

Tip Sheet for Handling Situations where an Individual with PWS Fixates on Another Person

- Individuals with Prader-Willi Syndrome (PWS) can fixate or obsess over people just as they can persevere on ideas, questions, or things. Just because a person with PWS fixates or gets 'stuck' on someone it does not mean it is sexual or malicious in nature. Obsessive disorders and behaviors are very common with persons with PWS.
- Sometimes when an individual with PWS fixates on someone they want as a "girlfriend" or "boyfriend" they are trying to fit in socially. Other times they may fixate on someone without the need to fit in. "Crushes" are very common and can be intense for a short period of time. And, persons with PWS can also be "fickle," breaking the heart of their boy- or girlfriend as they quickly move on to the next person.
- Making anything "taboo" will only increase its emotional pull, therefore trying to diminish this obsession by not allowing the person with PWS to interact with or talk about the person they are fixated on may have the opposite effect. Persons with PWS are often oppositional and will be drawn to do those things which they know they shouldn't in order to create a "stir."
- Use a direct approach. When not in an argument or outburst, share in clear and direct language what is appropriate behavior when interacting with this person. For example, "She wants to be your friend not your girlfriend" will likely not be effective because it is not clear enough. It might be more effective to say, "When you see her you can say 'hi' but then you need to keep going." Or, you might suggest that the person of interest is really like their brother or sister rather than boyfriend or girlfriend, and that is how they should be treated.
- People with PWS don't pick up on subtle social cues and they do not learn by watching appropriate behavior modeled by others. It is important to create clear, concrete, and understandable boundaries about what specific behavior is acceptable and what is not. They will also need to be consistently reminded of what appropriate behaviors are at home, school, work, and any other setting where social interaction occurs. Appropriate behavior includes both verbal and physical interactions.
- It's helpful to have the individual with PWS to give their input to create and write down the list of 'rules' that can be referred to whenever necessary. Individuals with PWS often respond very favorably to clear, written rules, especially those they've had input to create. For example:

Rules

- 1) Individual with PWS and [object of her affection] may talk and interact together during break times.
 - 2) Individual with PWS shall play/do xxx or xxx or xxx during other breaks.
 - 3) Individual with PWS may not hold hands or kiss or touch [object of her affection].
 - 4) Individual shall assist caregiver with important tasks/projects at the request of the caregiver, including: X, Y, Z
 - 5) Individual with PWS may write a letter to [object of her affection] during a break and take it home to her mother/father/caregivers to read. Letter shall *not* be shared with [object of her affection.]
- Try to use social stories or some other activity to teach appropriate social interaction, and then later you can reinforce it *in the moment*. Practice ahead of time, then prompt in the moment immediately before the interaction occurs. e.g. "Here comes your friend X, don't forget we're going to give them a high-five today then keep walking!"

- Set up a system of regular positive reinforcements to encourage appropriate social behavior.
- People with PWS often do not understand social rejection and do not know how to cope with it. If their effort to relate to the person they are fixated on is rejected they may respond with crying, yelling, or could escalate to a verbal outburst including profanity and threats. Provide empathy to help them manage their upset. While the words said can be disturbing it is unlikely any real harm will follow. However, in these situations it is possible that the parents or caregivers of the object of affection could become angry and demand a response from the worksite, school, or law enforcement. One strategy might be to reach out to the parents of the other individual involved to educate them on PWS and what is happening, as well as the steps being taken to positively manage the situation. Often, if people understand the behavior is a manifestation of a disability, it helps.

Other Helpful Tips

If a pattern of fixation has begun it may happen again in the future. But knowing the steps to take in response will help to prevent a crisis situation from developing. Because the person with PWS is limited in ability to react to social rejection, supervision and environmental management are essential. This includes:

- Creating activity schedules that limit or put boundaries on opportunities for interaction.
- Preventing any “unsupervised” interactions (i.e. social events).
- Having people who understand the person with PWS and the situation available to manage any outbursts that arise in the moment.

Sometimes it can be helpful to "prescribe the symptom" to alter an obsessive/compulsive symptom. Frequently, *having* to perform/think of the obsession saps the power of the obsession and persons eventually become 'bored' with *having* to perform it. Therefore, one intervention to play with: Individual with PWS shall be directed to think about qualities she likes of xxx (object of her affection) for a full five minutes every day for one week, e.g., from 10:00 a.m. to 10:05 a.m. She may *not* think of *anything* else other than the qualities she admires about the other individual. She *must* use the entire five minutes thinking about qualities she likes about xxx (object of her affection). She may *not* skip any day of the week.

Special Notes

Prader-Willi syndrome is a medical/brain disorder and this individual's obsessive/compulsive fixation may be a result of the physiological manifestations of PWS, and therefore may need to be treated, at least temporarily, with a psychotropic medication.

If law enforcement becomes involved share with them as soon as possible PWSA’s statement for Law Enforcement and contact a crisis counselor at 800-926-4797.