



# 6th International Prader-Willi Syndrome Caregivers' Conference

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## Friends, partnerships and sexuality in PWS

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## Workshop Summary

### Friends, partnerships and sexuality in PWS

**Workshop Leaders:**

Patrice Carroll, Director of PWS Services, Latham Centers, USA and  
Neil Gumley, The Orange Hive, Australia

**Workshop description:**

This workshop on friendships, partnerships and sexuality focussed on the unique challenges that people with PWS face in forming and maintaining friendships as well as navigating their sexuality.

Discussions centered around healthy relationships, addressing social deficits and creating an appropriate education in relation to sexuality. An emphasis was on the importance of effective education, communication and the dignity of risk.

**The presentation used to facilitate the workshop is available [here](#).**

### Key question

Healthy relationships are a key factor in living a quality life. Disruptions in appropriate social skills, cognitive impairments and challenges in day-to-day living can impact a person's ability to form and keep relationships. Is a person less deserving of meaningful relationships simply because they need more support in creating and keeping them or should we, as caregivers, work to create an environment where relationships skills can be learned and improved upon with practice and support?

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### Friendships

As a group the workshop participants discussed **Friendships** for people with PWS.

- Definition of Friendship
- The need for early socialisation
- Risks vs. benefits
- Facilitating Friendships
- Maintaining healthy Friendships
- What can go wrong?
- Reflections

Takeaway points were:

- People with PWS can be great at making friends. Participants described the people with PWS that they work with, using words such as “caring” and “detail oriented”.
- Immature theory of mind - character traits can be misconstrued due to immature theory of mind.
- Everyone has a different definition of friendship.
- Social media contagion – could sway the view of any individual.
- Dignity of risk – everyone deserves the chance to learn from experiences that may not benefit them.
- People with PWS are often grouped with people on the spectrum in a special needs classroom. Those individuals might not necessarily reciprocate the friendship relationship. This bars individuals with PWS from learning these important skills early on – early socialisation.
- In a friendship we must be able to vocalise different likes and dislikes. Immature theory of mind will prevent individuals with PWS from coming to these thoughts themselves.

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## Relationships

As a group the workshop participants discussed how we define **Relationships** for people with PWS.

Takeaway points:

- There are many different kinds of relationships a person will have in their lifetime. With healthcare professionals, friends, carers, employers, community, family, and so on.
- As professional providers of care we can support people with PWS to develop and maintain healthy relationships through our own understanding.
  - o Provide caregivers access to good training
  - o Set professional boundaries
  - o Ensure a Community of Practice – all should be working in the same ways.

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## Sex and Sexuality

As a group the workshop participants discussed **Sex and Sexuality** for people with PWS.

- PWS vs. Neurotypical sexual functioning
- Define sexual relationships
- Mechanics/anatomy considerations
- Ideas of sexuality/informed consent
- Shelter or explore? The dignity of risk
- What could go wrong?

Key questions discussed included:

- Is it comparable to having sex with someone who is intoxicated?
  - o What if both people were compromised?
  - o Receiving food by giving sexual acts
- Is hyperphagia the same as being compromised or intoxicated?
- Social-emotional age
  - o If an individual is functioning at a 2–3-year-old level, where is the line drawn for sexual activity? Even if they are at the biological age of consent?
  - o What if an individual never reaches the “appropriate” social-emotional age?

Takeaway points:

- There is no specific test or assessment that a neurotypical person needs to complete in order to engage in sexual activity. These external forces only come into play when a disability is present.
- Access to appropriate training for both caregivers and people with PWS is important.
- As caregivers we should understand consent. Services in your area may support education as to how this is defined in your country.
- All should be aware of the [UN Declaration of Human Rights](#).

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## What can go wrong?

The workshop leaders stressed that it is okay for things to go wrong. That is how we all learn.

- Everything is good in theory!
- It's ok to get things wrong
- It's important for caregivers to review situations together as a team
- Caregivers should be on the same page as their community in how they handle situations regarding relations and sexuality.

## Scenarios: Breakout groups

### Scenario 1: "Edward"

Edward developed an obsessive fixation on a neighbour, a young mother with two small children. After a friendly exchange during a walk, Edward began a fictional relationship with her claiming that she was flirting with him and therefore wanted to start a relationship. Initially Edward simply told stories about their relationship, claiming the children were really his and that they had a wedding date set etc. But soon, Edward began sneaking out of the house to look through her fence and this quickly turned into him looking into her windows at night. Because children were involved this could have easily turned into a legal case resulting in "sexual predator" charges. Explaining this to Edward had no impact because he believed that the police would side with him because he waved to the police each day and they waved back. He enjoyed interactions with the police in the community and had no fear of being arrested. We tried having this woman write him a letter telling him that she was not interested in a relationship and to leave her alone, but he believed that she was coerced into authoring this letter. With little left to try we met with the police and asked them for assistance. The first thing we tried was to bring him to the police station and show him the jail and explain that this is where he would be if he continued to stalk and trespass and look in her windows at night. We explained the conditions in jail and why his actions were criminal in nature. This worked for about two weeks, but he eventually went back to this behaviour. The neighbor was growing increasingly afraid, frustrated and impatient, and began calling the police on her own. Finally, the police took action of their own and brought him into the jail cell overnight and pressed charges. Edward appeared in front of a judge who put him on probation (the judge went easy on him, likely because of his disability). Edward stayed away from her for three weeks and then started again.

Some suggestions for further intervention included:

- Offering Edward socialisation with a peer group to meet common peers.
  - Hope was that Edward could find a more appropriate way to connect with the right person.
- Discussing boundaries including “no means no”.
- Introduce more community members and social interactions.
- Distractions with real life interactions – activities, sports, dances, replacement behaviour.
- Report to the police when he did NOT engage in these negative behaviours.
- Redirection and complete pivot of the obsession or ‘story.’
- Psychiatric evaluation.
- Relocation.

### **Scenario 2: “Celia”**

Celia became obsessed with a peer in her school and stalked him in person, by phone and on social media. She lost interest in her favourite activities and did nothing but focus on where he was, what he was doing and who he was spending time with. She would text and email girls that he spent time with and threaten to kill them and burn their house down. She would stand on his lawn and yell for him to come outside. Soon she began throwing objects at his house and windows when he did not respond. We arranged a meeting between Celia and her peer with social workers and her family present. We met with the peer ahead of time and helped him with a script. This was similar to an intervention. He told her clearly that he was not interested in a relationship with her and that if she stopped stalking him, he would agree to still say hi to her when they passed each other in the hall. He explained that if she did not stop then he would not like her and he would never say hi to her again. Celia continued and her peer stopped saying hi causing an escalation in behaviours at school and at home.

Some suggestions for further intervention included:

- Meeting 1:1 with Celia and a carer to better understand Celia’s intentions, expectations, and her side of the story – what she likes etc.
- Proper education in appropriate interactions – modeling, counseling, etc.
- Social group and social stories – blatantly explaining what is expected if interest in a peer is prevalent.
- Introduce new activity.
- Continue to offer previous coping skills and liked activities.
- Introduce new and build off real social skills.
- Changing classes around to limit interaction.
- Risk assessment – could these threats happen?
- Friendship match making.
- Figure out if there’s an external problem.
- Meditation and mindfulness.

**Scenario 3: "Shane"**

Shane had become obsessed with a woman that he met at church. She was married and had brief encounters with Shane weekly during church service. Shane spoke of her as if they were a couple and began to become physically aggressive towards her husband when he saw them touching in church. Shane would have extreme behavioural outbursts when anyone tried to tell him that she was married and not involved with Shane in any way. As this behaviour became increasingly more intense Shane required daily physical interventions and also started to inflict self-injury on himself. Church services were an important cultural experience for the family but going to church with Shane consistently led to a behavioural outburst.

Action was needed to resolve this situation:

- Speak to Shane about what he wants, and why that specific person.
- Figure out Shane's understanding of relationships.
- This would make it easier to identify the communication route to use with Shane.
- Speak to Shane and possibly have a meeting with both parties to speak about the situation – mediated.
  - o The woman would be spoken to first to see if there were any precursors.
  - o She was encouraged to speak to Shane to explain that she was in fact married to another man. Ask she make her wants explicitly clear.
- Provide a safe place to have these conversations.
- Identify when he is becoming escalated to help and support him at the earliest point of time.
- Provide alternative opportunities – social groups, similar peers etc.
- If nothing worked, relocating Shane to another church.

**Scenario 4: "Lisa"**

Lisa is 14 years old and has consistently wanted to have a best friend since she was a small child. Recently a neurotypical peer befriended Lisa and soon they started referring to each other as best friends. Lisa was happier than her parents had seen her in years, but they started noticing some troubling things regarding this new relationship. Lisa began spending all of her time on the phone with her friend, avoiding homework and family time. Her friend told her that she would no longer be friends with her if she ignored her calls. Lisa was caught stealing from her teacher's purse and the teacher suspected that her friend had encouraged her to do this. Her parents knew that this was not a healthy relationship and worried that her new friend was a bad influence on her. What could her parents do to promote a healthier relationship while respecting Lisa's strong desire for friendship?

Participants suggested things which the parents could discuss with Lisa:

- How did Lisa and her friend meet?
- Does she understand the impact of her learned behaviours? - not completing homework, stealing etc?
- Does she have additional opportunities to meet people outside of school? If not, provide these opportunities.
- Participate in appropriate social groups with structured activities.
- Normalise her behaviour – 14-year-olds are on their phone all the time.
  - o Guidelines – complete responsibilities before using her phone.
- Closer supervision when she is using the phone.



**Scenario 5: "Jake and Linda"**

Jake and Linda are both adults diagnosed with PWS. They have expressed interest in having a sexual relationship. Jake is his own guardian and has a moderate IQ. Linda is not her own guardian and has a lower IQ. How can we access consent from Linda? Linda has verbally expressed her desire for a sexual relationship but is not her own guardian and her parents do not want her to have a sexual relationship.

There was lots of discussion around this scenario:

- Important to understand if both parties know what sex really is – more than holding hands, etc.
  - If so do they understand consent?
- Consent – you sign consent for sky diving, should it be different for sexual relations?
- The country matters – can the law deny sexual activity? This really depends on the country and or state.
- Parent wishes, do they have control/should they?
- The concerns of the parents matter as well – are there other options? Sex workers, masturbation etc.
- Ultimately, Jake and Linda could choose what they want to do.
- Parents really do not have control anymore.

Recommendations included:

- Behaviour specialist to assess IQ.
- Understand their knowledge of sexual activity.
- Outside resources and sex education.
- Role playing: "Jake, do you want a hug?" "Yes, or no."
- Filling in body silhouettes – Red: you cannot touch me there; green: you can touch me there; yellow: you must ask to touch me there.
- Replacement behaviour.
- Parent involvement – parent groups.
- Explain and educate parents that this is a human right and is normal behaviour.
  - work with the parents to understand their concerns and figure out a plan.

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**Bonus interview**

Watch workshop leaders Patrice and Neil answer some commonly asked questions about Friends, Partnerships and Sexuality in PWS.

Video link: <https://youtu.be/aaYYue-B5bw>



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