

Social life and relationships

18—25 years



Introduction

People with PWS may often appear self-centred and not always interested in other people, but a good social life and learning the skills to handle relationships in a mature manner are very important to their self esteem and emotional development - as with all adults.



Family relationships

The family of an adult with PWS has spent many years assimilating and perhaps rejecting the particular difficulties of their relation with PWS. Certain patterns of behaviour within the

family become the norm, and these are very difficult to change.

There may be a tendency to continue to treat the person with PWS as a child "for their own good". Although people with PWS do not have a particularly mature attitude to life, and find it difficult to deal with many situations, they continue to develop in these areas just as the rest of us do, albeit more slowly than most. The rest of the family should therefore be prepared to adjust their perceptions of the person as they become older.

The law certainly recognises the rights of people with learning disabilities, and families may sometimes come into conflict with professionals over this issue.

Continued ...

Our Way of Life

*You may find it helpful to give your son or daughter **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.*

*There is also a workbook **Let's Talk about PWS** mainly aimed at children with PWS, but which may be at an appropriate level for your son or daughter.*



Family relationships (continued)

Family relationships can depend on whether the person with PWS is an only child, the eldest, the youngest, or anywhere in between. A person who is the oldest in the family may be expected to act in a more adult fashion than someone who has always been the baby of the family.

Brothers and sisters may feel jealous of the attention being given to the person with PWS (or vice versa), which can result in a great deal of tension within the family. It is important that everyone in the family feels special in their own special way.

Family milestones

As brothers and sisters leave home, go to college, get jobs, and perhaps get married, the person with PWS may begin to realise that some of these things may not happen to them, and may need a lot of support when these family events happen.

Stress should be placed on the value of the person with PWS to the family, such as their role as aunt or uncle to their brother or sister's children. People with PWS should also be encouraged to develop their own interests.

Social relationships

Many adults 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, especially if they feel under pressure.



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, eg 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

People 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.

Some people may feel comfortable in clubs for people with learning difficulties, such as the Gateway Clubs run by Mencap. Others may feel that they do not "fit in" with the intellectual levels of clubs for people with learning disabilities, and feel happier being involved in youth clubs, church fellowships, Women's Institutes, snooker clubs, cricket clubs, etc.

Of course, all clubs should be vetted for access to food, and a strategy for dealing with this agreed upon. If necessary, a family member, friend, or local volunteer could be enlisted to keep a friendly eye on your son or daughter.



There are, of course, many other activities which people with PWS enjoy, and which provide physical and mental stimulation. Here are just a few: walking, riding, swimming, dancing, snooker, darts, yoga, photography, typing, weaving, rug-making, voluntary work for environmental organisations,

helping the elderly, helping with play groups, looking after pets, sewing, knitting, listening to music, and of course, jigsaws and Wordsearch puzzles.

A holiday away from home can provide a real break for both your son or daughter and you, but it will need careful planning. There are some organisations which can provide a holiday for people with learning disabilities, but careful consideration needs to be given to the question of food intake.



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.

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.





Sexuality and sexual relationships

Because most 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.

It is important for your son or daughter to be as well-informed as possible, depending on their intellectual level and capacity to understand what sexual relationships mean. They may have learned much about sex at school, college or day centre, 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.

Another reason to inform your son or daughter about sex, and in particular 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.

People with PWS are usually aware of their sexual identity as a male or female, and how society reacts to that identity. People with PWS are just the same as everyone else in that they would like a "special person" who loves them, and who they can love 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.

Sexual relationships in PWS

Little is known about the sexual relationships of people with PWS. Many people with PWS embark on relationships when they move away from home, particularly when moving into a residential home, where they meet other people with PWS or other learning disabilities.



These relationships often involve engagements and marriage plans, but are often short-lived and may cause a great deal of distress to one partner who is not ready for the relationship to end, when the other decides to move on - usually to someone else in the same establishment. However, some relationships are stable and can provide both parties with a very supportive and loving relationship - much depends on the emotional development level of the parties involved.

There is no reliable data about what form these relationships take. 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.

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.

Marriage

Legally, someone with a learning disability has the same rights as anyone else to live with someone and get married, provided they are over 16, able to give their consent and understand what marriage is.



In the UK, we are aware of a few women with PWS getting married – usually to someone with another learning disability. In such situations, the couple usually live together within a supported living situation. We are not aware of a man with PWS getting married.

When marriage is realistically contemplated (as opposed to situations where it is unrealistic, as described on the previous page, the couple will need to show that they understand what marriage involves and that they are capable of consenting to it.

Fertility and pregnancy

Five 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.

Telling your son or daughter about the very slim chance of having a baby should be done as simply as possible; and 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.

Inappropriate behaviour

Some individuals may use sexual phrases and swear words in their everyday conversations and in letter-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. Specialist behaviour therapy should be sought if this is a persistent problem.

Some people with the syndrome may become very obsessive about another individual. Those who persist in this type of behaviour may need counselling from someone with experience of people with learning disabilities.

Social life and relationships

Literature for sex education

There is currently no PWS-specific literature for sex education. A general book recommended by one parent of a child with PWS are:

- *Talking together – about sex and relationships*

Both books are by Lorna Scott and Lesley-Kerr Edwards and are available from the Family Planning Association and Amazon.



The Family Planning Association also has a section on their website for parents of children with learning disabilities, which may also be appropriate for your adult son or daughter:

Sexual identity issues

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.

PWSA UK

Suite 4.4 , Litchurch Plaza

Litchurch Lane

Derby DE24 8AA

Tel 01332 365676

Fax 01332 360401

E: admin@pwsa.co.uk

W: www.pwsa.co.uk

Reg Charity No: 1155846

© PWSA UK