

Social life and relationships 13–18 years



Introduction

As the young person with PWS grows older, the gap between them and their peers usually becomes noticeably wider, especially in the area of emotional maturity and the ability to form lasting relationships.

Their emotional development appears to be arrested, or much slower, than other people's.

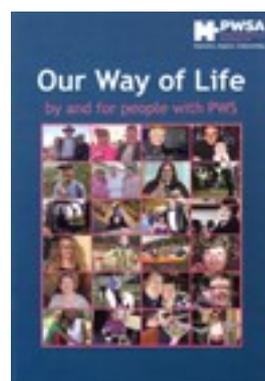
However, they can be helped to have a good social life and to learn the skills to handle relationships in a more mature manner.

Talking about PWS

Some parents make the decision not to say anything about PWS, but to treat their child as normally as possible. This does have some benefits, but if you have done this in the past, you may now be considering how to tell your son or daughter about the implications of having the syndrome.

Whatever you tell your son or daughter, always tell the truth as you know it.

It is unfair to raise expectations, but at the same time it is very important to stress all their good points if you are telling them something negative as well. It is also very important to keep their level of self-esteem high, so always praise them if they do something well, behave well, or do something they have never done before.



Let's talk about PWS

You can use this workbook to help explain about PWS.

Our Way of Life

You may find it helpful to give your son or daughter a booklet produced by PWSA UK by and for people with PWS, called "Our Way of Life" which explains PWS as simply as possible, and also features photos and life stories of young people who have the syndrome.

Both publications are free to families with a young person with PWS.

<https://www.pwsa.co.uk/about-pws/publications/>



Photo by Kate Lloyd Photography

Going out alone

Between the ages of 13 and 18 most teenagers without PWS begin to explore the outside world on their own – but this depends on how much freedom parents are willing to allow their son or daughter, the local environment and the maturity of the teenager.

The same considerations apply in many respects to teenagers with PWS, with the added issue of access to food and (for some) learning disabilities such as being unable to tell the time or deal with money. Generally speaking, it is probably best to approach this in very small steps to see how your son or daughter copes – at what age you do this depends very much on their individual abilities.

Driving

Some people with PWS may ask if they can learn to drive, and it is not unknown for a few people with PWS to be able to do this – much depends on individual abilities. However, all the risks and benefits to the individual should be weighed up before proceeding.



Family relationships



For any family, their child's teenage years can be difficult, and this is also the case for the family with a teenager with PWS. It can be especially difficult, however, as the person begins to realise how different they are from others of their own age in terms of how independent they are able or allowed to be. In a family situation, younger brothers and sisters may well have more independence than the person with PWS.

It is thus important to provide your son or daughter with at least some degree of responsibility, e.g. for various household chores, which will allow them to have self-esteem and status within the household. Allow them to "grow up" but at a pace that suits them, not in comparison with other teenagers. Try to maintain a balance between no longer treating your son or daughter as a child, but not expecting too much of them as they continue to develop.

On the other hand, brothers and sisters may feel jealous of the attention being given their sibling with PWS. It is important that everyone in the family feels special in their own special way.

In the normal course of events, brothers and sisters leave home, go to college, get jobs, and perhaps get married. These options are more limited for people with PWS, but not entirely outside the realms of possibility. They may leave home, but to live somewhere else in a supported or residential capacity; they may go to college, but more than likely within a special needs unit or with support, and they may get voluntary work or a part-time job rather than full-time work.

Your son or daughter will need support during the teenage years to see these as worthwhile alternatives and to accept their own limitations. It is important that they are not "set up to fail" by giving them false expectations of what they can achieve in life. It is better to be honest and positive about your son or daughter's abilities, and to help them develop their own interests.

Continued ...

Family relationships (continued)

Stress should also be placed on the value of your son or daughter to the family, such as their role as aunt or uncle to their brother or sister's children.



Photo by Kate Lloyd Photography

Social relationships

Many people with PWS find social relationships difficult. Typically, people with the syndrome may focus on one topic to the exclusion of all others, find it difficult to answer direct questions, butt into conversations with a topic totally unrelated to the one which is being talked about, or be very withdrawn in some situations.

They may find it difficult to make eye contact, get too close to the person they are talking to, or use a rather bossy or even aggressive tone of voice.

On the other hand, many are friendly and polite. They are often happiest in a one to one relationship with an adult or a younger child.

If you wish to try to alter a social behaviour which causes particular concern, you could try role play with your son or daughter to try to change it. You behave as they usually behave, and ask them how they feel about that. They may then see that it would be helpful to change.

Further role play could then concentrate on ways of making the behaviour better. You could agree visual cues to warn that the mark is being over-stepped, e.g. a hand movement, or you could agree a phrase such as, "Please wait until I have finished speaking," or "Could you speak more quietly, please?"



Leisure interests and holidays

Teenagers with PWS should be encouraged to join in with all types of social and leisure interests, as this broadens their experience of social relationships and helps to keep them stimulated.

Many youth clubs offer inclusive activities for people with learning difficulties, while the activities available at Mencap's Gateway Clubs may be more suitable for those who do not feel comfortable in an integrated environment.

Other options include church youth clubs, sewing clubs, snooker clubs, cricket clubs etc. It is best to warn the club in advance about possible issues around food, and ensure that these can be addressed before your son or daughter starts to go there.

Continued ...

Social life and relationships

Making contact with others with PWS

Many young people with PWS find it helpful to communicate or mix with others with the syndrome. They realise that there are others who share the same experiences, and it helps them to come to terms with and have a better understanding of the syndrome.

Because of the rarity of the syndrome, it is often difficult to find another person with PWS in the locality, but many communicate as pen-pals through the PWSA UK, or meet up at PWSA-organised conferences, holidays or local meetings.

Facebook and similar social networking sites can be very helpful for the person with PWS to interact with people they would not normally meet, as are online interactive games. However, access requires careful monitoring and usually parental control.



Leisure interests and holidays (continued)

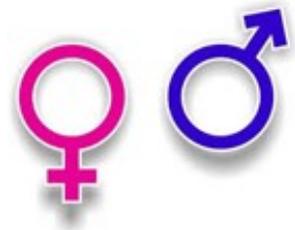
If necessary, a family member, friend or local volunteer could be enlisted to keep a friendly eye on them. You may need their help too, with transport.

There are many other activities in which teenagers may be encouraged to take an interest. These may include: walking, bowls, riding, swimming, dancing, darts, photography, typing, weaving, rug-making, voluntary work, helping the elderly, helping with playgroups, looking after pets, sewing, knitting, listening to music, and so on. Several people with PWS have completed award schemes such as the Duke of Edinburgh award.

It may also be useful to start thinking about introducing your son or daughter to the idea of being away from home by taking advantage of respite care or holidays offered by voluntary organisations.

Sexuality and sexual relationships

Because people with PWS do not develop fully sexually, and because the chances of having a child are slim, some parents may feel that "the facts of life" are irrelevant to their son or daughter with PWS.



However, people with the syndrome should be aware of how their bodies differ from those of other people, and also be able to consider a sexual relationship, and what the implications are, even if it is not for them. They will almost certainly have learned about sex at school.

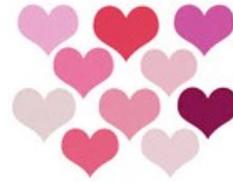
Little is known about the sexual relationships of people with PWS. In recent years, the growth of people with PWS living in specialist PWS residential homes has meant that more people with PWS have entered into relationships with others with the syndrome. Anecdotally, we know of other people with PWS who are in relationships with people who do not have the syndrome, although they usually have some other type of learning disability.

Information can be complicated by people with PWS claiming to have had a sexual relationship with another person when in fact their relationship has not extended beyond kissing and cuddling. Some people may say they are married, having a baby, or having sex with someone when it is manifestly not true.

This carries implications for investigations into sexual abuse. Whilst the person's allegations should be taken very seriously indeed because people with the syndrome are at special risk of being abused or exploited (and such cases have been proved), it should also be borne in mind that the person could be fantasizing, ignorant of the mechanics of sex, or even manipulating a situation to get their own way about something.

It is important for your son or daughter to be as well-informed as possible. They may have learned much about sex at school, but they should also understand how their body will develop slightly differently from most other people's. It is also important help your son or daughter to understand that they are unlikely to be able to have a baby - even if they get married. We know of women with PWS getting married, but none of a man with PWS getting married to date.

Sexuality and sexual relationships (continued)



However, at least four births to women with PWS have been reported worldwide (none in the UK). To date there have been no instances of a man with PWS fathering a baby. Due to the rather complicated genetics of the syndrome, there are varying chances of the baby either having Angelman syndrome where the mother has PWS, or Prader-Willi syndrome where the father has PWS.

It may be helpful to identify other people in your circle of family and friends who have not had babies, to show that it is quite normal not to have children. Some people are quite happy with the idea of being an uncle or aunt, or a special friend to a friend's baby.

Another reason to inform your son or daughter about sex and also about contraceptives, is the risk of sexual infection. They need to be able to recognise if they have a sexual infection, and to know that they can guard against infections by the use of condoms etc.

Some individuals may use sexual phrases and swear words in their everyday conversations and in writing. This can be very distressing to the person on the receiving end, but usually the person with PWS is unaware of the seriousness of their actions. Some people with the syndrome may become very obsessive about another individual. Those who persist in this type of behaviour may need sexual counselling from a professional counsellor with experience of people with learning disabilities.



In many ways, the level of sexual development of most people with PWS can be seen at a similar stage to that of an 8-12 year old child. There is a definite interest in sex, but some confusion as to what is entailed in it, and a low understanding of the responsibilities that go with it. Relationships are often made and broken within days, although long-term relationships are not unknown.

People with PWS are usually aware of their sexual identity as a male or female, but anecdotally there have been cases where a man with the syndrome feels that he would be happier as a woman - the lack of sexual development and the pseudo-breasts which are often associated with obesity mean that others may sometimes mistake a man with PWS for a woman. Treatment with male sex hormones may help, but again professional involvement should be sought.

Like most other people, though, people with PWS would like to have a relationship with a "special person" who loves them, and who loves them in return. Even if the relationship never goes beyond kissing and cuddling, it can still be a very important part of their life to the person.

Social life and relationships

Growing up with PWS

This resource, produced by PWSA UK, is a series of short, 3D animated, videos which explain various aspects of sex and relationships, as well as hygiene. The videos can be viewed separately as and when appropriate to the age, gender and understanding of the person with PWS. A set of notes for parents and carers accompanies the videos. The topics are:

- Introduction
- Growing up and body changes (male/female)
- Be safe online
- Menstruation and periods (girls and women)
- Growing up and feelings
- Keeping clean and fresh (male/female)
- Saying "No"
- Different types of relationships
- Adult relationships and saying "Yes"

<https://www.pwsa.co.uk/information-for-families/growing-up-animations>

Family Planning Association



The Family Planning Association has a section on their website for parents of children with learning disabilities:

<https://www.fpa.org.uk/advice-parents-and-carers/if-your-child-has-learning-disability>

PWSA UK

Suite 4.4 , Litchurch Plaza

Litchurch Lane

Derby DE24 8AA

T: 01332 365676

E: admin@pwsa.co.uk

W: www.pwsa.co.uk

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