

A Full Life Without Limits

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Prader-Willi California
Foundation is a proud
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Our Mission

Individuals with PWS should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with PWS depends greatly upon the knowledge and support of the community around them. PWCF provides individuals with PWS, their families, and professionals with a state network of information, advocacy and support services.

Parent Name
Address
City, State Zip
Email

Dear Parent | Family Care Provider:

This letter contains critical information to help you advocate for the health and safety of your loved one with PWS.

There are new rules and regulations that significantly affect group homes, supported living providers, day programs, vocational work sites, and any provider that receives Federal funding, most often paid via the Regional Center system. These new rules are outlined in the Centers for Medicare and Medicaid Services' Home and Community-Based Services (HCBS) Rules and Regulations.

HCBS' new Rules and Regulations place enormous emphasis on meeting the wants, wishes and dreams of the disabled individual as they are expressed at the Individual Program Plan (IPP) meeting. The name of the process for gathering this information is called Person-Centered Planning (PCP). The individual's wants, wishes and dreams are to be incorporated into the IPP document, and the IPP Team's job is to design a program that meets those expressed wants, wishes and dreams.

The IPP is a legal document; whatever is written in the IPP must be implemented and whatever is *not* written in the IPP may *not* be implemented. Now more than ever before, the IPP must be written with extreme attention to detail and foresight.

HCBS's new Person-Centered Planning process directs and guides the writing of the IPP and has extraordinary power that affects the health and safety of your loved one. Arguably the most significant provision is that "**individuals have freedom and support to control their schedules and activities and have access to food any time.**"

As you know, this provision is life-threatening to persons with PWS. We now know that even just one overeating episode can lead to death from choking, stomach or bowel rupture, or stomach or bowel necrosis. Therefore, **persons with PWS cannot have free access to food** and in fact **need an environment where food is securely restricted with locks.**

PWCF's HCBS Task Force has been working closely with the Centers for Medicare and Medicaid Services (CMS), Community Care Licensing (CCL), the Department of Developmental Services (DDS), and various PWS specialists to develop new tools to help families and providers advocate for a safe environment for your adult in their out-of-home placement, work or day program, recreational settings, and *all* community settings.

The key to this safety is having adequate "proof" or documentation written into the PCP/IPP. Without this documentation, providers may have no legal choice but to allow your loved one to have unfettered access to food whenever they request it. If your loved one receives *any* service from the Regional Center or *any* federal funding from *any* source, those providers are bound by the HCBS Rules and Regulations and may *have* to allow your loved one access to food upon demand *unless* the PCP/IPP prohibits it, or they risk losing their Federal funding.

To help families and providers obtain necessary documentation, PWCF's HCBS Task Force has developed new tools and reminds families to utilize existing tools:

- 1) **PCP/IPP Template Cheat Sheet - New**
- 2) **Physician's Note Template - New**
- 3) **Individual Agreement Regarding Food and Locks - New**
- 4) **Individual Agreement Regarding Elopement and Locks - New**
- 5) **Obtain a Limited Conservatorship**
- 6) **Obtain a Special Needs Trust and Will**

PCP/IPP Cheat Sheet Template

Now more than ever before, creating a detailed and appropriate Individual Program Plan is critically important. Every service and aspect of care your loved one receives from any entity that is funded in any way by the Regional Center system and/or Medicare and/or Medi-Cal must comply with the new HCBS Rules and Regulations. Every aspect and detail of the delivery of that service must be clearly written in the PCP/IPP. If it's not included or described in the IPP, service providers can't/won't do it. PWCF has created a new template PCP/IPP Cheat Sheet to help you know what to include in your loved one's PCP/IPP. We have also created new tools that you can add to your PCP/IPP, including a Physician's Note template and Individual Agreements for locking food and securing door and window exits.

Physician's Note Template

The Physician's Note template is a new and critically important tool developed to meet some of the new documentation requirements. The Physician's Note is to be **completed by you and one of your loved one's physicians**. At your next Regional Center IPP meeting, discuss the Physician's Note and **have it entered in the PCP/IPP**. The signed Physician's Note should be **shared with every service provider including the residential provider, day program provider, vocational work site provider, recreational program provider, and volunteer site administrator** to help them better understand each symptom your loved one experiences and the necessary treatment or management strategies. The Physician's Note is available in written form and a PDF format for easy emailing.

Individual Agreement Regarding Food and Locks

Another new tool developed to help you meet health and safety documentation requirements is the Individual Agreement Regarding Food and Locks. This new tool is an "agreement" with the individual with PWS that he or she may not have access to unauthorized food, even and especially when expressing emotional upset, and is to be incorporated into the PCP/IPP and distributed to all professional providers. This Agreement document is recommended because new Federal and State regulations lean heavily toward meeting the expressed wants and wishes of the disabled individual who, in the case of PWS will likely at some point request food outside their snack and meal schedule. This Agreement is not a legally binding contract but does serve as additional documentation to help professional providers *not* give food to your loved one if your loved one requests or demands it.

Individual Agreement Regarding Elopement and Locks

If your loved one has a history of eloping or running away, this new Agreement can help ensure their health and safety. Like the Agreement Regarding Food, this new tool serves as documentation that your loved one authorizes the doors and windows are locked to prevent them from eloping. The Agreement Regarding Elopement and Locks should be incorporated into the PCP/IPP and distributed to all professional providers.

Limited Conservatorship

In the eyes of the law a person who is 18 years or older is deemed an adult capable of handling their own affairs and making all of their own decisions. There is no legal protection of an adult who has PWS or *any* developmental disability unless there is some legal arrangement in place. In California, this legal arrangement is called a Limited Conservatorship.

Once your loved one with PWS turns 18 you as their parent or care provider have no legal rights if you don't have Limited Conservatorship. If your loved one runs away or chooses to live somewhere dangerous, you have no legal right to keep him or her safe. If your loved one is hospitalized you have no legal right to direct medical care or even receive information from the doctors. If your loved one enters into a contract or charges money on a credit card, they are legally obligated to pay the debt or incur legal consequences. If your loved one steals food or other items from a store, you have no legal input to their defense. **Limited Conservatorship gives you the legal authority to help your loved one make important life decisions and ensure their health and safety.**

A family member usually serves as the person responsible for ensuring the care of the individual with the disability; this person is called the Conservator. Anyone, however, including a professional agency, can serve as a Conservator.

There are seven powers that a Conservator can hold to assist and support the disabled individual: 1) determine where the individual lives; 2) have access to confidential records and papers; 3) consent to marriage or enter into a registered domestic relationship; 4) participate in a contract; 5) give or withhold medical consent; 6) control over social and sexual contacts and relationships; and 7) make decisions concerning education.

The proposed Conservator will speak to a judge to request the powers they believe are appropriate for your loved one. Your Regional Center Case Coordinator can help you start the process of Limited Conservatorship.

Will and Special Needs Trust

A Will allows you to direct the distribution of your property and leave assets to your children, grandchildren, other heirs, or charities. If you die without a Will, the State of California will determine how to distribute your estate and assets, not you.

If your loved one with PWS has or inherits any assets, including life insurance or retirement benefits, that total more than \$2,000 he or she will be ineligible for Social Security benefits and Medi-Cal. Assets your loved one with PWS received from Medi-Cal are subject to immediate repayment for care they previously received. Medicare may be the only health care benefit your loved one receives which does not offer the same benefits as Medi-Cal. Assets left to others to care for your loved one could be lost to creditors, litigation, divorce, etc.

A Special Needs Trust allows your family to avoid probate and the accompanying delay, court costs and attorney fees, allows you to leave money for your loved one's care without disqualifying them from government benefits, and will allow extra money every month to make his or her life more wonderful.

Without a Will and a Special Needs Trust there is no guaranteed security or protection.

Both your Will and Special Needs Trust should be written with an attorney who specializes in these documents. If the Special Needs Trust is not written correctly, it can't protect your loved one. While PWCF does not endorse or recommend any organization or attorney, the following organizations may be helpful:

- [Special Needs Alliance](http://www.specialneedsalliance.org/find-an-attorney/california)
- [Academy of Special Needs Planners](http://www.specialneedsanswers.com/california-special-needs-planners)
- [The State Bar of California](http://www.calbar.ca.gov/Public/Need-Legal-Help/Lawyer-Referral-Service)

The new HCBS Rules and Regulations give adults with PWS and others with disabilities *enormous* rights to control their lives. Without written documentation in the format accepted by CMS, DDS and the Regional Center these rights actually *prohibit* parents, care providers, and even conservators from overruling them, *even when they are dangerous to your loved one*. Therefore PWCF encourages parents, care providers and conservators to:

- 1) **Immediately have your loved one's "main" physician complete the Physician's Note;**
- 2) **Talk with your loved one about the Agreement Regarding Food and Locks and, if appropriate, the Agreement Regarding Elopement and Locks, and ask them to sign the Agreement(s);**
- 3) **Schedule an IPP meeting with your Regional Center Service Coordinator that incorporates Person-Centered Planning and have the Physician's Note and Agreement(s) made a part of the PCP/IPP;**
- 4) **Secure a Limited Conservatorship if you haven't already done so;**
- 5) **Create your Will and Special Needs Trust if you haven't already done so.**

Now more than ever, parents, conservators, and care providers *must* play an active role at all Person-Centered Planning IPP meetings. Review *all* of your Regional Center reports *as soon as you receive them and immediately make any necessary corrections or clarifications*.

Please know that PWCF is here to assist and support you, your loved one and your family. Contact the PWCF Office with any questions or to speak with any member of PWCF's HCBS Task Force. On behalf of PWCF's Officers, Board of Directors, and staff we send you our warmest wishes.

With warmest regards,

Emily Dame, M.Ed.
Executive Director

HCBS Task Force Members:
Lisa Graziano, M.A., Chair, Austin de Lone, Lesley de Lone,
Diane Kavrell, Tom McRae, Paula Watney

Agreement Regarding Elopement and Locks

To the best of my ability I understand that I have a medical disorder. The name of this medical disorder is Prader-Willi syndrome.

To the best of my ability I understand that one of the symptoms of this medical disorder is elopement or running away. Sometimes I elope in search of food and sometimes I elope for other reasons.

I cannot control this symptom. I cannot stop myself from trying to elope or run away.

To the best of my ability I understand this symptom can be very dangerous to me and threatens my health and safety.

I want all of my care providers, including family members and professional staff, to always try to keep me safe. To the best of my ability I understand that supervision alone may not be adequate or enough to keep me from successfully eloping or running away.

Therefore, I agree that the home environment in which I live should be securely locked at all times.

I do not waive this authorization even when the elopement symptom causes me to become upset.

This agreement may only be changed during my Person-Centered Plan/Individual Program Plan at which my parent(s) and/or conservator is present.

Printed Name _____ Date _____

Signature _____

Witness _____ Date _____

Agreement Regarding Food and Locks

To the best of my ability I understand that I have a medical disorder. The name of this medical disorder is Prader-Willi syndrome.

To the best of my ability I understand that two of the symptoms of this medical disorder are an insatiable appetite (hyperphagia) and the inability to feel full or recognize feeling full.

To the best of my ability I understand that for my own health and safety, my food must be managed properly.

I know that I will receive all of my authorized meals and snacks.

I want all of my care providers, including family members and professional staff, to always try to keep me safe.

Therefore, I authorize that all food items and beverage items and money be securely locked so that I cannot access them.

I do not waive this authorization even when the hyperphagia symptom causes me to become upset.

This agreement may only be changed during my Person-Centered Plan/Individual Program Plan at which my parent(s) and/or conservator is present.

Printed Name _____ Date _____

Signature _____

Witness _____ Date _____

FOR CONSUMERS AND FAMILIES:

People with intellectual and developmental disabilities are provided many services because of the Lanterman Act. Many services people receive are paid for with state and federal money from the federal Centers for Medicare and Medicaid Services (CMS). Therefore, California must comply with what is called the Home and Community-Based Services (HCBS) Final Rule. This rule sets requirements for HCBS settings, which are places where people live or receive services. Each state has until 2022 to help providers comply with the HCBS Final Rule.

The HCBS Final Rule Applies to:

- Residential and non-residential settings; including certified and licensed homes
- Day programs, and other day-type services
- Employment options and work programs

The HCBS Final Rule Does NOT Apply to:

- Nursing homes
- Hospitals
- Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)
- Institutions for mental diseases (IMD)

What is the Goal of the HCBS Final Rule?

To enhance the quality of services provided by:

- Maximizing opportunities and choices for individuals
- Promoting community integration by making sure individuals have full access to the community
- Making sure individuals have the opportunity to work and spend time with other people in their community who do not have disabilities
- Ensuring individual preferences are supported and rights are protected
- Establishing person-centered service planning requirements, which includes a process driven and directed by the individual to identify needed services and supports.

All Settings

The Final Rule requires that you can:

- Spend time in, and being a part of, your community
- Work alongside people who do not have disabilities
- Have choices regarding services and supports, and who provides them
- Have control of your schedule and activities

Residential Settings

Provider Owned or Controlled

In addition to the requirements applicable to all settings, the Final Rule requires that you have:

- Choice about your roommates
- Privacy in your room, including a lock on your door
- Control of your schedule and activities
- The ability to have visitors of your choosing, at any time
- Freedom to furnish and decorate your room
- A lease or other legal agreement, protecting you from eviction

Home and Community-Based Services (HCBS)

Final Rule

FOR PROVIDERS:

How will your service as a provider change?

If you are a service provider who provides services to multiple consumers in the same location, we have to make sure these services do not isolate individuals from the community. The Final Rule says that settings must be integrated and support full access to the community. As a provider, you may need to modify where and how your service is delivered to meet the HCBS Final Rule. Policies and program designs may need to be changed and training to your staff may be necessary to assure their understanding of the new expectations.

Assessing Provider Settings

All providers will soon be required to complete a self-assessment survey that will help determine whether or not a setting complies with the HCBS Final Rule or if modifications are needed. For settings that require changes, there will be time to develop transition plans. Training will be provided on the self-assessment process and expectations, and additional information will be posted on the DDS webpage.

Where can I find more information?

To ask a question, make a comment, or get more information about the HCBS Final Rule, email HCBSregs@dds.ca.gov.

For more detailed information on the HCBS Final Rule and California's Statewide Transition Plan, please visit:

<http://www.dds.ca.gov/HCBS/>

<http://www.dhcs.ca.gov/services/ltc/Pages/HCBSStatewideTransitionPlan.aspx>

<https://www.medicaid.gov/medicaid/hcbs/index.html>



CMS' HCBS Final Rule Requirements

The setting:

1. Is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community to the same degree of access as individuals not receiving Medicaid HCBS.
2. Is selected by the individual from among setting options including non-disability-specific settings and an option for a private unit in a residential setting.
3. Ensures an individual's rights of privacy, dignity and respect, as well as freedom from coercion and restraint.
4. Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to: daily activities, physical environment, and with whom to interact.
5. Facilitates individual choice regarding services and supports, and who provides them.

In provider-owned or controlled residential settings:

6. The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services.
7. Each individual has privacy in their sleeping or living unit; including doors lockable by the individual, choice of a roommate if sharing a unit, and the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
8. Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
9. Individuals are able to have visitors of their choosing at any time.
10. The setting is physically accessible to the individual.

Person-Centered - Individual Program Plan Cheat Sheet

This document will help guide you in the creation of your loved one's IPP, showing you what information you should or may wish to include in this critical document.

For more information or for assistance contact us
www.PWCF.org | info@pwcf.org | 800-400-9994 In CA

SERVICE PLAN FOR:

DOB:

MEETING DATE:

ABOUT CLIENT:

There should be a section that describes the many positive qualities and characteristics of your loved one.

There should be a section that describes the activities that your loved one enjoys, including with whom he or she enjoys doing them.

CIRCLE OF SUPPORT:

There should be a section that describes the individuals who are a support system to your loved one.

HOPES AND DREAMS FOR THE FUTURE:

This section is the "heart and soul" of a Person-Centered Plan. This section should describe your loved one's wants, wishes and dreams for today and into the future. This section's intent is not limit or edit your loved one's stated wishes but to simply reflect them.

You may wish to include language that reflects, "While *Name* prepares for his goals, he will continue to reside in his current home to utilize the benefits of this structured, safe environment."

LONG RANGE GOALS:

This section should include obtainable long range goals. For persons with PWS, obtainable goals do not include independent living, unsupervised access to food or learning to control food intake.

- 1.
- 2.
- 3.
- 4.

PERSONS WHO HELPED WITH THE PLAN:

This section should list everyone who participated in writing the Person-Centered Individual Program Plan.

LIVING OPTION:

This section should describe the residential options for your loved one and/or the current residential setting.

Desired Outcome: Language in this section might include: "To continue to reside in a safe, comfortable home that provides a safe, stimulating, comfortable environment."

CLIENT: *Name*

PAGE: 2

LIVING OPTION (continued):

Plan: Language in this section might include:

1. Regional Center will continue to fund Client's residential care [if living outside the family home].
2. Training and guidance will be sought from the Prader-Willi California Foundation as needed/requested by anyone involved in the care of Client.
3. The RSP, behavior advisor, and trained staff will maintain the home's schedule, consistency and fairness, maintain positive rewards systems and de-stressing techniques that work for Client.
4. Client will be given supervision and guidance from the RSP to budget for and make small purchases with P&I monies.
5. Regional Center will fund 1:1 staffing for two family vacations per year if determined to be necessary. This service will be discussed quarterly and implemented accordingly.

DAILY LIVING NEEDS: Language in this section should include:

Because Client has a medical disorder that causes the symptoms hyperphagia and insatiable appetite, Client shall not be given unauthorized access to food at any time, despite any and all expressed desires in the moment. The name of this medical disorder is Prader-Willi syndrome; more information may be found at www.PWCF.org and www.pwsausa.org.

Additional language in this section might include:

Client is able to do most other self-care tasks, but needs assistance with completing them. H/she is capable of showering, but needs help with xyz. H/she *is/is not* able to pick out appropriate clothing and dress self. Toileting *is/is not* done independently. Client needs encouragement to eat within a reasonable time frame.

Desired Outcome: Client will continue to increase independence in as many areas of self-care as possible.

Plans:

1. Client will continue to increase responsibility for taking care of his own hygiene, laundry, and personal belongings.
2. With assistance from staff as needed, all of *Name's* self-care needs will be completed daily.
3. Regional Center service coordinator will monitor *Name's* progress quarterly and as needed.

Target Date:

PWCF's PCP-IPP Cheat Sheet

CLIENT: *Name*

PAGE: 3

BEHAVIORAL HEALTH: Language in this section might include:

Client continues to be monitored for unwanted behavior including: "Temper tantrums, Emotional outbursts, Physical Aggression, Property destruction, Picking at skin, Fabrications/lying, Non-Compliance, Being rude to family and staff, Elopement, etc." You may wish to indicate or summarize any behavioral incidents since last IPP, or quarter, or month.

Language in this section should include:

Because Client has a medical disorder that causes the symptoms hyperphagia and insatiable appetite, Client shall not be given unauthorized access to food at any time, despite any and all expressed desires in the moment. See *Agreement for Individual with PWS – Food*. If appropriate, include a statement in the PCP-IPP that stipulates, "Client shall not have access to the key that opens the knife drawer without staff authorization. **Include a signed Agreement for Individual with PWS – Food**

If Client has a history of wandering or elopement: A residential setting can lock exits and/or install delayed egress as long as the PCP-IPP contains appropriate documentation to justify the need for each progressively restrictive intervention. If appropriate, include a statement in the PCP-IPP that states, "Client has a prior history of the symptom to wander or leave the home without authorization. He/she may not have access to the key/code that opens the door. See *Agreement for Individual with PWS – Elopement*." **Include a signed Agreement for Individual with PWS – Elopement**

Desired Outcome: Client will replace challenging and maladaptive behaviors with more appropriate ways of expressing his needs.

Plan: Language in this section might include:

1. Staff will obtain PWS Behavior Training from PWCF as needed
2. Staff will follow Behavior Consultant's written plans to address each behavior
3. Staff will continue to implement the facility reinforcement/incentive program
4. Staff will continue to provide a consistent, structured environment that fosters trust and healthy relationships.
5. The RSP will fund behavior services that include written reports.
6. Regional Center will monitor progress and well-being.

Target Date:

CLIENT: *Name*

PAGE: 4

EDUCATIONAL/VOCATIONAL/DAY/RECREATIONAL PROGRAMS:

Language in this section should describe client's educational and/or day program and recreational program including current placement setting(s), progress in each setting, and future goals.

Educational Program Specific Goals:

- 1.
- 2.
- 3.

Vocational Work Program Specific Goals:

- 1.
- 2.
- 3.

Day Program Specific Goals:

- 1.
- 2.
- 3.

Recreational and Physical Activity/Exercise Program Specific Goals:

- 1.
- 2.
- 3.

Desired Outcome: Language in this section might include:

Client will participate in and enjoy his/her educational/day program/recreational activities. One or more of these activities shall occur on a daily basis so that client is as busy as he or she would like to be. Recreational activities shall incorporate physical activity/exercise as stipulated on the Physician's Note. At least all of the restrictions regarding access to food as listed in other sections of this PCP-IPP shall apply to the educational/vocational/day/ and recreational programs.

Plans: Language in this section might look like:

1. Regional Center will fund the day program and transportation to and from sites.
2. Transportation will be provided by sites.
3. Client will maintain good rapport with staff and peers and continue working on identified goals.
4. Staff will obtain PWS Behavior Training from PWCF as needed.
5. RC service coordinator will monitor progress on all sites at least on a quarterly basis.
6. Sites will provide written reports semi-annually.

Target Date:

PWCF's PCP-IPP Cheat Sheet

CLIENT: *Name*

PAGE: 5

MEDICAL STATUS: This is the section to include your Physician's Note tool which should be shared with all care providers as appropriate.

This section should state, "See Physician's Note" and address at least each of the following needs categories:

- **Ambulation:**
- **Requires assistance with Medication: Special Diet:**
- **Physical Activity/Exercise Needs:**
- **Physician Names, Addresses, Phone/Contacts:**
- **Conditions/Medications:**

Desired Outcome: Language in this section might include: "Client will maintain optimal health."

Plan: Language in this section might include:

Client will receive an annual physical and routine check-ups when due, including dental and vision exams. Staff will arrange for all medical appointments and provide transportation and help client follow physicians' orders, including medication regimens as prescribed. Medi-Cal will fund all medical services. Client's P&I to fund those necessary services (co-pay's, medications, etc.) that Medi-Cal does not cover. Medi-Cal/Denti-Cal to fund dental services. Regional Center service coordinator will monitor client's health and well-being on a quarterly basis and as needed.

Restricted Health Condition: Language in this section might include:

Client lives at the Xyz Home, an Adult Residential Facility. Client has the following restricted health conditions: Prader-Willi syndrome. Client is followed by Dr. Xyz for this medical condition. **See attached Physician's Note.**

Language in this section should also include this language: "Because Client has a medical disorder that causes the symptoms hyperphagia and insatiable appetite, Client shall not be given unauthorized access to food at any time, despite any and all expressed desires in the moment. The name of this medical disorder is Prader-Willi syndrome; more information may be found at www.PWCF.org and www.pwsausa.org."

Plan: Language in this section might include:

1. CPC will monitor Client on a quarterly basis and provide quarterly documentation regarding health status.
2. CPC will confer with Regional Center physician when Health Care Team discussions are required.
3. RSP/Staff will have adequate training in providing appropriate Special Health Care Needs required by Client and will document training which has occurred.
4. Medi-Cal will fund all medical services.
5. RSP will transport Client to all medical appointments.

Target Date:

NEXT MEETING DATE:

CLIENT'S RESPONSIBLE PARTY: Parent 1 Name Parent 2 Name / Co-Conservators

Physician's Note - Symptom & Treatment Checklist

My patient _____ DoB _____ has a diagnosis of Prader-Willi syndrome, type (ICD-10: (ICD-10-CM: Q87.11) and requires individualized supports and services that are unique to this diagnosis. Or My patient has a diagnosis of PWS-like (ICD-10-CM: Q87.19) and requires individualized supports and services that are unique to this diagnosis.

Prader-Willi syndrome (PWS) is a rare, complex, genetically-based life-threatening medical disorder. Symptoms associated with PWS are believed to be caused in part by a defect in the brain's hypothalamus, an important supervisory center that controls the release of hormones that regulate growth, muscle tone, breathing, body temperature, sexual development, appetite, metabolism, the regulation of the sleep-wake cycle, the expression of emotions, and many more functions of the body.

The following supports and services are necessary for the health and safety of the individual you are serving:

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Hyperphagia	<p>PWS hyperphagia is a life-threatening, uncontrollable genetic drive to eat that is not satiated regardless of the quantity of food consumed.</p> <p>PWS hyperphagia includes preoccupations with food; food seeking, foraging; manipulation, sneaking, hiding, and hoarding food; and eating unusual food-related items (e.g. sticks of butter, pet food, mouthwash, rotten food taken from trash).</p> <p>PWS hyperphagia causes food-related anxiety that frequently results in dangerous behaviors (e.g. verbal aggression; physical aggression; elopement; burglary; theft; self-injury; lack of regard for personal safety).</p> <p>There is no learning to control PWS hyperphagia. Treatment consists of restricted access to food and continuous supervision. No currently known medication reduces or eliminates this life-threatening symptom. PWS hyperphagia has caused fatality from a single food gorging incident.</p>	<p>Frequently, very low calorie diets are needed to achieve or maintain a healthy weight (e.g., 800 – 1000 kcal/day if the patient is not treated with growth hormone). Adjust diet to patient requirements, following weight closely. Patient should be provided with a food secure environment that includes:</p> <ul style="list-style-type: none"> • Food should be locked at all times. • Menus for breakfast, lunch, dinner, and snack should be posted (patient should be aware in advance of what meals/snacks will consistent of). • Meal/snacks should be consistently offered at the same time throughout the day, every day. • Adult supervision should be provided during all snack and meal times. • Registered dietician trained in PWS should provide specific outline/amounts/ types of food offered for meal plan. 	<ul style="list-style-type: none"> • Patient should receive a maximum of _____ calories per day consisting of _____% Protein _____% Carb
<input type="checkbox"/>	Anesthesia & Medication Sensitivity	<p>Individuals with PWS can safely undergo anesthesia. Risks are related to their general health before the procedure. The majority of complications do not appear to come from general anesthesia, which is always closely monitored, but from poorly monitored conscious sedation.</p>	<p>Only a physician familiar with the patient and their individual medical needs should make medical decisions. Patients undergoing general anesthesia should be assessed by a pulmonologist first, probably with a sleep study, to see if they need CPAP/BiPAP afterwards. Coming out of general anesthesia takes longer so the gas passer should consider leaving them intubated longer and take their time to wake up. Observe overnight after general anesthesia, even for simple procedures, due to respiratory compromise and apnea, at least for children under 3 years old. After surgery, may need restraints to prevent the individual from pulling IVs, etc. or skin picking.</p>	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Anxiety	Excessive, disproportionate worry or fear that is triggered by <i>any</i> stressor or frustration. Persons with PWS typically feel high levels of anxiety all the time.	Maladaptive, unwanted behaviors are often attempts to reduce the level of anxiety the individual is feeling. Implement PWS Behavior Management Protocols*. Psychotropic medication may be prescribed to reduce symptoms.	
<input type="checkbox"/>	Apnea-Central	Breathing is impaired because the brain doesn't send proper signals to the muscles that control breathing.	Diagnosed by a Sleep Study. Use of continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BPAP) at night.	
<input type="checkbox"/>	Apnea-Obstructive	Breathing is impaired due to upper airway obstruction.	Diagnosed by a Sleep Study. Assess for need for adenotonsillectomy. Weight loss, use of continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BPAP) at night.	
<input type="checkbox"/>	Attentional Deficits	Difficulty sustaining attention to tasks, especially non-preferred tasks. Instability to sustain attention especially when food is accessible or on one's mind.	Continuous reminders to return to task. Psychotropic medications may be helpful. Removal of food from the environment.	
<input type="checkbox"/>	Autism Spectrum	A neurological and developmental disorder that begins in early childhood and lasts throughout a person's life. It is a wide range (spectrum) of conditions characterized by challenges with social skills, repetitive behaviors, speech and non verbal communication.	Treatments include intensive sustained special education programs and behavior therapy early in life. Available approaches include: applied behavior analysis, structured teaching, speech and language therapy, social skills therapy and occupational therapy. Medications may be helpful for symptom management.	
<input type="checkbox"/>	Behavior Management Deficits See also: • Autism Spectrum • Elopement • Lying and Confabulation • Repetitive Behavior • Self Injurious Behaviors • Skin Picking • Theft • Wandering	The PWS hyperphagia food drive underlies many food-related behavior problems but is not the sole reason for unwanted or maladaptive behaviors. Additional common symptoms include argumentative, stubborn and oppositional behaviors, impulsivity, inflexibility, obsessive and/or ritualistic behavior, high need for predictability and sameness, sensitivity to real or perceived stressors or frustrators, sedentary and slow moving, and aggressive verbal and physical behaviors.	Implementation of and adherence to PWS-specific behavior management strategies is essential. ABA treatment approaches used for persons with Autism often <i>increase</i> behavior problems in persons with PWS. Request PWS behavior management educational materials and/or training from the Prader-Willi California Foundation (PWCF) or the Prader-Willi Syndrome Association (USA).	
<input type="checkbox"/>	Bone Mineral Deficiency	Reduced bone minerals due to decreased production of sex or growth hormones, hypotonia with decreased physical activity and deficient intake of calcium and vitamin D with calorie-restricted diets.	Increased sunlight exposure, nutritional therapy (vitamin D and calcium supplements), hormonal replacements (estrogen and testosterone), growth hormone therapy, and weight bearing resistance exercise.	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Cognitive Deficits	The patient's mental processes that lead to the acquisition of information and knowledge and drive how the patient understands and acts in the world. Areas of cognitive functioning include: <ul style="list-style-type: none"> • Attention • Decision making • Judgment • Language • Memory • Perception • Planning • Reasoning • Visuospatial • General fund of knowledge 	Early intervention therapies including physical therapy, infant stimulation therapy, and growth hormone therapy initiated < age 2 years may improve cognitive functioning. Assessment of adequacy of vitamin and mineral intake by a dietician, and prescription of appropriate supplementation, is indicated. Supplements that may provide cognitive benefit but for which there are no controlled studies include Coenzyme Q-10, fish oil, certain B vitamins, and acetyl-L-carnitine.	
<input type="checkbox"/>	Depression	Persistent sad, anxious, or "empty" mood. Feelings of hopelessness or pessimism. Feelings of guilt, worthlessness, or helplessness. Loss of interest or pleasure in hobbies or activities.	Traditional psychotherapies, such as Cognitive Behavior Therapy, may not be helpful due to lack of insight necessary for progress, and symptoms of confabulation (story-telling). Psychotropic medications may be necessary to decrease symptoms.	
<input type="checkbox"/>	Developmental Delays	Lack of expected typical physiological development in childhood.	Early intervention therapies including physical therapy, occupational therapy, infant stimulation therapy, oral motor therapy, and speech and language therapy.	
<input type="checkbox"/>	Diabetes Type II Mellitus	A group of diseases that result in too much sugar in the blood (high blood glucose).	Treat as in the general population. Diet compliance is a significant concern. Weight loss is important, and the diabetes may resolve with significant weight loss in obese patients. Monitor blood sugar levels and keep them at goal set by physician, and combination of diet, exercise and medication.	
<input type="checkbox"/>	Edema	Swelling caused by excess fluid trapped in the body's tissues.	Treat underlying cause. Medication is often necessary.	
<input type="checkbox"/>	Elopement	When the person leaves a setting without authorization when departure presents a threat to the safety of the patient or others. Elopement generally occurs when individual is in search of food.	Continuous monitoring. Alarms on all exits including windows and doors for people with a prior history of elopement.	
<input type="checkbox"/>	Epilepsy	A neurological disorder in which nerve cell activity in the brain is disturbed causing seizures.	Treatment includes medications to control seizures. For some, the ketogenic diet can help, however this diet requires medical supervision.	
<input type="checkbox"/>	Gastroparesis	Slow, delayed emptying stomach. Stomach distention, hard, bloated; reflux. Vomiting rarely occurs in persons with PWS.	Chronic condition. Serve smaller sized meals; provide cooked rather than raw vegetables; medication such as low dose metoclopramide or antibiotic.	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Growth Hormone Deficiency	A feature of PWS that causes short stature, small hands and feet, dysmorphic facial features, weaker muscle tone, low bone density and strength, reduced respiratory function, and slower metabolism.	<p>Growth hormone therapy (GHT) is a standard of care for PWS. GHT may be prescribed based solely on the genetic diagnosis and growth pattern rather than the results of GH deficiency testing. Decisions about appropriate age to begin GHT and doses should be made by an experienced endocrinologist, with consultation from a PWS endocrine specialist when necessary.</p> <p>Infants & Children: When started in infancy or childhood GHT can improve height, weight, respiratory function, body mass, strength, agility, and may help with cognitive development.</p> <p>Adulthood: When prescribed in adulthood, GHT has shown positive results in areas of bone strengthening, leaner muscle mass, and increased energy. Dosing for adults is a low “maintenance” dose. Too high a dose after the growth plates close may cause acromegaly. Insurance companies may require GH stimulation test to prove GH deficiency.</p>	
<input type="checkbox"/>	Hypotonia See also "Muscle Tone"	Low muscle tone involving reduced muscle strength. Nearly all infants with PWS exhibit severe muscle weakness. Muscle tone improves with age but individuals never develop normal muscle strength and often fatigue easily.	Growth hormone therapy (GHT) can significantly improve hypotonia though it does not normalize muscle tone. GHT is generally recommended throughout the lifetime to reduce many PWS symptoms including hypotonia. Physical therapy is recommended during childhood and regular physical activity is recommended throughout the lifetime including strengthening exercises and activities.	
<input type="checkbox"/>	Kyphosis See also "Scoliosis"	Commonly referred to as a “dowager’s hump,” kyphosis is an unnatural curving of the upper back that creates a hunchback appearance in the posture. It is rare to have pure kyphosis or pure scoliosis; usually there is a combination (kyphoscoliosis) with one component more remarkable than the other.	People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to kyphosis. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. See "Kyphoscoliosis" for more detailed intervention information.	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	<p>Kyphoscoliosis</p> <p>See also “Kyphosis” and “Scoliosis”</p>	<p>Kyphosis is an unnatural curving of the upper back that creates a hunchback appearance in the posture. Scoliosis is a lateral (sideways) curvature of the spine.</p> <p>Scoliosis and kyphosis are common symptoms. It is rare to have pure kyphosis or pure scoliosis; usually there is a combination, kyphoscoliosis, with one component more remarkable than the other.</p>	<p>People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to kyphosis, scoliosis or both. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. People with PWS balance themselves differently; they tend to keep their head out more forward and have an increased kyphosis. If attempting to correct kyphosis to “normal” there is a high likelihood the surgery will fail, with the patient still flexing forward but peeling away from their spine hardware.</p> <p>Infants and Children: Do not have babies sitting up independently until they can pull themselves up to that position. Otherwise, babies tend to slump into a hypotonic position which we believe activates kyphoscoliosis. Rather, have infant sit in a chair inclined about 60° and emphasize tummy time. Get first screening spine film upright sitting when the child can reliably sit by themselves (usually 12-18 months); continue at least yearly for the first 4 years. Exercise is <i>extremely</i> important; therapeutic horseback riding is an important adjuvant. Casting for the very young, or bracing may be prescribed to correct or limit the curvature. If possible, delay surgical options until age 6 or 7 years. Use a “growth friendly” or expandable implant to allow child to grow while maintaining spine as corrected as possible.</p>	
<input type="checkbox"/>	<p>Lying, Confabulation</p>	<p>Lying to avoid blame, telling untrue and sometimes elaborate stories that the individual may believe are true, inflating one’s abilities or skill set. A common symptom in persons with PWS.</p>	<p>While honest most of the time, many persons with PWS will lie without use of logic or reasoning to avoid blame, especially but not limited to food acquisition. Some people may tell elaborate untrue stories to gain attention or for no apparent gain.</p>	
<input type="checkbox"/>	<p>Metabolic Abnormality</p>	<p>Poor utilization of calories leading to obesity if uncontrolled. Medications, vitamins and supplements are metabolized slowly.</p>	<p>Provide healthy foods that contain necessary vitamins and minerals within a low calorie diet. Restrict access to unauthorized food. Medications should be started at low doses and increased slowly and with caution.</p>	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Muscle Tone See also "Hypotonia"	The tension in muscles, even when in a relaxed state. Hypotonia is the medical term to describe low muscle tone. It is at times incorrectly confused with the amount of muscle or weakness	Low muscle tone (hypotonia) in newborns with PWS results in poor sucking and a "floppy" posture. Beyond infancy, hypotonia may lead to poor posture, varying degrees of spinal curvature, problems with balance, coordination, and sensory integration skills. Increase strength to compensate for hypotonia through assuring adequate physical activity.	
<input type="checkbox"/>	Obsessions & Perseveration	Continuous, repeated, undeterred focus on a particular topic, issue, or person that can interfere with the flow of the day. Attempts to restrict someone from their obsession may result in exaggerated emotional responses and extreme anger.	Anxiety can contribute to obsessions and perseveration. Reduce stressors that are causing anxiety. Behavioral strategies can help to mitigate: <ul style="list-style-type: none"> • Adhere to the schedule and routine; minimize change. When change needs to occur, prepare individual in advance when possible. • After answering a question 3-4 times, remind the individual the question has been asked and answered, then ask them to answer their own question. • Psychotropic medication may help reduce symptoms. • Care providers are encouraged to be patient and maintain a sense of humor especially with this symptom. 	
<input type="checkbox"/>	Pain Sensitivity	Patients with PWS can have a very high tolerance for pain and the severity of their symptoms may be overlooked. Patients are often poor at localizing pain. Sensitivity to pain may be diminished or absent, even in severe injuries or internal medical condition. There is often bruising or swelling for reasons unknown to the patient.	All injuries should be reported to and carefully assessed by the caregiver. Elevate and apply ice to injuries as needed. Individual may require examination by a physician to rule out injury, fracture or other health problem.	
<input type="checkbox"/>	Poisoning - Accidental	Persons with PWS may eat spoiled or rotten foods, or items they believe are food but are poisonous such as ice pack filling, large quantities of alcohol, etc.	Because persons with PWS usually lack ability to vomit, gastric suction, known as stomach pump may be necessary. Emergency rooms should be made aware of the decreased ability to vomit. Vomiting can signal a life-threatening situation. Caution is advised using Syrup of Ipecac which can increase poisoning.	
<input type="checkbox"/>	Psychosis	Disruptions to a person's thoughts and perceptions that make it difficult for them to recognize what is real and what isn't. Psychotic symptoms include visual and/or auditory hallucinations and occur more frequently in persons with UPD subtype.	Reduce environmental stressors. When using any psychotropic medication, start with a low dose and increase dosing slowly; metabolism is generally much slower in persons with PWS which means medication stays active in the body longer.	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Reflux	Gastroesophageal reflux (GERD), also known as acid reflux, is a condition where stomach contents come back up into the esophagus. Severity may be increased in infants with hypotonia. Decreased ability to vomit is a feature of PWS. Less common in PWS is rumination, the voluntary regurgitation of gastric contents.	After eating a meal, avoid lying supine (back position); instead prop at a 30 degree incline. Emergency rooms should be made aware of the decreased ability to vomit. Because the ability to vomit is often absent, vomiting can signal a life-threatening situation. Medications to treat reflux may be helpful.	
<input type="checkbox"/>	Repetitive Behavior	Repetition in movement and/or thoughts. Examples may include repeatedly putting things in containers such as backpacks, etc. and then taking them out. Repetitive behavior can be characterized and measured using the Repetitive Behavior Scale-Revised (RBS-R).	For people with PWS, high levels of anxiety are common and contribute to repetitive behavior. Work to reduce the stressors causing anxiety. Behavioral strategies and/or psychotropic medications may be helpful. Care providers are encouraged to be patient and maintain a sense of humor especially with this symptom.	
<input type="checkbox"/>	Respiratory Disorder	Any condition that inhibits breathing.	Treat the underlying cause.	
<input type="checkbox"/>	Saliva Disorder-Dry Mouth	Most individuals with PWS have low saliva production. The result is dry mouth symptoms including thick, sticky saliva that will often appear as a thick white foam around the mouth. Dry mouth can adversely affect dental health, interfere with swallowing, and affect speech.	Use dry mouth products to stimulate saliva and reduce symptoms (e.g., over the counter ACT toothpaste or prescription pilocarpine (Salagen) or cevimeline (Evoxac). Teeth should be brushed frequently. Provide adequate fluoride to prevent dental decay. Biannual dental visits are recommended.	
<input type="checkbox"/>	Scoliosis See also "Kyphosis"	Scoliosis is a lateral (sideways) curvature of the spine. Scoliosis is a common symptom of PWS. It is rare to have pure kyphosis or pure scoliosis, usually there is a combination (kyphoscoliosis) with one component more remarkable than the other.	People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to scoliosis. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. See "Kyphoscoliosis" for additional, more detailed intervention information.	
<input type="checkbox"/>	Self-Injurious Behavior	Many people with PWS engage in skin picking but can also engage in cutting, hair pulling, nail biting, burning, rectal picking, etc. Bruises, cuts, open sores and scars are common and can lead to false allegations of physical abuse.	One pilot study and anecdotal reports from parents show that the supplement N-acetyl cysteine (NAC) has been effective in reducing or eliminating skin picking. SSRI medications have sometimes been effective to reduce symptoms. Insect repellent, wearing long sleeves and pants when person is outdoors help to prevent bug bites and other irritants that can lead to skin picking. See also "Skin Picking."	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
<input type="checkbox"/>	Sensory-Motor Integration Problems	Due to low muscle tone, individuals with PWS often experience problems integrating all senses: visual, tactile, auditory, vestibular, and proprioceptive systems. Symptoms typically look like sensitivity to tags, seams, hats; decreased balance; impaired depth perception.	Treatment generally consists of Sensory Integration Therapy, with particular focus on integrating the visual, tactile, vestibular, and proprioceptive systems.	
<input type="checkbox"/>	Sexual Development Disorder	Both males and females with PWS experience hypogonadism, disrupted function of sex hormones, and decreased fertility/infertility. Without sex hormone therapy, sexual maturity does not fully develop.	Refer to an endocrinology specialist. Testosterone may be prescribed for boys to increase penile development, voice deepening, and body hair. Estrogen therapy may be prescribed for girls to increase breast growth and induce regular menstrual cycles. Some endocrinologists may prescribe sex hormone therapy to improve bone strength especially when the patient is not treated with growth hormone therapy. Sex hormone therapy helps “normalize” body form and may provide a greater sense of “normalcy” within the peer group which can improve self esteem.	
<input type="checkbox"/>	Skin Picking	Skin picking (Excoriation Disorder) is the repetitive and compulsive picking of skin which results in tissue damage. This can include nose picking, hair pulling, nail biting and removal, and rectal digging. Can be worse during times of stress or boredom.	Skin picking often increases during stress. Implementation of and adherence to PWS environmental management strategies is essential; contact PWCF and PWSA for educational materials. Behavioral treatments include diversion to alternative activity, frequent application of antibacterial ointment, keeping nails short, using protective dressings. Supplements such as N-acetyl cysteine (NAC), and psychotropic medications such as Topamax, SSRIs can be helpful. Closely monitor for skin picking post surgery; surgical site infections or dehiscences (wound rupture) occurs frequently from skin picking and may require protective bandages or braces to limit accessibility.	
<input type="checkbox"/>	Sleep Disorder-Cataplexy	A sudden loss of muscle tone triggered by intense emotion. In PWS, often triggered by food consumption. Symptoms range from slurred speech to total body collapse.	Medications used to treat narcolepsy are often used to treat cataplexy, including Provigil (modafinil), Nuvigil (armodafinil).	

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<input type="checkbox"/>	Sleep Disorder-Hypersomnia	Excessive daytime sleepiness.	Seek a possible underlying cause, such as sleep apnea or medications causing drowsiness. Most hypersomnia in PWS is of unknown cause. Treatment may consist of CPAP, BiPAP, caffeine, or medications including methylphenidate (Ritalin), modafinil (Provigil) or antidepressants such as fluoxetine (Prozac), citalopram (Celexa), paroxetine (Paxil) or sertraline (Zoloft). Sodium oxybate (Xyrem) may help treat excessive daytime sleepiness associated with narcolepsy.	
<input type="checkbox"/>	Sleep Disorder-Narcolepsy	Extreme tendency to fall asleep during any type of activity at any time of the day. Frequently occurs in relaxed surroundings in persons with PWS.	Medication is usually necessary. Ritalin helps to reduce excessive daytime sleepiness and improves alertness. Other medications include Provigil (modafinil), Nuvigil (armodafinil). Sodium oxybate (Xyrem) may help treat excessive daytime sleepiness associated with narcolepsy.	
<input type="checkbox"/>	Slow Bowel	Slow moving bowel causes constipation and/or diarrhea. Common in PWS. Diarrhea symptoms may indicate severe constipation.	Adequate water intake; daily exercise; osmotics to keep stool soft, making elimination easier, including: <ul style="list-style-type: none"> • First try dietary changes such as prunes, increased fluids, etc • Polyethylene glycol (Miralax) • Lactulose (Kristalose) • Magnesium citrate • Magnesium hydroxide (Milk of Magnesia). DO NOT use Imodium or Pepto-Bismol to treat diarrhea as these may lead to bowel necrosis or rupture and cause death.	
<input type="checkbox"/>	Swallow Problems	Swallow dysfunction may be a contributor to morbidity in PWS. Food particles do not always clear the esophagus. Choking is a common symptom. Aspiration may be common wherein particles of food or liquid enter the lungs which may be lead to pneumonia.	All care providers should know how to administer the Heimlich maneuver. Cut food into smaller pieces. Remind individual to eat slowly. Use the “Sip & Chase” intervention: small sips of liquid following bites of food may help clear the esophagus.	
<input type="checkbox"/>	Temperature Regulation Disorder	Due to dysfunctions in the central nervous system, the range of body temperature can vary significantly without apparent cause. Hypothermia (low body temperature) and hyperthermia (high body temperature) can easily occur and be life-threatening. Hyperthermia has been known to occur after receiving anesthesia. Fever may be absent despite serious illness or infection.	Know the patient’s baseline temperature, which typically runs lower than the general population. hyperthermia, heat exhaustion and heat stroke require immediate medical attention. Treat hypothermia immediately by warming the individual with blankets and seek medical attention.	

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<input type="checkbox"/>	Theft	Theft of both food and non-food items is common due to impulsivity and lack of judgment regarding consequences. Theft of money to be used to purchase food is common.	Especially for the individual known to take items, continuous supervision is required.	
<input type="checkbox"/>	Thyroid Disorder- Hypothyroidism	Occurs when the thyroid gland is underactive. Can cause weight gain, fatigue, weakness, slow growth, dry or coarse hair, rough or pale skin, cold intolerance, muscle cramps or aches, constipation, irritability and/or depression. May be a cause of prolonged hypotonia in infants. Occurs at any age and is found in 15% of people with PWS.	Thyroid function tests are recommended in all patients. Thyroid disorders are typically well-managed with medication.	
<input type="checkbox"/>	Unreliable Self Reporting	Due to altered /diminished pain awareness, or factitious disorder, suggestibility or medication seeking.	Always assess for actual illness or injury.	
<input type="checkbox"/>	Vitamin(s) Deficiency	Lack of vitamins because of dietary deficiency. Low levels of vitamin C, vitamin D, and calcium contribute to decreased bone mineral.	Treat with vitamins and supplements.	
<input type="checkbox"/>	Wandering	The person strays into unsafe territories and may be harmed. The most dangerous form of wandering is elopement in which the person leaves an area and does not return.	Continuous monitoring.	
<input type="checkbox"/>	Other:			
<input type="checkbox"/>	Other:			
<input type="checkbox"/>	Other:			
<input type="checkbox"/>	Other:			

Physician's Signature: _____ Date: _____

Physician's Contact Info/Stamp:

For more information about Prader-Willi syndrome or to request PWS Behavior Management protocols or a PWS Behavior Management Training contact the Prader-Willi California Foundation or the Prader-Willi Syndrome Association (USA)

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