

Anxiety in Turner Syndrome

The Turner Syndrome Anxiety Project is a collaboration between Turner Syndrome Colorado and the eXtraOrdinary Kids Clinic and Research Team to respond to parent and patient questions about anxiety in Turner syndrome. We surveyed 135 community members and conducted 10 interviews.

Anxiety is like an iceberg... there is much more beneath the surface.

Many people with Turner syndrome experience social anxiety.

Doctor's appointments and health problems associated with Turner syndrome can trigger anxiety.

Difficulty sleeping is a symptom of anxiety that continues through adulthood.

Some people with Turner syndrome feel anxious about "being different" from their family and peers.

Many symptoms of anxiety are not easy to notice. This might be looping thoughts, muscle tension, body pain, worries, and fear of conflict.

Triggers for anxiety may change with age. Although some, like uncertainty or new settings, remain throughout life.

Anxiety can look and feel different at different ages, but avoidance and insomnia persist throughout the lifetime.

Many people don't know about the connection between anxiety and Turner syndrome. This can make it hard to get a diagnosis and receive care.

Anxiety impacts the whole family.

There is HOPE!
There are anxiety interventions that work for people with Turner syndrome.



For more information visit

turner-syndrome.org/turner-syndrome-anxiety-project



In collaboration with



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Handouts are for general information only. Information provided is not intended to be a substitute for specific medical advice from a medical provider.

Does Your Child Have Turner Syndrome?

How anxiety could be affecting your child.

What is anxiety?

Anxiety is having persistent and intense worries about everyday situations.

Symptoms of anxiety for people with Turner syndrome can include avoidance, insomnia, worries, perfectionism, refusal, or shutting down. Some symptoms and triggers change as your child gets older.

You Are Not Alone

Managing complex medical conditions, day to day life, and anxiety can feel overwhelming, but you are not alone.

50% of respondents reported experiencing anxiety four or more days per week

	Early Childhood	School Age	Adolescent	Adult
Triggers	<ul style="list-style-type: none"> Noisy and Bright Settings Doctor's Appointments 	<ul style="list-style-type: none"> Unresolved Issues and Conflict Overstimulation 	<ul style="list-style-type: none"> Recalling Negative Experiences Managing Expectations 	<ul style="list-style-type: none"> Recalling Negative Experiences Dealing with Conflict
Symptoms	<ul style="list-style-type: none"> Tantrums Aggression Hyperactivity 	<ul style="list-style-type: none"> Fidgeting Clinging Complaints of Illness 	<ul style="list-style-type: none"> Looping Thoughts Body Tension 	<ul style="list-style-type: none"> Negative and Looping Thoughts Avoidance

Where Does Anxiety Happen?

Parents work hard to accommodate anxiety at home every day.

71%

of individuals with Turner syndrome said anxiety was triggered at school or work

78%

of individuals with Turner syndrome said they expressed their anxiety at home

61%

of caregivers said they saw symptoms of anxiety mostly at home

Helpful Strategies

Families use many strategies to help manage the symptoms of anxiety.

The most helpful were:

- Therapy
- Daily medication
- Being with friends
- Taking a "Mental Health" day
- Calming activities like listening to music or meditation

Resources

- [Turner Syndrome Colorado](#)
- [Children's Colorado Turner Syndrome Clinic](#)
- [Turner Syndrome Society of the United States](#)
- [NAMI - anxiety disorders information](#)

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