

## **“When Rituals or Obsessions Become a Problem” in People with Prader-Willi Syndrome**

Many people with Prader-Willi Syndrome (PWS) engage in repetitive behaviours and rituals. Sometimes these behaviours can be beneficial and are often used by parents and carers to implement a predictable routine. For example, having set times and routines involving exercise and meals is often the cornerstone of a healthy lifestyle for an adult living with PWS. A predictable routine can also help to alleviate anxiety. A routine reduces idle time and the possibility of unscheduled opportunities for additional food.

However, not all rituals are beneficial and over time some people with PWS can become so set in following a routine that this can lead to problems, for example hoarding or refusing to do anything until they have completed a particular routine. In addition, if the rituals involve other people it can create further problems and even develop into an unhealthy or unwelcome obsession with another person.

### **Some examples of problematic rituals and obsessions include:**

- Asking repetitive questions or repeating the same statement over and over
- Hoarding
- Ordering and arranging objects
- Refusing to throw out old clothes
- Collecting cheap items such as newspapers, pamphlets, pens, magazines or hairclips to the point where their bedroom is cluttered
- Squeezing a shampoo or shower gel bottle too many times, so using “too much”
- Excessive use of tissues, toilet paper, sanitary pads
- Wanting to wear the same set of clothes each day
- Becoming obsessed with a favourite hobby e.g. playing video games
- Insisting on only doing particular jobs at work and refusing to do other work
- ✚ Refusing to be served at a store by anyone other than a particular person
- ✚ Refusing to go out with anyone other than a favourite worker, in the case of paid support
- ✚ Becoming obsessed with a friend at work and insisting on sitting next to them all of the time
- ✚ Phoning others at set times or repeatedly asking about them to the point where they are fixated on them
- ✚ Becoming obsessed with what someone is doing
- ✚ Making unrealistic demands on a friend e.g. expecting them to stay with them all of the time at a party or gathering

The last 6 points can be very difficult to manage as they involve other people and may cause much stress for those people. They may require serious management to prevent very complicated situations for all.

## A parent writes

*It was very difficult for my daughter to let some of her toys and magazines go. Fortunately, she is very aware of the poor and others less fortunate than her. I used this as a reason for her to part with her collectables and so she was finally prepared to pass them on to other children in need of toys and magazines.*

## Why do people with PWS engage in Rituals?

Research has shown that many people with PWS engage in greater levels of repetitive and ritualistic behaviours than the general population. This drive to seek and collect items is thought to be genetically related to the drive to seek and consume food. It is a well-known trait of PWS and can be challenging for the family and others. It can be stressful for the person with PWS by disturbing their attention and engagement in activities, even those they enjoy. Rarely can the person with PWS explain why he/she practices these behaviours or rituals. People with PWS often have fixed beliefs and can be very resistant to change, so challenging routines and rituals can result in severe and violent reactions.

The behaviour seen has been likened to the ritualist behaviour seen in people on the autistic spectrum. In some cases routines and rituals may help to reduce anxiety. They can also be enjoyable for a person with PWS, therefore separating this behaviour from Obsessive Compulsive Disorder. In addition, routines and rituals can give a sense of structure, security, control and predictability to the person with PWS.

## What can you do when rituals and obsessions appear to be getting out of hand?

Here are simple and practical strategies that can help minimise the negative impact of rituals or obsessions.

- Encouraging acceptance of change is important. Whenever discussing plans or routines it is useful to remind the person with PWS that things could change e.g. reminding them that 'life is an adventure and we are never sure what will happen. There could be changes but we will make the most of them.' However, for some people who have such fixed ideas or feelings for situations, change will still be almost impossible, despite the reasoning.
- Agreements can be useful, for example, if hoarding items is an issue, allocate a specific box or cupboard to store those items. Make an agreement that once the box or cupboard is full some items will need to be thrown out or better still, donated for a charitable or worthwhile use, before a new item is put into the space. Part of an agreement to buy a new magazine could be discarding old one first. Visualising an agreement helps people with PWS understand a plan, more easily.
- Mix it up! Sometimes it is good to have some changes in rituals which are planned and discussed in advance. This can help to build skills in accepting changes. Compliment the person with PWS on their "maturity" in being able to make or accept change. Flexibility cards are useful visual tools that can be used when a change is about to happen.

- Encouraging and negotiating small changes to set routines or rituals from time to time can be very helpful. For example, if somebody insists on using the same cutlery, cups, plates and placemat every breakfast and putting them in same position each day, you could negotiate a change to just one item and then build to more changes over time. Using a person they really like as an example of someone who is doing/using the same, can be helpful.
- Using visuals to set out a routine. These can be helpful to limit the time that is spent on a hobby or ritual that is becoming an obsession e.g. limiting the amount of time spent playing video games; set a timer with a visual display of passing time for bathroom use and other activities that need to be limited.
- Setting clear boundaries and rules around relationships can help with obsessions about others, for example, explaining that you can't call people after a certain time at night or that you can only call them a certain number of times per week.

If there is an obsession about another person, it is useful to find out if there is any relationship with food, for example, does the person who serves them coffee also give them a free biscuit? If this is case you may be able to stop them from doing this by explaining the problems it causes.

Obsessions with people can develop if they do not set boundaries when they first meet someone with PWS. Therefore it is important to educate any new friend and encourage them to not allow the person with PWS to manipulate them into giving them food, money or other items. It might also be best not to give the person with PWS their phone number. Likewise, it is important for them to point out to the person with PWS, if they feel that they are being inappropriate in their requests or conversations.

- Working with the rituals and routines to encourage positive behaviours. For example, if someone is obsessed with getting a magazine, consider walking with them to the shops each week to get it rather than driving.
- Sometimes a new ritual can be related to food but you may not realise it at the time e.g. if every day a person with PWS starts to leave work early and is adamant that they must leave by a set time it may be that they have found some unsupervised food or money that they can access at that time. Therefore it always important to investigate any possible links with food.
- Discussing personal space and also the types of conversations and behaviours that are appropriate with other people. Role playing both acceptable and unacceptable behaviour, with the person with PWS is a good visual way to demonstrate what you mean.
- If a new ritual or routine is developing, and you are concerned that it will cause problems in the future, it is better to change it before it becomes too entrenched.

*A parent relates:* every Saturday two friends, one with PWS, shared a lift to a soccer game as they were both on the same team. The person with PWS wanted to leave for the game increasingly early and eventually it put pressure on the friendship, because the other person did not want to arrive ridiculously early to the games and preferred to sleep in. After a number of weeks, a later time was set to leave for the games. However, in retrospect, it would have been better and easier to have acted sooner before things got out of hand.

- It can be helpful to monitor, supervise and limit internet use, as unhealthy relationships can readily form online. People with PWS are often vulnerable. In addition they may not understand what is considered acceptable and appropriate behaviour when they are online.

Changing ritualistic or repetitive behaviour is not always easy, and may take time. Praise any positive change in the behaviour but try to ignore or divert from arguing and resistance to change. Be patient and consistent when you suggest a strategy or idea to initiate change. Sometimes, offering an appropriate reward for acceptance of change can direct attention from the change.

#### ***When an Obsession is Linked to Psychosis***

Psychosis is a mental disorder that impacts a person's perception or understanding of reality. It can include hearing voices, hallucinations or irrational beliefs, all of which can be frightening and seem very real. People with PWS are known to have a higher incidence of psychosis. Obsessions can also be linked to psychosis, so it is important to monitor obsessions that appear to be irrational. Psychosis in people with PWS can be linked with an increase or change in repetitive and ritualistic behaviours. If you are concerned that an obsession is becoming increasingly irrational or if you believe that there is the possibility that your person with PWS is suffering from mental illness, it always best to seek medical advice. Similarly, if there is a marked reduction in a previous obsession for no obvious reason, watch for signs of low mood or depression. A medical assessment will be required to diagnose and treat a mental illness, such as depression or psychosis.

Managing repetitive behaviour and rituals in people with PWS will create change for them. Remember, change can be very stressful for people with PWS as it threatens their sense of security and can increase their anxiety. With gentle, positive talk and replacing what is removed or changed with something desirable or understandable will help the person with PWS accept that change does occur and may be needed.

**Change is hard for all of us, but together we do it if we must**

**Make today a special day...change a little, in some way**