Disclosure

The information provided by speakers in educational presentations is for informational use only and does not constitute medical advice.

HDSA encourages individuals to consult a medical professional about any advice, treatment, nutritional supplement or regimen mentioned as a part of this presentation.
Modules

1. Registered Dietitian’s Role in HD
2. What is a healthy diet?
3. Good Nutrition: “Brain Healthy” diet
4. Weight Changes & Calorie Needs
5. Swallowing Safety
6. Dental Health
7. Let’s Cook! Tips for an HD Kitchen
8. Enteral Nutrition
Registered Dietitian’s Role
Nutrition Assessment

• Estimate calorie & protein needs
• Monitor weight status, GI function, skin
• Ensure adequate macronutrient & vitamin/mineral intake
• Consider stage of HD
  – Feeding difficulties
• Consider potential barriers
  – Financial, equipment, education, support, resources
• Intervene/make recommendations as needed
Basics of a Healthy Diet
What is a Healthy Diet?

- Variety
- Less processed foods
- Whole grains
- Lean protein
- Healthy fats
- Low-fat dairy
- Antioxidants
- Vitamins/minerals
- Fiber
My Daily Food Plan

Based on the information you provided, this is your daily recommended amount for each food group.

**GRAINS**
9 ounces

**VEGETABLES**
3 1/2 cups

**FRUITS**
2 cups

**DAIRY**
3 cups

**PROTEIN FOODS**
6 1/2 ounces

Make half your grains whole
Aim for at least 4 1/2 ounces of whole grains a day

Vary your veggies
Aim for these amounts each week:
- Dark green veggies = 2 1/2 cups
- Red & orange veggies = 7 cups
- Beans & peas = 2 1/2 cups
- Starchy veggies = 7 cups
- Other veggies = 5 1/2 cups

Focus on fruits
Eat a variety of fruit
Choose whole or cut-up fruits more often than fruit juice

Get your calcium-rich foods
Drink fat-free or low-fat (1%) milk, for the same amount of calcium and other nutrients as whole milk, but less fat and Calories
Select fat-free or low-fat yogurt and cheese, or try calcium-fortified soy products

Go lean with protein
Twice a week, make seafood the protein on your plate
Vary your protein routine—choose beans, peas, nuts, and seeds more often
Keep meat and poultry portions small and lean

Find your balance between food and physical activity
Be physically active for at least 150 minutes each week.

Know your limits on fats, sugars, and sodium
Your allowance for oils is 8 teaspoons a day.
Limit Calories from solid fats and added sugars to 360 Calories a day.
Reduce sodium intake to less than 2300 mg a day.

Your results are based on a 2600 Calorie pattern.

This Calorie level is only an estimate of your needs. Monitor your body weight to see if you need to adjust your Calorie intake.

Get your daily food plan and track your calorie intake at www.choosemyplate.gov
A “healthy diet” for HD

- Focuses on:
  - Adequate calories
  - Nutrient dense foods
  - Small, frequent meals
  - Snacks
  - Atmosphere/cues
  - Liquids between meals
  - Supplements
  - Appropriate texture
  - Limited caffeine

ChooseMyPlate.gov
Adding extra calories/protein

- Use cream, whole milk, evaporated milk, or condensed milk instead of low fat or skim milk
- Add cheese, sour cream, butter, margarine, or oil to vegetables
- Add avocado to salads, or top with creamy-style dressings
- Add cream or butter and sugar to cereal
- Scoop ice cream over fruit, cake, pie, or waffles
- Add extra mayonnaise to tuna, egg, or chicken salad
- Try cream cheese or peanut butter on crackers, bagels, fruit, or carrot sticks
- Add coconut cream to shakes or main dishes for extra calories and a tropical taste
- Sauces and gravies add calories to meat and potatoes
Benefits of Home Cooking

More likely to eat balanced, healthy diet

- Increased fruit/vegetable intake (vitamins, fiber)
- Increased dairy (calcium, vitamin D)
- Less snack or junk food = healthier families

Increased nutrient intake

- Less processed food
- Lower sodium
- Know what you are eating
- Costs less
- Easier to modify food textures & calories at home

Beyond nutrition

- Solidify the family unit
- Protected time together without interruptions
- Time for kids to interact with parents
Eating Together

- Make it a **priority** – establish a meal time/day
- Make it **simple**
- Make it **pleasant** and fun – plan meals together, prepare meals together, avoid distractions
Eating Out with HD

• Plan ahead
  – Look at menu online
  – Check wheelchair accessibility, etc.
  – Dine during “off peak” times

• Pack the things you need
  – Supplements/snacks

• Consider dexterity
  – Finger foods
  – Appropriate utensils

Examples of Soft Entrees

Chinese: Steamed buns, steamed dumplings, Lo Mein (soft noodles)
Diner: Macaroni and Cheese, meatloaf, mashed potatoes, green beans
Italian: lasagna, eggplant parmesan, meatball hero
Mexican: quesadilla, burrito
Key Points

✔ Eat a balanced diet
✔ Use www.myplate.gov to find out more about how many calories you need, and to get meal planning tips
✔ Eat together with family or friends
✔ If you are planning to eat out, plan ahead
“Brain Healthy” diet
Brain Healthy Diet Basics

• Having a diet that is **adequate in calories** to maintain a healthy weight is the most important dietary factor with HD

• **Individualized diet plans** are the best for the ever-changing needs of a person with HD

• Based on research literature for the general population, and some more common neurological conditions, such as dementia, there are some dietary factors considered to be “brain healthy”
Vitamin B12

- Research has shown that Vit B12 deficiency that is prolonged may cause nerve damage
  - Keeps nerves and blood cells healthy
- Found only in animal foods (meat, dairy, eggs, poultry, etc.)
- Most people in the US get enough B12 if they include animal foods in their diet
  - Monitor/supplement as needed
Antioxidants

- Prevent potential oxidation in the body that may damage cells
- **Color** is important when choosing foods with antioxidant properties – foods with deep, rich color tend to be higher in antioxidants
  - Ex: Vitamin E, Vitamin C
- Choose a variety of fruits and vegetables to get these into your body
- It is currently unknown whether there is a specific need for people with HD
Essential Fatty Acids

- Essential fatty acids cannot be made by the body
- Function
  - Reduce blood triglycerides & cholesterol
  - Synthesize hormones
  - Skin integrity, normal growth, reproduction
  - Retina and vision health
  - Can be oxidized for energy
- Studies regarding the use of omega-3 fatty acids to protect against cognitive decline in individuals with neurological disorders are inconclusive.
- General recommendation: 1,000-2,000 mg/day

*Disclaimer: Omega 3 fatty acids can have a blood thinning effect so check with your doctor before taking a supplement!
Sources of Essential Fatty Acids

- Canola Oil
- Olive Oil
- Walnuts & nut butters
- Avocados
- Salmon/fish oil
- Flax Seed
Key Points

 ✓ There is no one “super food” that can cure HD
 ✓ Eat a variety of foods & textures
 ✓ Try to include at least one “brain healthy” food at every meal
 ✓ Talk to a Registered Dietitian (RD) about what foods are right for you
Weight Changes & Calorie Needs
Weight Changes
Factors Regulating Calorie Expenditure

- Age
- Gender
- Physical Activity
- Illness, infections, fever

Special Factors Relating to HD
- Chorea
- Loss of Coordination
- Difficulties Eating
How do you know you’re getting enough?

- Estimate 14 calories per pound of body weight
  - Go to www.myplate.gov to get a personalized estimate of calorie needs (or ask an RD!)
- Increase or decrease intake as needed
- Monitor your weight
- How do clothes fit?

How Much Weight Loss is too Much?
Consult a medical professional if you lose 5 percent of your weight within a few weeks or 10 percent within six months.
Key Points

✓ Maintain a healthy weight (with a little to spare!)
✓ See a Registered Dietitian (RD) to learn about ideal body weight & calorie needs

✓ IBW

Men: 106 lbs first 5’ + 6 lbs per inch over 5’
Women: 100 lbs first 5’ + 5 lbs per inch over 5’

{ +/- 10% }

✓ BMI calculator (online)
Swallowing Safety
Swallowing Safety
Swallowing

HD can affect some phases of the swallowing process

- Generally present in middle stage
  - Involuntary movements
  - Decreased muscular control
  - Sudden inhalation, coughing, choking
- Risk of aspiration pneumonia

See a Speech Language Pathologist (SLP) for a baseline exam and tips/strategies for safe swallowing, and an Occupational Therapist (OT) for ideas of adaptive equipment that can help.
Warning Signs

- Coughing or clearing the throat during meals
- Losing food or liquid from the mouth
- Holding food in the mouth
- Difficulty chewing food
Strategy: Pay attention to texture

- **Particulates**: Little pieces of food or foods that break into particles/pieces in the mouth (*peanuts, rice, popcorn, peanut M & M’s, corn, etc.*)

- **Crunchy**: Raw vegetables like carrots, broccoli, apples, some crackers or chips

- **Chewy**: Inability to chew fully (*dense breads/bagels, dense meat like steak or pork chops, etc.*)

- **Stringy**: Celery, lettuce, pineapple, fruit with skins like grapes or apples
Strategy: Diet modifications

- May need to eliminate or transform certain foods
- Change from a Regular diet to a Mechanical soft diet
  - Cut meats into small pieces
  - Moisten meats with sauces/gravies
  - Cook all vegetables until soft
  - Limit fresh fruit with tough skins/coarse texture
    - Introduce canned fruit, applesauce, baked fruit
Strategy: Diet Modifications in Later Stages

➢ Transition from a Soft diet to a Ground or Pureed diet

• Dysphagia Diet - Levels 1, 2, 3 may be recommended by a Speech Pathologist
• People with HD will have increased dependence on others for assistance with feeding
• Might be a struggle to get enough calories each day
  – Weight loss may start
• Supplements
  – High calorie shakes
  – Homemade milkshakes
  – Powder/liquid protein
Physical Strategies to Avoid Choking

- SMALL sips
- Head in a neutral position - don’t tilt up
- Eliminate distractions
- Small size straws
- Avoid gulping
- Go slow, chew thoroughly
Strategy: Thickened Liquids

- Nectar thick, honey thick, pudding thick
- Determined by SLP
- A variety of thickeners and thickened beverages are available
Postures to Enhance Safe Eating

• Sit as close to table as possible - place elbows on the table to stabilize the upper body
• Place a pillow or wedge cushion at the back to support the body to stay forward
• Be sure feet are flat on the floor, or place a box or stool under the feet for support
Key Points

- See a Speech Pathologist (SLP) for a baseline exam and tips/strategies for safe swallowing
- See an Occupational Therapist for ideas for adaptive equipment
- Look out for signs of trouble swallowing
- Changing the texture of the food can help
- Enteral nutrition can be an option when someone is unable to consume an adequate amount of food, as well as in other situations like medical crises
Dental Care

- See your dentist regularly
- Brush after meals and snacks
- Remember to floss
- Talk to your dentist about special issues and problems like dry mouth
Finding a Dentist

Questions to Ask The Dentist:

- Do you have experience with someone with HD, or another movement disorder (i.e. Parkinson’s disease)?
- Do you have experience dealing with a patient who is extremely anxious?
- Do you have experience with individuals with swallowing difficulties?
- Do you have experience with patients who have trouble keeping their mouth open?

Helpful Hints:
- Visit your dentist in the morning
- Plan several, shorter dentist visits, rather than fewer, longer ones
Adaptive equipment can make brushing easier

Dr Barman’s Superbrush

Interdental brush

Collis-curve brush
Enlarged plastic handles suitable for toothbrushes

Mouth Angle Expander
Key Points

- Take good care of your teeth
- Ask about adaptive equipment
- Find a dentist who can help
Let’s Eat: Tips for a HD Kitchen
One meal for the whole family is possible if you...

- Plan ahead
- Get help from the rest of the family
- Have the right tools available in the kitchen
A pastry cutter or potato masher
A blender and/or food processor
Dishes with sides
A “keep warm” dish
Sports Cups
Utensils with larger handles
Key Points

- Plan ahead for healthy meals / snacks
  - Keep leftovers in freezer, single size portion
  - Sauces, gravies to flavor and moisten foods
- Keep ready to eat snacks or supplements on hand
- Consider purchasing food processor, blender, or other tools for ease of meal preparation
- Adaptive equipment can make mealtime easier
Enteral Nutrition (EN)
Indication for EN (or tube feeding)

- EN is used when someone is unable to consume an adequate amount of food orally
  - Usually in middle-late stage of HD

- EN can be used as a supplement to oral intake of foods and/or fluids, or as a sole means of providing nutrition

- EN can be used on a temporary basis, when a medical condition does not allow the person to eat normally

Talk to your loved one and a medical professional about the different options before they become necessary.
Formula Types

- Range from 1.0-2.0 calorie/ml
- Varying ratios of macronutrients, electrolytes, osmolarity, fiber and water
- Individualized
- Registered Dietitian (RD) will determine type of formula, method and rate
Methods of EN

- **Continuous** – Runs 24/7 – usually if NPO
- **Intermittent /Cycled** – Runs only part of the day (i.e. overnight, 12 hours, etc.)
- **Bolus** – Bolus is given either via syringe or gravity (drip without a pump) – typically at meal times
- **Supplemental** – Given in addition to eating if unable to eat adequate calories (but it could be done by any of the above methods)
EN Tube Types
For More Information

Huntington’s Disease Society of America
Website: www.hdsa.org
E-mail: hdsainfo@hdsa.org
National Helpline: (888)HDSA-506
References

HDSA Family Guide Series: Nutrition & HD
Available at www.hdsa.org/publications

We Are HDSA: February 2012 (eating well with HD); May 2011 (Food Away from Home)
Available at: http://www.hdsa.org/articleconnect

EHDN Guidelines (Nutrition, oral feeding, oral healthcare) Available at:
http://www.hdsa.org/ehdnpubs