

DO'S AND DON'TS WHEN LIVING WITH THE ADULT WITH PRADER-WILLI SYNDROME

- DO** Keep food inaccessible at all times. People with PWS cannot fight their compulsion to get it. Put it away and lock the cupboards and refrigerator.
- DO** Keep their lives structured. People with PWS need structure and routine. Pre-plan changes.
- DO** Praise and recognize good performances. A lot of mileage can be obtained with a few words, smiles and hugs.
- DO** Listen to a person who needs to talk. The time it takes may alleviate or prevent unpleasantness later.
- DO** Include the person with PWS in planning and programming. They feel a need for some control and will cooperate 100% if they feel it was their idea.
- DO** Keep sight of the fact that the hand of a person with PWS is quicker than your eye!
- DO** Enjoy your treats in private. It is very hard for the person with PWS to watch others enjoying the goodies he is denied.
- DO** Use smaller plates and cups, spread the food out, and add extra non-fattening items such as carrot, dill pickles or diet Jello to make the amount on the plate look larger.
- DO** Inform neighbors, relatives, teachers, workmates, everyone with whom the individual comes in contact with that the resident has PWS – and then inform them again. But do ensure confidentiality; reveal only that which should be revealed.
- DO** Be consistent. Persons with PWS thrive on routines and knowing exactly what the guidelines and rules are.
- DO** Remember, that logic and reason will not prevail when the person with PWS gets upset and/or “stuck” on an idea or position.
- DO** Try to help the person understand his behavior and take steps to improve. Most persons with PWS will try with varying degrees of success to improve, particularly if those around them show understanding, concern, and empathy. Many are very unaware of how physical they have become during a tantrum.
- DO** Anticipate or note a problem or crisis in the making and devise ways to circumvent the behavior.
- DO** When there is a power struggle, or supposed misunderstanding, go to the written program and allow no argument.
- DO** Give a set of the rules, written simply, to each individual. Read and discuss them so they are clearly understood.
- DO** Use a positive approach to such problems as stealing, perseveration, manipulation, etc.
- DO** Establish a positive reinforcement program, particularly on an individual basis, using rewards as often as possible, or using withdrawal of privileges as needed and understood.
- DO** Treat each individual with respect and dignity.

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DO NOT's

- DO NOT** leave food accessible. It is generally best to lock kitchens and other food sources to remove temptation which is one of the most common reasons for misbehavior and tantrums.
- DO NOT** nag. Once a behavior has been dealt with, do not keep bringing it up. Temper tantrums should be discussed and then forgotten. It is generally better to choose a later time when the person and the staff member are no longer upset, angry or hurt. Wait until calmness prevails and then make appropriate plans to avoid a similar episode.
- DO NOT** get into an argument. If the person with PWS is building up to a disagreement, try to walk away, or guide the person to a private area and discuss it there. If peace cannot be restored, call upon a supervisor, if there is one, or make a decision and be prepared to live with the consequences. Frequently discussions can be ended if you give them the last word. (Make the statement, I will make one more comment and then you can make one more comment and then the subject is closed.)
- DO NOT** tease or be sarcastic. People with PWS find it difficult to assimilate such tactics and could cause them to become orally abusive or even physically assaultive. Introducing these circumstances will end in unpleasantness all around. But don't treat clients with kid gloves and a ten-foot pole either! Persons with PWS want to belong! Some good-natured teasing is accepted, enjoyed and looked forward to.
- DO NOT** use food for reward or punishment. Withholding dessert without a previous plan would be viewed by a person with PWS as unfair. If this is pre-planned and used, be sure the person leaves the room and does not watch others eat.
- DO NOT** interfere with home visits unless the person with PWS and the family have agreed on a special program in advance. Family relations should be kept as solid and pleasant as possible. Malicious behavior just before going home, however, may require parental and staff intervention.
- DO NOT** lose your temper in front of the person with PWS. Object to bad behavior, but don't get into a shouting match. It is good to let the person know you have objections to inappropriate behavior and that you have no intention to accept it, but losing your temper will not accomplish anything and will only escalate the emotional intensity of the situation. As soon as feasible, set up a program for improvement.
- DO NOT** ignore poor table manners. Set up a program for proper table manners and adhere to it. Speed of eating can be somewhat modified with course servings rather than the full meal served at once. It is permissible to ask the person to leave the table and complete the meal later when behavior warrants discipline.
- DO NOT** promise anything that you cannot or will not do. People with PWS are uncomfortable with inconsistency and uncertainty. If changes are necessary, prepare the person so they do not feel deserted or threatened.
- DO NOT** have an unstructured program. Keep the daily routine as structured as possible. It is very important for a compulsive person to know of changes, however minute, in advance.
- DO NOT** forget to praise and recognize good performances. A lot of mileage can be obtained with a few words, smiles and hugs.

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DO NOT's (continued)

- DO NOT** ignore the person with PWS who has an obvious need to talk. The time it takes may alleviate or prevent an unpleasant episode later.
- DO NOT** hesitate to ask for professional help. It is better to acquaint doctors, psychologists, psychiatrists, social workers, etc. with the problems of persons with PWS so they are prepared to address a situation as it arises.
- DO NOT** threaten a person with PWS with being excluded from a program for bad behavior. They must understand that the program is there to help them, and no matter what they try, they are there to stay.
- DO NOT** exclude the person with PWS, their parents, care providers and significant others from the planning and programming. A steady exchange of ideas and suggestions will make for a much smoother program. The only way to learn how to help a person with PWS is to honestly share good and bad experiences and put the information into beneficial planning with all involved cooperating.
- DO NOT** fail to supply verbal and written information to all organizations that will be involved with the person with PWS (such as schools, workshops, day activity centers, churches, clubs, even stores and other public places where the people may be partaking of services.) Police should also be made aware of the syndrome if it is likely that shoplifting or running away may be a problem. The more information all these people have the more likely they will be to respond to the person with PWS with understanding and good judgment.
- DO NOT** assume if the person has lost weight, that they are able to manage the hyperphagia symptom – food drive – caused by Prader-Willi syndrome. *There is no cure.*
- DO NOT** lose sight of the humorous aspects of every situation. Hang on to your sense of humor while figuring out ways to handle situations that arise.
- DO NOT** forget that Prader-Willi syndrome is a LIFE-THREATENING, lifelong, non-inherited medical condition.

For more information about Prader-Willi syndrome or to request an inservice training contact

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