

# Education, work and training 18–25 years



## Introduction

There are many ways in which a person with PWS can continue their education after they have left school, either to reinforce knowledge already learned, or to learn new skills. Your son or daughter's EHC Plan, if they have one, still applies up to the age of 25. You can find out more about this from Contact a Family at <https://contact.org.uk/advice-and-support/education-learning/education-beyond-16/>

## Further or Higher Education

The main options after the age of 18 are:

- to continue at school until age 19
- local college of further education
- specialist college, as either a residential or day student.

## General considerations regarding going to college

It might be helpful to consider the following questions:

- What does he hope to achieve by going to college?
- Has he discussed his ideas with a Careers Advisor for people with disabilities?
- Has he had any work experience in the chosen area of interest?
- Can the college offer a programme in the chosen area of interest and at the appropriate level?
- Does he also want to gain independence, social skills, and practice taking more responsibility? Should this be included in his programme?
- What previous support arrangements has he had? What has worked most successfully for him?
- How will he travel to and from college? Has he had experience of traveling independently?



**Note: For ease of reading, the text sometimes refers to “he, him, his”, but the details are equally relevant to girls, unless otherwise stated.**

## “Full time” college courses

You may be surprised to learn that a “full-time course” at a FE (Further Education) college is not Monday – Friday, all day. It may be that the course is only on for two days a week, or for a shorter period of time each day.

The “full time” basis refers to funding, not attendance. Also holidays tend to be longer than school holidays, so you may need to think carefully about finding additional activities or caring resources for the remainder of the week.



## Residential colleges

There are a few residential colleges in England and Wales who are willing and able to make provision for people with PWS. The PWSA UK maintains a short list of those colleges we are aware of who have had experience of PWS, but makes no recommendations. A Directory of National Specialist Colleges is published by NATSPEC <https://natspec.org.uk/>

### Funding for residential or specialist colleges

For detailed information about applying to go to a specialist college and EHC Plans, see <https://natspec.org.uk/families-and-students/applying-for-a-place/>

With regard to funding, Natspec say:

*“For students with high needs (with support costs over £6,000), funding comes from two organisations, the Education and Skills Funding Agency, which pays for place funding (sometimes called Elements 1 and 2), and the Local Authority, which pays the remaining support costs, sometimes called top-up funding or Element 3.*

*Each local authority will have its own approach to the funding process; for example they will have their own forms and policies. They must include this in their Local Offer. The Local Offer should be on your local authority’s website.*

*The discussion about the funding is usually between the college and the local authority. However, you may get involved in some of the discussions about the details of the learning programme and the type of support that is needed.”*

### Challenges and dilemmas: Essential requirements for colleges



When looking at whether a college is appropriate - whether local or residential - it might be helpful to inform the college that the following requirements are very important. Can the college provide them?

- Staff awareness of PWS: the nature of the syndrome, physiological and psychological, and how this impacts on dietary and behavioural issues.
- Tight structure. Controlled access to food. It is unlikely that the person with PWS will be able to cope without external support to provide the necessary controls. Without this, battles over food will always be the presenting issue, preventing staff and student moving beyond this in terms of social and emotional development.
- Leisure facilities, good range of activities and options available to the student. Structured supported access, whilst allowing the student to experience a feeling of independence.
- Curriculum. A full timetable allows less opportunity to dwell on food issues.
- Very clear agreements, with both positive and negative consequences detailed. If you don’t have this, the student is unable to make informed choices about their behaviour, and they will not be aware of the consequences of behaviour.
- Access to the wider community, developing and practising skills in real life situations.

### Considerations about residential options

When considering a residential college, you will probably find it helpful to think about the following topics, and ask the college if you are unsure about their stance on any of these issues.

- What guidelines/boundaries are to be agreed about access to food?
- Is cooking, shopping and budgeting for meals an option? If so, how often will this happen, and how will it be supervised or managed?
- What problems might be presented by eating in the college canteen? Would it be preferable/possible to eat in a smaller group or individual setting?
- What if agreed guidelines on food management are broken? What outcomes would be most helpful?
- Will your son or daughter agree to regular weight checks by the college (by someone they trust, or a keyworker, for example)? If not, what alternative arrangements, if any, should be made?
- What supervision is required when away from the college site?
- What strategies which you have found helpful in the past might be put in place from the start at college to help with managing behaviour difficulties?
- If there is a risk of harming self or others, what strategies would staff at the college need to adopt to manage the situation?



- Is your son or daughter able to manage their own money? If not, or if not appropriate to be in full control of own money, what assistance would they be prepared to accept and how should this be put into operation?
- Is physical exercise important? If so, how often? Will staff be needed to support this?
- If there is disagreement between you, your son or daughter, and the college about the management of a problem, how should it be resolved?
- There may be times when the college will not be able to reach agreement with you or your son or daughter about a particular issue. Are you/they willing to accept this?
- Would you and your son or daughter be prepared to agree a contract with the college that covers these sorts of issues in advance?

### Information for college staff

**You can show the PWSA UK leaflet, which you will find in this pack, “Information for College Staff” to colleges 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 son or daughter.**

### Adult Education Classes

**There are many courses on offer in adult education classes, ranging from handicrafts to basic reading and maths. The latter can sometimes offer one to one help, using volunteers. Check in your local paper, library or at advice centres for details.**

## A good practice model for residential colleges supporting a student with PWS



The following points are examples of good practice which you may wish to look for when choosing a residential college:

- Social and emotional support from a mentor team, to help your son or daughter come to terms with some of the frustrations around having PWS.
- Support to explore issues around independence and what this actually means to your son or daughter.
- Work around developing self-awareness, recognising own emotions, channelling them, and responding appropriately.
- Anger management work.
- Daily timetabled exercise, to build self esteem and empower your son or daughter on matters of weight and physical well being.
- Close working relationship with you.
- Where possible, counselling and psychological support. Preferably this should be with someone trained, or, aware of PWS.
- A co-ordinated and supportive approach. Frequent meeting between departments and your son or daughter to provide feedback and reinforce success.
- It is essential to have your son or daughter's co-operation, who has to be willing to work with staff and make a conscious choice to attend the college to achieve their study goals.

## Training, work experience and employment

If people with PWS are not in further education, they will still benefit from having an occupation. Some of the types of work which people with PWS already do, are:

- Helping with playgroups
- Gardening
- Assisting the elderly in residential care
- Basic office work
- Packing or light assembly work
- Craftwork
- Working with animals
- Kitchen work and cooking (to be carefully considered first)



They may do this as a paid job (usually part-time) or as a volunteer, or as part of a work experience scheme. The Disability Employment Advisor at your local Jobcentre may be able to suggest some work experience or training schemes which would be suitable for your son or daughter.

If any kind of paid work is being considered, consider how this will affect the person's benefits. This can be very complex, depending on how many hours are worked, and it might be helpful to seek advice from a Welfare Rights Advisor. In practice, very few people with PWS are currently able to maintain a full-time paid job. Reasons why full time work is impractical for people with PWS are usually tiredness during the day, general slowness in completing tasks, behavioural difficulties or problems with food. However, with the appropriate support, they can make a very valuable contribution to the community, and their individual talents can be given constructive outlets.

## Points to consider when looking at paid or voluntary work for people with PWS

There are several issues surrounding people with PWS and work, even if the work is on a voluntary or work experience basis. Each person should have their own person-centred plan drawn up, as individuals' needs and abilities will differ. Issues which may affect the person-centred plan or need to be considered include:



- Tiring easily, and needing time during the day for a nap. Some people are more able to work in the mornings than later in the day.
- Communication problems. Some people are very articulate but have difficulty understanding complex instructions. Others have speech problems which make it difficult for them to be understood. Employers should be aware of how any of these problems affect the person with PWS and what is the best way of dealing with them.
- Poor muscle tone. Strenuous work is likely to be difficult for many.



- Different needs for stimulation. Some people with PWS are very happy to do repetitive jobs which require them to focus completely on the job in hand. Others need more stimulating work, with a variety of tasks to keep them motivated.
- If things go wrong or do not go according to plan, or if items are lost or mislaid, the person can have a disproportionately intense reaction to this. Employers need to be aware of this, and the best ways of managing it (eg time out)
- Issues around food. Some cope better than others with the potential to access food, but most find it difficult. Other employees or volunteers should be warned to keep their own food supplies out of sight and it could be that food cupboards in staff kitchens etc need to be locked.
- Working in a food environment such as a cafe is a possibility for a few, but with suitable provisos in place (eg regular weighing to ensure that the person isn't taking food; or a strict rule about staff generally not being allowed to help themselves to food).

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## Education, work and training

### Best practice guidelines for employers

**PWSA UK has published best practice guidelines for anyone considering taking on a person with PWS, whether paid or voluntary. These can be downloaded from the website at <https://www.pwsa.co.uk/information-for-professionals/employers>**

**Please contact the PWSA UK office if you require a hard copy.**

## Points to consider when looking at paid or voluntary work for people with PWS (continued)



- Environments which are very hot or very cold are not suitable for people with PWS. They have adverse body reactions to extreme temperatures and some are unlikely to realise that they have become over-heated or too cold, and will dress inappropriately.

- Human resource/personality tests and answers to interview questions can be misleading. More able people with PWS may be looking for jobs, especially in large organisations, which include personality tests or interviews. They are more likely to score highly on "theoretical" questions such as, "What do you know about the Disability Discrimination Act?", but less highly on questions on managing situations, such as, "What would you do if a colleague complained about your work?"

High scores in one area may produce an average which would obtain the person the job. However, it is important to look at the type of job they are applying for and ensure that, if it does include elements on which the person has scored low, they receive training and support to manage these issues.

### Day services

Many local councils are modernising their day services with the aim of "providing young people with learning difficulties with new opportunities to lead full and purposeful lives."

It is therefore worth investigating what day services operate in your area: some may be run by the local council, others by voluntary organisations or charities. A good day service should offer the following:



- job training and work experience, or opportunity to do voluntary work
- basic education
- art and craft work
- home management, shopping skills, independent living skills (and a willingness to adapt these to the needs of someone with PWS).
- leisure and recreation
- part-time attendance at local colleges

In most areas you will have to pay a charge for attendance at day centres or extra-curricular activities.

Some local authorities are now phasing out day centres in favour of other alternatives, such as smaller group activities within a community setting.

## Free Telephone Legal Advice Service - Special Education

Education Lawyers at **Langley Wellington LLP Solicitors** offer a free initial telephone advice surgery to families of young people 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 son or daughter 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 college

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)

## Education, work and training

### We are here to help

**Most young people with PWS are very happy at college or doing other activities when the environment is right.**

**But if you are concerned about your son or daughter, call our PWSA Support Team who will be pleased to offer guidance on how you could address the situation.**

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