

## Speech and language in PWS 13–18 years



### Introduction

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

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.

### 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.

More rarely **dyspraxia** occurs, although it is now thought that dyspraxia is more common in children 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 e.g. a communication book or Voice output device.



**NOTE:**

**Words**

**in orange are explained in the glossary at the end of this leaflet.**

**The role of the speech and language therapist**

**The Speech and Language Therapist's (SLT) role is to assess and diagnose which, if any, speech and language, or communication difficulty the individual is presenting with.**

**This may not be because of PWS. If any disorder is found the SLT will advise on the best way to enable the individual to reach their maximum communication potential. S/he will liaise with parents, teachers, carers, teachers and anyone else who is a regular part of the person's environment.**



## 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 an educational 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.

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## 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**.

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## Pragmatic Disorder

Pragmatic skills concern the child's ability to use language appropriately in social situations; this can cause a significant barrier to learning if not dealt with. Problems in development of these skills are less easy to spot and to diagnose, and may be thought to be behavioural.

The children 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 children 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 small number of teenagers with PWS may also have an Autistic Spectrum Disorder (ASD) and it is easy to miss this because of the difficulty or delay in social skills development. 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 teenager to understand, and has led to situations where the person is punished or ignored because of it.

## Speech and Language Therapy (SLT)

Service Delivery may include:

- **Consultation and advice about how people can support the teenager's communication needs.**
- **Teaching parents/ carers to work with their son or daughter and giving specific work for them to do.**
- **Advice to others involved with the teenager to maximise communication opportunities in different environments e.g. home, school, college.**
- **Assessment and explanation of the result, which includes the impact of any difficulty the teenager may have.**
- **Hands on therapy with the teenager, probably with backup practice for home (the therapy programme may be carried out by an SLT support worker under the guidance of a qualified SLT)**
- **Re-assessment of the impact for the teenager.**

### Difficulties of direct (hands on) therapy

The SLT supporting your son or daughter may advise that direct therapy is not the way forward. This will be decided on their clinical needs.

Teenagers who are resistant to therapy, as is the case with many with PWS, will become distressed and not achieve as much as they could. There may be a need for constant and prolonged repetition of work for learning to take place; this cannot be achieved in weekly therapy sessions.

Individuals may not generalise what they learn in a specific situation, so that the trend now is for development activities to be devised which can be built into the teenager's daily routine, or carried out within his school curriculum, rather than specific 'therapy sessions' taking place.

Rewards for carrying out therapy activities must be carefully prepared according to the individual's interest, and must not be food-based.

### How to access SLT services

Every teenager with difficulties in the following skills should be assessed by an SLT:

- Eating and drinking (if it is suspected there is a physical cause)
- Saliva control (excessive salivation for the individual's age)
- Speech (if not intelligible to the adults in the person's environment)
- Language development (if not in line with the teenager's other development, or to establish whether this is the case)
- Pragmatic skills or any other problem that is causing difficulty with communication

Most Health Trusts operate an open referral system, so that parents can request that an SLT give advice about their child by telephoning the local SLT department. If the individual has a EHC Plan (previously Statement of Need) and SLT is specified, it is a legal requirement for the Education Authority to ensure that this is provided.



**NOTE:**

**Speech and language therapists work in episodes of care so the teenager may move in and out of the service as their needs change.**





## Remember!

Not all children

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.

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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.



Thank you  
to Fiona  
Whyte  
Reg  
MRCSLT,  
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