

Melva Buck - ADULT FMD

I was born into a home with 4 children. I had a much older brother and sister and a younger brother. Much of my memories are a blur. My mother seemed to have severe problems with pain, menopause and possibly depression. I became very emotionally bottled within. It seemed as I felt everything but nothing. I do believe that through my childhood experiences, I developed a sure gut feeling for what was important. My onset of menstruation was in sixth grade.



I remember school being very confusing that year. I now believe that I had ADD. I maintained good grades but seemed to hold onto only a little information at a time. During this period, my knees started to slide out of place. There was intense pain and severe swelling after each event. This repeated often, but the last time was while crossing a street. A car slammed on brakes to avoid me, and my mom took me to a doctor. I had knee surgery to correct the muscles pushing on my kneecaps. I spent the summer in casts from the hip to the ankles. The scars from the surgery wrapped around each knee. Through the years, they widened and puckered. They never faded. A few other scars also did the same. With this intense scarring at 13, I chose never to wear shorts again. I am very light skinned. I also noticed during this time that I had multiple visible blue veins over much of my body. My teen years were uneventful other than my periods. They were very painful. I took medications as needed and thought everyone else had the same horrible pains. The other big issue in my childhood was my stomach. Any event that triggered emotions, like my birthday, also triggered my stomach. I had severe constipation issues. It would include a migraine type headache and throwing up. I was diagnosed at 18 with Irritable Bowel Syndrome. The medication for that changed my life. I was no longer trapped by the severe symptoms.

I married at 18. I tried desperately to get pregnant for a few years. I finally succeeded at 22. I always had uneventful pregnancies until the last trimester. My OBGYN discovered that I tended to start dilating early with no pain. I could walk around, shop, or live normally at 7 centimeters with no discomfort at all. I had to be induced with each pregnancy to start labor. I still continued to have some bad headaches, but not to the same frequency as before my IBS medication. I started having higher blood pressure the week before each period. My doctor started me on diuretics for that week which helped.

I chose to be a stay-at-home mom. I thought my health was excellent other than frequent back issues. If I slept wrong or lifted something heavy, then my back would get intense nerve tingling pains. If my neck was involved then I would feel the neck and headache pain. I started seeing a chiropractor who would do adjustments on my spine. The adjustments always brought immediate relief. I was told by a hospital doctor after a slipped disc incident that I had a curved spine. I went to the chiropractor for years, thinking that the curved spine made my back easily prone to misalignment. My family's health had never been a big concern. My Dad had an aortic aneurysm, but I thought it was possibly an age related heart defect. In 1992, my older brother, age 46, died from a brain aneurysm. My

anxiety soared, since I looked like an identical twin to my brother. My doctor tested me for a brain aneurysm, but mistakenly did the CT without contrast. So all looked great. At 38, I was the proud parent of a 15 yr old, a 13 yr old, a 1 yr old and newborn twin boys. I was very busy but very proud. I developed uterine prolapse after the twin pregnancy. I was told to do frequent exercises to help. As the last children were about to enter school, I decided to get my nursing degree. I enrolled in classes at a nearby college. One day, soon after I had enrolled in my degree, I developed a horrible headache with neck pain. I really thought it was just another bad headache. I kept going until the day I bent over to pick up something off the floor. I felt a wham in the side of my head and I knew that I was about to pass out. I bent my knees to squat on the floor and laid down. I only remember glimpses of memories of a rescue truck and hospital.

I awoke fully in the hospital a few weeks later. I had two aneurysms that had been hemorrhaging in my brain causing the last headache. When I bent over, they had ruptured. The doctor had performed open skull surgery to clip the aneurysms. They had ran a dye catheter to the brain before surgery and noticed that I had funny looking arteries in the carotid. The procedure caused my carotid artery to dissect. They also found smaller aneurysms on the other side of my head. I was informed at this time that I had Fibromuscular Dysplasia.

I spent the next year, recuperating from the surgery. I was placed on antiseizure medications and Coumadin. The dissection had caused a large blood clot to form on my carotid. My doctors always seemed to be unsure about my medical course. They often needed second opinions. I really felt like a freak or at least the only person in the world like this. I guess this phase was denial. At first, I just could not deal with anything else other than getting well and stronger. I distinctly remember the day that I decided to look up Fibromuscular Dysplasia on the internet. There were one or two articles. The article said.. "usually associated with an early death". This was the anger stage. I cried and I got angrier. I decided to research my options and educate myself.

Through sheer luck, I found an online Fibromuscular Dysplasia support group. I saw where there were other people out there just like me. We chatted, we talked, we grew to love each other, and we learned. I started taking research notes, comparing symptoms, and in general accumulating data. This gave me control over my disorder. Because we had our FMD start in different areas, I learned where the other areas could be. I also learned the symptoms. I had no doctor in my area with this knowledge, so I elected to be in control of my own course of medical care. I set up my own preventative care and took in researched data to let my doctors know what to look for. I kept the doctor's who listened and dismissed those who did not. During this action phase, I found out that I have associated heart conditions, mesenteric artery problems, and renal problems. I also followed a cyst on my thyroid for two years. I felt it one day while driving and made my own appointment to follow up. It was cancer and I caught it before it spread. I have numerous documents that saw it on a scan and said it was probably nothing. During my first visit to a heart doctor, he asked why I was there if I had no symptoms. I answered that I had mammograms every year, but I did not believe that I had breast cancer. He acted like I was ridiculous, but he tested me anyway. We found an enlarged heart, mitral valve prolapse, and an enlarged aorta. We found the mesenteric problem after a trip to the emergency room with severe abdominal pain. The doctors wanted to do an emergency angiogram to open the 60% stenosis. I was told that

there was a high rate of dissection during the procedure. I just wanted to talk to the support group about it. I refused the angiogram and left. I found out through a vascular surgeon the following week that no angios are needed if only one artery to the intestines is affected. The severe pain was from diverticulosis.

My elderly mother started to have cognitive problems. I decided to move her into my home. She had many various symptoms that seemed odd. I kept asking her doctor the reasons for her odd symptoms, and he did not know. I decided to look up each symptom on the internet and find a reason. I kept seeing Ehlers Danlos. I finally went to their site and I could not believe it. It was like reading my whole life story. I made an appointment with the NIH study. They confirmed my diagnosis for EDS. I started to study and take notes on EDS. I quickly realized how similar the two conditions were. About this same time, my FMD group decided to have a small meeting. I flew to Colorado and met several of them. When I entered the room and saw them, I realized that we all probably had a combination of FMD/EDS. Several of them also visited the NIH study. It was confirmed that they did indeed have both.

I now finally began to feel that I fully understood my whole life. I understand the hormonal surges at puberty and menopause and how it related to my FMD/EDS. It explained my knees, my scar issues, IBS, my back issues, and my ADD like symptoms. I understood my visible veins, severe headaches, pregnancy issues, and aneurysms. After menopause, I followed a declining path of high blood pressure, fluid retention, thyroid issues, mitral valve prolapse, dilated aorta, Rheumatoid Arthritis, bouts of Bursitis, and early eye cataracts and glaucoma. I now have a name for all my maladies and that helps a lot. Fibromuscular Dysplasia Society of America has really worked hard to make Doctors more aware of Fibromuscular Dysplasia. We can now find numerous sources of up-to-date information online and at their website. They joined with NORD and The National Kidney Foundation to further spread the data on FMD.

Thanks to this great organization, people with FMD in the future will not be faced with the unknowns that I had to face. I hope they will be able to find up to date information on their computers and Doctors who understand the course of our disorder better.