

Behaviours of concern in PWS

Children and adults with PWS are usually happy, friendly, sociable and loving individuals, so it can sometimes come as a shock if they exhibit behaviours of concern, or when emotional distress begins to escalate into physical aggression.

Understanding behaviours of concern in PWS

Behaviours of concern in any one, regardless of whether or not they have PWS, usually results when someone has reached the limits of their tolerance of a situation. People with PWS are much more vulnerable to stress than the general population, and generally speaking, have higher levels of anxiety and frustration. They can also find it difficult to identify and control their emotions, acting impulsively.

Most find it difficult to deal with change, and have difficulties processing information, so that it takes longer for them to work out what's happening and why. The combination of these factors means that behaviours of concern are more likely to happen in PWS, and sometimes this results in aggression.

However, the onset of mental health problems such as psychosis and an escalation of anxiety and mood disorders, can be influenced by stress, and this must be considered as a possibility if the behaviour isn't easily connected to other triggers.

Triggers

These are some of the more general triggers, not only for behaviour, but for emotional distress of any kind:

- Anxieties around food; presence of food in the room or nearby
- Frustration at not being able to do what he or she wants to do
- Communication or speech and language problems
- Feeling under pressure (whether or not the pressure is actually there)
- A "chaotic" environment with too much stimulus and/or too little structure
- In a low or unstable mood
- Unrealistic expectations on the part of others
- Real or perceived unfairness in a situation
- Change of any kind
- False expectations or disappointment
- Bullying, or physical or sexual abuse by others
- Harsh tone and disciplinary attitudes from carers
- Additional undiagnosed medical and learning disability conditions (e.g. autistic spectrum disorder)
- Unable to identify their emotions

There are many other individual triggers. Finding out the cause may be difficult; those with PWS may be triggered by something that happened in the recent past and that they have only just processed. Shifting blame or giving another reason for a behaviour of concern can also make it difficult to identify.

Preventing or minimising behaviours of concern

Create the right environment - In view of all the considerations, the environment for someone with PWS has to be “right”- it is up to others to provide the environment in which they can thrive. It is most likely the environment, or other people in that environment, which are the cause of behaviours of concern when it only occurs in certain situations, e.g. at school, but not at home, or vice versa.

For many of those with PWS, their behaviour will stabilize when in a structured, low-stress environment, where food access is controlled, boundaries are clear and a consistent approach is adopted by everyone involved.

Everyone working with the individual should be aware of potential triggers and how to avoid them.

Recognise signs of emotional distress and act before the situation escalates - Each individual may have their own way of showing that they are becoming distressed: rubbing or shutting eyes, wringing or waving hands etc. Over time you will recognise what they are, and sometimes it's possible to take the person to a calm, safe space, acknowledge that they are becoming upset, and address any issues they may have - particularly if these appear to be relatively minor.

Teach coping skills and behavioural relaxation techniques

Coping skills - Coping skills should be a part of the daily programme of activities for people with PWS, and they will need to be taught to the individual. Carers may need to demonstrate how to practice the techniques, and give lots of praise when they are done correctly. When the carer perceives an escalation, they can cue the person to use one of the practiced techniques. In this way, they can try to use these before they begin to display a behaviour of concern.

These skills include:

- Deep breathing
- Stress relief through sensory balls
- Listening to music
- Learning how to communicate feelings appropriately
- Taking a break

Behaviour relaxation techniques

Learning simple breathing control exercises and how to tense and release different muscles groups throughout the body can help reduce feelings of anxiety, or calm an individual who is feeling upset.

Adopting a Relaxed Posture - Encourage the person with PWS to sit comfortably in an arm chair, hands should be placed palms down along the arms of the chair in a resting position. Encourage the person to rest their head back in the chair and put both feet up on a foot rest, and take slow deep breaths and close their eyes.

Tensing and Releasing – Show the individual how to tense the following muscle groups in turn. Each tensed position should be held for a slow count of 10, and then relaxed so muscles go floppy like jelly. Repeat each position at least three times.

- Hold arms out and clench fists
- Pull shoulders up to ears
- Push both arms down on arm rests
- Strongman (tense biceps)

- Push both knees together
- Push head back hard into head rest
- Open mouth and eyes wide
- Close eyes and scrunch up face

Abdominal Breathing – Encourage the person with PWS to lay back in a comfortable chair with their feet up, hands on belly, with fingers interlinked. Show them how to breathe deeply into their belly, not their chest, so that their belly moves in and out. You'll know if they are doing this correctly as their interlinked fingers will separate slightly.

Breathing Elephants – Ask the person to take a very deep breath in and as they exhale, try and count as many elephants as they can until they run out of puff “one elephant, two elephants, three elephants...”etc. (They should not continue to breathe normally as they count, the object of the exercise is to regulate breathing). This is a good, fun exercise which can be done as a competition with another person to see who can count most elephants before they run out of breath!

Managing behaviours of concern

The person who is being attacked is not necessarily the cause of the aggression, which is often focussed onto the nearest available object or person.

Your immediate response and throughout should be calm and low key, ignoring screaming and shouting. Be aware that people with PWS are very sensitive to tone of voice; even the slightest hint of irritation, cajoling, or frustration on your part will be picked up by them. Do not argue with a PWS person; this will only escalate or prolong the incident. Threats and bribery are ineffective.

It is futile to attempt to reason with a PWS person in the middle of emotional distress`, e.g., saying “things aren't that bad” will not work - the thinking and problem solving part of their brain is “offline” at this time.

Make the environment as safe as you can, and direct other people away from the incident.

After an incident

The person with PWS will usually need time to recover and calm, and many will be exhausted. Provide a calm, low stimulating space, where they can go and lie or sit quietly. Many often go to sleep.

Wait until everything is calm again, and then, if possible, try to address the issue in a sensitive manner and find out what caused it. This isn't always possible, however, because the individual may become upset again, feel under pressure or be unable to identify a cause. What may seem a very minor issue can make a person with PWS very anxious or frustrated, and sometimes it's relatively easy to ensure that issue is addressed, but often there are more deep-seated concerns.

The most important thing after a behaviour of concern resolves is to get the person back into the program of the daily schedule as soon as possible.

Parents - Help for you

If your son or daughter is displaying a behaviour of concern, it can be very stressful. He or she may direct this behaviour towards yourself or other family members, or it may be directed at children and teachers at school or college, staff in day centres or residential homes and supported living. Many describe their situation as “walking on eggshells” -

never sure when the next behaviour will occur, or if you will receive a call to collect your son or daughter from school or college, with a threat of, or actual, exclusion.

The important thing to remember is that PWS is a very complex disorder and that your parenting skills are not necessarily at fault. You may need help from experts (see below) who can carry out a thorough analysis of what is happening with your son or daughter and recommend management strategies or treatments.

On very rare occasions, this may mean moving them out of their present circumstances into something more appropriate (e.g. from mainstream to special school, or from supported living to residential care), or into a specialist treatment centre. Again, this is not an indication of failure on your part, and may well be in your son or daughter's best interests, providing them with an environment in which they are better able to cope.

Recognise when you are reaching a situation in which you personally are unable to cope:

- Feeling helpless or powerless
- Breaking down in tears
- Dreading phone calls
- Feeling frightened of the person with PWS
- Wanting to run away

Talk to your GP or call social services and ask for help. Remember too that the PWSA UK is here to offer a listening ear, or to liaise with authorities. You can reach us by phone on 01332 365676 (Mon – Thu, 9 am – 5 pm, Friday 9am – 1pm, answerphone at other times), email supportteam@pwsa.co.uk or on Facebook (search for Prader-Willi Syndrome Association UK).

Help from experts

If you have tried everything, or the aggression is becoming a danger to others or the person themselves, ask your GP, community nurse, consultant or social services for a referral to psychiatric services or the CAMHS (Child and Adolescent Mental Health Services) in your area. When you go for the referral, make sure you take along information about PWS, including this leaflet, and the information entitled The Mental Health of People with Prader-Willi Syndrome.

If the psychiatrist has little or no experience in working with someone with PWS, we can provide contact details of someone they can speak to for more information.

In some cases, medication may be prescribed. As a general rule, this should be at a lower dose than normal.

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