

# Understanding Facioscapulohumeral Muscular Dystrophy



Facioscapulohumeral muscular dystrophy (FSHD) is a genetic disease of the muscles. It causes your muscles to break down and weaken over time. It can develop quickly or slowly. FSHD targets the muscles of the face, upper arm or shoulder blade, legs, and stomach. FSHD is the third most common type of muscular dystrophy.

FSHD can show up at any age. But it is often diagnosed in people who are in their teens or 20s. Children with FSHD tend to have more severe cases. Over time, they may lose the ability to walk. But most people with FSHD have a normal lifespan.

## How to say it

FAY-shee-oh-SKAP-yoo-loh-HYOO-muhr-uhl

MUHS-kyoo-luhr DIHS-troh-fee

## What causes facioscapulohumeral muscular dystrophy?

FSHD is a genetic disease. It is often passed down in families.

It is diagnosed through genetic testing.

## Symptoms of facioscapulohumeral muscular dystrophy

The symptoms of FSHD can develop slowly over time. Or they can appear and get worse quickly. They often affect one side of the body more than the other. Along with muscle weakness, you may also feel pain.

Muscle weakness often starts in the face, especially around the mouth and eyes. You may have trouble smiling, whistling, or closing your eyes. It may then spread to your upper arm muscles—your biceps and triceps. Your shoulder blade may start to jut out of your upper back.

As FSHD gets worse, the muscles in one of your legs may start to weaken. Over time, about 1 in 5 people with FSHD need a wheelchair. The muscles in your stomach may also get weak. That may cause your belly (abdomen) to stick out. The inward curve of your back may become greater.

## Treatment for facioscapulohumeral muscular dystrophy

There is no cure for FSHD. Treatment tries to limit pain and disability, and maintain your quality of life. The types of treatment also depend on the severity of your condition case. Having a specialist healthcare provider (physiatrist or physical medicine and rehabilitation doctor) oversee your care is advised. Your healthcare provider may advise:

- **Physical therapy.** You can learn exercises or stretches to improve your movement and range of motion, especially in your shoulder. It can help with your daily living.
- **Exercise.** Aerobic exercise and weightlifting can help ease muscle weakness. It can also keep your heart healthy.
- **Pain relievers.** Nonsteroidal anti-inflammatory drugs (NSAIDs) and other medicines may help ease pain and keep you active.
- **Walking and other movement aids.** A cane, walker, or braces can help keep you mobile. In severe cases, you may need a wheelchair.
- **Respiratory care.** In rare cases, FSHD can affect breathing. You may need support for breathing, especially while sleeping.

- **Surgery.** If your shoulder blade is sticking out a lot, surgery may help. It can reduce pain and weakness and improve range of motion.

You will also need regular medical care. It's important that your healthcare provider keep track of how well you can move, as well as your vision, hearing, and breathing.

Mental health counseling can help you and your family cope with the pain and disability of FSHD. Think about talk therapy (counseling) for yourself and family counseling for your family. You may also want to join a support group.

Also think about seeing a genetic counselor. This is a healthcare provider with special training in genetics. The counselor can explain genetic testing. They can also estimate the chances that a relative may be affected by FSHD.

## Possible complications of facioscapulohumeral muscular dystrophy

- Foot drop. Muscle weakness of the lower legs causes this condition. The weakness affects walking and increases the risk of falling.
- Vision and hearing problems
- Trouble breathing

## When to call your healthcare provider

Call your healthcare provider right away if you have any of these:

- Fever of 100.4°F (38°C) or higher, or as directed by your healthcare provider
- Pain that gets worse
- Symptoms that don't get better, or get worse
- New symptoms

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