

# HDSA Publications

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<b>General Information</b>	
<b>Fast Facts About HD</b> HDSA, 2000. Presents key information about HD and HDSA.	Free, limit one per person**
<b>Huntington's Disease: A Guide for Families</b> HDSA, 1996, 21-page booklet. This short booklet offers an overview of HD.	\$2.00 each**
<b>Lifting the Veil of Huntington's Disease</b> Recommendations to the field from the Huntington's Disease peer workgroup.	Download Only

<b>Genetics and Genetic Testing</b>	
<b>Genetic Testing for Huntington's Disease: A Guide for Families</b> HDSA, 2009, 18-page booklet. An introductory guide to genetic testing for HD.	\$2.00 each**
<b>Genetic Testing Packet</b> Includes the following: 'Genetic Testing for Huntington's Disease - What's New?' Randi Jones, Ph.D. The Marker, Vol. 7, No. 1, 1994. 2 pages. List of HD testing centers. 'On Not Taking the Test' Alice Wexler, Ph.D. 1 Page. 'Life Goes On' The Marker, Spring 1994. 1 Page. 'Left Wondering' The Marker, Spring 1992. 2 Pages.	Download Only
<b>We've Got the Gene! But What Does It Mean?</b> Nancy Wexler, Ph.D. The Marker, Vol. 6 No. 2, 1993, 1 page.	Download Only
<b>Genetic Clairvoyance</b> Richard Saltus, The Boston Globe Magazine, 1995, 9 pages. The impact of a negative test result on a woman undergoing testing and her family.	Download Only
<b>The Neurogenetics Genie: Testing for the HD Mutation</b> Steven Hersch, MD, PhD; Randi Jones, PhD; Walter Koroshetz, MD; and Kimberly Quaid, PhD., Neurology, Vol. 44, No. 8, August 1994. 5 pages. Explanation of the testing guidelines written for health professionals.	Download Only

<p><b>Genetic Testing for Huntington's Disease: Its Relevance and Implications.</b> US Huntington's Disease Genetic Testing Group Revised 2003, 27 Pages. Presents the current diagnostic usefulness of genetic testing for HD and discusses the results of surveys that evaluate issues related to testing individuals at risk for this disease. This publication is extremely useful not only to those working in the HD community, but to all professionals who care for patients with adult-onset genetic disorders.</p>	<p>\$7.50 each**</p>
<p><b>Huntington's Disease: The Facts</b> By Dr. Oliver Quarrell, Oxford University Press, 2007. Written for a British audience by Dr. Oliver Quarrell, a consultant in Clinical Genetics, this "popular" guide to HD covers a wide range of topics including the genetic basis for HD, the disease's effect upon the brain and body, the psychological effects of HD, genetic counseling and current research directions. Some information may not be applicable in the US (e.g., insurance and legal information).</p>	<p>\$27.50 each</p>

<p><b>Caregiving</b></p>	
<p><b>Caregiving Packet</b> Includes the following: "Practical Hints for Care Givers' HDSA, 1988, 9 pages. Covers eating, swallowing, clothing, cleanliness, communication, smoking, recreation and attitudes. 'Nursing Tips: A Collection of Caregiving Hints' Beryl Westphal, 1995, HDSA, 9 pages. A compilation of professional caregivers' suggestions on feeding, communication, behavior and other daily concerns. 'Huntington's Disease Management' Edward Bird, et al., Middlesex County Hospital, MA, 1984, 6 pages. Dressing aids, relaxation, nutrition, communication, and physical fitness.</p>	<p>\$5.00 each</p>
<p><b>Nursing Approaches for Clients with Huntington's Disease</b> Winkie Simpson, Horizon, No. 76, Spring 1995, Huntington Society of Canada, 3 pages. Discussion of nursing strategies used at Runnymede Chronic Care Hospital, Toronto, Ontario.</p>	<p>Download Only</p>

<p><b>A Caregiver's Handbook for Advanced-Stage Huntington's Disease</b>          Jim Pollard, 2000, 69 pages. Written by medical professionals for at-home or care-center caregivers, this book addresses the unique circumstances presented by late-stage HD. Practical tips about how to care for an individual with HD cover eating and nutrition, communication, safety, hygiene, cognitive changes, emotional changes, medical issues and much more. Extensive indices provide a variety of medical, social and product resources.</p>	<p>\$7.00 each**          Temporarily Out Of Stock</p>
<p><b>Long Term Care: A Guide for Families</b>          Suzanne Imbriglio, PT, Virginia Goolkasian LSW/MS, Ann Murfitt LICSW. This pamphlet contains information about skilled nursing facilities, addressing special needs of HD patients and how to advocate for your loved one in a Long Term Care Facility.</p>	<p>\$2.00 each**</p>

<b><i>Clinical Care</i></b>	
<p><b>A Physician's Guide to the Management of Huntington's Disease (2nd Edition)</b>          Adam Rosenblatt, MD, Neal G. Ranen, MD, Martha A. Nance, MD, and Jane S. Paulsen, PhD. HDSA 1999. Includes in-depth information on: the general principles of treatment, a new section on genetic testing, updated information on medications, and an expanded section on the management of cognitive and behavioral problems.</p>	<p>\$12.50 each or          \$10.00 each for          25 or more**</p>
<p><b>Evaluating Driving Capacity in HD</b>          Allen J. Rubin, MD, University of Medicine and Dentistry of New Jersey, 1994, 11 pages. Practical guidelines to assist physicians and other professionals in making this difficult determination.</p>	<p>\$3.00 each</p>

<b><i>Physical and Occupational Therapy</i></b>	
<p><b>Huntington's Disease at Mid-Stage</b>          Suzanne Imbriglio, PT, Clinical Management, Vol. 12 No. 5, Sep/Oct 1992, American Physical Therapy Association, 11 pages. Explanation of how physical and occupational therapies benefits people with HD. Practical advice on designing a plan that combines maximum independence with minimal risk.</p>	<p>Download Only</p>
<p><b>Physiotherapy for Huntington's Disease Patients</b>          Anne Hoy, 5 pages, 1991. Discusses treatment and exercises.</p>	<p>Download Only</p>

<p><b>A Physical Therapy Program for HD Patients</b> Inez Peacock, Clinical Management in Physical Therapy, Vol. 7, 1987. A 7-page collection of information about her physical therapy program. Includes actual exercises.</p>	Download Only
<p><b>Occupational Therapy in Huntington's Disease</b> Cheryl Hicks, 5 pages. Describes group activities to help with physical, intellectual and psychological problems.</p>	Download Only
<p><b>Physical and Occupational Therapy for Huntington's Disease: A Guide for Families</b> Suzanne Imbriglio, PT, HDSA, 1997. Provides helpful information and resources for people in all stages of HD.</p>	\$2.00 each**

<b><i>Juvenile Huntington's Disease</i></b>	
<p><b>The Juvenile HD Handbook: A Guide for Physicians, Neurologists and Other Professionals</b> Martha Nance, MD, 2007. This book provides readers with information about Juvenile HD, including genetic testing, when it is appropriate to perform the test, how to understand your HD affected child, and what to do if you find yourself in compromising situations as well as where to turn for help.</p>	\$7.00 each**
<p><b>Juvenile HD: A Guide for Families</b> Edited by Martha Nance, MD, Randi Jones PhD, Suzanne Imbriglio PT &amp; Betsy Gettig MS/CGC. This pamphlet defines Juvenile HD, diagnosis, specific medical issues, prognosis of the disease, financial, legal &amp; social issues and more.</p>	\$2.00 each**
<p><b>The Juvenile Onset HD Resource Directory</b> Comprehensive resource guide for families of children affected by Juvenile Onset HD. Information about federal, state and local programs.</p>	\$10.00 each**

<b><i>Behavior</i></b>	
<p><b>Behavioral and Sexual Problems in Huntington's Disease</b> Shirley Dalby, from Horizon, No. 64, 1992, Huntington Society of Canada, 4 pages. This article by veteran British social worker Shirley Dalby, discusses in everyday language the kinds of changes in mood and behavior that can be experienced by</p>	Download Only

people with HD.	
<p><b>Understanding Behavior in Huntington's Disease: A practical guide for individuals, families and professionals coping with HD</b></p> <p>Jane S. Paulsen, PhD, 2000, 46 pages. A must-read for anyone who deals extensively with an HD-affected individual, this book explains not only the behavior challenges created by HD, but their origin in the HD-affected brain. By understanding the basis of these behaviors, Dr. Paulsen is able to suggest effective ways of dealing with and preparing for them. The book also covers environmental, individual and health factors that contribute to behavior problems. Problem-solving tips and techniques are given for behaviors arising from communication difficulties, memory problems, cognitive break-down and emotional instability.</p>	<p>\$7.00 each** Temporarily Out of Stock</p>

<b><i>Nutrition and Swallowing</i></b>	
<p><b>Coping with Speech and Swallowing Difficulties in Huntington's Disease: A Guide for Families</b></p> <p>Lynn Rhoades, MS, CCC-SLP, HDSA 1998, 26-page booklet.</p>	<p>\$2.00 each**</p>
<p><b>Mealtime Manual for Huntington's Disease Patients</b></p> <p>Folstein et. Al. Baltimore HD Research Center Without Walls, 1983 11 page guide to feeding, including recipes.</p>	<p>\$3.00</p>
<p><b>Managing Swallowing Difficulties Associated with HD</b></p> <p>Estelle R. Klasner, M.A., CCC-sp, Reg. OSLA, Huntington Society of Canada, 1990, 13 pages. This booklet offers explanations, diagrams and strategies for the family member and professional.</p>	<p>Download Only</p>
<p><b>Nutrition and Huntington's Disease: A Guide for Families</b></p> <p>Ann Gaba, MS, RD, EDM, HDSA, 1997, 26-pages. Discusses the nutritional needs in early, middle and late stage HD, provides hints for increasing calorie intake and recipes.</p>	<p>\$2.00 each**</p>

<b><i>Personal and Family Issues</i></b>	
<p><b>Telling the Children</b></p>	<p>Download Only</p>

Shirley Dalby, 2 pages. How, why, when to tell children about HD.	
<b>Suicide and Huntington's Disease</b> Allen J. Rubin, Horizon, No. 68, 1993, Huntington Society of Canada, 6 pages. Personal perspectives of three HD family members, followed by a psychiatrist's thoughts on the subject.	Download Only
<b>Huntington's Chorea: Its Impact on the Spouse</b> Hans & Koeppan, 1980, 6 pages. Case reports.	Download Only
<b>Living at Risk for Huntington's Disease: Walking the Tightrope</b> Randi Jones, PhD, Huntington's Disease Society of America, 1998, 84 pages. An in-depth examination of issues and problems common to people at risk for HD. Offering practical guidance and professional insights, this book includes sections on relationships, coping, predictive testing, resources, planning ahead, and life after a positive test result.	\$8.00 each
<b>Is Daddy OK?</b> Janet Howes, ACSW 2004, 24 pages Book is ideal for kids, age 6 through 12 who have a parent, family member or other adult in their life who is affected by HD. Book is intended to serve as tool for parents to read along with children or as a starting point for discussions about how the story relates to their specific experiences. A percentage of the proceeds from this book go to HDSA programs.	\$12.95 each

<b><i>Counseling, Psychosocial Issues, Support Groups</i></b>	
<b>Psychosocial Aspects of Genetic Disorders: Implications for Practice</b> Kathleen Kirk Bishop, The Journal of Contemporary Human Services, April 1993, 5 pages. This article explores some of the issues that arise for families following the diagnosis of a genetic disease.	Download Only

<b><i>Research</i></b>	
<b>Toward a Cure – Current Issue</b> Highlights recent research advances.	Free, limit one per person**

<b>The Marker - Current Issue</b> Highlights recent research advances.	free, limit one per person**
<b>Past Editions of Toward a Cure</b>	Download Only
<b>Past Editions of The Marker</b>	Download Only

<b>DVDs</b>	
<b>Nanny's Birthday</b> HDSA, 1990. 38 minutes. Presentation by Australian psychiatrist Dr. Edmond Chiu, a leader in caring for people with HD for over 20 years. Includes demonstration of caring techniques to enhance the quality of life for people with HD and footage from the HD unit at the Terence Cardinal Cooke Health Care Center in New York City.	\$10.00 each
<b>Living With HD: A Nurse's Perspective</b> Middlesex County Hospital, 1989, 30 minutes. Deals with a variety of care issues for patients with HD in a long-term care facility.	\$10.00 each
<b>Claudia's Challenge</b> HDSA, Massachusetts Chapter. 42 minutes. Profile of Claudia Frank, who confronts the challenge of HD and leads an active and fulfilling life by making good use of available community resources.	\$10.00 each
<b>Communication Strategies For People With HD</b> Huntington Society of Canada, 1993. 20 minutes. Addresses the speech and language difficulties associated with HD and offers suggestions for improving communication.	\$10.00 each
<b>Caring DVD</b> Huntington Society of Canada, 1985. 110 Minutes. Discusses four major care topics: <ol style="list-style-type: none"> <li>1. How to Deal with Difficult Behavior</li> <li>2. Mobility</li> <li>3. Speech and Communication</li> <li>4. Nutrition and Swallowing</li> </ol>	\$20.00 each

<b>Others</b>	
<p><b>Kissing in the Kitchen</b>            by Betsy Ratner, 2000, 59 pages. Verses of challenged love and recipes for relief. "This is an inspired and remarkable book expressing eloquently the traumas that human beings feel at the expense of disease. Not only is it good reading, but it is also in the service of an excellent cause- to eliminate Huntington's Disease. The writings will be enjoyed by all."            Percentage of the proceeds from this book benefit HDSA programs.</p>	\$11.95 each
<p><b>Homeward Journey. Poetry of Leslie Foor</b>, 2003, 140 pages            Depicts a young writer's life through the art of poetry. Mr. Foor was affected by HD in his mid thirties but he never gave up hope. He continued to write poems until his struggle with the disease ended at the age of 48.            Percentage of the proceeds from this book benefit HDSA programs.</p>	\$14.95 each
<p><b>This Land Was Made for You and Me: The Life and Songs of Woody Guthrie</b>, Elizabeth Partridge, 2002, 217 pages            In his short lifetime, Woody Guthrie wrote more than 3,000 songs. In this honest and gripping biography, meet and travel the country with the man who created such a rich musical legacy for America.            Percentage of the proceeds from this book benefit HDSA programs.</p>	\$21.99 each
<p><b>Woody Guthrie: Poet of the People</b>, Bonnie Christensen, 2001, 16 illustrated pages. This book celebrates the life and times of Woody Guthrie. Using his most famous song "This Land Is Your Land" the author has created a stunning picture book that is at once a biography for Woody's youngest fans and a moving ode to folksingers of all ages. Autographed by author            Percentage of the proceeds from this book benefit HDSA programs.</p>	\$16.95 each

<i>Foreign Language Publications</i>	
<b>Huntington: Toda Una Historia</b> , 119 pages, Spanish	Download Only
<b>Doenca de Huntington: Nao ihe toca a si...mas toca a todas</b> Portuguese	Download Only
<b>Problemas de conducta en la enfermedad de Huntington</b> 90 pages, Dr. Jane Paulsen, Spanish Asociacion de Corea de Huntington Espanola (ACHE)	Download Only
<b>Que es la Enfermedad de Huntington?</b> <b>Una guia para ninos (entre 8 y 14 anos)</b> , 9 pages, Spanish Asociacion de Corea de Huntington Espanola (ACHE)	Download Only
<b>Enfermedad de Huntington: un camino a la Esperanza</b> 17 pages, Spanish Asociacion de Corea de Huntington Espanola (ACHE)	Download Only

