

How to Deal With People Who Don't Believe in Fibromyalgia

Source of Information:

<http://hubpages.com/hub/How-to-Deal-With-People-Who-Dont-Believe-in-Fibromyalgia>

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Though Fibromyalgia awareness is spreading and more research is being done every year Fibromyalgia is still considered a “controversial” diagnosis.

This poses a problem for those of us who have it. Not only because of all the myths that surround the condition but also because we don't know what to call it. Is it a condition? A disease? Simply a diagnosis? And also because inevitably, if you are open about the state of your health you are going to come upon the people, who narrow their eyes, raise one eyebrow and cock their heads. You may get a grunt, a laugh, a jerky smile.

Whether it's from a new doctor, an old friend, a family member or a colleague it's hard to know how to deal with it when someone looks you in the eye and tells you the condition that has had such a huge impact on your life does not exist. Unfortunately this is not at all an uncommon reaction. Fibromyalgia is often called the “invisible illness” because people who have FM look perfectly healthy.

The most important thing to remember, whenever you are dealing with people questioning your condition, your symptoms or your honesty is that their ignorance is just that, ignorance. A lack of education, rather than malice. Try not to get too defensive. Remember that if you let yourself get all worked up pain symptoms will likely follow. Though, this can be so much easier said than done.

From the easiest to handle non-believers to the hardest read on to learn how to deal with doctors, friends, boss', colleagues, family and even a spouse who are resistant to the truth.

Doctors

Sometimes people not believing in FM can actually stem from a misunderstanding. There are a number of reputable doctors and researchers that believe that FM is not a disease, but they are not entirely sure what it is. It is important to remember that most of these doctors are not telling you that you're symptoms don't exist.

The problem for them lies in the fact that though there are many theories about what causes FM none of them are proven beyond a doubt. Doctors are (understandably) leery to accept anything that hasn't been proven, and so they hesitate to even call FM a condition.

When you come upon these doctors in your travels through the medical world try to remember that they are not suggesting that your symptoms are feigned. They are not calling you lazy, feeble or a liar. They are simply playing it safe.

On the other hand there are doctors who genuinely do not believe that anything about FM is real, odds are they still don't think you're faking your symptoms but if you come across one that does (which I certainly have) all you can really do is turn around and walk right out of their office, never to return. I decided, after being dismissed by one doctor and later finding one who could properly diagnose me to write a calm and informative letter to my old doctor in hopes of saving future patients the trouble I had.

Friends

I'm doing this in order of how difficult it is to deal with when these people claim that what you have does not exist. Comparatively to the rest of the list Doctors are pretty easy to handle. If they are being difficult you can just walk out the door, there is no personal relationship to harm.

In the case of friends you had before you got sick you may find that they either

- a) have prior misconceptions about your condition or
- b) googled it and came across all the nonsense on the internet claiming it's not true.

The best thing you can do in this situation is try to remain calm. Let your friend know how difficult it is for you to know they don't believe you and show them some material from a medical source. Let them know that while there are people in the world who are not yet convinced, that's because this condition was only recently better understood. Tell him/her that right now you need their support more than ever.

Once they've read the material you directed them to let them know that they can ask you any questions they have, and try to answer them honestly but curb anything that may come across like whining.

If after all this they still refuse to believe you, turn them loose. Developing FM brings a world of pain and stress on your shoulders, the energy output of education resistant friends can be too much. If they're not even going to try, they may not be worth it.

Boss

Working with FM can be very challenging and there are many people with this condition who find that they simply cannot work a regular job anymore. If you're lucky enough to be at a job that can make allowances for your new condition you will likely face the choice of whether or not to "come out" as an FM sufferer to your boss.

First of all, I would say that it is vitally important to tell your boss that you have developed FM. You have a choice about telling your co-workers but your boss, who will be fielding your sick calls, will need to know what's behind them.

Like your friends your boss may have preconceived notions about FM. The best thing you can do, again, is to direct them to medical material that they can peruse. If they are not interested in reading up talk to your doctor (if you have an empathic one) about having a conversation with your boss, or

writing them a note, about the seriousness and reality of your condition. It's very hard for someone outside of the medical field to argue with a doctor.

If you find your boss is staunchly resistant, and is refusing to make allowances that are necessary to your health and well-being it may be time to consider switching jobs. You don't need the stress of a boss who is expecting you to perform exactly as you did before you got sick, it will only make you feel worse. A new job may mean a new FM-friendly boss.

Colleagues

Unlike your boss your colleagues don't necessarily have to know that you have FM. You must make the decision about how frank you want to be with them based on your comfort level and on how much your FM is affecting your interpersonal relationships at work.

If you decide to "come out" to your colleagues you may find that some of them will not believe a word you've said. It is true that in the past people have been misdiagnosed with FM and have recovered from whatever it is that they did have. But diagnostician are considerably more careful now and they have a great deal more research to back them up than they did in the past and this is exactly what you can tell them.

In the last twenty years great strides have been made in the understanding of FM. This has resulted in a large movement towards even more research. A number of clinical tests have been done and today over 80% of doctors firmly believe that FM is a very real condition.

When dealing with your colleagues you're not going to want to direct them to medical material or give them your doctor's phone number. **You may never be able to change their minds but if you tell them that mental imaging CT scans have proven that your reaction to pain and other stimuli as well as your overwhelming fatigue is very very real they make keep quiet.**

Finally, if your co-workers are being abusive, cruel or extremely vocal about their disbelief in FM you may have to accept that at the end of the day you have no control over other people's minds but you can choose whether or not you want to continue working in an abusive environment.

The possibility that you may have to change jobs not only because of your condition but also because of its reception is a very real one. This may be a tough transition, especially if you are new to FM, but getting yourself into a safer and more supportive environment is going to be so worth it in the long run.

Family

When you are diagnosed with a condition that has such an extreme effect on every aspect of your life it can be the last straw when a group of people that you simply cannot walk away from decides that they do not believe either in your diagnosis or your condition.

This is where you will often find your family googling your condition and perusing article after article. As I'm sure you've experienced it's easy to unconsciously direct your search engine to the result you're looking for. For example if you search, "Is Fibromyalgia real?" you will find a number

of articles telling you why it's not and the many things that people discovered that made their symptoms go away including but certainly not limited to:

- Finding bacteria in their digestive systems,
- dehydration,
- excess weight,
- poor eating habits,
- lack of exercise,
- drinking,
- smoking,
- vitamin deficiencies and more...

I can tell you from experience that remedying any and all of these problems will make you feel better, but if you were correctly diagnosed with primary FM they will not cure you.

The first thing to do, before letting yourself go hoarse trying to convince them is of course directing them toward medical reading material about your condition, this includes lists of symptoms and new research.

Then invite them to come with you to your doctors appointments and ask your doctor any and all questions they have. This saves you from getting defensive trying to field their questions, which may feel to you like attacks.

Finally, sit them all down, if you can, and tell them that this is one of the worst (if not the worst) things that has ever happened to you. That the symptoms often feel like too much for you to handle and now more than ever you need their love and support. You need them to be there to help you and to listen to you.

If all of this still fails miserably the best thing you can do is limit contact and explain to them exactly why. Remember, at the end of the day you have no control over them, only over yourself.

Spouse

I can't even begin to imagine how hard it must be to be suffering from this condition and have a spouse question your pain or the reality of your illness. I know that when I first experienced the pain of FM, along with its other symptoms, my husband admitted to having a moment of disbelief, but one that was quickly resolved.

I also can't imagine how difficult it must be for a spouse, especially one that's sceptical by nature to watch their partner suffering from invisible pain that doesn't seem to respond to medication and then to find article after article claiming that FM is not real.

The first thing to address when your partner questions the reality of your condition is whether or not they believe that you are experiencing the symptoms. If it's only the diagnosis that they are having trouble with direct them (like your friends and family) to reading material that will tell them all about your condition. Then invite them, implore them if you must, to join you when you go to doctors' appointments. Encourage them to ask any and all questions that they might have.

There are many online support groups and message boards that have special sections for the friends and family members of people living with FM. There they may even be able to get in touch with others who once harboured a similar scepticism.

On the other hand, if your partner is questioning whether or not you are experiencing the symptoms of FM the job of convincing him or her may prove harder. It's important to ask yourself, as well as your spouse, why it is that they think you are lying about your symptoms. What do they suppose you are trying to accomplish?

Finally explain to them that FM is called the "invisible illness" because sufferers look perfectly fine, our healthy looking bodies, in fact, are the reason that so many of us have suffered in silence for so long. Describe exactly how you feel to them, so that they don't feel that your symptoms are nebulous or vague. All of the symptoms for FM have a scientific explanation; however it is an explanation that is only recently being fully understood.

Developing FM is most likely one of the most challenging times in your life; I know it was for me. Your spouse needs to know that you need their support 100%.

The sad fact is that there are a number of relationships that have broken up when one person has developed FM. The invisibility of the condition will put a strain on existing trust issues.

Having FM changes your role in your life and in your home. Your partner may feel resentful about having to do so many of the things that you used to do. There are however a number of ways that you, your partner and your family can make it easier to live together with FM as a new part of your life.

Try to remember that you having this disease means that your partner has to deal with it every day of their life as well. Both of your lives will change forever.

Conclusion

It's important to remember that FM isn't going away. The vast majority of people, who have it, have it for life. It's not worth the pain or the fatigue of trying to convince people who just won't budge.

When you are diagnosed with a life-altering condition like Fibromyalgia the most important thing to do is to take care of yourself and your illness. The people around you, however, are often completely unavoidable and their lack of belief can have a huge impact on your life and even your pain. It has been proven that there is a neurophysiologic link between high stress and high pain, especially in people with chronic pain conditions. Luckily, in the face of facts, recent research and empathic doctors most people can't keep up their resistance.

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