

# Behaviour management



## Introduction

Almost every child with Prader-Willi syndrome presents with behaviour which can bring challenges to either themselves, or those around them, or both. However, this varies considerably between individuals.

Behaviours that challenge range from very mild to very severe, and each individual may display differing behaviours. These in turn may vary with age, circumstances and emotional development.

The degree of learning disability does not necessarily affect the severity of behavioural challenges. Those who have only mild learning disabilities are just as likely to have behaviours that challenge as those with a severe learning disability.

This article gives an overview of why behaviours that challenge occur in PWS, as well as suggestions on how to manage them. However, an in-depth knowledge of your child is required to know how and when to apply different types of management techniques.

It is important to remember that, while this article focuses on behaviours that challenge in PWS, children with the syndrome have many positive characteristics which often offset their difficulties to a large extent. They are known to be friendly, sociable, kind and caring, and many have a wonderful sense of humour. Each individual will also have other traits which are equally positive. Good behavioural management can bring these positive traits to the fore even more.

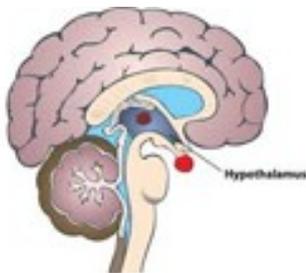


## Common types of behaviours that challenge in PWS

- **Temper outbursts (tantrums, rages)**
- **Food seeking and/or stealing**
- **Resistance to change, argumentativeness**
- **Perseveration (asking the same question, or reverting to the same subject over and over again)**
- **Compulsive behaviour and insistence on routine**
- **Attention-seeking and manipulative behaviour**
- **Skin-picking**
- **Lying and blame-shifting**

## Factors influencing behaviour in Prader-Willi Syndrome

As with every other form of behavioural difficulty, not just those in PWS, there are many factors which are involved. These may include cultural and social influences, as well as parental or carer attitudes. At the other end of the scale, other genetic factors, apart from the PWS, may have some effect on the individual. However, there are certain elements which arise directly from the effects of PWS, and should always be taken into account when managing behaviour.



### Problems arising from imbalance in the hypothalamus

Our understanding of PWS leads us to believe that these effects almost all arise from some kind of dysfunction or chemical imbalance within the hypothalamus region in the brain.

Although some progress has been made in finding medications which will help with some aspects of these imbalances, we still have a lot to learn, and there is no "magic bullet" for any aspect of behaviour in PWS. It is important to bear in mind that certain aspects of PWS behaviour stem directly from physical disturbances in the brain, and may not necessarily occur because the child with PWS is being "naughty", "bad" or "difficult".

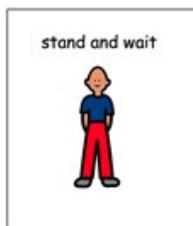
These physical disturbances may result in:

- Feelings of hunger, even after a meal, and thus the drive to eat and to seek out food
- Immature social skills
- Arrested or delayed emotional development
- Lethargy, somnolence and/or disturbed sleeping patterns
- High pain threshold (difficulty in feeling pain)
- Poor body thermostat (ability to keep the body at the right temperature).



#### Note:

For ease of reading, the text refers to "he/him" but all the information is equally applicable to girls.



### Specific emotional and learning disabilities

Many children also have specific emotional and learning disabilities which can impact on behaviour. These may be evident even where the child is functioning at a relatively high intellectual level. These include:

- Difficulties in processing spoken information, with greater skill at understanding visual cues. In other words, show the child how to do something or what you want them to do by means of pictures, signs or actions, rather than telling them.
- Speech and language disorders which can be frustrating for both the child with PWS and the listener. These vary considerably from one child to another. You can find out more about these in the article on **Speech and Language in Prader-Willi syndrome**. <https://www.pwsa.co.uk/assets/files/speech-5-13.pdf>
- Difficulties with short term memory, but a good long term memory; ie they may forget something learned only a few days or even minutes or hours before, but can remember significant events, such as journeys and celebrations, from a long time ago, and in quite a lot of detail.

## Specific emotional and learning disabilities (continued)



- Mood swings, going from happiness to anger or sadness in a very short time period, sometimes triggered by relatively trivial events.
- Difficulties in appreciating that what happens in one situation may or may not happen in another. This means that once a fact is learned, it is difficult for the child to "unlearn" it (this is particularly problematic if the "fact" proves to have been incorrect) or to appreciate that it may not always apply.
- A rigid method of thinking, often in terms of "black and white" which makes grey areas, "don't knows", and abstract concepts difficult for the child to understand.
- Difficulties with understanding time and numbers.

### The attitudes of other people



The attitudes of other people are also very important.

Likely to have a **negative** effect on a child with PWS's behaviour are:

- Aggressive attitudes and tones of voice
- A confrontational approach
- Being overly sympathetic
- Being in conflict with another parent/carer/relation - both giving different rules to the child with PWS or arguing in front of him
- Saying "Don't" as a means of trying to stop your child doing something.

Likely to have a **positive** effect are:

- Firm, but loving and caring attitudes
- Ability to keep a sense of humour, and to see and exploit the funny side of a situation
- Ability to give clear guidelines and boundaries and stick to them
- Praise, and stressing the positive aspects of your child with PWS
- Saying "Do" as a way of showing him how to do something correctly, (ie instead of saying "Don't leave the door open", say "Please shut the door").

## Behaviour management

### What can make behaviour worse

A number of factors can make these behaviours worse, such as:

- Major changes in daily routine or environment
- Changes in diet or meal routine
- Conflicts of opinion amongst others in close relationship to the child with PWS
- Unexpected happenings or upsets
- Major life stresses such as bullying, teasing, bereavement, moving residence, changing schools etc.

On a daily basis, very minor occurrences can affect behaviour. For example:

- Proximity to meal times
- Tiredness
- Minor change to routine
- Change in room or air temperature
- Mild teasing
- The child being unable to get their own way
- "Trigger" words or situations which are individual to your child.

## Managing behaviour



Bearing all the factors in the previous sections in mind, the following sections are offered as suggestions to help manage behaviour. Not all will work with everyone, nor all the time. Usually it is necessary to be always "one step ahead".

Some behaviours will be reinforced if they result in your child getting what he wants. Thus your child may "act up" in one environment where his behaviour is "rewarded" by others "giving in", but not exhibit that behaviour in another environment where others take a firmer stance.

Quite often behaviours are very different between home and school, which may reflect how your child is reacting to the people around them and the environment they are in.

Many people have noticed that individuals with PWS experience genuine remorse after an outburst of behaviour, and are really sorry for what happened, but this does not seem to prevent them from doing it again.

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## Communication

Problems may arise simply because your child has not fully understood the information which has been given him. If he has additional problems with short term memory, parts of complex sentences may be forgotten. Any information being passed needs to be broken down into small sentences or phrases to enable your child to absorb completely what is being said. Even if your child's intellectual ability is apparently relatively high, this may still be the case.



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## Temper outbursts



Temper outbursts, sometimes described as "tantrums" or "rages" are probably linked to the immature emotional development of people with PWS, and share many similarities with the type of tempers displayed by most two to three year olds.

Just as some little children seem more prone to tantrums than others, children with PWS also vary considerably in the type and degree of tempers. It is very difficult to say why this variation occurs, but is most likely a mixture of all the influences which were previously mentioned.

In any one individual, tempers may increase or decrease over time, depending on circumstances. The years between 12 and 25 may be more difficult (as with many youngsters without PWS). Temper outbursts can manifest in any of the following ways, from fairly mild to severe:

- Screaming
- Swearing
- Throwing things
- Hurting themselves
- Crying at length, more often occurring at the end of an outburst.
- Being aggressive and violent towards other people

### Things that may trigger a temper outburst



Researchers have found that people with PWS are more prone to temper outbursts than people without PWS at similar levels of development, and that they are more vulnerable to having a temper outburst, as are others without PWS who have hypothalamic or limbic damage. (Limbic relates to the part of the brain concerned with basic emotions and instinctive actions).

This does not mean that people with PWS will always have outbursts, but that in certain situations they are more vulnerable to having them. Sometimes it is difficult to find a reason for the temper outbursts, but the most common "triggers" are listed below.

- Being denied food
- Being unable to get their own way (not just over food)
- A change in routine
- Someone else using their possessions
- Attention-seeking
- Tiredness
- Confusion or misunderstandings
- Teasing

There are several techniques which can be tried to help your child. Knowledge of your child and how different things affect them is essential, as everyone is an individual.



### Managing the environment to avoid outbursts

Many potential outbursts can be avoided by providing the right environment to suit your child's needs. This might include:

- A structured day, with plenty of advance warning if changes are planned.
- Unpressurised tasks or expectations. For example, don't expect your child to be ready to go out in five minutes if it normally takes them 20 minutes - give them plenty of warning, possibly using a "countdown" system, with a reminder at 15 minutes, then at 10 minutes, and so on. This is particularly important for those with higher intellectual levels who may be placed under greater pressure, because more is expected of them, but which they are often unable to deliver in the time space allowed. This includes educational tasks.
- If your child finds it difficult to be around food (most, but not all, do), remove food from sight, do not allow others to eat in front of your child and, if necessary, lock food away.

Continued ...

### After an outburst

**Identifying the cause of the outburst may determine how it is handled afterwards. Essentially, there are two main causes.**

**In the first instance, he has had the outburst because he cannot get his own way, wishes to divert attention away from something else he has done, or is attention-seeking. Once he has calmed down, it may be possible to talk very simply about your expectations about behaviour.**

**The second cause of outburst occurs when something externally has upset him: an unexpected change to routine, teasing or bullying, or a disappointment. Again, support can be given to your child to help him overcome outbursts in the future, but this can be in a more sympathetic manner - just as you would console anyone else who has been upset by a circumstance beyond their control.**

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## Managing the environment to avoid outbursts (continued)



- Ensuring that all who come into contact with your child are giving the same message about what they expect in the way of behaviour.
- Help your child to learn techniques to keep calm such as deep breathing, listening to music, using worry beads or stress balls.
- Put up notices and pictures to remind your child to "keep calm" and/or of what happens when during the day.

- It may be useful to discuss in advance with him situations he finds difficult and how to cope with them.

## Look for signs of imminent outbursts

You probably recognise signs of increasing agitation, which vary from one child to another - sometimes it can be something as small as a slight quivering of the mouth, or a single tear rolling down the cheek. This is the time to try to head off the outburst before the storm begins to gather force:



- Use a calm tone of voice. Try not to show by your tone that you are exasperated, angry or becoming impatient. Do not raise your voice at all.
- Distract attention away from the subject or situation by doing or saying something unexpected (and preferably funny), or talking about another topic which you know is of interest to him.
- Praise your child for something they have done, or remind him how well he coped in a previous, similar, situation.
- Direct or take your child to a quiet place for a few minutes to listen to relaxation tapes or soothing music (especially if you suspect tiredness is a factor).
- Don't "wind up" the situation by arguing or trying to reason with your child at this point. It is often better to make a non-confrontational remark, or say nothing at all.
- Keep very calm and cool. If possible, bring someone else in to take over.



## "Weathering the storm"

Sometimes, even though every effort has been made to prevent an outburst, one will still occur. Then it really is a case of "weathering the storm" and, once over, everything goes back to normal again.

The outburst can vary from prolonged screaming and shouting (anything from 10 minutes to 2 hours) to, in a very small minority, violent and aggressive behaviour – although this is less likely to be evident in very young children. There are no quick and easy answers to managing an outburst, but the techniques on the next page may help to alleviate the situation.

### Managing an outburst

- Remove your child from the situation if necessary or remove the audience. (This of course is not always possible.)
- Take any other action necessary to ensure his safety and that of others.
- Stay very calm, talk softly and as little as possible.
- If possible, get someone else to take over if you are the object of the outburst.
- Do not attempt to reason or argue with him, even if he is undoubtedly in the wrong.
- Do not give in to his demands.
- Try distraction and humour again.



### The use of medication in severely challenging behaviour

Generally speaking, the use of medication is not the first option for severely challenging behaviour, especially in children of this age, where it is used only very rarely.

Only after every other avenue, technique or environmental change has been tried and failed should it be considered, and then in consultation with a psychiatrist or other consultant.



If your child is showing violent or aggressive tendencies, you can request a leaflet about this from the PWSA Office. You can also find it online at <https://www.pwsa.co.uk/assets/files/Aggressive-or-violent-behaviour.pdf>

### Anger management techniques



Ways to help your child, especially as they get older, might include basic anger management techniques:

- Relaxation tapes (although you may need to do the exercises with your child so he can understand what to do).
- Help your child to identify physical feelings associated with emotional states, so he can recognise in advance when he might lose control, and take an agreed course of action, such as going to his room.
- Ask your child to identify "triggers" i.e., what upsets him. You may find that the first answer he gives is not the real reason.
- Getting rid of angry feelings by hitting a cushion or similar object. Be aware that although this can help some children, for others it may increase the anger and they will then be unable to "switch it off".
- Design visual aids such as pictures and symbols to help remind your child what to do.
- Brisk walking or other physical activity
- Listening to music.
- Using hand-held computer games to take his mind off the situation.





## Food seeking and/or stealing

This type of behaviour can be particularly difficult. It helps to understand it if one imagines how it feels to be very hungry indeed: irritable, irrational, desperate to eat something (sometimes anything), thinking about where to get food from, etc.

As far as we know, this is how people with PWS feel for a good deal of the time, as the mechanism which tells them they are full does not function very well.

In many, this seems to be an "addiction" to food, just as some people are addicted to alcohol or drugs, with similar outcomes if they do not get it.

However, this also varies from child to child, ranging from some who have only a relatively mild preoccupation with food, to others who will go to extraordinary lengths to obtain it.

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## Managing the environment

Managing the environment is an important aspect of addressing challenging food-seeking behaviour. Depending on the severity of the problem, the following techniques might be used:



- Keep the kitchen locked, or make it "off limits".
- Use locks and/or alarms on fridges and freezers.
- Keep dustbins and rubbish bins locked.
- Help your child to understand why he needs to keep to a lower calorie diet and not get too overweight.
- Ensure others do not eat in front of your child.
- Alert neighbours and shop-keepers to the problem, especially if stealing/begging food or money is a particular difficulty for older children out in the community.

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## Managing food stealing



Even with the most alert parents and carers, many children with PWS can still manage to access food, sometimes in the most devious of ways.

Excessive weight gain is an almost certain sign that extra food is being obtained in some way, and it is sometimes very difficult to spot the loophole in the system. Look for the less than obvious!

For instance, offers to run errands for teachers, or requests to go to the toilet, may take your child conveniently past kitchens or delivery vans. School friends who have items in their lunch box they do not like may be happy to give them away.

If your child is caught taking forbidden food, the immediate outcome may be a temper outburst, and that may need to be dealt with first. However, there are other points and techniques which might be tried.

- If you say to your child "Did you take that chocolate?" he may vehemently deny it, despite evidence such as wrappers in his pocket, or chocolate on his mouth and fingers. It is better to say "I know that you took that chocolate" if a denial is likely. Make sure however that you are absolutely certain you are correct before you say things like this. You can then move on to dealing with the problem, rather than getting involved in a "No, I didn't", "Yes, you did" situation.

## Managing food stealing (continued)

- Opinions vary as to whether denying an item of food at the next meal (e.g. pudding) is viable or even humane. Much depends on your child - some will agree to this, others will not. On the other hand, giving a special food treat or meal as a reward for not stealing can be an option, again depending on your child.



**Bear in mind that this behaviour is the consequence of a physical urge, and is not pre-meditated "bad behaviour", and it is very difficult for your child to understand the concept of theft. Any efforts made by your child to overcome the urge to take food should be praised.**



### Resistance to change, argumentativeness

Researchers have found that children with PWS find it very difficult to switch from one thing which is engaging their attention to another. This leads them to appear stubborn and refusing to "move on". Added to this are the specific learning difficulties which make it difficult for the child to understand abstract concepts.

Usually, they are not being deliberately difficult - they are having genuine difficulties coping with a situation. However, in some cases, attention-seeking or manipulativeness may also underlie this behaviour - knowledge of your own child is essential in this respect.

### Managing resistance to change

Sometimes your child may absolutely refuse to move or comply with your requests. In extreme situations, this may put him, and you, in personal danger. For instance, sitting down in the middle of the road and refusing to move. These are some ideas to deal with the situation, but creative thinking plays a large part in this one!



- Try to help your child onto the next step by suggesting a pleasurable activity to do next. However, care needs to be taken to avoid him taking advantage of this because he can begin to feel he is being rewarded every time he acts up.
- Keep very calm. Don't yell or shout.
- If safe to do so, ignore your child, and go on with what you were doing, especially if you suspect they are attention seeking.

## Behaviour management

### YouTube resources about managing behaviour in PWS

Behaviour and mental health in PWS - Tony Holland (IPWSO and PWSA Ireland)  
Behaviour and mental health in PWS - Tony Holland <https://www.youtube.com/watch?v=5MfuGXRXY>

Unique Behavioral Features of Prader-Willi Syndrome— Elizabeth Roof (USA) <https://www.youtube.com/watch?v=98GvGJ9DaCo&t=2s>

Prader-Willi, Understanding and Managing Behaviour Part 1—Janice Forster (USA) <https://www.youtube.com/watch?v=OfF4e6Elnh8>

Understanding and reducing problematic behaviours in persons with Prader Willi syndrome - Kate Woodcock <https://www.youtube.com/watch?v=9ldH1HiSDpo&t=330s>

## Managing the environment



Helping your child to make decisions and to expect change may contribute towards reducing resistance to change.

- Get your child used to the idea of choice by presenting simple alternatives as often as possible, eg "Would you like to wear a red jumper or a blue jumper today?"
- If you know a request is likely to result in resistance, help your child to move on by suggesting a reward if he complies. This can be a practical reward such as a toy or magazine, or the promise of extra time spent with a favourite person or on a favourite activity.
- If you know a change is going to happen, try to present it in a positive light eg "a big surprise" or give control back to your child by saying, "such and such is going to happen ... can you help me by ...."
- Give known alternatives well in advance, "If the weather is wet, we will..." "If Mrs Jones is out, we will ..."
- Use visual aids – pictures and diagrams – to help your child understand what you want him to do.
- If a particular situation always results in resistance, try to find out why this is happening. Has something bad happened in this situation in the past? Does it put your child in contact with people or places they feel uncomfortable with? Sometimes the resistance may be a coping device on the part of your child, who has genuine reasons why they do not want to do something, but cannot find a way to tell you.

## After an episode of resistance to change

It is sometimes possible to talk through what happened, and point out the problems which it incurred. Even if they were not dangerous, it may have made you late for an appointment or upset others. Try to find out why it happened, so that you can both discuss what to do next time.



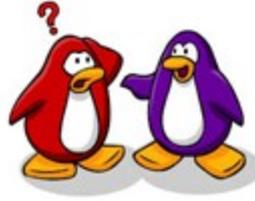
## Perseveration (asking the same question, or reverting to the same subject over and over again)

This type of behaviour can often be noticed in very young children, who continually say "Why?" after every question. In PWS it may be linked to this stage of emotional development, as well as their specific learning difficulties (eg auditory processing difficulties) and language difficulties. It can become very wearing to the listener. Very often the subject returned to will be food or meal-times. Here are some suggestions to help with this:

- Ask your child to repeat back what you have said to them, and then reassure him that his facts are correct.
- Do not continue to argue or reason with your child. This will only add to his confusion.
- Divert the topic of conversation onto something else.
- Draw your answer so that he can see it visually.

## Perseveration (continued)

- If the answer to his question is genuinely "I don't know", you may need to explain why you don't know. Otherwise he may think that if he keeps asking, sooner or later you will know the answer. He may also think he is just being fobbed off.
- Be aware that if you keep answering the question every time it is asked, this may constitute a "reward" to your child, in that they are getting your attention. He may continue just to get the response from you.
- If it is a certain topic which is being fixated on, tell your child that they have x minutes more to talk about it, and then you are going to change the subject or walk away. If necessary, show them when they will have to stop by pointing to a clock.



## Behaviour management

### PWS and autistic spectrum disorder

**"True" autistic spectrum disorder (ASD) is found in a small minority of children with PWS— see <https://www.pwsausa.org/wp-content/uploads/2017/06/Autism-With-PWS.pdf>**

**However, many children with PWS show some of the characteristics of ASD such as obsessive behaviour, dislike of loud noises and resistance to change. In these instances, children respond well to management techniques used in ASD.**

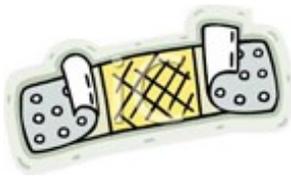
## Obsessive-compulsive behaviour

Researchers have found that this type of behaviour is more common in people with PWS than in the general population. It can be on a relatively minor scale, such as collecting brochures or doing things in a particular order, but it can become more serious if the obsession is centred on another person - this may often be a member of staff at school or another pupil. Other types of obsession may be with certain objects and picking at clothing. Skin-picking, which is very common, is addressed on the next page.

### Managing obsessive behaviour



- Suggest that hoarded objects are sold at a car boot sale to make money for a special treat.
- Divert attention away from the person or thing he is obsessed with.
  - Try to channel it into more positive activities e.g. craftwork.
- With staff at schools, change the teaching assistant regularly, or use several people as key support staff.
- Reduce the opportunities to be with the person (or thing) he is obsessed with, and support the person who is the subject of the obsession to appreciate that they may need to remove themselves physically to assist in diversionary tactics.
- Have another person present who gives him a lot of attention to divert attention away from the person he is obsessed with.
- Use time spent with the favoured person as a "reward" for good behaviour for not bothering them for the rest of the day, but limit the time to around 15-30 minutes.



## Skin picking and spot picking

Skin picking or spot picking is very common in PWS. Sometimes it begins when a child is quite young, sometimes when they are much older. Like other behaviours, it varies in severity. Skin picking is often provoked by small spots and grazes, which are picked continually, and thus never allowed to heal. However, sometimes wounds are made where there was no wound previously. Any area of the body can be a target. Most common are the limbs and the head or face, but other areas may suffer, including, in a few instances, the rectum.

It is thought that skin picking is actually a pleasurable activity for the child with PWS, as their high pain threshold does not warn them that the activity is becoming dangerous. Skin picking releases endorphins in the brain which make the child feel good, as well as enforcing the addictive nature of the habit. It often occurs when the child is bored, watching television, or anxious. Although it is often more distressing to the onlooker than the child themselves, skin picking does present serious problems because of the risk of infection into the wound.

### Managing skin picking

- Keep your child's hands busy with small toys or objects to handle, hand-held computer games, some form of craftwork, rolling wool into balls, or use worry beads, stress balls, or kush balls.
- Teach your child basic first aid, the need to keep sores bandaged and to apply antiseptic ointment. Note that in a few cases, care must be taken that your child does not eat the ointment.
- Negotiate a reward for not picking the wound, and give the reward when it is fully healed.
- In conjunction with the reward system, use visual aids (eg ticks/stars for every time picking does not occur in each day) to show how picking is decreasing. Reward "along the way" eg, when three ticks/stars are gained, a token is given, and when an agreed number of tokens are collected, they can be "cashed in" for an agreed reward.
- Massage or stroke your child's skin for 15 minutes each day.
- Be aware that an increase in skin picking behaviour can be a sign of anxiety about some other area of life.
- If related to boredom, provide more activities.
- Keep finger nails short to avoid infection.



### "Lying", blame-shifting and story-telling



Lying usually occurs when a child thinks they will get into trouble for having done something, or to "cover up" by denying that they did anything. There is also a tendency to blame someone else for what has happened. Many non-PWS children exhibit very similar behaviour. Remember that lying is quite an abstract concept, and many children with PWS may have real difficulties in recognising what they say as lying. If they say it to themselves, it *becomes* the truth to them

## Managing “lying”, blame-shifting and story-telling

- Do not agree with the lies or the story, but it is unwise to be too confrontational.
- Ensure good communication within the environment so that everyone knows as much as possible about what is happening on a daily basis, and will thus be able to spot more easily if your child is lying, story-telling, or telling the truth
- Make sure your child knows when they will get into trouble for doing something, and when it may not be their fault. Sometimes your child will lie or shift the blame just because they think they may be in trouble (eg losing a personal item).

## Mental health problems

Research into mental health problems in PWS is still in its early stages, but there is some evidence to suggest that mental health problems may be more common in PWS than in the general population. By no means would everyone with PWS experience mental health issues though. It almost always only affects teenagers and adults, but very rarely it may affect younger children.

Mental health problems may take a variety of forms:

- Depression
- Lethargy (extremely withdrawn and refusing to take part in normal social activities or even to get out of bed)
- Extreme mood swings
- Severe anxiety
- Acute psychotic episodes (feelings of persecution resulting in bizarre behaviour, often with extreme anxiety, hallucinations and mood abnormalities). Researchers have found that there seems to be a greater tendency to psychosis in those who have the disomy form of PWS. You can find out more about psychosis on our website at <https://www.pwsa.co.uk/pdfs/mental-health-with-specific-focus-on-psychotic-illness>

Most mental health problems in PWS can be helped with medication, bearing in mind the need for careful dosage, and the advice of a psychiatrist should be sought. Other strategies may also be helpful. Exercise has a beneficial effect on mood.

If you are concerned that your child may have a mental health problem, consult your GP or other health professional for referral to CAMHS (Child and Adolescent Mental Health Services).

## Behaviour management

### Other sources of help

**If your child's behaviour is becoming too much for you to manage, contact your GP, other health professional or local social services department, who can refer you to a Child and Adolescent Mental Health Service (CAMHS)**



The

**Challenging Behaviour Foundation (CBF) is an independent charity providing information, support and workshops around challenging behaviour associated with severe learning disabilities to families and professionals.**  
**Family support line: 0300 666 0126**

**[support@theCBF.org.uk](mailto:support@theCBF.org.uk)**

**[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)**



## Further information from the International PWS Organisation

If you would like a hard copy of any of the articles below, please contact the PWSA office

### Story-telling in PWS

[https://docs.wixstatic.com/ugd/a71d4c\\_beb14ea282e8415d8339ca739a37284e.pdf](https://docs.wixstatic.com/ugd/a71d4c_beb14ea282e8415d8339ca739a37284e.pdf)

### Coping with change

[https://docs.wixstatic.com/ugd/a71d4c\\_8a2d60002e7aa4637ae9d67b6e5f518b.pdf](https://docs.wixstatic.com/ugd/a71d4c_8a2d60002e7aa4637ae9d67b6e5f518b.pdf)

### Managing a meltdown

[https://docs.wixstatic.com/ugd/a71d4c\\_d5c6c19c85c444bf9b12099e1e8d9cbe.pdf](https://docs.wixstatic.com/ugd/a71d4c_d5c6c19c85c444bf9b12099e1e8d9cbe.pdf)

### Skinpicking

[https://docs.wixstatic.com/ugd/a71d4c\\_5385ce87c6e9b0d04423c273739003df.pdf](https://docs.wixstatic.com/ugd/a71d4c_5385ce87c6e9b0d04423c273739003df.pdf)

### Setting boundaries

[https://docs.wixstatic.com/ugd/a71d4c\\_e512389e05b64f53a11e6f9f0d742ce7.pdf](https://docs.wixstatic.com/ugd/a71d4c_e512389e05b64f53a11e6f9f0d742ce7.pdf)

### Promoting positive behaviour

[https://docs.wixstatic.com/ugd/a71d4c\\_2c66429cb92144e884f6ffbbb195521f.pdf](https://docs.wixstatic.com/ugd/a71d4c_2c66429cb92144e884f6ffbbb195521f.pdf)

### Rituals and obsessions

[https://docs.wixstatic.com/ugd/a71d4c\\_c0951d2448914c249427a5a2ec677dbb.pdf](https://docs.wixstatic.com/ugd/a71d4c_c0951d2448914c249427a5a2ec677dbb.pdf)



**You may find  
"Let's Talk about  
PWS" [https://  
www.pwsa.co.uk/about-  
pws/publications/](https://www.pwsa.co.uk/about-pws/publications/)  
useful to help your child to  
understand his feelings.**

## On the positive side



Managing PWS can sometimes be wearing for all concerned, and a sense of humour is a must. Most children with PWS also have a wonderful sense of humour, which can be tapped in to and used to help them overcome some of their difficulties.

Because lack of control is such an important feature in their lives (ie over food and emotions), whenever possible try to "give back" control by entrusting your child with important tasks, praise whenever he does something right, or even just when he is feeling a little low. Positively develop and build his self-esteem.

Negotiation about behaviour with your child with PWS can have very positive outcomes. Things that others may consider insignificant maybe very important to a child with PWS, and sometimes it is relatively easy to reach a compromise by rewarding in very small ways.

Start each day anew. Your child will have mostly forgotten what happened yesterday, and so must you.

**Other  
behavioural  
difficulties**

**This article has focussed on the main behavioural difficulties which affect people with PWS, but there are some behaviours which are less commonly associated with PWS, which may be manifested, eg attention-deficit disorders and autistic spectrum disorders.**

**Specialist advice should be obtained for these.**

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