Friendships, Partnerships and Sexuality in PWS

Neil Gumley, Director, The Orange Hive, Australia
Patrice Carroll, LICSW Director of PWS Services, Latham Centers, USA
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?
Important Information

- Hot Topic
- No Right or Wrong answers
- Our own Observations
- Respect one another
- Facilitate Discussion
- Ask Questions!!!!
Meet Neil and Patrice

Intros
Friendships

- Definition
- The need for early socialization
- Risks vs. Benefits
- Facilitating Friendships
- Maintaining Healthy Friendships
- What can go wrong?
- Reflections
Defining Friendship

Let's Define what friendship means to you

We all have differing views of what friendship mean us and how we define what friendship means

Now, Let's define friendship from the point of view of someone with PWS

Complexity
Early Socialization

• What do we mean by "Early Socialization"?
• Tendency to Protect children
• Play groups
• School
• Clubs
Facilitating Friendships

- Our role we can play in facilitating friendships
- When and why do we intervene
- Our definition of a good friend is not universal
Maintaining Healthy Friendships

- The honeymoon is over
- Egocentric nature
- Theory of mind
What Can Go Wrong
Partnerships/Relationships

- Definitions
- Family
- Friendship/acquaintances
- Professional/community relationships/paid caregivers
- Sexual relationships
- Maintaining relationships
- What could go wrong?
Definition of Relationships

How do we define relationships?

Many different types of relationships
Family

- Parents
- Siblings
- Extended family
Professional/Community Relationships

- Paid carers
- Access to the correct training
- Professional boundaries
- Health professionals

- Care giving understanding
- Community of Practice (all working on the same page)
- Community Relationships
Maintaining Relationships

Understanding Healthy relationships

Positive relationships

The importance of maintaining "healthy" relationships

Negative relationships
Sex and Sexuality

- 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?
Mechanics/anatomy considerations

• How it all works for someone with PWS:
  o Delayed or incomplete Puberty
  o Hypogonadism
    ▪ Decreased function in the ovaries and testes
  o Small Gentelia
  o Reduced Libido
Sexual Relationships

- Boyfriends and girlfriends
- Boundaries
- Access to appropriate training for both carers and participants
Understanding Consent

- The education of consent
- Services in your area
- UN Declaration of Human Rights
Everything is good in theory!  
It’s ok to get things wrong  
Important to review as a team  
Same page with their community
Scenarios/Breakout Groups

- Instructions for breakout groups