PRADER-WILLI SYNDROME ASSOCIATION

Food Safety—Locks and Alarms

In order to keep a child or adult with Prader-Willi syndrome (PWS) safe and secure, parents and care givers must use locks and/or alarms to help this individual by preventing him/her from accessing food. Although this may seem cruel, it is life saving. Locks and 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.

At What Age Should Locks Be Applied? Many parents want to know at what age locks should be applied. There is no universal age; it is very individual. In some rare cases, a child with PWS may have a very strong food drive at a young age. He/she may search or steal food at the age of 3 or 4 years. Others may be older. In other cases, parents may not have to apply locks until their child is in the teens.

Keep Food Out of Sight. Keeping food out of sight is a common, courteous practice that most parents and care givers do – no matter what degree of intensity exists in the person's food drive. It may help to divert the individual's mind away from food, at least for a period of time. Having food out of sight may provide less temptation, thus preventing the person from experiencing anxiety, guilt and failure. When people leave food out, the person with PWS is less able to focus on other activities; he/she is being set up for failure. The uncontrollable biological urge to seek out the food can be overwhelming. Even when the food drive is not as strong, people with PWS are always very interested in food and can gain weight on a lower number of calories than their peers. Any steps that can help them with this challenge must be taken.

Which Way is Best? When it becomes time to apply locks and/or 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. Any way that helps the person with PWS to "be safe" and prevents food access – is the best and correct one.

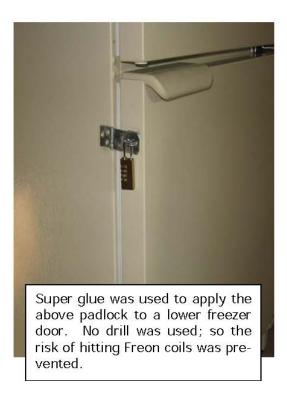
Samples and Resources: The following pages show some examples of the more common ways and products that parents and caregivers have used to make their home "food secure". Websites are also shared. Many people find it easier to go to their local hardware store while others prefer to surf the internet and purchase items online. There may be other resources or Web sites you may find. This is just a sample.

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1. In this picture, a 2" x 1/2" x 1/8" flat mending strip was screwed into existing screw hole on top of the refrigerator. These holes are also found in the space between the upper and lower compartments on the refrigerator. These holes are normally used to reverse the direction a refrigerator door opens. You simply remove the plastic cap that covers the hole and screw on the strip.







Depending on the child or adult, some families are able to use simple child-lock devices on the refrigerator. This would only be applicable for the person with PWS is not a strong food seeker.

A FEW TIPS

LOCKS:

- *Pad locks
- *Bicycle locks
- *Combination locks Magnetic locks

(*Have keyless models that prevent fear of losing keys)

ALARMS:

There are several models available through Radio Shack and other companies that make safety devices for persons with Alzheimer's and other forms of dementia.

REFRIGERATORS: HOW TO PREVENT DRILLING INTO FREON COILS

Use Super Glue to attach hasps. When using this method wait 12 hours before attaching locks. This will help to make sure that the glue is set.

How Will We Know When It is Time To Apply Locks?

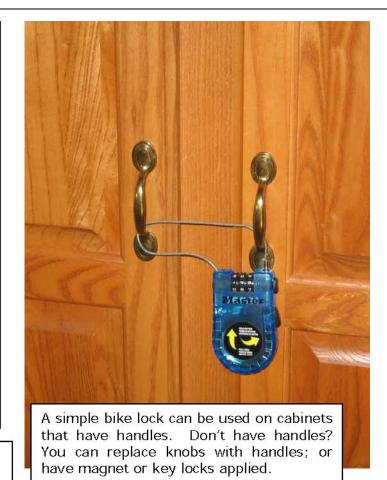
There is no specific age or pre-determined time that locks are applied. Some may need to apply them when the child is very young; others may not need to do this until they are older. Things that may indicate the time is near or now include:

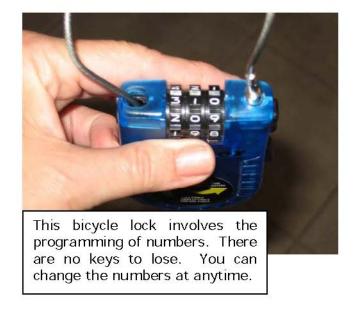
- You start to see an increase preoccupation with food with more observable food seeking behavior.
- You may also see an unexplainable weight gain.
- · You discover that food is missing.
- They may tell you that they are taking food.

Once locks are applied, many persons with Prader-Willi syndrome (PWS) report feeling "safer". The burden of temptation and guilt is removed. It is often more difficult for parents and family members than it is for the person with PWS.

Initially if the younger child has fine motor weaknesses, child-safety locks may be enough. Once their weaknesses become less, you will need to apply stronger, more secure locks.

Often times, parents report that they "just knew" it was time.









Magnetic Locks – A magnetic lock is applied to the inside of the cabinet door and inside the cabinet itself. A special magnet device ("a key") is used to release the magnet in order to open the door. You can flip the magnet and deactivate it when the lock is not needed. This locking system cannot be seen from the outside of a cabinet. There are some brands that require small screws to secure the locks; there are others that use a sticky-tape to apply. These are available on line or in areas of stores where child safety products are found.

Alarms

There are many different types and brands of alarms available. There are motion detec-tors, window and door alarms. These alarms can be set to sound as a chime or as a loud piercing sound. Many of these devices allow you change their position to various room locations. Some use batteries; others may be plug-ins.

WHERE TO LOCATE LOCKS AND ALARMS:

Local hardware stores.

Radio Shack

Stores that sell child safety products – Toys R Us, Babies R Us,

Brands or Product Names First Alert Safety 1st Kidco

WEBSITES:

www.marinelocks.com

Refrigerator locks—enter code PWSA for a discount

www.radioshack.com

door alarms and chimes, portable motion detectors alarm/chime

www.safetyandsecuitrycenter.com

Door and window alarms, door knob alarms,

https://secure17.nexternal.com (Alzheimer's Store

Online Store)

Invisible Cabinet Locks – magnetic locks (additional keys), child-proof Refrigerator latch (good for the less aggressive), door and window alarm Seat Belt Alarm

www.babyuniverse.com

Tot loks – magnetic locks (additional keys), door alarms,

There may be other website that carry these products. This is just a sample of some that parents have shared.