

Developing your child's potential and preparing for school 2–5 years



Introduction

There are many things you can do to help your child make the most of his abilities. All parents have periods of feeling down or depressed about their child's future, but you can help to make that future better for your child by supporting him to cope with the problems of PWS while he is still young. If your child was diagnosed early you should already be receiving plenty of help from your paediatrician, health visitor, speech therapist, play development specialist, physiotherapist, etc. However, facilities do vary considerably between areas, and you may have to do your own research to discover what is on offer, especially for services provided by voluntary organisations. Your local

library or special needs development services may prove good sources of information.

Developmental milestones

There is no set age when babies with PWS reach developmental milestones, but, generally speaking, they are as follows:

- **Sitting unaided** – 12 months or longer
- **Walking** – 19 months or longer
- **Speech** – variable, may not start till 3 years or later

If you have concerns about your child's development in any of these areas, discuss them with your paediatrician or GP. Your child may have individual reasons, possibly unrelated to PWS, for his developmental delay.

Potty training

Potty training techniques used with all babies should also work for babies with PWS, although they may take longer. But if you are having particular difficulties, contact the PWSA UK office for further information.



Note:

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

Child development services and Portage

Most areas of the country have a service whereby a child development specialist will come to your home to help you devise a tailor-made plan for your child's development and an independent service known as Portage is available in many areas.

www.portage.org.uk

The service might include play ideas to stimulate mental action, and simple exercises or physiotherapy to strengthen your child's muscles and help him to go on to new milestones.



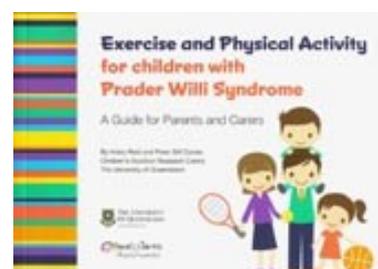
Physical development and exercise

Your child will continue to need encouragement with physical activities, even though he may well be walking by now. 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 in this pack.

Children can be helped to learn to run, jump, hop, skip or ride a bike. A lot of patience and positive encouragement may be needed, but the advantage of being able to move more quickly and easily will help considerably in keeping his weight within reasonable limits, as well as making it easier for him to join in with other children's play. Toddler gyms can be helpful if the instructors are understanding of your child's capabilities.

You can download a helpful booklet, produced in Australia, from our website: Exercise and Physical Activity for Children with Prader-Willi Syndrome - A guide for parents and carers which gives lots more information and ideas: http://media.wix.com/ugd/a71d4c_083a2139228f42ceada273ffb128308f.pdf



Water play and swimming

Most children like activities in water, and children with PWS are no different. Almost all children with PWS love swimming and even very young babies can benefit from sessions in the teaching pool or special hydrotherapy pools.

How you can help your child's development

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 the leaflet about dietary management that you will find enclosed with this pack. 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.



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?"

How you can help your child's development (continued)

Talk through situations where the outcome is unpredictable, e.g. "If grandma isn't in when we arrive, we will go for a walk."

Simple colouring, tracing over wavy lines, and very simple dot-to-dots can help with pencil skills and number work – preparing the ground for when your child starts school.

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 simple 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, and as you read to him.



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.

Playdoh type products can help develop muscles in your child's hands, but it is not a good idea to use this if your child shows a tendency to eat non-food products.

Behaviour management

Most children of this age have behaviour which is not so different from that of other children without PWS. One important thing to remember is not to give in to demands from temper tantrums – this is merely rewarding bad behaviour and if you do give in, it may well cause you problems later in your child's life.

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. Contact the PWSA UK office for a free leaflet on Behaviour Management from or download it from the PWSA UK website.

You might also find **The Challenging Behaviour Foundation** helpful for information and support. See **Useful Agencies and Websites** <https://www.pwsa.co.uk/assets/files/useful-agencies-children.pdf> for contact details.



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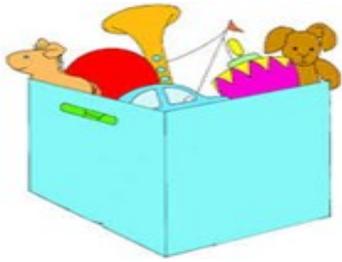
Positivity and praise

There can be a positive side to your child's rigid thought patterns, in that you can use these to instill 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.



Child-minders, playgroups and nurseries

If your child is not already in nursery or playgroup, it is a good idea to start looking around now. Going to nursery will help your child's social skills and be a good preparation for school life.

If you wish to place your child with child-minders, or in a playgroup or nursery, you can search on the internet for suitable special needs placements in your area, or ask your health visitor or child development centre. You should research all the possibilities thoroughly, particularly about how the child-minder or nursery can manage your child's dietary needs within the context of other children – many will already have a “healthy eating” policy in place, or would be willing to adopt one.

Many parents take their children to ordinary local play groups and nurseries and, on the whole, this can work well, as long as the playgroup leader and helpers are prepared to understand and accommodate the need for special rules with regard to food. For example, make sure low calorie squash or semi-skimmed milk is available – even if you have to bring it yourself.

Other parents prefer to take their children to playgroups for children with special needs. Both types of playgroup can work well. In an ordinary group there is more chance for your child to learn to integrate into other children's play and games, whilst in a special needs group there is less competition and more attention, and a chance to share experiences with other sympathetic parents.

Information for nursery and primary school staff

Information for Nursery Staff is useful to give to your child's nursery <https://www.pwsa.co.uk/assets/files/Nursery-staff.pdf> and **Information for Primary School staff** to give to your child's school. <https://www.pwsa.co.uk/assets/files/primary-staff.pdf>



Preparing for school and the EHC plan

Generally speaking it is very important for children with PWS to have an Education, Health and Care Plan (EHC), or its equivalent in Scotland, Wales and Northern Ireland, even if they appear to be doing well – their special needs around food will impact on their educational environment.

Usually professionals already involved with your child will be able to advise you on procedures in your area and how to go about getting an Education, Health and Care plan (EHC), or equivalent, for your child, but you can also contact the Local Authority (LA) yourself to request an assessment.

An assessment is the first step to getting an EHC plan. The law says that a child must have an EHC plan if they have, or may have, special educational needs. The assessment is an investigation into your child's health, care and educational needs and is carried out by your LA.

After the assessment, the LA must write to tell you whether or not they are going to make an EHC Plan, with reasons for the decision.

Continued ...

Preparing for school and the EHC plan (continued)

If the LA are not going to make a plan they must write to you within 16 weeks to tell you this. You will have the right to appeal and the LA must give you information about this.

The organisations mentioned in the box on the right can help with the appeal, or you can contact PWSA UK for specific advice about how the syndrome affects, or might affect, your child.

* EHCs are replacing Statements of Educational Needs in England.



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Organisations providing information and support about special needs education

Contact a Family
(0808 808 3555)

[https://
contact.org.uk/](https://contact.org.uk/)
produce some excellent factsheets on special educational needs for children in England, Scotland, Wales and Northern Ireland (procedures and policies vary in each country).

You can also get information from IPSEA (Independent Parental Special Education Advice)
www.ipsea.org.uk

and from SOS!SEN (Independent Helpline for Special Educational Needs) 0300 302 3731
<https://sossen.org.uk/>

PWSA UK
Suite 4.4
Litchurch Plaza
Litchurch Lane
Derby DE24 8AA

01332 365676
admin@pwsa.co.uk
www.pwsa.co.uk

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Finding the right school



Because children with PWS vary so much in their abilities, it is important to remember that a school that is right for one child with PWS may not be right for another. It is up to you and your LA to decide which will be best for your child.

Most schools are only too pleased to show parents of prospective pupils around and, if possible, you should take advantage of this to get an idea of the general "feel" of the place.

If you are unsure whether mainstream, a unit attached to mainstream, or a special school is right for your child, look at all the available options, and in doing so it may be useful to consider some of the points below:

- What do the educational abilities of the other pupils appear to be? Are they about the same level as your child's?
- Are the classrooms bright and welcoming?
- Are the teachers interested in what you have to say?
- Would the level of support be sufficient to meet the needs of your child, including at break and lunch times?
- Has the school any previous experience of a child with PWS and, if so, was the experience a successful one?
- Are they willing to read literature or learn more about PWS?
- Is the school willing to adapt to your child's dietary needs?
- Are there facilities for children with disabilities, such as adapted toilets, ramps etc.?
- Practical considerations such as distance from home may enter into things, although, if necessary, most areas will provide a taxi/escort service.

