Behavioral Support

- Speak in concrete terms; people who have PWS frequently have difficulty with abstract terms.
- Let the individual who has PWS know what to expect – what time an activity will take place, what will happen, etc.
- It's ok to set limits on repeated questions. For example, "I've answered that question two times, so I will answer it one more time and then we can talk about something else."
- Keep your promises. If you say you're going to do something, do it.
- Do not "punish" or threaten to punish unwanted behavior by taking anything away, especially food.
- Reasoning with someone when they're upset generally does not work. Do not tell someone who is upset that "everything will be ok." Instead, let them know you understand they are upset by repeating their words and showing empathy.
- Redirecting the individual to a new or desired activity will often be successful. There may be times, however, when you may need to just give the person time to calm down.
- Allow the child/adult's parent to manage a behavioral issue in their own way. It may not be how you manage your children, but they likely deal with similar behaviors frequently and know best how to manage their child's upset.
- If someone with PWS is left in your care be sure to stick to the schedule and follow the parent's instructions for dealing with any behavioral issues that may arise.

Prader-Willi California Foundation and the national **Prader-Willi Syndrome Association | USA** have an extensive amount of materials available for families, friends, physicians, therapists, caseworkers, residential providers, school staff, and other care providers. Please contact PWCF or PWSA (USA) when we may provide more information, support and advocacy services to you, your child, your friend, patient, or student.

To learn more about Prader-Willi syndrome and how you can help call us or visit www.PWCF.org

Prader-Willi California Foundation is a non-profit 501(c)(3) charitable organization established in 1979. An affiliate of the Prader-Willi Syndrome Association (USA), PWCF is dedicated to supporting individuals with Prader-Willi syndrome, their families, and the professionals who serve them.

pwcf .org Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

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Prader-Willi
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PRADER-WILLI SYNDROME

Someone You Know Has Prader-Willi Syndrome

How You Can Help

Tips for Extended Family, Friends, and Babysitters

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General Support

The single most important thing you can do is to be supportive.

Supportive means ***not*** asking (or thinking) "will he/she outgrow PWS?"

- Supportive means ***not*** telling your family member or friend what they should be doing (what worked for your kids is most likely not going to work for a child with PWS)
- Supportive means ***not*** telling your son or daughter that your grandchild doesn't need all that "stuff" (therapy, extra attention, special equipment or toys; whatever "stuff" happens to be controversial) because the child "looks just fine." Most parents spend a significant amount of time researching what their child needs — reading PWS message boards, websites and newsletters. If the parents believe their child needs the questionable thing, odds are the child needs it.
- Supportive means ***not*** saying "you worry too much about food; one little piece won't hurt." One little extra piece *does* hurt, not just in extra calories that individuals with PWS have absolutely no room for, but in breaking the routine and creating future expectations for extra food. Parents worry about food because they ***have*** to in order to protect their child.
- Supportive means saying "you're doing a great job" or "Johnny is lucky to have you for his parent."
- Supportive means educating yourself by visiting knowledgeable PWS sites (there's a list on our website), instead of Googling it which often leads to inaccurate or outdated information.
- Supportive means becoming a member of PWCF and PWSA (or the PWSA chapter/affiliate in your state) to receive their newsletter with the most up-to-date, accurate information.
- Supportive means attending PWS events: Walkathons, support group meetings, trainings, conferences, etc.
- Supportive means offering a helpful hand: babysitting either the child with PWS or the siblings, or all of them; helping to run errands; helping clean the house; taking your friend out to dinner away from the kids for some adult conversation.

Remember that food is a **constant source of anxiety** for the individual with PWS. Holiday meals or meals away from home and the normal routine are very stressful for both the individual with PWS and their family. Anything that you can do to reduce that anxiety is greatly appreciated by the individual and the family.

Food Support

If you're having someone with PWS visit your house:

- Remove all candy, mints, and nut dishes that you may typically have out.
- To the extent possible remove food from kitchen counters. Out of sight is not necessarily out of mind for the person with PWS, but it definitely helps.
- Discuss food to be served at meals/parties ahead of time with the parent. This allows the parent to prepare by:
  - Bringing an alternative for their child
  - Cutting calories elsewhere in the day to allow for a treat/ higher calorie meal
  - Letting the child know what to expect
  - Helping you choose good options for their child or adult
- Let the parents know what time you plan to serve meals or snacks.
- Avoid talking about food in front of the individual with PWS. For example "Who wants pie?" after Thanksgiving dinner can be very stressful. Perhaps your family member was going to leave before pie was served or maybe they were going to allow a small piece as a snack but it's not time yet.
- Avoid eating in front of the individual with PWS if it is not also time for them to eat.
- Do not offer the individual with PWS any food or beverages without asking (away from the person with PWS) their parent first.
- Defer any questions about food to the parent, or defer to the plan provided if the individual is left in your care.
- If someone with PWS is left in your care, follow their food plan exactly.
- Remember that for the individual with PWS "just one" or "just a little bit" ***does*** hurt.

If you're out at a restaurant, amusement park, etc. with someone who has Prader-Willi syndrome:

- Discreetly discuss when to eat if a set time has not been decided beforehand.
- Avoid eating in front of the individual with PWS if it is not also time for them to eat.
- Do not offer the individual with PWS any food or beverages without asking (away from the person with PWS) their parent first.
- Defer questions about food to the parent, or defer to the plan provided if the individual with PWS is left in your care.
- If you or your child want a treat (cookie, ice cream, etc.) find a time to eat it away from the individual with PWS.

Social Support

People who have Prader-Willi syndrome typically have deficits in their social skills. They may stand too close, miss social cues, or struggle with what to say. If you take a little extra time, you will likely be rewarded with some very delightful interactions!

Children with PWS particularly struggle with peer relationships. The following tips are ways you can help:

- Allow extra time for the individual to respond; it may take them a little longer to understand what you've said or to collect their thoughts.
- Keep in mind that people with PWS often take things very literally; they may have problems if you use sarcasm, metaphors, or idioms.
- Include the individual with PWS in games, outings, etc.
- Facilitate interactions with other children.
- Structured games and activities work better than open play activities.
- Teach your own children to be patient and encourage them to play and interact with the child or adult who has PWS.

Individuals with Prader-Willi syndrome are generally loving, sweet, and kind individuals who often have a difficult time managing their emotions which can sometimes lead to behavior problems. Structure and routine are extremely important. Unexpected events, no matter how small or exciting, can turn into a meltdown. Keeping the follow tips in mind will help you, your friend or family member and most importantly, the individual with PWS.