

Welcome to The fibro Warriors

Surviving a typical Fibro Flare day – How to cope and explain it to others

A Fibro Flare is a sudden resurgence of symptoms of fibromyalgia. Fibromyalgia is real, despite the popular misconception that portrays fibromyalgia as a fake diagnosis doctors throw at whiny patients to make them stop complaining. That, or they have no clue what their patients are suffering from, so they label it fibromyalgia.

The Fibromyalgia Syndrome diagnosis has been around for a long time, albeit under the name Fibromyalgia “only” since the mid-1970s. That means 40 some odd years of patients suffering in silence from the fear of being shamed, ostracized, mocked or ridiculed by society as a whole, and even worse, by their own loved ones. We call these brave patients Fibro Warriors. They fight every day for the opportunity to live their life like anyone else.

Some days are worse than others. Those are referred to as Fibro Flares. When your fibromyalgia symptoms act up, there is no telling where the pain will hit next.

As a widespread chronic pain syndrome, the most difficult thing to understand for non-Warriors is that the pain travels. That is in part why people think it’s a fake affliction, since there are no two days alike, no two lists of symptoms alike, no pain relief techniques alike.

I have decided to walk you through a typical day. Some days, not all of those things will happen. But some days, all of those things and more will affect me, my kids, my husband and my loved ones.

This is a difficult exercise for me. I have taken the stance of brutal honesty. Going hour by hour, moment by moment, I am taking you on a very personal and intimate journey. I ask for your indulgence. I am a flawed human being, as we all are. I promise you to be truthful, and to express my feelings as earnestly as possible.

Please be kind when you read this journal. This is me, as vulnerable as I have ever been.

Fibromyalgia is not a joke. Fibromyalgia is real.

And there is no cure.

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5:45 AM – The first alarm goes off. I turn it off. I am trying to open my eyes, but you know what? It's just not happening right now. Back to closing my eyes.

6:00 AM – The second alarm goes off. Dang. I worked at a school for a while, and one of my students showed me how I could just turn off the alarm by pressing the "home" button on my iPhone. I did not know that. And unfortunately, now I know. That means that instead of struggling to snooze the alarm, my brain takes me straight to the home button.

It requires less brain power, and in turn limits my mental efforts. Sadly, it also means all of these actions are now automated behaviors. In other words, I do it without even realizing it. I don't even have to actually wake up, and most mornings, I cannot recall ever turning off my alarms.

6:10 AM – Third alarm. I turn it off.

6:15 AM – Fourth alarm. Note how the alarms are set to be closer together by now. It makes falling back asleep useless. At least that is what I hope to trick my brain into thinking. It ain't working, Folks. It just ain't.

6:20 AM – Fifth alarm. Am I kidding me? I seriously need to get up.

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6:25 AM – Sixth alarm. What is wrong with me? I just cannot physically wake up! I am constantly exhausted. I don't think human beings are supposed to wake up tired. No matter what I try, I do not get any rest. Some days, I feel like I may just as well stay asleep, because, what's the point? I'm going to feel like a zombie all day long anyway.

6:30 AM – Seventh alarm. Who does that? I cannot be the only one, right? But let's face it: what other people do really has no impact on my life. In the meantime, I am quite ashamed of myself. All the more reason to stay in bed. On the bright side, I have not gone back to sleep.

I was too guilty to close my eyes. I feel like I am letting everyone down and the laundry list of symptoms and syndromes is whirling and twirling in my head.

For me to be miserable is one thing, but I am making other people miserable too, especially those around me. Ugh. I hate myself sometimes. But I think I hate fibromyalgia even more.

6:32 AM – Kid #1, my oldest daughter, is 15. She knows I don't do mornings. Every day of the week, she comes in my room to gently remind me that I have to get up. For real this time.

6:33 AM – Kid #2, my youngest daughter, is 11. She also knows mornings and I don't mix. Every day, she crawls in bed with me and tells me lovingly that I need to wake up.

6:34 AM – Ugh. I might as well get up. What else is there to do?

6:40 AM – I took my meds when I finally woke up enough to move. The "moving" part is a term I use loosely. When I wake up, there is the extreme fatigue, but there is also the soreness.

Every morning, it feels like a train ran over me in my sleep. Sure, sometimes, it's only a two-car light rail, but sometimes it's a 90-car freight train. Loaded with coal.

6:45 AM – I am finally out of bed. It only took one hour. I've seen worse. Today will not be a really super duper bad day. It will only be a super duper bad day. Since that is my normal, go me! It takes me a good while to unfold every limb and move my spine around.

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It is like every muscle and joint was sprayed with some kind of freeze-ray straight out of a 1964 episode of Star Trek. Beam me up, Scotty! I'm just about done with all this!

How does it feel?

Every muscle in my body is as sore as if I had competed in every single category at the Summer Olympics. From my feet to my neck, everything takes a long time to loosen up enough to move around.

Some nights, I will have cramps that wake me up screaming. I think it comes from the Restless Leg Syndrome, which is associated with fibromyalgia. I constantly move my lower legs, and they tense up.

It is difficult to find a comfortable position to sleep in due to the costochondritis, and inflammatory response on my ribs and sternum (breast plate). As you know, there is pressure on your rib cage no matter which sleep position you choose.

I also have sleep apnea and narcolepsy. Quality sleep is a rarity. I take meds to control the symptoms and to wake up in the morning, and I have a c-pap machine.

For those who do not know what a c-pap is, it is a continuous flow of air being forced into your nose, to force your body to breathe. During phases of apnea, your brain slows down so much that it "forgets" to breathe.

After a few seconds, your brain realizes it gone done mess up, so it sends an emergency signal to your lungs to take in as much air as possible RIGHT NOW, you idiot lungs, she's gonna die! Oxygen! Oxygen! Or something to that effect. True story. Anyhow, my own gasping for air wakes me up, but not quite enough to remember it in the morning. When I had my sleep study done, they told me that O stopped breathing 56 times per hour.

As a result, there is no way I ever reach the restful part of sleep. Add to that the pain and the grogginess from the narcolepsy, and voila! You've got the crankiest woman to have ever graced the surface of the earth under my house!

What can I do to make it better?

Well... I have eight alarms total in my bedroom. I place some of them away from my bed, because eventually, the beeping of the alarm will annoy me enough to get up.

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I also try to take my meds early on in the cycle. This way the meds can start acting before I get out of bed. Hopefully, it helps take away the edge of the pain and allows me to move around. The pain is worse when my body is "cold."

Growing up, my hometown's soccer coach would spray a mixture of menthol and camphor on mild injuries during games. It took away the pain for a while, but the next morning, after the injury had time to rest, it would hurt like crazy. It is a bit like this for me, and every Fibro Warrior out there. Our bodies need to warm up for the pain to decrease.

I do not like the idea of my daughters having to wake me up. That kind of role reversion makes me uneasy. I should be the one waking them up, not the other way around!

Luckily, some days I can muster the strength to get up before them. I live for those small moments of victory over fibromyalgia. I feel like every small battle won makes me a stronger person.

And of course, to control the sleep apnea and the narcolepsy, I use a continuous pressure machine called a C-pap machine, as well as prescription medications that allow me to stay alert during the day.

One day, I was driving out of state for work, and I woke up on the highway. It was the scariest thing I have ever experienced. I had fallen asleep and I kept on driving. I don't know how long I was asleep for, and it probably could be measured in seconds, if that, but it was still quite the awakening for me.

6:55 AM – I hop in the shower. OK, so maybe I don't hop. Let's be realistic. I waddle gracelessly toward the shower door, hit my toes on the wall, cuss at everything that is inanimate in the bathroom, and open the shower door. I turn on the water and back away slowly... Water is not my friend. I'll explain.

7:00 AM – I think the water is warm enough for me to attempt it. I step in the shower, and that is the single most uncomfortable thing that can happen to me right now. Two reasons for that.

First, cold water and hot water both hurt me. Fibromyalgia means that you gain some odd hypersensitivity to the most mundane things. Like hot and cold water. Think about it: fibromyalgia affects your central nervous system, so nerve stimulation is bound to be messed up.

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Second, the water dropping on my shoulders hurt me. If the water repeatedly hits the same spot, say on my shoulder, it starts with an extraordinary feeling of pressure on that point, and soon it turns into bona fide pain. So I constantly have to move around. Ugh. And now you know why water is not my friend. It takes me a minute to figure out a bearable flow and temperature. But it's all good now.

7:05 AM – The warm water does feel good on my back, shoulders and glutes. I'm pretty certain you guys can do without the visual of me in the shower, so let's just go over this quick.

One: I can't lift my legs. My hips are so damaged by the fibromyalgia that I physically cannot move them up. I have what the doctor called "greater trochanter bursitis."

The fluid-filled "sacs" on the side of the hip joints get inflamed. The trochanter is the large muscle on the side of your leg that holds the hip and the pelvis together. When those puppies are inflamed, I am oh-so-happy to have a seat in my shower!



Two: Washing my hair takes forever. I would have been the poster child for bad excuses in the 50s. "Oh, Johnny, I'm sorry! Of course, I think the world

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of you! But I can't go out tonight. I have to wash my hair." Boom! Just like that, Johnny got friend-zoned! But I digress.

What makes it hard to wash my hair is that if my arms are over my head for more than a few seconds at a time, they become weak and sore. I imagine that would be the feeling weight lifters get when they throw that bar over their head.

They can only hold it up there for so long, because it hurts their arms. Same for me. Except without the weights. Or the leotard. I don't have one to those.

7:15 AM – I'm out of the shower. The towel slipped to the floor. Shoot. Now I am to bend down to get it. Easier said than done. There was a time where I could have maybe used my feet to lift the towel off the ground, but those days are long gone. I can't bend down. Not this early in the day, at least. Oh well. Air drying it is.

7:25 AM – OK, I am dressed and ready to go. Kinda. The kids are ready for school, so off we go. Going down the stairs hurt like a motherlover. My plantar fasciitis is acting up. The bottom of my feet, and sometimes the sides, feels like I have put my feet in a medieval torture machine that stretches my tendons every which way. Not fun.

7:30 AM – Ready to go. Again. I slip on my \$100 shoes. Yep, you read that right. I have extremely expensive shoes. Why? Simply because I need exceptional, and durable, arch support in my shoes if I want to be able to walk more than 25 feet.

If I don't have good arch support, my plantar fasciitis makes me want to curl up in a ball and cry. I figured that I could spend a bit more money on shoes. I have to say that was a very good move!

7:35 AM – I step outside and the elements hit me. Are you for real, Mother Nature? Seriously?

Either it's Winter (in Minnesota) and the temperatures are below 0* Fahrenheit. This entails freezing your bootie off, and your hands, and your everything else. Also, it often means there is snow or ice everywhere.

It makes walking more difficult, because I do NOT want to fall! Plus, I need to scrape up my car and dig it out of the snow bank. Nothing like intense physical labor first thing in the morning!

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Or, if it's not Winter, it's Summer. That means it is stupid hot, like 90°F. And humid. OMGosh, the humidity! When you have 100% humidity in the air and it's not raining, you step outside and water beads starts forming on your skin for no good reason. For real, summer.

What is your point? That's just dumb. (The opinions expressed in this piece are those of the author only. For all I know, maybe there are people out there who like that type of weather. That would be insane, but anything is possible.)

7:50 AM – We get to Kid #1's school. Looks like she will be on time today! Yay, go me!

8:05 AM – Unfortunately for Kid #2, she will not be on time. Again. The kid has had more tardies than I care to tally up in the past school year. Between my issues and her issues, mornings are just chaotic, and horrible, and slow and fast, and overall just nope. After three tardies, she gets detention. And like a trooper, she has served her detentions with a smile, assuring me that it is all good.

How does it feel?

It feels like I am the worst mother in the world. My self-esteem suffers greatly from my inability to do things like everybody else. Being unable to perform simple tasks, like bend down or wash my hair, makes me feel inadequate. It's hard to explain.

Physically, the pain is tough. It feels like my spine will snap in half if I push it too fast, too much. I wish I could enjoy the "hot therapy" of the shower, but it stresses me out.

Most of my day is spent trying to figure out how to not get hurt.

What can I do to make it better?

First of all, I need to take my meds right away, after my first or second alarm. This way, it guarantees me a smoother transition from supine to vertical positions. OK, I'm not that fancy. I meant from laying down to standing up.

Also, gently stretching while still in bed ensure my muscles are moving around before I put too much pressure on them.

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I have slippers that are almost as expensive as my shoes, and it helps me tremendously when I slip them on before my feet touch the ground. I have flat feet. And when I say that, I mean so flat that you can't even slide a piece of paper under my feet when I stand up! So having that arch support first thing in the morning helps my (non-existent) arches for the rest of the day.

I have heard that there are some stretching exercising one can do to minimize plantar fasciitis symptoms, such as standing on the edge of a step and digging your heels down toward the step below.

It stretches your tendons and muscles in your feet and calves. I have personally tried it a few times, but it required too much discipline to do that every day!

I know that expensive shoes are not in everyone's budget. Honestly, they're not really in my budget either. But I have found that if I look around shoe-reseller online, I can stumble upon some amazing clearance deals. It allows me to buy \$100 shoes for \$30, and I'm all over those savings, baby!

The Minnesota climate is quite nice in the Spring and Fall, but Winter and Summer can be brutal. As a Fibro Warrior, I need to be able to adapt to the weather. That means lots and lots of layers. And yes, even in the Summer, because air conditioned rooms can "shock" my body if I come from outside, which means my body will tense up so much, it hurts.

As for the kids being late for school, well... This is the biggest point of contention for me. I absolutely HATE that my kids are suffering the consequences of my condition. It is not fair to them, and it is not OK. I know that. Yet I cannot change it.

I make resolutions, like everyone else. But within two weeks, a flare-up hits me and all good habits become obsolete. And I hate myself for that. So the depression takes over, and it makes things even worse.

As a matter of fact, I was fired last Winter from the school my daughter attends. The reason was "excessive tardiness." Now, I'm not going to go into crazy details here, but legally speaking, I should not have been fired as I am protected under the ADA.

I won my unemployment hearing, and it was clearly established that I was terminated without cause. But that is besides the point. The point is that my fibromyalgia has prevented me from keeping a job. Trust me, that is a sucky

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feeling. So now, I am not even looking for a “regular” job anymore. I have returned to my career in Mystery Shopping, and I write.

8:10 AM – Now that the kids have been dropped off, I need to go on with my day. Motivation is tough, as always. My meds are starting to work on the pain and I can at least move around without wincing. Almost.

8:20 AM - I am on my way to my friend’s house. A few of us moms are meeting up. I am not a stay-at-home mom per se anymore, since my kids are 15 and 11. But I can’t really hold a traditional job either. My ability to work is too unreliable.

I concentrate on freelance jobs or independent contractor jobs these days, but sometimes the Fibro Fog is so thick I can’t see anything through it. Enough of that, I am heading toward my coffee date and by Jove, I will enjoy it!

9:00 AM – I have to cancel the coffee date. There is no way I can sustain any kind of intelligible conversation this morning. I cannot understand the radio program I am listening to, and I had to turn it off because it took too much brain power while I was driving. About that coffee date... I’m the one who suggested it. I asked to meet up so we could talk and laugh and all that good stuff. And I am the one canceling it. **sigh**

9:20 AM – I get home and think about all the things I have to do. I quickly become overwhelmed and realize that my day cannot go on if I don’t get some rest.

9:30 AM – I lay down for half an hour. I set up two alarms. It’s not as much as in the morning because my narcolepsy meds are working. I still need the cpap machine for my sleep apnea though. That’s the only way I can get any type of restful sleep. I was supposed to write an article or two, but that is just not happening. Good nap, y’all.

10:00 AM – I wake up somewhat refreshed. The sleep attack has worn off and the fog has lifted. Thank goodness! I lay in bed a bit longer because I found a nice, comfy position and I’m afraid that if I move, I won’t be able to be this comfortable again. So I grab my phone and look for online support. I head to thefibrowarriors.com to read articles and comments, and then I head over to Facebook where I read over The Fibro Warriors group posts.

10:15 AM – I was thinking about getting a massage or something similar this morning, but I don’t want anyone touching me right now. The clothes on

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my back feel like they are laced with porcupine needles. It's not a nice feeling. At all.

I turn to my one of the other tricks I keep in my bag-o-feel-good: aromatherapy. I either use essential oils or candles. I like both equally. I recently discovered melting wax, too.

I know it's not a revolutionary new product and I am aware that it has been around for a while, but I have to admit that they make me nervous a little bit. I don't like the idea of the burning hot wax staying hot even when I turn off the warmer. Maybe that's just me.

I turn on the TV and relax for a minute. The day is already passing by fast!

How does it feel?

Are we being honest? Yes? Well it feels pretty crummy. For crying out loud, I made the plans and I can't even meet up with my friends! But I'll tell you what's even worse: looking stupid because you can't take part in a simple conversation, or falling asleep while people are talking to you.

There is no better way to make sure your friends think you hate them or you find them so boring you fall asleep. And yes, this has happened to me. It is utterly embarrassing and I feel like a pretty terrible human being when that happens.

The no job thing? I try not to think about it too much. I am very fortunate to have a husband who is understanding. He is a good provider for me and our kids, but I know that not every Fibro Warrior out there has that kind of support system. And to you guys, I say: I am sorry. But in all the darkness around us, there is a bright light I have found in TheFibroWarriors.com.

When I think about what could make me feel better, I sometimes lament my inability to follow through. A good massage is wonderful, but unfortunately, a good massage therapist is rare. Dang.

What can I do to make it better?

I mustered up the courage a while back to tell my friends about all of my issues. I sat them down and chose a day I was feeling OK, and I just bombarded them with everything I am going through. I don't necessarily recommend doing it that way, because I think I overwhelmed them.

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Honestly, I felt like I was the biggest whiner on the face of the earth. I felt I was like, "Oh poor me, boo-h00, listen to my laundry list of misery." But you know what? I am glad I told my friends about everything.

I am not looking for pity, but maybe a little bit of understanding when I have to cancel plans. My friends are real friends. I hope you have people in your life my friends. Everyone deserves a Leslie, and a Shelly and a Katie! And no, I can't share them. They're all mine! Mwahahahaha!!!!

When it comes to pain relief, I believe your mind is as important as your physical body. Whether you are a spiritual person or not, I think we can all agree that when you feel good in your head, your body feels good too.

In my own experience, if I am happy and relaxed, I don't tense up my muscles as much, and it tends to reduce my pain level.



I have a good massage therapist. You should get one, too! Here is the trick: there is nothing wrong in looking around for a good therapist. When you buy clothes, do you buy the first thing you put your hand on, or do you browse to find your style and your size?

Massage therapists are a heck of a lot more expensive than clothes, therefore it is perfectly acceptable to look around for the perfect therapist.

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Ask questions, see if they know what fibromyalgia is, ask what technique they use. All of these elements and more ensures you will find the right fit for your massage therapy.

I recently discovered MPS therapy. It stands for Micro Pulse Something Something. I could look it up, but nah. I don't really need to know what it stands for.

All I know is that it's been working for me. It sends tiny electrical signals or impulse from one acupuncture needle tool to another, each placed on either side of my spine. If you've heard of TENS therapy, it's the same idea, except it works a bit deeper in the muscle mass.

I have been delighted with the results. Reading about it made me a bit skeptical of its legitimacy, because it is mostly unknown at the moment, so I figured I would just go with it and see how I feel. And I feel good. In my book, that's a winner.

In order to clear my mind and enjoy the day, I love using aromatherapy. I find that lavender and vanilla are scents that make me feel better. I'm not sure there is a universal consensus on what oils are better than others.

I think it is something very personal and you to play around with mixed oils to see which one makes you feel better. For example, I absolutely love orange blossom, neroli, bergamot... These scents send me back to when I was a kid.

My grandma used to make little fabric pouches she would sew shut after filling them with lavender flowers. We would put them in our drawers and closets and it smelled so good!

She also cooked with orange blossom extract, and to this day, it is my all-time favorite taste and smell. It brings me back to a time when I had no worries and no burdens. And certainly no fibromyalgia.

And just so we are on the same page, aromatherapy is absolutely portable nowadays. I sprinkle some on a leather necklace I wear every day, and I sniff it throughout the day when I feel my mind is spiraling out of control. One of my daughters has a bracelet made with lava beads.

The beads are very permeable, so they soak up the oils. It's a great way to use aromatherapy when she needs it, without being too obvious. And finally, I regularly place some essential oil blends on my air vents in my car. It keeps the car fragrant and helps me re-center when I'm stuck in traffic.

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Finally, it is important to find that one spot in the house that is just yours. Mine is on the couch, last seat to the left near the chaise, with an ottoman for my feet. No one gets to sit there besides me. And my dog, of course. But not the kids. No siree! It is my spot.

The pillows are just right. I know it is always comfortable for me, and it provides me with a constant in my chaotic, busy life. No matter how weird, painful or bad the day has been, I am always welcome and relaxed in my spot. Therefore, I strongly suggest you find your spot in your house too.

10:30 AM – OK, enough of that relaxing business. We're not here to lounge on the couch all day. Mostly because if I stay inactive too long, I will be unable to move again, but whatever.

Let's just pretend that it is because I am a productive member of society! Anyhow, I have some gardening to do. Kinda. See, we don't have a yard. Years ago, I laid down bricks over the entire area (which isn't that big) to avoid having to do the whole gardening bit.

Turns out weeds find a way to grow between bricks. I guess I should have known that, but I did not, so... Now I have to cut down the weeds.

We're being honest with one another here, right? Good. I actually received a notice from the city's Weed Inspector (you can't make this stuff up!) in essence telling me that I should take a machete to the jungle around my house. I don't have a machete, so I settle for heavy duty hedge clippers. Those suckers won't survive long now. But holy moly, I think I'm going to pay for it tomorrow...

Regardless, it feels pretty dang good to get things done! Go me!

11:15 AM – Land Ho! I can see the ground! I bet you didn't think I could do it, M. Weed Inspector!

OK, enough of that gloating. I feel good right now. Nothing hurts, I'm in a good mood and I am motivated. I have some chores to do around the house, and I tackle the laundry. Like a lot of people, my washer and dryer are in the basement, and my bedrooms are upstairs.

I have a couple loads to do, so I go up and down two full flights of stairs twice. ** pardon me while I catch my breath – cough ** Wow. I did not remember this whole "stairs" thing being an Olympic sport. It should be.

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I get some groceries that were left overnight in my car. Toilet paper (no worries, I poop rainbows and unicorns, so we're good, I can talk about it). I have exactly ZERO energy left in me to bring it to the upstairs bathroom.

I'm just going to leave it there at the bottom of the stairs. It will provide me with hours of amusement as I watch every family member gracefully leap over it, push it aside or trip and face plant over it. But you and I know this is going to stay on the bottom step for two days before someone gets annoyed enough to bring it upstairs!

11:45 AM – The Post Office closes at noon. I live a couple blocks away. We don't have mail delivery service in our little Minnesota haven. We have a PO Box and we need to get the mail there every day (or every week or two, in my case). After the Stairmaster workout earlier, my calves are on strike. Let's not even talk about my motivation: the union is about to get involved...

Post Office. Must go. So... Far...

Oh well. There's always tomorrow.

12:00 PM – Look at the time! The Post Office is closed now. What a shame. And to think I needed to go there today... Alright, time for lunch! Who's hungry?

Turns out, not me. My appetite comes and goes, and I think it hasn't come home yet. I heat up a cup a tea (Earl Grey or Bust!), and grab a pack of cookies. I sit down in my spot, and mindlessly eat cookies. Hey, one doesn't get morbidly obese by eating salad!

How does it feel?

I am on top of the world! I accomplished something today, and I am proud of that. The "garden" needed tending, and I tended to it. Score one for me! It is not every day that I can say I have done something, or contributed to the household.

Sometimes, I feel like I am letting everyone down, including myself. I don't have a steady job, yet my house could be featured on Hoarders. Stuff piles up, and I can't keep up with everything that needs to be done. There are days when I am not able to do anything AT ALL.

Not a thing. When my husband comes home from work and he has to do laundry, or when my kids want to invite friends over, that's when I feel the lowest. What kind of person does that?

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Realistically, I did not do that much today, yet I feel like I have lifted my own body weight three times over, in reps of 15, five minutes apart. Talk about feeling useless, pathetic and miserable all wrapped in a fat envelope. I am going to feel this physical effort in my entire body later today...

What can I do to make it better?

This is not rocket science. I know that. You know that. So why do we keep on doing this to ourselves?

There are two components to the feelings expressed above.

One – I should never let things pile up so much that they become overwhelming. Putting things off to tomorrow because today won't work for me just isn't a good solution.

Two – I should learn to pace myself and do things little by little.

If you have not noticed it, this is the ultimate contradiction: take it easy, but do something. How in the world are we supposed to do that? Moderation, schmoderation. I guess if I did half loads of laundry, it would be more manageable. Or if I took care of one part of the yard at a time and rotate. I don't know. Honestly, I have no clue how to manage this one in an intelligent manner.

What I know, however, is that my family loves me. They understand (most days!) that I need help doing simple things. So they help. My love for them is infinite, and I think this may be reciprocal (most days!).

As for how my house looks? I do not follow my own advice, because it is hard. My advice is this: if your friends love you, they want to visit with you.

They are not interested in judging how your house looks. And if they do, then they are not worthy of your friendship. Trust me, I have to work on this one, but I believe that when I achieve that mindset, things will be a lot easier for me.

When it comes to nutrition, I joke about being fat, but we all know that is just a front. Of course, I feel disgusting. Of course, I am ashamed of my 320 pounds and counting. I am a human being, and when other human beings look at me like I am a freak of nature, it hurts.

I put on a brave face, and most of the times I do believe it when I say I don't care what other people think. And then there are those times when I

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do care what they think. What can I do to make this better? Lose weight. I know it will also help with my various health issues.

Unfortunately, it is easier said than done.

I have stopped buying junk food to leave it around the house. No more cookie lunches for me! We will see how long it lasts, but the idea is to make the availability of junk food more difficult, to hopefully reach a point where the effort it requires to get to the junk food is greater than the instant gratification reward. Baby steps.

Oh and, I also found some tools to help me do things around the house with less effort. For example, I have hedge clippers with extended handles, so I don't have to bend down so much.

I also fold my clothes on a TV tray so I don't have to bend down (recurring theme?) to fold them on my bed. Little things like this make repetitive jobs a lot easier, and a lot less stringent on the body.

12:30 PM – I'm done with my cookie lunch, and I feel guilty. Of course. I head on over to the sink, where the dishes from last night stare at me. If I wait any longer, they might start talking to me. I probably should wash them.

Problem is, standing over the sink at a weird angle makes my lower back lock and hurt like crazy. If you've never had a cramp in your lower, I don't recommend it.

It happens to me once in a while, where it goes beyond discomfort or even pain: the muscles actually cramp up like a charlie horse waking you up at midnight. It's not pleasant, and if you can avoid it, please do.

12:45 PM – I can move again, but now I feel this dull ache on my lower back. Perfect timing to go grocery shopping. Honestly, there is no good time to go grocery shopping. I'm not a fan. Pushing the cart helps keep my balance, so that's a start.

Getting in and out of the car hurts. My gosh, I whine a lot!

1:30 PM – My little Goddaughter is 2. She is the cutest, most adorable little girl ever. And boy, does she have energy... My friend needs to run an errand, so I head over to her house to watch the baby while she's gone.

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That little girl melts my heart, and I just can't say no to her. So, yeah. Dance party she wants, dance party it shall be! I have a LOT of fun with her. Little humans are amazing.

Strangely enough, when I have fun, my pain isn't as prevalent. Have I discovered a cure? Should every Fibro Warrior get to borrow a toddler or a baby? With a "use as needed" label? Ummm... Probably not...

2:30 PM – Time to go get the kids from school. Thankfully, my oldest takes the bus. It makes the back and forth a lot easier at the end of the school day. I still have to go get the little one. Due to special needs of her own, she goes to school about 40 miles from home. No bus. I know it is the right thing to do for her, but my goodness, there are days I just don't want to drive that far.

3:00 PM – Traffic is at a stand still. This is quite a rare occurrence around here, but the downside of living in a rural area is that sometimes, farmers need the road as much as commuters do. So here we are, watching middle schoolers pass us on their bikes. All this sitting around and not moving business makes my back hurt, and it is almost as if some sciatica is setting in.

I'm a bit on the grumpy side, and I don't really want to talk right now. This whole chronic pain business is seriously cutting into my quality time with my kiddo. I have had some amazing conversations with the kids in the back seat.

Something about not staring me in the eye makes them open up easier. Maybe they feel less threatened? Come to think of it, maybe it's the same principle as the stereotypical therapist sitting behind you while you lay down on the couch. I can't believe I had not thought about this earlier!

3:45 PM – We are finally home, and it is time for homework. I swear, one of these days I'm just going to walk out on the kids and come back two hours later. I despise homework. I'm quite passionate about my hatred of homework, actually. To a certain extent, I dislike homework as much, if not more, than the kids themselves.

The day is drawing to an end, I'm tired, I'm annoyed that I did not accomplish half of what I had set out to do today, and balancing chemical equations would have been fun under any other circumstances, but by golly, not now. Not. Now.

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4:00 PM – No, honey, of course I don't mind taking you to play practice. I am glad you are engaged in extra-curricular activities. It's great. On a side note, though, could please not sign up to volunteer at two different places when you have theater club? That would be fantastic. And this way, maybe I won't flinch in fear every time I hear the words "practice" and "volunteer." Maybe.

How does it feel?

I feel like I am skipping on my family duties, like the dishes and all. Have you ever heard of a stay-at-home parent (because who are we kidding – that is essentially what I am) not doing one chore during the afternoon? There is always something to do! How can I think it is OK to leave dishes in the sink for days? Disgusting.

I feel like I am constantly complaining about something. My knee hurts. My elbow hurts. My foot hurts. Whine, whine, whine. Nobody wants to hear me whine, yet I don't even realize I whine all the time.

Not being to keep up with my own kids, or with my Goddaughter, is one of the worst feelings there is. You want to do what? Every other kid is doing it? So you want me to do this with you? Sorry, Honey. Ain't happening. This old woman here needs to rest. Again.

It is frustrating for me, and for every one around me. I feel like a burden, and it's only a matter of time before people stop trying to get me to do things with them.

Oh, hello, there, depression.

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Let's talk about homework for a bit. Homework, my dear enemy. I know why kids have homework, and I understand the reason why they take it home. But for the love of all that is good in this world, can we make sure the homework they take home is actually on the same topic as what they have just studied? I don't want to go back three months to see if I am still understanding the ionization of lead properly. Good Lord.

You want to be in theater? Sure. You want to volunteer at the food shelf? Sure. You want to help at the therapeutic riding horse farm? No problem. You want to help your elderly neighbors with their garden chores? Of course. You want to take driver's ed? Who's gonna pay for that? You? Why yes, Darling, of course you can!

Can I take a nap, now? Because just thinking about it is overwhelming. I am that one parent who just sits on the parking lot and dozes off while waiting for her kids. Keep it classy, Minnesota.

What can I do to make it better?

I've said it before (I think), but let me say it again (or for the first time, in case I'm recalling this wrong): communication is key. If you don't tell your

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own family when you need help, when you need a break or when things need to change, you will never be able to survive.

I say this knowing full well the implications of what I just said. Without any kind of help or support system, you simply cannot survive a life of chronic pain. Talk to your loved ones, let them know that you need to be able to modify your shores and your daily activities according to your pain level, and that it is unpredictable for the most part.

If your loved ones have a hard time remembering, remind them. And of your loved ones do not understand or do not want to cooperate, then do what you can and nothing more anyway. There is no reason to wreck your physical body and your mind over household chores.

Not worth it. You are a valuable asset to your family, and if they cannot see it at the moment, then so be it. Just don't feel like you have to go to extremes (which may seem like nothing to healthy people, by the way) just to keep up with societal norms.

The solution I have found for my daughters regarding homework is doing homework at school. I have asked my kids to stay after school during the homework help hours in the media center.

There are teachers available for answers, and there are resources galore. If homework does not get done for reason x, y or z, then so be it. I have become somewhat of a fatalist, to be honest.

It is what it is. No sense in getting upset over what I cannot change. In addition, my middle schooler was offered the opportunity to have a National Honor Society student tutor her once a week. And suddenly, harmony is back in our house after school. No more tears and screams! Yeah!

As for the extracurricular activities, I had a heart-to-heart with the kids. I am proud of them and thrilled that they want to help around the community and participate in school-sponsored activities.

But here is the deal: if there is no school shuttle to take you wherever practice is happening, I can only take you if there is no other activity planned that day. I physically and emotionally cannot handle three or four activities between 3 PM and 7 PM. That's crazy talk, my dear. And I don't do crazy.

5:00 PM – Dinner time. Dang it. I almost forgot about dinner. I had planned a healthy meal for tonight, with the groceries I bought earlier. Since I have

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no energy or patience right now, I'm just going to wing it. Cereal for dinner, kids!

6:00 PM – I ate some junk food for dinner again tonight. That stuff is depleting my energy levels at the speed of light. I am so tired right now, I can't even interact with anyone. I just want to go to bed. It is like my internal clock is off.

6:10 PM – I close my eyes for a few minutes while sitting on the couch and instruct the kids to wake me up no matter what excuse I give them to leave me be.

6:25 PM – The alarm I had set on my phone wakes me up. Kinda. I keep my eyes closed and feel around for my phone, to shut it off. Kid #2 shakes me gently and tells me I have to wake up.

I open my eyes and I feel groggy, like when someone wakes you up at 3 AM. I do not like this feeling at all! The room is spinning a bit and my eyes have a hard time adjusting and focusing. Fibro Fog. Ugh.

6:30 PM – My husband comes home from work. He is tired after a 10-hour shift, and when he asks me what is for dinner, he doesn't look too thrilled about the whole gourmet cocoa puffs thing. He ends up making himself a peanut butter and jelly sandwich.

6:45 PM – The family goes on a bike ride. Of course, when I say that, it's everyone but me. I don't even own a bike anymore. My joints hurt so much, it's not even funny. I've tried before to go on a stationary bike, but my coccyx (tailbone) cracked. No joke. I fractured my butt. Nice.

7:45 PM – They comes back from their ride. Inside jokes are flying around me and I can't catch any of them. It's high school all over again. The cool kids have shared experiences and they can start sentences without finishing them, because everyone is laughing. Boo-hoo me.

How does it feel?

I feel like a loser when I buy healthy foods and I don't eat it. It costs a bit of money to buy fresh vegetables for example, and sometimes it all goes to waste because my energy level is so low. I hate fibromyalgia. Cereal for dinner is fun once a year, but when it is cereal night twice a week, something's gotta give. This cannot be healthy for my kids. I am a bad mom.

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I have never heard of a grown-up needing two naps a day to function. This is absolutely ridiculous. I feel so inadequate. I am not able to interact with my family the way I want and it is driving me nuts.

Of course, the more I think about it and the more it bothers me. Problem is, no matter how hard I try to stay awake, I am falling asleep and I cannot control it. I can feel my eyes rolling back in my eyelids, and the noises are muffled.

Sometimes, I even see things that are not there. My brain thinks it is asleep but my eyes are still open, so the dream realm is crossing over with reality. That can be super scary at times, actually, because I cannot tell the difference between what's real and what's just my brain working overtime.

If you have ever heard of somnambulism, it is a bit like this. I don't really sleep walk or sleep talk, because I am not asleep, but I do and say all sorts of ridiculous things. Which makes for funny stories.

Having my kids be my keepers is not something that will win me the best mom award. Realistically, I should be the one waking up my kids, not the other way around. Talk about role reversal!

I feel like I am useless. I can't even make dinner for my husband, who has no choice but to work long hours since I can't hold a "regular" job. He comes home tired, and the least I could do is have some dinner ready. But no. He ends up eating cereal. Which is not as fun for a 47 year-old man as it is for an 11 year-old kid. Just saying.

It hurts me deep when I see my husband and my kids go off without me. It's not that they don't want to hang out with me, but they want to do stuff I physically cannot do.

So here I am, staying home, not knowing what to do with myself for the next hour or so. And when they come back and they obviously had a great time, I feel jealous and a bit bitter, too. Not quite the altruist I try to portray...

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What can I do to make it better?

Here is the deal: I need the healthy foods. It is essential to my quality of life. Some days, I just feel super motivated and I buy stuff I think I will like, but then when I get home, my motivation is gone and the food goes to waste.

I need to remind myself to only buy the foods I know I will eat for sure. I need to make the meals in my head before I even head out to the store, and if there are more than three or four steps to the preparation process, I need to be honest with myself: do I have the energy to do this, and will this energy still be there in three or four hours. If the answer is no, then I buy something else.

Having easy to make healthy foods at home is a must. I keep a tub or two of hummus in the fridge, and baked crackers to go with it. I also have a few jars of salsa as a back-up. This way, when I cannot cook anything healthy/fancy, I turn to the easy dips and voila! Healthy meal, no prep!

Now as far as the naps go, I need to accept that it is my reality. I have a chronic illness, and sometimes I view myself as a victim a bit too much. Some other times, I feel entitled a bit too much. I need to find a healthy

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middle ground. Yes, I need naps. No, it does not mean that I can just go and sleep anytime I want to.

Realistically, the world does not revolve around me (shocker, right?). That means that there are things that need to be done at certain specific times. I have to find a way to balance my fatigue and work around those task or moments that require my full attention.

Turns out for me, family time is one of those moments. I highly dislike being sleepy during the few hours I see my kids during the day. So I try to fit in a small nap when I'm not so exhausted that I can't function anymore.

Once again, communication is key. When sleep paralysis sets in (meaning I can see and hear everything, but I cannot move at all), my family knows that all it takes to bring me back to reality is shake my hand gently.

This signals to my brain that I am not in dream world, and I need to be able to move around. To be honest, sleep paralysis is kind of cool. It's a very relaxing feeling once you know what is going on. All of your muscles are limp and you are just sort of floating in your own body. Very trippy, for sure!

My chronic conditions, including fibromyalgia, are part of my life. Without feeling like a victim, it is good to communicate with those around you.

Once they know, they will be more understanding of the times when you cannot do anything. That does not mean they will always remember, so it is also my job to gently remind them that I am trying my hardest, but today just isn't a good day. I need to learn to express my needs without guilt, shame or embarrassment. It is what it is.

Sometimes, when I see my family or my friends having a good time without me, I tend to revert to that little girl who had to go to bed while her parents were still visiting with friends or family. I want to be a part of everything, and knowing that I can't makes me melancholy.

I have slowly accepted the fact that they are making memories without me, but it doesn't mean I can't make memories with them too. So instead of just staying home when they go on a bike ride, I go with them to the trail head and either wait for them there or walk a bit on the trail. It makes me feel less alone and more included.

7:50 PM - Time to think about sending the kids to bed. At 15 and 11, they are fully autonomous when it comes to things like this. This makes it quite

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easy for me, but I have to say that I do miss their younger years, when they needed me more. Selfish, I know.

8:00 PM – Goodnights have been said, kisses have been blown and blankets have been tucked. Boo-yah! Another successful bedtime. -

8:03 PM – You know... I can't wait for summer, when there is no bedtime. I miss them! Ha!

8:10 PM – My husband asks me if I will watch a show with him. I agree despite an irresistible urge to just sleep. After a few minutes, I wake up a bit. Unfortunately, my mind may be up, but my legs are asleep. Argh! And I just getting comfortable, too!

8:45 PM – I knew eating junk food was not a good idea. I have some gallbladder issues, which is a common occurrence among Fibro Warriors. It gives me severe stomach cramps.

9:30 PM – My husband goes to bed. I follow him, thinking I can probably fall asleep too, since I am so tired.

9:40 PM – I guess I'm not too tired after all. I think I'm going to head downstairs to relax a bit. Actually, I'm going to write a bit. These articles don't write themselves! I grab my laptop, go to my spot on the couch, put my legs up on the ottoman, and get writing.

10:30 PM – I go back to bed. This time for real! I have had a long day, and I think the sandman just dropped by. My eyelids are heavy, and my bed is calling me. I take my meds, and I settle in. It feels good to be laying down. Good night!

How does it feel?

Bedtime is always a bitter sweet moment for me. I absolutely love the great individuals my kids are becoming, and at the same time, I sometimes miss their younger days. At least then, they had no idea that I am not like the other moms.

They did not have points of reference, and as far as they knew, every mom took naps longer than the kids. Now, they sometimes have this incredulous look, and I fear that they think I am lazy. And don't like myself for that reason. I feel like I am a terrible role model for them. It's a good thing their dad is awesome.

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I sometimes feel a bit obligated to stay up and spend some time with my husband without the kids. We don't have too many occasions to spend time just the two of us. But at the end of the day, my body and my mind are not in sync.

I try to find a comfortable spot, but even my own spot on the couch isn't right. My legs are heavy and next thing I know, they are asleep. So I have to move around.

Have you ever tried to watch TV with someone who moves around constantly, then asks questions because they missed a part? It's annoying. Like, really annoying.

My gallbladder is getting to be a huge nuisance. Fibro Warriors often have gastro-intestinal issues, and gallbladder is probably the mildest of them all. At least it's not Irritable Bowel Syndrome! I hear IBS patients suffer horrible cramps for hours on end. Not my idea of fun.

I hate not being able to sleep when I want, especially when I feel so sleepy most of the day. What's up with that? I feel my loved ones may think I say I'm tired just so I can get out of doing chores. Gosh, I keep on disappointing everyone.

Which is part of the reason I got back upstairs. I have obligations I cannot keep up with, and it worries me. So I try to work on those things, but it ends being so late at night that I just kind of give up.

I finally get to lay down and put this day behind me. That is, if my mind will let me.

What can I do to make it better?

First of all, any parent will tell you that kids growing up is part of life. That's just the way things go. I think my real problem is that I feel guilty for not being able to give my kids 100% of my energy at all times.

Because of my list of chronic conditions, I feel like my kids have been robbed of their childhood, because they have had to do chores around the house for as long as they can remember. But really, what kid doesn't have to participate in keeping the household tidy and organized?

Every kid has chores to do! My guilt is misplaced and I'm pretty sure the energy I spend feeling guilty could be better spent elsewhere.

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I need to realize that I am not a bad role model. As a mom, most of what I do is for my kids. I love them unconditionally, and they mean the world to me.

A bad role model is someone who is not there at all, or is intentionally missing out on their kids' milestones. I am too harsh on myself, really.

I wouldn't dream of being this harsh or judgmental looking into someone else's life. Why I am so hard on myself is a mystery. But I'm pretty sure that accepting me for me would make things a lot better.

And same goes for my husband. If I stop to think about it, I'm sure he would prefer one hour with me in a good mood, rather than three hours with me feeling miserable. That good old quality over quantity thing.

As for my gallbladder issues, well, I know what to do to minimize flares. I need to avoid spicy foods and fatty foods. Do I? Of course not! That would be too easy... I shouldn't joke, because it sounds like I'm avoiding doing the right thing on purpose, and I'm not.

It's quite hard to eat the right thing. As we have seen above, stocking the right kind of foods will help, but there are always those times when you just want to eat a couple slices of pizza. With jalapenos. And that, my friends, is not good for my gallbladder.

At some point, I will have to face reality: my diet and my weight do affect my fibromyalgia, and I need to get those under control. The episodes of gallbladder inflammation alone are a good motivator. My doctor has talked to me about a new type of medication that could help reduce food cravings. I will give it a go in the Fall.

Finally, I need to understand that I don't owe anyone anything. I think I do, but I don't. My husband, my kids, my friends, they love me for who I am and they accept me for who I am. The people who don't understand? I don't need them in my life.

I need to start being more positive. Of course, I need to follow through on my obligations. But sometimes, the schedule will be altered to accommodate Fibro Flares. That's just the way things have to be.

Recently, I have started repeating to myself, almost like a mantra, the following: I am loved, I am worthy. It is high time I start loving myself! Worrying about things late at night will do nothing but keep me up.

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I have several meditation soundtracks on my phone that I can play if I have a hard time falling asleep. It calms my mind, and when my mind is calm, my body tends to relax too.

Any chronic pain sufferer will tell you the same: a good night sleep is golden, so I'm off to enjoy my slumber!

11:45 PM – Just kidding. There is no way I can find a comfortable position. I've been laying there for over one hour. I'm tossing and turning and tossing some more. I cannot fall asleep. I guess I'll just get back up and go watch some TV. I'll make an herbal tea. I heard it could help me sleep. At this point, it's worth giving it a try.

12:30 AM – I go back to bed. Seriously, I need some sleep. As it is, I will get six hours of sleep at best. How in the world am I going to function properly tomorrow? No wonder I take naps. Is this what insomnia is? I'll have to look at it closer tomorrow.

12:50 AM – I fall asleep some time between 12:45 AM and 1:00 AM. About time!

2:15 AM – Are you kidding me?!? I wake up, because, well... I have to go to the bathroom. That'll teach me to drink tea before bed!

5:00 AM - My husband gets up for work, and I briefly wake up with him. I may not wake up all the way, but I'm certain this cannot promote restful sleep. I cannot be surprised when I feel tired: I don't sleep profoundly for more than a few hours a night! I'll never be able to go back to bed.

5:05 AM - I am back asleep. I guess I was getting overly worried for nothing. Let's see where this nap takes me!

5:45 AM – My first alarm rings. Time to do it all over again. Good morning, friends!

How does it feel?

This fibromyalgia business is taking a serious toll on me. I am constantly battling pains and aches all over my body. If only I knew where the pain will hit next, but it's a giant guessing game, and I never win.

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It is frustrating beyond belief to lay there in bed, and not be able to close my eyes. My Restless Legs Syndrome, a very common co-morbidity for Fibro Warriors, is keeping me up. I constantly have to move my legs.

It is hard to explain, but it's like this urge to move your legs that you cannot control. It would be equivalent to walking on hot sand: it won't burn your feet, but it is so unpleasant that you have to shift from leg to leg.

I am concerned that my tossing and turning will wake my husband. He has to wake up early tomorrow, so it is better for me to just get up and let him sleep. Except that when I get back in bed, I am worried I will wake him up. This is a catch-22 type of situation.

Have you ever been so comfy in bed, but you know that if you don't get up, you'll just pee in your bed? That's me. Almost every night. I finally got the pain to quiet down, and now I have to get up to go to the bathroom.

This is unbelievable. And why don't I just go ahead and play trumpet in the hallway? That'll have the same effect of waking the whole house up...

Quickly wake up with my husband, and right back to bed. Oh, how I would love to have one long, uninterrupted night of restful sleep! Here I go again, whine whine whine...

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Aaaaannndddd.... Back to the grind... My alarm goes off, and I just turn it off without even realizing it. Until the second alarm rings. And the third. And...

What can I do to make it better?

Insomnia is a great issue for Fibro Warriors. It is hard to explain that I am constantly tired, no, not tired: fatigued, exhausted, incapable of functioning properly. Yet, slumber is an elusive beast that only shows up once or twice a week.

I have tried herbal teas to help me sleep, but the side effects (full bladder!) were almost worse than the positives. I have started keeping Melatonin on my night stand. It is a natural supplement that promotes sleep.

Whether the effect is psychosomatic or not, I do not know. And I do not care. I sleep better when I take a low dose of Melatonin – I take 3 mg, same as what doctors recommend for a 5 year-old child. It works for me.

There are many supplements available out there to help you get a good night sleep. Talk to your doctor, or your pharmacist. They will gladly help you navigate the supplements world.

I could control my Restless Legs Syndrome with medication, but they made me sleepy. So now, I just preempt the RLS attacks: whenever I am off my feet, I elevate my legs and I will purposefully shake my feet until they feel almost numb.

It sounds silly, but it's a little trick I have learned helps control the urges to move my legs when I am laying down. And on bad days, I just put one foot out of the bed and shake it gently, so I don't wake my husband. It works well as it provides my body with the "moving" sensations.

All in all, being negative does not help. But I know how hard being positive can be. Here is the deal, though. Sometimes, when I feel down, I force myself to smile.

I tell myself how awesome I am and how worthy I am. A little narcissism does wonders to the soul! On very bad days, I smile so much, my face feels funny. But hey, whatever it takes, right?

If you had any doubts, reading this account of 24 hours of my life will make you see that Fibro Flares are no fun. They are exhausting, trying and painful.

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As Fibro Warriors, we know what we are going through. It is important for us to remember that we are the only ones in our bodies. Yes, I know, it sounds stupid when you read it out loud. But it's true!

The idea here is that no one else but us knows exactly how we feel at any given moment. We need to communicate with our loved ones so they know what we are experiencing.

I'm not advocating whining all the time. And I'm not saying that all non-Fibro Warriors are insensitive pigs. Realistically, everyone falls somewhere in the middle.

We need to be honest with our loved ones, and the only way to do that is by being honest with ourselves first. It is OK to admit that we have limits. It is OK to ask for help.

There is nothing to be ashamed of. I struggle with that a lot, personally. I have feelings of inadequacy and guilt, but when I look at it objectively, I do the best I can with the cards I was dealt.

I chose to share with you my day-to-day life. This was not an easy exercise, as I took you through some very personal thoughts and feelings. I am still not sure if I am happy to have done so or not. I feel naked, you know. It's like I've let down any type of barrier that could protect me from public opinion.

Please be kind. Your experience will be completely different from mine, but I hope you can find yourself in a few things described above. If it can help you talk to your loved ones about how you really feel, then it was all worth it.

Keep fighting the good fight, Fibro Warriors!