

People with PWS and work – Best Practice Guidelines for Employers

Introduction

Most people with PWS are more than capable of work, whether voluntary or paid, and are just as keen as other people to contribute to their communities. So it may be surprising to learn that, to date, very few people with PWS have full time jobs. This is partly because of the complex nature of the syndrome and partly because trainers and employers are not always aware of the particular environmental boundaries that may need to be put in place for people with PWS. Without which, the person with PWS may well be "set up to fail" from the outset. This document outlines how best to approach making a work or volunteer opportunity a successful win/win situation for all.

Types of work

Many people with PWS have natural, innate skills which are often required in many workplace situations:

- a preference for repetitive work
- good attention to detail
- good long term memory
- enjoy caring for others

Areas where people with PWS have already successfully worked, either voluntary or paid, usually part-time, include:

- Light production work
- Basic clerical work
- Laundry work
- Gardening
- Posting leaflets
- Animal care
- Shelf-filling in shops
- Charity shops
- Representing people with learning disabilities through agencies such as local Partnership Boards
- Teaching assistant in IT
- Classroom Assistants
- Milk round Assistant

Some have also helped to care for the elderly or disabled or had jobs in catering. However, these may not suit everyone with PWS, especially if there are issues around access to food.

The above is by no means a complete list. However, to enable people with PWS to reach their full potential in the workplace, there are several cause and effect issues that may need to be considered, along with the management and coping strategies which can help.

Challenges associated with PWS

One of the major challenges for people with PWS is that they feel hungry most of the time. They will thus be driven to seek and eat food at every opportunity. This is an instinctive drive for them, and one which they cannot readily overcome. Hence, the environment in which they are working must be a largely food-free one.

Another challenge is behaviour. Often, although their intellectual abilities may be relatively high, people with PWS function at a much more immature level when it comes to emotional and social skills. Sometimes they find very trivial events, such as losing a pen, very upsetting. They may also find it difficult to move on from one task to a new one or attach themselves to one colleague and will only take orders from them.

These issues can be successfully minimized with the appropriate management and guidelines put in place.

Finally, many people with PWS need more sleep than most people in order to function well. This is one reason why a full-time job may be out of the question - towards the end of the day, the person will become increasingly tired, less capable of completing tasks, and behaviour may deteriorate. See the sections below for common sense tips on assessing and managing these challenges.

Assessing the person for work

Firstly, it is important to remember that individuals with PWS are all different, and have different levels of ability and different personal characteristics, as does everyone else. Some have severe learning disabilities, a few others have obtained certificates in higher education; most are described as having mild to moderate learning difficulties. Similarly, all have different social and emotional abilities and levels of development, and different responses to a food environment. Hence a person-centred tailored plan is very important for someone with PWS. When drawing up the plan, it might be useful to consider some of the following characteristics and issues which apply to people with PWS generally and may apply to any one individual.

- **Challenges around food** Some people with PWS cope better than others with the potential to access food, but many do find it difficult. Working in a food environment such as a cafe is a possible option for some, but with there will need to be suitable provisos put in place (eg an agreement with the person that they will be weighed regularly to ensure that the person isn't taking food).
- **Communication problems** Some people seem very articulate but have difficulty understanding complex instructions - this may not be evident on first meeting. Others have speech problems which make it difficult for them to be understood. Employers should seek to be aware if any of these problems affect the person with PWS and find the best common sense way of dealing with them.
- **Difficulties with strenuous physical work** Most people with PWS have poor muscle tone. Strenuous work is likely to be difficult for many.
- **Difficulty coping with stressful situations** If things go wrong or do not go according to plan, or if items are lost or mislaid, the person can have a disproportionately intense reaction to this, and may be so upset that they cannot carry on working that day. Although getting to know the individual and what makes them tick should minimise this.
- **Changes to personnel within the work place** People with PWS get used to working with certain people, so if changes of personnel are planned, they should be made aware of this and, where possible, meet new colleagues in advance.
- **Office or factory banter** Many individuals have quite a literal way of thinking and sometimes do not get a joke or irony within a situation. There may be occasions on which this causes upset and misunderstanding. But as always this can generally be addressed via conversation with key people.
- **Room temperature** Environments which are very hot or very cold are not suitable for people with PWS. They may have adverse body reactions to extreme temperatures and some are unlikely to realise that they have become over-heated

or too cold, and will dress inappropriately. Common sense safeguards will therefore need to be put in place to avoid this.

- **Need for structure** Most people with PWS work best in a structured workplace where expectations are clearly defined, consistent and maintained.
- **Need for extra sleep** People with PWS generally tire easily, and may need time during the day for a nap. Some people prefer to work in the mornings, when they are fresh, rather than later in the day.
- **Different needs** Some people with PWS are very happy to do repetitive jobs which require them to focus completely on the job in hand. Others need more stimulating work, with a variety of tasks to keep them motivated. Some individuals may also have very personal individual needs which do not apply generally to everyone with PWS.
- **Small stature, small hands and feet** Until recently most people with PWS did not receive growth hormone treatment. This means that they are usually smaller than the general population, and have small hands and feet. Finding work uniforms, shoes, etc, may be more difficult. Tasks which require good muscle strength and reach in the hands may be difficult, but there may well be other tasks which are well-suited to people with smaller hands.

Personality tests

Human resource/personality tests and answers to interview questions can be misleading. More able people with PWS may be looking for jobs which include personality tests or interviews. They are more likely to score highly on "theoretical" questions such as, "What do you know about the Disability Discrimination Act?" but less highly on questions on managing situations, such as, "What would you do if a colleague complained about your work?"

High scores in one area may produce an average which would obtain the person the job. However, it is important to look at the type of job they are applying for and ensure that, if it does include elements on which the person has scored low, they receive training and support to manage these issues.

Management of PWS in the work setting

It is very important in achieving a successful outcome that people working directly with the person with PWS should have some awareness training in the syndrome, especially in the areas of the medical characteristics, dietary management and behaviour management. Good communication and consistency between staff members and the person's family or care staff is also essential to achieving a positive success for all involved. There are various strategies which can be used to help a person with PWS within the work setting. These include:

- Always praise for good work and appropriate behaviour
- Colleagues should be informed of the reasons why and be asked not to leave food on their desks or in unlocked drawers, and - in some rare instances - money should not be left around. Although this is generally good office practice anyway.
- Office parties and celebrations should be thought about in advance in order to considerately and creatively organise it so that food is not left lying around and there are lower calorie options available for the person with PWS - and anyone else on a diet - to enjoy.
- Make rules as to "off limits" areas and ensure that these are adhered to.
- Identify a key person to whom the person with PWS should address concerns. Rotate the key person on a regular basis (if possible) if the person with PWS tends to become over-reliant or obsessive about them.

- Wherever possible, inform the person about changes in advance. Written or pictorial daily schedules could help to direct the person to what is happening each day.
- Involve the individual with PWS in planning, but avoid presenting them with open-ended choices. An "either or" approach works best. (ie "Either we do the photocopying today or we do it tomorrow", not "When shall we do the photocopying?")
- Avoid getting into arguments and limit excessive questioning where possible.
- If possible, provide a "time out" area or quiet room for the person to go to if they become overemotional, so that they have a space to calm down.
- Make it a requirement of the job for the person to replace items broken or taken without permission - ie within their contract (or agreement, if carrying out voluntary tasks)
- Ensure the person is not distracted by the environment. For example, their work station should not be placed close to the staff kitchen or a coffee or food-dispensing machine.
- Establish boundaries, specific standards and expectations prior to starting work, and give the person a pictorial or written copy of these to sign for their agreement.
- Monitor any access to money within the workplace.
- Structure set breaks throughout the day.

Developing skills

Most people with PWS are better at some areas of work than others and most share some problems in learning, cognition and perception. To help them develop their skills to the best of their ability, the following strategies may be helpful.

- Instructions should be on a step by step basis, and may need to be repeated several times, and reinforced by visual prompts (written or pictorial) and checklists.
- Learning by doing is important - quite a lot of practice may be required to succeed at a task
- Monitor the learning of new skills closely - people with PWS often find it difficult to "unlearn" something which they are doing incorrectly.
- Self-monitoring can be inadequate. Provide supportive feedback in a non-accusatory and nonconfrontational manner.
- People with PWS find it difficult to switch attention from one task to another. Similarly, what they have learned in one situation, they may not be able to transfer to another. They will require extra time and support to do this.

Model Work place agreement

I, wish to attend the work placement at

To be accepted on the placement I agree to the following:

- I will attend to work in a clean presentable manner.
- If my support worker (or parent) deems that I am not presentable I shall not attend.
- I will be ready to leave for work at the agreed time of.....
- I understand the vehicle will leave on time and will leave if I am not ready.
- I will attend for work at for a prompt start.
- Lunch will be at
- Afternoon session will be at
- Lunch will be a packed lunch.
- No drinks need to be taken as these are provided by (employer). (Employer) supplies drinks for their workforce by way of token key in a vending machine. The

support staff that accompany will hold the keys and assist in dispensing drinks (if appropriate)

- You may drink your drinks at the work station.
- You will eat your lunch in the room provided. Support staff to be in attendance at all times that I am in the lunch room.
- I agree to be back at the work station by for a prompt return to work.
- Support staff to take a break from so that they can have a cigarette if they wish. I will be at the work station during this period.
- I agree that I will drink tea, coffee or water. Support staff will have sweeteners for the drinks.
- I will have a drink at,, and with my lunch. If the working day is extended for any reason you may have an additional drink. This will be determined by the support staff.
- I agree to follow instruction given to me by (employer and colleagues) and the support staff.
- I will not disrupt other workers and will remain at the work station unless I have reason to leave and have notified the support staff.
- I will not take bags into the work place as all items required will be provided.
- is a strict no smoking work place. The only time workers may smoke is during the lunch break at the designated area.
- If I do not follow this agreement or the (employer) working conditions I understand that I may be suspended from attending for a period of time.
- Signed Date Worker
- Signed Date Home manager or Parent

Case study

A national builders' merchant had agreed to employ a person with PWS from a group of residential homes specifically for people with PWS. The initial thought was that the person should be based at Head Office but there wasn't a real job there and it would not work unless the person was doing a real job. It so happened that the manager of the local branch near the residential homes already knew something about PWS, so this seemed a better place to start. A job was available for a shelf-filler. After liaising with the branch manager, the residential home sent out a job spec to its staff to see if they could identify a person who would be right for the job. It was important to send out to staff in the first instance, so as not to raise expectations amongst the residents. As a result of this exercise, eight possible people were identified - amongst them, David (all names have been changed to preserve anonymity).

What makes David suitable for the job? David ticked every box. His age was right, he had got a lot of work experience and he could work in a male environment. David's personality is really suited to the job. He is sociable and gets on with most people, is outgoing and can cope with banter. He is enthusiastic, hard-working, pays attention to detail and will finish a job. David is loyal and punctual and can deal with having a vending machine around. He is able to learn new skills. David was happy to take a packed lunch and be flexible about when he ate.

What makes the branch the right one for a person with PWS? Each branch of this national firm has its own personality. As well as having the manager as a positive role model for staff, the branch generally has good vibes. There are regular customers and it has women employees. David has been accepted very quickly and his being there has brought the team closer. David's colleagues are quite protective of him.

First steps David had a mini-interview with the branch manager and, on being offered the job, received full induction and training. At first David's parents were a little bit worried. With good communication and reassurance that David would have enough support they felt better. They are now very proud of him. Initial support David was offered quiet support for the first six weeks. A member of staff, Terry,

from the residential home went with him for the first three times. Terry knew David and had experience in the building trade. He helped David and the staff at the branch. David was worried that the staff and customers would have a lack of understanding but he was pleasantly surprised.

There was no deadline on how long David had support. Before David started it was made clear who he would go to if he had any problems. The branch were clear that feedback on David's work should be done through staff at the residential home. David decided after six weeks that he was confident to go on his own.

Issues at work

There have been a number of issues since David has been at work:

- The temperature of the taps needed adjusting as there was a risk of David scalding himself.
- There were some difficulties over shoes. Initially there was trouble getting steel toe capped boots in David's size (people with PWS who have not received growth hormone treatment usually have much smaller feet than normal). Then David liked the boots so much he wore them all the time and got very sore feet. David's feet are checked regularly and he wears thick socks.
- There was an issue around David drinking too much hot chocolate. This was resolved through a clear agreement with David and good communication with staff at the branch. David's keyworker at the residential home also discussed the issues with him.
- There was an issue about David's pay interfering with his benefits. This required liaison with the firm's payroll section.
- There was an issue around David opening packets with his teeth. This was picked up when he was being supported at first. David was made aware of the Health and Safety Issues and this was soon resolved.

Important lessons

- It was important that the right person dealt with the right issue – work issues were dealt with by the branch manager, but issues relating to personal or PWS were dealt with by David's keyworker and other support staff.
- Planning was important to stop things becoming an issue – potential problems with the Christmas Party were talked about in advance

Positive impact and outcomes

- A sense of making a valuable contribution, self-worth and satisfaction
- Improved self-esteem, self-confidence and well-being
- Recognition, being appreciated and valued as a real member of a team
- Undertaking a task/job that others really value and makes a difference
- Broader social network and inter-action
- Improved health and well-being in the longer term
- Raising the profile of PWS and breaking down barriers and discrimination
- Leading the way for the younger generation of people with PWS to live full and active lives in their community
- Helping employers and colleagues to understand disability and PWS
- An empowering and life affirming experience for all.

Additional information - available from PWSA UK office or online at www.pwsa.co.uk

- About PWS
- Behaviour Management
- Dietary Management
- Information for hospital and A&E staff

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