

## Story-telling in PWS

### **A parent writes:**

The situation arose over the then-imminent wedding of a fellow participant in the exercise class for whom Gemma had developed a strong affection. She had listened to the evolving discussions in the class about this lady's plans to marry, from concept to detail and had over some months articulated to me the hope that she would be invited to the wedding. As it happened, no-one from the exercise class was invited. Plans firmed for a venue, menus were chosen, and some intense fitness work was happening so she could 'fit into her wedding dress and be looking great' for the big event. We put Gemma's constant repetitive talk about the wedding progress and hopes for an invitation down to the frequently-demonstrated perseveration associated with PWS, probably not understanding how intense was this particular wish. The bride-to-be also kindly took Gemma out for lunch one day, taking time off work to do so. More such catch-ups were promised, though none had occurred. (and still haven't).

One afternoon after a morning exercise class, Gemma came to me saying that she had just remembered Jane, the exercise therapist, had spoken to her that morning reminding Gemma not to forget to RSVP to the bride about her invitations. Gemma clarified that the bride wanted to pick her up from work (at Secret Garden Nursery) one day the following week and take her out for dinner, leaving her partner at home to look after their daughter (an unusual event, apparently). Gemma also was invited to the wedding, and to travel down with the bride, partner and daughter on the Friday preceding the wedding, stay overnight with them, and they would bring her back home on the Sunday after the wedding, if that was all ok.

Gemma then sent an email to the bride accepting these kind invitations. Later that night I received a phone call from the bride saying that she was a little concerned because the discussions/invitations had never happened. I also spoke to the receptionist, whom Gemma was certain had overheard the conversation and had supposedly reminded her not to forget to reply. The receptionist assured me that neither conversation had happened. Both the exercise therapist and bride expressed their affection for Gemma, but were concerned for her well-being.

Gemma was so certain the conversations had happened, clearly 'remembering' every word, expression and her excitement at what had been said. It was this 'clarity' that made it so hard for her to accept that it didn't happen and caused her to wonder if she was going mad. I am not sure the psychologist and (subsequently) psychiatrist that we visited were able explain to her satisfaction why it had happened, and to this day I think she still occasionally wonders if it did. She worries less about her sanity these days because there have been no similar episodes since, but it took a while.

Story telling is common for individuals with PWS, especially among higher functioning people like Gemma. Not all story telling results in such complex stories. There are several variations of this behavior in PWS.

First, there is the simple lie. Typical children lie to escape punishment or to avoid doing something they don't like doing or don't want to do. Lying in PWS is often about food. For example, a young person with PWS might tell his teacher that his mother did not feed him breakfast, so that he will get another one at school. Also, people with PWS of all ages are likely to lie when confronted with theft of food or other items, even if they are caught in the act. The act of lying implies that a person is telling a falsehood; that is, they know that what they are saying is untrue. Sometimes a person with PWS will make a statement that



you know is false, but they believe that it is true at that point in time. For example, a young woman steals a CD from a peer at the work program. When confronted by her mother, she says that she did not steal the CD because it was hers. The young woman argues with certainty that the CD is hers, until her mother finds the same CD in the young woman's collection.

The second form of story telling is *wishful thinking*. This is the type of story that Gemma told. She wanted to be included in her friend's wedding. Her story is a fantasy, but she believed that it was true. She did not have the capacity to test the reality of this story. She was not able to see the content from a perspective other than her own. She was emotionally invested in it, and she wanted it to be true.

The third form of story telling is *confabulation*. Confabulation is defined by dictionaries as: *the production of fabricated, distorted or misinterpreted memories about oneself or the world, without the conscious intention to deceive or the replacement of a gap in a person's memory by making-up stories that he or she believes to be true*. In addition to faulty memory, there is another form of confabulation which is similar to the puzzle assembly abilities among individuals with PWS. In this form, pieces of information that the person has heard are put together into a story. The information can come from conversations, news releases or movies. Because the person is assembling this information into a story, they believe that it is true.

Confabulation is different from lying because the person is making up and telling stories that he or she genuinely believes to be true. In turn, the person believes that you, the listener, should also believe that what they are saying is true. The person tells the story in a clear and consistent manner, and the content of the story is believable in that it *could* actually have happened. Although the story itself is false, some of the information contained within the story is true, and this is what makes the story believable. The story is put together from facts, memories, or what the person has heard, read or seen. Confabulation can range from the subtle changing of a story, to a quite bizarre invention.

The details in these stories may be contradictory, but suggesting this to the story-teller can cause problems. The story-teller will object to your contradictions no matter how clearly you present them, and if an argument ensues, you will not win. Also, the story-teller can become very upset, anxious, and often becomes the 'victim' so that the listener 'can no longer be trusted'; is no longer their friend; never believes them; is calling them a liar' and so on.

Some of these stories can lead to more difficult situations, especially when the content of the story involves physical or sexual abuse or emergency calls. When the story-teller is so convinced they are telling the truth and they are believed, higher authority intervention occurs, involving the police or emergency medical personnel. For example: a boy took his parents cell phone and called police early one morning saying that he had awakened to find that everyone in his family had been killed by an intruder; he had escaped by hiding in the bathroom, but the intruder was still in the house. When his mother woke-up in the morning and opened the front door to pick up the paper, she was greeted by the police emergency team! Another example is a young man who claimed that he had been sexually molested. There was no evidence of abuse

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(and there may not be even in real cases of sexual abuse) and the timing of the event in the story was impossible, but the young man was so insistent and believable, the accused staff person lost his job anyway.

Sometimes, it is difficult to decide if a story is confabulation or delusion. Confabulations are usually consistently and accurately repeated within a given context, but they might change from listener to listener. Over time, the person may admit that the story was untrue or deny ever telling it. Delusions are fixed false beliefs related to psychosis; they do not change over time unless the underlying condition is treated. Examples include: a psychotic man who believed that he was being controlled by a she-devil who was pinching him repeatedly; a boy who believed that the characters in a TV show or video game were real, and he could converse and interact with them. Some stories have grandiose content such as a middle aged woman saying that she had three sets of triplets, or a young man who stated that he was a championship ballroom dancer. Grandiose delusions are associated with mood elevation and usually resolve when the mood disorder is appropriately treated with medication.

Other stories revolve around religious themes or follow the death of a loved one. Stories of seeing angels or having conversations with loved ones who have died are not considered to be pathological. Usually these stories bring comfort to the grieving person.

#### ***How do you investigate the “event” when your person with PWS tells you?***

When confabulation indicates abuse, neglect or danger, it must be investigated. The first step is to make sure that he/she is safe. Second, if at all possible, you should take in all the information and react with neutral emotion. How these stories are managed is critical to prevent them from being told again; situations involving police and emergency medical staff are usually highly reinforcing to people with PWS. Make note of the time frame of the story; there may be inconsistencies that indicate doubt. Supporting evidence is essential. Don't lead the person on by asking questions or suggesting additional information. For example, if the person says, “My Daddy touched me last night.” Ask, “How did he touch you?” or “Where did he touch you?” Don't ask, “Did he touch you between the legs?” No matter how outrageous the story is, always consider the possibility that the person is telling the truth!

- Pay attention to the details of the story and write them down.
- Have someone else ask the person with PWS how their day is going. If he/she has had a traumatic event, they are more likely to tell the same story the second time to a different person.
- Most people who have had a traumatic event will show emotional distress; the story teller may appear to be detached.
- Alert the parent or guardian about the situation.
- Proceed with an evaluation by police or medical personnel, if indicated.





### ***Why do people with PWS make up stories?***

The precise reason why people with PWS tell stories has not been scientifically investigated, but clinicians and parents alike, have some theories about why it occurs. Some scientists believe that story telling is a developmental phenomena, and people with PWS remain more child-like in their thinking and behavior. Others believe that the short term memory problems typical of people with PWS cause them to make up details and interferes with their ability to test the reality of those details.

One aspect of the way people with PWS think (*a cognitive trait*) causes them to see things only from their own point of view. They *can* accept another person's viewpoint, but *not at the same time* that they are expressing their point of view, especially if they are emotionally invested in the story. At a later date, they might admit that the story they told is untrue or say they never told it. But when they are telling a story, they really do believe that it is true. That's why they are so convincing and it is so difficult for them to admit that the story is made-up. Another cognitive trait is their ability to take little pieces of data and create a whole picture - like putting a puzzle together. They can overhear a conversation, get tiny bits of information and make quite a convincing story. The story is most effective if there is an audience. Usually there is a lot of attention directed toward the content of the story and the person who tells it. Attention encourages the story-telling because of the interest it is given, even though it is false.

Sometimes the person with PWS has something to gain from telling the story. A person with low self esteem might tell a story to sound important. Or, a person with PWS might tell a story to access food or money or just attention. Sometimes stories cover up responsibility or guilt, like the man who was charged for breaking and entering a service station and stealing chocolate. He told police that the window was left open, and he thought someone might be inside committing a burglary, so he climbed in to investigate. That's when he saw the chocolate and took it.

### ***What is the best way to help the person overcome their tendency to 'spin' the truth?***

Janice Forster MD, (Developmental Neuropsychiatrist of the Pittsburgh Partnership and advisor to FAMCARE and IPWSO) suggests the following strategies:

First, in order to understand the nature of the problem, ask these questions:

- Is this pattern of behaviour typical of the person with PWS?
- Is the person high functioning?
- Does the person have a lot of freedom in his/her life?
- Has the person been diagnosed with bipolar disorder or is he/she receiving any medications that might cause grandiosity or mood activation?
- Has the person been diagnosed with a psychotic disorder?
- Are the parents the legal guardians, or does the person consent for him/herself?





***Managing this behaviour is challenging. Here are some helpful tips:***

1. **Reduce his/her degree of freedom.** He/she may have access to too many people and too much information. This may enable him/her in a negative way. If the information for the stories is coming from the computer, leisure time can be limited or supervised.
2. **Take away the audience.** This means that you have to alert every one that he/she comes in contact with, that he/she is a storyteller. They should listen but always react in a neutral way. Although the truth should be doubted, there is always the possibility that a story could be real. Then, try to redirect the person to a safe topic that everyone knows is true, like "Tell me about your sports card collection" or "Tell me about the first time that you went to a football game?" Or, if in a day program or school environment, teach staff an intervention "That's an interesting story, but I'll have to check with your parent," or, "It must make you feel important to think that you're related to a sports star." It's not helpful to ignore, and it's not helpful to attempt to dissuade. Helping him or her to save face is important.
3. **Turn the content of the story into an asset.** If he wants to be a sports star, or she wants to be a film star, then they need to live the life-style, including weight loss and exercise. (Special Olympics can be a wonderful way to provide an appropriate level of competition, together with appropriate exercise.)
4. **Use social stories.** Social stories are a helpful tool for teaching morality like why it's a good thing to always tell the truth and why there are consequences for lying. Most confabulators are creative people, so maybe they can write some social stories with you.
5. **Alert the police.** Be proactive with the police. Tell them that story telling is part of your child's repertoire. Give them your telephone number so they can call you if they become involved. If your son or daughter already has experienced the police, I would strongly advise you to obtain guardianship, or advocate for them. As intelligent as they may appear, they will not be able to advocate for themselves, although the court may find them competent.
6. **Consider therapy.** If your person with PWS is high functioning, he/she may be dealing with feelings of inadequacy due to having PWS, so their stories are all about being someone else who doesn't have the syndrome.
7. **Adjust medications** if they are contributing to the situation.
8. **Punishment never works.** When a person with PWS truly believes their thoughts are based on reality we must remember to be aware of their sensitivity to "blame." Overreacting to their stories, ridiculing their confabulation or blaming them for "causing trouble" will not help the situation, no matter how embarrassing or far reaching the implications of the story have become.

Remaining calm and supportive while providing the person with PWS the security they need to express his/her thoughts, then gently redirecting the conversation allows them to be heard without enhancement.

