

Residential care and supported living

18-25 years



Introduction

In a PWSA UK survey of parents of adults carried out in 2006 just under half of adults with PWS surveyed were living at home with their parents. The other half were living in various types of residential care or supported living situations.

With better health management, there is likely to be an increasing number of people with PWS outliving their parents, or their parents are becoming too old to care for them.

Even if your son or daughter lives at home now, the question of living away from home is one which may well arise sooner or later, and it is better to think about this in advance, rather than when a crisis occurs.

Types of residential placement

One of the first issues to consider is the type of living situation which would be suitable for your son or daughter. Should they live independently; in supported living with some supervision; with other people with different learning difficulties; or in homes specifically for people with PWS? In fact, the most suitable option will vary from person to person, but it is unlikely that anyone with PWS will be able to live away from home for any length of time without some form of supervision.

Generally speaking, people who live independently with minimum supervision obtain the quality of life and freedom they want. It may go on for a number of years, but the price is usually severe obesity, failing

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Help from PWSA UK and the Residential Homes List

The PWSA UK can offer help and advice at any stage.

Please remember that, although we maintain a list of homes with experience of people with PWS, the information on the list is provided by the homes themselves, PWSA UK can never recommend homes.

Contact us to obtain an up-to-date copy of this list.



Types of residential placement (continued)

health, and early death. Even in some non-specific PWS residential homes, people have fared a very similar fate: plenty of freedom to eat, and go where they like, followed by hospitalisation and sometimes death. Those who live in controlled environments generally remain active and healthy. The price such people pay is the loss of many freedoms which most of us would take for granted, although many people with PWS do welcome the structured lifestyle offered as it helps them to cope more easily with the syndrome.

Specialist PWS provision and the Residential Care and Supported Living Forum

In the past few years, there has been a rise in specialist provision for people with PWS, with currently over 100 placements available with various providers, most of whom are private organisations. The PWSA UK itself does not run any residential homes, but it does run a Residential Care and Supported Living Forum, where providers can meet to discuss best practice. It also maintains a list of homes with experience of supporting people with PWS, but does not make any recommendations.



Supported (assisted) living

Supported (or assisted) living is now the option usually first suggested by social services, in line with current general policies for people with learning and physical disabilities. This is a relatively new concept for the care of people with PWS and requires careful planning. It must involve appropriate and meaningful daytime activities, supervision and planning of food purchasing and budgeting, and reliable support systems, with back-up staff available.

The support systems should be able to react quickly to crisis situations such as large increases in weight or mental health problems, or even to perceived crises on the part of people with PWS eg they have lost a valued item – not being able to find it can result in major temper outbursts. A crisis management plan in case situations like these occur should be in place right at the start of a supported living placement.

Although supported living can work, the PWSA UK has learned of many instances where it has not. These include:

- Insufficient, inconsistent or nonexistent support eg there is no monitoring to ensure support staff arrive on time or indeed arrive at all.
- There is a gap between the support planned and that actually delivered. Staffing shortages lead to agency staff being used, usually untrained in PWS. One individual who moved to supported living with minimum support hours died, due to obesity related medical issues, after gaining seven stones in five months.
- At the commencement of a scheme, highly trained and knowledgeable support staff are often put in place. However, when, for whatever reason, these individuals leave the scheme, they are not replaced by staff with similar knowledge or skills. There may be over-reliance upon individual support staff, leading to "burn out".

Continued ...

Supported (assisted) living (continued)

- Due attention has not been paid to the location and to the fact that a person with PWS does not have capacity in respect of food and, therefore, temptations must be put beyond their reach e.g. supported living unit behind a chip shop, takeaway or supermarket; the kitchen facilities and food being fully accessible to people with PWS.
- Due to insufficient support of staff, the threshold at which staff begin to feel uncomfortable is reduced, resulting in inability to successfully manage behavioural difficulties and hence there is placement breakdown.
- Unsuitable accommodation for support staff within the unit e.g. no "safe" space for staff to have "time out" or record and store important information without the person with PWS being able to access that information and possibly remove or destroy it.
- People with PWS are vulnerable adults and there is an inappropriate balance between the competing needs of independence and protection e.g. the desire for food can be extremely compelling, leading to financial and sexual exploitation.



- Some people with PWS have a higher intellectual level than their ability to function within the social environment, leading to inappropriate care packages. They are perceived to be much more able than they actually are. Equally, a person with PWS may have an exaggerated sense of their own coping skills. This has led to expectations not being met and relationship breakdown between support staff and the individual concerned.
- Inappropriate assessment and ongoing monitoring of a placement e.g. a person with PWS begins to feel isolated. In one case, this issue was not identified and the individual absconded on several occasions, eventually leading to placement breakdown.
- People with PWS are prone to behavioural difficulties and have limited social skills. The timing and extent of "tantrums" are highly unpredictable. A provider of supported living is therefore required to ensure 24/7 support or have in place monitoring and support at very short notice - if not, a crisis situation can occur.

Important considerations for supported living and Prader-Willi syndrome

This article is [available on our website](#) and is aimed at social and care managers who are considering placing someone in supported living. It contains expert advice from Prof Tony Holland and discusses a case which sadly resulted in an avoidable early death.



Residential care and supported living

Successful supported living schemes

Successful supported living schemes are those that have been planned well in advance and where the issues on this page have been addressed.

The environment has been purpose built or modified to enable the tenant to make safe and appropriate use of their home.

Staff have been recruited and selected who would be most likely to work successfully within the framework of supported living and, where the living arrangements will be shared, the prospective tenants have been matched in social need and ability.

The individuals receive high levels of support ensuring there is a staff presence in the house or nearby at all times.

The staff have been trained in PWS and have a manager that is dedicated to the scheme.

Getting an assessment and funding for residential care or supported living



If you are thinking about residential care or supported living for your son or daughter, the first step is to contact your local Social Services Department and ask for an Assessment of Need. This may take a while to complete, but in the process the assessor will be able to form a clearer picture of the needs of your son or daughter.

Even if residential care is still a long way from your thoughts, it is advisable to make yourself known to Social Services if you are not already: the longer the authorities know about you, and the more they know about PWS, the better able they will be to make realistic decisions about your son or daughter's future. Waiting lists for homes are usually long, so if you find one you and your son or daughter particularly like, it is a good idea to put their name down early.

Pave the way for this major change in the life of your son or daughter by discussing the options with them in advance, and by trying to look at those options as realistically as possible. You may have to do this very gently, and over quite a long period of time. It is also useful to help your son or daughter to acquire some of the skills they may need (eg doing their own laundry, cleaning etc) in preparation for their future situation.

Funding in Scotland, Wales and Northern Ireland

There are different eligibility criteria and various differences in how funding is allocated in England, Scotland, Wales and Northern Ireland, and may change from time to time, but they should be available from your local social services office. It is beyond the scope of this article to go into all of these.

Getting the provision you want

Social services will probably suggest local Supported Living first (see previous page), but it is up to you and your son or daughter to decide if this is suitable. If you are not happy with what is available locally, you may need to look further afield. Social services cannot refuse to place your son or daughter in a home if it is in another part of the country, and if the individual's needs cannot be met locally, and would cost no more than your social services would normally pay. You may have to go to appeal if social services refuse to pay in the first instance. Don't be afraid to ask the service provider of your chosen placement for help in talks with social services particularly with regards to funding.

If you feel you are getting nowhere, there is a complaints procedure, and it can be helpful to involve local councillors, voluntary groups (including the PWSA UK), and your MP. Getting together with other parents in a similar situation locally is very helpful if you want to put pressure on the authorities to provide appropriate care.

Health funding

Additional or alternative funding can sometimes be obtained for health-related or complex needs from the NHS – your social worker can tell you more about this. However you should be aware that if the total funding comes from Health, your son or daughter may lose their Disability Living Allowance or PIP. Total health funding is more likely to occur where the person is not classed as having a learning disability, and therefore is not perceived as having social needs, or where the person's weight is becoming life-threatening and/or there are other mental or physical health issues.

Finding a suitable placement

The PWSA UK keeps a list of homes in the UK who have had experience of residents with PWS, and are willing to consider accommodating others.

(NB: The PWSA UK has a policy of not recommending ANY homes - it is up to the parents, social worker, and person with PWS to decide whether the home suits their needs).

The PWSA UK publication, **Beyond the Veneer** is useful to give to providers who do not have a good knowledge or experience of PWS, as this describes the various needs of people with PWS and the risks associated with not meeting these needs.



Residential care and supported living

Contribution to care from savings

Each local authority will have money in their budgets to arrange residential care for people who are assessed as needing it.

However, in England (and at the time of writing) if the person needing care has more than a certain amount in savings, they will be required to contribute an amount towards that care.

It therefore makes sense to think carefully about the amount of money you intend to leave in your will for your son or daughter.

*It is usually better to leave the money in trust than to leave money outright. Seek legal advice if you intend to do this. See also **Preparing for the Future and Making a Will and Setting up a Trust.***

Government Allowances



Please note that there are widespread

*changes to the benefits system occurring (see separate leaflet on **Benefits and Allowances**) which may well impact on the information above. If in doubt, contact your local Citizens Advice Bureau or Welfare Rights Centre.*

Currently In the residential care setting, your son or daughter's care component of the Disability Living Allowance (DLA) or Personal Independence Payment (PIP) and Employment and Support Allowance (or Incapacity Benefit or Severe Disability Allowance) will be taken by the home towards its fees, and this will be "topped up" by social services and/or health services.

The mobility component of DLA or PIP, if there is one, is most likely to be used by the home towards general travelling around, but they are not entitled to it as of right.

Usually an agreement is made, dependent on the level of visits, general travel etc,

between the home and the parents as to how the mobility allowance is spent. Make sure you are clear about this. Your son or daughter will retain a small weekly personal allowance from their benefits to spend as they wish.

If they go into supported living, they will be entitled to housing benefit and income support as well as their disability benefits, and will have far more money available to them.

Please check this information, as this may change in line with government policy over time, and depending on whether you live in England, Wales, Scotland or N Ireland.



Choosing a home

Once you have located one or more possible homes, do take the time to visit them. Wherever possible, take your son or daughter along with you – although you will know best if this is likely to cause them unnecessary anxiety. Here are some of the things to bear in mind when you visit:



- If you live in England, ask to see the latest **Care Quality Commission (CQC)** report on the home. All homes' reports are also on their website. In Scotland, homes are registered and regulated by the **Care Inspectorate**. In Wales, it is the **Care and Social Services Inspectorate Wales**, and in Northern Ireland, the **Regulation and Quality Improvement Authority**.



- Ask to see the home's mission statement. This will give you a flavour of how the home operates and its relationship with its residents.
- Speak to other residents. You can usually see quite easily whether they are happy.
- Ask about staff turnover. Homes with a fast turnover of staff are not always best for people with PWS, who like a degree of stability in their lives.
- Speak to other parents who have sons or daughters at the home (not always possible, of course)



- Ask about how parents are involved in care plans. A good home will usually be happy to learn from parents' experience about their son or daughter's needs.
- Ask if the home does assessments, whereby a person stays a few days to see how they like it and to allow the home to assess if they can meet their needs.
- Ask about contact with GPs and other health services in the area. How much do they know about PWS? Can they advise on diet, behavioural problems,

mental health problems and physical problems, should these occur? Would they seek a second specialist opinion if necessary?

- Ask about activities and daily plans for residents. Are they appropriate for your son or daughter? Are residents encouraged to keep busy?
- Ask about any specific problems your son or daughter has (be honest!), and how the home will cope with them. These might include food-seeking, behaviour problems, poor social skills, language and communication problems, and emotional instability.
- Ask to see any management guidelines that the home has, eg about restraint policy, abuse procedures, medication procedures.
- Don't be afraid to ask as many questions as you like and write them down beforehand so that you do not forget any.
- Remember that the brochure which the home may give you is a marketing tool used by them to attract customers. Be prepared to question any statement in the brochure very closely if you have any doubts about its validity. Most homes would be only too pleased to back up their claims with facts and figures.

Continued ...

Choosing a home (continued)

- Are there opportunities for a social life, outings etc?
- How much freedom to come and go do residents have? Is a check kept on their whereabouts? If so, how is this carried out?
- How is food served and cooked? Ask to see a menu.
- How easy is it for you to get to the home for visits? - How easy is it for your son or daughter to visit you?
- Is there some sort of complaints or advocacy system in operation whereby residents can air any grievances or complaints they may have?
- What is the home's attitude to personal development and sexual relationships? - How much choice is a person allowed? (ie What limits are placed on them?)
- Is there a parents' support committee?
- What is the "exit policy"? What happens if your son or daughter doesn't fit in, settle down, or their needs change in the future? What happens if the home feels that they can't cope?



What next?

Once you have settled on a home, and once you have the funding in place, then your son or daughter can make the move. You will probably have lots of worries about how they will settle.

Remember that, unless you are very frail or ill, you are still your son or daughter's legal guardian and therefore should have a say in their welfare.

A good home should keep you informed about progress and any possible problem areas which arise. A preventative approach may help avoid situations which result in crisis.

It may be a good idea to ask for a written letter from the home when your son or daughter moves in, indicating what level of practical care, health care, education (if appropriate), training, leisure activities, day-time occupation (paid or otherwise) they intend to provide, what contacts they will maintain with you, and what will happen if your son or daughter does not fit in or becomes unhappy there.

It would be unreasonable to expect any residential home to provide exactly the same facilities as your son or daughter had when they lived with you.

Residential care and supported living

Some tips from a parent who has been through the process of finding residential care

- *Be prepared for a long battle – you will need strength and determination.*
- *Companies providing care homes are businesses. Beware the "Placement Manager" whose job is to fill places in their homes – some are ethical, some are not. Make sure that the home meets you and your son or daughter before they offer a place – it is easy to fall prey to homes who offer placements based on telephone calls only if you are desperate.*
- *ALWAYS visit and ALWAYS talk to the home manager – they know best which clients they will be able to cope with.*
- *Talk to other parents if you can.*

Help from PWSA UK

If you are experiencing particular difficulties in either persuading health and social services to fund care, or if you feel the home does not understand your son or daughter's needs, we have considerable experience in helping families with these issues.

We can also offer in-house training to residential homes and supported living organisations. There is a cost associated with this training.

For further information or help, please **Contact Us**

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What next? (continued)



They have the needs of other residents to consider as well, and are often constrained by staffing, legal, contractual or budgetary limitations.

You must be prepared to relinquish much of the control and "speaking for" your son or daughter that you had when you lived at home, although a good residential home will always listen to and act on reasonable concerns.

Unfortunately, we all have a different idea of what is "reasonable". If you have a good partnership with the home, they should be able to tell you if they feel that the demands you are making are overstepping what they are capable of meeting, and why this is. Equally, you should make an effort to listen to their point of view. It is important to remember that the priority for everyone is the happiness and quality of life of all the people with PWS within the home.

What if it all goes wrong?

If you begin to have real doubts about the home, or your son or daughter repeatedly says they are not happy there, you can sometimes resolve this by visiting the home and talking to staff there. If this does not work, then you should approach social services again and ask them to investigate. You and your son or daughter are within your rights to ask for a move.

If you have a copy of the written letter provided by the home when your son or daughter started, you can use this to refer to in areas where you perceive the home to be failing (for instance, they may have promised two outings a week, and only one a fortnight is being offered).

On the other hand, the home themselves may feel that the care they offer is not meeting the needs of your son or daughter, especially if behavioural or weight problems begin to escalate. Negotiations will then take place between the home, yourselves and social services to look at a different placement.

In rare cases, where the safety of the staff and other residents is at stake, a "notice to quit" may be given which gives a relatively short time in which to make other arrangements. Make sure that you know the procedures and home's reasons for giving notice to quit before your son or daughter becomes a resident. Do not be pressurised into having your son or daughter back to live with you again if you feel you will be unable to cope.