

Bibliography - Appendix A, Care Subcommittee References and Resources

Periodicals, Articles, Abstracts

Brammer LM; (1992) Coping with Life Transitions (Social Interaction Model; Predictable Overlapping Stages; Coping Attitudes and Skills); MI: Eric Clearing House on Counseling and Personnel Services; pages 2-6

Byock I; (1998) Dying Well: Peace and Possibilities at the End of Life; NY: Riverhead Books.

Ferrell BR; Virani R; Grant M; (1998) Improving End-of-Life Care Education in Home Care; *Journal of Palliative Medicine*; 1: 11-18

Gillick MR; (2000) Rethinking the Role of Tube Feeding in Patients with Advanced Dementia; *New England Journal of Medicine*; 342:206-210 and responses in same volume 342:1755-1756

Kristjanson LJ; (2001) Establishing Goals: Communication Traps and Treatment Lane Changes; Oxford University Press, pages 332-337.

Lodi R; Schapira AH; Manners D; Styles P; Wood NW; Taylor DJ; Warner TT; (2000) Abnormal in vivo Skeletal Muscle Energy Metabolism in Huntington's Disease and Dentatorubropallidolusian Atrophy; *Annals of Neurology*; 48:72-76

Nance MA; (2001) The Juvenile HD Handbook; NY: Huntington's Disease Society of America.

Nance MA; (2001) Youth and Juvenile Huntington's Disease: Finding Time for Fun; *The Marker*; HDSA.

Paulsen JS; (1999) Understanding Behavior in Huntington's Disease; NY: Huntington's Disease Society of America.

Pollard J; (1999) "Looking Beneath the Veil," presentation at Huntington's Disease Association of Ireland Annual Grand Meeting, Roscommon, Ireland.

Pollard J; Best R; Imbriglio S; Klasner E; Rubin A; Sanders G; Simpson W; (1999) A Caregiver's Handbook to Advance-Stage Huntington's Disease; NY: Huntington's Disease Society of America.

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

1. Hopes and Dreams newsletter (author unknown), page 1, “Coping with Caregiver Grief” (summer 1999).

2. Sobel and Cowan, (2000) "The Impact of Genetic Testing for Huntington's Disease on the Family System"; American Journal of Medical Genetics; Vol.90: No.1
3. Wexler: Living Out the Dying: HD, Grief and Death, 1975
4. Doka, (1989) Disenfranchised Grief, Lexington MA: Lexington Books
5. Anonymous, (1999) "Coping with Caregiver Grief", Hopes and Dreams newsletter, page 1.
6. Byock I; (1997) Dying Well: The Prospect for Growth at the End of Life; Putnam Publishing
7. Moskowitz C; Marder K; (2001) "Palliative Care for People with Late-Stage Huntington's Disease"; Neurologic Clinics; 19:4
8. Alzheimer's Association website: www.alz.org/resourcecenter/programs.htm

Additional Periodicals, Abstracts, Articles Used in Education Subcommittee report but not specifically cited:

- Clerico C; (2001) "Huntington's Disease, Occupational Therapy, and Lemonade"; OT Practice; 6:6, 17-20
- Dunn H; (2001) Hard Choices for Loving People; VA: A & A Publishers
- Lyons M; Orozovic N; Davis J; & Newman J; (2002) "Doing-Being-Becoming: Occupational Experiences of Persons with Life Threatening Illnesses"; American Journal of Occupational Therapy, 56:285-295
- "Measuring Quality of Care at the End of Life: A Statement of Principles"; (1997) Journal of the American Geriatrics Society; 45:526-527
- Pollard J; (1999) A Caregiver's Handbook for Advanced-Stage Huntington's Disease; Huntington's Disease Society of America
- Prochnau C; Liu L; Boman J; (2003) "Personal-Professional Connections in Palliative Care Occupational Therapy"; American Journal of Occupational Therapy; 57:2, 196-203
- Sobel S; Cowan D.B; (2000) "The Process of Family Reconstruction after DNA Testing for Huntington's Disease"; Journal of Genetic Counseling; Vol 9: No. 3
- Sobel S; Cowan D.B; (2003) "Ambiguous Loss and Disenfranchised Grief: The Impact of DNA Predictive Testing on the Family as a System"; Family Process; Vol. 42: No. 1

Steinhauser K; Clipp E; McNeilly M; Christakis N; McIntyre L; Tulsky J; (2000) “In Search of a Good Death: Observations of Patients, Families and Providers”; *Annals of Internal Medicine*; 132:825-832

Teno J; Fisher E, Hamel M; et al.; (2000) “Decision-making and Outcomes of Prolonged ICU Stays in Seriously Ill Patients”; *Journal of the American Geriatric Society*; 48:S70-S74

Thibeault R; (1997) “A Funeral for My Father’s Mind: A Therapist’s Attempt at Grieving”; *Canadian Journal of Occupational Therapy*; 64(3):107-114

Volicer L; Hurley A; (1998) “Hospice Care for Patient’s with Advanced Progressive Dementia”; NY: Springer

Wolpe D; (1999) *Making Loss Matter: Creating Meaning in Difficult Times*; Putnam Publishing

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

1. Shoulson I.; (1981) Huntington's disease: Functional capacities in patients treated with neuroleptic and antidepressant drugs; *Neurology*; 31:1333-1335.
2. Shoulson I, Fahn S; (1979) Huntington disease: clinical care and evaluation; *Neurology*; 29(1):1-3.
3. Di Maio L, Squitieri F, Napolitano G, Campanella G, Trofatter JA, Conneally PM; (1993) Onset symptoms in 510 patients with Huntington's disease; *J Med Genet*; 30(4): 289-292.
4. Penney JB, Jr., Young AB, Shoulson I, Starosta-Rubenstein S, Snodgrass SR, Sanchez-Ramos J, et al.; (1990) Huntington's disease in Venezuela: 7 years of follow-up on symptomatic and asymptomatic individuals; *Mov Disord*; 5(2): 93-99.
5. Brandt J, Bylsma FW, Gross R, Stine O, Ranen N, Ross CA; (1996) Trinucleotide repeat length and clinical progression in Huntington's Disease; *Neurology*; 46:527-531.
6. Kiebertz K, MacDonald M, Shih C, Feigin A, Steinberg K, Bordwell K, et al.; (1994) Trinucleotide repeat length and progression of illness in Huntington's disease; *J Med Genet*; 31(11): 872-874.
7. Illarioshkin SN, Igarashi S, Onodera O, Markova ED, Nikolskaya NN, Tanaka H, et al.; (1994) Trinucleotide repeat length and rate of progression of Huntington's disease; *Ann Neurol*; 36(4): 630-635.
8. Kirkwood SC, Siemers E, Stout JC, Hodes ME, Conneally PM, Christian JC, et al.; (1999) Longitudinal cognitive and motor changes among presymptomatic Huntington disease gene carriers; *Arch Neurol*; 56(5): 563-568.
9. Sorensen SA, Fenger K; (1992) Causes of death in patients with Huntington's disease and in unaffected first degree relatives; *J Med Genet*; 29(12): 911-914.
10. Haines JL, Conneally PM; (1986) Causes of death in Huntington disease as reported on death certificates; *Genet Epidemiol*; 3(6): 417-423.
11. Farrer LA; (1986) Suicide and attempted suicide in Huntington disease: implications for preclinical testing of persons at risk; *Am J Med Genet*; 24(2): 305-311.
12. Maat-Kievit A, Losekoot M, Van Den Boer-Van Den Berg H, Van Ommen GJ, Niermeijer M, Breuning M, et al.; (2001) New problems in testing for Huntington's disease: the issue of intermediate and reduced penetrance alleles; *J Med Genet* 38(4): E12.
13. McCusker EA, Casse RF, Graham SJ, Williams DB, Lazarus R; (2000) Prevalence of Huntington disease in New South Wales in 1996; *Med J Aust*; 173(4): 187-190.
14. Almqvist EW, Elterman DS, MacLeod PM, Hayden MR; (2001) High incidence rate and absent family histories in one quarter of patients newly diagnosed with Huntington disease in British Columbia; *Clin Genet*; 60(3): 198-205.
15. Falush D, Almqvist EW, Brinkmann RR, Iwasa Y, Hayden MR; (2001) Measurement of mutational flow implies both a high new-mutation rate for

- Huntington disease and substantial underascertainment of late-onset cases; *Am J Hum Genet*; 68 (2):373-385.
16. Harper PS, Lim C, Craufurd D; (2000) Ten years of presymptomatic testing for Huntington's disease: the experience of the UK Huntington's Disease Prediction Consortium; *J Med Genet*;37(8):567-571.
 17. Binedell J; Soldan JR; Harper PS; (1998) Predictive testing for Huntington's disease: II. Qualitative findings from a study of uptake in South Wales; *Clin Genet*; 54 (6): 489-496.
 18. Quaid KA; Morris M; (1993) Reluctance to undergo predictive testing: the case of Huntington disease; *Am J Med Genet*; 45:41-45.
 19. Tyler A; Ball D; Craufurd D; (1992) Presymptomatic testing for Huntington's disease in the United Kingdom. The United Kingdom Huntington's Disease Prediction Consortium [see comments]; *Bmj*; 304(6842): 1593-1596.
 20. Huntington Study Group; (1996) The Unified Huntington's Disease Rating Scale: reliability and consistency; *Movement Disorders*; 11(2):136-142.
 21. Marder K; Zhao H; Myers RH; Cudkowicz M; Kayson E; Kiebertz K; et al.; (2000) Rate of functional decline in Huntington's disease; *Huntington Study Group. Neurology*; 54(2): 452-458.
 22. Kirkwood SC; Su JL; Conneally P; Foroud T; (2001) Progression of symptoms in the early and middle stages of Huntington disease; *Arch Neurol*; 58(2):273-278.
 23. Nance MA; Sanders G; (1996) Characteristics of individuals with Huntington disease in long-term care; *Mov Disord*; 11(5): 542-548.
 24. Murman DL; Chen Q; Colucci PM; Colenda CC; Gelb DJ; Liang J; (2002) Comparison of healthcare utilization and direct costs in three degenerative dementias; *Am J Geriatr Psychiatry*; 10(3): 328-336.
 25. Bolt JM; (1970) Huntington's chorea in the West of Scotland; *Br J Psychiatry*; 116(532): 259-270.
 26. Dewhurst K; Oliver J; (1970) Huntington's disease of young people; *Eur Neurol*; 3(5):278-289.
 27. Barron LH; Warner JP; Porteous M; Holloway S; Simpson S; Davidson R; et al.; (1993) A study of the Huntington's disease associated trinucleotide repeat in the Scottish population; *J Med Genet*; 30(12): 1003-1007.
 28. Chiu E; Teltscher B; (1978) Huntington's disease: the establishment of a national register; *Med J Aust*; 2(8): 394-396.
 29. Folstein SE; Chase GA; Wahl WE; McDonnell AM; Folstein MF; (1987) Huntington disease in Maryland: clinical aspects of racial variation; *Am J Hum Genet*; 41(2):168-179.
 30. Barozak P; Pedlar A; Hunter S; Betts T; (1987) Institutional care for patients with Huntington's chorea: is there a better alternative?; *Bull R Coll Psychiatry*; 11:187-188.
 31. Simpson SA; Davidson MJ; Barron LH; (1993) Huntington's disease in Grampian region: correlation of the CAG repeat number and the age of onset of the disease; *J Med Genet*; 30(12): 1014-1017.
 32. Arai Y; Sugiura M; Washio M; Miura H; Kudo K; (2001) Caregiver depression predicts early discontinuation of care for disabled elderly at home; *Psychiatry Clin Neurosci*; 55(4):379-382.

33. Chang BL; Brecht ML; Carter PA; (2001) Predictors of social support and caregiver outcomes; *Women Health*; 33(1-2): 39-61.
34. Sorensen SA; Fenger K; Srensen SA; (1992) Causes of death in patients with Huntington's disease and in unaffected first degree relatives; *J Med Genet*; 29(12): 911-914.
35. Di Maio L; Squitieri F; Napolitano G; Campanella G; Trofatter JA; Conneally PM; (1993) Suicide risk in Huntington's disease; *J Med Genet*; 30(4): 293-295.
36. Imaizumi Y; (1989) Mortality rate of Huntington disease in Japan: secular trends, marital status, and geographical variations; *Jinrui Idengaku Zasshi*; 34(2): 169-178.
37. Mezey M; Teresi J; Ramsey G; Mitty E; Bobrowitz T; (2000) Decision-making capacity to execute a health care proxy: development and testing of guidelines; *J Am Geriatr Soc*; 48(2): 179-187.
38. Goldblatt D; (2001) A messy necessary end: Health care proxies need our support; *Neurology*; 56(2): 148-152.
39. Poertner LC; Coleman RF; (1998) Swallowing therapy in adults; *Otolaryngol Clin North Am*; 31(3): 561-579.
40. Applebaum PS; Grisso T; (1995) The MacArthur Treatment Competence Study; *Law Hum Behav*; 19(2):105-174.