

Ehlers-Danlos Syndromes (EDS)

Ehlers-Danlos syndromes (EDS) are caused when joints, ligaments, and sometimes other body parts are too flexible. There are different EDS types, each one caused by changes to a different gene. Most people with EDS have a relative with it also.

The most common problem in EDS is flexible joints that stretch too far. Flexible joints can cause:

- Cracking and popping in joints with normal use
- Joint pain
- Neck and back pain
- Ankle sprains or “rolling” the ankles
- Joint subluxations (joints pop slightly out and back in)
- Joint dislocations (joints come entirely out of place and have to be put back in)
- Increased risk of injury during sports or other exercise
- Posture problems, with headaches and muscle pain

Other problems are less common, and not everyone with EDS has them. They can include:

- Skin that is overly stretchy, tears easily, heals slowly, or heals with wide or thin scars
- Skin that seems transparent (veins are easy to see)
- Cold hands and feet
- Low blood pressure (Some people feel faint or lightheaded when standing up, and may have a faster than normal heartbeat when standing or exercising)
- Easy bruising
- Varicose (swollen) veins
- Aneurysms (swelling of arteries)
- Swollen lumps under the skin, around the joints, or on the backs of the heels
- Fibromyalgia (pain all over)
- Migraines or other kinds of headaches
- Problems sleeping

Kind of EDS	How common?	Main problems	Is there a genetic test?
Hypermobile (hEDS)	Most common	Joints are too flexible	No
Classical (cEDS)	Less common	Joints are too flexible Skin is very flexible and soft Scars are wide and thin Easy bruising	Yes
Vascular (vEDS)	Rare	Joints are too flexible Aneurysms form in blood vessels Organs or aneurysms can rupture	Yes

Your health care provider will help you find out if you have EDS, which type, and how to find treatment. You may need to see a specialist in genetics, or other specialist who knows about EDS, to help answer these questions.

Treatment for EDS

Treatment for EDS is to help you function better, have less pain, and take good care of your joints. The list below are some common treatments for EDS.

Physical therapy teaches you about your body and how to improve your health through exercise. It can teach you to protect your joints and make the muscles around them stronger. You can learn to have better posture, which can decrease pain. As you get stronger, you become less likely to hurt your joints or muscles. If you are given exercises to do on your own, it is important to do them every day in order to get stronger and feel better.

Occupational therapy helps you to use your hands and arms with less pain. Along with exercises to make you stronger, you may be given splints or braces to help make flexible joints more stable.

Orthotics (splints or braces) can be used on your feet, ankles, knees, or other joints that are too flexible or painful. These will let you walk and stand with less pain, and you will be less likely to have sprains or other joint injuries.

Your health care provider will help you decide if medicine would be helpful to reduce joint pain and muscle pain.

Injections can help decrease pain in sore joints, muscles, and spine. Not all EDS patients need injections. Your health care provider will work with you to decide if these can help you.

Coping and pain management training teaches you to manage your pain better and have a better life. You can learn to set goals for yourself and work to meet those goals. You may learn ways to “pace yourself” so that you don’t do too much activity at once and cause a flare of pain. You can learn ways to relax, distract yourself, or meditate to help manage your pain.

With the right care and some hard work, people with EDS can have a more relaxed and happy life. If you think you might have EDS or need help, talk about your options with your health care provider.

To learn more about EDS, please visit:

- The Ehlers-Danlos Society: www.ehlers-danlos.com
- EDS Wisconsin: www.edswi.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 © 11/2019. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8098