Hypermobility Spectrum Disorders

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

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 experience joint pain, joint injuries such as sprains, or “clumsiness” because of loose ligaments. The types of HSD include:

- **Generalized (G-HSD):** Many hypermobile joints.
- **Peripheral (P-HSD):** Hypermobile at hands and feet, but not elsewhere.

- **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.

(The **Ehlers-Danlos Syndromes** [EDS] are a separate set of inherited conditions that look like G-HSD, but include a number of other problems. Your doctor will help you figure out whether you have an HSD or EDS.)

People with HSDs may experience 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, it is important to take good care of your body if you have a HSD. There is no cure for HSDs, so 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 conditions. Talk to your doctor or nurse to make sure these other problems have been checked for and ruled out. There may be tests to check your eyes, blood vessels, and heart to make sure all are working well.

**Exercise**
People with HSDs can get help from a good exercise program and expert advice, most often from a physical or occupational therapist. Exercises that increase strength can help you to 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, because their joints and muscles are more flexible than normal. Stretch only those muscles that are very tight, cramping, or have been specified by your therapist or other experts. Good posture is very important in HSDs, and you will be taught ways to help you with this.

**Braces and Splints**
If a hypermobile 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 and decrease stress on the ankles and knees
- Ankle supports
- Finger joint splints
- Spine supports

Your health care provider should guide you in your choice of splints or braces.

**Treating Fatigue and Lightheadedness**
Patients with low blood pressure, lightheadedness 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 whether you should try these things.

**Lifestyle Changes**
Most patients with HSDs live productive and happy lives. Some limits on activity can help reduce the risk of pain or being injured. These limits vary from person to person. Talk to your health care provider to learn which ones apply to you.

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

HSDs may cause an increased risk of back pain or other problems in the later months of pregnancy. To prevent this, pregnant women with HSDs or those who plan to become pregnant should consult with their health care providers.

**Medicines and Supplements**
If medicines for pain are needed, your doctor can help you find the best choices.
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 for HSDs. Herbal “joint health” products are not proven and could be harmful. Check with your doctor before you start to use any over-the-counter supplement.

**Treatments Applied to the Skin**
Some people get short-term relief from ointments, gels or 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. (For more details, please see *Health Facts for You* #5934 “Trigger Point Injection”). Bursitis or tendon pain may also be helped by injections. Your doctor will help you decide whether these are right for you.

**Mind/Body Therapies**
As with all chronic pain problems, pain from HSDs can be treated using relaxation, meditation, massage, and other non-drug methods. 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 JHS well, instead of letting it manage you.

Good luck!