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## **Health Tips**

FSHD is highly variable, even among family affected members. Each person is different and possesses a unique combination of genetic and environmental factors that influence his or her body and health in general and FSHD in particular. A physician should be your source for specific clinical information\*, but here are some basic tips.

### **Keep Healthy Habits**

Managing FSHD requires, first and foremost, managing one's overall health. Healthy habits and practices will help with managing FSHD, while poor ones such as smoking, poor diet, not getting enough sleep and high stress will make it harder.

### **Speak Up and Be Persistent**

FSHD can affect things in ways that are not obvious or direct. For example, a doctor who lacks experience in muscular dystrophy may not be able to find the cause of a specific pain and basic tests such as an x-ray will not offer any indications as to the pain source.

A neurologist, orthopedist or physical therapist with experience in muscular dystrophy may have an educated hunch about the cause of pain and may be able to provide the appropriate relief measures.

### **Medications Will Vary from Patient to Patient**

The side effects of some medications and other medical treatments may be more problematic for some FSHD patients than for people without FSHD. If a patient has FSHD and has been prescribed specific medications by a physician, the patient should monitor any side effects closely and notify their doctor accordingly.

### **Flu Shots, Surgery and Inactivity**

Because of the muscle breakdown caused by FSHD, inactivity can be even more problematic for FSHD patients than for other people. To reduce the risk of flu and the resulting inactivity, some FSHD patients take flu shots even though other young and middle-aged adults typically aren't encouraged to get flu shots.

Some surgeries can be done using either a general or a local anesthetic; some people with FSHD who can tolerate the pain explore with their surgeons the possibility of using a local anesthetic to shorten the period of inactivity. Regarding surgery, see also "Pulmonary and Respiratory Health and FSHD."



## **Beware of Blood Clots During Long Periods of Immobility (e.g. Flights)**

FSHD patients who can't walk may be at risk of developing blood clots on long airplane flights or other situations where one is required to be immobile for an extended duration. On the advice of their doctors, some people take an anti-blood clotting prescription medication before flights to reduce the risk of clotting.

## **Dealing with Pain**

A majority of FSHD patients report pain, which often can be chronic. Pain may be related, at least in part, to overuse of muscles and to fatigue. Not many studies have been done about pain in FSHD. Whether and how to treat pain is a decision for each patient in consultation with his or her doctor.

For a discussion of treating pain, please see our Physical Therapy and FSHD [brochure](#) written by Wendy M. King, P. T., and Shree Pandya, P.T., M.S.

## **Cardiac Involvement and FSHD**

FSHD per se is not thought to cause cardiac complications, and patients in general have normal longevity. This predisposes them to the usual age-related cardiac complications, and management of these problems is the same as in non-dystrophic patients.

## **Pulmonary and Respiratory Health and FSHD**

Pulmonary and respiratory complications may occur with FSHD. Evaluation of the symptoms and signs of respiratory insufficiency should be sought during routine clinic visits in patients with moderate to severe FSHD. Patients are encouraged to regularly monitor respiratory functions, as one might experience insufficiency over a long period of time without presenting signs.

Fatigue is often part of FSHD because the muscles have to work harder than normal muscles, but fatigue may also result from respiratory impairment, including sleep apnea and lower than normal forced vital capacity. If a patient feels fatigue or exhibits signs of sleep apnea (such as breathing in a labored manner or momentarily not breathing during sleep), this should be discussed with a doctor. This may require persistence because some doctors, even experienced neurologists, don't associate FSHD with respiratory problems.

If a patient is experiencing respiratory insufficiency, it can be initially managed with nighttime non-invasive pressure support, typically a BiPAP machine. In very severe cases, patients may require the use of a ventilator. For FSHD patients with respiratory insufficiency, care should be taken not to suppress respiratory drive with narcotics. In trauma, emergency room, surgery and anesthesiology settings, it is important to notify the doctors about FSHD and any respiratory problems the patient might have or be at risk for.



## **Physical Therapy and FSHD**

A physical therapist (PT) who is experienced with FSHD patients can be invaluable. For example, physical therapists can:

- Administer some exercises directly (e.g., stretching)
- Teach patients how to perform other exercises

FSHD patients ask their doctors to prescribe physical therapy when:

- It feels like their FSHD is progressing more rapidly than usual
- They want periodically to monitor how they perform their exercises
- Rehabilitating specific conditions or injuries such as strained or pulled muscles or injuries from falls.
- They want a “tune up!”

## **Exercise and FSHD**

As with all exercise, it's important for FSHD patients to consult their doctors first. Here are a few exercises that many people find beneficial.

### **Swimming**

Many FSHD patients swim regularly as it has a low impact on the joints and bones, with a low risk of injury. The buoyancy of the water provides resistance, which affords the opportunity for gentle exercise and stretching. It also enables some people to do things they are unable to do on land - for example, someone who can't stand or walk on land may be able to stand and walk in water.

Watsu, a form of massage done in the water, combines the benefits of ordinary massage and being in the water. Both massage and Watsu should be done only by certified professionals.  
[www.Watsu.com](http://www.Watsu.com).

### **Standing Frame**

For some people with FSHD who can no longer walk, standing with the aid of a standing frame can be beneficial. A standing frame is a piece of equipment that can straighten and elevate a person into a standing position, and support him in that position. Using a standing frame can help maintain range of motion and reduce the possibility of contractures, relieve pressure on the posterior, increase circulation, reduce stress, realign the internal organs and provide weight bearing to preserve bones.

## **Surgical Treatments in FSHD**

A number of surgical methods have been developed to address some of the debilitating loss of functional muscle such as [scapular winging](#). Not every patient is a suitable candidate for surgery. A surgeon must have a thorough understanding of FSHD, experience with the procedure, and must carefully assess each individual to determine the risk and potential benefit, including whether a patient will be able to go through physical rehabilitation after surgery.

## **Assistive Technology and Equipment for FSHD**

Various forms of professional consultation, resources and technologies can help FSHD patients in their daily lives. Here's a sampling of various tactics.

### **Consult an occupational therapist (OT)**

An occupational therapist (OT) is a healthcare professional trained in rehabilitation who helps people learn how to do the activities of daily life. OTs can help FSHD patients improve function, increase comfort and reduce stress, fatigue and risk of injury. They can also provide home visits to observe the actual conditions of daily living and recommend ways of improving safety, efficiency, comfort and convenience. Home visits also help caregivers find ways to improve comfort and efficiency. Consider the viability of coordinating a joint home visit by an OT and a physical therapist as this can be especially effective.

Some OTs are also experts on workplace ergonomics. Many employers are willing to pay for an ergonomics consultation. If an employee has a disability as defined by the Americans with Disabilities Act, the employer may be legally required to do so. Simple and inexpensive modifications in the workplace can often improve the ability of someone with FSHD to perform efficiently, comfortably and safely.

### **Use voice recognition software**

Computer use can strain and fatigue the hands, wrists and arms of people with FSHD; this can be alleviated via voice recognition software.

### **Assistive technology**

As FSHD progresses, patients may need to use assistive technology and equipment including wheelchairs, scooters, canes, walkers, lifters, reachers, ramps, electric beds and commode/shower chairs. OTs are experts in assistive technology and equipment – consult them for more guidance.

### **Driving**

Some people's FSHD progresses to the point where they begin to feel uncomfortable or unsafe driving. At this point it is critical to have their driving evaluated by an adaptive driving expert.



Some hospitals have adaptive driving programs which are usually staffed by an OT who is also a certified driving instructor. Evaluations are expensive and insurance usually doesn't cover them. But if driving is necessary to maintain employment, the rehabilitation agencies of some states may pay part or all of the cost of an evaluation, adaptive driving equipment and training. An increasing variety of adaptive driving technology is available, from simple mechanical hand controls to sophisticated electronic controls.

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