

## Telling your child about PWS



As with any other child, perhaps the best time to tell your child anything is when he starts asking questions, although some children may not do this.

Very young children may not understand much beyond the fact that if they eat too much they will get fat/unhealthy and will not be able to run around.

As time goes on, gradually introduce more information about PWS at a level your child will understand.

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 it is worthwhile bearing in mind that at some point they will have to know, and perhaps it is better to grow up with that knowledge, assimilating it gradually and at a pace which suits their development.

If they learn at a much later stage, it is often all at once and can come as a great shock and seriously upset your child's expectations of his future.

Whatever you tell your child, 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 him something negative as well.

It is also very important to keep his level of self-esteem high, so always praise him if he does something well, behaves well, or does something he has never done before.

You may find it helpful to use the workbook, **Let's Talk about PWS** <https://www.pwsa.co.uk/about-pws/publications/> when discussing PWS with your child.



**Note:**

**For ease of reading, the text refers to "he, him, his", but the details are equally relevant to girls, unless otherwise stated.**

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## Telling your child about sex, relationships and how his body develops

Your child will probably learn about sex in all the usual ways: from asking you, seeing programmes on television, from other children and from school. You may also find **Growing Up with PWS** (see below) a helpful resource.

Many schools introduce sex education programmes from an early age, but they do inform parents if they are going to do this. It may be helpful to contact the school to let them know about the ways in which people with PWS develop differently on a sexual level, and discuss how their lessons can be adjusted accordingly. This may be something as simple as introducing the idea that not everyone can have babies. (Note, though, that worldwide there have been at least 4 reports of women with PWS having babies).

If your child asks about sex, try to give simple, truthful answers. It is important that he gains a balanced view of how he will fit into the adult world. He still needs love and cuddles and the opportunity to develop close relationships with other people. You also try to make him aware of “stranger danger” and what is acceptable behaviour and what is not.

### Growing Up with PWS

This resource, produced by PWSA UK, is a series of short, 3D animated, videos which explain simply some of the body changes which a person with PWS may, or may not, undergo, as well as various aspects of sex and relationships. 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 (girls and women)
- Growing up and body changes (men)
- Be safe online
- Menstruation and periods (girls and women)
- Growing up and feelings
- Keeping clean and fresh (girls and women)
- Keeping clean and fresh (men)
- Saying “No”
- Different types of relationships
- Adult relationships and saying “Yes”

You can find Growing Up with PWS on our website <https://www.pwsa.co.uk/information-for-families/growing-up-animations>