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Torticollis

(wry neck, fibromatosis coli or inflammatory pseudotumor of the neck)

Patient and family information, brought to you by the Education Committee of APSA

Overview - “What is it?”

Torticollis or wry neck or fibromatosis coli occurs in 0.3-2.0% of babies. It is a condition where the side muscle of the neck, sternocleidomastoid, (See Figure 1) becomes inflamed. The inflammation causes the muscle to tighten and shorten, tilting the back of the head towards the affected side and rotating the chin away from the affected side. Because it usually happens on one side only, the condition results in the child’s head tilting to one side all the time. It usually affects babies in the first few months of life. There is no known cause but sometimes it is associated with birth trauma from a breech delivery. It is often mistaken for a tumor as it can appear like a fixed mass in the lower neck on one side.

In rare situations, it does occur in older children, secondary to trauma to the neck or certain spine conditions.

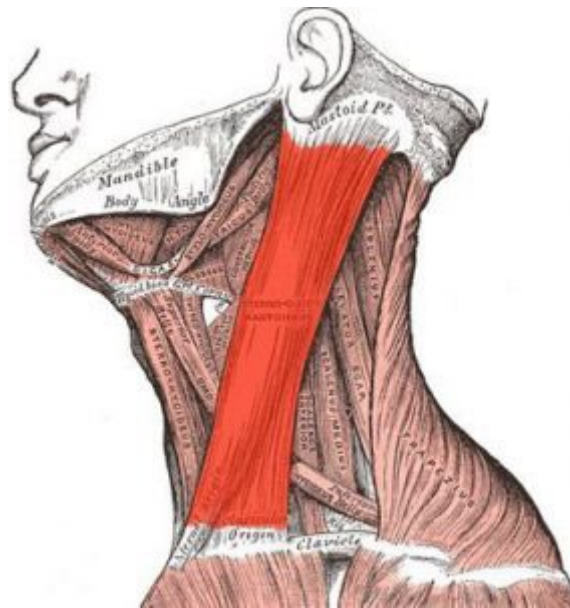


Figure 1: Sternocleidomastoid muscle.

(Image courtesy of: <https://upload.wikimedia.org/wikipedia/commons/1/1a/Sternocleidomastoideus.png>)

Signs and Symptoms - “What symptoms will my child have?”

The parents notice that the head is tilted one way and the chin is rotated towards the other side, forcing the baby to look to one direction. Because the back of the head is pulled towards one side the eyes become uneven, with the one on the affected side being higher than the other. Often there will be a firm mass in the neck on one side.

If left untreated, two long-term problems arise. The head and skull grow lopsidedly. The child’s vision can be affected because of the abnormal position of the eyes.

Diagnosis - “What tests are done to find out what my child has?”

Physical examination: All that is needed to make the diagnosis in an infant are the physical findings of the rotated chin and tilted head and a physical examination that shows a tight sternocleidomastoid muscle.

Ultrasound: If there is doubt regarding the diagnosis, an ultrasound is obtained. Torticollis looks very distinctive on ultrasound. In general, ultrasound is done prior to any surgery.

Review of history: Tumors of the sternocleidomastoid muscle are very rare and can present with a thickening of the muscle. In a patient older than a few months of age with new onset torticollis, a thorough search for a cause (spine conditions, trauma, tumors, certain antipsychotic medications) should be done.

Treatment - “What will be done to make my child better?”

Physical therapy: Aggressive physical therapy exercises under the direction of a physical and occupational therapist will loosen up the muscle over the course of a few months. Most infants do well with this treatment alone.

Surgery: In rare situations, the condition is discovered late and the sternocleidomastoid muscle is scarred irreversibly. Surgery is required to release the muscle.

Preoperative preparation: The child should have a shower or a bath the night before or the morning of surgery. The child should not eat anything solid for eight hours before surgery.

Procedure: It is an outpatient procedure, meaning the child would likely be able to go home the same day of his or her surgery. An incision is made on the affected side of the neck and the muscle is divided.

Benefits and risks: The risks are small and include infection and bleeding and recurrence of the scarring. The procedure is done as a last resort to prevent the flattening of the skull and the vision problems. It is rarely needed.

Home Care - “What do I need to do once my child goes home?”

Physical therapy: If this is recommended, parents are taught the physical therapy exercises by the therapist. It is important to keep doing the exercises faithfully as directed by the therapist. Placing attractive objects in the room away from the affected side encourages the baby to look towards that side and complements the regimen of physical therapy.

If surgery is required:

Diet: Your child may eat a normal diet after surgery.

Activity: Your child will have to resume physical therapy promptly after surgery. Ask the surgeon when therapy should start.

Wound care: Surgical incisions should be kept clean and dry for a few days after surgery. Most of the time, the stitches used in children are absorbable and do not require removal. Your surgeon will give you specific guidance regarding wound care, including when your child can shower or bathe. Wounds should be kept dry for three days; shower can resume after that. Soaking the wound (baths, swimming) should wait about one week after surgery.

Medicines: Medicines for pain such as acetaminophen (Tylenol®) or ibuprofen (Motrin® or Advil®) or something stronger like a narcotic may be needed to help with pain for a few days after surgery. Stool softeners and laxatives are needed to help regular stooling after surgery, especially if narcotics are still needed for pain.

What to call the doctor for: Call your doctor fever or if the wounds are red or draining fluid.

Follow up care: Your child should follow-up with his or her surgeon 2-3 weeks after surgery to ensure proper postoperative healing.

Long Term Outcomes - “Are there future conditions to worry about?”

Long-term outcomes are excellent with physical therapy only and rarely is an operation required. Once it is resolved, there are no other future conditions to be concerned about.

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