Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

CAREGIVER PRIORITIES FOR AGING IN PRADER-WILLI SYNDROME

Compiled and Edited by:
Lynn Garrick, RN, MSN
Katrina Kozak, MSPC
Stacy Ward, MS, BCBA

Developed in partnership with:
PWSA I USA
Latham Centers



Information developed from the PWSA I USA Residential Providers Sharing Sessions

We asked 20 providers to rank the following areas of most importance in their experience providing support for someone aging with Prader-Willi syndrome. **This booklet, based on a survey, years of experience, and countless deep conversations, is designed to better prepare caregivers working with someone diagnosed with PWS; a "cheat sheet" curated by those with first-hand experience.** We thank everyone who came together and helped to gather this information. Collaboration and sharing are key to our success in this field!

Please note that there are also many clickable links (as indicated in blue font) in which you can research in more detail the world of PWS. Additionally, we use the terms "caregiver," "caretaker," "staff," and "provider," interchangeably throughout the text - while in each agency the terminology and culture may differ, the goal of our work is the same.

Residential care provides holistic support across the lifespan by addressing physical, emotional, social, and spiritual needs while respecting each person's cultural and religious beliefs. Providers must adapt care to different life stages, honor traditions, and create an inclusive, person-centered environment. This meaningful responsibility is embraced with passion, as providers are dedicated to uplifting the whole person and fostering dignity, well-being, and a strong sense of belonging every day.

- Lynn, Stacy, and Katrina






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01

CARE DURING HOSPITALIZATION



Hospitalizations can be difficult for everyone involved, including but not limited to the patient with PWS, the Caregiver, and the medical staff.

Helpful Documents and Resources (with hyperlinks!)

Important Considerations for Routine or Emergency Treatment
PWSA | USA
Reprinted from The Gathered View (ISSN 1077-9965)

Medical Alert for Patients with Prader-Willi Syndrome: Information for Health Care Professionals in an Inpatient Setting
PWSA | USA

Prader-Willi Syndrome Medical Alerts (Booklet)
PWSA | USA

Prader-Willi Syndrome (PWS) - Information for hospital staff
PWSA | UK

Top tips for triaging & treating children with PWS
PWSA | UK
© 2018 Rae Vacher Lowe (mum of Gideon)

CAN PROMPT: Medical Concerns, Behaviors, PWS 101
Latham Centers, Inc.

A Caregiver Checklist

- **In Preparation for an Emergency**
  - Have “grab and go” folder which may contain:
    - current medications
    - diagnosis
    - emergency contacts
    - insurance info
    - Medical Alert Booklet (PWSA | USA)
  - Bring favorite things to help occupy time, for example:
    - Activity Set
    - iPad
    - Puzzles
  - Create a modified “About Me” paper to hang in room
    - Brief on PWS
    - Behavior
    - Food sensitivities
    - Triggers
    - Passions
  - Work with local hospitals and rehab facilities that are frequently used if possible, to provide education and build relationships
    - Ask medical facilities what information you can provide that will stay in the patient’s portal

- **During Visit**
  - Provide staff support in the facility as much as possible
  - Get on approved “Call” list
  - Utilize the “About Me” paper, make visible in room
  - Food Considerations
    - Speak with dietitian to work with dietary restrictions
    - Inform staff around medical safety issues, such as complications swallowing
    - Pre-order food for the week
    - Bring in food from group home
    - Educate key nursing staff -charge nurse-
  - Have one-two key people check in daily and ideally at each change of shift; develop your “communication leads.”
  - Work closely with discharge planning team to ensure safe plan to return home
    - Needed supplies/equipment
    - Staff training if needed
    - Needed therapies scheduled to come to home or schedule outpatient
  - Provide educational materials to hospital/rehab staff as needed
  - Advocate for team meetings as needed while inpatient

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CAN PROMPT

How to Respond to a Medical Appointment for an Individual with PWS

C **CLEAR AREA:** Clear and secure area of items that could be damaged or ingested (edible, non-edible).

A **ADVICE:** Staff/guardians know this individual best. Listen to their concerns. Let them address unsafe or concerning behaviors.

N **NPO**: Request that the individual is NPO (only water), food and drink provided by program. Giving food raises anxiety.

P **PAIN**: People with PWS have a VERY high pain tolerance. Complaints should be taken seriously.

R **REACT**: Keep a neutral tone & steady facial expressions. Individuals can be easily agitated, leading to aggression.

O **OVERWHELMED**: People with PWS can become very confused. Do not ask leading questions.

M **MANIPULATION:** Individuals with PWS may use different strategies to try to access extra food.

P **PERSEVERATE:** It is commonplace for someone with PWS to perseverate on the same issue, topic, or concern.

T **TAKE AWAY INCENTIVE OF FOOD:** Individuals with PWS may view trips to the ER as an opportunity to receive extra food.

Medical Notes about people with Prader-Willi syndrome

- **High pain threshold -** may not describe symptoms accurately.
- **Lack of fever** even when infection is present.
- **Inability to vomit** due to poor muscle tone.
- **Slow gastric motility.**
- **Lack of satiety.** Staff/guardians will provide food, this decreases anxiety.
- **Hyper-sensitivity to medications and anesthesia.**
- **Stomach distention/bloating/vomiting** can be signs of an emergency.
- **Respiratory illness** can be more serious due to poor muscle tone, making deep breathing difficult.
- **Easily fatigue** and **unsteady gait.**
- **Skin can easily bruise.**
- **Poor impulse control.**

My name is_____ I am here because (role)_____

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Someone with PWS may display the following behaviors

- **Run away** to obtain food or take food from others.
- **May not accurately report** symptoms or history of illness.
- **Skin picking:** skin lesions lead to infections caused from skin picking, leading to more skin picking.
- **Agitation:** can lead to aggression when routines changes or expectations are not met.

If someone is yelling but not getting violent, leave the room when possible, to allow the staff/guardian to create a safe space.

What should medical professionals do to help bring my client or family member back down to baseline?

What should you not do with my client or family member? What are their triggers?

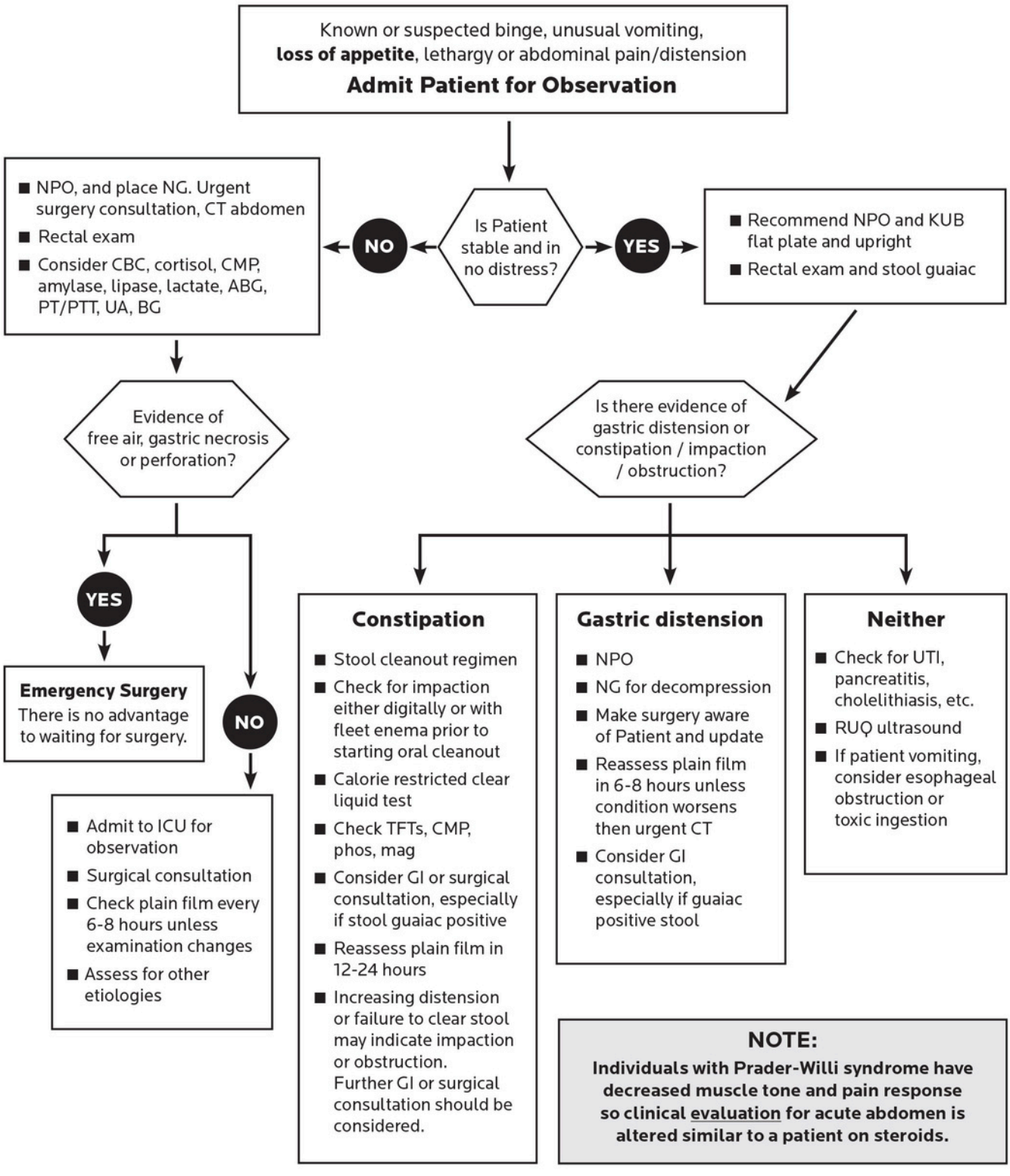
What are other things that are important to know about this client?

Patient Name: _____

Primary Medical Contact Name: _____

Medical Contact Number: _____

Evaluation of Individuals with Prader-Willi Syndrome with New GI Complaints



Credits: James Loker, M.D., Pediatric Cardiologist • Ann Scheimann, M.D., M.B.A., Gastroenterologist
PWSA | USA Clinical Advisory Board Members • www.pwsausa.org • 941.312.0400

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02

END-OF-LIFE CARE

The following information was borrowed from "End-of-Life Care Planning for Individuals With Special Needs." In this piece by Lee Pruitt, published December 16, 2025, the key takeaways are:

Beginning end-of-life care discussions long before a crisis arises, using clear, plain language like "dying" and "death" allows the person with an intellectual or developmental disability (IDD) time to understand and revisit topics gradually.

Individuals with IDD have the right to express their preferences. Adapt the conversation using visuals or short discussions, and offer concrete choices to help them communicate their desires.

Once their wishes are known, work with trusted supporters to formally document them in legal forms such as advance directives to ensure their voice is honored in all future care decisions.

How to Discuss End-of-Life Care

Use Clear, Concrete Language

Instead of using euphemisms such as "passing away" or "going to sleep," use plain terms like "dying," "death," and "serious illness." Explain one idea at a time and check for understanding by asking the person to explain something in their own words.

Adapt the Conversation to the Person's Communication Style
Depending on the person's abilities:
· use pictures, social stories, visual schedules, or body diagrams
· allow gestures, devices, or communication boards
· break conversations into short discussions over days or weeks

Offer Choices Whenever Possible
Instead of abstract questions, such as "What do you want at the end of your life?," offer meaningful, relatable options, such as:
· "If you are very sick, would you want to be at home or in a hospital?"
· "If machines can help you breathe, would you want that all the time, just to get better, or not at all?"
· "Who do you want to help make decisions for you if you cannot speak for yourself?"

Involve People They Trust
Trusted supporters can help translate medical information or reinforce key concepts. This may include family members, long-term caregivers or direct support professionals, case managers, or health care providers familiar with intellectual and developmental disabilities.

Provide Repetition, Reassurance, and Time
Revisiting these topics multiple times is normal. Approach the conversation with patience, validate emotions, answer questions honestly, and re-explain concepts as needed.

Document the Person's Wishes
Once the person's preferences are clear, families can help complete documents such as:
· advance directives
· POLST or MOLST forms (depending on state)
· guardianship or supported decision-making agreements

A Compassionate and Person-Centered Approach
Discussing end-of-life care with a loved one with an IDD is not about preparing for the worst but about honoring who they are, what matters to them, and how they want to live. When families create supportive, accessible, and respectful conversations, they build trust, ease fear, and ensure that their loved one's voice remains central at every stage of life.

03

DEMENTIA

Where do the Researchers Stand?

Scientists and researchers continue to investigate the prevalence of dementia in the aging person with Prader-Willi syndrome. There is one thing of which everyone is clear: we need more data and research. Additionally, previous diagnoses and family history will impact the dementia diagnosis.

At this point, as providers, we can continue to stay up to date on the research, and continue to care for the individuals in our care with the utmost concern for changes that we see in each of them. We can encourage psychological evaluations at a younger age than what is typical for most people aging, and as always, continue to be empathetic to our clients' needs and body changes.

Increased Brain Age: what is it all about?

*A*ccording to Azor, Cole, Holland et al., who conducted a study 2019, "participants with PWS showed signs of premature brain aging and early onset atrophy rather than a fundamental arrest of brain development." While most of the adults in their study showed an "increase in predicted brain age," there have not been many studies conducted in this area.

To learn more about this particular study, and the details of increased brain age, please click here, https://pmc.ncbi.nlm.nih.gov/articles/PMC6412082/

Helpful Videos regarding PWS, featuring Lynn Garrick and Barb Dorn are:
PWS Aging Research and Health Updates, 2025

Part 1: https://www.youtube.com/watch?v=0IbxiQERDbQ
Part 2: https://www.youtube.com/watch?v=yrDdfCuutNA

A Case Study to Consider

Male, 40 years old, Deletion subtype
My son turned 40 in Dec 2025. I feel his memory is getting shorter. Forgetting a lot. Also, talking to himself. He never really did this, but it seems to be doing it a lot lately. Is this normal for adults. We are going to his primary soon. Should he have any test done?

In response, on the Ask Nurse Lynn Forum, Lynn Garrick, wrote:
New forgetfulness and increased or new self-talking in a 40-year-old with Prader-Willi syndrome should be evaluated promptly, as they may signal medical, psychiatric, or neurological issues rather than normal aging. Possible causes could include thyroid or vitamin deficiencies, metabolic changes, medication effects, mood disorders, seizure activity, or early dementia.

At his upcoming visit, consider requesting lab work (CBC, CMP, thyroid, B12, folate, vitamin D, HbA1c, lipid profile, cortisol, IGF-1), neurological evaluation and/or cognitive testing, psychiatric assessment, and review of sleep health/BIPAP data. Early assessment can help identify and treat reversible causes. Because cognitive decline and psychiatric changes can develop earlier in adults with PWS, early evaluation is critical to identify treatable causes and slow or prevent progression. While this may seem like a long list, it's important to bring these questions to the provider's attention so nothing is overlooked—covering these areas now can make a real difference in long-term outcomes.



Image from Adobe Stock

04

AGING AND NUTRITION

Metabolic Changes and Weight Management: Energy Needs and Nutritional Phase

Older adults with PWS may need fewer calories than similarly sized adults without PWS because reduced lean muscle mass, hypotonia, and lower activity can reduce energy expenditure. Individual needs may change with age, mobility, illness, medications, endocrine treatment, and body composition. A registered dietitian or medical provider should establish and review the person's calorie plan. [1, 2, 3]

Some adults may enter phase 4 of PWS, in which appetite is no longer insatiable. This occurs only for some people and does not mean that food security or supervision should be removed. Continuing or unexplained weight loss, reduced appetite, or the need to keep increasing calories is not a defining feature of phase 4 and should prompt a medical assessment. [1, 2]

Weight Monitoring

Weight should be measured at the frequency specified in the individual's nutrition or medical plan. Weekly measurements under consistent conditions may be used for adults in a PWS specific program; daily weights under consistent conditions is preferable which allows for weight changes to be noticed immediately and fact finding to assess reason for gain or loss. More frequent measurements may be ordered when clinically indicated. Use the same scale, similar clothing, and approximately the same time of day. Record trends and follow the plan's notification thresholds. [2, 3]

Staff should not independently increase or decrease calories because of a weight change. Unexpected weight loss or gain should be communicated to the nurse, dietitian, or medical provider for review.

As a best practice, individuals should be weighed before leaving for and upon returning from day visits, home visits, or any time they have been away from the supervision of agency staff. Monitoring weight before and after these absences helps identify any significant changes that may have occurred while the individual was away.

If a notable weight change is observed, staff should closely monitor for additional changes from the individual's baseline, such as not finishing meals, refusing meals, reporting that they do not feel well, or complaining of pain. When these signs are present, staff should follow agency policy and the individual's care plan or medical protocol for obtaining prompt medical evaluation, as these symptoms may indicate a serious condition, including stomach perforation, that requires immediate attention.

Mobility and Exercise

Some adults experience reduced mobility as they age. Physical activity should be adapted to the person's abilities and medical status rather than abandoned. Regular, approved activity can support mobility, muscle strength, bone health, endurance, and weight management. A physical therapist or other qualified clinician may be needed when gait, balance, pain, fatigue, or function changes. [2, 3]

Fiber, constipation, and gastroparesis

A fixed low-fiber target, such as 15 grams per day, is not appropriate for every person with PWS. Fiber may support bowel regularity for some people. Others may need a lower-fiber, softer, or more thoroughly cooked diet when gastroparesis, delayed gastrointestinal transit, swallowing difficulty, or another gastrointestinal condition is diagnosed or suspected. Fiber and texture changes must be individualized by the medical and nutrition team. [2, 3]

When a clinician prescribes lower-fiber or softer foods, examples may include well-cooked vegetables and soft canned or frozen fruit prepared to the person's prescribed texture. These are examples only; the individual plan determines what is safe.

04

Dysphagia, Choking, and Aspiration Concerns

The following pages and chapters outline the nuances of swallowing, and the importance of learning about them as a residential provider for people with PWS. It is essential for health and safety of the aging population with PWS to be aware of the signs of a swallowing problem, the factors that may increase risk, and tips for safe dining habits.

Swallowing problems in PWS may be hidden. Video fluoroscopic studies have identified problems with pharyngeal and esophageal timing, clearance, and coordination between breathing and swallowing. Participants in one study did not show expected attempts to clear residue or cough, even when residue remained. Rapid eating combined with impaired swallowing can increase the risk of aspiration, food impaction, and airway obstruction. [4, 5]

A person may appear to eat normally while food or liquid remains in the throat or esophagus, or while liquid enters the airway without coughing. The absence of coughing does not establish that swallowing is safe. [4, 5]

Caregiver Role During Meals

Suggested plans/precautions are in place prior to providing care. Examples may include person centered plan, Individual Service Plan, Behavior Support Plan, Dining Safety Support plan, medical orders, rights denial form, etc.

Before serving the meal, staff or caregivers must know the person’s current food texture, drink thickness, supervision level, positioning, bite and sip size, pacing method, adaptive equipment, criteria for when to stop their meal, and emergency instructions. Please note the “Individual Dietary Guidelines Sample” Sheet on the following pages.

Caregiver Role During Meals, cont'd

Before the meal

- Confirm that the meal and drink match the current order and Dining Safety Support Plan which outlines the rationale for additional support needed for the meal, staff guidelines, and review process.
- Check labels and preparation requirements rather than relying on memory.
- Ensure that the staff member assigned to direct supervision is ready before the food is served. Strategically plan to serve the meal so the person at greatest assessed risk is not left alone with the meal, even briefly.
- Confirm that emergency equipment required by policy is available and that assigned staff are trained in choking response, first aid, and CPR.
- Support the prescribed upright position and any foot, trunk, head, or seating supports identified by the treatment team.
- Reduce unnecessary noise, rushing, screens, and other distractions.

During the meal

- Provide the documented supervision level. "Staff nearby" is not the same as direct one-to-one observation when the plan requires direct supervision.
- Use the prescribed bite and sip sizes. Do not decide bite size from the size of the utensil.
- Use the prescribed pacing method. Examples may include one bite at a time, placing the utensil down between bites, waiting until chewing and swallowing are complete, or taking an approved sip between bites.
- Offer only the liquid type, thickness, cup, straw, and sip size permitted by the plan. A sip between bites is not appropriate for everyone.
- Use brief, respectful prompts between bites. Do not ask the person to talk while food or liquid is in the mouth. Conversation should remain calm and should not be distracted from swallowing.
- Use counting, timers, portioned utensils, controlled-flow cups, or other tools only when they are included in the individual plan and staff have been trained to use them.
- Observe for changes in breathing, voice, alertness, chewing, swallowing, posture, pace, and behavior throughout the meal.

Caregiver Role During Meals, cont'd

After the Meal

- Follow the individual's prescribed post-meal positioning and observation plan. When treatment is appropriate, encourage the person to remain upright for at least 60 minutes after eating. Gentle activity, such as a supervised walk, may help support digestion and gastrointestinal motility (processing speed), provided it is safe and consistent with the individual's outlined care plans.
- Document concerns, interventions, intake, and notifications according to policy and the individual plan.
- Clean and store adaptive equipment according to the manufacturer's instructions and infection-control policy.

What to Document

- Date and time; location; staff present; and whether the event occurred before, during, or after the meal.
- Exact food or drink, prescribed IDDSI level, preparation, bite or sip size, cup or utensil, and positioning.
- Objective observations, such as coughing, throat clearing, color change, voice change, food retention, breathing change, or decreased responsiveness.
- Actions taken, the person's response, who was notified, medical advice received, and follow-up required.
- How the event differed from the person's normal baseline.

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INDIVIDUAL DIETARY GUIDELINES

Individual: DOB:

Reason: Dysphagia. Missing teeth and dental issues causing difficulty chewing her food thoroughly and at a safe pace.

Latham Diet: Latham Menu PWS Diet

Modified Diet:

Solids: IDDSI Level 4 - Pureed

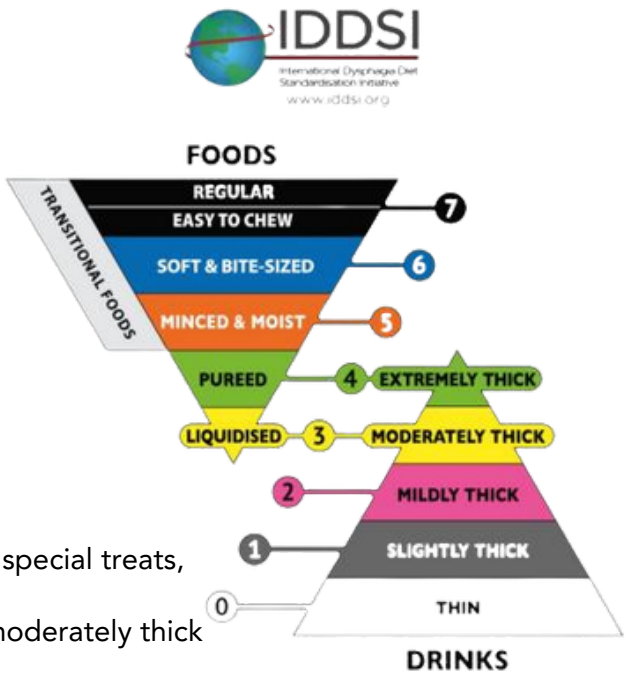
Liquids: IDDSI 3 Moderately Thick

Medications: Whole in applesauce

Food Allergies: No known food

allergies No Bread, No Mixed

Consistencies



Dietary Restrictions/Changes to Regular Diet:

- See Substitutions per Menu Guidelines
- Magic Cup: Exercise incentive, replacement for birthdays, special treats, whipped cream, etc.
- Refer to IDDSI handouts for pureed food guidelines and moderately thick liquids for preparation.

Safe Swallowing Strategies:

- Sit upright for all meals and snacks. Stay upright for 30 minutes after all meals, snacks and medication passes.
- Take single small bites and sips.
- Alternate foods and liquids during meal.
- Do not talk while eating or drinking.
- Make sure there is plenty of time for mealtimes- no rushing, eat slowly.
- Swallow two times per bite
- Supervision with meals for strategy cueing

Contact 's Doctor For:

- Difficulty swallowing, chewing, or breathing during meals (wheezing, shortness of breath, or fast / noisy breathing).
- Any concerns of aspirating (food or liquid getting into the lungs), coughing during mealtimes that does not
  go away, increase in secretions, labored breathing, sometimes accompanied with fever or other change in
  status.

Provider's Signature Print Name Date

3 MODERATELY THICK

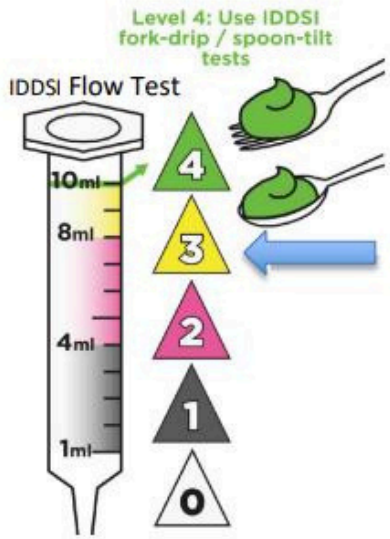
IDDSI
International Dysphagia Diet Standardisation Initiative
www.iddsi.org

Level 3 Moderately Thick Liquids for Adults

What is this thickness level?

Level 3 - Moderately Thick drinks:

- ✓ Can be drunk from a cup or taken with a spoon
- ✓ Need some effort to drink them through a *wide* diameter straw
- ✓ Have a smooth texture with no lumps, fibers or seeds



Why is this thickness level used for adults?

Level 3 – Moderately Thick drinks may be used if your tongue control is not good enough to manage Mildly Thick, Slightly Thick or Thin drinks. Moderately Thick drinks allows more time for the tongue to "hold and move" the drink. These drinks are best taken from a cup or using a spoon.

How do I measure my liquid or drink to make sure it is Level 3 Moderately thick?

It is safest to measure Moderately Thick drinks using the IDDSI Flow Test *and* the IDDSI Fork Drip Test. These tests measure how thick a liquid is by how fast it flows through a 10 mL syringe in 10 seconds and how quickly it flows through the prongs of a dinner fork. IDDSI recommends that you use a 10 mL syringe to check to make sure you have the correct thickness level using the instructions below. For Level 3-Moderately Thick liquids there should be *no less than 8 mL remaining* in the syringe after 10 seconds of flow. Your clinician may give you a specific number between 8-10 mL to aim for. Using the IDDSI Fork Test the liquid should drip slowly in dollops through the prongs of a fork.

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See videos of the IDDSI Flow Test and IDDSI Fork Drip Test at www.IDDSI.org/framework/drink-testing-methods/



IDDSI Fork Drip Test
Drips slowly in dollops through the prongs of a fork

4 PUREED

IDDSI
International Dysphagia Diet Standardisation Initiative
www.iddsi.org

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Level 4 Pureed Food for Adults



What is this food texture level?

Level 4 – Pureed Foods:

- ✓ Are usually eaten with a spoon
- ✓ Do ***not*** require chewing
- ✓ Have a smooth texture with no lumps
- ✓ Hold shape on a spoon
- ✓ Fall off a spoon in a single spoonful when tilted
- ✓ Are ***not*** sticky
- ✓ Liquid (like sauces) must not separate from solids

Why is this food texture level used for adults?

Level 4 – Pureed Food may be used if you are not able to bite or chew food or if your tongue control is reduced. Pureed foods only need the tongue to be able to move forward and back to bring the food to the back of the mouth for swallowing.

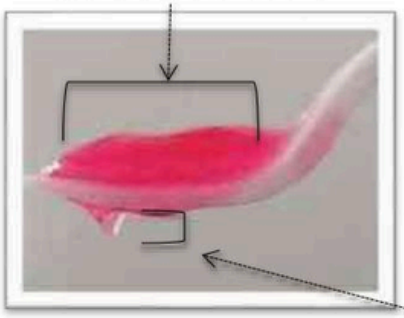
It's important that puree foods are not too sticky because this can cause the food to stick to the cheeks, teeth, roof of the mouth or in the throat. Pureed foods are best eaten using a spoon.

How do I test my food to make sure it is Level 4 Pureed?

It is safest to test Pureed Food using the IDDSI Fork Drip Test *and* the IDDSI Spoon Tilt Test.

See videos of the IDDSI Fork Drip Test and IDDSI Spoon Tilt Test at
www.IDDSI.org/framework/food-testing-methods/

Extremely thick liquids sit in a mound or pile above the fork



A small amount may flow through and form a tail below the fork

IDDSI Fork Drip Test
Liquid does ***not*** dollop, or drip continuously through the fork prongs



IDDSI Spoon Tilt Test

Sample holds its shape on the spoon and falls off fairly easily if the spoon is tilted or lightly flicked

Sample should ***not*** be firm or sticky

Pureed food must pass both tests!

Intended for general information only
Please consult with your health care professional for specific advice for your needs



PUREED

IDDSI
International Dysphagia Diet Standardisation Initiative
www.iddsi.org

For safety, AVOID these food textures that pose a choking risk for adults who need Level 4 Pureed food

Food characteristic to AVOID	Examples of foods to AVOID
Mixed thin + thick textures	Soup with pieces of food, cereal with milk
Hard or dry food	Nuts, raw vegetables (e.g. carrot, cauliflower, broccoli), dry cakes, bread, dry cereal
Tough or fibrous foods	Steak, pineapple
Chewy	Lollies/candies/sweets, cheese chunks, marshmallows, chewing gum, sticky mashed potato, dried fruits, sticky foods
Crispy	Crackling, crisp bacon, cornflakes
Crunchy food	Raw carrot, raw apple, popcorn
Sharp or spiky	Corn chips and crisps
Crumbly bits	Dry cake crumble, dry biscuits
Pips, seeds	Apple seeds, pumpkin seeds, white of an orange
Food with skins or outer shell	Peas, grapes, chicken skin, salmon skin, sausage skin
Foods with husks	Corn, shredded wheat, bran
Bone or gristle	Chicken bones, fish bones, other bones, meat with gristle
Round, long shaped food	Sausage, grape
Sticky or gummy food	Nut butter; overcooked oatmeal/porridge, edible gelatin, konjac containing jelly, sticky rice cakes
Stringy food	Beans, rhubarb
Floppy foods	Lettuce, cucumber, uncooked baby spinach leaves
Crust formed during cooking or heating	Crust or skin that forms on food during cooking or after heating, for example, cheese topping, mashed potato
'Floppy' food	Lettuce, cucumber, baby spinach leaves
'Juicy' food	Where juice separates from the food piece in the mouth, for example watermelon
Visible lumps	Lumps in pureed food or yoghurt

What to watch for in a residential setting

Swallowing abnormalities are increasingly recognized in individuals with PWS. Because individuals with PWS may not always show typical warning signs, aspiration can occur silently.

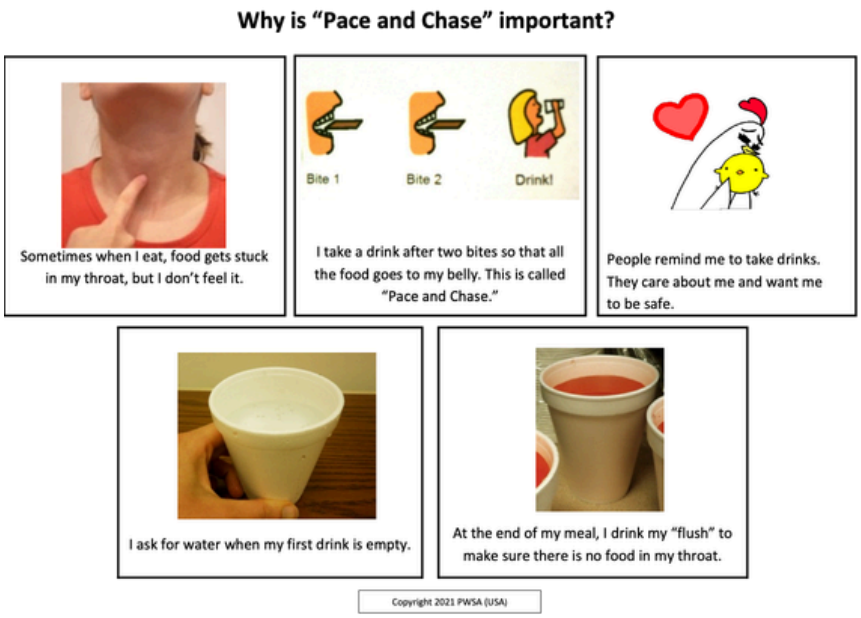
Aspiration occurs when food, liquid, or saliva enters the airway rather than the esophagus. Repeated aspiration can lead to aspiration pneumonia, chronic lung inflammation, and recurrent respiratory infections.

Risk factors for aspiration in aging individuals with PWS include:

- Weak oral and pharyngeal muscle tone
- Poor chewing or rapid eating behaviors
- Gastroesophageal reflux disease (GERD)
- Sedating medications
- Poor posture or scoliosis
- Fatigue or illness
- Dental problems or poor dentition

Residential providers should watch for warning signs such as:

- Coughing or throat clearing during meals
- A “wet” or gurgly voice after eating or drinking
- Recurrent pneumonia or bronchitis
- Unexplained fevers
- Prolonged mealtimes
- Food pocketing in the mouth
- Increased respiratory symptoms after meals



Swallowing in Prader-Willi Syndrome (PWS)

A Family-Friendly Guide

What Is Swallowing?

Swallowing is something our bodies do every day. When we eat or drink, food and liquid should go **down the right tube** into the stomach. Sometimes, things can go **down the wrong tube** into the airway. This is called **aspiration**.

Most people cough when this happens. But many children and adults with **Prader-Willi syndrome (PWS)** may not cough. This is called **silent aspiration**. Even though you cannot see it, it can cause breathing problems or infections.

Why Do People With PWS Have Trouble Swallowing?

Children and adults with PWS may have:

- **Low muscle tone**, which makes swallowing harder.
- **Trouble coordinating** breathing and swallowing at the same time.
- **Delayed swallowing**, meaning food stays in the throat longer.
- **Food left behind** in the throat or esophagus after swallowing.

Doctors have done special X-ray tests called **swallow studies**. These studies show that many babies, children, and adults with PWS have:

- Trouble moving food or liquid to the right place.
- Liquid getting into the airway without coughing.
- Food getting stuck in the throat or esophagus.

This can happen even when the person looks like they are swallowing fine.

Signs of Swallowing Problems

Many times, there are **no clear signs**. But sometimes you may notice:

Coughing during or after eating.
Watery eyes or runny nose when eating.
Food getting stuck.
Taking a long time to eat.
Frequent chest colds or lung infections.

If you see these signs, tell your child's doctor.

How Families Can Help

Even though swallowing problems can be hidden, there are things you can do to help keep your child safe.

1. Make Mealtimes Calm and Slow

- Avoid rushing.
- Encourage small bites and slow sips.
- Give time to chew well.

2. Use the Foods and Liquids Recommended by Your Child's Team

Some children may need:

- Thicker liquids.
- Softer foods.
- Help sitting upright while eating.

3. Know When to Ask for a Swallow Study

Ask your doctor for a swallow study if your child has:

- Frequent pneumonia or breathing problems.
- Trouble feeding as a baby.
- Gagging or choking.
- Sudden behavior changes with food.

4. Practice Good Habits

- Keep mealtimes distraction-free.
- Make sure your child sits upright.
- Encourage drinking sips of water during meals if allowed.

Teaching Your Child How to Swallow Pills

Many children with PWS need daily medicines. Learning to swallow pills safely is important and can take time.

Tips for Teaching Pill Swallowing



Start small!
Begin with smaller pills. Practice with water.

Use simple steps.



Sit up tall.



Put the pill on the tongue.



Take a sip of water.



Swallow!

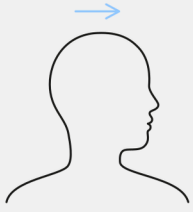


Move up slowly.
Increase the size of the pill slowly.

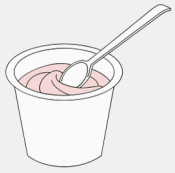
Try different swallowing methods.



Use a straw.



Tilt the head slightly forward.



Put the pill in Greek yogurt or cottage cheese, only if the medication allows for it

06

EMPLOYMENT & RETIREMENT

The Intersection of PWS and the Workforce

According to Neil Pasricha, the equation or formula for happiness is simple: Subjective Well-Being (S), Life Circumstances (C), and Voluntary Activities (V). H=S+C+V. This equation does not change for the people in our lives with PWS. Instead, what changes, is the environment in which the people in our lives can be successful.

It is essential that we modify the environment in order to meet the needs of the person. Modification ideas range from revising the workday hours to colleague trainings, and many are listed below.

Ultimately, it comes down to what matters most to the person, and their intersection of interests and abilities: what are they passionate about and will be able to stay interested in, as well as what are they capable of. Moreover, ask them: “what does success look like to you?” That said, there are many environments that a person with PWS may be successful, with appropriate modifications in place. In this chapter, we will explore successful modifications

There are many variables that caretakers need to consider, including but not limited to:

- environment
- sensory stimulation (lights, noises)
- food security
- hours (individual fatigue)
- temperature

Helpful Tools

- Revised work schedule
  - Shorter periods of time allow for less on-the-job fatigue
  - By selecting a time before or after lunch hour eliminate chances for lapsed food security, for example: 1:30-4pm shift
- Trainings
  - Education is IMPORTANT; educate the others working at the business about PWS as a diagnosis. Options are:
    - short training at a team meeting
    - providing information about PWS for the hiring team
- Schedule and routine; consistency in:
  - the days that the person works
  - what they do while working

06
EMPLOYMENT & RETIREMENT

Successful Work Placements

Successful work placements are inspiring. While for some people, volunteering will be the answer, for others, it will be paid employment. Regardless, the important thing is that our clients have an ability to work when able, retire when necessary, and age gracefully. In our chapter about *Making Life Meaningful*, we dive more deeply into volunteer successes.

With all work placements and volunteer jobs, there may be risks and considerations. It's important to weigh out all the concerns of placements; for people with PWS with high food seeking behavior, it can often be difficult to find appropriate placement.

- Animal Care: whether a volunteer position at a rescue league, or a clerk at a pet store there is an immediate draw for many to work with animals.
- Clerical Work: when you ask a job coach about vocational successes, many will report clerical work including sorting, shredding, etc.
- YMCA and other gyms: A small gym often does not center itself around food.
- Volunteering at Community Centers, Councils on Aging and other Aging Centers
- Landscaping and outside work: Also not often food related, landscaping allows for physical activity in addition to meaningful and routine work.

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EMPLOYMENT & RETIREMENT

Testimonials of success from your friends at Latham Centers

Client A grew up loving planes. He loved plane rides, looking at planes, building planes, watching planes, etc. When asked about his aspirations, he declared that he wanted to be a pilot. His staff came together, and with the support of a local airport, created a position in which Client A documented the planes returning to the airport. Client A loves his job, and he is doing meaningful work that contributes to the flow of the airport.

Client B loves talking to people. As a middle-age adult, she was able to work at a Chamber of Commerce helping to organize brochures, meet people, suggest travel adventures for new people arriving to town, etc. As she aged, standing and talking to visitors wasn't as easy, but she was able to help with some of the "behind the scenes" tasks around the office. Ultimately, when transportation became more difficult, Client B decided to retire on her own terms.



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07

HOME MODIFICATIONS

As the person with PWS ages residential providers will continue to tackle new and different challenges. Modifications may need to be made in residential environments. Common challenge areas are:

1. Entry and Exit Points
2. Stairlifts for multistory homes
3. Raised toilets
4. Lowered counter tops
5. Non-slip showers
6. Roll-in Showers/Tubs
7. Grab bars
8. Leveling of floors and removing thresholds
9. Replace all doorknobs with handles
10. Remove rugs, carpets, and anything else that could lead to slipping
11. Hoyer Lifts (portable patient lifts)

Smart Technology that can be helpful in our Residential Environments

1. Self-locking refrigerators
2. Sleep mats
3. Body Smart Scales
4. iHealth Line

Home Fall Prevention Checklist for Older Adults from the Center for Disease Control outlines helpful techniques that can be used for residential homes.

Plans & Schedules

As somebody with PWS ages, plans will need to change with them. The following is one example.

07

Individual Protocol Sheet
(with emphasis on home modifications)

Mobility	Transfer Tips Include
Daily Schedule	Morning Time Routine: Lunch Routine: Dinner Routine: Nighttime Routine
Dietary Guidelines	
Off-Loading	
Depends and Chucks	
Toileting Tips	
Showering Tips	
Incontinence	
Shower & Schedule Tips	
Adaptive Equipment	Protective Devices, etc.
Tips for Bed Mibility	
Data Tracking in Therap	

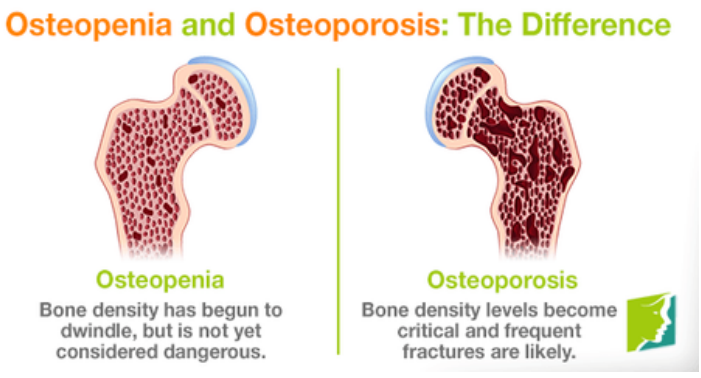
BONE & GI HEALTH

Bone Health and Osteoporosis

Osteoporosis is diagnosed with a dual-energy X-ray absorptiometry (DEXA) scan. A DEXA scan is a painless low dose X-ray procedure. DEXA scans of children and adolescents should be interpreted only by experts experienced in scoring these scans in pediatric patients. DEXA scans which are interpreted compared to adult standards (T-scores) often overestimate the presence of osteoporosis in children and adolescents. Although the normative pediatric databases are small, the interpretation of the DEXA scan should contain an age-, gender-, and race-matched Z-score. Frequently radiologists or other individuals who evaluate DEXA scans do not have access to this information. A T-score (for adults) that is between 1 and 2 standards deviations below normal is considered osteopenia (weak bones), while a T-score that is more than 2 standard deviations below normal is considered osteoporosis. You should ask your physician to provide you with the T-score. DEXA scans should be monitored every one to two years in adolescents and adults with PWS.

If osteopenia or osteoporosis is present on DEXA scan, the primary treatment is maximizing vitamin D and calcium intake in the diet. A nutritional consult should be obtained to assess current dietary intake of calcium and vitamin D. Current recommendations for adults (note that pediatric standards vary according to age) are that dietary calcium for individuals with low bone mineral density should be at least 1,500 mg per day and vitamin D intake should be at least 600-800 IU per day. Some studies indicate that even these amounts may be inadequate to significantly improve bone mineral density. Ideally, serum 25 vitamin D levels should be followed, with the desired concentrations being at least 30-32 ng/ml in order to improve bone mineral density.

For more information, please access the PWSA | USA Clinical and Scientific Advisory Board Consensus Statement.



Osteopenia and Osteoporosis: The Difference | Menopause Now

GI: Colorectal Function in Adults with PWS

In 2014, Kuhlmann et al., published a research article entitled, “A descriptive study of colorectal function in adults with Prader-Willi Syndrome: high prevalence of constipation.”

The study evaluated twenty-one patients with PWS and concluded that constipation is very common in PWS, and that “patients with PWS have an increased prevalence of prolonged gastrointestinal transit time (GITT) and palpable stools in the rectum at digital rectal examination.”

To read the whole article, click here.

Constipation

Constipation is very common in individuals with PWS and can become more complex with age. This is due to reduced muscle tone, slower gut motility, decreased activity, medication side effects, and changes in diet and hydration. In PWS, constipation may not present typically—individuals may have high pain tolerance, making symptoms less obvious until complications occur (e.g., vomiting, abdominal distention, or bowel obstruction).

Constipation in PWS is often part of a whole-gut motility issue, meaning the stomach and intestines may move more slowly overall—not just the colon.

Best Practices Include

- Daily BM tracking
  - (frequency, consistency using Bristol Stool Chart, ease of passage)
- Monitoring for changes from baseline
  - e.g., fewer BMs, loose stools after constipation = possible overflow)
- Watching for early warning signs:
  - Decreased appetite
  - Vomiting or gagging
  - Abdominal bloating
  - Behavioral changes (irritability, withdrawal)
  - Clear communication across shifts and with nursing/medical providers
  - Following individualized bowel protocols and escalation plans

Types of Constipation Medications (and how they work)

- Osmotic Laxatives (e.g., polyethylene glycol, lactulose)
  - Pull water into the stool → makes stool softer and easier to pass
  - Often used daily as a baseline medication
  - Requires adequate fluid intake to be effective
- Stimulant Laxatives (e.g., senna, bisacodyl)
  - Stimulate the bowel to contract and move stool forward
  - Helpful when motility is slow
  - Often used **in combination** with osmotic agents
- Stool Softeners (e.g., docusate)
  - Help mix water into stool → softer consistency
  - Less effective alone in PWS but may support other therapies
- Bulk-Forming Laxatives (e.g., psyllium)
  - Add fiber to increase stool bulk and promote movement
  - **Use with caution in PWS:** require good fluid intake and adequate motility
  - Can worsen symptoms if hydration or motility is poor
- Suppositories/Rectal Treatments (e.g., glycerin, bisacodyl suppositories)
  - Work locally to stimulate a bowel movement
  - **Useful for rescue or situations**
  - Should be part of a clearly defined protocol

Hydration and Diet

- Fluid intake is critical: dehydration worsens constipation
- Encourage consistent fluid intake throughout the day
- Maintain a structured, consistent diet
- Avoid sudden large dietary changes without adjusting bowel supports

Positioning: The “Squatty Potty” Approach

- Using a footstool (like a squatty potty) can help align the rectum in a more natural position to promote easier, more complete bowel movements

- Encourage unhurried, routine toilet sitting times, especially after meals

High-Risk Times: Outings and Home Visits

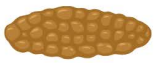
Changes in routine can significantly impact bowel patterns

After special outings or home visits:**

- Monitor closely for **missed BMs or changes in stool pattern**
- Be aware of **dietary differences** (higher fat, sugar, or unfamiliar foods)
- Watch for **reduced fluid intake**
- Resume structured routines promptly upon return
- Consider proactive adjustments per the individual's bowel plan
- Please note the GI Algorithm Chart in the first chapter of this booklet, under hospitalizations.

Knowing your clients' types of stool is important!

Bristol Stool Chart
Types of Poop

Type 1		Hard lumps or small pepples VERY CONSTIPATED
Type 2		Lumpy, hard, and sausage shaped SLIGHTLY CONSTIPATED
Type 3		Sausage shaped with cracks along the surface NORMAL
Type 4		Resembles a thin sausage or snake NORMAL
Type 5		Soft blobs with clear edges LACKING FIBER
Type 6		Mushy and fluffy with ragged edges INFLAMMATION
Type 7		Entirely liquid INFLAMMATION

09

HORMONES AND AGING

The Importance of Hormonal Health

Hormonal health is one of the most important, yet sometimes overlooked, aspects of aging well in PWS. Because PWS is rooted in hypothalamic dysfunction, many people with PWS have lifelong differences in the systems that regulate growth hormone, sex hormones, thyroid hormones, and stress hormones. In residential care settings, these hormonal issues can quietly shape strength, stamina, weight, mood, sleep, bone health, and day-to-day function. When they are missed, the person may appear to be “getting old” too quickly. When they are recognized and treated, staff may see better mobility, steadier function, improved comfort, and a better quality of life. Treatable medical conditions, including hormone problems, should be addressed “to avoid too early aging,” and recommend yearly review of testosterone or estrogen, thyroid function, and other health markers in aging adults with PWS.

Hormone Related Topics in Relations to the Residential Setting

Growth hormone has the strongest evidence base for aging in PWS. Across childhood and adulthood, low growth hormone activity contributes to lower lean body mass, reduced muscle strength, increased fat mass, and poorer exercise tolerance. These changes matter greatly in residential settings because they can appear to be ordinary aging while reflecting a treatable endocrine problem. Peer-reviewed reviews of adults with PWS likewise conclude that growth hormone treatment appears safe for many adults and improves body composition, a major issue because poor body composition is closely tied to cardiometabolic risk in this population. Adults with PWS face increased risk of type 2 diabetes, metabolic syndrome, cardiovascular disease, and loss of lean body mass, with endocrine dysregulation playing a significant role.

For residential providers, this means that slowing down, fatigue, difficulty rising from a chair, more falls, reduced walking tolerance, or a need for more help with stairs should not automatically be dismissed as “just aging.” These changes may reflect worsening sarcopenia, untreated growth hormone deficiency, deconditioning, obesity-related strain, or a combination of these factors. Staff observations are often what first bring the pattern into focus. Documenting gradual loss of endurance, increased daytime sleepiness, reduced participation in usual routines, or changes in transfers and gait can help the medical team see that endocrine reassessment may be needed. In older adults with PWS, preserving function is often just as important as treating the syndrome.

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Bone health sits at the intersection of hormones and aging. Adults with PWS are already vulnerable to low muscle tone and lower activity levels, and when hypogonadism is added, the risk of osteopenia or osteoporosis rises further. This can lead to fractures, chronic pain, reduced mobility, and loss of independence.
In residential settings, prevention matters: encouraging safe weight-bearing activity, monitoring vitamin D and calcium levels, arranging bone density testing when indicated, and ensuring endocrine treatment plans are followed can all help protect long-term function. For aging adults with PWS, protecting muscle and bone is not only about preventing injury. It is about preserving dignity, mobility, and the ability to remain engaged in daily life.

Sex hormone deficiency, or hypogonadism, is another major driver of aging-related decline in PWS. Hypogonadism is very common in PWS, and peer-reviewed reviews show that untreated hypogonadism can worsen muscle weakness, obesity, osteoporosis, and fatigue.
This has direct implications for residential care because low testosterone or low estrogen may contribute to what looks like frailty: less strength, lower energy, poorer balance, reduced bone density, and increased fracture risk. In practical terms, an older resident with PWS who is becoming weaker, less active, or more stooped may need endocrine evaluation, not just more assistance.



Photo from PWSA | USA 2026 Residential Providers Conference

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Thyroid disease can also mimic accelerated aging. Adults with PWS may develop hypothyroidism, and untreated hypothyroidism can worsen fatigue, slow thinking, constipation, weight gain, feeling cold, slowed heart rate, and reduced physical stamina. A 2021 review of thyroid function in adults with PWS found hypothyroidism in about one in six adults in one cohort and recommended yearly screening with free T4 and TSH because untreated disease can negatively affect metabolic rate, body mass index, and cardiovascular risk.
In a group home or supported living setting, this matters because staff may be the first to notice subtle changes such as a resident sleeping more, moving more slowly, becoming less expressive, or struggling more with constipation or cold intolerance. These signs warrant medical follow-up rather than being written off as solely behavioral or age-related decline.

Adrenal function is more complex. Earlier concerns existed about central adrenal insufficiency in people with PWS, especially during severe illness, but recent research shows that this condition is very rare in adults with PWS. According to a large study, central adrenal insufficiency was excluded in 81 of 82 patients, and none of the 200 adults who underwent surgery without hydrocortisone stress dosing showed signs of hypocortisolism. As a result, the authors recommend against routine hydrocortisone stress dosing for all adults with PWS.
For residential care, the practical takeaway is balance: providers should not assume adrenal crisis is common in every aging adult with PWS, but they should remain alert during acute illness, surgery, or unexplained collapse and ensure the medical team considers endocrine causes when clinically indicated.

In Conclusion

Overall, hormones do not explain every aspect of aging in PWS, but they strongly influence how aging is experienced. Growth hormone affects body composition and physical function. Sex hormones affect strength, energy, and bone health. Thyroid hormones affect metabolism, cognition, and stamina. Even when a person’s hormonal disorder has been known for years, needs may change with age, weight changes, medications, sleep problems, or reduced activity. In residential care settings, the best approach is proactive rather than reactive: an annual medical review, careful tracking of functional changes, communication between staff and clinicians, and a low threshold for reassessing treatable endocrine issues. Aging in PWS should never be approached as a simple, inevitable decline. Many of the changes that appear to be “aging” may actually be modifiable signs of under-recognized hormonal dysfunction.

10
ACTIVITY AND EXERCISE

The importance of physical activity in the (Aging) PWS Population

Individuals with Prader-Willi Syndrome (PWS) experience a unique set of physiological and behavioral challenges that make regular physical activity essential to their health and well-being. These challenges commonly include low muscle tone (hypotonia), decreased strength, reduced stamina, impaired balance and coordination, and a significantly lower metabolic rate. Without consistent opportunities for movement and exercise, individuals with PWS are at increased risk for falls, broken bones, weight gain, reduced mobility, and other related health complications.

Residential providers should strive to provide structured exercise opportunities that support the health and well-being of the individuals served. Through regular physical activity, individuals can build muscle strength, improve endurance, enhance balance and coordination, and support healthy weight management. Exercise also contributes to improved mood, greater independence, and an overall enhanced quality of life.

To support these goals, providers should offer a variety of exercise options designed to address different areas of physical development and fitness. Activities should be selected to promote engagement while targeting strength, flexibility, balance, cardiovascular endurance, and functional mobility. By incorporating regular exercise into daily routines, providers aim to support lifelong healthy habits and empower the individuals in our care to reach their fullest potential.

Some adults experience reduced mobility as they age. Physical activity should be adapted to the person’s abilities and medical status rather than abandoned. Regular, approved activity can support mobility, muscle strength, bone health, endurance, and weight management. A physical therapist or other qualified medical professional may be needed for assessment when gait, balance, pain, fatigue, or function changes.

10
ACTIVITY AND EXERCISE

KEY PRINCIPLES AND TAKEAWAYS

Exercise, for the person with PWS, must be adapted accordingly. Ultimately, the goal is to move our bodies; whether doing seated exercises, dancing, weight lifting, or cardio.

As exercise routines are developed, it is important to understand the clients stamina, fall risk, bone health, and other medical conditions.

As part of any exercise time, staff or caregivers' engagement and active encouragement helps motivate, builds trust and relationships between the individual and the staff or caregivers.

Developing the Exercise Program

When developing an exercise program, it should avoid being solely based on targeting one type of exercise such as walking. Incorporating various types of exercises helps address multiple facets of their health and wellness needs. Here are some areas to think about when you are developing an exercise program.

- Strength,
- Cardio,
- Stretching/ Flexibility,
- Balance,
- Resistance Band,
- Walking/Movement,
- Miscellaneous,
- Home Exercise Program (Hep) (Usually developed by a Physical Therapist)
- Stamina

All these areas can incorporate exercises which meet the needs of our older individuals. Having similar exercises for those individuals that may not require an adaptive or modified exercise will help with continuity of programming that does not single out any one person. There is no reason that those individuals without modified exercise needs can do the same as their older housemates, it assists if there are feelings of fairness and possible preferential treatment for the older individuals.

Developing the Exercise Program, cont'd

As part of the development of the program there can be exceptions which may apply for individuals participating in structured programs such as:

- Day program where exercise activities are part of their day
- Sessions with a personal trainer,
- Exercise Classes at a gym/recreation center etc.
- Special Olympics

These activities may fulfill portions of their exercise requirement if you decide those can be counted as part of the exercise requirement for the day.

Concluding Thoughts and Suggestions

- Staff or Caregivers are responsible for supervising exercise activities to ensure exercises are completed safely and correctly.
- Staff or Caregivers should have a consistent means of documenting completed exercises which allows for shifts to communicate with each other who has started their exercise and how many minutes it has been completed in the AM and PM.
- The exercise program should have clear cut-off time frames of when exercise needs to be completed by, that way consistency can remain amongst Staff or Caregivers and the individuals know when they should have completed their exercise time.
- Use of creative scheduling which identifies a non-preferred activity in this case exercise to be finished by the time of a preferred activity, such as dinner.
- Meals should never be withheld if the individual does not want to complete the exercise.
- The exercise program may need recognition or reward to encourage participation on a regular basis for those individuals who are not intrinsically motivated. That may be something they can receive after completion daily, weekly or both.
- Competition can be motivating as long it is not against each other but rather against themselves or the threshold set, such as completing 60 min of exercise Monday – Saturday (Sunday being a free day) receive a sticker or Staff or Caregivers initials on a chart and at the end of the week they get a recognition for doing their exercise.
- It is key that Staff or Caregivers understand the program and the parameters of meeting the exercise goals, this allows for consistency and avoids unnecessary power struggles because of inconsistencies.

11
COMMUNITY ENGAGEMENT & MAKING LIFE MEANINGFUL

"The greatness of community is most accurately measured by the compassionate actions of its members."

-Loretta Scott King

Making life meaningful: what does it truly mean?

For each person you ask, they may answer this question differently. For the folks in our life with PWS, finding a community that is accepting and understanding of the unique needs can be challenging. That said, it is up to us as caregivers to find and/or create opportunities.

The following are important considerations:

- Working before or after mealtimes, but ideally not during
- Sensory stimulation, for example: loud noises or blinking lights
- Stamina and Excessive Daytime Sleepiness
- Medical Concerns
- Ability to access food, for example: a grocery store, or a day program that focuses on culinary

Different opportunities that we have found successful for the PWS Population:

- Day Programs
- Volunteering
- Paid Employment
- Arts and Crafts Fairs

Successful Vocational/Employment Opportunities of the past have been:

- Animal Rescue League
- Libraries
- Retail
- Office environments
- Theater and the Arts

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Success Stories from our Community

Creating our own Day Program
Latham Centers, 2025

When some of our residents were “kicked out” of previous day program placements. Whether asked to leave for food-stealing, disruptive behaviors, or medical complexities, a variety of individuals found themselves with a void in their lives and the staff at Latham Centers came together to create their own small day program

The Adult Day Program staff have provided a Monday-Friday rotation for these individuals with varying opportunities ranging from Drawing Class to Outside explorations, and Volunteering to Bingo. Individuals who otherwise felt they were falling through the cracks are now part of this program, engaging with one another and the larger community. Most importantly, they have the supports they need to feel successful and understood.



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URINARY ISSUES

Urgency to Urinate

Many adults with PWS have issues with urinary incontinence. Generally, people feel the need to urinate when the bladder is half full (about one cup) and has extreme urgency when the bladder is near full (about 2 cups). Individuals with PWS do not feel that initial “half full” urge to urinate, and by the time they do feel the need to go, the bladder is nearly full.

Here are some things you can do:

- Plan regular bathroom breaks
- The flow of a person with PWS is different as well, and he or she should be encouraged to wait several seconds before stepping away from the toilet. It may take up to 30 seconds for the flow of urine to start.
- Encourage the person in your life with PWS to take in fluids during the daytime and less so in the evening. Overnight incontinence is extremely common. Restricting fluids after dinner will help with this.
- Avoid shaming of any kind. This will only foster sneaking behavior around incontinence such as hiding wet underclothes and pants, unwanted behaviors due to embarrassment or guilt, etc.

Nighttime (and Daytime) Incontinence

Incontinence, whether during the day or night, may become more common and can be related to decreased muscle tone, constipation placing pressure on the bladder, medication side effects, cognitive or behavioral challenges, or delayed access to toileting support. Because many individuals with PWS may not independently initiate toileting, it is important for caregivers to establish structured toileting schedules, provide regular prompting, and ensure timely assistance. At the same time, maintaining adequate hydration and proactively managing constipation are key components of prevention.

UTIs in the Aging Population

Individuals with PWS may also have an increased risk of UTIs, particularly due to factors such as incomplete bladder emptying, poor perineal hygiene, prolonged use of briefs or pads without prompt changing, and low fluid intake. As individuals age, they may require more hands-on support with hygiene, and this becomes a critical area for caregivers to monitor closely. Proper front-to-back cleaning, assistance or supervision after toileting, routine changing of briefs or pads, and monitoring for skin breakdown are all essential practices. Without this level of support, the risk of infection increases significantly.

Recognizing UTIs in individuals with PWS can be challenging because of decreased pain sensitivity and a high pain tolerance, meaning classic symptoms like burning or pain with urination may not be reported. Instead, caregivers should watch for more subtle signs such as sudden behavioral changes, increased irritability, regression in continence, foul-smelling or cloudy urine, fatigue, decreased participation in activities, or new confusion. Fever may be mild or even absent, so changes in behavior or function should always prompt consideration of a possible medical cause, including infection.

Environmental supports and adaptive products can play an important role in maintaining urinary health and dignity. These may include absorbent briefs and booster pads (which may require a waiver or prior authorization for coverage), waterproof mattresses and bedding, bedside commodes or urinals for easier nighttime access, external catheter systems such as PureWick for appropriate individuals, and wearable moisture sensors that alert staff when wetness occurs. Ensuring that bathrooms are easily accessible, well-lit, and free of barriers can also help reduce accidents.

Additional prevention strategies include encouraging consistent fluid intake throughout the day, tracking urinary patterns, and coordinating with healthcare providers when UTIs are suspected or recurrent. Medication reviews may also be necessary to identify any contributors to urinary retention or incontinence. Caregivers should consult with a physician or healthcare provider whenever there are known or suspected changes in urinary patterns, new or worsening incontinence, signs of possible infection, or any unexplained change in behavior or function. Prompt medical evaluation is important to prevent complications and ensure appropriate treatment.



PureWick | Gienic

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When aging and urinary concerns get complicated

We advise that you consult with a specialist, or uro-gynecologist, for people having urinary incontinence as there are multiple ways to go about treating these issues in both males and females.

The order of increasing invasiveness is:

- Kegels/PT/bladder training
- Meds
- External tibial nerve stimulators
- Botox*
- implantable tibial nerve stimulator (Alta Viva)
- Sacral nerve stimulator implant (Interstim)*

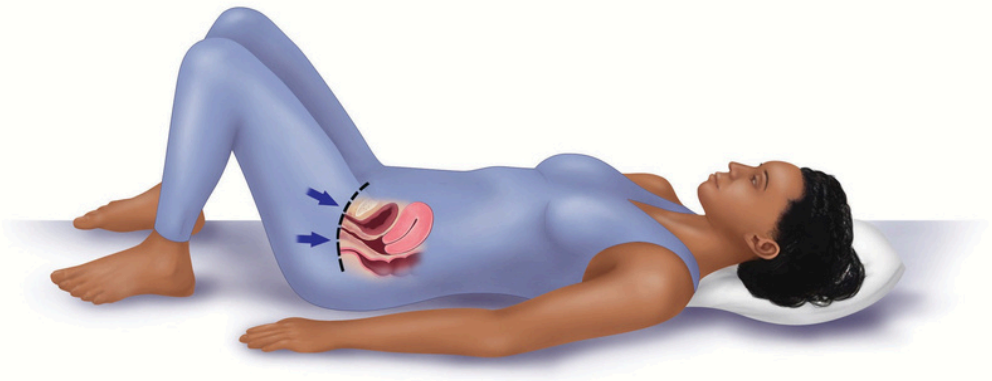
* these work the 'best,' and in our experience, better than meds and Kegels



Photo from PWSA | USA 2026 Residential Providers Conference

Pelvic Floor Muscle Exercises and Bladder Training

If you are experiencing urinary leakage, pelvic floor muscle exercises (Kegels) and bladder training are two things you can do to help control your urinary symptoms.



Pelvic Floor Muscle Exercises

Learning how to strengthen the pelvic floor muscles can help reduce or stop urine leakage. Pelvic floor muscle exercises (PFME) are most helpful for women with mild to moderate urine leakage. Women with severe urine leakage often need more than exercises to improve.

Like any other form of exercise, it is important to do PFME correctly and regularly. Unfortunately, because pelvic muscles are hidden from view, it is hard to know if you are doing them correctly. To be sure that you are working the right muscles:

- Imagine you are going to pass gas and squeeze the muscles that would prevent that gas from escaping from your rectum. Exercising the muscles around the rectum will also strengthen those around the vagina and under the bladder.
- Use a hand mirror to look at your vaginal opening and the perineum (the space between the vagina and rectum). You should see the perineum lift up when you contract your pelvic muscles.
- While lying or sitting, place one finger inside your vagina. Squeeze as if you were trying to stop urine from coming out. You should feel your finger lifted and squeezed if you are correctly contracting your pelvic muscles.
- No one should be able to tell you are doing PFME – if you are visibly moving, you are not using the right muscles.
- You should not be contracting the gluteus ("butt") or thigh muscles.

Keep your stomach and back muscles relaxed as you work those pelvic muscles. And, do not squeeze your legs together or hold your breath while doing the exercises. Try this routine:

1. Start by pulling in and holding a pelvic muscle squeeze for 3 seconds then relax for an equal amount of time (3 seconds).
2. Do this for 10 repetitions three times a day
3. Try to hold for 1 second longer each week until you are holding for a 10 second squeeze.
4. Remember to rest and breathe between contractions. Relaxing can be as important as squeezing.
5. At the beginning, do the exercises while lying down. As you get stronger; do the exercises while sitting or standing.

If you are not sure that you are doing the exercises correctly, ask your medical provider at a pelvic exam to check if your squeeze is working the right muscles. Or, ask for a referral to a physical therapist who specializes in pelvic floor muscle rehabilitation. The physical therapist will also check your back and abdominal strength, your gait and your posture. These all affect how your pelvic muscles work.

LEARN THE TERMS

Pelvic floor muscle exercises (Kegels): Exercises that strengthen the muscles of the pelvic floor. Regular daily exercising of the pelvic muscles can improve and even prevent urinary and bowel leakage.

Bladder training: Behavior therapy that helps you wait longer between bathroom trips, so that you go to the bathroom when it's convenient rather than when you feel that sudden urge to go.

Pelvic floor muscles: The bowl-shaped muscles in the pelvis that support the vagina, bladder, and rectum.

Urethra: Tube from the bladder to the outside of the body that urine passes through during urination.

Overactive bladder (OAB): Urinary urgency, usually with frequency and nocturia, and sometimes with urinary urgency incontinence. This occurs without an infection or other health problem.

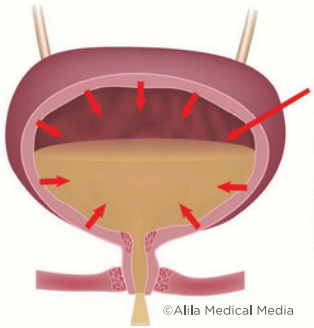
Constipation: Having a bowel movement fewer than three times a week, along with straining to produce a hard bowel movement.

Pelvic Floor Muscle Exercises and Bladder Training

About Bladder Training

Now that you've got the right muscles and good strength, it's time to put that muscle to work!

Normally, the bladder can hold urine for 2 to 4 hours—then you feel an urge and should be able to walk to the bathroom and urinate normally. Women with overactive bladder feel a sudden urge to urinate immediately, which is called urgency. This urgency may lead to urine leakage. Bladder training can help hold the urine longer and overcome that gotta-go sensation without medicines or surgery.



CONTRACTING BLADDER

The muscle that lines the bladder, called the detrusor muscle, squeezes down too often and too powerfully. This causes urine to come out at the wrong times. Common things that bring this on are hearing running water, putting your key in the door at home, or seeing the toilet.

Bladder training programs involve urinating on a schedule. Over time, you increase the time between bathroom trips. This helps to increase the amount of urine that your bladder can hold. The goal of bladder training is to feel less need to rush to the bathroom frequently. Here are the steps to better bladder control:

STEP 1: Talk with your provider about your bladder symptoms. Get checked for a bladder infection or other health issues that can cause these symptoms. Keep a bladder diary. Write down the time when you urinate, how much you urinated, as well as what and how much you drink. In addition, log every time you feel the need to go.

STEP 2: Review the diary with your provider and decide on the best approach to bladder training. Make a commitment to get your bladder in shape either on your own or with help. Research shows bladder training reduces frequency and urgency. But, just like other exercise programs, bladder training requires motivation. With practice, this will get easier. Ask about working with a physical therapist if you think that would help you.

STEP 3: Make a training schedule. Most women start by urinating every 30 to 60 minutes during the day—whether or not you feel the need to go. If you get the urge to go before the scheduled time, do not run to the bathroom. Try some of the following strategies:

- Practice your PFME squeeze as explained above. This helps to close off the urethra, preventing urine from leaking. Continue to squeeze until the need to go fades. Another option is to quickly squeeze and release the muscles, distracting the bladder from squeezing.
- Cross your legs or sit on a hard surface.
- Distract your mind. Count backwards from 100.
- Shift your position. You might found that leaning forward helps to settle your bladder.

STEP 4: After 1 to 2 weeks, if you are not having leaking accidents, increase the time between bathroom trips by 30 minutes. Stop making those "just in case" visits to the bathroom.

STEP 5: Be patient and stick with it. You may notice improvement within a couple of weeks. However, the bladder retraining period can take several months. Below are additional tips to help make your bladder training a success:

- Maintain a normal body weight. If you are overweight, losing a small amount of weight (even 10% of what you weigh) can help with bladder leakage. Extra weight can increase the urge to go.
- If you smoke, quit. Smoking can lead to lung problems, which make you cough often. Coughing can promote urinary leakage. Nicotine can also cause bladder spasms.
- Treat constipation. Constipation can make OAB and urine leakage worse.
- Learn about side effects of your medicines. Ask your provider if any of your prescribed or over-the counter medicines might be worsening the gotta-go feeling. If so, discuss alternate options.
- Drink when you are thirsty, but do not overdrink. Drink only enough so that your urine is a light yellow color. Spread your drinks across the day to help control your need to urinate.
- Stop drinking two hours before you go to bed. This will help to decrease your need to get up during the night to use the bathroom.

Stop or limit any drinks that irritate your bladder. This can include drinks with alcohol and caffeine, artificial sweeteners or diet drinks.

Three Takeaways

1. **By exercising your bladder and pelvic floor muscles, you can help control the urge to urinate.**
2. **Bladder training is effective for many women—stick with your schedule and give yourself time to relearn when to respond to the need to go. This can mean you avoid medicines and surgery.**
3. **When done correctly, pelvic floor muscle exercises can help reduce or stop urine leakage. If you are unsure about your technique, ask for a referral to a pelvic floor physical therapist.**

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RESPIRATORY HEALTH

Respiratory health requires careful monitoring as individuals with PWS age. People with PWS may be at increased risk for respiratory complications due to a combination of hypotonia, weak respiratory muscles, abnormal ventilatory control, scoliosis, obesity, and reduced physiological response to low oxygen or elevated carbon dioxide levels.

These vulnerabilities may make respiratory illnesses more severe and recovery more prolonged compared with the general population. As individuals age, additional factors such as reduced mobility, chronic health conditions, and medication effects may further increase respiratory risk.

Hypoventilation and Associated Health Risks

Hypoventilation occurs when breathing is too shallow or slow to effectively remove carbon dioxide from the body. Individuals with PWS may have impaired ventilatory control and diminished physiologic response to high carbon dioxide and low oxygen levels.

Untreated hypoventilation can contribute to:

- Chronic low oxygen levels
- Elevated carbon dioxide levels
- Pulmonary hypertension
- Right-sided heart strain
- Systemic hypertension
- Headaches and fatigue
- Cognitive or behavioral changes
- Increased cardiovascular risk

These risks may worsen during respiratory infections, sedation, or medication changes.

For some individuals, non-invasive ventilation such as CPAP or BiPAP may be required to support safe breathing during sleep.

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Infection Control and Respiratory Illness Prevention in Residential Settings

Respiratory infections can spread quickly in residential environments. Individuals with PWS may be particularly vulnerable to complications from respiratory illnesses due to underlying breathing abnormalities, aspiration risk, and reduced physiologic responses to illness.

Residential programs should implement infection prevention measures that protect residents while supporting continuity of care.

Staff experiencing symptoms of an upper respiratory infection (URI) such as cough, sore throat, fever, nasal congestion, or other respiratory symptoms should follow organizational illness policies. When staff must remain on duty while recovering from mild symptoms, appropriate infection control precautions should be used.

These may include:

- Wearing a medical mask while providing direct care
- Practicing strict hand hygiene before and after resident contact
- Avoiding close contact with residents during coughing episodes
- Limiting exposure during meals or medication administration when possible
- Using additional personal protective equipment (PPE) when appropriate

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Sleep-Disordered Breathing and the Importance of Sleep Studies

Sleep-related breathing disorders are very common in individuals with PWS.

These may include:

- Obstructive sleep apnea (OSA)
- Central sleep apnea
- Sleep hypoxemia
- Sleep hypoventilation

Because individuals with PWS may not reliably report symptoms, caregivers and staff must actively observe for changes and advocate for evaluation when concerns arise.

Sleep studies should be considered when there is:

- Loud or persistent snoring
- Pauses in breathing during sleep
- Morning headaches
- Excessive daytime sleepiness
- Behavioral changes or irritability
- Decline in concentration or functioning
- Unexplained fatigue
- New or worsening hypertension
- Weight changes or scoliosis progression

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TEMPERATURE INSTABILITY

The Why

The area of our brain which regulates temperature is the hypothalamus. As has been documented, studied, and proven, the person with PWS's hypothalamus works differently, and therefore their temperature regulation is affected. Additionally, you may notice that the person with PWS may not express to you that they are very hot or very cold. As providers, there are things that we can do to protect our family and/or clients as they age.

Hypothermia:
Prevention and Appropriate Steps to Take

The following is borrowed from "Hypothermia and Prader-Willi Syndrome - An Overview," by B Dorn, RN, BSN (https://www.pwsausa.org/wp-content/uploads/2022/11/Hypothermia-and-Prader-Willi-Syndrome-%E2%80%93-An-Overview.pdf)

Many children and adults with PWS may have factors that make them more susceptible to hypothermia.
There are some steps that parents and caregivers can take to prevent and monitor for this condition.

- Know the person with PWS' baseline temperature.
- Check the person's temperature daily for 2-4 weeks to determine his/her average temperature. In many cases it will be below 98.6 F – the average temperature.
- When the outside temperature is low - make sure the person with PWS wears appropriate clothing and/or keep the person with PWS indoors or minimize time outdoors.
- **Keep the thermostat in the home at a reasonably warmer temperature. As the person with PWS ages, this temperature may need to be higher.**
- **Don't let the person sleep in a cold room – this is especially true for infants and older adults with PWS. Apply extra blankets, flannel sheets as needed for sleeping. Dress in warm pajamas and/or blanket sleepers.**

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What to do if Severe Hypothermia is Suspected:

If you suspect that a child or adult with PWS has severe hypothermia, immediately WARM the person with blankets. If wearing wet clothes, remove and dress in warm clothing. Take to the nearest Emergency Department for evaluation. All cases must be investigated to rule out illness, brain tumor or other brain abnormality and/or medication reaction. In most cases, there is no specific treatment unless an illness, brain abnormality or medication have been found to be the cause.

What about heat and the person with PWS?

Based on the same evidence as above, there are preventions that we can take to reduce the likelihood of heat exhaustion in our friends with PWS, and additionally noticeable symptoms of which we can be aware.

Anne Fricke says, “Heat exhaustion is serious and often presents with heavy sweating, rapid pulse, dizziness, fatigue, cool and moist skin with goosebumps, muscle cramps, nausea, and headache. These symptoms might be less apparent in those with PWS, so watch for red cheeks, exhaustion, and fatigue. Rapidly cool an overheated person by moving them to a cool area, removing most clothing, and using wet towels on key areas like the neck, underarms, and groin. Ensure they sip the coldest beverage available for maximum hydration. Heat stroke is an emergency, marked by stopped sweating and possible confusion or collapse—call 911 immediately and continue all cooling efforts. Stay vigilant and keep your loved ones safe in the heat” (https://www.pwsausa.org/staying-safe-in-the-heat/).

Fricke also suggests several ways to keep your loved ones safe in the heat:

- Plan activities for early morning OR evening when it’s cooler
- Use hats, umbrellas, and portable fans
- Always wear sunscreen (and watch for burns)!
- Keep frozen water bottles handy
- Encourage your loved one to stay hydrated
- Let the car cool before getting to the driveway or parking lot
- Wear light, loose-fitting clothing
- Take frequent breaks
- Find cool places to rest
- Use cooling vests, towels, and gel pads

LathamCenters

Individual:

Location:

DOB:

Latham Centers Hypothermia Protocol

Diagnosis: Hypothermia is a medical emergency that occurs when your body loses heat faster than it can produce it, causing a dangerously low body temperature. Secondary to PWS diagnosis, this individual experiences hypothalamic dysregulation that can lead to temperature dysregulation, especially in times of stress such as during an infection. The normal body temperature is around 98.6°F. Hypothermia occurs as your body temperature falls below 95°F. To obtain this individual's core temperature, the temperature must be taken rectally. This individual's baseline rectal temperature is usually around 94°F.

Signs and Symptoms of Hypothermia: Shivering is often the first sign, but importantly, as hypothermia worsens, shivering stops and you will begin to see worsening symptoms such as difficulties with coordination, slurred speech, significant confusion, drowsiness, apathy or lack of concern, weak pulse, shallow, and slow breathing.

Routine / Standing Medication Orders and Treatments:

Rectal Temperatures ONLY. Rectal temperatures are considered the most accurate form of taking body temperature. This individual has their rectal temperature taken daily in the morning. Rectal temperature should also be taken for the following reasons:

- If individual is showing signs of hypothermia including delayed cognition or processing, slurred speech, mottling (presents as a red or purple marbled appearance), says they are cold, starts shaking or shivering, or any other change in presentation that seems concerning or not normal for them.
- If core temperature is below 94° F. report to on-call immediately and begin Warming Protocol. Staff will receive next steps from on-call nursing depending on the temperature and symptoms reported.
- See Next Page for Step-by-Step instructions for taking rectal temperatures.

If the temperature is < 92° F and she is displaying symptoms of hypothermia, then initiate EMS.

Warming Protocol:

- Individual should be seated in her bed or recliner.
- Restore warmth gradually by adding heated blanket , close doors/windows, start the heater in room, and give warm fluids (6oz at a time of hot tea, up to 2 cups), apply winter hat, socks and gloves, they can also wear their heated vest- Monitor for improvement or worsening symptoms.
- Please take a heart rate, pulse oximetry, and blood pressure. Call On-Call Manager with vital signs and to report the initiation of Warming Protocol if not done so already.
- Re-check her temperature 30 minutes later and until the goal temp of ≥ 94° F.
- Report repeat temperature to On-Call Manager/Nursing to review each time.
- If temperature does not improve/symptoms continue, call 911 within an hour. If temp slowly continues to rise and they are not symptomatic, continue protocol.
- **If after 1 hour, there is no improvement with use of protocol, 911 should be initiated.**

Core temperature should return to 94° F or above. If the temperature is restored, nursing will follow up with a skin check and full assessment, then contact doctors as needed (such as to determine if there is a source of infection).

Remind individual to wear warm clothing, hats, gloves, coats, and heated vest, particularly during winter and while outdoors. During the warmer months individual should wear pants and a long-sleeved shirt.

Doctor Signature : _____ Date : _____

How to Take a Rectal Temperature:



Supplies Needed: All are located in the top drawer of dresser in her bedroom.

1. Flexible tipped digital thermometer
2. Thermometer cover
3. Lubrication
4. Gloves

Instructions:

1. Wash hands. Wear medical gloves for this procedure.
2. Position the individual on their side with the hip flexed. If unable to get in choice position, often times prefers to lean over bed.
3. With permission from individual, pull down their pants and underwear exposing buttocks.
4. Place disposable cover over probe and lubricate it, press the “on” button.
5. Use one hand to gently separate the buttocks and insert the thermometer approximately 1 inch into the rectum. Do not force the thermometer in and stop if you meet resistance.
6. Wait until the thermometer beeps to remove it (usually no more than one minute).
7. Obtain the reading and assist with pants and positioning so that they are comfortable.
8. Document the temperature on treatment sheet. See full Hypothermic protocol for temperature readings under 94° F and subsequent interventions.
9. Discard disposable cover and gloves in the trash. Wash the thermometer with an alcohol wipe.
10. Wash hands.

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DENTAL HEALTH

Complications during the Aging Process

Because of lifelong dental challenges, aging adults with PWS are now facing many dental issues and financial challenges. Because we know more today about dental issues facing people with PWS, many more persons are getting preventive dental care and doing more to maintain oral health. Some adults have experienced the loss of tooth enamel, as well as severe teeth grinding, resulting in deterioration and loss of teeth as they age. Others have problems resulting in the need for root canals, tooth extractions and ultimately dentures. These services can be extra challenging because most state Medicaid programs may not cover these services and they are very expensive. Medicaid services are determined by both federal and state regulations. Certain services are considered mandatory, and every state must provide them to qualify enrollees.

Dental care for adults is not considered mandatory, so states provide dental services as an optional benefit. Some states only provide emergency dental care services, such as extractions when an infection is present. Others may cover partial or complete dentures if it is determined a medical necessity for a patient. While each state may define “medically necessary” differently, it may mean that a patient must show a significant loss of teeth or bite alignment. There may only be coverage of dentures made of certain materials. Your dental care professional can help you determine what options are available to you so you can get coverage with your Medicaid provider. (See section on Finding a Dental Professional later in this article for suggestions on locating dental services.)

Dentures

There are different types of dentures dependent upon the extent that teeth need replacing.

• **Partial Denture** is usually removable, artificial teeth that replace multiple teeth in the upper or lower portion of the mouth. They can enhance chewing and help with speech. You need to have teeth remaining to attach the partial dentures to. Some are removable and typically attached with a clasp. They can be made of plastic, polymers, or metal.

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Dentures, cont'd

• **Complete Denture (**also known as a full denture, false teeth, or plate) is a removable appliance used when all teeth within a jaw have been lost and need to be prosthetically replaced. A complete denture is constructed when there are no more teeth left in an arch.
• **Permanent Denture** (also referred to as a full denture supported by dental implants) are replacement teeth that are attached to dental implants to provide a solid foundation for permanent replacement of teeth. Dental implants (posts) are surgically implanted into the jaw, and they are used to anchor the teeth in place. They are designed to not be removable or only removed by a dentist, when needed.

Finding Dental Professionals

• Many persons with PWS benefit greatly from having dental insurance coverage. Many families are able to provide dental insurance for the person with PWS. • Finding dental professionals who accept Medicaid or other financial assistance can be very challenging, and reimbursement for dental services in these programs is often inadequate. Contact your state dental association for a list of providers.
• Some dental care providers have opted to donate their services in lieu of utilizing financial assistance. Contact your state dental association to see if they have a Donated Dental Services Program in your state.
• Community health clinics often have free or reduced-fee dental clinics. Special Olympics in some areas provide dental services. Watch for regional FREE dental clinics.
• Consider utilizing a dental school for care.
• For persons on Medicare and Medicaid, check to see if a Medicare Advantage program is available in your state or area. Many plans offer additional dental services.
• Many dental professionals will work with patients to set up a payment plan. Determine your budget and see if this is feasible and possible.

Good dental health is important for everyone. It helps with communication, eating and improves the quality of life for persons with PWS. Research has also documented the importance of good oral health in maintaining and improving your mental health, preventing cardiac complications, and helping with your overall health in general.

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SODIUM AND THE BODY OF THE PERSON WITH PWS

Low Sodium? Why it matters so much in our population.

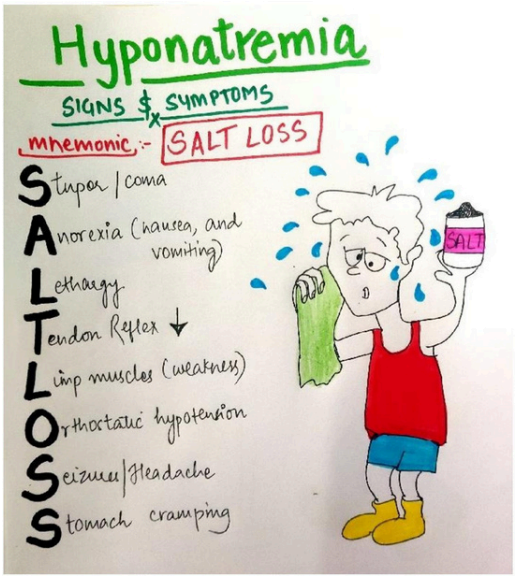
Low sodium levels may happen more often in people with PWS than in the general population. This can happen for a variety of reasons because of the unique hypothalamic, endocrine, medication and behavioral factors seen in PWS.

Typical daily fluid intake is one-two liters per day. The goal is not to restrict healthy hydration but to ensure safe consistent fluid intake. The normal lab value for sodium is typically 135-145mEq/L. Many physicians will order a blood test called a Basal Metabolic Panel (BMP) which includes a sodium level.

Common causes of low sodium:

- Excessive fluid intake
  - Drinking from sinks, toilets, filling up water bottles excessively
- Medication side effects
  - Some SSRI's (Sertraline, Fluoxetine, Paroxetine, Citalopram, Escitalopram)
  - Some antipsychotics (Risperidone, Olanzapine)
  - Some anticonvulsants (Carbamazepine, oxcarbazepine)

"The condition of having an abnormally low level of sodium in the blood that is typically marked by nausea, vomiting, headache, confusion, fatigue, and muscle cramps and that when severe may be life-threatening if untreated."
-Mirriam-Webster

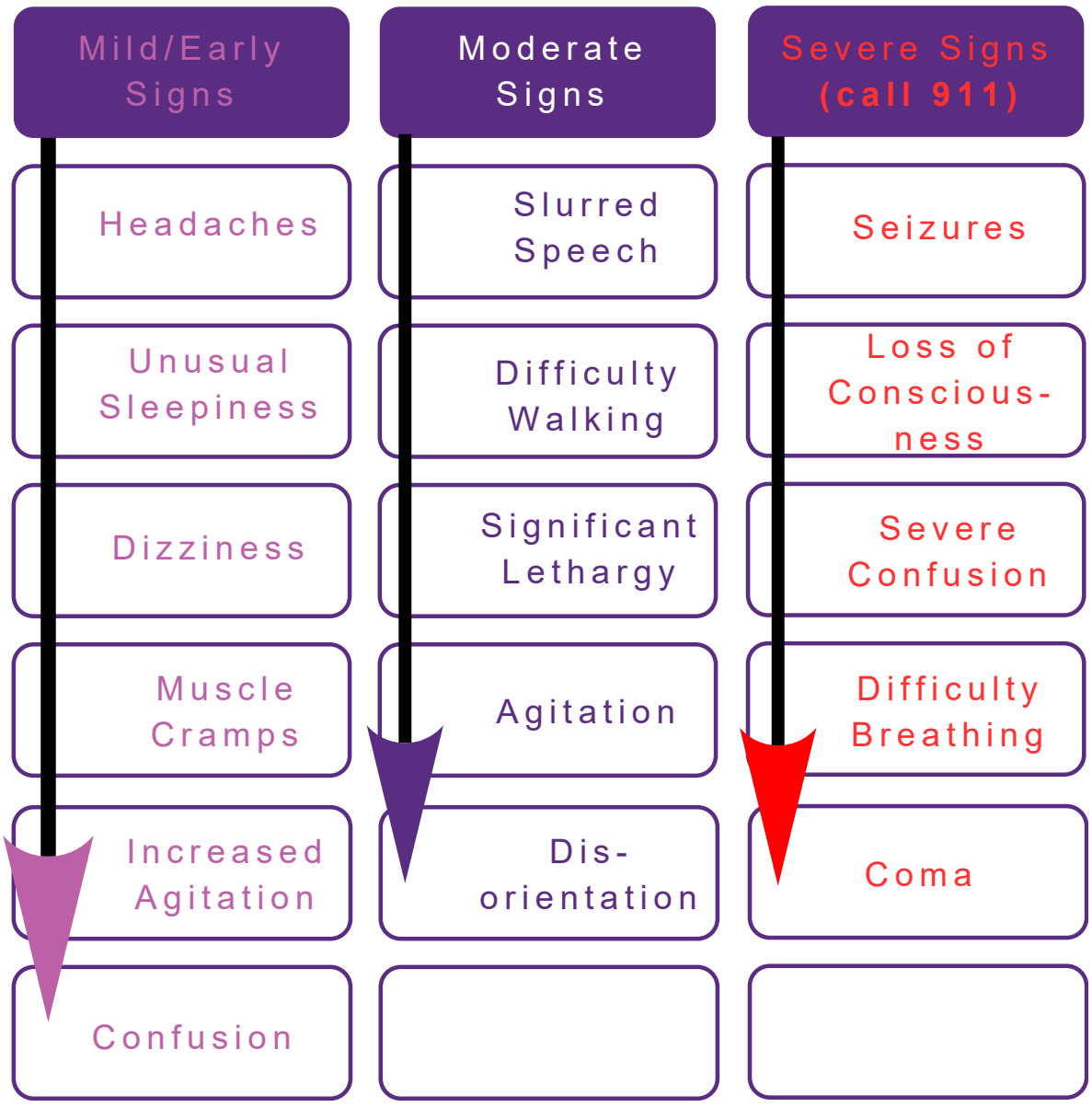


Hyponatremia Symptoms Mnemonic - SALT LOSS

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SIGNS OF HYPONATREMIA

This Chart outlines the signs of hyponatremia, ranging from mild/early to severe. Follow the arrow down the column to determine the immediacy of the signs that you see with your clients.



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SKIN HEALTH

Common Skin Issues

People aging with PWS often experience a range of skin-related concerns that can affect their health, comfort, and quality of life. Skin issues may arise from repetitive behaviors such as skin picking, reduced pain sensitivity, obesity-related skin changes, and underlying hormonal or metabolic differences associated with the condition.

These concerns can increase the risk of infections, delayed wound healing, and chronic skin damage if not recognized and managed early. Understanding the unique dermatologic challenges associated with PWS is an important part of providing comprehensive care and supporting overall well-being.

Common Skin Issues include:

- Edema and lymphedema
- Skin infections (cellulitis)
- Skin picking and rectal picking
- Bruising
- Decreased mobility and pressure sores/ skin tears
- Topical yeast infections
- Peri-care
- Weekly documented (more frequently if needed) skin assessments
    - upload pictures if possible into EMR (electronic medical record), if not describe and measure
- Dermatology visits yearly for skin cancer screening
- If decreased mobility consider PT eval for proper size wheelchair/walker-
- Pressure mapping for wheelchair cushions
- Evaluation for specialty mattress and or hospital bed which insurance will cover

An Aging Checklist for the Residential Setting

As people with PWS age in a residential setting, the caregiver takes on a unique role. The following checklist serves as a helpful guide and covers a wide array of topics, many of which are included in this booklet.

PWS Aging Signs Checklist for Residential Care Providers

Monthly / Quarterly Observation Tool

Cognitive & Mental Health Changes			
Increased confusion or forgetfulness		Neuropsych eval	
Decline in problem-solving or planning		Track cognitive tasks	
Changes in language or word finding		Speech therapy referral	
New or worsening anxiety or fears		Psychiatry consult	
Withdrawal from preferred activities		Behavioral health	
New or worsening OCD behaviors		Medication/CBT review	
Mobility & Physical Function			
Decrease in walking speed or endurance		PT referral	
Increased falls or unsteadiness		Fall risk assessment	
Loss of muscle tone/strength		Review GH, PT plan	
Difficulty with stairs, rising from chairs		Functional mobility plan	
Worsening scoliosis/postural changes		Ortho review	
Cardiovascular and Metabolic Health			
Fatigue or shortness of breath		Cardiology workup	
Swelling in legs or ankles		Check cardiac/kidney	
New/worsening hypertension		Medication review	
Changes in cholesterol/glucose		Lab monitoring	
Unexplained weight loss		Nutritionist referral	
Bone Health & Endocrine Signs			
Frequent fractures or bone pain		DEXA scan	
Shortened height/spine changes		Endocrine consult	
Loss of GH therapy benefits		GH dosing review	
Signs of menopause/andropause		Hormone panel	
GI slowdown or constipation		GI consult/diet review	
Sleep & Breathing			
Increased daytime sleepiness		Sleep study	
Snoring or apnea symptoms		BiPAP/CPAP review	
Resistance to sleep equipment		Re-education/device check	
Frequent waking during the night		Sleep hygiene adjustment	
Morning grogginess		Adjust sleep schedule	
Sensory & Neurological Health			
Vision changes		Eye exam	
Hearing issues		Audiology referral	
New tremors/coordination issues		Neuro consult	
Headaches, dizziness, seizures		Urgent medical eval	
Social, Emotional, and Behavioral			
Reduced social interaction		Increase engagement	
More rigid/resistant to change		Behavioral support	
Regression in self-care		OT reassessment	
Increased emotional outbursts		Medication/therapy review	
Paranoia or psychosis symptoms		Urgent psych referral	

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An excerpt from

Adults with Prader-Willi syndrome:
Medical care: Overview
Medical care: Evaluation

To read the entire article, click here!

In 2018, the Clinical and Scientific Advisory Board published a detailed article covering medical care for adults with Prader-Willi syndrome.

The below listed examinations are recommended during the medical visits. IPWSO recognizes that access to health services and to specialists may vary considerably. This document summarizes the main health needs that are recommended in the context of available resources.

Careful medical history, with emphasis on the following:

- *Medications and doses - assess for medications no longer necessary and drug interactions.*
- *Weight - assess for recent changes and comparison to the last examination.*
- *Food environment - access to food at home, at work and in between. Extent of supervision. Dietary interventions.*
- *Physical activity/exercise - routine hours per week.*
- *Respiratory difficulties - shortness of breath with activity.*
- *Sleep abnormalities - snoring, signs of apnea, insomnia, daytime drowsiness.*
- *Gastroenterological problems - reflux, toilet habits, constipation and its treatment, rectal picking (common and potentially resulting in fistulas or infection in PWS).*
- *Bed-wetting - and possible sign of a urinary tract infection.*
- *Sexuality, relationships and education - menstrual cycles, contraception in both sexes.*
- *Skin picking - can cause infections.*
- *Mental/emotional/psychological states.*
    - *Behavioral problems - e.g., severe temper tantrums.*
    - *Unusual habits - e.g., perseveration, repetitive behavior, autistic features.*
    - *Psychiatric symptoms – psychosis, mood disorder, severe behavior changes.*

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To read the entire article, click here!

Careful medical history, with emphasis on the following.
Cont'd...

- *Living situation - e.g., living at home, with other intellectually delayed individuals, or in a special center? Assess the patient's social and financial situation and the knowledge of the caregivers about PWS.*
- *Work situation/day program - Is there educational input and satisfying activity?*

- ***General relevant body examination, including:***
  - *Height, weight, and body mass index (BMI, kg/m2).*
  - *Vital signs - evaluate for hypertension or possible medication induced arrhythmias.*
  - *Dental - inspection of teeth for signs of reflux, teeth grinding, severe decay.*
  - *Heart auscultation - evaluate for cardiac insufficiency, cor pulmonale.*
  - *Lung auscultation - irregular ventilation/atelectasis?*
  - *Abdominal exam - evidence of constipation?*
  - *Back and joint inspection - scoliosis, kyphosis, joint abnormalities?*
  - *Leg edema? Ulcers?*
  - *Feet and foot position - special shoes needed?*
  - *Skin examination - signs of skin picking, sores, infections?*
  - *Genitals in men for cryptorchidism (if present, refer for surgical evaluation)*

Blood tests (yearly or every two years): Recommend as fasting blood test at 8am, for lipids, glucose and diurnally active Testosterone

- *TSH, free T3, free T4 (i.e., thyroid function tests).*
- *Hemoglobin A1c or fasting blood glucose.*
- *Vitamin D (25-DH), calcium, phosphorous.*
- *Hemoglobin and blood cell count.*
- *Na+, K+, creatinine (hyponatremia may suggest excess fluid intake or side effects of medications).*
- *Blood lipids, cholesterol, liver enzymes.*
- *Men: testosterone, LH; Women: estradiol, FSH (if not given sex hormone treatment).*
- *IGF-1: for those treated with growth hormone, confirming dose and compliance.*

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To read the entire article, click here!

Cont'd...

OTHER recommended examinations:

- *Ophthalmology examination every 2 - 3 years.*
- *Dental examination and hygiene twice a year or more often if needed.*
- *Hearing evaluation in those with poor speech and those over 50 years. If possible, the following is also recommended:*
- *Evaluation by an endocrinologist to assess pituitary/hypothalamic function and risk for diabetes.*
- *Evaluation by a medical geneticist to ensure the correct genetic testing has been accomplished and for genetic counseling for future recurrence risks for the family.*
- *Dietician (or equal) every 6 months, assuring knowledge of PWS requirements.*
- *Physiotherapy assessment of joints, muscles and recommendations for motor activities.*
- *DEXA (for bone mineral density and body composition) every 3 years.*
- *Sleep studies to evaluate central or obstructive sleep apnea or narcolepsy, if indicated.*



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CONTACTS THAT ARE IMPORTANT FOR ALL RESIDENTIAL PROVIDERS TO HAVE ON DECK

Based on where you live and your surrounding supports, the journey looks different for everyone. The below is our recommendation for who to call and when, AKA:

WHO TO CALL - Staff Flow Guide

Is this a LIFE-THREATENING emergency (choking, unresponsive, severe injury)?
→ IF YES: Call 911
- Next, notify On-Call Supervisor and Family/Guardian
- Also, bring or reference PWS Medical Alerts

Is this a MEDICAL concern (non-emergency)?
→ IF YES: Call Nurse, PCP, or Specialist
- If unsure: Call PWSA | USA for guidance
- Notify Supervisor

Is this a BEHAVIORAL or CRISIS situation?
→ IF YES:
- Follow Behavior Support Plan
- Call On-Call Supervisor
- Contact PWSA | USA Crisis Line
- Consider Mobile Crisis if needed

Is this a SUPPORT or GUIDANCE question?
→ IF YES, you have a variety of options:
- Call PWSA | USA (Family Support or Crisis Line)
- Behavior Specialist / BCBA
- Supervisor
- Family (if appropriate)

Always document and follow up. When in doubt, Call PWSA | USA: (941) 312-0400

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Residential Contact Checklist

PWS-Specific Contacts
□ PWSA | USA Crisis Line
□ State/Regional PWSA Chapter
□ PWS Specialist / Consultant

Medical Contacts
□ Primary Care Physician
□ Endocrinologist
□ Psychiatrist / Behavioral Health
□ Other Specialists
□ Pharmacy
□ Preferred Hospital

Emergency Contacts
□ 911
□ Local ER
□ Mobile Crisis Team
□ Poison Control
□ Local Police (non-emergency)

Family / Guardian
□ Parent/Guardian
□ Emergency backup contact
□ Legal guardian

Program / Agency
□ Program Director
□ On-Call Supervisor
□ Case Manager
□ Nurse
□ Behavior Specialist

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Residential Contact Checklist, cont'd

Behavior & Crisis Supports
□ Behavior Support Plan
□ Crisis Plan
□ Behavior Consultant

Day Program / Employment
□ Day Program Contact
□ Employer / Job Coach
□ Transportation Provider

Community Supports
□ Safe people
□ Peer mentor
□ Faith/community contact

ALL CONTRIBUTORS

Dr. Patrice Carroll	Latham Centers
Lynn Garrick	PWSA | USA, AME Homes
BJ Goff	PWS Education Specialist
Kendra King-Blischke	Latham Centers
Katrina Kozak	Latham Centers
Darren Redmond	Latham Centers
Marguerite Rupnow	PWSA | USA, Prader-Willi Homes
Stacy Ward	PWSA | USA

A FINAL NOTE FROM A RESIDENTIAL MANAGER

Balancing Individual human Rights with Lifelong health and Well-Being in Prader-Willi Syndrome: a best practice approach for Residential Homes

Adults with PWS possess the same fundamental human rights as other adults, including the right to express preferences, participate in decisions, and say no. A diagnosis of PWS does not eliminate those rights. At the same time, PWS creates unique challenges involving hyperphagia, food seeking, metabolism, behavioral regulation, and physical activity. Residential providers therefore have an obligation to respect autonomy while also maintaining a duty of care regarding foreseeable health and safety risks.

The goal should not be to choose between autonomy and protection. The goal should be supported autonomy.

In practice, this means creating an environment in which the individual has meaningful choices within a predictable and clinically appropriate structure. Rather than simply telling someone, “You must exercise,” staff can provide choices such as walking, swimming, basketball, dancing, or another preferred activity. Instead of framing nutrition entirely around restriction, individuals can participate in appropriate choices involving meals, healthy foods, activities, and personal goals.

Importantly, the right to say no does not mean that staff stop supporting the person toward healthier choices. A refusal should be respected according to the individual’s rights, capacity, clinical plan, and applicable regulations. Staff should continue to educate, encourage, motivate, offer alternatives, and revisit opportunities without allowing support to become coercion or a power struggle.

This balance is supported in peer reviewed research. Hawkins, Redley, and Holland examined the tension between duty of care and autonomy in a specialized PWS residential setting. Their research found that support staff continually balanced two legitimate responsibilities: protecting individuals from risks associated with PWS while recognizing autonomy and promoting independence.

The most effective residential environment is therefore neither one of control nor one of complete disengagement. It is an environment of structure, consistency, education, meaningful choice, encouragement, and respect.

Our responsibility is to create an environment where people with PWS are respected as adults, offered meaningful choices, encouraged toward healthy decisions, protected from serious foreseeable risks, and supported in building the healthiest, most independent, and most fulfilling life possible.

Darren Redmond, M.Ed.

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