

# Help 4 HD International

Educating The World About Huntington's Disease

## POSITION STATEMENT: Death with Dignity

Because Huntington's Disease (HD) and Juvenile Huntington's Disease (JHD) is an inherited, fatal brain disorder, all families in this community will face questions about death, most often prematurely.

With rare exception, no other human condition causes as much suffering as this fatal brain disorder. The disease progresses slowly, demanding that families cope with continued loss and anticipatory grief for decades. Because it is genetically inherited, parents struggle with the fear of having passed the fatal gene on to their offspring. It is not uncommon for an unaffected family member to be caring for two or three generations at the same time.

Care is palliative only. There is no treatment that will delay the onset or slow the progression of this brutal neurological disease. Over time, those affected will lose the ability to think, move, eat, care for themselves, walk, and talk. This difficult journey is often punctuated with significant psychiatric and behavioral challenges - not simply from 'coping' with this fate, but as a part of the neurological decline. The juvenile form is especially cruel with incapacitation early on in childhood.

Certainly, those affected suffer greatly, and those who live with, care for, are related to and involved with their care suffer as well. Day after day, year after year, decade after decade, the families and care partners bear witness to the ravages of this disease and the continued loss of everything their loved one was.

Most of them—those affected and those not affected—think about death. Some talk about it; others don't. It is not uncommon for those living with the disease to express that they "don't want to live like this." It is common for them to make requests of loved ones to take action on their behalf in the event they cannot. A minority of them take their own lives while they can. It is natural to want to be relieved of misery and suffering - not only for the one suffering from the disease, but some patients also feel the need to relieve others from the perceived burden of caring for them.

Our health care system does not have a systematic and uniform way of helping these people. Families are often at the mercy of a system that is designed for acute problems with an identifiable solution. HD/JHD families are often misunderstood, feared, and ignored. We have programs, drugs, counselors, and health care providers who do a heroic job when 'terminal' is predictable. Not so the case with people who are forced to die slowly over decades.

Health care services are not designed to be ‘long-term’ with the ability to support families through the course of this disease. Care partners exhaust themselves not only with the physical and emotional care they provide, but also from the constant advocacy and negotiation required to get appropriate care and services.

It is an important part of this position statement to articulate, even in a small way, the daily struggle of coping with HD/JHD. It is important to understand that theirs is not an easy road with good solutions. Most often the decisions they have to make are simply which is the least awful - time and time again. It brings one to a better understanding why people can cogently and passionately discuss their wish to be relieved of their suffering, even before death is imminent.

Death with Dignity Acts and Death with Dignity Laws are NOT targeted to this population (even though they should be). They are designed for people with a more predictable ‘end of life,’ (having six or fewer months to live), and those suffering from conditions that are known to be terminal and/or causing great bodily pain. They also require a person to be mentally competent at the initiation of their end-of-life journey, which in the end stages of HD can be compromised. Certainly, none of these statutes address terminally ill children.

To date, there are only six states that have Death with Dignity laws/statutes: California, Colorado, District of Columbia, Oregon, Vermont, Washington.

Montana currently does not have a statute but has safeguards for physicians who honor a terminally ill, mentally competent person’s request for aid in dying.

The mission of HELP 4 HD International is to educate the world about HD/JHD using social media platforms, outreach and educational events. HELP 4 HD International is focused on providing information to families, empowering them to get the help and support they need on their journey. The individuals who make up this organization each share an HD/JHD journey, most of whom have faced death of a loved one.

HELP 4 HD International supports efforts to increase services and support for HD/JHD families, including palliative care from the time of diagnosis through their loved ones’ remaining lifespan. This includes educating the community about what options are available to them at any time in their journey to retain as much control as they can.

HELP 4 HD International is not a lobbying group and thus does not participate in activities to promote legislation on this issue. Neither does HELP 4 HD International have an official position on what families “should” or “should not” do. We believe, though, that Huntington’s patients should have the right to choose death with dignity by a prior health care directive, a prior appointed agent, and, if necessary, physician assistance in order to enable people with HD to access the mercy that Death with Dignity laws intend.