Nutrition and Myotonic Dystrophy

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Objectives

- Basics of a healthy diet
- Recommended amounts of fiber and water
- Suggestions for coping with dysphagia
- Suggestions for managing weight
- Where to go and who to speak to for reliable nutrition information
Basics for a Healthy Diet

• Nutrition recommendations for Myotonic Dystrophy is not that different than the rest of the population
• Increase fruits and vegetables, lean meats
• Limit sweets and sweetened beverages

• There are no special foods that will make you healthier
• There are special considerations to be mindful of with DM
Getting Started on a Healthy Diet

• Increase fruits and vegetables
  • Low calorie, high nutrient and fiber content, helps with constipation and weight management

• Use more lean meats
  • GRILLED, BAKED, or BROILED
Getting Started on a Healthy Diet

• Increase fluids
  • Water is best, helps fill you up and helps with constipation

• Increase your intake of whole grains

• Decrease sugary drinks, juice and desserts
  • This will help with weight management
Special Considerations

• Decreased muscle mass

• Difficulty biting, chewing and swallowing
  • Dysphasia

• Constipation

• Weight management
  • All of these things are related
Special Considerations

• What do I drink instead of soda, juice and sweetened beverages?
  • Water, flavored water
  • Low fat milk, 2-3 servings if you are overweight
  • Whole milk 2-3 servings if you are underweight

• Do I need sports drinks? NO
Special Considerations/Weight Management

• Decreased muscle mass:
  • May lead to decreased activity
  • Both lead to lower calorie needs

• This is where limiting sweets, sodas, juices, fats can help
• Increasing high nutrient dense food will help with weight management
• It is important to be as active as possible

• Activity burns calories and helps with constipation
Special Considerations

• Weakness in facial muscles can lead to problems biting, chewing and swallowing
  
• Dysphagia diet I, II and III
  
• Eat naturally soft foods, chicken salad, ham salad, egg salad, tuna salad
• Grits, polenta, orso
• Applesauce, watermelon, soft mashed fruits and vegetables such as bananas, berries, sweet potatoes, spaghetti squash
  
• Smoothies
Special Considerations/Constipation

- Constipation
  - GI tract is a muscle and may not work well
  - Need to maximize fiber and fluid
  - May still need “extra” help

- How much fiber?
  - The easy answer is “More”
    - Adults: 25-35 gm per day
    - Children:
      - 1-3 years: 19 gm
      - 4-8 years: 25 gm
      - 9-13 years: 25-30 gm
      - 14-18 years: 25-35 gm

- Key is to increase slowly
Fluid Recommendations

• Children
  • 5-8 years: 5 glasses
  • 9-12 years: 7 glasses
  • 13+ years: 8-10 glasses

• Adults 13 yrs and up:
  • At least 8 to 10 glasses per day

  • *all are 8 ounces glasses
After increasing fiber and fluid you may still need help

- We often use polyethylene glycol or lactulose
- Stool softeners
- Discuss with your doctor or dietitian
A word about Smoothies 😊

• Great way to get protein, fruits, vegetables, fiber and dairy all in one drink

• Caution: they can be high in calories
  • Should not drink them in addition to a meal unless you are having trouble gaining weight or getting enough protein

• Suggest using them for “special times”
  • Sick days when you cannot eat
  • When someone is especially tired and it is easier to drink than eat
Smoothies/Protein shakes

- **Commercial products**
  - Suggest looking for products that are high protein but lower in calories

- **Homemade**
  - Be careful what sweeteners you use.
    - Fresh fruit is healthy but combined with yogurt, juice and honey it packs a lot of calories
Feeding Tubes

- Some children and adults are unable to take enough food by mouth safely

  - A feeding tube can provide support in the short term or the long term
  - As long as there is no aspiration present, eating by mouth can continue
    - Nasogastric tubes are considered a short term method to provide nutrition
    - Gastrostomy tube is a longer term method to provide support
Where to Get Answers

- Should look for the help of a registered dietitian/nutritionist
  - RDNs have a degree in nutrition and have completed an approved internship
  - LDN means RD is licensed in the state where they practice
  - All hospitals hire RDNs

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- What does this all mean
  - MPH=masters degree in public health
  - RD=registered Dietitian/nutritionist
  - LDN=licensed dietitian/nutritionist
Reliable Nutrition Information

• Contact the Academy for Nutrition and Dietetics for an RDN near you

• Myotonic Dystrophy Foundation Website

• USDA
In Summary

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Thank you!