

Aging Well with Muscular Dystrophy: Dealing With Pain

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Chronic pain is something that many people, including many people with muscular dystrophy (MD), face on a day-to-day basis. In fact, preliminary results of our recent survey of people with MD show that 249 out of 321 people (78%) reported at least some daily pain. Of these individuals, 25% rated their average pain as being "severe," or greater than five points on a scale of one (no pain) to ten (most severe pain). While these findings may be of little comfort to those experiencing MD and pain, if you are one of these, it may be nice to know that *you are not alone*.

Although the results above are preliminary, our previous survey with a smaller number of participants (257) also found pain to be a very common issue for people with MD. About 71 percent of the survey participants reported pain, and a greater percentage of people with facioscapulohumeral muscular dystrophy (FSHD) reported that they had pain (82%) than people with myotonic muscular dystrophy (MMD) (64%).

Members of the National Registry of Myotonic Dystrophy and Facioscapulohumeral Muscular Dystrophy Patients and Family Members have been very important to our studies and have completed many surveys. We appreciate the support of members of the Registry and the other muscular dystrophy patients who have completed our surveys and "drive" research about pain.

Duration and location of pain symptoms

In our initial survey, patients who reported pain said that they have experienced pain for an average of 12 years. We also asked people about *where* they experience pain most frequently. People responded that they most frequently felt pain in the lower back and legs. Back pain was reported in 66% of people with MMD and 74% of people with FSHD. Leg pain was reported in 60% of people with MMD and 72% of people with FSHD. Differences were found between people with MMD and FSHD in where the most intense pain was located. People with MMD reported greater pain intensity in the hands, legs, knees, ankles, and feet compared to FSHD patients. FSHD patients reported a greater frequency or more occurrence of pain in the shoulders and hips. Knowing where the most common and most severe types of pain occur is a good start to finding ways to help reduce that pain.

Daily activities affected by pain

Another problem with pain, and why it needs to be addressed, is that it often interferes with activities that are important to people. We asked about these problems in our initial survey, and found that pain interfered most with recreational activities, ability to get around, normal work, and enjoyment of life.

Common pain treatments

Finally, we found that up to 78 percent of those in the initial survey had tried at least one kind of pain treatment, such as aspirin or ibuprofen (78%), heat (71%), acetaminophen (70%), strengthening exercises (64%), and physical therapy (57%). Even though 71% of people in the survey reported pain, only a portion of these participants were using any pain treatment at the time of the survey (aspirin or ibuprofen, 46%, acetaminophen, 34%, strengthening exercises, 29%, range of motion, 29%, and heat, 26%). The next step is to investigate ways to reduce the interference of pain in important daily activities and to test what methods are most effective in reducing pain. It will also be important to understand

more about which coping methods are both effective and easy to use, so that people can incorporate them into their lives and continue to use them to manage their pain.

Important information to drive research and clinical care of pain

The amount of pain that people with MD report may not surprise anyone experiencing MD, but this is critical information to support further research about MD and pain. From such research, we can determine which areas of pain are most important to target, and researchers can begin to design and test interventions to reduce the degree to which pain interferes with daily activities. In future columns, we'll discuss research findings regarding different treatment options for pain management.

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