

What is congenital muscular torticollis?

Torticollis means twisted neck.

- Congenital muscular torticollis (CMT) is most often caused by a tight muscle on one side of the neck.
- Congenital means it was present at birth, but CMT may happen within the first few months of life.

Your child may hold their head tilted to one side and turn their head to the opposite or same side.

- Head tilt to the right is called right torticollis.
- Head tilt to the left is called left torticollis.

Treatment for torticollis:

- Depends on your child's age, the age their therapy started, and how severe (bad) the tightness of the neck muscles are.
- May involve your child wearing a semi rigid neck collar.

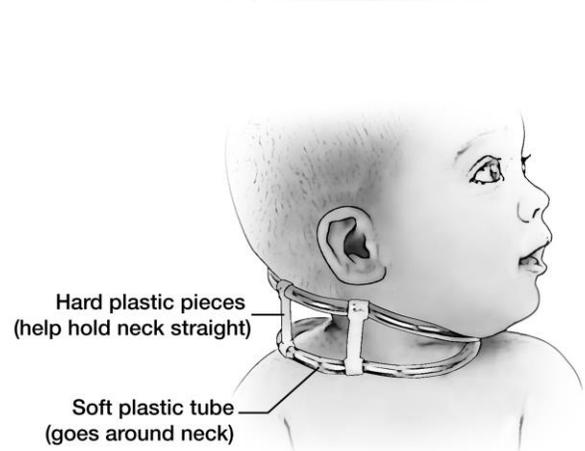
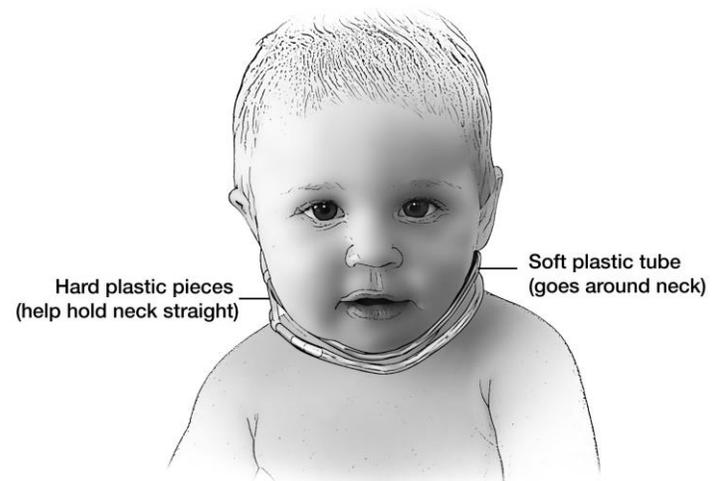
What is a TOT collar?

TOT stands for Tubular Orthosis for Torticollis. Tubular means it is made of a piece of tubing and orthosis means brace.

The TOT collar is used to help babies and children who have CMT.

It has 2 parts:

- A soft plastic tube that goes around the neck, like a turtleneck shirt
- Hard plastic pieces that are placed on the tubing to help to hold the neck straight
 - The hard plastic pieces are put on the side where the muscles are tight. This means:
 - If your child has right torticollis, the hard pieces are on the right side. The child in the pictures has right torticollis.
 - If your child has left torticollis, the hard pieces are on the left side. This will look the opposite of the pictures shown here.
 - The pieces separate the neck and help keep the head up in place and in the middle. This makes it hard for your child to tilt their head.



In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

TOT collar, continued

Why is a TOT collar used?

Torticollis makes it hard for your child to hold their head up in place, straight and in the middle. The TOT collar helps your child hold their head in the right place and corrects the torticollis.

When is it used?

The collar is used for babies and children that:

- Can sit by themselves.
- Have good movement in their neck.
- Have good strength in their neck.
- Tilt their head more than 5 degrees to the side away from the tight neck muscle side.

Does my child need physical therapy while using the collar?

Yes, your child will still need physical therapy (PT). You must also do your child's exercise program at home. The TOT collar:

- Is only used to help improve how your child holds their head in a corrected position.
- Does not take the place of exercises that your child needs.

How can I help keep my child safe when using the collar?

Your child needs to be awake and always supervised by an adult when wearing the collar. To help keep your child safe, a TOT collar should:

- **NOT** be used when your child is asleep or in the car.
- **ONLY** be used when your child is awake.
- **ONLY** be used when an adult is supervising your child.

How do I care for my child with the collar?

Your child's therapist will talk with you about how to care for your child. Some guidelines are:

- Check your child's skin a few times each day to make sure there are not any red spots or other skin problems.
- Make sure the TOT collar fits well and does not twist out of position.

Your child's therapist:

- Will show you the right position for the TOT collar.
 - Most often, your child's ear will be in between the 2 hard plastic pieces.
 - Sometimes, the therapist may choose a different place for the 2 hard plastic pieces.
- May cover the TOT collar and add padding.
- Can show you how to clean the collar.

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TOT collar, continued

When should I call my therapist?

Call your child's therapist if:

- You have questions about when your child should wear the collar.
- You have questions about exercises and activities your child can do while wearing the collar.
- You take off the collar and see red spots or other skin problems that do not go away within 30 minutes.
- The collar moves a lot, and you have trouble keeping it in the right place. Please take off the TOT collar and call your child's therapist if you are not sure whether the TOT collar is fitting or working right.

Therapist's name: _____

Phone number: _____

Email address: _____

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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