

Muscular dystrophy - the face and shoulders

Facio-scapulo-humeral (FSH) muscular dystrophy is generally considered more benign (less serious) than other forms of muscular dystrophy. A feature of FSH is that it is usually asymmetrical. This means that some muscle groups on one side of the body are stronger than they are on the other side of the body.

Typical features of facio-scapulo-humeral muscular dystrophy

A characteristic facial appearance often develops, including:

- The eyes appear to be slightly open when the affected person is sleeping. This is due to weakness of eye closure muscles.
- There are less facial lines due to age than usual.

This characteristic facial appearance is more noticeable when the muscles are in use: for example, during speech.

Muscle weakness in the shoulders and arms may lead to:

- 'Winging' of the scapulae (shoulder blades): the shoulder blades protrude backwards, especially when the arms are held forward
- Reduced muscle bulk between the shoulder blades
- Difficult, or an inability, to raise the arms: some people first notice a problem in sport, for example, serving at tennis
- Weakened ability to bend and straighten the elbow, which is due to weakness of the upper arm muscles.

Lower limbs and back

The selective pattern of muscle weakness may include:

- Foot drop due to weakness of muscles in the front of the leg
- Weakened ability to straighten the hip joints. The knees may also be affected
- Lordosis (sway back). In severe cases, the abdomen may become protuberant and the shoulders excessively held back.

Eyes and ears

In severe early onset FSH muscular dystrophy, deafness is a frequent problem. Changes also occur in the eyes, although this seldom affects vision. However, people with FSH muscular dystrophy should have their eyes checked regularly.

Difficulties caused by FSH muscular dystrophy

Difficulties include:

- Trouble combing hair, hanging out washing and reaching high shelves, due to an inability to raise the arms
- A tendency to trip due to the foot drop
- A tendency for one or both knees to give out
- Difficulty with stairs and steps.

Levels of severity

Those most severely affected by FSH muscular dystrophy are handicapped in infancy or early childhood, and are unable to walk by adolescence or early adulthood. At the other end of the spectrum, even an experienced doctor would find it difficult to tell that a person had the condition.

Progression of the disease

On average, FSH muscular dystrophy progresses slowly and the level of severity eventually seems to plateau (level off). In very mild cases, it may not be possible to detect that the disease is progressing. People affected by FSH of 'average severity' usually retain the ability to walk and have a normal life span.

Where to get help

- Your doctor
- Muscular Dystrophy Association Tel. (03) 9320 9555

Things to remember

- FSH muscular dystrophy is generally considered to be a more benign form of muscular dystrophy.
- FSH muscular dystrophy usually affects one side of the body more than the other.
- Foot drop and an inability to raise the arms are typical symptoms.

This page has been produced in consultation with, and approved by:

Muscular Dystrophy Association

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