



Speech and language in PWS

18—25 years

Introduction

Adults with PWS may have the same range of disorders of speech and language development that can occur in any adult.

There is also the possibility of additional problems associated with the syndrome.

These may be caused by:

- Learning disabilities e.g. retrieval of information and memory deficits.
- **Physiological** characteristics e.g. high arched palate causing inaccurate articulation.
- Low muscle tone making it difficult to make the fast accurate movements required for clear speech.

Most people with the syndrome do have some difficulty with speech and/or language at some time during their lives.



Note:

Words in **blue bold** are explained in the glossary at the end of this leaflet.

Difficulties associated with PWS

Articulation

Inaccuracy of movements and inability to change quickly from one tongue or lip position to another (sometimes described as **dysarthria**) are often features of PWS. This is caused by the combination of the characteristic high arched palate and the small lower jaw. **Hypotonia** in the **oral** muscles can also contribute.

Continued ...

Accessing Speech and Language Therapy for Adults

If the adult himself is concerned about any aspect of his ability to communicate, and therefore sufficiently motivated to change, advice can be obtained from an SLT by self-referral.

This service may be available through a day Centre or college, or a Community learning disability team. If none of these are available contact the local SLT service via the adult department at your local hospital.



Articulation (continued)

More rarely **dyspraxia** occurs, although it is now thought that dyspraxia is more common in people with PWS than in the general population. This condition can lead to extremely poor intelligibility and may mean that an augmentative method of communication is needed eg a communication book or Voice output device.

Language disorder

Many people with PWS experience language delay as younger children. More rarely a specific language learning difficulty exists. The person may not be able to understand language adequately, leading to confusion, frustration and difficulty learning.

This may be mistaken for a learning disability, but only collaboration between an SLT and a psychologist can determine the origin of the problem.

Some people may experience difficulty with expressive language, with their verbal comprehension more intact, this is similar to a language delay, but more pervasive and persistent in nature, so that the ability to express ideas and comment on events does not develop along expected lines.

Fluency

Most non-PWS children experience a stage of non-fluency, usually between the ages of 3 and 5 but for the individual with PWS it can be later occurring and last longer. Occasionally it can develop into a true stammer, but this would probably have been present if the person had not had PWS as there is a strong genetic component in the incidence of stammering within families. Some individuals with PWS are unusually fluent.

Pragmatic Disorder

Pragmatic skills concern the individual's ability to use language appropriately in social situations. Problems in development of these skills are less easy to spot and to diagnose, and may be thought to be behavioural.

The individuals will talk a lot, but the language is inappropriate and social interaction, conversation and turn-taking skills are affected, making it harder to form relationships and friendships. These individuals are often not referred to SLT service because they can speak, although SLTs are the appropriate professionals to give advice and support in this situation.

Autistic Spectrum Disorder

A number of adults with PWS may also have an Autistic Spectrum Disorder (ASD). We have also heard of a few individuals with an ASD diagnosis where it was not realised that their difficulties with social skills were because of a delay in this area of development due to PWS, not ASD.

Repetitive use of language (Perseveration)

This is the term used for the habitual discussion of one topic, often associated with an obsession with food. It may take the form of the constant repetition of a question, even after an answer has been given several times.

This is extremely difficult for people who are not familiar with the individual to understand, and has led to situations where the person is punished or ignored because of it.



Therapy for adults

Some or all of the disorders mentioned above can persist into adult life. This may be because SLT was not available at the appropriate moment during the child's development, or it may be that any learning disability meant that they could not learn the required skills.

Speech may still not be intelligible, either due to lack of therapy, or because there are insurmountable physiological problems. Lack of intelligibility can lead to frustration and a lack of confidence in speaking to anyone outside those who are familiar with the persons' speech patterns. Some young adults will appear to cope well when communicating with family and in school until they leave and the support of those familiar with them is withdrawn. If there is an impact on the person's life then an SLT can provide advice on ways to support the person which may or may not include alternative or augmentative methods of communication.

Some self-help suggestions

Inhibition of the desire to communicate or inappropriate use of language can cause considerable embarrassment. The following ideas may be helpful.

- Attendance of a group where speaking is a natural part of the activity, eg drama group, self-advocacy, discussion group.
- Attendance at a course on assertiveness or confidence-building.
- Rehearsing. This involves practising aloud situations that might arise which require you to speak, eg a visit to the doctor. Practice what you want to ask, and the answers to the questions the doctor might ask. Also practice useful phrases, so that when someone speaks to you, you will know what to say. Do this with someone you know and trust and you should soon find you can build up more situations where you have something to say. Start with family and friends and progress to asking for something in a shop, then making a phone call, etc.

Puberphonia

Puberphonia is a failure of the voice to break in young adult men and may occur in PWS.

The voice remains high pitched and childish, and is a great disadvantage socially. Advice about this should be sought from a consultant endocrinologist, via the local hospital.

Service delivery

The type of support required would be decided on clinical need and might include:

- *Assessment with advice*
- *Outpatient attendance and home practise*
- *Group therapy with others with a similar presentation*
- *Advice and training to allow the person and carers to deal with the problem themselves*
- *Support within the day to day environment e.g. college, care home or residential place.*

Note

Not all adults with PWS will have all or any of these problems, and some of them might have been there if the individuals had not had PWS.

Thank you



Thank you to
Fiona Whyte
Reg MRCSLT,
Clinical lead SLT
– advisor to the
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PWSA UK

Suite 4.4 , Litchurch Plaza

Litchurch Lane

Derby DE24 8AA

Tel 01332 365676

Fax 01332 360401

E: admin@pwsa.co.uk

W: www.pwsa.co.uk

Reg Charity No: 1155846

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Glossary

Articulation Production of meaningful speech sounds by co-ordinated movement of tongue, lips, teeth palate and jaw.

Clinical Relating to treatment of a medical condition.

Dysarthria Inability to make accurate rapid speech movements. Generally such speech is slow, with indistinct consonants and long intervals between words. Overall effect is of slurred or indistinct speech.

Dyspraxia Disability of motor programming of articulatory movements or lack of voluntary control over the muscles needed for speech, neurological in origin. Characterised by difficulty in imitating words or repeating them accurately and/or poor sequencing of sounds in words, and/or sentences.

Expression The ability to use language in a way meaningful to the listener.

Fluency The flow of speech.

Hypotonia Lack of tension and strength in the muscles.

Oral Relating to the mouth.

Physiological Physical characteristics (e.g. shape of lips, tongue, palate).

Signing The use of a sign language system e.g. Makaton.

Verbal comprehension The ability to understand the spoken word.