

Nutrition Recommendations for Children and Families with PWS

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Nutrition Recommendations for Children and Families with PWS

OVERVIEW

- **Traditional Guidelines**
- **CURRENT Recommendations**
 - *Quality*
 - *Quantity (portion sizes)*
 - *Balance (protein, carbs/fiber, fat)*
 - *Variety*
 - *Drinks*
- **Convenience**
- **Meal Scheduling**
- **Special Occasions**
- **Family Responsibilities**
- **Summary**

Nutrition Recommendations for Children and Families with PWS

TRADITIONAL PWS NUTRITION RECOMMENDATIONS

Focuses on strict calorie-restriction targeting a specific weight

Disadvantages:

Limits dietary fat intake due to high calorie content

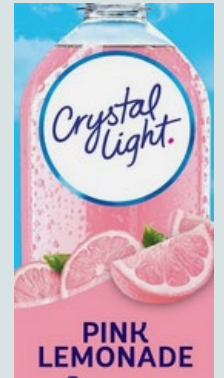
- Dietary fats are important for brain health, growth, development, satiety

Does NOT limit sugar substitutes/non-nutritive sweeteners (NNS)

- NNS may increase appetite

Calorie counting can be tedious, labor intensive, and time-consuming

Inappropriately associates weight & low-calorie products to health



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CURRENT PWS NUTRITION RECOMMENDATIONS



Current nutrition recommendations are not necessarily unique or highly specialized, but typically are more strict and more disciplined

Limited flexibility due to cognitive rigidity, “black and white” thinking

Focuses on sustenance (physiologic nourishment) vs indulgence

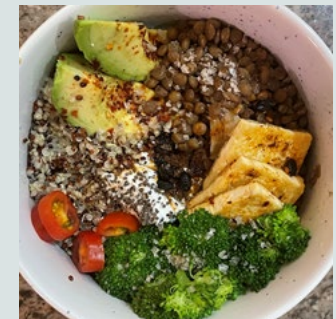
- De-emphasizes indulgence and glorification of food
- Limits NON-hunger eating (emotional, behavioral, time-based, food as a reward, etc.)
- Due to significantly lower calorie needs, there are less opportunities for “empty” or low-nutrient density foods



Recommendations are based on Mediterranean Diet

Recommendations focus on four key aspects

1. Quality
2. Quantity (i.e. portions)
3. Balance
4. Variety



Nutrition Recommendations for Children and Families with PWS

QUALITY

Focus on balance

Protein

Non-starchy vegetables

Complex carbs: WHOLE grains, beans, legumes, starchy vegetables

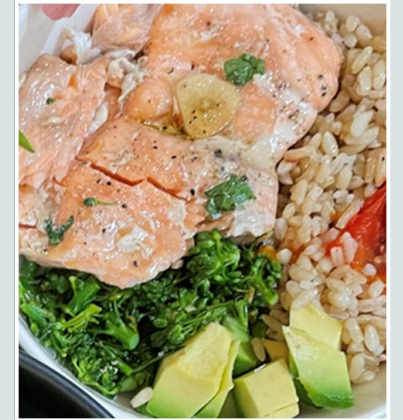
Limits

Refined grains

Excessive added sugar

Sweets and treats and any other “sweet-tasting” foods

NO sugar substitutes/sweeteners



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EXAMPLES OF SWEETENERS

- **Acesulfame Potassium** - Sunnett, Sweet One
- **Aspartame** - Nutrasweet, Equal
- Neotame
- Soluble Corn Fiber
- Saccharin - Sweet 'N Low, Sweet Twin, Sugar Twin
- **Sucralose** - Splenda
- **Stevia**/Rebaudioside - A Sweet Leaf, Sun Crystals, Steviva, Truvia, PureVia
- Allulose
- **Monk fruit**
- Sugar alcohols – **xylitol**, **erythritol**, mannitol, sorbitol, maltitol
- Tagatose
- Advantame
- Inulin (chicory root)
- Tapioca Fiber (prebiotic fiber)



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QUALITY - GUIDANCE ON “SWEET TASTING” FOODS

Fruit

- *Fresh* fruit only
 - **NOT** canned, processed, dried, freeze-dried, “fruit cups”, jelly/jam, applesauce, “fruit snacks”
- Limited frequency (twice per day, or LESS)
- Limited portion sizes
 - Significantly smaller than your commonly perceived portion
- **Always** serve with protein/fat



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QUALITY - GUIDANCE ON “SWEET TASTING” FOODS

Common “sweet tasting” foods generally NOT recommended:

- Sweetened DRINKS
- Breakfast cereals
- “Bars” (granola, protein, fruit bars, etc.)
- Processed fruit
- *Flavored yogurts, flavored oatmeal*
- Granola
- Muffins
- Jello/pudding
- Sweet condiments (ketchup, teriyaki, BBQ, fruit-flavored vinaigrettes, honey mustard, Chic-fil-a sauce, etc.)
- Syrup, honey



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QUALITY

Examples of sugar-containing foods that are generally OK to consume

Plain/Original Cheerios

Tomato Sauce

100% whole grain bread/products

Sausage

Refried beans



Nutrition Facts

Serving size: 1 1/2 cup (39g)

Amount per serving	140
Calories	As Packaged

Food component / Nutrient	Amount As Packaged	% DV* As Packaged
Total Fat	2.5g	3%
Saturated Fat	0.5g	3%
Trans Fat	0g	—
Polyunsaturated Fat	1g	—
Monounsaturated Fat	1g	—
Cholesterol	0mg	0%
Sodium	190mg	8%
Total Carbohydrate	29g	10%
Dietary Fiber	4g	15%
Soluble Fiber	2g	—
Total Sugars	2g	—
Incl. Added Sugars	1g	2%
Protein	5g	—

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QUALITY

Low nutrient-density foods are not recommended because they (1) tend not to be satisfying or satiating and (2) offer minimal nutritional benefit

Examples:

White flour

Rice cakes

Cassava flour

Tapioca flour

Rice flour

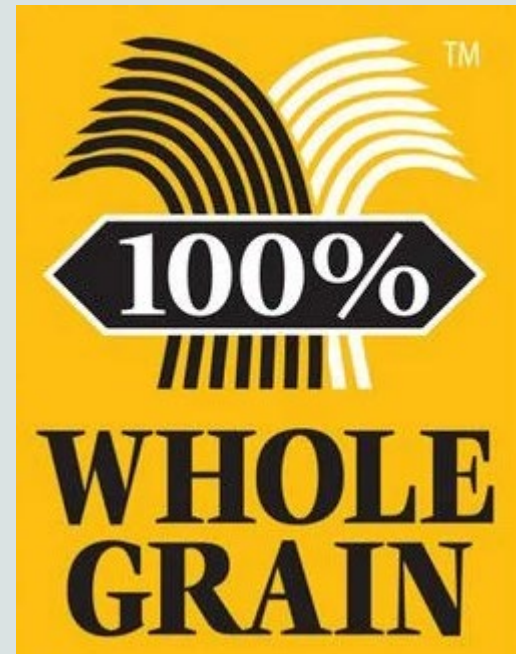
Potato starch

Veggie straws

Pirate's booty

Pretzels

Look for 100% WHOLE grain products



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QUANTITY

Portion sizes are *highly* variable/individualized to specific needs

Based on growth, weight trends, activity level, body composition, genetics, etc.

General recommendations/handouts are only a starting point

Most important: appropriate growth and weight gain

Generally, portions are significantly smaller when compared to general population

Due to low tone/lean mass and typically decreased energy needs

Fruit is limited to twice per day (or less) and recommended to be served with a meal or with protein/fat



- Carbohydrates (whole grains, starchy vegetables, legumes, beans) – 1 fist (at each meal)
- Protein – 1 fist (at each meal)
- Non-starchy vegetables – 1 fist (at each meal)
- Nuts & Seeds – flat (*not* piled up) in the palm of hand (2x per day maximum)
- Fruit – flat (*not* piled up) in the palm of hand (2x per day maximum)



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QUANTITY

Guidance on snacks

Do NOT assume a snack(s) is needed

- Do not offer food unless requested/showing signs of hunger

If your child is easily distracted, they may not be truly hungry

Lighter snacks are typically preferred

- Non-starchy veggies (carrots, cucumbers, tomatoes, peppers, etc.)

No carb-only snacks

- If serving fruit or whole grain/starch, serve with protein/fat (nuts, seeds, cheese, meat, eggs, olives, avocado, etc.)

Do NOT schedule snacks (or meals)

- Keep snacks “as needed”
- Allow flexibility in mealtimes; intentionally build “noise” into the schedule



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BALANCE

1. Protein

2. Carbohydrates

Starchy source of fiber (“complex carbs”)

- **WHOLE** grains, starchy veggies, beans/peas/legumes

Non-starchy source of fiber

- **Non-starchy** veggies

NO carb-free (or low carb, keto, etc.) meals

NO carb-heavy meals

3. Fats

Unsaturated/plant-based fats are preferred

Typically, fats are already included with the protein or added to the cooking process

1. Vegetables (NON-starchy) (~ ¼ - ½ of meal)

Carrots	Cucumbers	Green Beans	Broccoli	Cauliflower	Spinach	Lettuce
Tomatoes	Celery	Zucchini	Yellow Squash	Asparagus	Bell Peppers	Onions
Brussel Sprouts	Artichoke	Cabbage	Kale	Snap Peas	Okra	Collards
Bok Choy	Eggplant	Spaghetti Squash	Swiss Chard	Turnips		

2. Protein (~ ¼ of meal)

Beef	Pork	Chicken	Turkey	Salmon	Tuna	White Fish	Shrimp
Crab	Lobster	Scallops	Clams	Eggs	Greek Yogurt	Nuts	Seeds
Cottage Cheese	Duck	Soy/Tofu/Tempeh	Lamb/Goat				

3. Carbohydrate (~ ¼-½ of meal)

WHOLE grain Bread	WHOLE Grain Pasta	Quinoa	Brown Rice	Wild Rice		
Barley	Oatmeal	Black Beans	Kidney Beans	Pinto Beans	White Beans	
Lima Beans	Chickpeas (<u>Garbanzo</u>)	Green Peas	Hummus	Black-Eyed Peas		
Edamame	Lentils	Sweet Potato	<u>Potato</u>	Whole Grain Couscous	Farro	Millet
Pumpkin	Butternut/Acorn Squash	Popcorn	Buckwheat	Amaranth		



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BALANCE

PWS Meal Checklist

1. UNSWEETENED DRINK

- Plain water, white milk, unsweet tea, La Croix, HINT water, etc.

2. PROTEIN (~ 1/3 of meal)

- Meat, fish/seafood, eggs, poultry, pork, nuts/seeds, *plain* Greek yogurt, cottage cheese, soy/tofu, etc.

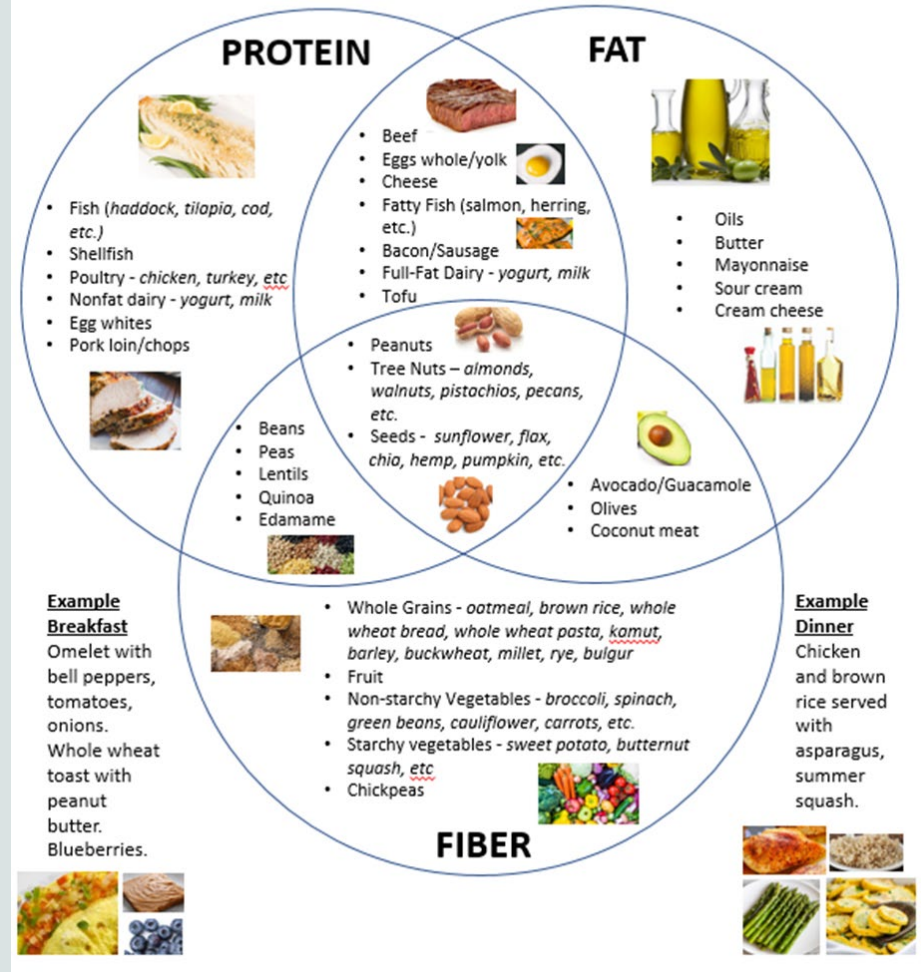
3. NON-STARCHY VEGETABLE (~ 1/3 - 1/2 of meal)

- Examples: green beans, broccoli, cauliflower, tomatoes, peppers, spinach, carrots, cucumber, celery, zucchini, yellow squash, cabbage, kale, etc.

4. CARBOHYDRATE (~ 1/3 of meal)

- 100% *WHOLE* grain (100% whole wheat, *plain* oatmeal, brown/wild rice, etc.)
 - NO refined grains like white flour, white rice, white pasta
- Starchy vegetable/bean/legume
 - Beans, peas, potatoes, quinoa, lentils, chickpeas, butternut squash, etc.

Building a Balanced Meal



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VARIETY

Encourage a large variety of foods, textures, and flavors from a *young* age

Do *not* stop offering disliked foods

Do not rely too much on favorite foods

Do not let your child's food preferences determine what is being served

Continue to encourage new and different foods/flavors/textures etc.

Nutritional variety:

Ensures the body is properly nourished

Reduces risk of nutritional deficiencies

Encourages diverse gut microbiome

Can reduce any selective ("picky") eating



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DRINKS!

Unsweetened drinks only

Plain water

Milk or milk alternatives

Unsweet tea

Squeeze of sour fruit (lemon, lime) into water

Beware of clever marketing: “no sugar added”, “no artificial sweeteners”, “sugar free”, “zero calorie”, etc.

These products are likely sweetened with alternative sweeteners (i.e. stevia, monk fruit, erythritol, sucralose, etc.)

Build PLAIN water into *daily* routine (lots of ice can help)

Start EARLY, be consistent, do NOT offer alternative



Nutrition Recommendations for Children and Families with PWS

MEAL IDEAS

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Breakfast	Egg, Sausage, Raspberries, Whole grain toast	PLAIN Greek Yogurt Blueberries Cinnamon Oats	Omelet w/ Tomatoes Peppers Whole grain toast Strawberries	PLAIN Greek yogurt Whole grain pancake with peanut butter Cherries	Egg Oatmeal Cinnamon Strawberries	PLAIN Greek Yogurt Blueberries Whole grain toast	Peanut Butter on Whole grain pancake Sliced almonds Blackberries
Lunch	Steak Cauliflower Carrots Sweet Potato	Chicken and Bean Chili Onions Tomatoes Yellow Squash	Salmon Broccoli Wild rice	Ground Turkey Tomatoes Cauliflower Black Beans Avocado	Salmon Spinach Quinoa	Steak Asparagus Butternut Squash	Chicken Carrots Lentils
Dinner	Turkey Meatballs Broccoli Whole grain or Chickpea Pasta	Salmon Brussel sprouts Brown Rice	Turkey Spinach Tomatoes Onions Black Beans Avocado	Shrimp Green beans Quinoa	Fish Roasted carrots Whole grain couscous	Baked chicken Green beans Sweet potato	Pork Asparagus Peas

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CONVENIENCE, QUICK MEALS

- Quick, “no cook” meal examples



Breakfast	Lunch	Dinner
Peanut butter, whole grain toast	Deli meat, Triscuits, carrots	Tuna, whole grain bread, cucumber
Cashews, Josephs Pita	Pre-boiled egg, popcorn, bell peppers	Sunflower seeds, canned black beans, carrots
Almonds, Original Cherrios	Plain Greek yogurt (+ fruit, cinnamon), edamame, tomatoes	Deli turkey, chickpeas/hummus, steam-in-bag green beans



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CONVENIENCE, SNACKS

- Harvest Snap Pea Crisps

- Whole grain crackers/bread (+ protein/fat)

- Hippeas



- Crunchsters



- Bada Bean Bada Boom

- Cheese



- Meat

- Eggs

- Popcorn (+ protein/fat)



- **Nuts/seeds**

- Beef jerky/meat stick

- Yogurt (PLAIN)

- Dried chickpeas

- Peanut butter

- Peanut butter puffs

- Chicken/tuna salad

- PLAIN Cherrios (+ protein/fat)

- **Veggies** (carrots, tomatoes, cucumbers, peppers, celery, etc.)



- Dried veggies

- Hummus

- Dried seaweed

- Edamame or dried edamame



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MEAL “SCHEDULES”

A strict schedule can exacerbate behaviors when schedule is not/cannot be followed

Can contribute to worsening OCD-type behaviors and cognitive rigidity

Maintaining flexibility in schedules is preferable and recommended

May need to intentionally build “noise” into daily routine

Base meals around activities, not the clock/specific times

Ensure your child knows that food will be provided, but is not dependent on a specific time

Avoid “feeding the clock”



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SPECIAL OCCASIONS

Sweet treats (cookies, cakes, cupcakes, brownies, ice cream, etc.) are OK on extremely special occasions (~ 5 times per year)

Birthdays

Special holidays

Big vacations

Examples of occasions that are NOT special:

- “on weekends”
- Friday nights
- “Wednesdays”
- After dinner (i.e., dessert)
- “only when we go out to eat”
- Classmate’s birthday



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FAMILY ROLES

TEAM effort

Whole-family approach - Proper nutrition is beneficial for everyone in the family

Parents/Main Caretakers

Do not cater to children's likes and dislikes; your children are not "customers", and you are not a "waiter/waitress"

Should treat all children similarly

Do not let own food preferences determine what is being served

Understand your food anxiety will spill over to your children

Acknowledge potential risk of disordered eating in other family members

Grandparents

Do not show love through food (use other forms of rewards: toys, books, game, quality time, money, adventures/trips, etc.)

Siblings

No sharing of food

Awareness of access to food

Maintain a healthy relationship with food

Nutrition Recommendations for Children and Families with PWS

SUMMARY

- Quality – no sweet-tasting foods! Focus on Mediterranean Diet
- Quantity – small portions, especially fruit
- Balance – protein, complex carbs, non-starchy veggies (no carb-free meals & no carb-heavy meals)
- Variety – do not serve the same foods over and over. Continually offer new and non-preferred foods.
- Drinks – UNSWEETENED only
- Convenience – meals/snacks do not have to be fancy or complicated!
- Meal schedules – maintain flexibility; snacks not necessarily needed
- Special occasions foods ~ 5 times per year
- Family Roles – parents are in charge! Do not cater to your child

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QUESTIONS?