

## Prader-Willi Syndrome Association of WI, Inc.

	<p><b>Note Taking Study Guide</b></p> <p><b>Health Maintenance and Emergency Care for Adults with Prader-Willi Syndrome</b></p>
	<p>Barb Dorn, RN, BSN PWS Consultant PWSA of WI, Inc 2008</p>

The following is a study guide that accompanies a Power Point presentation on Health Maintenance and Emergency Care for Adults with Prader-Willi Syndrome (PWS). The study guide is designed to help persons who provide health advocacy and care for adults with Prader-Willi Syndrome. It presents important health information in an effort to assist in preventing and managing health issues in the adult with Prader-Willi syndrome. It will also allow you to become more informed health advocates. Feel free to jot down additional notes.

This presentation is not meant to replace any information or instructions that may have been given by a health care professional. If you ever have any questions, consult with the prescribing health care professional. You may be an educator to the health professional about Prader-Willi syndrome. Share what you know and advocate on behalf of this person.

**You Are an Important Part of the Health Care Team! You are ...**

- A health educator to the person with Prader-Willi syndrome (PWS). You teach him/her health habits and practices.
- Instrumental in detecting health problems or conditions.
- An educator to health care providers and an advocate for the person with PWS.

The presentation has been divided into 2 parts.

- The first part – Health Maintenance - focuses on health issues that can be addressed and prevented on a daily basis. Some are an inherent part of PWS while others can be prevented when life style issues and habits are addressed.
- The second part – Emergency Care – focuses on health issues that are of a more urgent nature.

**Objectives:**

After reviewing the Power Point presentation on Health Maintenance and Emergency Care for Adults with Prader-Willi Syndrome, the person will be able to:

1. Identify common health issues that may be seen in the adult with PWS and institute measures that promote wellness and prevention of complications related to these issues.
2. Teach and encourage residents with PWS to implement positive health strategies.
3. Identify serious health concerns that require immediate evaluation by a health care professional.
4. Share appropriate health information and resources to health care providers.

Please feel free to contact PWSA of WI, Inc or PWSA (USA) for any questions about this presentation or health issues that may be facing the person with PWS.

There is an additional program designed to educate teens and adults with PWS so they too can become informed health advocates. This program is titled, “Staying Fit: What You Can Do”. Contact PWSA of WI, Inc for more information.

**STUDY GUIDE: Health Maintenance**

	<p>Name part of the brain is responsible for the problem of excessive appetite in the person with PWS.</p> <p>_____</p>
	<p>List the main reason for the uncontrollable appetite in the person with PWS.</p> <p>_____</p>
	<p>List the benefits of environmental supports in the person with PWS.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>Name things that can be done to assist the person with PWS to prevent food seeking.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>Name the essential part of the weight management plan.</p> <p>_____</p>
	<p>List some ways a person with PWS can prevent sun burn?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>In the case of an injury, list the frequency an injury be assessed.</p> <p>_____</p>
	<p>Is it safe to assume that no complaint of pain means an injury is minor and can be ignored?</p> <p>_____</p>
	<p>List the openings of the body a person with PWS may pick at.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>List the 2 most successful approaches that may be tried to help prevent and manage skin picking in the person with PWS.</p> <p>1. _____</p> <p>2. _____</p>

**STUDY GUIDE: Health Maintenance**

	<p>List 4 specific strategies that may be used to assist the person with PWS with skin picking.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> <li>4. _____</li> </ol>
	<p>List 2 strategies that may need to be considered in severe cases of skin picking.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> </ol>
	<p>Identify the 3 major signs of a wound infection.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> </ol>
	<p>List 2 strategies that may be tried for the person with PWS who has a rectal picking problem.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> </ol>
	<p>State 4 common causes of constipation in persons with PWS.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> <li>4. _____</li> </ol>
	<p>List 4 steps that can be used to prevent constipation in persons with PWS.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> <li>4. _____</li> </ol>
	<p>Indicate how much fluid a person with PWS should drink in 1 day.</p> <p>_____</p>
	<p>What is the recommended limit in fluids that a person with PWS should drink at one time?</p> <p>_____</p>
	<p>State the name of the health condition or problem that can occur when a person drinks too much fluid at one time.</p> <p>_____</p>

**STUDY GUIDE: Health Maintenance**

	<p>List 4 symptoms of water intoxication.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> <li>4. _____</li> </ol>
	<p>Define Gastroparesis.</p> <p>_____</p>
	<p>List 1 step that may be taken if a person is diagnosed with Gastroparesis.</p> <p>_____</p>
	<p>List 2 common causes of Osteoporosis in persons with PWS.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> </ol>
	<p>List 3 strategies that may be tried to help prevent Osteoporosis.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> </ol>
	<p>Define Scoliosis.</p> <p>_____</p>
	<p>Name one thing you may want to suggest as a health advocate for a person with PWS who is being seen for back problems.</p> <p>_____</p>
	<p>List the 3 most common dental problems seen in persons with PWS.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> </ol>
	<p>List the 3 common reasons that dental problems may be seen in persons with PWS.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> </ol>
	<p>Identify 4 ways to assist the person with PWS with dental health.</p> <ol style="list-style-type: none"> <li>1. _____</li> <li>2. _____</li> <li>3. _____</li> <li>4. _____</li> </ol>

**STUDY GUIDE: Emergency Care**

	<p>List one item you should take with you when you when you take a resident with PWS to the Emergency Room.</p> <p>_____</p>
	<p>Name 4 possible symptoms of severe Gastric Illness.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p>
	<p>When is severe Gastric Illness most often seen?</p> <p>_____</p>
	<p>When should medical help be sought if gastric illness is suspected?</p> <p>_____</p>
	<p>What should be done for all cases of vomiting?</p> <p>_____</p>
	<p>Explain the pain response in a person with PWS.</p> <p>_____</p>
	<p>Name 4 things to do to help a person with PWS who is injured.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p>
	<p>List 2 reasons that put most persons with PWS at higher risk for respiratory illness?</p> <p>1. _____</p> <p>2. _____</p>
	<p>List 2 steps you can take when caring for a person with PWS who has a bad cold.</p> <p>1. _____</p> <p>2. _____</p>
	<p>List 2 common treatments for sleep apnea.</p> <p>1. _____</p> <p>2. _____</p>

**STUDY GUIDE: Emergency Care**

	<p>List problems that a person with PWS may experience in relation to temperature control.</p> <p>_____</p>
	<p>List 4 strategies you may want to try in helping the person with PWS with temperature management.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p>
	<p>Name the 5 common symptoms of diabetes.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p>
	<p>What symptoms often alert the caregiver of a person with PWS that he/she may be demonstrating symptoms of diabetes?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>Name 3 common symptoms of heart or vascular problems.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>Describe 3 things you can do if you notice symptoms of heart or vascular problems.</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p>
	<p>List 2 risk factors that persons with PWS demonstrate for Obstructive Sleep Apnea.</p> <p>1. _____</p> <p>2. _____</p>
	<p>List the types of medications that persons with PWS may be most sensitive to.</p> <p>_____</p>
	<p>Describe measures you can take to make sure you are informed about the medications you are administering:</p> <p>_____</p> <p>_____</p>

**STUDY GUIDE: Emergency Care**

List 7 common side effects of many mood altering medications along with 1 strategy to help with these.

Side Effect:	Things to do to help:
1.	
2.	
3.	
4.	
5.	
6.	
7.	

State the type of juice it is best to avoid serving to persons with PWS who are taking medications.

\_\_\_\_\_

You are an important part of the team in teaching, modeling and advocating for the health needs of a person with Prader-Willi syndrome. I hope you found this educational program helpful.

There is a post-test available if you wish to see how much you can recall following the viewing.