

## Information for College Staff



### Introduction

Prader-Willi syndrome (PWS) is a complex developmental disability that results from a defect on chromosome 15. It causes a malfunction in the area of the brain called the hypothalamus, which controls aspects such as appetite, temperature and emotion.

PWS can be characterized by:

- Hypotonia (low muscle tone)
- Hypogonadism (underdeveloped sex organs)
- Hyperphagia (uncontrollable hunger)
- Cognitive impairment
- Challenging behaviours

NB The combination of hypotonia and hyperphagia means that the individual with PWS needs fewer calories than others of the same age to maintain a healthy weight.

Health professionals that may be involved with this child include:

- Dietician
- Endocrinologist
- Geneticist
- Occupational Therapist
- Ophthalmologist
- Orthopedic nurse or surgeon
- Orthoptist
- Orthotist
- Physiotherapist
- Speech therapist

(You may need to seek advice from the above in addition to reading this leaflet)



### YouTube information video

You can view a 35 minute YouTube video which gives more information about students with PWS in a college setting at [https://www.youtube.com/watch?v=\\_urhtHjtyPQ&feature=youtu.be](https://www.youtube.com/watch?v=_urhtHjtyPQ&feature=youtu.be)

**A young adult with Prader-Willi Syndrome is joining your college**

**This pack contains information which will help you to manage their needs, maintain a safe environment and facilitate learning.**

**But do remember— if you have any queries, we are here to help.**

**We are only a phone call or email away.**

## What's special about this young person?



Please remember that PWS is just a part of your student. They will have similarities and differences, as all other pupils do. Many people with PWS have specific and valuable attributes and skills.

Many have excellent reading and writing skills as well as fine motor skills and are particularly clever with jigsaw puzzles and fine handiwork. They often have excellent long term memory and visual processing skills.

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## What to expect from your student and how you can best support them

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### Learning Disabilities and challenges

Many people with PWS experience some level of learning disability. The level of which varies from one individual to the next. Please do be aware that even if the student presents as able, there may be underlying issues with regard to comprehension and cognitive ability. It is common for people with PWS to face challenges in expressive language use and short term memory.

#### What can you do to help?

Ensure instructions are repeated and ask the student to repeat instructions back to you. Check understanding and include 'refreshers'/ revisit previous work regularly.

### Dietary needs and food seeking behaviours

Food seeking behaviours are common in people with PWS and the student is likely to have lots of anxiety surrounding food. These types of behaviour are a result of the damage to the hypothalamus, meaning a person with PWS is unable to experience the sensation of fullness. It is very unlikely that a person with PWS would be able to make informed or safe decisions around food, particularly when left unattended.

#### What can you do to help?

It is important that all staff are aware and familiar with the student's dietary needs. It can sometimes be helpful to make other students aware of this too, providing you have parental permission. Anxiety can be reduced if food is kept out of sight and some form of food 'security' is in place. This might include keeping food storage areas locked, clearing empty plates away immediately after eating or ensuring lunch boxes are not left unattended. It is advised that you discuss any food within the classroom with the student's parents or carers beforehand and that any food consumption for special occasions is arranged with them in advance. This can allow parents/ carers to 'borrow' calories from their evening meal. The student will need reassurance of his/her food routine which should include fixed times.

### Emotional challenges

Some people with PWS have difficulty in controlling and understanding their emotions. You may find that emotional outbursts occur when the person feels anxious, frustrated, confused or that the situation is out of their control.

#### What can you do to help?

Ensure staff work together to reduce anxiety and to create positive and safe working environments. Reassure the student where possible and focus on achievements and goals.

## What to expect from your student and how you can best support them (continued)

### Anxiety

Most young adults with PWS suffer from some form of anxiety. Anxiety levels can increase when the individual is faced with changes to their routine or when they are unable to predict the near future. At times, you may be able to see the person's anxiety growing with behaviours such as skin picking or fidgeting.



### What can you do to help?

Ensure lines of communication between other staff and parents/carers are open in order to provide consistency and reassurance. Squeeze balls or similar could help to channel anxiety into a physical sensation. Be clear about rules and routines and try not to deviate from these. If a change occurs that is unavoidable, inform the student as early as possible and be prepared to confirm these changes as often as needed.

### Perseveration or repeated questioning

Repeated questioning is a common feature of PWS, which usually occurs when the person requires reassurance or if they have been unable to process the information given. On occasions, the person may use repeated questioning to gain 1:1 attention and verbal responses.

### What can you do to help?

Agree to answer the question just 3 times. On the 3rd occasion, ask them to repeat your answer back and confirm they have understood your response. If the student persists, try reducing verbal responses by shaking/nodding your head, or using visual reminders which they can refer to (eg. if the question is "what time is lunch?" try drawing a clock face on a paper plate to indicate your answer).

### Time management

Some young people with PWS struggle to move on from one activity to another, and you may find they are reluctant to move on until the task is completed. Most individuals with PWS are able to focus more effectively on several smaller tasks, as oppose to one large, on-going project.

### What can you do to help?

Provide short activities and be clear on time frames or when you expect it to be completed. Ensure a gentle reminder is given as to how much time is remaining. If the student insists they cannot move on until the task is complete, try using an 'extension card', enabling them to borrow time which they can cash in later.

Continued ...

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### Rewards

**Positive behaviour should always be rewarded as people with PWS respond well to praise.**

**They are also likely to enjoy responsibility and being told they've "done a good job". Doing this can boost the individual's self-esteem and confidence.**

**Most importantly, food should never be used as a reward for a person with PWS.**

**It can be useful to record achievements and praise on a graph or star chart. You can make this available for the person to refer to and the visual representation will make this accessible to them.**

**When rewarding the whole class with food items, ensure you have consulted parents before-hand. They may provide a low calorie alternative or make arrangements for the calories to be borrowed from their evening meal.**

## What to expect from your student and how you can best support them (continued)

### Day time sleepiness



Note that people with PWS can often suffer from disturbed sleeping patterns. It is likely that this person will grow tired throughout the day and may require frequent rest breaks.

### What can you do to help?

Ensure you have a quiet space available where the person can go to rest. It may be that the person requires a short nap (approx. 10 mins), and this may be required more than once a day.

## The right approach

The attitudes of other people are also very important.

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



- Aggressive attitudes and tones of voice
- A confrontational approach
- Being overly sympathetic
- Displaying dislike of the person
- Not talking to the person
- Talking to the person too much
- Being in conflict with another person in authority- both giving different rules to the teenager with PWS, or arguing in front of him.
- Saying "Don't" as a means of trying to stop him 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 the person 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").

### Quick Tips for Behaviour Management

- Use positive language
- Keep verbal responses to a minimum during behaviour incidents
- Use humour where possible
- Appear disinterested in negative behaviour
- Be consistent with your responses as a whole staff team
- Use a structured discipline procedure
- Work collaboratively with parents/carers

## Your college environment

Many potential outbursts can be avoided by providing the right environment to suit your students 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 them 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 the student 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 him or her and, if necessary, lock food away.
- Ensuring that all who come into contact with the student are giving the same message about what they expect in the way of behaviour.
- Help them 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 them to "keep calm" and/or of what happens when during the day.
- It may be useful to discuss in advance with him or her situations they find difficult and how to cope with the situation.

## Finding the right level of independence

Young adults with PWS respond well to responsibility and the concept of Independence. It is likely that your student will be keen to learn independent living skills. However, it is worth bearing in mind that very few will have the capacity to live independently in adult life (most living at home or in residential or supported living arrangements).

Finding a level of independence whilst maintaining a safe environment can be a difficult balance, particularly around food. If the student takes part in a Life Skills course, try to focus the food preparation and shopping modules on Healthy Eating, or even Living with PWS. Speak to parents about their plans for the future, or what they hope for their son/daughter to achieve. This can avoid setting unrealistic expectations or setting the student up for disappointment later in life.

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### Socialising with peers

**People with PWS tend to be very sociable and friendly in nature. However, it's important to be aware that the young person may need some support in communicating and understanding social boundaries.**

**Using social stories or role play can help with this and it can be helpful if you work on concepts such as turn taking in conversation.**

**Do remember that people with PWS tend to be emotionally immature and may struggle to identify or communicate their emotions. You should also note that people with PWS are unlikely to ever reach full sexual development and extra care should be taken when dealing with sex and relationships.**



## Supporting this young adult

Many young adults with PWS will have an Education, Health and Care plan. In addition to the support outlined in this, we would always recommend some form of support during social times and when around food to avoid high levels of anxiety or food seeking behaviours. People with PWS respond well to 1:1 support, and often this will be a requirement of their EHC plan.

If you do already have support in place, do bear in mind that it can be very easy for people with PWS to become attached to this person, particularly if they are together for the entire working day. You may notice some obsessive behaviours surrounding this person. Whilst the consistency and reassurance of a familiar face can be beneficial, it is important to avoid the pupil taking 'ownership' of their support worker. This can be easily overcome by the staff member working with various students in the classroom, showing that he/she is not there solely for the student with PWS.

It is common for young people with PWS to be fond of adult company and the individual may need some support in socialising with peers. Encouraging them to take part in lunchtime clubs or activities is beneficial in aiding their social development. You may find that the person will still require the support of a TA/support worker during these times, and it can often be useful to provide a quiet, 'safe' place if they become overwhelmed.

Sometimes a Positive Support programme can help develop social skills and relationship skills. You may notice the student struggles with conversational skills such as turn taking, waiting for others to finish speaking or listening to others. In cases such as these, it can be useful to play turn taking games such as board games or role playing games.

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## If you are a residential college ...

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If the student lives on site, it is important to have strong lines of communication between teaching staff and care staff. This means you are able to keep accurate records regarding diet and is helpful when trying to reach or maintain a healthy weight. It also enables you to prepare for any potential behaviour incidents and to help the young person to manage their emotions. Some college's use a diary which the student carries with them, although this may not be appropriate for all individuals. Alternatively, try setting up a group email between staff so that information can be circulated quickly and easily.

It is important to think about the practical aspects of the students living environment, with careful consideration around food and kitchen areas. Many residential organisations operate a "locked kitchen", where meals are prepared for the residents with no further access to food. However, this is not appropriate for all organisations, particularly those who provide provision for a range of learning disabilities.

## Things to consider with regard to residential college

When preparing for a student with PWS to join you, you will probably find it helpful to think about the following topics, and discuss with parents if you are unsure.



- What guidelines/boundaries are to be agreed about access to food?
- Is cooking, shopping and budgeting for meals an option? If so, how often will this happen, and how will it be supervised or managed?

## Things to consider with regard to residential college (continued)

- What problems might be presented by eating in the college canteen? Would it be preferable/possible to eat in a smaller group or individual setting?
- What if agreed guidelines on food management are broken? What outcomes would be most helpful?
- Will the young person agree to regular weight checks by the college (by someone they trust, or a keyworker, for example)? If not, what alternative arrangements, if any, should be made?
- What supervision is required when away from the college site?
- What strategies have parents found helpful in the past which could be put in place from the start at college to help with managing behaviour difficulties?
- If there is a risk of harming self or others, what strategies would staff at the college need to adopt to manage the situation?
- Is the young person able to manage their own money? If not, or if not appropriate to be in full control of own money, what assistance could you offer and how should this be put into operation?
- Is physical exercise important? If so, how often? Will staff be needed to support this?
- If there is disagreement between you, the young person, and the parents about the management of a problem, how should it be resolved?
- There may be times when parents will not be able to reach agreement with you or the pupil about a particular issue. Are you/ they willing to accept this? Could you offer some sort of contract to cover these sorts of issues before they occur?

## A good practice model for residential colleges supporting a student with PWS

The following points are examples of good practice which you may wish to consider when supporting a young person with PWS:

- Social and emotional support from a mentor team, to help the young person to come to terms with some of the frustrations around having PWS.
- Support to explore issues around independence and what this actually means to the individual.
- Work around developing self-awareness, recognising own emotions, channeling them, and responding appropriately.

Continued ...

## Information for College Staff



**We have a useful LEAPS Framework available on request, which includes further guidance for staff.**

**Contact us for a copy**



**Growing up with PWS**

**This is a series of animations which aim to explain to people with PWS how their bodies might grow differently to other people's and also about relationships.**

**<https://www.pwsa.co.uk/information-for-families/growing-up-animations>**

## A good practice model for residential colleges supporting a student with PWS (continued)

- Anger management work.
- Daily timetabled exercise, to build self esteem and empower the young person on matters of weight and physical well being.
- Close working relationship with home.
- Where possible, counselling and psychological support. Preferably this should be with someone trained, or, aware of PWS.
- A co-ordinated and supportive approach. Frequent meeting between departments and the young person to provide feedback and reinforce success.
- It is essential to have the young person's co-operation, who has to be willing to work with staff and make a conscious choice to attend the college to achieve their study goals.

### Special Medical Concerns

There can be health complications in PWS so it is important to be aware of warning signs that something is wrong.

If your student vomits it is imperative that this is taken seriously. People with PWS are unlikely to vomit at all and doing so **may** be a sign that something is wrong.



Due to their high pain threshold, any complaints of pain or discomfort should also be taken seriously. Most people with PWS will only complain of this if the pain is extreme, and even then the person may only describe it as an ache or discomfort.

It is important that all staff are aware that bruising can occur easily, even as a result of a slight knock or bump. People with PWS also have poor body thermostats so the pupil may need extra support and guidance regarding appropriate dress.

Please do not assume that the person is able to attend to their own personal care or toileting. If you are unsure, his/her parents/carer will be able to direct you.

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