

Coming to terms with the diagnosis



Introduction

All parents and family members have varying emotional responses to the diagnosis, but all of them are natural.

You may not be feeling the same as your partner, or your child's grandparents, but everyone's feelings are just as valid.

It may take a while for you to come to terms with your own feelings about the diagnosis, and they may well change over time, going through different stages. You may be able to identify with some or all of the feelings described in this article.

Our knowledge of PWS is growing all the time and in the years since it was first recognised, treatments such as growth hormone therapy are now available which make our children's lives so much better.

With research continuing, it is likely that other aspects of PWS will eventually become treatable, so it is important to bear these positive messages for the future in mind.

You may also find support groups and online forums very helpful in coming to terms with the diagnosis. You'll find details of these in **Useful Agencies and Websites**. <https://www.pwsa.co.uk/assets/files/useful-agencies-children.pdf>

In the following pages we will explore some of the very natural reactions you may experience when your child is given a diagnosis of PWS. Remember, we are always here to help if you would like a friendly chat about your feelings or just a listening ear.

A different journey



There is a wonderful short essay written by Emily Perl Kingsley in 1987 which is often used by special needs advisers and organisations to help parents come to terms with this different journey which they find themselves on. It is called "Welcome to Holland!" and you can read it at www.our-kids.org/Archives/Holland.html



Grief

You may feel that your hopes for your child's future have suddenly been shattered and feel grief for what your child might have been or done in their life. You will need to come to terms with the knowledge that you and your child are now going down a different road to the one you had envisaged.

Depression

Perhaps you feel depressed at the thought of what the future holds, or suspect that you will be unable to cope. If these thoughts have occurred just after your baby was born, it may be difficult to tell whether your depression results from hormonal changes after pregnancy (and would have occurred even if your baby did not have PWS), or the fact that your baby has PWS – or both. Your GP or health visitor can offer practical help and advice. Depression usually passes fairly quickly, but if it persists, do discuss your feelings with your GP.

Anger and bewilderment

You may feel angry, confused or bewildered that things have turned out differently from what you had expected. “Why, of all the people in the world, did it have to happen to me?”

Guilt

You may feel guilty that PWS has occurred because of something that you or your partner did or did not do before you conceived or while you were pregnant. You may feel that it is a kind of “punishment” for something you did in the past. Our current knowledge is that no-one is to blame; nor could PWS have been prevented.



Disbelief

You may experience a feeling of disbelief. “How can they say there is anything wrong with my child? How do they know? He'll be OK once he (or she) gets older.” Sometimes one parent may be feeling this, whilst the other is more accepting of the diagnosis. This seems to be a particularly common feeling amongst grandparents and other family members. Sometimes many years will pass before the diagnosis is fully accepted.

Rejection

Some parents experience a feeling of rejection of their child, particularly if the diagnosis occurs soon after birth. Labour may have been very difficult, or by Caesarean section. The baby is not crying, not wanting to be fed, and is probably in a special care unit. Initial bonding with your child may thus be difficult, and the shock of diagnosis can make things much worse. Hospital or medical personnel will be aware of this possibility and will generally take steps to offer counselling, advice or practical help if you explain your feelings to them.

Relief and justification

If the diagnosis has come several months after your child was born, you may have always suspected there was something different about your child, and that you are not just an “anxious parent”. It also means that having the diagnosis can open gateways to the specialist care your child needs.

Sharing your feelings

If you are having difficulties with coming to terms with your feelings, and you think they are having a negative effect on you, your child, or other family members, a trained counsellor may be available through your GP.

However, it is often parents of other children with disabilities – not just PWS – who can offer the understanding and sympathy you may need; many will have struggled with the same feelings as you. See **Useful Agencies and Websites** <https://www.pwsa.co.uk/assets/files/useful-agencies-children.pdf> for information about organisations who can help.

The PWSA UK also runs special events for parents from time to time in different areas of the country. If you are a member of the Association or have signed up for our weekly e-News, **Instant News**, we will notify you of any that are happening in your area, but you can also visit our website www.pwsa.co.uk for details of events across the UK. (You can sign up for Instant News on our website too.)

You can also read about how other parents of babies with PWS came to terms with the diagnosis in the PWSA UK booklet, **Our Babies** <https://www.pwsa.co.uk/about-pws/publications/>



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Some quotes from other parents

“I don’t like to say there’s something wrong with my son, he’s just different.”

“We’re sure everyone who comes into contact with our little girl benefits. When things get difficult sometimes, we look at her smile or watch her while she sleeps, and we know we have been given a very special person. She may need lots of time and patience, but we all get so much back.”

“We’ve had to deal with more emotions during the first months of our baby’s life than many parents face in a lifetime. You’ve got to take care that PWS doesn’t overtake your child’s individuality, and become the most important thing about them. We’re just happy to have such a loving, beautiful baby who we will never take for-granted. And so far the smiles have far outweighed the tears.”



Mis-diagnosis

A wrong or mis-diagnosis can occur, but it is quite rare, and even less likely these days with sophisticated genetic testing techniques. However if, as your child gets older, he shows traits markedly different from those you would expect in someone with PWS, you should raise your doubts with your child’s consultant and ask for further testing.

Thinking about the future

It can be difficult to keep yourself from thinking about the future and, of course, it is very sensible to think about what may happen in the years ahead and to make provision for it; although as time goes by there will be new developments and changes.

One of the most important developments in recent years has been growth hormone treatment, which has transformed the physical appearance of children and adults with PWS. As more research is carried out, we can expect new treatments for other aspects of PWS as well.

So it is important to be able to maintain a balance. It can be difficult to appreciate and help your child now, if you are always worrying about what he or she will be like when they grow up. If you can build on your child's strengths and support their weaknesses, your child has a much better chance of a happy adult life than if you do nothing but worry.



A quote from a parent

“Caring for my daughter was a completely different world to the one I had been preparing for during my pregnancy and all the rules were different. But I’ve found it to be a rewarding world where the achievements are greater, and just to see her cheeky smile fills me with the greatest pleasure

possible. I no longer mind the challenges I face. I’ve also gained confidence and a respect from others I didn’t have before.”

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