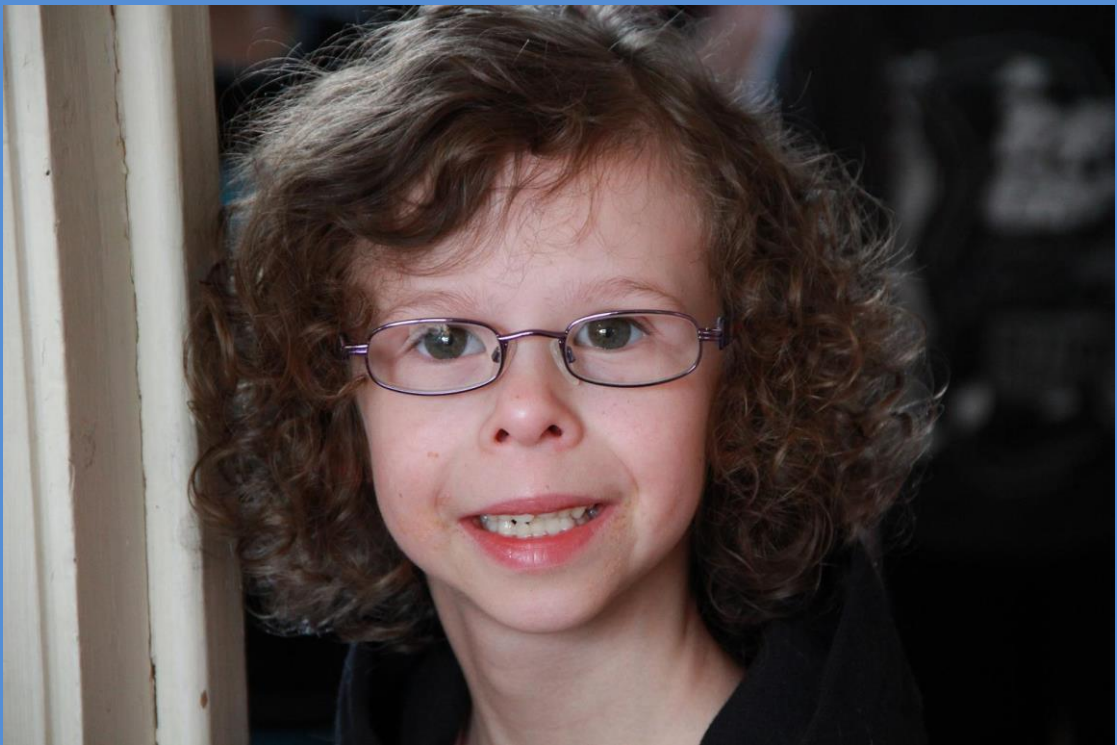


# Anxiety in young people with Williams Syndrome

*A Guide for Secondary Education*



## About this booklet

This booklet aims to help teachers:

- To understand the relationship between anxiety and Williams Syndrome
- To recognise signs of anxiety in children with Williams Syndrome
- To identify ways to help children with Williams Syndrome to manage their anxiety

## What is Williams Syndrome?

Williams syndrome is a relatively rare developmental disorder with a genetic cause. Only about 1 in every 20,000 people has Williams syndrome. There are a number of genes missing on chromosome 7 and this creates the distinct medical, physical and behavioural characteristics we associate with the disorder. For example, people with Williams syndrome have distinctive facial features meaning they tend to look similar to each other, and in terms of intellectual ability, Williams syndrome is typically associated with mild to moderate learning difficulties.

When interacting with someone who has Williams syndrome you may notice that they are very talkative, outgoing and friendly. People with Williams syndrome are often very interested in socialising and thrive on opportunities to interact with others. Although seeming to be very capable in social situations, their relatively strong language skills might mask their difficulties with making sense of social situations or the information being discussed. Indeed, their strengths with social skills and language (relative to their general intellectual ability) may often be much more proficient than their spatial abilities which can lead to difficulties for example doing puzzles, drawing or following directions.

The main mental health concern associated with Williams syndrome is **heightened anxiety** and this booklet focuses on describing, identifying and managing anxiety in this group. The information has been prepared for teaching and educational providers working with those who have Williams syndrome.

## What is anxiety?

Everyone feels anxious some times. When we feel anxious, we usually have strong physical feelings in our body. These physical feelings are a signal to our body to initiate a 'fight or flight' response. This causes our heart to beat faster to pump blood to our muscles so that we have energy to either run away or fight off danger. These physical feelings are meant to provide very strong and powerful signals that we need to do something and most of us find them uncomfortable and aversive. This may make us avoid situations that make us feel anxious, as avoidance makes us feel better in the short-term, by enabling us to avoid these anxious feelings. However, the more we avoid these situations, the less opportunity we have to face our fears and learn how to manage them and the more anxious we feel about them, making it even more difficult to face our fears in the future. This is known as an 'anxiety cycle'.

### **When we are anxious we:**

- Think anxious thoughts
- Have uncomfortable physical sensations in our body
- Act in ways to make ourselves feel better



There are different types of anxiety and some of these types might affect people with Williams syndrome more than others, and more than people who do not have Williams syndrome. We also know that some types of anxiety can increase with age for young people with Williams syndrome.

For example, our research with parents indicates that Williams syndrome can be associated with difficulties of Separation Anxiety Disorder, Generalised Anxiety Disorder and many individuals have specific phobias. Concern anticipating upcoming events can also be a significant issue in this group. As adolescents, young people with Williams syndrome can also experience an increase in social anxiety as they experience new and changing relationships and social opportunities.

## Anxiety in Williams Syndrome

### **Difficulties with social situations**

Despite being very sociable in nature, young people with Williams syndrome can often find social situations hard to understand and this may be especially the case when the situation is new or they are faced with a large number of people. In these situations a person with Williams syndrome may feel overwhelmed and will often have difficulty working out what another person might be thinking or feeling, or how that person might react (e.g. struggling to get jokes). As a result, people and situations can seem unpredictable and scary, which can lead to feelings of anxiety.

### **Routine**

Many individuals with Williams syndrome prefer to have a fixed, daily routine including knowing exactly what is going to happen each day. If there is a change in routine, young people with Williams syndrome may feel very anxious or upset.

## **Sensory Sensitivity**

Young people as well as adults with Williams syndrome can be highly sensitive to sights, smells, tastes, touch and most commonly, sounds and may become very anxious or upset when exposed to these triggers. Some individuals may actively avoid situations in which they know that the trigger might occur, or situations that are entirely unfamiliar (just in case!).



Most people can tell us when they are anxious, but some people with Williams syndrome may have difficulties understanding and describing their emotional experiences accurately. They may therefore not be able to say when they are anxious. This can result in a build up of anxiety, which could lead to distress some time after the original event has finished. For some young people who have difficulties expressing their feelings, anxiety can present as what appears to be an angry outburst.

## **Common signs of anxiety in Williams Syndrome**

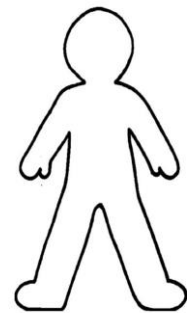
- Refusing to go to school / college
- Increased engagement in special hobbies (as avoidance or distraction)
- Greater insistence on routines and sameness
- More frequent or more intense angry reactions
- Being 'clingy' or upset
- Repetitive questioning
- Hurting themselves
- Distress or agitation when separated from familiar others

## Common triggers for anxiety in Williams Syndrome

- Changes in routine (e.g. teacher at school / college is sick)
- Changes in environment (e.g. changing / moving between classes)
- New or unfamiliar situations
- Difficulty with social situations (e.g. other people joking or laughing)
- Feeling under pressure to speak / interact in social situations
- Sensory sensitivities / over-stimulation (e.g. extreme noise)
- Fear of a particular situation, activity or object (linked to a specific phobia)
- Seeing anxiety in other people

## Useful hints and strategies for the management of anxiety in Williams Syndrome

- ◆ Develop emotional literacy / vocabulary, using lots of 'feelings' words (happy, sad, worried, scared) in stories and conversations. Modelling the use of emotion words 'I feel happy today because...', 'I was worried yesterday that I had missed my bus...'
- ◆ Help the young person to identify physical signs associated with emotions, including happiness, anxiety etc
  - You could discuss how the person is feeling, or depending on ability could give them a body outline picture to note physical signs



- ◆ Help the young person to identify triggers for their anxiety
  - This may be hard for some young people but more possible for others. Between you and the person with Williams syndrome you could keep a note of when they appear anxious and what might be causing this anxiety. It may be appropriate to share these observations with the young person. If this can be achieved it will help them to begin to perhaps identify the early signs that they are becoming anxious and begin to use some of the techniques outlined below to 'nip the feeling in the bud' before it becomes overwhelming.
- ◆ Teach relaxation techniques
  - This can include taking deep breaths, counting slowly to 10 and thinking about relaxing thoughts
  - Encourage the young person to practice these strategies when they are calm, and then guide them to use them when anxious
- ◆ Working with parents – keep each other informed about situations that raise anxiety and techniques that seem to work to reduce it.
- ◆ Use visual timetables or pictures to show what will happen next so that they have some warning of a change in their routine and know what to expect.
- ◆ Maintain a calm, non-anxious approach when dealing with the person's anxiety. If they see that you are stressed, then this may raise their anxiety levels.
  - Use a soothing tone to deliver a clear and calm message, with calm and relaxed body language
- ◆ Reward the young person for being brave – if they manage to confront their fear (or even a bit of it), they deserve a reward! But make sure they know what the reward is for! Often emotional rewards such as a clap work well.

## Some final thoughts

Remember that there are things that some young people may never like or never feel 100% comfortable with. It is a personal decision whether it is worth trying to get a particular individual used to things they get anxious about. However, the aim of any anxiety intervention is not to eradicate triggers or sources of anxiety entirely, as this would be impossible. Rather, the aim is to increase tolerance and provide a toolkit of skills and techniques for the individual to use when they might be experiencing anxiety. With these techniques in mind it may be possible to minimize the impact of anxiety on educational attainment.

## Further information and guidance

Williams Syndrome Foundation website:

<http://www.williams-syndrome.org.uk>

WS Research Group website:

<https://www.dur.ac.uk/psychology/research/newwilliamssyndrome/>

Social Media

<https://www.facebook.com/NWSResearchGroup>

<https://www.facebook.com/WilliamsSyndromeFoundationUK>

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