

Health and social services

25—40 years



Health and social care assessments

A health and social care assessment with the social services department of your local council is often the first step towards getting the help and support you need for the person with PWS. The assessment is also known as an 'assessment of need'. You can read more about this in the leaflet on [Residential Care and Supported Living](#). You can also request one even if there is no intention of leaving home. Services you or the person with PWS may need might include:

 **Note:** This is not the same as any Education, Health and Social Care Plan (EHC Plan) which apply up to the age of

- Applying for benefits
- Practical alterations to your house such as downstairs toilet/shower/extension.
- Equipment such as wheelchairs and stairlifts
- Daytime activities for the person with PWS
- Advice on diet
- An interpreter
- Physiotherapy, occupational therapy or speech therapy
- Information about voluntary groups who can offer support
- Help to take a holiday

- Respite care
- Day care and day services

You can request a health and social care assessment via the government website, which will re-direct you to the appropriate social services department for your area www.gov.uk/apply-needs-assessment-social-services (England and Wales only)

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Benefits and allowances

See the separate leaflet for information on Sources of financial help and government allowances.

The government is currently making widespread changes to the benefits system and this may well affect some of the information in this leaflet.



Health and social care assessments (continued)

However, because there is a finite amount of money available, and sometimes scarce resources, health and social services managers may have to look at ways of meeting needs other than the most obvious or the most costly.

Most social services departments now have teams of people who are experienced in learning disability, and include people such as social workers, community nurses for learning disability, community dietitians, occupational therapists etc, who should all be able to offer advice. In some areas you will be asked to pay towards some of the services you receive. See also the section on the [Care Act 2014](#) at the end of this article.

Your son or daughter can be placed on a local Disability Register: this ensures Social Services do not lose track of you even if you do not require very much help at the present time. The Disability Register also helps Social Services Department plan for future needs.

Direct payments (see also “Personal Budgets” on the next page)

Direct payments allow a person who has been assessed as needing particular services from social services to receive cash to arrange and pay for those services. They are means-tested on the income and savings of the person with PWS, so in some cases people will contribute to the cost of their care.

The person with PWS or their parent or guardian takes on all the responsibilities of an employer, such as payroll, meeting minimum wage and other legislative requirements and establishing contracts of employment. In practice, most social services can refer you to another agency who can take care of all the bureaucracy for you - but you still remain ultimately responsible for the employment of anyone you employ.

Respite Care

Respite care is available for adults with learning disabilities, but it is becoming increasingly difficult to obtain in some areas. Where it is available, even if you did not use respite services when your son or daughter was a child, it is worth considering now they are adult. Respite gives you a break away from one another, and can be very helpful to the person with PWS in learning how to cope away from home, making new friends, and preparing the way towards living away from home permanently.



Respite care can take a number of forms and may vary from one area of the country to another. There may be special respite centres, or schemes whereby your son or daughter goes to stay with another family. Some areas offer sitting schemes where someone comes to your home to sit with the person whilst you go out. Increasingly these are being funded by Direct Payments (see above).

A good respite care scheme should be able to meet most of your son or daughter's dietary and behavioural management needs. Make sure that they understand about the syndrome by giving them leaflets from the PWSA UK, but be prepared for a few difficulties in the early days.

You can find out more about respite care from your Social Services Department. You should be aware that you may have to provide a very detailed case to get respite for your son or daughter, as this is a very scarce resource in some areas.

Health care

Once your son or daughter reaches 18, their care under the paediatrics department at your hospital will usually cease.



If there are any ongoing concerns, their care will be transferred to one or more adult health specialisms. You may find yourself having to explain PWS to a whole series of separate specialists. Possibly the best specialists for PWS are either endocrinologists or general physicians.

Although there are now a few multidisciplinary clinics for children with PWS, there is only one specialist service for adults with PWS to our knowledge. This is based in London, and is usually fully booked. Please enquire with PWSA first if the clinic is taking further patients, as this may vary from time to time.

The leaflet on **Health Care** and **Information for hospital and A&E staff**, enclosed with this pack, might be useful to give to specialists.

Hospital specialists

Your GP can refer you to hospital specialists. You will find a leaflet in this pack which is aimed specially at GPs and gives them more information about PWS. Those which you or your son or daughter are most likely to require referral to are:



- **Neurologist** - for diseases of the brain such as epilepsy.
- **Endocrinologist** - specialises in the metabolic and hormone system of the body, including growth, thyroid functions, sexual development, and diabetes.
- **Psychiatrist** - specialises in mental illness and/or learning disabilities. Psychiatrists may hold clinics in health centres.
- **Clinical Psychologist** - specialises in mental functioning.
- **Orthopaedic doctor** - for bone diseases and injuries (eg scoliosis).
- **Ophthalmologist** - for eye diseases.
- **Lymphoedema clinics** – for fluid and swelling in the limbs and, sometimes, other parts of the body
- **Gastro specialists** – for constipation, diarrhoea and other conditions linked to the digestive system.
- **Orthotist** – for manufactured aids to help the body function – often footwear.

Health and social services

Personal budgets

Personal budgets are pots of money for social care services. A person has to have had a health and social care needs assessment before they can be offered.

They can be managed by councils or another organisation on behalf of individuals. They can also be paid as a direct payment, or a mixture of both.

When the amount of social care funding has been allocated, the individual (or their parents or carers) and the local authority will work together to decide how to spend it, usually by means of a care plan.

The local authority will continue to monitor the care package and will revisit the plan if it is not delivering for the individual.



Other health professionals

- **Community Nurse** - help with the practical aspects of nursing at home, such as changing dressings, giving injections, advice on incontinence etc. May be attached to GP practices or services can be obtained through your Health Authority.
- **Community Psychiatric Nurse** - help people with mental health problems. Some specialise in people with learning disabilities who also have a psychiatric problem. In some places you can refer yourself or your son or daughter directly to the community psychiatric team, in others you may have to go through your GP or hospital psychiatrists.
- **Community Learning Disability Nurse** - help and advice on topics such as managing behavioural difficulties, planning for future needs, and optimise an individual's health. Nurses and team can be contacted direct. Numbers may be found in the phone directory under health or social services. Your GP can also arrange a referral.
- **Dietitian** - for advice on diet. Some dietitians work in hospitals, some in community teams, and some in GP practices.
- **Occupational Therapist** - for advice on daily tasks such as dressing, washing, going to the toilet, and on aids and adaptations to your home such as handrails, commodes, installing a downstairs toilet. Occupational therapists may work in hospitals or be part of your local community team.
- **Physiotherapist** - for advice on treating and relieving pain, and ways of increasing mobility and muscle tone. In some areas physiotherapists can visit you at home; in others you will need to visit them in hospital or in health centres.
- **Continence advisor** - for advice on managing incontinence (bedwetting and soiling). Some authorities have specialist continence advisors (usually nurses).
- **Dentist** - some dentists now take private patients only, but you should be able to find a dentist who takes NHS patients in your area. To find out about local dentists, contact your Health Authority.
- **Chiropodist or Podiatrist** - for advice on foot problems and special footwear. Services vary from place to place, and clinics may be held in surgeries, health centres or hospitals. Your GP can arrange a consultation, or contact the district chiropody service.

Voluntary organisations

Voluntary organisations tend to fill in the gaps left by the statutory authorities. Some of the services they may provide include:

- Parent support groups
- Carers groups
- Respite care
- Advice on financial and welfare problems
- Advocacy
- Interpreters and services for ethnic minorities
- Self help groups for a range of problems
- Individual volunteers to carry out specific tasks, eg taking the person swimming one day a week.

If you have a local Voluntary Service, they will be able to provide you with the names of local voluntary services. Your Social Services Department, library or Citizens Advice Bureau should also be able to provide this information.

Dealing with professionals

Most professionals will allow you to accompany your son or daughter to an appointment, but you should be aware that in the interests of patient confidentiality, if the person with PWS requests a private appointment, this will be granted.



If at all possible take another adult with you when you go for the appointment. This could be a friend or relative, or an advocate. There are several ways in which this could be helpful:

- To discuss what has been said when you get home, and to make sure you have understood the consultation. They may also help to explain any difficulties to the person with PWS.
- To offer support during the consultation, particularly if you have strong points to put across.
- To support your son or daughter if they become upset during the consultation, and if necessary to go with them to another room until they calm down.
- To offer support after the consultation, particularly if it has been a stressful one.

If you see the professional with your son or daughter, most professionals will speak to them directly. Try not to butt in unless you feel the person with PWS is really struggling for a reply. If you do not understand the terms the professional is using, or he or she is using abbreviations with which you are not familiar, don't be afraid to ask what they mean. If necessary, write down the professional's answers.

Don't be afraid to disagree with a professional, or to ask for a second opinion, which is a right, not a request. Be prepared to give reasons why you disagree. Try to remain calm and polite, however difficult it may be.

If your son or daughter is likely to become upset by difficult consultations or prognoses it may be a good idea to ask to see the consultant in advance on your own. The consultant may need your son or daughter's prior consent for this.

You can also give the leaflet **Information for GPs** to your son or daughter's doctor for further information.

Going into hospital

If your son or daughter has to go into hospital, enquire if there is a Learning Disability Liaison Nurse (or similar) available to help explain what is happening.

The NHS also publish a useful guide:

www.nhs.uk/livewell/childrenwithlearningdisability/pages/going-into-hospital-with-learning-disability.aspx

You might also find it helpful to give hospital staff the leaflet enclosed with this pack.

The Care Act 2014

Major changes to the care system in England are just being introduced, beginning in April 2015. The Care Act 2014 includes rights for both those receiving care and their carers.

Initial changes apply only to the care system for older people and younger adults with disabilities.

Four major changes are being introduced:

- The creation of national eligibility criteria establishing for the first time when someone should be entitled to help - to date, it has been up to councils to set their own criteria
- A duty on councils to offer schemes by which those who need to pay for residential care can get a loan from their local council, which is then paid back from their estate after death
- Giving carers for the first time the same right to assessment and support as the people they care for; before, they had to provide "substantial care on a regular basis" to get an assessment
- Those who pay for care themselves will be entitled to go to councils to get advice and information about the care system.

The Public Bodies (Joint Working) Act is also introducing reform in Scotland, where NHS and care budgets are being merged to provide more streamlined services.

For further information about the Care Act 2014 see <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets--2>

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