

Palliative Care in Huntington's Disease

By Richard Dubinsky, M.D., University of Kansas Medical Center, HD Workgroup Chair



The 18-month project on palliative care, administered by the Huntington's Disease Society of America and sponsored by the Promoting Excellence in End-of-Life Care program, of the Robert Wood Johnson Foundation, is nearing completion. The End-of-Life Care program is a multi-year project, headed by Ira Byock, MD, a leader in the field of palliative care. The main goal of the program is to provide care and support to people dying of chronic illnesses and their families. The report of the HD Workgroup is scheduled for publication and dissemination in early June of this year. The report will cover the need for palliative care in those with Huntington's Disease and their families, and the resources that exist to meet those needs, as well as a call for the allocation of resources to fulfill the unmet needs.

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Today healthcare focuses on the treatment and cure of disease, yet many conditions are not curable and only the



symptoms can be treated. Palliative care can take many forms, including providing information, alleviation of pain and discomfort, and offering resources for families and caregivers. Hospice provides a full range of palliative care for those at the end of life. In Huntington's Disease, the need for palliative care is much earlier, takes many forms, and changes throughout the course of the disease. In the initial meeting of the HD Workgroup, palliative care was divided into the areas of education, care, and research and public policy.

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The need for *education*, as an aspect of palliative care, begins when the possibility of Huntington's Disease is first raised. Some members of the Workgroup actually defined the need for education as beginning at conception. But no matter how early the need for education may be as an aspect of palliative care, the needs change over time. Early on, there is the need for education about the basic facts of Huntington's Disease, including the genetics, clinical manifestations, and time course. As the disease becomes clinically apparent, the educational needs change to meet the change in occupational, behavioral and functional status. Unmet educational needs exist in training for medical students, physicians, nurses, social workers, therapists, as well as with first responders, mental health professionals, and most importantly the families of those with Huntington's Disease.

Providing care can be defined in many different ways. This Sub-Committee of the HD Workgroup chose to look at several dimensions or "domains" of care including autonomy, dignity, meaningful social interaction, communication, comfort, safety and order, spirituality, enjoyment, nutrition, and functional competence. They provided examples of the best possible care and worst-case scenarios as well as ways to change care to meet the needs of the patients and their families.

Through a gap analysis of the unmet needs in palliative care, the *research* sub-committee of the HD Workgroup were able to identify many areas that had very little information available to determine the needs for HD.

For example, a great deal is now known about the course of Huntington's Disease, but information is lacking about patients towards the end of life, specifically those in long-term care facilities. Their needs are not well known, and little is known about how people with Huntington's Disease spend the last few months or years of their lives.

The *public policy* changes that are needed to help those with Huntington's Disease and their families are many, and may be similar to those for many neurodegenerative diseases. Specific needs include coverage for medications, in-home care designed to keep people in the community and with their families as long as possible, and improvements in coverage for long term care. An extension or redefinition of Hospice benefits to before the last six months of life is also needed.

The scope of this project was ambitious; the call for action, based upon the results of the HD Workgroup, is even more so.



As a community, we need to disseminate the report to those who provide education and care to those with Huntington's Disease. We also need to advocate for improved and expanded healthcare coverage as we strive to maintain the dignity and comfort of those who need it the most, our families, friends, and patients.

The members of the HD Workgroup are involved in the care of people with Huntington's Disease, in other chronic degenerative disorders, and in the arena of public policy. The membership of the Sub-Committees included:

Education Sub-Committee:

Chair – Marilee Monnot, Ph.D. University of Oklahoma; Carol Clerico, OTR, HDSA Center of Excellence at the

University of Virginia Health Systems, Brookes Cowan, Ph.D., University of Vermont, Gary Barg, Editor, *Today's Caregiver*.

Care Sub-Committee:

Chair – Tetsuo Ashizawa, M.D., University of Texas Medical Branch, Martha Nance, M.D., HDSA Center of Excellence at Hennepin County Medical Center, Barbara Heiman, LISW, HDSA Center of Excellence at Ohio State University Medical Center, H. Taylor Butler, LICSW, HDSA Center of Excellence at Emory University, Frances Saldana, HD family caregiver.

Research and Public Policy Sub-Committee:

Chairs – Kathleen Shannon, M.D. Rush-Presbyterian-St. Luke's Hospital, Peter Como, Ph.D., HDSA Center

of Excellence at the University of Rochester, Charles Diggs, Ph.D. American Society of Speech-Language-Hearing Association, Bruce Jennings, M.A., The Hastings Center, Richard Dubinsky, M.D., University of Kansas, Chair HD Workgroup.

HDSA thanks

The Robert Wood Johnson Promoting Excellence in End-of-Life Care Program
for their commitment to palliative care and end of life issues for HD

HD Workgroup will lead HDSA's Focus on the Family Forum at HDSA Annual Convention!

Join members of the HD Workgroup on Friday, June 6 at 10:30 a.m. in a panel discussion as they explore palliative care and end of life needs for HD. Peter Como, Ph.D. will Chair this informative forum that will identify gaps and barriers to the delivery of services as well as discuss the many recommendations to the field that will be released shortly by the Robert Wood Johnson Promoting Excellence in End-of-Life Care program. Panelists will also include Tetsuo Ashizawa, M.D. Chair of the Care Sub-Committee, Richard Dubinsky, Chair of the HD Workgroup and acting Chair

of the Education Sub-Committee, Kathleen Shannon, M.D., Chair of the Research Sub-Committee, Bruce Jennings, M.A. for public policy, and Frances Saldana for caregivers. A question and answer session will close the Forum. This is an exceptional opportunity to hear about the findings of this innovative Workgroup specifically organized for Huntington's Disease and the recommendations they will be making to public policy makers, educators, professional caregivers, healthcare professionals and family members. Be sure to attend this groundbreaking Forum on June 6.

The HDSA Focus on the Family Forum is partially underwritten by a grant awarded to HDSA to explore palliative care/end of life issues for the Robert Wood Johnson Promoting Excellence in End-of-Life Care program. Ira Byock, M.D., Director of the Promoting Excellence in End-of-Life Care program, will give a keynote address, via videotape, as part of the HDSA Annual Convention's Opening Ceremony.