

Further education and options after school



Introduction

Your son or daughter can leave school at the end of the school year in which they turn 16. However all young people must stay on in some kind of education or training until they are 18 years old. This can be combined with paid or voluntary work.

Your son or daughter could:

- stay on at their school or in a different school
- go to a mainstream or specialist further education college
- go straight into residential care or supported living (which usually offer college courses as part of their daily activities)
- do an apprenticeship
- work and do part time training.

For most teenagers with PWS, the first three options are those which are usually chosen.

General considerations regarding going to college

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.

Further questions and issues to consider are listed on the next page.

Continued ...



Note:

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

After 16

Contact a Family has some very useful information about the transition process leading up to and after 16 years of age, which varies, depending on whether you are in England, Wales, Northern Ireland or Scotland.

<https://contact.org.uk/advice-and-support/sen-national-advice-service/education-beyond-16>



General considerations regarding going to college (continued)

- What does your son or daughter hope to achieve by going to college?
 - Have they discussed their ideas with a Careers Advisor for people with disabilities?
 - Have they 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 your son or daughter also want to gain independence, social skills, and practice taking more responsibility? Should this be included in their programme?
 - What previous support arrangements has your son or daughter had? What has worked most successfully for them?
 - How will they travel to and from college? Have they had experience of traveling independently?

Information for college staff

You can show the PWSA UK leaflet, which you will find in this pack, **Information for College Staff** <https://www.pwsa.co.uk/assets/files/college-staff.pdf> 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.

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 colleges

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?

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Further information

Challenging Behaviour Foundation have produced a useful booklet called *Planning for the Future*, which provides the tools families require as they start to plan for future support and opportunities for their sons and daughters, including education, housing, employment and community involvement for the individual.

Although CBF deals mainly with severe challenging behaviours, much of the information is just as valuable to those with less severe needs.

www.challengingbehaviour.org.uk/education-housing-social-care/planning-for-the-future-pack.html



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 - 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; they have to be willing to work with staff and make a conscious choice to attend the college to achieve their study goals.

Finding a residential college

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, 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.

After college and other options

Employment - paid and voluntary

It is still very difficult for anyone with a disability to get fully employed work, and this is no less the case for people with PWS. Sometimes they may be educated beyond their ability to actually perform work in the hurly burly of the "real" work world, and this can be a difficult limitation for them to assimilate.



In addition, the tendency to become easily tired, general slowness, issues around access to food, and behaviour problems can also create difficulties in employment.

If paid work is found, benefits may be affected, and there may be problems around the person not wishing to be advised on how they should spend earned income. The temptation will always be there to spend income on food. In many work situations, and in travelling to work, there are increased opportunities to access food, with all the problems that in itself brings.

So it is wise to bear in mind that expectations may not always be realised, and to guide the person towards work which is no less valuable, but which may be more appropriate - or towards part-time or voluntary work.

Some suggestions, based on what people with PWS are already known to be doing, are:

- helping with playgroups
- gardening
- assisting the elderly in residential care
- simple office work
- packing
- light assembly work
- craftwork
- working with animals
- kitchen working and cooking (to be carefully considered first)

Investigate local voluntary group schemes for introducing people with learning disabilities to work - these tend to vary widely from one area to another.

The PWSA UK produces a best practice leaflet **Guidelines for Employers** which you can order from the PWSA office. It is also available to download from the PWSA website at <https://www.pwsa.co.uk/assets/files/employers-best-practice.pdf>

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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.



After college and other options (continued)

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.

Parental rights after 18

As the law currently stands, when your son or daughter reaches 18, you have few rights over them, no matter how disabled they are. You have no legal rights to decide where your adult son or daughter lives or what they do. This also applies to consent for medical treatment. In most cases, this isn't too much of an issue, as it is good practice to consult with parents, but it may become a difficulty if your son or daughter's views are opposed to yours.



There are various methods of obtaining control over your son or daughter's benefits and wider issues around making decisions. You can find out more at <https://www.gov.uk/browse/births-deaths-marriages/lasting-power-attorney>

You may have to prove that your son or daughter lacks capacity to make some decisions, particularly around accessing food, but this may extend to wide issues such as going out and about independently. You can find out more about the Mental Capacity Act and how it can be used in the leaflet **The Mental Capacity Act: Supporting People with PWS** which can be ordered from the PWSA UK office or accessed online at <https://www.pwsa.co.uk/assets/files/Mental-capacity.pdf>

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