



pwsa AUSTRALIA

prader-willi syndrome association

Providing Prader-Willi Syndrome support in residential settings.



Funded by the National Disability Insurance Scheme

www.pws.org.au

Who is this guide for?

This guide is for providers of integrated services (managers, supervisors and direct care staff) who assist people with Prader-Willi Syndrome (PWS) in shared, supported disability accommodation. It is also relevant for anyone supporting people with PWS in short-term accommodation.

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?

TRANSITION TO ALTERNATIVE ACCOMMODATION

- People with PWS are unable to make appropriate life decisions on their own. Their parent/guardian, or someone who knows the person well, needs to be involved in all levels of the planning and implementation of the transition to out of home care or to another supported residence.
- For someone with PWS, a change of routine, expectations and relationships may trigger acute anxiety and behaviour changes. This transition must be carefully planned and implemented with clear communication between all participants.

PREPARING FOR THE COMPLEXITY OF PWS

- Suitable options for residential care and support will vary according to the needs of the individual person with PWS. Regardless of the type of setting selected, the person with PWS will require substantive 24 hour supervision and support for the rest of their lives. Independent living is rarely achieved successfully.
- Staff who support the person with PWS need to be highly organized, creative, intuitive, consistent and, above all, positive. This will reduce anxiety in the participant. It will also help to get cooperation, motivate and develop socially appropriate behaviours which are less dangerous to themselves and those who support them.
- To maintain highly skilled staff who can successfully meet the needs of people with PWS, managers must provide support and ongoing professional development. High turnover of staff is a major problem when trying to provide a consistent routine and house rules to support people with PWS.
- It is often difficult to provide the preferred configuration of living in a PWS specific environment in existing housing stock and modification or alterations may be needed to ensure a PWS safe environment.
- Houses/units or townhouse developments in either PWS specific or mixed ability accommodation should incorporate robust features required for a PWS safe environment into the development and building plans.
- The appropriate level of support for people living with PWS will differ from what is considered appropriate levels for other residents with equivalent intellectual or behaviour disorders. In mixed ability settings, the needs of all the residents have to be considered. People with PWS need to live with Restrictive Practices, particularly in regards to food accessibility which will impact on other residents. The complex needs of people with PWS will need to be reflected in the staffing ratios for the residential setting.

How will you provide optimum service to someone with PWS?

To promote safety and personal growth, it is important for all necessary support to be in place before a person with PWS moves in to a residential setting. These supports need to be:

PWS SPECIFIC TRAINING

All staff, including casual staff, should participate in PWS training in the areas of dietary and behaviour management, effective communication strategies and health and wellbeing. Training must be ongoing and made available to all new staff, before they start working in the residential setting. The use of casual staff should be minimised and, if used, must take PWS training.

AUDIT OF THE RESIDENTIAL SETTING

The residential setting must be as PWS friendly as possible. This may require some alterations to the physical environment to ensure it is robust and makes restrictive practices as inconspicuous as possible.

***A checklist to audit the environment for PWS support is in Appendix 1.**

INFORMATION GATHERING

As an accommodation provider, gather detailed Information to identify how the agreed supports will be delivered by the residential support team. This includes support for daily living, capacity building and community access.

- Meetings with the parents/carers or someone who knows the adult well need to be scheduled. These should be both with, and without, the participant present. Make sure that information supplied by the person with PWS, upon which decisions are being made, is corroborated by another party.
- It is important to establish links with the parents/guardian for ongoing information sharing to help ensure consistent supports and an ongoing positive supportive relationship.

ESTABLISH LINKS WITH THE PARTICIPANT'S DISABILITY SUPPORT WORKERS

These may include the NDIS Plan Manager, Support Coordinator, day program provider, supported /mainstream workplace, recreation support providers, sporting groups and case manager, if the person with PWS has one.

The steps are:

- Set up communication networks between the different disability support workers
- Identify any transport and /or timetable difficulties. A travel training program may need to be initiated or alternative transport may need to be organized.

A similar linked network should be established between key medical professionals involved in the care of the person with PWS especially the endocrinologist, dietitian, other lifestyle professionals and GP. Otherwise they may give contradictory advice, confusing the participant.

FAMILIARIZATION WITH THE NEW NEIGHBOURHOOD

Organize times for the person with PWS to visit their new home prior to moving in to meet other residents and their key worker. Help them become familiar with the layout of their new home and neighbouring surrounds. Inform neighbours and any nearby shop staff of the strict dietary needs of the person with PWS to discourage them from providing extra food/beverages.

ENSURE STAFF ARE CAPABLE OF EFFECTIVELY SUPPORTING THE PARTICIPANT WITH PWS AND ALL HAVE:

- a shared understanding of best management strategies
- received communication about, and have implemented the Code of Conduct for the residential setting
- skills for listening, mood monitoring and delivery of pre-emptive responses.

Helpful Tips

The person with PWS may feel reluctant about, or even strongly resistant to, moving into 'a PWS house' thinking they will get less food access. Therefore, it is better to avoid this term and emphasise that it's actually a home where residents have healthy options and choices.



Include the person with PWS in discussions where possible, but be aware that they take time to absorb information. They find it hard to shift their thinking to a new idea. At times they will feel over-whelmed with information and, to avoid anxiety, it may be better to give a concise version of your information.



Further information

The International 'Standards of Care & Best Practice Guidelines for Prader-Willi Syndrome'
www.ipwso.org.au

Beyond the Veneer - A guide to the essential features of residential care and supported living for adults with Prader-Willi Syndrome, Jackie Waters (2012)
Order via <http://www.pwsa.co.uk/information-support-advice/publications/>

Residential care and supported living resources, for Prader-Willi Syndrome UK
<http://www.pwsa.co.uk/information-support-advice/professionals/residential-care.html>

Supporting Adults with Prader-Willi Syndrome in Residential settings, B. Goff.
Order via Prader-Willi Syndrome California Foundation, USA
<http://www.pwsausa.org/product/supporting-adults-with-prader-will-syndrome-residential-settings/>

Video: Prader-Willi Syndrome Residential Staff Training – Prader-Willi Syndrome California Foundation, with support from PWSA USA
<http://www.pwsausa.org/product/pws-residential-staff-training-dvd/>

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>

Positive Behaviour Strategies: Tips for Working with people who have Prader-Willi Syndrome
<http://www.pwsausa.org/positive-behavioral-support/>

Video: Food security and the TRAIN model – Dr Janice Forster, 2015
<https://www.youtube.com/watch?v=BzOT8ow6Uvo>

Prader-Willi Syndrome Association of Australia
www.pws.org.au/research

Appendix 1 - Accommodation Audit

In preparing to provide residential accommodation for people with PWS, it is important to conduct an audit. This needs to include both the physical environment and the staff capabilities.

Needed	How
Food security arrangements	Secured pantry and refrigerator and rubbish bins
Office security	'Out of bounds areas' are needed to prevent theft of money and food. Areas must be clearly identified eg tape on the floor
Lockable cupboards	In residents' rooms to provide a sense of control of their environment and privacy. Also can prevent the theft of money and valuable personal belongings.
Exercise area	With a variety of suitable equipment available
A weighing centre	Needs to be in a private area
Visual displays such as display boards	These can show daily routines, staff or routine changes, code of conduct of the setting and house rules.
Night time supervision	This may involve alarms with codes, movement monitors and active overnight shifts. The person with PWS is at risk from obtaining extra food or going out alone to find food if left unsupervised. Some require assistance with their sleep apnoea equipment during the night.
Supports and structures are already in place	These should be part of the house for all residents, not just the person with PWS. The person with PWS should feel confident that they are moving into a secure environment with appropriate routines and structures already in place. The person with PWS tends to find frequent changes of routine difficult to cope with so it is preferable to have one major change of routine rather than many changes of routine in response to emerging problems.

STAFF CAPABILITIES

It is important that all staff have:

[A shared understanding of the complexities of PWS particularly:](#)

- People with PWS tend to talk a lot and will often get repeat themselves. While it is important to readily engage with the person as they really appreciate this social activity it is also important to have strategies to end discussions in a sensitive and respectful manner.
- People with PWS can be very manipulative and the staff should be aware of the many ploys they use. Response to allegations needs to be considered only after hearing both sides of the story.
- People with PWS tend to overestimate their abilities. They may lie about and exaggerate their skills and planning abilities and may, inadvertently, place themselves at risk. Staff need to be very wary about allowing the participant into an environment where they cannot manage the risk, despite verbal assurances that they can.

A shared understanding of best management strategies:

- Consistent dietary, exercise and behaviour management is key to successful outcomes.
- Use team meetings to discuss and establish a consensus on how staff will manage the following:
- Food security during the preparation, serving and storage of food
- Exercise and recreation activity schedules
- Access to money. Staff should be informed about the reasons why food and money must not be accessible.
- Ensure that the importance of good communication skills is understood by all staff
- Have a clear behaviour management action plan for when things go wrong and any behavioural outbursts
- Avoid getting into arguments and limit excessive questioning
- Be aware of lying and exaggeration where the truth can get in the way of a good story
- Provision and use of a time out space in a private area.

A Code of Conduct in place with expectations clearly and concisely communicated:

- Allocate a key worker who the person with PWS can go to if there are any problems. The role of the key worker must be clearly explained to the person with PWS
- Establish a communication protocol between the key support worker and the house manager and a process for resolving issues in a timely fashion.

The key support worker role will include:

- Revisiting the house expectations and code of conduct when needed to confirm that the person with PWS does, in fact, understand what it means for them.
- Making sure the person with PWS knows how to use the visual display boards to get information about daily routines, activity schedules, medical appointments and staff changes
- Introducing the dietary management and exercise routines
- Taking the time to help the person with PWS to get to know the new neighbourhood facilities they will be using such as the swimming pool, gym, and library.
- Providing extra support and prompts if needed until the new routines and schedules are bedded down.

Good active listening, pre-emptive responses and mood monitoring skills:

- **Monitor mood** and behaviour carefully and pre-empt any triggers in the environment that cause increased anxiety. Listen to concerns, likes and dislikes respectfully and tweak the routines and structures accordingly.
- **Positive plans** with verbal, and sometimes tangible, rewards to obtain co-operation and task completion. Support and guidance will be needed to assist the person with PWS achieve personal growth and development in their daily living skills, which will promote increased independence and an improved self- image.
- **Provision of opportunities** for the person with PWS to establish and maintain relationships with their peers and family members. This can be strengthened through training and modelling of positive social skills, verbal support and guidance.
- **Celebration** of group achievements through positive peer praise and recognition.
- **Fostering** of a homely environment that is respectful, caring and fun.

Glossary

SHARED SUPPORTED ACCOMMODATION

This type of accommodation provides integrated housing and support for people with PWS. It is sometimes called a Group Home or Community Residential Unit. The service provider supplied both the residence ('bricks and mortar') and the services to support daily living. A resident often had other funding to provide recreation and day time activities. It includes a variety of accommodation models that address the needs and levels of support required by people with PWS Including:

- small group homes that usually accommodate 4-6 residents which may, or may not, be PWS specific.
- other living arrangements that may include individual unit clusters where staff are available to support the needs of the people living there. These residential settings also may, or may not, be PWS specific.

NURSING HOME ACCOMMODATION

This type of accommodation is provided for people with PWS with chronic long term health needs which are deemed to be unable to be met in other residential settings. Typically, the other residents are much older. Generally, the homes are not well equipped to cope with the over-eating and behavioural characteristics of PWS.

SHORT TERM FACILITY BASED ACCOMMODATION

Short term facility based accommodation (sometimes known as respite) is another option available to meet the needs of the participant and their family or carers. It can provide a flexible and more purposeful, social skills experience for the participant (rather than just 'minding').
