

## Williams Syndrome

Williams Syndrome is a rare genetic condition giving rise to both physical and mental disabilities. Research indicates that it is caused by a deficiency in the gene that controls the synthesis of elastin. The condition can be difficult to ascertain without a blood test (known as the F.I.S.H. Test) and often the disorder can remain undiagnosed for many years.

People with Williams Syndrome have characteristic facial features that become more pronounced as the child grows. They are not always noticeable on an individual basis, but when a group of WS people are observed together they do become more apparent. Sometimes only a trained geneticist will be able to see these traits.

### Children with WS may

- be small for their age
- have low-pitched voices
- have super-sensitive hearing
- be excessively anxious or fearful
- have a short attention span
- display obsessive behaviours
- be hyperactive
- be overly friendly - no shyness of strangers
- have language delay
- have poor communication skills

Children with Williams Syndrome will tend to show overall developmental delay and learning difficulties from mild to severe. Some display disproportionate abilities in some areas, however, and many have very good memories.

### Socially

They are loveable and sociable children, and empathise easily with others' feelings. They will chatter non-stop, and are eager to please, especially adults. It has been observed that although they are very outgoing and disinhibited with adults, their peer group relationships are not as good. They are nearly always excessively anxious children, fearful for the welfare of friends, family and strangers, of heights, imagined disasters and unknown situations. They may be inappropriately friendly with people they do not know, and 'stranger-danger' should be taught early. Appropriate greetings to various people should also be taught and practised regularly.

### Language

Although their language may have been delayed in their very early years, by school age their verbal skills are often superior to those of other children in their year group. They will speak fluently and correctly, with an excellent vocabulary, but this may conceal some inadequacies of comprehension. They may have very little skill in taking turns in a conversation, and maintaining a subject appropriately.

### Medical

Children with WS may suffer from heart problems, including murmurs, infantile hypercalcaemia (high levels of calcium in the blood or urine) resulting in feeding problems, irritability, constipation and sometimes kidney disorders. Children with Williams Syndrome may also have dental problems and raised blood pressure. They are often of small stature and build.

### Motor skills

They will probably have coordination problems, and difficulties in the areas of visual-spatial information, in sequencing and construction tasks.

### At home:

Feeding, sleeping and toileting problems are associated with Williams Syndrome.

Many young children have fads with the food they will accept. Some refuse all 'lumpy' textures or new tastes. New flavours and textures should be explored, however, as fussy eaters will cause problems at school. Reward him for trying one spoonful of a new food at a meal. If your child has raised levels of calcium he may need to be put on a low-calcium and Vit D restricted diet. Your GP / consultant will advise you.

The sleeping problems may be part of their all-encompassing anxiety. A firm and consistent approach is needed, and establishing a relaxing, enjoyable and regular routine at bedtime will ease anxieties. Leaving a light on, a favourite toy, lullabies and reassuring words will all help.

Toileting is a difficult area, and you may find it best to ask your Health Visitor or local health clinic nurse for advice.

The young person with Williams Syndrome will find dressing and undressing difficult. Allow him extra time, and break down any long, complicated tasks into smaller components: teach one skill at a time.

### The following might help also:

- Velcro on shoes rather than laces / buckles
- clothes that are not too tight
- avoid ties - they are very difficult
- shirt buttons: larger holes and buttons
- socks: short ones if possible: long nylon socks are difficult to handle
- clothes with a distinctive front and back are best, for example, a V-neck sweater

### At school

His poor attention and communication skills will require sympathetic and consistent interventions. He will work best in a quiet and distraction-free environment, and he is likely to need some 1:1 guidance from an adult in order to complete tasks successfully. Teachers should not ignore the usefulness of a reward system for doing as he is asked for a certain length of time, and consider making use of any specific interests the child has - if he likes watching the fish in the fish tank, or looking at a favourite book, make this his

reward for sitting still during story time. However, many children with Williams Syndrome have good memories, and some may have specific talents, i.e. musical ability. Nurture these!

If his way of getting your attention or responding to his own frustrations is a temper tantrum, then firm and consistent handling is important. He must see you will not give in to him, or pay him any attention, until he calms down. Do not confuse him by giving in one day, but not the next. If tantrums occur frequently, try to monitor what has led to the event: is it a sudden noise (school bell), a particular child or teacher coming too close, or even moving from one task to another (which?). If you can discover a trigger, then it might be possible to either remove the trigger, or the child, just before the next occasion.

#### Other Useful Contacts

For more information and to find out if there is a support group near you, contact

**The Williams Syndrome Foundation** Ltd 161 High Street,  
Tonbridge, Kent TN9 1BX

**Web:** [www.williams-syndrome.org.uk](http://www.williams-syndrome.org.uk)

**Tel:** 01732 365152

**Fax:** 01732 360178

**Email:** [john.nelson@williams-syndrome.org.uk](mailto:john.nelson@williams-syndrome.org.uk)

#### Publications

**Contact the WSF** above for their reading list and check on [www.amazon.co.uk](http://www.amazon.co.uk).

#### Internet sites

**Contact a Family** has a wonderful website on many children's disorders. Their page on Williams Syndrome is at [www.cafamily.org.uk/Direct/w15.html](http://www.cafamily.org.uk/Direct/w15.html).

**The National Institute for Neurological Disorders and Stroke's** page on WS is at <http://www.ninds.nih.gov/disorders/williams/williams.htm>.

#### Overseas

**The American WS Foundation** has several helpful papers, including guidelines for parents and teachers, at [www.wsf.org](http://www.wsf.org).

**The US Williams Syndrome Association** site is at [www.williams-syndrome.org](http://www.williams-syndrome.org).

Note: The OAASIS Information Sheets use 'he'/'his'/'him' rather than the cumbersome 'he / she'/'his / her'/'him / her'. No sexism is intended.



[www.cambianeducation.com](http://www.cambianeducation.com)

Cambian is the largest provider of specialist residential education and care for young people with Autism, Asperger Syndrome and other associated complex needs in the United Kingdom. Cambian is trusted by hundreds of parents and over 70 Local Education Authorities

#### OAASIS publications

- SEN Information Sheets
- First Guide to ...
- Cards explaining 9 learning disabilities
- Legal advice Information Sheets
- SEN 'How to' guides

All OAASIS publications can be downloaded from [www.oaasis.co.uk](http://www.oaasis.co.uk)