

Introduction

This meeting was a special topic meeting, run as part of the PWSA UK's Residential Care and Supported Living Forum, which meets three times a year for professionals in this field to share experience, knowledge and good practice. As this was a special topic meeting, it was also open to parents, social workers and others with an interest in the subject.

Speakers presented on their own experiences of supported living, its pros and cons, and what worked best for the people with PWS in their care. What came across quite strongly was that individuals with PWS can be very different from one another, with a range of abilities and needs, so that one size in supported living does not necessarily fit all.

However, there were several areas which speakers agreed were necessary for supported living to work well in PWS, as well as pitfalls to avoid. These notes combine thoughts from all our speakers.

What we know about PWS and supported living

The knowledge that has been acquired by PWSA UK regarding supported living has been mainly through telephone calls to the Association and training we deliver to supported living organisations. We have been able to identify 25 individuals currently in supported living, of whom only one is reported to be doing well. However there are likely to be many more we do not know about.

Issues which have been reported to PWSA UK include:

- Significant weight gain
- Inadequate support
 - Absconding
 - Staff burn out
 - Left alone at night
- Mental capacity assumed
- Vulnerability to others – being given food
- Sharing home with inappropriate others
- Physical aggression – being given notice
- Difficulties for staff in setting boundaries where mental capacity is assumed and no DoLS in place

Location - The right property in the right location with the right facilities

It is crucial to get the right property:

- **Size** (if live-in staff, min 3 bedrooms or 2 reception rooms)
- **Location** Locations near fast-food shops, garages, mini-supermarkets, etc are setting the person up to fail, as there is an ever-present temptation to get food from these sources. Also, the local community itself needs to be considered: will the individual fit in with it?
- **Facilities** –think ahead – wet rooms, no steps, ability to convert for wheelchair access etc later in life.

Longevity built in - remember people with PWS rarely embrace change and moving is high on the stress spectrum. The right type of lease and/or housing association structure should be in place.

Remember, it is the individual's home, not the support organisation's workplace - adapt procedures and strive to make it a home not a mini residential home

One set-up which worked well was where the person with PWS had a flat in the grounds (or next to) an existing residential home. Extra staff were always available if need be, and the person was not socially isolated, but also had their own space. This also helped residents in the main house, who were not so subject to the challenging behaviour which could arise on the part of the person with PWS.

Care plans

- The care plan must have input from the individual with PWS but also be realistic both in terms of what each party can expect from the other. It also needs an over-riding “get out clause” (eg, “but if the manager says...”)
- Use simple language with additional visual signs.
- Update care plan and risk assessment documents regularly. Circumstances will most likely change as the person “pushes boundaries”.
- Ensure that an “emergency folder” for health professionals is kept with relevant and up to date information about PWS generally and the individual in particular.

Daily activities

A full timetable of activities is essential to keep the person’s mind off food. Wherever possible, these should include part-jobs, paid or voluntary, to help the person’s self-esteem and sense of community. Creative thinking is often needed to make sure that activities are appropriate and meaningful to the person – they may not be what the person used to do in a previous setting.

Finances

Access to finances should be carefully considered and monitored, as any extra money is very likely to be spent on food when out and about.

Individual vs shared tenancies

Shared tenancies can work if everyone has PWS or needs restricted access to food for other reasons. They are unlikely to work where others do not have PWS and have access to cooking and the kitchen, even when a rota basis and personal cupboard space are instituted. The proximity of food, and the ability of others to cook foods which may not be appropriate for someone with PWS can be extremely difficult for the individual to tolerate, with resulting challenging behaviours.

Shared tenancies also give more opportunities for social interaction, as well as visiting places together.

Some people with PWS tend to be very possessive over space and possessions. Individual tenancies can help with this.

Food – shopping and cooking

Various methods are used to help control access to food, as the temptation to eat all available food at once is usually too great for people with PWS, as well as the risk of eating inappropriate items such as frozen food, sauces or uncooked food.

- Plan menus with the person with PWS in advance to prevent requests for “extra” items to be bought at the shops.
- Keeping food locked within a cupboard or separate room within the person’s home may work, but this can result, in some cases, in the person with PWS making repeated attempts to access this eg by manipulating or intimidating staff, or by gaining access to the key or door code. It is better, if

possible, to keep food in an entirely different location (eg in a main house to which the supported living home is attached). However, this in itself can cause anxiety: the person may complain that others are taking their food, or that portions are not the same every day – if food is being cooked in a main house.

- For one individual, for whom all other options had been tried, the answer was to subscribe to **Diet Chef** - vegetables and salads can be prepared by the person and added to the meal. This gives the person a greater sense of control over their food.
- Where all individuals have PWS, it is possible to introduce a locked kitchen, and supervision in meal preparation. Many individuals become very anxious around meal preparation – especially when “competing” with others in a shared tenancy, and may thus be happy for staff to take over food preparation.

Staffing

- Staff should be available at short notice 24/7 as challenging behaviour can arise very suddenly and unpredictably.
- Staff teams should be small, trained, reliable and committed, but not so small that burn-out occurs by too much unsupported 1:1 work. Around 4 to 5 people works well.
- Staff working 1:1 can feel quite vulnerable, stressed and isolated if they do not have access to immediate back-up and advice from a manager. Regular team meetings can also help with this, as well as identifying issues that may be affecting one or all staff members.
- New staff should be inducted gradually into the setting, shadowing existing staff in the first 2 – 3 weeks. Involve the person with PWS in their training.
- All staff should always present a consistent approach to the person, and be clear about boundaries.
- The person with PWS should be involved in choosing staff, but be aware that favoured staff members may become less liked if they say or do something that the individual objects to. Staff should be supported to realise that this, along with verbal abuse, is rarely something personal, but that they are just the immediate target of the person’s anger or distress.
- Training on the specific needs of people with PWS is a must. Staff should not be expected to manage situations of which they have no understanding. Training should emphasise: limiting access to food, mental capacity, medical issues and hidden risks (eg high pain threshold and lack of vomiting reflex).

Assistive technology

Assistive technology can be helpful in supporting individuals with PWS in their own homes. It requires a robust and regular assessment and review purpose to ensure it is being used in the appropriate circumstances and is also providing the anticipated outcomes for the supported individuals.

Some examples could include:

- If the individual is preparing their own food, use talking scales so that staff can unobtrusively monitor how much food is being weighed out.
Talking scales can also be used in the bathroom to make weighing more fun, and again for the purpose of staff monitoring.
- Door sensors can be useful, but there must be 24 hour monitoring and robust procedures in place should the person leave the property or access areas which are out of bounds.
- Mobile phones are useful for the person with PWS to keep in touch with staff, especially if they are out in the community unsupported (only for more independent people who have been appropriately risk-assessed).

- GPS can be helpful in locating people who abscond or those who are able to be out in the local area but may need specific geographical boundaries.
- Communication aids can be very helpful for those with limited speech or articulation problems.
- Prompting devices can be used to help the individual perform daily tasks, such as taking a shower or making a drink.
- With increased risk of sleep apnoea, bed sensors which detect small movements can be used to keep people safe. They can also be used to alert staff when the person has got out of bed.

Further information about Hft's personalised (or assistive) technology services

Assessments and previous history

Do not assume that because a person acted in a certain way in one environment they will act the same way in another. Environment, relationships with others and access to food have a great influence on the way a person with PWS behaves. Hence past history, likes and dislikes, may not necessarily be the same in a supported living situation.

If possible, arrange for staff to spend time with the person with PWS before they enter the supported living situation, so that the transition is smoother.

Summary of pros and considerations

Pros

- Greater sense of independence
- More person-centred
- Greater choice (theoretically) in choosing staff
- Greater privacy
- (in some situations) The person can have a pet and be responsible for their care. Make sure pet food is stored away safely, and that the pet eats it food at the same time as the person with PWS.
- Responsible for cleanliness in the house, gives a greater sense of personal control.

Considerations

- Location of amenities have to be taken into account
- Greater opportunity to abscond/ food seek
- Greater risk of hoarding behaviour
- Risk of coming in to contact with people who may abuse
- Staffing may not always be consistent (also affected in part by Individual supported changing staff frequently)
- Risk of boyfriend/girlfriend/parents/friends/family bringing in food

Many thanks to our speakers:

- Samantha Kingston (formerly of Consensus Care)
- Martin Harris (Wrixon Care)
- Mo Whittingham (Hft)
- Vincent Scaife and Sarah Weston (Hft)
- Jackie Waters (PWSA UK)