

# Bone Health in Duchenne Muscular Dystrophy

This fact sheet is about bone health in people with Duchenne muscular dystrophy. You might want to start by reading the Endocrine Information Sheet, which introduces you to some basic topics. When we say “you” in this fact sheet, we mean the person with Duchenne.

## What is osteoporosis and what causes it?

Strong bones need lots of physical activity, good nutrition, enough sunshine, and your growth and puberty hormones. People with Duchenne often have weak bones (called osteoporosis). This is because they are not running and jumping that well. They may be treated with steroids, which can also cause weak bones. Weak bones can break more easily (called fractures).

## How do I know if I have osteoporosis?

You can not feel osteoporosis. There is no pain unless you have a fracture. Sometimes people learn that they have osteoporosis because it can show up on X-rays or other tests. If you have a broken leg or arm, the doctor may be able to tell on the X-ray that you have osteoporosis. If you have a sore back, the doctor might look at your X-ray and see that one of your back bones has a small fracture. Most boys like you have osteoporosis and many never have a broken bone.

## What can I do to improve my bones?

To keep your bones as strong as possible, you need to eat a healthy diet with enough calcium and vitamin D. A dietician can help you pick a healthy diet. You need to drink milk and eat cheese, yogurt, and other foods with lots of calcium. Your doctor may give you extra calcium and vitamin D if you need it. Keeping as active as you can helps your bones too. Don't forget to buckle up—this is especially important if you have weaker bones.

## What tests do I need if I have osteoporosis?

You should have regular check-ups for back pain, fractures, growth, puberty, and how much calcium and vitamin D is in

your diet. If your doctor thinks you might have osteoporosis, you might have a spine X-ray or a DXA scan. Different doctors choose different ways to check your bone health.

## Can my osteoporosis be treated?

If you have osteoporosis your doctor will talk to you about treatment choices. Choices include:

1. Keeping a close eye on your bone health and not give you any medication for your bones;
2. Sending you to see a doctor who is an expert on osteoporosis;
3. Talking to you about other medications that help with low hormone levels and bone health; and
4. Giving you a medicine called bisphosphonates. They generally help to increase bone health and reduce any back pain caused by fractures. You and your parents should talk to your doctor about how it might help you versus the possible side effects that you wouldn't like.

## What are the most important things to remember about osteoporosis?

- People with Duchenne often have weak bones (osteoporosis).
- You need to be on a program to check your bone health, especially if you are taking steroids.
- You need to have enough calcium and vitamin D in your diet.
- You should keep as active as you can.

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- If you need treatment for osteoporosis, ask lots of questions about your choices and side effects that could hurt you.

### What should 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](http://www.parentprojectmd.org/site/DocServer/Family_Guide.pdf?docID=9321)