



Behavioural Management



Understanding and managing behaviours

One of the keys to successful caring – Empathy – walk in the shoes of the person with PWS: “We ask people who by definition have the fewest adaptive abilities to make the most adaptations all the time.”¹

The most common types of behaviour difficulties associated with PWS are:

- Temper outbursts
- Food foraging
- Arguing, stubbornness and resistance to change
- Perseveration-talking about the same subject over and over again
- Obsessive-compulsive obsessive behaviour
- Attention seeking and manipulative behaviour
- Skin picking
- Lying
- Behaviour associated with mental health issues-depression.

**YOU CAN'T CHANGE
THE BEHAVIOUR OF
A CHROMOSOME**

**“If the person with PWS is not responsible for the behaviour,
they cannot be blamed for the behaviour”**

¹ Ann Donnellan (2001)



Behavioural Management (cont'd)

Daily Management

- 3Rs of Management :Clear Concise Consistent.
- Initiate intervention prior to problem starting.
- Remove or decrease conditions that instigate behaviour problems.
- Present conditions that increase the likelihood of appropriate behaviour. Give an illusion of choice. When all choices are removed, may regress to childlike or even bizarre behaviours.
- Don't give in to tantrums. A person with PWS can't reason, so divert their attention.
- Logical consequences, time out & parent effectiveness training don't work.
- Money should not be available to buy extra food.
- Use of telephone and credit cards should be monitored.
- Rules and regulations made clear, written down and prominently displayed. Helps reduce power play, manipulation struggles and tantrums.
- Use lots of visual reminders - use lists , stop watches, board- maker, planning calendars, house rules poster. This assists with time management skills.
- Time occupation - exercise or planned activities can distract the person from food obsessing, reduce stress, agitation and moods. It is also good for overall health and wellbeing.

Positive outcomes

- The attitudes of other people are very important – empathy.
- Don't argue with anyone with PWS.
- Firm but loving and caring attitude.
- Give clear guidelines and stick to them.
- Let it go if it is not important, or respond once, let it go and ignore it.
- Know your limits - Need to know our own buttons.
- Cheat- Distract, Say something non-committal.
- Use humour .Turn it into a joke.
- Praise and stress positives.
- Defer to a high authority.

What not to do

- Don't** take it personally
- Don't** nag, tease or argue
- Don't** ignore bad behaviour
- Don't** lose your temper
- Don't** promise anything you cannot or will not do
- Don't** try to talk things out
- Never** hesitate to ask for professional help

“Our understanding of PWS leads us to believe that the these effects almost all arise from some kind of dysfunction or chemical imbalance within the hypothalamus in the brain.”...some medications may help some but there is no magic solution.”²



Behavioural Management (cont'd)

Mental Health

People with PWS are prone to specific problem behaviours and are also at risk of developing additional mental health problems such as “affective illness” (depression and bipolar disorder) and “psychotic illness” that are characterised by fluctuating moods, hallucinations and delusions. Whilst the behavioural problems tend to be present in childhood and may continue to adult life, psychiatric illness may develop for the first time in the teenage years or early adult life.

Psychiatric Disorders:

- Sleep disorder
- ADD & ADHD
- Oppositional defiant disorder & conduct disorder
- Obsessive compulsive disorder
- Anxiety disorders
- Mood disorders
- Dysthymia & depression
- Bipolar mood disorder
- Psychosis
- Impulse control disorder
- Factitious disorder.

If a person exhibits behaviours outside their usual patterns mental health issues should be considered and referred for assessment .

Indicators of the onset of mental illness:

- The deterioration of existing problem behaviour
- Withdrawn and tearful
- Temper outbursts
- Talking excessively
- Over activity
- Excessive irritability
- Severe mood swings.

Management of mental illness in PWS

- Medication is but one component of a treatment plan
- Lower the extent and nature of demands
- Create a calm environment where possible
- Consistent and informed approach to support.
- Communicate with other members of the care team regularly (GP, medical specialists,)"

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