

Short Stature (Height) in Duchenne Muscular Dystrophy

This information sheet is about short stature (height) 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 information sheet, we mean the person with Duchenne.

What is “short stature”?

“Short stature” is defined as height below the normal range. Being short does not affect your health. Some boys and men are not bothered by being short. However, it is possible that your short stature may make you feel unhappy or worried.

What causes short stature?

Short stature is common in boys with Duchenne. The main reason for short stature is that steroids cause slow growth. Boys with Duchenne who are not on steroids may also be shorter than expected.

How is short stature monitored?

It is important that your doctor keep a record of your growth. This will show if your growth begins to slow down. Your family should talk to your doctor about the possibility of slow growth before starting steroids. In general, concerns about growth do not prevent the use of steroids.

What tests need to be done?

If your growth is slow, your doctors should check your health and diet, and check whether you have started puberty. Your doctor might do blood tests to make sure there aren't other causes of slow growth. Another test is a “bone age” or hand X-ray to see how much time there may be before you stop growing. Your doctor might send you to see an endocrinologist (hormone doctor).

What can we do about it?

It is normal for doctors to watch short stature without doing a treatment since short stature does not cause you any health problems. Some doctors believe it may be easier for you to move around and for other people to help you if you are short.

If you are taking steroids, sometimes a doctor might talk to you about decreasing your levels of steroids to see if you grow faster—but this may reduce your strength.

Using growth hormone is not standard care for Duchenne. Growth hormones may have unwanted side effects. We don't know much about if, when, or how to use growth hormone in Duchenne. If you are considering using growth hormone, you should make a decision after getting as much information as possible from your doctors.

Some people with Duchenne are bothered about being short. If you feel bad or concerned, psychological support can help you adjust and feel better.

Summary & important facts to remember:

- Short stature can be an issue for boys with Duchenne, especially those who are on steroids.
- Measuring growth regularly is important.
- Talk to your doctor if you are concerned about growth.
- Usually the doctor doesn't need to do anything about short stature except for keeping an eye on growth.
- You may be referred to an endocrinologist.
- Psychological support may be very helpful if you are concerned about being short.

What resources are available and how can I learn more about it?

The Diagnosis and Management of Duchenne Muscular Dystrophy: A Guide for Families
http://www.parentprojectmd.org/site/DocServer/Family_Guide.pdf?docID=9321