MANAGING DYSTONIA WITHOUT BOTULINUM TOXIN: EXERCISES AND TIPS

Anna Castagna¹, Elisa Andrenelli² e Marina Ramella¹

¹ IRCCS Fondazione Don Carlo Gnocchi, Milano, Italy
² Department of Experimental and Clinical Medicine, Neurorehabilitation Clinic, Universita’ Politecnica della Marche, Ancona, Italy

#STAYHOME

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• Breathing exercises

• The five tibetan exercises

• Stretching exercises
• Postural rules
Breathing

• Process that allows us to introduce oxygen (O2) and eliminate carbon dioxin (CO2)

• Organ
  • Lung

• The pump
  • Chest wall
  • Respiratory muscles
  • Nerve centers
  • Nerves
Inspiration

- Chest walls and lung expand
- Air gets in

Expiration

- Chest walls and lung withdraw
- Air gets out
Quiet breathing

**Inspiration**

- Active due to inspiratory muscles
  - Diaphragm
  - External intercostal muscles

**Expiration**

- Passive (elastic return)
Forced breathing

**Inspiration**

- Active due to respiratory muscles
  - *Sternocleidomastoid*
  - *Scalene muscles*
  - Pectoralis major and minor
  - Latissimus dorsi
  - Serratus anterior

**Expiration**

- Active
  - Internal intercostal muscles
  - Abdominal muscles
Importance of breathing

Internal Rhythm (12/15 acts per minute)

• Synchronization with movement facilitates the perception and integration of sensorimotor information

• Paying attention to it promotes muscle relaxation (es during meditation)
Yoga- Pranayama

Prana: breath
Ayama: length, control, expansion

The alternate nostril breathing. Breath control takes place during the classic four stages for each nostril:

1. inspiration
2. respiratory pause after inspiration
3. exhalation
4. respiratory pause after exhalation

Execution of pranayama exercises is better to be done after motor exercises.
Yoga

• Asana

Molecular Signature of the Immune Response to Yoga Therapy in Stress-related Chronic Disease Conditions: An Insight

HN Venkatesh, H Ravish, CR Wilma Delphine Silvia, and H Srinivas

The therapeutic value of yoga in neurological disorders

Shri K. Mishra, Parampreet Singh, Steven J. Bunch, and Ray Zhang

doi: 10.4103/0972-2327.104328

Annals of Indian Academy of Neurology

doi: 10.4103/0972-2327.104328

Ann Indian Acad Neurol.
The five Tibetans (P. Kelder)
**Starting position:**
- Standing
- arms outstretched, horizontal with the shoulders
- Look at your right hand (if possible)
**Spin clockwise**
Rite or exercise

- Lie down
  - hands flat down alongside of the hips
  - Fingers together
  - Palm down
- Flex head
- Raise the feet until the legs are straight up with feet extended back
- Return
3° Rite or exercise

• Kneel position
  • hands at sides
  • palms flat against the side of legs
  • Toes on the floor
• Flex head (chin on chest)
• Lean backward
• Return
4° Rite or exercise

- Sit erect
  - Palm on the floor with fingers together pointing the feet
  - Extended knee
- Flex the head (chin on chest)
4° Rite or exercises

- Extend the head
- Extend trunk with lifting of the pelvis off the ground (if possible the final position of the pelvis is parallel to the ground)
- Return
5° Rite or exercises

- Lie flat with the chest down
  - Head extended
  - Arms and legs extended
  - Support on the foot fingers
- Flex the pelvis without moving hands and feet until you reach an upside down V position
- Return
How to do the exercises

- Silent place
- A yoga mat
- Daily exercise
- First week each ritual must be repeated 3 times
- Each subsequent week increase in 2 reps until you reach 21 reps each day
- You can do it in the morning or evening better without food
- You can skip one day
Suggestions

• Perform the exercises VERY SLOWLY
• Associate breathing with movement and relaxation
• Try to perceive your body and your breath
• NEVER evoke pain
• DO ONLY what you can
• NEVER overload the system
• If you cannot do an exercise, go on with the four left
AVOID performing the exercises if:

- Pregnancy beyond the 6th month
- Recent surgery (less than 3 months)
- Recent heart attack (less than 3 months)
- Dilated heart disease
- Heart valve problems
- Hypertension
- Dizziness
- Lumbar problems or abdominal hernias
- Other neurological diseases
- Hyperthyroidism
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• Stretching exercises
• Postural rules

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Exercises for upper limbs and shoulders

**Stretching**

Repeat 3 to 5 times per exercise session
Hold this position for 10 more seconds

![Stretching exercises](image)
Exercise for trunk muscles

Strengthening muscles to support the back

Stretching exercise

Repeat 10 times per exercise session

Repeat 3 to 5 times per exercise session
Hold this position for 10 more seconds
CERVICAL DYSTONIA

TORTICOLLIS

LATEROCOLLIS

RETROCOLLIS

ANTEROCOLLIS
CERVICAL DYSTONIA

A. Stretch and relax the overactive agonist muscles that are in spasm.

B. Strengthen the antagonist muscles that can oppose to the torticollis.

BRING THE HEAD POSITION BACK TO NEUTRAL

Dystonia (World Federation of Neurology Seminars in Clinical Neurology, Volume 3) by Theodore L. Munsat, Joseph Jankovic
A. STRETCHING EXERCISES

• The stretching exercises will be applied to the overactive agonist muscles

• The exercises can be done in the standing or seated position

• Standing position: the height of the handhold should be about the mid-thigh level, close to where the hand rests naturally. You may use a heavy table or desk to grasp

• Seated position: a sturdy chair (with a backrest and without wheels) with a suitable leg or crossbar. For some exercises requiring a handhold in front of the patient, the front edge of the seat may be grasped

• If any movement produces pain patients should stop
Stretch the muscles in the back of the neck (Splenius Capitis, Levator Scapuli)

**Torticollis plus retrocolli**

Stretching for the left-sided muscles will be described. The entire procedure may be reversed if the patient requires stretching of the right-sided muscles.

- Grasp the handhold with the left hand
- Slowly lean the body toward the right side, allow the left shoulder to relax and be pulled downward
- Turn the head about $45^\circ$ toward the right, then tilt it into a direction away from the left arm. Hold this position for 30 seconds
- If the sensation of stretch begins to subside, reach over the top of the head with the right hand and gently pull along the direction of the stretch. Hold this position for 10 more seconds
- Relax
Stretch the sternocleidomastoid (SCM) muscle

TORCICOLLIS

Stretching for the left SCM will be described. The entire procedure may be reversed if the patient requires stretching of the right SCM.

• Grasp the handhold behind or underneath with the left hand

• Lean the body slightly so that the left shoulder is pulled downward.

• Turn the head toward the left side

• Tilt the head backward

• Tilt the head slightly so that the right ear moves closer to the right shoulder. Hold this position for 30 seconds

• If the sensation of stretch begins to subside, use the fingers of the left hand around the chin and slowly push upward.

• Hold this position for 10 more seconds

• Relax
Stretch Sternocleidomastoid on Both Sides

ANTEROCOLLIS

• Grasp a handhold behind or underneath with both hands, slowly lean the body backward to pull down the shoulders.

• Keep the head in the neutral position and then slowly tilt it backward

• Hold this position for 30 seconds

• Relax
Stretch Trapezius superior, Levator Scapulae, Sternocleidomastoid, and Scalenes

**LATEROCOLLIS**

- Stretching for the left-sided muscles will be described. The entire procedure may be reversed if the patient requires stretching of the right-sided muscles.

- Grasp a handhold with the left hand leaning the body to the right allowing the shoulder to be pulled downward

- Tilt the head sideways to the right

- Hold this position for 30 seconds

- If the sensation of stretch begins to subside place the right hand over the top of the head and slowly pull to the right

- Hold this position for 10 more seconds

- Relax
Stretch Splenius Capitis (SC)

RETROCOLLIS with a rotational component

- Stretching for the right SC will be described. The entire procedure may be reversed if the patient requires stretching of the left SC.

- Turn the head toward the left, then tilt it downward, tucking in the chin toward the chest

- Hold this position for 30 seconds

- If the sensation of stretch begins to subside, place the fingers against the side of the chin and gently push to rotate the chin toward the left shoulder

- Hold this position for 10 more seconds

- Relax
B. STRENGTHENING EXERCISES of antagonist muscles

- In most cases, the antagonists will be those muscles that correspond to the agonists on the opposite side of the neck.

- To strengthen any muscle, it is necessary to use it to exert a force against resistance. Thus, a suitable object against which to push is needed like a pillow-sized block of soft foam rubber. Alternatively, use an opposing hand or fingers.

- If the patient cannot perform an exercise against resistance, the movement by itself should first be tried.

- Sitting, standing, or lying position.
**Strengthen Sternocleidomastoid on One Side**

**TORCICOLLIS**

Torticollis toward the left (overactivity of the *right* SCM)

Strengthening of the left SCM will be described
(This entire procedure may be reversed if the patient requires strengthening of the right SCM)

- Seated position parallel to a wall. The right shoulder should just barely touch the wall. The foam block is placed on top of the right shoulder flush with the wall with the side of the face placed against the block

- Turn the head to the right until it is pressing as hard as is comfortably possible

- Hold this position for 30 seconds if possible

- Relax
- Repeat 3 to 5 times per exercise session, and increase as tolerated

- As an alternative to the pillow place a hand on the side of the face
Strengthen trapezius and levator scapulae

TORCICOLLIS and RIGHT LATEROCOLLIS

Stretching the left-sided muscles will be described. The entire procedure may be reversed if the patient requires strengthening of the right-side muscles.

- Grasp a hand- hold with the left hand
- Shrug the left shoulder without moving the head
- Try to keep the arm straight and not try to lift by bending the arm at the elbow.
- Hold for 30 seconds if possible
- Relax
- Repeat this exercise 3 to 5 times per session, increasing as tolerated to a maximum of 12 repetition
Strengthen Splenius Capitis (SC) and Others on One Side

ANTEROCOLLIS with rotational component

Strengthening of the right SC will be described. The entire procedure may be reversed if the patient requires strengthening of the left SC.

Starting position: lying on the back with the foam pillow underneath the head.

Turn the head approximately 45° to the right.

Tilt head backward pushing it into the foam pillow.

Hold the position for 10 seconds.

Relax.

Repeat the exercise 3 to 5 times per session, increasing as tolerated, to a maximum of 12 repetitions.
**Strengthen Sternocleidomastoids on Both Sides**

**RETROCOLLIS**

- **Starting position:** lying flat on the back
  - Lift the head straight upward and tilt the chin slightly toward the chest. Use 2 fingers to push against the forehead in order to provide resistance
  - Hold this position for 10 seconds
  - Relax
  - The patient should repeat this exercise 3 to 5 times per exercise session, increasing as tolerated, to a maximum of 12 repetitions.
Strengthen Sternocleidomastoid, Trapezius, Levator Scapuli, and Scalenes

LATEROCOLLIS with shoulder elevation

Strengthening for the right-sided muscles will be described. The entire procedure may be reversed if the patient requires strengthening of the left-sided muscles.

- Starting position: seat on a chair with the right shoulder touching the wall. Place the foam pillow on top of the right shoulder flush with the wall. Place the side of the head against the pillow.
- Tilt the head sideways to the right and push into the pillow as hard as comfortably possible.
- Hold this position for 10 seconds
- Relax
- Repeat this exercise 3 to 5 times per session, increasing as tolerated, up to 12 repetitions.
- As an alternative to the pillow place a hand against the side of the face.
Strengthen Splenius Capitis and Others on Both Sides

ANTEROCOLLIS
Strengthen all of the muscles that tilt the head straight backward

• Starting position: lying on the back on a firm surface with the pillow underneath the head

• Tilt the head straight backward, pushing into the pillow as hard as comfortably possible

• Hold this position for 10 seconds

• Relax

• Repeat this exercise 3 to 5 times per session, increasing as tolerated, up to 12 repetitions.
KINESIOTAPING

KT is a special therapeutic tape made of elastic cotton fiber and acrylic adhesive in a wavy pattern.

KT can be applied to increase proprioception, reduce pain and oedema, relieve muscle spasms. It can be used to reduce muscular tension (inhibition technique) or strengthen weak muscles (facilitation technique).
Kinesiotaping in cervical dystonia

Kinesiotape (KT) should be applied according to inhibition technique with paper-off tension over the over contracted muscles by means of Y-shaped tape (a single strip being cut down in the middle to produce 2 tails) or I- shaped tape (a single strip). Apply KT with the muscle placed in a position of maximum stretching from muscle insertion to origin in order to produce a pulling force opposite to the direction of muscle contraction and to reduce the tension in the muscle. Keep KT for 5 days, thus replace it.

In case of allergic reaction to tape, remove it. The colour of the tape is not relevant.
Sensory Trick- Geste antagoniste

• Manoeuvre that temporarily improves dystonic posture

• In most cases, it is a tactile or proprioceptive stimulus in a particular body area.

• Imaginary tricks: sensory tricks with mental imagery as the effective agent.

• Forcible tricks are atypical tricks: manoeuvres similar to sensory tricks but necessitate the use of force, and are always antagonistic to the direction of the dystonia

• The prevalence is about 17–89%, with majority quoting 70–80%.
Sensory tricks

Effectiveness

• The duration of effect of sensory tricks upon introduction of the stimulus can be variable.

• Patients with cervical dystonia had sensory trick responses that lasted from a few seconds to more than 1 minute.

• Patients with sensory tricks effective for more than 1 min tend to have shorter disease duration

• If the trick stimulus is maintained, the patient should achieve a prolonged effect

• Sensory tricks appear to be more effective in patients with rotatory torticollis

Sensory tricks are useful tools in the diagnostic process but also during rehabilitation treatment so the patients should be urged to seek them out
Sensory trick in cervical dystonia

- Touching specific parts of the face, cheek, chin, occipital and temporal region, forehead, nose, mastoid, occipital region, back of neck.
- Raising the arm and holding the finger near the target region without touching the face, or prior to touching the face.
- Imagining or merely thinking about performing a sensory trick.
- Visual fixation at a specific target, focusing on stationary objects while walking, looking at oneself in the mirror.
- Resting the back of the head or neck, bending the trunk forward, resting the back or shoulder, yawning, wearing a collar/a scarf, leaning the elbows on the armrest.
- Atypical tricks: forcible tricks with counterpressure to the cheek, temple, chin, back of head, mastoid, forehead. Those appear to be more effective in severe patients.

Sensory tricks in writer’s cramp

• 5 minutes immersion in cold water.
• Shifting pen holding, holding pen between index finger and thumb vertically, writing with a closed fist.
• Use pens of different sizes and calibres, using chalk and blackboard or painting.
• Touching specific part of the contralateral normal hand to a specific part of the dystonic hand.

Sensory tricks in apraxia of eyelid opening, blepharospasm

Tight goggles or spectacles, Lundie Loops. Device inserted in glasses to mimic touch to lateral eyelid.

Touching/pulling eyelids, tape on eyebrow.

Touching specific parts of the face (forehead, nose, side of eyelids, chin).

Pushing back of the head.

Massaging cheek bones, eyelid, forehead.

Closing the jaw, chewing gum.

Touching bitemporal skin beside eyes.

Covering the eye.

Picking teeth.

Wearing a cap or turban.

Lorenzano et al., 2019
Sensory tricks in Meige syndrome

- Sleeping/relaxing, talking, singing/humming, pulling on upper eyelid, pinching back of the neck, yawning, belching, sucking in or blowing out cheeks, drinking cold and/or alcoholic beverage.

Krack 1994
Sensory tricks in Lower cranial dystonia, oromandibular dystonia

- Toothpick in mouth, holding object clenched between the teeth, dental splint, touching lip, touching lower corner of face.
- ‘Mandibular sensory trick device’
- Touching tongue to palate, biting lips, swallowing, pulling face up, bending neck forward.
- Chewing gum, sucking.
- Kissing, whistling.
- Pen/cigarette/tongue depressor in mouth.
- Biting food/plastic between left upper and lower molars → dental prosthesis device 3 mm above molar.
- Smiling, singing, talking, thinking about talking.
- Biting piece of cotton or plastic.
- Dental splint.
- Playing with larger mouthpieces if musicians.
- 5 minutes ice massage of facial muscles.

Sensory tricks in Laryngeal dystonia

Grimacing, laughing, loud background noise.
Sensory tricks in Runner’s dystonia

• Holding hands over head
• Run in a clockwise direction
• Mental imagery of running in a clockwise direction.
• Beach walking
• Applying pressure with hand at hip

Sensory tricks in Camptocormia

- Low-slung backpack
- Using wheeled walker
- Pressing back against hallway.

Sensory tricks in DYT1 dystonia

- Piano playing

Recommendations for daily activities and environmental adaptations

In case of cervical dystonia: Try prone position with head turned to the side that corrects dystonia
Recommendations for daily activities
Ergonomic Checklist for Desk Activities

To reduce fatigue and pain

CHAIR
Chair height allows the feet to rest flat on the floor, or, if not, a footrest is used.
The chair provides lumbar support, or if a lumbar roll is added, it does not sacrifice seat depth. The seat depth provides coverage for most of the thigh yet does not allow the feet to dangle.
In case of cervical dystonia use a headrest.

UPPER EXTREMITY POSTURE
The upper arm is able to stay in a relaxed position, close to the body.
The elbow is positioned at a 90-degree angle.
Both wrists are maintained in a neutral position.

HEAD AND NECK POSTURE
Computer monitor height facilitates a neutral cervical position.
Recommendations for daily activities

Position of the speakers in the room: in case of cervical dystonia the speaker should sit on the side that corrects the dystonia: the patient can use sensory tricks
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Full presentation at www.dystonia-europe.org