

## Your child at school 5–10 years



### Introduction

It should be borne in mind that each child with PWS is an individual, and one child will have varying abilities from another.

It is essential that each child is assessed as an individual in order to reach their full potential, but some account should also be taken of the effects which Prader-Willi syndrome will bring into that child's life.

In **England**, ideally your child should have started school with an Education, Health and Care (EHC) Plan, which can be issued for any child or young person between 0 and 25 years of age. This can provide him with additional support hours. EHC plans were introduced via the Children and Families Act 2014 in September 2014.

### Every child with PWS has different abilities.

You can show the PWSA UK leaflet **Information for Primary School Staff** <https://www.pwsa.co.uk/assets/files/primary-staff.pdf> to potential schools for their guidance. It tells them about the dietary and other management needs of children with PWS, but you should also provide them with specific information which is individual to your child.

### Statement of Need

If your child already has a Statement of Need from the previous system, there will be a transition period until an EHC Plan comes into force.

You can find more details about this at <https://contact.org.uk/advice-and-support/sen-national-advice-service/changing-from-the-old-system-to-the-new/>



#### Note:

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

### Scotland, Wales and Northern Ireland

Contact a Family have a range of leaflets to advise parents in Scotland, Wales and Northern Ireland about the systems for special educational needs in those countries, which are all slightly different from arrangements in England:

**Wales:**  
<https://contact.org.uk/media/380068/senwales.pdf>

**Scotland:**  
<https://contact.org.uk/media/359976/additionalsupportlearningscotland.pdf>

**Northern Ireland:**  
<https://contact.org.uk/media/380065/senni.pdf>

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## The EHC Plan in England: Key Principles



The key principles of the EHC plan are as follows:

- The local authority and other agencies must involve families in preparing the plan.
  - EHC plans should describe what the child or young person can do or has achieved.
  - EHC plans should be clear, concise, and understandable to everyone.
  - The LA must consider how the outcomes can best be achieved, and must take into account the evidence from the EHC needs assessment.
- EHC plans must specify the outcomes the child or young person wants and needs to achieve. An outcome is the positive difference the support will make to a person.
  - Planning should include support and advice for families about alternative ways of receiving support, for example, through a personal budget.
  - EHC plans should show how education, health and care will work together and support the young person to achieve their outcomes.
  - EHC plans should include plans for the future – for example planning for transition to adulthood.



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### More information and help with EHC Plans

Contact a Family <https://contact.org.uk/> have a good advisory service to help with getting your child the right support at school, with lots of information about assessments and EHC Plans, and can also advise on the situation in Wales, Northern Ireland and Scotland. Other helpful organisations for anything to do with education are IPSEA <https://www.ipsea.org.uk/> and SOS!SEN <https://sossen.org.uk/>



### Getting an EHC Plan in England

The first step towards getting an EHC Plan is for your child to have an EHC needs assessment. You or your child's school, or other professionals working with you and your child can request this in writing at any age from your local authority (LA). Each LA may have a slightly different process, but they must all follow the basic requirements of assessment.

The LA must then write to you within six weeks to tell you if they are going to go ahead with an assessment. You have the right to appeal if they decide not to assess him. If the assessment is agreed, then information will be gathered from you, your child's school, health and social care professionals, and others whose input may be considered reasonable. This information should be provided within six weeks. The LA must then write to tell you whether they are going to make an EHC Plan. If they are not, they must tell you this within 16 weeks.

If the LA decide to make an EHC plan, they should provide you with a draft plan and then a final plan within 20 weeks of the initial request.

## Choosing the right school for your child

Your LA will inform you about schools in your area. You can also learn about these from other parents of special needs children. You should visit all the possible schools and check if they can meet your child's needs.

It is very important that a clear understanding of what PWS entails is available to everyone involved from the very beginning of your child's education, so that the school can make any necessary adjustments to the environment or teaching methods.

They may have already taught a child with PWS before, but this does not necessarily mean the school is right for **your** child.



## Your child at school

### Mainstream or special school?

Many children with PWS start their education in mainstream primary, with varying degrees of support. Others will begin their education in special needs schools.

Because of the range of ability in PWS, each child's schooling needs will differ from another's.

Surveys of schooling of children with PWS carried out by PWSA UK in the past have seen that there is a marked rise in attendance at special schools as age increases.

Nevertheless, there is a significant minority of youngsters with PWS who do very well in mainstream school and have achieved several GCSE passes

## Your child at school



It is important to maintain a good relationship with your child's school, and address any concerns early on. A home-school diary is a good way of doing this.

If you feel that your child's school is no longer meeting his needs, you should request a review to address your concerns and to consider whether he might be better placed in another school.

### Access to food

Make sure all school staff, including office staff, transport escorts, caretakers, and dinner ladies and playtime supervisors, are aware of the need to control access to food. The leaflet **Information for Primary School Staff**, <https://www.pwsa.co.uk/assets/files/primary-staff.pdf> can be used to let them know why this is so essential.

### Classroom support

It is important to ensure you have sufficient hours of classroom support. If you feel that your child needs more classroom support, you can request a review and provide a detailed log which should include the following information:

- Is the class being disrupted by your child - how often, how long for etc.?
- Is your child being limited in access to education because of lack of support - how, when?
- What is your child like at playtime and lunchtime? Is extra support required at these times - how long for?

Continued ...

## We are here to help

**Most children with PWS are very happy at school when the environment is right. But if you are concerned about your child and/or the school, please call our PWSA Support Team who will be pleased to offer guidance on how you could address the situation.**

### PWSA UK

**Suite 4.4 , Litchurch Plaza**

**Litchurch Lane  
Derby DE24 8AA**

**T: 01332 365676**

**E: [admin@pwsa.co.uk](mailto:admin@pwsa.co.uk)**

**W: [www.pwsa.co.uk](http://www.pwsa.co.uk)**

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## Your child at school (continued)

### Special occasions

Agree with the school beforehand how special occasions will be handled. If the class is going on an outing, or if the class is celebrating a child's birthday, it is not necessary to exclude your child on account of his special dietary needs.



You may wish for him to have special lower calorie treats or food provided by yourself, or for your child to be given a small portion of the treat as long as you are informed and can make adjustments to his meal when he comes home.

### Free Telephone Legal Advice Service – Special Education

Education Lawyers at **Langley Wellington LLP Solicitors** offer a free initial telephone advice surgery to families of children with Prader-Willi Syndrome.

Their telephone appointments last up to 30 minutes and they can provide information about the relevant law, how it applies to your child and appropriate next steps/options for you to consider relating to:-

- Special Educational needs for children between 0-25 years  
The Education, Health and Care Needs Assessment process from start to finish
- Transfer from Statements of Special Educational Needs to Education, Health and Care Plans
- Education, Health and Care Plans
- Appeals to the Special Educational Needs and Disability Tribunal
- Choosing an appropriate school

If you would like to take advantage of this service, please contact **Education Lawyers** on 01452 555166 or go to [www.educationlawyers.co.uk](http://www.educationlawyers.co.uk)