your loved one's ashes were scattered. Prayers, toasts and other tributes in your loved one's honor also may be helpful.

Q: When should I start dating?

A: The traditional one-year period of mourning is usually observed. However, some people may choose to seek companionship earlier — and some may never choose to do so. Only you will know when the time is right. It's important to remember that you are vulnerable and to be cautious.

Q: Should I attend a bereavement support group?

A: Everyone needs help from others during times of intense grief. Most people rely on the support of friends and family. Some seek counseling from clergy or other spiritual advisers. To find a support group, contact local faith communities, the YMCA, YWCA, a local hospice, or contact Widowed Person's Service of AARP at (202) 424-2260. Support groups aren't for everyone. So if you try and it doesn't feel right or seem to help, don't feel badly about dropping out.

Q: How will I know when I'm getting better?

A: Many experts encourage widows to keep a journal. Periodically reading earlier entries provides tangible evidence of improvement. As one participant in a chat room for young widows said, "You know you are getting better when you wake up one morning and don't have to force yourself to breathe." Another milestone is when you can talk about memories with a smile instead of tears. Remember: Things will never be the same, but you can and will feel happiness again.

AARP Grief and Loss Programs

Offers a variety of programs in which volunteers reach out to widows.

601 E Street, NW
Washington, DC 20049
(202) 434-2260

www.aarp.org/griefandloss

Hospice Foundation of America

Offers information to professionals and families about caregiving, terminal illness, loss and bereavement.

2001 S Street, NW, Suite 300
Washington, DC 20009
(202) 638-5419 or 1-800-854-3402

www.hospicefoundation.org

Parents Without Partners

Offers support, information and resources for single parents.

1650 S. Dixie Highway, Suite 510
Boca Raton, FL 33432
(561) 391-8833

www.parentswithoutpartners.org

ElderHope, LLC

Offers online support, forums, seminars, classes, and bereavement materials

P.O. Box 940822
Plano, TX 75094-0822
(972) 768-8553

www.elderhope.com

National Hospice and Palliative Care Organization

Provides a search for hospice and palliative care, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.NHPCO.org

Society of Military Widows/National Association of Uniformed Services, Inc.

Offers information and support to military widows.

5535 Hempstead Way
Springfield, VA 22151
(703) 750-1342

www.naus.org

PALLIATIVE CARE

by **Russell Portenoy**

If you find yourself diagnosed with a life-threatening illness, you can ask for palliative - or comfort - care at any point in your treatment to get the most quality of life. And, experts recommend, the sooner the better.

“(Palliative care) does not have to be reserved for the last weeks or the last months of life,” said Ronald Schonwetter, chairman of the American Board of Hospice and Palliative Medicine and professor at the University of South Florida College of Medicine. Your doctor can provide palliative care or, in some instances, may refer you to a specialist or palliative care team, available in many hospitals.

Remember: Asking for palliative care doesn't mean you're giving up on efforts to prolong your life. What you will be doing is recognizing that your psychological, social and spiritual needs are just as important as treating your disease.

Here are some other tips:

- Recognize that pain is not an unavoidable part of the disease. It nearly always can be controlled with medicines or more sophisticated treatments.
- Understand that narcotics offer the best treatment for pain for most people. Don't be afraid to use them or other strong medicines. When used appropriately, these drugs are safe, rarely cause problems with addiction and can work for as long as you need them. Your doctor should explain how to use them safely and effectively. Don't hesitate to ask for a referral to another doctor if yours is unable or unwilling to help.
- Appoint a health care surrogate as soon as you can. Choose a family member or a friend, but it should be someone you can count on to make your wishes for treatment known should you become incapable of making them yourself. Discuss your options and how you want them handled before there is a crisis. For example, would you want to be put on life-support to be kept alive?

...AND PAIN MANAGEMENT

by **June Dahl**

Reprinted with the permission of Partnership for Caring. *Finding Our Way: Living with Dying in America* can be accessed at <http://www.findingourway.net/index.html>

Here's something that should come as no surprise: The thought of dying in pain scares Americans. Over the past 25 years, significant advances have been made in treating the pain that accompanies critical illness. And new standards from the Joint Commission on Accreditation of Healthcare Organizations require health-care facilities to assess and manage pain.

Still, much of it goes unrelieved. That's because doctors and patients both harbor concerns about addiction to pain medication, as well as its side effects. And yet numerous studies find no evidence that the medical use of narcotics for pain control in the dying leads to addiction.

Here's how to get the most effective treatment for pain:

- Patients need to talk openly and honestly to family members and caregivers about their pain.
- It's essential to report where and how much you hurt, what the pain feels like and how your pain is affecting your life.
- Tell your doctors and nurses what makes your pain better or worse and disclose any medicines or other treatments you have been using to get pain relief.
- It's always good to write down your questions before you see your doctor because it is easy to forget something during the stress of an appointment. Better yet, take a friend or family member with you when you meet with a doctor or nurse.
- Always remember that your pain can be relieved, that you won't become addicted to pain medicines and that you should never hesitate to tell your doctors and nurses about your pain.
- The American Cancer Society, the American Alliance of Cancer Pain Initiatives, the Cancer Information Service of the National Cancer Institute and the American Pain Foundation offer print and Web-based materials.
- Your local hospice can help with the variety of issues faced by the critically ill.
- Finally, encourage your churches and synagogues, senior citizen organizations and service clubs to host public meetings on pain management and palliative

care. Contact your local hospital, long-term care facility or home health agency to suggest they sponsor public meetings on critical end-of-life care issues.

Palliative Care Overview

Provides an overview of palliative care and pain treatment.

www.medbroadcast.com/health_topics/death_dying/

American Medical Association, Institute for Ethics

EPEC (Education for Physicians on End of Life Care Project)

Offers information on end-of-life care education for professionals.

515 N. State St.
Chicago, IL 60610
(312) 464-4979

www.ama-assn.org

American Board of Hospice and Palliative Medicine

Provides information on palliative care and a directory of ABHPM certified physicians.

9200 Daleview Court
Silver Spring, MD 20901
(301) 439-8001

www.abhpm.org

Center to Advance Palliative Care

Search the latest resources in palliative care available to hospitals and health care systems.

Mount Sinai Hospital
One Gustave L. Levy Place, Box 1070
New York, NY 10029-6547

www.capcmssm.org

National Hospice and Palliative Care Organization

Provides a search for palliative care and hospice, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.nho.org

Palliative Care Corner

Offers resources for patients and providers.

13947 Silven Ave NE
Bainbridge Island, WA 98110
(206) 855-8026

www.painconsult.com

ADVANCE DIRECTIVES

By Robert Bendiksen and Bernard Hammes

Before drawing up an advance directive, think through these questions and then discuss them with your loved ones:

- Who should make your health care decisions if you can't make them yourself? Is this person someone who knows and would honor your values and views? Can he or she make complex decisions in stressful situations?
- If you had an irreversible brain injury, at what point would you reject CPR, a feeding tube and antibiotics?
- Do you have any religious, spiritual or philosophical beliefs central to your life that would influence what medical treatments you would or would not want?
- If organ or tissue donation is a possibility, would you want to donate?

Questions to consider if you have a specific illness:

- Early Alzheimer's disease: What would you want to happen if you stopped eating because of your Alzheimer's? If you developed an overwhelming infection, at what point would you want antibiotics stopped?
- Progressive lung disease: Would there be a time when you would not want the support of a breathing machine?
- Chronic kidney failure: Under what circumstances would you want dialysis stopped?
- Congestive heart failure: When would it make sense not to attempt resuscitation?

Once you've answered these questions, here's how to tackle an advance directive:

Advance directives are written instructions regarding the provision of health care for use when you become incapacitated. They may be completed on your own or with assistance from a health professional or an attorney.

Use forms valid for your state and have them signed, dated and witnessed properly. Generally, health providers do not charge for the form or for assistance in completing it. You may revoke an advance directive at any time by saying it is revoked, indicating so in writing or by destroying the document.

There are two types of advance directives. Not all states require both:

1. Living wills state your medical treatment preferences should you become incapable of making health care decisions.
2. A durable power of attorney for health care appoints a surrogate or proxy decision-maker for health care decisions should you become incapacitated. It could include any special instructions and preferences.

Other considerations:

Those over age 70 or who have a progressive disease are prime candidates for writing advance directives. But anyone over the age of 18 can start to think about it. Disconnecting life support from a critically injured young person is an emotional issue which often leads to years of conflict and ends up in court when family members can't agree on what the injured person would have wanted and there is no advance directive. Advance directives first became popular when the family of Karen Ann Quinlan, a 22-year-old who sustained irreversible brain damage in 1975, successfully sought to disconnect her life support.

The AARP estimates that 35 percent of advance directives can't be found when they're needed. Keep copies in a safe place, but not a safe deposit box. Some people keep copies in their glove compartment. You also should give copies to whoever will act as your proxy in case you become incapacitated, as well as your doctor and hospital.

To be on the safe side, if you live part of the year in a different state, draw up an identical advance directive using the official documents from that state.

Hospital emergency rooms may not be able to honor an advance directive since the staff may have little time to properly evaluate it.

Aging with Dignity

Provides the Five Wishes Living Will, legal in 33 states (\$5 fee).
1-888-5-WISHES

www.agingwithdignity.org

U.S. Department of Health and Human Services

Guidelines on advance directives.

www.hcfa.gov/pubforms/advdir.htm

AARP

Information on obtaining and completing advance directives.
601 E St., NW
Washington, DC 20049
1-800-424-3410

www.aarp.org/endoflife/

American Medical Association

Booklet on advance directives.
515 N. State Street
Chicago, IL 60610
(312) 464-5000

www.ama-assn.org/public/booklets/livgwill.htm

Partnership for Caring: America's Voices for the Dying

Provides free, state-specific living wills.
PFC Publications – Publications Office
325 East Oliver Street
Baltimore, MD 21202
Hotline: 1-800-989-9455 (option 2)

www.partnershipforcaring.org

Gundersen Lutheran

End-of-Life Care

Programs that help health care providers implement advance directives in hospitals.
1836-1910 South Avenue
La Crosse, WI 54601-5494
(608) 782-7300 or 1-800-362-9567

www.gundluth.org/eolprograms



CULTURE AND DIVERSITY

By LaVera Crawley

If you're a minority facing a life-threatening illness, it's vital to have access to medical information that's understandable, respectful and culturally appropriate.

Here are some tips to open the lines of communication for patients, families and their health-care providers: If you or an ailing family member does not speak English, insist on the services of trained medical interpreters who not only can provide translation, but also help you negotiate across the cultural divide of medicine and community values. Depending on your community, many health-care facilities offer medical translation services. If they don't, commercial medical translating services, including AT&T Language Line® Services (800-752-6096 or www.language.com), may offer an alternative.

When communication gets bogged down, patient advocacy services, available at many medical centers and hospitals, can help you navigate through the health-care system. Ask your local community hospital about its patient relations or patient advocacy office.

The odds of finding services that respect your heritage increase dramatically if staffing and volunteers at health facilities reflect the communities they serve. Consider volunteering at local hospices, end-of-life organizations and other medical institutions.

Tuskegee University National Center for Bioethics in Research & Health Care

The nation's first bioethics center is devoted to engaging the sciences, humanities, law and religious faiths in exploring moral issues involving research and medical treatment of African Americans and other underserved people. The Center provides leadership in cultural diversity and death and dying.
1209 Chambliss Street, Tuskegee Institute
Tuskegee, AL 36088
(334)-724-4612

www.tubioethics.org

ACCESS to End-of-Life Care: A Community Initiative

Formed in 1997 by a group of experienced hospice nurses, social workers and administrators, this advocacy group provides education about death, dying and grieving.

P.O. Box 460478
San Francisco, CA 94146-0478

www.access2eolcare.org

Assuring Cultural Competence in Health Care

The Health and Human Services Office of Minority Health has published national standards on culturally and linguistically

appropriate services (CLAS) in health care, available online.
OMH Resource Center
P.O. Box 37337
Washington, DC 20013-7337
1-800-444-6472
<http://www.omhrc.gov/clas/>

Growth House Inc.

Provides background and health agency referral services with a strong focus on diversity, including a section on gay and lesbian issues
www.growthhouse.org/

HIVInSite

The University of California San Francisco offers comprehensive information on issues surrounding HIV/AIDS
<http://hivinsite.ucsf.edu>



SPIRITUALITY AND FAITH

by **Hugh Maddry**

Consider this a true once-in-a-lifetime opportunity. For those facing the end of life, this precious time holds out a chance to explore spiritual destinies and question the role of spirituality, faith or religion in your life. At the core of all religions is an attempt to answer age-old questions about the meaning of life. Many who grew up in a particular faith look deeper into the teachings of that religion when they see death coming nearer. But you don't have to take on a specific religion to find meaning.

Here are some questions that can start you on your journey for answers:

Why do I have to face such a difficult situation?
Why am I being tested this way?
Where is my God or Higher Power in all this suffering?
What is the meaning of my life?
Who am I?
What happens after I die?
Where did I come from? Where am I going?
Do I have a soul?
What is my relationship with God or a Higher Power?
How can I come to peace with God or a Higher Power?

Ethical Wills

Offers a way to leave your legacy by writing down your values and beliefs.

www.ethicalwill.com

Compassion Sabbath

An interfaith initiative to help clergy and congregations minister to seriously ill and dying people.

1021-1025 Jefferson St.
Kansas City, MO 64105
816 221-1100

www.midbio.org/cs/index.htm

Gilda's Club Worldwide

Offers emotional and social support to those living with cancer and their families.

5 Madison Ave., Suite 609
New York, NY 10016
(212) 686-9898

www.gildasclub.org

Supportive Care of the Dying: A Coalition for Compassionate Care

A non-profit coalition committed to bring about cultural change regarding pain and symptom management and relief of suffering for persons living with and affected by life-threatening illness.

c/o Providence Health System
4805 NE Glisan St., 2E07
Portland, OR 97213

(503) 215-5053

www.careofdying.org

National Hospice and Palliative Care Organization

Provides a search for hospice and palliative care, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314

(703) 837-1500

www.nho.org

American Association of Pastoral Counselors

Provides information about pastoral counseling, resources and a searchable directory of pastoral counselors.

9504-A Lee Highway

Fairfax, VA 22031

(703) 385-6967

www.aapc.org

LAST RITES

by Thomas Lynch

The numbers are fairly convincing on this: 100 percent of us will die.

Here are some tips to help make this event as neatly planned as possible for you and your family:

- Plan ahead for age and illness, death and bereavement. Talk openly with your family about your concerns and preferences. Get information about funerals, cremation and expenses in advance.
- Don't be afraid to ask for help. Your pastor, rabbi, priest, imam or shaman can help you shape the important questions. Often it is the asking, more than the answers, that helps us the most.
- Rely on faith to allay your fears. Whether you are devout or lapsed in your religion, your faith — with its doubts and wonderments and uncertainties — or your spirituality will help you through the darkest and most difficult hours.
- Make the acquaintance of a licensed funeral director you can trust, someone who is accountable by name and reputation. Ask around. Get referrals. Deal with someone who has more than a commission or sales quota in the transaction. Find someone you could call in the middle of the night if someone you love died and you needed help.
- Let your family take part in the decisions that they will have to live with. You can pre-plan the funeral but you cannot pre-grieve the grief.
- Don't confuse a casket for a funeral. The most expensive casket will not get you into heaven — or keep you out.
- Be wary of “memorial counselors,” “death care professionals,” package deals and telemarketers who call you in the middle of dinner trying to sell you something.
- Keep the difficult vigils with the dying, the dead and the bereaved. The gift of presence, the ministry of listening, the human kindness of being there, the power of witness — these are essential exercises in

humanity.

- If you've lost someone, make time to mourn. Go the distance. Weep, laugh, pray, love, give thanks and praise, comfort, mend, honor and remember.

Beliefnet

Billing itself as the “source for spirituality, religion and morality,” Beliefnet is an online community that offers comprehensive information on death, grief, bereavement and funerals. Especially worthy are this site's comparative religion features.

www.beliefnet.com

“Funerals: A Consumer's Guide”

Published by the Federal Trade Commission.
1-877-FTC-HELP

www.ftc.gov/bcp/online/pubs/services/funeral.htm

National Public Radio's series “Exploring Death in America”

An exceptionally wide-ranging and well-balanced collection of “voices” and resources including bibliographies, interviews, sample chapters from important texts and personal stories.

www.npr.org/programs/death/

“On Our Own Terms – Moyers on Dying.”

This groundbreaking PBS series, first aired in the fall of 2000, spurred an ongoing program of community outreach.

www.thirteen.org/onourownterms

The American Association for Death Education and Counseling

A professional organization dedicated to promoting excellence in death education, bereavement counseling and care of the dying.
342 North Main Street
West Hartford, CT 06117-2507
(860) 586-7503

www.adecc.org

The Last Acts® Campaign

A national outreach program for end-of-life issues, including hospice care, public policy debates, and funding issues. A comprehensive site, it is a wonderful resource for individuals and communities seeking better care for the dying and bereaved.

1951 Kidwell Drive, Suite 205
Vienna, VA 22182
(703) 827-8771

www.lastacts.org

The Funeral Consumers Alliance

Provides information for consumers about funeral ethics, affordability and legal issues.

P.O. Box 10
Hinesburg, VT
(802) 482-3437.

www.funerals.org

The National Funeral Directors Association

Offers useful consumer guidelines, demographic information and helpful links to other national and international organizations.

13625 Bishop's Drive
Brookfield, WI 53005
1-800-228-6332

www.nfda.org

CAREGIVING

by Karen Orloff Kaplan and Ira Byock

Caring for an ailing loved one can take its toll, but there is help. Here are some practical tips from

www.caregiving.com.

- **Get things in order.** Find financial information, including investments, bank accounts and tax returns, and names of lawyers, bankers and accountants. Locate life insurance policies, birth certificates and funeral arrangements papers. Have the names and phone numbers of all physicians as well as information about all prescribed medications at your fingertips. Find Social Security and Medicare cards. Help your charge complete living wills and durable powers of attorney for health care.
- **Ask questions.** Speak with the doctor about diagnosis and prognosis. Ask what you can expect in the future. Advocate for your loved one. Spend time in the library and on the Internet conducting your own research. Contact local agencies to get more information.
- **Get informed.** Learn about hands-on techniques, such as transferring safely, proper skin care and lifting properly. Ask your home health aides or visiting nurses to show you the proper techniques or contact your local American Red Cross to find a caregiving class offered in your community. Log your care recipient's health in a diary, and include notes about meal consumption, techniques that worked, medication dosages and times and any changes in medical condition. This journal will be helpful during doctor appointments and to update family members.
- **Talk it over.** Make sure all family members have the same information you do. Find out what family members can do to help, even if they're out of state. Develop a plan of care. For instance, who will help Mom with her groceries? Who will help her bathe and dress in the morning? Who will take her to her doctors' appointments?
- **Make time for yourself.** This is vital. Pursue your own interests and hobbies. Caregiving is stressful. All caregivers need time away; it's good for everyone. Attend a support group regularly or find an outlet to vent your frustrations, whether it's

friends, family or a daily journal.

- **Set limits.** Determine at what point you can no longer provide care. For instance, some caregivers decide they are uncomfortable when a care recipient becomes incontinent.
- **Remember why you're here.** Although your loved one may act "childish" or may be unable to fully care for herself, always respect her need for independence and choices. Encourage her to do as much as possible for herself — you'll both benefit.
- **Look ahead.** Seek out options for the day when you no longer can provide care. Visit several retirement centers, assisted living facilities and nursing homes to find one that you are comfortable with.
- **Share, share, share.** The best resource for family caregivers is other family caregivers. A network of social support is important for everyone. Sharing your experiences with others is a great way to help yourself and others.

Caring Road

Interactive site offering support and information for caregivers, including chat rooms, links and a disease directory.

www.caringroad.com

Department of Pain Medicine and Palliative Care

New York Beth Israel Medical Center

New York Beth Israel Medical Center has created the Caregiver Resource Directory to help family caregivers feel less alone and overwhelmed.

www.stoppain.org

The Family Caregiver Alliance

Provides resources, including information about specific diseases and related public policy news.

690 Market Street, Suite 600

San Francisco, CA 94104

(415) 434-3388

www.Caregiver.org

The American Pain Foundation

Provides a survey to screen yourself for depression and access to on-line support.

201 N. Charles Street, Suite 710

Baltimore, MD 21201-4111

www.painfoundation.org

Partnership for Caring: America's Voice for the Dying

A consumer advocacy group, offers state-specific, advance directive documents to print or order. You'll also find "Talking About Your Choices", a booklet that introduces issues surrounding end-of-life decision-making.

PFC Publications – Publications Office

325 East Oliver Street

Baltimore, MD 21202

Hotline: 1-800-989-9455 (option 2)

www.partnershipforcaring.org

The National Alliance for Caregiving

Provides information from pertinent studies, tips for caregivers and a searchable resources directory.

4720 Montgomery Lane, Suite 642
Bethesda, MD 20814

www.Caregiving.org

The National Family Caregivers Association

Offers practical information and answers to frequently asked questions (FAQs), as well as "A Guide to Improving Doctor/Caregiver Communication."

10400 Connecticut Avenue, #500
Kensington, MD 20895-3944
1-800-896-3650

www.nfcacares.org

The Midwest Bioethics Center

Makes available Caring Conversations

(www.midbio.org/workbook.pdf), a workbook to help start conversations, including advance health care planning and advance directive forms.

1021-1025 Jefferson Street
Kansas City, MO 64105
1-800-344-3829

www.midbio.org

Empowering Caregivers

A comprehensive site offering information, emotional and spiritual support through featured expert columns, articles on caregiving, journal exercises, a newsletter, forums, chats, healing circle, caregiver and caregiving spotlights, inspiration, humor and more.

National Organization For Empowering Caregivers
425 West 23rd Street Suite 9B
New York, New York 10011
(212) 807-1204

www.care-givers.com

HOSPICE

by Stephen Connor

Most Americans don't know what hospice is, according to research conducted by the National Hospice Foundation. Nearly 75 percent don't know that hospice care can be provided at home and less than 10 percent know it provides pain relief for the terminally ill. Nearly 80 percent don't think of it as a choice for end-of-life care and 90 percent don't know that Medicare pays for it.

Here are some questions to ask when you're looking for a good hospice program:

- What services does hospice provide?
- What kind of support is available to the family/caregiver?
- What roles do the attending physician and hospice physician play?
- What does the hospice volunteer do?
- How will hospice meet our spiritual and emotional needs?
- How does hospice work to keep the patient comfortable?
- How are hospice services provided after hours?
- How and where does hospice provide short-term inpatient care?
- Can hospice be brought into a nursing home or long-term care facility?

Medicare and private insurance, including new long-term care policies, cover many, if not most, hospice services for anyone with a terminal illness, including cancer and non-cancer diseases. While you should check with your insurance provider for specifics on your coverage, here is a list of what Medicare will cover:

- Physician services for the medical direction of the patient

- Regular home visits by registered nurses and licensed practical nurses
- Home health aide and homemaker services, such as dressing and bathing
- Social work and counseling services
- Chaplain services for the patient and loved ones, if desired
- Medical equipment, such as hospital beds
- Medical supplies, such as bandages and catheters
- Drugs for symptom control and pain relief
- Volunteer support to assist patients and loved ones
- Physical therapy, speech therapy, occupational therapy, and dietary counseling

Keep in mind that hospice care is intended to supplement caregiving provided by families or other loved ones, so Medicare will not cover primary caregiving. For those who don't have family or other loved ones to provide care, hospices will work with the patient to find the care they need to be safe at home or help them move to another setting. New long-term insurance policies also may cover these caregiving expenses when Medicare doesn't.

HospiceWeb

Offers a message board, a list of answers to frequently asked questions (FAQs) about hospice and links to numerous hospice-related sites throughout the world.

www.hospiceweb.com

American Hospice Foundation

Includes a collection of articles with practical information for the dying or the grieving. Offers "Grief at School Training Guide & Video" to help teachers respond to grieving children and on-site training workshops.

2120 L Street, NW, Suite 200
Washington, DC 20037
(202) 223-0204

www.americanhospice.org

Hospice Foundation of America

The site provides guidelines for choosing hospice, tips for dealing with grief and other consumer resources, such as a collection of hospice readings and Web links. Call the foundation to find a hospice near you.

2001 S Street, NW, Suite 300
Washington, DC 20009
(202) 638-5419 or 1-800-854-3402

www.hospicefoundation.org

American Academy of Hospice and Palliative Medicine

Includes a selection of links to general hospice informational sites.

4700 W. Lake Ave.
Glenview, IL 60025-1485
(847) 375-4712

www.aahpm.org

The Hospice and Palliative Nurses Association

Check on background and credentials for hospice nurses.

Penn Center West One, Suite 229

Pittsburgh, PA 15276

(412) 787-9301

www.hpna.org

National Hospice Foundation

Informs the public about the quality end-of-life care that hospice provides;

including information on choosing a hospice and communicating your

end-of-life wishes.

1700 Diagonal Rd, Suite 300

Alexandria, VA 22314

(703) 516-4928

www.hospiceinfo.org

National Hospice and Palliative Care Organization

Offers a hospice database and provides statistical and educational material about hospice care. Or call the toll-free HelpLine at (800) 658-8898 to find a hospice near you.

1700 Diagonal Road, Suite 300

Alexandria, VA 22314

(703) 837-1500

www.nhpco.org

NURSING HOMES

By Len Fishman

For most people, nursing homes are like black boxes. You can't tell what's inside, and they all seem alike. But there are important differences, and it's not that hard for a shopper to tease those out to make an informed and thoughtful choice.

Here's how:

- The first thing to do is talk to people you trust: friends, a doctor, a social worker — preferably people who have lots of contact with nursing homes. They are in the best position to make meaningful comparisons. Your state or county Offices on Aging are good places to find listings and maybe get opinions “off the record.” Long-term care ombudsman programs are also good sources of information.
- Consider whether it is important to you that a nursing home has a particular affiliation — religious, ethnic, fraternal or otherwise. About one-third of the nursing homes in the United States are nonprofit; most of these are religiously sponsored and offer some clerical and spiritual services. Many nursing homes will even try to arrange for access to these services.
- Location, location, location. The axiom about real estate applies to nursing homes as well: You want to pick a facility that friends and relatives can visit as often as possible. Why? Because nothing matters more to a resident than those visits, and because even at very good nursing homes, staff pay more attention to residents whose families are present. Those interactions help staff focus on “what's left rather than what's lost,” as nursing home professionals put it. That is, the staff sees a fuller human being when a resident interacts with the people who love her. Family members and staff can really bond with each other, and everyone starts to feel that they're part of a team.
- Visit the homes you are considering. Talk with the nursing home staff, and, more important, with the residents and their family members. Ask to talk to members of the residents' council. They will be among the more lucid and verbal informants, with an

insider's view broader than most. Here are two good questions to ask staff:

1. “How are you going to accommodate what's unique about my Mom? If she wants to eat breakfast later than your norm, or be wheeled outside at a certain time of day, how will you handle that?” Get a sense of whether she'll have to conform to the facility, or whether it will confirm to her, or at least meet her halfway.
2. “Is there an active volunteer program?” If there is, that's both a meaningful sign of community support as well as a significant source of stimulation for residents.

- Ask to see the two most recent state and federal inspection reports. This is public information. If there are serious violations, you want to know.
- Contrary to what many Americans believe, Medicare coverage for nursing home care is extremely limited. Many of the nursing home residents covered by the Medicaid program started by paying with private funds until “spending down” — using up their assets — and qualifying for Medicaid.

Finally, don't beat yourself up. Remember that 80 percent of long-term care in the United States is provided by families in their own homes. When families make the choice to put a loved one in a nursing home, it's because they've honestly run out of alternatives. Console yourself with this truth: Almost no one puts a mother or father in a nursing home until it's absolutely necessary. You can figure out which facility will give your loved one the best quality of care and the best quality of life. And then remember that your own attentiveness to your loved one at the nursing home you choose can make a world of difference.

Alternatives to nursing homes:

Just 10 years ago, if you were old and frail and couldn't get by without help, chances were you would end up in a nursing home — whether or not you really needed that level of care. That world is gone. In the last decade there has been an explosion of alternatives to nursing homes for long-term care. The tradeoffs are pretty clear: Nursing homes generally offer more institutional surroundings and more care. Assisted living facilities offer more home-like settings, with less care. Assisted-living residents who become too frail must move on to a nursing home. So it's important that prospective residents and their families understand up front that once a resident needs more intensive care, he or she will be

asked to leave. While seven in 10 nursing home residents are covered by Medicaid, assisted living is mainly for those who can afford it.

Here are some brief descriptions, from the most independent to the most intensive.

- **In-home care.** Most seniors want to remain independent — in their own homes — for as long as possible. In-home assistance can be as limited as Meals on Wheels or as extensive as around-the-clock nursing care. The challenge is putting all the pieces together. Home health agencies provide personal care and nursing services. Often, though, what a senior really needs is help with things like housekeeping, transportation and adapting the home to make it handicap-accessible. Care managers and eldercare service companies are sprouting up to fill this need.
- **Subsidized senior housing.** There are nearly 1.5 million units of subsidized senior housing throughout the United States for seniors with low to moderate incomes. Many of these apartment buildings offer transportation, shopping, laundry and other services. Some provide meals. These may be the most cost-effective facilities — the best of them can extend a senior’s independence for years. Because they are so popular, seniors must plan ahead: waiting lists can be years long.
- **Adult day care.** For the frail senior, especially a patient with dementia, whose working family can provide care at night and in the morning, these programs provide structure, meals and, in some case, nursing care and medical monitoring during the day.
- **Continuing care retirement communities.** These self-contained senior communities provide housing, meals, activities, medical care and, if necessary, long-term care. These communities are for seniors who think ahead: Applicants must be capable of functioning independently when they enter. There’s usually a significant entrance fee but, in an all-inclusive “life care” facility, residents are getting care for life in a community that will help them live as independently as possible for as long as possible. Some facilities offer services a la carte — they charge less up front and more later if the resident needs more services.
- **Board and care homes.** This is the toughest category to describe because it is so diverse. These group living arrangements offer shelter, meals and help with eating, walking and bathing. But they can range

from upscale, hotel-like facilities to not-so-appealing boarding homes. Licensing and monitoring are highly variable.

- **Assisted living.** For the frail senior who can no longer live independently but isn’t ready for the intensive care that a nursing home provides, this can be an attractive choice. Assisted living — “nursing home light,” as some professionals call it — offers a more homelike environment, but with less staff, nursing and medical care than a nursing home. Residents generally live in private apartments, with a bathroom and modest kitchen. Staff members help them with bathing, dressing, eating and other activities.

To make the best choice, do your homework. For services in your area, try The Eldercare Locator, operated by the Administration on Aging of the U.S. Department of Health and Human Services, (800) 677-1116.

Medicare’s Website

Offers the Nursing Home Compare database, with information about every Medicare/Medicaid certified nursing home in the country, organized by state, county and city.

www.medicare.gov/Nursing/Overview.asp

“Your Guide to Choosing a Nursing Home”

A booklet available from the Health Care Financing Administration of the U.S. Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244
1-800-633-4227

www.medicare.gov/Publications/Pubs/pdf/nhguide.pdf



WHEN A CHILD IS DYING

By Bruce Himmelstein and Joanne Hilden

Here are tips for family members on dealing with the life-threatening illness and death of a child:

- Tell the doctors you want an honest answer about your child's prognosis and treatment options.
- Keep in mind that if you choose to stop pursuing therapy because the side effects are too severe, it can be a loving choice.
- Find a doctor or nurse who is an expert in symptom control. Your child can be comfortable, whether you choose to have her die at home or in the hospital.
- Talk about what your child has achieved in his life, no matter how old he is.
- Reassure and include siblings. They are too often neglected, or have unanswered questions and unnecessary guilt.
- Find out from the doctors what will happen in the actual time your child is dying so that what you see is not a surprise to you.
- While your child is still alive, make memories. Take a lot of pictures, save a lock of hair or fingerprints, record his voice, have him draw pictures and write for you.
- Take care of yourself. Let your friends, family and community help you.
- Prepare for the funeral. And let siblings help with that; it is important to them.
- Ask the doctors to tell you the really hard stuff — like the fact that if your child goes on a ventilator, he won't be able to talk to you any more.
- Get help from experts in grieving, even if you think you don't need it.

Remember: What you choose as right for your child and family cannot be wrong.

Growth House

Excellent source for books and other publications regarding end-of-life care
(415) 255-9045

www.growthhouse.org

The National Organization for Rare Disorders, Inc.

Provides information about rare pediatric illnesses.
P.O. Box 8923
New Fairfield, CT 06812-8923
(203) 746-6518

www.rarediseases.org/index.html

The Compassionate Friends

Provides grief support after the death of a child.
P.O. Box 3696
Oak Brook IL 60522-3696
(877) 969-0010

www.compassionatefriends.org

The Candlelighters Childhood Cancer Foundation

Offers support, advocacy and information to parents caring for children with cancer.
3910 Warner Street
Kensington, MD 20895
1-800-366-2223

www.candlelighters.org

Department of Symptom Control and Palliative Care M. D. Anderson Cancer Center

Provides information and resources about symptom control and palliative care.
1515 Holcombe, Box 08
Houston, TX 77030
(713) 792-6085

www.mdanderson.org/departments/palliative/

End-of-Life Care for Children Texas Children's Cancer Center Texas Children's Hospital

Offers information and resources for families and professionals on end-of-life care for children. Also, offers "The End-of-Life Care for Children" handbook, which encompasses most of the materials on the website.
Houston, TX

www.childendoflifecare.org/home.html

Project Joy and Hope for Texas

Offers news and resource information about end-of-life care and bereavement services for families with children with life limiting illness.

PO Box 5111
Pasadena, TX 77508
(713) 944-6JOY or toll free at (866) JOYHOPE

www.joyandhope.org/contact.html

Children's International Project on Palliative/Hospice Services (ChIPPS)

National Hospice and Palliative Care Organization

Offers information on the program to enhance the science and practice of pediatric hospice and palliative care
1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.nhpco.org

Children's Hospice International

Offers information on children's hospice care.

2202 Mt. Vernon Ave, Suite 3C
Alexandria, VA 22301
1-800-24-CHILD or (703) 684-0330

www.chionline.org

Pediatric Pain-Science Helping Children

IWK Grace Health Center, Dalhousie University
Offers resources, information and self-help for parents.
Halifax, Nova Scotia
Canada

is.dal.ca/~pedpain/pedpain.html

VIOLENCE AND UNEXPECTED DEATH

By Charles Corr

If you suddenly lose a loved one to a violent or unexpected death, you can expect to go through what professionals call “traumatic bereavement” — strong reactions of shock, pain, deep sadness, confusion, guilt and anger.

Here’s what may happen and how to deal with it:

- Any major loss from violence will affect family and friends differently. Remember all relationships have their own distinctive features and all losses are unique. Expect that these relationships may change in unexpected ways.
- Insist on your right to be yourself and do what you need to do to deal with what has happened. Don’t let others impose their own path or timetable for bereavement; this is your loss and your grief.
- It may be very difficult to believe that such a terrible thing could really have happened and extremely hard to fit that event and its implications within the assumptions that you might have previously held about the world, God and society.
- When criminal or civil proceedings complicate bereavement, seek help from individuals and organizations that are skilled in victim advocacy. They can help you find ways to be informed and involved, while also preparing you for the inevitable frustrations of dealing with the legal system.
- Be patient with yourself and others as you mourn. Especially at first, be content with just getting through a minute at a time, a single hour, or even just a portion of a day.
- Try to be tolerant of others who withdraw from you, don’t know how to help you or what to say, or are afraid of the intensity and duration of your grief. You might have behaved in similar ways before this happened to you.
- Share your needs with others. Ask them for the help you need and give them specific things to do for you.

- You may discover the most comforting support and most helpful guidance will come from individuals who have experienced similar losses.
- Don’t neglect yourself. Try to eat nourishing meals, drink plenty of fluids — but not much alcohol — and get the rest and exercise you need.
- Traumatic bereavement leads some people to think they are “losing their minds” or “going crazy”; remember that it may take time and effort to develop “new normals” in your life.
- You can move from being a victim to being a survivor. You will never be the same and you are likely to experience strong surges of grief from time to time, but you will be better than you are now.

National Donor Family Council of the National Kidney Foundation

Provides organ donation information and to families.
(212) 809-2210 or 1-800-622-9010

www.donorfamily.org

Mothers Against Drunk Driving (MADD)

An organization working to stop drunk driving, support the victims of this violent crime, and prevent underage drinking.
(214) 744-6233 or 1-800-GET-MADD

www.madd.org

National Organization for Victim Assistance

Provides information in victim’s rights, assistance and services.
1730 Park Road NW
Washington, DC 20010
(202) 232-6682 or 1-800-TRY-NOVA

www.try-nova.org

The Compassionate Friends

Provides grief support after the death of a child.
P.O. Box 3696
Oak Brook IL 60522-3696
(877) 969-0010

www.compassionatefriends.org

Bereaved Parents of the USA

Offers information and support to parents and families who are struggling with the death of a child.
PO Box 95
Park Forest, IL 60466
Fax (708) 748-9184

www.bereavedparentsusa.org

Parents of Murdered Children

Provides resources, support and advocacy information to parents of murdered children.
National POMC
100 East Eighth Street, Suite B-41
Cincinnati, OH 45202
(513) 721-5683 or 1-888-818-POMC

www.pomc.com

GRIEF AND LOSS

by Marcia Lattanzi-Licht

Here are some questions and answers to help you through the death of a loved one:

- What influences how we grieve? It depends not only on the age of the person who died, your relationship with him or her and the circumstances of death, but also on your own age and life experience, how much support you have, your beliefs and your personality.
- What does it feel like to grieve? You may experience any or all of the following: guilt or anger, restlessness, a sense of unreality about the loss, difficulty sleeping, eating and concentrating, mood changes, a loss of energy, constant thoughts of the person who died, and a need to talk about him or her.
- How do we “get over” grief? Grief is not an illness or disease to conquer. It is the response to loss. There is no timetable for grief. How soon you integrate the loss and learn to live with it depends on your relationship to the person who died and your own adjustment to the empty space he or she left behind. Be prepared for the fact that grief changes you.
- What is the best way to support someone who is grieving? Acknowledge the importance of the loss by attending the funeral or with calls, notes, visits or memorial donations. Offer practical help of meals, rides or babysitting. Be available to listen. Talk about the person who died, remembering personal qualities, stories or moments shared.
- What should you never say to a person who has lost a loved one? Never tell the person to think of things to be grateful for (no more suffering, remaining children, years shared, etc.) Never tell the person to hide grief, stop feeling grief, or that it’s time to “get back to normal.”
- What steps should an employer take when an employee loses a spouse or child? Employers can help by inquiring about the loss, listening, and being open to negotiating time off during the first year following widowhood.
- What are some ways to help children grieve? Depending on their developmental stage, they may have a hard time grasping the concept of death’s permanence. Children also tend to move in and out of grief; one minute they seem fine and the next they don’t. In general, explain as much as you can in a way they will understand. Don’t lie or hide the truth. Let them ask questions and give them plenty of time to talk. Try to maintain your family routines and rules. Tell your child that you feel sad and are grieving, and that it is OK if they feel the same way. But don’t lean on him or her for support. Get counseling for yourself, so you can be stronger for your child. Tell your child’s teacher what has happened. And try to make sure many caring people are available to your child.
- Are there resources on the Web that can help grieving people? Yes, but do not let Web-based grief sites substitute for personal interaction with others. Also, be wary of Web sites that try to take advantage of your bereavement, particularly ones that want to sell you something — memory quilts made out of the loved one’s clothes, candles, journals, commemorative lighted portraits, memorial trees or vanity press biographies. If you see the words, “A Treasured Gift for Those Who Mourn,” hold on to your wallet.
- Where can I get help? Look for bereavement support close to home first. Contact your church, synagogue or mosque; hospices and hospitals; mental health or counseling centers; funeral homes or local aging organizations.

AARP

Information for widows and widowers.
601 E St., NW
Washington, DC 20049
1-800-424-3410

www.aarp.org./griefandloss/

Hospice Foundation of America

Offers information to professionals and families about caregiving, terminal illness, loss and bereavement.
2001 S Street, NW, Suite 300
Washington, DC 20009
(202) 638-5419 or 1-800-854-3402

www.hospicefoundation.org

The Compassionate Friends

For parents who have lost a child.
PO Box 3696
Oakbrook, IL 60522
(877) 969-0010

www.compassionatefriends.org

National Hospice and Palliative Care Organization

Provides a search for hospice and palliative care, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.nhpco.org

The Center for Grieving Children

Provides educational and support materials to grieving children, teens, their families, schools and other community agencies who support them.

49 York Street
P.O. Box 1438
Portland, ME 04104
(207) 775-5216

www.cgcmaine.org



VISION FOR THE FUTURE

by Dan Tobin

Here are 10 tips to help you navigate through the end of life:

- Get a plan. Keep the person with advanced illness at the center of the conversation when orchestrating a plan. Gather information in a calm manner, focusing on one problem at a time. And remember: Each person's situation will be unique, so custom-fit the plan to the individual.
- Get informed. Open and maintain a clear channel of communication with your doctors in order to understand your illness and the treatments available.
- Keep everyone on the same page. Have frequent conversations with family members so that everyone understands the choices, the planning process and the timetable.
- Broaden the plan. From the start, incorporate community services and caregiver support in the plan so that family members don't burn out from caregiving just when they're needed the most.
- Confront fear. Facing and discussing fears can lessen their power and help smooth planning. Write down a list of the biggest fears and discuss them with friends, family and your medical team.
- Control the pain. Work closely with your medical team to make pain-control and symptom management centerpieces of your treatment plan.
- Stay calm. Consider using stress management techniques, like relaxation or other forms of meditation.
- Go with the flow. Monitor medical conditions as the illness changes course. When the time comes for moving beyond cure-based or life-prolonging care, be ready to shift gears into a palliative, or comfort, stage of treatment. Look into the benefits of hospice. Think of dying as a natural part of life, and see these changes as akin to a running river.
- Know the power of dying. With attention and sensitivity, this final phase can provide a rich well of

life-changing and consciousness-raising experiences, both for patient and family. See it as the precious chapter of life that it is, a time to reach closure with respect and dignity. For many, this is a time to say farewell, to be introspective, and to search for meaning in life as well as find peace of mind.

- Use your time well. Look for opportunities for closure — to say goodbye, to ask for forgiveness, to forgive others, and to embrace love as the meaning of life.

Partnership for Caring: America's Voices for the Dying

Download forms for advance directives tailored to your state; join a consumer advocacy group focused on improving end-of-life care.

PFC Publications – Publications Office
325 East Oliver Street
Baltimore, MD 21202
Hotline: 1-800-989-9455 (option 2)

<http://www.partnershipforcaring.org>

The National Hospice and Palliative Care Organization

Provides a search for hospice and palliative care, as well as statistics, resources and information.

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(703) 837-1500

www.nhpco.org

American Academy of Hospice and Palliative Medicine

Find board-certified hospice and palliative care physicians.

4700 W. Lake Ave.
Glenview, IL 60025-1485
(847) 375-4712

www.aahpm.org

The Last Acts® Campaign

Research latest news on legislative, educational and policy initiatives from local, state and national organizations.

1951 Kidwell Drive, Suite 205
Vienna, VA 22182
(703) 827-8771

www.lastacts.org

Growth House

Excellent source for books and other publications regarding end-of-life care.

San Francisco, CA
(415) 255-9045

www.growthhouse.org

Aging With Dignity

Provides Five Wishes, an advance directives planning document.
1-888-5-WISHES

www.agingwithdignity.org

AARP

Offers extensive information on and support for caregiving, illness, grief, widowhood, funerals, wills and estate planning and advance directives.

601 E St., NW
Washington, DC 20049
1-800-424-3410

www.aarp.org/endoflife

The Center for Advanced Illness Coordinated Care, in collaboration with the Veteran's Administration Healthcare Network of Upstate New York at Albany

Find guidance on coping with the complexities of serious illness through the "Walking the Advanced Illness Road" section.

113 Holland Avenue (111t)
Albany, NY 12208
(518) 626-6088

www.coordinatedcare.net

Community-State Partnerships to Improve End-of-Life Care

Find out what individual states are doing to organize health care professionals, educators and policymakers.

(816) 842-7110

www.midbio.org

Project on Death in America

Lists innovations in the arts, social work, education and public policy.

Open Society Institute
400 West 59th Street
New York, NY 10019
212-548-0150

www.soros.org/death

Center to Advance Palliative Care

Search the latest resources in palliative care available to hospitals and health care systems.

Mount Sinai Hospital
One Gustave L. Levy Place, Box 1070
New York NY 10029-6547

www.capcmssm.org

Missoula Demonstration Project

Research tool for communities interested in setting up models for improved care at the end of life.

320 Main Street
Missoula, MT 59802
(406) 728-1613

www.dyingwell.com/MDP.htm

Promoting Excellence in End-of-Life Care

Research innovative programs that have received grants and technical support to change the face of dying in America.

The University of Montana
1000 East Beckwith Avenue
Missoula, Montana 59812
(406) 243-6601

www.endoflifecare.org

Americans for Better Care of the Dying

Track changes in public policy, as well as reforms in pain management and support for family caregivers.

4125 Albemarle Street, NW, Suite 210
Washington, DC 20016
(202) 895-9485

www.abcd-caring.org