

We Are HDSA!



 Huntington's Disease
Society of America

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Nutrition in HD - **Make it a matter of taste**

By Karen Tarapata

For many people with HD, mealtime is not a pleasure. Swallowing has become difficult and choking is a concern. It may take quite a bit of time to simply get the food down. Occupational therapists and nutritionists recommend people with HD reduce noise and distractions at mealtime and focus strongly on getting enough calories. They also recommend that people with HD choose thickened liquids and soft or pureed foods to minimize the danger of choking. All of these suggestions will help prevent bad things from happening during meals. The question is - what can a caregiver do to make positive things happen at mealtime?

The answer is to add flavor, zest, savor and aroma. These are the things that make food appetizing. Food can and should be delicious. Eating is one of life's greatest and most basic pleasures. Making food more tasty can help caregivers address many of the nutrition issues that affect people with HD: the need for calorie-rich food, the need to eat food with modified textures and the need to maintain focus while eating.

Many foods that add flavor will also add the extra calories that people with HD require to maintain their weight. These could include: lemony hollandaise sauce, buttery gravy, pan drippings (strain out for the crunchy bits), bacon fat, sour cream or stroganoff sauce, plain or flavored cream cheese, alfredo sauce, pesto sauce, peanut sauce, mayonnaise, or smooth guacamole. What rich delicious sauces are long-time favorites in your home?

Choking is a major concern for people with HD and changing the texture of food can help. To reduce problems with swallowing, caregivers are encouraged to: avoid foods with mixed textures like minestrone soup, scrambled eggs and macaroni and cheese; cook food longer so it becomes softer; mash food with the back of a fork, put food into the blender or food processor; and thicken fluids to a yogurt or a creamed soup consistency. That said, soft or pureed food doesn't mean bland baby food. Food with a smooth texture can still have adult flavors and aromas. What foods did your loved one

enjoy before swallowing became a concern? What were the dominant flavors in your family's favorite recipes? How do you add these tastes to the foods they can now eat?

There are wonderful flavoring options you can add to foods that have been pureed or food processed, including: smoky barbecue sauce, strained red eye gravy, Szechuan stir fry sauce, ginger soy sauce, marinara sauce, a little hot sauce, mild green chiles, taco seasoning, chili powder, beef or chicken bouillon, curry powder, strained soft cooked garlic, onions and green peppers, seasoned salt, powdered parmesan cheese, celery salt, garlic powder.

To add flavor and interest to pureed vegetables, think about options like: creamy blue cheese, ranch or Caesar dressing, olive oil and lemon or balsamic vinegar, even cheese sauce. These can be blended in or poured on top.

There is room for great creativity and personal choice in the seasoning of food, whatever the texture. Be sure to ask your health care provider about the food consistency that is most appropriate for your loved one at this time.

Making food more flavorful can help your loved one maintain their focus on eating and increase the enjoyment and quality of life. Here are a few more tips that may make for a more successful mealtime:

- Reduce distractions. Turn off the television at mealtime. Limit conversation.
- Have your loved one sit in a straight chair at the table with both feet on the floor. Sitting upright reduces the possibility of choking.
- Try serving one food at a time. Encourage them to eat slowly.
- Encourage them to drink liquids only after a bite has been swallowed successfully. "Washing food down" with liquid can lead to choking, as can the use of straws.

Nutrition:

Nutrition and HD, from our family guide series, provides information about the nutritional needs of a person with HD and includes several delicious recipes. *Nutrition and HD* can be downloaded for free online, or contact Anita Mark-Paul, Information and Fulfillment Coordinator, at amarkpaul@hdsa.org for a copy. Please note that the first copy is free and every additional copy is \$2.00

Myths about HD:

HDSA is researching myths and misinformation about HD. If you have recently heard any myths or misinformation about HD, please fill out the survey at www.hdsa.org/myths. The information gathered will be used for future initiatives.

Ask the Social Worker:

In December's *Ask the Social Worker*, the question "What will my husband's HD look like?" is answered. You can read this and past *Ask the Social Worker* articles at www.hdsa.org/atsw. If you have a question that you would like answered, please e-mail Seth J. Meyer at smeyer@hdsa.org with the subject line *Ask the Social Worker* and check back to see if your question is answered!

Caregiver's Corner:

February 22

Spirituality & HD

Lunch & Learn:

March 20

Workplace Accommodations for HD

You can access older webinars by going to www.hdsa.org, in the Living with HD Section.

By Stacey Hoffman, RD, LD, CNSD, Director of Clinical Nutrition, HDSA Center of Excellence at Hennepin County Medical Center

You might not think of talking with a Registered Dietitian to help you through the different stages of Huntington's disease (HD), but in reality, nutrition is greatly affected by HD. Nutritional needs change during the course of the disease, and chorea and swallowing problems only add to the difficulty in getting adequate nutrition. Registered Dietitians are food and nutrition experts who can improve your health and well-being by evaluating your needs, teaching you what you need and how to get it.

People with HD have unique nutrition needs. While there are no large studies indicating that a specific nutrient or food will help prevent HD or its symptoms, there is evidence that eating a well balanced diet that includes a variety of antioxidants, omega-3 fatty acids and B vitamins is beneficial for overall health. This includes foods like fish, whole grains, fortified breads and cereals, fruits and vegetables. People who eat well are better able to maintain a healthy weight (even with HD), are ill less frequently and adapt more easily to the changes that occur during the course of this disease.

With HD, we focus on several things when it comes to nutrition. First, enjoy your food! Second, don't skip meals. In order to meet your nutrition needs, eating only one or two meals a day isn't going to be enough. You need to snack and eat regularly in order to get in all of those nutrients, and that applies to everyone with and without HD! Next, include a variety of foods. This sounds like an easy task but sometimes requires a little planning and help from family and friends. And lastly, modify calorie intake and textures when needed. As the disease progresses, your needs change and you may need to eat more calorie dense foods or eat softer foods and a dietitian and speech pathologist together can help you with that.

An example of changes to food textures and calories are below:

In the early stages, a typical dinner might consist of steak, potatoes with butter, salad with dressing, and skim milk.

- In this stage, not many texture or calorie changes may be needed. It's a good time to focus on eating regular meals and eating a variety of foods.

In the middle stages, try changing your meats to something softer like meatloaf with a sauce, mashed potatoes with gravy, green beans with butter, whole milk, and cheesecake for dessert.

- In this stage, modifying textures may be needed. Sauces help to moisten the food but also add calories. Things like chili, quiche, casseroles with small pieces of meat & vegetables, or pasta dishes are great meal choices. This is also the time when higher calories are often needed so the use of higher fat food items such as butter, sour cream, whole milk is recommended. For a healthier version of high fat foods, try things like avocados, hummus, olives, coconut milk, nut butters, etc.

In the late stages, food textures may need to be changed even further and pureed foods might be necessary. Having an immersion blender or food processor available is helpful. Try pureeing meats with gravy or a flavorful casserole with a small amount of broth or milk. Creamy soups like clam chowder or butternut squash soup are full of flavor, high in calories and can be pureed for smoother textures. To get a variety of fruits and vegetables in your diet while eating pureed foods add pureed fruit to smoothies or hot cereal or use mashed sweet potatoes or squash for a vitamin packed side dish.

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Educational Events:

March 10:

Illinois Chapter
UC Irvine

March 31:

St. Louis Chapter

HDSA Educational Grants Program:

HDSA is pleased to announce the renewal of the grant program designed to help support HDSA field-based educational events, including guest speakers for support groups in 2012. To apply for an educational grant, please contact Deb Lovecky at Dlovecky@hdsa.org or Jane Kogan at Jkogan@hdsa.org.

Going Green!

Want *We Are HDSA!* delivered right to your inbox? Then sign up for the e-mail edition of *We Are HDSA!*. For more information or to sign up, please contact Seth J. Meyer at smeyer@hdsa.org. To read past issues of *We Are HDSA!*, visit the HDSA website at www.hdsa.org.

HDSA Annual Convention:

27th Annual HDSA Convention
June 8-10, 2012



For more information or to register, please visit www.hdsa.org/convention.

These are two recipes adapted from the "*Recipes from the Heartland*" cookbook written by the Upper Midwest Region of HDSA in 2011.

Chicken Noodle Casserole

- 6 ounces pasta, cooked & drained
- 1 10.75 ounce can cream of chicken soup
- 1 6 ounce can evaporated milk
- 1 cup shredded cheddar cheese
- 2 cup chicken breast, cooked and chopped
- 1 cup chopped celery

Preheat oven to 350 degrees. Lightly grease 1 qt. casserole dish. Combine all ingredients and place in casserole dish. Bake uncovered for 30 minutes or until lightly brown and bubbly.

**TIPS: Add frozen vegetables to increase the nutrient content of this casserole. Use regular, not skim, evaporated milk and regular cream soup, not low fat to increase the calories. Top with cheese or sour cream to add more calories if needed.*

Mashed Potato Layer Bake

- 3 ¼ pound baking potatoes, peeled, chopped and cooked
- 1 8 ounce pkg. chive and onion cream cheese spread, divided
- ½ pound sweet potatoes, peeled, chopped and cooked
- ½ cup sour cream, divided
- ¼ cup shredded cheddar cheese
- ¼ cup shredded or grated parmesan cheese, divided
- ¼ teaspoon salt
- ¼ teaspoon pepper

Preheat oven to 375 degrees.

Place potatoes in separate bowls. Add half of the cream cheese, sour cream, salt and pepper. Mash until creamy.

Stir half of the parmesan cheese into baking potatoes and half of the cheddar cheese into sweet potatoes. Layer half of each of the potatoes in a 2 quart, clear casserole dish. Repeat layers. Bake 15 minutes. Top with remaining cheeses. Bake 5 minutes more or until cheese is melted.

**TIPS: This dish can be made ahead without cheese topping. This is a great smooth side dish to serve with pureed turkey and gravy and a glass of whole milk for a high calorie meal.*

Convention **Scholarship Program**

Sponsored by Lundbeck

Eligibility

- Convention scholarships are only open to **first time** convention attendees who are non-Nevada residents of the United States. Applicants must be 18 years or older as of March 23, 2012.
- The scholarship application is available online on the HDSA website, www.hdsa.org/scholarship.
- Applications must be post-marked no later than midnight, **Friday, March 23, 2012** and mailed to:

Convention Scholarship

Huntington's Disease Society of America
505 Eighth Avenue, Suite 902
New York, NY 10018
Attention: Robert Coffey

- Applications may also be submitted by fax to 212-239-3430.
- **Applicants will be notified no later than April 13, 2012 as to whether they have been awarded a scholarship.**

What does the scholarship cover?

TRAVEL BY PLANE

- Round-trip airfare up to \$500 per person for up to four family members (please note you must book and pay for your airfare and you will be reimbursed at the Convention);
- Hotel accommodations for up to four family members at the Red Rock Resort for 3 nights, June 7 - June 9; and
 - (If your family includes a National Youth Alliance (NYA) member who will be attending HDSA's NYA Day on June 7, you will receive 4 nights, June 6 - June 9)
- Convention Registration Fees for up to four family members.

TRAVEL BY AUTOMOBILE

- Roundtrip mileage reimbursement at 55.5 cents per mile;
- Hotel accommodations for up to four family members at the Red Rock Resort for 3 nights, June 7 - June 9; and
 - (If your family includes a National Youth Alliance (NYA) member who will be attending HDSA's NYA Day on June 7, you will receive 4 nights, June 6 - June 9)
- Convention Registration Fees for up to four family members.

What doesn't the scholarship cover?

- Hotel incidentals
- Transportation to and from the hotel/airport.
- Meals not provided as part of the Convention registration.

HDSA Advocacy **Video Contest**

Be HDSA's guest at the 27th Annual Convention this June!

HDSA is holding its first ever Advocacy Video Contest! Members of the HD community are invited to submit a short (up to 60 second) video about why it's important to advocate for HD and HDSA. HDSA will bring the producer of the best video and one guest to the HDSA Annual Convention in Las Vegas. Entries will be accepted through midnight, March 15, and the winner will be announced during May HD Awareness month activities. Please visit www.hdsa.org/advvideo for more information, full prize details, contest rules and instructions on how to enter.

Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

