



FMDSA

• FIBROMUSCULAR DYSPLASIA SOCIETY OF AMERICA •

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You're reading this because someone you care about has a disease that you've probably never heard of: fibromuscular dysplasia (FMD). FMD is a disease that affects the arteries in the body and is most commonly found in the arteries near the kidney or in the neck, but it can be found in any artery in the body. The arteries of someone with FMD may have segments of narrowing and bulging, and on imaging the most common form of FMD may appear to look like a string of beads. Other people with FMD may have only one narrowed segment in their arteries. Both are caused by abnormal cell growth in the artery. A person with FMD might have the disease in several arteries which could then affect several organs.

The symptoms a person experiences depends on which arteries are affected. If there is FMD in the renal arteries (supplies blood flow to the kidneys), the person might have high blood pressure. If FMD is in the carotid or vertebral arteries (in the neck, supplies blood flow to the brain), the person might have headaches, neck pain, pulsatile tinnitus (whooshing noise in the ears), or dizziness. Although these are some of the most common symptoms, FMD varies a lot from person to person, and the person you know may have other symptoms. Some people have aneurysms, or dissect (tear) an artery, some have strokes and some have lost a kidney. There are also patients that are diagnosed that have no symptoms at all.

Unfortunately, there is still much doctors do not know about this disease. They don't know what causes it, and although there are treatments for some of the symptoms, there is still no cure.

How much FMD affects a person's daily life also varies from person to person. Some people can live mostly the same as they did before the diagnosis. For others, the disease can significantly affect their day-to-day life; they are no longer able do many of the activities they used to.

Being diagnosed with something like FMD can be terrifying. It can be very difficult to live with some of the symptoms. Even if that person looks completely healthy on the outside, believe them if they say that they struggle with what's happening on the inside. For many patients, not working is not an option and they still have to go about their daily activities even on the days when the symptoms are unpleasant, the pain is bad or the future is scary.

While this person needs you to validate their challenges with FMD, they also need you to think of them as the person you love and care about and they need your support.

The balance between these two things—thinking about the disease and the person—isn't always easy to figure out. What this person needs to hear from you may change from day to day. It may change with the months and years following the diagnosis.

It can be hard to respond to someone with a chronic disease. It can be difficult to know what to say and what to do. You should know that even if you can't understand what your loved one is going through, just being there for them is what they need the most.

For more information on FMD, please visit fmdsa.org.

Together, we have created a world, where FMD patients and researchers from around the globe, are coming together and taking action, to ensure the best possible treatments and outcome for those diagnosed with the disease.