



Healthy eating for Erdheim-Chester Disease

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“There is no life without Nutrition”





What Is Erdheim-Chester Disease (ECD)?

A Rare Disease

ECD is characterized by the abnormal multiplication of histiocytes, a white blood cell, which build up in different tissues, leading to various complications.

Fewer than 1 in 1 million people worldwide (real prevalence unknown).

Multi-System Impact

ECD can affect multiple body systems including the heart, kidneys, bones, skin, brain, and lungs.

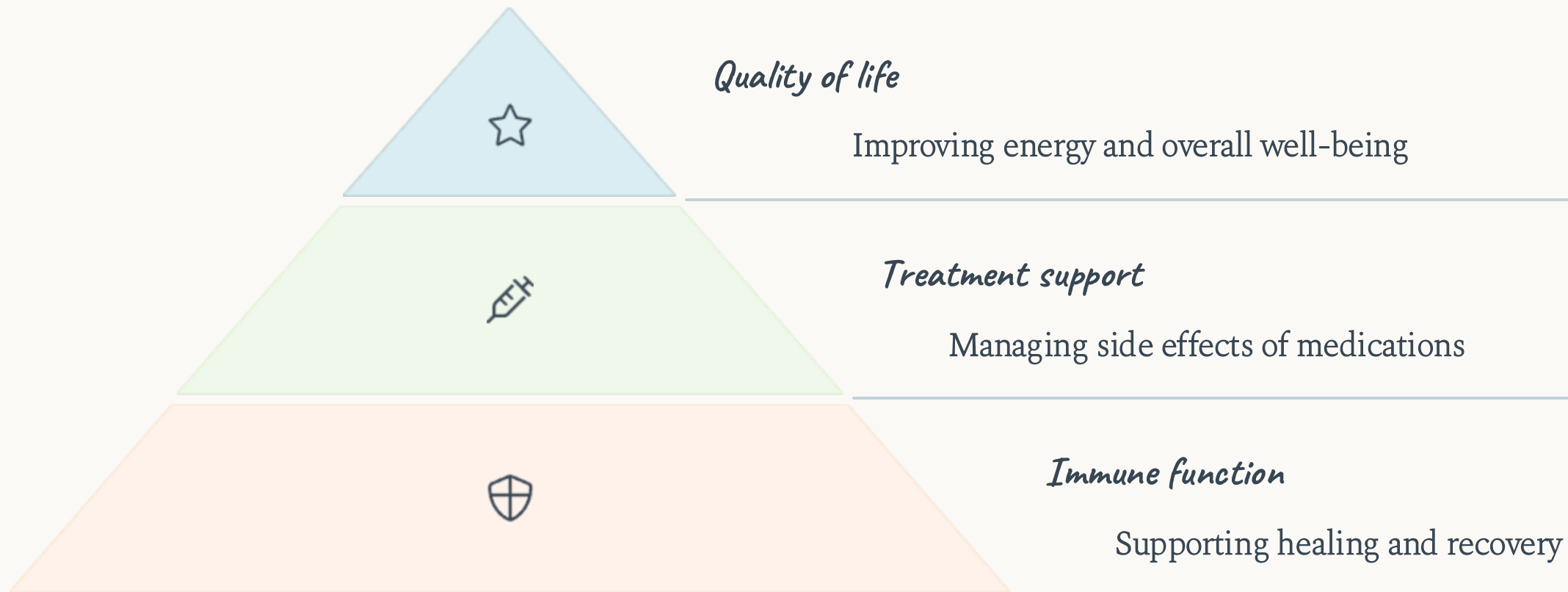
Each patient experiences a unique pattern of organ involvement, which influences both symptoms and treatment approaches.

Inflammatory Process

The disease process in ECD triggers inflammation, tissue damage, and changes throughout the body.

These changes can affect how your body processes nutrients and may increase your nutritional needs.

Why Nutrition Matters in ECD



- While there's no specific "ECD diet" that can cure the disease, proper nutrition plays a **vital supporting role**
- **Weight control** can help prevent complications and improve quality of life
- Nutrition must be adapted if there are difficulties in swallowing - **Dysphagia**
- Nutrition can help **modulate inflammation** and support metabolic health



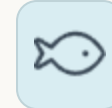
Core Principles: evidence-based diet for ECD



Anti-inflammatory foods

Colorful fruits and vegetables, rich in polyphenols and antioxidants, reduce inflammatory markers.

Eat berries, leafy greens, and cruciferous vegetables daily.



Omega-3 rich foods

Regular consumption of fatty fish like salmon, mackerel, and sardines can help modulate inflammatory cytokines and support cardiovascular health.



Complex carbohydrates

Whole grains provide sustained energy and important nutrients. They help maintain stable blood sugar levels, which is especially important if you're taking medications that affect glucose metabolism.



Foods to limit

Reduce intake of highly processed foods, added sugars, and refined carbohydrates, which may contribute to systemic inflammation and metabolic stress.

Modify intake based on your specific organ involvement.

Anti-inflammatory foods: detailed examples

Berries

Blueberries, strawberries, and blackberries contain anthocyanins that reduce oxidative stress and inflammation.

- Add to oatmeal/yoghurt/kefir.
- Blend into smoothies.



Leafy greens

Spinach, kale, and other greens provide antioxidants and beneficial phytochemicals.

- Add to soups and stews.
- Create nutrient-dense salads.
- Blend into smoothies.



Healthy fats

Extra virgin olive oil, avocados, and nuts provide monounsaturated fats with anti-inflammatory properties.

- Olive oil as primary cooking oil.
- Avocado in sandwiches and salads.
- A handful of walnuts or almonds daily.



Fatty fish

Blue fish is rich in omega-3 fatty acids that help reduce inflammatory markers.

- At least 2-3 servings weekly.
- Try simple baked or grilled preparations.
- Consider canned options for convenience.



Hydration & bone health

Optimal hydration

Proper fluid intake is essential, and particularly critical if kidney involvement.

- At least 8-10 cups of fluid daily (unless contraindicated)
- Choose water, herbal teas, and naturally flavored waters
- Limit caffeine and alcohol, which can increase dehydration
- Be aware of possible swallowing difficulties - **dysphagia**



Bone health support

Since ECD often affects the skeletal system, nutrition to support bone health becomes particularly important.

- **Calcium**-rich foods: dairy, fortified plant milks, leafy greens
- **Vitamin D** sources: fatty fish, egg yolks, fortified foods
- Discuss supplementation with your healthcare team



Individualization: adapting to your needs



Assess your ECD involvement



Consult your medical team



Develop a personalized plan

- Patients with **cardiac** involvement may benefit from a heart-healthy, sodium-modified diet,
- those with **kidney** involvement might need to monitor protein, potassium, and phosphorus intake.

Always discuss significant dietary changes with your **healthcare team**, they can interact with medications or affect organ function.

A **registered dietitian** with experience in complex conditions can help develop a plan for your specific requirements.

Practical tips & addressing challenges



Time-saving strategies

- Batch cook healthy meals.
- Prepare ingredients in advance, freeze in portion-sized bags.
- Keep pre-cut vegetables and quick proteins like hard-boiled eggs ready for meals.



Managing poor appetite

- Eat small, frequent meals, rather than three large ones.
- Try nutrient-dense options like smoothies, nut butters, and avocado when solid foods seem challenging.
- Eat when appetite is highest!



Family involvement

- Include you family in meal planning and preparation.
- Family meals improve nutrition for everyone and provide social connection.



When to seek help

- Significant weight changes.
- Persistent digestive issues.
- Difficulty maintaining adequate nutrition.
- If symptoms interfere with eating.

Takeaways & questions

Complementary approach

- Nutrition is a supportive strategy to the medical treatment, not an alternative.
- An internal environment that supports healing helps manage symptoms while your prescribed treatments address the disease directly.

Balanced, mindful eating

- Focus on a predominantly plant-based diet rich in whole foods, with adequate protein and healthy fats.
- Pay attention to how different foods affect your unique symptoms and energy levels. A food journal may help to identify patterns.



Personalized guidance

- Request a referral to a registered dietitian to consider your specific manifestations, treatment regimen, and personal preferences.
- Regular follow-ups help adjust your nutrition plan as your condition evolves.

Thank you very much / Muchas gracias

We welcome your questions and experiences.

Sharing what has worked for you may help others in the ECD community.

Remember :

- while nutrition is important, it's just one aspect of your comprehensive care plan,*
- always consult with your healthcare team before making significant dietary changes.*



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