

BEYOND THE DIET – For The Dietician

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From 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 case 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 first 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, the 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 A DIETICIAN 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 as strong a food-foraging drive. On the other hand, if a child keeps gaining weight and the parent states that the child never sneaks food, do not necessarily believe it. 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 this child 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 regarding tracing down where he was getting the forbidden food.

How do you lock up the food?

If the situation requires locks – who is going to show the family 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.

Do you suggest keys and doing careful key checks, or do you recommend using combination locks or alarms? 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. 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 buy “Matt-proof” locks (hinges with the screws on the inside). 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.

Working with young families

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 the family is considering buying a new refrigerator, they may want to consider a side-by-side model where they 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 the child is older – Who is in control in the family – the child or the parents?

If it is the child, (especially if the child is older), it will be essential to also 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.

What and who make up the parents’ support system?

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.

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

It is unfair to think that you can set up a complicated diet requiring a lot of food measurements and calculations and expect a parent overwhelmed with other responsibilities to follow it long term.

If it is a single parent who is poor and has other children, remember to think about resources. Does the family have a microwave? If so, think of 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 a 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. Remember that diet is a lifetime issue. Make it a diet both parents and child can live with.

Above all, as a dietician, try to remain patient with the family.

As I stated above, there are significant variances with each child 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. Before slapping a parent’s hand, make sure you are willing to help them with all of the details, funding, and personnel support needed to follow up with weight control – and help them again – and again.

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.”*

John died shortly after this was written. We did not find a cure in his lifetime, but I have promised my own son Matt, who is 27 years old, that in his lifetime we will find a drug to abate the deadly hunger. Meanwhile, we need all of the help, support, and compassion you can muster as a dietician to make the long road to weight control a little easier.