

Resources for End of Life Issues

{niftybox width=180px,float=right,textalign=left}Related: WebCafe's online support forum: Dealing with grief and loss
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Do Not Resuscitate Orders

Advance Directives

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Final Days Websites

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Miscellaneous

For Children whose parents have cancer

Recommended Reading

Books For Kids

This section of WebCafe surveys some of the many practical areas which may need to be considered when moving into and through 'The Dying Time'.

This selection of resources is by no means exhaustive; nor will it prescribe or describe, because what feels right for one may not be right for someone else. We are not lawyers or physicians. We are presenting areas which we think are important to consider and address. Laws and customs vary by state and country, and you will need to familiarize yourself with your local regulations and resources when making your plans. There is much available information, and the pathway each journey takes is very personal.

DNR Orders: [Do Not Resuscitate Orders]

Please check your search engine under "DNR Orders" for material for your geographic area. Laws and hospital administrative procedures vary by state, and there may even be certain religious hospitals which mandate more restrictive use of these orders. DNR orders typically are written into the patient's hospital chart, may have to have hospital administrators' input or oversight, and may have to be renewed after any change in the patient's condition or on a specific timetable.

www.health.state.ny.us

The New York State Department of Health has a guidebook for patients and families on DNR Orders

www.premack.com also

has information on these orders. He is a lawyer who writes on this topic and has information clarifying the various types of DNR orders.

Advance Directives

This is an umbrella term for a variety of specific plans and instructions concerning end of life issues, management of medical states or conditions,

and whom you designate to make medical decisions for you. Laws concerning advance directives vary by state and country so please check the regulations for your area. Hospice and palliative care staff might be especially helpful here. There are also standard forms which each hospital maintains, and which may be addressed with you and your family on, or soon after, admission.

www.hcfa.gov/pubforms

This site has information and forms for advanced directives.

<http://cis.nci.nih.gov>

Ask for fact sheet 8.12

www.familydoctor.org

Handouts on DNR and advanced directives

www.blackwomenshealth.com

information about advanced directives

Living Wills

This is a legal document outlining what you want done [or not done] for you during your last days. Again, there may be state and hospital constraints, so local legal advice may be helpful and even necessary. In a living will you may also be designating someone to be your healthcare proxy, someone to make medical decisions for you when you are no longer capable of doing so. Multiple copies of this document must be available-in your hospital chart, in the hands of family members who will be making decisions, in the hands of the treating physician, etc. It cannot be locked in a file cabinet in a lawyer's office along with your regular Last Will and Testament.

www.sentex.net for locating

information around the world on living wills

www.nysba.org for pamphlets
and proxies

Power of Attorney

This is an important legal document in which one person grants to another the power to make important personal decisions. In this case, the decisions may have to do with finances and any other affairs which may need to be dealt with. It is especially important for a lover or domestic partner to have one of these in place, as they may not have any legally recognized decision making standing regarding the patient. It should be written by the grantor's attorney, insuring that the grantor's wishes are encompassed; and then reviewed by the grantee's attorney, so that unwelcome or unexpected responsibilities or risks are not being assumed. Legal involvement is also important because it must be drafted in compliance the laws of the jurisdiction in which it will be filed, and to withstand legal challenges. Regulations and specifics vary by state and country. The scope of the document can range from general to specific, and may also have temporal limitations. It should clearly reflect the scope and/or limitations of your actions, as desired by the person granting this power of attorney.

Final Days Websites:

www.choices.org This is a non-profit organization dedicated to helping people make end of life decisions.

www.partnershipforcaring.org

www.beliefnet.com

www.compassionindying.org

www.deathwithdignity.org

www.finalthoughts.com

www.hemlock.org hemlock@hemlock.org

www.funerals.org - information about laws and planning

www.health.state.ny.us/nysdoh/consumer/patient/funeral.htm

A New York State site about state regulations and FAQs about funerals.

www.wnet.org/archive/bid/index.html This was a PBS 1997 program called "Before I Die" which dealt with end of life medical and ethical issues, and personal choices.

www.crossingthecreek.com

This is a personal and non-technical approach to what to expect. An especially helpful section contains information about what to expect as different body systems begin to stop functioning. This site focuses on physical changes, relationships, personal development, and life transitions.

www.pbs.org/wnet/onourown/terms/

This was a wonderfully sensitive Bill Moyers program on dying, including many good discussions and tools.

http://www.acponline.org/public/h_care/7-final.htm

This page from the site of the American College of Physicians has a lot of good information on the final weeks of life.

Hospice sites

www.hospicefoundation.org

Hospice Foundation of America: site provides information about hospice, including caregivers' stories.

www.hospicenet.org

There is information about how to find a local hospice, end of life issues, caregiving, bereavement, and FAQs about hospice.

www.nhpco.org

Run by the National Hospice and Palliative Care Organization, this presents information about hospice services.

www.hospice.web

Hospice Web provides information about hospice service and has a national directory of hospices.

www.americanhospice.org

The American Hospice Foundation provides much hospice information, and maintains useful links and listings of hospices with websites.

www.chionline.org

This site is for Children's Hospice International, a site for support of dying children and their families.

www.hospicepatients.org

This Hospice Patients Alliance: Consumer Advocates site has information on symptom management regulations and focuses on the consumer advocate issues of hospice care.

Other sites [600,000+] are available through your search engine under "Hospice."

Miscellaneous

These next two sites are not specifically devoted to hospice or services for the dying, but are helpful resources for locating services.

www.carescout.com

is a link to various assisted living resources. Click on "assisted

living" and then type in your county.

www.senioroptions.com/management.html

is a very helpful site for locating a case manager, a sort of private social worker who can help you locate services in particular geographical areas, and may also help you figure out exactly what you need. This is especially helpful if you are trying to locate services for someone who does not live near you.

Sites for Children Whose Parents Have Cancer:

www.kidscope.org

Recommended Reading

Cancer as a Turning Point - Lawrence LeShan - an excellent book on having cancer, with an extraordinary chapter on dying, on working with and being with the dying patient, on unfinished business, and some exceptional mediations.

On Death and Dying: Elizabeth Kubler-Ross

Life Lessons: Elizabeth Kubler-Ross

Final Gifts - Callahan

Final Exit - Derek Humphrey

The Mourning Handbook - Fitzgerald

Will the Circle Be Unbroken - Studs Turkel

The Tibetan Book of Living and Dying

Caring for the Dead - Lisa Carlson

Readings for Remembrance and Memorials - E Munroe

When we Die - The science, culture and rituals of death - Cedric Mims

For Children:

The 10th Good Thing about Barney - J. Viorst

When Someone Very Special Dies - - Heegard

Help Me Say Goodbye - Silverman

The Day I Saw My Father Cry - Cosby

Sadako and the 1000 Paper Cranes - E. Coerr

Many thanks to Karen J. Greene for compiling these resources for WebCafe