

Bone Health in Duchenne Muscular Dystrophy

This information sheet is about bone health in people with Duchenne muscular dystrophy. It is written for parents and caregivers. You might want to start by reading the Introduction to the Endocrine System Sheet, which introduces you to some basic topics.

What is osteoporosis and why do some people with Duchenne have it?

Osteoporosis is a condition in which there is thinning of the bones (reduced bone mineral density, or BMD). When bones are less dense, they become weak and brittle, which can lead to fractures. Strong bones depend on adequate physical activity, good nutrition, sun exposure, and hormones that are important for growth and puberty. People with Duchenne often develop osteoporosis due in part to lack of activity and as a side effect of steroid medication.

How do I know if my son has osteoporosis or a fracture?

People cannot feel osteoporosis unless there is a fracture, which can be painful. Fractures of the spine are more common in steroid-treated patients, may become painful over time; and can usually be diagnosed by X-ray. If your son has a limp, painful leg or arm, or back pain, his doctor may order X-rays to determine if he has a fracture and/or thinning of the bones.

What can I do to help prevent osteoporosis from developing?

To keep his bones as strong as possible your son needs to have regular bone health monitoring. It is recommended that he eat a healthy diet with adequate calcium and vitamin D intake. A dietician can help you pick a proper diet and may recommend dairy products (milk) as a source of calcium. Physical activity may be recommended by his doctor, if possible and appropriate for his condition, to help keep bones healthy. If your son uses a wheelchair, he should always wear a seatbelt to help prevent falls and fractures.

What tests may be ordered to monitor bone health?

Your son should be on a program to monitor his bone health, especially if he is taking steroids. This program involves regular check-ups to monitor for back or limb pain, fractures, growth, pubertal development, and calcium and vitamin D intake. An X-ray of the spine may show fractures that could be the cause of back pain. A DXA scan is a type of X-ray which is used to measure BMD to see if there is thinning of the bone. An X-ray of the left hand and wrist (called a bone age) helps to interpret the DXA scan and assess pubertal maturation.

How is osteoporosis treated?

If your son develops osteoporosis, your doctor or a bone health specialist will describe the various treatment options. These may include:

1. Observation, with proper diet and physical activity and no medications;
2. Calcium and/or vitamin D supplements, which should not exceed age-related guidelines; and
3. Treatment with a class of medication called bisphosphonates. These can be given intravenously (by a needle in his vein) or taken by mouth in liquid or pill form. They generally help to preserve bone mass and reduce the risk of fractures and back pain. Your son may need to take bisphosphonates for several years. A bone health specialist can explain the benefits and possible side effects of bisphosphonate treatment.

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What are the most important things to remember about osteoporosis?

- People with Duchenne often develop weak bones (osteoporosis) due to lack of physical activity, steroid treatment, and/or hormone deficiencies;
- If your son develops a limp, or back or limb pain, you should report it to your son's doctor;
- Your son should be on a program to monitor his bone health, especially if he is taking steroids;
- Your son should maintain adequate calcium and vitamin D intake and may be prescribed supplements;
- Your son should be physically active if recommended by his doctor;
- Your son may be prescribed bisphosphonate treatment for his osteoporosis. When considering any new treatment, discuss the benefits and possible side effects with your son's doctor.

What can I read to learn more?

The Diagnosis and Management of Duchenne Muscular Dystrophy: A Guide for Families.

http://www.parentprojectmd.org/site/DocServer/Family_Guide.pdf?docID=9321