

CARING FOR YOUR CHILD WITH TURNER SYNDROME

What Is Turner Syndrome?

Turner syndrome is a rare genetic disorder related to a defect in chromosomes. Chromosomes consist of genes that are made up of DNA. Chromosomes inside cells contain a unique blueprint for each person's development. Turner syndrome affects only girls, who are missing a chromosome that females normally have. This defect leads to physical symptoms that vary and can be mild or severe.

What Causes Turner Syndrome?

The cause is one of the X chromosomes in females being partly or completely missing. The reason why this chromosome is missing is unknown.

What Are the Symptoms of Turner Syndrome?

Babies with Turner syndrome grow slowly and often have feeding problems.

Common physical features include a short webbed neck, short height, wide chest, large or low-set ears, and low hairline at the back of the neck.

Ovaries often don't develop, so neither do breasts. Older girls will be late having their first period or may not have periods. Almost all females are unable to become pregnant.

Heart and kidney problems, hearing loss, and clumsiness may be present. Usually, girls and women have normal intelligence but rarely may have slight learning problems.

How Is Turner Syndrome Diagnosed?

A health care provider may suspect Turner syndrome because of a baby's appearance. A chromosome test is done to see whether an X chromosome is missing and confirm the diagnosis.

For this test, a small sample of blood is collected. Chromosomes from blood cells are counted, and their size and shape are studied. This arrangement of chromosomes is called a karyotype.

Other tests may be needed to check for other problems, such as heart or kidney disorders, caused by Turner syndrome.

How Is Turner Syndrome Treated?

Treatment with hormones can help correct some abnormalities. Hormones are chemicals in the body that control growth and other body functions.

Growth can improve by giving growth hormones. This treatment can increase height by several inches.

In early teen years, female hormones may be given. They will help physical development, such as breast growth and starting periods.

Other medicines are used as needed, such as for heart or kidney problems.

Specialists will help the health care provider choose the best treatment. These specialists include a geneticist for chromosome problems and an endocrinologist for hormone treatment.

DOs and DON'Ts in Managing Turner Syndrome

- ✓ **DO** use medicines as directed.
- ✓ **DO** follow up with an endocrinologist in addition to your primary care health care provider.
- ✓ **DO** help your daughter exercise, eat healthy, and keep to a normal body weight.
- ✓ **DO** call the health care provider if she needs special help with school.
- ✓ **DO** call the health care provider if she feels depressed.

✓ **DO** look for and join a support group. Ask your health care provider for help finding one or for more information.

⊗ **DON'T** stop using medicines without asking your health care provider first.

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FOR MORE INFORMATION

Contact the following sources:

- Turner Syndrome Society: Tel: (800) 365-9944; Website:
<http://www.turnersyndrome.org>
- The Endocrine Society: Tel: (888) 363-6274; Website: <http://www.endo-society.org>

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