

Nutritional Implications and Considerations

Eating Well to Stay Well with Erdheim-Chester Disease

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Outline

- Nutrition Basics
- Dietary Modifications or ECD Specific Diet?
- Potential Side Effects of Treatment Modalities
- Symptom Management
- Q&A

Fueling Your Body

- Overall nutrition and intake can greatly impact your well being
- What we eat provides energy for our bodies in time of wellness and in chronic illnesses
- Different disease states can impact your body's nutritional requirements



Key Elements of Healthy Eating Patterns

- **Consume a healthy eating pattern that accounts for all foods and beverages within an appropriate calorie level.**
- **A healthy eating pattern includes:**^[2]
- A variety of vegetables from all of the subgroups—dark green, red and orange, legumes (beans and peas), starchy, and other
- Fruits, especially whole fruits
- Grains, at least half of which are whole grains
- Fat-free or low-fat dairy, including milk, yogurt, cheese, and/or fortified soy beverages
- A variety of protein foods, including seafood, lean meats and poultry, eggs, legumes (beans and peas), and nuts, seeds, and soy products
- Oils

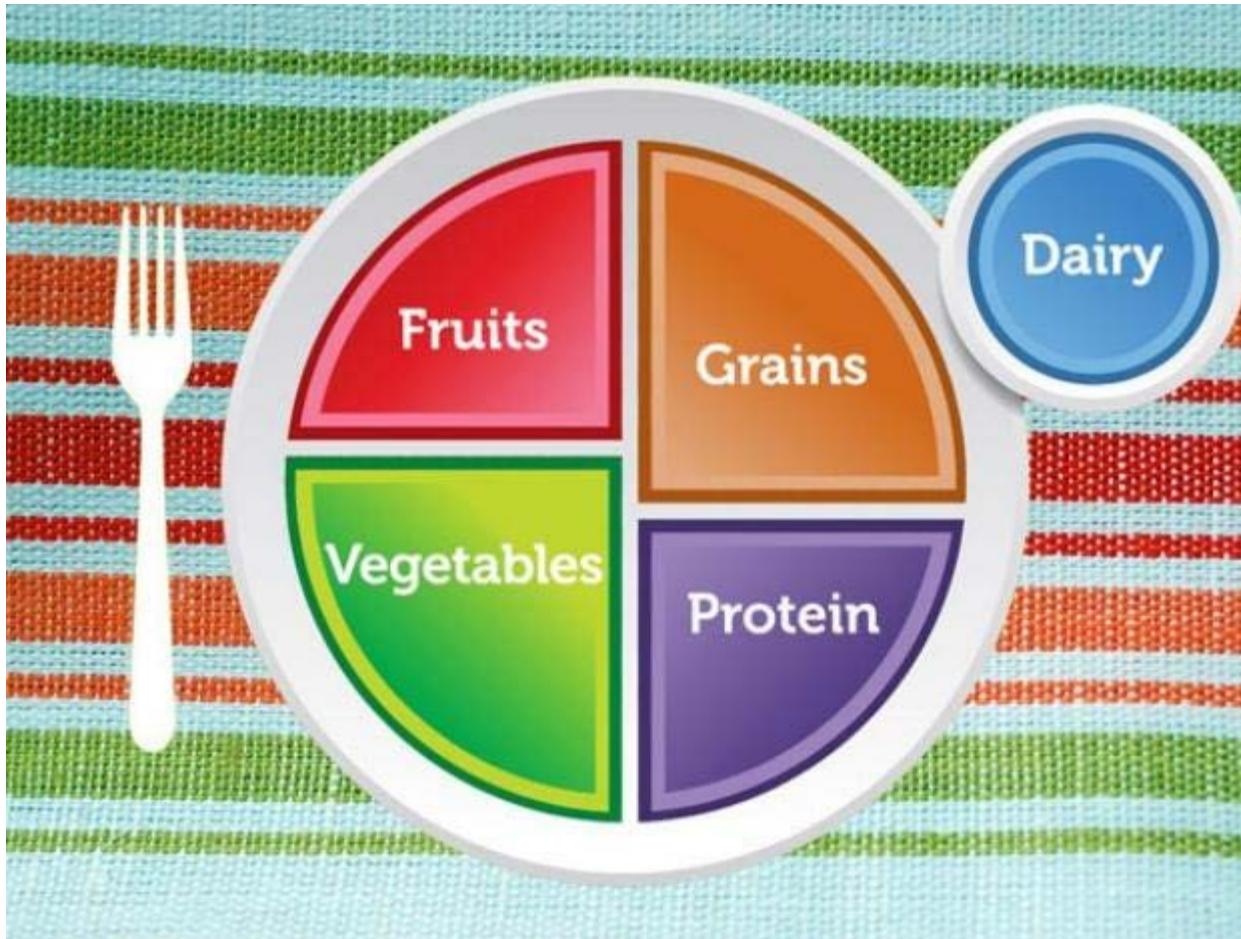
Key Elements of Healthy Eating Patterns

- A healthy eating pattern limits:
- Saturated fats and *trans* fats, added sugars, and sodium
- Consume less than 10 percent of calories per day from added sugars^[3]
- Consume less than 10 percent of calories per day from saturated fats^[4]
- Consume less than 2,300 milligrams (mg) per day of sodium^[5]
- If alcohol is consumed, it should be consumed in moderation—up to one drink per day for women and up to two drinks per day for men—and only by adults of legal drinking age

Associations Between Dietary Components and Health

- Research shows vegetables and fruits are associated with a reduced risk of many chronic diseases
 - including CVD
 - may be protective against certain types of cancers
- Evidence indicates whole grain intake may reduce risk for CVD and is associated with lower body weight.
- Research also has linked dairy intake to improved bone health, especially in children and adolescents

Choose My Plate



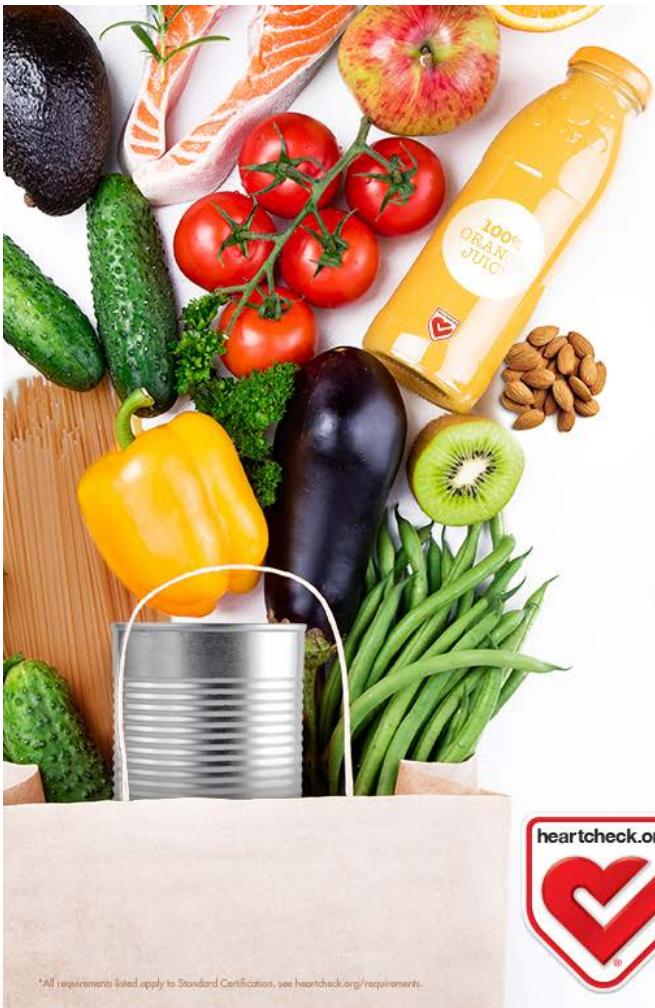
ECD Tailored Diet

- No specific diet for ECD
- Diet needs (both macronutrients and micronutrients) vary per person
- A general healthy well balanced eating pattern is appropriate for most patients
- Focus on healthy weight maintenance, heart health, bone health
- Possible diet consistency modifications based on neurological deficits

Heart Check Mark by American Heart Association

- The Heart-Check mark is a simple tool to help you Eat Smart. When you see it, you can be confident that a product aligns with the American Heart Association's recommendations for an overall healthy eating pattern
- The Heart-Check Certified Product List is updated twice a month
- Recipes available as well
- <https://www.heart.org/en/healthy-living/company-collaboration/heart-check-certification/heart-check-certified-recipes>

Heart Check Mark by American Heart Association



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The Heart-Check mark is a simple tool to help you Eat Smart. When you see it, you can be confident that a product aligns with the American Heart Association's recommendations for an overall healthy eating pattern.

1000+ products carry the Heart-Check mark. Look for the Heart-Check wherever you shop—it's in almost every aisle!

This is some of what it takes to be Heart-Check certified*:

|SOURCE OF NUTRIENTS

Beneficial Nutrients (naturally occurring):

10% or more of the Daily Value of 1 of 6 nutrients (vitamin A, vitamin C, iron, calcium, protein or dietary fiber)

|LIMITED IN BAD FATS

Saturated Fat:

1 g or less per standard serving size and 15% or less calories from saturated fat

Trans Fat:

Less than 0.5 g per label serving size and per standard serving size. Products containing partially hydrogenated oils are not eligible for certification.

|LIMITED IN SODIUM

Sodium:

One of four sodium limits applies depending on the particular food category: up to 140 mg, 240 mg or 360 mg per label serving, or 480 mg per label serving and per standard serving size.*



*All requirements listed apply to Standard Certification, see [heartcheck.org/requirements](#).

TO LEARN MORE, VISIT
HEARTCHECK.ORG

Healthy Eating Patterns for Bone Health

- Eating a variety of fruits, vegetables and low fat dairy products will provide several nutrients that contribute to bone health
- Calcium
 - Dairy
 - Green leafy vegetables
 - Calcium fortified foods such as soymilk, snacks, bread
- Vit D
 - Fatty fish –salmon, tune, mackerel
 - Egg yolks
- Magnesium, Vit C and Vit K, lycopene rich produce
 - Watermelon, bell peppers, guava, citrus fruits



Treatment Modalities

- Vemurafenib, Dabrafenib , trametinib
 - Nausea (32 to 37%), hand and foot syndrome
- Trametinib, cobimetinib, binimatinib
 - Diarrhea, edema
- Interferon alfa
 - Nausea, anorexia, fatigue, diarrhea, flu like symptoms
- Vinblastine
 - Fatigue, neuropathy, constipation
- Cladribine
 - Nausea (22%), neutropenia (70%)
- Glucocorticoids
 - hyperglycemia

Symptom Management and Dietary Strategies

- **Nausea**
 - Avoid foods with strong odors
 - Small frequent meals
 - Try bland, starchy or salty foods
 - Focus on fluid
 - Take meds with meals if possible
 - Take your time, pleasant atmosphere
 - Have friends and family help prepare food

Symptom Management and Dietary Strategies

- **Fatigue and Decrease Appetite**
 - Small frequent meals
 - Easy to chew foods, lots of liquids
 - Convenient foods that take little preparation
 - Focus on hydration
 - Nutrient dense foods/beverages
 - Light physical activity as able

Symptom Management and Dietary Strategies

- **Constipation**

- Plenty of liquids
- Naturally sweet beverages
- Insoluble fiber foods (fruits and vegetables, whole grains)
- Stool softeners
- Physical activity as able

Symptom Management and Dietary Strategies

- **Diarrhea**

- Small frequent meals
- Soluble fiber foods (BRAT diet)
- Limit or avoid caffeine
- Limit insoluble fiber foods
- Reduce concentrated sweets
- Make sure to keep up with your fluids
- antidiarrheal

Symptom Management and Dietary Strategies

- **Electrolyte replacement and monitoring**
- Sources of K+
 - Bananas, oranges, apricots, potatoes (white), tomatoes
 - https://www.nutritioncaremanual.org/client_ed.cfm?ncm_client_ed_id=153
- Sources of Magnesium
 - Beans (black, navy, white), avocados, spinach, swiss chard, nuts, peanut butter, oatmeal, pumpkin seeds, eggnog
 - https://www.nutritioncaremanual.org/client_ed.cfm?ncm_client_ed_id=151

Symptom Management and Dietary Strategies

- **Neutropenia**

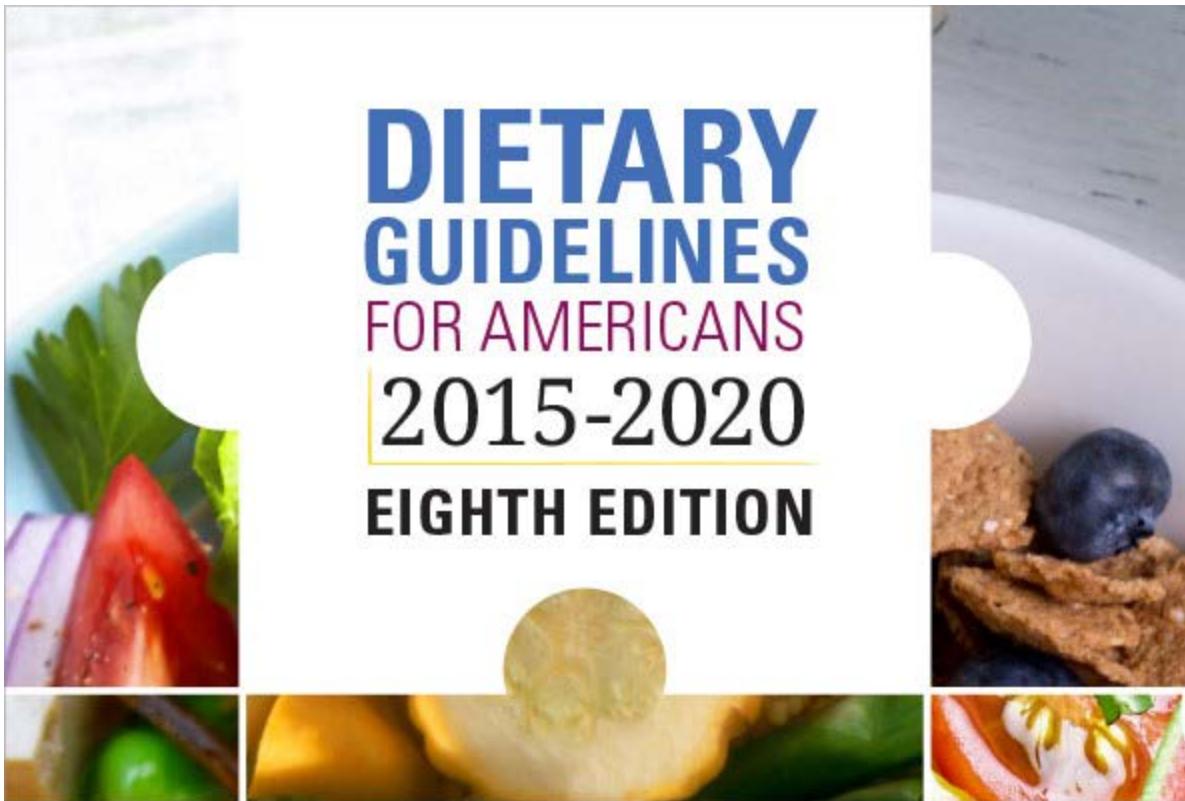
- Well washed or cooked fruits and vegetables
- Safe food handling procedures
- No raw seafood
- Avoid sick contacts
- Eat within your own environment

Symptom Management and Dietary Strategies

- **Weakness and swallowing difficulties**
 - Choose softer foods
 - Cut food into smaller pieces
 - Moisten foods with sauces and gravies
 - Take your time with chewing
 - Alternate soft solids with sip on liquids
 - Follow with SLP

References

- <https://health.gov/dietaryguidelines/2015/guidelines/>



References

- <https://www.choosemyplate.gov/>
- www.uptodate.com
- American Heart Association www.heart.org
- Micromedex

Thank You!

- Rebecca Donnenberg, RD, CSO, LDN
 - rebecca.donnenberg@orlandohealth.com
- <https://www.eatright.org/find-an-expert>
 - Able to search by zipcode for RD