

Your child at school 10 to 13 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 articles, **Information for Primary School Staff** <https://www.pwsa.co.uk/assets/files/primary-staff.pdf> or **Information for Secondary School Staff** <https://www.pwsa.co.uk/assets/files/Secondary-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.



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>

The EHC Plan in England: Key Principles



Photo by Kate Lloyd
Photography

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.



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

Many children with PWS start their formal education in mainstream primary, with varying degrees of support – anything from 5 hours a week to full-time. Others will begin their education in special needs schools.



Occasionally, other types of school may be attended: speech and language disorders, autism spectrum disorders, or physical disabilities. 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 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 achieve several GCSE passes.

Transition to secondary school



Your child may be well-suited to his current school, but the transition to senior or middle school can present with difficult choices. Some children have successfully transferred to mainstream secondary, but others have found this a difficult step to take, and careful planning needs to be carried out to ensure success. Besides any need for educational support, several

factors should be taken into account:

- Is the level of classroom support adequate to ensure that temper outbursts, which may increase in the teenage years, can be handled with minimum disruption to the rest of the class?
- Is the level of support adequate to ensure that your child will not have easy access to self-service catering, tuck-shops, vending-machines and other pupils' school bags and lunch-boxes?
- Does the journey to and from school include possible opportunities for obtaining food from shops, cafes and petrol stations? (some older children with PWS will unfortunately take food from shops without paying for it)
- Is the school spread over several buildings and locations, or does it have a large number of steps and stairs? If so, can the timetable be arranged so that lessons are held in classrooms close to one another, or can allowances be made for your child potentially arriving late in class, due to the slowness with which many children habitually move, or other physical disabilities they may have.

Continued ...

Your child at school

Residential schools

A small minority of children with PWS find it difficult to access local schooling provision once they reach secondary level, usually because of the behavioural and dietary management aspects of the syndrome.

Although there are no residential schools specifically for people with PWS, some have experience in managing pupils with the syndrome. A list of these schools is available from the PWSA UK.



Photo by Kate Lloyd Photography

Transition to secondary school (continued)

- Does the school have an 'ethos' of consideration for children with special needs?
- Does the school have a robust anti-bullying policy?
- Is sex education handled in a sympathetic way?

- Different information may need to be given to children with PWS about how their bodies will develop. See **Telling your child about PWS** <https://www.pwsa.co.uk/assets/files/15-Telling-your-child-about-PWS-generic.pdf> for details of a video resource **Growing Up with PWS** which could be helpful in this respect.

Classroom support

It is important to ensure your child has 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?

Information for school staff

You can show the PWSA UK leaflets, **Information for Primary School Staff** <https://www.pwsa.co.uk/assets/files/primary-staff.pdf> and **Information for Secondary School Staff** <https://www.pwsa.co.uk/assets/files/Secondary-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.

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 very useful tool, even for older children and teenagers, as some children with PWS are very good at manipulating one person against other (e.g. coming to school and telling the teacher that they have had no breakfast, and can therefore have more lunch).

However, some parents have reported that their child reads everything in the diary, which can cause problems - or they hide or destroy the book. In such cases, liaison could be carried out by email, text or phone once the child has left for home.

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.



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.

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 leaflets mentioned on the previous page can be used to let them know why this is so essential.

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

Your child at school

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.

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