

NUTRITION GUIDELINES

for Phelan-McDermid Syndrome



Food
and its
critical role
in overall
health

Food isn't just fuel—it's nourishment, connection, and care. For individuals with Phelan-McDermid syndrome, the right nutrition can make a *meaningful* difference in energy, digestion, growth, mood, and overall well-being. This guide was created to help caretakers of those with Phelan-McDermid Syndrome feel more confident and supported as they make choices about what foods are best.

Inside are simple, real-life tips that are practical, doable, and backed by both science and experience. These general guidelines are meant to be a starting point to make things just a little easier.

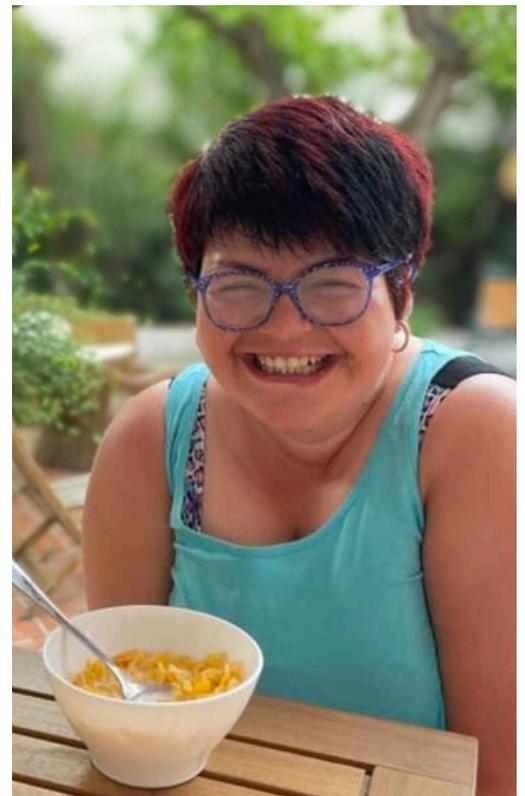
The information you need

Guide to Good Nutrition

2025 | First Edition

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This guide was created by Chardell Buchanan, MA, RDN with consultation from Cara Dubinsky, MS, RDN, CDN. This guide has been reviewed and approved by the Phelan-McDermid Syndrome Foundation Medical Advisory Committee (MAC).

Disclaimer: This guide is intended for educational purposes only and provides general nutrition guidelines for people with Phelan-McDermid Syndrome. It is not a substitute for medical advice, diagnosis, or treatment. Please consult with a qualified healthcare provider or a licensed practitioner before making any changes to a nutrition or supplement routine.

FOUNDATIONS OF A HEALTHY DIET FOR PHELAN-MCDERMID SYNDROME

Choosing what to eat for Phelan-McDermid Syndrome doesn't require perfection—it just takes some consistency and intention. These foundational guidelines are a great starting point for supporting health through good nutrition.

VARIETY IS KEY

Offer a mix of food groups every day.

- Fruits & vegetables
- Whole grains
- Lean proteins
- Healthy fats
- Dairy or fortified alternatives

Not all foods have the same nutrients in the same amounts. The bigger the variety of foods you eat, the more exposure to different nutrients you get.



Fruits & Veggies

Fruits and vegetables provide *essential* vitamins, minerals, and fiber.

- Aim for a fruit AND a vegetable at every meal and a fruit or a vegetable at every snack.
- Offer different colors, textures and varieties.
- Enjoy them raw, cooked, or blended into smoothies.

Water & Fiber

Water helps *everything* function better, including digestion and energy. Be sure to offer water **FIRST** every time and drink it throughout the day. Try to avoid sugary drinks and limit juice to 8 oz a day (especially if experiencing chronic loose stools).

IMPORTANT: *Increasing fiber too quickly without enough fluids can lead to constipation, so go slowly and start increasing water before adding more fiber.*





FOUNDATIONS OF A HEALTHY DIET FOR PHELAN-MCDERMID SYNDROME

Include Healthy Fats

Healthy fat is important for brain development and support as well as vitamin absorption. Offer more of these foods to increase healthy fats and omega-3's:

- avocados
- olive oil
- almonds
- walnuts
- sunflower seeds
- fish, and specifically salmon
- ground flaxseeds
- chia seeds



Limit Added Sugars & Processed Foods

Highly processed foods and added sugars when eaten in large amounts may negatively affect energy, gut health, and behavior. Having them every once in a while is fine, but the majority of time try to avoid foods with long ingredient lists or artificial dyes and choose whole, real foods when possible.

Offer Protein at Every Meal & Snack

Protein supports growth, immune health, and provides energy.

Things like meat, poultry, and eggs are good protein sources, but don't forget beans, legumes, tofu, milk (and anything made from milk like cheese and Greek yogurt), and nuts/nut butters as they are also good sources of protein.

Try to include a protein source every time.



EAT GOOD TO FEEL GOOD



Vitamins & Minerals *in foods*

Supporting Nutrient Absorption

It's not just food—it's also how well the body can use it. These simple food pairings and tips help the body to absorb *more* of the key nutrients needed to grow, learn, and thrive.

Fat-Soluble Vitamins (A, D, E, K)

These vitamins absorb best when eaten with a source of fat. Try this:

- Serve a glass of milk with a nut butter and jelly sandwich
- Add olive oil to cooked veggies
- Include avocado or full-fat yogurt with meals

Zinc & Protein

Zinc supports immune function and is better absorbed when paired with protein. Try this:

- Include chicken, lean beef, or fish at meals
- Add cheese, eggs, or Greek yogurt to snacks
- Use beans and nuts or nut butters

Plant-Based Iron & Vitamin C

Iron from plant foods (like spinach or beans) is harder to absorb, but vitamin C helps! Try this:

- Add strawberries to oatmeal
- Squeeze lemon over spinach salad
- Serve beans with bell peppers or oranges



SUPPLEMENTS TO CONSIDER

Why Supplement?

Some individuals with Phelan-McDermid syndrome *may* benefit from supplements to support nutrient needs, digestion, mood regulation, and energy.

Always consult a qualified healthcare provider or Registered Dietitian Nutritionist before starting or changing supplements.



Commonly recommended with Phelan-McDermid Syndrome

- **Multivitamin (MVM):** General daily coverage of essential vitamins and minerals
- **Vitamin D:** Supports bone health, mood, and immune function
- **Magnesium:** May help with constipation and relaxation
- **Vitamin E:** Supports neurological function
- **Zinc:** Immune support and growth (take with meals containing protein)
- **Omega-3:** Brain, behavior, and mood support
- **B-complex with B12:** Supports energy and neurological health
- **Probiotic:** Gut health and digestion

Side Note: *Iron and zinc supplements should not be given at the same time as iron can reduce zinc absorption. For zinc and iron foods, this is not an issue.*

COMMON GASTROINTESTINAL SYMPTOMS

CHEWING & SWALLOWING

Individuals with Phelan-McDermid syndrome often face feeding difficulties, including low muscle tone, reflux, constipation, and texture sensitivity. Here are some practical tips to support these challenges.



Common Challenges

- Low muscle tone affects the entire body *including* the muscles needed for chewing and swallowing.
- Difficulty handling textures (crunchy, fibrous, too thin and too thick liquids, etc.).
- Overstuffing food in the mouth to aid in mastication (chewing) of foods which can lead to a choking risk.

How to Help

- Cut foods into bite-sized portions, especially foods that are choking hazards like grapes.
- Cook fruits and vegetables to reduce texture issues.
- Serve moist, soft foods like yogurt, eggs, and blended soups.
- Encourage slower pacing while eating to avoid overstuffing.



Building a Team

It's important to have a competent team when supporting chewing and swallowing challenges. Work with a speech-language pathologist (SLP) to get therapy that is tailored for specific needs. Consider a feeding class, also offered by a SLP or other trained professional, to help with things like texture sensitivities or picky eating. For school aged children, remember to include your child's school in any interventions implemented so they can be properly reinforced in all settings.



COMMON GASTROINTESTINAL SYMPTOMS

CONSTIPATION

Individuals with Phelan-McDermid syndrome often face feeding difficulties, including low muscle tone, reflux, constipation, and texture sensitivity. Here are some practical tips to support these challenges.



Common Challenges

- Low muscle tone affects the entire body including the muscles of the digestive tract making it difficult to move food through.
- Not eating foods that are high in fiber and not getting adequate amounts of water.
- Reduced level of movement or activity.



How to Help

- Start with increasing water, offer water first, *every time*.
- Slowly introduce more fiber-rich foods like fruits, vegetables, whole grains, beans, legumes, nuts, and seeds.
- Be cautious with fiber supplements—check with a qualified healthcare provider to prevent impaction.
- Be as active as possible based on mobility. For extra help, work with a physical therapist to tailor a plan to meet movement needs.
- Screen for potential undiagnosed GI conditions, food allergies, or intolerances.

Side Note: *For those who use tube feeding as part of their nutrition care, please work with a Registered Dietitian Nutritionist to make sure fiber and water needs are met and constipation is avoided.*



COMMON GASTROINTESTINAL SYMPTOMS

GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Individuals with Phelan-McDermid syndrome often face feeding difficulties, including low muscle tone, reflux, constipation, and texture sensitivity. Here are some practical tips to support these challenges.



Common Challenges

- Discomfort during or after eating, including arching, gagging, or irritability.
- Frequent spit-up or vomiting, which may reduce nutrient absorption.
- Avoidance of certain foods or meals, due to discomfort or fear of pain.

How to Help

- Eat smaller, more frequent meals instead of large portions to reduce pressure on the stomach.
- Sit upright for 30 minutes after eating.
- Avoid reflux-triggering foods (like citrus, tomato, chocolate, mint, and fried foods) and monitor how individual foods affect the reflux.

Could it Be a Side Effect?

It's possible. If reflux is persistent or severe, ask a qualified healthcare provider about possible medication adjustments or further evaluation with a GI specialist. Consider working with a Registered Dietitian Nutritionist to get reflux under control.



HEALTHY WEIGHT



How to Gain Weight the Right Way

Many individuals with Phelan-McDermid Syndrome need to gain weight. It's important to focus on quality nutrition, not just calorie quantity. Promote weight gain with nutrient-dense, supportive foods.

Don't rely on sugary foods or processed snacks to increase weight. Avoid "empty calorie" foods that don't offer nutrition along with energy.

Best Tips for Adding More Nutrients + Calories to Meals

- Aim for 3 meals + 2 snacks daily.
- Choose high-quality, whole foods.
- Use the plate method: $\frac{1}{2}$ fruits and veggies, $\frac{1}{4}$ protein, $\frac{1}{4}$ whole grains.

Examples

Add extra cheese to burgers, pasta, or veggies.

Mix in avocado with smoothies or serve on top of a turkey burger.

Use panko crusts on chicken or fish to boost calories and taste.

Choose protein-rich pastas and add lean meat to sauces.

GET MORE

support

You don't have to do this alone. Nutrition and feeding can feel overwhelming, but there are professionals ready to support.



Consider Adding to Your Team:

Registered Dietitian Nutritionist (RDN):

Especially one with experience in rare diseases or pediatric feeding

Speech-Language Pathologist (SLP): For chewing, swallowing, or texture sensitivities

Occupational Therapist (OT): For help with fine motor skills and self-feeding

Physical Therapist (PT): For help with movement and activity

Pediatrician / Neurologist: For medical management and ongoing care



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Connect with RDNs Who Understand Phelan-McDermid Syndrome

We're here for you! As both registered dietitians and fellow Phelan-McDermid syndrome parents, we understand the unique challenges and joys you face. If you have questions about caring for someone with Phelan-McDermid Syndrome and their nutrition, supplements, or feeding routines, feel free to reach out. You don't have to navigate this journey alone—we're just an email away.

