

Nutrition and HD



Huntington's Disease

Family Guide Series



Huntington's Disease
Society of America

Nutrition and Huntington's Disease: A Guide for Families

Family Guide Series

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Disclaimer

Statements and opinions in this book are not necessarily those of the Huntington's Disease Society of America, nor does HDSA promote, endorse, or recommend any treatment mentioned herein. The reader should consult a physician or other appropriate healthcare professional concerning any advice, treatment or therapy set forth in this book.

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Introduction

Everyone can benefit from good nutrition and proper eating habits. For people with HD, good nutrition has been proven to be an important part of maintaining health and maximum functional ability. The purpose of this guide is to combine current dietary guidance for all people – such as reduction of calories, avoidance of trans fats, increased consumption of fruits, vegetables, and whole grains - with information about the special issues that affect nutrition in persons with HD and strategies to address these issues

Nutrition and Huntington's Disease

Research has shown that people with Huntington's Disease often have a lower than average body weight for height, and may have higher than average calorie needs. This may be due to chorea, metabolic changes, or some other factor yet undiscovered. There is also some evidence that maintaining a body weight slightly above "desirable" weight will facilitate control of the disease. Therefore, people with HD should be encouraged to eat and every effort should be made to make eating enjoyable.

Many symptoms of HD can interfere with eating: reduced voluntary motor control, involuntary movements, problems with chewing and choking, as well as changes to cognition that may cause the individual to become distracted and overwhelmed by mealtime activity. Overcoming these challenges is an important part of maintaining good nutrition for the person with HD.

As the disease progresses and other activities become limited, food and eating will take on even greater importance. The introduction of special utensils,

dishes and modified seating, will help the person with HD continue to feed themselves as long as possible.

When it is no longer possible for the person with HD to meet his or her nutritional needs with an oral diet, enteral feedings (tube feeding) may be considered. Tube feedings may be given as a supplement to an oral diet, to provide extra fluids in case of swallowing difficulty, or as a sole means of nutritional support.

Nutritional Needs in Early Stage HD

In the early stages, depression resulting from the diagnosis can cause decreased appetite and/or changes in usual eating habits. Some people have reported food “cravings,” especially for high carbohydrate foods. There is no harm in indulging these cravings, as long as other foods are eaten to maintain a balanced diet. However, any significant weight change, whether increase or decrease, should be reported to your healthcare provider.

Reduced self-control is a symptom of the disease. Because excessive intake of caffeine can cause tremors, and possibly exacerbate involuntary movements, intake of coffee, black tea, cola, and energy drinks should be limited and monitored by the caregiver if needed.

When starting medications, be sure to find out if they have any known side-effects that can affect appetite and/or weight. Some common ones are listed on page 8.

Nutrient – Drug Interactions

- MAOIs – need to avoid dietary sources of tyramine (i.e. aged cheeses, liverwurst, red wine, very ripe fruits).
- SSRIs – may cause weight loss or gain, alterations in appetite, increased or decreased glucose levels.
- Anti-Anxiety drugs – may cause changes in appetite and weight.
- Anti-Psychotic drugs – may also cause changes in appetite and weight.

Antioxidants

There have been many studies looking at antioxidants as potentially beneficial to health. There are numerous compounds known to have antioxidant properties. A number of these are “phyto-nutrients,” found in fruits and vegetables. While no one specific antioxidant is recommended, a diet rich in a variety of fruits and vegetables is appropriate for anyone. The table on the next page lists some examples of food sources of various phyto-nutrients

Color Code Sources of Phyto-Nutrients in Vegetables and Fruits

Color	Phyto-Nutrients	Sources
Red	Lycopene	Tomatoes, pink grapefruit, watermelon, guava
Purple/ Red	Anthocyanins, polyphenols	Berries, grapes, red wine, prunes
Orange	α -, β -carotene	Carrots, mangoes, pumpkin
Yellow/ Orange	β -cryptoxanthin, flavonoids	Cantaloupe, peaches, oranges, papaya, nectarines
Green/ Yellow	Lutein, zeaxanthin	Spinach, avocado, honeydew, collard and turnip greens
Green	Sulforaphanes, indoles	Cabbage, broccoli, brussels sprouts, cauliflower
White/ Green	Allyl sulphides	Leeks, onion, garlic, chives

Antioxidant Supplements

Use of antioxidant supplements such as Coenzyme Q10, Vitamin E, or Creatine should be discussed with your primary care provider.

Healthy Fats

Dietary fats and oils are the most concentrated source of calories in the diet. Research has shown that some types of fats have specific health benefits, while others are detrimental. Trans fats, that are sometimes found in processed foods or deep-fried foods, have been identified as harmful. Heating fats to a very high temperature (where they start smoking) can cause production of “free radicals” that are also potentially harmful to health. In contrast, some types of fats have been found to have specific health benefits. These include: olive oil, fish oil, avocado oil, walnut oil, evening primrose oil, borage seed oil, and flax seed oil. These can be incorporated into your diet, or taken as supplements. As with the antioxidants, if you are taking a supplement, be sure to discuss with your primary healthcare provider.

Nutritional Needs in Mid-Stage HD

In middle-stage HD, symptoms of HD will increasingly interfere with the ability of the individual to get enough nutrition. These symptoms may arise from the motor, cognitive or emotional disorders associated with HD. The person with HD may need to get more nutrition from a smaller volume of food. Offering high-calorie snacks and adding extra calories to regular recipes will help the person with HD maintain his or her weight.

Tips for Increasing Calorie Intake

Here are some nutrient-dense foods to try:

- Avocados
- Smooth (not chunky) nut butters
- Sesame tahini
- Rich soups like clam chowder or lobster bisque
- Baked mashed sweet potatoes or winter squash
- Hot cereals mixed with pureed fruit
- “Better Butter” added to foods for extra calories: $\frac{1}{2}$ soft butter mixed with $\frac{1}{2}$ flaxseed, walnut, or olive oil

Motor control and the Movement Disorder

Involuntary movements (chorea) and a reduction in control over voluntary movements may make eating a challenge. Special tableware may help.

- Dishes with sides, also called “soup plates” or “pasta dishes” can make picking up food less messy. These are readily available in most department stores.
- Sports cups with a cover and straw attached can be helpful in preventing spills.
- Spoons and forks with larger handles can make picking up food easier. Rubber sleeves to slip onto the handles of your current tableware are also available. Both of these can be bought at a medical supply store.
- A heated “keep warm dish” can be used to keep food warm throughout a meal for a slow eater.

Unawareness

Another common symptom of middle-stage HD is a lack of self-awareness. The individual may not realize how hungry they are until the food is right in front of them. Consistent, scheduled mealtimes can help avoid exhaustion and emotional outbursts caused by unrecognized hunger.

Distraction and Irritability

Distractions at mealtime can also create problems for people with HD. They may be overwhelmed by noise and activity and be unable to concentrate on the task at hand – eating. Certain things may be more distracting to some individuals than others, so some experimentation may be needed to come up with ideal arrangements for eating. Needs will also change with various stages of the disease, so

flexibility is key. Some suggestions for a successful mealtime include:

- Create a quiet, calm atmosphere at mealtime
- Allow extra time for the person to eat the meal
- Turn off the TV or radio
- Have enough light and supportive seating
- Keep conversations simple – no big decision making
- Keep the focus on eating

Chewing, Choking and Swallowing

Problems with choking and chewing may also arise at this stage. Tips for coping include:

- If the individual eats so fast that they choke, try offering six to eight smaller meals a day instead of the usual three. Frequent feeding can stave off the most high level hunger and diminish the eating urgency that can cause choking. Another approach is to offer frequent snack or liquid supplements between meals.
- Pay attention to which foods and/or beverages seem to cause coughing and choking. Identifying “problem foods” can save further trouble later on. Dry, flaky or crumbly foods are often the culprits.
- Cut meat and vegetables into small pieces, and taking small amounts in each bite.
- Choose soft, moist foods. Try mashed potatoes, noodles, soups, casseroles, yogurt, puddings, gelatins, soft cheese, ice cream, milk shakes, creamed cereals, and macaroni and cheese.
- Add moisture to foods with gravies, cream sauces, salad dressings, broth, sour cream, mayonnaise, or butter.
- Chew food well. Sip liquids with a straw.

- Stay away from very acidic or spicy foods that may burn the throat if irritation is a problem. (These include: citrus fruits and their juices, tomatoes and tomato juice, and spices like red pepper, black pepper, chili powder and hot curry powder.)
- Add a thickener (such as Thickit® or Thicken-Up®) or cornstarch to liquids to make them easier to swallow.

The HD Kitchen

Having the right equipment may make preparing and serving meals for the person with HD much easier. Some suggestions are listed below.

- A blender and/or food processor can be very helpful in preparing shakes, soups and sauces, and for pureeing favorite foods when a very soft consistency is needed. If possible, get one that has more than one container, to allow for preparation of multiple foods quickly.
- A juicer can be useful for a person who cannot chew fruits and vegetables well. If swallowing is a problem, try adding thickening powder or mix the juice into a thick shake or soup for a nutritional boost.
- A pastry cutter or potato masher can serve many purposes in mixing and mashing foods. These are also helpful for adding “extras” like butter or sour cream to a dish.

Nutritional Needs in Later Stage HD

When it is impossible to get an adequate intake from an oral diet, tube feeding may be an option. It is possible to do this at home, given proper training. Tube feedings may be used to supplement oral intake of food and fluids, or they may become the primary source of nutrition.

Tube Feeding

Tube feedings (also called enteral feeding) are given when a person is unable to eat or tolerate enough food and/or oral supplements to meet her/his nutritional needs. Specific feeding instructions depend on the amount and type of tube feeding being used. If you are taking care of someone who is on tube feeding, you will need specific directions from their healthcare providers (dietitian, physician, and/or nurse).

There are three basic kinds of feeding tubes:

1. A *naso-gastric tube* (NGT) is threaded through a nostril, down the throat and into the stomach. This type of feeding is usually temporary, and does not require surgery to be put in. One disadvantage is that it can be pulled out accidentally. A naso-gastric tube can also interfere with swallowing, which can be a disadvantage if the person is able to eat anything.
2. A *peri-epigastric tube* (PEG), also called a gastrostomy tube (G-tube), is a tube that is implanted through the abdomen into the stomach. It functions in essentially the same way as an NGT. Formula flows through the tube into the stomach. It is usually for longer-term use. Since it does not pass down the throat, the patient can receive both tube feedings and an oral diet. It is often beneficial to continue oral feeding for as long as possible, even if the quantities given are not nutritionally significant, as this can provide significant psychological benefits. Another type of tube in this category is called a “button” tube. It is a very short tube attached to the stomach with a longer “snap on” tube for use during feedings. When the tube is not in use, a plastic cap covers the opening. These can be useful for people who do not receive a 24-feeding.
3. A *jejunostomy tube* (J-tube) is implanted below the stomach, directly into the small intestine. It functions similarly to tubes leading into the stomach, but with several differences. The advantage of a J-tube is that it reduces the risk that the formula will come back up the esophagus and enter into the trachea and lungs. This is called “aspiration,” and for

someone at high risk of aspiration, the J-tube might be the preferred option. Increased probability of diarrhea, and increased probability of the very narrow tube getting clogged are some potential disadvantages.

Feedings are either “continuous” or “bolus” servings. As the name suggests, continuous feedings run down the feeding tube at a fixed rate throughout the day and/or night. Tolerance problems are usually minimized when feedings are given this way. A very weak or debilitated person may need to be fed continuously in order to tolerate enough intake to meet his/her needs. Patients at risk for regurgitation because of limited stomach capacity need continuous feeding. Most people who are just starting out on tube feedings are given continuous feedings, then gradually changed over to bolus feedings.

A “bolus feeding” is a set amount of formula run down the feeding tube at specific times during the day. Bolus feedings are essentially the equivalent of a meal consisting of formula. These usually, but not always, correspond to breakfast, lunch and dinner times. Some regimens include one or more bolus “snacks” as well, for a total of four to six feedings per day. Bolus feedings are usually more convenient for caregivers, since feedings are administered only at specific times, and larger amounts are given at each sitting.

It should be noted that for some people, the weight and strength gained from tube feeding lead to improved swallowing ability. This improvement may enable a person to resume eating an oral diet.

Some Additional Tips About Tube Feedings:

1. Position the person so that he/she is sitting up, or at least so the upper-body is above the level of the stomach.
2. Practice good sanitation. Wash your hands before handling the feeding equipment. Wash feeding bags with water. Do not use soap, as it will stick to the inside of the bag and get into the formula. This can cause diarrhea.
3. Feedings should be given at room temperature to minimize the risk of cramping and/or diarrhea. Open cans of formula should be kept in the refrigerator, and discarded if they are not used in 24 hours. Refrigerated cans should be taken out 15-20 minutes before a feeding, and allowed to warm up to room temperature.
4. Always flush the feeding tube with water after a feeding. This will help to prevent the person with HD from getting dehydrated. It will also prevent the tube from getting clogged.
5. If medications are to be given through the tube, use liquid forms if available. If not, always be sure that the pills are finely crushed. Flush the tube with water to wash them down.
6. If the tube seems to be clogged and a small flush of water isn't effective, a flush of about 100mls of cola may do the trick. You can also try dissolving about $\frac{1}{4}$ teaspoon of meat tenderizer in a teaspoon of water and placing it into the tube. Wait five minutes before flushing again. If none of these strategies work, contact your healthcare provider(s) for assistance.

Recipes for some delicious, soft foods

Strawberry Rhubarb Loaf

Sift together:

- 1 1/2 cups whole wheat flour
- 1 1/2 cups unbleached white flour
- 2 cups sugar
- 1 Tablespoon salt
- 1 Tablespoon baking soda
- 1 Tablespoon cinnamon

Combine with:

- 3 eggs, and 1 1/4 cups canola oil

Add:

- 1 1/2 cups chopped strawberries,
and 1 cup chopped rhubarb
(Or all strawberries, or all rhubarb
if you prefer)

Divide equally into 2 non-stick loaf pans. Bake at 350F for 1 hour.

Cool before slicing.

Blueberry Corn Muffins

- 2/3 cup whole-wheat flour
- 2/3 cup all-purpose flour
- 2/3 cup cornmeal
- 1 tablespoon baking powder
- 1 teaspoon ground cinnamon
- 1/4 teaspoon salt
- 1 cup blueberries (frozen)*
- 1 egg
- 2/3 cup milk
- 1/2 cup honey
- 3 tablespoons canola oil

*Frozen blueberries will retain their shape and color better.

Preheat oven to 400°F. Coat 12 standard 2 1/2 inch muffin cups with cooking oil spray, or paper cupcake wrappers.

Whisk whole-wheat flour, all-purpose flour, cornmeal, baking powder, cinnamon and salt in a large bowl. Add frozen blueberries and toss to coat.

Beat egg in a medium bowl. Add milk, honey and oil, mixing until well combined. Add the wet ingredients to the dry ingredients and stir until just combined. Scoop the batter into the prepared pan, filling each cup about two-thirds full.

Bake the muffins until the tops spring back when touched lightly, 18 to 22 minutes. Let cool in the pan for 5 minutes. Loosen the edges and turn the muffins out onto a wire rack to cool slightly before serving.

Steamed Brown Bread

- 1 cup rolled oats
- 1 cup yellow corn meal
- 1 cup whole wheat flour
- 1 cup molasses
- 1 teaspoon baking soda
- 1 teaspoon salt
- 2 cups hot water

Combine all ingredients in a bowl.
Mix thoroughly.

Divide batter between 2 clean, ungreased, coffee cans (or cans from something else of a comparable size).

Cover the tops of the cans with waxed paper, with a rubber band to hold it in place.

Place cans into a stock pot, and add water to the pot about 1/2 way up the sides of the cans.

Cover the pot and let the breads steam over a medium heat for about one hour. (Turn down the heat if the cans are bouncing around a lot)

Carefully remove the cans of bread from the water and let cool.

Flip the bread out of the can.
(Some vigorous shaking may be necessary...)

Slice and enjoy!

Maple Sweet Potatoes

2 pounds sweet potatoes (about 4 medium)

1/2 teaspoon salt

1 tablespoon maple syrup

1/2 teaspoon lemon juice

Peel the sweet potatoes and cut into pieces. Cook in boiling water until soft. Drain and transfer to a large bowl.

Add salt, maple syrup and lemon juice.

Stir with a hand mixer until smooth.

Reheat as needed prior to serving.

Roasted Butternut Squash

1 large butternut squash (about 2 pounds)

1 tablespoon walnut oil

1/8 teaspoon salt

1 tablespoon lemon juice

1 tablespoon maple syrup

2 tablespoons pomegranate juice

Peel the squash, then slice it in half lengthwise. Scrap out the seeds with a spoon and discard them. Cut the peeled squash into 1/2 inch chunks.

Spread squash on a baking tray coated with non-stick spray.

Bake at 400F for 8 – 10 minutes until fork-tender.

Slide the cooked squash into a mixing bowl, and toss with walnut oil, salt, lemon juice, and pomegranate juice.

Serve warm.

Turkey/Vegetable Meatloaf

- 1 pound ground turkey
- 1 medium zucchini, shredded
- 1 cup finely chopped onion
- 1 cup finely chopped red bell pepper
- 1/3 cup uncooked whole-wheat couscous
- 1 egg, lightly beaten
- 2 tablespoons Worcestershire sauce
- 1 tablespoon Dijon mustard
- 1/2 teaspoon ground pepper
- 1/4 teaspoon salt

Preheat oven to 400°F. Generously spray two nonstick loaf pans with cooking oil spray.

Gently mix turkey, zucchini, onion, bell pepper, couscous, egg, Worcestershire, mustard, pepper and salt in a large bowl. Equally divide the mixture between the loaf pans.

Bake until the meat loaves are cooked through or an instant-read thermometer inserted into the center registers 165 degrees F, about 45 minutes. Let the loaves stand in the pans for about 5 minutes before serving.

Salmon Burgers

- 1 pound canned salmon, drained
- 1 egg
- 1/4 cup bread crumbs
- 2 tablespoons finely chopped red onion, or scallion
- 2 tablespoons finely chopped fresh cilantro
- 1/2 teaspoon finely chopped peeled fresh ginger (or 1/4 teaspoon powdered ginger)
- 1/4 teaspoon salt
- 1/8 teaspoon ground pepper
- 1 tablespoon extra-virgin olive oil

Place salmon into a mixing bowl and stir in egg, bread crumbs, onion, cilantro, ginger, salt and pepper. Divide the mixture into 4 patties, about 1 inch thick. Chill in the refrigerator for at least 20 minutes (or up to 2 hours) before cooking.

Heat oil in a large nonstick skillet over medium heat. Add the burgers and cook until browned on both sides and just cooked through, 3 to 5 minutes total. Serve with your favorite burger toppings, with or without a roll as desired.

Other resources

Many books and resources are available on-line. Additional recipes which may be appropriate can be found in:

The Non-Chew Cookbook

By J. Randi Wilson

The I-Can't-Chew Cookbook: Delicious Soft Diet Recipes for People with Chewing, Swallowing, and Dry Mouth Disorders

By J. Randi Wilson

The Dysphagia Challenge

By Pam Womack, RD

Easy-to-Swallow, Easy-to-Chew Cookbook: Over 150 Tasty and Nutritious Recipes for People Who Have Difficulty Swallowing

Donna L. Weinofer, MS, RD, Joanne Robbins, PhD, CCC-SLP, and Paula A Sullivan, MS, CCC-SLP.

Notes

HELP FOR TODAY. HOPE FOR TOMORROW

HDSA Mission

The Society is a National, voluntary health organization dedicated to improving the lives of people with Huntington's Disease and their families.

To promote and support research and medical efforts to eradicate Huntington's Disease.

To assist people and families affected by Huntington's Disease to cope with the problems presented by the disease.

To educate the public and health professionals about Huntington's Disease.

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