Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

Written Request for Waiver or Exemption

This template is designed for residential providers' use to request that Community Care Licensing (CCL) issue a waiver to authorize restricting access to food with locks. Copy this template on to your stationary, enter the applicable CCL Regional Office address, and edit as needed. If you need assistance contact Evelyn Schaeffer, CCL Assistant Program Administrator, at (916) 653-9272.

Date

Name of Community Care Licensing Regional Office
Address
City, State Zip

RE: Request for Waiver or Exemption for Consumers' Health and Safety Needs
for facility to serve persons with Prader-Willi syndrome
ICD-9: 759.81 Prader-Willi syndrome
ICD-10: F07.0 Personality change secondary to a medical condition - PWS

Dear xx:

My name is xx and I am the owner and operator of xx, an Adult Residential Facility / Supported Living Agency. I write to request a Waiver to securely lock at all times my home's refrigerator, cupboards, and anything that contains food and beverages. I request this waiver to ensure the health and safety of my home's residents, all of whom have Prader-Willi syndrome (PWS) as confirmed by a physician's report.

Ordinarily we do not restrict our residents' access to food. However, we are serving residents who have a diagnosis of PWS and therefore require that their access to food (and money which could be used to purchase food) be restricted with locks.

PWS is a life-long and life-threatening medical disorder which causes substantial deficits and functional limitations in all major areas of life including:

(1) Self–care
(2) Receptive and expressive language
(3) Learning
(4) Mobility
(5) Self–direction
(6) Capacity for independent living
(7) Economic self–sufficiency

There are **significant medical symptoms of PWS which necessitate a Waiver** authorizing us to lock our food sources which include but are not limited to:

Hyperphagia : A hallmark symptom of PWS is the **physiological, unrelenting biochemical drive to eat coupled with a lack of feeling satiated, or full, or even discomfort despite the quantity of food consumed.** No medication controls or even reduces the PWS hyperphagia food drive symptom, which lasts throughout the individual's lifetime.

Slow Metabolic Rate: PWS slows the metabolic rate to almost half what it should be. My residents with PWS require almost half the calories as their typical peers and will gain an enormous amount of weight very quickly on even a few extra calories.

Gastroparesis (Slow Emptying Stomach): The rate of emptying of stomach contents is significantly slower than the norm which means that food remains in the stomach and digestive tract much longer than it should. As more food is consumed, the stomach is stretched which can result in gastric rupture or gastric necrosis, often resulting in death.

Slow Emptying Bowel: The rate of emptying of bowel contents is significantly slower than the norm which means that feces excrement remains in the intestinal tract much longer than it should. As more food is consumed, the bowel is stretched which can result in bowel rupture or bowel necrosis, often resulting in death.

Dysphagia (Swallowing Problems): The swallowing and esophageal transport of food in individuals with PWS is impaired. The rapid eating associated with the syndrome coupled with dysphagia greatly increases the risk of choking, aspiration, pulmonary infection, and asphyxiation. Additionally, food impaction within the esophagus and/or unexpected regurgitation can also result in airway occlusion and/or aspiration.

Impaired Pain Threshold: Lack of typical pain signals is common and may mask the presence of infection or injury. My residents with PWS may have difficulty localizing the pain or may not complain of pain until infection or damage is severe.

My residents with PWS must have external food controls and be supervised every moment of the day and night or they are at risk for dying prematurely from choking, gastric necrosis, gastric rupture, bowel necrosis, bowel rupture, from behavioral complications related to their hyperphagia food-seeking drive, or from complications related to morbid obesity.

For PWS, "external food controls" are physical locks.

When food is secured with locks at all times, my residents with PWS will be medically safer.

Because persons with Prader-Willi syndrome lack basic adaptive functioning skills, lack the ability to properly provide for their activities of daily living, cannot live independently at any time in their lives, and are unable to be economically self-sufficient and live an independent, self-directed life, **they depend upon a safe and secure residential environment**. One of the most basic health and safety standards of care for persons with PWS is that **all sources of food – including money – must *always* be securely locked *and* that staff are well-trained in PWS providing supervision at all times, day and night.**

All PWS professional organizations, including the International Prader-Willi Syndrome Organization, the national Prader-Willi Syndrome Association (USA), and the state Prader-Willi California Foundation, advise that access to food (and money with which to purchase food) be restricted with locks to ensure the health and safety of persons diagnosed with PWS. It is well documented in journal articles, books, and training videos that the standard of care for persons with PWS is restricted access to food utilizing physical locks.

In the file of each of my residents is a **Physician's Note** that prescribes that their food and beverages be restricted with physical locks for each of my residents. Other residents will not be adversely affected by granting of the waiver because they too require restricted access to food.

Each of my resident's **Individual Program Plan** instructs the Adult Residential Facility to securely restrict access to food and beverages with locks.

Each of my resident's **Person Centered Plan** instructs the Adult Residential Facility to securely restrict access to food and beverages with locks.

Prader-Willi syndrome is a unique and extraordinarily difficult syndrome to manage, thus all individuals with the syndrome need specialized care for the duration of their lives. **In order to keep our residents with PWS safe and ensure their health and safety, I need a Waiver authorizing me to lock our home's food sources at all times of the day and night.**

Thank you for your consideration of this information. I am happy to provide you with whatever additional information that is necessary for you to authorize our Waiver.

Sincerely,

Name
ARF/SLS Name

References

Grey matter volume and cortical structure in Prader-Willi syndrome compared to typically developing young adults. Manning KE, Tait R, Suckling J, Holland AJ, PubMed **Neuroimage Clin.** 2017 Dec 20; 17:899-909. doi: 10.1016/j.nicl.2017.12.027. 2018.

Driscoll D, Miller J, Cassidy S, Schwartz S. Prader-Willi syndrome. Journal of GeneReviews. Funded by the NIH. 2014

Goldstone A., Holland A, Hauffa B, Hokken-Koelega A, Tauber M. Recommendations for the diagnosis and management of Prader-Willi syndrome. Journal of Clinical Endocrinology & Metabolism, 10.1210/jc.2008-0649. 2008

Managing PWS: A primer for psychiatrists. L. Gourash, J. Forster

Medical Overview: A diagnosis and reference guide for physicians and other health professionals for treatment of individuals with PWS, article, Prader-Willi Syndrome Association (USA)

What is Prader-Willi Syndrome? Prader-Willi California Foundation

Prader-Willi Syndrome Synopsis. Prader-Willi California Foundation

Supporting the Adult with PWS in the Residential Setting, Barbara J. Goff, M.Ed., Prader-Willi Syndrome Association (USA)

PWS Residential Staff Training DVD produced by the Prader-Willi California Foundation with support from the Prader-Willi Syndrome Association (USA)

PWS Behavior Management Strategies DVD produced by the Prader-Willi California Foundation

PWS Behavior Management Strategies: Beyond the Basics, video and flash drive produced by the Prader-Willi California Foundation