

Nutrition and HD

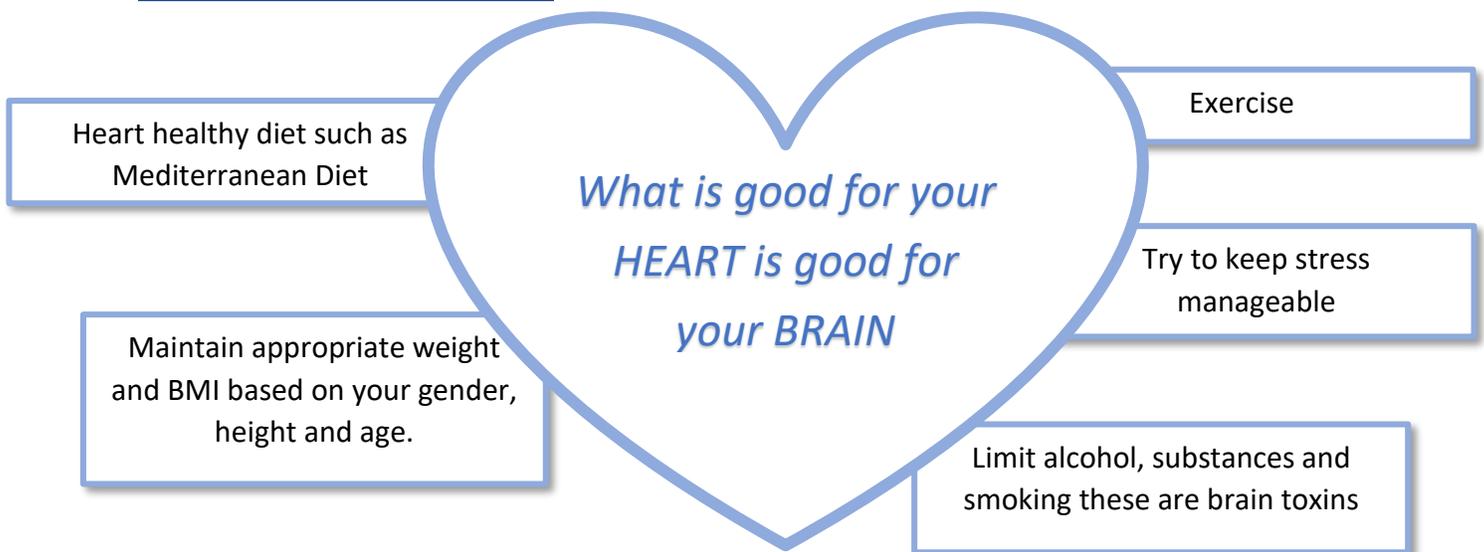
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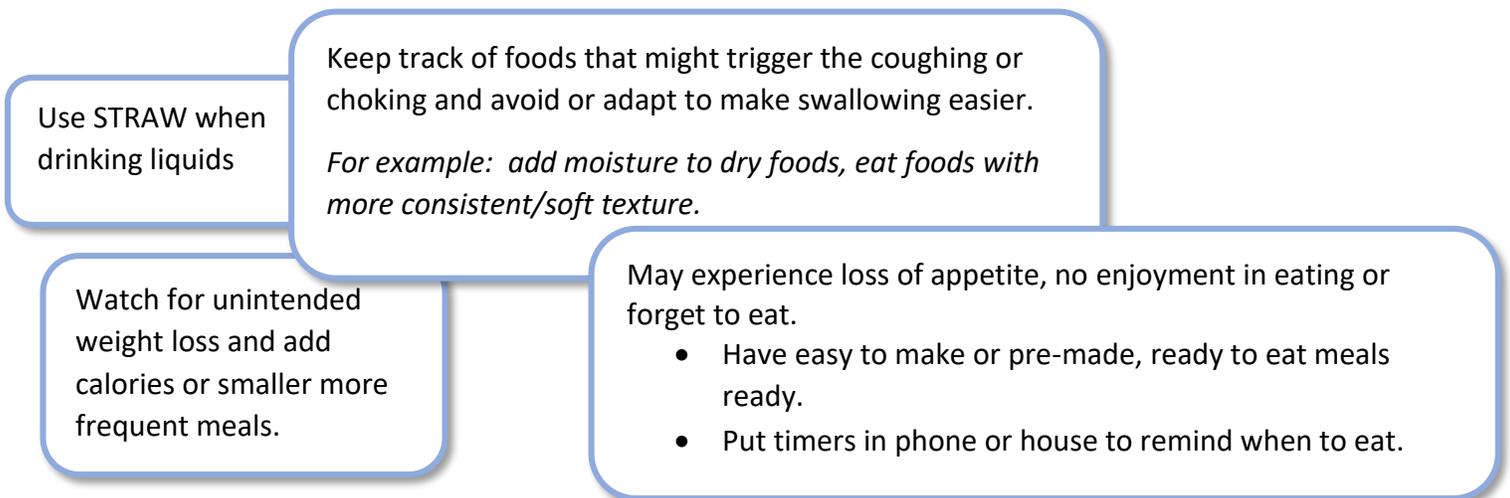
Over the course of HD, nutrition needs will change. Below are some of the common recommendations for maintaining proper nutrition throughout the disease. The information below is for information ONLY, please consult your HD team for recommendations that are specific to your medical needs.



Prodromal & Early Stage:



Middle Stage: same recommendations as above, watch for swallow difficulties that can trigger increase in choking OR coughing when eating or drinking.





Late Stage: same recommendations as above. Swallowing may get more difficult and may have increased weight loss due to not able to consume needed calories to maintain weight.

May benefit from nutritional supplements or support (Ensure, Boost, Feeding Tube)
see below for more discussion on these recommendations

If losing weight, increase calories per meal (see below for ideas)

Consider soft, pureed foods to minimize swallow difficulties

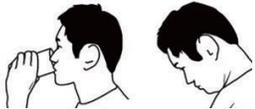


Swallow Difficulties in Huntington's Disease

Swallowing difficulties can happen at any stage of HD and will increase in difficulty as the disease progresses. Difficulty swallowing also known as “dysphagia” is common in Huntington's disease. Food, liquids, or saliva can enter the throat resulting in coughing, choking, and over time aspiration pneumonia, dehydration, or weight loss.

Tips for Swallowing Difficulties

Tucking the chin when swallowing



Using large straws and flexible straws for drinking

Eat slowly, minimize distractions (i.e. t.v., heavy discussion, etc)

Take small bites and only take one bite of food at a time.

Assist the person with HD to eat and drink.

Sit upright 90 degree to at least 45-degree angle for meals

Using commercial thickener in liquids to help make them easier to swallow

Alter food textures: eating soft foods, chopping, grinding, or puree depending on which texture is best for you. You may be referred to a speech therapist for swallowing evaluation and advice.



Useful feeding tools to help with swallowing:

Blender or Food Processor
for pureed/smoothies

Large handled utensils or
Liftware (balance utensils)
for better grip and feeding
independence

High sided plates, divided
plates to help scoop food
onto utensil easier.

Cups with handles, built in
straws, lids for better grip
and minimize spilling.

Low flow cups – special
cups that reduce the flow
of liquid to minimize
choking/coughing.



Assisting a Choking Adult: Anyone that eats food is at risk of choking. If needed you can assist a person who is choking to dislodge the food item.

Step 1.

Determine if the person can speak or cough.
If not, proceed to the next step.



Step 2.

Perform an abdominal thrust (Heimlich Maneuver) repeatedly until the
foreign body is expelled.



Step 3.

A chest thrust may be used for markedly obese persons or in late stages
of pregnancy.



If the adult or child becomes unresponsive **perform CPR.**
If you see an object in the throat or mouth, remove it.



Dehydration in Huntington's Disease: People with HD are at risk for dehydration, especially in warmer climates during the summer months. Our bodies are 60% water and need approximately 8 glasses of water per day to maintain hydration. Bodily fluids are lost through sweating, breathing, urination, and bowels. Failure to replace these fluids can result in dehydration.

Why are people with HD more prone to dehydration?

Cognitive impairment can alter a person's perception of thirst. People with HD who have difficulty organizing their thoughts and actions may be unaware they are thirsty, not remember to drink enough fluids, or express the need to drink.

Dysphagia (difficulty swallowing) can also be a risk for dehydration. Many people with dysphagia need to have all their liquids thickened. Complex fluid preparation and fatigue can make it difficult to maintain an adequate fluid intake, especially if additional fluids

Motor impairment & chorea may prevent some people from getting access to fluids. They cannot drink it if they are unable to get to it! Chorea can interfere with a person's ability to get a drinking container to their mouth. This can lead to frustration, which may cause the person to avoid drinking fluids.

Symptoms of dehydration:

Dry Mouth

Decreased urination
or dark colored urine

Low Blood Pressure
or Fast heart rate

Change in mental
status or confusion



Preventing dehydration: Remember that a person with HD may not ask for fluids or tell you they are thirsty; therefore caregivers, family and friends need to anticipate this need and plan accordingly

Have fluids within reach and remind to drink frequently: aim for 8oz every few hours, increase for persons in warm/home climates or those that sweat more

Drinks with electrolytes are helpful if there has been vomiting, diarrhea, intense exercise or fever to maintain proper hydration

During extreme heat, stay indoors, A/C preferably; if you must go outdoors try to go in morning which is usually the coolest time

Always have fluids available when not at home (water bottles)

If there is concern about fluid intake, consider logging fluid intake: date, time & amount of fluid intake, daily should have 80-100oz and increase to 140+oz in hot climates

Have cups with handles or water bottles with a spout or straw easily accessible



When to seek medical attention for dehydration:

Change in mental status or confusion

Unable to drink by mouth

Change in VITAL signs (increase heart rate, decreased blood pressure or temperature)



IDEAS to Increase Calorie Intake

Eat 4-6 smaller meals daily

Set a regular schedule for meals

Add high calorie snacks, nutritional drinks or shakes to increase calories and protein

Make shakes/smoothies, snacks in advance for easy grabbing

Shakes/smoothies in bulk & freeze in individual serving cups

Place 1-2 in refrigerator each night to be eaten the next day

High calorie foods:

- Oatmeal, hot cereal
- Cheese & cream cheese
- Cream (heavy or whipping)
- Eggs
- Ice cream, yogurt, puddings
- Milk Powder- mix in with other foods to add calories and protein
- Oat Bran- can be mixed into food to increase calories and nutrients
- Nuts & nut butters- nuts can be finely ground and mixed into foods
- Salad dressing, mayonnaise, sour cream
- Sugars: honey, syrup, jam, frosting
- Whole milk
- Avocado
- Mashed sweet potatoes
- Gravies, sauces
- Hummus
- Oils: Coconut Oil, Avocado Oil, Olive Oil
- Mashed potatoes, macaroni and cheese, pastas, soft textured casseroles, beans, tofu,

Nutritional or Protein Supplements:

- Ensure or Boost
- Carnation Instant
- Protein Powder
- Muscle Milk
- Scandishake



Where to add extra calories

Shakes/Smoothies

- Use a blender, juicer, or food processor
- Add ice cream, fruit, oils, protein powder/nutritional drinks, nut butters, yogurt, ground chia or flax seeds, avocado, etc. for additional calories and protein.
- Choose flavors that the HD person enjoys.

Vegetables

- Add cheese, cream, sour cream, protein to mashed potatoes.
- Add cheese to vegetable sides (broccoli, asparagus, cauliflower, etc)
- Add sauces (BBQ, ketchup, gravy, marinara sauce, pesto/alfredo, butter sauces, tahini, etc.)
- Choose flavors that the HD person enjoys.

Protein

- Add sauces to meat to add calories and add moisture to help with swallowing: (BBQ, ketchup, gravy, marinara sauce, pesto/alfredo, butter sauces, tahini, etc.)
- Choose flavors that the HD person enjoys.

Fruit

- Pair with yogurt, pudding for added calories.
- Pair with nut butters
- Add marshmallow, cream or yogurt sauce/dip.
- Choose fruits with soft texture to prevent swallowing difficulties



Community/Food Resources

Below are some community resources or businesses that you may want to consider in meeting your nutritional and food needs:

- Meals on Wheels (cooked meals delivered to those that qualify)
- Angel Food Ministries
- Food Banks
- Community Centers/Senior Centers
- Home Delivery Meals/Subscriptions
- Grocery Delivery

Help and support is available check out:

[HDSA.org](https://www.hdsa.org)

[HDSA Center of Excellence](#)

[HD Support Groups](#)

[Help4HD](#)

[Area Agency on Aging \(by County\)](#)

[Call 211 for info and resources in your area](#)