

Your teenager at school 13 to 18 years



Photo by Kate Lloyd Photography

Introduction

It should be borne in mind that each person with PWS is an individual, and one person will have varying abilities from another. It is essential that each young person 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 person's life.

In **England**, ideally your son or daughter 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 person with PWS has different abilities.

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

Statement of Need

If your son or daughter 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>



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.

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.

Secondary school

Some young people have successfully transferred to mainstream secondary, but others have found this a difficult step to take. If there are problems at your son or daughter's current mainstream school, consider if any of the following are contributing to those.



- 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 son or daughter will not have easy access to self-service catering, vending machines, tuck-shops, 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 young people 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? Is this causing problems with lateness or mobility? 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 son or daughter potentially arriving late in class, due to the slowness with which they move, or other physical disabilities they may have.
- Does the school have an 'ethos' of consideration for teenagers 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 teenagers with PWS about how their bodies will develop. The 3D animation video resource **Growing Up with PWS** which could be helpful in this respect. <https://www.pwsa.co.uk/information-for-families/growing-up-animations>

If these issues cannot be addressed, then it might be best to look for another, more appropriate, school.

Residential schools

A small minority of young people 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 and further education colleges is available from the PWSA UK.

Your teenager at school

Choosing the right school

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.



Your teenager at school

It is important to maintain a good relationship with your son or daughter's school, and address any concerns early on. A home-school diary is a very useful tool, even for teenagers, as some youngsters with PWS are very good at manipulating one person against another (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 son or daughter 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 teenager has left for home.

If you feel that your son or daughter's school is no longer meeting their needs, you should request a review to address your concerns and to consider whether they might be better placed in another school.

Classroom support

It is important to ensure you have sufficient hours of classroom support. When making an application to the LEA for classroom support it is important to include a detailed log which should include the following information:

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

Further or higher education

The main educational options after the age of 16 are:

- to continue at school
- local college of further education
- specialist college, as either a residential or day student.
- See the article **Further Education and Options after School** <https://www.pwsa.co.uk/assets/files/options-after-school.pdf> for more information.

Managing your son or daughter's expectations

Most schools, especially mainstream, are keen for their pupils to do well academically and positively encourage pupils to reach high grades in their exams.

Whilst many people with PWS are able to obtain GCSEs and the like, they may be expecting to get A* grades, as that is what the school is promoting.

It's important to work positively with the young person to help them to realise that some occupations (e.g. doctor, teacher) may not be possible, but that work in a lesser position in the same field is just as valuable.



We are here to help

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



Your teenager at school

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

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