

Food Security for Persons with Prader-Willi Syndrome

Food security is a vital part of caring for the person with Prader-Willi syndrome (PWS). In order to keep a child or adult with PWS safe and secure, parents and care givers use many different strategies to help them remain safe and secure. Physical adaptations may include locks, motion detectors, enclosed kitchen and/or pantry. Many of these may be used solely or in combination. Emotional adaptations are often used to help most, if not all individuals with PWS. These steps help to lower anxiety and help them remain in engaged in their activities.

PWS is a spectrum disorder, you may see varying degrees of food seeking, as well as varying approaches to managing access to food. For some, it is often enough to use simple “child-lock” devices. However, often the food drive may increase and the need for greater food security becomes necessary. For others, food seeking behaviors may be very intense at a young age so parents must take steps to make their home very secure early in their child’s life.

Food security may seem cruel, but it saves lives. Locks and motion alarms are safety measures. They improve the quality of life for the person with PWS, as well as those who support them. Locks and/or alarms can:

- Prevent binge eating, which could result in death.
- Prevent extraordinary weight gain which results in morbid obesity and many medical complications.
- Prevent anxiety and guilt over being able to seek out and eat food they know they should not have.
- Allow those who support them the ability to sleep and do other activities that may draw them away from the need for constant surveillance of food sources.

Emotional Adaptations for Food Security

- Keep food out of sight.
- Have predictable times for snacks and meals.
- Communicating any changes related to timing or food expectations.
- Preplan and discuss outings that could impact any aspect of food.
- No eating in front of a person with PWS unless they are eating or drinking similar items.
- Keep types of food served the same for everyone.
- Be aware of smells. They can cause or raise anxiety.

There is no universal age in which locks or alarms should be installed; all individuals with PWS are unique. In rare cases, a child with PWS may have a very strong food drive at a young age; others may be older. This uncontrollable, biological urge to seek out food can be overwhelming. Even when the food drive is not as strong, people with PWS are typically very interested in food and can gain weight on a lower number of calories than their peers. Any and all steps that can help them with this challenge must be taken.

When it becomes time to apply locks and/or motion alarms, many families are faced with a dilemma of trying to figure out the best method to secure their food. There are many ways that

families do this; there is no one right way. Anything that helps the person with PWS to “be safe” and prevents food access – is the best and correct one.

The following show some examples of the more common products that parents and caregivers have used to make their home “food secure”. There are more options for refrigerator locks, as well as locks for cabinets. Many people find it easier to go to a local hardware store, while others prefer to purchase these online. The following are just a few examples.

Refrigerator Locks

There are different ways to lock a refrigerator. There are locks available that do not require you to drill into the refrigerator. If a refrigerator coil is hit by a drill, it will be damaged. All of these can be found by doing a web search, online stores or at local department stores.

For Those Who Don't Require a High-Level Security:

Often times, younger children with PWS do not have the strength or fine motor ability to open cabinets or refrigerators, so parents may be able to use child safety locks.



For Those Who Require a Higher Level of Security:

As the person with PWS grows older, more secure locks are often needed.



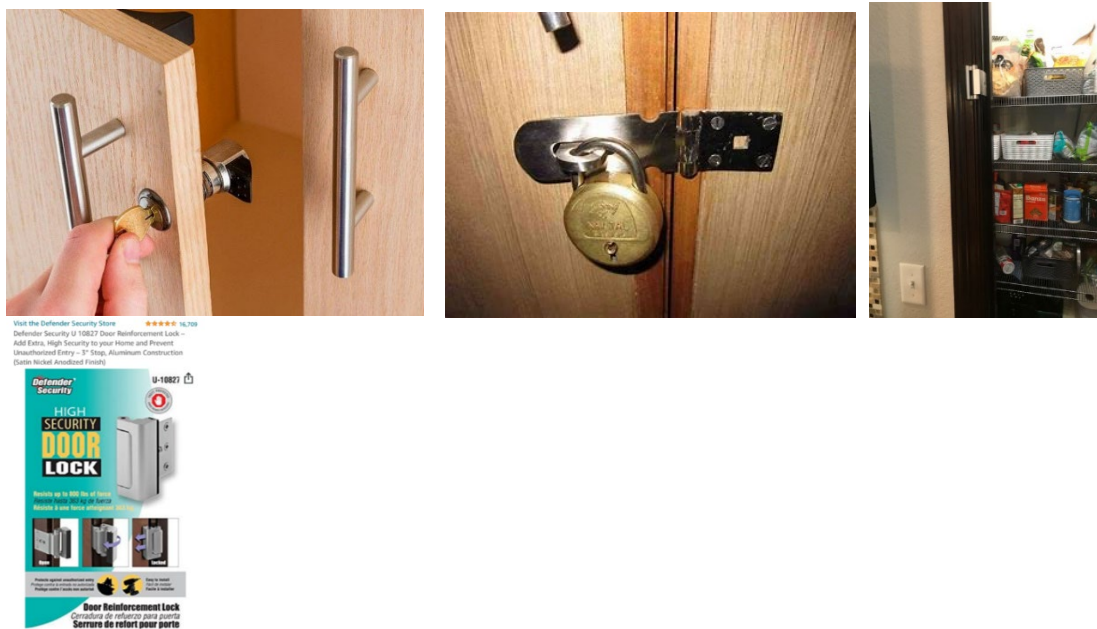
Cabinet Locks

Just like refrigerator locks, there are options for those who need to lock their cabinets. An enclosed locked pantry is used by some. However, many kitchens today have an open layout so many people lock a few cabinets that contain all food items. If you are unable to make permanent changes to cabinets, there are some ways to provide this security.

For Those Who Don't Require a High Level of Security:



For Those Who Require a Higher Level of Security:



Motion Alarms

Some people use motion alarms, either alone or in combination with locks to help provide food security. Websites that provide security for those with Alzheimer's disease or other forms of dementia can offer several resources.



A Few Tips:

- Use products that work best for you and your family
- Examples of locks include – bicycle locks, pad locks, magnetic locks, and Marine locks
- Some prefer to use keyless models to minimize the “lost keys”
- To locate these items, do an online search for “refrigerator locks” or “cabinet locks”
- PWSA I USA also offers Marine locks for sale on our website – Shop – Prader-Willi Syndrome Association I USA (pwsausa.org)

How Do I Know When It’s Time to Lock?

There’s no specific age when locks need to be applied. Some require them as a toddler. Others may not need them until they are older. Some things to keep in mind:

- You start to see a greater preoccupation with food with more food seeking behavior
- You see unexplainable weight gain
- You discover food is missing
- They tell you they are taking food

Once locks are applied, many persons with PWS report feeling “safer”. It provides emotional and physical security for these individuals. It’s often more difficult for the parent and family members than it is for their loved one with PWS. Often times, parents report that they “just knew it was time.” What is most important is to keep the person with PWS safe.

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