

This e-book was created to help parents, grandparents and others raising children with Prader-Willi syndrome (PWS). There is not a one size fits all solution to behavior or eating problems, but there are styles that seem to work better than others with children who have this syndrome.

The sections are broken down into:

- **Food Control**
- **Behavior Management**
- **Family**
- **School Information (Basics)**
- **Medical**
- **Miscellaneous**

If you are able to start some of these strategies early, it will be easier. If you are starting later, it may take some time to see results. Remember, if you are trying to establish new boundaries, children will often work at getting you to go back to the old “normal” ways, so be patient and try to look long term. It is easier to establish boundaries in the beginning if you can.

The articles selected are one and two page handouts that will hopefully provide practical strategies. Most of the suggestions on behavior can be applied to all children, even those without a disability, to help reinforce positive behavior.

There is an exercise DVD included and it is a great way to start making exercise a fun and routine activity. Check with your doctor to make sure it is alright for your child to engage in this activity. If your child is heavy, you may want to start exercise in a pool. They do not have to swim, just start by moving around in the water.

If you have any questions about this E-Book or would like more information, please feel free to contact PWSA (USA) at (800) 926-4797 and ask for a family support counselor.

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FOOD CONTROL

This section will help with controlling your child's food to assist with weight control. If your child is older and you are starting a menu plan, be patient, it will take time and there may be more behaviors until they are certain you are going to stick with the new food plan and that food is not accessible.

If you are already working to control the food, you may find that your child really likes the new plan. The foods they will be eating are lower in calories and they can have more variety. Start with the 1000 calorie menu and then go from there. Some people who have PWS use an 800 calorie meal plan to lose and maintain weight, some it's 1200 calories, so weigh your child weekly and see what works for them.

Families and therapists often mistakenly believe the person with PWS cannot be happy unless they have as much food as they demand. If food security is in place, their anxiety will go down and in the long run there will be a decrease in stress and behavior problems surrounding food.

Remember When Food Security is fully implemented; weight and behavior are both managed successfully and simultaneously.

If you need more help with food control or a food plan or you have any questions about this section call PWSA (USA) at (800) 926-4797.



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PRADER-WILLI SYNDROME – A PARENT’S PERSPECTIVE

BY JANALEE HEINEMANN

“Prader-Willi Syndrome – what’s that?” I asked as most people do, when I first met my new husband, Al, who was raising his six-year-old daughter, Sarah, and seven-year-old son, Matt, who has the syndrome. Being a social worker and having raised three children of my own, I thought I knew a lot about child rearing. As our relationship grew, I decided that before I made a commitment to the marriage, I needed to make a commitment to researching the syndrome. Although I found some medical articles dealing with the diagnosis and physical aspects, I found the realities and impact of the syndrome could not be comprehended until I actually lived it. The following represents our blood, sweat, and tears, and laughter of how we have survived the syndrome over the last seven years.

PW DIET SECRETS (for parents only)

Although our policy with kids has always been one of honesty, a child with PWS must live daily in an unfair situation, so anything we can do to allow our son, Matt, feel he is being treated a little more equal in this unequal world of weight management, we’ll do. Now, the trick is to always stay a little bit smarter, more devious, and more alert than he is. Anyone, who has lived with a child with PWS, knows that when it comes to food, this is quite a challenge. One that we don’t always win. But, the fact is. Matt did lose 32 pounds in a year. When Al was raising the kids alone, he attempted many diets with Matt, with no success. There was always the angry struggle of Matt having to eat different than the rest of the family and never having his favorite foods. Frequently “giving in” and the fine art of “sneaking” made eating all his lettuce salads a futile effort.

We have all read the dietary advice from nutritionists and doctors. Although I agree with their diet programs’ clinical correctness, the reality is, I have to also live with a child with PWS. In searching for the path of least grief, I have come up with my own offbeat advice.

Lock Away Temptation—It would have been hard to convince us before, but the pain and grief of putting locks on the refrigerator and cupboards was ours—not Matt’s. He not only understood, but also seemed relieved that the responsibility of not sneaking food was taken from him. Matt knows he has no control. As he said to us, “I try not to sneak. But my hand reaches for the refrigerator and I can’t stop it.”

The Fine Art of Sneaking—Perhaps children with PWS live in an unfair world, but why rub their noses in this unfairness? I was appalled by an article on behavior management on adolescents with PWS who were forced to sit with half the plate of food in front of them. They were punished if it was touched. (Perhaps we should also try electric prodders on the refrigerator!) Since we are fortunate enough to be able to eat more than Matt is, the least we can do is be discreet about our eating. (Sneaky is another word for it.) Matt’s sister, Sarah, is allowed snacks and extra treats, but only if she asks out of sight and sound of Matt, and eats

them discreetly. Perhaps when Sarah grows up, her husband will have a difficult time understanding why she prefers to eat behind the bedroom door, but it allows her the privileges of other kids and Matt is no worse off for what he doesn't know. As for ourselves, we have a "stash drawer" and lock ourselves in the bedroom—for more than sex!

The Hand is Quicker Than the Eye—Preparing the food with less grief has been helpful. We don't allow Matt to fix his own food; dish his own plate out; or hover in the kitchen while meals are being prepared. Although Matt was not happy at all about not being able to "help out" in the kitchen anymore, (after all, his goal in life is to become a chef) he has finally accepted the fact that is the way it would be. Now, he isn't as aware of where we are skimping on his food, and we don't have to be as alert to whether his hand is being quicker than our eyes.

Dinnertime Drama—Serving the food can also become a fine art. Although Ozzie and Harriet Nelson would be appalled at the thought of their kids eating in front of the TV, we quit kidding ourselves long ago of being able to emulate the Nelsons. Thus, we generally allow Matt and Sarah to eat in front of the TV, and have their food all set up on trays. This accomplishes several things: (a) Matt is less aware of who gets what portion. (b) The TV reduces his obsession with keeping an eye on the food. (c) Food is dished out of pans directly onto the plate—saving dirty dishes (an extra bonus) and having to guard the table. (d) We then have the opportunity to sit down to a peaceful meal and conversation.

Garnishing the Garnish—Food content requires visual skills along with the usual nutritionist's advice. Matt gets the same food we do, but in smaller portions. We use a smaller plate, smaller cup, and spread the food out more on the plate. We also add in non-fattening foods (i.e. carrot, dill pickle, diet Jell-O) to make it look like more. Since he may only get one-half a banana or apple, it is cut up into slices and served in a bowl to make it less obvious that it's only half. Less visible foods are skipped (i.e. butter, mayonnaise on sandwiches and potatoes). The "finishing touch" is to serve Matt a little bit smaller portion than we plan on him eating, so that he can come back for "one more spoonful".

Surviving the Cafeteria—As you can see, we have attempted to select the path of least grief—for Matt and for ourselves. Attempting to pack a diet lunch for school is one of those unrewarding chores we decided to avoid. Matt is allowed to buy the hot lunch and skips one fattening item on the menu (i.e. the potatoes or the desert). Which item is skipped is his choice (providing it's not the salad). He receives great praise from his teacher who monitors his choice. Of course, this would mean nothing if Matt were sneaking leftovers or snacks from other students. We keep in close touch with the school, his teacher, and the cooks, to see that Matt is closely monitored in the lunchroom —always reminding them that although Matt may appear to be initiating great control over his diet, his hand may be quicker than all of their eyes. The teacher has explained to Matt's classmates why it is so important for Matt's health not to give him any of their food.

The Payoff—Self-Pride—Every child with PWS is a little bit different on how much they can eat and not gain weight. Besides, rare is the case where you can truly monitor your child's every calorie. So, we have a Sunday morning weigh-in. We keep a chart on the refrigerator and at first, when Matt lost two pounds, he was rewarded with a small toy. At this point, we have been

able to eliminate the reward. Matt gets enough self—satisfaction in his weight loss to want to continue. As he says with a total lack of modesty while beaming with pride, “I think I world’s champion weight loser!”

Love Means Saying “No”—All of your hard work will be to no avail if others are “treating” your child behind your back. I do not feel we, parents of a child with PWS, have to apologize to others when we request that they do temporarily what we do every day of the year. If relatives and friends really care about you and your child, they will not sabotage your efforts. In fairness to others though, they first need to be educated. This may mean swallowing your pride, (for Al, it was hard at first to admit the extent of Matt’s problems), and taking the time to explain PWS in detail with all of it’s do’s and don’ts to friends, neighbors, relatives, babysitters, etc. If everyone is treating your child with the same consistency that you do, there won’t appear to be “good guys” and “bad guys”. A child is not going to understand why Grandma (or heaven forbid—Daddy!) slips him/her a treat, yet Mommy always says “No!”. Although we acknowledge to Matt that life has not been fair to him, and that we are truly sorry for his continual hunger and frustration, gradually Matt has learned that with Prader-Willi, “No” can be a very loving word.

Obesity Still Kills or When Food is Deadly

By: Janalee Heinemann MSW, PWSA (USA) Director of Research & Medical Affairs

Although many of our children and adults who have Prader-Willi syndrome (PWS) are slim in this day and age due to early diagnosis, education of parents and other care providers, plus growth hormone, I do not want us to get too complacent. PWS is still the deadly appetite. Recent calls for help that I have received in our crisis program included: girl, 5 yrs, 117 lbs; boy 9 yrs, 126 lbs; girl 13 yrs, 254 lbs; boy 11 yrs, 220 lbs; teen 326 lbs; male 24 yrs, 550 lbs;-- and the list goes on.

In studying the 163 PWS deaths that are in our **PWSA (USA) Study of Death** database, Dr. Stevenson wrote: *“Regarding the obesity related deaths, in removing all pediatric cases and cases where cause of death was unknown or clearly not obesity related (accidents, choking, etc. – although some of them may have some obesity component), the average weight at death for these individuals was 257 lb.”* Besides people with PWS being at greater risk of obesity, this obesity puts them at risk to die of obesity related complications. In separate international reports of deaths in PWS, there have been a large proportion (half or more) that were related to respiratory or cardiorespiratory disease. Dr. Linda Gourash (Pittsburgh Partnership) reports in her poster presentation, **Clinical Presentation of Obesity Hypoventilation and Right Heart Failure in Prader-Willi Syndrome**, *“The all too familiar clinical picture of shortness of breath, decreasing physical activity, and leg swelling seen in morbidly obese persons with Prader-Willi syndrome is due to hypoventilation during sleep, leading eventually to respiratory failure with or without right heart failure. The onset may be rapid or slow but is always insidious, that is, initially unrecognized.”*

Mortality in Prader-Willi Syndrome from New South Wales,(published in Am J Ment Retard. 2006 May) the authors of the study state: *“Prader-Willi syndrome is a substantial risk factor for death, above the risk related to intellectual disability alone. Those with Prader-Willi syndrome have higher mortality rates than those with intellectual disability in general. They have a much higher estimated mortality ratio than a comparison group with mild or borderline intellectual disability. The pattern of death in those with Prader-Willi syndrome suggests that obesity-related disease is a likely major risk factor. Management of caloric intake is truly a life-and-death issue for people with this syndrome.”*

Please remember, and remind your relatives and schools, when you are showing your child love during this holiday season, with Prader-Willi syndrome, you can love your child to death.

BEYOND THE DIET – For Parents

By Janalee Heinemann - Prader-Willi Syndrome Association (USA)

Because of the number of crisis cases that come into our 800-telephone number, I feel the need to address the most common errors I find in the management of weight control with PWS and PWS-like children. In most of the cases we get involved with that are due to the life-threatening weight of a child, I find that the physician first sends the parents to a dietician, then views the parents as failures because the child continues to gain weight in spite of the dietician's clinical advice.

One child who paid the ultimate price was Christine Corrigan, a 13-year-old from California who died weighing 680 pounds. I was involved as an expert witness when her mother was charged with felony neglect, and the case brought international media attention. One of the charges was that her mother had not taken her to a physician in a year. But facts showed that before her final year of life, Christine's mother had taken her to both a doctor and nutritionist 90 times. During this time Christine had been put on a typical diet, and Marlene, Christine's mother, was admonished because Christine kept gaining weight.

What was not taken into consideration is that it takes far more than a diet to get weight under control when you are dealing with a child who has Prader-Willi syndrome or a PWS-like disorder such as hypothalamic obesity.

THE FOLLOWING ARE IMPORTANT REALITIES FOR PARENTS TO CONSIDER:

How much of a food forager is the child?

Some of our children with PWS are much more creative at getting food than most people can imagine. One example from hundreds I could give is the boy who would crawl into his parents' bedroom on his hands and knees in the middle of the night. He would then slip his hand under the mattress directly beneath his mother to get the kitchen keys she had hidden between the mattress and box spring. After getting food, he would slip the keys back under the mattress without waking her.

It took his mother months to figure out the mystery of how he was getting food!

Some children with PWS do not have nearly that strong a food-foraging drive. You may believe that your child does not sneak food. However, if your child continues to gain weight in spite of the fact that the food you are providing him or her is only what's on the diet plan, suspicion and investigation are in order. Remember that the hand of a child with PWS is often quicker than the eye of the parent or teacher.

How many calories does it take for the child to gain weight?

Many dieticians put the child on a regular diet of 1,500 calories and then think that the parents are not being honest when their child continues to gain weight. It is not unusual to have to put a child or an adult with PWS on as low as 800 calories a day. For our family, daily weigh-ins were important because Matt could gain five pounds in a day. It also helped us in our role of playing detective in regard to tracing down where he was getting the forbidden food.

Locking up the food

If the situation requires locks – who is going to show you how to install and maintain a locked environment in the home? Many a PWS family has ruined their refrigerator or freezer by drilling into the Freon coils.

Perhaps you may choose to use padlocks with keys and do careful key checks to be sure all are accounted for. Once our son Matt was so concerned about his weight gain that without request, he handed over the hidden key he found that we forgot we had.

Another time, we discovered he could unlock the cabinet and refrigerator locks with a bobby pin in 60 seconds or less! In another instance, his older brother Tad came home to find Matt hot and sweaty – and working on unscrewing the last hinge on a locked door. Tad took Matt with him to the hardware store to buy "Matt-proof" locks (hinges with the screws on the inside).

Some families prefer to use combination locks. Combination locks (you can buy them in pairs with the same combination if you're locking more than one thing) solve the problem of hiding or losing keys--and eliminate the constant searching by the person with PWS for them. Just make sure it is the type that you can change the combination if your child mysteriously figures out the combination. One family wrote the combination down in code--and their daughter with PWS figured out the code!

Other families have successfully used some sort of alarm system. There is no right answer – but alternatives have to be weighed, and often a family will need outside assistance to work out the system that is best for their family.

BEYOND THE DIET – For Parents

If Your Child is Young

Locking up food is not as awful as it sounds as long as the family keeps a sense of humor and a sense of compassion for their child and teaches the same to their other children. Also, if your family is considering buying a new refrigerator, you may want to consider a side-by-side model where you can just wrap a lock around both handles.

A family may find it better to consider locks sooner rather than later. Our son was actually relieved that we put locks on, saying "I try and try, but my hand still reaches into the refrigerator." It was nice to be able to go to the bathroom without worrying about what Matt was doing.

I once received a call from a mother who decided to start locking when her daughter was 18 or 19. Unfortunately, by then her daughter had a mind of her own and had just chased two different locksmiths out of the house that week.

If your child is older – Who is in control in the family, the child or the parents?

If your child is the one in control, especially if the child is older, your family may find it essential to involve a professional who can assist the family with good behavior management skills. As would be expected, food reduction will temporarily create more acting out, and parents will need to learn "tough love" skills.

Who else in the extended family and community needs to be educated?

The parents may not be the problem at all. It may be grandma or the neighbor or the day care provider who is giving extra food to the child. This list could go on and on, since food is everywhere in society. Loved ones often think, "Just one cookie won't hurt." Since feeding our children is typically a sign of love in all societies, and food is a basic essence of life to exist, it goes against all loving instinct to deprive our children of food.

I remember one of the many times when Matt was gaining mysteriously. We had previously educated the pre-school staff and told them we would feed Matt breakfast at home to spare them the concern of what he could have. But we discovered that unknown to us the cook had quit, and Matt had convinced the new cook that he was never fed at home.

If the family has several children or few resources – keep the diet simple.

It is unfair in such situations to think that you or your dietician can set up a complicated diet requiring a lot of food measurements and calculations and then expect, when you are a parent overwhelmed with other responsibilities, that you will be able to follow it long term.

A single parent with limited finances and other children must think about resources. Does the family have a microwave? If so, consider foods in pre-prepared packages that will work. Seven different Weight Watchers or Lean Cuisine dinners that the child can choose from (if the calories fit) with a diet Jell-O pre-packaged dessert may be much more realistic than expecting that that parent will weigh or measure and cook each meal. It also may prevent conflict. Our children do well with sameness. Special funding for these pre-packaged meals may need to be considered, but remember, it is a lot cheaper to supplement the food cost than to pay for all of the obesity related medical complications the child could potentially acquire.

Diet is a lifetime issue. The diet has to be one that both parent and child can live with.

Have a Support System

Don't hesitate to seek out someone, some agency, or some group who can help you with all of the details, funding, and personnel support—and yes, personal support—needed to follow up with weight control. This is not something a single parent can handle alone without a lot of outside support – and a critical or too lenient spouse may be worse than no spouse at all when it comes to reducing or maintaining the child's weight.

As I stated above, there are significant variances with each child or adult with PWS. Some will ask for more food and make mild attempts to acquire more food if it is available but that is all. On the other hand, other children will go to such extent to forage for food that they will sneak out of the house in the middle of the night, rummage garbage cans, and con everyone including the bus driver at school into giving them food. I have had parents out of desperation (more than one) lock their children in the bedroom at night – then have charges pressed against them for doing so.

Although we feel that with this type of disability a child/adult's right to live outweighs their right to food and freedom, throughout the constant challenge of weight control we need to never lose our compassion.

A young man who had Prader-Willi syndrome, John Simon, wrote "We have a heart, soul, mind and spirit and need you to understand us. Understanding and caring are two of the most important things you can do for us...I could feel sharp teeth tearing at my stomach like piranhas and still do. I know I need someone to keep the cupboards locked and I need someone to keep me active and to control my weight. I want to have some fun in my life.... If the government has money to fund crisis situations why can they not prevent situations from becoming a crisis? I need full support NOW before I get into a crisis situation. I want to live and I am sure you want the same for your child."

Follow the Principles of Food Security

NO DOUBT-*No doubt when the next meal or snack will be served*

Plus

NO HOPE-*No hope to obtain unauthorized food*

=

NO DISAPPOINTMENT-*That unauthorized food is not available*

*concept created by Janice Forster, M.D. and Linda Gourash, M.D. of *The Pittsburgh Partnership Specialists in PWS*

NO DOUBT

No doubt when the next meal or snack will be served

- *Establish consistent routines for food consumption. Determine when food will be served (every 2 ½-3 hours) Breakfast / Morning Snack / Lunch / Afternoon Snack / Dinner*
- *Determine your response when asked for food before mealtime.*
- *Establish consistent rules for food consumption*
- *Food served on plates. No family-style bowls on table.*
- *No second helpings unless you ALWAYS do seconds.*
- *Serve food on smaller size plate. Cut food in small pieces, spread out to fill entire plate. Baggie of snack cut or cracked into multiple pieces looks like more.*
- ***To someone with PWS, it's all about quantity.***

NO HOPE

No hope to obtain unauthorized food

- *If food is available, the individual with PWS can do little else but think of ways to get that food. Access to food creates hope. Hope creates anxiety. Anxiety creates the potential for unwanted behaviors. Eliminating access to food reduces behavior problems.*
- *Restrict access to food by using locks on the refrigerator, food pantry, kitchen, medicine cabinet, liquor cabinet, etc.*
- *Establish rules for type, quantity of food prior to attending parties, restaurants, etc.*
- *Put a lock on the food puts a lock on the thought that unauthorized food is available.*

- **NO DISAPPOINTMENT**

Life is good when there's no disappointment!

FOOD SECURITY Checklist for the Family

NO DOUBT

- My child has a menu posted. He/she always knows what he/she is eating for the next meal.
- My child takes his/her lunch to school/work.
- My child is rarely disappointed about food./ He always gets exactly what he is expecting. 😊
- My child sometimes corrects others about his/her diet. 😊
- My child knows when he/she is going to get a treat well in advance. There are no surprises.
- My child never receives unplanned treats.
- My child rarely asks about what he/she will be eating. He/she already knows. 😊
- My child knows when his/her meals are scheduled during the day. 😊
- I never threaten my child that a meal will be delayed or changed in any way.
- My child has scheduled zero calorie treats built into his /her daily schedule.
- My child knows that if his usual menu is disrupted for any reason he can always count on the same “alternate”.

NO HOPE

- My child does not have free access to calorie free foods or beverages other than water.
- During meal preparation, another member of the family is assigned responsibility for watching my child with PWS.
- My child rarely argues/tantrums about food. 😊
- When we go to a buffet at a restaurant or party, my child knows that I will be preparing his/her plate.
- My child has someone assigned to be with him/her during lunch at school/work.
- My child does not keep his/her own money.
- At this moment, there is no unlocked food anywhere in my home.
- [As far as I know] My child has not successfully stolen extra food in the last 2 weeks. 😊
- We have a plan for every special occasion and my child knows what the plan will be well in advance.
- Even though my child knows and expects his/her diet, I know that he cannot be trusted to maintain it him/herself. 😊
- My child never prepares his/her own plate.
- When we “dine out” or “order out”, we get the menu in advance so that my child knows exactly what he/she may order.
- My relatives/neighbors never offer my child food. I have successfully explained to them why they must never do this. 😊

😊 = signs of success. If you have all of these signs of success your food security is complete!

FOOD SECURITY Checklist for the School/ Workplace

NO DOUBT

- This student/worker has a menu posted. He/she always knows what he/she is eating for the next meal.
- OR
- This student/worker brings his/her lunch to school/work.
- During any food preparation, another member of the team is assigned responsibility for watching this student/worker with PWS.
- This student/worker is rarely disappointed about food; he/she always gets exactly what he/she is expecting. 😊
- This student/worker sometimes corrects others about his/her diet. 😊
- This student/worker knows when he/she is going to get a treat well in advance. There are no surprises.
- This student/worker knows that if his usual menu is disrupted for any reason he/she can always count on the same “alternate”.
- This student/worker rarely asks about what he/she will be eating. He/she already knows. 😊
- This student/worker knows his/her schedule every day.
- This student/worker knows when his/her meals are scheduled during the day.

NO HOPE

- This student/worker is never offered food that is not planned in advance and cleared with his/her family or residence.
- I never threaten this student/worker that a meal will be delayed or changed in any way.
- This student/worker has scheduled zero calorie treats built into his /her daily schedule.
- This student/worker has no access to calorie free foods or beverages other than water.
- This student/worker rarely argues about food. 😊
- This student/worker has someone assigned to be with him during lunch at school/work.
- This student/worker has no opportunity to get food during transitions or transportation. He/she is continuously supervised or the food is stored out of reach.
- At this moment there is no unlocked food anywhere in the areas where this student/ worker is permitted.
- This student/worker does not have access to money or to vending machines.
- We have a plan for every special occasion such as birthdays or holiday celebrations and this student/worker knows what the plan will be well in advance.
- Even though this student/worker knows and expects his diet, the entire team understands that he/she cannot be trusted to maintain it him/herself. 😊
- This student/worker has not successfully stolen extra food in the last 2 weeks. 😊
- The other students/workers never offer this student/worker food. Our team has successfully explained to them why they must never do this. 😊
- Our team never uses treats as unplanned rewards.

😊 = signs of success. If you have all of these signs of success your food security is complete!

HELPING WITH DIET MANAGEMENT

Children With Prader-Willi Syndrome at School

Karen Murphy, M.S., R.D. - Betty Lucas, MHP, R.D. - University of Washington, Seattle, Washington

What is Prader-Willi Syndrome (PWS)?

Prader-Willi Syndrome (PWS) is a genetic disorder characterized by hypotonia (low muscle tone) and poor feeding in infancy, incomplete puberty, short stature, behavior problems, and some degree of mental retardation or learning disability. Poor eating and even failure to thrive due to hypotonia in the early months may later become preoccupation with and a powerful drive for food, often resulting in extreme obesity.

Children with PWS are typically sociable, outgoing and good-natured with a desire to please adults. Most have a good sense of humor and a strong sense of empathy. They can also be persistent, perseverative, stubborn and very self-centered. Transition and change can be challenging for them.

A noninherited birth defect, it is estimated to affect 1 in 12,000 to 15,000. PWS is found in both sexes and is not associated with any specific racial/ethnic groups, socioeconomic classes or geographical regions.

What are the Nutrition Concerns?

Most children with PWS are unable to “feel full”. Thus they have a continuous urge to eat, and they will eat as long as food is available. Since their appetite is never satisfied, excessive weight gain can begin in early childhood unless intervention is provided.

Children with PWS have been found to have lower energy (calorie) needs compared to children of similar age, height and sex. Therefore, a lower energy intake is required to maintain appropriate weight for height. To accomplish this, these children need constant and very careful supervision at all times around food. Children with PWS are extremely clever and quick at obtaining food.

Excessive weight gain can lead to medical problems such as diabetes, heart disease and asthma. These conditions tend to appear during adolescence unless weight is controlled by intervention involving all caregivers. If weight gain reaches morbid obesity, it can be life-threatening.

What are the School Issues Related to Nutrition and Eating Behavior?

Most children with PWS must be supervised at all times, food is everywhere today. This includes supervision before, during and after school, during lunch and between classes. Without supervision, the child may be able to take food from others, search through trash cans, pilfer food from a cupboard or refrigerator, or buy it from a vending machine or school

store. Older children may steal money to buy food, get peers to get them food, or accept food their classmates don't want.

Some preschools and most Head Start programs serve food family style (i.e., food is placed on the table and children serve themselves). This can cause a problem for children with PWS because, unsupervised, they can serve themselves large portions of food. They will require help and very careful supervision to see that their servings are appropriate for their energy needs.

Adolescence with more independence brings even greater challenges in managing their access to food, both at home and at school. Providing supervision of food and diet while allowing them opportunities to make good food choices can help set the stage for lifelong success.

Can a Child with PWS Participate in the School Lunch Program?

Yes, all children with special needs are assured a modified school lunch, if needed, according to Section 504 of the Rehabilitation Act of 1973 and the current Individuals with Disabilities Education Act (IDEA). A written prescription for the child's modification can be obtained from a medical provider. The diet prescription should include the child's medical condition, why it restricts his or her diet, and appropriate substitutions (e.g., changing texture, omitting foods, altering energy intake).

Receiving modified school meals that are reduced in energy is very appropriate for children with PWS. If local schools or districts are not familiar with modified school meals, parents and educators should contact the state USDA Child Nutrition Program (National School Lunch and Breakfast Programs) in their state education agency. Some states have developed forms for modified meals that can be given to the medical provider.

Children with PWS have an energy requirement of approximately 8-9 kilocalories per centimeter (kcal/cm) of height for weight loss, and 10-11 kcal/cm for weight maintenance. This is approximately 20-30% less than their same age and sex peers. Although the ranges of appropriate intake vary, the majority of them will have a specific energy amount that they are to be served at each meal. For example, a child may need a 200 calorie breakfast, 300 calorie lunch, and one 100 calorie snack during the school day. There are many ways to reduce the energy level in the school lunch and still provide similar foods. See accompanying chart for specific examples.

HELPING WITH DIET MANAGEMENT Children With Prader-Willi Syndrome at School

CALORIES IN COMMONLY SERVED FOODS*

FOOD	CAL.	SUBSTITUTE	CAL.	CAL. SAVED
8 oz. Whole Milk	150	Nonfat Milk	90	60
Fried Chicken (4 Chicken Nuggets or 1/2 Breast)	200	Baked Chicken (1/2 Breast w/o skin)	150	50
Vanilla Ice Cream (1/2 cup)	150	Vanilla Frozen Yogurt or Low Fat Ice Cream (1/2 cup)	100	50
1 serving Apple Cobbler	300	Unsweetened Applesauce (1/2 cup)	55	245
20 French Fries or Tater Tots	235	Baked Potato (1/2 large)	105	130
Taco w/ Cheese	370	Taco w/o Cheese	270	100
Large Peanut Butter Cookie	150	10 Animal Crackers	115	35
Banana Bread (1 slice)	200	1 Banana	100	100
Ranch Dressing (1 Tbsp.)	95	Low Calorie Ranch Dressing (1 Tbsp.)	40	55

* Calories from Food Values, Bowes and Church, 1994

How Can an Individualized Education Plan (IEP) Help Children with Prader-Willi Syndrome Meet Their Nutrition Goals?

An IEP is a written plan that describes the educational goals and objectives for a student, program modifications and/or adaptations, and services that will be provided. The parents, by law, are members of the team that forms this plan. For

children from birth to 3, this plan is called the Individual Family Service Plan (IFSP).

Following are examples of nutrition objectives that can be included in an IEP or IFSP of a child with PWS:

- Sarah's mother will provide all regular snacks for her daughter. For special occasions (i.e., holidays and birthday parties), Sarah can have 1/2 portion of a single treat, and this will be reported to the family.
- Food is not to be used as reinforcement for LaMar. LaMar's teacher will record his food intake at breakfast and lunch in the daily journal, which is sent home.
- Since Head Start meals are served family style, the teacher will help serve Rachel's food. Parents will review the monthly menu ahead of time and will mark appropriate foods or portions (i.e., 1/2 portion of spaghetti, nonfat milk instead of 2%).
- The school nurse will weigh Ashley monthly, record it on the appropriate growth chart, and report to family.
- Michael will be supervised at all times, before and after school, in the classroom, at lunch and between classes.
- Adam will receive a modified school lunch of 350 calories, according to his diet prescription, in the high school cafeteria.
- Armando's vocational training at school or in the community will not include food service or situations where there is food handling or access.
- Joshua will participate in adaptive PE three times a week.

Summary

Children with PWS must be supervised at all times; they can be clever and quick in obtaining food!

Food should not be used as reinforcement in the classroom.

Parents and school staff need to work together to meet the nutritional needs of the child.

Nutritional needs and diet management can be incorporated in an IEP or IFSP.

Children with PWS can participate in the school lunch program and receive lower energy (calorie) meals.

WEIGHT & BEHAVIOR MANAGEMENT

Managing Prader-Willi Syndrome

Two of the most outstanding characteristics of Prader-Willi syndrome (PWS) are insatiable appetite and behavior problems.

Prader-Willi Syndrome is a birth defect also characterized by hypotonia (weak muscles), developmental delays, short stature if not treated with growth hormone, small hands and feet, incomplete sexual development, and cognitive deficits which may or may not be at the level of mental retardation.

The craving for food is complicated by the fact that people with PWS have poor calorie utilization, gaining weight on approximately one-half the calories required by a normal person. The constant presence of food in our society creates further difficulty in the struggle to control appetite.

There are no easy answers to any of the problems surrounding the management of this unique condition. The following "do and don't" suggestions have come from parents, professionals, and observations of persons with PWS. In addition, use good humor, kindness, affection, determination and respect, seasoned with flexibility and good judgment, and there will be a good amount of success.

Behavior management should be intervention/prevention oriented. For best results, pre-schedule, preplan, avoid arguments and anticipate.

Weight management should be individualized and include daily or weekly weigh-ins, complete control of food intake, environmental barriers to food access and diets acknowledging that fewer calories are required.

Prader-Willi: A Multistage Syndrome

The initial stage of Prader-Willi syndrome is characterized by low birth weight and subsequent failure to thrive.

The infant is very weak, usually cannot nurse or suck, and must be fed with special nipples or tubes. NOT gaining weight is a problem, Depending on the degree of hypotonia, this stage can continue for the first couple of years.

A program of good nutrition, proper food intake, and exercise started as soon as possible, rather than after weight starts to accumulate, will be extremely beneficial.

Behavior problems may be few or nonexistent in the young child, although individuals vary. A little stubbornness usually appears first, often progressing to temper tantrums.

The next stage reflects thriving almost too well. The food compulsion may surface with improvement of hypotonia, usually between the ages of two and four, but possibly earlier or later. Behavior may include greater stubbornness, temper tantrums increasing in number, length and intensity, and food sneaking, stealing and hoarding.

When weight gain starts, complete control of caloric intake, aided by locks on cabinets and refrigerators, is essential. Without such control, 95 percent develop weight problems. A well-balanced diet limiting calories is a lifelong necessity.

DO

- Keep food inaccessible at all times. Persons with PWS cannot fight their compulsion to get at it. Put it away and lock the cupboards and refrigerator.
- Keep their lives structured. They need structure. Preplan changes.
- Praise and recognize good performances. A lot of mileage can be obtained with a few words, smiles and hugs.
- Listen to a person who needs to talk. The time it takes may alleviate or prevent unpleasantness later.
- Include the person with PWS in planning and programming. They feel a need for some control and will cooperate 100 percent if they feel it was their idea.
- Keep sight of the fact that the hand of a person with PWS is quicker than your eye.
- Enjoy your treats in private. It is very hard for the person with PWS to watch others enjoying the goodies he is denied.
- Use smaller plates and cups, spread the food out, and add extra nonfattening items such as carrots, dill pickles or diet Jello to make the amount on the plate look larger.
- Inform neighbors, relatives, teachers, babysitters, classmates, everyone with whom the child with PWS comes in contact - and then inform them again!
- Be consistent. They thrive on routines and knowing exactly what the guidelines are.
- Remember that logic and reason will not prevail when the person with PWS gets upset and/or “stuck” on an idea or position.

DON'T

- Use food as a reward or punishment except on a very limited basis.
- Assume, if the person has lost weight, that the problem is now “cured”.
- Nag. Once a behavior has been dealt with, do not bring it up again. Discuss temper tantrums and then forget it.
- Argue. Make the statement, allow the person one more comment, warn that the discussion is over and stick to it. You will never win an argument.
- Tease, be sarcastic, or even use subtle humor. People with PWS do not respond well to such tactics.
- Ignore bad behavior. Try interventions to prevent it.
- Lose your temper. Easier said than done, but do whatever it takes to keep your cool; nothing will be gained if you lose control.
- Promise anything that you cannot or will not do. Persons with PWS rarely accept change.
- Ignore poor table manners. They are capable of using utensils; they can slow down; they can stay until the meal is finished without additional food.
- Try to talk things out with a child with PWS. It does not work!
- Lose sight of the humorous aspects of all of this. Hang on to your sense of humor while figuring out “how to lock up the apple tree”.
- Hesitate to ask for professional help. IPWSO can give good references.
- Forget that this is a life-threatening situation.

FOOD SECURITY for Prader-Willi Syndrome

Food insecurity contributes to over eating, poor nutrition and obesity. **FOOD SECURITY** is defined as *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.
- **No hope** of getting anything different from what is planned.
- **No disappointment** related to false expectations.

Here are some ways to achieve FOOD SECURITY:

1) Secure food accessibility across *all* settings by:

- a) Controlled access to:
 - i) Refrigerator, freezer and pantry
 - ii) Vending machines
 - iii) Money

- b) Avoiding any spontaneity related to food
- c) No snacks on demand
- d) No food left out
- e) No “free” foods or beverages
- f) Absolute portion control
- g) Pre-packaged condiments

Have a Plan

A person who needs food security should never enter a “food situation” without knowing what the plan is for maintaining his or her dietary needs.

Some individuals need all of these measures; others only some.

2) Supervise food exposure:

- a) At stores
- b) During food preparation and mealtime
- c) During special occasions (birthday parties, seasonal celebrations, etc.)
- d) When dining out in the community...
 - i) Access menus from restaurants in advance and decide what will be ordered.
 - ii) In general, buffets are understood to be “off limits?” Or, if unavoidable, it is understood that the plate will be prepared by someone else.

3) Post the schedule for mealtimes and snacks.

4) Post the schedule and the menus for meals and snacks.

5) If necessary, because of raised expectations or anxiety, avoid places and social situations associated with excess food

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.

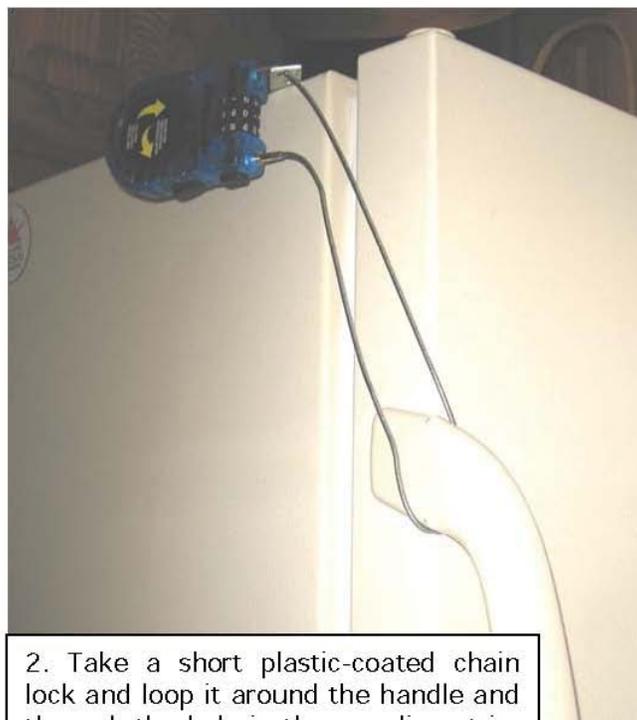
Which Way is Best? When it becomes time to apply locks and/or alarms, many families are faced with a dilemma of trying to figure out the best method to secure their food. There are many ways that families do this; there is no one right way. Any way that helps the person with PWS to “be safe” and prevents 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.

Food Safety—Locks and Alarms



1. In this picture, a 2" x ½ " 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.



2. Take a short plastic-coated chain lock and loop it around the handle and through the hole in the mending strip. The advantage is that you don't have to deface the refrigerator.



Super glue was used to apply the above padlock to a lower freezer door. No drill was used; so the risk of hitting Freon coils was prevented.



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.

Food Safety—Locks and Alarms

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?

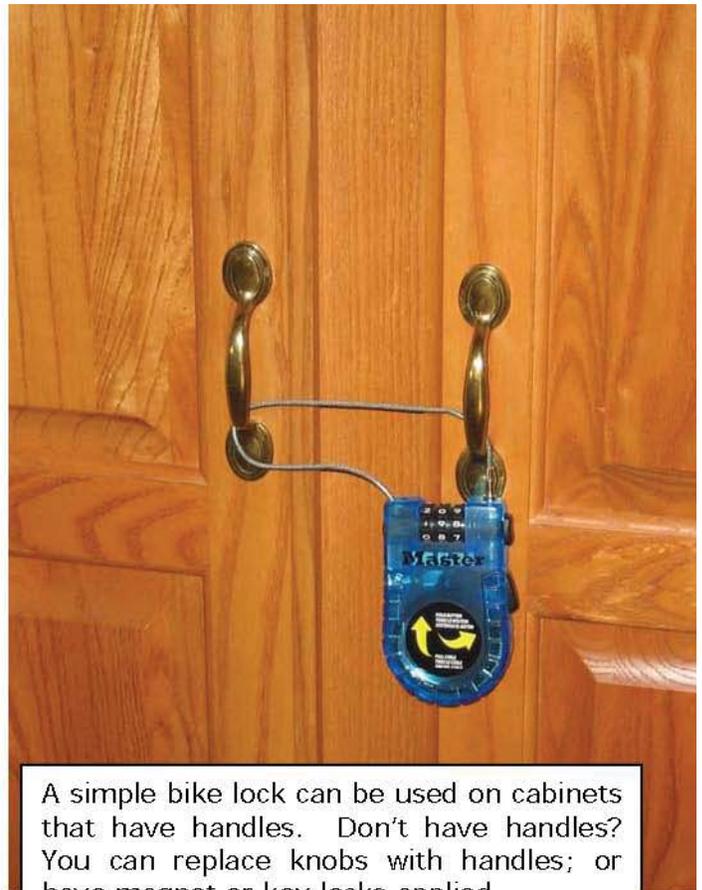
There is no specific age or pre-determined time that locks are applied. Some may need to apply them when the child is very young; others may not need to do this until they are older. Things that may indicate the time is near or now include:

- 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.

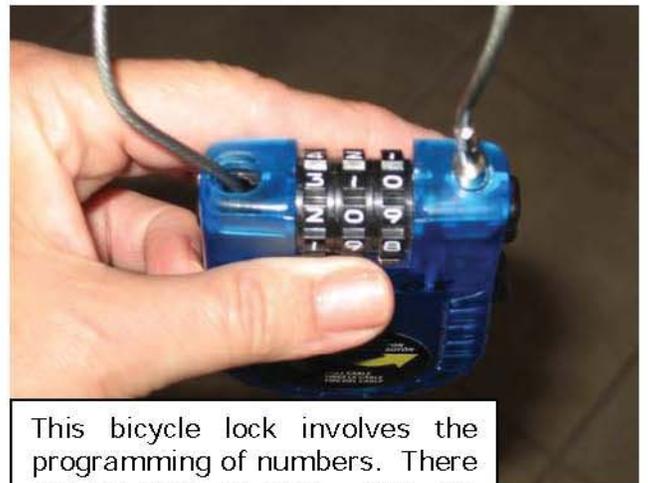
Once locks are applied, many persons with Prader-Willi syndrome (PWS) report feeling "safer". The burden of temptation and guilt is removed. It is often more difficult for parents and family members than it is for the person with PWS.

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.

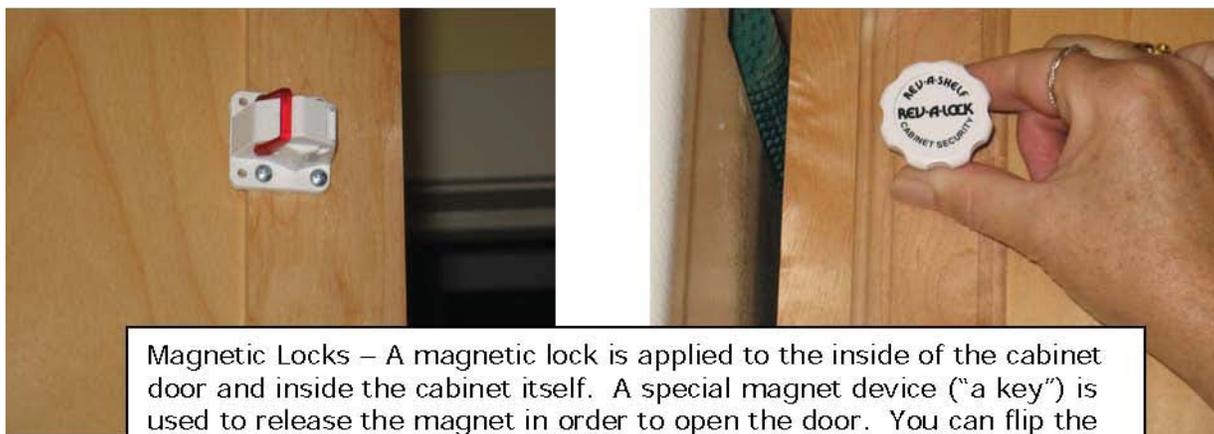


A simple bike lock can be used on cabinets that have handles. Don't have handles? You can replace knobs with handles; or have magnet or key locks applied.



This bicycle lock involves the programming of numbers. There are no keys to lose. You can change the numbers at anytime.

Food Safety—Locks and Alarms



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 detectors, 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.safetyandsecuritycenter.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 locks – 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.

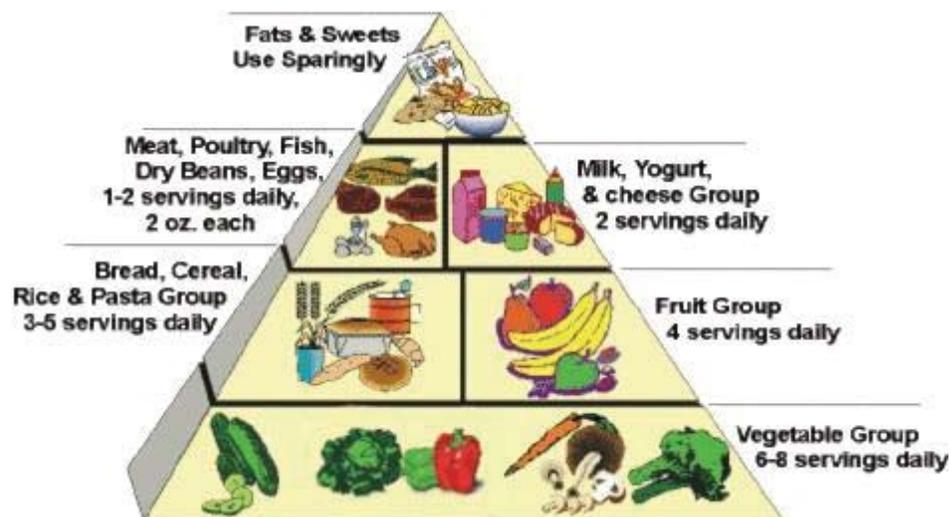
GENERAL TIPS FOR THE PWS FOOD PLAN

1. Decide on a daily calorie goal (800, 1000 or 1200).
2. Weigh and measure all food.
3. Add vegetables to make plate fuller.
4. Use spray butter and spices to make food taste better.
5. A lot of people who have PWS do not like plain water. Adding a flavor can help with liquid intake.
6. Post a weekly calendar of all meals and snacks & when they are. A calendar will also encourage reading, provide reassurance of when and what they will eat next.
7. Keep the environment free of food and lock up all food in the kitchen.
8. Make meals well balanced- well balanced meals that are low in fat and salt will allow more food for the number of calories.
9. Provide an activity out of the kitchen while meals are being prepared.
10. All meals should be portioned out and brought to the table by the parent.
11. When there is a special event involving food, incorporate these calories into the food plan. So for example, if there is pizza for a birthday party, limit the amount (1 or 2 slices), and then have a healthy salad for the other main meal.
12. Plan eating out. Some families eat out every other Friday night and incorporate the calories into the daily calorie intake for the week. *Just remember, people with PWS have a hard time changing plans, so once you start a food routine it can be difficult to change.*

Food List				
<p style="text-align: center;"><u>Foods that are Low in calories</u> Be careful of quantity</p>	Asparagus Bamboo shoots Broccoli Brussels sprouts Cabbage carrots Cauliflower Celery Cucumbers Green beans Green onions greens	Lettuce Mushrooms Onions Peppers Radishes Sauerkraut Sour pickles Dill pickles Sprouts Squash Tomatoes zucchini	<p style="text-align: center;"><u>Condiments</u></p>	Tabasco sauce Soy sauce-lite Horseradish Garlic Cinnamon Herbs Spices Flavorings Mustard Vinegar No-oil salad dressing
<p style="text-align: center;"><u>Light foods</u> These foods need to be weighed and measured</p>	Non-fat milk Reduced fat cheese Low-fat cottage cheese Low fat yogurt Lentils Dried beans Turkey-lite, no skin (baked) Chicken-lite, no skin (baked) Baked fish Tuna in water Lean read meat	Apples Applesauce sugar free Apricots Bananas blackberries cantaloupe cherries grapefruit Grapes Nectarines oranges Papaya Pineapple Peaches no sugar Plums Prunes Strawberries Tangerines watermelons	Potatoes (dry) Sweet potatoes Peas winter squash Broth based soups Low calorie bread English muffins Unsweetened cereal Grits Tortillas (lite) Spaghetti Rice cakes Rice Bran Barley Bulgar	

Editors' Note: The USDA's Food Guide Pyramid provides an appealing graphic tool for thinking about a day's food portions, but it simply adds up to too much food for someone on a Prader-Willi diet. We asked the Children's Institute if they could adapt the new pyramid to the typical PW diet for families that might wish to use it as an alternative to the Exchange System, the Red-Yellow-Green (Stoplight) Diet, or other methods of counting calories. The Institute was glad to oblige but urges those who have been through the Institute's program to continue using the Red-Yellow-Green Diet that they learned there. The Prader-Willi Food Pyramid that follows may not be appropriate for young children or for those on growth hormone therapy, and it should not be considered a substitute for individualized dietary guidance. Dietary guidance preferably should come from a nutritionist who is familiar with PWS.

The Food Pyramid Guide to Daily Food Choices, designed by the U.S. Department of Agriculture for adults who need 1,600 to 2,800 calories a day, represents the relative portions of foods to eat each day to maintain a healthy weight and body. To make the Food Pyramid usable for people with Prader-Willi syndrome, a few changes have to be made.



The first change needed is to adjust the number of daily servings for each food group in order to reduce the total calorie level to 800 to 1,200 a day. These lower levels will provide for weight loss or maintenance for the adult or teenager with PWS, whose calorie needs are about 60 percent of those without PWS.

Second, although the five main food groups—bread, vegetable, fruit, meat, and milk—remain the same, the positions of two of the groups need to be changed on the pyramid to reflect a change in the recommended number of servings. Each group has a specific number of servings that determines its position on the pyramid.

The Food Groups

The USDA Food Pyramid has a base of the Bread group, which would provide the highest number of daily servings. The PW Pyramid, on the other hand, has as its base the **Vegetable group**, with 6-8 servings a day. For those familiar with the Red-Yellow-Green Diet, these would be "GO" foods, i.e., foods low in calories and fat. Making the vegetable group the base of the pyramid and the bulk of the diet will allow a large volume of food to be eaten without many additional calories.

The **Bread** group, which includes cereal, pasta, and rice, moves up the pyramid with a decrease in number of servings to three to five per day. We would also include starchy vegetables like corn, peas, and potatoes in this group because they have the same amount of calories per serving as breads.

The **Fruit** group includes fresh fruit, canned fruit, juice, and dried fruits. Many people think of fruit as a "free" food. While it is a good snack and a good source of fiber and vitamins, it does have calories that should be counted if one is on a restricted diet. The daily servings should be four—one at each meal and one for snack.

The **Milk** group includes yogurt, milk, and cheese. To fit the needs of the person with PWS, the servings per day should be two, and the products chosen should be nonfat or low in fat. Fat-free, sugar-free frozen yogurt also can be used as a milk serving.

The **Meat** group includes meat, fish, poultry, eggs, peanut butter, and cooked dried beans. The USDA also includes nuts in this group, but due to their high fat content they should be eliminated from the PW Pyramid. And the USDA suggests two to three meat servings per day of 2- to 3-oz. portions. To decrease the calories for the PW meal plan, we changed the portion size to 2 oz. and suggest one to two servings a day. This means that a person on 800 calories could divide the 2 oz. serving to provide 1 oz. at lunch and 1 oz. at dinner, and a person on 1,200 calories could have 2 oz. at lunch and 2 oz. at dinner.

Serving Sizes

Except for the meat group, the serving sizes on our PW Pyramid are unchanged from the USDA Food Pyramid. They are as follows:

- **Vegetable:** 1/2 cup cooked **or** 1 cup raw
- **Bread:** 1 slice bread; 1/2 cup rice, pasta, **or** starchy vegetable; 1 oz. cereal
- **Fruit:** 1/2 cup canned, 1/2 cup **or** 1 piece fresh, 1/4 cup dried; 1/2 cup juice
- **Milk:** 1 cup skim milk **or** lite yogurt, 1 oz. cheese, 1/2 cup frozen fat-free sugar-free yogurt
- **Meat:** 2 oz. cooked lean meat, fish, **or** poultry; 1 egg, 1/2 cup cooked dried beans; 1 tablespoon peanut butter

Fats, Oils, and Sweets

The top of the USDA Pyramid shows fats, oils, and sweets. These are denoted by symbols that are concentrated in this area and dispersed throughout the other groups. The USDA suggests that these foods be used sparingly to add extra calories. These foods include butter, margarine, regular dressing, candy, sugars, sweets, fatty desserts, gravy, and fried foods, to name a few. The foods from this group add unwanted calories and few nutrients to the Prader-Willi diet. They should be limited to once a month for an 800-calorie plan and once a week for a 1,200-calorie plan. We have deleted the fat symbols throughout the PW Pyramid, because all foods chosen should be low in fat and sugar.

Using the modified pyramid as a guide to weight loss and maintenance, in conjunction with a favorite exercise program, can be an easy way to ensure a healthy, nutritious diet for the person with Prader-Willi syndrome.

For additional information on the Red, Yellow, Green System for Weight Control, contact registered dietitian, Katie Burns, RD, LDN, at The Children's Institute by calling 1-412-420-2307.

Updated:

Brown Bag Lunch Ideas

Lunches can be a challenge, especially for school when you are trying to maintain a 800-1200 calorie meal plan. The following are suggestions for school lunches; they will give you a place to start. They are balance, low fat and mindful of the calories.

Lunches under 300 calories:

1 slice lite whole wheat or white bread
1 TBSP peanut butter
1 TBSP lite jelly
½ cup vegetable soup
½ cup non-fat milk
Calories=285

1 slice lite whole wheat or white bread
1 hard-boiled egg
2 TSP fat free mayonnaise
½ pear
½ cup non-fat milk
Calories=285

½ toasted English muffin
2 TBSP pizza sauce
¼ cup shredded mozzarella cheese
½ fresh apple
½ cup non-fat milk
Calories=255

1 slice lite whole wheat or white bread
1 oz sliced turkey
½ slice cheese
2 slices tomato
½ cup sliced peaches, in lite syrup
½ cup non-fat milk
Calories=295

Lunches under 350 calories

2 slices lite whole wheat or white bread
¼ cup water pack tuna
2 TSP sweet pickle relish
¼ cup shredded lettuce
2 TSP fat-free salad dressing
½ cup fresh peaches or in water
½ cup non-fat milk
Calories=335

2 slices lite whole wheat or white bread
1 oz shaved ham
½ slice fat-free cheese
½ cup vegetable soup
½ cup non-fat milk
Calories=335

1000 Calorie Menu – Week 1

	Breakfast	Lunch	Dinner
Sunday	1 Egg Beater - scrambled 2 slices Diet Toast ½ c. Melon 4 oz. Skim milk Sugar-Free Cocoa 6 oz. Tomato Juice	2 oz. Pepper Steak ½ c. Steamed rice 1 c. Wax beans ½ c. mandarin oranges 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	½ c. Chili (no beans) 1 Baked potato- small 1 c. Mixed veggies Fresh apple 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Monday	½ English Muffin 1 Tbsp. Sugar Free Jelly 1 Banana- small 8 oz. Skim milk 1 Egg Beater - scrambled	1 ½ slice Thin Crust Cheese Pizza 1 c. Green beans ½ c. Peach slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Roast Pork ½ c. Corn 1 c. Zucchini ½ c. Applesauce 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Tuesday	1 Pancake 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Peach slices 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Baked Fish 1 Baked Potato- small 1 c. Broccoli ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Roast Beef ½ c. Mashed Potatoes 1 c. Cauliflower Fruit cocktail 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Wednesday	1 Hard Cooked Egg 2 slices Diet Toast 1 Banana- small 4 oz. Skim milk Sugar Free Cocoa 6 oz. Tomato Juice	2 oz. Hot Dog ½ c. Baked beans 1 c. Carrot slices ½ c. Pear slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Baked Chicken ½ c. Steamed rice 1 c. Spinach ½ c. mandarin oranges 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Thursday	1 French Toast 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Mixed fruit 8 oz. Skim milk 1 Egg Beater - scrambled	½ c. Sloppy Joe 2 slices Diet Bread 1 c. Brussel Sprouts ½ c. Apricot halves 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Roasted Turkey ½ c. Stuffing 1 c. Green Beans 1 Banana- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Friday	1 c. Cereal 1 Pear- small 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Veggie Burger 2 slices Diet Bread 1 c. Mixed Vegetables 1 Fresh orange- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	½ c. Tuna Salad on 2 slices Diet Bread 1 c. Beets ½ c. Peach slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Saturday	½ Bagel 1 Tbsp. Fat Free Cream Cheese 1 Apple- small 4 oz. Skim milk 4 oz. Light Yogurt 1 Egg Beater - scrambled	2 oz. Baked Chicken ½ c. Parslied noodles 1 c. Carrot slices ½ c. Applesauce 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Hamburger 2 slices Diet Bread 1 c. Broccoli ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello

1000 Calorie Menu – Week 2

	Breakfast	Lunch	Dinner
Sunday	1 Egg Beater - scrambled 2 slices Diet Toast ½ c. Melon 4 oz. Skim milk Sugar-Free Cocoa 6 oz. Tomato Juice	2 oz. Lemon baked fish ½ c. Steamed rice 1 c. Stewed tomatoes ½ c. Pear slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	¾ Stuffed Green Pepper- small 1 c. Capri blend veggies ½ c. Fruit Cocktail 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Monday	½ English Muffin 1 Tbsp. Sugar Free Jelly 1 Banana- small 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Meatball ½ c. Bowtie pasta w/ ¼ c. tomato sauce 1 c. Carrots ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Pork Loin 1 Baked potato- small 1 c. Beets ½ c. Applesauce 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Tuesday	1 Pancake 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Peach slices 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Baked Fish ½ c. Mashed sweet potatoes 1 c. Green Beans ½ c. Peach slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Veggie Burger on 2 slices Diet Bread 1 c. Zucchini 1 Orange- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Wednesday	1 Hard Cooked Egg 2 slices Diet Toast 1 Banana- small 4 oz. Skim milk Sugar Free Cocoa 6 oz. Tomato Juice	2 oz. Roast Turkey ½ c. Mashed potatoes 1 c. Capri blend veggies 1 Banana- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	1 ½ Stuffed Shell w/ tomato sauce 1 c. Spinach ½ c. Fruit cocktail 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Thursday	1 French Toast 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Mixed fruit 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Hot Dog ½ c. Baked beans 1 c. Broccoli ½ c. Pear slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	1 ½ slice Thin Crust Cheese Pizza 1 c. Cauliflower ½ c. Apricot halves 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Friday	1 c. Cereal 1 Pear- small 8 oz. Skim milk 1 Egg Beater - scrambled	1 Grilled Cheese Sandwich (2 oz. cheese on 2 slices diet bread) 1 c. Zucchini 1 Apple- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Baked Fish Florentine ½ c Whipped potatoes 1 c. Carrots ½ c. Peach slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Saturday	½ Bagel 1 Tbsp. Fat Free Cream Cheese 1 Apple- small 4 oz. Skim milk 4 oz. Light Yogurt 1 Egg Beater - scramble	2 oz. Hamburger on 2 slices Diet Bread 1 c. Mixed vegetables ½ c. Mandarin oranges 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Baked Ham ½ c Parslied noodles 1 c. Green Beans ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello

1000 Calorie Menu – Week 3

	Breakfast	Lunch	Dinner
Sunday	1 Egg Beater - scrambled 2 slices Diet Toast ½ c. Melon 4 oz. Skim milk Sugar-Free Cocoa 6 oz. Tomato Juice	2 oz. Veggie Baked Fish ½ c. Corn 1 c. Carrots ½ c. Mandarin oranges 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Meatball ½ c. Rigatoni with ¼ c. tomato sauce 1 c. Broccoli ½ c. Apricot halves 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Monday	½ English Muffin 1 Tbsp. Sugar Free Jelly 1 Banana- small 8 oz. Skim milk 1 Egg Beater - scrambled	¾ c. Cheese Ravioli with ¼ c. tomato sauce 1 c. Wax beans ½ c. Peach slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Roast Turkey ½ c. Mashed Potatoes 1 c. Carrots 1 Apple- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Tuesday	1 Pancake 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Peach slices 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Baked Chicken ½ c. Peas 1 c. Brussel Sprouts ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Hamburger on 2 slices Diet Bread 1 c. Zucchini ½ c. Pear Slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Wednesday	1 Hard Cooked Egg 2 slices Diet Toast 1 Banana- small 4 oz. Skim milk Sugar Free Cocoa 6 oz. Tomato Juice	¾ c. Macaroni and Cheese 1 c. Broccoli ½ c. Apricot halves 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Italian Seasoned Chicken ½ c. Oven brown potatoes 1 c. Cauliflower ½ c. Fruit cocktail 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Thursday	1 French Toast 1 Tbsp. Sugar Free Syrup or Jelly ½ c. Mixed fruit 8 oz. Skim milk 1 Egg Beater - scrambled	2 oz. Roasted Pork ½ c. Mashed Potatoes 1 c. Capri blend vegetables 1 Orange- small 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Hot Dog ½ c. Baked beans 1 c. Spinach ½ c. Apricot halves 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Friday	1 c. Cereal 1 Pear- small 8 oz. Skim milk 1 Egg Beater - scrambled	1 ½ slice Thin Crust Cheese Pizza 1 c. Green Beans ½ c. Pear slices 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Lemon Pepper Fish ½ c. Rice 1 c. Beets ½ c. Applesauce 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello
Saturday	½ Bagel 1 Tbsp. Fat Free Cream Cheese 1 Apple- small 4 oz. Skim milk 4 oz. Light Yogurt 1 Egg Beater - scrambled	2 oz. Veggie Burger on 2 slices Diet Bread 1 c. Spinach ½ c. Fruit Cocktail 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello	2 oz. Baked Ham 1 Baked potato- small 1 c. Cauliflower ½ c. Pineapple tidbits 4 oz. Skim milk 2 c. Salad 2 Tbsp. diet dressing Diet Jello

Snack List

Evenings, PT Goals, and Friday nights

	WEEK 1	WEEK 2	WEEK 3
Sunday	½ c. Baby Carrots w/ ½ c. Celery Sticks ½ c. Canned Pineapple ½ c. Diet Jello	1 c. Marinated Green Beans 1 Apple	1 c. Cauliflower Florets ½ c. Canned Apricot Halves
Monday	1c. Cucumber Slices 1 frozen Fruit Juicee ½ c. Diet Jello	1 c. FF Creamy Coleslaw ½ c. Canned Pears 1 Sugar-Free Popsicle	1 c. Baby Carrots ½ Dill Pickle Spear 1 frozen Fruit Juicee
Tuesday	½ c. Celery Sticks w/ ½ c. Green Pepper Strips ¼ c. Salsa 1 Banana – small	½ Dill Pickle Spear 1 c. Cucumber Slices 1 Orange	½ c. Marinated Cucumbers w/ ½ c. Red Onions 2 Tbsp. Raisins ½ c. Diet Jello
Wednesday	1 c. Marinated green beans ½ c. Canned Peaches 1 Sugar-Free Popsicle	½ c. Marinated Tomatoes w/ ½ c. Sliced Red Onions 15 Grapes ½ c. Diet Jello	½ c. Marinated Green Peppers w/ ½ c. Fresh Mushrooms ½ c. Canned Pineapples 1 Sugar-Free Popsicle
Thursday	½ c. Marinated Wax Beans ½ c. Sliced Red Onions 1 Apple	½ c. Marinated Green Beans w/ ½ c. Fresh Mushrooms ½ c. Canned Peaches	½ c. Marinated Wax Beans w/ ½ c. Green Beans 15 Grapes
Friday PT Snack for Goals	½ c. Carrots w/ ½ c. Zucchini Sticks 1 can Diet Soda	½ c. Celery Sticks w/ ½ c. Pepper Strips 1 can Diet Soda	½ c. Broccoli Florets w/ 4 Tomato Wedges 1 can Diet Soda
Friday	1 c. Cucumbers in FF sour Cream ½ c. Fruit Cocktail ½ c. Diet Jello	1 c. Broccoli Florets 1 Frozen Fruit Juicee ½ c. Diet Jello	1 c. Plain Beets ½ c. Canned Peaches ½ c. Diet Jello
Friday Friday night movie snack	1 whole Pickle 1 can Diet Soda	1 whole Pickle 1 can Diet Soda	1 whole Pickle 1 can Diet Soda
Saturday	½ c. Baby Carrots w/ ½ c. Broccoli Florets ½ c. Canned Pears	½ c. Baby Carrots W/ ½ c. Celery Sticks 1 Orange ½ c. Diet Jello	1 c. Broccoli Florets ½ c. Cinnamon Applesauce

Exercise Essentials

A person with PWS has a very low metabolic rate, so they do not “burn” calories like people who do not have PWS. In order for a person to not become obese they need to eat less calories and exercise. Growth hormones (GH) can also help with gaining weight. They are a hormone that does much more that facilitate growth, they also help develop muscle mass and muscle burns more calories.

Exercise

Exercise is helpful for the person/child with PWS on many levels.

- Burns calories
- Helps lose weight
- Helps with Cardiopulmonary health
- Helps in preventing/treating depression
- Releases endorphins in the body
- Increases bone density and builds muscle tone

How much exercise?

If possible do some type of exercise at least an hour a day. Realistically, 5 days a week would be great. Exercise should be continuous and as vigorous as possible. Frequent rest or breaking the exercise into different session may be necessary at the beginning. They can break their routine into two Sessions to help manage time, exercise 20-30 min. in the morning and 20-30 min. in the afternoon or evening. Exercise programs should show a progression of increased activity, faster walking, longer distances, so that they can improve and maintain cardiopulmonary fitness levels. If a person with PWS is obese, walking or exercise in a swimming pool is great and will help protect their joints from injury.

Make exercise fun, not a chore. Most of our children with PWS love to participate with others so involve the whole family.

Get up and get moving!

- Dance to your favorite music on the radio or a Zumba DVD.
- Walk the dog increasing the speed each week.
- Play ball in the swimming pool.
- Learn to swing and pump your legs!
- Play kick ball.
- Walk on a treadmill while watching your favorite TV show.
- Play catch with a beach ball.
- Go on a hike.
- Participate in team sports.

