

Over the River and Through the Woods...

Grandparents of Children with PWS

by Marsha H. Lupi, Ed.D., Hunter College
of the City University of New York

Becoming a grandparent, whether it is for the first, second, or fourth time, has been said to be a very special and wonderful event. It differs from parenting because the need to be the rule-maker, watchdog, and disciplinarian is no longer the grandparents' responsibility and is taken over by Mom and Dad before and after visits. Going to Grandma and Grandpa's house is to be fun, a time to be showered with treats, and grandparents "looking the other way."

Grandparents also play a critical role in the adjustment or readjustment of the new or growing family of their son or daughter, particularly if their grandchild has been born with a disability. The various kinds of support available from grandparents may include helping with child care, family finances, boosting the self-confidence of a new mom or dad, and sharing family culture and traditions. Moreover, positive feedback and help given by grandparents can have a positive impact on mother-child interaction and sibling anxiety.

Grandparents can thus be seen as very important to the health and welfare of the new family. If they never come to terms with their own grief at the birth of a grandchild with a disability, it may have devastating effects on their son or daughter and his or her family life, particularly if they remain distant and disapproving.

Grandparents of children with Prader-Willi syndrome may face some special

issues in their relationship with their grandchild and his/her mother or father. After all, a grandchild with Prader-Willi syndrome presents a host of very specific and intricate limits and patterns of behavior that may require certain responses from anyone entrusted with his/her care. Some questions brought to mind when grandparenting a child with PWS are: "What happens when Jimmy wants an extra slice of cake Grandma made?" and "Do grandparents of Susie ignore her little white lies?". These questions are merely illustrative of some of the things that grandparents may naturally do "in the line of duty," but they undoubtedly have different consequences in the realm of Prader-Willi syndrome.

A survey conducted in the Spring of 1991 by this author in New York State lends some insight into the above questions and the overall area of grandparenting a child with Prader-Willi syndrome. It helps to provide insight into any differences that may exist in the style in which grandparents relate to their PWS grandchild and their own son or daughter.

The survey found that grandparents of children with PWS:

1. see their grandchild with the same frequency that grandparents of nondisabled grandchildren do, usually once a week;
2. assume occasional care, usually babysitting when their son or daughter and spouse have plans for an evening out;
3. take their grandchild on the same outings as grandparents of children

without disabilities (i.e., parks, zoo, malls, movies);

4. attempt to follow the dietary restrictions or plan that their son or daughter and spouse have for their grandchild;
5. make an effort on a regular basis to remove food from their grandchild's view—that is, they "lock up" temptation;
6. occasionally "slip up," giving extra treats (and admit it!);
7. continue to have a fairly supportive and stable relationship with their own son or daughter if it was in existence before the birth of the grandchild with PWS;
8. would like to receive on-going information and support from professionals and other grandparents.

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While these findings come from a small sample (N=25), they begin to give a picture of the grandparenting process as one of love and concern by the grandparent of the child with Prader-Willi syndrome. Further research in this area is being conducted by this author. If you are interested in participating in future studies, please contact:

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(Editor's Note: The Gathered View invites grandparents of children with PWS to write about their experiences for publication in a future issue. Send articles or letters to the PWSA National Office.)



Emily (on lap) and her Grandmother Betty Winter model sweaters with Emily's Mom Nancy Weingart and sister Elizabeth.

"It comes to mind what an important part grandparents play in our lives. If it were not for them, I couldn't have attended the national PWSA conference in July. In my day-to-day struggles, I forget sometimes the role grandparents have in my life. I believe maybe I take them for granted because I know they would be there for me. It may take a little longer for grandparents to understand our children with PWS, but we have to remember how long it took us to understand ourselves.

"For many of us, the grandparents have been our backbone of support. They have contributed much to the organization in many ways. I hope the grandparents realize just how important they are, although it may go unsaid. For the parents of our young children, we're advocating for their rights. For the parents of the older children and adults, we're struggling for a group home. For the grandparents of all ages, it only matters that they give support, love, and understanding in every way possible so we can make a better life for their grandchildren with PWS."

Doris Oakley, President, PWSA of North Carolina
(adapted from the May 1993 PWSA-NC newsletter)

The World According to Matt

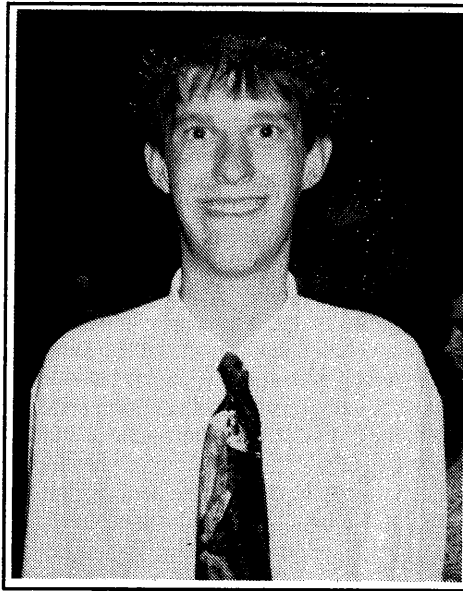
by Janalee Tomaseski-Heinemann

Al and I have discovered that having a son with Prader-Willi syndrome who is in a supportive living program doesn't totally eliminate the problems of the syndrome from your life. It just means that the syndrome is no longer all-consuming. Dealing with it intermittently gives us a new appreciation of how frustrating and puzzling PWS can be at times. Most of our visits with Matt are positive and he is often sweet on the phone—but there are times he can still cause turmoil in our lives.

One example of this was the trip we took in August for Al's brother's wedding. Our traveling companions were Matt and our two grandsons. The first issue we had to deal with was Matt's attire. Although we think the world of Matt's staff, in his "home" Matt is given more freedom than we are comfortable with to decide what he wants to wear. We personally feel that if he wants to be treated "normal," he must look "normal." For this trip, we made a special effort to alert the staff that Matt would need to have appropriate clothing. So we cringed when Matt walked out wearing white shorts, red and blue socks with Christmas trees on them, a wrinkled green tee-shirt, and carrying his winter jacket over his shoulder. To add that extra GQ flair, he had shaved the sides of his head with his electric shaver. Al leaned over to me and whispered, "Cool misses Matt by a mile." His suitcase and bag had what seemed like a year's worth of clothing stuffed into them. My first delicate challenge was to get him to change his outfit and leave three-fourths of his clothing behind. Fortunately, he was eager enough to go that it went better than it might have gone under other circumstances.

The rest of the trip went fine until the wedding reception, where food was an issue, as expected. The main problem came from our attempt to allow Matt some independence. We let him roam

on his own at the reception hall after the food was cleared from the tables. What we didn't know was that all the food was still accessible and that Matt was making many clandestine trips to the kitchen and slinking out the back door. What embarrassed and amazed us later was



Matt Heinemann looking sharp.

that we had let our guard down. The other part that bothered us was that none of the relatives who saw Matt sneak the food bothered to alert us to the problem. So, being oblivious to any problems, we had a good evening dancing and visiting, our grandsons had fun running away from the girls who were trying to get them to dance, and Matt had a great evening stuffing himself. Matt did take time out from his food fest now and then to dance. In his suave demeanor, while dancing with his cousin Jodie, he casually told her, "Jodie, did you know that my sister doesn't like you?"

The next morning, Matt started his day being irritable and pushed for more food at breakfast. One thing we have found with Matt is that if he is given too much latitude with his eating, it only makes him push for more. I'll never forget the pool party at Al's boss's home years ago. Matt was very slim at that point and was doing exceptionally well on his diet. We decided that just this once we would

give him a lot of free rein at eating. The only restriction we set was that he drink the diet soda we had brought. Keep in mind that Matt had never been allowed regular soda pop. Getting more food than he ever had was not enough for Matt. He insisted that he was not going to drink the diet soda and got himself upset enough that he ended up hollering and taking off down the street. So we left the party embarrassed and learned a lesson. Small, limited, pre-arranged diet exceptions work out as a special treat, but too much freedom seems to have the reverse effect.

Due to Matt's testy mood, and the severe gas he had from eating all the food the night before at the wedding reception, the eight-and-a-half-hour drive home was a real "treat." We used an old ploy and had him sit in the back seat of the van where we could pretend not to hear him, but we couldn't avoid smelling him. About every 15 miles our grandsons would yell, "Matt!! Roll the windows down, everybody!!" And so we continued the long drive home passing cars, passing gas, and passing time by singing "Ninety-nine Bottles of Beer on the Wall."

Matt continued to be pushy about food all day and was argumentative, but on the whole he held his composure in front of his nephews. It is interesting to note that he has the ability to control himself enough not to "lose it" in front of them. Toward the end of the trip, Matt got on the car phone and tried to talk the staff into having a second supper ready for him when he got there. Al called the home back and explained that Matt had already eaten. When Matt got into his house and the boys were back in the van, he immediately unleashed his verbal abuse on the staff and at Al and myself as we walked out the door—and that is the difference. We now can shut the door behind us on the torrent of ranting and raving that guaranteed to consume the evening. God bless the staff for being there in our place. We pray every day for their health, understanding, and fortitude.

Staff Changes

Tere Schaefer leaves the position of executive director on October 29. Her replacement will be announced in the near future. Gretchen Gogel, assistant executive director, has been appointed acting executive director for the interim.

A Farewell Message from Tere

Right now the nation waits to see the change in health care. We all face change as a key factor in our lives. PWSA(USA) must also face change to survive, grow, and develop. The board of directors desires leadership to improve the financial stability of the organization, broaden outreach and partnerships with larger organizations, and provide visionary experience for the future of what PWSA(USA) can be. I have heard it said there is a right leader for a right time in any organization; a decision has been made that I am not this leader. Mr. Stewart Maurer of the board of directors is chair of the search committee for this new leader. This change may cause uneasiness within the organization; please continue to be supportive.

After all, PWSA represents the human touch of understanding, informing, and updating the world on individuals with PWS. Each year my gratitude for this touch grows when I experience the laughter of individuals and parents at the annual conference, and travel across the country to train and educate others on the complexities of the syndrome.

These training experiences have included the formation of group homes. I am always delighted to see a facility that will provide a lifetime of love and care to adults with PWS, where they will not be faced with the tortuous temptation of food, will not be ridiculed by others, and will have a supported social life.

Among the joy, the struggles continue, and there are still many individuals with PWS who face life-threatening obesity and severe lack of services. The most difficult situation I face is to say, "I'm sorry I don't have anything to recommend," or "the only service you can get is clear across the country." People call looking for the hope and answers. Unfortunately, the answers are difficult to accept and can be discouraging. I continue to be saddened by the difficulties individuals experience in getting the support and services they need to deal with all the aspects of the syndrome. I often hear parents say, "If it's not one thing, it's another. If it's not food stealing, it's behavior; if it's not behavior, it's tantrums or fabrication of stories." However, when we share our stories and difficulties we make PWSA a strong supportive place to provide hope, joy, and knowledge.

It is also difficult to know many families whose sole support is our bi-monthly newsletter. The stress of this syndrome is never to be underestimated, and we continue to pray for medical technology to provide the help which is so desperately needed.

As I depart I would like you all to know I have greatly appreciated your support, ideas, and enthusiasm. PWS will forever be part of my life, and I will never forget the passion for care all of you possess. My sincerest wishes to you all in your continuing challenges and triumphs.

Tere Schaefer

Election Resolution

As reported in the last *Gathered View*, PWSA's election procedures were challenged by Mr. Sheldon Tarakan following the July board of directors election. Members of the board and officers have reviewed the election in detail and found that no bylaws or policies were violated. However, it has been determined that the nominating and voting procedures need to be more defined. As board members and officers, we want always to be open to growth, change, and constructive criticism. Therefore an ad hoc committee has been formed to develop revisions to our current election procedures. This committee will present its recommendations to the full board for their approval at the semi-annual meeting in January.

The election will stand as is in order to maintain an operating organization, but to avoid any appearance of bias or unfairness, the two contested positions will be held for one-year (rather than three-year) terms, and there will be a new election of these two positions at next year's general membership meeting.

Janalee Tomaseski-Heinemann
President


On the Move

Dr. Suzanne Cassidy has taken a new position as Director of the Center for Human Genetics at Case Western Reserve University in Cleveland, Ohio. Dr. Cassidy was formerly with the University of Arizona. She serves on both PWSA's board of directors and its scientific advisory board.

Correction

The last issue of *The Gathered View* reported that, at its July meeting, the PWSA board of directors granted \$17,500 to the publications committee for the revision of specific publications and videos. The committee did request that amount, but there was no board vote at that time on the full proposal. Subsequent to the July meeting, the board voted by mail to proceed with updating the Medical Overview video and approved a \$5,000 grant for that project.

We need your HELP!

 Nearly five years ago, many of you submitted the names of professionals who treated your child with PWS. The collected names are the basis of our current directory which desperately needs updating. We need each of you to again search your address books for the names of physicians, psychiatrists, nutritionists, speech, occupational, and physical therapists, etc., who have assisted your child. We also need to

update our list of group homes and alternative placements for individuals with PWS. The directory is invaluable to parents around the world with newly diagnosed children. Many of you have spent years educating the professionals about PWS. Please spare the next generation of parents the same frustration and send names, addresses, and phone numbers to the National Office before December 1st.



Trick or Treating

Taking the Nightmare Out of Halloween

This spooky, fun-filled day signifies the beginning of treat season. We've asked a few of the chapters to share their thoughts on how to make this sugar-packed holiday one that individuals with PWS can enjoy.

GEORGIA CHAPTER

(Dottie Cooper & Hope Mays)

- Never trick or treat alone. Ask other kids you are trick or treating with to not eat along the way.
- Trade treats with another family member for: money, toys, healthier treats, privileges, movie, etc.
- Allow treats (limited number) to be eaten Halloween night only, then throw out the rest.
- Dole out one piece per day for dessert; if candy in the house is too stressful, pick out just a few & dole out daily.
- Give out packets of raisins, baseball or other sport/nature cards, small packets of crayons (most large toy/departments stores sell them bagged for Halloween).
- Call on neighbors ahead of time to have special treats for your child. We go to only five or six houses; they give him fruit, a dollar, small toy, water pistol, etc.
- Organize a neighborhood party with games, costume contest, etc. to cut down on trick or treat time. Low calorie supper ideas include: low fat cheese/wheat bread sandwiches cut in pumpkin shapes, low calorie items on thin crust pizza and decorate as Jack-o-lantern face, diet soda - orange, of course, orange slices, apples, and other fruit, sugar free gelatin cutouts in Halloween shapes.
- For school parties allow one item (i.e. one cookie, one cupcake, one whatever). Ask teacher to not allow room mothers to bring so much candy. But suggest offering small toys or activities instead. There are lots of options besides food.

NORTHWEST (Joane Underwood)

We do let our eight year old go trick or treating with her brothers. We of course go along to chaperon. We allow her to pick one candy for snack. She can keep all the gum. Then we put the rest of her candy up out of reach. We take away pieces of candy gradually over the next week or so and she doesn't seem to notice. Then after a week or so we tell her the candy is "too old" and throw the rest away. It seems to work so far but it won't be so easy when she learns to count better!

ILLINOIS (Fred Batliner)

The parents who did allow trick or treating monitored what was received and what their children were allowed to eat. For past years' Halloween celebrations the chapter awarded non-food prizes for the best costume and for bobbing for apples. Popcorn and diet soda were served.

WISCONSIN (Barb Dorn)

School: I always offer to contribute to the classroom party at Halloween time. I usually send pumpkin jello jigglers. I get to be creative by painting Jack-o-lantern faces on the jigglers with food coloring. The kids love them. I have also contributed sugar-free lemonade (with a small amount of red food coloring added to make it look orange) or Tropicana Lite Orange Cranberry Juice (18 calories per 6 oz. serving) mixed with diet 7 UP or diet Sprite.

Last year, Tony's teacher wanted to frost sugar cookies as part of the Halloween activities. I however suggested using popcorn cakes and cheez whiz spread. (You can also make up a separate container of fat free cream cheese and food coloring for your child with PWS.) I try to suggest a snack that is not only low in calories but also nutritious. You also need to consider the "acceptability" of these foods by your child's classmates. Popcorn cakes vs. rice cakes are usually a bigger hit and accepted more readily.

I also must emphasize to the teachers that Tony doesn't need all the treats sent on that day. I ask them to pick two treats (the lowest in calories) in addition to the jello jigglers. That means Tony can have jigglers, Sugar Free lemonade, plus two more items. For Tony to have four things usually makes him very happy.

I also send treat bags filled with non-food items. I have picked up skull rings, stickers and/or Halloween pencils. Many times you can get good deals on the treat bags and stuffers at craft stores as well as department stores.

Home - We do allow Tony to go trick or treating. We always discuss the entire game plan and arrangements before anyone leaves the house. My husband accompanies both boys and they are limited to a designated number of houses on our street. When they come home, all the candy is inspected and they are able to pick out three pieces of candy to eat Halloween night. Then, the candy is placed out of sight and touch. Every day, Tony is able to pick out one piece of candy to put in his lunch. (The lunch room during

post-Halloween time can be quite the "candy store".) My thoughts are if Tony has at least one piece of candy of his own he won't feel so bad and be a part of the gang. I secretly thin out the volume in Tony's bag and I do allow his brother to have more access to his own candy. (His brother is not aware of this however.)

It is a tough time for everyone. At times I feel guilty doing it this way but I also try to cut portions a little and make some other cuts in his diet. We usually don't gain any weight over Halloween; now Christmas is another story. Good luck and happy holiday.

ONTARIO (Joan MacKinnon)

Here's what I did:

- Informed teachers what Jon could have to eat if there was a party at school. Previous to this, they had been "taught" about PWS. It didn't always work and he got extra, but I never have been all that uptight about these occurrences. I just try to close the "loop-holes" for the next time.
- He was allowed to go door-to-door to a limited number of the neighbors that he knew but always accompanied by one of the family or a worker.
- I stipulated and got his agreement from the very first time, that he was to bring all his "goodies" home and he could eat one thing (his choice) Halloween night. The rest I would keep in a spot only I knew about and each day he could have one thing for his lunch or dinner or snack. He agreed to give Mom, Dad, and his sister a treat too, so that reduced the bagful a bit.
- Most years, he stopped asking about them as time went on, and months later I was able to throw out the candies and other high calorie stuff unknown to him.
- It was very difficult to dissuade him from having a costume and going door-to-door when he was in high school. We let him go with supervision just to neighbors and good friends who knew him and understood. I think he was 18 or 19 before he was able to give it up and act as the "door-answerer" at our home.
- The house of pop- "loot" we give out at our are things like small bags corn or peanuts, pencils or apples (the latter in the early years when there was not the scare about people trying to injure children).
- I think it is important for the readers to know that Jon has a "low normal" intelligence. I started this from the time he first began going "trick-or-treating".



A Prader-Willi Food Pyramid

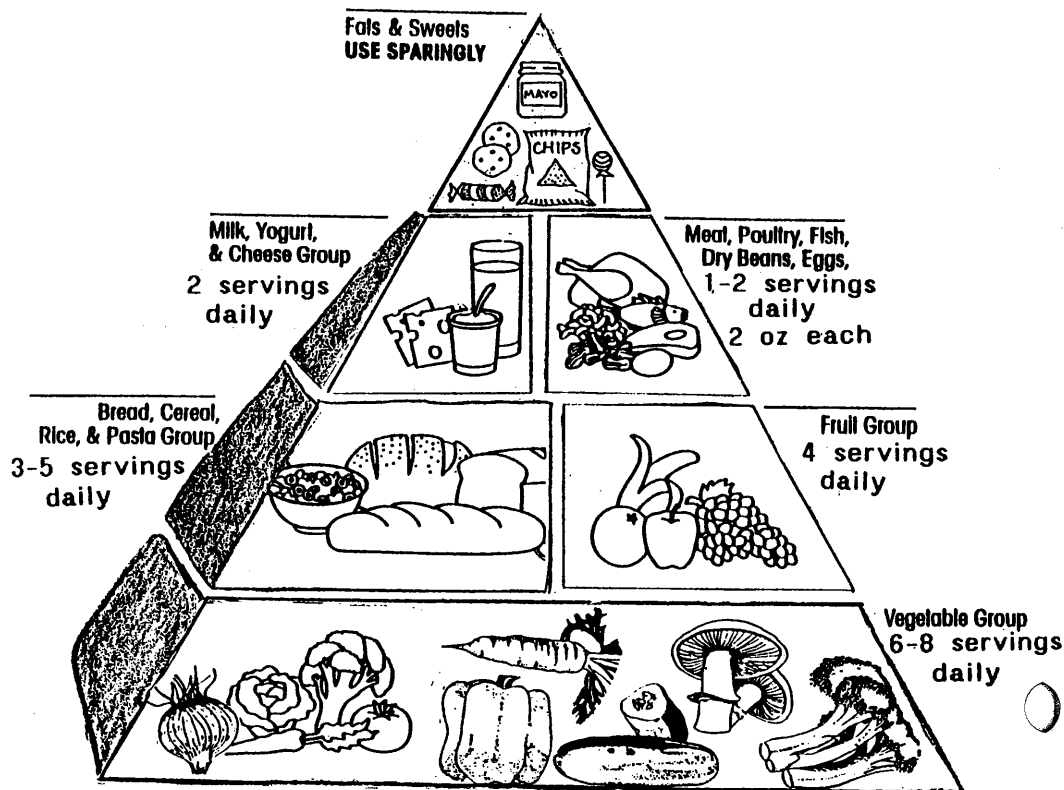
by Beverly Ekaitis, DTR, dietetic technician at The Rehabilitation Institute of Pittsburgh (TRI)

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 Rehab 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. TRI was glad to oblige but urges those who have been through the Rehab's program to continue using the Red-Yellow-Green Diet that they learned there. The Prader-Willi Food Pyramid may not be appropriate for young children without further adaptation and should not be considered a substitute for individualized dietary guidance, preferably 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 2½-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: ½ cup cooked or 1 cup raw
Bread: 1 slice bread; ½ cup rice, pasta, or starchy vegetable; 1 oz. cereal
Fruit: ½ cup canned, ½ cup or 1 piece fresh, ¼ cup dried; ½ cup juice
Milk: 1 cup milk or yogurt, 1 oz. cheese, ½ cup frozen fat-free sugar-free yogurt
Meat: 2 oz. cooked lean meat, fish, poultry; 1 egg; ½ cup cooked dried beans; 2 tablespoons 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 dressings, 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 this 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.

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Getting Through the Grief

by Lota Mitchell, M.S.W.

The 60 or so national PWSA conference attendees awaiting the speaker for a session entitled "Bereavement: Understanding Your Grief" were startled to discover a clown coming down the aisle toward the podium—a most unexpected turn of events. Eloise Cole, a nationally known grief specialist, had just arrived in the person of Rainbow the Clown. Rainbow, using many sight props, acted out being a happy clown, plunging into the depths of grief, and slowly ascending back to enjoying life again. Then, shedding her clown role, Ms. Cole interwove her own story of loss, when her two beloved stepsons died in young adulthood from muscular dystrophy, with insights into the grieving process that we all go through in dealing with loss.

We associate mourning and bereavement with death, with the loss of a beloved person. And indeed it is. But grieving also goes on with other losses that come to us throughout our lives—the loss of a job, of a meaningful relationship, of a limb, of a pet, of health when a chronic or life-threatening disease is diagnosed.

When a baby is born with a birth defect, parents experience the loss of the perfect child which they have expected and dreamed of so joyfully for all the months of waiting. As the dreams come tumbling down, it is almost as though the baby had died. In a very real sense the perfect baby has died, and another has taken its place. Parents of children diagnosed with Prader-Willi syndrome go through a period of grieving, which they may not recognize for what it is.

Eloise Cole says that grief is nature's way of healing a broken heart—but what a difficult process it is. You feel isolated because friends don't want to be around all that doom and gloom; but, on the other hand, you find it hard to be with happy, laughing people. You think constantly of the loss, have trouble concentrating, and find yourself doing "dumb things." Cole told of searching for baked potatoes which were not in the oven where they were supposed to be—and which finally turned up in the refrigerator, where she had put them to bake. Motivation for everything is low, anxiety is sky high, the world is upside down, others can't understand your reality, and—to say the least—you are crabby. You're filled with pain mixed with disbelief, shock, denial, helplessness, anger, and guilt.

Rainbow the Clown tried to find ways to get rid of the pain. She tried stuffing it away; she tried being so busy she wouldn't notice it; she tried being so strong she wouldn't feel it; and then she tried taking care of others to distract herself. Nothing worked. The pain was still there, and she just ended up exhausted.

She began to learn that she needed people to listen to her pain, that she needed to talk about it, that she couldn't keep everything bottled up. It was important to surround herself with supportive friends and family. She learned that journal-writing helped—putting the pain on paper. She learned that rest and good nutrition helped—but alcohol and drugs didn't!

Caring for Yourself:

- Take some time each day for yourself—you'll be a whole lot better with everyone else if you do.
- It's easy to see pain ahead, harder to see pleasure; so create things to look forward to and to be excited about.
- Watch out for negative self-talk. Give yourself permission if (when?) you screw up.
- If you lose your temper, just go back and apologize.
- Try new things, like breakfast in the park or audition for a play.
- It's OK to laugh, and it's OK not to be super-serious all the time.
- Keep a box for special notes, which you can reread on bad days for a spirit-lifter.
- Celebrate your victories; give yourself "gold stars" when you accomplish something that is hard for you.
- Find things that give you some pleasure and help to restore hopefulness.

Elizabeth Kubler-Ross, a doctor who pioneered the study of death and dying, identified five stages that the dying person goes through, and these apply to grieving other losses also. They are: Denial (No, not me!), Anger (Why me?), Bargaining (If me, then ...), Depression (Woe is me!), and Acceptance (Yes, me.). However, there is not a nice, neat progression from stage to stage. Individuals grieve differently. One may go back and forth between the stages, spend lots of time in one and skip another, or even be in two stages at the same time.

Anger!! Why me? Cole suggested ways to work through your anger. You could scream in the shower, the closet, or into a tape recorder. Write in a journal or a letter (though it is sometimes wise not to mail it). Beat, throw, or kick pillows. Garden. Clean. Exercise. Find nonjudgmental listeners. Try this exercise:

I am so angry I could _____
and then I would _____
and then I would _____
and after that I would _____

Finally, Cole had suggestions about caring for your marriage. She observed (as no doubt we all have!) that men and women don't do things the same way. Husbands and wives may not grieve the same way. For example, she might desperately want to talk at a time when he might not be able to listen to it. But maybe he could give her 15 minutes of listening when he couldn't tolerate a whole hour. It is important to be really clear about what you need and problem-solve around it. Ask for it; don't expect the other to guess. Just because you've been married for years doesn't mean you can read each other's mind—your spouse might not have a clue.

Cole shared that if there was any one thing that saved her marriage, it was taking a half hour each day with her husband to talk about who they were that day—what each was feeling about himself or herself—rather than about what they were going to do that weekend, or what they were going to eat that night, or the bills and problems.

(Note: A video, "Rainbow's Remedy," is available through Eloise Cole's company, Creative Resources, 6845 East Lewis Ave., Scottsdale, AZ 85257, for \$45 plus \$3.00 shipping; or the tape may be borrowed from the PWSA National Office. While the focus is on the grief experience following the death of a loved one, there are useful insights into the mourning process and moving toward acceptance and renewal. Portions of this tape might be useful as a discussion tool for chapter meetings.)

Lota Mitchell is co-editor of *The Gathered View*, a former chair of the PWSA Board of Directors, and an employee assistance program counselor for Westinghouse Corp. in Pittsburgh, Pa.

In Memory of a Special Little Girl

Cherie Hope Hendricks

March 30, 1986 - March 3, 1993



After a bout of the flu the previous month, 6-year-old Cherie developed undiagnosed diabetes, and skyrocketing blood sugar led to her sudden death last March. Her mother, Martha Hendricks, of Gilbert, West Virginia, wants to warn other parents about the possibility of a common illness triggering diabetes. Martha also sent a copy of a letter she wrote to the doctor who had diagnosed Cherie's PWS—a letter which, as she said, turned into a journal. We would like to share portions of it with our readers.

... When Cherie was a baby, and we first realized that something was wrong, I loved my baby, but I resented the handicap. I always prayed for God to heal her because I just knew she had to be made right. But about two years or so ago, I was made to realize that it is not God's will to heal everyone, and that realization devastated me ... I was all torn up and called my mom. She came and talked and prayed with me. We asked God to help me "to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference."

... She was in her third year of school ... at a school just for handicapped children. ... One of her teachers told me that each morning when the kids came in that some were sleepy or grumpy or happy, but Cherie was the only one who came in each morning happy and smiling. Just a few months ago our pastor at church gave her a special plaque for always having a smile. Everyone who knew Cherie loved her. ... we were always so proud of her, just proud and glad that she was ours. We were always especially proud whenever she would learn to do the least little thing, because nothing ever came easy for her, except smiling.

... Cherie weighed about 106 and was 4'2". She had beautiful, shiny blond hair and the prettiest color of blue eyes. And she had

freckles and little buck teeth that were just so. ... Cherie was so special. At times I felt like we were not worthy to have her. But I reckon God thought differently because He chose to place her in mine and Zachary's care.

... We have a big family and Cherie was left out by no one. ... She was precious to us all. On Sundays we would all gather at Mom and Dad's house for dinner. We never wanted to place a cloud of doom and gloom over Cherie's head because of her problem with food or her handicap. We would always try to find the humor in things. During dinner my dad would slide his hand towards Cherie's plate pretending to get it, and she would yell out, "Mama Nay, Papa Leeloy (his name is LeeRoy, but she could only say Leeloy), mine, no!" She loved to tease and cut up; she was like her dad. Her Papa Dee loved to wrestle with her, because all the while he would be gently wrestling with her, she would be getting a workout. And she would yell for her Mama Neet, "No, Papa Dee!" And then Mama Neet would say, "Papa Dee, you leave that baby alone!", and then she would pretend to smack him, and he would groan like she was really hurting him. Cherie would giggle; she loved every minute of it. ...

... We had some great times. But we had our share of bad times also. I was telling my mom how I wish I could take back every harsh word, every bad moment, and my mom said, "Martha, if all the love that was lavished on Cherie could be weighed in the balances, it would far outweigh all else." ...

... Cherie's struggle with life is over ... she is healed now. I am so glad for God, for the hope that He gives us. I'm so glad to know that this is not the end, that we will see Cherie again someday, and until then she is in the utmost of safe keeping ... in the presence of the Lord. But still our hearts are so sad ...

... I just wanted you to know a little more about Cherie besides her address. She was worth knowing.

Sincerely,
Martha Hendricks

About Diabetes and PWS

Diabetes mellitus—so-called "sugar diabetes"—is often mentioned in the literature as a problem associated with Prader-Willi syndrome. In fact, it is not much more common in the Prader-Willi population (5-10 percent¹) than in the general population (6 percent²). In those with PWS, diabetes usually appears in the adolescent or adult years as a result of obesity. This is the most common form of diabetes, and it responds well to weight loss and dietary therapy.

All forms of diabetes involve a hormone from the pancreas called insulin, which enables the body to store the food it consumes for energy. In the person with diabetes, insulin either is lacking or is not doing its job properly. The result is that, instead of being stored in the cells and the liver, the foods that are eaten raise glucose levels in the blood (blood sugar), which over time can damage many of the body's organs and systems.

There are two major types of diabetes, defined by whether or not insulin injections are required to keep the person alive. About 90 percent of people with diabetes are Type 2—not dependent on insulin injections—and the majority of these are obese. Type 2 diabetes develops slowly, often without symptoms, and is typically diagnosed through routine urine screening for blood sugar levels. Type 2 diabetes is sometimes treated with insulin and may progress to the insulin-dependent form of diabetes if the pancreas loses function. It has been recommended that people with PWS have annual urine screenings after 5 years of age to check for elevated blood sugar.³

Type 1, or insulin-dependent, diabetes was formerly known as "juvenile diabetes" because it occurs most often in children and young adults. It is characterized by an abrupt onset of symptoms and can progress rapidly to death if insulin is not injected. Type 1 diabetes occurs because of an inherited defect in the immune system that results in the destruction of the body's own insulin-producing mechanism. It is thought that environmental factors such as infection, stress, or too much food can trigger this process. The classic symptoms of out-of-control diabetes—increased urination, thirst, and hunger, often accompanied by weight loss and lethargy—usually lead to diagnosis and life-saving insulin treatment. Any child who exhibits this combination of symptoms should receive immediate medical attention.

For more information about diabetes, consult your physician and/or your local office of the American Diabetes Association (ADA), listed in the white pages of the phone book. The national office of the ADA also can provide publications and referrals to specialists in your area. Write to them at: American Diabetes Association, 1660 Duke St., Alexandria, VA 22314.

¹Suzanne B. Cassidy, M.D., 1992 PWSA national conference presentation

²*Diabetes Mellitus: Diagnosis and Treatment*, Mayer B. Davidson, M.D., Churchill Livingstone Inc., 1991, p. ix.

³Randell C. Alexander and Louise R. Greenswag, "Medical and Nursing Interventions," *Management of Prader-Willi Syndrome*, Springer-Verlag, 1988, p. 60.

Conference Camaraderie



There are two best things that happened at the Prader-Willi conference in Phoenix. One of them is meeting new PW children that I did not meet at the 1989 conference in Calgary. It is always neat going to conferences and seeing more Prader-Willi kids just like me. This is because I know that I am not alone.

... There were some Prader-Willi kids that face the same problems that I have to face every day. I found out that I am not the only one who gets teased. Another thing is that they have feelings just like me when something happens to them. I saw that there were other PWs that like doing word finds and doing coloring, etc., They were just not children doing it but teenagers as well. This made me feel real comfortable that I am not the only one who likes doing things like that. ...

The major thing was that I thought that I was going to be the only PW that was going to smoke at the conference. I found out that I was not the only one ...

I thought that I was going to be the only one in Phoenix from the 1989 conference and I found out that there were two others from four years ago in Calgary ...

I walked in to where we usually meet every day and I noticed a friend of mine crying. I asked her why and she told me. I found out that she picks her sores but she usually finds a solution and fixes that problem. Every time she gets upset instead of picking her sores right down to the bone she takes something and either breaks it or rips it up. The only difference was that she had a solution to the problem and I didn't. Just the same I felt that I was not alone. I think that I might try to have something on hand that I can rip up if I get the urge to pick ...

It was wonderful to be at another conference again after so long. It was also nice and fun to stick around my best friend Richard and spend a lot of time with him. He also has Prader-Willi syndrome.

*Trevor Thom, age 18
Canada*

A Tribute to the Chausows

The last issue of The Gathered View included an article by Hy and Ruth Chausow on mainstreaming and a notice of the death of their daughter, Diane. The following is excerpted from a tribute to Diane and her parents written by Alan Spector, executive director of the group home where Diane lived at the time of her death.

... Diane had a way of imprinting herself on all she met. She was unforgettable. One lovely, touching, funny, unusual, amazing story after another. No one will ever be able to forget Diane.

That's good.

Diane came from a truly remarkable family. A mom and dad who are as creative as they are capable. They fought for Diane. They supported and nurtured her. They shared their concern for their daughter with all of us, advocating for recognition of Prader-Willi syndrome so that others could be helped and things would be easier for them. Single-handedly, they educated local and state officials. Forming a statewide group, they reached out to other parents and their children.

The Chausows were the driving force behind the opening of the first small group home for individuals with PW in Illinois. They used their talents and hearts to help select and train staff, shape and create new procedures, and

support in every way this program that was so desperately needed. Hy earned a place on the Glenkirk Board of Directors, where he is an informed and capable contributor to oftentimes difficult association matters. Ruth's smile can even be heard over the phone, and her skills have made her a virtual authority on PW and parent issues throughout the state and beyond. Ruth sits on the Program Services Committee that guides all Glenkirk programs. Such generous, talented people.

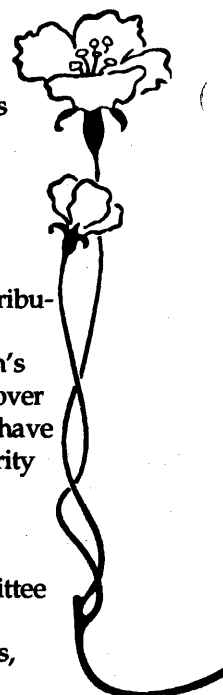
We thank Diane for sharing them with us.

Now our last earthly conversation with Diane is concluded. We are left with wonderful memories, and we have learned much from her. She leaves a legacy of which we all would be proud. Surely, some day we shall meet again. I can see it now.

Looking over her glasses, standing at her station, this time smiling. "What are you doing, Alan? Just looking around?"

"No, Diane, I came to see you." She would like that. Mission accomplished.

*Alan Spector
Executive Director, Glenkirk
7/13/93*



Sibling Study Update

Replies to the sibling survey have been dribbling in, one or two a day, and they are still coming. It has been fun, interesting, and exciting to receive them. I'm looking forward to putting it all together in an article for an upcoming *Gathered View*. I want to encourage all those siblings who have not yet sent in your questionnaire to do so. I especially encourage responses

from adult siblings, who can look at having a brother or sister with PWS from the vantage point of time. The questionnaire appeared in the July-August issue of *The Gathered View*; if you need another copy, just call the PWSA National Office. Thanks for your participation!

Lola Mitchell

Ask the Parents

Q: *What do you do when your child with PWS has destroyed property—either their own or someone else's—in a tantrum?*

Several responses were phoned in—

A: The mother of a 7-year-old daughter felt the best thing she could do was count to 10 and ignore the whole situation.

A: The mother of a 13-year-old girl who had damaged an expensive piece of school equipment required her daughter to give the school all the money from her piggy bank so she would experience consequences from her behavior.

Another member wrote about her experience and posed a new question—

A: ... We had a situation where my son wrecked his dresser drawers. I made him glue them back together (took him several hours). The dresser wasn't useable afterward, but I think it helped him think twice the next time. Trev was about 16 at the time and is high functioning.

The biggest problem we are having is one of dishonesty. He seems to feel free to take almost anything. Purses always have to be locked up—even those of visitors. I suspect now his theft includes small toys, etc., as some have appeared with no satisfactory explanation as to where they came from. When we go visiting others, we can only go where people fully understand the problem and where the place has been prepared (no money available). Also he has been caught shoplifting a number of times. The police laid charges at my request the last time, but it never got to court. They felt it

wouldn't do any good. If others have suggestions, I would be very interested.

Your newsletter continues to be a great help to us.

Harriet Thom
Canada

Other questions phoned in by parents in recent months include:

Q: *What kind of locks and alarms are best, and where do I get them?*

Q: *How do you get insurance for individuals with PWS? How do you get insurance to pay for growth hormone?*

Please call, write, or fax your answers or questions to the National PWSA Office.

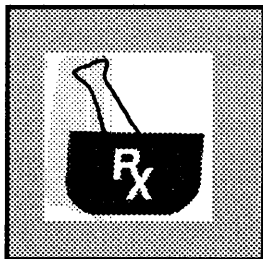
Ask the Professionals

Hunger Curbing Chemicals?

Vanja A. Holm, M.D.
Chair, PWSA Scientific
Advisory Board

One reader saw an article in the *National Enquirer* in February entitled "Want to lose weight?

Get a whiff of this" and wonders if the report might be applicable to persons with PWS.



This is a catchy heading for a brief article describing how some people lost weight by sniffing from an inhaler containing a foul-smelling chemical three times in each nostril when they felt an urge to eat. As the "taste" of food (except salty, sweet, bitter, and sour) is experienced through smell, there is some logic to the suggested treatment. However, it is said not to work for people with a poor sense of smell and, even more significant to PWS, for people who eat to relieve anxiety. Not that anxiety drives the overeating behavior in PWS. Instead

an even stronger, genetically determined force in the central nervous system (brain) compels the person with PWS to eat indiscriminately. Some years ago one of our nutrition students at CDMRC in Seattle ran an experiment with a few of the youngsters in the PWS clinic to assess their ability to taste. They had no problems distinguishing the overly salty cookie from the regular one or the very bitter chocolate pudding from the ordinary one, saying "This tastes terrible." They ate it anyway. Thus it seems unlikely that the inhalator treatment of noxious chemicals will dissuade persons with PWS from eating excessively.

There are other concerns about this story. The nature of the chemical to be used has not yet been determined, so safety is an unknown quantity. No scientific studies have been conducted and published. Anyone who thinks that this treatment is worth trying better wait for reports published in a more reliable medical journal than the *National Enquirer*.

Another reader sent in parts of an article on cholecystokinin. In contrast to the subject previously dis-

cussed, cholecystokinin is being studied extensively both in this country and abroad. The submitted note refers to studies done by Dr. Lieveise and colleagues from the University Hospital of Leiden, Netherlands. They and others have published many papers in respected medical journals on cholecystokinin and obesity (at last count, 33 in the past five years).

Cholecystokinin is a gut peptide (hormone released in the intestines) which is one of the factors involved in the signals to the brain indicating satiety. Studies comparing eating behaviors during intravenous infusions (that is how this product is given at the present time) of cholecystokinin and normal saline (salt water) on obese individuals have shown variable effects, some discouraging. However, one interesting study from the University of Kentucky showed that cholecystokinin produced satiety in obese subjects with hypothalamic disorders. It has long been known that children with trauma to the part of the brain where the hypothalamus is located become obese, in fact develop what some of us call "acquired PWS." It is not known what all this means in practical terms for individuals with PWS, but stay tuned. We will likely hear more about it soon.

Blue Jeans that Fit

If you've had trouble finding department store jeans that fit your child, you might want to check out a product recommended by Jacquie Roach, a parent from Texas. She saw the ad for *eSpecials* jeans in a Down Syndrome newsletter, but ordered them for her child with PWS.

Designed by the frustrated parent of a child with Down Syndrome, the special jeans have a number of features that make them ideal for some of our children with PWS:

- shorter-than-average leg length;
- a Velcro closure (with a false snap on the front for looks) and an oversized zipper pull tab;

- a three-piece, contoured waist band that keeps jeans in place;
 - classic five-pocket blue jean styling;
 - waist sizes from 22 to 42 inches in a wide variety of lengths.
- The price is \$29.95 plus \$4.50 postage and handling (plus \$2.17 tax in California) per pair. The manufacturer promises a full refund up to 60 days after purchase if you're dissatisfied for any reason. To order, send waist and inseam measurements and correct payment to: *eSpecials*, P.O. Box 1177, Larkspur, CA 94977. For more information, write or call Diane Cole at (415) 924-7960.

Share a Favorite Holiday Recipe



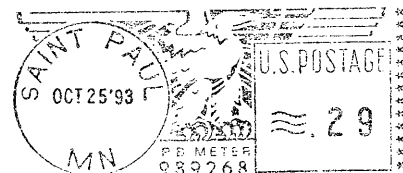
In the December issue of *The Gathered View*, we would like to publish recipes for some special low-calorie dishes that would fit into a holiday meal or party gathering.

Do you have a family favorite you'd like to share? Send as many as you like; if we get more than we can include in our newsletter, we can make them available separately. Please send

them to the National Office **before Thanksgiving**. Thanks for your help!

The Gathered View is the official newsletter of the Prader-Willi Syndrome Association and is sent to all members. The opinions expressed in *The Gathered View* represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of PWSA (USA). Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA (USA). Membership dues are \$21 per year Individual, \$26 per year Family, \$31 per year for Agencies/Professionals (U.S. Funds). Send dues, change of address, and letters to: 1821 University Ave., W., Ste. N356, St. Paul, MN 55104-2803. Any questions? Call us at: 800-926-4797 or 612-641-1955 or Fax 612-641-1952.

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