

Hypermobility Spectrum Disorders

Your doctor has found that you have hypermobile joints. The ligaments, tendons, and other structures that support your joints stretch more than normal. Most people inherit this feature from a parent. Sometimes people with hypermobility are referred to as “double-jointed.” They do not have extra joints, just very flexible ones.

Hypermobility may affect many joints. You may be able to:

- Bend your spine forward and backward more than usual.
- Bend your fingers or toes backward or sideways more than usual.
- Bend your knees or elbows backwards.
- Move your legs in unusual ways or easily do “splits.”

Not everyone has the same amount, severity, or location of hypermobile joints. Doctors classify people with hypermobile joints into hypermobility spectrum disorders (HSD). People with HSDs tend to have joint pain, joint injuries (sprains) or “clumsiness” due to loose ligaments.

The types of HSD include:

- The **Ehlers-Danlos Syndromes (EDS)**: A group of different conditions causing hypermobile joints. Your doctor will help you figure out whether you have an EDS or one of the other HSDs. See Health Facts for You #8098, “Ehlers-Danlos Syndromes,” to find out more.
- **Generalized (G-HSD)**: Many hypermobile joints.
- **Peripheral (P-HSD)**: Hypermobile at hands and feet only.

- **Localized (L-HSD)**: Hypermobile at a single joint or group of joints.
- **Historical (H-HSD)**: Older people who are not hypermobile now but were when they were younger. They can still have joint pain and other problems.

People with HSDs may have some of these other conditions:

- Joint “popping” or “cracking”
- Flat feet
- Frequent ankle sprains
- Back pain
- Widespread aching pain or fibromyalgia
- Osteoarthritis
- Problems with healing (thin scars) or fragile skin
- Easy bruising
- Varicose veins
- Low blood pressure, dizziness when standing up
- Fatigue

Whether or not you have pain, you need to take good care of your body. There is no cure for HSDs. Taking the proper steps now may reduce your chances of having pain, arthritis, or other problems later in life.

Diagnosis

HSDs sometimes go along with more serious health problems. Talk to your health care provider to make sure these other problems have been checked for and ruled out. There are tests to check your eyes, blood vessels, and heart to make sure all are working well.

Exercise

A physical or occupational therapist can help you find a good exercise program and give you advice. Strength training helps support your joints and reduce extra motion. This may help protect the joints from harm. Light aerobic exercise may be helpful in keeping a healthy level of fitness.

Most people with HSDs do not need a lot of stretching, their joints and muscles are more flexible than normal. Stretch only those muscles that are very tight, cramping, or muscles that your therapist has told you to stretch. Good posture is very important, and you will be taught ways to help with this.

Braces and Splints

If a joint is getting painful or has arthritis, splints or braces may help to reduce pain, improve function, and prevent extra motion.

Tools used may include:

- Elbow or knee supports to prevent abnormal bending
- Arch supports in the shoes to support flat feet
- Ankle supports
- Finger joint splints
- Spine supports

Your health care provider will help you in your choice of splints or braces.

Fatigue and Faintness

People with low blood pressure, faintness when standing up, or fast heartbeat may feel better if they wear support stockings, drink plenty of fluids, and add salt to their diet. Talk to your health care provider about trying these things.

Activity

Some limits on activity can help reduce the risk of pain or injury. These limits vary from person to person. Talk to your health care provider to learn which ones apply to you.

Lifting, carrying, or other motions can cause harm or pain. They are safer if you maintain good posture, exercise, use splints or braces where needed, and take rest breaks.

HSDs may increase risk of back pain or other problems in pregnancy. To prevent this, pregnant women with HSDs or those who plan to become pregnant should talk with their health care providers.

Medicines and Supplements

Your doctor can help you find medicine for pain, if needed.

Some people have tried over-the-counter products to reduce their joint pain. Glucosamine and chondroitin is not harmful, but has not been proven to work. Herbal “joint health” products are not proven and could be harmful. Talk with your doctor before you use any over-the-counter supplement.

Skin Treatments

Some people get short-term relief from ointments, gels, creams, or by putting heat or ice on painful areas. Your health care provider can advise you on the best treatments.

Injections

Areas of muscle “knotting” and pain (trigger points) can sometimes be helped by special injections. See Health Facts for You #5934 “Trigger Point Injection.” Bursitis or tendon pain may also be helped by injections. Physical therapists may use “dry needling” techniques. Your doctor will help you decide if any of these are right for you.

Mind/Body Therapies

Pain from HSDs can be treated using relaxation, meditation, massage, and other non-drug methods. Mindfulness-based stress reduction (MBSR) can be very helpful. You can learn this through classes or using programs for your smartphone or computer. Talk with your health care provider to see if any of these are right for you.

People with HSDs can lead full lives. If you take good care of your body and follow the advice of your health care team, you should be able to manage your HSD well, instead of letting it manage you.

Good luck!

For more information:

The Ehlers-Danlos Society: www.ehlers-danlos.com

EDS Wisconsin: www.edswisconsin.org

Hypermobility Syndromes Association:
www.hypermobility.org

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 3/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6412.