

FACTSHEETS FOR HEALTHCARE PROFESSIONALS:

Diet in Huntington Disease

The importance of maintaining weight

People with Huntington disease (HD) burn a lot of calories, so it's important to make sure they maintain a healthy weight.

People with HD who are underweight are more likely to:

- Lose muscle mass and therefore feel weaker
- Catch infections and take longer to recover
- Develop pressure ulcers if their mobility is reduced
- Take longer to recover from illness, operations or wounds

According to anecdotal evidence, providing a high-calorie diet can help to minimize some of the symptoms of HD, including:

- Involuntary movements
- Cognitive problems
- Speech and swallowing difficulties

Aim for a weight at the top end of the healthy range (a BMI of 24–26).

Good nutrition is a team effort

Maintaining good nutrition requires a multidisciplinary team that periodically reviews nutritional and dietary needs. The team should include:

- A speech language pathologist to deal with swallowing difficulties
- A dietitian, to assess nutritional needs and suggest an appropriate diet
- An occupational therapist, to suggest strategies for self-feeding
- A physiotherapist, to assist with positioning during eating and drinking

- A social worker, to assist with counselling and/or applications for financial aid, if necessary
- Caregivers, to prepare meals and/or assist with feeding
- Catering staff, to prepare meals
- Most importantly, the person with HD

Assessing calorie requirements

Calorie requirements can change over the course of the disease, so monitor the person's weight regularly and adjust the diet as necessary.

Managing nutrition

- Aim for a balanced diet that includes all the essential nutrients.
- Remember that "healthy eating" guidelines may not apply to someone who is undernourished.
- People with HD can be challenged by changes to their routine. If their diet is poor, negotiate small, gradual changes and recognize that their diet may never be ideal.
- For people with HD living at home, take into account the abilities and dietary needs of the family and/or caregiver.
- Ordinary food is usually more enjoyable than meal replacement shakes or puddings. Eating may have social and psychological benefits.
- Five or more mini-meals through the day may be a better option than three large meals.

Mealtime tips

- Loss of motivation is a common problem in HD, so you may need to prompt individuals to eat.

- HD causes uncontrollable muscle movements that can mean a lot of food is spilled during mealtimes. If this is the case, increase the portion size to compensate. Having the person wear wrist weights can also help to reduce involuntary movements.
- Create a warm and welcoming eating environment, with limited stimulation or distraction.

Strategies for adding extra calories

As a rule, it's better to add extra calories through food whenever possible than to use meal replacement shakes or other supplements.

Snacks between meals

- Cheese and crackers
- Sandwiches with fillings such as cream cheese, peanut butter or jam
- Milk-based drinks such as milkshakes, smoothies or hot chocolate
- Cookies and cakes

- Thick and creamy yoghurt

Extra calories at meals

- Plenty of butter, jam, etc. on bread or toast
- High-calorie puddings with extra cream, evaporated milk, ice cream, etc.
- Homogenized milk fortified with powdered milk (2 tablespoons per cup)

Supplements

- Meal replacement shakes or puddings
- High-calorie powders
- Protein powders
- High-calorie liquids

Swallowing

As the disease progresses, swallowing becomes more difficult and choking becomes a risk. When this happens, adjust the person's diet so that the texture and consistency of the food makes it easy to swallow. See the Huntington Society of Canada's factsheet *Swallowing in Huntington Disease* for more details.

Adapted from: *Huntington's Disease Association's Standards of Care*, Huntington's Disease Association / St. Andrew's Healthcare

<http://www.hda.org.uk/download/fact-sheets/HD-Standards-Of-Care.pdf>