



Loeys-Dietz Syndrome:

Orthopedic Care (Care of the Bones and Joints)

People with Loeys-Dietz syndrome (LDS) need special orthopedic care (care of the bones and joints). Because each person with LDS is different, it is important to talk with your doctor about what care is right for you. Here are ways to care for the bones and joints of a person with LDS.

CARE FOR THE CERVICAL SPINE (NECK)

X-rays of the cervical spine (neck) are used to look for problems in the neck. These problems include:

- abnormal vertebrae (bones of the spine)
- subluxation (incomplete dislocation) of the vertebrae in the neck
- unstable vertebrae in the neck

When the x-rays show any of these, you should see an orthopedist (a doctor who cares for bones and joints) or a neurosurgeon (a doctor who operates on the brain and spine) to talk about the problem and what you should do to take care of it. In some cases, the doctor will recommend cervical spine fusion (surgery to join together the bones in the neck).

ALWAYS CHECK THE CERVICAL SPINE BEFORE HAVING SURGERY

Before people with LDS have any kind of surgery they should have an x-ray of the neck to check for cervical spine instability (any unstable vertebrae in the neck.) Having this x-ray study is important because cervical spine instability can affect intubation procedures (how the doctor places the tube in the throat used for breathing during an operation).

NON-SURGICAL CARE OF THE BONES AND JOINTS

Non-surgical care of the bones and joints may include:

- checking for scoliosis (curving of the spine) and regular measuring of the size of any curve to see if surgery to straighten the spine is needed.
- bracing for scoliosis
- orthotics (special shoe inserts) for loose ankle joints or misshaped feet
- harnesses or braces for loose or dislocated joints
- checking for poor mineralization of the bones (osteoporosis) that can make the bones more likely to break



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SURGICAL CARE OF THE BONES AND JOINTS

Surgery used to manage problems in the bones and joints includes:

- Surgery for scoliosis. Only some people with LDS need scoliosis surgery. The guidelines for the surgery are similar as for Marfan scoliosis surgery.
- Surgery to repair either pectus excavatum (a chest that sinks in) or pectus carinatum (a chest that sticks out). This is done when a person wants a more normal looking chest. In rare cases, pectus repair surgery is needed to improve heart or lung function or for other medical reasons.

WAYS TO LEARN MORE

- Contact the Marfan Syndrome Support Group Ireland at info@marfan.ie.
- Talk to your doctor. Sometimes it helps to use information like this fact sheet when you speak with the doctor.
- Visit the Marfan Syndrome Support Group website at www.marfan.ie.
- Visit the Loeys-Dietz Foundation website at www.loeysdietz.org.