



Facioscapulohumeral Disease (FSHD) & Social Support



A GUIDE FOR FRIENDS & FAMILY

by Kelly Mahon
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www.fshsociety.org

About this brochure

The information contained in this guide is based on interviews with 12 people with FSHD. Excerpts from the interviews appear as quotations throughout the guide.

This guide has two goals:

- To help the friends and family of people with FSHD understand what daily life with the disease is like.
- To recommend the kinds of social support friends and family can offer their loved one with FSHD.

“To get to the support you need, first be really honest.”

Receiving a diagnosis of facioscapulohumeral disease (FSHD) is difficult for affected people as well as their family and friends. If someone you know has been diagnosed recently, you may have noticed that there is a lot of factual information available on FSHD: What its symptoms are, how it is inherited, and what you can expect as the disease progresses. But you also may have noticed a lack of information about what you can do to support someone with FSHD. This brochure is meant to help fill that gap and guide those who want to support a loved one with FSHD, but don't know how.

What is social support?


Social support refers to actions that help a person deal with stress. There are two major types of social support:

TANGIBLE SUPPORT: Behaviors that help a person accomplish a task or solve a problem. An example would be opening a door for someone in a wheelchair.

EMOTIONAL SUPPORT: Behaviors that comfort or console, without trying to solve a problem. An example would be hugging a person who is crying.

Why is social support important?

FSHD can cause your loved one to experience many kinds of stress. This, in turn, creates a need for you to provide your loved one with social support. Many studies have shown that people who have a chronic disease like FSHD are healthier—physically and mentally—when they have a high degree of social support.



“This is not old age. This is not normal weakening. You don’t know what tired is.”

What is it like? Understanding FSHD

A good first step in supporting your loved one is to understand better what he or she is going through. The next part of this brochure will answer the following questions:

PHYSICAL: What tasks are difficult for someone with FSHD?

SOCIAL: How does FSHD affect my loved one’s social life?

EMOTIONAL: What is my loved one with FSHD feeling?

COMMUNICATION: How does my loved one prefer to talk about FSHD?



“It’s hard to do a lot of the house cleaning.”

Physical aspects of FSHD

Leg weakness can affect your loved one’s ability to:


- Run
- Walk—Inclines are a special challenge
- Stand for more than a few minutes
- Ascend stairs—especially if there’s no railing
- Get out of a chair from a seated position

Shoulder problems can affect patients’ ability to lift their arms. This can make certain activities difficult, like:

- Washing and styling their hair
- Brushing their teeth
- Shaving their face
- Getting dressed
- Showering
- Eating—getting their hands to their mouth
- Drinking from heavy cups
- Reaching—like getting a book off a high shelf
- Extending their arm to shake hands
- Changing a light bulb
- Writing on a chalkboard

General fatigue and overall muscle weakness can affect your loved one's ability to:

- Clean—especially push a vacuum cleaner
- Change sheets
- Carry groceries or shopping bags
- Push a heavy shopping cart
- Bend down to pick things up off the floor
- Do laundry
- Cook
- Load and unload the dishwasher
- Complete yard work



“The inability to smile makes it hard for people to understand the mood of a social interaction without the familiar facial cues.”

Social aspects of FSHD


Social situations can present challenges for people with FSHD. Here are some of the ways FSHD can affect your loved one's social interactions:

FALLING: Your loved one likely is scared of falling down. Many people with FSHD look at the ground when they walk because uneven terrain—a loose brick or uneven sidewalk—increases their chances of falling. They often look for railings to hold on to, and may try to avoid walking long distances.

INABILITY TO SMILE: The facial weakness associated with FSHD can make it hard or impossible for your loved one to smile. For this reason, many with FSHD have been told that they seem angry, upset, or unfriendly to others, which can make meeting new people and developing new relationships difficult. This also is why some people with FSHD do not like having their photo taken.

BEING DIFFERENT: Being different from one's peers, especially in youth, can be hard for a person with FSHD. If their symptoms are mild, people with FSHD might try to "keep up" with healthy peers, especially in school gym class or in sporting events.

DATING: Some people with FSHD find dating to be challenging. They struggle with when to disclose their diagnosis and want to strike a balance between doing so too soon and waiting too long.

 *“Sometimes I look at fields and think, ‘I would just love to go running through that field.’ But I know that I can’t.”*



Emotional aspects of FSHD

Living with FSHD can cause your loved one to experience powerful emotions. Here are some things your loved one with FSHD may be feeling:

FRUSTRATION WITH PHYSICAL LIMITATIONS:

People with FSHD have to redefine their physical abilities constantly. They may experience frustration when they no longer can do something they could do in the past.

WORRY ABOUT CAREGIVERS: People with FSHD may have concerns about their dependence on their caregiver(s) and the demands FSHD puts on their friends and family. They may also worry about the health and safety of the caregiver(s) that they rely on.

WORRY ABOUT THE FUTURE: Since FSHD is a progressive disease, your loved one likely worries about the future. Here are some of the worries your loved one may have:

- **“Will my friends and family be there for me?”** People with FSHD appreciate reassurance from their family and friends that they will always be there for them—even when their FSHD gets worse.
- **“Will my children be okay?”** Since it is an inherited disease, people with FSHD fear passing it on to their future children. If a person already has a child with FSHD, it is often very difficult to watch his or her child’s FSHD progress.
- **“How can I stay positive?”** People with FSHD sometimes struggle to plan for the eventual worsening of their symptoms while also “staying in the moment” and taking advantage of their current abilities.



“Now I’m much more open about my FSHD with people, whether they’re a friend or a stranger, because I believe it’s about educating now... the more I tell people about FSHD, the more awareness it will create.”

Communicating about FSHD

For many people with FSHD, it can be difficult to talk about their diagnosis “at first.” This can mean different things for different people. For example, it could take some people a month to become comfortable talking about their FSHD, while it could take others a decade.



Many people eventually feel very comfortable discussing their FSHD—not only with their friends and family, but also with strangers. They may recognize the opportunity to increase awareness of the disease.

What can you do?

There are many things you can do to support the person with FSHD in your life.

TANGIBLE SUPPORT

- **Offer help with physical tasks.** Offer to get an item off a high shelf or carry groceries into the house.
- **Anticipate needs.** Call ahead to make sure a restaurant is accessible; obtain a ramp for your home; offer to visit his or her home; ensure seating when in public places.
- **Make accommodations with a smile.** Be sincere in your efforts to accommodate the person with FSHD, like choosing an activity everyone can enjoy. People with FSHD know when you feel like you're "suffering through" for them.
- **Donate money to FSHD research.** Donate to organizations that fund research on FSHD.

“Everybody’s on a different journey. It takes each one a different time to get there.”





“I have an incredibly great life, so I don’t want FSHD to overshadow what I have here and now.”

EMOTIONAL SUPPORT

- **Be comfortable having tough conversations.** People with FSHD are sensitive to discomfort in others and are likely to “shut down” if they sense you do not want to talk about FSHD.
- **Engage in direct conversation about your mutual fears.** People with FSHD value direct conversation about your fears and theirs regarding the future.

- **Encourage networking with other people with FSHD.** Many find comfort in talking to other “FSH-ers,” whether online, on the phone, or in person.
- **Understand that FSHD has wide-ranging implications.** The reason your loved one might not want to do something could be because of the FSHD, even if it doesn’t seem related—like not wanting to hold a baby or take a long road trip.
- **Know when to use tough love.** Though it is important to recognize how hard FSHD can be, people with FSHD sometimes rely on their loved ones to help them end the “pity party.”

Tips from “FSH-ers”: what not to do

- Don’t minimize the person’s FSHD experience by saying, “It’s not that bad,” or “It could always be worse.”
- Don’t hesitate to ask how you can help—offers of assistance generally are appreciated, even if the person declines your offer.
- Don’t express too much worry or be overprotective—your own fears and anxiety can make the person with FSHD feel worse, even if you have the right intentions.
- Don’t always try to solve the problem—sometimes, a person with FSHD just wants you to listen.
- Don’t exclude people with FSHD from activities because you think they can’t participate.
- Don’t treat people with FSHD as if they are less intelligent than an able-bodied person.
- Don’t forget that things you might find easy—walking to lunch, standing in line at the store, sitting for long stretches of time—can be very difficult or impossible for your loved one to do.

Remember: It’s (still) a wonderful life!



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*For more information about FSHD,
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