

## What is it?

Williams syndrome (WS) is a random genetic mutation disorder that presents at birth, affecting both boys and girls equally. WS is caused by the deletion of genetic material from a specific region of chromosome 7. This disease is characterized by an array of medical problems that can range in severity and age of onset. However, all cases are characterized by dysmorphic facial features, cardiovascular disease, and developmental delay. These disabilities occur in conjunction with striking verbal abilities, highly social personalities, and an affinity for music.

## What are characteristics?

- Heart and blood vessel problems
- Low muscle tone and joint laxity
- Reflux
- Dental abnormalities
- Hypercalcemia
- Developmental Delays
- Hearing sensitivity
- Kidney problems
- Hernias
- Facial characteristics
- Chronic ear infection



Characteristic facial features:

- small upturned nose
- wide mouth
- full lips
- small chin
- puffiness around the eyes

## Suggested school accommodations

Most children with Williams Syndrome have some form of learning difficulties but they can significantly vary. As they age, you may notice the child struggling with concepts like spatial relations, numbers and abstract reasoning. Many children with WS appear scattered in their level of abilities across domains. Although a child with WS may be very social, remember to monitor their support systems and social interactions as they often have a difficult time understanding social cues.

### **Physical/Medical**

- Therapy to improve muscle tone, strength and ROM
- Therapy to improve fine motor skills
- Note anxiety and fears (ex. noise of school bells, alarms)

### **Communication**

- Provide visual and picture tools for learning
- Incorporate music wherever possible
- Offer direct, step-by-step instruction

### **Emotional**

- Promote peer interaction
- Encourage safe relationships
- Develop social skills
- Respond to high praise, rather than tangible rewards

### **Scheduling**

- Provide frequent breaks
- Provide visual schedule to prevent perseveration on upcoming events

## SHNIC school nurses information:

### Specific health issues for individual health care plans

- Diagnosis that is complete; noting all characteristics
- PT/OT/SLP/Vision services and hearing specialists / communication with staff
- Baseline cardiac assessment including heart rate monitoring orders with reportable parameters
- Blood pressure monitoring orders with reportable parameters
- Note if student wears a Medic Alert bracelet for cardiovascular emergencies
- Orders for weight checks, if applicable
- Orders for temperature regulation
- Fever protocol including PRN medications
- Nutrition orders including feeding protocol, positioning for feeds
- Note toileting protocol and communicate/educate staff
- Baseline skin assessment, including use of orthotics if applicable
- Orders for physical activity/ positioning restrictions



## HELP PROMOTE AWARENESS of WILLIAMS SYNDROME

### Sensory Processing Issues and Anxiety



Learn More at: [wschanginglives.org](http://wschanginglives.org)

#### Resources & Manuals

Williams Syndrome Association  
[www.williams-syndrome.org](http://www.williams-syndrome.org)

Williams Syndrome: Changing Lives Foundation  
[www.wschanginglives.org](http://www.wschanginglives.org)

Williams Syndrome Foundation  
[www.williams-syndrome.org.uk](http://www.williams-syndrome.org.uk)

**I have Williams syndrome**

Which means sometimes:

- I am overly talkative and disruptive
- I can invade your space unknowingly
- I can act or respond inappropriately
- Loud and startling noises bother me
- I am very happy when you are happy
- I get upset when you are sad

[www.wschanginglives.org](http://www.wschanginglives.org)

**Here is what you can do to help**

When I am:

- Over talking: Say "It's my turn to talk." or "Please be quiet now."
- Invading space: Say "Please back up and then we can talk."
- Acting inappropriately: Say "I don't like that, can you please stop."
- Startled by a noise: Say "It's no big deal. I'm okay and so are you."
- Very happy: Say "Thanks for being so happy. It makes me happy."
- Very sad and upset: Say "It's okay, we all get sad sometimes."

Thank you for helping me learn how to be a good friend!

[www.wschanginglives.org](http://www.wschanginglives.org)