



“Managing a Meltdown” in People with Prader-Willi syndrome

Most people with Prader-Willi Syndrome (PWS) have meltdowns from time to time. This varies from person to person and is a serious problem for those families affected. The levels of anxiety seen in people with PWS cannot be understated. Most of the difficult, anti social behaviour demonstrated by people with PWS can be related to their inability to express and/or deal with anxiety or emotions they are feeling. They can be upset by something we would just take for granted, or it could be over something that occurred yesterday or last week, as well as something that may have just occurred but has not yet even acknowledged by others. It is often “either all or nothing”. They may become highly anxious about a particular meal being served slightly differently and they may show minimal emotion when a family member dies. Preparing them for outings or events is a key strategy for addressing potential anxiety.

People with PWS think differently! They take longer to process information they are given and may become confused when given too much information at the same time. They can present as stubborn or oppositional when really they are just taking time to 1) understand the information they have received and 2) respond with an appropriate response. If they do not like what they are hearing they may not be able to express this fact, but will instead “act out” the anxiety they are experiencing.

What is a meltdown?

A meltdown is when a person is unable to control themselves due to heightened emotions. The behaviour that results can be anything from refusing to communicate or move, to uncontrollable screaming and crying and in more extreme cases self-harm, violence and recklessness. Some behaviours may just be attention seeking and will cease, if ignored.

Why do people with PWS have meltdowns?

People with PWS have a number of underlying issues that could cause them to have meltdowns. Firstly, most people with PWS appear to be anxious for much of the time so they may be on edge even before anything goes wrong or changes.

Their anxiety can be increased when they are around food or even when they are thinking about food or an upcoming social event. Anxiety takes many forms and can be seen in behaviours such as: avoidance, non-compliance, denial; perseveration; muddledness; frustration; argumentativeness; a drop in communication levels; compulsive behaviours.

People with PWS are ritualistic or like to do things in a particular way and therefore can become upset if things don't happen in a specific order. They have trouble regulating their emotions due to the issues they have with the area of the brain known as the hypothalamus. The hypothalamus has an effect on behaviours and is thought to impact on aggression and fear. This combination of factors is thought to increase the frequency and intensity of meltdowns seen in people with PWS.





What should you do when a person with PWS is experiencing a meltdown?

These are simple and practical strategies that help to minimise the impact of the meltdown:

- In the early stages of a meltdown it is important to validate the emotion that is being expressed. That is say to the person experiencing the meltdown “I can see that you are upset about what is happening. I understand that it is upsetting for you” OR “I can see that you are anxious. What is bothering you? Let’s work on coping strategies”.

*Coping strategies can be slow counting or deep slow breathing.

- In the early stages you may be able to redirect the person with a firm calm voice. You may be able to work with them to solve the problem by offering two alternatives. For example if you ran out of coffee you could ask “Would you like a tea or a cold drink instead?”
- Another strategy is to guide them through the process of solving a problem. For example in the situation above you could say “Well we don’t have any coffee what can we do about that?”
- Often it is impossible to stop a situation from progressing to a meltdown. If this happens remain as calm as possible during the incident. Getting upset or reacting emotionally to the situation will usually make things worse. Think before you act or speak. Speaking in a calm, assertive and confident voice can help. Avoid yelling and try to remain in control of your own emotions. Try not to show fear, anger or frustration.
- Keep yourself safe and out of harm’s way. Consider the safety of others that are in the vicinity and try to discourage them from exposing themselves to harm or becoming involved. Consider the safety of the person having a meltdown. You may need to move dangerous objects away. In cases of violence or recklessness people may need to leave the area. You may need to seek help.
- Give the person time and space to calm down if possible. In a house they can be encouraged to retreat to their room until they are calm. In a workshop environment they could be encouraged to go to a safe area such as a change room or vacant office. In a public space try to encourage them to calm down in a quiet and safe area away from other people.
- If the person yells at you tell them that you can’t help them unless speak in a soft calm voice. Refuse to respond or answer their question until they speak calmly. While this strategy may take time it can often help to calm the situation.
- Offer a cool drink or a wet towel. Encourage the person to wipe their face down before you discuss the situation further.



- Retreating to your own room and locking the door can be a good strategy if you are in your own house and it is safe to do so. Then you can come out and talk only once the person has spoken to you in a calm and respectful voice. This works well if they are trying to get you to agree to an unreasonable request. Be prepared to retreat back into your room if they yell or scream at you again.
- After some time the meltdown will end. It is important to be positive afterwards. Resist the temptation to immediately discuss the incident or tell them what they did wrong. You can always mention it once time has passed. For example the following day or later that night. You should try to avoid reigniting the anger or frustration. Once the incident has been discussed calmly try not to refer to it again.
- It is best to continue on with the rest of the day as far as is possible. It is important to move past the episode.

Some strategies that parents and carers have found successful in dealing with meltdowns:

- As with our other children, if they threw a tantrum when they were little, we constantly used time-out in her room with the door open. We never gave in to unreasonable demands.
- We never used violence or aggressive behaviour ourselves. We built up her self-esteem from a young age.
- If possible, we would talk through the issue and try to help her to understand both sides of the issue.
- We always discuss and prepare for events or outings that could potentially cause anxiety.
- When our son becomes aggressive or violent and we can no longer reason with him, we remove ourselves from the situation and let the meltdown run its course. We remain nearby to make sure he doesn't hurt himself, but without him knowing we are there.
- teach coping skills every day!
The best way to learn to manage feelings of frustration is to practise often, when anxiety is minimal. Over time, these skills will be remembered during episodes of increasing anxiety.
*Some effective strategies are: slow breathing, counting, using stress relief objects eg music,

Although meltdowns occur commonly in people with PWS, by practising successful management strategies the frequency and intensity of meltdowns can be reduced.