

A Patient Guide to Feeding Issues in Turner Syndrome

Girls with Turner syndrome may struggle with various feeding difficulties, especially during infancy. Parents may be at a loss when it comes to helping their daughters get the necessary nutrition. This guide will offer some helpful tips you can try at home. Remember to discuss your concerns with your daughter's pediatrician.



Causes of Feeding Problems

Narrow, ridged palate (roof of mouth)

This can cause problems during breastfeeding, bottle feeding, or eating solid foods, as it can make it difficult for your daughter to control the food in her mouth and "clear" her mouth of food and drink. Some foods might get stuck in the roof of the mouth and may even cause a gagging reflex.

Upper respiratory infections and other congestion

Think about the last time you had a cold. Nothing smelled or tasted right, did it? Girls with TS can be prone to upper respiratory infections, which can make food unappealing, especially if they have sensory processing difficulties.

Pain from ear or sinus infection

Upper respiratory infections can directly affect your daughter's appetite—but in this case, it is usually because chewing or sucking with an ear infection can cause great pain.

Reflux or regurgitation

Girls with TS are more prone to reflux, so as babies they can have a tendency to spit up a lot after eating, especially as they transition into more solid foods.

One small study found that girls with TS tended to have what is called "delayed gastric emptying," a condition in which the stomach muscles do not function properly to allow it to be emptied completely. This can cause nausea and vomiting.

Hyperactivity

If your daughter has a hard time focusing at mealtime, this can lead to easy distraction, which makes it hard for them to sustain a long enough mealtime to get the food they need.

Jaws, teeth, or chewing problems

Many girls with TS have some issues with their jaw shape, teeth overcrowding, or tongue movement. All of these can affect eating, especially as they transition into more solid foods.

The Problem:

Oral Motor Dysfunction

A girl with oral-motor dysfunction will have physical difficulty controlling her tongue, mouth, and jaw muscles. This will make it difficult to breastfeed, chew, or suck from a straw.



Who can help?

A speech-language pathologist (or therapist) can evaluate, diagnose, and treat girls with feeding problems related to oral-motor dysfunction.

The Problem:

Sensory Processing

Some children may have a hypersensitivity to certain food smells or textures. This can cause them to avoid eating many types of foods.



Who can help?

A speech-language pathologist or occupational therapist can evaluate your daughter if you suspect her feeding problems are sensory related.

The Problem:

Reflux and Regurgitation

Some feeding problems are related to the gastrointestinal system, and can cause reflux, or excessive "spitting up." Delayed gastric emptying has also been suggested to cause nausea and vomiting as well.



Who can help?

A gastroenterologist is a doctor who specializes in treating conditions related to the esophagus, stomach, and intestinal tract. The TS clinical care guidelines recommend screening for celiac disease beginning at 2-3 years of age.

The Problem:

Ear Infection/Congestion

Frequent ear and upper respiratory infections are not uncommon in girls with TS. This can often cause pain with chewing or sucking.



Who can help?

An otolaryngologist (ENT) is a doctor who is specially trained to diagnose and treat conditions related to the ears, nose, and throat.

Helpful Tips:



Be patient

Especially as your daughter gets older and is trying to feed herself, this whole situation is likely even more frustrating to her than it is to you!

Find the right tools

Check with your doctor or therapists to see if there are different utensils that might help her manage it better, or bottles and/or nipples if you are bottle feeding her. If you are breastfeeding, a lactation consultant may be able to offer some helpful tips/tools.

Try smaller meals

If she struggles with reflux or spitting up, feed her smaller meals more frequently, rather than larger ones further apart. If this doesn't work, talk to your doctor about medications that might help.

Introduce new textures

This can help heighten her curiosity about food. Colors and a nice presentation may help, too. Avoid foods that you know make her gag or set off aversions. If she struggles with chewing, keep meals soft and wet.

Get her involved

Involve her as she gets older in the process of making meals, setting the table, etc. Give her the chance to help you pick out what foods to make and eat.

Avoid "mouth stuffing"

Encourage her to swallow all of her food before taking another bite. This will help if she has a high palate. Some girls may have difficulty feeling the food in their mouths, so they will try to overstuff.

Overall, try to find ways to help your unique butterfly find the mealtime methods that work best for her! Don't hesitate to reach out to us at TSSUS or ask your doctor and/or therapist if you need help.



Resources:

Ark Therapeutic Products

Products for speech & oral motor development, sensory integration, oral defensiveness, texture aversions, fine motor, drinking, feeding, chewing, and more.

www.arktherapeutic.com

Special Needs Feeder®

Special feeding bottle designed for babies with facial or oral problems that hamper their ability to maintain adequate suction for feeding. The specially designed valve and silicone feeder adjust milk flow to suit baby's needs.

www.medelabreastfeedingus.com

The newly-updated Clinical Care Guidelines for Girls and Women with TS can be found on the TSSUS website.

References:

"Delayed Gastric Emptying: a Novel Gastrointestinal Finding in Turner's Syndrome." Staiano, Annamaria; Salerno, Mariacarina; Di Maio, Salvatore; Marsullo, Giuseppe; Marino, Antonio; Concolino, Daniela; Strisciuglio, Pietro. Published 1996 in Archives of Disease in Childhood.

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"Oral Motor Dysfunction and Feeding Disorders of Infants with Turner Syndrome." Mathisen, Berenice; Reilly, Sheena; Skuse, David. Published 1992 in Developmental Medicine and Child Neurology.

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