

Facioscapulohumeral Muscular Dystrophy



A GUIDE FOR SCHOOLS

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Introduction

The purpose of this booklet is to provide information about facioscapulohumeral muscular dystrophy (FSHD) and the impact FSHD can have on students' experiences during the school day. FSHD is a highly variable disease that affects each student differently, yet some difficulties are common to many students. Our goal is to help you prepare for some of the challenges faced by students with FSHD, and to facilitate a positive experience for both you and your students. In an effort to achieve this goal, we have gathered information from scientific reports, current and former students, and school staff who have experience working with students with FSHD, and have added insights from our own experience. We hope this guide will help you and your students achieve success in the classroom and beyond.

About FSHD

CHARACTERISTICS

FSHD, one of many forms of muscular dystrophy, is the most prevalent muscular dystrophy in children and adults.² Like all muscular dystrophies, FSHD causes progressive muscle weakness. Weakness is most often seen in the face (facio), shoulder girdle (scapulo), and upper arms (humeral), but can also occur in abdominal and leg muscles. This results in some or all of the signs and symptoms listed below.^{3,4}

COMMON SIGNS AND SYMPTOMS OF FSHD

- Decreased or flattened facial expression
- Scapular (shoulder blade) winging
- Inability to lift arms overhead
- Excessive curvature of the low back (lumbar hyperlordosis)
- Inability to lift feet up (foot drop)
- Difficulty walking
- Fatigue



Facial weakness is a distinctive feature of FSHD. Weakness ranges from mild to severe. Weakness can cause a "flat" facial expression, asymmetrical smile, and difficulty closing lips.



Scapular winging is a common sign of FSHD. Winging can be mild or severe, and is often asymmetrical.

Other features occur in only a small subset of students with FSHD.^{4,6} Although these signs and symptoms are less frequent, when present, they can have a large impact on classroom performance.

LESS COMMON SIGNS AND SYMPTOMS OF FSHD

- Hearing impairment (usually affecting high pitch sounds)
- Quiet or unclear speech
- Pain
- Vision problems (rare)
- Breathing concerns (rare)
- Heart problems (rare)

ONSET

Most individuals notice weakness due to FSHD in their late teens or 20s.⁷ Some people, however, may have very mild symptoms that go unnoticed until other family members are diagnosed. In a small percentage of individuals, weakness is evident in early childhood. Children with weakness caused by FSHD at an early age are categorized as having infantile FSHD.

INHERITANCE

FSHD is a genetic disorder. It is usually inherited from a parent, although children with infantile onset are more likely to be the only person in their family to have the disorder due to spontaneous genetic mutations.⁸ FSHD can affect both males and females, and can be inherited from either parent. Even when FSHD affects more than one family member, the severity of the symptoms can vary greatly from person to person within a family. A student's specific progression of symptoms cannot be predicted by the severity of symptoms observed in that student's family members.

NOTE: Additional information about the characteristics, prevalence, inheritance, and typical symptom progression in FSHD are available in the publications listed in the “Additional Resources” section.



Lordosis occurs due to weakness in the abdominal muscles, particularly the lower abdominals.³

WHAT TO EXPECT

Unlike some other types of muscular dystrophy, FSHD rarely affects cognition or intellect. However, many students with FSHD require modifications during the school day due to signs and symptoms of the disorder, including hearing impairment, weakness, fatigue, or pain.

The progression of FSHD is usually slow, but periods of relatively rapid progression can occur.⁸ Children with infantile FSHD have more severe weakness and a faster rate of progression than those diagnosed in young adulthood.⁷ They are more likely to use a wheelchair before the age of 18 and more likely to have hearing loss.⁸

Unlike some forms of muscular dystrophy, FSHD is typically not life-shortening.⁴ Most students with FSHD are just as likely as students without FSHD to live a full life, have careers, marry and have families.

FSHD has no cure, but some effects of the disorder can be minimized. Use of assistive technology devices and educational supports can reduce the impact of FSHD on school performance.

WHAT IS ASSISTIVE TECHNOLOGY?

An assistive technology device is “any item, piece of equipment, or product system... that is used to increase, maintain, or improve the functional capabilities of a child with a disability (Authority: 20 U.S.C. 1401(1)).”¹ Assistive technology devices can be helpful in addressing mobility, communication, hearing, and fine motor concerns. Walkers, speech output devices, hearing aids, computer programs, and adapted pencils are just a few examples of assistive technology. School-based physical therapists, occupational therapists, speech-language pathologists and audiologists can assist in determining if assistive technology is needed, and provide suggestions for assistive technology that will meet the specific needs of students.

Impact of FSHD at School

The experiences of students with FSHD are highly variable; some students experience problems that affect only one aspect of school whereas others encounter difficulties in many areas. A team of people can help identify areas of concern and make a plan to address them. Teams often include students, parents, teachers, and related service providers, such as physical therapists, occupational therapists, and speech-language pathologists. A 504 plan or an Individualized Education Program (IEP) could be appropriate for outlining the services needed to support students with FSHD. The plan might include assistive technology and classroom adaptations.

A NOTE ABOUT CONFIDENTIALITY

Each student and family feels differently about sharing personal information. All team members must have a clear understanding of what information can be shared openly, and what information should be kept private. Even when outward symptoms of FSHD are apparent, respecting the feelings and privacy of students and allowing them to share details about FSHD in their own way is important. The wishes of students and families might change and should be respected at all times.

Strategies to Address Difficulties Associated with FSHD

To help you anticipate problems that might arise for students with FSHD, we have provided an overview of aspects of school life that are most likely to be difficult for these students. Subsequent sections provide details about common problems as well as potential strategies that address the following areas: classroom activities, mobility, transportation, communication, meals and snacks, social and emotional considerations, physical education, and extracurricular activities. We hope these sections help guide you to think about activities that might be difficult for the student you are working with, and stimulate discussion about activities we have not specifically mentioned. Physical therapists, occupational therapists, speech-language pathologists, and other related service providers can assist in determining which strategies are most likely to meet students’ individual needs.

Based on conversations with current and former students with FSHD and their families, we recommend the following approaches when working with students with FSHD:

- Include them in decisions about their educational plans.
- Avoid isolating or singling them out as the only students using an alternative strategy. When possible, allow all students to use the strategies selected. If a student with FSHD benefits from sitting in a chair instead of sitting on the floor, for example, offer chairs to all students.

- Consider the specific context in which chosen strategies might be helpful. Students could require different strategies in different situations. A student might walk inside the school building, for example, but require a wheelchair outside.
- Hold them accountable to the same academic standards as their peers, while allowing them to demonstrate their knowledge in alternate ways when necessary. Maintaining high standards will help prepare students for post-secondary education or competitive employment.
- Maintain central access to students' educational plans and health information, and ensure that information follows students throughout their academic career. This will help facilitate sharing of information relevant to future planning, especially during transitions between grades, buildings, and school districts.
- Encourage students to consider their individual strengths and limitations when considering options for post-secondary education and employment. Some features of FSHD could limit success in some careers or college settings. Fatigue and weakness, for example, can affect an individual's ability to do jobs requiring physical labor and could make travel difficult. Unclear speech could create challenges in phone communication. Frequent inclement weather, hilly terrain, and lack of building accessibility could affect success on a college campus.
- Identify one or more key people within the school system for the student to contact for additional assistance as specific concerns arise. A teacher, guidance counselor, nurse, or other staff member might be appropriate options.

Areas of Concern

CLASSROOM ACTIVITIES

Although FSHD does not typically affect cognition, other factors associated with FSHD can impact learning. If you have concerns about classroom performance, meet with students and parents to talk about your concerns. Consider that:

- untreated hearing loss can be misinterpreted as lack of understanding or lack of intelligence;
- speech and articulation problems can be the result of undiagnosed hearing loss, which can occur before muscle weakness is identified;⁸
- students experiencing fatigue or pain may have problems focusing on classroom instruction or completing lengthy assignments;
- students might miss school for health care visits or treatments;
- students with significant weakness will be at increased risk for respiratory infections, which can lead to lengthy or frequent absences; and
- FSHD might not be the only factor affecting school performance.

CLASSROOM ACTIVITIES

Potential Difficulties

Raising hand in class

Potential Strategies

- Establish a way for students to gain attention that does not require arm raising, such as another physical cue or an audible cue
- Encourage regular participation in classroom activities by calling on students with FSHD as often as other students

Sitting in a standard chair without leaning or falling over

- Consider the need for desk modifications or use of chairs with extra support

Standing for long periods of time

- Consider using counter height stools during classes that require standing

Writing on wall-mounted chalkboards or white boards

- Use interactive whiteboards, computer links, or other technology that does not require lifting arms above the waist

Handwriting

- Use computer technology to help with written assignments
- Provide students with written or typed notes, allow audio taping, or use assistive technology for note-taking
- Allow alternative test-taking if written tests are difficult; computer-based or oral testing might be appropriate
- Consider whether speech recognition software would be helpful to reduce the physical demands of writing and typing; an occupational therapist, speech-language pathologist or other staff familiar with this technology

A NOTE ABOUT FATIGUE AND PAIN IN FSHD

Fatigue can make focusing in class difficult for students with FSHD. Students tell us that their fatigue is variable, and usually unpredictable. Older students report pain more commonly than grade school students. Pain occurs most often in the neck, shoulders, and low back. Sometimes pain can be avoided by providing a classroom chair with good back support, limiting overhead reaching, and avoiding other physical activities that are difficult. If pain appears to be limiting performance, discuss this with your school team. Students' health care teams might be able to suggest methods to help control pain.

MOBILITY

Students with FSHD often have limitations in their ability to move around. Mobility limitations range widely from student to student, so the specific needs of students are important to consider. Strength decreases over time, therefore movement throughout the school building should be reassessed routinely. Building and playground accessibility can affect students' mobility and safety, and should also be reassessed routinely. It is important to plan ahead for building modifications that will be needed in future years, including installation of ramps, elevators, and accessible bathroom facilities.

Some students with FSHD require use of a wheelchair or scooter. The need for a wheelchair typically develops gradually, after progressive loss of strength and use of other mobility aids, such as braces, canes or walkers. Sometimes, however, the transition can happen quickly. This is most common after a broken bone.

MOBILITY

Potential Difficulties

Walking long distances

Potential Strategies

- Try to arrange schedules and classrooms to limit the distances students must travel throughout the day
- Discuss whether a power wheelchair or scooter would be helpful for traveling long distances
- Allow extra time between classes; let students with mobility limitations leave class a few minutes early or arrive a few minutes late
- Make an emergency plan that accounts for mobility limitations to ensure safe and speedy movement to safety; be sure to practice this plan during emergency drills

Walking up and down stairs, curbs, steep ramps or uneven ground

- Ask students if architectural barriers (e.g. heavy doors, stairs, slippery or uneven surfaces) limit participation in specific classes or activities
- Provide supervision or assistance for students who are unsteady
- Ask a physical therapist to determine if assistive devices would be helpful
- Offer use of a ramp or elevator

Getting up from the floor

- Avoid activities on the floor; have students sit in chairs instead
- Offer assistance to students getting up from the floor after a fall; ask students how to best help them

MOBILITY CONTINUED

Potential Difficulties

Keeping balance; frequent falls

Potential Strategies

- Put students with mobility limitations at the front or the back of the walking line
- Ask a physical therapist or medical team member if braces, canes, a walker, or wheelchair might be helpful
- Ensure there are clear paths for movement in the classroom

Carrying books

- Suggest use of a rolling backpack or other option for carrying books as an alternative to a traditional backpack
- Provide an extra set of books (one set at home and appropriate texts in each classroom)
- Consider use of electronic books and media
- Provide lockers or cubbies on each floor of the building or at each end of long hallways to allow storage of books and materials close to each classroom

A NOTE ABOUT FALLS & USE OF WHEELCHAIRS

Many students with FSHD will fall at school and might have difficulty getting up from the floor without help. Falling and needing help are embarrassing or frustrating for some students. It is often helpful to identify ways to assist a student up from the floor, and provide training to all staff likely to help a student after a fall. Having a sturdy surface, such as a chair or table, available for the student to push up on can be helpful.

If a student falls several times per week, consult the family, physical therapist, or the student's medical team to determine whether a walker, wheelchair, bracing, other assistive device, or changes to the school environment are needed. The need for safety and the desire to keep students walking will need to be carefully balanced.

Transitioning to using a wheelchair can be emotionally challenging for students. Some students resist the use of a wheelchair for as long as possible, whereas others view the wheelchair as a means to increased freedom. Acknowledge students' feelings, and respect their desires for independence, whether that is through walking or use of a wheelchair.

From a health standpoint, walking for as long as possible has many potential benefits, including promotion of bone strength, joint flexibility, blood flow, and cardiovascular, respiratory, and emotional health. These benefits must be carefully balanced with potential disadvantages, including risk of injury due to falls and increased fatigue related to the effort needed for walking. It is essential to include students and their families in decisions about using a wheelchair at school, and to plan for wheelchair accessibility well before a student is expected to need it.

Transportation

Transportation can be a challenge for students with limited mobility. Students might have difficulty walking long distances to school or walking between the student parking area and the building. Students who require wheelchairs or scooters might have difficulty finding accessible transportation, especially when using public transportation. Transportation needs should be considered for all students with mobility limitations, even those who do not regularly receive school-provided busing, as transportation needs might arise for field trips and other school-related outings.

TRANSPORTATION

Potential Difficulties

Walking long distances to school or a transit stop

Potential Strategies

- Talk with your student's family and medical team to determine if a power wheelchair or other assistive devices are needed for travel to/from school
- Allow parking close to the building for students who drive to school

Negotiating bus steps

- Provide a small step stool to bridge the distance to the first step, which is often large
- Provide assistance getting on/off buses
- Discuss whether an accessible bus is needed

Fatigue due to lengthy trip to school

- Limit the length of bus trips
- Discuss alternate transportation arrangements

Wet, icy, or snow covered paths

- Make sure paths to the school building are clear during inclement weather
- Work with other team members to determine if assistance or use of an assistive device is needed in some situations

Rough terrain, curbs or steep ramps

- Make sure that the outside of the school building is accessible for all students

COMMUNICATION

The presence and severity of communication problems in students with FSHD vary greatly. Facial weakness, hearing loss, and difficulty with speech can all impact communication. Facial weakness often results in a mismatch between students' facial expressions and the emotions they are trying to express. Unfortunately, teachers and classmates can incorrectly interpret decreased facial expression as depression, boredom, anger, or dismissive behavior.

COMMUNICATION

Potential Difficulties

Limited facial expression

Potential Strategies

- Listen to students' words, rather than depending on facial expressions to interpret meaning, particularly when students are expressing emotions that conflict with their expression, such as joy, happiness, or surprise
- Verify your interpretation if there is a mismatch between facial expression and the emotion conveyed through words

Hearing impairment

- Provide seating close to the teacher; if hearing is better on one side, position students to maximize use of their "better ear"
- Provide seating away from major sources of noise such as aquariums, hall noise, heating/cooling units, computer/equipment fans and other noise sources
- When speaking, try to face students who rely on visual cues to supplement auditory information
- Consult a speech-language pathologist, audiologist or other team member to determine if assistive technology (such as hearing aids or assistive listening devices) would be beneficial
- Recognize that severity of hearing loss may also contribute to decline in students' speech output

Unclear or slurred speech

- Allow students to supplement oral presentations with pre-recorded presentations, written assignments, or use of visual aids (e.g., PowerPoint) as additional context from visuals will aid the listener in understanding unclear speech

COMMUNICATION CONTINUED

Potential Difficulties

Unclear or slurred speech

- Consider use of pre-recorded presentations; presentations can be recorded when students are not fatigued, and can be divided and recorded in short segments
- Request assessment for alternative/augmentative communication systems (such as voice output devices or text-to-speech programs) by a speech-language pathologist or other person with expertise in this area

Low speech volume

- Be mindful of the impact fatigue might have on speech volume; consider having students with FSHD present early in the day
- Position listeners close to the student when speaking
- Consider options for alternative/augmentative systems (such as voice amplification or voice output devices) following consultation with a speech-language pathologist or other person with expertise in this area

Potential Strategies

ADDITIONAL INFORMATION ABOUT SPEECH PRODUCTION

Many people who are diagnosed with FSHD in their teens or early adult years do not experience problems with speech production. Nasalized speech, however, might affect how well others can understand them. For those with infantile FSHD, speech production problems are more common due to increased incidence of oral muscle weakness and hearing loss. Speech production concerns could include:

- difficulty with production of the majority of consonant lip sounds, including m, b and p;
- errors in sounds that use the lips and require movement of the lips for accuracy, including the sounds s, z, f, v, zh (as in measure), ch, and j (as in judge);
- difficulty producing vowel sounds which typically are produced with more lip movement, such as -o- as in rope, or -oo- as in room;
- omission or substitution for the lip sounds (e.g., dod for mom; dee for bee or pea);
- difficulty developing speech production of higher pitched consonant sounds, including f, sh, s, z, zh, p, t, and k, due to high frequency hearing loss;
- difficulty with inflection, intonation and proper rate of speech (spacing and pauses between words); and
- difficulty producing certain sounds, often those higher in pitch.

MEALS

Meal and snack time can be a stressful part of the day for some students with FSHD. Facial weakness can cause difficulty in closing lips around food and result in open-mouthed eating, leading to food spillage or messy eating. The social stigma of being viewed as a “messy eater,” or being encouraged to “close your mouth when you chew,” add pressure to an already difficult activity. Eating can lead to muscle fatigue. Physical demands, such as carrying a tray, finding a seat, opening containers, and cutting food can also make meal times challenging.

MEALS

Potential Difficulties

Carrying lunch tray

Potential Strategies

- Offer assistance with carrying lunch trays
- Provide seating close to the lunch serving area to shorten the distance students must carry their trays

Opening containers and cutting food

- Offer help opening containers and cutting food
- Discuss need for adaptive utensils with an occupational therapist or other team member with expertise in this area

Chewing and swallowing

- Ensure size and texture of food items are correct for students with special diets
- Arrange schedule to allow more time for eating to avoid choking, which can occur as a result of rushed eating
- Avoid drawing attention to students by encouraging them to chew with their mouths closed or be less messy; due to weakness, they likely cannot
- Offer to allow eating in a different location with a small group of friends instead of a large lunch area, if the student chooses

Food selection

- Promote healthy food choices and discuss special dietary plans with parents; maintaining a healthy weight is an important part of the management of FSHD because excessive weight can make mobility more difficult for students with muscle weakness

SOCIAL AND EMOTIONAL CONSIDERATIONS

Students with FSHD adapt to their condition in a variety of ways. Receiving a diagnosis of FSHD and experiencing progression in symptoms can result in anxiety, denial, fear, sadness, self-consciousness, embarrassment or anger. Some students adapt quickly to changes, whereas others struggle in silence, withdraw from friends and teachers, act out, or choose risky behaviors to “fit in.” Young children might sense that they are different from their peers, but may not fully understand the differences. In contrast, older students are typically very aware of any differences that exist, but might not want to acknowledge these differences openly.

When the ability to take part in routine school activities is compromised, social isolation can be a concern. Students who cannot communicate well or keep up with their peers physically, for example, might feel upset or left out. Even students with minor manifestations of FSHD, such as isolated facial weakness, can experience emotional and social difficulties related to apparent or perceived differences.

SOCIAL AND EMOTIONAL CONSIDERATIONS

Potential Difficulties

Self-confidence and self-advocacy

Potential Strategies

- Encourage students to have input into decisions about themselves and their school plan
- Help students build advocacy skills related to social, academic, and personal needs
- Help students identify their individual strengths

Connecting with peers

- Encourage all students to respect individual differences
- Discuss options for raising awareness of FSHD or teaching respect for individual differences
- Consider that many teens do not want attention brought to them, and would prefer to share information about FSHD with their peers on a “need to know” basis
- Discuss need for social skills development to initiate and maintain friendships
- Help establish access to peer support through local or online support groups and social networks

Expressing emotions

- Be supportive and understanding of emotional concerns
- Offer opportunities to speak with a school counselor or other personnel who offer support

PHYSICAL EDUCATION

Students with FSHD often have difficulty in physical education, particularly with sit-ups, pull-ups, push-ups, reaching overhead, throwing a ball, and climbing a rope or other apparatus. For those with more severe weakness, walking or running will be difficult.

Physical education can be a fun experience for students if activities are modified to align with their skills. Experts believe students with FSHD can participate in typical recreational activities without causing muscle damage.¹⁰ Exercise, however, will not stop the progression of weakness.¹¹

PHYSICAL EDUCATION

Potential Difficulties

Keeping up with peers

Potential Strategies

- Allow students to set their own limits and take rest breaks as needed
- Allow students to “opt out” of challenging tasks within a given class, unit, or semester
- Consider alternative options to traditional physical education programming, such as individualized fitness plans and aquatic exercise

Sit-ups, push-ups and other strengthening exercises

- Allow modified exercises, alternative exercises or a reduced number of repetitions
- Consider substituting stretching exercises for strengthening exercises

Physical fitness tests

- Avoid timed tests, tests of strength, and other standardized tests

Ball activities, racquet sports, and other sport-specific skills

- Provide balls, racquets, bats and other equipment that are lightweight and easy to grasp
- Provide a low hoop or basket for target games
- Allow underhand tossing instead of overhead throwing

Self-confidence

- Help students identify activities that allow them to be successful
- Praise students for skills they perform well, rather than focusing on tasks that are challenging

Changing clothes

- Allow extra time for changing clothes
- Consider adjusting students' schedules to reduce the need to change quickly

Differences in physical appearance

- Allow showering before other students or in a private shower if students have concerns related to differences in physical appearance

EXTRACURRICULAR ACTIVITIES

Some young adults with FSHD report participating in a variety of school activities, including organized sports. For many, however, fatigue, weakness or other factors limit desire or ability to take part in extracurricular activities, particularly during high school.

Extracurricular activities are important for forming social networks and preparing for post-secondary education, so it is important to help students consider a variety of opportunities for extracurricular activities, including:

- taking part in student government, academic clubs, or school service groups;
- mentoring other students; or
- volunteering through community organizations.

EXTRACURRICULAR ACTIVITIES

Potential Difficulties

Band

Potential Strategies

- Discuss options for instruments that match the physical abilities of students, for example instruments that do not require strong facial muscles
- Consider lightweight instruments to make lifting and carrying instruments easier
- Offer assistance with turning and arranging music pages

Choir

- Consider options for assistive technology, such as voice amplification, following consultation with a speech-language pathologist, audiologist or other team member with expertise in this area
- Offer music stands or assistance holding and turning music

Speech, debate or drama

- Consider assistive technology, such as voice amplification, to increase speech volume
- Consider consulting a voice coach or elocution instructor to address speaking skills
- Discuss options for participating in a support role if physical demands are too challenging

Sports

- Help students select sports and positions that match their strengths
- Explore availability of recreational teams or adapted sports programs
- Suggest options for participation in a support capacity (e.g. manager, statistician)

Closing Thoughts

FSHD can present unique challenges for both you and your students. We hope that this guide helps you anticipate some of the obstacles frequently encountered when working with children and young adults with FSHD, and provides useful information to help you and your students. This guide is not intended to address all potential difficulties. Rather, we hope that it will serve to stimulate discussion as you strive to address the specific needs of your students.

Additional Resources:

General Information about FSHD:

FSHD Society: www.fshdsociety.org

Information about Neuromuscular Diseases for Teachers:

Muscular Dystrophy Association. A teacher's guide to neuromuscular disease. Available at <http://www.mda.org/publications/tchrdmd/>

Information about Physical Therapy & FSHD:

Pandya S. and Eichinger K. Physical therapy & FSHD: a guide for patients and physical therapists. Lexington, MA: FSHD Society; 2016. Available to download at <https://www.fshdsociety.org/resources/>

Support Networks:

FSHD Society on Facebook: <https://www.facebook.com/FSHDSociety/>
To join private Facebook groups for parents, teens, contact: info@fshdsociety.org.
FSHD Society yahoo groups: <http://health.groups.yahoo.com/group/fshdsociety/>
MDA FSHD Community: <http://mymda.mda.org/>

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