Understanding How Fibromyalgia Affects Your Family

by ADRIEL MALDONADO

We Are Not the Only Ones Suffering

Counselor Eric Patterson and fibro sufferer Adriel Maldonaldo discuss how fibromyalgia affects your family.

Some medical conditions are simple: they have a mild set of symptoms that can be treated easily with good results, have a limited influence on the life of the sufferer, and are one-dimensional.

Other medical conditions are more complex: they have a severe set of symptoms that lack a strong and reliable treatment plan and cross the line from physical to mental and last for an extended duration. These medical conditions are multidimensional as they impose their will on all areas of your life.

In the case of a chronic medical condition like fibromyalgia, you are not the only one who feels the impact. This condition has the ability to wreck havoc on a broader audience, including your family.

Adriel's Take on Family and Fibro

When you are suffering, when you are in pain, when you walk around dealing with fibromyalgia fatigue all the time, it is very easy to get wrapped up in yourself and your own suffering. It is easy to center your thinking on how your life has been affected by fibromyalgia — this is completely normal human behavior. But I feel it is important to remember that we are not the only ones who are suffering.

Our family and loved ones are also very much affected by this terrible illness. They often have to make sacrifices to help us, and they suffer because we suffer. It would be unhealthy for our relationships with them to become consumed with our own suffering, and not recognize theirs.

Watching a loved one in pain and suffering is not easy — it can cause intense emotional pain. It can also be a lonely life for them; they may give up opportunities to spend time with other people in order to be with us. They may not feel they can be open with us about their own problems because we have so many of our own.

They may have to make financial sacrifices to help and support us. Many fibromyalgia sufferers are unable to work much or at all. Doctor visits, medications and other medical expenses add up very quickly. This leaves a heavy burden on the shoulder of the person who is providing for the family. Family members may have to miss work to take us to and from the doctor, or simply to take care of us when we are unable to care for ourselves.

They may risk their own health focusing all of their time and attention on our health issues and not taking proper care of themselves. They may not go to the doctor when they need to, whether it be because of the time it takes or because of the expense, choosing to put those resources into our health rather than their own.

I could go on all day talking about the effects that I believe fibromyalgia has had on my family, but I thought it would be best to instead, ask them to share their insights with you. I posed a couple of thought-provoking

questions to my husband and mother. I gave them both plenty of time to mull the questions over before getting their answers. This is what they had to say.

I asked my husband Jorge:

How has having a wife with fibromyalgia affected your life?

“Well, I think the biggest thing would be that we don't do as much as before. We stay at home more and are limited in where we can go and how long we can spend at certain places. We don't spend time with our friends and family as much as we would like to.”

Do you ever wonder how life would be different if your wife did not have fibromyalgia?

“Not directly. But when you see couples doing stuff together, you can't help but wonder.”

My questions to my mother, Cathy, were basically the same.

How has having a daughter with fibromyalgia affected your life?

"The main way I have been affected is to feel great pain at seeing my daughter suffer. It's difficult knowing she spends so much time in pain, not to mention all the other symptoms she deals with physically, mentally, emotionally, all the doctors visits, medications, side effects, other people's reactions, or lack thereof, etc. It's difficult knowing every day is a struggle. It breaks my heart.

Next page: more from Adriel's mother and how fibro affects children.

Adriel's Take on Family and Fibro

"Before she was diagnosed, I didn't personally know anyone else with fibro, and I'd never heard of anyone as young as her having it, so I never made a connection between her symptoms and an illness like this.

"Looking back, we have talked about different symptoms she's had over the years, even when she was quite young, that we attributed to something else, but may have actually been early symptoms of fibro. How I wish I had known.

"It's very difficult accepting that at her young age there are so many things she misses out on."

Do you ever wonder how life would be different if your daughter did not have fibromyalgia?

"Of course I do. I think of how much easier her life would be, of all the things she and her husband could do together and with their sweet little boy, Levi, and that I would be able to see her more often.

"But I don't dwell on those thoughts. I'm basically a positive person. I don't like to dwell on things I cannot change or that make me sad. I admire her strength and her efforts to make the best life she can for her family under the circumstances, and I just want her to know I support her every step of the way.

"A wonderful hope for the future is a great asset in keeping a positive attitude! And knowing that many people have much worse things to deal with helps me be thankful for all the good things I have."

How Fibro Impacts Our Children

Children are also vastly affected by having a parent with fibro. They may miss out on some activities because there is no one able to take them, and they may have to spend time playing alone. They may even have to learn to care for themselves and even their parent at a young age.

I often feel a great amount of guilt because I am unable to take my son to the park, or even take him outside to play, as often as either of us would like. I feel guilty that he watches more TV than I would like him to, simply because he does not want to play on his own and I am unable to play with him.

But someone pointed out to me that as difficult as this situation is, my son is learning valuable life lessons from a very early age. He is being taught that we don't always get what we want, when we want it — not a fun thing to learn, but a necessary life lesson nonetheless.

He is also being taught that at times we have to put others' needs ahead of our own. This also teaches him the give and take necessary for healthy relationships with others.

He is being taught how to show love and compassion for others, to be kind and gentle. He is being taught to think about how his actions affect someone else. He is being taught to care for and help those less fortunate than himself.

I do love seeing the person he is becoming and the wonderful qualities he is displaying. He is more understanding of my limitations than many adults are.

What it boils down to is fibromyalgia is awful for everyone involved — I would be lying to you if I said any different. However, it is possible to have a happy, loving family life in spite of the difficulties we face. It takes kindness, compassion, patience, and most of all love — lots and lots of love.

Counselor Eric's Advice

Since lowering your stress will play an important role in the treatment of your fibro, working to address the needs of your family members can be valuable.

Have an Open Dialogue

The importance of assertive communication with your family members concerning your fibro diagnosis cannot be overstated.

Some might find the conversation difficult to have for fear of increasing the worries of others. Others will think family members are too old or too young to hear the news. Some will think "what they don't know can't hurt them."

These notions are each flawed; clear and accurate information grounded in facts is appropriate any time, for any audience. Without the proper information regarding your health and wellbeing, your presentation and actions may not make sense to them.

Disclosing your condition to them will be challenging, but it will aid your family tremendously.

Next page: providing helpful information, giving updates, and more ways to help your family.

Counselor Eric's Advice

Provide Helpful Information on the Condition

Once the condition is disclosed, point your family members towards the best fibro resources to answer all of their questions. Fielding all of their questions yourself can be intimidating and draining to your physical and mental health.

Collect some pamphlets from the doctor's office, gather some books at the library, and point them towards trusted sites online. This way, you have a level of control over the information and misinformation they are

receiving.

Discourage them from searching social media or online forums for material that could be biased or overly negative.

Give Frequent Updates

Letting your family members know how you are feeling and how your symptoms are can do a lot to ease their fears and concerns. When there is a lack of information, your family members may begin to fill in the blanks with their own perspectives and expectations.

Chances are excellent these thoughts will be inaccurate. This will increase their levels of stress and yours as you have to ease their fears and worries.

In your attempts to provide symptom information, keep the details simple, clear and concrete. Saying, “I’m not feeling that well today” is too vague and sure to induce some stress. Saying, “My pain is a seven out of 10 today” is helpful because of its measurability.

Be sure to point out when symptoms are low. Some people in your situation will find it necessary to only check in with your family when symptoms are high and assistance is needed.

If you only check in when you are too ill to come to Sunday dinner or you need a ride to the store because the pain is too intense, your family will think that your symptoms are always poor. Instead, try to check in when symptoms are both good and bad.

Increase Positive Interactions

Spend time engaging in activities you find fun and desirable as well as doing events your family appreciates. This will require an artful act of choosing what activities to complete with what family members.

Consider whether certain members would do well in groups or to be left for one-on-one interactions. You might consider adding exercise or healthy eating to the list of activities since these will yield a direct benefit to your fibro symptoms.

Encourage Mental Health Treatment

Sometimes the stress of your family member is too much for you to take on the responsibility. This could create an unwanted cycle of your condition increasing their stress, their stress increasing your stress, and this added stress flaring your condition.

If your family member is having a strong reaction to your symptoms, it could be an indication they would benefit from mental health counseling. Many people undergo counseling as they adjust to a major life change, even if the change does not impact them directly.

A chronic condition like fibro is perceived as a loss that may require a period of grief and mourning for some family members. A counselor can serve as a guide leading your family member to a place of acceptance and lower stress.

Fibro is a condition that requires various treatments over a longer period of time to manage its influence. Sometimes even the best treatments lead to poor results, which causes the effects of the condition to spread outside of the sufferer and to the sufferer’s family.

Through preventative communication, positive interactions, and increased self-care of the family member, everyone’s stress can shrink. Change the cycle of stress to change your fibro.