

# Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders

## What is hypermobility?

Hypromobility is when your joints are too flexible. Joints are areas of your body where two bones meet. Most joints bend, letting your body move. Some examples of joints are your shoulders, elbows, wrists, fingers, knees, ankles, and toes.

## What are hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders?

Hypromobile Ehlers-Danlos syndrome (EDS) (A-lurz DAN-loss SIN-drome) and hypromobility spectrum disorders are conditions where your joints stretch more than normal. People with these conditions are at risk of injury because their joints are too flexible.

People who have hypromobile EDS/hypromobility spectrum disorders may be at risk for other medical problems, such as:

- Abdominal cramping, bloating, loose stools, or constipation
- Anxiety
- Bladder problems
- Chronic pain
- Dizziness when standing up
- Easy bruising
- Feeling tired
- Joint problems such as arthritis and dislocation
- Problems with skin healing (scars)

## How will my doctor diagnose my condition?

Your doctor will examine you to see how flexible your joints are. Your doctor will also check your skin and eyes and listen to your heart. They may use tests (including blood tests) to decide which hypromobile condition is present.

Different people have different amounts of joint flexibility, skin problems, and other medical conditions. People with more of these symptoms may have hypromobile EDS, which is usually more severe than hypromobility spectrum disorders.

Sometimes these conditions can cause more serious problems with your eyes, blood vessels, or heart. Ask your doctor whether you need more testing for these problems.

## What should I do if I have one of these conditions?

There is no cure, but often you can control your symptoms by making healthy choices. Taking good care of your body may prevent joint injuries and arthritis in the future.

### Physical activity

- You should stay active but avoid activities that put too much stress on your joints. Activities to avoid include playing golf or swinging a bat.
- Don't overstretch. Instead, focus on gentle activities that make you stronger to make your

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## Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders *(continued)*

joints more stable. Good activities include walking, bicycling, and water aerobics. Go slowly to avoid getting too tired. Avoid activities that cause pain after they are over.

- Your family doctor and physical therapist can tell you what exercises to do.
- Taping or bracing joints that are too flexible may help prevent injuries by providing extra support.
- Tai chi (TY-CHEE, a form of exercise that uses slow, controlled movements) can help reduce falls and decrease pain in conditions like hypermobile EDS.
- Having good posture at home and work can help prevent pain and injuries. Physical therapists and ergonomics specialists (people who study how our body works best with furniture and machines) can help you with good posture.

### Healthy lifestyle

- Your body repairs itself during sleep; try to get seven to eight hours of sleep per night.
- Maintain a healthy weight.
- Eat a healthy diet; websites such as <https://www.choosemyplate.gov> and <https://oldwayspt.org> have good information about eating healthy.
- Don't have more than one to two alcoholic drinks per day. Don't smoke or use drugs.

### Mental health

- Relaxation, meditation, and massage can help reduce pain and manage stress.
- A type of counseling called cognitive behavior therapy can help people with hypermobile EDS to move better and feel better.
- Sometimes patients with hypermobile EDS feel like they are a burden to others. Talking about those feelings with family, friends, or a counselor can help.

- Maintain purpose in life with work and hobbies and by helping others.

### Other treatments

- Medicines such as acetaminophen (one brand: Tylenol) and anti-inflammatory drugs such as ibuprofen (one brand: Advil) can be used when your pain flares up.
- Applying heat or cold may reduce pain.
- If you faint or feel light-headed, let your doctor know. Getting up slowly, wearing support stockings, and drinking at least eight glasses of water per day can help.
- You might not react like other people do to numbing medicines used in medical procedures. Ask your doctors about how this might affect your care during and after any medical procedure.

Your family doctor will manage your care. It may involve a team of people like physical therapists, occupational therapists, counselors, and other kinds of doctors.

The more you understand your condition, the more you can help yourself live a better life. You can also help the people who care for you to help you even more.

### Where can I get more information?

#### The Ehlers-Danlos Society

<https://www.ehlers-danlos.com>

<https://www.youtube.com/channel/UC652wu-mvi2ghwQN-is7LIQ/>  
videos (patient education videos)

#### Hypermobility Syndromes Association

<https://www.hypermobility.org>

#### UW Health: Hypermobility spectrum disorders

<https://www.uwhealth.org/healthfacts/pain/6412.html>

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