

## HD Books and Movies

Below is a list of books and movies with Huntington's Disease as the subject. This list is NOT exhaustive nor is it an endorsement that UC Davis HDSA Center of Excellence endorses the information, interventions, recommendations or feelings expressed in each book/movie. This is an informational resource so you may explore additional perspectives and information about HD. If you find a HD movie or book that is/was helpful to your family and it is not listed here, please e-mail Lisa Mooney, HD Social Worker at [lkjer@hdsa.org](mailto:lkjer@hdsa.org), with title, author/director and request to have it included.

Title	Author/Director	Overview
 <b>Alive &amp; Well</b>	Josh Taft	Alive & Well is a powerful documentary film about the human condition, which follows seven resilient people coming to terms with the profound reality of living with the hereditary chronic illness known as Huntington's Disease (HD).
 <b>Bound for Glory – Autobiography</b>	Woody Guthrie	First published in 1943, this autobiography is also a superb portrait of America's Depression years, by the folk singer, activist, and man who saw it all. Woody Guthrie was born in Oklahoma and traveled this whole country over—not by jet or motorcycle, but by boxcar, thumb, and foot. During the journey of discovery that was his life, he composed and sang words and music that have become a national heritage. His songs, however, are but part of his legacy. Behind him Woody Guthrie left a remarkable autobiography that vividly brings to life both his vibrant personality and a vision of America we cannot afford to let die.
 <b>Breaking the Cycle</b>	Robert Rippberger	A documentary on Huntington's Disease, a family torn apart and how a bike ride and one courageous Matt Austin brings them together.
 <b>Can You Help Me?</b>	Thomas Bird, MD	This book shares the surprising, insightful, challenging, and even encouraging stories of patients and their families who live with HD. Having seen patients for more than 40 years, Dr Thomas Bird, a pioneer neurogeneticist, adds a human touch to this genetic brain disease that devastates persons during mid-life when they can least afford it. With a brief history of Huntington Disease and the occasional scientific detail, the true heart of the book is the human experience of the disorder in which some compelling stories of people of all ages and in all walks of life who feel trapped by a progressive degenerative brain disease from which there is no escape.
 <b>Dancing at the Vatican</b>	Brian Moore	An emotionally charged, moving documentary about sufferers of the last 'hidden disease' on earth, authored by former Emmy award winning TV reporter Charles Sabine, following Huntington's Disease Patients from Latin America on a life changing journey to the Vatican and an audience with His Holiness Pope Francis.
 <b>Dancing with Elephants</b>	Jarem Sawatsky	This book is about how he learned to accept his prognosis, and not live in fear of it, but rather to dance with the 'Elephant in the room'. The author imparts his learnings on how to accept the changes to his mind, body, and soul and endeavors to help the reader do the same.

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 <b>Faces of Huntington's</b>	Carmen Leal-Pock	<p>Faces of Huntington's is an incredible collection of stories, essays, poems, and quotes of those who are in some way connected to Huntington's Disease. The book focuses on over sixty people who have HD, are at risk, caregivers, other family members, and friends. It is a beacon of light in what is often a dark world. Somehow, despite the horror of Huntington's Disease, there is loving support, a positive attitude, and unending hope. There are stories that make you rejoice at the unswerving faith and those that make you cry at the senseless loss. Faces of Huntington's gives readers a glance at the faces of heroes. It is guaranteed to bring tears of joy, hope, love and compassion to your eyes.</p>
 <b>Gene Hunter</b>	Nancy Wexler	<p>Nancy Wexler is the daughter of a Huntington's patient and is at risk for this disease. Finding this gene is a vital step toward preventing or curing Huntington's and thus saving lives. Nancy's work takes her all over the world, specifically to small villages in Venezuela where the mysterious gene affects more people than anywhere else on the globe. Blood samples generously donated by the villagers hold the clues to discovering the gene.</p>
 <b>Grandma Has Huntington's Disease and It's Okay</b>	Dr. Kelsey M. Finn	<p>This book tells the story of a grandmother who has Huntington's disease, a genetic condition, from the perspective of her grandson, Leo. This book is intended to serve as a way to communicate with children about HD, and help children understand what it means for them and their family member affected by HD.</p>
 <b>Her Mother's Daughter</b>	Huntington's Disease Society of America, Rae Maxwell	<p>Her Mother's Daughter, a film by Rae Maxwell and produced by HDSA, introduces the world to Kathi O'Donnell and shows the devastating impact that Huntington's disease (HD) &amp; juvenile Huntington's disease (JHD) has had on the O'Donnell family. The film is a window into Kathi's inspiring journey as a caregiver as we see the different stages of HD &amp; Juvenile Huntington's disease. Her Mother's Daughter is a powerful documentary of family, love and hope – across generations and against all odds.</p>

Title	Author/Director	Overview
 <b>Huntington's Dance, The</b> <b>Film</b>	Chris Furbee	<p>In 1995, Chris Furbee received a distress call from his aunt: his mother, Rosemary needed immediate care. After many years with little contact with his family, Chris returned to the remote coal-mining town in his native West Virginia. Walking through the front door of his mother's house, Chris found a shocking sight. The house was turned upside down. Hundreds of partially smoked cigarettes, piles of trash &amp; food were strewn about. It appeared that an emaciated stranger was lying on the couch, seemingly half-dead. After searching the house he discovered the person who was on the couch was in fact his mother. As the days unfolded, Chris realized that Rosemary was in complete denial of her condition. With few resources organized, Chris had to find ways to provide critical medical care for his mother who not only resented his help and felt he was meddling in her life but who also felt there was nothing wrong with her. Chris' coping mechanism was to set up a video camera in the dilapidated garage and share his deepest feelings of love, anger, and confusion. His thoughts about how to cope with the disease that he had run from years before were all captured on camera. From 1995 to the present, Chris chronicled his experiences in learning to cope with the potential hereditary nature of Huntington's Disease an illness that slowly eats away at your nervous system and your mind and in the process he created the documentary, Huntington's Dance.</p>
 <b>Huntington's Disease &amp; Me:</b> <b>A Guide for Young People</b>	Alison Gray	<p>Young people affected by Huntington's need to have correct and up to date information as early as possible young people want to know the truth and this must be provided in such a way that it is informative and factual, as well as supportive. With predictive testing available to those eighteen and over, the young must have this information early so that they have time to consider the implications of testing, not only on themselves, but also their family and friends. This book provides information about HD and offers strategies for coping with the immediate and long-term challenges. It is soundly based on the experiences of young people themselves. Some have just learned that HD is in their family, others are considering predictive testing themselves. Some have already experienced the loss of a parent. The Book shows that the experience of coping with HD is not all negative. Young People with HD families gain strength and courage. They learn to face the present and future with love, acceptance, compassion and hope. This book is an essential guide for that journey for both young people and adults.</p>

Title	Author/Director	Overview
 <b><i>Hurry Up &amp; Wait</i></b>	Jimmy Pollard	HD presents an ongoing series of challenges for all members of the family. This book discusses exercises to simulate the cognitive difficulties faced by those with HD, a collection of tips to accommodate them in your home or care home, a strategy to develop new approaches to solving care problems and commentary on common problems faced by family caregivers and those they love.
 <b><i>I Fight for Understanding: 31 Days of Coping With Huntington's Disease</i></b>	Ginnievive Patch (Author), Sharon McClellan Thomason (Editor, Illustrator, Foreword)	This book began as a series of tips on a Facebook page for caregivers of people with HD/JHD. The roller coaster is a metaphor not just for the ups and downs of living with HD/JHD, but also for the breakneck speed and unpredictability with which changes often occur. Just when you're riding along smoothly, things begin to build up, and just when they reach their peak, you plunge with your loved one into the abyss that always seems to be waiting just over the top. But it doesn't end there. Everything levels out again, and you rock along, only to hit the rise, peak, and plunge once again. Over and over, you ride the roller coaster with your loved one who has HD/JHD, and every time, it can be just as scary and unpredictable as it was at the beginning of the ride because, you see, you never know what's coming around that blind corner!
 <b><i>If You Were Here</i></b>	Alice Peterson	When her daughter Beth dies suddenly, Peggy Andrews is left to pick up the pieces and take care of her granddaughter Flo. But sorting through Beth's things reveals a secret never told: Beth was sick, with the same genetic condition that claimed her father's life, and now Peggy must decide whether to keep the secret or risk destroying her granddaughter's world.
 <b><i>In-Between Years: Life after a positive Huntington's Disease test</i></b>	Steven Beatty	This book is for those of us going through the "in-between years": the years following our HD genetic testing, but before the symptoms of the illness have begun to take hold. The years when we may struggle with this look into the crystal ball we've been given, for whatever reasons are personal to us. The years when we symptom-hunt and worry about every forgotten purse and each trip and stumble. The years when we watch and care for other Huntington's disease affected loved ones and wonder, how long until it's our turn. How I coped with the present. Steven Beatty is part of a Huntington's disease family himself and received a positive result on his HD predictive genetic testing in 2015. Since that time, he has developed a passion directed at advocating for the Huntington's disease community

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 <b><i>Inside the O'Briens: A Novel</i></b>	Lisa Genova	<p>Joe O'Brien is a forty-three-year-old police officer from the Irish Catholic neighborhood of Charlestown, Massachusetts. A devoted husband, proud father of four children in their twenties, and respected officer, Joe begins experiencing bouts of disorganized thinking, uncharacteristic temper outbursts, and strange, involuntary movements. He initially attributes these episodes to the stress of his job, but as these symptoms worsen, he agrees to see a neurologist and is handed a diagnosis that will change his and his family's lives forever: Huntington's disease.</p>
 <b><i>It's a Bird</i></b>	Steven Seagle	<p>As comic writer Steve explores the myth and meaning of Superman for an undesirable assignment, he finds himself delving into some secrets of his own family along the way. A graphic novel that follows a young man and his feelings and experiences of Huntington's disease.</p>
 <b><i>Learning to Live with HD</i></b>	Sandy Sulaiman	<p>Learning to Live with Huntington's Disease is one family's poignant story of coping with the symptoms, the diagnosis and the effects of HD. This book presents the struggles and strengths of the whole family when one member loses their future to a terminal illness. Told by the sufferer and other significant family members, the individuals describe the burden of watching yourself and others for symptoms of HD, including involuntary movements, depression, clumsiness, weight loss, slurred speech and sometimes violent tendencies. The family recounts the challenge to remain united and describes how they approached issues such as whether or not to be tested for HD, how much information to disclose to relatives, whether to have children or not and guilt if one sibling inherits the illness and one does not. Both honest and positive, the author stresses the importance of re-inventing yourself and your present, prioritizing relationships and retaining a sense of humor.</p>

Title	Author/Director	Overview
 <b><i>Life Interrupted</i></b>	Katie Lee Jackson, Vicki Owen, Pat Wolf, Sharon McClellan Thomason, Lisa Davenport, Ben Lamoreau, and Frances Saldana	<p>Living the unimaginable, twelve Huntington's disease patients and caregivers share true stories of struggle, devastation, and life-shattering events as they travel the journey that is HD. Along the way, you'll meet ordinary people who develop extraordinary strength, courage, and perseverance as they try to counterbalance the chaos of lives falling apart as HD shows up like an out-of-control wrecking ball. One woman struggles for years to find her biological family, then discovers more than she expected. Agonizing parents watch helplessly as their children endure years of pain, lose every bit of their quality of life, and die far too soon, some from the juvenile form of HD. Couples fall in love, marry, and start their families just in time for this horrific disease to step in and rip everything away, eventually taking their soulmates' lives and leaving them with the knowledge that their children, too, may face the same terrible fate. Witness the strength of these families as they rise to the challenge and advocate to be the last generation ever to live with the horrors of Huntington's disease, a genetic neurodegenerative disease that has often been called the worst disease known to mankind.</p>
 <b><i>Life Interrupted, Part 2</i></b>	Sharon McClellan Thomason, James Torrington Valvano, Ginnievive Patch, Stacey Sargent, Dorothy Gerber Pearce, Kinser Cancelmo, Terry Tempkin, Georgia Porter, Katrina Hamel, and Nancy Sweet	<p>Life Interrupted, Volume 2, continues to tell the stories of people living with Huntington's and Juvenile Huntington's disease. From mothers who have lost their precious children to JHD and HD to patients who are living with HD, all are compelling stories of strength, perseverance, and courage. Some are caregivers for multiple generations; some didn't know about the disease being in the family until it struck with all its fierceness. All are stories of unbelievable struggle, loss, and hope.</p>
 <b><i>Living with Huntington's Disease: What I've Learned as a Caregiver</i></b>	Sharon McClellan Thomason	<p>Huntington's disease (HD) has been called "the worst disease known to mankind." So what happens when your child, the person you love most in this world, is diagnosed with this monster? The author shares her experiences and what she's learned along the way, including how to advocate for your loved one and the grief and resilience that go hand-in-hand with living with HD.</p>

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 <b><i>Living With Passion: A Young Woman's Huntington's Disease Journey to Truly Live with Passion</i></b>	Alexandra Kathleen Boothby	My memoir is about me, a young woman who is living with a fatal neurodegenerative disease, Huntington's Disease, but doing so passionately. My goal is to choose happiness each day, and some days being happy is easier than others. My disease is only a part of my life, it's definitely, not my whole life. Being diagnosed with Huntington's Disease has positively affected my outlook on life and I strive to portray that in my memoir. I try to live in the moment, and live passionately, fearlessly, happily, and imperfectly. I would love for you to read my journey. I'm hoping it makes you have happy tears and that my Huntington's Disease will change your life for the better just as it with mine. My book helps people in the HD community to see a positive light in HD and it helps any one who is struggling with change and transitions.
 <b><i>Mapping Fate</i></b>	Alice Wexler	This is an account of the how Huntington's disease affected one family. The author tells of how her mother died of the disease, how she herself stood a 50-50 chance of inheriting it, and how her sister and father sought first to find the gene and then find a cure.
 <b><i>MIND OF MY MADNESS. (My Battle Against Huntington's Disease!)</i></b>	John J. Howard	Taken to poetry as a weapon to do BATTLE against my RARE DISEASE enemy, Huntington's Disease!. My journey began as a effort to raise awareness for H-D, which is an INCURABLE fatal genetic brain disorder...over time a slow gradual killer. (Very often described as a combo of ALS, Parkinson, & Alzheimer's) Many of my family members have passed due to H-D, including my Mother, Sister, my brother currently requires on wheelchair, I also am H-D positive. A H-D family can be pretty difficult experience, but I decided it was time TO TAKE THE POWER BACK! I have written over 150 poems over the last 5 years or so, more or less documenting my emotions within that time period of my own growth, and also sharing those poems with my H-D community who has responded amazingly. They have cried the same tears I have cried, so I also continue to remain active for them.
 <b><i>Portraits of Huntington's</i></b>	Carmen Leal	Portraits of Huntington's is a joyful collection of profiles, essays, and quotes for and about those with Huntington's Disease. Portraits of Huntington's features award winning artist Ruth Hargrave's incredible portraits of eight individuals or family groups who are all in some way touched by this genetic disease. Joy is a choice. Happiness is based on a set of circumstances, and Portraits of Huntington's asks us to choose joy. As with Faces of Huntington's, in each chapter is thematic, Knowledge, Laughter, Patience, Compassion, Faith, Love, Hope, and Joy. Whether you are a person with Huntington's Disease, a caregiver, someone at-risk, a family member, a professional, or someone who simply cares, we all need joy in our lives. Somehow, despite the horror of Huntington's Disease, remarkable heroes are choosing joy every day. I hope their inspiring lives, coupled with my stories and Ruth's portraits, will encourage you to choose joy.

Title	Author/Director	Overview
 <b><i>Rules for 50/50 Chances</i></b>	Kate McGovern	<p>Seventeen-year-old Rose Levenson has a decision to make: Does she want to know how she's going to die? Because when Rose turns eighteen, she can take the test that tells her if she carries the genetic mutation for Huntington's disease, the degenerative condition that is slowly killing her mother. With a fifty-fifty shot at inheriting her family's genetic curse, Rose is skeptical about pursuing anything that presumes she'll live to be a healthy adult-including her dream career in ballet and the possibility of falling in love. But when she meets a boy from a similarly flawed genetic pool and gets an audition for a dance scholarship across the country, Rose begins to question her carefully laid rules.</p>
 <b><i>Saint Vitus' Dance</i></b>	Jill Rubalcaba	<p>Thirteen-year-old Melanie feels angry and guilty because she is worried about herself instead of her mother, who has Huntington's chorea, a hereditary condition, until Melanie finds the strength to face her mother's illness and her own uncertain future.</p>
 <b><i>Shattered Dreams---But Hope: Encouragement for Caregivers of Huntington's Disease and Other Progressive Illnesses</i></b>	Laquita Higgs and Elton Higgs	<p>Shattered Dreams--But Hope by Drs. Laquita and Elton Higgs, is a book of both testimony and advice: testimony born out of the school of trial and suffering, and advice born out of practical experience in being long-term caregivers. Laquita and Elton have for the last 26 years been caregivers to two adopted daughters with early onset Huntington's Disease (HD), which is hereditary, and they offer a gripping account of their extended experience in adjusting to the challenges of long-term caregiving, followed by sober practical counsel to others who are involved in similar caregiving experiences. A final chapter speaks specifically of the role of Christian faith in coping with the stresses of their long struggle. In the Appendices are a short talk given after Cynthia's funeral by her older sister Liann and several poems by Elton on the emotional impact of his and Laquita's relationship with their disabled daughters.</p>
 <b><i>Someone Else's Life</i></b>	Katie Dale	<p>How can you face your future when your past it a lie? When Rosie Kenning's mother, Trudie, dies from Huntingdon's disease, her whole world falls apart. Not only does Rosie desperately miss her mum, but now she has to face the fact that she could have inherited the fatal illness herself. Until she discovers that Trudie wasn't her biological mother at all ...Rosie is stunned. Can this be true? Is she grieving for a mother who wasn't even hers to lose? And if Trudie wasn't her mother, who is? But as Rosie delves into her past to discover who she really is, she is faced with a heart-breaking dilemma - to continue living a lie, or to reveal a truth that will shatter the lives of everyone around her...</p>
 <b><i>The Lions Mouth Opens</i></b>	Lucy Walker	<p>Follow a courageous filmmaker/actress as she prepares to learn if she has inherited the incurable brain disorder, HD.</p>

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 <b><i>The Longest Journey</i></b>	Nathan Appfel	This 'beautiful and bold' film follows a blue collar family cycling 3,000 miles, 24 hours a day from coast to coast in the Race Across America to raise awareness for a terminal illness the mother is battling. Will they succeed in one of the most grueling races in the world, or will they succumb to the brutal elements? You'll walk away ready to share this film with friends and family.
 <b><i>The Warriors - Fighting the Incurable Juvenile Huntington's Disease</i></b>	Help4HD	Documentary following several families caring for youth with Juvenile HD.
 <b><i>The Woman Who Walked Into the Sea</i></b>	Alice Wexler	This title presents a groundbreaking medical and social history of a devastating hereditary neurological disorder once demonized as 'the witchcraft disease'. When Phebe Hedges, a woman in East Hampton, New York, walked into the sea in 1806, she made visible the historical experience of a family affected by the dreaded disorder of movement, mind and mood her neighbours called St. Vitus' dance. Doctors later spoke of Huntington's chorea, and today it is known as Huntington's disease. This book is the first history of Huntington's in America. Starting with the life of Phebe Hedges, Alice Wexler uses Huntington's as a lens to explore the changing meanings of heredity, disability, stigma, and medical knowledge among ordinary people as well as scientists and physicians. She addresses these themes through three overlapping stories: the lives of a nineteenth-century family once said to 'belong to the disease'; the emergence of Huntington's chorea as a clinical entity; and the early-twentieth-century transformation of this disorder into a cautionary eugenics tale. In our own era of expanding genetic technologies, this history offers insights into the social contexts of medical and scientific knowledge, as well as the legacy of eugenics in shaping both the knowledge and the lived experience of this disease.
 <b><i>Twitch</i></b>	Kristin Powers	This documentary will follow Kristen Powers as she discovers whether she has inherited the same disease that killed her mother. It will also raise awareness about Huntington's Disease to help reduce the stigma that surrounds this brain disease that affects speech, mobility and thinking. By sparking a national conversation about this disease, we can hopefully make this generation the last one with the disease through education, participation in clinical trials, and research funds. Finding a cure could potentially unlock the mysteries to other neurological illnesses such as Parkinson's, Alzheimers, ALS and various forms of dementia.
 <b><i>Walking the Tightrope</i></b>	Randi Jones, PhD.	An in-depth examination of issues and problem 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.

Title	Author/Director	Overview
 <b><i>Watching Their Dance: Three Sisters, a Genetic Disease and Marrying into a Family At Risk for Huntington's</i></b>	Therese Marin-Cutcher	<p>Huntington’s disease, considered the cruelest disease on our planet is the Marin family secret that the three sisters, Lora, Marcia and Cindy, discover when they visit an aunt they have not seen in years. The story begins with John Marin, their brother, and Therese Crutcher, his fiancé, learning of the news that the siblings have a 50/50 chance of inheriting the disease which has no therapy or cure. The news shakes Therese to her core, and she questions her engagement to John. After much soul searching, Therese takes the biggest gamble of her life and marries the love of her life knowing the possible consequences of her decision; at least two of the Marin siblings will fall prey to the disease and one of them could be John. The book chronicles the life of John and Therese, over thirty years, as they journey through life shrouded in the uncertainty of Huntington’s disease. The story explores how living at risk for Huntington’s impacts their life on a daily basis, how Huntington’s is a factor in every important decision, how it impacts relationships, and addresses the coping skills Therese uses to manage and survive unimaginable stress and anxiety. Their lives were filled with unpredictability and pain, and yet full of love, good times, and great joy. Therese discovers acknowledging that her world could change overnight has made her life much richer. She learns to overlook shortcomings and to compromise, to let go of anger, to find joy in the simple things. The Marin siblings taught her—and can teach readers—about embracing life, forgiveness, and unconditional love.</p>
 <b><i>When Given Lemons</i></b>	Lauren Holder	<p>Lauren Holder is a young woman who deals daily with the struggles of Huntington’s Disease, whether it is in her own personal life, a member of her family, or a friend of the Huntington’s Disease community. She first learned of Huntington’s Disease at the age of fifteen after her grandfather was diagnosed with it. This is the story of her relationship with her grandfather and how Huntington’s Disease played such a huge role in it, taking their relationship from almost nonexistent to something special, a bond that changed her life.</p>

Title	Author/Director	Overview
 <b><i>You'll Miss Me When I'm Gone</i></b>	Rachel Lynn Solomon	Eighteen-year-old twins Adina and Tovah have little in common besides their ambitious nature. Viola prodigy Adina yearns to become a soloist—and to convince her music teacher he wants her the way she wants him. Overachiever Tovah awaits her acceptance to Johns Hopkins, the first step on her path toward med school and a career as a surgeon. But one thing could wreck their carefully planned futures: a genetic test for Huntington's, a rare degenerative disease that slowly steals control of the body and mind. It's turned their Israeli mother into a near stranger and fractured the sisters' own bond in ways they'll never admit. While Tovah finds comfort in their Jewish religion, Adina rebels against its rules. When the results come in, one twin tests negative for Huntington's. The other tests positive. These opposite outcomes push them farther apart as they wrestle with guilt, betrayal, and the unexpected thrill of first love. How can they repair their relationship, and is it even worth saving? From debut author Rachel Lynn Solomon comes a luminous, heartbreaking tale of life, death, and the fragile bond between sisters.

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