

■ *Eating and Nutrition*

PREVENTING WEIGHT LOSS

Providing adequate nutrition can be the single greatest clinical issue in caring for a person with HD. Maintaining body weight will be a constant challenge for both of you. It is estimated that some people with HD, particularly in the more advanced stages, require a diet of up to 5000 calories a day just to maintain their weight. No wonder many people with HD say they are always hungry!

In long-term care facilities, nutritionists should consider double and triple portions for people with HD. In fact, free access to food may be the order of the day. When he asks for more food, some say reflexively, "But you just ate!" It may be more appropriate to say, "Oh, you just ate, but can I get you something else?!" Someone in the later stages of HD who is overweight is very rare. Take his requests for more food or supplements as seriously as you would anyone else who is very, very hungry.

Constant hunger can make it difficult to wait for lunch and dinner. Perception of time may be altered. It may be helpful to serve five or more "mini-meals" throughout the day and while the patient is awake at night. This prevents constant hunger and may help to minimize gulping. Another strategy is to increase caloric intake by creating a diet of high-calorie foods. Imagine: A person with HD can have a weekly menu of dishes that most people prefer, but choose to avoid because they're so high in calories!

SOME HIGH-CALORIE RECIPES

If each mouthful of food is so difficult to chew and swallow, then maximizing the number of calories in each bite can only help. There are anecdotal reports that those who reach an ideal body weight report feeling better in general, may metabolize medication more smoothly, and maintain function longer than those who have had

significant weight loss. Unfortunately, the involuntary movements that may knock food to the floor, the swallowing disorder, and the great concentration needed to chew safely complicate getting those calories into the digestive tract.

People often supplement their meals with high-calorie drinks. These commercially manufactured supplements, common in long-term care facilities for many years, are now available in most local pharmacies. Family and professional caregivers have cleverly invented “super-calorie” foods to quickly boost calorie intake at a single meal. Recipes for two such examples, a “Super Shake” and a “Super Cereal”, are provided below. High-protein, high-calorie powders that add calories to shakes, puddings and other foods are available through commercial institutional food distributors and local retail health food stores across North America.

Caregiver Tips

- Give frequent meals and high-calorie snacks and drinks to prevent weight loss.
- Help the person with HD eat until full.
- Ensure eating is slow and deliberate.
- Beware hot drinks. A decreased sensation of heat can cause burns!

Super Shake (Single Serving)

Whole Milk 6 ounces
Ice Cream 2 scoops
Ovaltine™ 2 teaspoons
High-protein high-cal. additive* ... 1½ scoops
Fruit add to taste

In a blender, blend milk and high-protein additive together; add Ovaltine™. Blend in two scoops of ice cream (or more) and fruit to preferred thickness.

Super Cereal (Single Serving)

Evaporated Milk 7 ounces
Margarine 2 tablespoons
Cream of Wheat™ 1-1/2 ounces
Brown Sugar 1-1/4 ounces
Cinnamon

Heat evaporated milk in a saucepan. Dissolve margarine and brown sugar in heated liquid. Add cereal until it thickens. Add cinnamon to taste.

Super Cereal (Serves 30)

Evaporated Milk 1 #10 Can
Margarine 1/2 pound
Cream of Wheat™ 14 ounces
Brown Sugar 1 pound
Cinnamon

As above. Add Cream of Wheat™ slowly to reach preferred consistency.

** High-protein high-calorie additive powders are readily available in nearly all health food and nutrition stores.*

IN SUMMARY...

Eating is one of the primary pleasures in life. Against all odds, most people with HD struggle to eat independently, then with assistance, for as long as they are able. However, with difficulty controlling the movements to get the food to their mouth, involuntary movements that interfere with eating, altered or puréed food, drool, bibs, sudden inhalation and possibly coughing, a meal can be a messy affair. A committed caregiver can make a big difference by taking the time to help the person with HD take in as much food as possible, as safely as possible.