



pwsa AUSTRALIA

prader-willi syndrome association

A practical guide to supporting people with Prader-Willi Syndrome in the workplace, day program or volunteer setting.



Funded by the National Disability Insurance Scheme

www.pws.org.au

Who is this guide for?

This guide is for anyone, particularly supervisors and hands-on staff, who are supporting a person with Prader-Willi Syndrome (PWS) in mainstream employment, disability supported employment, a day program setting or volunteer work.

What is Prader-Willi Syndrome?

PWS is a complex, multistage genetic disorder which affects multiple systems in the body. It significantly impacts behaviour, mental and physical health. People with PWS require cognitive, social, learning and health support throughout their lives. A person with PWS can live a healthy, fulfilling life when they have ongoing, consistent support from people who understand the intricacies of the syndrome.



Learn more about PWS
from the international
organisation

www.ipwso.org



What impact does a participant with PWS have on your role?

Despite many people with PWS only having a mild intellectual disability, PWS is one of the hardest syndromes for people to live with, both for people with PWS and those who support them. **Knowing them as an individual is vital to their safety and wellbeing.**

Employers, managers and those who support people with PWS need to understand the importance of providing a PWS specific work environment and appropriate support. Putting appropriate support measures into the workplace will involve shared responsibility between different support workers. This process requires the close cooperation and coordination of all parties involved in providing workplace support. Work placement or day programs often fail because there has not been coordinated support.

People with PWS can work very successfully in a variety of work settings, provided appropriate support is maintained. They can make a valuable contribution to the workplace yet very few have achieved their full employment potential. In part, this is due to the complex nature of PWS.

Supervisors must be aware of:

- Vigilance with food security
- Misleading indications of the person's real capabilities from interviews and formal assessments
- Communication problems - poor auditory processing skills makes it difficult to follow verbal instructions
- Difficulties with strenuous or prolonged work due to poor muscle tone
- Difficulties coping with stress and anxiety in the workplace when things don't go to plan or there is a perceived slight or unfairness or an unplanned change in routine
- Poor temperature regulation means some workplaces which involve working in extreme hot or cold conditions are unsuitable
- High pain tolerance may make some tasks a high safety risk
- Overriding need for consistent structure and routine
- Easily fatigued – due to reduced muscle bulk, low muscle tone and sleep apnoea
- Small physical stature and small hands and feet, in those who have not been on growth hormone, may make some tasks physically challenging.

People with PWS are unreliable when reporting their state of health. Patience and observation are needed to determine if the person needs medical assistance. It is recommended that a copy of PWS Medical Alert Brochure is included in the participant's file.

A change of routine, expectations or relationships may trigger periods of acute anxiety and resultant behaviour changes. The transition to work, in particular, must be carefully planned and implemented, with clear channels of communication between all parties.

How will you provide optimum service to a person with PWS?

The Employer, Day Program Manager, Employment Support Worker and/or Workplace Key Worker should endeavour to put in place a support plan.

The plan will need to recognize the individual's goals as well as environmental adjustments, adaptations and solutions that incorporate the following:

TRAINING

Staff who work directly with the person with PWS should be trained in dietary and behaviour management, medical characteristics and effective communication strategies. This training should be undertaken before the person with PWS starts at the workplace. Training should be ongoing and made available to all new staff.

WORKPLACE AUDIT

Staff will need to conduct an audit of the workplace or program setting to make sure that the environment is as PWS friendly as practical. This may require some adjustments to the physical environment that should be completed prior to the person with PWS starting. This audit should include:

- Limiting access to food in the workplace except at designated eating times
- High level of supervision to monitor food seeking behaviour.
- Security checks of the staff office areas – 'Out of Bounds' areas need to be clearly defined and communicated.

INFORMATION GATHERING

Schedule meetings with the parents/carers or someone who knows the adult well, in the information gathering discussions. This should be both with, and without, the participant present. Make sure that information supplied by the person with PWS is corroborated by another party.

ESTABLISH LOCAL SUPPORT NETWORK

- **Establish links with the parent/guardian:** Good communication and consistency between staff, the person's family or residential care staff is essential to achieving success in the workplace.
- **Establish links with the other agencies:** Contact others who are going to be working with the person with PWS. These may include the Disability Employment Service (DES) or Job Service Australia (JSA), day program provider, or TAFE/training settings. A work experience or transition to employment program may also be relevant.
- **Set up communication networks between the different disability support workers.** Be aware of the transport arrangements and identify any timetable difficulties that can provoke anxiety. A travel training program may need to be initiated, but will usually exclude independent travel.

FAMILIARIZATION WITH THE WORKPLACE OR DAY CENTRE

Organize for the participant to visit their new workplace prior to starting work. They can meet their co-workers and become familiar with the layout of their new workplace. The level of support may need to be increased while the new work routine is being established.

MATCHING THE WORK TASKS TO THE PERSON'S SKILL AND PERSONALITY

It's important to gather information from the person with PWS and their family/carer to find out their likes and dislikes, skill levels and triggers for behavioural outbursts.

SHARING BEST MANAGEMENT STRATEGIES APPROPRIATE TO THE WORKPLACE

There is a high risk of overestimating the capabilities of a person with PWS. Consistent dietary and behaviour management are the keys to successful outcomes in the workplace.

Have team meetings to establish a consistent approach in the workplace in regards to food security arrangements. Colleagues should be informed about the reasons why food and money isn't to be easily accessible and why offering extra food to someone with PWS is not appropriate.

Identify key worker(s) who the person with PWS can go to if there are any problems in the workplace. Establish a protocol of communication between the support worker/key worker and the employer. Establish a process for resolving issues in a timely fashion.

Have a clear behaviour management plan when things go wrong:

- Avoid getting into arguments. Limit excessive questioning
- Be aware of exaggeration where the truth can get in the way of a good story
- Provide a time out space in a private area

COMMUNICATING EXPECTATIONS AND CODE OF CONDUCT CLEARLY AND CONCISELY

- **The person with PWS should have a written and/or visual copy of their signed workplace agreement.**
 The support worker should discuss the workplace agreement with the person with PWS to make sure he or she understands what it means for them. They need to be given the opportunity to ask questions before they sign it. The workplace agreement should be reviewed regularly.
- 'Out of Bounds' areas should be clearly defined.
- Try to implement an allocation of, and limitation of, time for bathroom use.
- Use short sentences when giving information or instructions to the participant.
- People with PWS are often poor communicators and miss social cues. They need some support to hold a conversation without dominating.

IMPROVING WORK PERFORMANCE

The following organisational arrangements are recommended:

- Use visual display boards or lists for daily routines, activity schedules, training sessions and staff changes. If possible, communicate any changes of routine or expectations in advance.
- Use prompts for task switching such as timers or computer alerts. People with PWS find it very difficult to switch their attention from one task to another. Consequently they may need an external prompt to switch to another task and time to mentally assimilate the request.
- People with PWS find it difficult to understand or remember complex instructions. To assist memory recall use lists or visual signs that break the task into smaller steps.
- Do not assume transfer of skills from one situation to another. It is important to check that instruction has been understood and that they know what they are required to do.
- If possible, organize the workplace so the work can be completed in one area to assist with familiarization and skill learning.
- The person with PWS should be positioned where they won't be distracted by environmental factors eg coffee machine or staff kitchen.
- Provide, where possible, flexible or part time work to allow the person to work within their physical limits.
- Where possible, involve the person in workplace planning meetings once the major decisions have been made.
- Avoid open-ended choices. An 'either/ or' option is more useful.
- Regular feedback is very important. A person with PWS has very poor self-monitoring skills. They are reliant on supportive feedback provided in a non-confrontational fashion.
- Use commonsense and a realistic PWS perspective when considering risk assessment in the workplace.
- Positive reinforcement for good work and appropriate behaviour will ensure positive outcomes for all concerned.

Helpful Tips

Maintain companionship with, or an awareness of the person with PWS and direct them to the task at hand. One to one support is generally required when near places of food access, to ensure no unwarranted or inappropriate food access.



A person with PWS may take money to get food. For them it is not 'stealing' but an act of survival. When dealing with such a situation, their inability to control the drive to eat should be taken into account.



To encourage the person with PWS to cooperate, it is a good idea to 'ask for their assistance' rather than request them to do something directly.



Display a set of workplace rules for all employees to see and understand.



Identify a person of higher authority to whom the person with PWS can refer for boundaries and confirmations, and to whom car-givers can deflect to for decisions, in all their environments – each shift of the day program or work.



Give the person limited choices, which helps to direct their thinking and give them a sense of control. For example, don't say: "what would you like to do this morning", but say: "would you like to use the computer or work in the garden this morning?"



Further information

Management of PWS in the Work Setting: A Guide for Employers and Supervisors

<http://www.pwsausa.org/product/management-of-pws-in-the-work-setting-a-guide-for-employees-and-supervisors/>

Understanding PWS – Accessing the community

www.pws.org.au/

How does a person with Prader-Willi Syndrome think

<http://www.pwsausa.org/wp-content/uploads/2015/12/How-a-Person-With-PWS-Thinks-GA-543.pdf>

Prader-Willi Syndrome - Behaviour Management Strategies

<http://www.pwsausa.org/wp-content/uploads/2016/02/Behavior-Tool-Kit-from-Prader-Willi-California-Foundation.pdf>

Video: My Deadly Appetite: Prader-Willi Syndrome - US documentary

<https://www.youtube.com/watch?v=ItCFFINaIBc>

Prader-Willi Syndrome – an overview (Better Health Channel)

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/prader-will syndrome>

Prader-Willi Syndrome Association of Australia

www.pws.org.au/research

Australian Medical Alert Brochure

www.pws.org.au/

Glossary

Employers are responsible for making reasonable adjustments and adaptations to the workplace to enable the person to work in a safe environment.

Agencies and organisations involved in providing support in the workplace include:

- **Disability Employment services (DES) and Job Search Australia (JSA)** are responsible for assisting the person with PWS to build up their skills base and to assist them in maintaining employment with ongoing support.
- **Supported Employment - Australian Disability Enterprises (ADE) Australian Disability Enterprises** are commercial businesses that provide employment for people with disability who need ongoing support to maintain their employment. Their employees engage in a wide variety of work tasks. They can also provide work experience in a supported environment to prepare employees to work in the open market. For fact sheets and further information see: www.fahcsia.gov.au/sa/disability/progserv/providers/AustralianDisabilityEnterprises/Pages/AustralianDisabilityEnterprises.aspx

The person's NDIS Plan funds support for the person with PWS who works in a Disability Supported workplace (ADE).

- **Day Services Supports:** These services provide people with a disability the opportunity to increase their independence, skills, community participation and general quality of life. Day supports may be provided through a Day Service or Personalized/Individualized supports, or a combination of the two.

Day Program services provide supports across a range of lifestyle areas including daily living and vocational skills, community participation and inclusion and recreation. Day programs and services aim at enhancing abilities, independence, community participation and quality of life. Personalized/individualized supports are when the person with PWS can determine the activities they participate in, the time of day or week the supports are required and whether they want to share the supports with anyone else. Individualized Supports are developed specifically by and for the person in line with the informal supports and funding available to them.

http://www.sasi.org.au/documents/School_Leaver_Resource_Guide.pdf

- **Volunteer work** – Volunteering in the workplace provides a means of getting experience and learning new skills in different types of work settings. Volunteers provide unpaid service to the community. It can be a short term or long term placement. Volunteering may also form a part of a Day Services Program.

NOTE

The NDIS Plan can provide support to access transport to get to the workplace and assistive technology when deemed reasonable and necessary.

In certain instances, the NDIS will fund supports to assist the person with PWS when the adjustments and adaptations are beyond the requirements of the DES and JSA.

The NDIS will also assist the person with PWS who is not eligible for DES OR JSA support.