

HD Beliefs and Myths

HD is an untreatable incurable disease.

What happened to my affected parent will happen to me.

It's unsafe to talk about HD (because of discrimination, misunderstandings, and loss of opportunities. Talking about it only makes things worse anyway.)

I'm completely alone. (HD is such a rare disease.) (No one can help me)

Doctors (and health care providers) don't know and don't care about my problems.

HD Beliefs and Myths

Family myths

Treatment myths

- HD is an untreatable incurable disease.
- Medications make things with HD worse.
- Doctors (and health care providers) don't know what they are doing and don't care about my problems.

Stigma

- People with HD lose their mind.
- You think I'm crazy when you send me to a psychiatrist.
- It's unsafe to talk about HD (because of discrimination, misunderstandings, and loss of opportunities, people will get upset. Talking about it only makes things worse anyway.)
- I'm completely alone. (HD is such a rare disease.) (No one can help me)

Fatalism

- What happened to my affected parent will happen to me.
- Mindset of fatalism.
- Be a subject not an object
- Nothing I can do about it so why try?

Medical providers myths

Treatment is limited

- Chorea is the most important symptom to treat.
- Why diagnose someone with early stage or prodromal HD? The psychiatric symptoms aren't treated any differently than garden variety adjustment disorders
- The only thing I can do for you is offer you genetic testing if your parent has HD.
- Providing care for HD patients is very hard
- HD patient are high risk and have difficult to treat and recalcitrant psychiatric symptoms.
- HD families are always in crisis.
- I don't have the resources to help patients or families with HD
- I don't have the full multidisciplinary care team so can't do a good job.