

Delayed Puberty in Duchenne Muscular Dystrophy

This information sheet is about delayed puberty 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 puberty?

Puberty is the process when hormones cause a person's body to change, mature, and eventually to be able to reproduce. In boys, testosterone is the hormone that causes many of the changes seen during puberty. Some signs of puberty are facial hair, pubic hair, body odor, acne, your son's voice getting deeper, and a growth spurt. Puberty hormones are also important for bone health. Puberty usually starts between 11-14 years. It takes a few years to be completed.

How do steroids affect puberty?

If your son is taking steroids, his puberty may:

1. Start late,
2. Not start at all, or
3. May not continue normally once it has started.

Your son's dose of steroids and the age that he started steroids may affect when he starts puberty.

If your son has delayed puberty he may look a lot younger than he really is. Compared to boys his age he 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 keep in mind that people with Duchenne who are on steroids may have some puberty changes in their late teens and twenties.

Sometimes the way your son looks may cause other people to treat him like he is younger. This may be especially

upsetting to your son when he is a teenager or young adult and does not want to be treated like a child.

There are some good sides of delayed puberty. Being short may make it easier for your son to get around and easier for you to care for him. 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 son's puberty might be delayed by taking steroids, you need to remember that regular use of steroids is still recommended because it helps your son maintain his muscle strength. You and your son should talk to his doctor about how steroids might affect his puberty so your family can be prepared.

When should I be concerned?

You and your son should talk to your son's doctor if he doesn't have signs of puberty by age 14, or anytime you are worried. The main health concern of delayed puberty is that your son's bones aren't getting hormones that make them stronger (see the bone health fact sheet).

Emotional concerns (such as feeling bad about looking young or being short) are very important concerns. Encourage your son to talk to his doctor about any concerns.

What tests should I talk to my son's doctor about?

Your son may not need any tests if his puberty is delayed. Your son's doctor will work with you and your son to watch for signs that puberty is starting. The doctor will review your son's health history, family history, medications, and do a physical examination to see if he needs any more tests (like an X-ray of his hand to check his bone age or a blood test to check hormone levels).

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Parents and caregivers, please encourage your son to talk to his doctor alone for part of each visit—you can offer to leave the room for part of the visit. He needs the opportunity to talk to another trusted adult. This is also good practice for him as he becomes a young adult and takes more control over his own healthcare.

What can my son's doctor do about delayed puberty?

Your son's doctor may recommend that he sees a pediatric endocrinologist (hormone doctor), especially if he is concerned by delayed puberty or being short.

If your son seems to be having problems with his self-esteem, emotional adjustment, or social interactions, evaluation by a psychologist or other mental health professional should be a top priority. Counseling or other kinds of behavioral or social interventions can help your son feel better about himself.

Your son has several choices about his treatment (or not having treatment). Talk to your son and his doctor about choices including:

1. Changing the dose of steroids. If changing your son's steroid dose, the doctor needs to check carefully for changes in his muscle strength and ability.
2. An endocrinologist may consider treatment with testosterone (the male puberty hormone) to help with puberty changes. This will bring on typical male teenage behaviors such as mood swings and more interest in sex, as well as, change the way your son's body looks. However, these medicines have their own side effects and complications, and not many doctors have much experience with using testosterone to help people with Duchenne who are on steroids start puberty.

Important facts to remember:

- Delayed puberty is common in people with Duchenne who are treated with steroids.
- You should talk about delayed puberty with your son and his doctors.
- Encourage your teen to talk with his doctor alone.
- Delayed puberty may not need to be treated, but your son's doctor should monitor it.

- Seeing a pediatric endocrinologist (hormone doctor) is often useful to discuss your concerns and treatment options.

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