

Anxiety in Williams Syndrome

*A guide for supporting adults
with Williams syndrome*



About this booklet

This booklet aims to help those who support adults with WS:

- ⇒ to understand the relationship between anxiety and Williams Syndrome
- ⇒ to recognise signs of anxiety in Williams Syndrome
- ⇒ to identify ways to help adults 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. A number of missing genes on chromosome 7 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 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. Socializing can be considered a strength and a particular interest for some people with Williams syndrome in childhood, but it is not necessarily a strength when they become adults. This may be because adults with Williams syndrome do not keep up with their peers in terms of their social skills which means differences become apparent during adolescence and adulthood.

Good language skills (relative to general intellectual ability) can mask with visual spatial abilities. Therefore, people with Williams syndrome can be poorer at some tasks than you would expect based on their language, for example with managing money, telling the time, or following directions. Therefore functioning in everyday life for adults with Williams syndrome can involve a number of challenges related to this uneven profile of ability.

The main mental health concern for adults 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 individuals who support adults with Williams syndrome.

What is Anxiety?

Everyone feels anxious sometimes. When we feel anxious, we can 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.

Anxiety can also be experienced as worry, for example thoughts that constantly spin around in our minds and impact on our ability to carry out daily activities. When we worry we can feel over-emotional and sometimes we might not feel able to explain how we are feeling.

Both the worry and physical sensation of anxiety may make us avoid situations that make us feel anxious. Although avoidance makes us feel better in the short-term, the more we avoid these situations the less opportunity we have to face our fears and learn how to manage them. 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



Anxiety in Williams Syndrome

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 example, our research with parents indicates that Williams syndrome can be associated with difficulties of Separation Anxiety, Generalised Anxiety Disorder and many individuals have specific phobias (frequently linked to sounds). As **adolescents**, young people with Williams syndrome can experience an increase in social anxiety as they experience new and changing relationships. In **adulthood** we know there can be an increase in worry about the future and fear of future separation from parents. Across all ages, anxiety about uncertain events (anticipatory anxiety about what 'might' happen) is an aspect of anxiety in Williams syndrome.

Sensory sensitivity

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!).

Routine

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

Difficulty with social situations

Despite being very sociable in nature, people with Williams syndrome can often find social situations hard to understand. This may be the case when the situation is new or there are a large number of people. In these situations a person with Williams syndrome may feel overwhelmed and 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. In adulthood we know this can be a particular difficulty and can lead to some adults wanting to withdraw and stop social interactions. These difficulties can make people with Williams syndrome feel lonely, as they often have a very strong desire for companionship.

Changes in family life

Changes in family life can often have a significant impact on adults with Williams syndrome. Illness of a family member, or even a sibling getting married and having children, can lead to increased anxiety. Illness of a family member, particularly a parent, can lead to worries about the future (losing a parent, being alone). A sibling getting married or having children can lead the person with Williams syndrome to worry about their own circumstances, highlighting feelings of 'being different'. It is important to recognise that these changes (normal family life), can have a considerable impact on an adult with Williams syndrome.

Most people can tell us when they are anxious, but some adults 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 / trigger. For some adults 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 college / work (or refusing to leave the house)
- ⇒ Increased engagement in special hobbies (as avoidance or distraction)
- ⇒ Greater insistence on daily routines and sameness
- ⇒ More frequent or more intense angry or emotional reactions
- ⇒ Distress when separated from familiar others ('clingy')
- ⇒ Repetitive questioning
- ⇒ Hurting themselves

Common triggers for anxiety:

- ⇒ Changes in routine (e.g. college tutor is ill / boss is off sick)
- ⇒ Changes in environment (e.g. changing / moving between locations)
- ⇒ New or unfamiliar situations
- ⇒ Difficulty with social situations (e.g. other people joking)
- ⇒ Feeling under pressure to speak / interact in social situations
- ⇒ Sensory sensitivities / overstimulation (e.g. extreme noise)
- ⇒ Fear of a particular situation, activity, or object (linked to a specific phobia)

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), for example in social 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 individual to identify physical signs associated with emotions, including happiness as well as anxiety

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 person with Williams syndrome to identify triggers for their anxiety

This may be hard for some 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 person to practice these strategies when they are calm, and then guide them to use them when anxious

- ⇒ Working with other carers – keep each other informed about situations that raise anxiety and techniques that seem to work
- ⇒ Use visual timetables or pictures to show what will happen next so that they have some warning of a change in routine
- ⇒ 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 person for being brave e.g. if they manage to confront their fear (or even a bit of it)

Some final thoughts

Remember that there are things that some 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 daily functioning. We hope this booklet gives you a resource to think about these issues and to start a conversation about anxiety.

Further information and guidance


Williams Syndrome Foundation website:


www.williams-syndrome.org.uk

WS Research Group website:

www.durham.ac.uk/psychology/research/newilliamssyndrome

Social Media

 NWSResearchGroup

 WilliamsSyndromeFoundationUK

This booklet has been produced by members of the North East Williams Syndrome Research Group: Dr Deborah Riby, Dr Mary Hanley, and Dr Jacqui Rodgers

For further information please contact:

Williams.syndrome@durham.ac.uk

This booklet is part of the support package for families of WS of all ages in relation to anxiety—supported by the Williams Syndrome Foundation and