



NOT ALONE

Coping With a Diagnosis of Facioscapulohumeral Muscular Dystrophy (FSHD)

FOR THE NEWLY DIAGNOSED AND THEIR LOVED ONES,
FROM THOSE WHO HAVE TRAVELED THIS ROAD BEFORE YOU

"We're not alone."



*"We're not all by
ourselves."*



*"There are people
who understand."*



The information contained in this guide is based on in-depth interviews with people who identify with one or more of the following categories:

- 1 Young people** recently diagnosed with FSHD
- 2 Mature adults** recently diagnosed with FSHD
- 3 Parents of a child** or children recently diagnosed with FSHD
- 4 Partners of adults** recently diagnosed with FSHD

Excerpts from the interviews appear as quotations throughout.

This guide seeks to:

- Describe the range of emotions you may be feeling upon receiving a diagnosis of FSHD
- Promote understanding between the diagnosed person, their parents, and their partner
- Introduce the FSHD Society as a resource—you are not alone

This brochure is not a substitute for professional counseling or mental health treatment.

There's no "right" or "wrong" reaction to receiving a diagnosis of facioscapulohumeral muscular dystrophy (FSHD). Whether it's you, your child, or your partner who has the disease, you are all affected by the news. Here are just some of the emotions you may experience.

Shock

"When the diagnosis finally came it was like, what? We were both completely shocked. We weren't prepared."

Fear

"What's the balance between planning for tomorrow like everybody else and being a little too worried about the progression of the disease?"

Isolation

"Sometimes you feel really, really alone, and there's no rule book that you can follow."

Denial

"I got the diagnosis but didn't really deal with it until I actually had to."

Anger

"As soon as [the doctor] said muscular dystrophy, it was like, you just broke my heart and I hate you."

Depression

"Emotionally, we have to deal with the pain of a progressive neuromuscular disease and the hopelessness of that."

Acceptance

"There's no sense in wishing I could run up that hill. I can't. It's like a fish wishing they could fly."

Newly diagnosed adolescents & young adults

- “Smiling is the universal hello, and I can’t do that. So making friends is a little bit hard.”
- “I basically left home at 18 to prove that I could; I couldn’t let anyone else tell me what the limitations were. I had to figure it out myself.”
- “The name of the disease is not as important to me as the actual lifestyle and making sure that the choices that I make are not detrimental to my health.”
- “A lot of the people who have FSHD are really older, and they don’t really know what it’s like to be a teenager who has it, what they’re going through. Being a teenager alone is hard enough.”



Newly diagnosed adults

- “I kept feeling I was overweight and out of shape, but I wasn’t. I was just tired all the time.”
- “It’s easy to get caught up in sort of these *what if?* potential realities and then how bad things could get.”
- “It’s a very suffocating disease. Your world is constantly changing.”
- “I really try to appreciate what I *can* still do because, if I sit here today and complain about walking with a cane, one day I may *wish* I could walk with a cane.”
- “I’m single, and that’s the main thing that makes it uncomfortable. *When* do I tell someone this? *How* do I tell someone this?”
- “Physically, can I have children? *Should* I?”
- “I don’t want to be a burden to anyone.”
- “I just want to live as absolutely normal as I can for as long as I can.”



Parents of newly diagnosed children

- “As a mother [with FSHD], it’s hard knowing that you can’t get down there and play with your children or lift them up when they were little. The reverse side is, because I have a child who also has it, watching your child get weaker and knowing that there’s nothing you can do.”
- “The last thing I want is anyone to feel sorry for us.”
- “One thing that I have tried to do, that I *don’t* think is the right thing, is [to] overcompensate for them. I think that’s where my wife is a good balancing act for me. She tries to treat them just like anybody else.”
- “Our son devolved into depression, a clinical depression, a suicide attempt.”
- “Every person on this planet needs an advocate, and the parent should be an advocate.”
- “It’s hard enough on the parents but, just remember, *you* don’t have it.



Partners of newly diagnosed adults

- “This is a complication that only changes *some* of the activities that we share. For example, I will do all of the heavy lifting.”
- “[I worry about] being able to have the money that we’re going to need to have all these modifications, builds, and accessible car, and all those kinds of things.”
- “If the kids are diagnosed, I’m sure he’ll have that level of guilt. Even though he knows he shouldn’t.”
- “I always wonder what our retirement’s going to be like, you know? If I’m going to be doing things alone or if we’re going to figure things out.”
- “How the genetics could be handed down. That’s when it was really devastating. I spent many times crying in the shower, you know, wondering what our future was going to be like.”
- Sometimes I get pissed off a little, thinking, that’s not fair to me that I can’t do something because he can’t. At the same time, I’m like, well, that’s not fair for him.”
- As a couple, I think it only solidified our relationship and the determination to pull through this together.”



With time, many people interviewed identified a silver lining in the diagnosis.

Young people

“FSD has made me who I am today. I’ve had to deal with things that most people haven’t, and I think it’s sort of added to my maturity.”

Adults

“Big relief at knowing there was a real cause for all that weakness. Just knowing, hey, this is real. It’s not just in my head.”

Partners

“FSD is part of what makes my wife the strong, courageous, and kind woman I fell in love with. I wouldn’t change a thing.”

Parents

“In the grand scheme of things, we’ve been dealt nicer cards than others I know personally.”



the importance of connection

The FSH Society is the world's largest research-focused patient organization for FSHD, one of the most prevalent forms of muscular dystrophy. We have transformed the landscape for FSHD research and are committed to making sure that no one faces this disease alone.

Our Vision

A world free of the suffering caused by FSHD

Our Mission

Find treatments and a cure for FSHD while empowering our families

"You have access to someone in your peer group that's been through it. Even if only one or two years ahead of you. To say, 'This is what you can expect; you're going to be fine.'"



Call the FSHD Society at (781) 301-6060, or email info@fshdsociety.org for more information on how to get access to these resources.

On the web

- FSHD Society website: www.fshdsociety.org
- FSHD Society on Facebook: www.facebook.com/FSHDSociety/
- Private Facebook groups (FSH Friends, FSHD Parents, FSHD Teens/Young Adults): Contact us to learn how to join a private group

In person

- Peer-to-peer counseling by a patient or caregiver
- Referrals to professional counselors with FSHD experience
- Attend one of our chapter meetings or local support groups (listed on the Events Calendar at www.fshdsociety.org)

For more information about FSHD:

- **FSHD Society**—www.fsdhsociety.org
- **Muscular Dystrophy Association**—www.mda.org





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“There are a lot of other people out there who are willing to lend a hand, lend their knowledge, and lend ideas.”

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This guide was researched and written by Kelly Mahon Hessler. Kelly, who was diagnosed with FSHD at age 26, is a professional writer in Washington, DC. She dedicates this guide to the project participants and the FSHD community at large for their support.