

# Atlanto-Axial Instability: (AAI): What You Need to Know

**Atlanto-axial instability (AAI) is a condition that affects the bones in the upper spine. In this handout, you will learn about AAI and how it affects people with Down syndrome. You will also learn about the causes, signs and symptoms of AAI.**

## WHAT IS AAI?

**Atlanto-axial instability (AAI)** is a condition that affects the bones in the upper spine or neck under the base of the skull. The joint between the upper spine and base of the skull is called the atlanto-axial joint. In people with Down syndrome, the **ligaments** (connections between muscles) are “lax” or floppy. This can result in AAI where the bones are less stable and can damage the spinal cord.

## HOW MANY PEOPLE WITH DOWN SYNDROME HAVE AAI?

One or 2 out of every 100 children with Down syndrome have symptoms of AAI, but doctors do not know the exact number yet. AAI is less common in adults with Down syndrome.

## WHAT ARE THE SYMPTOMS OF AAI?

If your son/daughter has any of these symptoms, call the doctor right away.

- Change in the way your son/daughter walks
- Gets tired easily when walking
- Pain, numbness or tingling in the neck, shoulder, arms or legs
- Head tilting to one side
- Trouble moving the neck or holding it up
- Weakness in the arms or legs
- Loss of bladder control (having accidents)

## HOW DO DOCTORS TEST FOR AAI?

If your child has symptoms of AAI, the doctor will suggest an **X-ray**. If the X-ray results are abnormal (different than usual), the doctor will order another imaging test, like a **computed tomography (CT) scan or magnetic resonance imaging (MRI)** test.

## IS IT SAFER TO GET JUST AN X-RAY?

In previous years, doctors thought all people with Down syndrome should have regular X-rays to check for AAI. This is no longer true. An X-ray is low-cost and low-risk, but it does not always tell whether a person has AAI or not.

Sometimes, an X-ray shows AAI when there are no symptoms. If this X-ray is repeated, the AAI might go away. This means routine X-rays are not helpful. It is better to let your doctor know if your son/daughter is having symptoms.

## HOW DO DOCTORS TREAT AAI?

Treatment depends on your son/daughter's symptoms. In severe (very bad) cases, your son/daughter might need neck surgery. In less severe cases, physical therapy can also help.

If your son/daughter does not need surgery, it is important for him/her to be very careful playing sports or doing other physical activities. The doctor will tell you which sports and activities are safe for your son/daughter.

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Adapted from “Problems with the upper spine in children and adults with Down syndrome (DS)” by E. Margolis, B. Henry, B. Sandella and M. Stephens.