

Food Accessibility in the Workplace

For most if not all individuals with Prader-Willi syndrome (PWS), having food accessible in the workplace will impede their ability to concentrate and perform the task at hand because their mind will be more focused upon how to obtain that food item. To maximize performance and minimize behavioral problems, employers must control access to food items throughout the worksite. For most worksites, it is realistic and manageable to make relatively minor changes to accommodate the employee with PWS in order to help him be a productive, valued and valuable employee

It is *not* realistic to expect that someone with PWS can modify his behavior away from taking the bag of chips or eating others' lunches if that food is available to him no matter *how* many tokens or prizes incentivize the person not to take food.

The hyperphagia food drive is brain-driven. The solution is controlling the environment.

It is often helpful to someone with PWS to post the day's work schedule, including snack and lunch breaks. Having a concrete schedule to view and refer to can be quite helpful. Keeping employee lunches and other food items in a manager's office or in some other secured area is highly recommended. Limiting access to vending machines and/or limiting access to money that may be used to purchase food items from vending machines, mobile food trucks, local fast-food restaurants, etc. is also highly recommended.

With your support, people with Prader-Willi syndrome can be productive and happy workers.



One Final Tip

Praise the person in situations where they do not take food when you see he could have.

The use of praise in general will go a long way for the typical person... and even longer for the person with PWS.



For More Information about PWS

For more information about Prader-Willi syndrome or to speak with someone about how to organize or manage your classroom to assist your student with PWS please visit the PWCF website at www.PWCF.org or call the PWCF toll-free in California at 800.400.9994 or outside California at 310.372.5053.

Prader-Willi California Foundation is a non-profit 501(c)(3) charitable corporation established in 1979. An affiliate of the national Prader-Willi Syndrome Association (USA), PWCF is dedicated to supporting individuals with PWS, their families, and the professionals who serve them.



**Prader-Willi
California Foundation**

Supporting People with Prader-Willi Syndrome

Prader-Willi California Foundation
1855 First Street, Suite 201 | San Diego, CA 92101
310.372.5053 • 800.400.9994 (Toll Free Within CA)
info@pwcf.org • PWCF.org

An Affiliate of Prader-Willi Syndrome Association (USA)

800.926.4797 • info@pwsausa.org • pwsausa.org

Food Security at Work

**for the Adult with
Prader-Willi Syndrome**



**Prader-Willi
California Foundation**

Supporting People with Prader-Willi Syndrome

Prader-Willi Syndrome Causes an Insatiable Appetite

Prader-Willi syndrome (PWS) is a non-inherited genetic disorder. PWS causes a host of symptoms including hyperphagia, or insatiable appetite. **Persons with PWS do not feel satiated or “full” no matter how much they eat**; the brain continuously and relentlessly drives someone with PWS to seek out and eat more food. At the same time, the body metabolizes food at generally half the normal rate, so someone with PWS will gain weight at a tremendous rate on few calories.

Food Security in the work setting at all times and in all circumstances is imperative.



There is no known treatment or appetite suppressing medication to eliminate or even reduce the hyperphagia caused by PWS. It must be understood that for the adult with PWS there is no "behavior modification" in regard to food. It is not realistic to expect that the adult with PWS can “learn to control himself” and not eat food that is available. While some individuals may be able to manage their behavior for a day or even a week or two, this does not constitute genuine modified behavior; there will come a day when the person, despite knowing that he should not, will attempt or succeed at eating excess food. Individuals with PWS know they’re not supposed to eat “unauthorized” foods; they simply cannot overcome their biochemical drive to eat. For the adult with PWS the emphasis is always on prevention. *The key to managing the hyperphagia caused by PWS and reduce the incidence of food-related behavior issues is to maintain Food Security within the school environment.*

But Just “One” Can’t Hurt... Can It?

For the person with PWS, just “one” or just one food binge can hurt...

It can even be deadly. Here’s why:

Rapid Weight Gain

Due to a reduced metabolic rate and other endocrine issues persons with PWS can quickly gain large amounts of weight on very few calories. A diet considered healthy for a adult without PWS can cause rapid weight gain for the adult with PWS. The daily caloric intake of the person with PWS must be strictly monitored; even just one cookie or one extra slice of pizza every now and again can mean the difference between a healthy weight and a tip of the scale into morbid obesity. If a person with PWS is known to have obtained extra food during the day caretakers must be notified so that they may compensate and reduce the person’s caloric intake for the remainder of the day or week.

Choking

Choking is a particular hazard for persons with PWS. Individuals with PWS often eat much too quickly and do not adequately chew their food before swallowing. Sneaked or stolen food will be eaten very, very quickly to avoid detection or loss of the forbidden item. Low muscle tone and poor coordination exacerbates the choking risk.

Severe Gastric Illness

Abdominal distention or bloating, pain, and/or vomiting may be signs of life-threatening gastric inflammation or necrosis and is more common in PWS than in the general population. Thinner individuals appear to be at even greater risk. Rather than localized pain the individual may complain of a general feeling of unwellness. If a person with PWS has these symptoms, especially following a known or suspected binge-eating episode, immediate parental notification and hospitalization is warranted as this may be a life-threatening situation.

Lack of Vomiting

Vomiting rarely occurs individuals with PWS. Emetics may be ineffective and repeated doses may cause toxicity. The presence of vomiting may signal a life-threatening illness.

PWS’ Impact in the Workplace

It is unrealistic to expect a person with PWS to maintain focus on the task at hand when he knows that a food or beverage is or may be obtainable; the drive to eat is too strong and will affect behavior and school performance. For most adults with PWS, having *any* food *anywhere* in the work site will impede their ability to concentrate and work. Maintaining Food Security will help improve pro-

The Solution: Food Security

Food Security, a term coined by PWS experts Linda Gourash, M.D. and Janice Forster, M.D., refers to “the ready availability of nutritionally adequate and safe foods with an assured ability to acquire acceptable foods in socially acceptable ways.” The Principles of Food Security are:

No Doubt when meals will occur and what foods will be served plus

No Chance/Hope to obtain anything different from what is planned equals

No Disappointment related to false expectations.

Some ways to achieve Food Security include:

- Secure access to food across *all* settings:
 - Controlled access to all food sources including the cafeteria, lunch boxes, hallways, vending machines and money
 - Avoid any spontaneity related to food: no snacks on demand and no food left out
- Supervise food exposure at all times
- Post the schedule for snack and lunch times

The Hand is Quicker Than the Eye

Regardless of cognitive function, a person with PWS can be quite adept at obtaining food. You should be aware that people with PWS have been known to:

- Take food out of someone else's lunchbox
- Take food from someone else’s lunch tray
- Trade valuable items such as jewelry and money for food
- Eat their own packed lunch and attempt to obtain more food from the cafeteria
- Steal food from the cafeteria or other workers
- Take half-eaten or discarded food from the trash
- Take food from backpacks left in corridors while on the way to the restroom
- Eat all of their lunch on the way to work

There is no end to what PWS may drive an adult to do to obtain food. People with PWS may not be truthful about whether or what they’ve eaten regardless of the “evidence.” It is generally not recommended to ask “Did you eat that?” but rather presume food was eaten and notify the caretakers.