

AFTER THE DIAGNOSIS ROAD MAP

Many thanks to the Minnesota chapter of HDSA including Jessica Marsolek, Jim Goodchild, Arlene Jennings, Lora Horan-Kimsal, and Noreen Hoft for their original idea for this document.

1

Learn about Huntington's disease

Learn [here](#) or [here](#).

2

Educate your Family and Friends about HD

1. Tell those closest to you that HD affects everyone differently, but most will experience profound changes in mood, thinking abilities, and movements.
2. Communicating with children deserves special consideration because they are also at risk of inheriting HD.
3. Good sources for educational information are:
[hdreach.org](#), [hdbuzz.net](#), [hdsa.org](#), [hdyo.org](#)

3

Establish an Emotional Support Network for Coping with the Diagnosis

1. Family, friends, and faith group members.
2. Learn more [here](#) or [here](#).

4

Consider who should be on your Medical Care Team

1. Physicians experienced with HD are rare and may take some effort to find. Huntington's disease Centers provide multidisciplinary specialists in more than 50 hospitals across the US.
2. [Learn more](#).
3. View a complete listing of HDSA Centers of Excellence [here](#).

5

Start or continue Practicing a Healthy Lifestyle

1. Eat well and exercise regularly.
2. Surround yourselves with people who are kind.
3. [Learn more](#).

6

Take Stock of your Finances

1. People active in their careers with family members they are supporting can work with financial planners and estate lawyers.
2. Learn how you can use state and federal government assistance programs.
3. Government Programs include Social Security, Social Security Disability Insurance, and Supplemental Social Security.
4. Figure out how Medicaid, Medicare, and your insurance may work together.
5. [Learn more](#).

7

Update or make Legal Arrangements

1. Creating a Will, Advanced Directives, and Power of Attorney agreements provides clear instructions for how you want to live and your wishes for end-of-life care.
2. Learn more [here](#) and [here](#).

8

Changes to Nutritional Requirements as HD Progresses

1. Likely need more calories.
2. Swallowing challenges may create a need for alternative foods with different consistencies.
3. Discuss the eventual use of a feeding tube with medical professionals and care partners while in the early stages of HD.
4. [Learn more](#).

9

Create a Safe Home Environment

1. Update layouts and make alterations in the home to prevent slips, falls, bumps, and bruises.
2. Plan for natural disasters.
3. Learn about reducing aggression and increasing safety in the home.
4. [Learn more](#).

10

Develop a Long-Term Care Plan

1. Options include: Care at home by care partner or professional caregivers, assisted living, group home, nursing care facility.
2. Hospice Care.
3. Learn more [here](#) and [here](#).

11

End-of-Life Considerations

1. Provider Orders for Life-Sustaining Treatment (POLST) – communicates the directives to medical care providers about treatment in an emergency.
2. Living Will/Healthcare Directives – declare your wishes regarding end-of-life medical care if unable to communicate your desires.