

Developing your child's potential 5–10 years



Introduction

Even though your child will now be at school, it is still important to educate and stimulate him in the home environment, introducing him to various different activities.

Many children with PWS love organised activities such as Brownies or Cubs – provided there is a sympathetic and understanding leader. Other activities such as drama, music or dance groups, going swimming or to a football or other sports match with other family members or friends are all of great benefit – just as they are to all children.

Physical development and growth hormone treatment

Keep up your child's exercise programme, but make sure it is fun for him, or he will lose interest. Any sort of activity is helping to develop muscles and burn up energy, and should become part of the daily routine. Possible activities are many and various: playing chase games, bike or trike riding, jumping on trampoline, Nintendo Wii and similar games machines, climbing frames etc. Sometimes you will find that you need to put in a lot of encouragement to get your child to exercise, but the more he does, the easier it will become for him.

Those receiving growth hormone treatment should have fewer problems with low muscle tone, and hence physical abilities may be better. If your child is not receiving growth hormone treatment, and you think they are not growing at the same rate as other children of their age, or their muscle tone is particularly low, ask your paediatrician or GP for advice.

You can find out more about growth hormone treatment in the information sheets included **Growth Hormone therapy in Prader-Willi Syndrome – UK practice** <https://www.pwsa.co.uk/assets/files/GHT-UK-Practice.pdf> and **Growth Hormone for children with PWS** <https://www.pwsa.co.uk/assets/files/GHT.pdf>



Note:

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

Encouraging and motivating

Continue to encourage and motivate your child throughout his school life, and praise even the smallest achievements.

Like all children, children with PWS thrive on praise and cuddles. Always be aware of your child's strengths and weaknesses.

Children with PWS have a lot to teach us about being a parent, so do not forget they are helping you to reach your potential too.



Helping your child's general development and behaviour

Whatever your child's general level of ability, it is important to try to stretch him that little bit further. However, it is equally important that you do not try to make him attempt more than he is capable of doing. He will soon give up or refuse to do something if he is pushed too hard.

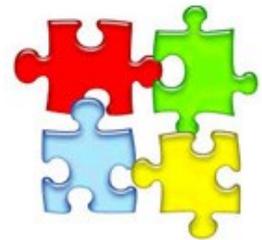
Children with PWS can be very set in the way they think about or react to things. You can help your child become more adaptable by helping him to understand that life is never "black or white". Offer simple choices, such as "Do you want to wear your red jumper or your blue jumper today?" Talk through situations where the outcome is unpredictable, e.g. "If grandma isn't in when we arrive, we will go for a walk."

There can be a positive side to your child's rigid thought patterns, in that you can use these to instil in him some good habits. If he gets used to doing things in certain ways, then there is a likelihood that he will always do them like that – particularly if you praise him when he behaves well.

Do not make a habit of using food for a reward, although in exceptional circumstances you might want to do this – much depends on your individual circumstances, and your child's attitude to food. Generally speaking, smiles and cuddles are of far more value, and do not have any calories.

Reading is often a relative strength in children with PWS, although some will struggle. You can help your child by reading to him and looking at books together and going to free library sessions for children.

Maths and number work may be a difficult area, so help your child to learn about numbers by counting lots of different objects in daily life, or by counting objects in books, and counting how many are left over if you cover some up.



Help to improve your child's memory skills by playing children's versions of the card games "Pelmanism" or "Pairs" and by singing songs and nursery rhymes together.

Your child may well show an aptitude for jigsaw puzzles. Do praise him if he has this ability, or any other special skill, as it will help to raise his self-esteem. Your child may also enjoy playing educational games on computers, tablets etc.

Managing appetite

Most children will have begun to display a greater interest in food by the time they reach five years old, although in some this still may not be evident. Carry on, or begin, teaching your child about a healthy diet and put into practice some of the ideas you will find in **Dietary Management** <https://www.pwsa.co.uk/assets/files/Diet-5-10.pdf> Activity and mental and physical stimulation are now even more important, as they will help to keep your child's mind off his next meal.

Your child's relationships with others

Children with PWS often find it difficult to learn social skills such as taking turns, waiting until another person has finished speaking, or listening to what another person has to say.

There are lots of ways you can help develop these skills, such as:

- Playing turn-taking games such as board games
- Gently reminding him to “Wait until so-and-so has finished speaking, and then you can have your say.”
- Playing imaginary role games like doctor and patient, shopkeepers, TV interviewers etc.

Many children with PWS seem to relate better to adults or younger children. This is possibly because adults are more likely to be patient with them and give them more attention than their peers. Younger children are more likely to follow orders, as many children with PWS like to “lay down the rules”.

However, it is important to encourage friendships at school and invite school friends around to play. This may help other children understand your child's special needs, as well as giving you child extra stimulation and exercise.



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Challenging behaviour

There are a few children with PWS who begin to display challenging behaviour at this age. If you are concerned about your child's behaviour, or its effect on you and your family, contact your GP, social services or paediatrician for advice and possible referral to a Child and Family Therapist service or similar. The article on **Behaviour Management** <https://www.pwsa.co.uk/assets/files/Behaviour-children.pdf> may be helpful.

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