



DMD CARE UK
BEST CARE FOR ALL



i Information Leaflet

PUBERTY & TESTOSTERONE TREATMENT IN DUCHENNE MUSCULAR DYSTROPHY (DMD)



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What is puberty?

Puberty is the period when a child's body develops into an adult.

This process often takes about three years. The average age when puberty starts in a boy is approximately 11 ½ years (range 9-14).

Changes that happen during puberty in boys include:

- (a) Growth of the penis and size of the testes.
- (b) Development of pubic and underarm hair.
- (c) Deepening of the voice.
- (d) Growth spurt.
- (e) Development of stronger bones and muscles.

Puberty starts when the pituitary gland (a pea sized gland that sits in the middle of the brain) releases two puberty initiating hormones: luteinizing hormone (LH) and follicular stimulating hormone (FSH). These two hormones make the testes bigger, which then produce the male hormone (testosterone). Testosterone causes pubic and underarm hair growth and an increase in the growth of the penis.

How is puberty affected in DMD?

If your son is taking steroid medicine (Prednisolone or Deflazacort), it is very likely that his puberty will start late, never start or start but not progress normally.

Steroid medicines used in DMD mainly affect the release of the puberty initiating hormones from the pituitary gland (LH, FSH).

This affects testosterone production by the testes. Lack of puberty may affect your son's self-esteem. Boys with DMD have weaker bones with an increased risk of fractures due to the underlying condition and long-term use of steroid medicines. Puberty hormones help to make bones thicker and stronger. If puberty is delayed or absent, this may further weaken your son's bones.

When should I be concerned about my son's puberty?

Your doctor should examine your son for signs of puberty about once a year from around 12 years of age.

Your doctor may refer your son to another specialist (endocrinologist) for assessment of pubertal development including the size of his testes. Testosterone treatment is recommended by 14 years of age, if there are no signs of puberty. It may be considered from 12 years of age if there are no signs of puberty together with concerns about weak bones.

The endocrinologist may request blood tests to look at the hormones that control puberty and an x-ray of your son's hand and wrist to determine growth potential.

What treatment can my son have for delayed puberty?

The doctor will discuss and suggest testosterone treatment, if appropriate.

Treatment can be given by monthly injections or daily gels over two to three years. This mimics the gradual increase in testosterone levels during puberty.

Testosterone treatment will lead to an increase in size of the penis, development of pubic as well as body hair. Your son will look more physically mature, and his voice will deepen with time. Often, this will help him to feel more confident and similar to his friends. In addition, there may be some increase in your son's height. Testosterone may also help strengthen his bones by stabilizing bone density.

What will happen if my son starts testosterone?

Your son will be monitored roughly every six months to assess his pubertal development.

If your son's testes size is increasing on testosterone treatment, the doctor will consider stopping the treatment. If this happens, he may be making sufficient hormones himself for puberty to progress.

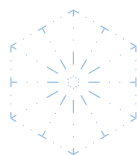
Your doctor may stop testosterone treatment after your son has received it for two to three years. The doctor will take blood tests to see if he needs to continue taking testosterone. Some young men with DMD who continue to take steroid medicine will not make sufficient testosterone and may need to continue testosterone treatment into adult life. If steroid medicine is reduced or stopped, it may trigger their own puberty. Therefore, the need for on-going testosterone treatment will be reviewed accordingly.

How can I find out more information?

If you wish to find out more, please ask your nurse or doctor in clinic.

DMD Care UK is a nationwide initiative to ensure every person living with Duchenne in the UK has access to the best care. DMD Care UK is funded by Duchenne UK and Joining Jack. They work closely with the John Walton Muscular Dystrophy Research Centre in Newcastle and in collaboration with the North Star Network, funded by MDUK.

Find out more at dmdcareuk.org



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Reviewed by the Patient Advisory Board of Duchenne UK.

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