

2019 Myotonic Annual Conference

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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 a 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, orzo
 - 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

Special Considerations/Constipation

- 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
- Robin Meyers, MPH, RDN, LDN
- 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

- Basics of a healthy diet
- Recommended amounts of fiber and water
- Suggestions for coping with dysphagia
- Suggestions for managing weight
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Thank you!

