

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 child 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 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, 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. In most instances, careful examination will reveal that the pattern of bruising is clearly unlike that found in typical cases of child abuse and should not be mistaken as such.

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. 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 must use locks and/or alarms to keep them safe. In addition, persons with PWS can gain weight very easily and they require a very low calorie diet. Even though these measures seem extreme, food seeking behaviors in many of these individuals are so strong that these sort of supports can be life saving.

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 are 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. For more information, please visit our website or contact our national office.

