

The Future - Residential options for adults

What are the options?

‘Where is it best for an individual with PWS to live?’ is one of those questions for which there is no single right answer. Everyone’s personal circumstances, wants and needs are individual and should be factored into any decision making process, however there are three main options:-

1. At home with family members
2. In a residential care setting (can be PWS specific or not)
3. In a supported living setting (typically not PWS specific)

Each option has its own pros and cons and will meet different needs for different people, therefore, the options need to be given consideration in the context of the individual concerned before deciding what is right for them. However, it is worth noting that to date, it is rare for an individual to live fully independently without any level of support.

1. At home with family members

For those individuals where the balance of independence is currently being effectively managed and all parties are happy, this can be a successful option for all concerned. All members of the household are typically aware of the rules and routines within the home and for the majority of the time these work for everyone. That said there might be times when these can be challenging and boundaries may need to be restated or adjusted to help all involved. Boundaries typically include steps to ensure the appropriate restricted access to food, such as locked cupboards or kitchens, and supervision when out in places where food can be accessed. It is also common for families to seek some form of respite care to enable all parties to benefit from time away from the family home.

2. In a residential care setting (can be PWS specific or not)

There are numerous organisations with homes throughout England, Scotland and Wales, however, we are not aware of any in Northern Ireland. The quantity of homes available is relatively low and the geographical spread is sporadic.

Some organisations offer homes that are specific for those with PWS, with all residents having the syndrome. As a result, their set-up and practices enable the challenges of PWS to be understood and managed in a caring and secure environment. Their staff are generally knowledgeable and experienced in supporting individuals with the syndrome and this can be advantageous for all concerned. The number of residents accommodated in each home can vary and this should be considered when deciding on an appropriate home. These homes can often demonstrate their proven record of successfully managing individuals’ weight and/or behavioural management, and individuals with PWS have shared feedback that they prefer these controlled living arrangements, as it removes anxieties around food.

Some organisations do not have PWS specific homes, meaning they accommodate individuals with the syndrome in homes with other individuals who require additional support too. These environments can work for some individuals with PWS, however, discussions should take place with the providers as to how food access will be managed. This needs to be considered holistically in terms of food storage and preparation within the house, as well as within activities and should include implications for the others living in the house too.

3. In a supported living setting (typically not PWS specific)

This can typically be a solution suggested by social services, as an option to promote independent living. The main difference between this and a residential care setting is that the individual with PWS becomes the tenant of the property. Being a tenant means the individual typically has 'no rules' to abide by within their flat and this can present challenges for individuals with PWS. Therefore, it is important that careful consideration is given as to how the food seeking and challenging behaviour aspects of PWS can be effectively supported in these environments. Supported living settings vary in terms of size and set-up, but they typically consist of a group of flats, in which individuals live and have personal care support provided as agreed in their care plans. Support can also be delivered in a single flat/home too. One provider will supply the accommodation, as a landlord, and another provider will provide the personal care support, under separate contractual arrangements. This is covered more within the leaflet 'Considerations when selecting residential options for adults with PWS'.

There are many factors to consider when deciding which is the most appropriate setting for an individual with PWS. Whilst some of these are emotional, others are physical and relate specifically to the building and facilities a provider offers, including things such as access, specialist equipment and access to food. These are outlined further in the leaflet 'Considerations when selecting residential options for adults with PWS'.

All housing provision outside of the home has a cost associated with it and your local authority will guide you through the process applicable to your situation, in terms of how funds can be accessed. Further details are outlined in the leaflet 'How to access funding for residential options for adults with PWS'.

How they are governed and by whom?

Residential care homes are required, by law, to be registered with the Care Quality Commission (CQC) as they provide a regulated activity. This is the Government's regulator, which is an independent body, and it regulates all homes whether the NHS, local health authorities or commercial organisations provide them. The CQC states that it undertakes planned reviews of each care home every two years, which in almost all cases involves someone visiting the home. Inspectors talk to the people living in the home to find out what they think of their care, as well as talking to staff and management too. They also inspect the documentation and records the home keeps, all of which is assessed against five key criteria (Safe, Effective, Caring, Responsive, Well-led) before reaching an overall score for the home. CQC ratings, along

with the full visit report can be found here <https://www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home>

If homes fail to meet the expected standards, the CQC will ask the home to develop an action plan to improve their services within a stipulated deadline. If they fail to meet this deadline, they can give the providers warnings, fines or place restrictions on certain services, ultimately 'effectively closing' the home by removing their licence to operate. However, their aim is to improve conditions rather than unsettle and move people.

It is worth noting that the CQC does not settle individual complaints, but suggests they are first directed to the care home management team and, if not resolved, they are referred onto the Local Government Ombudsman for investigation.

Supported living providers that do not provide the personal care (which is known as a regulated activity), are not required by law to register with the CQC. Whilst the CQC does not regulate the supported living provision itself, the personal care that is provided, by a registered homecare agency or provider will be regulated.

How and where to find places

PWSA UK does not own or run any residential care or supported living provision and cannot recommend or endorse any provision, as every individual has different needs.

Social workers will be able to provide knowledge about general provision in your area, however, typically this will not be PWS specific, unless they have awareness of the syndrome from supporting others with the syndrome.

PWSA UK has a list of known organisations that would be open to discussions to provide an individual with PWS a home and/or have experience of doing so for others. This list includes the website and known contact details of the organisations as well as the CQC ratings. This enables family members to make contact directly with them to discuss specific needs and is available on request. You can call PWSA UK on 01332 365676 or email admin@pwsa.co.uk.

There are websites that provide general information to help in searching for residential options:-

- The Care Quality Commission (CQC)
<https://www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home>
- NHS
<https://www.nhs.uk/Service-Search/Care-homes-and-care-at-home/LocationSearch>
- Care Home.co.uk
<https://www.carehome.co.uk>

PWSA UK can provide support and training to any provision that is willing to support an individual with PWS. It would be advantageous for all parties for

contact to be made with the Association at the initial stages of discussions regarding a placement so the provider can fully understand the syndrome and potential requirements for the individual. This would enable adjustments to be implemented prior to them moving in and get things off to a great start.

For the opportunity to discuss information contained within this leaflet and/or your personal circumstance please contact PWSA UK via email – admin@pwsa.co.uk or telephone 01332 365676

Additional Information

The Care Act 2014 offers carers rights and protections for themselves and the adult they support, as they move into adulthood. Sky Badger has a useful leaflet that explains more about how it can help families and this information can be found here: www.skybadger.co.uk/2018/11/02/a-guide-to-the-care-act-2014/?gclid=Cj0KCQiA9dDwBRC9ARIsABbedBO3zLV53xoZVlEXbyH-HMMfsYKBmKesUvmLkiZMD-RNv0W3lArRp5MaAnrvEALw_wcB.

This leaflet has been developed taking into account information contained within PWSA UK's previous publication 'Beyond the Veneer', which was developed from a workshop held in 1996 for professionals with an interest in PWS from statutory services, medical teams and residential homes.