

Delayed Puberty in Duchenne Muscular Dystrophy

This information sheet is about delayed puberty 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 puberty?

Puberty is a process when your hormones cause your body to change. Some changes of puberty are more facial hair, pubic hair, body odor, acne, your voice gets deeper, and you grow taller. Puberty usually starts when you are between 11-14 years. It takes a few years to be finished.

How do steroids affect puberty?

If you are taking steroids, your puberty may:

1. Start late and change slowly or
2. Not start at all.

You may look a lot younger than you really are. Compared to boys your age you may be:

1. Shorter;
2. Have little or no facial, body, or pubic hair;
3. Have a smaller penis; and
4. Have a higher voice.

It is important to remember that boys with Duchenne who are on steroids may have some puberty changes in their late teens and twenties.

Sometimes the way you look may cause other people to treat you like you are much younger. This may cause you to be concerned. If it does, it is good to talk about how you feel with your parents or someone you trust. You could also talk to someone by yourself in private if you are worried about what people might say or think about you.

There are some good sides of delayed puberty. Teens and young men with delayed puberty do not have to shave and do not get pimples—at least until their puberty begins.

Even though your puberty might be delayed by taking steroids, you need to remember that steroids are still recommended because they help you stay stronger. If you have any worries or questions please talk to your doctor.

Will I need any tests?

You may not need any tests if puberty is delayed. Your doctor will watch for physical signs of puberty. Your doctor will do a physical examination to see if you need any more tests (like an X-ray of your hand or a blood test to check hormone levels). If you want to talk with your doctor in private without your parents, that is ok. If you are bothered about how you look, talk to your parents and your doctor. Your doctor might send you to a puberty specialist (endocrinologist) who can tell you about medicines that might help.

Important facts to remember:

- Delayed puberty is common in teens on steroids.
- You should talk about delayed puberty with your doctor.
- Seeing a puberty specialist might help you know if you need any treatment.

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

“Hormones and Me” Booklet Series: Delayed Puberty (APEG and Serono Symposia)

http://www.apeg.org.au/Portals/0/resources/hormones&me5_puberty&its_problems.pdf