

## **Allegations of Abuse and/or Neglect in the Person with Prader-Willi Syndrome**

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Because of some intrinsic features of the syndrome, parents, and care providers for persons with Prader-Willi syndrome (PWS) are at increased risk for accusations of abuse. The safety and well-being of a child or adult with Prader-Willi syndrome (PWS) is always number one priority and concern. While all reports or suspicions of abuse or neglect should be evaluated by a human service professional, it is important for the investigating professional to be informed regarding signs and behaviors that may be seen in many persons with PWS. We provide the following information to assist the professional during the investigative process.

### **Sores – Skin Picking**

It is common to see open sores across many parts of the body on a person with PWS. These sores typically result because of a serious skin picking habit coupled with a decreased sense of pain that, in unaffected individuals, would lead to cessation of the picking. Many persons with this disorder will pick at insect bites, sores, pimples, and other skin lesions. You may see fingernails that are bitten very short and cuticles that may be scabbed or scarred. It is common for many to pick at various openings of their body – nose, rectum, and vagina. In some cases, affected individuals will pick at areas of their skin for no apparent reason. These sores can be mistaken for cigarette burns. Many parents and caregivers have been accused of abuse. However, after a thorough investigation, most are found to be innocent.

### **Bruising**

Persons with PWS bruise easily. The exact cause for this is unclear. Common blood tests that are done to measure the body's ability to clot are typically normal. It is not uncommon to see a great deal of swelling in addition to numerous, sometimes large bruises after a minor bump or injury. Some people with PWS may demonstrate extreme behavior escalations that may result in assault of others or destruction of property. Parents and/or staff may take steps to prevent the individual from causing harm to self or others. In these cases, bruising often occurs. It is important for professionals to investigate these situations.

## Food Safety – Locks, Alarms and Food Restriction

The hypothalamus in the brain of persons with PWS does not function properly. The appetite control center is located in this area. When a person with PWS eats, the message of fullness never reaches their brain. They are always hungry and driven to find food. These individuals require structure around food in order to keep them healthy. PWS is a spectrum disorder which means individuals have varying degrees of food seeking behavior. Most persons with this disability require environmental supports to prevent access to food so they will not rupture their stomach or eat themselves to death. Parents and caregivers may need to use locks and/or alarms to keep those with higher food seeking behaviors, safe. In addition, many persons with PWS can gain weight very easily and they may require a very low-calorie diet. Even though these measures seem extreme, these sorts of supports can be lifesaving in those with strong food seeking concerns.

## Statements of Abuse or Neglect by the Person with PWS

Many people with PWS will go to extreme measures to try and get food. Some have falsely accused their parents and caregivers of hurting them or denying them food, in hopes that it will get them more food. We often do not know exactly why they make these allegations. Many may be angry living with this disorder and may target frustration and anger at those who love and care for them. We all want children and adults with PWS to be safe. We also want those who may be accused of possible abuse or neglect to be given a thorough and fair chance to receive an evaluation by a professional who has a clear understanding of PWS.

We want to believe that everyone who cares for the person with PWS is kind and understanding. Unfortunately, this is not the case. Staff at PWSA I USA can't make this determination. What we can do is provide information about PWS to help everyone make the most accurate assessment of the situation as possible. For more information, please visit our website or contact our national office.



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