

Adults with PWS Leadership Group Meeting – Oct 2020  
What We Think Is Important For Others To Know

Group 1

- We find it hard not to think about food.
- Help us to stop thinking about food or eating too much.
- Don't offer things that will be hard to say no and tell other people to do this.
- It's hard to say no.
- Help us around food.
- It's good to have support at mealtimes.
- It's easier if you keep food out of reach (or locked away).
- There is some disability with PWS but it affects people differently.
- We haven't all got the same learning disabilities and skills.
- PWS is a syndrome where you can't control yourself sometimes.
- Sometimes we feel more tired.
- Give us an opportunity to talk and think.
- Check to see how I'm feeling.

Group 2

- Ask first about having food around (give us a heads up).
- We don't need suggestions on diets & exercise from everyone we meet.
- Understand the basics about PWS. Don't overload with information.
- Every person with PWS is different – unique – needs are different.
- I'm not just PWS – I'm me.
- We don't need to be treated differently.
- Ask me/ about me before sharing my information.
- Things need to be at our pace.
- Have patience with understanding me.
- Be understanding of my energy levels.
- It's not my fault – PWS is not going to change.

Group 3

- Lock up food - fridge and pantry etc.
- Our food bill will definitely be high.
- All people with PWS need support care.
- Learn who we are as individuals.
- We like learning new things.
- We like films and games.
- We like questions.
- We need to exercise.
- We get tired very easily.
- Sometimes we need personal space.
- Don't take our temper bouts seriously.

Group 4

- As a person with PWS, I will often require more patience towards me.
- I need to be reminded of things I need to work on as I often forget.
- I like simple information, not too much that I forget.
- I like to be treated like an adult and for people to listen to me and pay attention.