

Bibliography - Appendix A, Care Subcommittee References and Resources

Periodicals, Articles, Abstracts

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Rosenblatt A; Ranan NG; Nance MA; Paulsen J; (1999) Physician's Guide to the Management of Huntington's Disease (Second Edition); NY: Huntington's Disease Society of America.

Web based Resources

Tomorrow's Tools for Improving End of Life Care (www.lastacts.org)

Advance Directives (available by state) (www.lastacts.org)

Values History Form (www.hsc.unm.edu/ethics/)

General Internet Resources

Aging with Dignity – site provides professionals and families with practical information, advice and legal tools needed to improve quality for care (www.agingwithdignity.org)

Brown University/Department of Neurology – provides news and educational materials related to neurology. Articles include driving and dementia (www.brown.edu/departments/clinical_neurosciences/articles/bo38396.html) and (www.brown.edu/departments/clinical_neurosciences/articles/ww44099.html)

Center for Bioethics and Human Dignity – helps individuals and organizations to address the pressing bioethical challenges, including managed care, end-of-life treatment, genetic intervention, euthanasia and suicide, and reproductive technologies (www.cbhd.org)

Hospice Foundation – non-profit organization that assists those who must cope either personally or professionally with terminal illness, death and the grief process (www.hospicefoundation.org)

Huntington's Disease Advocacy Center – provides information to family members affected by HD, including caregivers, living at risk, and newly diagnosed. See recipes for nutrition (www.hdac.org).

Huntington's Disease Society of America – organization dedicated to finding a cure for HD, providing support and services to those living with HD and their families, and educating the public and healthcare professionals about the disease. Literature may be found under Information/publications (www.hdsa.org)

International Huntington Association – federation of voluntary health agencies that share common concern for people affected by HD and their families (www.huntington-assoc.com)

International Labor Organization – a specialized United Nations agency that seeks the promotion of social justice and internationally recognized human and labor rights. There exist multiple definitions of competence. A generally accepted concept establishes it as an effective ability to carry out successfully some labor activity that is totally identified. Competence is not a probability of success in the execution of one's job; it is a real and demonstrated capability (www.ilo.org/public/english/region/ampro/centerfor/)

Last Acts – for professionals and volunteers working to improve care of the dying (www.lastacts.org)

Make a Wish Foundation – grants wishes to children with life-threatening medical conditions to enrich the human experience with hope, strength and joy (www.wish.org)

Promoting Excellence – for professionals and volunteers dedicated to long-term changes to improve healthcare for dying people and their families through technical assistance to innovative demonstrative projects addressing particular challenges to existing models of hospice and palliative care (www.promotingexcellence.org)

University of Kansas Medical Center – web site provides general information about HD including nutrition, safety, driving, smoking, speech and more.

(www.kumc.edu/hospital/huntingtons/)

University of Dundee/Department of Psychology – provides information about social competence focusing on curriculum-based approaches to enhance personal, social, emotional and behavioral competence and development for all pupils in primary and secondary schools (www.dundee.ac.uk/psychology/prosoc/socom.htm)

University of Chicago – provides information about feeding and nutrition issues for those affected by HD (www.lib.uchicago.edu/~rd13/hd/tube.html). This link provides information about various kinds of food suitable for HD

(www.lib.uchicago.edu/~rd13/hd/ideas.html)

University of California at Davis Medical Center – link describes gastric tube feeding (www.ucdmc.ucdavis.edu/edu/healthed/PtHndOut/asstrost.pdf)

Other Resources Information & Education

HDSA Centers of Excellence provide in-service training or educational programs for professionals caring for people with HD. The HDSA annual convention and HDSA state and/or regional mini-conventions provide education and resources for people with HD and their families.

Equipment and Devices

Physical, occupational and speech therapists have access to devices and equipment, and are knowledgeable about resources in the local area where materials can be purchased. Long-term care facilities that specialize in late stage HD care know where unusual items can be obtained and HDSA publications also provide information about items unique or special to HD. Devices that assist motor skills, such as a walker and wheelchair, may increase social competence. Communications devices may be critical.

Service Resources

Physicians, social workers, psychologists, financial advisors, legal experts, religious support, and home helpers play important roles. Physical therapists and speech language pathologists may increase the competence of the person with HD. They also play important roles in assisting communication and independence. Agencies and facilities for assisted living, long-term care and hospitals provide important services.

Appendix B – Education Subcommittee References and Resources

Cited Periodicals, Abstracts, Articles, Web sites

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General Internet Resources

Aging with Dignity – see Care Subcommittee description of web site (www.agingwithdignity.org)

American Hospice Foundation – dedicated to improving access to quality hospice care through public education, professional training and consumer advocacy (www.americanhospice.org)

Americans for Better Care of the Dying – organization dedicated to ensuring that all Americans can receive good end of life care by building momentum to reform; exploring new methods and systems for delivering care; and shaping public policy through evidence-based understanding (www.abcd-caring.org)

Caregiver.com – web site that includes specific newsletters, online discussion lists, back issues of Today’s Caregiver magazine and chat rooms for caregivers (www.caregiver.com)

Center to Advance Palliative Care – web site serves as a resource to hospitals and other healthcare venues interested in developing palliative care programs. CAPC is a nationally supported initiative of the Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine (www.capcmssm.org)

Choices in Dying – part of the Partnership in Caring initiative, which partners individuals and organizations in an effort to improve how Americans die (www.choices.org)

Compassionate Friends - this web site assists families in the grieving process following the death of a child of any age as well as provide information to help others to be supportive (www.compassionatefriends.org)

Completing a Life - organization that helps patients and families to learn about the practical, emotional, spiritual and medical issues faced by those dealing with an advanced illness (www.completingalife.msu.edu)

Children's Hospice International - provides education, training, and technical assistance to those who care for children with life-threatening conditions and their families. They promote hospice support through pediatric care facilities; encourage existing hospice, palliative and home care programs to include children and to include hospice perspectives in all areas of pediatric care, education and the public.

(www.chionline.org)

City of Hope Pain Resource Center (USA) - research, treatment and educational institution that is dedicated to the prevention and cure of cancer, HIV/AIDS, diabetes, and other life-threatening diseases (www.cityofhope.org)

Dying Well – web site of Ira Byock, M.D. Discusses end of life issues and how Americans can prepare for and have a better death (www.dyingwell.org)

End of Life Physician Education Resource Center – assists physicians and other educators who are involved in physician end of life education (www.eperc.mcw.edu)

Family Caregiver Alliance – California based organization that provides information about a variety of caregiver issues and specifically regarding California

(www.caregiver.org)

Growth House - organization to improve the quality of compassionate care for people who are dying through public education and professional collaboration

(www.growthhouse.org)

National Association of Home Care and Hospice - nation's largest trade association representing home care agencies, hospices, home care aide organizations, and medical equipment suppliers (www.nahc.org)

Hospice Foundation of America - non-profit organization that assists those who must cope either personally or professionally with terminal illness, death and the grief process

(www.hospicefoundation.org)

Huntington's Disease Society of America – see Care Subcommittee for description of web site (www.hdsa.org)

Last Acts – see Care Subcommittee description of web site (www.lastacts.org)

Innovations in End of Life Care – supports programs and projects in research, policy and practice that address critical challenges around the world in education, health, technology and human rights (www.edc.org)

National Family Caregivers Association - association that supports family caregivers as they cope with long term/chronic illness (www.nfcacares.org)

National Hospice and Palliative Care Organization – national non-profit organization whose mission is to advance the art and science of end-of-life care (www.nhpco.org)

National Patients Advocate Foundation – seeks to create access to insurance funding for evolving therapies, therapeutic devices and agents through legislative and policy reform (www.npaf.org)

National Respite Locator Services - site links to national respite locator services which helps parents, caregivers, and professionals find respite services in their state and local area. The service is also useful when a family travels or must move to another state

(www.chtop.com)

Partnership for Caring - non-profit organization that partners individuals and organizations in an effort to improve how Americans die (www.partnershipforcaring.org)

Promoting Excellence – see Care Subcommittee for description of web site

(www.promotingexcellence.org)

Appendix C – Research and Policy Subcommittee References and Resources

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