



Loeys-Dietz Syndrome:

Orthopedic Care (Care of the Bones and Joints)



The NMF gratefully acknowledges the Loeys-Dietz Syndrome Foundation for their partnership in creating this fact sheet. For more information about the Loeys-Dietz Syndrome Foundation, visit www.loeydietz.org.

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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22 Manhasset Avenue
Port Washington, NY 11050

516-883-8712
800-8-MARFAN
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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.

HOW YOU CAN LEARN MORE ABOUT LOEYS-DIETZ SYNDROME

- Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. When you call, you will speak with a nurse who can answer questions and also suggest ways to find a doctor who knows about LDS.
- Read the other NMF fact sheets on LDS. They have more information on LDS features, how LDS is different from Marfan syndrome and how LDS is diagnosed. They are available on-line at www.marfan.org or from the NMF Resource Center.
- Read the NMF fact sheet “Scoliosis and Marfan syndrome.” It is available on-line at www.marfan.org or from the NMF Resource Center.
- Go to the Loeyes-Dietz Foundation website at www.loeysdietz.org