

# A guide to nutrition for patients with Huntington's disease

This guide provides practical advice and information to help you make informed choices about your diet and manage your symptoms effectively

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# Introduction

Huntington's Disease (HD) is a complex neurodegenerative disorder that affects movement, cognition, and behavior. It can also significantly impact your nutritional needs and eating habits. This guide aims to provide you with practical advice and information to help you make informed choices about your diet and manage your symptoms effectively.

# Understanding Huntington's disease and its impact on nutrition

HD can cause a range of symptoms that directly and indirectly affect nutrition. These can include:

- **Increased calorie needs:** The involuntary movements associated with HD, known as chorea, can significantly increase energy expenditure, leading to higher calorie requirements [1].
- **Difficulties with swallowing (Dysphagia):** HD can affect the muscles involved in chewing and swallowing, making it challenging to consume enough food and increasing the risk of choking [1]. This can be particularly distressing, but there are strategies and support systems available to help you manage these difficulties.
- **Cognitive changes:** Problems with concentration, memory, and decision-making can make it difficult to plan and prepare meals or remember to eat regularly [2].
- **Changes in appetite:** Some individuals with HD may experience increased appetite, while others may have a reduced desire to eat [2]. Medication side effects can also influence appetite and may cause dry mouth [2]. If you're experiencing changes in your appetite or find it difficult to eat, it's important to discuss this with your doctor or a registered dietitian.

- **Weight loss:** Unintentional weight loss is a common concern in HD, often due to a combination of increased calorie needs, difficulty swallowing, and changes in appetite [1]. Maintaining a healthy weight is crucial for overall health and well-being.

# General dietary guidelines for people with Huntington's disease

While individual needs vary, some general dietary guidelines can help people with HD maintain their health and well-being:

- **Prioritize calorie-dense foods:** Choose foods that provide a high amount of calories in a smaller volume, such as avocados, full-fat dairy products, nut butters, and hearty soups [1].
- **Ensure adequate protein intake:** Protein is crucial for maintaining muscle mass, which can be compromised by weight loss and chorea. Include protein-rich foods like meat, fish, eggs, dairy, beans, and lentils in your diet [1].
- **Focus on soft and easy-to-swallow foods:** Opt for foods with a smooth consistency, such as mashed potatoes, yogurt, cooked cereals, and well-cooked vegetables. Avoid foods that are dry, crumbly, or require a lot of chewing [1].
- **Stay hydrated:** Drink plenty of fluids throughout the day, especially water. Consider using cups with lids or straws to make drinking easier. People with HD are at risk for dehydration, especially in warmer climates, so it's essential to be mindful of your fluid intake [7].
- **Eat smaller, more frequent meals:** Consuming smaller portions more often can be easier to manage than three large meals [5].
- **Create a pleasant eating environment:** Minimize distractions and create a relaxed atmosphere during mealtime [6]. Remember that food is more than just fuel; it's a source of pleasure and an important part of social and cultural events [6]. Try to make mealtimes enjoyable and share them with loved ones whenever possible.

- **Consider a mediterranean-style diet:** Some research suggests that a diet rich in fruits, vegetables, whole grains, and healthy fats may be beneficial for people with HD [8].
- **What's good for your heart is good for your brain:** Focus on a heart-healthy diet, which often overlaps with recommendations for brain health [7].
- **Foods to avoid:** Due to the risk of choking, it's generally recommended to avoid the following foods [1]:
  - Raw fruits
  - Flaky puff pastry
  - Granola
  - Tough, crusty bread
  - Nuts
  - Raw, stringy vegetables
  - Bacon
  - Tomatoes

# Specific nutritional needs for Huntington's disease patients

## Calorie intake

People with HD often require a higher calorie intake than the average person due to increased energy expenditure from chorea and potential metabolic changes. It's important to maintain a healthy weight and body mass index (BMI) to support your overall health [1]. While individual needs vary, some sources suggest a daily intake of 3,500 to 5,000 calories may be necessary [9]. It's essential to work with a healthcare professional to determine your specific calorie goals.

Here are some examples of high-calorie foods that you can incorporate into your diet: [10]

- Full-fat milk (you can add skimmed milk powder to increase calories)
- Yogurt (choose full-fat varieties)
- Double cream (add to cereals, fruits, puddings, soups, etc.)
- Cheese (full-fat cheeses like cheddar and Lancashire)
- Meat and fish (cook well and serve with gravy or sauce)
- Lentils and beans
- Sugar (add to drinks and desserts)
- Honey, jam, marmalade, golden syrup, treacle
- Butter and oil



## Protein intake

Adequate protein is vital for maintaining muscle mass and overall health. Aim to include protein in every meal and snack. Good sources include:

- Lean meats and poultry
- Fish and seafood
- Eggs
- Dairy products (milk, yogurt, cheese)
- Beans and lentils
- Tofu and tempeh
- Nuts and nut butters (if tolerated) [\[2\]](#)

## Vitamins and minerals

While there's no evidence that vitamin and mineral requirements are significantly altered in HD, it's crucial to consume a balanced diet that includes a variety of fruits, vegetables, and whole grains to ensure adequate intake of essential nutrients. Some research suggests that certain vitamins and minerals, such as vitamin B12 and antioxidants, may be particularly important for brain health [\[6\]](#).

## Fiber

Fiber is an important part of a healthy diet, and it can be especially helpful for people with HD who may experience constipation. Individual needs for fiber vary, so it's important to discuss this with your healthcare provider or a registered dietitian to determine what's right for you [\[11\]](#).

# Nutritional support in advanced HD

In the later stages of HD, chewing and swallowing may become increasingly difficult. If you're struggling to meet your nutritional needs through regular food, your doctor may suggest tube feeding as an option [1]. Tube feeding involves delivering liquid nutrition directly into your stomach through a tube. This can help ensure you're getting the calories, protein, and nutrients you need.

There are different ways that tube feeding can be administered: [6]

- **Continuous:** Running 24 hours a day, every day.
- **Intermittent/Cycled:** Running only part of the day (e.g., cycled overnight or running for 12 hours).
- **Bolus:** Given either via syringe or gravity (drip without a pump) at mealtimes typically.
- **Supplemental:** This could be bolus or intermittent and might be given in addition to eating if you're unable to consume enough calories.

Your doctor and healthcare team will work with you to determine the most appropriate type of tube feeding for your individual needs.

# Practical advice and meal planning tips for Huntington's disease patients

## Meal planning

- **Create a weekly meal plan:** Plan your meals in advance to ensure you're incorporating a variety of nutrient-dense foods and meeting your calorie and protein needs.
- **Make a grocery list:** Having a list can make shopping easier and help you stay organized.
- **Prepare meals in advance:** Cook larger batches of food and freeze individual portions for easy access on days when cooking is challenging.
- **Utilize convenient options:** Keep easy-to-prepare foods on hand, such as canned soups, frozen meals, and pre-cut vegetables.
- **Consider meal delivery services:** If cooking is becoming increasingly difficult, explore meal delivery services that offer healthy and appropriate options [\[1\]](#).

## Food preparation

- **Modify textures:** Adjust the texture of foods to make them easier to swallow. This may involve chopping, mashing, pureeing, or adding sauces and gravies [\[1\]](#).
- **Use assistive devices:** Consider using kitchen tools that can make food preparation easier, such as blenders, food processors, and potato

mashers [6].

## Eating habits

- **Sit upright while eating:** Maintain an upright posture to aid in swallowing and reduce the risk of choking [1].
- **Take small bites and chew thoroughly:** Eating slowly and chewing food well can help prevent choking [7].
- **Minimize distractions:** Avoid watching TV or engaging in intense conversations during meals to focus on eating [1].
- **Rest before meals:** If fatigue is a concern, consider resting for an hour or two before mealtimes to conserve energy for eating [1].
- **Use thickening agents:** If you have difficulty swallowing liquids, your doctor or a speech and language therapist may recommend using a thickening agent to make them easier to manage [2].
- **Assistive devices for eating:** A variety of assistive devices can make eating easier and more comfortable. These include: [1]
  - Utensils with thick handles
  - Plate guards to prevent spills
  - Cups with lids
  - Dishes to keep food warm
  - Plastic aprons to protect clothing

## Sample meal plans and recipes

Here are some examples of meals and snacks that may be suitable for people with HD:

### Breakfast:

- Oatmeal with whole milk, fruit, and nuts (if tolerated)
- Scrambled eggs with cheese and avocado
- Yogurt with fruit and granola (if tolerated)
- Smoothies with protein powder, fruit, and yogurt [\[12\]](#)

### Lunch:

- Soup with whole-grain bread
- Tuna salad sandwich on soft bread
- Chicken salad with crackers
- Leftovers from dinner

### Dinner:

- Shepherd's pie with mashed potatoes

- Chicken and rice casserole
- Pasta with meat sauce
- Salmon with roasted vegetables

### **Snacks:**

- Cheese and crackers
- Fruit with yogurt or nut butter (if tolerated)
- Hard-boiled eggs
- Pudding or custard
- Ice cream [\[10\]](#)

### **Recipes:**

Many online resources provide recipes specifically designed for people with HD, such as the Huntington's Disease Society of America (HDSA) Center of Excellence at UC Davis Health and the HDSA Tennessee Chapter [\[1\]](#). Here are a few examples from these resources:

- Salsa Chicken Rice Casserole [\[13\]](#)
- Hamburger Cheese Bake Casserole [\[13\]](#)

- [Bow Tie Pasta \[13\]](#)
- [Ham and Cheese Tater Tot Casserole \[13\]](#)
- [Tuna Noodle Casserole \[13\]](#)
- [Smoothies \[12\]](#)

# Importance of Working with a Healthcare Professional

It's essential to work with a healthcare professional, such as a doctor, registered dietitian, or speech-language pathologist, to develop an individualized nutrition plan that meets your specific needs and addresses any challenges you may be facing [4]. They can help you:

- Determine your calorie and protein needs
- Identify potential nutritional deficiencies
- Address swallowing difficulties
- Provide guidance on meal planning and food choices
- Monitor your weight and overall health
- Offer support and resources
- Early assessment and regular review of your nutritional needs are vital due to the variability in energy requirements and the potential for rapid weight loss [14].
- An occupational therapist can also be a valuable member of your healthcare team, providing practical tips and assistance with eating and drinking [2].



# Conclusion

Living with HD can present unique challenges, but with careful attention to your diet and by working closely with your healthcare team, you can maintain your nutritional well-being and manage your symptoms effectively. Remember to prioritize calorie-dense foods, ensure adequate protein intake, and focus on soft, easy-to-swallow options. Maintaining a healthy weight and staying hydrated are also crucial.

It's important to remember that everyone's experience with HD is different, and your nutritional needs will change over time. Regular check-ups with your healthcare team and ongoing adjustments to your diet will help you stay healthy and comfortable.

Beyond the physical aspects of nutrition, remember that food can be a source of enjoyment and social connection. Try to make mealtimes a positive experience, and don't hesitate to reach out for support and guidance when needed. There are resources and people available to help you navigate the challenges of HD and live as full a life as possible.

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