



BEHAVIOUR MANAGEMENT FOR PWS

BEHAVIOUR	MANAGEMENT STRATEGIES
<p><u>Preference for routine and predictability</u> is typical and therefore individuals often thrive in environments where activities are timetabled. However, their need for consistency also means that they may not cope well with changes in expectation (theirs or yours).</p>	<ul style="list-style-type: none"> • Clear visual schedules and outlines of expectation are helpful and reassuring. • Provide forewarning of possible changes; avoid sudden changes and rushing. • Allow time to process and accept changes. • Avoid making promises that can be broken. • Try to avoid vague, ambiguous answers such as 'perhaps' or 'we'll see' which increase anxiety. • Avoid open-ended questions or too much choice. • Reward flexibility.
<p><u>Task switching</u> is a common area of difficulty with individuals feeling compelled to complete tasks. Support is required during task switching to reduce anxiety which may manifest in frustration.</p>	<ul style="list-style-type: none"> • May respond well to rituals and visual cues or timetables. • Use verbal and visual countdowns. • Modify tasks so that there is less to complete. • Schedule activities that are typically difficult to stop before a motivating activity, i.e. lunch. • Use incentives but hurrying a person with PWS can make matters worse.
<p><u>Obsessive thinking or perseveration</u> Individuals with PWS can think or talk obsessively about a topic of interest. Their thoughts can become stuck on a subject or issue. Perseveration or repetitive questioning can be a sign of stress.</p> <p>It may be useful at times to channel obsessive behaviour into positive activities.</p>	<ul style="list-style-type: none"> • Bring a topic to a resolution. • Set limits for the amount of time they can talk on a topic. • Do not provide more information than is necessary and avoid grey areas which can raise anxiety. Avoid providing information too far in advance. • Answer questions specifically (not with maybe / later), check understanding by asking them to repeat answer, limit the number of times a question can be asked. • Offer a range of appealing alternative activities or a variety of people to meet / spend time with. • Use diversionary tactics.
<p><u>Rigidity in thinking</u> is common. Rigid thought processes mean that information is stored in an orderly manner and there is a strong need for routine and consistency. Once something is learned it can be seen as the only 'correct' answer or method and it is difficult to have a change of mind or relearn. Rigidity can lead to stubbornness and argumentativeness.</p>	<ul style="list-style-type: none"> • Activities which encourage more flexible thinking from a young age may help. • Praise flexible thinking. • Encourage an understanding that there may be differing opinions, perspectives, answers or ways of doing things. • Individuals with PWS value authority figures but when they 'authorise' information, it can become set in stone and if incorrect, it can be difficult to convince a person with PWS of this. On the other hand, their response to authority figures can be useful.
<p><u>Non-compliance</u> An oppositional response can be an automatic 'flight or fight' response when a person is feeling anxious. Individuals with PWS are known for their ability to dig their heels in and be extremely stubborn. Sometimes stubbornness may be a coping device when there are genuine reasons for not wanting to do something, but they cannot find a way to tell you. They may not be consciously aware</p>	<ul style="list-style-type: none"> • Provide limited preferential choices to allow a sense of control over decision making. • Create clear rules, boundaries, consistency and a calm environment. • Avoid just saying 'No' and confrontation. Negative reactions raise anxiety further. • Resolve issues with compromise, finding a new solution together. Avoid ultimatums. • Offer empathy but repeat your expectation, then ignore unwanted escalation behaviour as much as possible.

<p>of their reasoning. It may be that something has gone wrong earlier in the day which is a pre-cursor to the avoidance behaviour. Fortunately, individuals with PWS are eager to please, enjoy consistency and following rules. Routines and rules reduce anxiety.</p> <p>Occasionally, manipulation, lying or confabulation can be additional problems. Lying is an abstract concept and pupils with PWS may have difficulty in recognising what they say as lying.</p>	<ul style="list-style-type: none"> • Allow processing time for 'coming around' to a new way of thinking or an agreement. • Set a limited number of clear, positive goals for expectations of compliance and reward success. • In the event of extreme stubbornness that puts a person in danger, help them 'save face' by saying you need their help or try to move them on by offering a more pleasurable activity. • Focus on blame or recrimination fosters an atmosphere where manipulation or lying can flourish. • Ensure good team communication so that lying is identified and a behavioural pattern is prevented.
<p><u>Tenuous emotional control</u> is due to the impaired hypothalamus having poor control over emotional responses. Individuals can be volatile, becoming easily upset or frustrated.</p> <p><u>'Meltdown'</u> can be caused by sudden changes in routine or expectation, increased anxiety, pressurised tasks, confusion, sensory overload, communication difficulties, teasing, frustration, use of their possessions or other triggers.</p>	<ul style="list-style-type: none"> • Avoid false expectation and disappointment. • Acknowledge feelings and encourage communication about anxieties. Use tools such as feelings cards or the feelings thermometer. • Develop their understanding of how situations affect their emotions, 1. I can handle this. 2. This makes me uncomfortable. 3. This makes me nervous. 4. This can make me mad. 5. This can make me lose control. • Help them to identify their feelings and teach ways of coping with stress, i.e. using stress balls, listening to music, taking a break, relaxation. • Praise efforts to control emotions, especially in difficult situations. • Have a 'calm down' plan where a person may remove themselves to a safe area to calm down. The plan may include the availability of prepared calming activities. • Monitor for signs of an impending meltdown, learn to recognise triggers, signs and take preventative steps. • Stay calm and try distraction, perhaps humour. • Avoid discussion and reasoning during a meltdown; reflect afterwards.
<p><u>Lack of impulse control</u> means that individuals will not self-monitor their behaviour well. They are more likely to engage in risky or dangerous behaviour.</p>	<ul style="list-style-type: none"> • Discuss situations and environments beforehand, what your expectations will be and what will happen if a lack of self-control occurs. • Encourage self-monitoring and evaluation. Offer reminders of their evaluations so they can focus on what they need to control / improve.
<p><u>Aggressive behaviour</u> is rare but occasionally emotional outbursts can escalate to physical aggression.</p>	<ul style="list-style-type: none"> • List strategies a person can use when they are feeling anger, such as going for a walk, counting or rehearsed breathing exercises. • Have a plan for keeping the individual and others safe in the event of an aggressive behavioural episode. • Predict times when anxiety will be higher and emotional control is likely to be reduced, such as proximity to meal times, when tired, if teased.
<p><u>Sensory processing difficulties</u> Individuals with PWS may be over-sensitive to certain stimuli or under-sensitive sensory seekers, or both. Sensory processing difficulties often improve with age. They do not respond well to chaotic environments with too much stimuli or too little structure.</p>	<ul style="list-style-type: none"> • Consider seating for comfort and noise distraction. • Transmitters and headphones enable ability to block out other sounds and focus. • Avoid talking too much and information overload. • Hand fidget tools may improve concentration. • Earplugs can reduce hypersensitivity to noise.

<p>Common sensitivities are loud noises, smells, movement, balance, touch and clothing.</p>	<ul style="list-style-type: none"> • Hypersensitivity to fluorescent lighting may exist. • Pre-warn of high stimulus environments. • Provide space in crowded situations. • Water is often calming and stimulating. • A sensory diet, including sensory gyms and sensory boxes are useful developmental and management tools. • A quiet, sensory smart area is helpful. • New therapies target spacial awareness with vestibular-visual-auditory approaches involving listening programmes.
<p>Poor social skills Individuals with PWS are friendly and need friends, although they often lack the appropriate social skills to form and maintain healthy friendships.</p>	<ul style="list-style-type: none"> • Identify what is confusing about conversations, i.e. eye contact, turn taking, listening, expressing thoughts and responding to humour etc. • Teach, model, role-play conversational skills such as listening to what others say, thinking about what they say, putting thoughts into words. • Practise conversations with topics of interest. • Use social stories for situations such as making friends. • Individuals could engage with a social skill group in activities that are of interest to them. • Support individuals during activities with peers. • Clear rules may be needed about social appropriateness and in particular for interactions with the opposite sex.
<p>Self-harming behaviour can take the form of nail biting, skin picking, teeth grinding, teeth, hair or eyelash pulling and varies greatly in severity. It is usually a repetitive habit which worsens with boredom / disengagement and may be a form of self-stimulation. Sometimes it can even be to provoke a reaction or seek attention. Less frequently, it may be the result of anxiety or emotional distress. It is hard to stop due to difficulties in thought switching and lack of impulse control. Impaired neurological signalling also means pain or disgust may not be felt as intensely.</p>	<ul style="list-style-type: none"> • Use distraction and redirection. • Keep engaged and / or their hands busy. • Various lotions can moisturise wounds making them less tempting to pick. • Dress wounds and keep nails short. • Avoid giving attention to the behaviour – positive or negative attention. • If the behaviour is sensory seeking, provide more socially appropriate forms of stimulation, although avoid linking to the behaviour in case it rewards it. • Although the behaviour appears compulsive, medicines targeting OCD or anxiety often prove unhelpful. • A natural supplement called PharmaNAC (available in the USA) has proven beneficial.
<p>Increased risk for mental health issues Anxiety disorder is very common. Compulsive behaviours such as skin picking, hoarding and concerns with exactness are often seen in PWS, but some individuals will have a dual diagnosis of OCD. Oppositional defiance and problems with aggression can also be present. Occasionally, extreme impulsivity or attention deficit leads to a separate diagnosis of ADHD. There are also increased rates of 'thought' problems in PWS (seeing things / hearing voices / strange ideas). In rare cases, behavioural episodes can become more extreme and evaluation for psychotic disorders may be needed.</p>	<ul style="list-style-type: none"> • Possible interventions for psychiatric illness in PWS may involve supplements, medication and psychological strategies. • Little is known about the early phase of illness and risk factors that predict the emergence of psychosis in PWS. Research is ongoing although it is known that earlier intervention leads to improved health outcomes. <p>(The management of food related anxiety and food seeking behaviour is covered separately.)</p>