

# Dystonia



## What is dystonia?

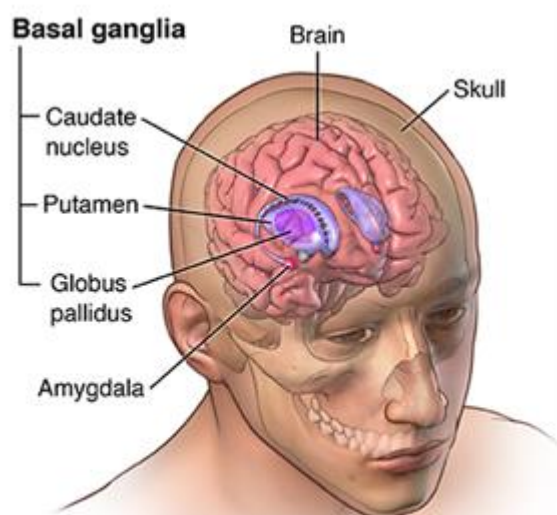
Dystonia is a disorder that affects the way your body moves. It causes your muscles to contract, which makes them move involuntarily. Or they may become stuck in an abnormal position. Dystonia can affect your entire body or a certain part. The movements can sometimes cause pain.

There are different types of dystonia, depending on which part of your body is affected:

- **Hemidystonia** affects a leg and arm on one side of your body.
- **Multifocal dystonia** affects at least two different parts of your body.
- **Segmental dystonia** affects at least two parts of your body that are next to each other.
- **Generalized dystonia** affects areas all over your body.
- **Focal dystonia** affects one particular area of your body.

## What causes dystonia?

Experts aren't exactly sure what causes dystonia. But they think it's related to a problem in the part of the brain called the basal ganglia. This is where your brain processes the information that helps your muscles contract. The theory is that your neurotransmitters, the chemicals that do the talking in the brain, are abnormal in people with dystonia. Dystonia, though, doesn't affect your intelligence or your ability to think. It isn't generally related to mental health issues. Sometimes, dystonia can occur after taking certain kinds of medicines. This is called tardive dystonia.



Research has pinpointed a number of different genetic defects that have been linked to dystonia. It can also be caused by a stroke, head injury, or other injury to the brain. These are called forms of secondary dystonia. In this case, the symptoms may be limited to one side of the body.

The first signs of dystonia can appear at any age, from children (usually between ages 5 and 16) to adults.

## Who is at risk for dystonia?

Scientists haven't yet determined the exact cause of dystonia. But certain factors can put you at risk for the disorder. These include:

- Family history (genes)
- Injury to your brain or nervous system
- Stroke
- Taking certain medicines such as neuroleptics
- Infections
- Poisoning such as from lead
- Doing highly precise hand movements, such as if you are a musician, artist, or engineer

## What are the symptoms of dystonia?

Symptoms may start slowly. For example, you might notice that your handwriting is worsening. You may get cramps in your feet, or you may lose control over your foot and find that it contracts or drags along.

Other symptoms of dystonia can include:

- Involuntary and rapid blinking that you can't stop
- A sudden tightening or turning of your neck to one side, particularly when you're feeling fatigued or stressed
- Trouble speaking
- A tremor in your voice
- Symptoms that worsen with tiredness, stress, or lots of physical activity

The symptoms of dystonia may stay the same or worsen over time. Some types of dystonia may be associated with other movement problems, such as Parkinson disease, or with psychiatric symptoms.

## How is dystonia diagnosed?

Diagnosing dystonia is a multistep process because no single test can give a complete answer. Your healthcare provider will usually do a physical exam and evaluate your symptoms. They'll also take a personal and family history to find out if you have any genetic indications for dystonia.

Other tests used to help diagnose dystonia include:

- Imaging of your brain with an MRI or CT scan
- Genetic tests to look for known defects linked to dystonia
- Tests to analyze blood, urine, and cerebrospinal fluid
- Electroencephalography (EEG) or electromyography (EMG)

## How is dystonia treated?

Your healthcare provider will take an individualized approach to your treatment. This may mean using a combination of things to help you manage pain and reduce muscle spasms. Your provider may try a number of different medicines that treat dystonia. These include medicines that affect the specific neurotransmitters acetylcholine, GABA, and dopamine. Other medicines that your provider might prescribe are anticonvulsants or injections of Botulinum toxin.

If you have a health problem causing dystonia, treating the problem may help the dystonia.

You may need surgery to treat dystonia, especially if you aren't able to manage symptoms with medicine. Surgery on the muscles or tendons can release the muscle contractures in some cases. But surgery can have negative consequences, such as destroying parts of your brain. Nerve injections can temporarily release the muscle tension as well. Stimulators (deep brain stimulation therapy) can be placed in the brain to help control the muscle movements better.

Other possible treatment methods include:

- New ways to manage stress
- Biofeedback
- Physical or speech therapy
- Wearing a splint on affected parts of your body

## What are possible complications of dystonia?

Constant muscle movement and contractions can result in fatigue and exhaustion. People also report that their symptoms worsen in stressful situations. Some people with dystonia may develop permanent malformations if their muscle spasms lead to constriction of their tendons.

## What can I do to prevent dystonia?

Even though you may not be able to prevent dystonia, genetic testing can reveal if you have a genetic defect that can cause dystonia. Speaking with a geneticist or a genetic counselor can help you decide if genetic testing is a good idea for you and your family.

## Living with dystonia

- Learn about dystonia and treatment options.
- Ask your healthcare provider to recommend a specialist who knows about dystonia.
- Find support groups so you can learn from others who have dystonia.
- Develop daily strategies that support adequate rest and restorative self-care, such as meditation.
- Develop a support system that includes family, friends, support groups, and online resources.
- Investigate complementary therapies, such as relaxation techniques, biofeedback, acupuncture, and meditation. Talk with your healthcare provider about gentle physical exercise options, such as tai chi or other soft martial arts.

## When should I call my healthcare provider?

Any involuntary muscle spasms or loss of control over muscles are symptoms that you should discuss with your healthcare provider right away.

## Key points about dystonia

- Dystonia affects how your body moves. The condition makes muscles involuntarily contract and can result in pain, fatigue, and exhaustion.
- It can affect your entire body or a certain part of your body.
- Experts aren't certain what causes dystonia. But they think it's a problem in the part of your brain called the basal ganglia.
- Treatments can help manage dystonia and prevent complications.
- Researchers have come a long way in understanding and treating dystonia. More research may reveal even more successful strategies.

## Next steps

Tips to help you get the most from a visit to your healthcare provider:

- Know the reason for your visit and what you want to happen.
- Before your visit, write down questions you want answered.
- Bring someone with you to help you ask questions and remember what your provider tells you.
- At the visit, write down the name of a new diagnosis and any new medicines, treatments, or tests. Also write down any new instructions your provider gives you.
- Know why a new medicine or treatment is prescribed and how it will help you. Also know what the side effects are.
- Ask if your condition can be treated in other ways.
- Know why a test or procedure is recommended and what the results could mean.
- Know what to expect if you don't take the medicine or have the test or procedure.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your provider if you have questions.

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