



## Williams Syndrome

**Williams Syndrome is a rare genetic condition. It occurs randomly and is non-hereditary. It is caused by a deletion on Chromosome 7 at the Elastin gene. Williams Syndrome affects about 1 in 18,000 people. Approximately 3,500 people in the UK have Williams Syndrome.**

There are a number of characteristics common to those affected by Williams Syndrome. These include:

- **Facial features:** people with Williams Syndrome have 'elfin' faces including a wide mouth with full lips; an upturned nose with a flattened bridge; slightly high, rounded cheeks; a 'starburst' pattern on the iris.
- **Heart problems:** most people with Williams Syndrome have a narrowing of the aorta above the aortic valve. Other, more serious heart and vascular conditions can also occur
- **Hyperacusis:** individuals with Williams Syndrome have a hyper-sensitivity to noises that are sudden/loud and/or of a certain pitch. This can cause extreme anxiety and distress.

### How Williams Syndrome affects infants and younger children:

Infants and younger children with Williams Syndrome have difficulties with feeding and growth as well as developmental delay and sensory integration problems. Issues usually include:

- Low birth weight
- Failure to thrive
- Slow growth and weight gain
- Delay in reaching developmental milestones
- Delayed speech
- Difficulty feeding
- Excessive vomiting
- Sleeping problems
- Irritability
- Constipation / prolapse
- Severe colic and reflux
- Texture intolerance
- Difficulty weaning
- Hypertension
- Strabismus

### Williams Syndrome in older children and adults

Williams Syndrome presents a range of medical, cognitive, social, sensory and behavioural difficulties in older children, teenagers and adults. There are some similar traits between Williams Syndrome and those typically seen on the autism spectrum.

# INFORMATION AND RESOURCES



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## Williams Syndrome

### Medical

- High blood pressure
- Early onset puberty / menopause and aspects of premature ageing
- Scoliosis
- Joint problems
- Hernia / prolapse
- Urology problems
- Kidney problems
- Mental health issues including anxiety and depression

### Difficulties around Communication

- Uninhibited behaviour
- Excessive talking
- Talking in an inappropriate and superficially 'adult' manner
- Over-friendliness with strangers coupled with a lack of knowledge about who can / cannot be trusted
- Difficulty making or sustaining friendships with peers
- Obsessional interests e.g. cars, trains, vacuum cleaners etc.
- High verbal ability masking lower cognitive achievement
- Emotional immaturity presenting as over-reaction to events
- Exaggerated displays of fear, excitement, sadness and happiness
- Difficulty self-regulating behaviour e.g. may 'hit out' when angry

### Sensory

- Difficulties and delays with all sensory systems affecting all aspects of learning and development
- Very short concentration span
- Easily distracted
- Fear of heights, open stairs and uneven surfaces

People with Williams Syndrome are extremely sociable, friendly, happy and loving. They have an affinity for music and excellent short-term memories. All of these strengths can be harnessed and early intervention helps individuals to realise their full potential.

The Williams Syndrome Foundation offers help, support and further information. It is run by families for families and professionals working with those diagnosed with the condition. Contact [www.williams-syndrome.org.uk](http://www.williams-syndrome.org.uk)

This resource has been developed in partnership with Claire Whitehurst who is a parent of a child diagnosed with Williams Syndrome to raise awareness to the needs of those living with this Neurodevelopmental condition.

**[www.addvancedsolutions.co.uk](http://www.addvancedsolutions.co.uk)**

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